POLICY ON END OF LIFE AND PALLIATIVE CARE IN THE EMERGENCY DEPARTMENT

1. PURPOSE

This policy is a document of the Australasian College for Emergency Medicine (ACEM). It aims to encourage honest discussion and awareness of end-of-life care (EoLC) planning within the community, ensure that emergency department (ED) staff are confident in providing good EoLC, and that EDs have systems and processes in place regarding recognising and appropriately caring for patients at the end of life (EoL).

2. SCOPE

This policy applies to all Australasian EDs, and pertains to the treatment of adults at the EoL.

This policy recognises the role that emergency medicine and EDs have in the continuum of EoLC within the diverse communities that they serve.

3. DEFINITIONS

The following terms are commonly used in relation to EoLC. These terms have been defined by the Australian Commission on Safety and Quality in Health Care (ACSQHC), the General Medical Council (GMC), the World Health Organisation (WHO), and the Working Group of the Clinical Technical and Ethical Principal Committee of the Australian Health Ministers’ Advisory Council.

End of life:

End of life is the period when a patient is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown. [1,2]

This period may be years in the case of patients with chronic or malignant disease, or very brief in the case of patients who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma. [1,2]

End-of-life care:

Includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the patient’s body after their death. [1,2]

People are ‘approaching the end of life’ when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- Advanced, progressive, incurable conditions;
- General frailty and co-existing conditions that mean that they are expected to die within 12 months;
- Existing conditions, if they are at risk of dying from a sudden acute crisis in their condition; or
- Life-threatening acute conditions caused by sudden catastrophic events.
Palliative Care:

An approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual. [3]

Substitute decision-maker:

A person appointed or identified by law to make substitute decisions on behalf of a person whose decision-making capacity is impaired. Substitute decision-makers have legal authority to make these decisions; the relevant legislation varies between jurisdictions (states and territories).

A document that appoints a substitute decision-maker to make health, medical, residential and other personal decisions (but not financial or legal decisions) is considered to be an Advance Care Directive (ACD). More than one substitute decision-make may be appointed under an ACD. [1,4]

Non-beneficial treatment:

Interventions that will not be effective in treating a patient’s medical condition or improving their quality of life. Non-beneficial treatment may include interventions such as diagnostic tests, medications, artificial hydration and nutrition, intensive care, and medical or surgical procedures. Non-beneficial treatment is sometimes referred to as futile treatment, but this is not a preferred term. [2]

4. INTRODUCTION

Palliative and EoLC has previously been associated with the palliation of patients with a diagnosis of terminal cancer. However, in both Australia and New Zealand, there are rising rates of chronic conditions such as diabetes and cardiovascular disease, as well as ageing populations. The changing demographic of both Australia and New Zealand, and the increase in the prevalence of chronic diseases, have resulted in a concurrent growth in the demand for EoL and palliative care services, as many patients are living longer with complex medical problems. [4]

The number of EoL associated ED presentations has also increased, despite much evidence to suggest that EoLC or palliative interventions are more beneficial for the patient if they are begun earlier and in the primary health care sector. [5] The ED has therefore become a location where EoLC plans are commonly discussed and initiated, or where established EoLC plans are implemented.

However, as EoL or palliative care associated hospitalisations are predicted to increase, training or educational opportunities for emergency physicians and nurses in EoLC, including communication with families and carers, will be necessary. [6] This training can be bolstered through initiatives that facilitate collaboration and improved communication between specialist palliative care teams, General Practitioners (GPs), palliative care physicians, counsellors and nurses and other medical staff.

5. POLICY

ACEM supports actions that can be implemented in order to prevent non-beneficial care and ensure that the wishes of patients are both known and acted upon in the ED, and therefore offers the following recommendations. [7]

- Emergency physicians and ED staff should establish a dialogue with patients at the EoL, as well as their carers, families and health care workers or health care team members, to ensure that there is a common understanding of the goals of care. Emergency physicians should advocate for the documentation of a patient’s values and wishes regarding medical treatment through advance care planning processes.
• ACEM considers that emergency physicians and staff should be provided with the relevant training and resources to provide patient goal-focussed EoLC within this context. This includes referral to specialist palliative care as and when required.

• ACEM recommends that discussions regarding EoL and appointment of substitute decision-makers should be had with all patients who are entering a Residential Aged Care Facility (RACF) who have a terminal or chronic illness, or who are very frail.
  o Dependent on the wishes of the patient, these discussions should involve their family, carer or, if appointed, a substitute decision-maker.
  o Wherever possible, ACEM considers that these discussions should lead to an ACD or Advance Care Plan (ACP), and that these ACDs and ACPs should be shared with all those involved in the care of the patient.
  o If the discussion does not come to sufficiently robust outcomes as to allow for an ACD or ACP to be written, these outcomes should be clearly documented. This documentation should accompany the patient if being transported to hospital.

• ACEM recommends that ACD and ACP discussions should also occur with patients (and their substitute decision-makers) who are being discharged from the ED or hospital to their home or aged care facility and who presented as a result of a decline in their health caused by incurable chronic disease, terminal illness or frailty.

• ACEM encourages use of screening tools, such as the Criteria for Screening and Triaging to Appropriate alternative care (CriSTAL) and the Supportive and Palliative Care Indicators Tool (SPICT), by EDs and emergency physicians in order to identify elderly patients at the EoL. [8,9] ACEM considers that these tools are essential in identifying patients who are at risk of dying as well as when it is time to begin discussions with these patients and their families regarding their EoL wishes, and can therefore assist in provided goal-focussed EoLC.

ACEM supports high-level initiatives and tools that can improve patient outcomes through enhancing quality of life at the EoL within the community as well as the ED, and therefore endorses the following standards and processes.

5.1 The National Consensus Statement: Essential elements for safe and high-quality end-of-life care

ACEM endorses the National Consensus Statement, a document developed by the ACSQHC, which intends to inform physicians and other healthcare professionals of recommended practices in the provision of EoL. [2] ACEM considers that all hospitals or health organisations involved in the provision of EoL or palliative services should utilise the National Consensus Statement as a guiding document in the development of their own standards or practices.

5.2 The EQuIP National Standards

The Australian Council of Healthcare Standards (ACHS) EQuIP National Standards were developed in response to the ACSQHC National Safety and Quality Health Service (NSQHS) Standards, and provide five additional standards against which organisations can be accredited. [10]

As the NSQHS Standards do not include specific actions on EoLC, the EQuIP National Standards provide Standard 12 Provision of Care, which provides two key criterion relating to EoLC and is strongly endorsed by ACEM. [11] These criteria relate to the implementation of policies and procedures that address requirements for advance care planning, culture and spirituality, and organ and tissue donation. [11] The criteria also encourage the provision of access to specialised services, such as pain management and support resources, to ensure that the needs of the patient are met, elements ACEM considers to be integral to high quality EoLC. [11]
5.3 Te Ara Whakapiri: Principles and guidance for the last days of life

Te Ara Whakapiri: Principles and guidance for the last days of life is a document developed by the New Zealand Ministry of Health (MoH), and is intended to offer guiding principles and components for the care of adults at the EoL. [12]

The principles offer guidance on EoLC in all settings, including the home, residential care facilities, hospitals and hospices. ACEM considers that Te Ara Whakapiri should be viewed a crucial document in guiding a holistic approach to EoLC that respectfully involves patients, carers, families and medical practitioners in the EoLC planning process.

5.4 Screening Tools

5.4.2 CriSTAL

The CriSTAL is a screening tool that identifies older patients at the EoL and quantifies the risk of death in hospital or soon after discharge. [8] This tool intends to minimise potentially harmful and non-beneficial treatment, and identify older patients who may benefit from care pathways that do not involve hospitalisation. [8] The CriSTAL also seeks to encourage patient, family, carer and medical practitioner discussions regarding the goals of EoLC. [8]

The proposed components of the CriSTAL to identify EoL status before hospital admission include conditions such as chronic heart failure or chronic kidney disease, as well as repeat Intensive Care Unit (ICU) admissions at previous hospitalisations. [8]

5.4.2 SPICT

The SPICT assists in identifying patients at risk of deteriorating and dying in all care settings. [13] This tool also provides indicators which clinicians can use to identify when it may be appropriate to initiate EoLC discussions with patients and their families or carers, as well as their substitute decision makers. [13]

The SPICT uses six indicators of deteriorating health. [13] These indicators are:

- Unplanned hospital admissions. [13]
- Performance status is poor or deteriorating, with limited reversibility. [13]
- Dependent on others for care due to physical and/or mental health problems. [13]
- More support for the person’s carer is needed. [13]
- Significant weight loss over the past 3-6 months, and/or a low body mass index. [13]
- Persistent symptoms despite optimal treatment of underlying condition(s). [13]
- Person or family ask for palliative care, treatment withdrawal/limitation or a focus on quality of life. [13]

ACEM therefore considers that the use of screening tools such as the CriSTAL and the SPICT, may assist in settings in which older patients, but also those with chronic disease or terminal illness, present as a result of a deterioration in their health or condition, such as the ED. ACEM therefore supports the use of these evidence-based screening tools in the ED, as identifying patients at risk of dying is critical to the delivery of patient-goal focussed EoLC.

5.5 Advance Care Planning

ACEM supports advance care planning, and notes that the use of an ACP or ACD, initiated at the Primary Care level, can reduce rates of non-beneficial care and associated hospitalisations, whilst also allowing patients to remain and be cared for in their home, RACF, or other preferred location. [14]
Advance care planning is fragmented across Australian jurisdictions, an issue that is not experienced in New Zealand. In both Australia and New Zealand, there is a low uptake of these processes amongst patients. [15,16]

Low uptake of the advance care planning process, and the associated barriers can have a significant impact on the provision of EoLC in the hospital and ED setting. There is significant evidence to suggest that EoL or palliative interventions are more beneficial if begun earlier for patients with life-limiting illness or who are approaching the end of their life due to old age. ACEM therefore considers that GPs, palliative care physicians and geriatricians should be considered as the linchpin of the advance care planning process. [17]

GPs should therefore be encouraged and supported to have discussions with their patients regarding their preference for EoLC or treatment of a terminal or chronic condition. Along with specialist palliative care providers, physicians or RACFs, GPs should also be encouraged to regularly monitor a patient’s ACD or ACP in accordance with the patient’s changing condition.

For elderly or terminally ill patients discharged from hospitals to receive palliative care in RACFs or their home, ACEM supports encouraging the completion of an ACD or ACP. This would ensure patient autonomy and avoid potential miscommunication between medical practitioners, carers, palliative care workers and family members.

In order to facilitate an uptake in Advance Care Planning, ACEM considers that existing ACDs or ACPs should be made easily available to ED staff, as well as other health service providers, through a centralised electronic system, such as the ‘My Health Record’. [18] As outlined in ACEM’s Choosing Wisely recommendation, ACEM strongly endorses the documentation of values and wishes around medical treatment. [19] The centralisation of such information could ensure that physicians and patients can work together to allow for a common understanding of the goals of care. [18]

ACEM considers that standardised formatting and language of ACDs and ACPs across all jurisdictions should be considered so as to assist health services in the provision of quality EoLC according to the wishes of the patient. ACDs, ACPs and advance care planning should also be underpinned by the best practice standards outlined in the National Framework for Advance Care Directives (2011). [4]

5.6 Community Initiatives

ACEM encourages discussion of EoLC and promotion of advance care planning within the community, and considers that initiatives such as Palliative Care Australia’s National Palliative Care Week and the National ACP Cooperative’s (New Zealand) Conversations That Count Day, are vital in raising awareness and understanding of palliative and EoLC. [20,21]

The Palliative Care Australia Dying to Talk website and Discussion Starter, and the ACP Cooperative ‘how to’ guide, also assist in raising community awareness of these issues, as well as providing resources to support people in having discussions with their family about their EoL wishes. [22, 23,24]

ACEM considers that raising awareness of palliative and EoLC and advance care planning processes could assist in ensuring that patients are willing to have a discussion involving their EoLC choices with their primary care provider. If these discussions were effectively documented, reviewed and updated through the relevant advance care planning processes and made available through the My Health Record, health services such as RACFs and EDs would be equipped with the necessary information to provide EoLC to patients according to their wishes.

5.7 Terminology

In order to provide further support to emergency physicians providing EoLC to patients in the ED, a shift in commonly used terminology should also be encouraged. Such a shift could also promote a better and more holistic understanding of EoLC processes to patients, their families and their carers.

For example, in place of the terms ‘do not resuscitate’ (DNR) or ‘not-for-resuscitation’ (NFR), ACEM endorses the use of the term ‘allow a natural death’ (AND). This term could prove more satisfactory, particularly for a patient’s family or carer, and also allows for consideration of palliative forms of care in order to ensure their comfort.
Furthermore, ACEM encourages physicians to avoid the use of the statement ‘there is nothing more we can do’, as this phrase denies the existence of palliative and other EoLC processes.

6. PROCEDURE AND ACTIONS

Between 70-80% of people state that their preference is to die in their own homes, however only 16-20% fulfil this wish. [25,26] Emergency physicians and ED staff should therefore support and advocate for the provision of EoLC to patients in their own home, RACF or other location of the patient’s choice.

Emergency physicians should be equipped with the skills and resources to provide needs-based EoLC within the ED if this is the location of choice identified by the patient. Emergency physicians should not be encouraged to defer EoLC discussions to GPs, palliative care physicians, inpatient bed units, RACFs or other health service providers if a patient has expressed interest in discussing their EoLC plan. If EoL discussions have taken place with a patient in the ED, ED staff should be confident in communicating this information to the patient’s GP, palliative care physician, or other relevant health provider.

ACEM encourages ED staff to seek to understand patients’ EoLC wishes and act accordingly. A better understanding of EoLC planning should be facilitated by providing emergency physicians with resources and information regarding commencing EoLC discussions, as well as utilisation of the National Consensus Statement and Standard 12 in order to provide patient-centred EoLC planning.

ACEM therefore considers that emergency department staff should be knowledgeable on the following:

- How to start a conversation with a patient regarding palliative and EoLC or advance care planning.
- Where to locate existing advance care plans, and how to make this search a routine enquiry when treating a patient at the EoL.
- How to assist patients with planning ahead using ACDs or ACPs, and knowledge of the relevant organisations who could further assist patients with the planning process.
- How to conduct “goal-directed assessments” which can assist in avoiding unwanted treatment. [27]
- The principles of substitute decision-making.
- How to obtain information from individuals who may be substitute decision-makers, or who have been given power of attorney.
- The legal and ethical implications of advance care planning, including ACDs and ACPs.
- Conflict resolution, and knowledge of the relevant mediation services. Cultural, spiritual and religious factors, and knowledge of the relevant services to which a patient could be referred.
- Psychosocial, carer and bereavement support, and knowledge of the relevant services to which a patient or their family/carer could be referred.

It is inevitable that for some patients, the commencement of EoL care will occur in the ED. However, appropriate training and resourcing of staff and EDs will ensure that EoL care planning and discussions are considered part of the emergency physician skill set. This will ensure that the patient’s goals of care are understood and appropriate EoLC provided.
7. REFERENCE LIST


8. DOCUMENT REVIEW

Timeframe for review: every five (5) years, or earlier if required.

8.1 Responsibilities

Document authorisation: Council of Advocacy, Practice and Partnerships
Document implementation: Standards Committee
Document maintenance: Policy and Research Department

8.2 Revision History

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