

End of life and palliative care in the emergency department

Policy P455

Document Review

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Revision History

Version	Date	Pages revised / Brief Explanation of Revision
01	Jul-16	
02	May-20	Definitions expanded. Changes made to content under the Policy subheading - Screening Tools. Overall streamlining of content and clearer Policy, and Procedure and Actions statements. Two new references and links to related documents and resources added.

Related documents

ACEM Policy on the Care of Older Persons in the Emergency Department

ACEM Policy on Organ and Tissue Donation

Related links

Advance Care Planning Australia

Advance Care Planning New Zealand

End of Life Directions for Aged Care

End of Life Law in Australia

1. Purpose and scope

This policy aims to promote discussion and awareness of end-of-life care (EoLC) planning, and to ensure that emergency department (ED) staff are confident in providing quality EoLC. The policy also describes ED systems and processes for recognising and appropriately caring for patients at the end of life (EoL).

This policy applies to all Australian and New Zealand EDs. It pertains to the treatment of adults at the EoL, recognising the important role emergency medicine and EDs have in the continuum of EoLC within the diverse communities that they serve.

2. Definitions

The following terms are commonly used in relation to EoLC. They have been defined by the Australian Commission on Safety and Quality in Health Care (ACSQHC), the General Medical Council UK (GMC), the World Health Organization (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 unexpected illnesses or events, such as sepsis, stroke or trauma. [1,2]

End-of-life Care

Includes physical, emotional, spiritual and psychosocial assessment, 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;
- life-threatening acute conditions caused by sudden catastrophic events.

Palliative Care

An approach that improves the quality of life of patients and their families who are facing problems associated with life-threatening illness. It seeks to relieve suffering through the early identification, correct assessment and treatment of distressing symptoms and other problems, whether physical, psychosocial or spiritual. [3]

Advance Care Planning

Involves planning for future health decisions in the event that a person may not be able to express their goals and wishes regarding their treatment and care. It is important that these preferences are discussed with family, carers or next of kin. Advance Care Planning can involve preparing an Advance Care Directive and appointing a substitute decision maker.

Advance Care Directive (Aust) and Advance Directive (NZ)

A legal document which clarifies a person's future preferences about their medical care and treatment. It can also appoint a substitute decision maker to make health, medical, residential and other personal decisions (excluding financial or legal decisions). More than one substitute decision maker may be appointed under an Advance Care Directive. [1,4]

Substitute Decision Maker

A substitute decision maker is a person appointed or identified by law (in some but not all jurisdictions) 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 and countries).

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 has sometimes been referred to as futile treatment, but this is not a preferred term. [2]

3. Introduction

Palliative care grew out of oncology and the care of patients with incurable cancer. However, in both Australia and New Zealand, there are rising rates of chronic medical conditions such as diabetes and cardiovascular disease, as well as an ageing population. The changing demographic, and the increase in prevalence of chronic diseases, have resulted in growth in the demand for EoL and palliative care services, as many patients are living longer with complex medical problems. [4]

The number of EoLC associated ED presentations has increased, despite evidence 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 discussions about limitations of medical treatment may be had [6], EoLC plans are discussed and initiated, or where established EoLC plans are implemented.

The emergency physician's role in EoL discussions [6] is focused on:

- screening for, and identifying the patient approaching EoL;
- initiating discussions about EoLC and incorporating these discussions in relation to limitations of medical treatment for the current and subsequent admissions; and
- where appropriate, initiation of discussions about limitation of medical treatment in collaboration with treating teams.

EoL discussions initiated in the ED should be documented and handed over to teams providing ongoing care.

The emergency physician's role in providing EoLC in the ED [6] is to implement the essential elements of 'good dying' [7] as the goal of care. This includes the care of the imminently dying.

This care should include:

- clinical expertise in recognising and managing common end of life scenarios including symptom control, EoL discussions, existential distress (existential distress at the end of life has been defined as hopelessness, burden to others, loss of sense of dignity, desire for death or loss of will to live and threats to self-identity [8]) and family distress;
- multi-disciplinary input and approach;
- provision of a suitable place for patients and families to be (consider whether the patient should return home or to a residential aged care facility); and
- promotion of collaboration with local palliative care providers to maximise educational opportunities for staff.

Emergency physicians and EDs should be trained in recognising imminent death and be able to provide a suitably private place for this phase of a patient's care. Appropriate anticipatory prescribing of medications and close collaboration with treating teams and palliative care services should occur.

4. Policy

4.1 ACEM supports actions that rapidly identify and act on patients' wishes about their care.

This may help avoid non-beneficial care [9]. The following recommendations are made:

- Emergency physicians and ED staff should commence a dialogue with patients identified as being at EoL to establish the goals of care, especially if limitations of medical treatment are considered. This conversation should include carers, families/whānau and involved health care professionals to ensure a common understanding of the goals of care.
- Emergency physicians and ED staff should be given training and resources to provide each patient with individual goal focused EoLC. This includes access to specialist palliative care as and when required.
- Health facilities should identify appropriate space to accommodate dying patients.
- Advance Care Planning discussions are initiated with ED patients (and their substitute decision makers) who are being discharged and who presented as a result of incurable chronic disease, terminal illness or frailty. Close liaison between emergency physicians and primary care providers to ensure appropriate transition of care and transfer of information should occur.
- Senior clinical input is advisable in identifying the patient who is progressing to EoL. Identifying such patients is complex but essential to providing the clinician with the opportunity to initiate goals of care/EoL discussions. Use of the "surprise" question can assist in this process [10,11]. Would you be surprised if the patient were to die in the next 6-12 months? Would you be surprised if the patient died during this admission? If the answer to this question is "no" then it may be appropriate to review the patient's situation and needs and to initiate goals of care discussions. Used alone this has significant limitations [12]. Utilisation of frailty assessment tools such as the Clinical Frailty Scale (CFS) may give additional support to clinician judgement.
- Screening tools such as Criteria for Screening and Triaging to Appropriate Alternative Care (CriSTAL)
 and the Supportive and Palliative Care Indicators Tool (SPICT) may also provide useful information for
 the clinician. [13,14]

4.2 ACEM supports high-level initiatives and tools that can improve patient outcomes through enhancing quality of life at the EoL within the community and the ED.

ACEM therefore endorses the following standards and processes.

Australian National Safety and Quality Health Service (NSQHS) Standards

The Australian Commission on Safety and Quality in Health Care (ACSQHC) incorporates EoL care as part of the comprehensive care standard [15]. There are key actions (Action 5.15-5.20) relating to: identifying a patient at EoL; clinician access to specialist palliative care advice; access to Advance Care Plans and documenting them in patient records; supervision and support for the workforce in delivering EoL care; regularly reviewing EoL care provided; and ensuring that patients, carers and families are involved in shared decision making at EoL. These standards are underpinned and guided by the National Consensus Statement: Essential elements for safe and high-quality end-of-life care.

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

The Australian National Consensus Statement, a document developed by the ACSQHC, intends to inform physicians and other healthcare professionals of recommended practices in the provision of EoLC. [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.

This Consensus Statement should also be used alongside the National Consensus Statement Essential elements for recognising and responding to clinical deterioration.

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. [16]

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 as a crucial document in guiding a holistic approach to EoLC that respectfully involves patients, carers, whānau, and medical practitioners in the EoLC planning process.

Programme of Experience in Palliative Care (PEPA)

PEPA have published a guideline for clinicians on cultural considerations for Aboriginal and Torres Strait Islander peoples at EoL. [17] It is important to consider the diversity of cultural and spiritual beliefs regarding EoL amongst Aboriginal and Torres Strait Islander peoples and asking questions in a culturally appropriate manner to understand the wishes of a patient and their family. This resource offers practical advice regarding language use and communication styles to provide culturally safe EoLC. It also details questions to ask the patient and family to understand their EoL wishes and the importance of engaging an Aboriginal Health Worker or Aboriginal Liaison Officer (if available) in their EoLC.

Screening Tools

There is currently no screening tool that can be highly recommended for ED identification of the dying patient. Emergency physicians will have experience in identifying the patient who is imminently dying (hours to days). However, identifying those who are at high risk of dying during their hospitalisation or within a 3-12-month period is more complex and available tools perform modestly.

"Surprise" question (discussed earlier)

Would I be surprised if the patient died in the next 6-12 months? Answering this question as "no" may enable an opportunity for the emergency physician to reassess the patient's situation and needs. It may lead to the start of conversations about goals of care and limitations of intervention that can be continued by the patient's primary care provider or hospital inpatient services. Unfortunately, using this alone has performed poorly to modestly especially in non-cancer patients [12]. Modified versions have been used in the ED with some success although its use alone as a screening tool cannot currently be recommended [10,11]. When used with an assessment of frailty in addition to physician gestalt more structure may be found to support this process.

Supportive and Palliative Care Indicators Tool

The SPICT assists in identifying patients at risk of deteriorating and dying in all care settings. [18] 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. [18]

Clinical Frailty Scale

Assessment of patient's functional state using the CFS (or other frailty tool) is useful in identifying those who are most frail and who may be progressing to EoL [19,20]. Higher degrees of frailty are associated with increased mortality [19]. The CFS is a pictorial tool that assesses frailty on a scale of 1 (very fit) to 9 (terminally ill) and more significant degrees of frailty are associated with a CFS of 6-9. This can give the emergency physician some confidence in initiating goals of care discussions with the patient or substitute decision maker.

ACEM therefore considers that the use of screening tools may assist in settings in which patients with chronic disease or terminal illness present as a result of a deterioration in their health or condition. Tools such as CriSTAL and SPICT are useful but may be more time consuming for routine use in ED.

4.3 ACEM supports all Advance Care Planning, and notes that the use of a well-documented Advance Care Plan (ACP) or Advance Care Directive (ACD), can reduce rates of non-beneficial care and associated hospitalisations, whilst also allowing patients to remain and be cared for in their home, residential aged care facility, or other preferred location. [21]

ACEM recognises that Emergency Departments are part of a patient's continuum of care. It encourages and supports GPs to have discussions with their patients regarding their preference for EoLC or treatment of a terminal or chronic condition. Emergency Physicians can assist this process by ensuring relevant ACP information is conveyed to the patient's GP after an ED attendance.

4.4 Existing Advance Care Plans or Advance Care Directives should be made easily available to ED staff, as well as other health service providers, through a centralised electronic system. [22]

As outlined in ACEM's Choosing Wisely recommendation, ACEM strongly endorses the documentation of values and wishes around medical treatment. [23] 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.

ACEM considers that standardised formatting and language of ACPs across all jurisdictions should be considered to assist health services in the provision of quality EoLC according to the wishes of the patient. ACPs and ACDs should also be underpinned by best practice standards and in accordance with relevant legislation [4, 24, 25]

4.5 ACEM supports the use of terminology promoting an holistic and compassionate understanding of EoLC processes.

A shift in commonly used terminology should be encouraged. For example, in place of the terms 'do not resuscitate' (DNR) or 'not-for-resuscitation' (NFR), ACEM endorses the use of the term 'allow natural death' or 'allow natural processes'. Other terms such as 'goals of care' and 'limitations of medical treatment' are also recommended to facilitate discussions.

These terms will prove more satisfactory, particularly for a patient's family or carer, and provide reassurance that good supportive and symptom focused care will continue while also allowing consideration of palliative forms of care in order to ensure the patient's comfort.

ACEM encourages physicians to avoid the use of the statement "there is nothing more we can do", as this phrase contradicts the existence of palliative and other high quality EoLC processes and supports.

4.6 ACEM believes emergency physicians have an important role in training and coaching of emergency medicine trainees in EoL decision making and discussions.

5. Procedure and actions

5.1 Health services should support emergency physicians and EDs with the necessary resources and training to facilitate provision of quality EoLC.

5.2 Emergency physicians and ED staff should support and advocate for the provision of EoLC to patients in their own home, residential aged care facility or other location of the patient's choice. [26,27]

Emergency physicians can assist this process by ensuring relevant information is conveyed to the patient's GP after ED attendance.

Close liaison with primary care or specialist palliative care clinicians when already involved with care, is encouraged. We recognise that Advance Care Planning needs to be regularly monitored and documents updated, when people are approaching the EoL, particularly those living in Residential Aged Care Facilities.

5.3 ED staff should be knowledgeable in the following:

- How to start a conversation with a patient regarding palliative and EoLC or Advance Care Planning.
- The importance of locating existing Advance Care Plans and making this search a routine enquiry when caring for a patient at the EoL.
- Assisting patients with planning ahead, using Advance Care Directives/Advance Directives and Advance

Care Plans, and knowledge of the relevant organisations who could further assist patients with the planning process.

- Conducting 'goal-directed assessment', which can assist in avoiding unwanted treatment. [27]
- Providing best possible symptom management in EoL and palliative crises that meet the patient's needs [28, 29]
- Understanding the local (relevant state legislation) law and guiding principles of substitute decision making.
- Obtaining information and direction from individuals who may be substitute decision makers.
- The legal and ethical implications of Advance Care Planning, including Advance Care Plans and Advance Care Directives/Advance Directives.
- 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.
- Appropriate use of EoL medications used to minimise distressing physical symptomatology. [28]
- Terminology promoting an holistic and compassionate understanding of EoLC processes.

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