AUSTRALIAN COMMISSION
ON SAFETY AND QUALITY IN HEALTH CARE

National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care in Acute Hospitals

Consultation draft – January 2014

Contents

Introduction

The Australian Commission on Safety and Quality in Health Care (the Commission) is seeking feedback on the draft *National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care in Acute Hospitals* (the Consensus Statement). The purpose of the Consensus Statement is to set out the expected standard of care and agreed practice for recognising and responding to people in need of end-of-life care in acute hospitals.

The health care that patients receive in the last years, months and weeks of their lives can help to minimise the distress and grief associated with death and dying for the individual, and for their family, friends and carers. The purpose of this Consensus Statement is to describe the elements that are essential for delivering safe and high-quality end-of-life care to patients who are being cared for in acute hospitals in Australia.

Many Australians spend much of their last year of life going in and out of hospital, and more than half of those who die each year do so in acute hospitals. Although there may be uncertainty about if and when a patient will die, if care is coordinated appropriately, the potential benefits of applying the elements of this Consensus Statement should outweigh the risks of repetition or duplicated effort. Even when treatment aimed at cure is continuing for patients who are identified as approaching the end of life, the interdisciplinary team should work with patients, their families and carers to 'plan for the worst while hoping for the best'.

This proposed Consensus Statement reflects the views of consumers, experts in the field, and the Australian Commission on Safety and Quality in Health Care. It has been derived from expert experience, published evidence, and developed in partnership with carers and consumers, representatives from public and private hospitals, professional colleges, jurisdictional health departments, and other government agencies.

When applying the elements of the Consensus Statement, it is intended that acute hospitals should consider how to work with external providers – such as residential aged care facilities, specialist palliative care services, general practitioners and social care agencies – to optimise collaboration and the coordination of end-of-life care as patients move in and out of hospital.

Safety and Quality of End-of-Life Care in Acute Hospitals: A Background Paper

A background paper, *Safety and Quality of End-of-Life Care in Acute Hospitals*, provided the foundation for the development of this Consensus Statement. It is available on the Commission's web site:
http://www.safetyandquality.gov.au/publications/safety-and-quality-of-end-of-life-care-a-background-paper/

During the preparation of the background paper a series of preliminary consultation interviews and focus groups were held with consumers and carers, interdisciplinary team members, hospital executives and policy makers from across Australia. Quotations from these interviews are used within the draft Consensus Statement.

Purpose

The Consensus Statement sets out suggested practice for the provision of safe and high-quality end-of-life care to patients in acute hospitals. To achieve this, hospitals would need to have systems in place to address all elements in the Consensus Statement. As a consensus statement, the document represents recommended rather than mandatory practice.

The Consensus Statement aims to provide guidance for health services to develop their own systems for delivering safe, timely and high quality end-of-life care in a way that is tailored to their population, resources and available personnel, whilst being in line with relevant jurisdictional or other programs. The Consensus Statement aligns with the National Safety and Quality Health Service Standards but the suggestions for action within it are not mandated.

The purpose of this consultation process (refer to page 36) is to elicit feedback which will allow the Commission to refine and finalise the Consensus Statement, and to identify mechanisms to support its implementation and practical application.

Terminology

There is a lack of clarity and agreement about the meaning of many terms that are commonly used in relation to end-of-life care. It is important for all those involved in the provision of end-of-life care to have a common understanding about what such terms mean in practice. Some common terms, and a description of what they mean in the context of this document, are listed in Table 1 below.

Table 1: List of terms

Term	Description
Advance care directive	An advance care directive is a type of written advance care plan that is signed by a competent adult. An advance care directive can record the person's preferences for future care and appoint a substitute decision-maker to make decisions about health care and personal life management.[1] An advance care directive has legal status and is recognised by the common law and relevant legislation (where it exists) in each state and territory in Australia.
Advance care planning	Advance care planning is a process of planning for future health and personal care whereby the person's values and preferences are made known so they can guide decision-making at a future time when that person cannot make or communicate his or her decisions. Formal advance care planning programs usually operate within a health, institutional or aged care setting after a life-limiting condition has been diagnosed, frequently requiring the assistance of trained professionals. However, people can choose to discuss their advance care plans in an informal family setting.[1]
Advance care plan	An advance care planning discussion will often result in an advance care plan. Advance care plans state preferences about health and personal care and preferred health outcomes. They may be made on the person's behalf, and should be prepared from the person's perspective to guide decisions about care.[1]
Carers and family	Those who are closest to the patient in knowledge, care and affection. Carers and family may include the biological family, the family of acquisition (related by marriage or contract), and the family and friends of choice (including pets).[2]
Clinicians	People who provide clinical care and/or medical treatments to patients.
Dying	In this document the term 'dying' is used in reference to the terminal phase of life, where death is imminent and likely to occur within days or hours and occasionally weeks. This is sometimes referred to as 'actively dying'.
End of life	Encompasses the period where a patient is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown.[2]
End-of-life care	For the purposes of this document, end-of-life care includes both care delivered when a patient is imminently dying (sometimes referred to as terminal care or comfort care), and the interventions that may be required by a patient who is living with a life-limiting disease and is likely to die within the next 12-24

	months.
	End-of-life care is intended to indicate medical treatment, ancillary treatment, and symptom control, and also includes spiritual, psychosocial and family support.
	It includes care of the body after death.
Goals of care	The aims for a patient's medical treatment as agreed between the patient, family, carers and health care team. Goals of care may also include non-medical goals such as returning home or reaching a particular milestone such as participating in a family event.
	Medical goals of care may include attempted cure of a reversible condition, a trial of treatment to assess reversibility of a condition, treatment of deteriorating symptoms, or the primary aim of ensuring comfort for a dying patient.
Interdisciplinary team	A team of providers who work together to develop and implement a plan of care. Membership varies depending on the services required to identify and address the expectations and needs of the patient, carers and family. An interdisciplinary team typically includes one or more doctors, nurses, social workers, spiritual advisors, pharmacists and personal care workers. Other disciplines may also be part of the team depending on the needs of the patient and the resources available.[2]
Limitations of medical treatment	Decisions to limit what treatments will be provided may be made when these will not be of benefit to the patient.
	There a number of terms commonly used to describe making limitations to the treatment that will be provided for a patient. Examples of these terms include limitations of medical treatment, withdrawal or withholding of care or treatment, limitations of care, futile treatment and appropriateness of treatment. All of these terms relate to the decisions that are made about what medical treatments will and will not be offered and provided to patients.
	These decisions should always be informed by the goals of care, which requires engaging with the patient's expressed values, as well as expert consideration of whether a particular medical intervention will or will not provide benefit to a patient at the end of life. It also includes consideration of the reversibility of a patient's condition, the effectiveness of the intervention in terms of its ability to prolong life, and whether attempting the intervention may contribute to reduced or increased suffering at the end of life. Additionally, the decision-makers need to consider the baseline condition of the patient, including their pre-morbid level of physiological reserve, frailty, and level of function or independence prior to hospitalisation.
	Decisions to limit medical treatment may avoid prolongation of dying but will not cause a patient's death. This is quite different from the practice of euthanasia where death is deliberately and purposefully hastened.
Non-beneficial treatment	Non-beneficial treatment refers to interventions that will not be effective in treating a patient's medical condition or improving their quality of life. Non-beneficial treatment may include

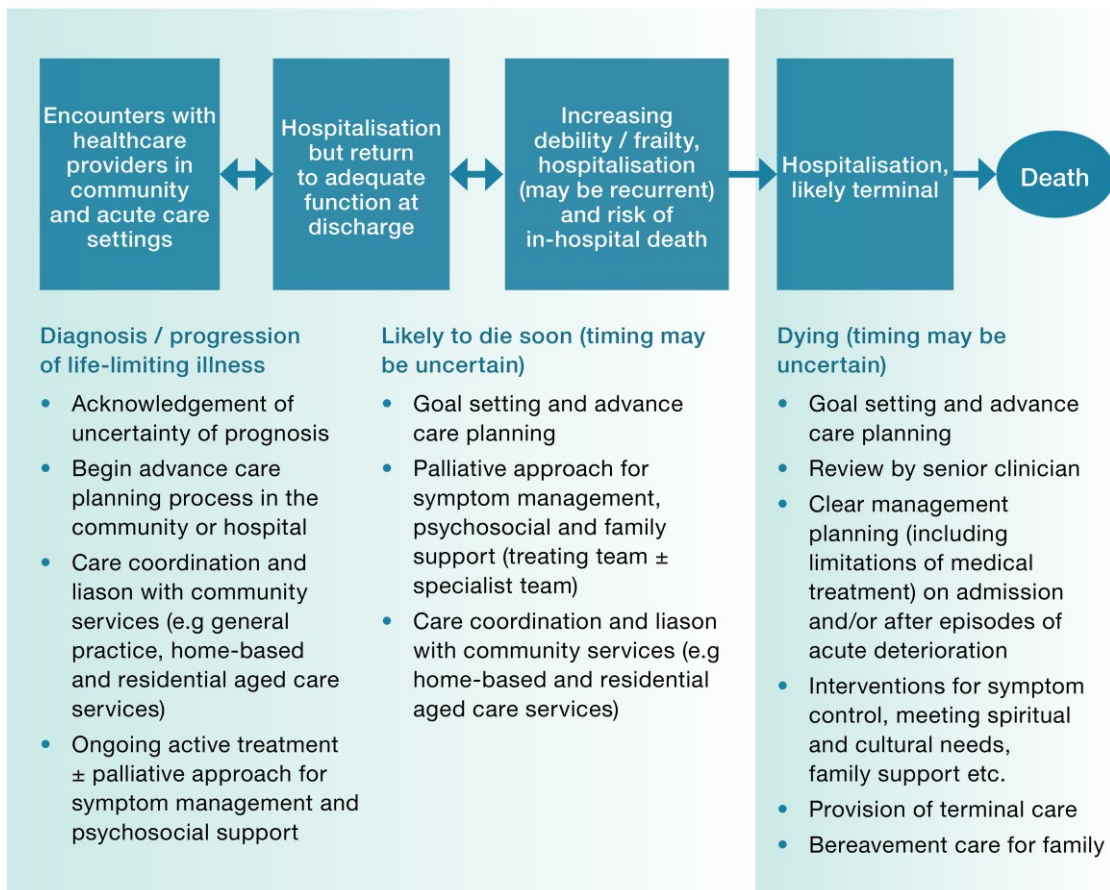|	interventions such as diagnostic tests, medications, the provision of artificial hydration and nutrition, the provision of intensive care, and medical or surgical procedures.
Palliative care	In this document palliative care refers to care focussed on the relief of symptoms, such as pain and breathlessness, and other problems associated with life-limiting illness. Palliative care is not limited to care of the dying; it may be necessary and useful well in advance of a patient's death. The primary goals of palliative care are to improve quality of life, optimise comfort and dignity and provide support to the patient, their family and carers. Palliative care interventions may be provided by the treating team or by specialist palliative care clinicians. All clinicians should be able to provide care consistent with a palliative approach, but specialist palliative care from providers with advanced training and expertise may be required for patients and families with complex care needs at the end of life.
Patient	A patient is the primary recipient of care.
Resuscitation orders/plans	Not for resuscitation (NFR) or do not attempt resuscitation (DNAR) orders or plans relate specifically to decisions to not perform cardiopulmonary resuscitation in the event of a patient having a cardiac or respiratory arrest. In some organisations, decisions about other specific treatments may also be listed as part of a resuscitation plan (for example, decisions to call a medical emergency team or transfer a patient to intensive care in the event that they deteriorate). Unless specifically excluded in the resuscitation plan, all other treatments and care should be provided in accordance with usual practice and the plan of care.
Substitute decision-maker	A substitute decision-maker is 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, though the relevant legislation varies from state to state. 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. A substitute decision-maker may be appointed by the person, appointed for (or on behalf of) the person, or identified as the default decision-maker by Guardianship Acts around Australia. More than one substitute decision-maker may be appointed under an advance care directive.[1] A preferred decision-maker may be nominated by a patient in a document such as an advance care plan but this in and of itself does not necessarily grant legal authority for this person to be a substitute decision-maker.

Scope

This Consensus Statement relates to situations where end-of-life care is indicated for adults who are identifiably approaching the end of their lives.

There are two particular periods of time near the end of life where it may be particularly opportune to apply the elements of this Consensus Statement:

1. When a patient is likely to die in the medium term (i.e. within the next 12-24 months) but there is potential for reversibility if episodes of acute clinical deterioration occur.

2. When a patient is likely to die in the short term (i.e. within days to weeks or during the current hospital admission) and any clinical deterioration is likely to be irreversible.

Figure 1 illustrates the type of end-of-life care interventions that might be needed as a patient approaches the end of life.

Figure 1: Opportunities to provide end-of-life care interventions in acute hospitals

Predicting prognosis and the timing of dying can be difficult. For some acute hospital patients it may be difficult to distinguish clinical deterioration that is reversible from deterioration which is irreversible and part of the normal dying process. In such cases, it may be appropriate to consider a time-limited trial of treatment to assess the reversibility of a patient's deterioration.

It should be acknowledged that the process of dying is not always straightforward and it is likely that aspects of care will need to be revisited as a patient's condition changes. For example, psychosocial and spiritual care needs may change over time and should therefore be repeatedly assessed.

In addition, some elements of the Consensus Statement may only be relevant at particular points in time while others are applicable across the whole patient journey. For example, some aspects of advance care planning may no longer be as relevant when a patient is actively dying, but good symptom control remains relevant during both terminal care and for quality of life over the longer term.

The Consensus Statement applies in all types of acute hospitals, from large tertiary hospitals, to small district and community hospitals. It applies to inpatient acute care and rehabilitation settings. It does not apply to situations where patients are primarily being treated by a specialist palliative care team. There are systems and structures in place in palliative care that may vary significantly from those within the general acute hospital and there are already a range of policies, processes and standards in place within the palliative care sector that support the delivery of high-quality, patient-centred end-of-life care.

This document does not relate to the practices of euthanasia or physician-assisted suicide, which involve the administration of medications in the deliberate attempt to hasten death.

Application of the Consensus Statement

The purpose of this Consensus Statement is to outline a proposed national approach to end-of-life care in acute hospitals. It is intended to be applied with careful consideration of the interface between clinical deterioration and end-of-life care. There are significant overlaps between this document, the *National Consensus Statement: Essential Elements for Recognising and Responding to Clinical Deterioration,* and *National Safety and Quality Health Service (NSQHS) Standard 9*. Therefore, systems, processes and structures for delivering safe and high-quality end-of-life care should work in synergy with those for recognising and responding to clinical deterioration.

This Consensus Statement provides high level guidance about the principles and actions that should shape end-of-life care in acute hospitals. There are many other national, jurisdictional, professional and local frameworks, guidelines, policies, directives and procedures related to end-of-life care (for example, the *National Framework for Advance Care Directives* outlines best practice for the use and application of advance care directives). This Consensus Statement is not intended to provide detail about the specific needs of particular populations of patients.

There are also standards and guidelines that apply in settings outside the scope of this Consensus Statement but which are relevant to its implementation. For example, the *Standards for Providing Quality Palliative Care for All Australians* were developed by Palliative Care Australia for use in specialist palliative care services. Both the Consensus Statement and the Palliative Care Australia Standards are relevant when considering how to develop systems that foster a collaborative approach between acute and specialist palliative care services.

Although the Consensus Statement does not apply to care provided in the community, the way in which acute hospitals communicate and coordinate with primary care services and residential care aged care facilities is a critical consideration when planning and implementing systems addressing the elements of the Consensus Statement.

Although the scope of this Consensus Statement is limited to acute hospitals, many of the principles and elements may also be applicable in non-acute settings such as residential aged care facilities or hospital in the home. Similarly, although the scope of the Consensus Statement is limited to the care of adults, many of the principles and actions may also be relevant for children at the end of their lives.

Intended audience

The Consensus Statement has been developed for:

- doctors, nurses and other members of the interdisciplinary team

- health service executives and managers responsible for the development, implementation and review of systems for delivering end-of-life care in individual hospitals or groups of hospitals

- providers of clinical education and training

- planners, program managers and policy makers responsible for the development of jurisdictional or other strategic programs dealing with the delivery of end-of-life care.

Guiding principles

1. Dying is a human experience and not just a medical experience. Caring for the cultural, spiritual and psychosocial needs of patients and their families and carers is just as important – and sometimes more important – as providing physical care.

2. Recognising when a patient is approaching the end of their life is essential to delivering appropriate and timely end-of-life care.

3. The potential for ambiguity and uncertainty associated with individual prognosis and the likelihood of response to medical treatment at the end of life must be honestly and openly acknowledged.

4. Safe and high-quality end-of-life care is patient and family-centred and, whenever possible, should be aligned with the values, needs and wishes of the individual and their family or carer. Such care should consider the patient's expressed wishes in regard to the circumstances, environment and place in which they wish to die.

5. A patient's needs, goals and wishes at the end of life may change over time.

6. Safe and high-quality end-of-life care requires the availability of appropriately senior, qualified, skilled and experienced interdisciplinary teams.

7. Safe and high-quality end-of-life care requires effective communication, collaboration and teamwork to ensure continuity and coordination between teams within and between settings and across multiple episodes of care.

8. When possible, end-of-life decision-making is shared between the interdisciplinary team, and the patient, their substitute decision-maker, family and carers. The interdisciplinary team have a responsibility to:

    - create opportunities for patients to make decisions about end-of-life care, and to communicate their values, goals and wishes regarding their care

    - provide timely and accurate information regarding the patient's clinical condition; its severity or stage; the expected disease trajectory; the available treatments; and the likelihood of response to such treatments

    - clearly communicate information to support patients, substitute decision-makers, family and carers to make decisions about their care and to check that they understand the implications, consequences and risks associated with such decisions

    - offer support to reduce the burden of decision-making

    - actively assist decision-making by offering expert opinion and advice

    - initiate the process of advance care planning and setting of treatment goals, and documentation and communication of limitations of medical treatment.

9. Patients and substitute decision-makers have the right to refuse burdensome medical treatments, including in advance of when such treatments may be indicated.

10. Care of a patient's body, and for families and carers, extends to the period after the patient has died.

Essential elements

These elements describe the essential features of systems for recognising and responding to patients who are approaching the end of life. The elements do not prescribe how care should be delivered. Hospitals need to have systems in place to address all elements in the Consensus Statement; however the application of the elements will vary according to the local circumstances of the hospital, the available resources, and the individual needs of the patient receiving care.

This Consensus Statement includes ten essential elements. The first five relate to the way in which end-of-life care should be approached and delivered. The second five elements relate to the structural and organisational prerequisites that are essential to the effective delivery of safe and high-quality end-of-life care.

A) Processes of care

1. Patient-centred communication and shared decision-making

2. Teamwork and coordination of care

3. Components of care

4. Using triggers to help recognise patients approaching the end of life

5. Responding to concern

B) Organisational prerequisites

6. Leadership and governance

7. Education and training

8. Supervision and support for interdisciplinary team members

9. Evaluation, audit and feedback

10. Systems to support high-quality care

The following sections provide information about each element. Within each there is a brief introductory statement followed by a list of actions that describe the necessary processes and systems to effectively address that element.

A) Processes of care

1. Patient-centred communication and shared decision-making

It's when [clinicians] see that they're very much in partnership with the patient and they're prepared to risk themselves to get alongside the patient. Giving the patient lots of time; being empathetic; being prepared to recognise that the patient has got a whole lot of other things going on as well as their disease.

Consumer

Key points

- The patient, substitute decision-maker, family, carers and clinicians are all essential participants in discussions and clinical decision-making at the end of life

- Having conversations about death, dying and the end of life requires knowledge, sensitivity and skill on the part of the clinician(s) involved

- It may be necessary to have a series of conversations in order to elicit the goals, values and wishes of a patient and reach shared decisions about the appropriate plan for their care

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Effective communication is an essential requirement for safe and high-quality end-of-life care. Higher levels of shared decision-making during end-of-life care have been associated with higher levels of family satisfaction with care,[3] and poor communication is a major factor in complaints relating to end-of-life care.[4-5]

This essential element primarily relates to the process of clinicians communicating with patients, substitute decision-makers, families and carers in order to make clinical decisions about care at the end of life. Depending on the needs and wishes of the patient concerned, other members of the interdisciplinary team may also need to be involved in these discussions.

There are a number of significant events that might indicate that conversations about end-of-life care should occur. In the acute hospital, significant events that might trigger these conversations include:

- diagnosis of a life-limiting condition

- admission of a patient living with a life-limiting illness

- when unexpected, significant physical deterioration occurs

- when a patient who is likely to die in the medium term (12-24 months) is admitted or deteriorates during their admission

- when a patient who is likely to die in the short term (days to weeks) is admitted or deteriorates during their admission.

The purpose of conversations about end-of-life care will vary depending on the circumstances of the patient. In some cases the primary purpose of communicating with patients, their families and carers will be to impart information. In other cases, decisions about specific aspects of care may need to be made. Regardless of the purpose of the conversation there is opportunity to begin or continue the process of shared decision-making.

Shared decision-making is a critical part of making sure that patients approaching the end of their lives are partners in their own care. It is more than just providing information to patients and their families or asking them questions to inform a clinically driven decision. It is a process that allows patients, substitute decision-makers, families and interdisciplinary teams to work together to make decisions based on the best scientific evidence available, the realities of the patient's clinical condition and treatment options, and the patient's choices, values and preferences. Doctors and other involved clinicians should use their clinical skills and experience, and their knowledge of the patient's values and preferences, to make recommendations that inform the decision-making process.

Actions

1.1 Clinicians should identify opportunities to have proactive and pre-emptive end-of-life care discussions in order to reduce the risk of having urgent, after-hours discussions in emergency situations.

1.2 Whenever possible, and in accordance with the patient's wishes, the clinical team should identify and involve the substitute decision-maker, family spokesperson, or other key contacts in discussions about end-of-life care.

1.3 Clinicians should seek to understand and be respectful and sensitive to the preferences and needs of patients, substitute decision-makers, families and carers from culturally and linguistically diverse backgrounds.

1.4 Whenever possible, clinicians should prepare for having conversations about end-of-life care. Necessary preparation may include:

- reaching agreement within the clinical team(s) about the patient's prognosis and what treatment options are appropriate to recommend

- ensuring familiarity with the patient's history and current condition, their family structure and cultural needs and preferences

- arranging adequate time for uninterrupted discussion

- arranging for the appropriate people to be in attendance (this may include substitute decision-makers, family members, the most senior doctor available, and other members of the interdisciplinary team such as interpreters, chaplains or social workers)

- ensuring that discussions with patients, their families and carers can be held in an appropriately quiet and private environment.

1.5 At all times the patient, substitute decision-maker, family and carers should know which clinician is responsible for leading and coordinating their care. Whenever possible this clinician should be directly involved in discussions about the patient's end-of-life care.

1.6 Whenever possible, clinicians should ensure that the patient, substitute decision-maker, family and carers are all present during key end-of-life discussions so that consistent messages can be given about treatment options and their likelihood of success, risks, and prognosis.

1.7 The lead clinician should provide an honest and straightforward summary of their clinical assessment of the situation, what they consider to be appropriate and feasible options for care, and the likelihood of the patient's condition improving in response to such care.

1.8 Clinicians should express empathy for the patient's situation and allow adequate time for those involved to absorb, process and react to the information they are being given.

1.9 Clinicians should check that the patient, substitute decision-maker, family and carers have a shared understanding of what has been discussed and any plan of care that has been agreed.

1.10 Clinicians should clearly document the content of the discussion and any agreed plan of care in the patient clinical record.

1.11 The content of the discussion, and plan of care, including any limitations of medical therapy or changes to a patient's resuscitation status, should be communicated to other members of the interdisciplinary team.

2. Team work and coordination of care

To be able to plan appropriate death as you would plan appropriate discharge at a multidisciplinary level, that would be good.

Nurse – public hospital focus group

Key points

- In order for a patient's end-of-life preferences and needs to be fulfilled, members of the healthcare team(s) who are involved in their care need to work together effectively

- The healthcare team includes: the interdisciplinary team in the hospital; the patient and their substitute decision-maker, family and carer; and any community care providers such as those working in residential aged care homes and general practices

- Processes should be in place to support care coordination and continuity, particularly at the interface between different services and teams (e.g. hospital and community based services or the treating team and after-hours care providers)

Patients often receive care from a range of organisations with different systems, roles and approaches to managing end-of-life care. Interdisciplinary teams include individuals with varied experience, values and perspectives on planning and providing end-of-life care. Unless there is an identified person who takes overall responsibility for coordinating a patient's care and ensuring effective communication and collaboration, patients can receive discordant information and poorly coordinated care.

The interdisciplinary team should respect and appropriately use each other's expertise, and that of the patient, substitute decision-maker, family and carers. For effective team work, roles and responsibilities need to be clear and processes need to be in place for the organisation and exchange of information.

The patient's goals of care, and the treatment plan, needs to be clear to all members of the interdisciplinary team so that care can be effectively coordinated. This includes ensuring effective communication and liaison with care providers in the community such as general practitioners, home care workers, and nurse managers of residential aged care facilities.

Actions

2.1 The clinician with overall responsibility for leading and coordinating a patient's care must be clearly identified.

2.2 The roles and responsibilities of different team members should be clearly defined and understood by all those involved in a patient's care, including by the patient themselves and by their family and carers.

2.3 If there is disagreement or ambiguity about the appropriate options for future treatment amongst the healthcare team or teams, then the range of views and the reasons for them should be discussed with the patient, substitute decision-maker, family and carers.

2.4 There should be appropriate processes in place to enable all team members, including junior clinicians, to engage with the broader team, voice concerns, and act on the expressed preferences of the patient.

2.5 It is the responsibility of experienced team members to provide supervision and support, mentorship and teaching to develop the skills and capacity of junior team members in relation to end-of-life care.

3. Components of care

You have to have a system in place for recognising that people are dying. You have to have a system in place for negotiating goals of care. You need to have in place advance care planning processes, and you need to ensure that you've got clinical processes in place for pain and symptom management, and care of the family. They're the very basic things that everybody should be entitled to.

National manager of palliative care – private hospital network

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Key points

- Processes should be in place to support proactive, anticipatory and individualised planning for end-of-life care

- Active medical treatments and end-of-life care are not mutually exclusive. Many patients may benefit from an approach where medical treatments for their disease are provided in conjunction with palliative interventions aimed at improving or maintaining the best possible quality of life and symptom relief

- Dying patients have a right to maintain their dignity, comfort and privacy and to be cared for respectfully and with compassion

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The goal of the interdisciplinary team providing end-of-life care should be to deliver care that is appropriate to the needs of the patient and aligned with their expressed wishes. Opportunities should be sought to identify the patient's goals and wishes for their future care, offer psychosocial, spiritual, cultural and emotional support, provide treatments that maintain or improve quality of life, and avoid unnecessarily burdensome and unwanted investigations and treatments.

For many patients approaching the end of life there will be a long period of transition where treatment for reversible complications or reversible episodes of clinical deterioration will continue. Patients at this stage may benefit from a palliative approach in conjunction with active medical treatment of their disease. This kind of dual care can enable improved support and symptom management and therefore assist patients to maintain their quality of life.

When a patient enters the terminal phase of their illness, some treatments will cease to provide benefit and may become uncomfortable and burdensome. For patients in the terminal phase of illness, the plan of care should generally be focussed on providing comfort to both the dying patient and their family and carers. The plan for a patient's terminal care should be clearly documented, including anticipatory plans for managing physical, psychosocial, emotional, cultural or spiritual distress.

Actions

3.1 Psychosocial, cultural and spiritual needs of a patient approaching the end of life should be assessed and care provided in accordance with their wishes and needs.

3.2 The process of advance care planning should be instigated or revisited for a patient who is identified as approaching the end of life.

3.3 In clinically appropriate circumstances, clinicians should ask about and document a patient's wishes in regard to donation of their organs after death.

3.4 Unnecessary burdens should be avoided for a patient who is approaching the end of life. For example, non-beneficial or unwanted observations, surgical interventions, investigations and/or treatments should not be prescribed or administered.

3.5 The goals of care, treatment plan and resuscitation plan for the current admission should be appropriately discussed with the patient, their substitute decision-maker, family and carers, and clearly documented in the patient clinical record by the treating medical officer or team. This should occur as early as possible in the patient's admission to hospital and be routinely reviewed and updated throughout the admission.

3.6 The goals of care, treatment plan and resuscitation plan should be revisited with the patient, substitute decision-maker, family and carers when significant changes in the patient's condition or circumstances occur. The patient, substitute decision-maker, family and carers should be enabled to request further discussion and a review of the plan at any point.

3.7 Information about advance care plans, goals of care, resuscitation plan and a patient's treatment preferences should be readily available to all clinicians involved in a patient's care, including those involved in caring for the patient in emergencies, after hours, and where relevant, in the community.

3.8 The rationale for decisions to discontinue or withhold non-beneficial observations, investigations and/or treatments should be clearly communicated to the patient, their family and carers. If there is unresolved concern or disagreement about stopping a non-beneficial observation, investigation and/or treatment then an independent second opinion should be offered with a view to resolving the situation.

3.9 The patient, their family and carers should not feel abandoned by the healthcare team when the goals of care shift from cure to comfort because the patient is dying. Care, compassion, open and honest communication about what to expect, and the comfort of the dying patient remain a priority.

3.10 All patients have the right to adequate pain relief and symptom control. Physical symptoms should be managed in alignment with a patient's wishes. For example, some patients may choose to tolerate discomfort in order to remain alert for as long as possible, whereas others may choose to tolerate a level of sedation in order to be pain-free.

3.11 Unless there is a clear and convincing reason not to do so, a dying patient should be supported to receive oral food and fluids for as long as they wish.

3.12 Family and carers should be supported to spend time with a dying patient in accordance with their wishes, including in the period immediately after death. Bereaved family and carers should know how to access bereavement support when they have left the hospital.

3.13 Clinicians should proactively seek alternatives to hospital-based care when appropriate and as preferred by the patient. If feasible this should include the patient's usual residence, a residential aged care facility, hospice or other palliative care facility.

4. Using triggers to help recognise patients approaching the end of life

It takes a lot of skill sometimes to recognise when somebody is dying.

Intensive care liaison nurse – public hospital focus group

Key points

- Recognition systems in acute hospitals should aim to identify patients at two critical points:

  ⇨ when a patient is likely to die in the medium term (i.e. within the next 12-24 months) but there is potential for reversibility if episodes of acute clinical deterioration occur

  ⇨ when a patient is likely to die in the short term (i.e. within days to weeks / the current hospital admission) and clinical deterioration is likely to be irreversible

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A fundamental first step in providing safe and high-quality end-of-life care is to recognise those patients who would be likely to benefit from such care. Considering the likelihood of a patient dying offers opportunities to identify their needs, review the goals and plan of care, and consider how best to align care with the individual's expressed values, goals and wishes. Routine use of simple trigger tools and questions can prompt clinicians to use their clinical judgement to make a holistic assessment of whether a patient might benefit from end-of-life care.

Clinicians should also be aware of the referral criteria, processes and timelines for accessing specialist palliative care services.

Actions

4.1 The 'surprise' question should be used by clinicians as a simple screening mechanism to recognise patients who could benefit from end-of-life care interventions.

- Would you be surprised if this patient died in the next 12-24 months?
- Would you be surprised if this patient died during this admission or in the next days or weeks?

4.2 Clinicians should recognise that when the patient, family members, carers or other members of the interdisciplinary team express concern or worry that the patient is approaching the end of their life, and/or has unmet end-of-life care needs, this is a critically important trigger for assessment.

4.3 Clinicians should consider additional triggers that may be useful prompts for recognition and review of patients who may benefit from end-of-life care interventions. Suitable triggers might be derived from condition-specific mortality risk prediction tools or from critical events. Examples might include:

- diagnosis of life-limiting conditions
- poor or incomplete response to medical treatment and/or the development of new clinical problems during the inpatient admission
- repeated calls to the rapid response team, particularly if the patient has been in hospital for more than one week

- advanced age, increased frailty and reduced mobility, increased dependence on others to assist in performing activities of daily living

- when the patient has been declined for interventions such as surgery, dialysis or treatment in intensive care

- third or fourth line chemotherapy

- prolonged stays in hospital.

5. Responding to concern

As physicians we are about investigating and treating…. It's a bit of a mind switch, that what you are doing is actually harmful and hurting rather than helping.

Doctor – public hospital focus group

Where do you go for help when [dying] is not being recognised? When there is a group of carers saying 'No, we shouldn't be escalating care here'. Where do you go in the hospital when there is conflict amongst health care workers about the level of care appropriate for an individual?

Intensive care liaison nurse – public hospital

Key points

- It should be as easy to access support for the provision of appropriate end-of-life care as it is to escalate care for reversible deterioration

- A patient in physical, psychosocial or spiritual distress requires rapid assistance from a suitably skilled care provider

- When responding to concerns that end-of-life care needs are not being adequately recognised or addressed, responders may require access to a second opinion from an independent senior clinician (including from a separate hospital)

- When managing conflict, complex family dynamics or ethical dilemmas, responders may require access to a person who is skilled in mediation, bioethics and/or the law

- Processes for responding to concern need to be appropriate to the size, role, resources and staffing mix of the acute hospital

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When concerns are raised about a patient approaching the end of life who is in distress, or there are complex needs related to end-of-life decision-making, it is important that capacity exists to obtain timely and appropriate assistance from a suitably skilled person or team. The nature and timing of the response may vary depending on the nature of the issue causing concern and the person who is escalating the concern. For example, a different response may be needed for concerns raised by a family member about a patient's physical pain or distress compared to the response required to resolve conflict or an ethical dilemma.

The initial response to concerns about end-of-life care issues may be provided by a member of the clinical team such as the senior registrar or consultant, or by a member of another team, for example an after-hours medical registrar or a specialist palliative care clinician. In some hospitals, for example small rural hospitals, responding to concern may require access to external clinicians, such as general practitioners, or the use of technology to access off-site speciality help.

Actions

5.1 The criteria and processes for accessing help for end-of-life issues that are causing concern should be clearly defined in relevant policies and procedures.

5.2 The patient, substitute decision-maker, family and carers should understand the triggers and process for requesting an urgent review.

5.3 Processes should be in place to enable patients, their substitute decision-maker, family, carers, and members of the interdisciplinary team to continue to escalate concern until a satisfactory resolution to the issue is achieved. This should include access to a second opinion if there are concerns that end-of-life care needs are not being adequately recognised or addressed by the clinical team.

5.4 Concern or worry that a patient is approaching the end of their life and has unmet end-of-life care needs should prompt multidisciplinary review of the goals of care and the treatment plan. This should apply regardless of whether the concern is raised by the patient, their substitute decision-maker, family or carers, or by a clinician.

5.5 Clinicians should have rapid access to specialist palliative care advice 24 hours a day and seven days a week.

5.6 Whenever possible, decisions to limit medical treatment, stop non-beneficial treatments, or begin terminal care should be avoided in the after hours period. Ideally these decisions should be made with input from the patient, substitute decision-maker, family and carers, the interdisciplinary team and the responsible medical officer. There will be necessary exceptions to this when a patient has deteriorated suddenly and irreversibly, and/or is in distress.

5.7 The responder(s) providing assistance in emergency situations should have access to support from a clinician of sufficient authority to make decisions about withholding or withdrawing non-beneficial treatments and providing terminal comfort care.

5.8 If the responder is not part of the clinical team they should communicate with the responsible medical officer in an appropriate, detailed and structured way about the outcomes of the call for assistance and the plan for follow up or further review of the patient.

5.9 Responders should document appropriate, detailed and structured information about the outcomes of the call for assistance, discussions with the patient and/or substitute decision-maker, and the plan for follow up or further review of the patient, in the health care record.

5.10 Whenever possible, responders providing assistance should use the call for assistance as a teaching and mentoring opportunity for other clinicians and students.

B) Organisational prerequisites

6. Leadership and governance

> *I think there has to be a consensus view driven through clinical governance as to the approach. The only way you're going to drive change is to have an agreed approach. In our organisation that can only be through clinical governance.*
>
> Surgeon – public hospital focus group

> *I think [there] needs to be responsibility from that higher level to say 'this hospital supports care of the dying'.*
>
> Nurse – public hospital focus group

Key points

- End-of-life care should be included in the governance system for the organisation

- Safety and quality of end-of-life care should be monitored by the executive level of governance in the organisation

- Leadership at all levels in the organisation is required for safe and high-quality end-of-life care

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For many organisations significant culture change will be necessary to develop successful and sustainable systems for delivering safe and high-quality end-of-life care and to effect improvements to the experiences of patients, their families and carers. To achieve this, a systematic approach and committed leadership is necessary. Executive and clinical leaders at all levels of the organisation's clinical and corporate governance structures should provide proactive and practical support to the interdisciplinary teams and managers responsible for delivering end-of-life care.

Actions

6.1 Patients, their families and carers should be partners in the development and governance of organisational systems for delivering end-of-life care.

6.2 A formal policy framework should exist outlining the organisational approach to end-of-life care. This should include issues such as:

- governance arrangements

- roles and responsibilities

- communication and documentation processes

- advance care planning and resuscitation planning processes

- alignment with systems for recognising and responding to clinical deterioration

- access to specialist palliative care advice and services

- the interface with external services such as community and social care providers, residential aged care facilities and external hospice providers

- clear dispute resolution processes including access to mediation, bioethics and legal support in situations of complex end-of-life decision-making or conflict

- training and education requirements

- access to professional clinical supervision and debriefing

- evaluation, audit and feedback processes and reporting requirements

- resources for the delivery and effective functioning of the system for providing end-of-life care.

6.3 This policy framework should apply across the acute hospital and identify any planned variations in its application that might exist in different circumstances (such as at different times of day).

6.4 The policy framework for end-of-life care should operate in synergy with recognition and response systems for patients who are clinically deteriorating.

6.5 Appropriate policies and documentation regarding advance care directives, limitations of medical treatment and end-of-life decision-making are critical in ensuring that the care delivered in response to deterioration is consistent with appropriate clinical practice and the patient's expressed wishes.

6.6 A formal governance process should be in place to oversee the development, implementation and ongoing review of systems for end-of-life care. If a committee has this role it should:

- have appropriate responsibilities delegated to it, and be accountable for its decisions and actions to the executive

- monitor the effectiveness of interventions and educations

- have a role in reviewing performance data

- provide advice about the allocation of resources

- include consumers, interdisciplinary team members, managers and executives

6.7 Organisations should have systems in place to ensure that essential resources required for the provision of safe and high-quality end-of-life care (such as private space for family meetings, equipment and medications) are always operational and available. Resourcing of specialist palliative care services is not within the scope of this Consensus Statement.

7. Education and training

I think when it comes to ongoing professional development they should be seeking ways to get the patient experience into that. At the moment there is only the complaints process for patients to get their experience across.

<div align="right">Consumer</div>

I found that staff just didn't know…. There was avoidance, yes, but they didn't know what to do, they didn't know what they were supposed to do. They haven't got that exposure or experience to know how to treat a dying patient, or that patients are allowed to die.

<div align="right">Tissue and organ donation nurse educator – public hospital</div>

Key points

- It is important that all care providers have a shared understanding of the local terminology, policies, processes and practices associated with end-of-life care

- The skills and knowledge required to manage end-of-life care are complex and need a specific educational focus

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Having an educated and suitably skilled and qualified workforce is essential to providing appropriate end-of-life care. Education should cover: identification of patients approaching the end of life; advance care planning; referral and communication processes both within the acute hospital and to local community and social care providers; relevant legislation and other regulatory frameworks; essential clinical management skills for providing palliative care; and communication and teamwork. It should also include education and training for junior medical staff regarding how to have discussions and conversations about end-of-life care.

A range of methods can be used to teach appropriate knowledge and skills about end-of-life care. These include face-to-face and online techniques, simulation, mentoring and supervised clinical practice. Organisations should also consider accessing existing external training programs.

Actions

7.1 All members of the interdisciplinary team should receive education about their roles and responsibilities in relation to the local systems and processes in place for recognising and managing end-of-life care. This information should be provided at the commencement of employment and as part of regular refresher training.

7.2 All doctors and nurses should be able to understand and apply the *Guiding Principles* and *Processes of Care* elements in Part A of this Consensus Statement.

7.3 Patients, families and carers should be invited to participate in providing training about end-of-life care. Patient stories can be powerful tools for teaching but it is important that patients, families and carers are adequately supported to share their experiences.

7.4 Junior doctors and nurses should be encouraged to take up the learning opportunities offered by participating in family meetings, multidisciplinary case review meetings, mortality and morbidity conferences and adverse event reviews.

7.5 All members of the interdisciplinary team should receive education about how to recognise and resolve feelings of moral distress and burnout in themselves and their colleagues.

7.6 Education should include understanding the legal framework in the jurisdiction of clinical practice.

7.7 Education should include specific cultural competencies for providing end-of-life care to Aboriginal and Torres Strait Islander peoples.

8. Supervision and support for interdisciplinary team members

I get asked to teach junior doctors about self-care and I tell them that unfortunately they are in a profession where bravado is seen as the way to operate…. We are very, very bad at this. I found as a junior doctor doing my physician training, learning to cope with the deaths of 17 or 18-year-olds on the oncology ward, I couldn't look to anyone in medicine, if tears came to your eyes you were not supposed to show anyone.

General medicine physician – public hospital

Often the patient is palliated and [the death] is okay but for us the process to get there was quite painful and distressing.

Nurse unit manager – public hospital

Key points

- Dealing with death and dying can be challenging for interdisciplinary team members

- Hospitals should facilitate access to peer support, mentoring and appropriate clinical supervision

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Dealing with death and dying can be challenging for members of the interdisciplinary team, and can add considerably to workplace stress. Chronic unmanaged stress can erode empathy and potentially contribute to poorer experiences for patients. It is important that systems are in place to facilitate access to peer support, mentoring and appropriate clinical supervision.

Supervision and support systems may help to enable learning and the development of skills in the delivery of end-of-life care, but their primary purpose should be to support members of the interdisciplinary team and to prevent or resolve distress.

Actions

8.1 A policy framework should exist outlining how supervision and support is provided to members of the interdisciplinary team.

8.2 Members of the interdisciplinary team should know when and how to access peer support, mentoring and clinical supervision. This information should be provided at the commencement of employment and as part of regular refresher training.

8.3 Members of the interdisciplinary team should know how to access support to defuse and debrief after particularly distressing or problematic episodes of care. This may involve accessing external services to facilitate formal debriefing.

8.4 Members of the interdisciplinary team should be supported to develop skills in self-care, reflective learning and providing peer support to colleagues.

9. Evaluation, audit and feedback

The quality of death is what I think we should be measuring, not the fact of death. There's all this literature about the fact of death, do MET [medical emergency team] calls save lives…but quality of death, well it's silent. The literature is just silent. We don't measure it.

Intensivist – private hospital

Key points

- Ongoing monitoring of the effectiveness of end-of-life care systems and processes is essential for quality improvement

- Evaluation should address the quality and safety of end-of-life care provided, not just the potential preventability of death

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Ongoing monitoring and evaluation of processes and systems for delivering end-of-life care is essential to establish their efficacy, track performance over time and determine priorities for improvement.

Actions

9.1 Data about the effectiveness of processes and systems for delivering end-of-life care should be collected, reviewed, and reported locally and over time.

9.2 It is vital for clinicians to lead evaluation and audit and to feed back aggregate, de-identified data to their peers and colleagues.

9.3 Monitoring and evaluation strategies should be developed to capture feedback about the quality of end-of-life care from multiple disciplines (e.g. medicine, nursing, social work), as well as from patients, substitute decision-makers, families and carers.

9.4 Evaluation and monitoring should be simple, inexpensive, feasible, and use routinely collected data, and data linkage, where possible.

9.5 Measures of the safety and quality of end-of-life care could include:

- correct treatment of symptoms

- alignment of the patient's expressed wishes with actual care

- feedback on the experiences of families and carers of patients who received end-of-life care

- whether any existing advance care directive or plan was enacted, or not

- the category of death (expected/unexpected/diagnosis)

- time lapse between the decision to palliate or referral to specialist palliative care and death

- transfers of care in the last week of life (for example transfers to or from intensive care).

9.6 Methods for collecting data could include:

- retrospective audit of case notes (for example, documentation of discussions, patient preferences, anticipatory plan of care, appropriateness and frequency of clinical observations)

- medication chart safety review (for example were inappropriate medications stopped, were palliative medications prescribed and administered appropriately)

- family and volunteer follow up (for example at 6 months)

- multidisciplinary mortality and morbidity review.

9.7 All deaths should be routinely reviewed to determine whether the quality and safety of the patient's end-of-life care was acceptable, and in what ways it could have been improved.

10. Systems to support high-quality care

In the same way that we are concerned about in falls management, or medication management, we should be concerned about safety and quality in terms of how we manage people at the end of their life.

National manager of palliative care – private hospital group

I see this as a multi-step process...we want to change the culture but that's not going to happen, [we] need to find concrete ways to change practice.

Palliative care consultant – public hospital

Key points

- Taking a systems approach to the provision of end-of-life care is necessary to embed and sustain improvements

- Systems for end-of-life care should be integrated into existing organisational and safety and quality systems to support their sustainability and opportunities for organisational learning

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Organisations should consider opportunities to systematise the approach to end-of-life care where this will support best practice. For example, by developing consistent processes for accessing palliative medications, the timeliness of treatment for distressing symptoms may be improved. Technological systems such as the personally controlled electronic health record may also provide benefits to patients, for example, by contributing to improved communication with external care providers and improved continuity and coordination of care as patients are transferred in and out of acute hospitals.

Actions

10.1 The policy framework, processes and systems for delivering end-of-life care should operate in synergy with recognition and response systems for patients who are clinically deteriorating.

10.2 Systems should be in place to support clinicians to work with patients, families and carers to receive, prepare, review and/or update advance care plans and directives. These systems should align with National Safety and Quality Health Service Standard 1: Governance for Safety and Quality in Health Service Organisations and Standard 9: Recognising and Responding to Clinical Deterioration in Acute Health Care.

10.3 Systems should be in place to provide access to essential palliative medications 24 hours a day and seven days a week.

10.4 Systems should be in place to provide timely access to input from specialist palliative care providers when required for patients with complex palliative care needs. This may include off-site access via video or teleconferencing.

10.5 Organisations should implement processes to improve communication between health services at transitions of care. This should include processes for communicating the content of discussions about prognosis and advance care planning.

10.6 Systems should be in place to facilitate appropriate documentation about end-of-life care, and to reduce the burden of documentation and data collection when possible.

10.7 Technological systems and solutions should be implemented where they will support safe and high-quality end-of-life care in accordance with the actions in this Consensus Statement.

How does this look in practice?

The following case study is fictional. It is designed to illustrate how the elements of the Consensus Statement might be translated into clinical practice.

Eric Kitchener, a 74-year-old man, has chronic pulmonary obstructive disease (COPD). Eric also has mild kidney failure due to medication-controlled diabetes. In the last 6 months Eric has been largely housebound. He ambulates with a wheelie frame and is able to accompany his wife to the local shops once per fortnight. He needs some assistance with dressing, and sleeps on 3 pillows due to his breathlessness. Eric's wife Elsie called an ambulance today because over the last 24 hours Eric's breathing became much worse than usual. Elsie is sorting things out at home, and will follow Eric to hospital as soon as she can.

Dr Craig Franks is the admitting emergency department (ED) registrar who assesses Eric when he arrives at the resuscitation room. He finds that Eric is cyanotic and very distressed by his shortness of breath despite continuous nebulisers administered in the ambulance. Eric is unable to talk because of his respiratory distress. Dr Franks learns from the ambulance officers that this is Eric's third admission in the last year and that he has been on home oxygen for the last six months.

Dr Franks considers the 'surprise' question and decides he would not be surprised if Eric died in the next few days, weeks or months. The hospital uses the Gold Standards Framework (GSF) to help to identify people who might benefit from end-of-life care. Applying the GSF criteria, multiple recent admissions and long term oxygen use in patients with COPD indicate a need to consider if a person has end-of-life care needs. But Eric is not currently able to talk, has no advance care directive, and no family present. Eric's breathing difficulty needs to be addressed urgently and Dr Franks decides he needs some input from his consultant to determine the right course of action.

Dr Franks calls the ED consultant, Dr Cornelia Latsis, for advice. Dr Franks and Dr Latsis agree that Eric would not benefit from intensive care but that a trial of treatment with intravenous antibiotics, intravenous hydrocortisone, bronchodilators, and non-invasive ventilation is appropriate, particularly given they are not sure of Eric's wishes at this stage. The two doctors agree that a not for resuscitation order should be documented because if Eric deteriorates to the point of suffering from a cardiopulmonary arrest, this will most likely be irreversible. Treatment is started, and the ED team prepare to hand over to the respiratory medicine team. Eric is commenced on non-invasive ventilation (NIV), which he finds tight fitting and uncomfortable.

Dr Sarah Patel is the respiratory consultant who takes over Eric's care when he goes to the medical high dependency unit. After reviewing Eric's history and his current condition, her opinion is that while he may survive to go home after this admission, Eric's COPD is likely to cause his death within the next few weeks or months. She agrees with the ED team's decision that he would not benefit from interventions such as cardiopulmonary resuscitation or intensive care and checks that this documentation is complete. She discusses the case with her team and they agree that the next priority is to speak with Eric and his family.

Dr Patel has never met Eric or his wife Elsie before this admission and she wants to know more about what they currently understand about Eric's condition and what his wishes are for his future care. On the ward round she explains that to develop a plan for Eric's care, she needs to understand what is most important to him, and to the family, at this stage of his life. Eric is currently reliant on the non-invasive ventilation for his breathing and cannot be moved to a private space so Dr Patel asks Elsie to

stay on after visiting time is over so that they can have as much privacy as possible to talk. She also asks if there is anyone else who should be present. Elsie rings and asks their daughter, Janine, who is Eric's appointed substitute decision-maker, to come in for the meeting.

Later that day Dr Patel, her junior registrar, Dr Rob Armitage, and Eric's nurse, Charlotte Wright, meet with Eric, Elsie and Janine. Chairs are brought to the bedside and introductions are made. Eric is alert and appears to understand what is going on, but he is finding it difficult to communicate verbally because of his shortness of breath and the presence of the non-invasive ventilation mask. Dr Patel starts by asking what the family understand about Eric's current condition.

Elsie says that she and Eric both know that Eric's COPD is getting worse, but he has been this bad before and got better again.

Dr Patel asks about how Eric manages at home and what kind of activities he enjoys. After some discussion of his usual routines, Janine adds that even when he is relatively well, Eric is not enjoying life much anymore, particularly now that he is fastened to the oxygen even at home.

Dr Patel tells the family that she is very worried because Eric is extremely unwell and may not recover. She says that at this stage of his disease it is still possible to try and treat exacerbations when they occur, but that even with treatment, Eric will die of his COPD soon.

Elsie starts to cry. She expresses shock and surprise that things are so bad, but goes on to say that she has been feeling very afraid for Eric as he hasn't been eating much and has been feeling worse all the time. Dr Patel and the other clinicians listen, and offer sympathy for the family's situation.

Dr Patel tells the family that she thinks at this stage it is reasonable to continue the current treatment with NIV and antibiotics to see how Eric responds over the next few days. She goes on to say that if Eric's condition deteriorates any further or he has not improved within the next week, then they should review things together again. Janine tells Dr Patel that when they did the substitute decision-maker paperwork Eric told her that he didn't want heroics at the end. Eric nods in agreement.

Dr Patel tells the family that if Eric has an episode of severe deterioration and is getting very distressed and short of breath, then the doctors and nurses will focus on keeping him comfortable and relieving his distress.

The family agree to the plan Dr Patel has outlined. Dr Patel tells them that her team will review Eric's progress every day and she will meet with Eric, Elsie and Janine again in a few days unless there is something new to report, or they have questions or concerns.

Dr Armitage documents the content of this discussion and the agreed plan in the clinical record. He documents triggers for urgent review by the home team or on-call registrar. These include upper limits for non-invasive ventilation pressures; upper and lower limits for respiratory rate, heart rate and blood pressure; respiratory distress; changes to Eric's level of consciousness including confusion or drowsiness; and worry from the family or the nurses. Eric's nurse, Charlotte, asks Dr Armitage to prescribe some doses of morphine that can be given as required to ease Eric's breathlessness.

Charlotte goes back to check on Eric and the family. She sees that Elsie is quite upset and tearful. Charlotte sits and talks with the family for a few minutes then offers a cup of tea. She reassures them all that no matter what, Eric will be cared for and kept as comfortable as possible. She knows that the family are Methodists, and she asks if they would like to see a chaplain. She also asks if Elsie and Janine would like

to meet with the social worker for support and further information about managing in the coming days and weeks. Charlotte tells them that she will make referrals to the dietician to arrange supplements to help keep up Eric's calorie intake, and to the physiotherapist to help Eric manage his respiratory secretions and maintain his mobility.

Over the next few days the dietician, physiotherapist, social worker, and hospital chaplain all visit Eric and the family. Strategies and plans are put in place to help Eric manage his breathlessness, respiratory distress and anorexia, and to offer ongoing practical and emotional support to the family.

Susanna Pralus is the nurse unit manager of the 38-bed general medicine ward and 4-bed high dependency unit where Eric is being cared for. When she started managing the ward, with input and support from the medical director, allied health and the ward's medical consultants, Susanna set up a daily interdisciplinary team meeting to ensure that a coordinated plan of care would be in place for every patient. From the outset there was a clear expectation that the on-take consultant attend, as well as at least one registrar and intern from each medical team with a patient being cared for on the ward. The nurse in charge, ward pharmacist, physiotherapist, social worker, occupational therapist and dietician also attend. The culture of the meetings fosters participation from everyone who attends, offers an opportunity for the interdisciplinary team to understand each other's roles and viewpoints, and to support and learn from each other. During the week Susanna runs the meeting, and on weekends the on-take consultant, registrar and the nurse in charge of the shift work together to run the meeting.

Eric's case is discussed at the interdisciplinary meeting every day, and a problem list is used to identify key events or issues that need to be considered. The template for the problem list includes items such as the status of planned investigations, consultations or interventions; unexpected or significant changes in the patient's condition, medical emergency calls, or falls occurring in the previous 24 hours; and discharge planning. Prompts are built in to the list to consider the need to update the patient and family members, follow up test results and consult with other specialties or disciplines, or liaise with community services. The list becomes a record of any decisions made and actions to be taken for each patient, and is filed in the patient record and reviewed at the following day's meeting. The list also helps to ensure a properly documented interdisciplinary plan of care, promotes the delivery of consistent messages to patients and families, and informs clinicians who are providing care in the after-hours period.

Over the next week Eric makes very little progress. Attempts are made to wean the non-invasive ventilation but without success. Eric has developed a pressure sore across his nose from the non-invasive ventilation mask. He says that he hates the mask, and the nurses report they are struggling to get it fitting comfortably. He has also stopped eating altogether and takes only sips of water. He is no longer tolerating getting out of bed, and he looks frail and exhausted. At the interdisciplinary meeting it is agreed that Eric is dying. It is decided that Dr Patel and Quentin Francis, Eric's nurse that day, should meet with the family to discuss stopping Eric's current medical treatments.

When Quentin and Dr Patel meet with the family, Dr Patel tells them that she is worried because Eric has not responded to treatment and has deteriorated significantly. She goes on to say that she thinks the current treatments are likely to be prolonging Eric's dying and adding to his suffering rather than providing him with any benefit. Elsie starts to cry, and says that she is not ready to let him go. Dr Patel reaches out to hold Elsie's hand and allows her to cry. After some minutes, Elsie says that she knows that Eric has had enough and that he has been telling her that

he is ready to die. Eric nods in agreement. Eric tries to remove the non-invasive ventilation mask and Quentin offers him oxygen through nasal prongs so that he can talk. Eric says clearly that he has had enough and just wants it all to stop.

Dr Patel checks that she has understood correctly that Eric would prefer to stop his current treatment, be kept comfortable, and allow natural death to come. She asks if Eric and the family understand that Eric will die quite quickly without the non-invasive ventilation. The family nod that they do. Dr Patel and Quentin reassure them that the healthcare team will work to manage Eric's respiratory distress and keep him comfortable. Dr Patel tells Eric, Elsie and Janine that things will take a little time to arrange and that she will speak with the family again later in the afternoon.

Dr Patel documents that she and the family are in agreement that continuing Eric's current medical treatment is no longer in accordance with his wishes or in his best interests. She writes that the non-invasive ventilation and antibiotics are to be stopped, and that he should be allowed to die naturally. A plan is put in place to start a subcutaneous infusion of morphine and midazolam before stopping the non-invasive ventilation and Dr Patel prescribes other palliative medications for symptom relief as required.

Quentin informs the nurse in charge, Belinda Evans, about the agreed plan. He asks if they could arrange to move Eric to a single room so that the family could have some privacy. Belinda manages to arrange for a room to be made vacant that afternoon and Eric is moved there. Quentin informs the hospital chaplain and the social worker that Eric is dying. They both visit and provide support to Eric, Elsie and the family. Dr Patel also visits to check in and see that Eric is comfortable and the family have no questions.

Eric's family and friends are encouraged to visit and be with him as much as they wish. When everyone has visited and the morphine and midazolam have started to take effect, the non-invasive ventilation is stopped. Eric dies later that day surrounded by his family.

Dr Patel approaches the family to discuss the possibility of corneal and whole eye donation. The family discuss this amongst themselves after reading literature they are provided. Later on Eric's wife is approached by Dr Patel, and she agrees that Eric would have wanted to donate his eyes to help the vision of others.

Quentin asks Elsie and Janine if they would like to be present while he washes Eric's body. They decline, but come back to see Eric again before he is taken to the morgue. When they are ready to go, Quentin gives them some leaflets and talks them through the information about the practicalities of choosing a funeral director, what to expect after bereavement, and where to find support.

At the interdisciplinary meeting the following day Dr Patel checks in with the team to see if anyone has any immediate questions or concerns about the way in which Eric's death was managed. An expected death audit form is commenced to ensure Eric's death is included in the monthly quality and safety death review.

Consultation process

The Commission is seeking comments on the consultation draft of the *National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care in Acute Hospitals*. Comments and feedback will help the Commission to refine and finalise the Consensus Statement, and to identify mechanisms to support its implementation and practical application.

The Commission is seeking written submissions from interested stakeholders and will also be conducting a series of workshops in each of Australia's capital cities during the consultation period. The purpose of the workshops is to seek in-depth and context specific feedback from acute care service personnel, patients, families and carers. Those interested in participating in these workshops should email an expression of interest to: endoflifecare@safetyandquality.gov.au

Purpose

The consultation process aims to determine:

- if the Consensus Statement accurately reflects the standard of care that should be expected by patients, families and carers receiving end-of-life care in acute hospitals
- if the Consensus Statement provides useful guidance to acute health services delivering end-of-life care
- if there are any major gaps, or missing principles or elements that need to be considered in the delivery of safe and high-quality end-of-life care
- how consumers can engage with acute hospitals to help implement the elements of the Consensus Statement
- which principles and elements should be given priority in the Commission's next phase of work
- what existing tools and resources would be helpful in implementing the Consensus Statement
- what tools and resources need to be developed to help implement the Consensus Statement.

Key consultation questions

Questions of particular interest include:

1. Is the intended purpose and scope of the Consensus Statement clear? Why or why not?
2. Does the Consensus Statement accurately reflect what you think the expected standard of care and practice should be? Why or why not?
3. Are the guiding principles clearly outlined? How do you think they could be applied in practice?
4. Are the essential elements clearly outlined? How do you think they could be applied in practice?
5. Is there any terminology that needs further exploration or clarification?
6. What enablers exist to help with implementing the elements of the Consensus Statement? How can these be leveraged to promote best practice?

7. What barriers to implementing the elements of the Consensus Statement exist? How do you think these can be addressed?

8. In what ways can consumers engage with acute hospitals to help implement the elements of the Consensus Statement?

9. What principles and elements do you think need to be addressed most urgently in acute hospitals? Please list in order of priority (i.e. 1 = highest priority)

10. What resources or tools do you need to help you implement the elements of the Consensus Statement?

11. What resources or tools already exist that could be used to help implement the elements of the Consensus Statement?

Submissions are not required to address any or all of these questions, and may respond or provide general comments on other issues relating to the Consensus Statement.

Submissions

Submissions can be sent by post or email. All written submissions should be received by close of business on **Monday 31 March 2014** to be considered in the consultation process.

Submissions should include:

- name, organisation (if relevant) and contact details

- responses to the consultation questions

- general comments

- additional information, for example, any tools, resources or research the Commission should be made aware of and that supports the content of the submission

Written submissions should be marked 'End-of-life care consultation' and posted to:

Consultation on the end-of-life care consensus statement
Australian Commission on Safety and Quality in Health Care
GPO Box 5480
Sydney NSW 2001

Submissions can also be emailed to: endoflifecare@safetyandquality.gov.au

All submissions received will be published on the Commission's website, including the identities of individuals and/or organisations making the submission. The Commission will consider requests to withhold part or all of the contents of any submission made. Any submission that includes personal information identifying specific individuals or organisations may be withheld from publication or de-identified before submissions are published.

Outcome of the consultation

The results of this consultation process will be used to further refine the Consensus Statement and to guide the Commission's next phase of work. Feedback will contribute to the identification of existing resources and tools, and, where necessary,

development of additional tools and resources to assist with the implementation of systems for delivering safe and high-quality end-of-life care in acute hospitals.

A consultation report will be made available on the Commission's website when the consultation process is closed and the submissions have been analysed.

Further information

Any questions relating to the submission process should be directed via email to endoflifecare@safetyandquality.gov.au or by calling the Commission on (02) 9126 3600.

Contributing documents

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The GSF Prognostic Indicator Guidance. The Gold Standards Framework Centre CIC, 2011. (Accessed 17 September, 2012, at http://www.goldstandardsframework.org.uk/Resources/Gold%20Standards%20Framework/General/Prognostic%20Indicator%20Guidance%20October%202011.pdf)

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1.Working Group of the Clinical Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council. A National Framework for Advance Care Directives. Australian Health Ministers' Advisory Council, 2011.
2.Palliative Care Australia. Palliative Care - Glossary of Terms. 1 ed. Palliative Care Australia, 2008.
3.White D, Braddoch C, Berenyei S, Curtis J. Toward shared decision making at the end of life in intensive care units: opportunities for improvement. *Archives of Internal Medicine* 2007;167(5):461-467.
4.Australian Commission on Safety and Quality in Health Care. Safety and Quality of End-of-Life Care in Acute Hospitals: A Background Paper. Sydney. ACSQHC, 2013.
5.Baird H, King B, Kerr R, Walker A. Care for the Dying in NSW A Review of the Data from the 2012 Quality Systems Assessment. Sydney. Clinical Excellence Commission, 2013.