safety and quality of

end-of-life care in acute hospitals

a background paper

contents

executive summary

Acute hospitals provide end-of-life care to the majority of people who die in Australia. The population is ageing and as the proportion of older Australians grows, it is likely that the numbers of people requiring end-of-life care in this setting will rise. The quality and safety of end-of-life care has important implications not only for the individual patient but also for their family, the people involved in providing that care and for society as a whole. Potentially preventable physical, emotional and spiritual distress can occur if care is less than optimal and there are significant cost implications for society if unwanted or inappropriate medical treatments are continued. Even with the considerable investment in palliative care services that already exists, and the implementation of initiatives such as palliative care guidelines, education programs, care pathways and advanced care planning programs, it appears that persistent gaps in the quality and safety of end-of-life care remain.

During 2012–13, the Australian Commission on Safety and Quality in Health Care (the Commission) undertook scoping and preliminary consultation work in an effort to understand the complexity of issues and barriers affecting the delivery of safe and high-quality end-of-life care in acute facilities. This background paper presents a précis of the current policy and clinical framework for end-of-life care within the Australian acute healthcare setting and as interpreted by consumers, clinicians and policy makers. It provides a platform for discussion about future work of the Commission to improve the safety and quality of end-of-life care.

The overall focus of acute hospitals is generally on diagnosis and treatment with a view to cure and discharge of the patient. In this context, recognition of the fact that a patient may be approaching the end of life and in need of interventions – such as conversations about their goals of care, limitations on treatment, a palliative approach to care, or provision of terminal care – is often delayed. Invasive investigations and treatments may continue beyond the point where they are effective, and may contribute to suffering at the end of life. Communication and care planning with patients and families may be poor; psychosocial and spiritual needs may be neglected; and patients may have suboptimal control of symptoms and pain at the end of life.

While a senior clinician is nominally responsible for a patient's overall care in hospital, junior clinicians are often responsible for the initial assessment and care planning and for much of the day-to-day decision-making, particularly out of hours. Junior staff often lack experience in recognising and managing end-of-life care needs and perceive that they lack authority to make decisions about limiting medical treatment. There is also evidence that they frequently fail to contact senior decision makers for help with patients whose condition is complex or deteriorating. Even when senior specialists are contacted, their professional focus on a single organ or disease group may mean that care is targeted to treatment of the presenting problem without holistic assessment of a patient's condition.

Most of the clinicians who participated in the preliminary consultation interviews felt strongly that end-of-life care should be part of their core business, but it appears that this is not always usual practice. Outsourcing end-of-life care to the medical emergency team, the palliative care team or the intensive care team appears to be common practice. This is less than ideal for patients as it

means that this type of care may be provided only in response to acute deterioration, by strangers, after hours, and in urgent circumstances.

Australia has been characterised as a 'death denying' society where many people are reluctant to consider their own mortality and talk with their families about what their wishes are for the end of life. Clinicians report that it is often much easier to continue treatment than to talk with patients and families about the end of life. There are a number of factors that contribute to clinicians avoiding these conversations. These include systemic factors such as shortage of time or a lack of appropriately private space; educational factors such as inadequate training and mentoring in necessary communication skills; and personal factors such as fear of complaints and litigation or discomfort with talking about dying.

Even when clinicians do discuss a poor prognosis with patients and relatives, the quality of communication can be variable – failures of communication are the most common reason for complaints in health care, and end-of-life care is no exception. Documentation of end-of-life conversations and any subsequent decisions about goals of care, limitations of treatment or palliative interventions is also variable and can contribute to considerable uncertainty for junior clinicians or those attending to patients outside of the usual hours of the treating team.

Pre-hospital issues also contribute to the variable quality and safety of end-of-life care in acute facilities. Limited availability of options for caring for the dying outside of hospital perpetuates the need to utilise acute hospital beds for this work. Poor uptake of advance care planning and the documentation of advance care directives in the community and in aged care facilities mean that the goals of care may be unclear when a patient presents to a hospital emergency department. Even when an advance care directive has been documented it may not be available or applicable at the critical moment.

It is clear that the factors contributing to less than optimal end-of-life care in acute hospitals are complex and do not lend themselves to easy solutions. The issues raised by participants in the consultation interviews aligned closely with findings in the literature. There appears to be a need to address change at every level – from changes to an individual clinician's practice to societal changes in attitudes toward death and dying. The path to achieving such change is challenging because although there is general agreement and some evidence about what the problems are, there is currently a lack of either clear evidence or consistent agreement about what the standard of care should be, or how to achieve it.

In previous work by the Commission regarding the processes of recognising and responding to clinical deterioration, the development of a national consensus statement was crucial in providing a basis for further work to integrate recognition and response systems into usual practice through the development of *National Safety and Quality Health Service (NSQHS) Standard 9*. Similarly, in order to work toward improving the quality and safety of end-of-life care in acute hospitals, it is first necessary to achieve consensus about the standard of care that should be expected.

The Commission proposes working with consumers, clinicians and other experts to develop a national consensus statement about the standard of end-of-life care that patients, families and carers should expect in acute care settings. Through reaching high level agreement on a consistent set of principles to guide the delivery of end-of-life care in acute facilities, a framework for accountability can then be developed to ensure positive change at the level of individual patient care. This may involve the development of a safety and quality or clinical care standard, evaluation criteria and/or training curricula. Additional tools and resources will be developed with a view to supporting and enabling patients, families and carers to participate in shared decision-making about their care at the end of life.

introduction

How people die matters. Although we know that many Australians receive excellent care at the end of life, it is clear that some do not. Most Australians die in acute hospitals, despite the majority of people reporting they would prefer to die at home.[1-2] In a system which is designed for rapid diagnosis and treatment with a view to cure and discharge of the patient, it appears that it is often difficult to provide high-quality end-of-life care.[3] Even with considerable investment in palliative care services nationally, and the implementation of improvements in models of care such as palliative care guidelines, education programs, care pathways and advanced care planning, there are some persistent gaps in end-of-life care.

During 2012–13, the Australian Commission on Safety and Quality in Health Care (the Commission) undertook scoping and preliminary consultation work in an effort to understand the complexity of issues and barriers affecting the delivery of safe and quality end-of-life care in acute facilities. A summary of the interviews and focus groups that informed this consultation is in Appendix B. This paper provides a summary of issues identified as well as existing policy approaches, evidence and opinion relating to the delivery of end-of-life care in acute hospitals. Quotes from interview participants are inserted throughout the paper to illustrate the issues discussed.

purpose and scope

The purpose of this background paper is to present a précis of the current policy and clinical framework for end-of-life care within the Australian acute healthcare setting and as interpreted by consumers, clinicians and policy makers. It provides a platform for discussion about future work of the Commission to improve the safety and quality of end-of-life care. As a first step in this work, the Commission is intending to develop a national consensus statement on the essential elements of safe and high-quality end-of-life care for patients in acute care hospitals.

The intended audience for this paper includes:

- consumer groups, consumers, and their families and carers
- clinicians and managers in the acute care sector
- policy makers.

For the purposes of this paper, 'end of life' is defined* as being that part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown.[4] End-of-life care combines the broad set of health and community services that care for people as they approach the end of life.[4] This paper is focussed on end-of-life care interventions that are usually provided in acute facilities.

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. These practices are currently illegal in all jurisdictions of Australia.

structure

This paper begins by providing some contextual information about why the Commission has decided to undertake work about the safety and quality of end-of-life care in acute hospitals. This is followed by two parts that provide information about current knowledge, policy and practice relating to end-of-life care.

Part A describes what is currently known about dying and the way in which care is provided at the end of life. Examples of community awareness, policy, educational and other initiatives are included to illustrate current national and international approaches to improving end-of-life care.

Part B explores common issues that affect the care of people at the end of their lives and that are faced by people who are responsible for delivering this care. These issues include:

- communication with patients and families
- recognising dying
- systems and processes of care in hospitals
- forward planning and limiting treatment
- training
- rural and remote settings
- end-of-life care for Aboriginal and Torres Strait Islander peoples.

The paper concludes with a brief summary and an outline of the proposed next steps to be taken by the Commission.

* Definitions of frequently used terms are available in Appendix A.

context

Ensuring that patients who deteriorate receive appropriate and timely care is a key safety and quality challenge. All patients should receive correct care regardless of their location in the hospital or the time of day. The Commission commenced a program of work in 2008 with the overall goal of saving lives and reducing harm by improving recognition and response to deteriorating patients. The *National Consensus Statement: Essential Elements for Recognising and Responding to Clinical Deterioration*[5] (the *Consensus Statement*) was endorsed by Australian Health Ministers in 2010. It informed the development of a comprehensive implementation guide, various supporting resources, and the *National Safety and Quality Health Service (NSQHS) Standard* for recognition and response to clinical deterioration in acute healthcare facilities.

The major focus of the program was to develop, implement and optimise systems to improve detection, recognition, escalation and response to clinical deterioration that might result in preventable morbidity and mortality. Increasingly, it is becoming apparent that for a significant number of patients, clinical deterioration in the acute hospital setting may not be preventable or reversible but a part of the normal dying process.[6-7] The *Consensus Statement* and the *NSQHS Standard* emphasise the importance of appropriate advance care planning in the context of patient deterioration, but the requirements for delivering safe and high-quality end-of-life care are not articulated.

This paper is focussed on the safety and quality of end-of-life care in the acute setting. In that context, it is necessary to consider how best to care for hospitalised patients with eventually fatal conditions who are at risk of, or actually experiencing clinical deterioration. Many of these patients are unlikely to benefit from invasive and burdensome therapies and may instead require end-of-life care that addresses their emotional and psychosocial needs and relieves distressing symptoms occurring during the natural dying process.[8-9]

part a

the current state of play

This section discusses the context within which end-of-life care is provided. Broad issues that have an impact on end-of-life care are explored. These include the complexity and fragmentation of service provision, common trajectories of decline amongst people with life-limiting conditions, and societal attitudes toward death, dying and medical treatment at the end of life. Policy and other approaches to improving end-of-life care are then discussed, including Australian and international, governmental and non-governmental initiatives.

1. end-of-life care: what do we know?

Advances in health care and general well-being mean that Australians live longer and can remain relatively independent despite multiple co-morbidities. Although most people state they wish to die at home, 52% actually die in hospital.[10] The most common trajectories of decline toward death involve either progressive loss of function or step wise reduction in function following episodes of acute deterioration. Toward the end of life, people often experience repeated hospitalisation and exposure to multiple healthcare providers. These frequent encounters provide opportunities for discussions about patient choices and preferences for therapeutic options toward the end of life. Unfortunately, issues such as fragmentation of care, a death denying culture, unrealistic media depictions, and variable legislation and funding models can hinder discussions, documentation and use of advance care plans.

Although the standardised death rate in Australia continues to decline over the long term, as the population increases, the actual number of Australians who die each year continues to increase, on average by 0.6% per year for males and 1.2% per year for females.[11] More than 146,000 people died in Australia in 2011, and it is thought that 25–50% of deaths could potentially be anticipated.[12-13] This has significant implications for services where end-of-life care is provided. Although Australia was placed second only to the United Kingdom in a recent study ranking the quality of end-of-life care services in 40 countries,[14] inadequacies in the quality of care for the dying persist both in Australia and internationally, particularly for those who die in hospital.[3,6,15-21]

> Ad hoc is very much the way things happen because people don't fit a system or a scheme. Some people at end of life come in through emergency, and no one knows who they are, and other people, palliative care have been here for, you know, [they are] known to us over a long period of time and there are good systems in place for those people.
>
> **Chaplain** – public hospital

> It's a real problem: we deal with quality of life; we don't deal with quality of death.
>
> **General medicine consultant** – public hospital

> To answer your question very directly, you asked 'Do people die well in this hospital?' They absolutely do not. People are allowed to linger for far too long, in far too much pain, and causing far too much distress to themselves and their family and the people who care for them … The current situation, to speak frankly, is completely unacceptable.
>
> **Intensive care consultant** – public hospital

1.1 a consumer's experience

A consumer whose mother was deteriorating in hospital after a prolonged illness describes her experience of trying to advocate for her mother to be referred to palliative care. This experience illustrates some of the difficulties of navigating the acute hospital system.

> My mother is wriggling about and she's thrashing in pain and she's stopped eating. She had really not been eating for about a week and a bit. My sister is convinced that she's decided to die. She's not responding, it's hard to get fluids into her. My sister chats to the nurse; she says 'I want to get her into palliative care, out of this place. This place has done this to her, we want to get her out, give her some comfort.'
>
> Along comes this consultant and the team and goes 'Huh! Palliative care? Your mother's not dying! The fact is she has no localised pain, she's a poor witness to pain. So therefore we don't think she's in pain.'
>
> I said, 'But she is suffering and we want some comfort and some relief.' He said, 'You have every right as a daughter to advocate for your mother but I am the consultant and I am the link liaison with the palliative care consultant and I will decide if she needs it. I am telling you she won't.'
>
> So what I did was I went to the [local community] palliative care service and spoke to the advisory person and explained the situation and asked what to do. She said the team should liaise with the palliative care service consultant in the hospital. So we were in a 'locked in' situation. There was absolutely no way we could get outside of that structure and have an independent view, even though the theoretical view was that even if she didn't have death about to imminently happen there were maybe some things that palliative care could suggest.
>
> **Consumer** – focus group interview

1.2 complexity and fragmentation

Ensuring that patients who are reaching the end of their lives have access to the right care at the right time by the right provider is fraught with difficulty. Patients who are in the last year of their lives may receive input from a great number of care providers in a range of care settings, and may present repeatedly to such settings. Care providers may include doctors, nurses and allied health professionals from non-governmental organisations, community care services, social services, hospitals, hospices and aged care facilities, as well as family and other carers. Each different care provider is likely to have a different level of training and experience in end-of-life care, and a different role in supporting the patient.

Transitions of care within and between services are high risk because some of these providers may have little understanding of each other's role and rarely communicate directly.[3,20] In a recent report on the care of the dying in New South Wales, gaps in communication between hospitals and paramedics were highlighted as a key issue.[3] Inconsistent and fragmented links within and between services and programs can lead to difficulties integrating care across the spectrum of community and acute healthcare services. The end result of this fragmentation is that patients and families may have to independently negotiate their way through complex systems with unreliable transitions between services, in order to access appropriate care.[22] For example, in a recent Australian academic paper studying the experiences of people with end-stage chronic obstructive pulmonary disease, the authors report that 'Care was fragmented, episodic and reactive,' and that patients and carers struggled to access appropriate services to meet their needs.[23]

It is often the case that processes of care within hospitals are also fragmented. A lack of clarity around processes for identifying surrogate decision-makers and advanced care plans, incomplete or inconsistent documentation, and the lack of a consistent approach to terminal care can significantly contribute to variations in practice.[3]

1. end-of-life care: what do we know?

Further complexity arises from fragmented funding arrangements and legal frameworks.[20] For example, states and territories have separate laws and guidelines governing advance care directives and substitute decision makers. The same terms may refer to different things in different jurisdictions, and the differing legal requirements for advance care directives can reduce their transferability between jurisdictions.[24] It is not certain how significant an issue this is, but it may be problematic when patients transfer between states or when clinicians begin work in a new state. Funding arrangements also vary, with different aspects of end-of-life care being funded by different governments and via different mechanisms.

1.3 trajectories of decline

Dying is no longer the relatively rapid process that it once was. Most people will die with 'unpredictable timing from predictably fatal chronic disease'.[25] As life expectancy increases and people age for longer, an increasing number experience a prolonged period of disability, frailty and illness as they approach the end of their lives.[26] Glaser and Strauss first described the concept of a 'trajectory of dying' in the 1960s. This term describes how an eventually fatal condition will change a person's health and functional status over the period of time leading up to their death.[27-28]

The four trajectories of decline that are commonly described relate to groups of conditions that are eventually fatal (see Figure 1 on page 11). These trajectories are:

1. **Sudden death:** unexpected, rapid death from causes such as trauma or acute myocardial infarction.

2. **Terminal illness:** commonly associated with conditions such as cancer, where there is a period of relative wellness until the condition no longer responds to treatment and quickly becomes overwhelming.

3. **Organ failure:** chronic organ dysfunction from conditions such as congestive heart failure results in progressively declining function with periodic acute exacerbations of the underlying condition. Each exacerbation is potentially fatal but prognosis is ambiguous.

4. **Frailty:** a slow but steadily progressive decline in function associated with conditions of advanced ageing such as frailty, dementia and stroke. Death may eventually occur from medical complications such as pneumonia.

In their study of United States Medicare patients who died, Lunney and her colleagues found that in 85% of those who died aged 65 or older, the pattern of decline could be classified according to the common trajectories associated with terminal illness, organ failure or frailty.[27] Frailty was the single most common trajectory of dying amongst this population. Increasingly, the concept of frailty is being explored as an independent predictor of subsequent death, and tools have been designed to assist in its objective scoring.[29-30]
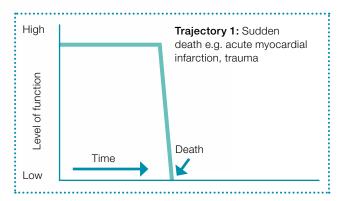
In Australia, chronic disease makes up more than 70% of overall disease burden.[20] Ischaemic heart diseases and cerebrovascular diseases consistently rank as the top two causes of death in Australia, followed by dementia and Alzheimer's disease, respiratory system cancers and chronic respiratory diseases.[31] Death rates from dementia and Alzheimer's disease have increased by 126% over the last decade and they are now the third most common cause of death in Australia.[31]
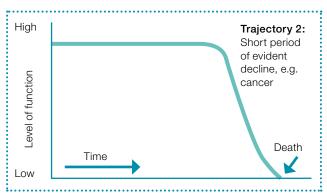
Palliative care services have traditionally been designed around the trajectory of decline associated with cancers. In Australia in 2008–09, 60.1% of all palliative care separations had a principle diagnosis of cancer.[32] Only one in three of the 74,276 people who died as admitted hospital inpatients had been palliative care patients at some time during their final hospitalisation.[32] Management of end-of-life care for those who are dying from chronic disease and frailty is generally managed by community and acute care services, and by aged care services such as residential care homes.
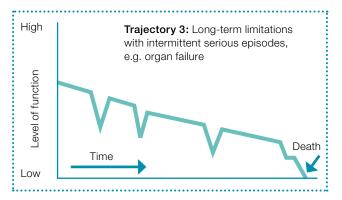
> Much of palliative care is actually seen as cancer related … you have palliative care when you are dying of cancer. I think the understanding that some of our 90-year-olds should be on a palliative care pathway – and should be on a palliative care pathway for maybe the last two years of their life, rather than the last two weeks of their life – is poorly recognised.
>
> **Medical director** – large private hospital
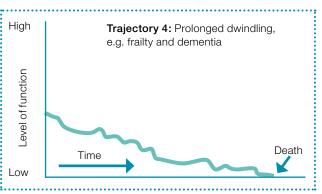
Figure 1: Trajectories of decline[27-28]

Trajectory 1: Sudden death e.g. acute myocardial infarction, trauma

Trajectory 2: Short period of evident decline, e.g. cancer

Trajectory 3: Long-term limitations with intermittent serious episodes, e.g. organ failure

Trajectory 4: Prolonged dwindling, e.g. frailty and dementia

1. end-of-life care: what do we know?

1.4 fear, denial and unrealistic expectations

Talking about death and dying is emotive and difficult for many people. In some cultures death and dying are taboo, and in some religions the sanctity of life is paramount and talking about concepts such as futility can be inflammatory.[17] Western societies, including Australia, have been characterised as 'death denying' and curative medical treatments are commonly prioritised ahead of palliative care and quality of life.[20] Clinicians' individual values, beliefs and experiences can also affect their behaviours and influence the way that they provide care to dying patients. For example, one study found that the religious beliefs of doctors influenced the way they reported managing ethically controversial decisions such as providing continuous deep sedation until the point of death.[33]

Interview participants suggested that fear and denial about facing issues around death and dying is common amongst clinicians as well as patients and families. This affects the approach of clinicians as well as the decision-making of patients and families. Many participants referred to fear as being a major barrier to talking about dying and planning for the end of life.

> I feel a lot of doctors are very scared about broaching the subject of somebody who is actively dying … they are so reluctant to talk to the family and say 'I'm sorry, but they're dying.' So they go through this whole rigmarole of 'Let's try this, let's try that' and the whole time it's just delaying the inevitable, giving them false hope.
>
> **Nurse** – public hospital focus group

> I think it's clinicians' fear. As my oncologist said, 'We're here to keep you alive.' When I asked him the question, some years ago, 'Look realistically, what's my time frame?' he didn't like that question.
>
> **Consumer**

> If we look at white Anglo-Saxon members of our community, we tend to believe that death is avoidable, that it's not going to happen to me. We don't see death as a part of life.
>
> **Policy officer** – state government end-of-life care working group

Participants also referred to fears held by clinicians about complaints or possible litigation stemming from involvement in end-of-life care. It was perceived that this can result in avoidance of dealing with dying patients.

> There is a big fear of liability and accountability so it seems some … doctors in particular, just won't get involved. If you didn't do anything in the room you don't get your name on the piece of paper.
>
> **Nurse unit manager** – public hospital focus group

A number of papers describe how television programs hugely inflate the success rates of interventions such as cardiopulmonary resuscitation (CPR).[8,34-35] Television may contribute to patients and families developing unrealistic expectations of the outcomes of such treatments. Many clinicians who participated in consultation interviews talked about the need to educate the public about the actual outcomes associated with CPR.

> I think we need some sort of public education campaign challenging those sort of TV dramas where people get resuscitated and are back at work next week …
>
> **Director of nursing** – public hospital

> There are many occasions where we just end up keeping going because a patient or family is just steam-rolling ahead. Even when patients have written plans they get overturned by these really strong families.
>
> **Intern** – public hospital

> It's just become ridiculous, the expectations. And this is one of the issues that we deal with on the front lines: just the expectations are made up by ER [medical drama] etc. That everything works; CPR is great. Or they've heard about one person, some distant relative that survived … So everyone that they know should go to the ICU [intensive care unit]. As against the 90-year-old person who quite possibly wants to die, it's often been my experience they go to the ICU because the relatives want them to go to ICU. And people just aren't allowed to die anymore, and die comfortably. You can't die with dignity.
>
> **Doctor**, medical grand round – public hospital

> It's the enormous expectation of society that we can do miraculous things. All these TV programs – they expect CPR to be invariably successful when we know one of four or five, maximum, survive. But that's not shown anywhere in TV so society's expectation is completely different to realism.
>
> **Intensive care registrar** – public hospital

Unrealistic expectations are not limited to patients and families. Consultation interview participants also talked about the way that some clinicians view the death of a patient as a failure.

> Death is everyone's business, it's our common lot. It's not a medical problem. Dying isn't a failure of medicine: it just is.
>
> **Medical director of palliative care** – public hospital

> Clinicians don't like talking about that [dying]; they're there to be positive, to keep you alive. To a certain extent, I think they see death as a failure on their part.
>
> **Consumer**

> It's like dying is a failure, and it's not. I know on my campus, they want to rush them over here [to the acute hospital] so they are absolved of the dying patient.
>
> **Site manager** – subacute hospital

2. policy and other approaches to improve end-of-life care

Action to improve end-of-life care can be taken in various ways. Despite a lack of high-quality evidence, multiple recommendations, position statements, quality measures, frameworks and strategies have been developed by governmental and non-governmental organisations.[36] Attempts to develop cohesive strategies for improving end-of-life care have been the focus of much work internationally. Numerous whole-of-system programs and specific clinical initiatives have been implemented. This section describes different examples of Australian and international initiatives.

In Australia, many improvement initiatives have targeted specific aspects of end-of-life care and there has been a lot of focus on the delivery of palliative care. It is difficult to reach conclusions about the impact of these initiatives on the safety and quality of end-of-life care delivered in acute facilities. Palliative care is a major part of end-of-life care but does not necessarily incorporate strategies such as advance care planning. Also, in acute facilities, specialist clinicians may not consider that palliative care is part of their remit and therefore some of the approaches targeting the delivery of palliative care may not be perceived as being relevant to their practice.

2.1 policies, strategies and programs

Policies, strategies and programs to address different aspects of end-of-life care exist in Australia at national, state and territory levels.

At the national level, the Australian Government Department of Health and Ageing has the **National Palliative Care Strategy**[13] and the **National Palliative Care Program**[37] in place. These aim to improve access to, and quality of, palliative care. Initiatives within the National Palliative Care Program include:

- grants for local community providers of palliative care services
- coordination of multi-site drug trials and applications for funding through the Pharmaceutical Benefits Scheme for palliative medications
- research and quality improvement initiatives for palliative care services, including the Palliative Care Outcomes Collaborative and Palliative Care Research Program
- educational programs, including the Palliative Care Curriculum for Undergraduates (PCC4U) and Respecting Patient Choices Program.

Most states and territories also have policies, strategies and programs about different aspects of end-of-life care. Some of these are in the form of guidelines or care pathways (discussed in the following section). Examples of other policies, strategies and programs are listed below.

- NSW Health has developed **Guidelines for end-of-life care and decision-making**.[38] These guidelines set out a process for reaching decisions about end-of-life care that emphasises the importance of communication, negotiation and consensus building, particularly when patients do not have the capacity to participate in decision-making. The draft **Advance Planning for Quality Care at End of Life Strategic and Implementation Framework**[39] provides direction for the development of a system-wide approach to advance care planning. It includes a range of implementation actions across the spectrum of aged and community care, primary care and acute care.

- In Western Australia, the Palliative Care Network Advisory Committee oversees a range of activities aimed at developing an integrated model of palliative care across the state.[40] These include the development of **Rural Palliative Care Networks, Metropolitan Palliative Care Teams** and the **Paediatric Palliative Care Program**.

- In South Australia the **End-of-Life Care Decision-Making Project** was undertaken in response to concerns about inconsistencies in practice in relation to resuscitation decisions and treatment at the end of life.[41] Policy, guideline and resuscitation planning documents have been developed and are currently out for consultation. The **Advance Care Directive Bill** was submitted to the South Australian Government in 2012 with a view to replacing previous legislation and creating a single form of advance care directive in South Australia.

- Tasmania's **Healthy Dying Initiative** is a public health promotion strategy which aims to engage the community in thinking and talking about the kind of care and treatment they would want when dying, and supporting those who are dying with the provision of appropriate and timely care.[42] As part of the initiative, resources have been developed to support advance care planning in the community and identification of goals of treatment in acute care.

2.2 community awareness

Some initiatives are targeted at the general public and take the form of campaigns, community education, social media or similar processes. In Australia, one example of a community awareness program linked to end-of-life care is the **National DonateLife Communications Framework** which is coordinated by the Organ and Tissue Authority. The aim of this education and awareness program is to encourage a national, informed conversation about organ and tissue donation. Initially, the aim is to get all Australian families talking about organ and tissue donation, and make their wishes about it known to their family, friends and loved ones.[43]

Other kinds of community awareness initiatives have been used internationally. For example, the **Conversation Project**[44] is a national campaign in the United States established in collaboration with the Institute for Healthcare Improvement. It aims to help people to talk with their families about what their wishes are for the end of life. A kit is provided to guide people through having 'the conversation' with their loved ones. This includes advice and prompt questions for getting started, 'where I stand' scales to help people to figure out what they feel about common scenarios encountered at the end of life, and tools and templates for recording the outcomes of these conversations. There are a number of other web sites which support people to talk about their wishes at the end of life. Examples of these are listed below and overleaf.

Examples of web sites supporting community awareness of advance care planning

A number of agencies have developed web sites containing information to support the public to talk about and plan for the end of life. Some Australian examples are listed below.

Healthy Dying Initiative
A health promotion initiative developed in Tasmania by the Department of Health and Human Services. Resources are provided for health professionals and the public about advance care planning and various aspects of palliative care.
www.dhhs.tas.gov.au/palliativecare/advance_care_planning_for_healthy_dying

Planning Ahead Tools
A New South Wales Government site providing information to help the public plan for their future health, welfare, financial and medical decision-making needs. Information about advance care planning and enduring guardianship is provided for the public and for healthcare providers.
www.planningaheadtools.com.au

2. policy and other approaches to improve end-of-life care

Respecting Patient Choices®

An advance care planning program that provides information resources to help consumers to develop advance care plans. It was originally developed in Victoria and is now funded under the National Palliative Care Program and supported by the Department of Health and Ageing.
www.respectingpatientchoices.org.au

There are also a number of international web sites providing information about advance care planning. Examples of these are listed below.

Caring Connections

The National Hospice and Palliative Care Organization is a national consumer and community engagement initiative in the United States which aims to improve care at the end of life. The web site provides resources and support for advance care planning as well as information and support for people dealing with aspects of death and dying such as grief and loss, pain, hospice and palliative care.
www.caringinfo.org

Dying Matters

A United Kingdom coalition set up by the National Council on Palliative Care which provides information and resources for advance care planning.
www.dyingmatters.org

Speak Up

A site set up by the Canadian Hospice Palliative Care Association providing information about advance care planning and improving end-of-life care.
www.advancecareplanning.ca

2.3 training and education programs

A number of training programs have been developed to address specific aspects of end-of-life care. In Australia, the National Palliative Care Program supports the **Palliative Care Curriculum for Undergraduates** (PCC4U) and the **Respecting Patient Choices** program.[45] These provide training, and information resources to help health professionals to improve their knowledge and skills about palliative care and advance care planning.

The **Program of Experience in the Palliative Approach**[46] (PEPA) is also funded under the National Palliative Care Program and aims to increase the skills and confidence of generalist care providers to work with patients requiring palliative care. Through the PEPA program, generalist healthcare workers can access educational workshops about the palliative approach, and clinical placements in specialist palliative care services. Reverse PEPA placements are also offered, where a specialist palliative care provider is placed in a generalist setting to provide teaching and support tailored to the setting.

Funding is also provided for the **CareSearch Palliative Care Knowledge Network**[47] as part of the National Palliative Care Program. It provides access to a range of resources, information and evidence about topics related to palliative care. Information is verified for its quality and is organised so that it is accessible to consumers, families, carers and health professionals.

Educational resources for consumers have been developed by various government and non-governmental agencies in Australia. An example of a specifically targeted resource is the **Kidney Stories Toolkit** which was developed by Kidney Health Australia. This includes flip chart educational tools about palliative care which are designed for use with Aboriginal and Torres Strait Islander patients who are living with life-limiting renal disease.[48]

Other educational programs have been developed to target particular groups of clinicians, for example the **Oncotalk®** program[49] which was developed in the United States with funding from the National Cancer Institute. This program is designed to help oncologists to improve their communication skills. Education modules in the program cover topics including giving bad news, managing transitions to palliative care and talking about advance care plans and 'not for resuscitation' orders.

2.4 legislation

In Australia, legislation about issues associated with end-of-life care is located at the level of the state or territory. There is considerable variation in the content and application of these laws. The two main areas of end-of-life care covered by legislation involve enabling people to nominate a substitute decision-maker, and laws governing advance care directives.

Currently there are jurisdictional variations in the content, structure and application of legislation governing advance care directives and health guardianship. This variability has an impact on a consumer's ability to transfer their documents from one state to another. It also has an impact on clinicians as they will need to learn and understand the local legislation when they move to work in a different state or territory.[24]

The **National Framework for Advance Care Directives**[24] sets out policy and practice goals for advance care directives in the future, in the context of current jurisdictional variation of the laws and processes governing the documentation and interpretation of advance care directives. The framework includes a code for ethical practice which describes the principles that should guide clinical practice. It also includes a set of best practice standards which aim to reduce variation between jurisdictions and promote consistent policy, practice and legislation across Australia.

2.5 standards

There are a number of sets of standards in Australia that are relevant for end-of-life care.

The **Standards for Providing Quality Palliative Care for all Australians** (the Palliative Care Standards) were first developed in 1994 by Palliative Care Australia, the peak national body for palliative care in Australia, in conjunction with the Australian Government Department of Health and Ageing and the palliative care community.[50] The Palliative Care Standards are designed to support quality management and improvement activities or benchmarking at a local, state or national level. The Palliative Care Standards are voluntary, but have been designed to be used in conjunction with, or as part of other accreditation standards for health services. There are thirteen Palliative Care Standards that cover issues including:

- ongoing and comprehensive assessment and care planning that is based on the uniqueness and holistic needs of the patient, carer and family
- coordinating care to minimise the burden on the patient, carer and family
- access to information, support and guidance about issues such as the role of the primary carer and bereavement
- the unique needs of the dying patient, maximising their comfort and preserving their dignity
- the commitment and orientation of the service to provide competent and compassionate palliative care that is based on quality improvement, research, collaboration and partnerships
- ensuring that there is access to palliative care for all people based on clinical needs.

2. policy and other approaches to improve end-of-life care

The **National Standards Assessment Program**[51] provides tools and resources enabling palliative care services to assess themselves against the Palliative Care Standards and use the results to prioritise and plan quality improvement activities. Services submit their findings to the National Standards Assessment Program and can undergo a peer review validation assessment. The program is funded under the National Palliative Care Program by the Department of Health and Ageing and participation is voluntary.

The *National Safety and Quality Health Service Standards*[52] (*NSQHS Standards*) were developed by the Commission with input from consumers, clinicians, health service managers, policy makers, technical experts and accrediting agencies. The primary aim of the *NSQHS Standards* is to protect the public from harm and improve the quality of care provided by health service organisations. From January 2013 assessment against the *NSQHS Standards* is mandatory for hospitals and day procedure services.

There are ten *NSQHS Standards* that are broadly relevant for the safety and quality of care of all patients, including those at the end of their lives. In addition, some specific items are included in the *NSQHS Standards* about preparing, receiving and documenting advance care plans.

The Accreditation Standards[53] for aged care services include four standards with multiple expected outcomes under each of these. Under the Health and Personal Care Standard, palliative care is one of 17 expected outcomes. This outcome also links to other expected outcomes such as the provision of pain relief, specialist nursing care, emotional support, privacy and dignity.

Internationally, the National Institute for Health and Clinical Excellence (NICE) in the United Kingdom has developed a Quality Standard for **End-of-life Care for Adults**[54] as part of the national **End-of-life Care Strategy**.[55] The standard sets out how high-quality end-of-life care services should be organised, and includes 16 statements describing high-quality end-of-life care. It defines 'end-of-life care' as that which is provided to adults (and to their families and carers) who are likely to die within 12 months, including those with incurable and life-threatening conditions and those who die unexpectedly.

A series of quality markers and measures[56] for end-of-life care have also been developed under the United Kingdom's End-of-life Care Strategy and these are linked to the NICE quality standard for end-of-life care. These include markers designed to evaluate the quality of care delivered in settings ranging from acute care hospitals to primary care services.

In Ireland, the **Hospice Friendly Hospitals** program describes four quality standards for end-of-life care in hospitals.[57] They present a shared vision of what end-of-life care in hospitals should look like with a focus on the needs of the patient, families, clinical staff, and hospital systems. The standards provide an aspirational target and stimulus for further work to improve the quality of end-of-life care in Irish hospitals.

2.6 financial incentives

There are some incentive programs related to end-of-life care internationally. In England, palliative care indicators are included in the **Quality and Outcomes Framework**, which is a voluntary incentive program for general practices.[58] The palliative care indicators included in the Quality and Outcomes Framework relate to the existence of a practice register of patients in need of palliative care, and the occurrence of regular multidisciplinary case review meetings where all patients on the register are discussed.[59]

In British Columbia, Canada, there is a **Family Practice Incentive Program** that includes a palliative care incentive. The aim of the incentive is to support general practitioners in the planning and coordination of end-of-life care for their patients. Specific payments are made for the preparation and documentation of a palliative care plans, and for ongoing telephone and email follow-up.[60]

2.7 guidelines and care pathways

Guidelines, care pathways and other similar frameworks relevant to end-of-life care are focussed on the care and services provided to people at the end of their life. A number of influential guidelines and care pathways have been developed internationally, and are now being used or adapted for use in Australia.

The **National Gold Standards Framework**[61] was developed in the United Kingdom in 2000 with the aim of improving palliative care in primary care settings. It provides a systematic approach to optimising the care delivered by generalist providers for patients nearing the end of life. It is concerned with helping people to live well until the end of life and includes care in the final years of life for people with any end-stage illness in any setting. It has now been extended from primary care to residential aged care and acute care facilities in the United Kingdom.

In the Gold Standards Framework there is a set of three trigger questions to identify patients who may be nearing the end of their lives. The answers to these questions determine the actions taken in different settings. The questions are:[62]

1. the Surprise Question: 'Would you be surprised if this patient were to die in the next few months, weeks, days?'

2. general indicators of decline – deterioration, increasing need or choice for no further active care

3. specific clinical indicators related to certain conditions (including cancer, organ failure and frailty/dementia).

Similar questions are used as part of the **AMBER care bundle**.[63] The AMBER Care Bundle was also developed in the United Kingdom to improve the quality of care for hospitalised adult patients who are at risk of dying imminently but are still receiving active treatment. Risk identification questions aim to identify those who are at risk of dying within one or two months. Identified patients who would benefit from advance planning are required to then have a documented medical plan put in place which includes resuscitation status and any other limitations of medical treatment. In addition, it is required that the plan be discussed and agreed with nursing staff, and with the patient and family. Daily monitoring and review of the plan is required for the duration of the patient's hospital admission.

The **Liverpool Care Pathway** for the dying patient (LCP) was originally developed in the United Kingdom as a tool for integrating best practices for the care of the dying into the acute care setting.[64] It is based on the model of care originally developed in the hospice setting and includes physical, psychosocial, spiritual and religious aspects of care.

The LCP has recently been the focus of some attention in the United Kingdom and an independent review into its use in National Health Service (NHS) hospitals was conducted in early 2013. The review panel found a number of broad systems issues that contributed to failures in the delivery of end-of-life care, as well as problems with the implementation and application of the LCP in practice. The review panel report stated that 'in the right hands the Liverpool Care Pathway can provide a model for good practice' but considered that there were considerable deficiencies in its application within the NHS.[65] The review panel made a number of recommendations calling for large scale systemic changes to the way that end-of-life care is organised and delivered in NHS hospitals. It also recommended that the LCP be replaced by individualised end-of-life care plans.

Examples of guidelines and pathways developed in Australia include the following:

*   The **Residential Aged Care End-of-Life Care Pathway** was based on the Liverpool Care Pathway and developed in Queensland. It aims to reduce transfers to hospital and enable residents of aged care homes to die comfortably in the familiar surroundings of their usual place of care.

2. policy and other approaches to improve end-of-life care

- In Tasmania a series of **Care Management Guidelines** and **Consumer Factsheets** about aspects of palliative care have been developed with funding through the Australian Government Local Palliative Care Grants Program.

- The Western Australia Cancer and Palliative Care Network has developed the **WA Palliative Care Resource Kit** to support the delivery of palliative care and the implementation of the **WA Liverpool Care Pathway**.

2.8 monitoring and reporting on outcomes

At this stage there is a lack of coordinated monitoring or reporting on processes and outcomes associated with the safety and quality of end-of-life care in Australia, particularly when this care is provided outside of specialist palliative care services. Palliative care service providers can voluntarily join the **Palliative Care Outcomes Collaboration**[66] which was funded as part of the National Palliative Care Program. This enables palliative care service providers to benchmark and measure some of the outcomes of palliative care against the Standards for Providing Palliative Care for all Australians.

In England, the Department of Health has developed a series of quality markers that align with their end-of-life care strategy. Included in this set are quality markers for use by different providers, for example, acute hospitals, primary care services and specialist palliative care services. The quality markers are not mandatory. An online self-assessment tool called the **End of Life Care Quality Assessment Tool**[67] was developed for a range of providers to measure their progress against 42 core specifications across the 16 quality statements in the NICE Quality Standard for End of Life Care. It includes both process and outcome measures and organisations can access benchmarking reports as well as reports on internal progress.

As a metric for measuring progress, the Atlas of Clinical Variation produced by the National Health Service includes the percentage of all deaths that occur at a person's usual place of residence as a clinical indicator.[68]

As well as these processes for national data collection and reporting, information about problems with end-of-life care can come from structured audit processes. For example a national audit of end-of-life care in hospitals in Ireland showed that care was frequently poorly planned and coordinated.[16] On the basis of the results of this audit four quality standards for end-of-life care in hospitals were developed that formed the basis of a new Hospice Friendly Hospitals program in Ireland.[69]

2.9 e-health

With the increase in initiatives to improve health and health care through electronic and technological means, there is now also potential to improve end-of-life care in this way.

In Australia, it is now possible to include the details of the custodian of any advance care directive in the Personally Controlled Electronic Health Record (PCEHR).[70] New Australian Government funding has recently been announced to enable the storage of advance directives in the PCEHR.[71]

In Scotland, an electronic palliative care summary has been developed that enables better coordination of care between service providers through improved communication.[72] Patient information is available to both regular day-time care providers and out-of-hours care providers such as emergency departments. Information from general practitioners can be updated and automatically sent to out-of-hours care providers. Anticipatory care plans can be developed which may include:

- medical diagnoses as agreed between GP and patient
- patient and carer understanding of diagnosis and prognosis
- patient wishes on preferred place of care and resuscitation status
- information on medication and equipment.

part b
issues in practice

In this section, evidence from the literature and from the preliminary consultation interviews is used to illustrate common issues faced by those responsible for delivering end-of-life care in practice. These include talking with patients about the end of life, recognising when end-of-life care should begin and diagnosing dying, the impact of hospital systems and processes, training, and specific issues related to providing end-of-life care in rural and remote areas and for Aboriginal and Torres Strait Islander peoples.

3. communication: having 'the conversation'

Clinician participants in the preliminary consultation interviews frequently referred to having 'the conversation'. This appeared to be a term that could cover any discussion with a patient that involved talking about end-of-life care, for example, talking about limitations on medical treatment or poor prognoses. A range of participants talked about the impact of the way in which conversations about end-of-life care are managed on patient and family decision-making.

I think one of the other things is the way you do the discussion itself. I've found it very interesting talking to families, who have [had] a junior registrar come through, do the discussion, and there's a family who is for everything, and when I explain what everything is, they go 'Oh, Christ, I don't want that.'

Doctor, medical grand round – public hospital

It comes back to communication. Medical or nursing staff might have kind of thought that they've told the person something and it's not till later that it becomes clear that the patient doesn't understand they're dying.

Nurse manager – regional palliative care network

'We are not going to do something for your loved one' is not a good way to approach it. A much better way is to say, 'we believe your loved one is in the end stage of their illness; what we want to do is provide the best appropriate care …'

Senior medical officer – remote hospital

The thing that impresses me is always just how easy these conversations are when I'm a general physician and how hard they are when I come in with my intensive care hat on three days later. I'd normally have the conversation in ED [emergency department] with the 85-year-old who comes in with pneumonia and say, 'Look, you know, you'll probably be better after a few days but pneumonia is a pretty serious illness, particularly at your age with other problems, and not everyone lives. Sometimes the treatment doesn't work.' That takes about two minutes and they go 'Jeeze, I'm 85 doc, I understand there's a limit to what you can do.' But if you're meeting the family three days later with a completely different set of expectations post MET [medical emergency team] call, it's a real struggle sometimes.

Intensive care / general medicine consultant – large private hospital

4. recognising dying and letting go

Knowing when to make the shift from curative treatment to planning for the end of life, and providing terminal care, can be an uncertain business. With increased longevity and the ability to treat diseases that were once quickly and universally fatal, the majority of people now die after long periods of living with, and being treated for, complex health conditions. Such conditions cause varying rates and levels of decline in function and frequently make prognosis difficult.[27-28,73] There is little evidence to guide clinicians through the process of deciding when patients should transition from active treatment to palliative care.[74] A range of consultation participants discussed the problem of timely recognition of when active treatment is no longer appropriate.

> We see a lot of over-treatment and we get a lot of very late referrals … We get called in sometimes within the final hours, or less than an hour, before someone will actually pass away.
>
> **Palliative care nurse** – public hospital

> Some bosses are very proactive with withdrawing treatment, comfort measures type thing and others are, like, 'People must have a 24 hour trial of antibiotics before they die, regardless of what they want …' So it's sort of a bit … arbitrary.
>
> **Medical registrar** – public hospital

> Normally once that decision is made, the actual passing is good; it's getting that decision made and having everyone on the same page. Once that is done, at least on our ward, the actual care is good.
>
> **Nurse unit manager** – public hospital focus group

> People don't even recognise that somebody's dying, let alone that they have to have a conversation with them. When you look at the stuff that comes out of the recognising and responding to the deteriorating patient work, you realise that nobody even gives a thought to the conversation because they didn't even recognise that this person was approaching the end of their life. That's, if there's a place, a fulcrum where the errors start to occur, it's there.
>
> **National manager of palliative care** – private hospital network

> Sometimes patients know they are dying and just hope someone actually mentions it at some point.
>
> **Chaplain** – public hospital

Patients may have multiple conditions and multiple specialists involved in their care. This can complicate prognosis further as what is treatable as a single problem may be life-limiting in combination with other diagnoses. Additionally, poor communication between different care providers can compromise holistic assessment of the need for end-of-life care.[8]

> It happened to me two months ago: my mother died. She got bumped around from one specialist to another for a year and I went along with it because I was too close to be her doctor. I just watched her and they said 'Oh she needs this and she needs that,' so she spent nine months of the last 12 in acute hospitals at $1000 per day. And my mother took enormous resources for no outcomes.
>
> **Intensive care consultant** – public hospital

5. systems and processes: the delivery of care in hospitals

There is a fundamental mismatch between the goals of acute care (curative treatment) and the delivery of safe and high-quality end-of-life care.[22,36] What Ken Hillman describes as the 'conveyor belt to intensive care'[75] means that it is not uncommon for people to be actively treated, often with inappropriate interventions such as cardiopulmonary resuscitation, intubation and intensive care, right up until the point of death.[36,76-77] There are many systemic issues in hospitals that can make it difficult to halt the conveyer belt and reassess what is right and appropriate for a patient who may be dying. These issues include:

- a prevailing focus on rapid investigation, diagnosis, treatment and cure with systems designed around the delivery of specialist care rather than around the needs of patients

- specialist teams who focus on the treatment of a single organ or group of diseases, sometimes in the absence of holistic assessment or clear definition of who holds primary responsibility for the patient's care

- a preponderance of junior staff with little training or experience in recognising dying or managing end-of-life care and limited or delayed access to expert decision makers who can recognise dying and implement an appropriate plan of care

- the growing role of METs in decision making about end-of-life care for patients in hospital

- suboptimal communication between healthcare teams and with the patient and family

- uncertainty of prognosis and failures to proactively plan for episodes of patient deterioration

- poor coordination and communication with community care providers such as general practitioners.

A number of doctors who participated in consultation interviews reported that it is generally much easier to continue active treatment rather than make a decision to stop.

> So the reality is, and I've felt it myself, you're on the ward, you're busy, you've got lots of patients to see and someone's acutely unwell and they look like they're dying. And you don't know whether they're dying because that's okay or whether they're dying and it should be something you want to prevent.
>
> There's an enormous amount of resource tagged to MET systems, access to Intensive Care Units (ICU) and support of failing physiology and you can get access to it any time, 24/7, 365 days a year at no more than five minutes' lead time. Mostly no questions asked because the default position is to preserve life. Whereas the resource and time required, if I'm a physician on the ward, to palliate someone is enormous. I'd have to pack up what I'm doing, come into the hospital and have a conversation that might take an hour and a half or two and a half hours out of my day.
>
> **Intensive care / general medicine consultant** – large private hospital

> It is much easier to continue to treat patients with all the stops out than to make a decision. It just is. This is the way we are taught: to do all we can. To admit our failings, if they are our failings, which they're not, is often difficult. But I can tell you it is much easier to just keep on trying, and that is wrong.
>
> **General surgeon** – public hospital

> I think that is one of our troubles in the acute tertiary hospital: you have everything available so you absolutely have to make a decision that you are not going to do this. It is so much easier to default that you will do it.
>
> **Doctor** – public hospital focus group

One participant also discussed the difficulties of de-escalating care when it is already in progress.

> I had a recent incident of a woman, a nursing home resident who had an advance palliative care thing documented in the notes and deteriorates, and an agency nurse decides to call an ambulance and they're brought to hospital and they get onto the conveyor belt and treatment is initiated. And, you know, it's almost criminal. And the next morning I've got to unravel, or put the toothpaste back in the tube, and just de-escalate and send the patient back … but you look a bit brutal …
>
> **General medicine consultant** – public hospital

5.1 the influence of medical specialisation

During the consultation interviews, there was frequent discussion of the focus of specialist clinicians on the organ or disease group of their specialty, with the suggestion that this can come at the cost of holistic assessment and management of end-of-life care needs. Many of those who raised this as an issue went to some lengths to express that this was an inevitability of specialisation rather than a criticism of the specialists involved.

> Almost every patient coming into hospital now has got type 2 diabetes, hypertension, high cholesterol, previous TIAs [transient ischaemic attacks], ischaemic heart disease, osteoporosis, history of falls, and those things don't add up to a specialist model. [End-of-life care] will never become part of the core business for the specialists; they're so good at their area. I'm not being critical of them but it will never be part of their core business. They're so busy, their conferences, their text books, their journals, are not about dying … to change that, it's like turning around a liner – it'd take years.
>
> **Intensive care consultant** – public hospital

> Somebody has to take ownership … You can be looked after by committee and nobody actually wants to tackle the hard bits.
>
> **Medical director** – large private hospital

> The majority [of consultants] are interventionists and they're into saving lives and thinking 'What can I do?' I don't think they step away easily and say 'We've done what we can for this patient; how can we help their journey to the end?'
>
> **Nurse** – public hospital focus group

5. systems and processes: the delivery of care in hospitals

The culture and training of different clinician craft groups can also have an impact on the way that dying patients are managed.[33,78] In an ethnographic observational study conducted in three ICUs in the US and New Zealand, it was found that there were significant differences in the way that end-of-life care was approached in a closed, intensivist-led ICU compared to an open, surgeon-led ICU.[78] Factors heavily influencing the intensivists' decision-making were the management of scarce resources and the patients' quality of life. In contrast, the primary goal of surgeons was to 'defeat death' at all costs. The researchers suggested that when the death of a patient is seen as a personal failure, there is a resulting unwillingness to accept that a patient may be dying and to stop consequent prolongation of inappropriate and futile intervention.

On the ward we have some specialist teams – like the liver transplant team and the surgical teams – who really don't see what the likely outcome is going to be for their patients. It's like they've done the operation, maybe inappropriately because the patient was so sick even beforehand, but afterwards it's like we have to do everything because we've done the operation. They sort of can't stop even if the patient is really sick and in pain, because they have so much invested.

Intensive care registrar – public hospital

5.2 escalating care as a junior clinician: navigating the medical hierarchy

In the literature about recognising and responding to patients who deteriorate in hospital, the failure of junior staff to seek advice from senior clinicians is frequently cited as a major contributing factor to suboptimal care.[79-81] In the delivery of end-of-life care, failures to ask for expert help may contribute to delayed recognition of dying and consequent failure to provide optimal terminal care.

A range of participants reported some general issues with the availability of treating consultants in regard to escalating care for patients who deteriorate, with particular difficulties relating to decision-making for those whose patients may be reaching the end of their lives.

They're just not present. From a surgical perspective, they're just not here. We're a surgical ward that would average a MET call per day and we run on an intern who just can't do it. So we treat, treat, treat to the point that we, God, you'd laugh at this, we're giving them antibiotics, fluids and feeds and they're on a morphine and midaz [midazolam] infusion. What the hell is that?

Nurse unit manager – public hospital

These escalation protocols involve the consultant who's never in the unit and has no idea who is an inpatient.

Intern – public hospital

One participant pointed out that the result of the lack of senior oversight is that junior doctors become responsible for clinical decision-making.

It's often the junior doctors who are making the decisions about 'Do we start this, do we chart that, do we stop this'. Our core decision-makers are that resident and registrar level … But if you've got a population of residents and registrars that are uncomfortable with those discussions and the clinical acumen of recognising dying then, unfortunately, you can go down that conventional active management path that may not provide the best thing for a patient.

Chief medical officer – public hospital

The perception of some participants is that failures to escalate care to consultant level are not always caused by a lack of availability but because junior doctors are afraid to call their seniors.

This is a big issue, escalation of decision-making … The problem, I think, with escalation of decision-making, is with the junior staff. They are frightened to contact their seniors; they don't want to be judged as having failed.

General surgeon – public hospital

Sometimes I just don't know if the consultants are aware. You know, the registrars have this hard and fast thing; it's Tuesday and I have to keep them going till the consultant visits on Thursday. They quite often don't want to ring them.

Nurse unit manager – public hospital

That's when you should be calling: when you don't know. They [junior staff] don't want to be made to feel incompetent; they don't want to be shouted at down the phone at two o'clock in the morning. These things happen, but you know, so what? You've got a sick patient there.

Clinical director of surgery – public hospital

Nobody gets cross if you call a MET call so it's easier than calling a consultant who might.

Chief executive officer / physician – public hospital

5.3 dying and the medical emergency team

In the course of dying in an acute care hospital, a patient's vital signs inevitably deteriorate. As their vital signs deteriorate, calls to the medical emergency team (MET) are triggered. Recent studies suggest it is common for clinicians from the MET to diagnose and manage dying patients in hospitals.[6-7] It has been found that approximately 30% of the work of MET clinicians involves dealing with issues related to end-of-life care, and that a new limitation on medical treatment was instituted by the MET in approximately 10% of MET calls.[7,82]

Escalation of care to the rapid response team is not always appropriate for patients who are approaching the end of life. The MET may be called to see a terminally unwell patient after hours, with an urgent need to make a decision about the appropriateness of medical interventions, and with limited knowledge of the patient's circumstances. A range of potential issues may result, including:

- limited capacity for patients with significant deterioration to express their wishes for treatment and contribute to the plan of care[7]
- inadequate time for ensuring that care is coordinated and communication with patients and families is of a high standard[7]
- increased stress for families and carers and the potential for conflict resulting from inadequate communication[36]
- futile and inappropriate interventions which may increase suffering (for example, cardiopulmonary resuscitation, intubation and ventilation)[7]
- incorrect decision-making from the MET regarding the withholding of care[7]
- moral distress for clinicians involved in providing futile or inappropriate care.[83-84]

5. systems and processes: the delivery of care in hospitals

A common theme emerging from consultation interviews was the use of the MET or intensive care clinicians to provide an authoritative second opinion, particularly in regard to diagnosis of dying and subsequent decision-making about limitations of medical treatment.

Participants also reported that the MET is frequently called to institute comfort measures for dying people, with a number of participants suggesting that nurses will often call the MET when they perceive that the treating team has not put in place an appropriate plan for end-of-life care.

> It's a different level of opinion and confidence that you get with the MET.
>
> **Nurse unit manager** – public hospital

> Recently I was looking after a 90-year-old person who was dying and the family were kicking up a fuss so I got ICU involved.
>
> **General medical consultant** – public hospital

> Probably a quarter to a third of METs are not medical emergencies – they are deteriorations that are expected and we get called to tell them that patients are dying.
>
> **Intensive care registrar on the MET** – public hospital

> Often there are doctors there and they sometimes know they need to [stop] but they don't have the power. They're present, but they need the ICU team to make the decision so they can go to their consultant and say 'Well ICU have said we should stop.'
>
> **Intensive care liaison nurse** – public hospital

> If a patient is deteriorating and the nurses don't have a plan – they hate a bad death – they'll call a MET so they can make dying a comfortable experience. They want a solution to the problem that they're having: a bit of morphine or a dose of midazolam to make things go easier.
>
> **Nurse unit manager** – public hospital

> If you've been designated not for resuscitation but you get a MET call at that time, most of the interventions you need are around things like managing your respiratory secretions or your airway in some way. They are really quality care/comfort care kind of measures – you're not actually trying to save a life.
>
> **General medicine consultant** – public hospital

> When we go to METs now the nurses will look at me and say 'I've been asking for days and nothing has happened.' So it's actually to relieve their frustration … A nurse gets very upset when the [treating team] won't write the NFR [not for resuscitation] up and she has to call a MET call to get assistance.
>
> **Resuscitation nurse** – large private hospital

Junior medical staff discussed their lack of preparedness for managing the symptoms of dying. They perceived the MET as a skilled and readily available resource.

> From an intern's perspective it's … the practicalities of dealing with a dying patient: the 'Oh my God this patient's in terrible pain, they're in great respiratory distress: what do I do?' And that's why the MET gets called, I think. It's 'I don't know what to do and this person looks really uncomfortable and I need help.' I don't think we get taught very well what to do when they're in terrible pain or have terrible secretions.
>
> **Intern** – public hospital

> Perhaps the MET is not the right thing for that, but they're the thing we have available and they're really good at it.
>
> **Intern** – public hospital

In contrast to the perspective of many junior ward clinicians, a number of MET clinicians raised concerns about whether they have the appropriate skills to manage end-of-life care.

> We've got a team that is designed and trained to prolong life at all costs, which is in direct competition with what you should probably be doing with these patients. I mean all of the interventions that we're designed to deliver in a MET team aren't in the list of the 20 things you should have before you die … It's my belief that people are dying a poor quality death after MET call. That's what I would articulate as the problem.
>
> **Intensive care / general medicine consultant** – large private hospital

Concerns were also raised about MET calls being made because of protocol, even when this was perceived as being inappropriate in the case of patients who are dying.

> When they arrest and die we get called for the drop in Glasgow Coma Score … and you say 'This person is not for CPR' and the nurse by the bedside says 'Yes, but they are still for MET calls.' OK, but they are now dead – what do you want us to do? Now that is clearly an education thing as well, but in their minds they've read the order that says I still need to call MET if something happens. And I would have gone to more than 10 of these in the last year.
>
> **MET nurse** – public hospital

> The nurses have to follow protocols and make MET calls even when it's clear to us that patients are dying.
>
> **Medical ward nurse** – public hospital

MET members discussed the diversion of time and resources that are required to manage end-of-life care issues.

> The MET, or the rapid response team, has effectively turned into the end-of-life team … it's a massive distraction and it's also a subversion of the original intent and role for rapid response. It's a big drain on the resource of our single rapid response team having to be trawling round the hospital sorting these things out at three in the morning when we have difficulty getting hold of our medical colleagues for consensus or families for notifications.
>
> **Intensive care consultant** – public hospital

5. systems and processes: the delivery of care in hospitals

> If my registrar spends the time sorting it out on the ward, that's an hour of their time and they're abandoning the other 12 patients [in the unit]. So they're actually better off retrieving them to ICU, wasting a day of ICU and solving it in the unit because there we have control of the patient. So although it's ridiculous, I'm taking patients in order to palliate them because there is no way I can facilitate that on the ward. It's not really a sensible use of ICU but it's a sensible use of the resources I've got, if that makes sense.
>
> **Intensive care consultant** –
> large private hospital

One participant discussed the negative consequences for patients and families that can result from the practice of bringing dying patients to the ICU in order to manage their care more efficiently.

> The amount of times our consultants just say, 'We're spending way too much time on outreach with this patient, just bring them to ICU so we can do end-of-life care here.' I remember getting very upset about that one day. The patients have been up there [on the ward] for ages, the family knows the nurses, and then they come into this ICU environment which can be very scary. Everything beeps, its white and fluoro lights everywhere, there are visitor restrictions … I don't think it's necessarily the best thing but I can see why it happens when we're spending all these resources trying to manage things remotely.
>
> **Intensive care liaison nurse** – public hospital

5.4 the role of specialist palliative care

Palliative care teams have specialist skills in communication and decision-making support, symptom control, psychosocial care and coordination of care for patients living with eventually fatal diseases.[85] There is evidence that access to specialist palliative care services can improve the quality of life experienced by patients at the end of life[86] and may even contribute to extending life for some groups of patients.[87] However, the hospice and palliative care movements of the 1960s and 1970s have traditionally focussed on the care of patients with cancer[88], and patients who are dying from other causes are less likely to have specialist palliative care providers involved in their care.[19,86] Interview participants discussed problems with accessing help from specialist palliative care teams in the acute hospital setting.

> The palliative care CNCs [clinical nurse consultants] are absolutely amazing but you need the OK to involve those guys. You know, they're really good when they're involved but the team has to approve the referral. With the surgical patients it can be a real battle to get them involved.
>
> **Nurse unit manager** – public hospital

> [Palliative care] aren't available 24 hours a day; they're Monday to Friday, nine to five. The person you get out of hours is the med reg.
>
> **Medical registrar** – public hospital

It has been reported that there is considerable uncertainty amongst acute care clinicians about when referrals to specialist palliative care should be made.[73,85-86,89] Interview participants also raised the issue of palliative care having become a specialty silo itself, partly because of its historical focus on patients with cancer, and partly because those outside the specialty may not clearly understand its role. A lack of consistent referral criteria was seen as problematic.

> Previously I [have] called palliative care and they say 'Are there any symptom issues?' I think we need to look at the palliative care referral system. Do they choose and select which patients …? We have difficulty getting the sense of when to get palliative care involved.
>
> **Doctor, medical grand round** – public hospital

It was also suggested that making referrals to palliative care can be more difficult than making referrals to other specialties because of the perception that a referral to palliative care is synonymous with approaching death.

> If a person comes in with chest pain and its cardiac, in many hospitals they will automatically refer them to cardiology. Whereas getting that referral to palliative care requires the consent of the patient if they are able, and the family, so there is much more to be negotiated. The patients or families will say 'No, I'm not ready' and that partly reflects the skills of the conversation … the home teams are unaware or feel uncomfortable having those conversations. There is a meaning with this referral that the other referrals don't necessarily have.
>
> **Palliative care consultant** – public hospital

> Palliative care and the concept of palliative care and dying, touch at the core of people's emotions in a way that no other clinical area does. So the influence on referring is often very much how the particular physician or surgeon feels … There are a lot of inherent values that influence referrals to palliative care.
>
> **Palliative care nurse** – public hospital

Participants with specialist palliative care experience were very clear that there are resource limitations that restrict their ability to provide care for all dying patients. Many stressed the importance of growing the ability of all healthcare providers to provide end-of-life care given that dying is a universal experience.

> Sometimes I feel like individual patients miss out on the expertise I've got to offer because I am trying to do things at a broader level so that everybody gets more than what they were getting before … It is very difficult and a huge ethical dilemma for us because of resourcing.
>
> **Palliative care consultant** – public hospital

> I don't want to do all the palliative care in the hospital: I can't! Cardiologists don't do all the heart problems in the hospital. I'm a specialist and I need to do the difficult ones, which means that all our general units should be capable of doing a bit of end-of-life care just like I can do a bit of cardiology.
>
> **Palliative care consultant** – public hospital

> I think we have to build capacity and capability for good death to happen anywhere that it is. Ideally a specialist [palliative care] unit is there to build capacity and care for the very most complex.
>
> **Director of nursing** – large private hospital

5. systems and processes: the delivery of care in hospitals

5.5 the role of nurses

Although there is little evidence in the literature to support the view that nurses are any more able to recognise dying than their medical colleagues,[90] a number of participants suggested that experienced nurses are skilled in recognising when patients are dying.

> We found that if it came to deciding who was really sick and likely to die, there was only one small group of people in the hospital who knew who they were, and they were the nurse unit managers or the in-charge nurses on various wards. You could go to them and get a completely reliable view as to what was going to happen.
>
> **Intensive care consultant** – public hospital

The concept of moral distress is defined as arising from situations where 'one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action'.[91] There is a great deal of literature exploring moral distress amongst nurses, particularly in relation to end-of-life care.[83,92-93] One of the main reasons for moral distress to occur in relation to end-of-life care is when nurses are participating in the provision of care that they perceive as being futile and prolonging the suffering of a patient and they feel unable to influence the treatment plan.[84,93-94] Many participants discussed the difficulties that nurses may experience in advocating for patients at the end of life, and the distress that occurs after a 'bad' death.

> You can advocate till you're blue in the face, often, and the medical staff may or may not listen.
>
> **Nurse** – public hospital focus group

> The consultants aren't the ones with the patients day-to-day; they're not the ones talking to the nurses and the family every day. I disagree that senior nurses can't diagnose dying: why should a nurse with 20 years of experience defer to an intern who is three months old? I've spent a medical lifetime asking senior nurses what they think we should do. I think if everyone on the ground thinks the patient is dying, the consultant doesn't have a right to say no.
>
> **Palliative care consultant** – public hospital

> We have a real divide between nursing and medical here. The experience is with the nurses but the disempowerment is staggering.
>
> **General medicine consultant** – public hospital

> Nurses constantly struggle to get adequate management of symptoms for someone at the end of life.
>
> **General medicine consultant** – public hospital

> Nurses are with the patient every day, talking to the families and patients, seeing the suffering.
>
> **Intensive care liaison nurse**

> A 'bad death' is the worst thing to manage. Nobody is more distressed than ward nurses and junior doctors if it has been an horrifically slow, bad death.
>
> **Nurse unit manager** – public hospital

6. planning ahead and limiting medical treatment

Identifying the wishes of patients and avoiding unwanted or inappropriate medical treatments are important components of delivering safe and high-quality end-of-life care. Some people may document advance care directives or plans well before the diagnosis of a life-limiting condition while others may require consideration of limiting medical treatment at the point of admission to hospital or after a critical deterioration in their health. In this section, issues relating to advance care directives, advance care planning and cardiopulmonary resuscitation are discussed.

6.1 advance care directives

Advance care directives are documents with legal status which outline the wishes of patients for their future care. The Australian Health Ministers Advisory Council endorsed a National Framework for Advance Care Directives in 2011.[24] This framework describes the goals with which policy and practice should aim to align, with the objective of improving uptake, transferability, recognition and implementation of advance care directives. However, variations remain in the state and territory laws which currently govern the documentation of advance care directives. The legal terminology used to describe common concepts also varies.

> Every single state has different sorts of advance care directives. There are issues with transferability.
>
> **Policy officer** – state department of health

There is continued debate about the efficacy of advance directives as a strategy for improving care at the end of life.[95-96] The prevalence of formally-documented advance care directives is very low[97-99] and even when they have been documented there are problems in applying them. These problems include difficulties in accessing documents at the critical time and difficulties interpreting legally binding advance care directives in unpredictable and uncertain circumstances.[24,99]

Clinician participants in consultation interviews generally believed that advance care directives are less than useful as tools to guide their clinical decision-making.

> Personally I think advance directives are worthless. They're not worth the paper they're written on. Because most advance directives I've seen say completely meaningless or nebulous terms like 'I don't want extraordinary measures.' Now what does 'extraordinary' mean? I mean, extraordinary to the cardiac surgeon with the enthusiastic scalpel is very different to extraordinary for a rural GP…
>
> **Intensive care consultant** – public hospital

> It has to be a meaningful document. We've found advance health directives that were really quite useless in light of a patient's disease that they actually had. A lot of people focus on completing the document as an outcome rather than understanding that the process of talking about it is more important.
>
> **Social worker** – regional palliative care network

6. planning ahead and limiting medical treatment

6.2 advance care plans and limitations on medical treatment

Advance care planning is a process where patients are assisted to identify and express their goals of care but may not necessarily document a formal advance care directive. Ideally, advance care planning is an iterative process that occurs over time in a series of conversations between a patient and their doctors, family and other carers. In some cases, when patients are given little warning of impending death, advance care planning may need to occur on, or during, admission to hospital.[36] This usually involves making decisions about any limitations on the medical treatments that will be offered for patients who are approaching the end of life.

For example, in a patient with end stage dementia who can no longer feed themselves, insertion of a percutaneously inserted feeding tube may not be appropriate, or for someone with terminal cancer or extensive cardiac disease attempting resuscitation in the event of cardiac arrest may not be appropriate.

Although consultation participants agreed that the process of undertaking advance care planning was useful when done properly, it appears that advance care planning remains the exception rather than the rule.[36,100]

For example, in one study of Australian cancer patients, only 27% had a plan outlining goals of care and limitations of medical treatment documented prior to the 48 hours before death.[77] In an Australian study of 15 patients living with end-stage chronic obstructive pulmonary disease, discussions about future wishes and advance care planning were absent.[23] A recent Canadian study[100] found that while many hospitalised elderly patients had discussed end-of-life preferences with

family members, only half of these patients had had a discussion with a member of the healthcare team. Of note, even when discussion with a health professional had occurred, agreement between patients' expressed preferences for end-of-life care and what was documented in the medical record was found in only one-third of cases. In a recent report from the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) in the United Kingdom, there were also consistent failures to formulate appropriate plans at admission to hospital for patients who went on to suffer cardiorespiratory arrest.[15]

> Where it falls down is that I'm on overnight, I'm covering 25 different units, I'm admitting patients on the request of a registrar who's at home and is going to be looking after the patient – I'm not the person who's going to be looking after the patient and I don't feel like I'm the appropriate person to talk to them about what they want.
>
> **Intern** – public hospital

Junior doctors who participated in consultation interviews talked about being reluctant to enter into discussions about limiting care or offering palliation when they are uncertain if their seniors will be in agreement that this is appropriate.

> My greatest fear when I go into having discussions with patients who I may not know very well, or big bosses I don't know very well, is whether the boss is going to support me after I have convinced the family that this patient should be made to feel comfortable and let nature take its course.
>
> **Medical registrar** – public hospital

During the consultation interviews and focus groups there was a great deal of discussion about the role of patients and families in making decisions to limit medical treatment. Many participants talked about the tensions that can arise when models of care emphasising patient autonomy conflict with the need to provide clear medical advice.

> If you look at most medical practitioners now, they'll say 'He's really sick and are you OK if we make him not for resuscitation?' Or 'What do you want us to do; do you want us to come and jump on his chest? It's your decision'. They think that's the right thing to do because they are respecting patient autonomy but it's putting people in a horrible psychological position.
>
> **Chief executive officer / physician** – public hospital

> To palliate is a medical decision. Well, too often, doctors put the relatives in the situation where they are asking the relatives to make the decision about palliation or not. It's a medical decision to palliate; it is not the relatives' decision.
>
> **Doctor** – public hospital focus group

> If you explain to people what is appropriate and inappropriate in terms of treatment – that if a person with metastatic cancer becomes ill they are unlikely to benefit from CPR – they understand. As long as you reassure them that if they become ill with something reversible like a mild infection they still get treatment.
>
> **Oncologist** – public hospital

> We're not obliged to ask the family what to do – we're obliged to involve the family in decision-making, but why do we go to the family and say 'What do you want us to do?' We force them into a corner where there is only one possible answer: do everything. They cannot provide any other answer. But the definition of 'everything' to them is different from the definition of 'everything' to us. So we think everything means CPR, intubation, dialysis, ECMO [extra-corporeal membrane oxygenation], heart transplants. Whereas to them 'everything' probably just means 'Don't leave our poor Granny in the corner on her own.'
>
> **Doctor, medical grand round** – public hospital

6. planning ahead and limiting medical treatment

6.3 cardiopulmonary resuscitation

The 2012 National Confidential Enquiry into Patient Outcomes and Death report on patients who underwent in-hospital cardiopulmonary resuscitation (CPR) in the United Kingdom found that resuscitation was wrongly attempted in many cases. The investigators found a substantial number of cases where 'not for resuscitation' (NFR) or 'do not resuscitate' (DNR) orders should have been made earlier but the initial assessment was deficient and nobody had recognised the danger of cardiac arrest.[15] Delays in discussion and documentation of resuscitation status are also common in Australian hospitals.[7,101-102]

> There can be confusion about whether a person is for resuscitation or not, whether they're end of life or not.
>
> **Social worker** – public hospital

A related issue that became clear during the consultation interviews is that different participants could mean quite different things when using the terms NFR or DNR. Some participants used NFR very specifically to mean not for chest compressions in the event of a cardiorespiratory arrest, while others used them interchangeably with terms such as 'for palliation' or 'for comfort care'. It appears that confusion about what such terms actually mean in practice is common.

> The difference between palliative care and a DNR order is completely fuzzy.
>
> **Medical director** – large private hospital

> It doesn't mean that now, but certainly when I was training if we wrote down NFR they were put in a side room and given morphine – that's what happened.
>
> **General medicine consultant** – public hospital

> I think people just write down NFR and don't actually think about what they're meaning.
>
> **Doctor, medical grand round** – public hospital

It is also interesting to note that the Chair of NCEPOD suggests that early decision-making about the appropriateness of resuscitation is closely related to the matter of informed consent. He proposes that in cases where there is an identifiable risk of cardiopulmonary arrest and the patient is capable of understanding the options, then informed consent should be obtained for the future provision of in-hospital CPR. If this is not done then he suggests that in-hospital CPR, similarly to surgery without informed consent, would constitute assault.[15]

7. training

Many clinicians lack the knowledge and experience needed to effectively manage end-of-life care discussions and basic palliative care.[103-105] In a survey of Australian general practitioners, more than one third of respondents reported that they had no undergraduate training in palliative medicine.[106] In a survey of undergraduate nursing schools in Australia it was found that there was minimal and inconsistent education about care of the dying included in curricula.[107] Both medical and nursing interview participants reported a lack of formal training about end-of-life care.

> I really don't think I was well prepared for end-of-life care.
>
> **Intern** – public hospital

> As undergrads… they get a little bit, the palliative care, the terminal care, rather than… well, they touch on end-of-life care but it's mainly about mopping brows…
>
> **Intensive care nurse** – public hospital

A lack of knowledge about basic palliative care may lead to:[8,104]

- suboptimal psychosocial care and symptom control for patients
- unsubstantiated fears that palliative care shortens life expectancy
- misinterpretation of terms such as 'futility' and 'do not resuscitate'
- reduced understanding of when to involve specialist palliative care teams.

Training is also required to develop the communication skills that are necessary to effectively help patients to plan for the end of life. Clinicians who lack these skills may avoid discussions about the end of life and contribute to patients developing false expectations or confusion about prognosis. Others may be too inexperienced or too focussed on a single aspect of a patient's care to recognise or effectively manage dying.[8,75,104]

> I have gone through a lot of anaesthetics, a lot of ICU: the amount of training I've had to have this conversation is slightly less than the square root of none… It is not part of basic training; it is not part of advanced training. There is no skill set that is taught at an undergraduate or postgraduate level that addresses this.
>
> **Intensive care consultant** – public hospital

> One of the real barriers is that we haven't embedded the need to have that difficult conversation in our training. Everyone kind of criticises our clinicians and says, well they're fobbing it off. I don't think they're fobbing it off, I think they're genuinely saying, 'I don't really want to do this, it's very confronting for me, I have to think about the language I use, the social or cultural issues for that particular patient, the need for a level of sensitivity…'
>
> **Chief executive officer** – local health network

> There's no training for surgeons or physicians about this. There needs to be some training in preparing patients and families for adverse outcomes and end of life discussions.
>
> **General medicine consultant** – public hospital

7. training

Although most nurses working in acute facilities will participate in providing end-of-life care to patients, it appears that the management of this care varies because of inconsistent levels of knowledge, skill and experience amongst the nurses providing care. One small retrospective study of the quality of end-of-life care delivered in a South Australian teaching hospital found significant gaps in the physical, psychosocial and spiritual care of the dying.[108] Another Australian study also highlighted the need for generalist nurses to develop skills in the delivery of palliative care.[86] Interview participants agreed that there are significant inconsistencies in practice.

> It's experience that teaches you, there is no special training. So you get variable practice amongst the NUMs [nurse unit managers].
>
> **Resuscitation nurse** – large private hospital

> If you don't know what you don't know, quite often it's like, am I meant to do something different or …? So they haven't got that exposure or experience to know how to treat a dying patient.
>
> **Nurse educator** – public hospital

A physician with responsibility for clinical training at the public hospital where she works reported that although there are opportunities for teaching about end-of-life care, this is not mandatory. She also highlighted the difficulties of teaching about end-of-life care.

> They [medical trainees] have to collect four what we call CEX (clinical examinations) where a clinician observes them in an interaction. That interaction could be end-of-life care but very often they stick to safe things like taking a history of chest pain or examination of the heart and its pretty low value … You can avoid this stuff like the plague. The whole system allows you to avoid this stuff if you want to. The doctors need [a] sort of framework for talking about end-of-life care. It's hard stuff because it's not as easy as teaching about blood gas management. It's more woolly; it's more grey; it needs to be taught by a clinician that they absolutely respect.
>
> **General medicine consultant** – public hospital

A consumer participant raised concern about end-of-life care medical education being provided within the hospital setting.

> As far as I can see, if you've done your degree and then you're put on the ward and the hospital is responsible to sign off your education and to deliver it, are you going to confess that you're out of your depth? Or talk about your emotions? Or are you going to put on the bravado? And you actually look up to the tough, arrogant doctors. That's what happens. So what I'm thinking is it's a bit like parents teaching their kids to drive – you pass on all the bad habits … So where can we do something more independent so those interns can learn in a neutral environment?
>
> **Consumer**

8. rural and remote health services

In small rural and remote health services generalist health providers are usually responsible for delivering end-of-life care. A different set of issues arise in this context. For example, providers may need to care for friends and family, manage very complex cases, and, due to their geographical isolation, may have difficulty accessing specialist equipment or medications, and clinical support, debriefing and supervision.[109-111] Consultation interview participants discussed a number of issues specific to working in rural and remote areas of Australia that can compromise the delivery of end-of-life care.

> We get people for three month contracts … By the time we have gotten them up to speed they are gone. So it is time to train somebody else and that can be exhausting.
>
> **Nurse manager** – very remote hospital

> There are issues around lots of things because much of the workforce is transient and that does add some problems.
>
> **Senior medical officer** – very remote hospital

> The anticipatory prescribing is very tricky, particularly if some of the local community pharmacies don't stock some of the medications.
>
> **Clinical nurse** – regional palliative care network

> Only an accredited GP can refer to [the private provider] who has the contract for provision of public palliative care in our region. It really limits access so people in need of palliative care can wait for sometimes weeks.
>
> **Nurse manager** – regional palliative care network

> With the rural GPs, sometimes they just aren't given that acknowledgement that the personal is the professional in that local community. The GPs still grieve; they've known these people in their communities for such a long time so they're quite disenfranchised in their grief and their relationships. I think that's something that does need to be acknowledged.
>
> **Social worker** – regional palliative care network

One participant from a very remote hospital suggested than in some cases, holistic assessment that someone is reaching the end of life was perhaps easier to do than in large metropolitan hospitals.

> Big hospitals tend to focus much more on interventions in health care. I guess rural guys sit back and look at the whole person a little bit more than perhaps happens in the cities.
>
> **Senior medical officer** – very remote hospital

9. end-of-life care for Aboriginal and Torres Strait Islander Australians

Health disparities between Aboriginal and Torres Strait Islander peoples and other Australians are well documented[112] and there is evidence that many Aboriginal and Torres Strait Islander people only reluctantly access healthcare services.[113] There are a number of specific issues related to the delivery of end-of-life care for Aboriginal and Torres Strait Islander people. For example, there may be cultural considerations that need to be considered such as different understandings of the causes of disease, or prolonged collective decision-making processes.[114] In their position statement, Palliative Care Australia writes that there is also 'a need to understand that all Aboriginal and Torres Strait Islander communities in Australia have a common heritage of loss, and that for an individual close to death and for their family and community, the impact of the loss and grief is often compounded by earlier experiences'.[115] Participants working in rural and remote areas raised many of these issues during the consultation interviews.

> Especially for the older people, the Stolen Generation, it can be hard to trust what the white fellas are saying, and I don't blame them.
>
> **Nurse manager** – very remote hospital

> Aboriginal people do not have that openness about death and grieving at all; it's a very difficult topic. There are layers and layers that go on underneath it that you really know nothing about in terms of how they respond to the situation.
>
> **Senior medical officer** – very remote hospital

> There is a lot of cultural stuff you need to be aware of, people get blamed for bad things happening and if you say there is nothing more that can be done and this person is going to die then you might be blamed. Another family might be blamed and then there might be some payback for that. There is all sorts of stuff that goes on that is probably not mainstream for Australia, but is mainstream for up here.
>
> **Senior medical officer** – very remote hospital

> I'm aware of nurses being terrified of giving pain relief in case… there is a bit of a fantasy that if you are responsible for killing an Aboriginal person they will come and get payback. Sometimes it's dispelling those myths…
>
> **Nurse manager** – very remote hospital

> It can be difficult, especially in this town. This town is a very disenfranchised town, with a lot of death. In two years 10% of our Indigenous population has passed, either through suicide or cancer or heart attacks. There is a fear in the community because of the number of people and the elders that have died from cancer. There is a fear of coming to the hospital because this is where family has died.
>
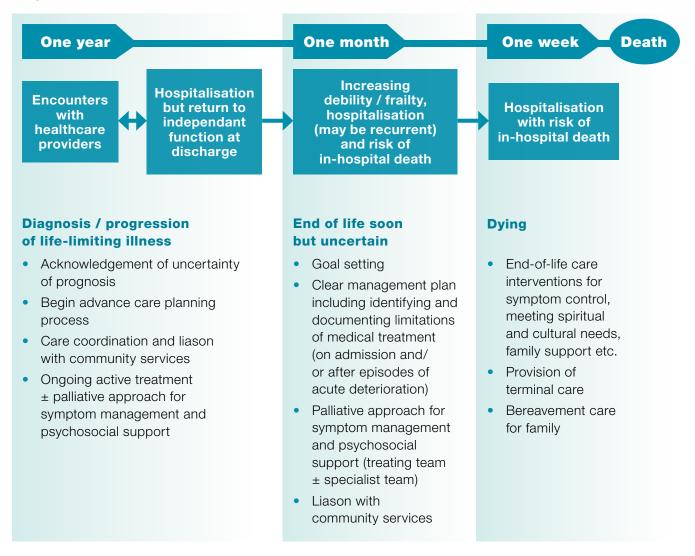> **Nurse manager** – very remote hospital

In recent years a number of programs have been established to address these barriers and better support remote health providers to deliver palliative care. These include initiatives such as the Rural Palliative Care Project[116] and various state-based programs such as the Western Australia Regional Palliative Care Program.[117]

conclusions

In the United Kingdom National Health Service *End of Life Care Strategy*, the authors write that 'How we care for the dying is an indicator of how we care for all sick and vulnerable people. It is a measure of society as a whole and it is a litmus test for health and social care services.'[55]

While an excellent standard of care is provided for many people who die in Australia, there are a number of opportunities for reducing variability and improving the safety and quality of end-of-life care delivered in acute facilities.

Figure 2: Opportunities for end-of-life care interventions in acute hospitals[118]

| One year | | One month | One week | Death |

| **Encounters with healthcare providers** | **Hospitalisation but return to independant function at discharge** | **Increasing debility / frailty, hospitalisation (may be recurrent) and risk of in-hospital death** | **Hospitalisation with risk of in-hospital death** |

Diagnosis / progression of life-limiting illness

- Acknowledgement of uncertainty of prognosis
- Begin advance care planning process
- Care coordination and liason with community services
- Ongoing active treatment ± palliative approach for symptom management and psychosocial support

End of life soon but uncertain

- Goal setting
- Clear management plan including identifying and documenting limitations of medical treatment (on admission and/ or after episodes of acute deterioration)
- Palliative approach for symptom management and psychosocial support (treating team ± specialist team)
- Liason with community services

Dying

- End-of-life care interventions for symptom control, meeting spiritual and cultural needs, family support etc.
- Provision of terminal care
- Bereavement care for family

conclusions

opportunities for improvement

With the ability to treat what was once untreatable, sudden death is now a rare event and most people now have multiple interactions with healthcare service providers in the last year of their lives. The changing pattern and pace of dying offers opportunities for patients to participate in planning care for the end of their lives; for ensuring that the burden of unwanted or unnecessary intervention is reduced; and for addressing symptom management, psychosocial and spiritual needs.

Although there may be considerable uncertainty about the timing of a particular patient's decline, there are a number of points where patients with life-limiting conditions commonly interact with the acute healthcare system. These points and some examples of possible interventions are illustrated in Figure 2, on page 41.

Despite these opportunities for intervention, and the implementation of a wide range of improvement activities such as palliative care standards, guidelines, training programs, care pathways and efforts to improve the evidence base, some persistent gaps remain. It appears that for many patients end-of-life care continues to be delivered reactively rather than proactively, particularly in the acute hospital setting. This has undesirable consequences not only for patients, but also for their families, carers and the clinicians who provide their care.

There is a lack of agreement about the appropriate measures and methods for evaluating the quality and safety of care for those who die in acute hospitals. Most current evaluation processes are focussed on the preventability of death rather than the quality and safety of care that the dying patient and their family received. There are agreed standards for specialist palliative care services, and the *National Safety and Quality Health Service Standards* for acute hospitals, but there is currently no agreed statement of what safe and high-quality end-of-life care in acute hospitals should look like.

priorities for change

It is clear that the factors contributing to less-than-optimal end-of-life care in acute hospitals are complex and do not lend themselves to easy solutions. The issues raised by participants in the consultation interviews aligned closely with findings in the literature. There appears to be a need to address change at every level – from changes to an individual clinician's practice to societal changes in attitudes toward death and dying. The path to achieving such change is challenging because, although there is general agreement and some evidence about what the problems are, there is currently a lack of either clear evidence or consistent agreement about what the standard of care should be, or how to achieve it.

There are a number of fundamental issues that need to be addressed. These include:

- **Talking about death and dying:** discomfort with discussing death and dying can lead to poor quality communication and avoidance of addressing end-of-life issues in a timely way.

- **Terminology:** a lack of shared understanding amongst patients, families, nurses, doctors and allied health clinicians about what terms such as 'palliative care', 'not for resuscitation', 'advance care planning' and 'advance health directive' actually mean can lead to miscommunication and variability in practice.

- **Acute care systems:** inconsistencies in the safety and quality of end-of-life care can occur if opportunities to address end-of-life care issues during a patient's journey through the acute care system are not recognised. Additional problems can occur because of a lack of clarity about who is responsible for ensuring that these issues are addressed.

- **Evaluating quality and safety:** deaths in acute care currently tend to be evaluated in terms of unexpectedness and potential preventability. This may divert attention from assessing the quality and safety of the end-of-life care provided.

next steps

In the previous work of the Commission's Recognising and Responding to Clinical Deterioration Program, the development of the *National Consensus Statement*[5] was crucial in providing a basis for further work to integrate recognition and response systems into usual practice through the development of *National Safety and Quality Health Service Standard 9*.[52] Similarly, in order to work toward improving the quality and safety of end-of-life care in acute hospitals, it is first necessary to achieve consensus about the standard of care that should be expected.

The Commission proposes working with consumers, clinicians and other experts to achieve consensus about what standard of end-of-life care patients, families and carers should expect in acute hospitals. A national consensus statement will be developed to articulate the overarching principles that should shape safe and high-quality end-of-life care in acute facilities. This will be forwarded to Australian state and territory government Health Ministers for their consideration.

Through reaching high-level agreement on a consistent set of principles to guide the delivery of end-of-life care in acute facilities, a framework for accountability can then be developed to ensure positive change at the level of individual patient care. This may involve the development of a safety and quality or clinical care standard, evaluation criteria and/or training curricula. Additional tools and resources will be developed with a view to supporting and enabling patients, families and carers to participate in shared decision-making about their care at the end of life.

references

1. Foreman L, Hunt R, Luke C, Roder D. Factors predictive of preferred place of death in the general population of South Australia. *Palliative Medicine* 2006;20(4):447-453.

2. Fischer S, Min S, Cervantes L, Kutner J. Where do you want to spend your last days of life? Low concordance between preferred and actual site of death among hospitalized patients. *Journal of Hospital Medicine* 2013;8(4):178-183.

3. 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.

4. Palliative Care Australia. Palliative Care – Glossary of Terms. 1 ed. Palliative Care Australia, 2008.

5. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: Essential Elements for Recognising and Responding to Clinical Deterioration. Sydney. ACSQHC, 2010.

6. Jones D. Diagnosing dying by the rapid response system. *7th International Conference on Rapid Response Systems and Medical Emergency Teams*. Sydney, 2012.

7. Jones D, Bagshaw S, Barrett J, Bellomo R, Bhatia G, Bucknall T, et al. The role of the medical emergency team in end-of-life care: a multicenter, prospective, observational study. *Critical Care Medicine* 2012;40(1):98-103.

8. Al-Qurainy R, Collis E, Feuer D. Dying in an acute hospital setting: The challenges and solutions. *International Journal of Clinical Practice* 2009;63(3):508-515.

9. Lamont E. A demographic and prognostic approach to defining the end of life. *Journal of Palliative Medicine* 2005;8(Suppl 1):S12-21.

10. AIHW. Australia's Health 2012 no. 13. Cat. no. AUS 156. Canberra. AIHW, 2012.

11. 1301.0 Year Book Australia Population Deaths. Australian Bureau of Statistics, 2012. (Accessed May 13, 2013, at www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/1301.0~2012~Main%20Features~Deaths~52)

12. 3302.0 Deaths, Australia, 2011 Australian Bureau of Statistics, 2012. (Accessed May 13, 2013, at www.abs.gov.au/ausstats/abs@.nsf/mf/3302.0)

13. Supporting Australians to Live Well at the End of Life National Palliative Care Strategy. Commonwealth of Australia, 2010.

14. Economist Intelligence Unit. The quality of death Ranking end-of-life care across the world. Singapore. Lien Foundation, 2010.

15. Findlay G, Shotton H, Kelly K, Mason M. Time to Intervene? A review of patients who underwent cardiopulmonary resuscitation as a result of an in-hospital cardiorespiratory arrest. National Confidential Enquiry into Patient Outcome and Death, 2012.

16. McKeown K, Haase T, Pratschke J, Twomey S, Donovan H. Dying in hospital in Ireland: An assessment of the quality of care in the last week of life, Report 5, Final synthesis report. Dublin. Irish Hospice Foundation, 2010.

17. The Economist Intelligence Unit. The quality of death. Ranking end-of-life care across the world. Lien Foundation, 2010.

18. National Audit Office. End of Life Care. London. National Audit Office, 2008.

19. McNamara B. Good enough death: Autonomy and choice in Australian palliative care. *Social Science and Medicine* 2004;58:929-938.

20. Palliative Care Australia. Health System Reform and Care at the End of Life: A Guidance Document. Palliative Care Australia, 2010.

21. Hardy J, Haberecht J, Maresco-Pennisi D, Yates P, Australian Best Care of the Dying Network Queensland. Audit of the care of the dying in a network of hospitals and institutions in Queensland. *Internal Medicine Journal* 2007;37(5):315-319.

22. Palliative Care Australia. End of life care is everyone's affair - tackling the challenge of 'end of life'. *Submission to the National Health and Hospitals Reform Commission*. Palliative Care Australia, 2012.

23. Crawford G, Brooksbank M, Brown M, Burgess T, Young M. Unmet needs of people with end-stage chronic obstructive pulmonary disease: recommendations for change in Australia. *Internal Medicine Journal* 2013;43(2):183-190.

24. 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.

25. Lynn J. *Sick to Death and Not Going to Take It Anymore! Reforming Health Care for the Last Years of Life*. Berkeley: University of California Press, 2004.

26. Australian Bureau of Statistics. Australian Social Trends March 2011. Commonwealth of Australia, 2011.

27. Lunney J, Lynn J, Hogan C. Profiles of older Medicare decedents. *Journal of the American Geriatrics Society* 2002;50:1108-1112.

28. Lunney J, Lynn J, Foley D, Lipson S, Guralnik J. Patterns of functional decline at the end of life. *Journal of the American Medical Association* 2003;289(18):2387-2392.

29. Hastings S, Purser J, Johnson K, Sloane R, Whitson H. A frailty index predicts some but not all adverse outcomes in older adults discharged from the emergency department. *Journal of the American Geriatrics Society* 2008;56:1651-1657.

30. Rockwood K, Song X, MacKnight C, Bergman H, DHogan D, McDowell I, et al. A global clinical measure of fitness and frailty in elderly people. *Canadian Medical Association Journal* 2005;173:489-495.

31. 3303.0 Causes of Death Australia. Australian Bureau of Statistics, 2011. (Accessed May 13, 2013, at http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/3303.0Chapter42011)

32. Australian Institute of Health and Welfare. Trends in palliative care in Australian hospitals. Canberra. AIHW, 2011.

33. Seale C. The role of doctors' religious faith and ethnicity in taking ethically controversial decisions during end-of-life care. *Journal of Medical Ethics* 2010;36:677-682.

34. Primarck B, Roberts T, Fine M, Carpentier F, Rice K, Barnato A. A comparison of televised and real-life emergency medicine. *The Journal of Emergency Medicine* 2012;In Press.

35. Diem S, Lantos J, Tulsky J. Cardiopulmonary resuscitation on television - miracles and misinformation. *New England Journal of Medicine* 1996;334:1578-1582.

36. Bloomer M, Moss C, Cross W. End-of-life care in acute hospitals: An integrative literature review. *Journal of Nursing and Healthcare of Chronic Illness* 2011;3(3):165-173.

37. Palliative Care: The Australian Government's National Palliative Care Program. Australian Government. (Accessed April 23, 2013, at http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-program.htm)

38. NSW Department of Health. Guidelines for end-of-life care and decision-making. NSW Department of Health, 2005.

39. NSW Department of Health. Advance Planning for Quality Care at End of LIfe Strategic and Implementation Framework. NSW Government, 2011.

40. WA Cancer and Palliative Care Network. Government of Western Australia. (Accessed April 23, 2013, at http://www.healthnetworks.health.wa.gov.au/cancer/home/)

41. Pirone C. Interview. Adelaide, 2012.

references

42. What is Healthy Dying? Tasmanian Government. (Accessed April 24, 2013, at http://www.dhhs.tas.gov.au/__data/assets/pdf_file/0006/96378/Web_Healthy_Dying_info_combined.pdf)

43. Organ and Tissue Donation for Transplantation National Communications Framework. Australian Organ and Tissue Donation and Transplantation Authority, 2009. (Accessed at http://www.donatelife.gov.au/the-authority/publications/437-national-communications-framework)

44. The conversation project. (Accessed 24 September, 2012, at http://theconversationproject.org/)

45. Respecting Patient Choices: Advance Care Planning. 2010. (Accessed 16 August 2010, at http://www.respectingpatientchoices.org.au/)

46. Welcome to PEPA. Program of Experience in Palliative Care. (Accessed April 24, 2013, at http://www.pepaeducation.com/default.aspx)

47. CareSearch, Palliative Care Knowledge Network. CareSearch. (Accessed May 13, 2013, at http://www.caresearch.com.au/caresearch/Default.aspx)

48. Palliative Care for People with Sick Kidneys. Kidney Health Australia. (Accessed April 24, 2013, at http://www.kidney.org.au/LinkClick.aspx?fileticket=OXyRpOH3g0I=&tabid=770&mid=1848)

49. Improving oncologists' communication skills. (Accessed April 18, 2013, at http://depts.washington.edu/oncotalk/learn/modules.html)

50. Palliative Care Australia. Standards for Providing Quality Palliative Care for all Australians. Palliative Care Australia, 2005.

51. National Standards Assessment Program. Palliative Care Australia. (Accessed May 13, 2013, at http://www.palliativecare.org.au/Standards/NSAP.aspx)

52. Australian Commission on Safety and Quality in Health Care. National Safety and Quality Health Service Standards. Sydney. ACSQHC, 2011.

53. Aged Care Standards and Accreditation Agency Ltd. Results and Processes Guide. Aged Care Standards and Accreditation Agency Ltd, 2009.

54. End of life care for adults quality standard. 2011. (Accessed 18 September, 2012, at http://guidance.nice.org.uk/QS13)

55. Department of Health. End of Life Care Strategy. London. Department of Health, 2008.

56. Department of Health. End of Life Care Strategy: Quality markers and measures for end of life care. London. Department of Health, 2009.

57. Hospice Friendly Hospitals Programme. Quality Standards for End-of-Life Care in Hospitals. Ireland. Irish Hospice Foundation, 2010.

58. Quality and Outcomes Framework. National Health Service. (Accessed April 23, 2013, at http://www.qof.ic.nhs.uk/)

59. Quality and Outcomes Framework Guidance for GMS Contract 2013/14. (Accessed April 23, 2013, at http://www.nhsemployers.org/Aboutus/Publications/Documents/qof-2013-14.pdf)

60. GP Services Committee Palliative Care Incentives. 2010. (Accessed April 23, 2013, at http://www.gpscbc.ca/system/files/GPSC%20Palliative%20Care%20Initiative%20Billing%20Guide-2010-revised_Nov_2010_0.pdf)

61. Enabling a gold standard of care for all people nearing the end of life. Gold Standards Framework. (Accessed April 24, 2013, at http://www.goldstandardsframework.org.uk/index.html)

62. 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)

63. How multi-disciplinary teams use the AMBER care bundle. Guy's and St Thomas' NHS Foundation Trust. (Accessed 17 September, 2012, at http://www.ambercarebundle.org/about/how-teams-use-amber.aspx)

64. Liverpool care pathway for the dying patient (LCP). The Marie Curie Palliative Care Institute. (Accessed 17 September, 2012, at http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/)

65. More Care, Less Pathway A Review of the Liverpool Care Pathway. 2013. (Accessed at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf.)

66. Palliative Care Outcomes Collaboration. University of Wollongong. (Accessed April 24, 2013, at www.pcoc.org.au)

67. End of Life Care Quality Assessment Tool Frequently Asked Questions. Public Health England. (Accessed April 15, 2013, at http://www.elcqua.nhs.uk/faq.php)

68. NHS Atlas of Clinical Variation. NHS, 2011. (Accessed 18 September, 2012, at http://www.rightcare.nhs.uk/index.php/nhs-atlas/atlas-downloads/)

69. About the Hospice Friendly Hospitals Programme. (Accessed 17 September, 2012, at http://www.hospicefriendlyhospitals.net/about-hfh/)

70. Personally Controlled Electronic Health Records. Australian Government Department of Health and Ageing. (Accessed April 24, 2013, at http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/content/pcehr)

71. Department of Health and Ageing. End of Life Care Canberra. Department of Health and Ageing, 2013.

72. Living and dying well: Building on progress. 2011. (Accessed 19 September, 2012, at http://www.scotland.gov.uk/Publications/2011/01/27090834/0)

73. Murray S, Sheikh A. Palliative care beyond cancer: care for all at the end of life. *British Medical Journal* 2008;336:958-959.

74. Gott M, Ingleton C, Bennett M, Gardiner C. Transitions to palliative care in acute hospitals in England: qualitative study. *British Medical Journal* 2011;342:d1773.

75. Hillman K. End-of-life care in acute hospitals. *Australian Health Review* 2011;35:176-177.

76. Angus D, Barnato A, Linde-Zwirble W, Weissfeld L, Watson R, Rickert T, et al. Use of intensive care at the end-of-life in the United States: An epidemiologic study. *Critical Care Medicine* 2004;32:638-643.

77. Middlewood S, Gardner G, Gardner A. Dying in hospital: Medical failure or natural outcome. *Journal of Pain and Symptom Management* 2001;22:1035-1041.

78. Cassell J, Buchman T, Streat S, Stewart R. Surgeons, intensivists, and the covenant of care: Administrative models and values affecting care at the end of life. *Critical Care Medicine* 2003;31(5):1551-1557.

79. McQuillan P, Pilkington S, Allan A, Taylor B, Short A, Morgan G, et al. Confidential inquiry into quality of care before admission to intensive care. *British Medical Journal* 1998;316:1853-1858.

80. Endacott R, Kidd T, Chaboyer W, Edington J. Recognition and communication of patient deterioration in a regional hospital: A multi-methods study. *Australian Critical Care* 2007;20:100-105.

81. Massey D, Aitken L, Chaboyer W. What factors influence suboptimal ward care in the acutely ill ward patient? *Australian Critical Care* 2008;21:127-140.

82. Parr MJA, Hadfield JH, Flabouris A, Bishop G, Hillman K. The Medical Emergency Team: 12 month analysis of reasons for activation, immediate outcome and not-for-resuscitation orders. *Resuscitation* 2001;50:39-44.

83. Browning A. Moral distress and psychological empowerment in critical care nurses caring for adults at end of life. *American Journal of Critical Care* 2013;22:143-151.

references

84. Hamric A, Blackhall L. Nurse-physician perspectives on the care of dying patients in intensive care units: Collaboration, moral distress, and ethical climate. *Critical Care Medicine* 2007;35(2):422-429.

85. Glare P, Auret K, Aggarwal G, Clark K, Pickstock S, Lickess J. The interface between palliative medicine and specialists in acute-care hospitals: boundaries, bridges and challenges. *Medical Journal of Australia* 2003;179:S29-S31.

86. Le B, Watt J. Care of the dying in Australia's busiest hospital: benefits of palliative care consultation and methods to enhance access. *Journal of Palliative Medicine* 2010;13(7):855-860.

87. Temel J, Greer J, Muzikansky A, Gallagher E, Admane S, Jackson V, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *New England Journal of Medicine* 2010;363:733-742.

88. Clark D. From margins to centre: A review of the history of palliative care in cancer. *The Lancet Oncology* 2007;8(5):430-438.

89. Rodriguez K, Barnato A, Arnold R. Perceptions and utilization of palliative care services in acute care hospitals. *Journal of Palliative Medicine* 2007;10(1):99-110.

90. Frick S, Uehlinger D, Zenklusen R. Medical futility: predicting outcome of intensive care unit patients by nurses and doctors – a prospective comparative study. *Critical Care Medicine* 2003;31(2):456-461.

91. Jameton A. *Nursing Practice: The Ethical Issues*. Englewood Cliffs, NJ: Prentice Hall, 1984.

92. Gutierrez K. Critical care nurses' perceptions of and responses to moral distress. *Dimensions of Critical Care* 2005;24(5):229-241.

93. Wilkinson J. Moral distress in nursing practice: experience and effect. *Nurse Forum* 1988;23(1):16-29.

94. Mobley M, Rady M, Verheijde J, Patel B, Larson J. The relationship between moral distress and perception of futile care in the critical care unit. *Intensive and Critical Care Nursing* 2007;23(5):256-263.

95. Fagerlin A, Schneider C. Enough the failure of the living will. *Hastings Center Report*, 2004:30-42.

96. Tinetti M. The retreat from advanced care planning. *Journal of the American Medical Association* 2012;307(9):915-916.

97. Bezzina A. Prevalence of advance care directives in aged care facilities of the Northern Illawarra. *Emergency Medicine Australasia* 2009;21:379-385.

98. Department of Health and Human Services. Advance directives and advance care planning: Report to Congress. Washington DC. US Department of Health and Human Services, 2008.

99. Rhee J, Zwar N, Kemp L. Uptake and implementation of advance care planning in Australia: Findings of key informant interviews. *Australian Health Review* 2011;36(1):98-104.

100. Heyland D, Barwich D, Pichora D, Dodek P, Lamontagne F, Tayler C, et al. Failure to engage hospitalized elderly patients and their families in advance care planning [online first]. *Journal of the American Medical Association Internal Medicine* 2013;April:1-10.

101. Jones D. The Medical Emergency Team and end-of-life care planning. *Inaugural International Advance Care Planning Conference*. Melbourne, 2010.

102. Micallef S, Skrifvars M, Parr M. Level of agreement on resuscitation decisions among hospital specialists and barriers to documenting do not attempt resuscitation (DNAR) orders in ward patients. *Resuscitation* 2011;82(7):815-818.

103. Forero R, McDonnell G, Gallego B, McCarthy S, Mohsin M, Shanley C, et al. A literature review on care at the end-of-life in the emergency department. *Emergency Medicine International* 2012;2012.

104. Gorman T, Ahern S, Wiseman J, Skrobik Y. Residents' end-of-life decision making with adult hospitalized patients: A review of the literature. *Academic Medicine* 2005;80(7):622-633.

105. Schroder C, Heyland D, Jiang X, Rocker G, Dodek P, Network. CRatEoL. Educating medical residnets in end-of-life care: Insights from a multicenter survey. *Journal of Palliative Medicine* 2009;12(5):459-470.

106. Australians not confident their end of life plans will be carried out – survey. 2012. (Accessed at http://www.palliativecare.org.au/Portals/46/NPCW2012%20images/120515%20PCA%20consumer%20media%20release%20-%20FINAL.pdf)

107. Johnson A, Chang E, O'Brien L. Nursing the dying: A descriptive survey of Australian undergraduate nursing curricula. *International Journal of Nursing Practice* 2009;15(5):417-425.

108. Parish K, Glaetzer K, Grbich C, Hammond L, Hegarty M, McHugh A. Dying for attention: palliative care in the acute setting. *Australian Journal of Advanced Nursing* 2006;24(2):21-25.

109. Reymond L, Charles M, Israel F, Read T, Treston P. A strategy to increase the palliative care capacity of rural primary health care providers. *Australian Journal of Rural Health* 2005;13(3):156-161.

110. Cumming M, Boreland F, Perkins D. Do rural primary health care nurses feel equipped for palliative care? *Australian Journal of Primary Health* 2012;18:274-283.

111. Rosenberg J, Canning D. Palliative Care by Nurses in Rural and Remote Practice: An Evaluation Report Queensland Southern Zone. Centre for Palliative Care Research and Education, Queensland Government, 2003.

112. Indigenous Health. Australian Institute of Health and Welfare. (Accessed April 12, 2013, at http://aihw.gov.au/indigenous-health/)

113. Sullivan K, Johnston L, Colyer C, Beale J, Willis J, Harrison J, et al. National Indigenous palliative care needs study: final report. Canberra. Australian Government Department of Health and Ageing, 2003.

114. Maddocks I, Rayner R. Issues in palliative care for Indigenous communities. *Medical Journal of Australia* 2003;179:S17-S19.

115. Pallaitive Care Australia. Improving access to quality care at the end of life for Aboriginal and Torres Strait Islander Australians. Canberra. Palliative Care Australia.

116. CareSearch Rural Palliative Care Project. (Accessed 12 April, 2013, at http://www.caresearch.com.au/caresearch/tabid/87/Default.aspx)

117. WA Cancer and Palliative Care Network. (Accessed 12 April, 2013, at http://www.healthnetworks.health.wa.gov.au/cancer/providers/hp_palliative.cfm)

118. Jones D. Opportunities for end of life care interventions in acute hospitals (personal communication), 2013.

appendix a: definitions

The following definitions have been adapted from the Glossary of Terms developed by Palliative Care Australia.[4]

Advance care directives

A set of documents containing instructions that consent to, or refuse, specified medical treatments and that articulate care and lifestyle preferences in anticipating future events or scenarios. They become effective in situations where the person is no longer able to make decisions. For this reason advance care directives are also referred to as living wills.

An advance care directive has legal status and therefore is part of the separate legislative arrangements in each state and territory in Australia.

Advance care planning

The process of preparing for likely scenarios near the end of life. This usually includes assessment of, and discussion about, a person's understanding of their medical condition and prognosis, values, preferences, and personal and family resources.

Advance care planning supports patients in communicating their wishes about their end of life.

End of life

That part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown.

End-of-life care

End-of-life care combines the broad set of health and community services that care for the population as they approach the end of life.

Eventually fatal condition

A progressive condition that has no cure and that can be reasonably expected to cause the death of a person within a foreseeable future. The definition is inclusive of both malignant and non-malignant illness and ageing.

A person has an eventually fatal condition if their death in the foreseeable future would not be a surprise.

Hospice

A hospice is a comprehensive service provided to people living with and dying from and eventually fatal condition. This may include inpatient care, respite care, and end-of-life care for people who are unable to die at home. Hospices may also offer day care facilities and community home visiting teams.

Palliation

To palliate is to alleviate a symptom without curing the underlying medical condition. The term is used widely in health care to refer to treatments or interventions (including surgical) that are focused on alleviation of pain or other symptoms, and is not necessarily limited to care provided for eventually fatal conditions.

Palliation in relation to end-of-life care is the relief of symptoms and suffering to help a patient feel more comfortable and to improve the quality of their life. Palliation of symptoms is a key goal of care for both end-of-life and palliative care.

Palliative care

Palliative care is care provided for all people living with, and dying from, an eventually fatal condition and for whom the primary goal is quality of life.

Specialist palliative care provider

A specialist palliative care provider is a medical, nursing or allied health professional recognised as a palliative care specialist by an accrediting body or who substantively works in a specialist palliative care service if an accrediting body is not available.

A palliative care specialist has specialist knowledge, skills and expertise in the care of people living with an eventually fatal condition and their families and carers, including in the management of complex symptoms, loss, grief, and bereavement.

Specialist palliative care services

Specialist palliative care services are provided by an interdisciplinary team of specialist palliative care professionals whose substantive work is with patients who have an eventually fatal condition. Specialist palliative care services are provided in care settings including community, home, hospitals, aged care homes, and hospices and palliative care units.

appendix b: consultation interview processes

Following an initial scoping of the international and Australian literature by the Commission, it became clear that information about the issues that influence the quality and safety of delivery of end-of-life care in acute hospitals was relatively deficient. To explore these issues further, a series of preliminary consultation interviews were conducted with health professionals, consumers and policy makers. The purpose of this informal, targeted preliminary consultation work was to identify:

- perceived key issues, challenges and opportunities relating to the recognition and management of end-of-life care for patients at high risk of dying in acute hospitals
- potential priorities for development of policy, resources and materials to support the recognition and management of end-of-life care for patients at high risk of dying in acute hospitals
- potential strategies to improve the recognition and management of end-of-life care for patients at high risk of dying in acute hospitals.

More than 40 focus group and individual interviews were undertaken over a four month period from November 2012–February 2013. Participants included medical, nursing, social work, pastoral care and executive staff from metropolitan public hospitals in New South Wales, Victoria, the Australian Capital Territory, Tasmania and Queensland, a large metropolitan private hospital in Victoria, and two small rural hospitals and a number of regional palliative care services in Western Australia.

Additional interviews were conducted with clinicians, policy makers and other experts nominated by contacts previously made within the Commission's Recognising and Responding to Clinical Deterioration Program. These included clinicians and policy officers from Australian Government and state departments of health and other agencies such as a healthcare complaints commission. Interviews were also undertaken with two consumers with experience caring for relatives at the end of life, and one consumer who has been diagnosed with a life-limiting cancer.