



Government of **Western Australia**
Department of **Health**

The End-of-Life Framework

A statewide model for the provision of comprehensive, coordinated care at end-of-life in Western Australia

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Foreword

Reforming end-of-life care in Western Australia

Since the formation of the WA Cancer and Palliative Care Network in 2006, a range of targeted palliative care projects have been established. These projects aim to complement existing services and address identified service gaps. They include:

- developing Models of Care for Palliative Care, Rural Palliative Care and Paediatric Palliative Care
- establishing Regional Palliative Care teams
- establishing metropolitan area health service palliative care consultancy teams
- developing and implementing an end-of-life care plan (the *WA Liverpool Care Pathway*, replaced in 2015 by the *Care Plan for the Dying Person*)
- rolling out the *Talking About End of Life* Residential Aged Care Facility project in metropolitan and regional areas
- initiating a range of Advance Care Planning and Advance Health Directive projects.

In 2014, the Office of the Chief Medical Officer and the WA Cancer and Palliative Care Network recognised the need for further reform in end-of-life care, particularly in the development of a statewide, coordinated approach to advance care planning. Following an initial forum in April 2014, key clinicians, health executives and consumers have been consulted widely in order to provide the foundations and catalyst for this reform.

As a result, the *End-of-Life Framework* has been developed. The *Framework* incorporates existing and new initiatives and provides a policy direction for end-of-life care, with a broader remit across acute health services. The initiatives are being led by the End-of-Life Framework Steering Group, under the direction of the Office of the Chief Medical Officer and the WA Cancer and Palliative Care Network, reporting to the State Health Executive Forum.

End-of-life care is everyone's business. As such policy-makers, executives, clinicians, researchers and the wider community all have a role to play to ensure that patients and families have access to high quality care and services at a time when they are possibly at their most vulnerable.

I look forward to working with you into the future as we build upon the foundations of the *Framework* and strive for real changes in the culture and delivery of end-of-life care in Western Australia.



Professor Gary Geelhoed
Chief Medical Officer
Assistant Director General – Clinical Services and Research

1. Executive Summary

The *End-of-Life Framework* (the *Framework*) aims to guide end-of-life care for Western Australians. It provides direction for best-practice care across a patient's end-of-life trajectory, commencing when they are diagnosed with a life-limiting illness or their death is expected. These stages include: advancing disease, increasing decline, last days of life, death; and bereavement support for family and carers. For each of the stages, the *Framework* provides guidance to clinicians, including triggers for consideration and recommendations for action. This approach to the provision of end-of-life care recognises that better end-of-life care starts early in the patient's disease trajectory. It also acknowledges the importance, at any stage in life, of individuals engaging in open and honest conversations and discussing their end-of-life preferences through Advance Care Planning.

In addition to providing the vision and scope, triggers and actions to improve end-of-life care, this document also describes the challenges and gaps that exist within the current health system. These include:

- an increasing demand for end-of-life care
- changing patterns of disease, with an increasing number of people having complex health needs and dying from a range of co-morbidities
- the unpredictable nature of non-cancer diseases, which contribute to patients with dementia, frailty and/or multi-organ failure receiving less than optimal care
- lack of adequate coordination and continuity of care across health settings
- the number of patients that are admitted to acute hospitals at end-of-life, many of whom die in hospital despite expressing a wish to die at home
- clinicians' ability to recognise and respond to clinical deterioration, discuss patients' goals of care and engage in open and honest conversations
- the unique and challenging issues faced by rural and remote clinicians and communities
- the need to provide targeted education and support to staff and clinicians working in primary health care, residential care facilities and generalist settings that can lead to system wide change
- greater recognition of the role of Specialist Palliative Care teams, including appropriate and timely referral
- the need for community awareness and understanding of death, dying, loss, palliative and end-of-life care and to recognise the limits of medical interventions
- aligning statewide end-of-life initiatives with the national policy agenda.

The *Framework* builds upon existing programs that have been established in Western Australia. It aims to guide and influence systemwide change in end-of-life care, to support clinicians in this essential and inevitable aspect of their work, and to help patients, irrespective of their diagnosis, to live well and to die well.

Figure 1 The *End-of-Life Framework*

Stages*		Triggers	Action	
1	<i>Would you be surprised if the patient died in the next 6-12 months?</i>	Advancing disease	<ul style="list-style-type: none"> Known advanced cancer or chronic disease Evidence of disease progression and/or symptoms Patient/family expresses concern about the future Would you be surprised if the patient died in the next 6-12 months? 	Consider: <ul style="list-style-type: none"> Advance Care Planning Palliative Care consultation
2	<i>Would you be surprised if the patient died this admission or in the next month?</i>	Increasing decline	As for Stage 1 plus: <ul style="list-style-type: none"> Increasing frailty Increasing symptom burden Increasing psychosocial support needs Not responding to treatment or non-adherence with treatment For hospital inpatients, would you be surprised if the patient died this admission? 	Consider: <ul style="list-style-type: none"> Referral to palliative care for ongoing care or palliative care consultation and/or shared care partnerships with palliative care
3	<i>Irreversible clinical deterioration, life expectancy one week or less</i>	Last days of life	<ul style="list-style-type: none"> Irreversible clinical deterioration Team decision of diagnosis of dying. 	Commence: <ul style="list-style-type: none"> Best practice care of the dying, e.g. <i>Care Plan for the Dying Person</i>
4		Death and bereavement	<ul style="list-style-type: none"> Death of patient 	Consider: <ul style="list-style-type: none"> Bereavement follow-up needs

* The stages are provided as a guide and are not intended to be prescriptive – each patient’s circumstances will be different and care should be provided accordingly.

2. Introduction

This document provides an overview of the *End-of-Life Framework* (the *Framework*), which aims to improve end-of-life care for all Western Australians in all care settings. It outlines the scope and vision to ensure that patients, irrespective of their diagnosis, receive high quality, safe, comprehensive and coordinated care at end-of-life. This vision for better end-of-life care encompasses all stages in the patient's journey from the point in their life where there is evidence of disease progression and/or symptoms, to increasing decline, through to the last days of life and bereavement.

The *Framework* also recognises the importance, at any stage in life, of individuals discussing their end-of-life preferences through Advance Care Planning (ACP)*. Engaging in open and honest conversations, discussing care preferences and acknowledging the limitations of treatment will assist us to view death and dying as part of life and allow us to live well and die well.

This document also describes the need for improvements in end-of-life care, including the current gaps and challenges, as well as Government policies that are driving change.

3. The End-of-Life Framework

The *Framework*, shown in Figure 1, provides a focus for the provision of best end-of-life care, across all stages in the patient's journey. This commences at the point at which there is evidence of advancing disease, to increasing decline, through to the last days of life and death and bereavement. Triggers for action and recommended actions are described for each of the four stages.

Further explanation of the four stages of the *Framework* is provided in Figure 2, including triggers for consideration and patient goals of care. Figure 3 illustrates the impact on patients and their families of receiving high-quality, safe, comprehensive and coordinated end-of-life care.

Patient case studies are provided in Figures 4, 5 and 6. These case studies aim to further illustrate each of the stages at end-of-life and the potential impact of recognising triggers and initiating actions.

4. Vision and scope

The *Framework* has been developed to address the existing gaps and challenges in care at end-of-life, as well as the increased recognition that better end-of-life care starts before the terminal phase of life.

The *Framework* provides an opportunity for systemwide, cultural change in the provision of end-of-life care in Western Australia. Adopting a structured, policy framework approach will assist services to provide good end-of-life care to patients and their families and, importantly, a structure to ensure that clinicians are supported in their work.

The *Framework* builds upon a range of existing programs across the full spectrum of end-of-life care, while also incorporating a new focus. This new focus recognises the importance of identifying patients whose health is declining as a result of advancing disease; and addressing their future needs and preferences through improved communication in areas such as ACP and goals of care.

***Advance Care Planning (ACP)** Advance care planning is an ongoing discussion between an individual, their carers/family and their health care team about their values, beliefs, treatment and care options; in particular, their wishes for future care should they no longer be able to do so at the time decisions are needed. Ideally these decisions should be documented in an Advance Health Directive.

Figure 2 The End-of-Life Framework: Triggers and Goals of Care across the stages of a patient's end-of-life trajectory

Stage 1 Advancing disease	Stage 2 Increasing decline	Stage 3 Last days of life	Stage 4 Death and bereavement
<ul style="list-style-type: none"> Known chronic disease or advanced cancer Evidence of disease progression and/or symptoms Patient/family expresses concern about the future Would it be a surprise if the patient died in the next 12 months? 	<ul style="list-style-type: none"> For hospital inpatients, would it be a surprise if the patient died this admission? Would it be a surprise if the patient died in the next 6-12 months? As for Stage 1 <i>plus</i>: <ul style="list-style-type: none"> Increasing frailty Increasing symptom burden Increasing psychosocial support needs Not responding to treatment or non-adherence with treatment 	<ul style="list-style-type: none"> Irreversible clinical deterioration Team decision: diagnosis of dying Family/carer recognition of dying (for people at home) 	<ul style="list-style-type: none"> Death of patient
<ul style="list-style-type: none"> Management and treatment of advancing disease Coordinated care Care which aligns with the National Safety and Quality in Health Care Standards Introducing concepts of Advance Care Planning or holding ACP discussions. 	<ul style="list-style-type: none"> Early identification of increasing decline Coordinated care Care which aligns with the National Safety and Quality in Health Care Standards Avoiding/preventing long-term hospital admissions or readmissions Holding/initiating or revisiting advance care planning discussions Communication of any ACP, Advanced Health Directive (AHD)* decisions across settings (including preferred place of care and place of death) Referral to supportive and palliative care services based on complexity and need. 	<ul style="list-style-type: none"> End-of-life care which aligns with the National Safety and Quality in Health Care Standards, regardless of setting Avoiding/preventing unwanted hospital admissions or readmissions Communication of and adherence to any documented ACP, AHD decisions Avoiding/preventing unnecessary and/or unwanted treatments and tests Supporting family, friends and carers to acknowledge ACP, AHD decisions or participate in decision-making where these have not yet been made Supporting patients to die in preferred setting (home, hospital, community). 	<ul style="list-style-type: none"> Support families/friends where death is at home Quality after-death care in the hospital Quality bereavement services

Triggers to consider

Goals of care
What we can offer patients

* **Advance Health Directive (AHD)** An Advance Health Directive is a legal document that is completed using a form which contains a person's decisions about future treatment in anticipation of a time when they may be unable to make reasonable judgments for him/herself. A valid AHD is legally binding and documents treatment decisions in which a person consents or refuses consent to future treatment according to specific circumstances. A valid AHD must be in the form or substantially in the form prescribed by the regulations.

Figure 3

A vision for good end-of-life care – what does it mean for patients and families?¹⁻³

- Receiving patient-centred care
- Establishing goals of care at diagnosis
- Living well in the time that is left
- Receiving access to a standardised level of care
- Accessing timely referral to specialist palliative care, if required
- Avoiding unnecessary interventions
- Reducing stress
- Planning for a 'good death'
- Communicating in an upfront, timely and respectful way
- Initiating Advance Care Planning
- Having wishes respected
- Continuity of care across health services
- Supporting family members and carers in their bereavement

5. End-of-life care in Western Australia

5.1 The increasing demand for end-of-life care

The proportion of older people in the population is increasing faster than population growth due to increased average life expectancy at birth and the ageing baby boomer generation.⁴ It is estimated that the number of Australians who die each year will almost double in the next 25 years,⁵ placing increasing demand on the provision of end-of-life care. Patterns of disease are also changing, with an increasing proportion of the population having complex healthcare needs and dying from a range of comorbidities.⁶ With an increase in the number of people living with chronic disease, 70 per cent of deaths are now clinically expected.⁵

5.2 Improving access to end-of-life care

End-of-life care has been shaped primarily through the needs of patients with cancer. Despite having a common set of needs, patients with life-limiting illnesses other than cancer have traditionally received significantly lower access to end-of-life care services⁷. As evidenced by the changing patterns of disease, most patient deaths are not cancer related. In a study that analysed deaths in Western Australia and hospital and emergency department use during the last year of life, 61 per cent of people were in hospital on their last day of life, and the majority (65.5 per cent) had a non-cancer diagnosis.⁸

The unpredictable nature of non-cancer disease trajectories is a contributing factor to accessing appropriate end-of-life care.⁹ This includes people with advanced organ failure such as heart failure or chronic obstructive pulmonary disease who typically experience relapses and remissions, or those who are dying from frailty, multi-organ failure or comorbidity, including dementia.¹⁰ The latter, in particular, is a vulnerable group and often fails to receive appropriate, coordinated care at end-of-life.¹¹

Patients with dementia encounter unique challenges to their physical and psychological wellbeing at the end-of-life. Compounding these challenges is the fact that dementia is often perceived as a normal part of ageing and also not widely recognised as a terminal disease, despite being the third leading cause of death in Australia.¹² People with dementia have little opportunity to express their care preferences, often do not die in their place of choice and are more likely to experience poorly managed pain control.¹³

An understanding at diagnosis that a patient with dementia will lose decision-making capacity provides an opportunity to encourage the documentation of wishes through ACP.¹⁴

5.3 Continuity of patient care across settings

The health system is currently organised by setting, including home, residential care, general practice and hospital, and this is challenging to continuity of care. Patients are required to navigate a fragmented system across a range of uncoordinated services that often do not match their needs. For patients who are already dealing with uncertainty regarding their declining health, a model that facilitates the continuity of care is paramount.¹⁵

In addition, general practitioners and residential care facilities experience a unique set of challenges which reduce their capacity to provide optimal care at end-of-life. For general practitioners, these include the increasing demands of patients with complex care needs and time pressures¹⁵ as well as inadequate funding mechanisms.¹⁶

Residential care providers face barriers in regards to adequate staffing, access to allied health providers and limited access to general practitioners with skills and knowledge in providing end-of-life care. Supporting and encouraging primary care providers to engage with patients and their families to discuss their wishes and facilitate ACP is a crucial step in addressing some of these challenges.¹⁷

The establishment of Primary Health Networks (PHNs) in the primary healthcare sector, including Perth North, Perth South and Country WA, will provide an opportunity to strengthen links in this key area. The objectives of the PHNs are to increase the efficiency and effectiveness of medical services for patients, particularly those at risk of poor health outcomes; and improve coordination of care to ensure patients receive the right care in the right place at the right time.¹⁸

5.4 Rural and remote challenges

Since the development of the Rural Model of Care in 2008 and the inception of the Regional Palliative Care teams, significant milestones have been achieved in providing a coordinated approach to end-of-life care for rural and remote patients in Western Australia. However, challenges still exist for patients, families and health providers. Findings of a preliminary palliative care survey conducted by the Royal Australian College of General Practitioners' National Rural Faculty revealed a number of areas of need, including:

- more training and education across the palliative care team
- additional funding for after-hours care
- the coordination of services and team-based planning
- improvements in identification of people who would benefit from advance care planning
- collaboration and partnership building across primary and tertiary healthcare settings.¹⁹

5.5 Dying in acute care

Dying in Australia is more institutionalised than in the rest of the world,⁴ with 50 per cent of Australians dying in hospital, despite 68 per cent indicating a preference to die at home.²⁰ Home deaths, which include people who die in residential care facilities, are half as prevalent in Australia as they are in New Zealand, the United States of America, Ireland and France.²¹

Hospitalisations in Australia have increased significantly for older age groups, with the hospitalisation rate for those aged over 85 increasing by 35 per cent for women and 48 per cent for men in the decade to 2011-2012.⁴

A high number of hospital admissions and emergency department presentations occur in the last 12 months of life. Frequently these acute care presentations and admissions are inappropriate and they can be distressing for patients. They also place increased stress on an already pressured health system.²²

5.6 The cost of dying in acute care

Research shows that 59 per cent of health care expenditure is incurred during a person's last three years before death, regardless of their age at death. This cost increases substantially during a person's last year of life and, in particular, increases substantially during their last three months of life.²³ Each year more than \$2 billion is spent on older people who die in hospital, with an estimated 9 per cent of all inpatient costs being allocated to patients aged 65 years and over in their last year of life.²⁴ Approximately one-third of all people who die in hospital will have only one admission – the one in which they die – at an estimated cost of \$19,000 for those aged 50 and over.⁴

With more people dying each year due to Australia's ageing population, the real costs of dying will increase accordingly. Policies to address this anticipated increase in costs are essential in order to manage the health budget.⁴

5.7 Recognising and responding to clinical deterioration

The acute care setting is designed to provide short-term, episodic care for mainly acute illnesses.²³ Patients are often intensively managed and the default position is to continue to treat symptoms. In addition, recognition of dying is frequently inadequate, resulting in missed opportunities to consider appropriate referral to specialist palliative care and to initiate end-of-life care plans.⁴

With an estimated 70 per cent of patient deaths now being ‘expected’⁵ there is a growing need for clinicians to recognise and respond in a timely manner to a patient’s clinical deterioration and to consider their unique goals of care. Clinicians have a responsibility to initiate and facilitate honest discussions with patients earlier in their illness trajectory and to assist them to make decisions about how they want to live for the rest of their lives.

“I believe healthcare needs to be judged, not just by the lives saved, but by the quality of death for those they can’t save.” (Intensivist, WA Health Clinical Senate, 2015)

5.8 Supporting clinicians in their practice

In addition to placing safety and quality at the forefront of end-of-life care for patients and their families, there is also a need to ensure that clinicians across all health settings are adequately trained and supported to provide this level of care. The quality of care at end-of-life is often dependent on a clinician’s experience and the resources available, leading to a wide variation in practices within and across health services.

“It’s hard for experts (health professionals) to listen to non-experts (carers), when they are the experts of their loved one. Listen to the carers and consumers a bit more.” (Carer, Consumer Care Focus Group, 2015)

5.9 Changing the culture of dying and planning for death

Culturally and in the community, the language used to talk about death often avoids the issue of dying. Frequently, terms such as “passed” or “passed on” are used, rather than direct language such as “death” and “dying”. Indeed, open discussion about death has regressed in relation to earlier times, when death was more common.²⁵

There is a need for public discussion on issues relating to death and dying, and in particular acknowledging and recognising the limits of care for patients whose health is deteriorating. Decision-making at end-of-life can be extremely stressful especially when honest conversations have not previously taken place, and when choices are being made in the “pressure cooker environment of a hospital.”⁴

A cultural change is required in order to encourage clinicians, patients and families to engage in honest conversations and to assist patients to make decisions about how they want to live until they die. Broader strategies are required to raise awareness and enhance community understanding of issues relating to death and dying, in particular the limits of medical interventions, the benefits of palliative care and the importance of ACP and AHD.

“...the idea that cure is improbable or impossible, or that continued life support is inappropriate or unkind, is unacceptable to many families. The wider problem here is that acknowledgement of the inevitability of death, and preparation for it, have largely lost their place in our culture. For many, an almost child-like faith in medicine and science has taken its place.”²⁶

Research indicates that real benefits for individuals and communities can result from strengthening society's awareness and understanding of death, dying, loss and palliative and end-of-life care. These include a greater willingness to explore issues of death and dying and the ability to commence and participate in conversations. In this way, individuals are able to support each other and are better prepared to consider timely access to palliative care.²⁷⁻²⁹

5.10 Specialist palliative care

Palliative care service provision is fragmented and greater coordination is required in order to provide an equitable service for patients and their families, based on a patient's needs. For those who require access to specialist palliative care, this is recommended earlier in a patient's illness trajectory. Evidence indicates that early referral is linked to improved quality of life and mood,³⁰ survival and reduced depression and stress burden for family caregivers.³¹

5.11 The national health agenda – driving policy change

End-of-life and palliative care is at the forefront of the national health agenda, with government policy driving change through policies and guidelines such as the *National Safety and Quality in Health Care Standard 9, Recognising and Responding to Clinical Deterioration in Acute Health Care*³² and the *National Palliative Care Strategy 2010: Supporting Australians to Live Well at End of Life*.³³

The National Palliative Care Strategy goals include:

- to significantly improve the appreciation of death and dying as a normal part of the continuum
- to enhance community and professional awareness of the scope and benefits of timely and appropriate access to palliative care services
- to build and enhance the capacity of all relevant sectors in health and human services to provide quality palliative care.

Figure 4:

Case Study 1: Six months prior to death Mr C – a 68-year-old man diagnosed with cancer

Mr C is a 68-year-old man who lives at home with his wife, daughter and son-in-law. He is referred by his GP to hospital for admission as he has been experiencing increasing nausea, vomiting and lethargy.

He has a history of lung cancer (diagnosed one year ago) for which he has been having chemotherapy. During his admission the doctors discover his cancer has spread throughout his lungs and also to his liver. Mrs C is upset about this as she believed his cancer was being treated by the chemotherapy. Mr C's treating team consider a different type of chemotherapy to help ease his symptoms.

While in hospital Mr C regularly tells nursing staff he wants to go home and that he dislikes spending time in hospitals away from his wife. Mr C starts the new chemotherapy in hospital and with his symptoms treated he is sent home. His GP is sent a discharge letter and he has a planned outpatient appointment in four weeks.

Opportunities to improve quality of care *prior* to this admission

Cancer diagnosis: there may have been an opportunity to introduce the concept of **Advance Care Planning (ACP)** to Mr and Mrs C once this diagnosis was made. Mr C may have used this time to discuss his goals of care with his family, treating team and/or his GP

Opportunities and key stages *this* admission

Disease progression (triggers/surprise question): the treating medical staff could **discuss prognosis and goals of care** with Mr C and his family as his condition has worsened and he is likely to need increasing care in the next 6 months.

Dislikes hospital (patient-centred care): there is an opportunity for the team and the family to consider the different options for care at home for Mr C in the future as his condition worsens. This may also include discussions about where **he may wish to be cared for when he dies**.

Options for care (specialist palliative care): this may be an opportunity to introduce palliative care services as an option in future care if needed or wanted at the time. (EQiP National Guidelines Standard 12; Criterion 4: End of life care – 12.12 Specialised services).

Figure 5

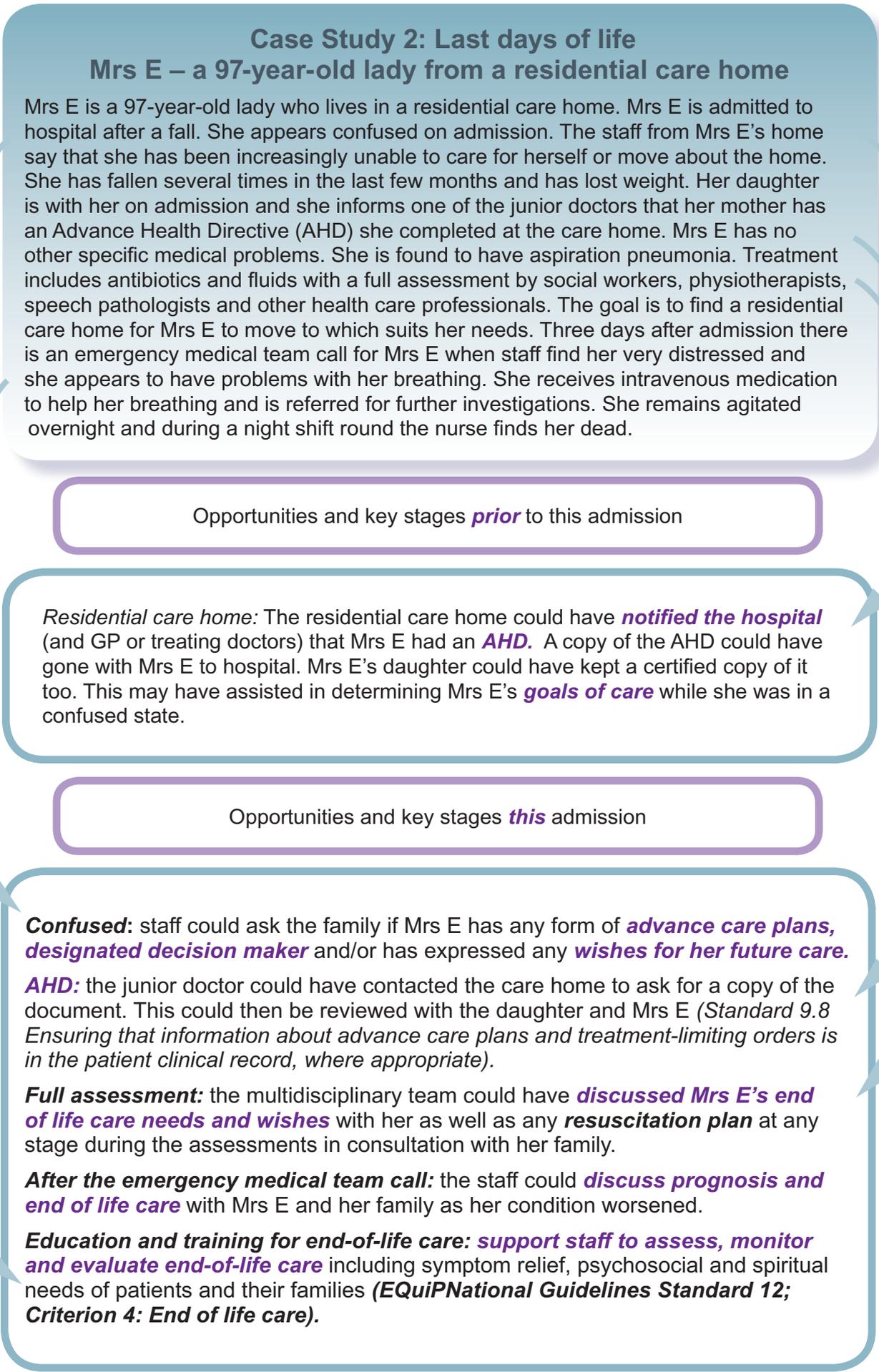


Figure 6

Case Study 3: Last months of life Mrs M – a 71-year-old lady with comorbidities

Mrs M is a 71 year old lady who lives at home with her adult son. She is admitted to hospital via the Emergency Department after a fall. She is found to have pneumonia. She has a history of alcohol dependence, type 2 diabetes, high blood pressure and irregular heartbeat. She has been in hospital five times in the past 12 months with increasing problems and difficulty coping with her diabetes at home. After several days in hospital she finds it more difficult to breathe and becomes agitated and aggressive. Her pneumonia worsens and she has bacteraemia. She is sent to the Intensive Care Unit (ICU) where her care continues for five days. Her condition improves somewhat and she is transferred back to a ward. After 14 days in hospital she is discharged home with some equipment to support her. There is a plan for community support services to assess her needs and assist her to manage at home.

Opportunities and key stages *prior* to this admission

Multiple admissions (triggers): there may have been an opportunity (triggered by multiple unplanned admissions) to start Advance Care Planning (ACP) discussions during at least one of these admissions. Mrs M may have used this time to discuss her wishes for her future care with her son, her treating doctors and her general practitioner.

Opportunities and key stages *this* admission

Admission: the admitting nurses and doctors could ask Mrs M if she has any form of **ACP** documented.

Worsening condition: the treating medical staff could discuss **prognosis and goals of care** with Mrs M and her family as her condition worsened. The practicality of an ICU admission could be discussed.

Post ICU: Treating medical staff could **discuss the future likelihood of ICU admissions** and determine what Mrs M and her family would like to do if ICU admission became likely again.

Plan for recurrent admissions: Mrs M may require more **community-based support** and health services to manage her care at home and **avoid unplanned hospital admissions**.

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