

# Learning Guide for Nurses

## 2020



**PEPA** Program of Experience in the Palliative Approach

**PEPA** Indigenous Program of Experience in the Palliative Approach



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- The PEPA National Team
- State and Territory PEPA Managers
- Project Director Dist. Professor Patsy Yates, Queensland University of Technology.

# Recognition

PEPA acknowledges and pays our deepest respect to the past, present and future Traditional Custodians and Elders of the many lands on which we work and live, and the continuation of cultural, spiritual and educational practices of Aboriginal and Torres Strait Islander peoples.

PEPA recognises the contributions and partnerships of Aboriginal and Torres Strait Islander and non-Indigenous Australians in the development, promotion and delivery of the program to ensure Aboriginal and Torres Strait Islander peoples have equal and genuine access to quality, holistic and culturally-responsive palliative care.



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# Section 1: Overview

## About PEPA

The Program of Experience in the Palliative Approach (PEPA) forms part of the Palliative Care Education and Training Collaborative (the Collaborative). As a national palliative care project, the Collaborative takes a strategic approach to education and training of the healthcare workforce and delivers programs for priority healthcare provider groups across primary, secondary and tertiary settings. Specifically, PEPA aims to enhance the capacity of health professionals to deliver a palliative care approach through their participation in either clinical placements with specialist palliative care services or interactive workshops.

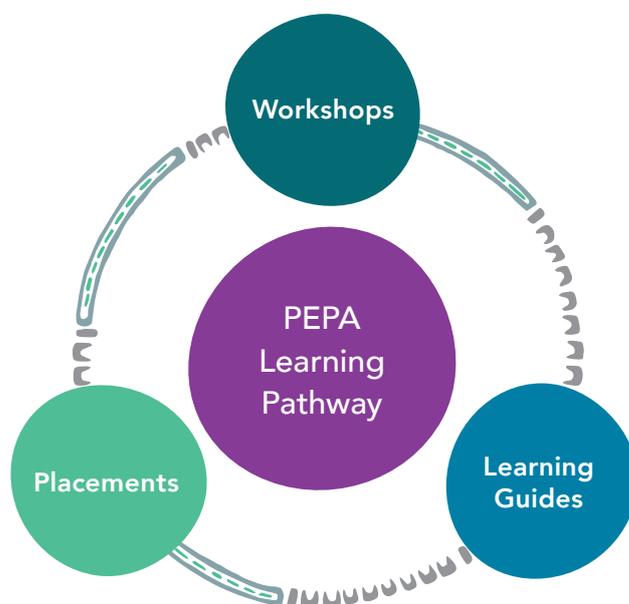
## Learning pathway

Nurses have an important role in supporting people affected by life-limiting illness. In all healthcare contexts, nurses work closely with individuals, families and carers during the end-stages of life. Developing an understanding of the principles of the palliative approach to care, and the skills required to assess and manage people's needs is important for all nurses.

The PEPA team acknowledges that palliative care is sensitive business, and deeply respects and acknowledges the journey that you are taking to improve the quality of life for those with life-limiting

illness and their families. The palliative approach reflects a positive and open attitude towards dying and death.

The PEPA learning pathway is aimed at assisting you to develop skills, knowledge and confidence in the palliative approach to care. We will focus on active comfort care and a positive approach to managing symptoms and reducing distress. This approach facilitates early identification of individuals' beliefs, needs and choices, and provides guidance for ways you can support them and their families, carers and community.



Workshops	Placements
<p>PEPA offers a range of workshops, including:</p> <ul style="list-style-type: none"> <li>• Palliative Care – with content tailored to participants working in acute care, aged care, community and Aboriginal and Torres Strait Islander healthcare professionals</li> <li>• Culturally-Responsive Care for Aboriginal and Torres Strait Islander Peoples</li> <li>• Culturally-Responsive Care for CALD Peoples</li> <li>• Mentoring Workshops.</li> </ul>	<ul style="list-style-type: none"> <li>• PEPA workforce placements entail supervised, observational placements (2–5 days) in community, inpatient and hospital-based consultancy specialist services, guided by a mentor.</li> <li>• Reverse PEPA involves a palliative care specialist travelling to your place of employment to facilitate small group learning. It is available in Aboriginal and Torres Strait Islander health settings, rural/ remote health and residential aged care settings.</li> </ul>

## Ongoing support

- To keep informed and connect to others in the PEPA network, you can follow us on [Facebook](#)
- For regular updates, [subscribe](#) to our eNewsletter
- To find out more about PEPA and to access the contact details of your local PEPA Manager, visit our [website](#)
- For Aboriginal and Torres Strait Islander health professionals, IPEPA welcomes you to join our [closed Facebook group](#) for a safe, supportive platform to ask questions and connect to others with an interest in palliative care.

## Introduction to the Learning Guide

This learning guide is a part of the PEPA learning pathway that is intended to help inform your journey around Palliative Care. It can be used to support workshops and placements, as a guide to key information and links to detailed content and learning resources. It also provides opportunities for reflection and ongoing learning, which will assist you in developing knowledge, skills and confidence for your day-to-day work.

### Components of the Learning Guide



#### Content Summary

A brief overview of the area of content



#### Reflection

An opportunity to reflect on how the area of content relates to your experiences



#### Learning Activity

An opportunity to apply content in a practical way



#### Resource Links

Links to detailed information or other types of resources (articles, videos, podcasts etc) on the specific area of content



#### Glossary

A list of common palliative care terms (and their meanings) that are used throughout the learning guide



#### References

A complete reference list is included at the end of the learning guide to provide links to further resources and readings.

## Notes

### Learning Objectives

When you have completed this learning guide, you will be able to:

1. Describe the palliative approach to care and outline important principles
2. Identify the principles of effective communication in palliative care
3. Describe advance care planning and its importance in providing care
4. Outline approaches to assessment in palliative care and describe commonly used assessment tools
5. Summarise common care needs for people with life-limiting illness and the multidisciplinary approach to managing these needs, including pain assessment and management, and medication use
6. Describe important aspects of caring for someone at the end of their life
7. Identify ways to support people who are experiencing grief and loss
8. Outline important aspects of self-care.

### Self-care

This learning guide will address a range of issues related to dying, end-of-life care and death, and considers the impact on family, carers and community.

Focusing on these issues can generate a range of emotions and responses. It is important to look after yourself and talk with a trusted friend or colleague if you need support.

#### **WARNING:**

Aboriginal and Torres Strait Islander people should be aware that this learning guide provides links to websites and resources that may contain images, names or voices of people who have passed away.



# Section 2: Palliative approach to care

## What is palliative care?

Palliative care helps people live their lives as actively and as comfortably as possible when living with a life-limiting or terminal illness. This approach to care responds to the holistic needs, experiences, preferences and care requirements of people with life-limiting illnesses or who are in the final stages of their life.

The focus of palliative care is on managing symptoms and providing comfort and support.

The two most common definitions of Palliative Care are:

World Health Organization	Palliative Care Australia
<i>Palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual. <sup>(1)</sup></i>	<i>Palliative care is person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary treatment goal is to optimise the quality of life. <sup>(2)</sup></i>



### Reflection:

Consider these questions:

1. What does 'person and family-centred care' mean to you?
2. What does 'life-threatening illness' and 'active, progressive, advanced disease' mean to you?
3. How do you think an 'incurable illness' would influence the care that a person needs?
4. What does 'quality of life' mean to you?

### Notes

## Key Concepts

Person and family-centred care	Life-limiting illness
<p>Care that places the person and their family at the centre of healthcare.</p> <p>This means that they are listened to, informed, respected and involved in their care – and that their wishes are honoured throughout their healthcare journey.</p> <p>The relationship between the person, their family and the healthcare team can be greatly strengthened by encouraging communication about things that matter so that the person knows more about their health and can be actively involved in decisions about their care.<sup>(3)</sup></p> <p><b>Resource Link:</b> <a href="#">CareSearch – Person-Centred Care</a><sup>(4)</sup></p>	<p>An active, progressive, advanced disease is known as a life-limiting illness.<sup>(5)</sup></p> <p>This term is used to describe a wide range of illnesses where it is expected that death will occur including: cancer, heart disease, respiratory disease, dementia, degenerative neurological diseases (eg, motor neurone disease and muscular dystrophy), chronic liver disease, chronic kidney disease, and other degenerative illnesses or significant deterioration.</p> <p>Palliative care should be available to all people living with an active, progressive, advanced illness, regardless of their diagnosis.</p> <p><b>Resource Link:</b> <a href="#">CareSearch – Living with Life-limiting Illness</a><sup>(6)</sup></p>
Curative vs Palliative care	Quality of life
<p><b>Curative care</b> involves treatment that is aimed at identifying and treating the source of the illness and promoting recovery.</p> <p><b>Palliative care</b> aims to comfort. It focuses on living well with worsening health, rather than curing and recovery from illness.</p> <p>Although it can be provided alongside curative care, the main aim of palliative care is to make sure that people have the best quality of life while they are alive and that they can live as actively as possible until death, while also supporting families, friends and carers in approaching death, grief and healing.</p> <p><i>Our ultimate goal after all, is not a good death but a good life to the very end.</i><sup>(7)</sup></p>	<p>Quality of life can be defined and experienced by each person in unique ways. A person's perception of quality of life is influenced by how different aspects of their life (physical, emotional, social and spiritual) interact and the importance of these aspects to them.</p> <p>To understand what quality of life means for each person, we need to consider their unique needs and how best to support them to live with purpose and comfort.</p> <p><i>People turn out to have priorities in their life besides just living longer. We need to ask people what their priorities are... If we don't ask, our care... isn't aligned with what matters most to them – and then you get suffering.</i><sup>(7)</sup></p> <p><b>Resource Link:</b> <a href="#">CareSearch – Quality of Life</a><sup>(8)</sup></p>



## Learning Activity:

From your reading of these descriptions and the information in the resource links, consider the following questions:

1. What do you think of when you hear the words, 'Palliative Care'?
2. How would you describe the palliative approach to a person and their family in your work context? Write out the wording/explanations you would use.
3. What is your role as a nurse in providing palliative care? Think about the various aspects of your current role.
4. What care or support would you like to see added to your workplace to improve the way palliative care is provided?

## Notes

## Who needs palliative care?

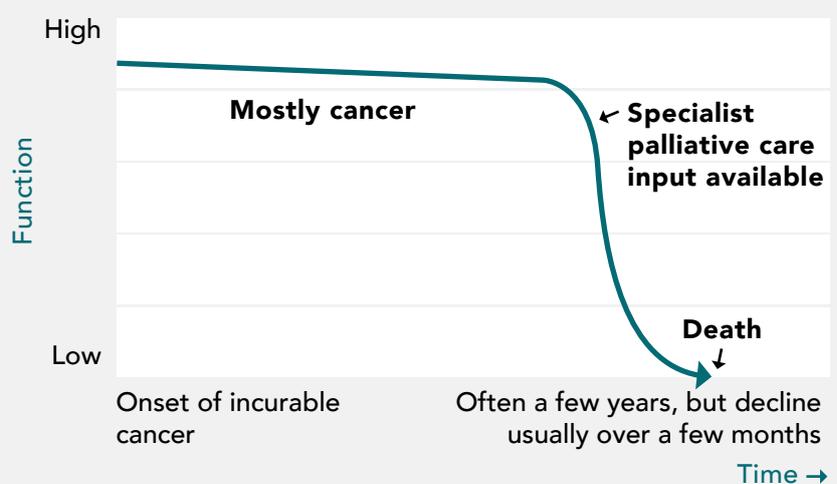
People affected by life-limiting illness experience decline in physical and/or cognitive function that is unique to the individual. However, these experiences typically follow three broad patterns, known as 'illness trajectories':<sup>(9)</sup>

### Illness Trajectories

#### Trajectory 1:

- A short period of obvious decline or deterioration
- These people may have good function for a long period followed by a few weeks or months of rapid decline prior to death

#### Short period of evident decline



#### Example:

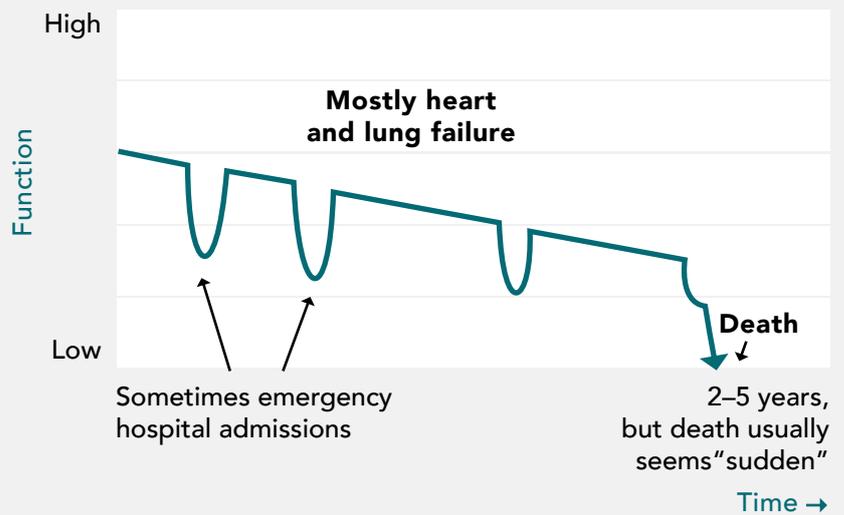
Joan is a 45-year-old woman with secondary breast cancer, which has spread to the bone and liver, who received her initial cancer diagnosis 10 years ago. She continues to receive a range of anti-cancer treatments. Joan is suffering from weight loss, decreased appetite and pain, and is increasingly weak and tired.

## Illness Trajectories

### Trajectory 2:

- Long-term illness with serious episodes
- Those with chronic illness such as, respiratory disease, heart disease, diabetes, kidney failure
- These people will have gradual decline in function.
- During each acute episode, the person is at risk of dying. If they recover, their function will continue to decline.

### Long term limitations with intermittent serious episodes



### Example:

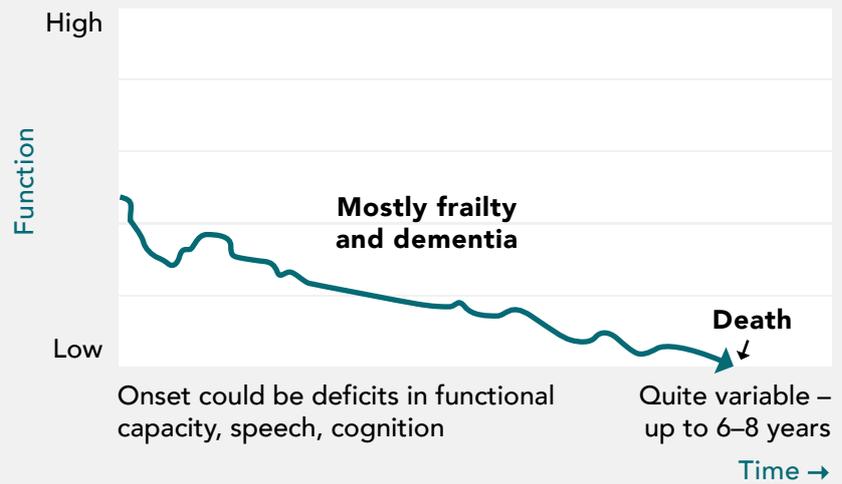
*Bob is a 69-year-old man with end-stage heart failure who is experiencing fatigue and increasing breathlessness. He has had three emergency hospital admissions in the past 12 months. He is concerned about what quality of life his future holds and when he will die.*

## Illness Trajectories

### Trajectory 3:

- Those who are aged and frail
- The person has a long-term progressive disability and decline in function
- Death may be caused by infections, falls or fractures.

#### Prolonged dwindling



#### Example:

*Hans is an 85-year-old man with arthritis and early-stage dementia. He is living alone and his family is becoming increasingly concerned for his safety. Hans is very forgetful, and his mobility is poor. His decline is likely to be slow, making it difficult to predict the dying phase.*

The palliative approach to care is extremely important for older people, with an approach that focuses on three connected elements – physical, psychosocial and spiritual, to maximise quality of life.

For nurses in community and residential care settings, many of the people you care for will be older people. They might have a cancer diagnosis or chronic disease (where their course of illness follows either Trajectory 1 or 2), but many will follow Trajectory 3 and have an unpredictable period of gradual decline.

**Please note:** The *Palliative Approach Toolkit* (no longer in use) included the term ‘palliative care trajectories’ (A, B and C) to describe expected timeframes for prognosis for people in residential aged care facilities. It is important to understand that this is not the same as the illness trajectories described in this section.

## Recognising when palliative care is needed

Recognising when a person requires palliative care can be difficult. However, it is important that it is introduced early if people are to be supported to have optimal quality of life.

**The Surprise Question** – “Would you be surprised if this person died in the next 6–12 months?” is used in many healthcare settings as a way to help identify people who would benefit from palliative care.<sup>(10)</sup>

The **Supportive and Palliative Care Indicators Tool (SPICT™)** – helps the healthcare team identify people who have general signs of poor or deteriorating health, and clinical signs of life-limiting illness, for assessment and care planning. SPICT-4ALL™ is a simplified version of the tool with less ‘medical’ language, designed to be used by people with life-limiting illness, and their family/ carers to help talk about care needs and support.<sup>(11)</sup>



## Resource Links:

[CareSearch: Living Longer, Dying Better](#)<sup>(12)</sup>

[ELDAC Toolkit: Recognise End of Life](#)<sup>(13)</sup>

[University of Edinburgh/NHS Lothian: SPICT](#)<sup>(11)</sup>

## Notes

## What type of care do people need?

Not everyone with a life-limiting illness will need access to palliative care specialists or in-hospital care. For many people, care can be managed in community settings with the support of primary healthcare staff.

Others will need access to specialist care from time-to-time for consultation and advice when symptoms (such as pain, psychological distress and reduced physical capacity) worsen. Those with complex and persistent needs will require ongoing specialist palliative care.

Palliative Care Australia describes three levels of palliative care, as summarised in the following table:<sup>(14)</sup>

Level 1: Palliative Care	Level 2: Specialist Palliative Care	Level 3: Specialised Palliative Care Services
<p>People living with a life-limiting illness whose needs are straightforward and predictable, including families and carers of these people.</p> <p>Ongoing clinical management and care coordination including assessment, triage and referral to other services and to specialist care as necessary.</p> <p>Health professionals involved in providing this level of palliative care do not, generally, work full-time in palliative care or in established multidisciplinary teams.</p>	<p>People living with a life-limiting illness whose needs range from straightforward and predictable to intermediate and fluctuating, including their families and carers.</p> <p>Palliative care for the person, carer and family where needs exceed the capability of the person's normal treating physician.</p> <p>Health professionals at this level provide assessment and care of more complex pain and distressing symptoms, counselling about illness progression, and assessment and management of psychosocial care needs and active implementation of advance care planning.</p>	<p>People living with a life-limiting illness whose needs include straightforward and predictable, intermediate and fluctuating, or complex and persistent, and their families and carers.</p> <p>Management of complex and persistent symptoms that are not effectively controlled by standard therapies, including palliative sedation therapy, palliative radiotherapy, percutaneous endoscopic gastronomy, other nutritional approaches and advance care planning.</p> <p>Health practitioners at this level often serve as a consultative service and provide education, counselling and support regarding complex issues relating to the life-limiting illness, the impact of different palliative management options, including conflict resolution between the person, their family and carers and non-beneficial treatment.</p>

The objective of a networked approach to the provision of palliative care services is to ensure that the right care is provided to the right people in the right setting with the right mix of health professionals. Networking requires that there are effective referral arrangements and consultative support services between generalist providers of palliative care (Level 1) and specialist palliative care services (Levels 2 and 3).<sup>(14)</sup>

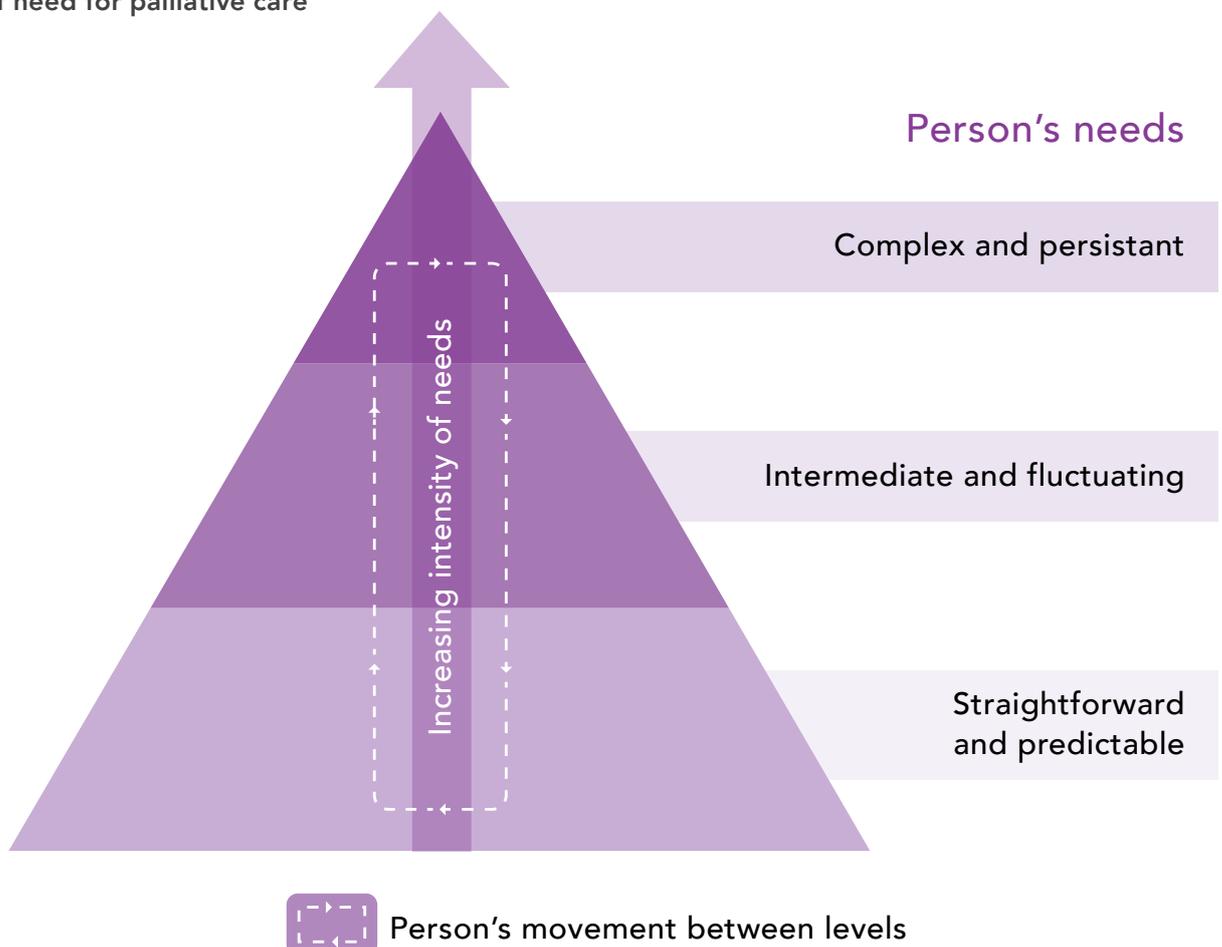
Most people move between these levels of care depending on their needs:

- Specialist palliative care services support primary carers by helping them to manage symptoms and ensure that support is always available. The type of care and support provided is guided by the person and their family, based on their needs, as part of a person-centred approach.

- As needs change, people with life-limiting illness will have care provided in many different settings, both community-based (eg, at home, residential care, community/GP clinics) and hospital-based (eg, palliative care wards/units, intensive care, emergency departments).

The phrase 'palliative care is everyone's business' is a way of emphasising that people affected by life-limiting illness can be found in all healthcare contexts, and highlights that all members of the healthcare team have a role to play. This is why it is important for all members of the healthcare team to have an understanding of the principles of palliative care and key aspects of the palliative approach to care.<sup>(15)</sup>

### Levels of need for palliative care



## Quality of life

The goal of palliative care is to provide comfort and to support the highest possible quality of life for the individual and their family.

Quality of life means different things to different people. It can include:

- Being comfortable and pain-free
- Being able to socialise or spend time with loved ones
- Having as much independence as possible
- Not feeling that they are a burden
- Feeling emotionally well.

## Notes



### Learning Activity:

1. View the Palliative Care Australia [video resource](#) 'What matters most?' and reflect on what quality of life means to you.
2. Write down three things that you believe bring quality to your life.
3. What would it mean to you if you were no longer able to achieve these things?

## Principles of Palliative Care

The [National Palliative Care Strategy](#) provides a vision for palliative care in Australia and communicates the guiding principles and goals for palliative care service delivery.<sup>(14)</sup> Quality palliative care in Australia reflects the core values and principles of:<sup>(15,16)</sup>

Principles	What does it mean?	What can you do?
<b>Dignity</b>	Dignity is the state of feeling worthy, honoured and valued. The dignity of the person should be prioritised through a person/family-centred approach to care. Every person is unique, and their care needs will be different and can change over time.	Respect the person's privacy, value their opinions and encourage autonomy (also called self-determination – taking control of their own illness journey).
<b>Empowerment</b>	Empowering a person gives them the power to make their own choices.  Empowered people are given the confidence and opportunity to make their own decisions based on the support and guidance of members of the healthcare team.	Work with the strengths and limitations of the person and their family/carers to enable them to manage their own situation and provide information so that they can make informed decisions about their care.
<b>Compassion</b>	Compassion is being able to feel for another person's suffering and wanting to help.	Actively listen and allow the person to discuss how they feel without feeling judged.
<b>Equity</b>	Equity in healthcare means everyone having access to the same levels of care.  Treatment options should be available to everyone with a life-limiting illness. Some people require more help to reach the same level of care as others.	Provide information to people regarding their choices for care or refer them to other members of the healthcare team who can provide further information.
<b>Respect</b>	Respect ensures thought for the person and that they are held in high regard.  Cultural respect ensures that the person and their family/community are held in high regard and that respect is maintained for their cultural practices and beliefs.	Demonstrate respect for the person and their family/carers. Provide a safe environment where all people affected by life-limiting illness can live and die with equity, respect and dignity. Listen non-judgementally and honour the wisdom and knowledge of the person.

Principles	What does it mean?	What can you do?
Advocacy	Advocacy is the act of supporting a person, action or belief.	Practise effective communication, ensuring you understand the person's wishes (through advance care planning) and supporting their wishes when the person is not able to speak for themselves.
Excellence	Nurses should aim to provide consistently high standards of care and support for both the person and their family/ carers.	Reliably demonstrate these core values. Keep up-to-date with required training, current evidence and new practices.



### Resource Links:

[National Palliative Care Strategy](#)<sup>(13)</sup>

[What is Palliative Care?](#)<sup>(16)</sup>

[Culturally Safe and Responsible Care](#)<sup>(17)</sup>

### Notes



### Reflection:

1. If you have been involved in the care of a person with a life-limiting illness, reflect on what you think was most important to them about the way they were cared for? If not, talk with one of your colleagues about their experiences.
2. Add some of your own points to the 'What can you do?' column in the table above.

## Care Standards

The National Palliative Care Standards<sup>(15)</sup> outline the standards and elements of quality care for all Australians by specialist palliative care providers. Although they are specifically designed for specialist palliative care providers, these standards provide an important framework for all healthcare workers involved in caring for people affected by life-limiting illness. The standards underpin safety and quality in healthcare, ensure consistency in service delivery and provide a nationally consistent statement about the level of care that people can expect from health services.

There are other national standards which relate to quality care provision for people with life limiting illnesses:

- Aged Care Quality Standards<sup>(18)</sup>
- Australian Commission on Safety and Quality in Health Care (ACSQHC) National Safety and Quality Health Service (NSQHS) Standards (Version 2)<sup>(19)</sup>
- ACSQHC National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care<sup>(20)</sup>
- ACSQHC National Consensus Statement: Essential Elements for Safe and High-Quality Paediatric End-of-Life Care<sup>(21)</sup>

The National Consensus Statements (shown above) were developed to support healthcare professionals who provide care in acute care settings where the care is not led by specialist palliative care providers. The essential elements within these statements are the features that are required in systems to ensure safe and high-quality care for patients who are approaching the end of life.



### Reflection:

Review the National Palliative Care Standards 1–6 (pages 13–18). Reflect on the specific strategies that you would apply to meet these standards when caring for people affected by life-limiting illnesses.

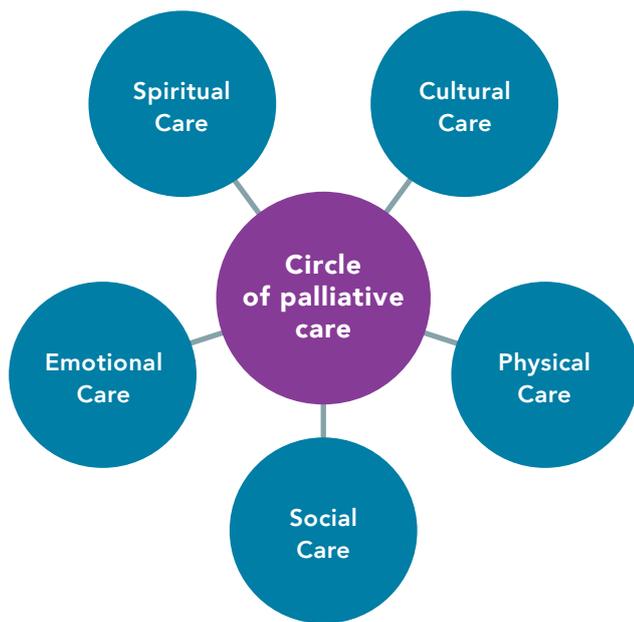
The impact of asking, ‘What do I need to know about you as a person to give you the best care possible?’ can be helpful in planning a person-centred approach to care. Reflect on when you may be able to include this in your daily practice.

## Notes

## Holistic care

Palliative care uses a holistic approach – managing pain and other symptoms while addressing the physical, emotional, cultural, social and spiritual needs of the person, their family and their carers.

It focuses on comfort, quality of life and living well.



### Spiritual Needs

Who we are, attitudes, relationships, behaviours, rituals, faith, religion, place of death, Dreamtime stories and songlines, meaning/purpose, and reasons for hope.

### Cultural Needs

Unique cultural and personal experiences.

### Physical Needs

Symptom understanding and management, information about treatment, body image, sexuality.

### Social Needs

Family, friends, community, neighbours, pets, financial/legal, support groups, respite, travel and accommodation, and family meetings.

### Emotional Needs

Depression, anxiety, denial, diagnosis, language differences, fear of hospital/treatment.



## Reflection:

Think about a person you know who is affected by life-limiting illness. Consider the following questions to identify how you can provide a holistic, person-centred approach that aligns with the principles of palliative care:

1. What do they know? What do they want to know?
2. What does 'quality of life' mean to them?
3. What is their story, life goals and legacy?
4. What are their beliefs/values?
5. Who are the significant people in their lives?
6. What are their significant roles in life?

7. What is important for them now and in the future?
8. What are the person and their family's preferences for information?
9. Who do they want involved in decisions about the care needed?

Think about ways that you might be able to talk with them about these things. Talk with a trusted family member, friend or colleague about this and make some notes about what you learn.

Further suggestions and resources on this are included in the '[Communication](#)' section.

## Paediatric palliative care

Quality paediatric palliative care enables a baby, child or young adult with a life-limiting illness to live in an environment where curative treatment can be a part of their life, but not their entire focus. It aims to provide the best quality of life through a holistic approach which supports the physical, emotional, social and spiritual aspects of the child and their family.

Many children who require palliative care are cared for by a multidisciplinary team including specialist palliative care providers as well as primary health and community health professionals. Understanding the care needs and being able to access relevant information will enable you to better support families where a child requires palliative care.



### Resource Links:

[Paediatric Palliative Care](#)<sup>(22)</sup>

[PCC4U Focus Topic 3: Care of children with life-limiting illness](#)<sup>(23)</sup>

## Ethical and legal issues

Planning and providing care for a person with a life-limiting illness can involve ethically complex decision-making. This can occur at any point along the illness trajectory. It is important for all healthcare providers to understand potential ethical dilemmas. Treatment decisions can challenge your values and beliefs. This can influence the care you provide or recommend and can cause tension between the person with a life-limiting illness, their family/carers, and healthcare providers.<sup>(24)</sup>

Examples of complex ethical issues encountered in palliative care include:

- Determining the method and timing of conversations with family members around the imminent death of a loved one
- Deciding when to withdraw treatment that is considered medically futile
- Use of artificial nutrition and hydration
- Use of palliative sedation
- Requests for assistance to die
- Requests for autopsy.

Four basic principles of biomedical ethics are autonomy (self-determination), justice, beneficence (doing good), and non-maleficence (doing no harm). For practice to be considered 'ethical' it must respect all four of these principles. Application of these principles assists in decision-making regarding issues such as informed consent, truth telling, confidentiality and respect.<sup>(25)</sup>

### Legal Resources

[End of Life Law in Australia](#) resources provide accurate, practical and relevant information to assist clinicians navigate the challenging legal issues that can arise with end-of-life decision-making. Information is presented about Australian laws relating to death, dying and decision-making at the end of life. These laws are very complex, particularly in Australia, where the law differs between states and territories, and where areas of uncertainty about the law exist. Clinicians can enhance their understanding of these laws and knowledge about legal rights and responsibilities at the end of life through undertaking these learning resources.<sup>(26)</sup>

## Notes

# Section 3: Communication

## Effective communication

Communicating well is at the heart of palliative care. It is an essential skill for helping a person and their family deal with the effects of chronic or life-limiting illness. The topics discussed in palliative care can often be difficult and, rather than one conversation, are usually a series of conversations with the person and their family.

There are a range of barriers to effective communication that exist in healthcare, including:

- Members of the healthcare team using a practitioner-centred communication style (eg, question and answer) rather than a person/family-centred style (eg, active listening, conversational)
- Use of medical terminology and jargon that the person is not familiar with
- Language issues or lack of use of interpreters
- Misunderstanding of health problems (diagnosis), illness and dying

- Mistrust of healthcare services due to negative past experiences
- Cultural and spiritual values/beliefs can affect responses and interactions with healthcare workers.

## Trusting relationship

Nurses frequently develop close relationships with people and are often relied on as guides throughout the palliative care journey. This can involve being translators of terminology, systems, and processes in relation to the healthcare experience.

The development of a trusting relationship relies on open, honest communication where the person feels they can ask any question and not be judged, and that they can express their opinions on their care and treatment in a safe environment where they can be respected.

There are two important components to a trusting relationship:<sup>(27)</sup>

Empowerment	Empathy
<p><i>Empowerment is the ability to mobilise the resources needed to make a person feel in control and have confidence in the goals they are attempting to meet.</i><sup>(28)</sup></p> <ul style="list-style-type: none"><li>• Empowered people are given the confidence and opportunity to make their own decisions based on the support and guidance of members of the palliative care team.</li><li>• You can empower people by listening and providing access to health information that helps people understand and make decisions about their healthcare.</li></ul>	<p><i>Empathy is the ability to appreciate another's experience, concerns and perspectives with the ability to communicate this understanding.</i><sup>(29)</sup></p> <ul style="list-style-type: none"><li>• Empathy in palliative care involves truly listening and trying to understand the person's journey by asking relevant questions.</li><li>• You can encourage the person to express their feelings; acknowledge their emotions and then respond with empathy. Allowing people to discuss their feelings gives them the opportunity to talk freely while you listen and guide the conversation.</li><li>• It is important to remember that your role is not to give advice. It is to listen and allow people to express their concerns and worries.</li></ul>

## Key points for conversations

In general, providing plain language explanations in an open manner to the person and their family will help to limit misunderstandings. Checking understanding (with clarification as required) should occur regularly throughout the conversation.

**Nonverbal communication:** It is important to remember that in conversations, the messages you send and receive are conveyed not just in words but in nonverbal channels as well. These include the way you talk (tone of voice, vocal clarity and expression) and your body language (facial expressions, posture, eye contact, touch, gestures). Emotions are often expressed subconsciously in nonverbal communication channels, so it is important to pay attention to these cues.

**Cultural influences:** It is important to be sensitive to the ways that culture can influence communication. For example, in many Aboriginal and Torres Strait Islander communities, direct statements about dying and death are usually not used. Alternative terms used include, not going to get better, bad/sad news, finishing up, passed on/gone, sorry business. It is important to check with the person and their family to find out the preferred words to use in conversations.<sup>(30)</sup>

Other important aspects of effective communication include:

- Identifying who the appropriate spokesperson for the family is and who should be included in conversations about the person's care. Clarifying who to contact in the event of deterioration in health status or death is equally important
- Professional jargon should be avoided, and any medical terminology used should be clearly explained
- Silence is often a key part of conversations as it provides an opportunity to consider and process information. Some people can feel that they do not have an opportunity to speak when no silences occur



## Learning Activity:

In the next few conversations you have, whether with colleagues, friends or family members, pay attention to the nonverbal aspects of communication and how you think the other person is feeling.

1. Check with them to see if your impression was correct. You might say something like, *'I noticed while you were talking that you seemed... Is that right?'* or *'It sounds like you're feeling... Have I got that right?'*
2. If you are not able to tell how they might be feeling, then it can be helpful to say, *'I imagine you might be feeling sad/scared/relieved... about this. Is that right?'*

Continue to practice this during conversations that are part of your work role to further develop your communication skills.

- Asking the person to summarise the information that has been discussed in their own words can also help to check understanding and allow for clarification if needed
- Documenting the conversation by writing a summary of what has been discussed in the health record
- Contacting other healthcare providers who are involved in the person's care to pass on important information.

## The PREPARED framework

The way you approach a conversation can influence how effective it is. The PREPARED communication framework outlines key strategies that can be used when communicating with a person with a life-limiting illness, their family and carers.<sup>(31)</sup>

Framework Elements		What you can do and say
<b>P</b>	<b>Prepare</b> for the discussion, where possible	<ul style="list-style-type: none"> <li>• Make sure you have the correct information about the person</li> <li>• Consider who should be present for the conversation.</li> </ul>
<b>R</b>	<b>Relate</b> to the person	<ul style="list-style-type: none"> <li>• <i>This has been a tough time for you and your family</i></li> </ul>
<b>E</b>	<b>Elicit</b> preferences from the person and their family	<ul style="list-style-type: none"> <li>• <i>Some people like to know everything that is going on with them and others prefer not to know too many details. What do you prefer?</i></li> </ul>
<b>P</b>	<b>Provide</b> information tailored to the individual needs of the person and family	<ul style="list-style-type: none"> <li>• Give information in small chunks, at the person's pace</li> <li>• Offer to discuss what to expect (in a sensitive manner), giving them the option not to discuss it if they would prefer</li> <li>• Use clear, jargon-free, understandable language</li> <li>• Engage in active listening – give your complete attention to them, and reflect what you think they have said, (<i>eg, If I've heard you right, you seem to be saying...</i>)</li> </ul>
<b>A</b>	<b>Acknowledge</b> emotions and concerns	<ul style="list-style-type: none"> <li>• <i>What worries you most about...? or What is your biggest concern at the moment?</i></li> </ul>
<b>R</b>	Foster <b>realistic hope</b> (eg, support, peaceful death)	<ul style="list-style-type: none"> <li>• <i>We will do all we can to assist you in whatever lies ahead for you</i></li> </ul>
<b>E</b>	<b>Encourage</b> questions and further discussions	<ul style="list-style-type: none"> <li>• <i>We've spoken about a lot just now. It might be useful to summarise what we've said...</i></li> <li>• <i>Is there anything that you don't understand or want me to go over again?</i></li> </ul>
<b>D</b>	<b>Document</b>	<ul style="list-style-type: none"> <li>• Write a summary in the person's health record of what has been discussed, if that is part of your role</li> <li>• Speak or write to other key healthcare providers involved in the person's care.</li> </ul>



## Resource Links:

NSW Health Resource: [Last Days of Life](#) <sup>(32)</sup>

VitalTalk Resources: [Establish Rapport](#) <sup>(33)</sup>  
and [Track and Respond to Emotion](#) <sup>(34)</sup>

[Clinical Yarning eLearning Program](#):  
a program to improve the effectiveness  
of communication of all healthcare clinicians  
who work with Aboriginal patients <sup>(35)</sup>



## Learning Activity:

1. Reflect on a time when you were involved in a difficult (bad news) conversation in the work environment.
2. Consider the approach that was taken and the impact (from your viewpoint) on the person and family. If you have not been involved in this kind of conversation in your work role, then consider your personal experiences.
3. Use the PREPARED framework to rewrite an approach to that conversation.

## Notes

# Section 4: Advance care planning

## What is advance care planning?

Advance care planning is a process where a person discusses what is important to them and their decisions about future healthcare with their family, friends and healthcare team. If, in the future, the person is not able to make decisions for themselves, or cannot communicate, their advance care plan guides their family and healthcare team in making decisions about treatment and ongoing care.

### Key points:

- The person can write their plan down to help ensure their preferences are respected. Ideally, an advance care plan is written down, but it can also just be a conversation
- In some states or territories, a person can write their preferences down in a formal document. Each state and territory have different forms and they are named differently
- An advance care plan does not need to be decided all at once. The person can take their time to think about their wishes and talk with family before making decisions
- An advance care plan can be changed at any time if a person's wishes or choices change
- A person can choose to have a 'substitute decision-maker' who can help guide the healthcare team in making decisions about ongoing care if the person is unable to speak for themselves
- Once an advance care plan is written, it is helpful if a copy of it is included in the person's health record (eg, at the GP or health clinic, and/or on [MyHealth Record](#)). Family members, including the person's substitute decision-maker if they have one, and the person's lawyer should also have copies.



### Learning Activity:

1. Watch the video resource [Be Open, Be Ready, Be Heard](#) by Advance Care Planning Australia. <sup>(36)</sup>
2. What are the key aspects of advance care planning?
3. Think about how advance care planning is viewed in your family/community.

### Notes

## Starting the conversation

Knowing how to start a conversation with someone about their wishes can be the hardest part of advance care planning. There are many resources available to help with this.



### Resource Links:

[Advance Care Planning Australia](#) <sup>(37)</sup>

[Dying to Talk Discussion Starter Online Card Game](#) <sup>(38)</sup>

[Advance Care Yarning for Aboriginal and Torres Strait Islander People](#) <sup>(39)</sup>



### Learning Activity:

Review the Advance Care Planning Australia resources for [Health and Care Workers](#).

As you read through the information, consider these points:

1. Make a note of the words and phrases that are used to talk about advance care planning. How could these be helpful for you when talking with people?
2. In your experience, what kinds of questions do people have about advance care planning?
3. What would you say to help people understand the importance of having an advance care plan?

Access the Advance Care Planning Australia website and look at the [Advance care planning in your state/territory](#) section. Make some notes about advance care plans in your jurisdiction.

## Notes

## Key points for advance care planning

When talking with a person and their family about advance care planning, it is helpful to consider the following:

<b>Make sure the right people are involved</b>	<ul style="list-style-type: none"><li>• Ask the person who else needs to be included in the conversation</li><li>• If the person has someone else who they want involved in the conversation, it is important to make sure they are included.</li></ul>
<b>Ask open-ended questions</b>	<ul style="list-style-type: none"><li>• <i>What does a good day look like to you?</i></li><li>• <i>Where would you like to be while you are sick?</i></li><li>• <i>What are you hoping for now?</i></li><li>• <i>What is important to you, what makes you feel good?</i></li><li>• <i>Is there anything that you need to do?</i></li><li>• <i>What would you like to do before you die?</i></li></ul>
<b>Clarify and check regularly</b>	<ul style="list-style-type: none"><li>• Check to make sure that what you understood from the conversation is what the person meant, and clarify any information if needed</li><li>• Check in regularly to see if the person's goals and wishes have changed over time.</li></ul>
<b>Ask questions about decision-making</b>	<ul style="list-style-type: none"><li>• <i>Would you like to make your own decisions about your healthcare or is there someone else you want to do that for you?</i></li><li>• <i>If something happened to you and you couldn't talk for yourself, who would you want the healthcare team to talk to, to help make decisions about your care?</i></li></ul>
<b>Reassure the person that their decisions will be respected</b>	<ul style="list-style-type: none"><li>• <i>Whatever you decide to do today will be written down so that the whole healthcare team know what your choices and preferences are</i></li><li>• <i>It is important to remember that any decision you have made can be changed if you think or feel differently about it later.</i></li><li>• Remind them that substitute decision-makers will only make decisions for them, if/when they are no longer able to communicate their wishes for themselves.</li></ul>



### Learning Activity:

Access one of the [Dying to Talk](#) online card game resources and consider your own responses to the questions. If you want to, make a time to discuss your responses with a family member or friend.

## Notes

## Section 5: Providing care



As highlighted in the key definitions of palliative care (covered in [Section 2](#)), the focus of palliative care is to prevent and relieve suffering by means of early recognition, assessment and treatment of symptoms, which can be physical, psychological and/or spiritual. <sup>(1)</sup>

Best practice palliative care requires an understanding of the person's illness, the symptoms that are commonly associated with the illness, and the person's perception of the effects of those symptoms on their quality of life. <sup>(2)</sup>

Due to the complex nature of life-limiting illness, people frequently experience multiple symptoms at any one time. Symptom management needs to consider the cause, potential benefits and burdens of treatment, illness progression, goals of care and the person's wishes. <sup>(24)</sup>

### Talking about symptoms

Symptoms are feelings or sensations in the body or mind that cause discomfort, pain or suffering. To support quality of life, the healthcare team needs to know about the distress (concern or worry) caused by a person's symptoms. If the healthcare team can understand this, then they can manage these symptoms.

Some helpful questions to use when talking with people about their symptoms include:

- *Of the symptoms that have been bothering you, what bothers you the most?*
- *How do the symptoms affect you? How much do they interfere with your life (eg, sleep, daily activities, your sense of wellbeing)?*
- *What ideas do you have about the managing of these symptoms?*
- *Do they make you worry about your health/illness? What are your concerns?*
- *How are these symptoms affecting your family and friends?*

## Symptom management

To be person-centred, any approach to symptom management must consider the wishes of the person and the goals they want to achieve.

These goals can range from the person wishing to maintain and improve functional levels, return to work, go to a family wedding or other social event, or wishing to be cared for at home when required. Throughout their illness, goals may need to be adjusted to cater for deterioration or increased symptom burden.<sup>(40)</sup>

Effective management of symptoms requires an approach that is:

- **Integrated:** one that involves holistic, multidimensional symptom assessment and management (eg, pain management can include both opioid analgesia, and education regarding relaxation strategies to manage the anxiety related to uncontrolled pain)
- **Targeted:** one that is directed at specific causal mechanisms and factors contributing to the concern (eg, different pharmacological agents can be needed to target different mechanisms or types of pain)
- **Tailored:** one that is suitable for the person's unique circumstances, beliefs and preferences (eg, people who do not have carers or adequate financial resources often require additional support from the interdisciplinary healthcare team).

## Notes

## Assessment tools

The Palliative Care Outcomes Collaboration (PCOC) is a national program that facilitates the use of standardised clinical assessment tools to measure and benchmark outcomes in palliative care. Palliative care assessment tools commonly used throughout Australia are summarised in the following table:<sup>(41)</sup>

<b>Palliative Care Phase</b>	The Palliative Care Phase identifies a clinically meaningful period in a patient's condition. The palliative care phase is determined by a holistic clinical assessment, which considers the needs of the patients and their family and carers. A change in palliative care phase represents a change in the person's clinical condition and/or a change in the patient's carers or family. These changes lead to a change in the patient's care plan.
<b>Symptom Assessment Scale (SAS)</b>	The SAS is an assessment tool that helps a person talk about how they are feeling about their symptoms. The person scores the symptoms themselves, or if needed a family member or a member of the healthcare team can help. These scores help to identify, communicate and escalate problems.
<b>Palliative Care Problem Severity Score (PCPSS)</b>	The PCPSS is a clinician-rated score of palliative care concerns that provides a summary measure of concerns in four domains: pain, other symptoms, psychological/spiritual and family/carer.
<b>Functional Assessment in Palliative Care (RUG-ADL)</b>	The Resource Utilisation Guide – Activities of Daily Living (RUG-ADL) is a four-item scale that measures motor function with activities of daily living: bed mobility, toileting, transfer and eating. Assessment is based on what the person does, not what they are capable of doing. It provides information on functional status, the assistance the person requires to carry out these activities and the resources needed for their care.
<b>Australia-modified Karnofsky Performance Status (AKPS)</b>	The AKPS is a single score between 10 and 100 assigned by a clinician based on observations of a person's ability to perform common tasks relating to activity, work and self-care.

PCOC provides the PCOC Assessment and Clinical Response Form which collates the assessment tools into one easy-to-use form. This means that the form includes the five essential, brief validated clinical assessment tools described above.<sup>(41)</sup>

## Notes



### Learning Activity:

Watch the PCC4U Case Scenario video of Herbert as he describes his symptoms, and answer the following questions.<sup>(42)</sup>

1. Using the PCOC Assessment and Clinical Response Form, identify how the Symptom Assessment Scale (SAS) and Palliative Care Problem Severity Score (PCPSS) help you understand the impact of Herbert's breathlessness?
2. Comment on whether these tools assess the multiple dimensions of the symptom.
3. Comment on how these tools assess the individual's experience of the symptom.
4. What advantages and limitations would these assessment tools have in practice?



### Resource Links:

CareSearch – Recognising the Last Year of Life<sup>(43)</sup>

End of Life Directions in Aged Care (ELDAC) – Recognise End of Life<sup>(13)</sup>

## Common symptoms and care needs

Symptoms and care needs that are commonly experienced by people with a life-limiting illness are summarised here. It is highly recommended that you explore the resource links provided to learn more about these needs and how they are managed.

Symptom/ Need	Description	CareSearch Resource Links
Pain	<p><b>Definition:</b> ‘an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage’<sup>(44)</sup></p> <ul style="list-style-type: none"> <li>• It is subjective (felt by the person) and has a physical, psychological and spiritual basis</li> <li>• Management requires a holistic approach involving pharmacological management and non-pharmacological interventions. More detail is provided in the following section.</li> </ul>	<p><a href="#">Patient Management: Pain</a><sup>(45)</sup></p>
Breathlessness	<p><b>Definition:</b> ‘the sensation of shortness of breath or difficulty breathing. It is an extremely common symptom but can be both distressing and frightening for patients and carers’<sup>(24)</sup></p> <ul style="list-style-type: none"> <li>• It is subjective (felt by the person) and describes their experience</li> <li>• Often caused by a combination of factors – underlying causes and progression of illness</li> <li>• Associated with fear, panic and anger</li> <li>• Management can involve treatment of the identified cause/s, modifying the environment and supporting psychological wellbeing.</li> </ul>	<p><a href="#">Patient Management: Respiratory Symptoms</a><sup>(46)</sup></p>
Fatigue	<p><b>Definition:</b> ‘a persistent and distressing sense of tiredness, which is not proportional to activity, not relieved by sleep or rest, and which interferes with normal functioning’<sup>(47)</sup></p> <ul style="list-style-type: none"> <li>• Often described as a feeling of ‘decreased/no energy’, ‘tiring easily’, ‘weakness’</li> <li>• Associated with decreased concentration, poor memory and lack of motivation, and has a major impact on quality of life, relationships and the person’s ability to manage their healthcare needs.</li> </ul>	<p><a href="#">Patient Management: Fatigue</a><sup>(48)</sup></p>

Symptom/ Need	Description	CareSearch Resource Links
Sleeping problems	<ul style="list-style-type: none"> <li>• Insomnia and poor-quality sleep are common symptoms in those requiring palliative care.</li> <li>• Assessment and management of sleeping problems needs to focus on modifiable factors which can contribute to sleeplessness (eg, pain, anxiety/depression, delirium, breathlessness/cough, nausea, itchiness, night sweats, reduced mobility, incontinence and medication)</li> </ul>	<a href="#">Clinical Evidence: Sleeping Problems</a> <sup>(49)</sup>
Nutrition and hydration concerns	<ul style="list-style-type: none"> <li>• Weight loss can confirm advancing illness and approaching death</li> <li>• Appetite is reduced as the person's illness progresses. The belief that promoting a good diet and stabilising the person's weight can delay death is not correct</li> <li>• Nausea, vomiting and constipation can be caused by the illness or can be a side-effect of treatment</li> <li>• They can be managed with medication, and/or changes in type, amount and frequency of food.</li> </ul>	<a href="#">Patient Management: Appetite Problems</a> <sup>(50)</sup> <a href="#">Constipation</a> <sup>(51)</sup>
Delirium and confusion	<p><b>Delirium:</b> the acute or recent development of confusion and altered consciousness occurring in a fluctuating manner (eg, exacerbation of agitation and confusion at night).</p> <p><b>Confusion:</b> a state of mind where a person's reactions to what is happening around them are inappropriate or unusual because they are unable to orientate themselves.</p> <p>Recognised by:</p> <ul style="list-style-type: none"> <li>• Changes in the person's behaviour</li> <li>• Changes in mood</li> <li>• Awareness of and orientation to time and place</li> <li>• Confusion that occurs suddenly or gradually.<sup>(47)</sup></li> </ul> <p>Management includes treating underlying causes (including reviewing medication), maintaining a consistent environment and daily routines, frequent reorientation, communicating clearly (including using visual/hearing aids).</p>	<a href="#">Patient Management: Delirium</a> <sup>(52)</sup>

Symptom/ Need	Description	CareSearch Resource Links
Suffering	<p>Suffering is a complex experience and often has many causes.</p> <p>Key points:</p> <ul style="list-style-type: none"> <li>• Suffering relates most strongly to physical symptoms but is also impacted by psychological and social distress, and existential concerns (eg, lack of meaning or purpose, loss of connections, loss of hope, loss of identity)</li> <li>• Suffering can impact on a person's quality of life, affecting their activities of daily living and can also increase the burden of care and distress to carers, family and other loved ones</li> <li>• Focusing on spirituality and consideration of spiritual needs can be a source of comfort for many people. The importance of religious practices for some people needs to be acknowledged, as this can bring a lot of comfort in stressful times such as this. Also, recognising that people have spiritual practices that do not have a religious foundation to them, but instead undertaking these forms of spirituality brings comfort and peace.</li> </ul>	<p><a href="#">Patient Management: Suffering</a><sup>(53)</sup></p> <p><a href="#">Patient Management: Existential Distress</a><sup>(54)</sup></p>

## Notes



## Reflection:

Think about three people you have known who have had a life-limiting illness.

Consider their experiences:

- What symptoms did they have?
- What worried them most?
- How did their symptoms affect their daily life and close relationships?
- What was done to relieve the person's symptoms and how effective was it?
- What else could have been helpful for them (consider the knowledge you have gained through reviewing the resource links in the previous table)?
- Review the [Symptom Assessment Scale \(SAS\)](#) links and consider how each of these people might have scored themselves.



## Resource Links:

[PCC4U Module 3 Excerpt: Common symptoms in Palliative Care](#)<sup>(55)</sup>

[Therapeutic Guidelines: Principles of symptom management in palliative care](#)<sup>(24)</sup>

## Notes

## Medications used in palliative care

Having an awareness of the types of medications that are used in palliative care (as summarised in the following table) can be helpful in supporting care needs.<sup>(56)</sup> More detailed information is available in the resource links below.

Medication Type	Uses
Analgesics	To treat pain, and in some cases breathing difficulty
Anticonvulsants	To treat depression, anxiety, pain or delirium
Antidepressants	To treat depression and sometimes pain
Antiemetics	To prevent and treat nausea and vomiting
Laxatives	To prevent and treat constipation
Sedatives	To treat anxiety, delirium, pain, nausea or other physical symptoms
Steroids	To treat a range of symptoms related to inflammation
Adjuvant medications	Medications that work with analgesics to relieve pain or improve symptom management.



### Resource Links:

[palliMEDS app](#) – An app that provides information for health professionals on eight palliative care medicines that have been endorsed by the Australian & New Zealand Society of Palliative Medicine (ANZSPM) for management of terminal symptoms<sup>(57)</sup>

[Caring@home - Medicine Handling Guidelines](#)<sup>(58)</sup>

[Clinical Evidence: Patient Care and Conditions](#)<sup>(59)</sup>

## Notes

## Assessing and managing pain in palliative care

Pain is a very common, and highly anxiety-producing, symptom in palliative care. For those with life-limiting illness, pain can be caused by the illness itself, treatments, resulting functional decline, or a comorbid illness. Early intervention decreases the amount of pain experienced and the quantity of analgesics used in the long-term.<sup>(60)</sup>



### Resource Links:

A comprehensive resource for pain assessment and management in palliative care patients can be found in the [Therapeutic Guidelines - Palliative Care Section](#):<sup>(24)</sup>

- Pain: assessment in palliative care
- Pain: management in palliative care



### Reflection:

Think about your experiences of caring for people with life-limiting illness who had pain.

With reference to the information in the above links, consider what you need to learn more about or become more familiar with that will support you to improve your ability to assess and manage pain in palliative care.

Use the following key points to guide your reflections:

- Assessment of pain (history, physical assessment, psychosocial assessment, pain scales)
- Making a pain management plan
- Supporting self-management/education
- Pharmacological approaches
- Nonpharmacological approaches.

## Notes



## Resource Links:

[Overcoming cancer pain: A guide for people with cancer, their families and friends](#)<sup>(61)</sup>

[CareSearch: Syringe Drivers](#)<sup>(62)</sup>

[PallConsult Learning Package – NIKI T34 Syringe Pump](#)<sup>(63)</sup>

[Therapeutic Guidelines – Chronic Pain: Nonpharmacological Management](#)<sup>(64)</sup>

## Role of Allied Health Professionals in palliative care

Many different health professionals work together to support the person with a life-limiting illness and their family/carers. Interdisciplinary teams are common in palliative care.<sup>(65)</sup> Allied health professionals are an essential component of the palliative care team as they bring a broad range of interventions, knowledge and experience to improve the quality of life for people with life-limiting illnesses.<sup>(66)</sup>

Allied health professionals have skills in assessment and interventions to improve the comfort, function and safety of the person and their family throughout their palliative care journey. They also play a key role in holistic problem-solving and adapting traditional therapies and interventions to the person's changing function.<sup>(67)</sup>

Allied health professionals contribute to the palliative care team in a range of ways: <sup>(67, 68)</sup>

<b>Aboriginal and/or Torres Strait Islander Health Professional</b>	Provide support, comfort and assistance to Aboriginal and Torres Strait Islander people who are receiving palliative care. They have an important role in improving the quality of communication between other members of the healthcare team and Aboriginal and Torres Strait Islander peoples through cultural brokerage
<b>Arts Therapist</b>	Use visual art-making, drama, dance and movement to improve physical, mental and emotional wellbeing
<b>Chiropractor</b>	Provides treatment for back pain and other disorders of the musculoskeletal system
<b>Dietitian</b>	Optimise nutritional intake, develop nutrition plan focused on the person's needs and wishes
<b>Medical Radiation Practitioner</b>	Provide diagnostic imaging and radiation therapy to assist with treatment and symptom management
<b>Music Therapist</b>	Provide opportunities for music-based experiences to improve quality of life
<b>Occupational Therapist</b>	Support continued or adjusted participation in valued and essential everyday activities
<b>Pharmacist</b>	Provide timely access to medications, assessment of medication plans and engagement with the palliative care team regarding ongoing management of symptoms
<b>Physiotherapist</b>	Maximise functional independence and help to provide relief from symptoms such as breathlessness and fatigue
<b>Psychologist</b>	Provide expert psychological assessments and interventions to effectively address often complex psychological issues
<b>Social Worker</b>	Provide counselling and support, expertise in solving practical problems, support with financial concerns, and advocate where necessary, make referrals to other agencies and provide support for grief and bereavement
<b>Speech Pathologist</b>	Develop strategies to support communication and swallowing.

Rehabilitative palliative care is an interdisciplinary holistic model of care which integrates rehabilitation, enablement, self-management and self-care. The aim of rehabilitative palliative care is to optimise function and wellbeing, by empowering the person with a life-limiting illness and enabling them to live as independently and completely as possible, with choice and autonomy, as their illness progresses. <sup>(69)</sup>

## Notes

## Section 6: End-of-life care



The end stages of a person's life (sometimes referred to as the terminal phase) can be a profound and memorable time for the family. These moments can provide a time for sharing thoughts and hopes, expressing love and support, and saying goodbye. It can also be a time when families experience extreme distress and require a great deal of support from the healthcare team. They often have specific concerns about end-of-life issues and need to understand what to expect.

### Core principles of end-of-life care

A care environment at the end of life where the person is respected through dignified care, can provide feelings of empowerment and strength. For some people, this can help them cope with the physical, cognitive and emotional issues experienced during the end of life.

End-of-life care is a part of palliative care and refers to the care provided during the last days or weeks of a person's life. At this time, it is important to remember the core principles of the palliative approach to care (as discussed previously).

Quality care at the end of a person's life is about:

- The rights of people and their families
- Supporting people's choices
- A holistic approach
- Supporting carers and family as part of person-centred care
- Life (not death)
- Providing comfort.

## Care needs at the end of life

During the end-stages of life, the person and their family need support from the healthcare team with a variety of needs, including:

- Being able to recognise the terminal phase, understanding what to expect, and how to communicate with loved ones about it
- Being able to be involved in providing care (eg, assisting with mouth care, pressure area care) and continuing to interact with the person (eg, talking, listening to their favourite music, reading their favourite book)
- Retaining control of what happens, especially pain relief and other symptom management, location of care, who is present and who shares the last days
- Maintaining dignity and privacy, including practical things like clothing choices, being in bed or a chair, having familiar items around
- Having choice over the place of care and where death occurs (eg, at home, hospice, residential aged care facility or in hospital)
- Being able to leave some form of legacy behind and having that choice supported as much as possible
- Being able to tell important stories while the opportunity remains
- Having access to information and expertise of whatever kind is necessary
- Having access to spiritual, cultural or emotional support as needed
- Having time to say goodbye
- To not have life prolonged needlessly.

## Legacy work and memory-making

For many people, it is important to be able to leave some form of legacy for their families after they die. This can help provide hope, healing and comfort for loved ones and serves as a reminder for them of the person's life, values and contribution. A legacy can be in the form of:

- Material things (eg, a scrapbook, a recipe book, hand-made items, cards or presents for future occasions, handprints, lock of hair)
- Stories – about their life/family, or those handed down the generations. These can be captured in videos, poems, songs or written form
- A life-review summary that outlines the key events in their life, significant contributions they made, causes or charities they supported, hopes for the future.

Memory-making activities can be very helpful ways for families, especially those with children, to remember the person who has died and to provide hope and comfort. These might be in the form of special trips or holidays, collating photos, planting a tree or garden, creating a memory box with special items, notes or stories.

## Dignity

The Patient Dignity Question (PDQ) is a simple, open-ended question that should be considered when interacting with people affected by life-limiting illness, "What do I need to know about you as a person to give you the best care possible?" This question can be used to identify care needs and plan the person's management.

The Patient Dignity Inventory (PDI) is an assessment tool that assists with detecting end-of-life dignity-related distress. It can assist the healthcare team to communicate more effectively, individualise supportive interventions and make referrals to other members of the team for specific needs.<sup>(70)</sup>

## Recognising end of life

Ideally, palliative care should be offered early in a person's journey with life-limiting illness or with increasing frailty, but unfortunately, this does not always happen. Recognising when a person's death is approaching is an important skill as it allows the patient, family/carers and the healthcare team to prepare.

A period of deterioration often occurs in the weeks leading up to the terminal phase which can be characterised by:

- Accelerating progress of the disease (eg, tumour enlargement, weight loss, worsening symptoms)
- Progressive loss of strength and energy leading to a decline in activity and mobility
- Increasing periods of sleep
- More frequent health interventions
- Trouble swallowing
- Loss of appetite/interest in food and drink
- Experiencing day-to-day deterioration that is not reversible.<sup>(24)</sup>

The period of time until the person dies is often uncertain and unpredictable. The focus during this time continues to be supporting their quality of life. The aim is to provide holistic care that is consistent with the person's values, goals and wishes, and to reduce suffering by managing symptoms.

The nurse's role, in addition to providing comfort and supporting care, is in recognising and responding to changes in the person's condition and communicating as needed with the other members of the healthcare team. This can allow for a review of treatment and interventions to improve comfort and enable focused support for the person and their family. With good care it is possible for most people to die comfortably.<sup>(71)</sup>

During the terminal phase, the person:

- Becomes bed-bound and requires extensive care to meet essential needs such as eating and drinking, moving in bed, hygiene, toileting etc,
- Sleeps or is sleepier more often, can be disorientated, restless/agitated, or can be poorly responsive or unconscious
- Becomes unable to swallow or does not feel hungry or thirsty
- Has reduced or no urine output
- Has changes in their breathing pattern, irregular or noisy breathing
- Shows signs of decreased blood flow (eg, pale or mottled skin, cold hands and feet).

When the terminal phase has been recognised, the **healthcare team** can:

- Review goals of care, needs and symptom management
- Consider the location of care and provide support as required (eg, supply of equipment and medications, access to other care services, liaison with specialist palliative care providers)
- Clarify and implement advance care plans
- Consider the withdrawal of treatment (including some medications) and activities that do not have a current clinical benefit
- Ensure that there are written instructions (eg, an advance care plan) to avoid inappropriate tests/procedures, transfers, and resuscitation attempts
- Provide information and support to prepare family and carers for the terminal phase.

## Notes



### Learning Activity:

In your experience caring for people and their families during the end stages of life, what were their main concerns and questions? What have you been asked about that you were unsure how to answer? What aspect of care would you like to learn more about?

Review the resources below and make some notes on what you learn about:

1. Ways to talk with family / carers about the end-of-life changes they observe in their loved one (eg, breathing disturbances, nutrition / fluid intake, nausea / vomiting, alterations in level of consciousness)
2. Providing comfort care
3. Managing pain during end of life
4. Managing dyspnoea and respiratory secretions
5. Managing agitation.



### Resource Links:

[Therapeutic Guidelines: Terminal care – care in the last days of life](#)<sup>(72)</sup>

[Patient Management: Care of the Dying Person](#)<sup>(73)</sup>

[Dying Matters: The Resuscitation Conversation](#)<sup>(74)</sup>

[CareSearch – At the end](#)<sup>(75)</sup>

## Dying at home

Some people want to be cared for and die at home. Providing support for the person and their family for this to happen is an important aspect of quality care. A person's family/carers need to know how to manage symptoms in the last days of life, have the necessary equipment and supplies provided and be able to contact the healthcare team at any time to ask questions. It is also important to ensure that the family/carers are physically and emotionally able to care for the person at home and to establish the specific support required.

Helping the family understand what to do when the person dies is a significant part of providing support during this time, and includes:

- What is likely to happen in the time leading up to death and at the time of death
- How to recognise that the person has died
- Understanding that spending some quiet time with the person before calling anyone is okay
- That it is not necessary to call the police or an ambulance when an expected death occurs at home
- The people who should be called – it can be helpful for them to make a list beforehand of people they want to tell

- That a doctor needs to come and certify the death. It is helpful for them to ask about the GP's wishes in relation to being called at the time of death (particularly if this occurs at night), or alternative arrangements if the GP is not available
- The need to contact a funeral director and plan for the funeral. The family might wish to have the body at home for some time before the funeral director is called (eg, parents of a deceased child). In these cases, the funeral director can be contacted in advance for advice on how to minimise deterioration of the body. Generally, the body should be placed in a cool room and positioned flat in bed with the arms straightened comfortably by the side. The funeral director will liaise with the family to arrange a time for transfer of the body.



### Resource Links:

[CareSearch – Planning for a Home Death<sup>\(76\)</sup>](#)

[ELDAC – Home Care Toolkit<sup>\(77\)</sup>](#)



## Dying in residential or acute care

Some healthcare facilities use a specific care plan for people who are in the final days or weeks of life. The use of an end-of-life care pathway or terminal care plan can help to focus the care required during the terminal phase.

A care pathway is different from a care plan:

- A care pathway represents the ideal way to manage most people with a specific problem
- A care plan is made for an individual person to meet their specific needs.

Care pathways use documents, sometimes flowcharts, to outline the steps of care to be followed by members of multidisciplinary teams. The resources below – *Residential Aged Care End of Life Care Pathway (RAC EoLCP)* and the *Care Plan for the Dying Person (CPDP)* are examples of care pathways that guide the provision of quality end-of-life care in residential and acute care.

It is important to acknowledge the roles that various members of the healthcare team have at this stage and a care plan or pathway can help provide direction regarding this.

## Notes



### Resource Links:

[Residential Aged Care End of Life Care Pathway \(RAC EoLCP\)](#) <sup>(78)</sup>

[Care Plan for the Dying Person](#) <sup>(79)</sup>

[ELDAC – Residential Aged Care Toolkit](#) <sup>(80)</sup>



### Learning Activity:

Investigate if your work setting uses a care pathway when someone is dying. If so, familiarise yourself with the tool and consider what your role is in supporting the dying person and their family.

## After death care

When a person has died in a healthcare facility or in community care, there are several requirements that need to be met. These include, completing legal requirements, notifying the person's family if they are not present, notifying the relevant members of the healthcare team, providing family support, preparing the body and arranging transfer of the body to the funeral director or mortuary.

Legal requirements after a death vary between states and territories, but in general include:

- Verifying the death/declaring life extinct – this can be done by a medical practitioner, nurse or paramedic. In some jurisdictions this is required before the body can be moved
- Completing the death certificate – this needs to be done by a medical practitioner, based on the person's health record
- If the body is to be cremated, any implanted pumps, cardiac devices or radioactive implants/injections need to be identified for the funeral director to remove prior to cremation
- Reporting to the Coroner if necessary (not usually required when the death is expected). Clarification regarding reporting requirements for an expected death can occur before the death to reduce family distress.<sup>(24)</sup>

Personal care after death should be performed within a few hours of the person dying to preserve their appearance and dignity. It is important to allow the person's family to have time alone with the deceased person if they choose to, and to allow them to be involved in bathing and dressing the body if desired. Everyone's choices are different at this time and can change from their original plans. It is best to ask them how they would like to be supported and/or involved at the time.

## Notes

Key aspects of personal care include:

	Examples
<b>Maintaining privacy</b>	<ul style="list-style-type: none"> <li>• Ensuring doors/curtains are closed.</li> </ul>
<b>Cultural considerations</b>	<ul style="list-style-type: none"> <li>• Be mindful of the cultural protocols or religious beliefs of the person and their family and carers.</li> </ul>
<b>Communication</b>	<ul style="list-style-type: none"> <li>• Empathetic, sensitive communication with family/carers.</li> </ul>
<b>Family/Carers</b>	<ul style="list-style-type: none"> <li>• If family wish to, they can assist with washing the body</li> <li>• Talk through what is happening with the family to ensure their wellbeing during, and after the process.</li> </ul>
<b>Respect</b>	<ul style="list-style-type: none"> <li>• Maintain the modesty of the person by covering the body with towels/sheets as you would if they were alive.</li> </ul>
<b>Position the body</b>	<ul style="list-style-type: none"> <li>• Lie the body flat and support the head with a pillow, close the eyes and mouth.</li> </ul>
<b>Wash the body</b>	<ul style="list-style-type: none"> <li>• Using warm water, wash the body, maintaining respect and dignity</li> <li>• The family may provide specific clothing to be worn, if not, a shroud can be worn</li> <li>• Pay attention to ensuring the face and hands are clean</li> <li>• Ensure the hair is neatly combed as the person would usually style their hair</li> <li>• Ensure dentures are in place if possible as they help to shape the face</li> <li>• Change the sheets and pillowcase.</li> </ul>
<b>Present the body respectfully</b>	<ul style="list-style-type: none"> <li>• Cover from the feet to the chest with a clean sheet ensuring the arms are out over the top of the sheet. It is important that family/carers can hold their hands if they choose to</li> <li>• The body should look like they are peacefully sleeping.</li> </ul>
<b>Prepare the viewing room</b>	<ul style="list-style-type: none"> <li>• Ensure seating, tissues and drinks are available</li> <li>• Ensure the room is clean and tidy with any excess equipment (eg, hoists etc) removed</li> <li>• Freshen the room air by opening a window if possible</li> <li>• Ensure the person's property is packed ready to give to the family (if appropriate) so they are not waiting unnecessarily. This needs to be documented appropriately.</li> </ul>
<b>Talk with the other patients/residents</b>	<ul style="list-style-type: none"> <li>• Ensure that there is someone available to talk through what has happened with the other patients/residents. In shared rooms and in residential care, other patients/residents are generally aware that someone has died. This needs to be acknowledged openly by staff and support provided if required.</li> </ul>

## Notes



### Resource Links:

CareSearch: Care of the Body<sup>(73)</sup>



### Reflection:

1. Recall your experiences of providing care for a person and their family after death.
2. Think about what you could add to the table above to expand on the actions/ activities that can be helpful at this time.

## Family and carer needs

After the person has died, the family and carers can benefit from support in relation to:<sup>(72)</sup>

<b>Cultural practices</b>	<ul style="list-style-type: none"><li>• The healthcare team should be mindful of the cultural protocols or religious beliefs of the person and their family and carers after the person has died (eg, some cultures expect burial to take place before sunset on the day of the death)</li><li>• Specific practices or wishes might be included in the person's advance care plan or you can ask the family (eg, 'Are there any particular things that you would like us to do now that are important for you culturally or spiritually?')</li><li>• The family and carers can appreciate you assisting with cultural protocols, or they may not want or need help.</li></ul>
<b>Saying goodbye</b>	<ul style="list-style-type: none"><li>• Irrespective of the location of a person's death, family and carers will want to say goodbye in their own way before the body is removed. How this is done is determined by personal preference and cultural practices</li><li>• Family members might wish to wash and dress the body with the support and direction of a member of the healthcare team, some prefer to leave it to the funeral director</li><li>• If the person was in a residential care facility, other residents, families and staff may wish to say goodbye in their own way (eg, a memories/condolences book, a candle, a guard of honour as they leave the facility). It is important to speak with your supervisor to discuss how this is done in your workplace.</li></ul>
<b>Emotional support</b>	<ul style="list-style-type: none"><li>• Healthcare providers need to be sensitive to the need for family members and carers to express their emotions and facilitate this appropriately</li><li>• Emotions can be expressed overtly or in silence. It is helpful to acknowledge the care that the family and carers gave, and the value it had for the person. At times, providing a calm, quiet and supportive presence is the most helpful action</li><li>• Members of the healthcare team who cared for the person may also need emotional support at this time.</li></ul>



### Resource Links:

[Palliative Care Australia – How to talk to someone who is grieving?](#)<sup>(81)</sup>

[Living and Dying in the Place that Matters Most](#)<sup>(82)</sup>



## Learning Activity:

Think about the times when you have cared for someone who has died. If you have not yet been involved in this, talk to a colleague about their experiences.

1. What were the things that you did that meant the most – to them, to their family, and to you?
2. Find out where, in your work setting, cultural practices or wishes are documented.
3. View the Palliative Care Australia video resource [How to talk to someone who is grieving](#) and make some notes about what is and isn't helpful to say at this time.

## Notes



# Section 7: Grief, loss and bereavement

## Understanding the words that are used

**Grief** is a way of describing how a person feels after they have experienced the **loss** of someone or something that is very important to them. The word **bereavement** is used to describe the whole reaction to the loss and includes the healing process.<sup>(83)</sup>



**Sorry Business** is the term that many Aboriginal and Torres Strait Islander peoples use to refer to grief and bereavement. It can also refer to a period of cultural practices and protocols associated with death. Sorry Business acknowledges that the grief experienced from a loss affects the whole person including their mind, spirit and body as well as the relationships they have with other people.<sup>(84)</sup>

During grief, people can experience a range of emotions, including:

- Shock or numbness (not feeling anything)
- Denial (not believing the loss has happened)
- Ongoing sadness and crying
- Anger at the person who has died or anger at themselves
- Guilt from thinking that perhaps something could have been done to avoid the loss
- Guilt arising from the fact that they are still alive – ‘survivor guilt’
- Relief because the loved one is no longer suffering, or relief that a new beginning can take place.

## Why it is important to grieve?

Grief is a normal response to loss and can be expressed in different ways and times. It is important to allow people (including yourself) to grieve in the way that feels natural and comfortable.

If a person has difficulty dealing with grief, it can affect their health and wellbeing. Signs that people need additional support to help them process their grief can be that they feel numb, shocked, sad, angry and/or guilty for a longer time than other family or friends.

Other signs might be that they:

- Find that family/friends seem to be ‘getting on with life’ and they do not feel able to
- Believe that their loved one is not actually dead, and will come back to them
- Start wanting to be alone more and feel like ‘no-one really understands them’
- Start picking arguments with family/friends for no reason
- Blame themselves for the death of their loved one
- Start using alcohol or other drugs more than usual to help cope with the pain
- Have bad dreams, find it hard to sleep or keep seeing their loved one’s spirit/ghost
- Feel like they do not want to go on living without their loved one – thoughts about suicide. If this is the case, they should seek help immediately.

If this is the case, it is important for them to talk with someone. Providing the person with options for support in their local area is very important, as well as providing them with national resources such as *Lifeline* and *Beyond Blue*.



## Resource Links:

[CareSearch – Bereavement, Grief and Loss](#)<sup>(85)</sup>

[Good Grief](#)<sup>(86)</sup>

[Lifeline Toolkit: Coping with sorrow, loss and grief](#)<sup>(87)</sup>



## Learning Activity:

Review at least one of the resources above and make a note of new things you have learnt as well as things you think are important for all members of the healthcare team to know.

## Notes

## Supporting children

Children need open and natural communication about illness, dying and death. Concepts should be presented in an age-appropriate manner, recognising that children's understanding of what death means develops mostly between ages six and eight years. There is wide variation in children's understanding, so it is essential to find out what the child understands before providing information to them. Ask the child what they already know and help them feel comfortable to ask questions.

Encourage the family to use simple language to explain honestly to the child what is happening. Suggest that they consider including children in visits to the sick person and attendance at the funeral and anniversary rituals—this normalises the experience of death and promotes the family as the continuing supportive environment. They should prepare the child for what they might see, hear and feel during visits or at the funeral, and later for the distress they may feel at significant times such as anniversaries.



### Resource Links:

[Children and Grief and Loss](#)<sup>(88)</sup>

[Supporting a Child through Grief and Loss](#)<sup>(89)</sup>



## Notes

# Section 8: Caring for yourself

## Stressors

When caring for people at the end of life, members of the healthcare team are confronted by suffering, deterioration, dying, death, and family grieving. The background and personal characteristics of some people and their families can create more stress than others or have a greater impact. For example, when the person is of a similar age, background or has similar life experiences to the care worker or their family.

Dealing with complex ethical dilemmas can also be stressful, (eg, when there is conflict about care decisions within the team, or between the team and a person or family).

Caring for people affected by life-limiting illness can prompt emotional reactions as you face your own mortality, or perhaps revisit personal experiences with loss, dying and death. Grief and bereavement can also be experienced in a different way, causing members of the healthcare team to confront issues that are difficult to resolve, including:

- Personal concerns, beliefs, morality and ethical views about dying and death – which can also trigger a trauma response depending on personal experiences
- Feelings of reluctance to take on complex problems because of time constraints
- Difficulty dealing with the uncertainty that dying and death can create
- Feelings of helplessness, for example if the team was unable to completely relieve the distress and pain of a person affected by life-limiting illness or if an outcome was unacceptable
- Caring for people with whom you identify in some way – including being involved in caring for a dying friend, colleague or family member
- Cultural anxiety caused by divergent cultural beliefs and experiences
- Accumulated losses.

## Effects of stress

Stress can impact the ability of those in the healthcare team to support people affected by life-limiting illness. It is important to have realistic expectations about the degree of support that can be provided. It is also important to identify the most suitable sources of support for you – both personally and professionally.

Stress can be experienced physically as fatigue, headaches, abdominal or other physical pain, trouble sleeping, weight loss/gain, decreased libido, and increased use of tobacco, alcohol or other drugs. Stressors can have emotional and spiritual effects which can compromise personal wellbeing.

Workplace stress that is not managed, can lead to:

### Moral Distress

- Psychological, emotional and physiological suffering
- Caused by acting in ways that are inconsistent with deeply held ethical values, cultural standpoints, principles or commitments.

### Compassion Fatigue

- Gradual weakening of compassion over time
- Can also occur when, in the process of providing empathic support, you personally experience the pain of people in your care and their families
- Can lead to burnout.

### Burnout

- Negative or cynical attitudes about people and their needs
- Negative attitudes to work, the workplace, colleagues
- Pervasive feelings of dissatisfaction and unhappiness
- Physical and emotional symptoms leading to absenteeism.

## Notes

## Wellbeing

Research has shown that the consistent practice of certain activities can improve wellbeing.

The Wheel of Wellbeing describes the integration of six important dimensions of wellness:

- Body – be active
- Mind – keep learning
- Spirit – give, be kind, be grateful
- People – connect with others
- Place – pay attention, take notice
- Planet – care for the planet.<sup>(90)</sup>



Image Source: [www.wheelofwellbeing.org](http://www.wheelofwellbeing.org)

Self-care is any activity that is done deliberately to take care of mental, emotional and physical health, and is a key part of supporting wellbeing. Strategies for personal self-care include a range of activities and these are unique to the individual.

When putting together a self-care plan, it is helpful to think through the different dimensions of wellness:

### Physical

- Maintaining a healthy lifestyle
- Scheduling regular breaks
- Learning relaxation techniques
- Having an independent GP to help you manage your own health
- Ensuring you get adequate sleep, regular exercise and time for holidays.

### Emotional

- Not taking work home where possible
- Maintaining a good work-life balance
- Being realistic with time and avoiding over-committing
- Practising mindfulness
- Having goals at work and personally
- Accepting the feelings that often come up when working with people who are dying.

### Social

- Spending time with close friends/family
- Maintaining community connections
- Maintaining healthy therapeutic boundaries
- Debriefing with colleagues regularly.

### Spiritual

- Participating in activities that bring joy – to yourself and others
- Pursuing spiritual development
- Maintaining connections with culture and community.



## Resource Links:

[Palliative Care Australia – Self-care matters](#)<sup>(91)</sup>

[Self-care Concepts](#)<sup>(92)</sup>

[Wellbeing Resources](#)<sup>(93)</sup>



## Learning Activity:

Download Palliative Care Australia’s [Self-Care Matters Planning Tool](#) and use it to help you reflect on and plan for your self-care.

## Notes

# Section 9: Summary

This learning guide has provided a range of information to support nurses to develop skills, knowledge and confidence in the palliative approach to care, and promote optimal care for those affected by life-limiting illness.

Each person will take something different away from this learning guide in accordance with where you are at in your palliative care learning journey and depending on which learning activities, reflections and resource links you engaged with.

## Notes

To embed your learning into practice, it is good to reflect on what you have learnt. You might find it helpful to consider these questions:

- What key points have you learnt that will help you in providing care for people with life-limiting illnesses and their families?
- What specific strategies do you plan to include in your approach to your role going forward?
- Do you see any difficulties using what you have learnt here as part of your work? If so, what strategies can you use to overcome these difficulties?

## Practice Tools

There are several apps available to support the practice of health professionals in the palliative approach to care. It can be helpful to use these as a way of supporting quality care.

Further information and download links are available from the following websites:

<b>CALD Assist</b>	An app developed to help clinicians communicate with patients from Culturally and Linguistically Diverse (CALD) backgrounds	Download link (only on the App Store for iPad) available at: <a href="https://apps.apple.com/au/app/cald-assist/id1181619372">https://apps.apple.com/au/app/cald-assist/id1181619372</a>
<b>MyGrief</b>	A bereavement support tool which provides high-quality bereavement information, tools and resources, from the Australian Centre for Grief and Bereavement.	Download links available at: <a href="https://www.grief.org.au/ACGB/Bereavement_Support/MyGrief.aspx">https://www.grief.org.au/ACGB/Bereavement_Support/MyGrief.aspx</a>
<b>Opioid Calculator</b>	The opioid equianalgesic calculator is designed for specialist and general medical practitioners as well as for medical students, nurses and allied health practitioners engaged in the care of patients with persistent pain. Developed by the Faculty of Pain Medicine, Australian and New Zealand College of Anaesthetists (FPM ANZCA).	Download links available at: <a href="http://www.opioidcalculator.com.au/">http://www.opioidcalculator.com.au/</a>
<b>PalliAGEDnurse</b>	This app helps nurses working in residential aged care, community care and general practice to care for older people with palliative care needs.	Download links available at: <a href="https://www.palliaged.com.au/tabid/4351/Default.aspx">https://www.palliaged.com.au/tabid/4351/Default.aspx</a>
<b>PalliMEDS</b>	Developed by NPS Medicinewise for caring@home, this app familiarises primary care prescribers with eight palliative care medicines that have been endorsed by the Australian and New Zealand Society of Palliative Medicine for management of terminal symptoms	Download links available at: <a href="https://www.caringathomeproject.com.au/tabid/5159/Default.aspx">https://www.caringathomeproject.com.au/tabid/5159/Default.aspx</a>
<b>SPICT</b>	This app includes information about the SPICT, advice on how to assess and plan care for people identified with it, and tips on effective communication.	Download links available at: <a href="https://www.spict.org.uk/spictapp/">https://www.spict.org.uk/spictapp/</a>
<b>Vital Talk</b>	The Vital Talk app is a tool to support health professionals to use the communication skills that they have learned in the clinical setting. It provides communication skill tips in the form of virtual 'pocket cards'.	Download links available at: <a href="https://www.vitaltalk.org/vitaltalk-apps/">https://www.vitaltalk.org/vitaltalk-apps/</a>



# Glossary

**Advance care planning** A process where a person discusses what is important to them and their decisions about future healthcare with their family, friends and healthcare team.

<b>Advocacy</b>	The act of supporting a person, action or belief.
<b>Autonomy</b>	A person's ability to make decisions for themselves. Also known as 'self-determination' or 'sovereignty'.
<b>Bereavement</b>	The total reaction to a loss and includes process of healing from the loss.
<b>Burnout</b>	Physical or mental collapse caused by overwork or stress.
<b>Care pathway</b>	The ideal way to manage most people with a specific health problem. Care pathways use documents, like flowcharts to outline the steps of care to be followed by members of the healthcare team.
<b>Care plan</b>	A plan made for an individual to meet their specific health needs.
<b>Compassion fatigue</b>	The gradual weakening of compassion over time.
<b>Coroner</b>	A person who is responsible for investigating and determining the cause of death for those cases reported to them. In all states and territories, a coroner is a magistrate with legal training, and is attached to a local court.
<b>Curative care</b>	Treatment that is aimed at identifying and treating the source of the illness and promoting recovery.
<b>Degenerative disease</b>	Diseases that involve the progressive impairment of both the structure and function of part of the body.
<b>Empathy</b>	The ability to appreciate another's experience, concerns and perspectives with the ability to communicate this understanding.
<b>Empowerment</b>	The ability to mobilise the resources needed to make a person feel in control and have confidence in the goals they are attempting to meet.
<b>Existential distress</b>	A person's experience of lack of meaning or purpose in life.
<b>Frail</b>	Weak or delicate.
<b>Grief</b>	A normal reaction to loss. It includes a range of responses: physical, mental, emotional and spiritual.
<b>Holistic care</b>	Care that treats the whole person – body, mind and spirit.
<b>Illness trajectory</b>	A way of describing the usual pattern that illnesses take from the time of diagnosis to the time of death.

<b>Life-limiting illness</b>	An active, progressive advanced disease. This term is used to describe a wide range of illnesses where it is expected that death will occur.
<b>Loss</b>	The severing or breaking of an attachment to someone or something, resulting in a changed connection.
<b>Moral distress</b>	Psychological, emotional and physiological suffering.
<b>Palliative care specialists</b>	Healthcare professionals who specialise in palliative care (with additional training) and work permanently in that role.
<b>Person-centred care</b>	Care that places the person and their family at the centre of healthcare.
<b>Primary healthcare staff</b>	Healthcare professionals who are the first level of contact that individuals, families and communities have with the healthcare system. They include, general practitioners, general practice nurses, midwives, and allied health professionals.
<b>Sorry Business</b>	The term that many Aboriginal and Torres Strait Islander peoples use to refer to grief and bereavement. It can also refer to a period of cultural practices and protocols associated with death. Sorry Business acknowledges that the grief experienced from a loss affects the whole person including their mind, spirit and body as well as the relationships they have with other people.
<b>Substitute decision-maker</b>	A friend or family member who is chosen by a person to help guide the healthcare team in making decisions about ongoing care if the person is unable to speak for themselves.
<b>Supportive and Palliative Care Indicators Tool (SPICT™)</b>	<p>SPICT™ is a tool designed to help healthcare professionals find people who might benefit from better supportive and palliative care, including thinking ahead and planning future care.</p> <p>SPICT-4ALL is a version of the tool with less 'medical' language, designed to be used by people with life-limiting illness, and their family/carers to help talk about care needs and support.</p>
<b>Surprise Question</b>	A trigger question used to help identify when a person is approaching the end of life (Would I be surprised if this person were to die in the next 6–12 months?)
<b>Symptom Assessment Scale</b>	An assessment tool that helps a person talk about how they are feeling about their symptoms.
<b>Terminal</b>	A progressive disease where death because of that disease can reasonably be expected within 6 months.



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# Record of Participation

This is to record that

Has completed

## PEPA Learning Guide for Nurses

### Learning Outcomes

When you have completed this learning guide, you will be able to:

1. Describe the palliative approach to care and outline important principles
2. Identify the principles of effective communication in palliative care
3. Describe advance care planning and its importance in providing care
4. Outline approaches to assessment in palliative care and describe commonly used assessment tools
5. Summarise common care needs for people with life-limiting illness and the multidisciplinary approach to managing these needs, including pain assessment and management, and medication use
6. Describe important aspects of caring for someone at the end of their life
7. Identify ways to support people who are experiencing grief and loss
8. Outline important aspects of self-care.

Learning Hours\*

Date completed

Signature

\*Please keep a record of the time taken to complete learning modules and refer to your professional regulating body for allocation of CPD points.



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Experience in the  
Palliative Approach

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