Learning Guide for Care Workers

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
- The End of Life Directions in Aged Care (ELDAC) project team
- The Palliative Care Outcomes Collaboration (PCOC) Aged Care taskforce
- Project Director Dist. Professor Patsy Yates, Queensland University of Technology.

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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.

Section 1: Overview

About PEPA

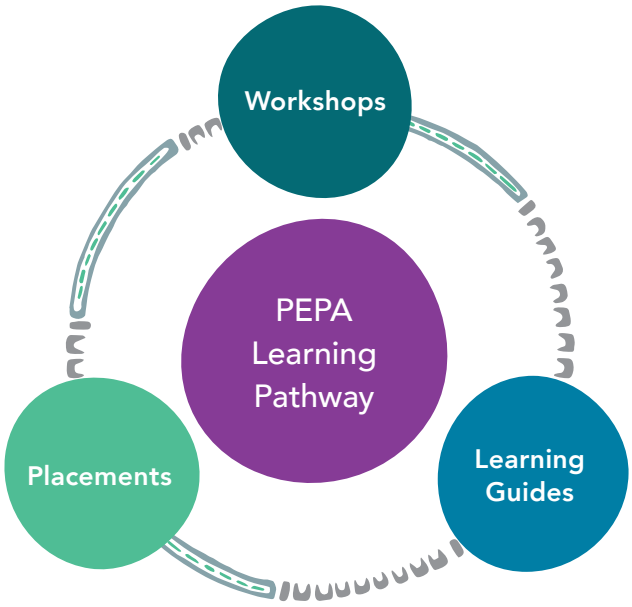
The Program of Experience in the Palliative Approach (PEPA) forms part of the Palliative Care Education and Training Collaborative (the Collaborative). As a national palliative care project, the Collaborative takes a strategic approach to education and training of the healthcare workforce and delivers 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

As a care worker, you have an important role in supporting people affected by life-limiting illness. In community, inpatient and residential care settings, care workers spend considerable time with people and have important opportunities to care for and comfort individuals, families and carers during the end-stages of life.

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, although it is important to note that 'palliative care' is not confined to the end stages of illness.

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
PEPA offers a range of workshops, including: • Palliative Care – with content tailored to participants working in acute care, aged care, community and Aboriginal and Torres Strait Islander healthcare professionals • Palliative Care for Aboriginal and Torres Strait Islander Peoples • Culture-Centred Palliative Care • Mentoring Workshops.	• PEPA workforce placements entail supervised, observational placements (2–5 days) in community, inpatient and hospital-based consultancy specialist services, guided by a mentor. • 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.

Ongoing support

- If you would like to keep informed and connect to others in the PEPA network, you can follow us on Facebook.
- You can also subscribe to our eNewsletter for regular updates.
- 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.

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. Summarise common care needs for people with life-limiting illness and how you can support the responses to these needs
5. Describe important aspects of caring for someone at the end of their life
6. Identify ways to support people who are experiencing grief and loss
7. 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.

PEPA Indigenous Program of Experience in the Palliative Approach

Notes

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 [1]

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.

Palliative Care Australia [2]

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.

Reflection:

Understanding the definitions

Take a few minutes to 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 is 'quality of life' to you?

Key Concepts

Person and family-centred care	Life-limiting illness
Care that places the person and their family at the centre of healthcare. This means that they are listened to, informed, respected and involved in their care – and that their wishes are honoured throughout their healthcare journey. 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. ***Resource Link:*** CareSearch – Person-Centred Care [3]	An active, progressive, advanced disease is known as a life-limiting illness. [4] 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. Palliative care should be available to all people living with an active, progressive, advanced illness, regardless of their diagnosis. ***Resource Link:*** CareSearch – Living with Life-limiting Illness [5]

Key Concepts *continued*

Curative vs palliative care	Quality of life
Curative care involves treatment that is aimed at identifying and treating the source of the illness and promoting recovery. Palliative care aims to comfort. It focuses on living well with worsening health, rather than curing and recovery from illness. 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. *Our ultimate goal after all, is not a good death but a good life to the very end.*[6]	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. 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. *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.*[6] ***Resource Link:*** CareSearch – Quality of Life[7]

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 care worker in providing palliative care? Think about the care activities in 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?

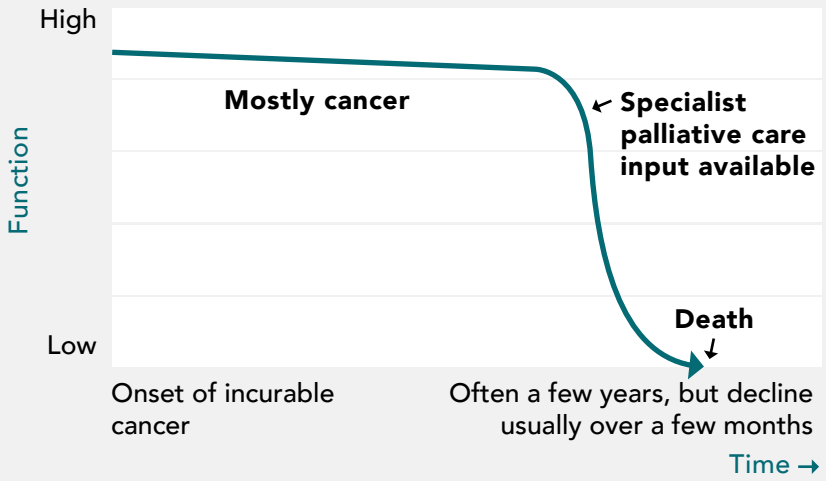
There are three ways that the health of people with life-limiting illnesses generally progresses. These are known as 'illness trajectories':[8]

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:

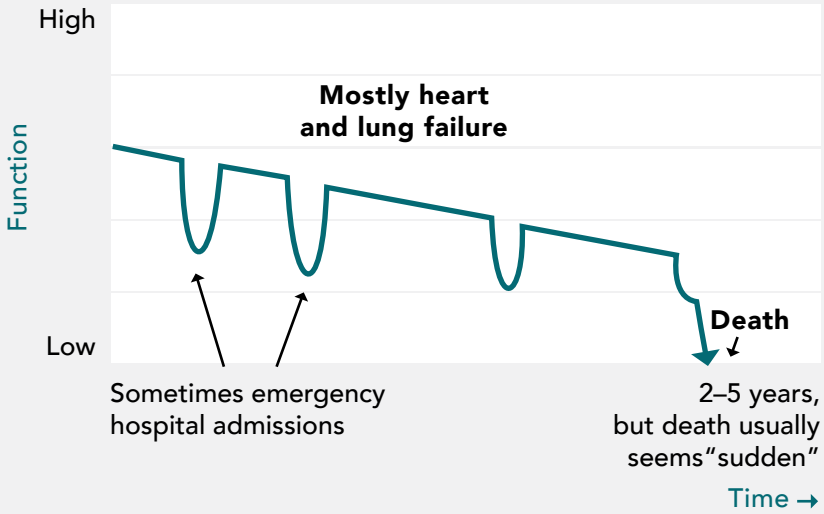
Joan is a 45-year-old woman with secondary breast cancer, which has spread to the bone and liver, who received her initial cancer diagnosis 10 years ago. She continues to receive a range of anti-cancer treatments. Joan is suffering from weight loss, decreased appetite and pain, and is increasingly weak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

Long term limitations with intermittent serious episodes





Example:

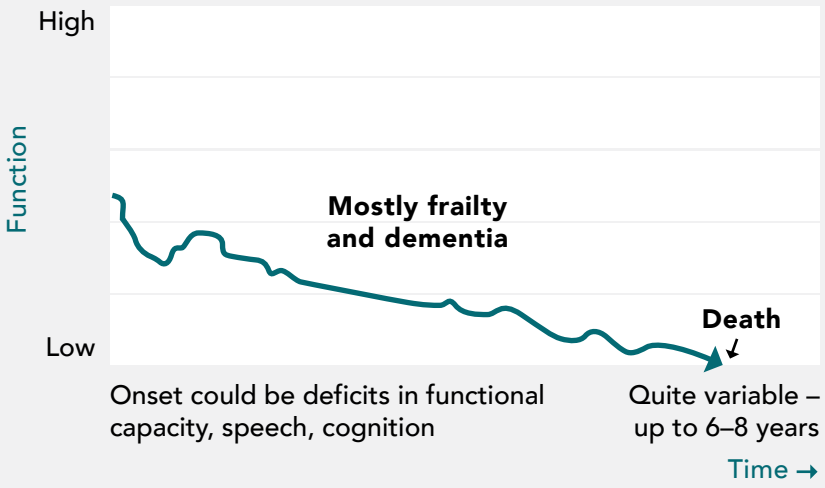
Bob is a 69-year-old man with end-stage heart failure who is experiencing fatigue and increasing breathlessness. He has had three emergency hospital admissions in the past 12 months. He is concerned about what quality of life his future holds and when he will die.

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 but 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.

Notes

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 care workers in community and residential care settings, most of the people you care for will be elderly. 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.[9]

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 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.

Resource Links:

1. CareSearch: Living Longer, Dying Better[10]
2. ELDAC Toolkit: Recognise End of Life[11]
3. University of Edinburgh/NHS Lothian: SPICT-4ALL™[12]

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.

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. [13]

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.

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?

Notes

Principles of Palliative Care

Principles [13, 14]	What does it mean?	What can you do?
Dignity	Dignity is the state of feeling worthy, honoured and valued. 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).
Empowerment	Empowering a person gives them the power to make their own choices.	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.
Compassion	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.
Equity	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.
Respect	Respect ensures thought for the person and that they are held in high regard.	Demonstrate respect for the person, their carer and family. 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.
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	Care workers 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:

1. Palliative Care Australia: What is Palliative Care?[14]
2. CareSearch: Culturally Safe and Responsible Care[15]

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 co-workers about their experiences.
2. Add some of your own points to the 'What can care workers do?' column in the table above.

Care Standards

The National Palliative Care Standards[13] outline the standards and elements of quality care for all Australians.

They provide an important framework for all healthcare workers involved in caring for people affected by life-limiting illness. 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[16]
- Australian Commission on Safety and Quality in Health Care (ACSQHC) National Safety and Quality Health Service (NSQHS) Standards (Version 2)[17]
- ACSQHC National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care[18]
- ACSQHC National Consensus Statement: Essential Elements for Safe and High-Quality Paediatric End-of-Life Care[19]

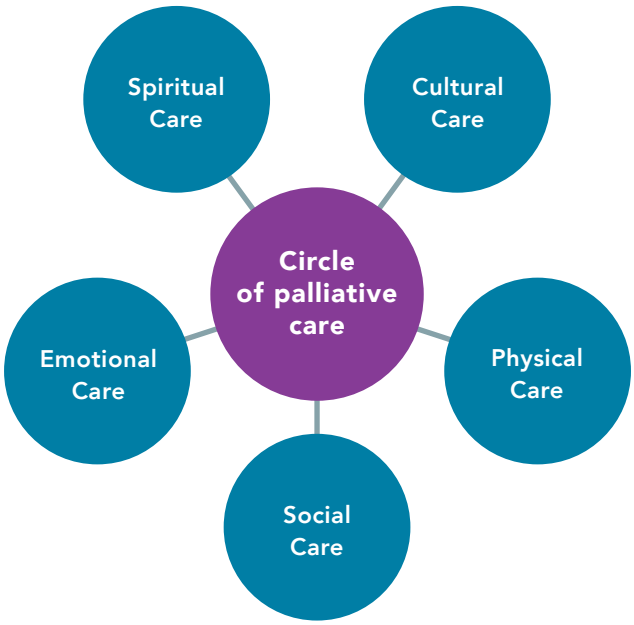
Notes

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.

The Five Domains of Holistic Care



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 co-worker about this and make some notes about what you learn.

Further suggestions and resources on this are included in the 'Communication' section.

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

Care workers, due to the amount of time they spend with people, often act as a guide through 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: [20]

Empowerment	Empathy
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. [21] • 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. • You can empower people by listening and providing access to health information that helps people understand and make decisions about their health care.	*Empathy is the ability to appreciate another's experience, concerns and perspectives with the ability to communicate this understanding.* [22] • Empathy in palliative care involves truly listening and trying to understand the person's journey by asking relevant questions. • 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 freely talk while you listen and guide the conversation. • 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.

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: Being 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. [23]

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

Learning Activity:

1. In the next few conversations you have, whether with co-workers, friends or family members, pay attention to the non-verbal aspects of communication and how you think the other person is feeling.
2. 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?*
3. 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?*
4. Continue to practice this during conversations that are part of your work role to further develop your communication skills.

- 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
- 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.[24]

Framework Elements		What you can do and say
P	**Prepare** for the discussion, where possible	• Make sure you have the correct information about the person • Consider who should be present for the conversation.
R	**Relate** to the person	• *This has been a tough time for you and your family*
E	**Elicit** preferences from the person and their family	• *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?*
P	**Provide** information tailored to the individual needs of the person and family	• Give information in small chunks, at the person's pace • Offer to discuss what to expect (in a sensitive manner), giving them the option not to discuss it if they would prefer • Use clear, jargon-free, understandable language • Engage in active listening – give your complete attention to them, and reflect what you think they have said (eg, *If I've heard you right, you seem to be saying…*)
A	**Acknowledge** emotions and concerns	• *What worries you most about…?* or *What is your biggest concern at the moment?*
R	Foster **realistic** hope (eg, support, peaceful death)	• *We will do all we can to assist you in whatever lies ahead for you*
E	**Encourage** questions and further discussions	• *We've spoken about a lot just now. It might be useful to summarise what we've said…* • *Is there anything that you don't understand or want me to go over again?*
D	**Document**	• Write a summary in the person's health record of what has been discussed, if that is part of your role. • Speak or write to other key healthcare providers involved in the person's care.

Resource Links:

1. NSW Health Resource: Last Days of Life [25]
2. VitalTalk Resources: Establish Rapport [26] and Track and Respond to Emotion [27]

Learning Activity:

1. Reflect on a time when you were involved in a difficult (bad news) conversation in the work environment. 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.
2. 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 has a different form and the forms 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.
2. What are the key aspects of advance care planning?
3. Think about how advance care planning is viewed in your family / community.

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:

1. Advance Care Planning Australia [28]
2. Dying to Talk Discussion Starter Online Card Game [29]
3. Advance Care Yarning for Aboriginal and Torres Strait Islander People [30]

Learning Activity:

1. Review the Advance Care Planning Australia resources for Health and Care Workers.

   As you read through the information, consider these points:

   - 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?
   - In your experience, what kinds of questions do people have about advance care planning?
   - What would you say to help people understand the importance of having an advance care plan?

2. 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:

Make sure the right people are involved	• Ask the person who else needs to be included in the conversation • If you are aware that there is someone else who should be involved in the conversation, it is important to make sure they are included.
Ask open-ended questions	• *What does a good day look like to you?* • *Where would you like to be while you are sick?* • *What are you hoping for now?* • *What is important to you, what makes you feel good?* • *Is there anything that you need to do?* • *What would you like to do before you die?*
Clarify and check regularly	• Check to make sure that what you understood from the conversation is what the person meant, and clarify any information if needed • Check in regularly to see if the person's goals and wishes have changed over time.
Ask questions about decision-making	• *Would you like to make your own decisions about your healthcare or is there someone else you want to do that for you?* • *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?*
Reassure the person that their decisions will be respected	• *Whatever you decide to do today will be written down so that the whole healthcare team know what your choices and preferences are* • *It is important to remember that any decision you have made can be changed if you think or feel differently about it later.* • Remind them that substitute decision-makers will only make decisions for them, when they are no longer able to communicate their wishes for themselves.

Learning Activity:

1. 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: Recognising and responding to needs

Recognising end of life

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.

Signs that a person is approaching the end of their life can include:

- More frequent health interventions
- Declining functional status
- Profound weakness
- Trouble swallowing
- Loss of appetite
- Weight loss
- Experiencing day-to-day deterioration that is not reversible.

The length of time that a person has left is often uncertain and unpredictable. The focus during this time continues to be on 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 care worker's role, in addition to providing comfort and supporting care, is in recognising changes in the person's condition and communicating this information with the other members of the healthcare team.

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?*

Resource Links:

1. CareSearch – Recognising the Last Year of Life [31]
2. Palliative Care Outcomes Collaboration (PCOC) – Talking about symptoms [32]

Notes

Assessment Tools

There are a range of tools that are used to assess a person's symptoms and care needs during the end-stages of life, and you may come across these in the person's health record.

Symptom Assessment Scale (SAS)

The Symptom Assessment Scale (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.

Stop and Watch Early Warning Tool

One simple tool that can assist care workers in identifying important signs that a person might be deteriorating is the 'Stop and Watch' Early Warning Tool. Care workers use this tool to consider changes that they have noticed while caring for the person that day and prompts them to discuss these changes with their supervisor at the end of the shift. [33]

S	Seems different to usual
T	Talks or communicates less than usual
O	Overall needs more help than usual
P	Pain (new or worsening) or participated in activities less than usual
A	Ate less than usual (not because of a dislike of food)
N	No bowel movement in three days or diarrhoea
D	Drank less than usual
W	Weight change
A	Agitated or nervous more than usual
T	Tired, weak, confused or drowsy
C	Change in skin colour or condition
H	Help with walking, transferring, toileting more than usual

Notes

Learning Activity:

1. Review the 'STOP and WATCH' tool and discuss with your supervisor ways that you identify and report changes in your workplace setting.

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	*Definition:* 'an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage' [35] • It is subjective (felt by the person) and has a physical, psychological and spiritual basis • Management requires a holistic approach involving pharmacological management and non-pharmacological interventions.	Patient Management: Pain [36]
Breathlessness	*Definition:* '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' [35] • It is subjective (felt by the person) and describes their experience • Often caused by a combination of factors – underlying causes and progression of illness • Associated with fear, panic and anger Management can involve treatment of the identified cause/s, modifying the environment and supporting psychological wellbeing.	Patient Management: Respiratory Symptoms [37]
Fatigue	*Definition:* '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' [38] • Often described as a feeling of 'decreased / no energy', 'tiring easily', 'weakness' • 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.	Patient Management: Fatigue [39]
Nutrition and hydration concerns	• Weight loss can confirm advancing illness and approaching death • 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 • Nausea and vomiting can be caused by the illness or can be a side-effect of treatment • They can be managed with medication, and/or changes in type, amount and frequency of food.	Patient Management: Appetite Problems [40]

Symptom / Need	Description	CareSearch Resource Links
Delirium and confusion	*Delirium:* the acute or recent development of confusion and altered consciousness occurring in a fluctuating manner (eg, exacerbation of agitation and confusion at night). *Confusion:* 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. Recognised by: • Changes in the person's behaviour • Changes in mood • Awareness of and orientation to time and place • Confusion that occurs suddenly or gradually. [38] Management includes treating underlying causes (including reviewing medication), maintaining a consistent environment and daily routines, frequent reorientation, communicating clearly (including using visual/ hearing) aids.	Patient Management: Delirium [41]
Suffering	Suffering is a complex experience and often has many causes. *Key points:* • 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). • 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 • 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.	Patient Management: Suffering [42] Patient Management: Existential Distress [43]

Resource Links:

1. End of Life Directions in Aged Care (ELDAC) – Recognise End of Life [11]
2. Palliative Care Outcomes Collaboration (PCOC) – Symptom assessment tool for care workers [34]

Reflection:

1. 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.

Notes

Section 6: 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.

Core principles of end-of-life care

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.

Recognising the terminal phase

The terminal phase refers to the last days of life when the person is actively dying. Recognising when a person's death is approaching is an important skill as it provides everyone with a chance to prepare. Many people fear the dying process and do not know what to expect, so it is helpful to explain it in simple terms. With good care it is possible for most people to die comfortably.[44]

Care workers can support the healthcare team by helping to recognise that a person is deteriorating (and likely to die within days), and communicating clearly with the person, their family, carers and community. This can allow for a review of treatment and interventions to improve comfort and enable focused support for the person and their family.

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, 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)
- 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.

Learning Activity:

1. 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?
2. Review the resources below and see if you can find some information to help you answer these questions in future.

*If you have not yet had experiences of this kind, you can ask a colleague about their experience and discuss these questions with them instead.

Resource Links:

1. Patient Management: Care of the Dying Person [45]
2. Dying Matters: The Resuscitation Conversation [46]

What can you do to support good end-of-life care?

Care workers have an important role at this stage. Working as part of the healthcare team, you can be a source of great comfort and support to the person and their family, carers and community.

End-of-life care needs, for the person and their family can include:

- Being able to recognise the terminal phase, understand what to expect, and how to communicate this to loved ones
- Being able to be involved in providing care (eg, assisting with mouth care, pressure area care) and continue talking with the person, playing their favourite music or 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 end
- Maintaining dignity and privacy, including practical things like clothing choices, being in bed or chair, having familiar items around
- Having choice over preferred 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 and facilitated 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.

Resource Links:

1. CareSearch – At the end [47]

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. People 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.

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:

1. CareSearch – Planning for a Home Death [48]

Dying in 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.

The role of the care worker is to provide ***comfort*** for the person and their family, while the role of the health professionals involved is to provide ***clinical*** care.

Resource Links:

1. Residential Aged Care End of Life Care Pathway (RAC EoLCP)[49]
2. Care Plan for the Dying Person[50]

Learning Activity:

1. 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. A doctor needs to certify and document the death, contact the Coroner if necessary (not usually required when the death is expected), and notify the person's family if they are not present. Nursing and other care staff are usually responsible for 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.

Care workers play an important role in supporting the healthcare team and (under direction from their supervisor and according to specific workplace policies) can be involved in:

- Confirming the identity of the person
- Assisting with preparation and transfer of the body
- Documentation of care provided, completion of care plans / care pathways, updating property records
- Supporting the person's family.

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
Maintaining privacy	• Ensuring doors / curtains are closed.
Cultural considerations	• Be mindful of the cultural protocols or religious beliefs of the person and their family and carers.
Communication	• Empathetic, sensitive communication with family / carers.
Family / Carers	• If family wish to assist with washing the body, check with your supervisor that they are available to provide support during the process • Talk through what is happening with the family to ensure their wellbeing during, and after the process.
Respect	• Maintain the modesty of the person by covering the body with towels / sheets as you would if they were alive.
Position the body	• Lie the body flat and support the head with a pillow, close the eyes and mouth.
Wash the body	• Using warm water, wash the body, maintaining respect and dignity • The family may provide specific clothing to be worn, if not, a shroud can be worn • Pay attention to ensuring the face and hands are clean • Ensure the hair is neatly combed as the person would usually style their hair • Ensure dentures are in place if possible as they help to shape the face • Change the sheets and pillowcase.
Present the body respectfully	• 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 • The body should look like they are peacefully sleeping.
Prepare the viewing room	• Ensure seating, tissues and drinks are available • Ensure the room is clean and tidy with any excess equipment (hoists etc) removed • Freshen the room air by opening a window if possible • Ensure the person's property is packed ready to give to the family (if appropriate) so they are not waiting unnecessarily • This should be completed with your supervisor, documenting all property in the appropriate manner.
Talk with the other patients / residents	• 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.

Resource Links:

1. CareSearch: Care of the Body[45]

Reflection:

1. Recall your experiences of providing care for a person and their family after death. 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:

Cultural practices	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) 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?*) The family and carers can appreciate you assisting with cultural protocols, or they may not want or need help.
Saying goodbye	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 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 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.
Emotional support	Healthcare providers need to be sensitive to the need for family members and carers to express their emotions and facilitate this appropriately 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 Members of the healthcare team who cared for the person may also need emotional support at this time.

Resource Links:

1. Palliative Care Australia – How to talk to someone who is grieving?[51]
2. Living and Dying in the Place that Matters Most[52]

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 / 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.[53]

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.[54]

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:

1. CareSearch – Bereavement, Grief and Loss [55]
2. Good Grief [56]
3. Lifeline Toolkit: Coping with sorrow, loss and grief [57]

Learning Activity:

1. 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.

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:

1. CareSearch: Children and Grief and Loss [58]
2. KidsHelpline: Supporting a Child through Grief and Loss [59]

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.

Wellbeing

Research has shown that the consistent practice of certain activities can improve our 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. [60]



Image Source: 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:

- Prioritising close relationships such as those with family and friends
- Maintaining a healthy lifestyle by ensuring adequate sleep, regular exercise, and time for holidays
- Not taking work home where possible
- Establishing and maintaining a good work-life balance – and not seeing this as a sign of weakness
- Scheduling regular breaks – including taking lunch breaks and tea breaks
- Fostering recreational activities and hobbies
- Being realistic with time and avoiding overcommitting
- Practising mindfulness
- Participating in activities that bring personal joy
- Pursuing spiritual development
- Maintaining a routine
- Maintaining connections with culture and community
- Learning relaxation techniques and practising regularly
- Having goals – at work and personally
- Accepting the feelings that often come up working with people who are dying
- Developing and maintaining healthy therapeutic boundaries
- Debriefing with colleagues regularly
- Establishing a relationship with an independent GP to assist you to manage your own health.

Resource Links:

1. Palliative Care Australia – Self-care matters [61]
2. CareSearch: Self-care Concepts [62]
3. Black Dog Institute Wellbeing Resources [63]

Learning Activity:

1. 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 care workers 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 they are at in their palliative care learning journey and depending on which learning activities, reflections and resource links you engaged with.

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?

Notes

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.
Advocacy	The act of supporting a person, action or belief.
Autonomy	A person's ability to make decisions for themselves. Also known as 'self-determination' or 'sovereignty'.
Bereavement	The total reaction to a loss and includes process of healing from the loss.
Burnout	Physical or mental collapse caused by overwork or stress.
Care pathway	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.
Care plan	A plan made for an individual to meet their specific health needs.
Compassion fatigue	The gradual weakening of compassion over time.
Coroner	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 and is attached to a local court.
Curative care	Treatment that is aimed at identifying and treating the source of the illness and promoting recovery.
Degenerative disease	Diseases that involve the progressive impairment of both the structure and function of part of the body.
Empathy	The ability to appreciate another's experience, concerns and perspectives with the ability to communicate this understanding.
Empowerment	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.
Existential distress	A person's experience of lack of meaning or purpose in life.
Frail	Weak or delicate.
Grief	A normal reaction to loss. It includes a range of responses: physical, mental, emotional and spiritual.
Holistic care	Care that treats the whole person – body, mind and spirit.
Illness trajectory	A way of describing the usual pattern that illnesses take from the time of diagnosis to the time of death.

Life-limiting illness	An active, progressive advanced disease. This term is used to describe a wide range of illnesses where it is expected that death will occur.
Loss	The severing or breaking of an attachment to someone or something, resulting in a changed connection.
Moral distress	Psychological, emotional and physiological suffering.
Palliative care specialists	Healthcare professionals who specialise in palliative care (with additional training) and work permanently in that role.
Person-centred care	Care that places the person and their family at the centre of healthcare.
Primary healthcare staff	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.
Sorry Business	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.
Substitute decision-maker	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.
Supportive and Palliative Care Indicators Tool (SPICT™)	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. 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.
Surprise Question	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?)*
Symptom Assessment Scale	An assessment tool that helps a person talk about how they are feeling about their symptoms.
Terminal	A progressive disease where death because of that disease can reasonably be expected within 6 months.

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PEPA Program of Experience in the Palliative Approach

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PEPA Learning Guide for Care Workers

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. Summarise common care needs for people with life-limiting illness and how you can support the responses to these needs
5. Describe important aspects of caring for someone at the end of their life
6. Identify ways to support people who are experiencing grief and loss
7. 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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