

Learning Guide for Aboriginal and Torres Strait Islander Health Professionals

2020



CULTURAL SENSITIVITY WARNING:

Please be advised that this resource contains material of a sensitive nature.
This resource may contain images of people who may have passed away/finished up.

PEPA Program of
Experience in the
Palliative Approach

PEPA Indigenous Program
of Experience in the
Palliative Approach



Acknowledgements

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- Aboriginal and Torres Strait Islander Advisory Group
- Aboriginal and Torres Strait Islander State and Territory PEPA staff
- 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

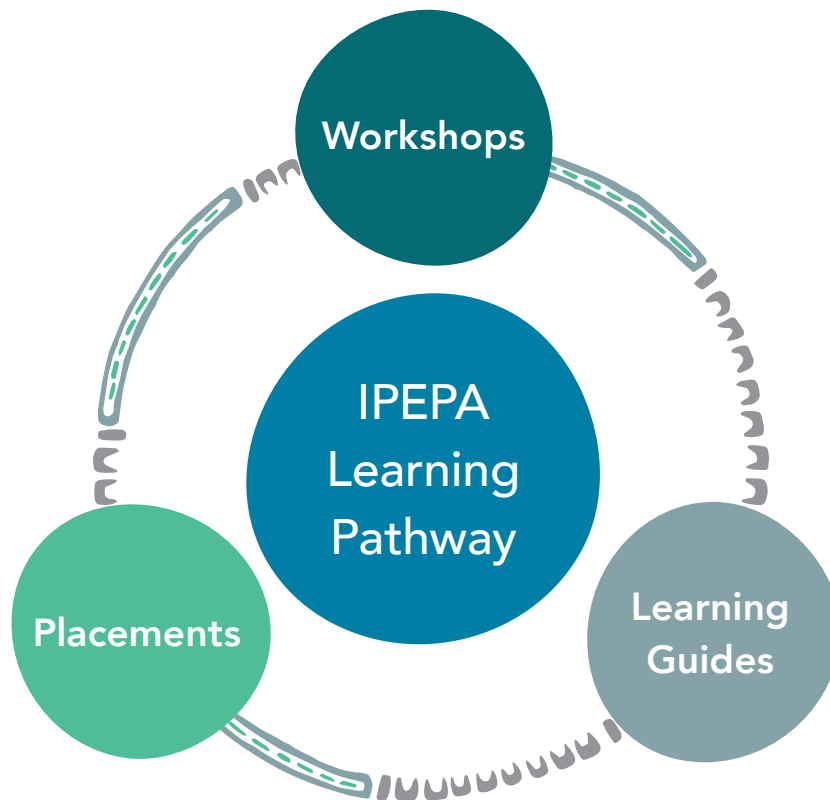
The Program of Experience in the Palliative Approach (PEPA) forms part of the Palliative Care Education and Training Collaborative (the Collaborative). As a national palliative care project, the Collaborative takes a strategic approach to education and training of the healthcare workforce and delivers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

As an Aboriginal and Torres Strait Islander health professional, you have an important role in supporting people affected by chronic, advanced and life-limiting illness. 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 finishing up / dying, 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, and link traditional and contemporary practices when caring for people who are finishing up. We will focus on active comfort care and a positive approach to managing symptoms and reducing distress. This approach facilitates early identification of the sick person's concerns, beliefs, needs and choices, and provides guidance for ways to support them and their families / communities.





Workshops	Placements
<p>PEPA offers a range of workshops, including:</p> <ul style="list-style-type: none"> • Palliative Approach Workshops – with content tailored to participants working in aged care settings, Aboriginal and Torres Strait Islander health professional roles, and general practice • Culture-Centred Care Workshops • Mentoring Workshops 	<ul style="list-style-type: none"> • 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 have a safe, supportive platform to ask questions and connect to other Aboriginal and Torres Strait Islander peoples, IPEPA welcomes you to join our closed [Facebook group](#).

You can also subscribe to our eNewsletter for regular updates, available at <https://pepaeducation.com/>

Introduction to the learning guide

This learning guide is a part of the IPEPA learning pathway that is intended to help inform your journey around Palliative Care. It can be used to support workshops and placements and / or 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.

Learning objectives

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

- Describe the palliative approach to care and outline important principles
- Identify the principles of effective communication in palliative care
- Describe advance care planning and its importance in providing care
- Summarise common care needs for people with life-limiting illness and how you can support the responses to these needs
- Describe important aspects of caring for someone at the end of their life
- Identify ways to support people who are experiencing grief and loss
- Outline important aspects of self-care.

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

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.

Sorry Business

This learning guide will discuss the spiritual and cultural needs of finishing up / dying, end-of-life care and death of a person as well as how these things impact on their 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 family member, friend or colleague if you need support.

Section 2: Palliative approach to care

What is palliative care?

Palliative care helps people live their lives as actively and 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 assistance.

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?

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. The relationships 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.</p> <p>Resource Link: CareSearch – Person-Centred Care ⁽³⁾</p>	<p>An active, progressive, advanced disease is known as a life-limiting illness.</p> <p>This term is used to talk about a wide range of illnesses where it is expected that death will occur. For Aboriginal and Torres Strait Islander peoples, the four most common types of life-limiting illnesses are heart disease, diabetes, respiratory disease and cancer. Palliative care should be available to all people living with an active, progressive, advanced illness, regardless of their diagnosis.</p> <p>Resource Link: CareSearch – Living with Life-limiting Illness ⁽⁴⁾</p>
Curative vs palliative care	Quality of life
<p>Curative care involves treatment that is aimed at finding and treating the source of the illness and supporting recovery.</p> <p>Palliative care aims to provide comfort. It focuses on living well with worsening health, rather than cure 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> ⁽⁵⁾</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 the different aspects of their life (physical, emotional, social, cultural 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> ⁽⁵⁾</p> <p>Resource Link: CareSearch – Quality of Life ⁽⁶⁾</p>



Artwork: palliative care

Michael J Connolly or Uncle Mick is an Aboriginal man from Charleville, south-west Queensland and a descendant of the Kullilla Tribe from the Thargomindah and Eulo region on his Father's side and from the Muruwari People from Goodooga and Brewarrina region of north-west New South Wales on his Mother's side who can trace their traditional, trade and diplomatic links with Central Desert as well as South Australian and Northern New South Wales' Aboriginal Communities.

Uncle Mick created the artwork below after reflecting on what palliative care means to him as an Aboriginal elder and artist. This artwork is respectful of both Aboriginal cultures and Torres Strait Islander cultures using colours and symbols that reflect both cultures and celebrates the cyclical concept of Life-Death-Life:

- **The footprints** are the journeys taken to and from health services and end-of-life care services (at the top of the picture), where the healthcare staff gather to share

important information and resources about the life-limiting illness and end-of-life care (shown by the helping hands coming in from the sides)

- **The dotted circles** at the bottom of the picture represent families and communities. Many have come in preparation for Sorry Business. Above this is the coolamon or canoe, both used for carrying items (food, babies or people) to nurture and support life
- **The oval shapes** in the centre represent moving through different stages in life's journey with the energy of the spirit as it leaves the journey in the last shape
- **The spray of cascading white dots** is symbolic of numerous things: the tears that come with Sorry Business, the Dhari and Spirit leaving the life journey and travelling back to the spirit world. As Sorry Business starts with the men and women, you can see the spirit meeting with the past present and future (rippling effect).



IPEPA Indigenous Program
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Palliative Approach

The design's core represents the individual, family and community. The eight symbols around this core represent the states and territories to reflect the national connection and wider community. It symbolises the safety of the environment, the reach and network that spread the word and education provided by IPEPA.

Together they can provide the right environment for Aboriginal and Torres Strait Islander peoples to understand palliative care and know that IPEPA is there to assist in the best way possible.

Your Care. Our Mob.



Learning Activity:

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

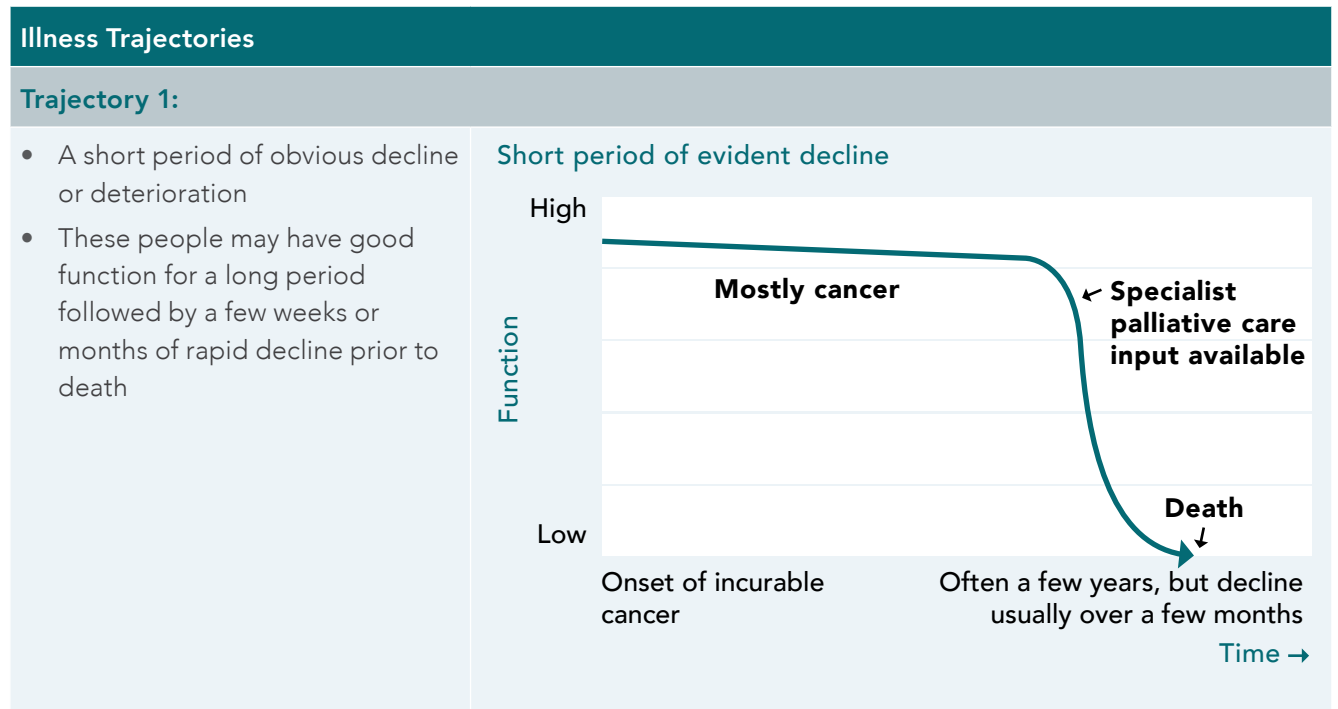
1. What do you think of when you hear the words, 'Palliative Care'?
2. Looking at Uncle Mick's artwork, what do you feel and think about this reflection?
3. How would you describe 'the palliative approach' to a person and their family in your work context? Write out the wording / explanations you would use.

Example: Palliative care is about making sure that people who have a serious illness can live comfortably and with purpose during the time that they have left.

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':⁽⁷⁾



Example:

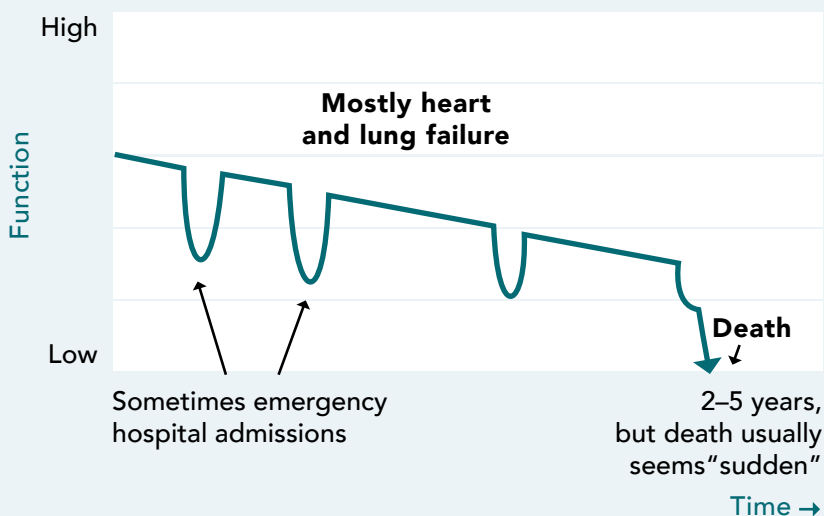
Joan is a 45-year-old woman with secondary breast cancer, which has spread to the bone and liver, who received her initial cancer diagnosis 10 years ago. She continues to receive a range of anti-cancer treatments. Joan is suffering from weight loss, decreased appetite and pain, and is increasingly weak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

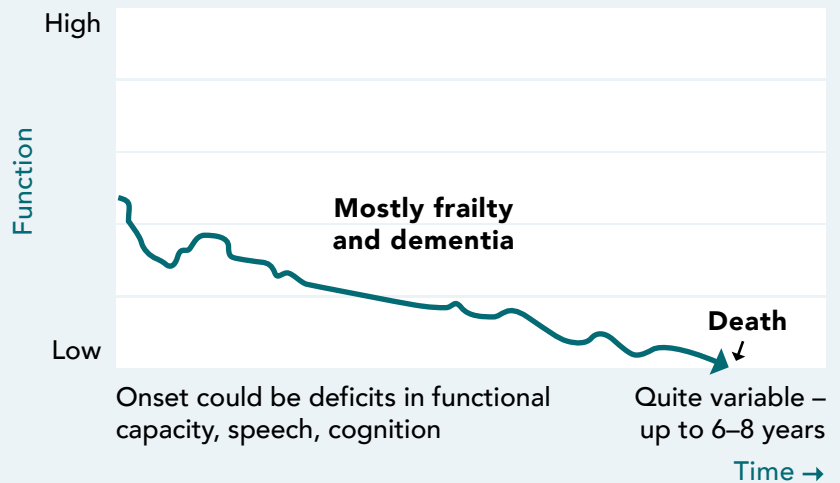
Tom is a 69-year-old man with end-stage heart failure who is experiencing fatigue and increasing breathlessness. He has had three emergency hospital admissions in the past 12 months. He is concerned about what quality of life his future holds and when he will die.

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:

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

Notes

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 Supportive and Palliative Care Indicators Tool (SPICT™) helps the healthcare team identify people who have general signs of poor or declining 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. [ELDAC Toolkit: Recognise End-of-Life^{\(8\)}](#)
2. [University of Edinburgh/NHS Lothian: SPICT-4ALL™^{\(9\)}](#)

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.

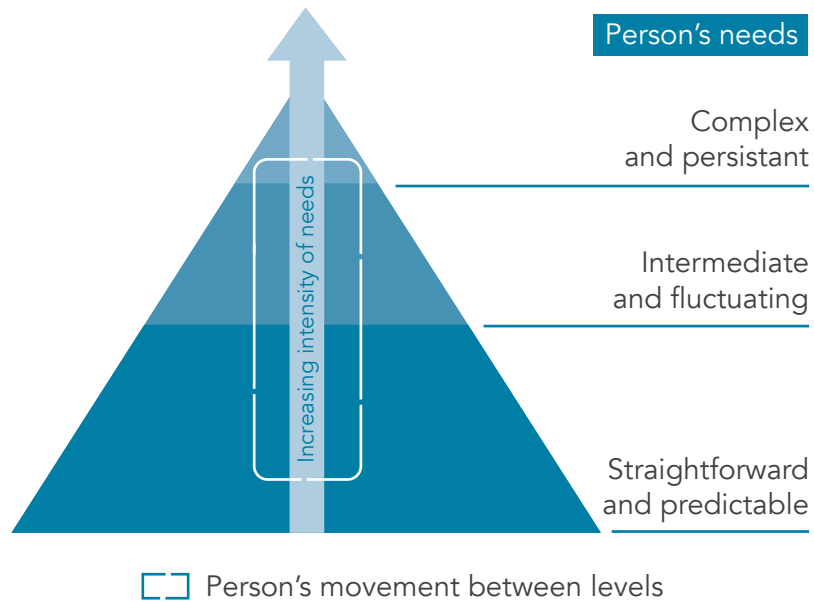
Others will need access to specialist care from time to time for consultation and advice when symptoms (such as pain, psychological distress and reduced physical capacity) worsen. Those with complex and persistent needs will require ongoing specialist palliative care.

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 it is the responsibility of all healthcare professionals to have an understanding of the principles of palliative care and key aspects of the palliative approach.⁽¹⁰⁾

Levels of need for Palliative Care



Notes

Quality of life

The following 'Wheel of Wellness' shows the various aspects of life that Aboriginal and Torres Strait Islander peoples consider important:

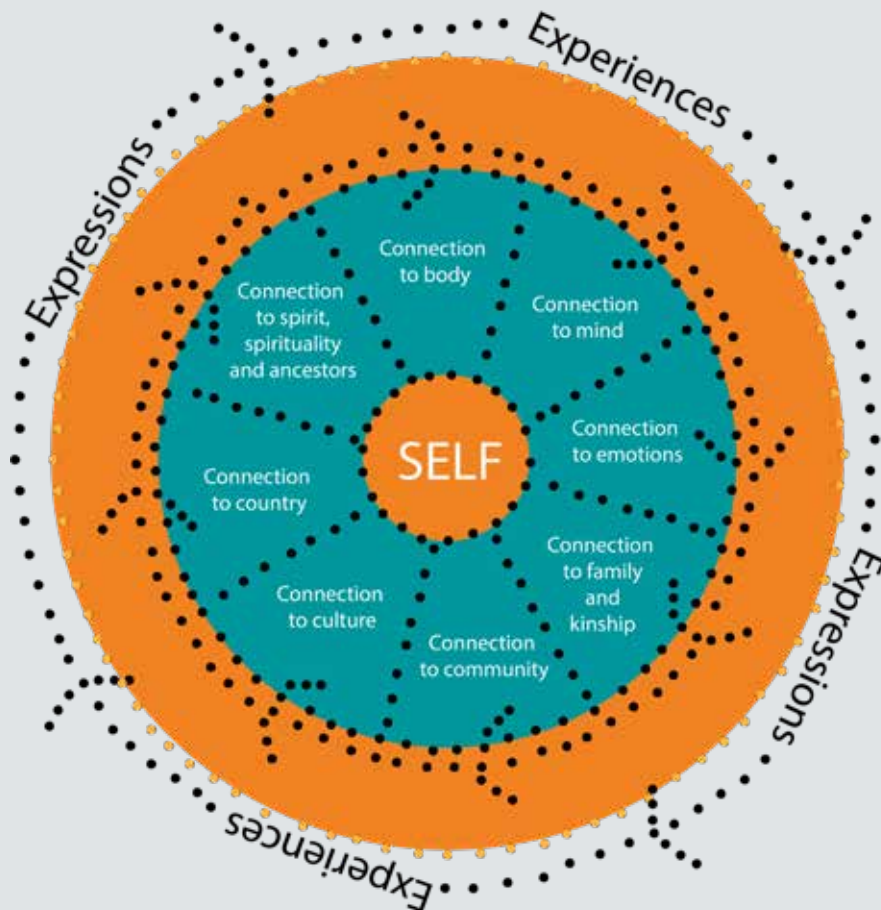


Diagram sourced from: Gee, Dudgeon, Schultz, Hart & Kelly, 2014, Aboriginal and Torres Strait Islander Social and Emotional Wellbeing ⁽¹¹⁾



Reflection:

Quality of life means different things to different people and can be influenced by culture. Looking at the areas in the 'Wheel of Wellness' image, what does quality of life mean to you?



Resource Links:

1. [HealthInfoNet – Social, Emotional and Cultural Wellbeing](#) ⁽¹²⁾

Key principles

Principles of palliative care ⁽¹³⁾	
Cultural safety	Cultural safety is a philosophy of practice that is about how a person does something, not what they do, in order to not engage in unsafe cultural practice that '... diminishes, demeans or disempowers the cultural identity and wellbeing of an individual' ⁽¹⁴⁾
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 regardless of geographical location, cultural background, language / literacy level, religion or sexual orientation. You can support equitable access to care by providing information and advocating for the person and their family / community as needed.
Autonomy	<p>Also called self-determination or sovereignty, autonomy is about making sure that individuals are encouraged and enabled to take control of their own illness journey.</p> <p>This links to the palliative care core values of advocacy and empowerment. You can advocate for a person and support their wishes by speaking up for them when they are not able to speak for themselves. Work with the strengths and limitations of the person and their family / community to empower them to manage their own situation.</p>
Importance of trust	Trusting relationships are a key part of being able to provide good palliative care.
Humane, non-judgemental care	Care for people affected by life-limiting illness needs to be humane, compassionate and non judgemental. This links to the palliative care core values of dignity (feeling worthy, honoured and valued) and compassion (being able to feel for another person's suffering and wanting to help).
Seamless care	The collaboration of the holistic multidisciplinary mix of healthcare professionals from all settings in providing care for the person and their family / community. Seamless care aims to provide continuity and consistency in staff caring for the sick person. It is important to introduce each new person / service prior to them turning up – people need to know exactly who they are dealing with and why.
Emphasis on living	Focusing on living, and quality of life rather than on dying.
Cultural respect	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.

Care provided in line with these principles ensures that the people you support can expect that:

- They are at the centre of all planning and decision-making around palliative and end-of-life care
- Their individual, cultural and spiritual needs are honoured when care is planned and delivered
- They and their loved ones are treated in the way you would want to be treated
- Their preferences and values are recognised and respected
- You, the sick person and their family are all treated with respect and dignity regardless of age, cultural background, religion or sexual orientation.



Resource Links:

1. [CareSearch – Culturally Safe and Responsible Care](#)⁽¹⁵⁾
2. [HealthInfoNet – Providing culturally appropriate palliative care to Indigenous Australians](#)^(16, 17)



Reflection:

Reflect on a time when you were involved in the care of a person with a life-limiting illness. What do you think was most important to them about the way they were cared for?

If you have not been involved in the care of someone with a life-limiting illness, talk with a trusted friend, family member or co-worker about their experiences.

Care standards

The [National Palliative Care Standards](#)⁽¹⁰⁾ outline the standards and elements of quality care for all Australians. They provide an important framework for all healthcare professionals involved in caring for people affected by a life-limiting illness. Standards reinforce 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 healthcare services.

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

- [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⁾
- [Aged Care Quality Standards](#)⁽²⁰⁾
- [Australian Commission on Safety and Quality in Health Care \(ACSQHC\) National Safety and Quality Health Service \(NSQHS\) Standards \(Version 2\)](#)⁽²¹⁾

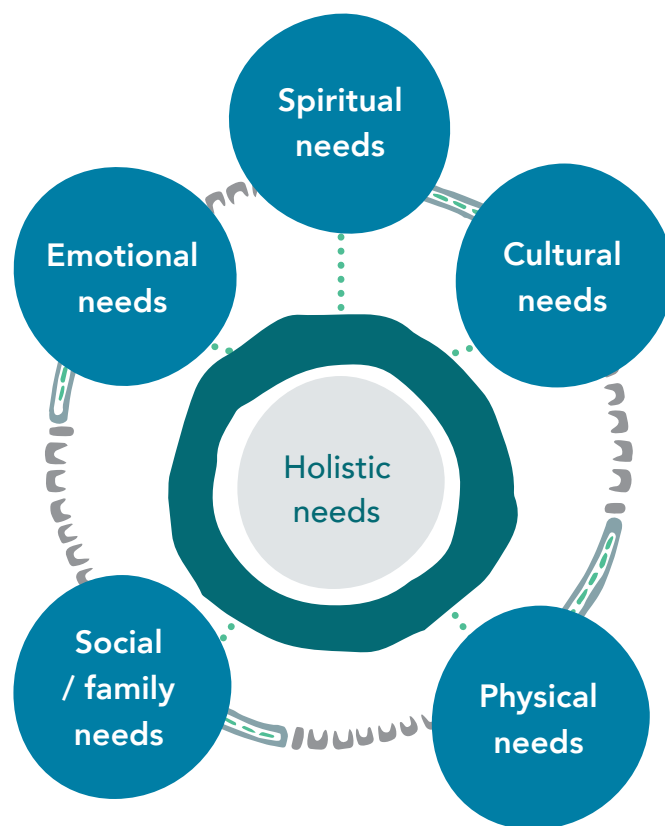
Notes

Family-centred 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 community. It focuses on comfort, quality of life and living well.

The kinds of needs that can be identified and supported as part of the palliative approach are summarised in the following table and diagram.

Holistic needs
Spiritual
Who we are, attitudes, relationships, behaviours, rituals, ceremonies, faith, religion, place of death, Dreamtime stories and songlines.
Cultural
Community, beliefs, rituals, ceremonies, family, groups, bush medicine, going back to Country, food, clothing, women's and men's business, grief practices and sorry business.
Physical
Symptom understanding and management, understanding around traditional western medicine, mobility, body image, sexuality, women's and men's business.
Social / Family
Family, friends, community, neighbours, pets, financial, support groups, respite, travel and accommodation, family meetings and being away from Country.
Emotional
Depression, anxiety, denial, diagnosis, language differences / use of interpreters, fear of hospital and mainstream medicine, and history.



Notes



Reflection:

Think about a person you know who is affected by life-limiting illness.

Consider the following questions to help work out how you could provide a holistic, family-centred approach to their care:

1. What do they know about their illness?
2. What do they want to know?
3. What does 'quality of life' mean to them?
4. What is their story, life goals and legacy?
5. What are their beliefs and values?
6. Who are the significant people in their lives?
7. What are their significant roles in life?
8. What is important for them now and in the future?
9. Who do they want involved in decisions about the care needed?

Talk with a trusted family member, friend or co-worker around ways to yarn with people about these things. Ask them how they start these kinds of conversations and what they have found works best. Make some notes about what you learn.

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:

1. [Paediatric Palliative Care](#)⁽²²⁾
2. [PCC4U Focus Topic 3: Care of children with life-limiting illness](#)⁽²³⁾

Notes

Section 3: Communication

Effective communication

Communicating well is at the heart of palliative care. It is an essential skill for helping a sick person and their family deal with the effects of chronic or life-limiting illness, and especially important when they are not going to get better. There are a range of barriers to effective communication that exist in healthcare, including:

- Health professionals using a practitioner-centred communication style (eg, question and answer) rather than person-centred
- Use of medical terminology that the person is not familiar with
- Inconsistencies between Aboriginal and Torres Strait Islander peoples' concepts of health, and the biomedical perspective
- Lack or absence of communication (making assumptions rather than asking)
- Provision of information that is not evidence-based or not believable based on the patient's previous experience
- Mistrust of healthcare services
- Language issues or lack of interpreter use
- Racism (including perceived racism).⁽²⁴⁾

Trusting relationship

Aboriginal and Torres Strait Islander health professionals act as navigators for people and their families through the palliative care phase of their healthcare journey. This can involve being translators of terminology, systems and processes in relation to the healthcare system.

The development of a trusting relationship relies on open, honest communication where people feel that 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 are respected.

There are two key components to a trusting relationship:

Empowerment

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.⁽²⁵⁾

- 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 healthcare.

Empathy

Empathy is the ability to appreciate another's experience, concerns and perspectives with the ability to communicate this understanding.⁽²⁶⁾

- Empathy in palliative care involves truly listening and trying to understand the sick person's journey by asking relevant questions.
- Encourage the person to express their feelings; acknowledge their emotions and respond with empathy. Allowing people to discuss their feelings gives them the opportunity to freely talk while listening and guiding the conversation.
- It is important to remember your role is not to give advice. It is to listen and allow people to express their concerns and worries.

Clinical yarning

The 'Clinical Yarning Framework' provides a way of approaching healthcare conversations that can help overcome communication barriers. It describes a way of communicating that is culturally secure, person-centred, encourages active listening and helps to build a trusting relationship.

Three types of yarning are described in the framework: ⁽²⁴⁾

Social yarn

- Showing an interest in the person (holistically)
- Developing relationship
- Finding common ground or connection
- Having a two-way exchange – sharing of life experiences.

Diagnostic yarn

- Hearing the person's 'health story'
- Using open-ended questions
- Allowing silences
- Interpreting their story through a clinical lens.

Management yarn

- Providing direct, 'straight-up' health information
- Using stories and metaphors to explain health conditions and build the person's motivation
- Developing a shared or agreed plan of care.

Yarns you have with people about life-limiting illness, dying / death, and end-of-life care can be very difficult. The way you approach a difficult conversation can impact on how effective it is.

In general, providing plain-language explanations in an open and honest manner to the sick person and their family will help to reduce misunderstandings. Checking their interpretation, and clarifying if needed, should happen regularly throughout the conversation.

Paying attention to nonverbal cues is an important part of ensuring effective communication. In conversations (in person and over the phone), the messages you send and receive are expressed, not just in words but in nonverbal cues as well. These include the way you talk (tone of voice, vocal clarity, pace and expression) and your body language (facial expressions, posture, eye contact, touch, gestures).



Resource Links:

1. Responding to Emotion – Respecting ⁽²⁷⁾



Learning Activity:

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.

1. Check with them to see if your impression was correct. You might say, *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 cannot 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.

Using the Clinical Yarning Framework is a helpful way to approach conversations with people about palliative and end-of-life care: ⁽²⁴⁾

Social yarn

- The way you approach the social yarn will depend on how well you know the person and their family already and whether you have family or community connections with them
- Ask them and their family about how they are, and what has been happening lately
- Acknowledge that this has been a hard time for them
- Remind them that you are there to provide support for them.

Diagnostic yarn

- Find out what their concerns are by asking open-ended questions (eg, *What worries you most about...?* or *What is your biggest concern at the moment?*)
- Listen well and check to make sure you have understood correctly (eg, *If I've heard you right, it sounds like you're worried about...*).

Management yarn

- Find out how much they want to know before providing information (eg, *Some people like to know everything that is happening or is likely to happen, others don't want to know too many details. What would you prefer?*)
- Give information in small chunks, at the person's pace
- Be honest, clear and to the point
- Use stories or metaphors to link what the person already knows with information about their illness and management
- Use pictures or sketches to help explain or reinforce verbal information
- Check that they have understood the information by going over key points
- Give culturally appropriate resources (eg, printed information, audio-visual resources) to support understanding
- Remind them that you are there to give support (eg, *I will do whatever I can to help you in whatever happens in the future*).

Notes

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
- Checking with the sick person and their family to find out the preferred words to use in conversations about dying and death (eg, *not going to get better, sick person, bad / sad news, finishing up, passed away, gone, sorry business*)
- 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.



Resource Links:

1. ['Yarn with me': applying clinical yarning to improve clinician-patient communication in Aboriginal healthcare](#)⁽²⁴⁾
2. [Sad News, Sorry Business](#)⁽²⁸⁾
3. [Clinical Yarning eLearning Program](#)⁽²⁹⁾
4. [Yarning about Palliative Care](#)⁽³⁰⁾



Learning Activity:

Reflect on a time when you were involved in a bad / sad news conversation and think about the approach that was taken. What was the outcome of this (from your viewpoint) for the person and family?

Use the *Clinical Yarning Framework* to plan a different approach to that conversation. Discuss your ideas with a trusted friend, family member or co-worker.



Reflection:

Watch the people in this About End-of-Life Care video resource tell their stories and think about the following questions:

1. How would you start yarning with one of these people about their health journey?
2. How would you demonstrate empathy and compassion during the conversation?
3. How could you empower them and their family to make decisions about the care they want in the future?
4. What could you do to help them navigate the palliative care services that are available in your area?
5. How could you advocate on their behalf to make sure their choices and wishes are honoured?

Discuss your ideas with a trusted friend, family member or co-worker.

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 in one go. 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 the person's wishes or choices change
- A person can choose to have a 'substitute medical treatment 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.



Reflection:

Watch the video resource [Finishing Up: Advance Care Plans on Groote Eylandt](#).

1. What do you notice about how advance care planning is talked about in this community?
2. Think about how advance care planning is viewed in your community and the ways people talk about it.

How can we start yarning?

Knowing how to start a conversation with a person 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 – Resources for individual jurisdictions](#) ⁽³¹⁾
2. [Taking Care of Dying Time](#) ⁽³²⁾
3. [Dying to Talk Discussion Starter Online Card Game – Indigenous](#) ⁽³³⁾
4. [Failing to plan is planning to fail: Advance Care Directives paper](#) ⁽³⁴⁾



Learning Activity:

Review the resource [Taking control of your health journey](#) from Advance Care Planning Australia. This has been written to help people understand what an advance care plan is and why it is important.⁽³⁵⁾

As you read through the resource, consider these points:

1. Make a note of the words and phrases that are used to introduce the subject of advance care planning. How could these be helpful for you when yarning 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?
4. Access the [Advance Care Planning](#) website and look at the resources for your specific jurisdiction.

Key points for advance care planning

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

Make sure the right people are involved	<ul style="list-style-type: none">• Ask the person who else needs to be included in the conversation.• If you are aware that there is someone else who the sick person wants to be involved in this conversation, it is important to make sure they are included.
Ask open-ended questions	<ul style="list-style-type: none">• <i>Where would you like to be while you are sick?</i>• <i>What are you hoping for now?</i>• <i>What is important to you, what makes you feel good?</i>• <i>Is there anything that you need to do?</i>• <i>What would you like to do before you go?</i>
Clarify and check regularly	<ul style="list-style-type: none">• 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.
Asking questions about decision-making	<ul style="list-style-type: none">• <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>• <i>If something happened to you and you couldn't talk for yourself, who would you want the health people to talk to, to help you make decisions about your care?</i>
Reassure the person that their decision will be respected	<ul style="list-style-type: none">• <i>Whatever you decide to do today will be written down so that your family and the healthcare team know what your choices and preferences are</i>• <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>• Remind them that substitute decision-makers will only make decisions for them, when they are no longer able to communicate their wishes for themselves.

A 'good' death

Being aware of your personal views about what a 'good' death would be for you is very important when leading or participating in advance care yarning. It helps you to avoid imposing your views on others when they are making decisions.

You can do this by thinking about various aspects of what a 'good' death might be like and considering how important each of these are for you.

A 'good' death for me would be one where:

- Death is painless or largely pain-free
- My end-of-life journey is short
- Death is sudden or unexpected
- Family and health professionals follow your wishes
- Death occurs 'naturally' – without technical equipment or machines
- It is peaceful
- It occurs during sleep
- My family and friends are present
- My spiritual and cultural needs are met
- I have a chance to sort any unfinished business
- I get an opportunity to say 'good-bye'
- I remain at home
- I die on Country
- I live until a key event happens (eg, something in your personal future)
- I have mental alertness until the end
- I can communicate until the end
- I have control of bodily functions until the end
- My family know my wishes for my funeral.⁽³⁶⁾



Learning Activity:

Access the [Dying to Talk](#) online discussion-starter cards and use them to guide your reflections on your own advance care plan. When you finish, save or print your choices and discuss with a family member or friend.

Notes

Section 5: Recognising and responding to needs

When is the end-of-life approaching?

Palliative care should be offered early in a person's journey with life-limiting illness or with increasing ill-health, but unfortunately, this does not always happen.

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

- More frequent health interventions or hospital admissions
- 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. Your role, in addition to providing comfort and assistance, is in communicating the changes you notice in the person's condition to other members of the healthcare team. Your ability to advocate for the sick person and their family / community's needs can have a significant impact on the quality of end-of-life care that they receive.

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 can be:

- *Of the symptoms that have been bothering you, what bothers you the most?* This type of question will help identify a primary symptom in one-third of patients that would otherwise be missed
- *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](#)⁽³⁷⁾

Assessment tools

A range of tools can be used to assess a person's symptoms and care needs, and you might come across these in the person's health record. You will not usually be involved in completing these tools as they are completed by the person / family or a member of the healthcare team. However, being aware of the tools and what they are used for can help you to better understand the person's care requirements.

The commonly used tools are summarised in the following table:⁽³⁸⁾

<u>Symptom Assessment Scale (SAS)</u>	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 health professional can help. These scores help to identify, communicate and escalate problems.
<u>Palliative Care Problem Severity Score (PCPSS)</u>	Health professional-rated score of palliative care concerns that provides a summary measure of concerns in four areas: pain, other symptoms, psychological / spiritual and family / carer.
<u>Functional Assessment in Palliative Care (RUG-ADL)</u>	This four-item scale measures motor function (mobility) with activities of daily living: bed mobility, toileting, transfer and eating. Assessment is based on what the person does, not what they can do. It provides information on functional status, the assistance the person requires to carry out these activities and the resources needed for their care.
<u>Australia-modified Karnofsky Performance Status (AKPS)</u>	The AKPS is a single score between 10 and 100 assigned by a health professional based on observations of a person's ability to perform common tasks relating to activity, work and self-care.

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 recommended that you explore the resource links provided to learn more about these needs and how they are managed.

Pain	<p>Definition: ‘an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage’⁽³⁹⁾</p> <ul style="list-style-type: none"> • 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. 	<p><u>Patient Management:</u> <u>Pain</u>⁽⁴⁰⁾</p>
Breathlessness	<p>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’⁽³⁹⁾</p> <ul style="list-style-type: none"> • 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. 	<p><u>Patient Management:</u> <u>Respiratory Symptoms</u>⁽⁴¹⁾</p>
Fatigue	<p>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’.⁽⁴²⁾</p> <ul style="list-style-type: none"> • Often described as a feeling of ‘decreased / no energy’, ‘tiring easily’, or ‘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. 	<p><u>Patient Management:</u> <u>Fatigue</u>⁽⁴³⁾</p>
Nutrition and hydration concerns	<ul style="list-style-type: none"> • 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, and can be managed with medication, and/or changes in type, amount and frequency of food. 	<p><u>Patient Management:</u> <u>Appetite Problems</u>⁽⁴⁴⁾</p>

Delirium and confusion	<p>Delirium: the acute or recent development of confusion and altered consciousness occurring in a fluctuating manner (eg, worsening of agitation and confusion at night).</p> <p>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.</p> <p>Delirium is recognised by:</p> <ul style="list-style-type: none"> • Changes in the person's behaviour • Changes in mood • Awareness of and orientation to time and place • Confusion that occurs suddenly or gradually. ⁽⁴⁵⁾ <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>	<p><u>Patient Management: Delirium</u> ⁽⁴⁶⁾</p>
Suffering	<p>Suffering is a complex experience and often has many causes.</p> <p>Key points:</p> <ul style="list-style-type: none"> • Suffering relates most strongly to physical symptoms but is also affected 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 • Recognising the deep relationship that Aboriginal and Torres Strait Islander peoples have to Country, the place of death can be a core consideration in end-of-life care. Some people prioritise their spiritual and cultural needs regarding place of death over their physical distress. • The importance of religious practices for some communities 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. 	<p><u>Patient Management: Suffering</u> ⁽⁴⁷⁾</p> <p><u>Patient Management: Existential Distress</u> ⁽⁴⁸⁾</p>

What can you do to support care needs?

While you might not be involved directly in assessing and managing symptoms, your role in supporting the sick person and their family to communicate and connect with the broader healthcare team regarding care needs is extremely important.

The main activities that can be done to support care needs are:

- **Patient advocacy** – helping people to understand their care options so that they can make informed choices about treatment and interventions, and helping them to communicate their care needs with other members of the healthcare team
- **Practical support** – helping with the practical aspects of care (eg, understanding medications, home set-up / equipment needs, travel arrangements, navigating appointments and services, legal / financial issues etc.).
- **Networking with other services** – looking at the services that the local Aboriginal and Torres Strait Islander health service offers, such as integrated team care coordination, aged and frail care programs, day clubs, Centrelink support, and other available services in the community
- **Cultural safety and security** – supporting other members of the healthcare team to understand the person / family's cultural and spiritual needs.

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.⁽⁴⁹⁾ More detailed information is available in the resource links.

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
Anti-emetics	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:

1. Clinical Evidence: Patient Management ⁽⁵⁰⁾
2. 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
3. Medicine (ANZSPM) for management of terminal symptoms ⁽⁵¹⁾



Reflection:

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

Consider their experiences:

1. What symptoms did they have?
2. What worried them most?
3. How did their symptoms affect their daily life and closest relationships?
4. What was done to relieve the person's symptoms and how effective was it?
5. What was your role in supporting assessment and management of symptoms?
6. What else could have been helpful for them (consider the knowledge you have gained through reviewing the resource links in the previous table)?

Section 6: End-of-life care

A care environment where the sick person is respected and feels loved and accepted can provide an end-of-life experience of empowerment, strength, courage and wisdom. This can help them and their loved ones cope with the physical, cognitive and emotional issues experienced during the end-of-life journey.

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 finish up / die comfortably.⁽⁵²⁾ If you can help a sick person and their family to recognise and acknowledge that the person is deteriorating and likely to finish up / die within days, this can allow for a review of interventions to improve comfort and enable focused support to be provided for the person and their family.

During the terminal phase, the sick person usually:

- 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 the person's goals / wishes, needs and symptom management
- Consider the location for 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.



Resource Links:

1. [Patient Management: Care of the Dying Person](#)⁽⁵³⁾
2. [Taking Control of Your Health Journey](#)⁽³⁵⁾
3. [Dying Matters: The Resuscitation Conversation](#)⁽⁵⁴⁾



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 did not know how to answer?

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 trusted family member, friend or co-worker about their experience and discuss these questions with them instead.

Notes

End-of-life care needs

As part of the healthcare team, Aboriginal and Torres Strait Islander Health Professionals have an important role at this end-stage of life. You can be a source of great comfort and support to the sick person and their family, carers and community, as you focus on supporting their needs.

End-of-life care needs, for the sick person and family / community 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, removing mirrors (if this is important)
- Having choice over preferred place of care and where death occurs (eg, on Country, 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
- Considering the possibility of returning to Country one last time
- 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.

'Finishing up' / dying on Country or at home

Some people want to be cared for and to 'finish up' / die on Country or at home. Providing support for the sick person and their family to enable this 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, 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 inform
- 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

Notes

- The need to contact a funeral director and plan for the funeral. The family might wish for the person's body to stay 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 area 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 to transfer the body.



Resource Links:

1. [CareSearch – Planning for a Home Death](#) ⁽⁵⁵⁾
2. [Article: Living and Dying in the Place that Matters Most](#) ⁽⁵⁶⁾



Learning Activity:

Identify the palliative care support networks that are available in your own local community. Make a list (with contact information) that you can use in future when required.

Family and carer needs

After the person has died, the family and carers can benefit from support in relation to:

Cultural practices	<ul style="list-style-type: none">• 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 people 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, <i>Are there any particular things that you would like us to do now that are important for you culturally or spiritually?</i>)• The family and carers can appreciate you assisting with cultural protocols, or they may not want or need help.
Saying goodbye	<ul style="list-style-type: none">• 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 person with the support and direction of a member of the healthcare team, some prefer to leave this to the funeral director.
Emotional support	<ul style="list-style-type: none">• It is important to be sensitive to the need for family, carers and community to express their emotions in their own way and for this to be facilitated 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 support.



Reflection:

Reflect on the times when you have cared for someone who has passed away. What were the things that you did that meant the most – to them / their family, and to you?

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 important 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 and 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 or birthdays.

Children may want to make something or do something special in the remembrance of their loved one and this should be recognised and accommodated where possible.



Resource Links:

1. [CareSearch – Children and Grief and Loss^{\(57\)}](#)
2. [KidsHelpline – Supporting a Child through Grief and Loss^{\(58\)}](#)
3. [Australian Centre for Grief and Bereavement – Grief Information Sheets: After the Loss of a Child^{\(59\)}](#)

Section 7: Grief, loss and healing

Grief is a way of describing the way a person feels after they have experienced the loss of someone or something that is very important to them. 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. For some Aboriginal and Torres Strait Islander peoples, grief is ongoing because of the unresolved and ongoing trauma caused by past policies of Administration such as the *Stolen Generations*.

Considering the complexity and sensitivity of this issue, the areas of grief, loss and healing are not covered in this learning guide. Grief, loss and healing training is delivered in PEPA's Aboriginal and Torres Strait Islander Health Professional Workshop.

If you would benefit from having a safe platform to connect to other Aboriginal and Torres Strait Islander peoples around palliative care, IPEPA welcomes you to join our closed Facebook group: <https://www.facebook.com/groups/PEPAIndigenous/>

There are various organisations that provide focused workshops and detailed information on this topic.



Resource Links:

1. Good Grief – Seasons for Healing⁽⁶⁰⁾
2. HealthInfoNet – Grief, loss and trauma⁽⁶¹⁾
3. Healing Foundation – Community Healing⁽⁶²⁾
4. Sorry Business⁽²⁸⁾
5. The Grief of Aboriginal and Torres Strait Islander Peoples: Australia's First Peoples⁽⁶³⁾
6. Working with Aboriginal and Torres Strait Islander Grief and Bereavement: A Resource for Workers⁽⁶⁴⁾
7. Toolkit: Coping with sorrow, loss and grief⁽⁶⁵⁾
8. Aboriginal and Torres Strait Islander Healing Programs: A Literature Review⁽⁶⁶⁾



Learning Activity:

Review some of the resources and make a list of the supports that are available to people in your community.

What kinds of resources are most likely to be helpful for you and the people you care for?

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 sick 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 healthcare professional or their family.

Dealing with complex ethical dilemmas can also be stressful, (eg, when there is conflict about care decisions within the team or within the family, 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. Sorry Business (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, moral 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 issues 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, community or family member
- Cultural anxiety caused by divergent cultural beliefs and experiences
- Accumulated losses.

Effects of stress

Stress can impact the healthcare team's ability 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 / or 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

The Wheel of Wellness below describes important aspects of staying strong from an Aboriginal and Torres Strait Islander perspective.

Experiences create expressions (eg, if a person has experienced trauma, a negative life event or an everyday stressor, they may express these experiences in response to what can seem like minor issues or situations).⁽¹¹⁾



In community, our connection to culture is our strength and it is how we restore our sense of self and identity. If our experiences and expressions begin to cycle (unaddressed) and we are not strong in our culture, the wheel will puncture and let out the 'air' or our buffer to negative experiences.

Other areas of our lives, that are core to our strength and self, begin to be impacted (eg, family, community, Country, Spirit, mind, body, emotions). Once one area or spoke of the wheel breaks, pressure is placed increasingly on the other areas and these can give way until the entire wheel breaks. It is important to pay attention to our entire wheel and all of our connections that make up the self.⁽¹¹⁾



Resource Links:

1. [Indigenous Wellbeing Centre](#)⁽⁶⁷⁾
2. [Connect to Wellbeing – Aboriginal and Torres Strait Islander Stories \(Video resource\)](#)⁽⁶⁸⁾
3. [HealthInfoNet – Taking Care of Yourself](#)⁽⁶⁹⁾



Reflection:

View the video resource [Keep yourself healed: Self-care for Aboriginal and / or Torres Strait Islander Health Workers](#) and consider the ways that the people in this video supported their own (and others') wellbeing.



Learning Activity:

Using the aspects described in the 'Wheel of Wellness', make a list of all the things that you do (or could do) to look after yourself.

1. What has been most effective?
2. What could you do more of?

Dadirri – Elder Miriam-Rose Ungunmerr

Dadirri is the practise of deep inner listening and quiet still awareness, which connects us and nurtures spiritual wellbeing.

The word, concept and spiritual practice that is *dadirri* is from the Ngan'gikurunggurr and Ngen'giwumirri languages of the Aboriginal peoples of the Daly River region (Northern Territory, Australia).

As Elder Miriam Rose Ungunmerr describes:⁽⁷⁰⁾

"Many Australians understand that Aboriginal people have a special respect for Nature. The identity we have with the land is sacred and unique. Many people are beginning to understand this more. Also, there are many Australians who appreciate that Aboriginal people have a very strong sense of community. All persons matter. All of us belong. And there are many more Australians now, who understand that we are a people who celebrate together.

What I want to talk about is another special quality of my people. I believe it is the most important. It is our most unique gift. It is perhaps the greatest gift we can give to our fellow Australians. In our language this quality is called *dadirri*. It is inner, deep listening and quiet, still awareness.

Dadirri recognises the deep spring that is inside us. We call on it and it calls to us. This is the gift that Australia is thirsting for. It is something like what you call "contemplation".

When I experience *dadirri*, I am made whole again. I can sit on the riverbank or walk through the trees; even if someone close to me has passed away, I can find my peace in this silent awareness. There is no need of words. A big part of *dadirri* is listening."

Notes



Resource Links:

1. [Dadirri \(Official Miriam Rose Ungunmerr Baumann Video\)](#)⁽⁷¹⁾
2. [Dadirri: an Indigenous Approach to Healing Trauma](#)⁽⁷²⁾
3. [Deep and respectful listening – insights into Aboriginal culture \(Podcast\)](#)⁽⁷³⁾



Reflection:

Choose one of the above resources to watch or listen to. Reflect on what you could do to begin a practice of deep inner listening.



Section 9: Summary

Notes

This learning guide has provided a range of information to support Aboriginal and Torres Strait Islander Health Professionals to develop skills, knowledge and confidence in the palliative approach to care, and link traditional and contemporary practices when caring for people who are finishing up / dying.

Each person will take away something different from this learning guide in accordance with where they are at on their palliative care learning journey.

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?
- If you are interested in continuing your learning journey or keeping up to date with IPEPA please feel free to connect with us:
 - [At a workshop](#)
 - [On placement](#)
 - On Facebook – [PEPA](#) and [IPEPA](#) (closed group)

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, life 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 with legal training, 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, emotion 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™)	<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>
Surprise Question	A trigger question used to help identify when a person is approaching the end of life (<i>Would I be surprised if this person were to die in the next 6–12 months?</i>)
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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Notes



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