

# Learning Guide for Medical Practitioners 2020



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

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



# Acknowledgements

This resource for the Program of Experience in the Palliative Approach (PEPA) has been developed with funding from the Australian Government Department of Health. (<http://www.health.gov.au/palliativecare>). The Department of Health provided funding for PEPA to work with Primary Health Networks (PHN's) to deliver a Palliative Approach Workshop for Medical Practitioners (GP) in each of the 31 PHN's from June 2017 through to July 2018. The funding demonstrated the Government's commitment to improving palliative care provision in Australia.

The PEPA Team acknowledges the contribution of the following individuals and groups in the development of this resource:

- 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.



# Copyright

As a part of this copyright you may download, display, print and reproduce this material in unaltered form only (retaining this notice) for your personal, non-commercial use or use within your organisation. Apart from any use as permitted under the Copyright Act 1968, all other rights are reserved. Requests and enquiries concerning reproduction and rights should be addressed to: [pepa@qut.edu.au](mailto:pepa@qut.edu.au)

In some cases, copyright also rests with the Australian Government's Department of Health in accordance with the contractual agreement between both parties. The user must acknowledge the contributions of the Department of Health in any relevant correspondence, public announcement, advertising material, research report or other material produced by or on behalf of the user in relation to the PEPA or Palliative Care Curriculum for Undergraduates (PCC4U) projects.

The user will respect the moral rights of the authors and acknowledge the contribution of the authors in any relevant correspondence, public announcement, advertising material or reports when using or quoting the work of the authors.

All logos and trademarks in this site are property of their respective owners.

© 2020 Queensland University of Technology, Brisbane.

To cite this learning guide, use the following:

PEPA Project Team (2020). *The Program of Experience in the Palliative Approach Learning Guide for Medical Practitioners*, Queensland University of Technology, Brisbane.

# Contents

<b>Section 1: Overview</b>	<b>1</b>	<b>Section 5: Assessing and managing symptoms</b>	<b>52</b>
About PEPA	1	Common symptoms	53
Learning pathway	1	Symptom assessment	56
Ongoing support	2	Assessment tools	58
Introduction to the Learning Guide	2	Assessing and managing common symptoms	60
Reflection: Part 1	4	Palliative interventions	65
<b>Section 2: Principles of Palliative Care</b>	<b>6</b>	Summary	68
What is Palliative Care?	6	<b>Section 6: Assessing and managing pain</b>	<b>69</b>
National Palliative Care Standards	14	The multidimensional experience of pain	71
Recognising death and the 'Surprise Question'	18	Barriers to effective management of pain	74
Assessment Tools	19	Assessing pain	76
What level of support does the person need?	22	Principles of pain management	77
Summary	24	Pain adjuvants	78
<b>Section 3: Communicating with people affected by life-limiting illnesses</b>	<b>25</b>	Opioids	79
Talking about dying and death	25	Breakthrough pain and opioid titration	81
The challenges faced by people diagnosed with life-limiting illnesses	29	Opioid rotation and switching	81
Spirituality	30	Opioid conversion	82
Developing spiritual support strategies	31	Non-pharmacological treatment	82
Communicating with children	33	Summary	83
Memory making	35	<b>Section 7: Self-care</b>	<b>84</b>
Cultural safety	36	Impact of accumulated stressors	86
Aboriginal and Torres Strait Islander Peoples	41	Professional boundaries	87
Culturally responsive care	42	Adopting self-care strategies	89
Interpreters	43	Self-care assessment	90
Summary	43	Developing your self-care plan	96
<b>Section 4: Advance care planning</b>	<b>44</b>	Reflective practice	97
Family meetings	45	Reflection: Part 2	98
Your role in advance care planning	48	Mindfulness	100
Advance Care Directives	48	Self-care resources	101
When does an Advance Care Directive apply?	49	Summary	101
Summary	51	<b>Resources</b>	<b>102</b>
		<b>References</b>	<b>104</b>

# Section 1: Overview

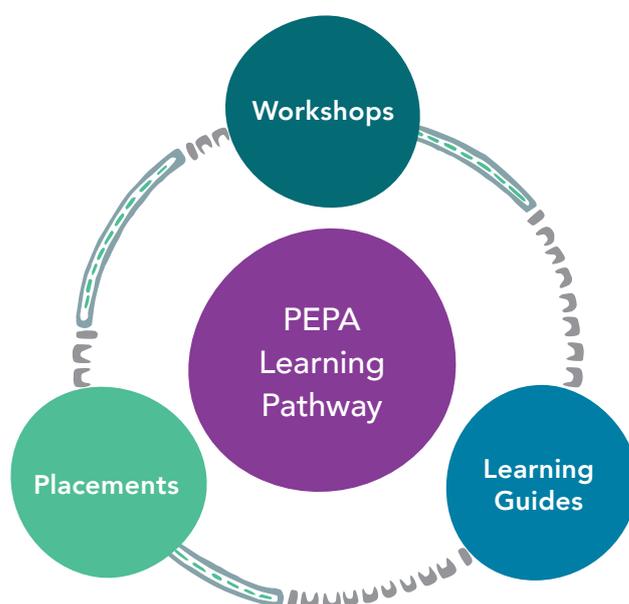
## About PEPA

The Program of Experience in the Palliative Approach (PEPA) forms part of the Palliative Care Education and Training 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 healthcare professionals to deliver a palliative care approach through their participation in either clinical placements with specialist palliative care services or interactive workshops.

## Learning pathway

These learning modules have been developed by a team of palliative care experts and reviewed by clinicians with extensive palliative care experience, including current medical practitioners. They will support GPs to build their capacity, improving networks between themselves and specialist palliative care services.

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



Workshops	Placements
<p>PEPA offers a range of workshops, including:</p> <ul style="list-style-type: none"> <li>• Palliative care – with content tailored to participants working in acute care, aged care, community and Aboriginal and Torres Strait Islander healthcare professional roles, and general practice</li> <li>• Palliative care for Aboriginal and Torres Strait Islander Peoples</li> <li>• Culture-Centred Care Workshops</li> <li>• Mentoring Workshops.</li> </ul>	<p>PEPA workforce placements entail supervised, observational placements (2–5 days) in community, inpatient and hospital-based consultancy specialist services, guided by a mentor.</p> <p>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.</p>

## 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 update
- 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 healthcare 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 the 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



### References

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

## Objectives

After completing the GP Learning Guide, you will have a better understanding of:

- The principles of palliative care
- Strategies for communicating with people and families about prognosis and goals and preferences for care
- Core skills and principles required for GPs when undertaking advance care planning and Advance Directives
- The principles for the management of common symptoms and health concerns associated with life-limiting illnesses.
- The principles for the assessment and management of pain in the palliative care recipient
- Self-care strategies to effectively manage the personal issues related to working in the palliative care field
- Resources to support medical practitioners to provide palliative care.

## Self-care

The subject of palliative care explores the experiences of people with life-limiting illnesses and personal responses to dying and death. This training may force you to face your own mortality and personal experiences with death and loss in ways that you previously have not. These issues can be very personal and may trigger emotions that you have not confronted before – or that you have suppressed. These emotions are natural, and you should talk to your colleagues, family or friends if needed. Ensure you review [Section 7: Self-care](#), to identify strategies for maintaining your own self-care when working with a person affected by a life-limiting illness.

### 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



3. How did the situation unfold?

4. What were your reactions to the situation?

5. What was the intent behind your actions?

# Section 2: Principles of Palliative Care

## What is Palliative Care?

The World Health Organization:<sup>[2]</sup>

*'Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting illnesses, through the prevention and relief of suffering by means of early identification and impeccable assessment and the treatment of pain and other problems, physical, psychosocial and spiritual'.*

**Palliative care is also applicable when caring for frail older people and people with chronic and nonmalignant conditions where death would not be a surprise in the next 12 months.**<sup>[3-6]</sup>

Palliative care is concerned with more than dying and death alone and focuses on people affected by life-limiting illness. This term incorporates the concept that people are actively living with illness – often for long periods of time – and that they are not simply dying.<sup>[7]</sup> Although death, and end-of-life care are an integral part of palliative care – living well with deteriorating health is the primary focus.<sup>[7-9]</sup>

This is a life affirming approach to medicine that concentrates on living and improving the quality of life for the individual, and their family and carers, throughout their illness.<sup>[7, 10-13]</sup> As a GP, this involves more than managing the physical aspects of illness, but also focuses on identifying and treating the spiritual, social, cultural and psychological symptoms and issues that may arise from the illness.<sup>[14]</sup>

Palliative Care Australia:<sup>[15]</sup>

*'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'.*

## Key concepts

<h3>Person and family-centred care</h3> <p>Care that places the person and their family at the centre of healthcare.</p> <p>The relationship between the person, their family and the healthcare team can be greatly strengthened by encouraging communication about things that matter so that the person knows more about their health and can be actively involved in decisions about their care.</p> <p><b>Resource Link:</b> <a href="#">Person-Centred Care</a><sup>[16]</sup></p>	<h3>Life-limiting illness</h3> <p>An active, progressive, advanced disease is known as a life-limiting illness.<sup>[17]</sup></p> <p>This term is used to describe a wide range of illnesses where it is expected that death will occur including: cancer, heart disease, respiratory disease, dementia, degenerative neurological diseases (eg, Motor neurone disease and muscular dystrophy, chronic liver disease, chronic kidney disease, and other degenerative illnesses or significant deterioration).</p> <p>Palliative care should be available to all people living with an active, progressive, advanced illness, regardless of their diagnosis.</p> <p><b>Resource Link:</b> <a href="#">CareSearch – Living with Life-limiting Illness</a><sup>[18]</sup></p>
<h3>Curative vs palliative care</h3> <p><b>Curative care</b> involves treatment that is aimed at identifying and treating the source of the illness and promoting recovery.</p> <p><b>Palliative care</b> aims to comfort. It focuses on living well with worsening health, rather than curing and recovery from illness.</p> <p>Although it can be provided alongside curative care, the main aim of palliative care is to make sure that people have the best quality of life while they are alive and that they can live as actively as possible until death, while also supporting families, friends and carers in approaching death, grief and healing.</p> <p><i>‘Our ultimate goal after all, is not a good death, but a good life to the very end’.</i><sup>[19]</sup></p>	<h3>Quality of life</h3> <p>Quality of life can be defined and experienced by each person in unique ways. A person’s perception of quality of life is influenced by how different aspects of their life (physical, emotional, social and spiritual) interact and the importance of these aspects to them.</p> <p>To understand what quality of life means for each person, we need to consider their <b>unique needs</b> and how best to support them to live with purpose and comfort.</p> <p><i>‘People turn out to have priorities in their life besides just living longer. We need to ask people what their priorities are... If we don’t ask, our care... isn’t aligned with what matters most to them – and then you get suffering’.</i><sup>[19]</sup></p> <p><b>Resource Link:</b> <a href="#">CareSearch – Quality of Life</a><sup>[20]</sup></p>



4. What is your role as a Medical Practitioner in providing palliative care?  
Think about external resources/referrals that could be utilised.

5. What care or support would you like to see added to your workplace to improve the way palliative care is provided?

## Key points underpinning the definitions of palliative care

Key point	Description	Your role as a GP
<b>Life affirming</b>	<p><i>'Palliative care affirms life and regards dying as a normal process and as a part of living. It intends neither to hasten or postpone death'.<sup>[2]</sup></i></p> <p>Palliative care is about living. It supports people to live their lives as completely and as comfortably as possible in ways that are meaningful to them by focusing on:</p> <ul style="list-style-type: none"> <li>• Living well with deteriorating health<sup>[11]</sup></li> <li>• Ensuring the best quality of life while they are alive<sup>[15, 21, 22]</sup></li> </ul>	<p>Provision of:</p> <ul style="list-style-type: none"> <li>• Symptom management</li> <li>• Resource assessment and procurement</li> <li>• Referrals to respite services</li> <li>• Links to services; in-home assistance/financial support</li> <li>• Cultural safety</li> <li>• Emotional, spiritual, and social support</li> <li>• Family-centred care including family case conferences</li> <li>• Counselling and grief support.</li> </ul>
<b>Quality of life</b>	<p>Palliative care will enhance quality of life, and may also positively influence the course of illness, by providing a support system to help patients live as actively as possible until death.<sup>[2]</sup></p>	<p>Questioning the following areas for care:</p> <ul style="list-style-type: none"> <li>• Are they comfortable and pain-free?</li> <li>• Are they able to socialise and spend time with loved-ones and people who are important to them?</li> <li>• Are they feeling they are a burden?</li> <li>• Are they as independent as possible?</li> <li>• Are they emotionally well?</li> </ul>
<b>Holistic care</b>	<p>Palliative care treats the whole person rather than just the symptoms of illness, in order to identify personal goals and preferences for care.<sup>[11, 23]</sup></p> <p>Needs include:</p> <p><b>Physical</b> – Physical symptom management</p> <p><b>Cultural</b> – Unique cultural and personal experiences should be considered</p> <p><b>Cognitive</b> – Management of psychological symptoms, financial and legal concerns regarding costs of care and advance care directives</p> <p><b>Social</b> – Social support, assessment of language and information disclosure preferences</p> <p><b>Spiritual</b> – Spiritual and existential concerns including fostering of hope.</p>	<p>Each person will have unique needs depending on their unique circumstances and needs. These needs can be met through a combination of:</p> <ul style="list-style-type: none"> <li>• Primary care</li> <li>• Appropriate referral</li> <li>• Provision of relevant information.</li> </ul>

Key point	Description	Your role as a GP
<b>Family inclusive</b>	<p>Family members who take on the role of carer can find the role very stressful and can benefit from support (with the consent of the person with the life-limiting illness).</p> <p>Family meetings are helpful to provide information, discuss the concerns and needs of both the individual and their family members and the care plan.</p>	<p>Support for the family/carers including:</p> <ul style="list-style-type: none"> <li>• Keeping the family informed</li> <li>• Explaining expectations of care and treatment</li> <li>• Education regarding care and management</li> <li>• Support with decision-making on end-of-life issues</li> <li>• Emotional and spiritual support</li> <li>• Bereavement support.</li> </ul>
<b>Symptom management</b>	<p>Many palliative conditions have complex symptoms and unrelieved issues can have a negative impact on a person's quality of life.</p> <p>Symptom management needs to occur from multiple perspectives:</p> <ul style="list-style-type: none"> <li>• The illness itself</li> <li>• Illness modifying-treatment</li> <li>• Comorbidities.</li> </ul>	<p>Impeccable management of symptoms is achieved through:<sup>[24]</sup></p> <p><b>Assessment</b></p> <ul style="list-style-type: none"> <li>• Attentional to detail</li> <li>• Assessment of individual needs</li> <li>• Likely causes and effects of symptoms</li> </ul> <p><b>Planning</b></p> <ul style="list-style-type: none"> <li>• Individualised treatment considering, availability of options, weighing the benefits against burdens, wishes of the individual/family</li> </ul> <p><b>Implementation</b></p> <ul style="list-style-type: none"> <li>• Explanation regarding likely symptoms and causes</li> <li>• Discussion on symptom management options and facilitation of multidisciplinary team</li> </ul> <p><b>Evaluation</b></p> <ul style="list-style-type: none"> <li>• Monitoring progress</li> <li>• Rapid escalation of extreme situations and potential changes to management plans.</li> </ul>

Key point	Description	Your role as a GP
<b>Starts early</b>	Palliative care is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications. <sup>[2]</sup>	<p>Early palliative care:</p> <ul style="list-style-type: none"> <li>• Emphasises active, comfort-focussed care and a positive approach to reduce suffering<sup>[11, 25, 26]</sup></li> <li>• Improves quality of life<sup>[2, 7]</sup></li> <li>• Helps to avoid burdensome interventions of low benefit<sup>[11]</sup></li> <li>• Reduce hospital admissions<sup>[27, 28]</sup></li> </ul>
<b>Team approach</b>	<p>Palliative care uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated.<sup>[2]</sup></p> <p>Primary care will often be provided by the GP, who coordinates care and referrals between the relevant health professionals, including specialist palliative care services.</p>	<p>Referrals may be made to range of healthcare professionals including:</p> <ul style="list-style-type: none"> <li>• Doctors</li> <li>• Nurses</li> <li>• Social workers</li> <li>• Physiotherapists</li> <li>• Occupational and speech therapists</li> <li>• Psychologists</li> <li>• Trained volunteers</li> <li>• Family members</li> <li>• Carers<sup>[29]</sup></li> </ul>

**Important note:**

All healthcare professionals who provide care to people living with a life-limiting illness, their families and carers should have minimum core competencies in the provision of palliative care.<sup>[7]</sup>

[Palliative Care Australia \(PCA\)](#) is the national peak body for palliative care and represents all those who work towards high quality palliative care for all Australians. Within the site you can also search your region to find available services.



## Learning Activity:

Improving the quality of life of individuals and their families is a central goal of palliative care. The World Health Organization states that palliative care '*will enhance quality of life, and may also positively influence the course of illness*'

1. How do you define quality of life?
2. How do you ensure you fully understand your patient's perspective on quality of life and what it means specifically to them?
3. Why is it important to understand a person's perception of quality of life and how it changes over time?

## National Palliative Care Standards

The National Palliative Care Standards build on the definition of palliative care in Australia and outline the standards and elements of quality care for all Australians.<sup>[7]</sup> They provide an important framework for all healthcare professionals 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.<sup>[30, 31]</sup>

<p><b>Care Standards 1–6</b> describe the systems and enablers necessary to deliver high quality care.</p>	<p><b>Standard 1</b> <b>ASSESSMENT OF NEEDS</b></p>	Initial and ongoing assessment incorporates the person’s physical, psychological, cultural, social and spiritual experiences and needs.
	<p><b>Standard 2</b> <b>DEVELOPING THE CARE PLAN</b></p>	The person, their family and carers work in partnership with the team to communicate, plan, set goals of care and support informed decisions about the care plan.
	<p><b>Standard 3</b> <b>CARING FOR CARERS</b></p>	The person’s family and carers needs are assessed and directly inform provision of appropriate support and guidance about their role.
	<p><b>Standard 4</b> <b>PROVIDING CARE</b></p>	The provision of care is based on the assessed needs of the person, informed by evidence and is consistent with the values, goals and preferences of the person as documented in their care plan.
	<p><b>Standard 5</b> <b>TRANSITIONS WITHIN AND BETWEEN SERVICES</b></p>	Care is integrated across the person’s experience to ensure seamless transitions within and between services.
	<p><b>Standard 6</b> <b>GRIEF SUPPORT</b></p>	Families and carers have access to bereavement support services and are provided with information about loss and grief.
<p><b>Governance Standards 7 to 9</b> describe expectations regarding quality management, quality improvement and benchmarking.</p>	<p><b>Standard 7</b> <b>SERVICE CULTURE</b></p>	The service has a philosophy, values, culture, structure, and environment that supports the delivery of person-centred palliative care and end-of-life care.
	<p><b>Standard 8</b> <b>QUALITY IMPROVEMENT</b></p>	Services are engaged in quality improvement and research to improve service provision and development.
	<p><b>Standard 9</b> <b>STAFF QUALIFICATIONS AND TRAINING</b></p>	Staff and volunteers are appropriately qualified, are engaged in continuing professional development and are supported in their roles.

The National Palliative Care Standards (5<sup>th</sup> Edition) are available from the [Palliative Care website](#). They can also be downloaded as a [PDF document](#).



## Learning Activity:

Review the National Palliative Care Standards 1–6.

Reflect on the specific strategies that you would apply in your practice to meet one of the standards when caring for people affected by life-limiting illness.

Maintenance of dignity is a core value in palliative care.

Within your scope of practice as a GP, what are some strategies that you would undertake to ensure a person's dignity is maintained?

Palliative care is provided to people who, regardless of age, have a life-limiting illness.

*It is not dependent on a specific medical diagnosis, but on a person's needs.<sup>[2, 8]</sup>*

## Illness trajectories

Three typical illness trajectories have been described for people with progressive chronic illness: [32–35]

**Cancer trajectory** – A short period of rapid decline

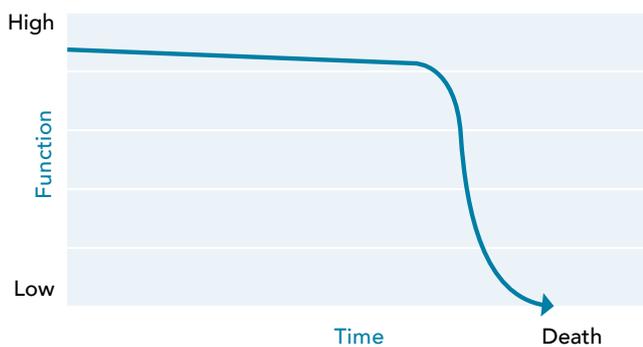
**Organ Failure trajectory** – Long-term (chronic) illness with intermittent (acute) episodes of severe illness

**The frail elderly/dementia trajectory** – Prolonged decline.



### Learning Activity:

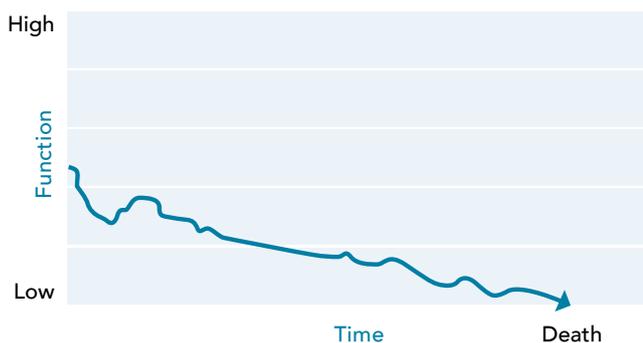
Link the correct decline trajectory for the illness descriptions listed below:



**Trajectory 2:** long term limitations with intermittent serious episodes



**Trajectory 3:** prolonged dwindling

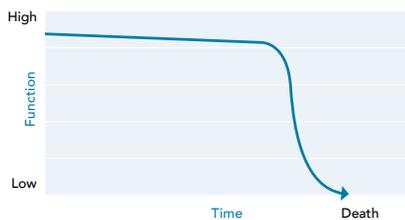


**Trajectory 1:** short period of evident decline, typically cancer



## Learning Activity:

Review the following three case studies and identify the trajectory that best describes their illness.



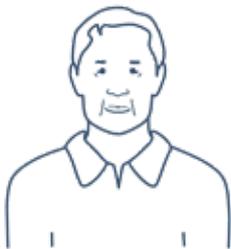
Short period of evident decline



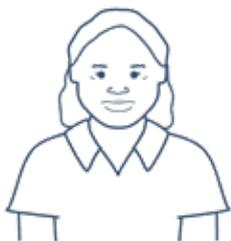
Long term limitations with intermittent serious episodes



Prolonged dwindling



An 85-year-old man with COPD, osteoarthritis, early dementia. He is living alone, but his family is becoming increasingly concerned for his safety. He is very forgetful, and his mobility is poor. He is a high falls risk and his decline is likely to be slow, making it difficult to predict the dying phase.



A 45-year-old woman with breast cancer. Initial diagnosis was ten years ago. Diagnosed with secondary breast cancer four years ago and continues to receive a range of anti-cancer treatments. Recently diagnosed with new metastases to the bone and liver. She is experiencing weight loss, loss of appetite and pain. She is increasingly weak and tired. Her condition has been stable for some time but could deteriorate rapidly as the disease progresses.



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

Palliative care should be based on need – rather than on prognosis or age. Individual needs may vary – and different people with the same illness can have different needs, based on their individual circumstances. Palliative care referral should include all people who would benefit from palliative care services – including people with chronic, malignant or non-malignant illness, even if the trajectory is ambiguous or unknown.

## Recognising death and the ‘Surprise Question’

*‘Would I be surprised if this patient died in the next 12 months?’<sup>[36]</sup>*

The ‘Surprise Question’ has been used to identify individuals at high risk of death who might benefit from palliative care services – or who might be approaching end of life.<sup>[36]</sup> It was designed as a way of predicting needs rather than exact prognostication and is more concerned about meeting those needs than providing defined timescales for when end of life will occur.<sup>[37, 38]</sup>

Identifying when people are entering the end of life phase is important if they are to have what is termed ‘a good death’. There are twelve principles of a good death:<sup>[39]</sup>

1. To have an idea of when death is coming and what can be expected
2. To be able to retain reasonable control of what happens
3. To be afforded dignity and privacy

4. To have control of pain and other symptoms
5. To have reasonable choice and control over where death occurs
6. To have access to necessary information and expertise
7. To have access to any spiritual or emotional support required
8. To have access to ‘hospice style’ quality care in any location
9. To have control over who is present and who shares the end
10. To be able to issue advance directives to ensure one’s wishes are respected
11. To have time to say ‘goodbye’ and to arrange important things
12. To be able to leave when it is time, and not to have life prolonged pointlessly.

## The SPICT™ Tool

The SPICT™ Tool is a guide to help identify deterioration in condition.<sup>[40]</sup>

Health can deteriorate at different rates depending on many factors such as age, weight and other long-term illnesses that the person may have. The SPICT™ Tool looks at health status rather than a prognosis giving an individualised assessment of deterioration.<sup>[40]</sup>

SPICT™ encourages:

- Assessment of people’s needs
- Identification of health issues
- Help strategies.

Review the [SPICT website](#) for more details.

## Assessment Tools

A range of assessment tools are available to assist you in assessing initial and ongoing needs and help to determine support and care management needs throughout the person's illness. These tools can help to elicit an understanding of the person's preferences and priorities for care planning purposes.<sup>[30]</sup> Needs assessments also help to determine the level of palliative care that an individual requires at the current point in their illness trajectory.<sup>[41, 42]</sup>

### Needs Assessment Tool for Progressive Disease – Cancer

From Centre for Health Research and Psycho-oncology

<https://www.caresearch.com.au/caresearch/Portals/0/Documents/PROFESSIONAL-GROUPS/General-Practitioners/NeedsAssessmentTool-ProgressiveDiseaseCHeRP.pdf>

### The PEPSICOLA aide memoire

A palliative care monthly review checklist from Gold Standards Framework website

### The Australia-modified Karnofsky Performance Scale

For assessing performance state and prognosis in advanced illnesses

<https://www.uow.edu.au/ahsri/pcoc/aged-care/assessment-forms/>

### The ECOG score

For assessing performance state and prognosis in advanced cancer

<https://ecog-acrin.org/resources/ecog-performance-status>

### Pain – Numeric Rating Scale

A simple validated pain assessment tool. From the [Cancer Pain Management Wiki](#)

### Abbey Pain scale

To assess pain in a person who is cognitively impaired or unable to communicate verbally

[https://www.apsoc.org.au/PDF/Publications/Abbey\\_Pain\\_Scale.pdf](https://www.apsoc.org.au/PDF/Publications/Abbey_Pain_Scale.pdf)

### Symptom Assessment Scale (SAS)

The standard symptom assessment tool used in Australian palliative care services. Assesses seven core symptoms

<https://www.uow.edu.au/ahsri/pcoc/aged-care/assessment-forms/>



## Learning Activity:

Why is it important to consider peoples preferences when identifying needs at the end of life?

Do you have any people with life-limiting conditions within your practice for whom you would answer 'YES' to the Surprise Question?

*'Would I be surprised if this patient died in the next 12 months?'*

What could be done to help improve their quality of life?

What palliative care services would be most beneficial to them?

If you answered 'NO' to the Surprise Question, what are some of the physical, psychological and social changes that could change your answer for this person?



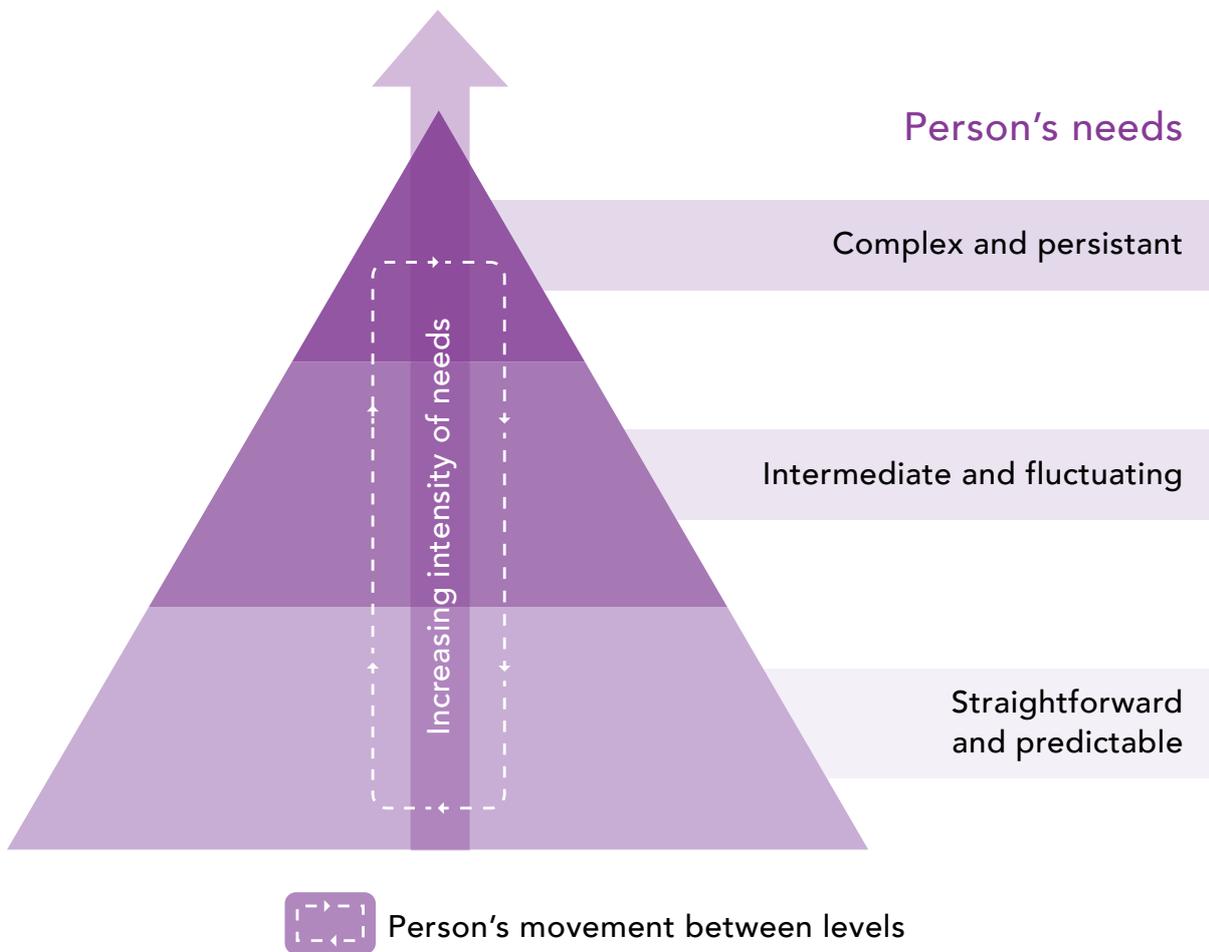
**Learning Activity:** *continue*

How would you discuss imminent end of life with a person?

## What level of support does the person need?

There are many factors that determine the type of palliative care a person needs – and the type of services that they require may change throughout their illness. Palliative Care Australia has defined three broad groups based on the complexity of individual needs for palliative care:

**Conceptual model of level of need for palliative care among people living with a life-limiting illness.**



(Source: Palliative Care Australia – Used with Permission. <sup>[8]</sup>)

Remember! A key factor influencing the type of service to provide people with life-limiting illnesses is the intensity of their needs. <sup>[7, 8, 43]</sup>

The National Standards identify the following levels of palliative care available to people with a life-limiting illness:

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

A critically important feature are the arrangements for networking, referral and palliative care consultative support services that should operate:<sup>[8]</sup>

- Between the three levels of palliative care services
- Between palliative care services and health and aged care services provided for people living with a life-limiting illness.

The objective of a networked approach to the provision of palliative care services is to ensure that the right care is provided to the right people, in the right setting, with the right mix of healthcare professionals.<sup>[8]</sup> Networking requires that there are effective referral arrangements and consultative support services between generalist providers of palliative care (Level 1) and specialist palliative care services (Levels 2 and 3).

## Summary

Core skills for GPs when caring for people requiring palliative care include:<sup>[8, 44]</sup>

- Early recognition of a person with acute or chronic illness who may be approaching end of life
- Identifying those who can benefit from a palliative approach to care
- Consideration and recording of the person's wishes
- Communicating with the individual and their family/carers about advance care planning
- Most people will die of nonmalignant illness with uncertain course
- Palliative care should be based on need not prognosis or age, including any chronic or malignant illness, even if the trajectory is ambiguous or unknown
- Planning for inevitable deterioration and crises at the end of life
- Symptom support
- Practical, emotional, and spiritual support
- Accessing resources and working with specialist palliative care teams

As a GP, providing and coordinating palliative care, it is your responsibility to support the person's needs throughout their illness. This requires an understanding of physical, social, psychological, and spiritual needs. People, carers and families who have these needs addressed in palliative care are documented to have positive end-of-life outcomes.<sup>[37, 45]</sup>

# Section 3: Communicating with people affected by life-limiting illnesses

Talking about dying and death are an essential part of providing support for people affected by life-limiting illness.<sup>[1, 2]</sup> Open conversations about dying and death, symptoms and clinical management can provide considerable relief to people affected by life-limiting illness.<sup>[1, 3-5]</sup> However, these conversations can be difficult for people to master.<sup>[3]</sup> Knowledge of appropriate communication techniques for delivering bad news can help to reduce the stress associated with these difficult conversations.<sup>[3, 4, 6-11]</sup>

## Acknowledging thoughts & feelings

This training explores the experiences of people with life-limiting illnesses and personal responses to dying and death. This training may force you to face your own mortality and personal experiences with death and loss in ways that you previously have not. These issues can be very personal and may trigger emotions that you have not confronted before – or that you have suppressed. These emotions are natural, and you should talk to your colleagues, family or friends if needed. You should also complete the final module in this suite – **Self-care** – to identify strategies for maintaining your own self-care when working with a person affected by a life-limiting illness.

## Talking about dying and death

Before we begin, what do you think of when you hear the term 'bad news'?

How would you define this term?

Information that drastically alters the world of an individual is termed bad news. Conveying bad news requires skilled communication techniques.<sup>[46]</sup> People generally expect their doctor to raise the subject of dying and death in a language that they can understand, which explains:<sup>[47-49]</sup>

- What is happening
- What might happen next
- How it might happen
- When it might happen.

Talking about dying and death, and communicating bad news or prognostic information, are a necessary part of caring for people affected by life-limiting illness.<sup>[47, 50, 51]</sup> These conversations can be extremely emotional and need to be handled sensitively.<sup>[52]</sup> A properly structured conversation can have a positive therapeutic effect for both the person with a life-limiting illness and their family,<sup>[46, 53]</sup> and can ultimately result in a 'good death'.<sup>[39, 54]</sup>

The SPIKES and PREPARED frameworks have been designed to provide a structured way of breaking bad news.<sup>[48, 55, 56]</sup>

## The PREPARED communication framework in clinical practice

<b>P</b>	<b>Prepare for the discussion:</b> <ul style="list-style-type: none"><li>• Ensure facts about the person's clinical circumstances are correct</li><li>• Ensure privacy and uninterrupted time for the discussion</li><li>• Mentally prepare for the conversation</li><li>• Negotiate who should be present during the discussion eg, <i>"Is there anyone else you would like to be here with you while we talk?"</i></li></ul>
<b>R</b>	<b>Relate to the person:</b> <ul style="list-style-type: none"><li>• Develop a rapport</li><li>• Show empathy, care and compassion during the entire conversation eg, <i>"This has been a tough time for you and your family..."</i></li><li>• Broach the topic in a culturally appropriate and sensitive manner</li><li>• Make eye contact (if culturally appropriate)</li><li>• Sit close to the person (if culturally appropriate)</li><li>• Use culturally appropriate body language</li><li>• Allow silence and time for them to express feelings.</li></ul>
<b>E</b>	<b>Elicit personal preferences:</b> <ul style="list-style-type: none"><li>• Identify the reason for this conversation and establish the person's expectations</li><li>• Clarify their understanding of the situation and establish how much detail they want to know eg, <i>"Some people like to know everything that is going on with them and what may happen in the future, others prefer not to know too many details. What do you prefer?"</i></li><li>• Consider cultural and contextual factors that can influence information preferences.</li></ul>
<b>P</b>	<b>Provide information that is tailored to the personal needs of all parties:</b> <ul style="list-style-type: none"><li>• Offer to discuss what to expect, in a sensitive manner, giving the person the option not to discuss it</li><li>• Provide information in small chunks at the person's pace</li><li>• Use clear, jargon-free, understandable language</li><li>• Engage in active listening ie, attend to the person completely, reflecting and repeating back what you think they have said eg, <i>"If I've heard you right, you seem to be saying..."</i></li><li>• Explain the uncertainty, limitations and unreliability of prognostic and end-of-life information – <i>"I know that people often expect healthcare professionals to know what is going to happen, but in truth we can usually only take educated guesses and can often be quite wrong about what the future holds, and especially how long it is. What we can be sure about is ... and what we don't know for sure is ..."</i></li><li>• Avoid being too exact with time frames unless in the last few days</li><li>• Consider the caregiver's distinct information needs, which can require a separate meeting (providing consent is given by the person with a life-limiting illness, if mentally competent)</li><li>• Ensure consistency of information and approach</li><li>• Use the words 'death' and 'dying' where appropriate.</li></ul>

<b>A</b>	<p><b>Acknowledge emotions and concerns:</b></p> <ul style="list-style-type: none"> <li>• Explore and acknowledge fears, concerns and emotional reaction eg, <i>“What worries you most about...?”</i> or <i>“What is your biggest concern at the moment?”</i></li> <li>• Be willing to initiate and engage in conversations about what can happen in the future and during the dying process eg, <i>“Do you have any questions or other concerns?”</i></li> <li>• Respond to distress where applicable.</li> </ul>
<b>R</b>	<p><b>Realistic hope:</b></p> <ul style="list-style-type: none"> <li>• Be honest without being blunt or giving more detailed information than desired</li> <li>• Do not provide misleading or false information that artificially influences hope</li> <li>• Reassure the person that support, treatment and resources are available to control pain and other symptoms but avoid premature reassurance</li> <li>• Explore and facilitate realistic goals, wishes and ways of coping on a day-to-day basis, where appropriate.</li> <li>• <i>“I (or our team or whoever applicable) will do whatever (I/we) can to assist you in whatever lies ahead for you.”</i></li> </ul>
<b>E</b>	<p><b>Encourage questions:</b></p> <ul style="list-style-type: none"> <li>• Encourage questions and information clarification</li> <li>• Be prepared to repeat explanations</li> <li>• Check understanding of what has been discussed and whether the information provided meets personal needs eg, <i>“We’ve spoken about an awful lot just now. It might be useful to summarise what we’ve said ... Is there anything from what I’ve said that you don’t understand or want me to go over again?”</i> Leave the door open for topics to be discussed again in the future.</li> </ul>
<b>D</b>	<p><b>Document:</b></p> <ul style="list-style-type: none"> <li>• Write a summary in the medical record of what has been discussed</li> <li>• Speak or write to other key healthcare providers involved in the person’s care.</li> </ul>

Source: Clayton, J., Hancock, K., Butow, P., Tattersall, M. & Currow, D. (2007). Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. MJA, 186 (12), S77-S108. Retrieved September 15, 2010, from [http://www.mja.com.au/public/issues/186\\_12\\_180607/cla11246\\_fm.html](http://www.mja.com.au/public/issues/186_12_180607/cla11246_fm.html).<sup>[3]</sup>

Reproduced with permission<sup>[57]</sup>

## The SPIKES communication framework

<b>S</b>	<b>Setting up</b> the conversation
<b>P</b>	Assessing the person's <b>perception</b>
<b>I</b>	Obtaining the person's <b>invitation</b>
<b>K</b>	Providing <b>knowledge</b> and information to the person
<b>E</b>	Addressing the person's <b>emotions</b> with empathic responses
<b>S</b>	<b>Strategy</b> and <b>Summary</b>

Review the '[Clinical Yarning Framework](#)' to understand frameworks for discussing dying and death with Aboriginal and Torres Strait Islander Peoples.



### Learning Activity:

What are some fears that a person with a life-limiting potential diagnosis may face?

What are your fears discussing these concepts with them?

## The challenges faced by people diagnosed with life-limiting illnesses

Individuals will react uniquely to a diagnosis or the prospect of a life-limiting diagnosis.

Responses to these challenges can come from:

- Fear of dying and death
- Pain, and the fear of pain
- Uncertainty about the future
- Loss of meaning and purpose
- Loss of spiritual direction or beliefs
- Challenges to beliefs
- Changing relationships and roles
- A sense of unfairness
- Feelings of isolation or loneliness
- Feelings of loss of control or worth
- Depression
- Loss of the sense of dignity
- Fears of being a burden or a dependent
- Fears of suffering
- Concerns about appearance and body image.

When a person is diagnosed with a life-limiting illness, life often changes – for the person and their family – into an existence marked by the symptoms and outcomes of their illness.<sup>[58]</sup> They are forced to develop a new way of living and seek further sources of control and support.<sup>[59]</sup>

An individual's coping ability can be dependent on the information communicated to them by their primary healthcare provider.<sup>[51]</sup> They need to feel safe and comfortable with their GP, to maintain trust in healthcare and possible symptom management – and to maintain hope and not feel abandoned. Providing people with the chance to express how they feel about their losses and concerns can often help them cope.

Consider the following ongoing communication pointers to add to your communication toolkit:

- What is the hardest thing about this for you and your family?
- What are you most frightened of?
- How are you coping?
- Do you feel like you are on top of this – or is it on top of you?
- What has helped you in the past with challenges?
- You are doing so well – I know that it does not feel like that, however...
- I have so much respect for...
- This may be the hardest thing you ever have to do in your life.

Communication will continue throughout the illness and is not a single event – just as the illness is not a single event.

Issues that may also need to be discussed include:

- People often become distressed and sad due to the compounding losses that they suffer due to their illness
- They can become concerned about their appearance and body image and about changing relationships with those close to them, including sexual relationships
- Personal issues, such as spirituality, intimacy, and sexuality, have not always been easy to discuss yet can be very important to people nearing the end of their life.

Ensure that simple (non-medical jargon) language is used, and open communication is encouraged to promote a trusting relationship where individuals feel they can ask questions and ask you to repeat information that they haven't properly understood.

The individual and their family may have cultural beliefs and preferences about dying and death that may influence how these issues are discussed. When caring for people from different cultural backgrounds to your own, you should be aware of the beliefs and preferences that are important to each person and their family.<sup>[47]</sup> This forms the basis of culturally appropriate care and cultural safety.

## Spirituality

Spirituality and religious beliefs are not necessarily the same. It is important however, to have open conversations about spirituality including:

- Spiritual needs
- Spiritual struggles
- Distress
- Pain
- Conflicts
- Resources of strength and belief
- Practices that impact on the health of the individual.

Providing people affected by life-limiting illness the time to reflect on the meaning and purpose of life and discussing their spiritual distress are important aspects of palliative care.

All healthcare professionals can be involved in spiritual conversations, but need to recognise their own limitations and refer to an accredited religious or spiritual practitioner when appropriate.



## Learning Activity:

Identify three statements that can instigate a sensitive, spirituality-based conversation with a person diagnosed with a life-limiting illness.

- 1.
- 2.
- 3.

## Developing spiritual support strategies

### Settings

- Identify places where the person feels safe.
- Ask the person what reminds them of this place. This might be a memory, a photograph, or a religious symbol.

### Stories

- Allow time for the person to share the story of their life.
- Listen to their story and ask questions to explore and expand this experience.

### Systems of belief

- Ask the family/person to explain their rituals and beliefs – it is important to support these beliefs, despite your own belief system.
- Arrange a visit from an accredited religious practitioner, if requested.
- Prepare for end of life.
- Document any specific rituals.



## Learning Activity:

Reflect on strategies that you could use in your practice to:

Develop rapport:

Acknowledge concerns:

Foster realistic hope:

Elicit preferences:

## Communicating with children

Parents diagnosed with life-limiting illnesses require support to communicate age-appropriate information with their children.<sup>[60]</sup>

Common concerns include:<sup>[61, 62]</sup>

- The impact of the illness on the child's routine
- Emotional wellbeing
- Understanding of the parent's illness.
- Often a parent's biggest worry is what to say if the child asks if the parent is dying.

Helping parents feel prepared to talk with children about their illness and possible death at any stage of illness has the potential to alleviate distress in both parents and children.<sup>[61]</sup>

Children require communication strategies appropriate to their level of understanding and readiness.

### Children up to 6 years

- Younger children are egocentric
- Reinforce that they are not being blamed for the illness
- Help them to understand that their behaviour will have no influence on the outcome. Don't tell them to 'be good' so that the parent can be well
- Reassure them that they will always be safe and cared for
- Explore their understanding of the illness and/or death
- Dispel guilt by correcting misconceptions and reassuring the child that nothing they did caused the illness or death

- Provide concrete descriptions of death:
  - his body does not work anymore
  - he can't see, hear, or feel anything
  - his heart stopped pumping and he stopped breathing.
- Be patient in repeating that the deceased will not come back.

### Children between 6–12 years

- Children in this age group can be concerned that they will not be accepted by their friends and peers and for some, being different for any reason can be distressing
- Children in this age group need:
  - Relevant information aimed specifically to their level of understanding
  - To maintain relationships with their peers
  - To continue to participate in affirming activities including sport, clubs, or social activities
  - Ongoing opportunities to talk about comments from their peers and how these comments make them feel.
- Provide a simple explanation of the diagnosis and treatment options
- Dispel misconceptions regarding causes of illness or death, as well as contagion
- Provide clear and accurate information about causes of death
- Help put guilt and other concerns in perspective by thinking together about the entire relationship rather than only the recent past.

## Children 12 years and up

- Adolescents are particularly vulnerable when a parent is seriously ill. Background tension is likely to be exacerbated
- Acknowledge and discuss changed family roles
- Maintain social relationships
- Access to specific and relevant information about dying and death
- Facilitate opportunities to talk openly about the illness with their parents.<sup>[32]</sup>
- Provide Information about the illness and treatment options
- Dispel misconceptions regarding causes of illness or death, as well as contagion
- Provide clear and accurate information about causes of death.

Remember that adolescents may seek information from other sources, such as the internet. Encourage them to check the accuracy of this information with their parents.

Review the PCC4U '[Age Appropriate Communication](#)' resource including ideas on conversation starters for relevant ages.

## Memory making

Memory-making is also an important activity for children at all ages. It also helps the person dying to feel that they are leaving a legacy.



### Learning Activity:

Identify three options for memory making activities you could suggest to parents of the following age range:

Up to 6 years:

6–12 years:

12 years and over:

[Cancer Council of Australia](#)

Further information and resources to support communication with children about cancer has been developed by Cancer Council Australia.

## Cultural safety

To provide palliative care and support that is culturally appropriate, communication practices need to take into consideration the cultural and diversity needs of the individual.

Culturally appropriate palliative care reflects an understanding of a person's background and the degree to which that background influences treatment decisions and communication practices.

Beliefs and practices about dying and death should be identified and respected, including:<sup>[47]</sup>

- Family participation
- Gender roles
- Communication rules guiding decision-making and the breaking of bad news
- Rituals—and the importance of these to the individual.



### Learning Activity:

Identify five ways that a person's diversity may be reflected.

- 1.
- 2.
- 3.
- 4.
- 5.



## Learning Activity:

Link the correct numerical answer to the statement:

How many languages (including indigenous) are spoken in Australia	25%
Percentage of population born overseas	3.3%
How many ancestories do Australians identify with?	Over 400
Percentage of the population identifying as being of Aboriginal or Torres Strait Island origin	Over 270

Correct answers:

- More than 400 languages (including indigenous languages) are spoken
- People identify with more than 270 ancestories
- One in four people are born overseas (25%)
- 3.3% of the population identifies as being of Aboriginal or Torres Strait Islander origin.<sup>[63]</sup>

In the context of dying and death, culture may influence:<sup>[64–66]</sup>

- Language and communication styles
- Beliefs about ill-health
- Family involvement in care
- Expression of pain and other symptoms
- Meaning of life, death, dying and grief
- Practices associated with care immediately after-death
- Beliefs about what happens to the body after-death
- Practices relating to complementary and alternative therapies.



## Reflection:

How does your own cultural background influence the type of care and support you provide?

A culturally safe approach to care requires healthcare professionals to: <sup>[67-70]</sup>

- Accept that everyone has their own unique culture
- Understand that individual views of the world, health, illness, dying, and death are influenced by culture and the power dynamics that this creates in and between cultures
- Engage with all people as individuals in a culturally safe and respectful way
- Foster open, honest, and compassionate professional relationships
- Be aware and mindful of their personal attitudes and values towards gender, race, religion, and sexuality
- Be self-aware and reflect on their practice – particularly in relation to how their own cultural background influences their decisions and behaviour (and how it can differ from the people that they are supporting)

- Be aware of the different communication styles and norms used by diverse cultures. For example, within some cultures holding another person's eye contact is disrespectful, while in others it is disrespectful not to
- Understand that all members of a cultural group do not have homogenous health needs, lifestyles, or beliefs about care, dying and death
- Act respectfully to empower the person
- Promote shared respect, meaning, knowledge and experiences.

**Unsafe cultural practice occurs when actions diminish, demean, or disempower the cultural identity of an individual.**

## Steps to cultural safety

### Step 3:

Cultural safety skill development of appropriate behaviours, attitudes, and communication strategies that reduce the gap of inequities in patient outcomes.

### Step 2:

Cultural appraisal or assessment to identify cultural domains of difference that need to be considered in the plan of person-family centred care.

### Step 1:

Cultural consciousness or awareness of the constructs of your own culture and recognition of unique and similar qualities of other cultural groups.

## PEPA provides workshops on Culturally Responsive Care:

Culture-Centred Care of People with Life-Limiting Conditions from Indigenous Australians' Perspectives

Culture-Centred Care of People with Life-Limiting Conditions from a Multicultural Perspective.

View the PEPA website to learn more:

<https://pepaeducation.com/workshops/culture-centred-care-workshops/>



## Resource Links:

Review the following links to find out more about cultural safety related to general practice.

[Australian Medical Association \(AMA\)](#)  
Equity Inclusion and Diversity

[RACGP Standards for general practices](#)  
Respectful and culturally appropriate care

Cultural safety means that it may be necessary to involve interpreters, cultural liaison workers or advocates from the person's community to assist and ensure that the information that you are providing is understood in a way that is meaningful to the individual. Many cultural groups place importance on the involvement of family and community members in decision-making, and this needs to be taken into account during symptom and illness management – and when breaking the news about the person's illness.<sup>[47]</sup>

[VITALtalk](#)

Provide strategies for holding difficult conversations

## Aboriginal and Torres Strait Islander Peoples

Aboriginal and Torres Strait Islander peoples make up approximately 3.3% of Australia's population.<sup>[63]</sup> Of this population 91% identify as of Aboriginal origin, 5% Torres Strait Island origin and 4% identify as both Aboriginal and Torres Strait Island origin.<sup>[63]</sup>

Recent data (2018) highlights that the leading causes of death for Aboriginal and Torres Strait Islander people compared to the non-Indigenous population.<sup>[71]</sup> This can have implications for the types of palliative care that is required amongst this community – and the treatments that are required.

Leading causes of death, by Indigenous status, 2014–2018.<sup>[71]</sup>

Rank	Indigenous	Non-indigenous
1	Coronary heart disease	Coronary heart disease
2	Diabetes	Dementia including Alzheimer's disease
3	Lung cancer	Cerebrovascular disease
4	Chronic obstructive pulmonary disease	Lung cancer
5	Suicide	Chronic obstructive pulmonary disease

	Cancer		Injuries
	Cardiovascular		Neurological
	Endocrine		Respiratory

Factors that significantly contributed to health and wellness status include:<sup>[72]</sup>

- Lack of exercise
- High alcohol consumption
- Biomedical factors (including high blood pressure and cholesterol and renal disease)
- Psychological factors.

These factors are also compounded by the systematic barriers experienced by Aboriginal and Torres Strait Islander communities in Australia, including:

- Discrimination and racism from healthcare professionals and health-based services – resulting in a general reluctance to use healthcare services<sup>[73–75]</sup>
- The dismissal of natural or cultural medicine by Western healthcare providers – resulting in an ambivalence towards Western medicine by Aboriginal and Torres Strait Islander people<sup>[76, 77]</sup>
- The association of illness and disease with spiritual factors such as curses, a form of punishment for past deeds and the notion of being sung ('placing bad magic on someone'), leading to a belief of 'wrong-doing' and fatalism.<sup>[77]</sup>

## Culturally responsive care

A culturally responsive approach is central to care for Aboriginal and Torres Strait Islander communities. This person-centred approach to care recognises that:<sup>[78, 79]</sup>

- Aboriginal and Torres Strait Islander peoples' view of 'health' involves not only the physical wellbeing of an individual, but the social, emotional, and cultural wellbeing of the whole community and includes a cyclical concept of life-death-life
- The place of dying and death is culturally and spiritually significant for many Aboriginal and Torres Strait Islander peoples. The need to 'return to Country' is often very important at the end of life – which can involve a physical return, or other elements from Country to symbolise a 'return to Country' where a physical return is not practical or possible
- The heterogeneity of Aboriginal and Torres Strait Islander culture means models of care need to be flexible to address the specific needs of different cultural groups
- Contemporary models of palliative and end-of-life care in Australia which are dominated by western traditions and the biomedical paradigm need to integrate Aboriginal and Torres Strait Islander traditions, values and cultural practice relating to palliation and end-of-life transitions
- Community-based local approaches to end-of-life care should be encouraged
- Aboriginal and Torres Strait Islander healthcare professionals should have a significant role in the delivery of quality end-of-life care
- Aboriginal and Torres Strait Islander communities have a common heritage of loss and trauma. The impact of loss and grief for Aboriginal and Torres Strait Islander people is often compounded by earlier experiences.

Aboriginal and Torres Strait Islander people, particularly those in rural and remote Australia, may find it helpful to have interpreters or cultural liaison workers present during important clinical consultations. Working in partnership with local Aboriginal or Torres Strait Islander community organisations may also facilitate cross-cultural care.<sup>[47]</sup>

There is considerable diversity among Aboriginal and Torres Strait Islander communities, and local practices and understanding may vary; it is important to engage with local Aboriginal or Torres Strait Islander health workers when providing care for members of these communities.<sup>[47]</sup>



### Learning Activity:

How can community-based local approaches to palliative care by Aboriginal and Torres Strait Islander healthcare professionals promote culturally safe palliative care?

## Interpreters

Interpreters should always be used to communicate with palliative care recipients who do not speak English as a first language. Similarly, people who are hard of hearing may also require an interpreter.

Family members should never be used to translate important information because:

- They are not neutral parties and have an emotional attachment to the person
- They are not professional interpreters, their ability to translate medical information is unknown
- It may not be appropriate for a particular family member to hear the information, or they may filter information.<sup>[47]</sup>

## Summary

Communicating bad news, or prognostic information is necessary when caring for palliative care recipients.

Frameworks to assist communication include:

- PREPARED
- SPIKES.

Safe communication also requires:

- Cultural awareness
- Cultural respect
- Integrations of cultural liaison representatives.

## Section 4: Advance care planning

When a person's values, choices and care preferences are discussed openly – and while they are still competent to make the decisions for themselves – then it is more likely that their wishes are respected at a time when they can no longer voice these decisions.<sup>[80]</sup> This can lead to a better end-of-life experience for everyone involved – the person, their family and carers and the healthcare team.<sup>[11, 37, 81]</sup>

End-of-life goal setting is a key palliative care skill. Discussions to establish goals of care ideally begin soon after diagnosis.<sup>[80]</sup> As a GP, you will work with the person to develop goals of care that target individual needs, values, and preferences. These goals should be medically appropriate to the person's prognosis and current stage of their illness trajectory – while also being realistic about what can be achieved.<sup>[82]</sup>



### Learning Activity:

How can you assess a person's preference for care?

What are some of the reasons that individuals with life-limiting illnesses may continue to have the goal of cure?



## Learning Activity *continued*

How would you respond to the following situations?

1. The person's goal may not be consistent with their prognosis

2. The care goals conflict with the goals and wishes of the family.

## Family meetings

Family meetings are opportunities for the healthcare team to discuss and understand the needs and wishes of both the individual and the family.

Discussions may involve:<sup>[83, 84]</sup>

- Establishing, clarifying, and reviewing goals of care
- Provision of information and resources to families
- Identifying supports that are in place for the person with a life-limiting illness and their family
- Explanation of care pathways and different strategies of care available to families.



### Resource Links:

Palliative Care Australia have developed these useful [conversation tools](#) as part of their Dying to Talk strategy.

Download the [PDF document](#) for detailed information on how to conduct a family meeting

Points to note about family meetings/conferences:

- Some family members may not be able to make decisions based on their current level of grief or shock
- Some family members do not always get along with other family members – and this is where understanding the family structure and dynamics can help
- Some members will have difficulty in communicating effectively or contributing to decision making, which can lead to difficult situations.

Over the course of their illness trajectory, a person with a life-limiting illness may experience a decline in their functional status. This can compromise several dimensions, including:<sup>[11, 85, 86]</sup>

- Cognitive
- Behavioural
- Psychological
- Social.

This loss of function can reach a point where the individual is no longer competent to make, or communicate, decisions about their care. An Advance Care Plan prepares for this time. This is a patient-centred approach, in which the wishes of the individual determine and plan medical responses. This aids self-determination, dignity, and the avoidance of suffering – which helps to improve end-of-life care and satisfaction for the person and their family.

**Advance care planning should commence early in the person's illness, preferably at diagnosis, and should be a part of routine clinical care.<sup>[87]</sup>**

An effective Advance Care Plan:<sup>[88–91]</sup>

- Outlines how to manage pain and other symptoms
- Describes how to provide cultural, emotional, and spiritual support
- Discusses which treatments will be included in the overall care plan – and which ones will not
- Helps family members make decisions about care options
- Helps everyone involved – healthcare workers, family and carers – know what to expect at different stages of the illness
- Describes how to support families and carers through the bereavement process.



## Learning Activity:

How can advance care planning assist people with life-limiting illnesses manage the progression of their illness?

How would you explain to someone that advance care planning is not euthanasia?

## Your role in advance care planning

The trusting relationship between a GP and their patients can promote a good platform to initiate conversations surrounding advance care planning. The focus of the conversations should surround realistic future treatment options and preferences, values, and outcomes.

A substitute-decision maker should be appointed to identify the person's perspective on subjects including:

- Financial planning
- Spiritual wishes
- Terminal care wishes
- After-death care wishes
- Funerals
- Other practical arrangements.

Advance care planning discussions may be challenging as issues around dying and death emerge.<sup>[92, 93]</sup>

To help guide these conversations it is important to:

- Ensure that end-of-life goals have been established
- Provide a clear definition of advance care planning
- Explain the benefits of advance care planning to the individual and their family
- Ensure that any carer who may be making decisions in the future understands the advance care planning process and the person's end-of-life goals<sup>[39]</sup>

- Encourage the individual to think about:
  - The values that are important in their life
  - Their treatment and care preferences
  - Their current health and possible future health problems
  - What they would want from future medical care
  - Their limitations.
- Arrange a family meeting if required
- Document discussions to ensure that all parties are aware.

## Advance Care Directives

An Advance Care Directive is the instruction that a person makes about their future medical treatment or healthcare if they lose capacity to make decisions.

Be aware that Advance Care Directives have different names and slightly different formats in each state and territory.



### Resource Links:

Review the [Advance Care Planning Australia website](#) and review the documentation and legal processes required for your state/territory.

Visit the [End of Life Law in Australia website](#) to review detailed concepts surrounding advance care planning in Australia.

## When does an Advance Care Directive apply?

Advance Care Directives generally apply only when the person loses capacity to make decisions. This might occur where a person is unconscious, has delirium or a cognitive impairment because of dementia. A clinician who fails to follow a valid Advance Care Directive can be liable under civil and criminal law.<sup>[94]</sup>

In an emergency, the doctor in charge will make medical decisions. The clinician will consider the person's wishes, by referring to their Advance Care Directive and/or talking to their substitute decision-maker and family. If the Advance Care Directive is not immediately available, life-prolonging measures may be started until the treating doctors discuss expressed wishes with the substitute decision-maker and family.<sup>[88]</sup>

Generally, a specific treatment decision in a valid Advance Care Directive must be followed, even if it refuses life-sustaining treatment which will result in a person's death. Giving treatment without a person's consent is considered assault, which is a criminal offence.<sup>[95]</sup>

If an individual does not make an Advance Directive, the treating team will continue to provide care based on clinical judgement, the individual's wishes and substitute decision-maker liaison.<sup>[88]</sup>

There are some situations in which a valid Advance Care Directive does not have to be followed, such as when:<sup>[88, 95–98]</sup>

- There are multiple Advance Care Directives in existence
- An Advance Care Directive is known to exist – but it cannot be located
- The Directive does not apply to the medical treatment circumstances that have arisen
- The person's circumstances have changed since the direction was given so the person would not have intended it to apply anymore
- The terms of an Advance Care Directive are uncertain or ambiguous eg, a person refuses 'heroic measures', but does not state what treatment they would consider a 'heroic measure'
- The person is requesting futile treatment (ie, the treatment is not clinically indicated or is non-beneficial).



## Learning Activity:

What steps would an individual have to take to participate in advance care planning in your state/territory?

How would the participant establish a substitute decision-maker?

What criteria needs to be met for a substitute decision-maker to commence decision making for the individual?

## Summary

Advance care planning is a person-centred approach to palliative care that considers the person's individual preferences for their own care at the end of life. By making plans now, the individual is able to participate in the decision-making for their own care in the future – preparing for a time when they may no longer be able to actively participate in that decision-making due to a loss of function or capacity.

These discussions should commence early in the person's illness and should be a part of routine care. For this to occur successfully, people need to be provided with clear and accurate information about their illness, prognosis, and treatment options so that they can make informed choices about their future care. They are then able to discuss these needs and wishes with their doctors and appoint a substitute decision-maker to make decisions when they are no longer competent to do so.

# Section 5: Assessing and managing symptoms

Palliative care symptoms should be identified early and through impeccable assessment. [7, 99, 100]

Initial and ongoing assessment should incorporate the person's physical, psychological, cultural, social and spiritual experiences and needs. [7, 8]

Review the illness trajectories below:



Short period of evident decline



Long term limitations with intermittent serious episodes



Prolonged dwindling



## Learning Activity:

How does understanding a person's illness trajectory assist in assessing and managing symptoms?

Why may two people with the same illness have different responses to the symptoms of that illness?

## Common symptoms

The severity and complexity of symptoms will be a subjective experience for each individual. Factors that can influence symptoms include:<sup>[45]</sup>

- Spiritual factors, including existential distress
- Psychological factors including anxiety and depression
- Cultural experiences and history
- Perceived meaning of the symptom
- Comorbidities causing other symptoms
- Social concerns, including loss of control, loss of income, change of family role and perception of how they are viewed by others
- Fear, myths, past experience
- Age of the person
- Performance status.

## Common symptoms in palliative care include:

Pain	Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. <sup>[101]</sup>
Fatigue	Can be an ongoing and distressing sense of tiredness, which: <sup>[102]</sup> <ul style="list-style-type: none"> <li>• Is not related to activity</li> <li>• Is not relieved by sleep or rest</li> <li>• Interferes with normal functioning.</li> </ul>
Swallowing difficulties	Dysphagia (swallowing difficulty) is a common condition among people receiving palliative care. <sup>[103]</sup> Dysphagia increases the risks of choking, Aspiration (breathing a foreign object or liquid into an airway) and aspiration pneumonia. <sup>[104, 105]</sup>
Cachexia and anorexia	Anorexia (lack of appetite) and weight loss in advanced life-limiting illness. <sup>[103]</sup> Cachexia affects the person's ability to cope with treatment. <sup>[106, 107]</sup>
Nausea and vomiting	Nausea can be intermittent or persistent, and either with or without vomiting. <sup>[108]</sup> Nausea and vomiting can arise from all parts of the gastrointestinal tract. It can have many causes including medications, anxiety, or disease progression.
Dry Mouth (Xerostomia)	Medications and dehydration through disease progression can cause xerostomia.
Constipation and bowel obstruction	This can be due to: <sup>[103]</sup> <ul style="list-style-type: none"> <li>• Dehydration</li> <li>• Lack of fibre</li> <li>• Reduced peristalsis</li> <li>• Lack of movement</li> <li>• Some medications.<sup>[103, 109, 110]</sup></li> </ul> <p>Obstruction can be from an intrinsic cause (eg, colon primary), extrinsic compression (eg, pancreatic cancer), or from peristaltic dysfunction (eg, due to ovarian cancer).</p>
Dyspnoea	People with dyspnoea often report feeling like they are: <sup>[111]</sup> <ul style="list-style-type: none"> <li>• Suffocating</li> <li>• Short of breath</li> <li>• Unable to get a breath</li> <li>• Drowning.</li> </ul>
Cough	Coughing can be a very distressing and an exhausting symptom for a person with a life-limiting illness. Common causes include: <sup>[111]</sup> <ul style="list-style-type: none"> <li>• Other illnesses (eg, asthma, heart failure)</li> <li>• Chest infections</li> <li>• Choking due to poor swallowing</li> <li>• Lung cancer causing airway irritation.</li> </ul>

<b>Delirium</b>	<p>A state of confusion potentially due to:<sup>[112]</sup></p> <ul style="list-style-type: none"> <li>• Medications</li> <li>• Dehydration</li> <li>• Infection</li> <li>• Poor oxygen levels in the blood.</li> </ul>
<b>Neurological and neuromuscular symptoms</b>	<p>Possible problems related to the nervous system can include:<sup>[111, 113]</sup></p> <ul style="list-style-type: none"> <li>• Headaches</li> <li>• Illness-related nerve damage</li> <li>• Sensory dysfunction</li> <li>• Dizziness</li> <li>• Poor coordination</li> <li>• Seizures</li> <li>• Movement disorders</li> <li>• Muscle cramps and spasms.</li> </ul>
<b>Psychological symptoms</b>	<p>Common psychological symptoms related to mental health function in palliative care include:<sup>[114]</sup></p> <ul style="list-style-type: none"> <li>• Distress</li> <li>• Depression</li> <li>• Anxiety</li> <li>• Suicidal ideation</li> <li>• Delirium</li> <li>• Sleep disturbance</li> <li>• Alcohol and other drug problems.</li> </ul>
<b>Skin problems and wound development</b>	<p>Skin condition concerns occur frequently in life-limiting illness and include:<sup>[115]</sup></p> <ul style="list-style-type: none"> <li>• Itching</li> <li>• Sweating</li> <li>• Skin infections</li> <li>• Pressure injury.</li> </ul> <p>Itching and sweating can be particularly troublesome and further reduce quality of life for a person with a symptoms.<sup>[116]</sup></p>

Symptom management involves trying to understand where and why these symptoms have developed. Physical symptoms experienced by people with a life-limiting illness can affect their ability to complete daily activities of living. There are many other symptoms that may be experienced and will also require addressing.

## Symptom assessment

A detailed clinical assessment is essential to ascertain the likely cause of each symptom and to develop an individualised patient-centred management plan.<sup>[117]</sup> To undertake a comprehensive evaluation of symptoms gather data from a range of sources, including:<sup>[118, 119]</sup>

- Conversations with the patient and their family
- Physical examination and clinical investigations
- Observation.

The clinical assessment can assist with discovering characteristics of symptoms including:

- Intensity
- Location
- Quality
- Temporal nature
- Frequency
- Pattern of disability.

## Factors to be considered when assessing patients

<b>Holistic approach</b>	Symptoms should be assessed from a perspective that identifies the impact on the person's quality of life. Many symptoms are multifactorial, or occur in clusters,
<b>Manage pre-emptively</b>	Consider which symptoms may need to be planned for considering illness trajectories and treatment options.
<b>Assess and reassess frequently</b>	Consider using simple assessment tools such as the Symptom Assessment Scale (SAS), Distress Thermometer, or a pain diary to screen for and monitor symptoms. Check for adverse effects of treatments, as well as benefits, regularly.
<b>Reversible or irreversible causes</b>	Assess whether problems are likely to be due to reversible or irreversible causes. Consider and discuss the likely burden associated with various treatment options (cost, difficulty of undergoing investigations, realistic improvement that might be expected etc.,).
<b>Consider options</b>	Consider both pharmacological and non-pharmacological management options. Ensure that medications are easily accessible and available in community pharmacies and are on the Pharmaceutical Benefits Scheme (PBS). Using the Palliative Care Schedule of the PBS and/or providing authority scripts allows core palliative care medications to be prescribed in larger quantities and may cost the patient less.
<b>Timely referral</b>	If a problem does not respond to primary care management, or is complex, refer to specialist palliative care for further advice.

A palliative approach should be considered for any patient when you would not be surprised if they died within the next twelve months, ie, the 'surprise question'.



## Learning Activity:

Describe the clinical history and investigations you would undertake to assess the causes and effects of breathlessness in patients with chronic heart failure?

How might the aetiology and experiences of breathlessness be similar or different for people with advanced lung cancer?

## Assessment tools

Numerous assessment tools exist to assist in the measurement and monitoring of symptoms and their impact.<sup>[118]</sup> These tools should be used appropriately and not as a substitute for a comprehensive, holistic assessment.<sup>[120]</sup>



### Resource Links:

The Palliative Care Outcomes Collaboration have detailed assessment forms found at the following website addresses:

<https://www.uow.edu.au/ahsri/pcoc/palliative-care/assessment-forms/>

#### **Palliative Care Problem Severity Score (PCPSS)**

The PCPSS is a clinician rated score of palliative care problems that provides a summary measure of problems in four domains: pain, other symptoms, psychological/spiritual and family/carer.<sup>[121]</sup>

#### **Symptom Assessment Scale (SAS)**

The SAS is rated by the person with a life-limiting illness, rather than a clinician. It assesses the degree of distress relating to seven common symptoms and identifies the person's priorities relating to specific symptoms.<sup>[122]</sup>

#### **Palliative Care Phase**

Phase is used to describe the distinct stage in the patient's journey. Phases are classified according to the clinical need of the patient and their family and carers. Phases may not be sequential, and a patient may move back and forth between phases.<sup>[53]</sup>

#### **Functional Assessment in Palliative Care. Resource Utilisation Group – Activities of Daily Living (RUG-ADL).**

This scale measures motor function with activities of daily living: bed mobility, toileting, transfer and eating. Assessment is based on what the person does, not what they are capable of doing. It provides information on functional status, the assistance the person requires to carry out these activities and the resources needed for their care.<sup>[123]</sup>

#### **Australia-modified Karnofsky Performance Status (AKPS)**

The AKPS is a single score between 10 and 100 assigned by a clinician based on observations of a person's ability to perform common tasks relating to activity, work and self-care.<sup>[123]</sup>



## Assessing and managing common symptoms

Symptom	Assessment	Management
Pain	Acute or chronic pain is assessed by performing a physical examination. For a palliative care patient, only perform investigations that will assist in diagnosis or in the management of the patient.	In palliative care, it is important to discuss a patient's expectations for pain management and to set both short- and long-term goals of care. Relief of pain may need to be balanced against the patient's desire to avoid adverse effects. As the patient's life-limiting illness progresses, it may be appropriate to set more realistic goals associated with mobility or social activity.
Fatigue	<p>Consider the following as possibly contributing to fatigue in a palliative care patient:<sup>[102]</sup></p> <ul style="list-style-type: none"> <li>• Concurrent physical symptoms—pain, breathlessness, hypoxia</li> <li>• Concurrent psychological and emotional symptoms—sleep disturbance, emotional distress, depression, anxiety</li> <li>• Illness-related sequelae—anaemia, electrolyte abnormalities, dehydration, cachexia</li> <li>• Illness-related muscle weakness—deconditioning, corticosteroid-induced myopathy, spinal cord compression, paraneoplastic myopathy, or neuropathy</li> <li>• Other comorbid systemic disease—fever, infection, endocrine disorder (eg, hypothyroidism)</li> <li>• Medications—opioids, antihistamines, antiemetics, diuretics, antihypertensives, benzodiazepines, other sedating drugs</li> <li>• Illness-modifying treatments—chemotherapy, radiotherapy, hormonal antineoplastic treatments</li> <li>• Progression of life-limiting illness.</li> </ul>	<p>The following general measures may improve fatigue in a palliative care patient:<sup>[102]</sup></p> <p>Explanation and education for the patient, family, and carers:</p> <ul style="list-style-type: none"> <li>• Adapting to living with symptoms related to life-limiting illness</li> <li>• Setting realistic goals and expectations.</li> </ul> <p>Planned, manageable physical activity:</p> <ul style="list-style-type: none"> <li>• Using energy conservation measures</li> <li>• Pacing and prioritising activities</li> <li>• Delegating nonessential activities</li> <li>• Appropriate dietary advice</li> <li>• Regular supportive contact from the multidisciplinary team, as appropriate, including <ul style="list-style-type: none"> <li>• Palliative care team, primary healthcare team, physiotherapist, occupational therapist,</li> <li>• Dietitian and others as required.</li> </ul> </li> </ul>

Symptom	Assessment	Management
<b>Swallowing difficulties</b>	<p>Dysphagia may present as:<sup>[104]</sup></p> <ul style="list-style-type: none"> <li>• Difficulty swallowing food or fluids</li> <li>• Coughing/choking during or after meals</li> <li>• Unintentional weight loss</li> <li>• Persistent throat clearing</li> <li>• A wet, gurgling voice after eating</li> <li>• Changes in breathing</li> <li>• Food/liquids travelling back up the throat or nose after swallowing</li> <li>• Feeling of food or liquids being stuck in the throat/chest</li> <li>• Pain while swallowing</li> <li>• Heartburn</li> <li>• Excessive secretions</li> <li>• Leakage of food or saliva from the mouth.</li> </ul>	<p>When swallowing difficulties are due to mediastinal masses or luminal obstruction, other treatments such as radiotherapy, chemotherapy, oesophageal stenting, or laser treatment may be appropriate. When the patient's condition precludes these approaches, a short trial of corticosteroids may give temporary symptomatic relief. Corticosteroids may also be given while other treatment options are being considered.<sup>[103]</sup> Nasogastric or percutaneous endoscopic gastrostomy feeding tubes may be considered for patients with long-term and/or progressive swallowing difficulties who are early in their disease (eg, motor neurone disease).<sup>[103]</sup></p>
<b>Anorexia, weight loss and cachexia</b>	<p>Appetite is a subjective symptom. Assessment and management of cachexia should identify and treat according to the stage (pre-cachexia, cachexia, refractory cachexia), and seek to treat potentially reversible factors. Nutritional assessment tools that include markers of inflammation can be of use to patients in palliative care.<sup>[106, 107, 124]</sup></p>	<ul style="list-style-type: none"> <li>• Avoid measuring weight in a patient with a life-limiting illness. Most patients and their carers understand they are losing weight already</li> <li>• Identify and treat clear causes if possible</li> <li>• Optimise management of nausea and vomiting, swallowing difficulties, mucositis, constipation, altered taste, and inadequately controlled pain</li> <li>• Present food in small servings to not overwhelm patients.</li> <li>• Whenever possible, present food in a socially normal situation.</li> <li>• Patient preference should be the guide for all meals, focusing on enjoyment of the taste of food rather than on quantity or balance of nutrition</li> <li>• Avoid strong cooking smells, which are a common trigger for nausea.</li> <li>• Pureed food may be useful for a patient with swallowing difficulties</li> <li>• Substitute meals protein supplement drinks.</li> </ul>

Symptom	Assessment	Management
<b>Nausea and vomiting</b>	<p>Consider both peripheral and central causes:<sup>[103, 108]</sup></p> <ul style="list-style-type: none"> <li>• Central causes of nausea include central nervous system (CNS) disease, biochemical abnormalities, infection, food and medication, anxiety, or depression.</li> <li>• Peripheral causes include gastrointestinal or intra-abdominal problems, such as reduced gastric emptying, obstruction, peritoneal disease, ascites.</li> </ul>	<p>Consider:<sup>[103, 108, 124]</sup></p> <ul style="list-style-type: none"> <li>• Identify the mechanism of the nausea and select an agent which acts on the most likely pathway involved. In multifactorial nausea, several pathways may be involved</li> <li>• Selection of a prokinetic agent is appropriate if nausea is caused by gastric stasis/reduced gastric emptying, but may potentially worsen pain and vomiting if used in obstruction</li> <li>• Rehydration may improve nausea</li> <li>• Optimise the management of constipation. The choice of aperients should be reviewed if the patient cannot tolerate them, or if large volumes of fluid are required. Occasionally rectal measures (suppositories or enemas) may be a better option.</li> </ul>
<b>Bowels</b>	<p>When assessing bowel complications:<sup>[103, 125]</sup></p> <ul style="list-style-type: none"> <li>• Always consider the possibility of bowel obstruction – especially in high risk patients (ovarian or bowel cancer, or those with peritoneal disease). The patient may present with symptoms of incomplete or intermittent obstruction. The main role for an abdominal x-ray (AXR) is to exclude obstruction.</li> <li>• Rectal examination should include an assessment of pelvic floor and sphincter functioning, checking for anal pathology, and looking for sources of pain on defecation.</li> <li>• Exclude metabolic causes eg, hypothyroidism, hypercalcemia</li> <li>• Review the patient's drug chart. Some of the medications associated with constipation include opioids, serotonin (5HT3) blocking antiemetics like ondansetron, anticholinergics, calcium and iron tablets</li> <li>• Assess hydration.</li> </ul>	<p>Management should include:<sup>[103, 109]</sup></p> <ul style="list-style-type: none"> <li>• Patient and family education</li> <li>• Address any reversible contributors including pain, fluid intake, mobility and activity levels, toileting arrangements</li> <li>• Address the multifactorial causes of constipation whenever possible.</li> <li>• Reduce polypharmacy and select less constipating opioids where appropriate.</li> </ul>

Symptom	Assessment	Management
Dyspnoea	<p>The assessment of dyspnoea includes an assessment of the patient's symptoms and psychological wellbeing, its impact on their ability to function, and the pursuit of an understanding of the cause(s) of the dyspnoea.<sup>[111]</sup></p>	<p>Consider:<sup>[111]</sup></p> <ul style="list-style-type: none"> <li>• Opioids are first line pharmacological management for dyspnoea patients with advanced disease or cancer.</li> <li>• Oxygen prescription should be individualised, based on a formal assessment of benefit after a therapeutic trial</li> <li>• Non-pharmacological allied health and nursing interventions</li> <li>• Refractory dyspnoea at the end-of-life, which causes severe distress and does not respond to medical management is a challenging problem. Sometimes sedation is required. Guidelines for sedation for refractory symptoms at the end of life have been proposed.</li> </ul> <p>View <a href="#">CareSearch website</a> on palliative sedation</p>
Neurological and neuromuscular symptoms	<p>Routine screening for distress is important because these problems may not be raised by patients spontaneously, and timely supportive care can greatly improve the person's quality of life. Appropriate referrals could include:<sup>[113]</sup></p> <ul style="list-style-type: none"> <li>• Social worker</li> <li>• Pastoral care worker or person from their faith community</li> <li>• Mental health professional</li> <li>• Palliative care specialist.</li> </ul>	<p>There are a range of neurological and neuromuscular symptoms in palliative care. Specific management plans for these symptoms can be found within the <a href="#">Therapeutic Guidelines</a>.</p>
Psychological symptoms	<p>Clinical guidelines and tools can be used to identify patients who require more in-depth assessment and treatment of psychological problems. Tools can also be used to assess and monitor symptoms over time; however, they are not diagnostic tools. The 'Distress Thermometer' and the Edmonton Symptom Assessment System revised (ESAS-r) are commonly used for palliative care patients.<sup>[114]</sup></p>	<p>There are a range of psychological symptoms in palliative care. Specific management plans for these symptoms can be found within the <a href="#">Therapeutic Guidelines</a>.</p>

Symptom	Assessment	Management
<b>Sleep issues</b>	<p>Assessment for sleep issue involves:<sup>[124]</sup></p> <ul style="list-style-type: none"> <li>• Reviewing sleep hygiene – where and when the patient sleeps, the physical environment, and cues for sleeping</li> <li>• Identifying and managing all potentially reversible causes of sleep disturbance as clinically appropriate</li> <li>• Identifying uncontrolled pain or other symptoms</li> <li>• Examining the effects of medication – for instance steroids</li> </ul> <p>Identifying any psychological issues that could be affecting the patient such as:</p> <ul style="list-style-type: none"> <li>• Depression leading to sleep fragmentation</li> <li>• Anxiety/fears.</li> </ul>	<p>Strategies for managing tiredness include:</p> <ul style="list-style-type: none"> <li>• Energy conservation, psychosocial interventions, and management of comorbidities (eg, pain, insomnia, depression)</li> <li>• Non-pharmacological approaches include relaxation, education about sleep hygiene, cognitive restructuring to reduce anxiety about sleep problems, and attention to any environmental factors that disrupt sleep patterns</li> <li>• Multicomponent approaches are more effective than single therapy.</li> </ul>



### Learning Activity:

Which of the above symptoms may present as clustering of symptoms?

How can you manage these symptoms from a holistic perspective?

## Palliative interventions

Realistic goals of care need to be established.

When discussing goals of care the following should be considered:

- The various treatment options available
- Adverse effects
- Expectations of the person and family members
- The effect of physical (geographical) and psychosocial (psychological, social, spiritual, existential, cultural) factors on the agreed goals of care
- The likely outcome if no treatment is given.

Once goals of care have been established, these can form the basis of a comprehensive symptom management plan including:

- Detailed holistic assessment
- Identification of appropriate interventions
- Implementation of interventions
- Ongoing evaluation and reassessment if necessary.

Comprehensive symptom management is achieved through:

### Setting the management plan:

- Development of individualised, patient-centred, symptom management plans
- Ensure that all options presented to the person are evidence-based and best-practice
- Consider disease-modifying treatment for progression of underlying life-limiting illness if it is contributing to symptoms and treatment is appropriate

- Treat potentially reversible intercurrent illness if it is contributing to symptoms and treatment is appropriate.
- Use concurrent treatment to relieve symptoms, including nonpharmacological and pharmacological therapies
- Consider the most appropriate and least burdensome route of administration when prescribing drug therapies. When possible, the oral route is preferred for drug administration in palliative care; however, circumstances can arise that require an alternative drug formulation or route of administration to achieve and/or maintain effective symptom control
- Use psychological and emotional support to assist the person (and their family and carers) to cope with symptoms
- Address social, spiritual, existential, cultural, and geographical concerns that may contribute to symptom presentation or management.
- Use anticipatory care planning that takes into consideration:
  - Expected worsening of symptoms
  - Development of possible new symptoms
  - Development of symptoms that may occur as a crisis or an acute terminal event.

### **Implementing the management plan**

- Provide clear communication
- Ensure flexibility in the care plan to be responsive to patient needs and changing priorities in their lives
- Provide the person with written details for whom to contact or how to seek medical assistance if symptoms worsen or do not improve, or if other problems occur
- Anticipatory prescribing is common practice in palliative care. Symptoms are anticipated before they occur, and pharmacological treatment orders are written to be initiated as necessary
- Be prepared for change. Many palliative illnesses progress quickly, and extreme situations of distress can require rapid changes to management plans.

### **Monitor the management plan**

- Ensure ongoing assessment and re-assessment occurs
- Realistic planning of follow-up care, ensuring the patient fully understands who, what, where, when and why?
- Review symptoms, if not improving, modify or stop treatment
- Fine tune the plan.



## Learning Activity:

Think of a time when you have implemented effective management of a patient in your practice.

Was it effective because it was:

- Holistic
- Integrated
- Targeted
- Tailored to the patient
- All of the above?

How did you know that it was effective?

- The patient was in control of their illness
- The patient was living on their own with no acute care needs
- Patient reported that they were well
- The patient's family and carer reported that they were well
- All of the above?

## Summary

The ultimate goal of healthcare services, and palliative care in particular, is for the maintenance or improvement of health/illness-related quality of life.<sup>[34]</sup> Your role as a healthcare professional is to help people with life-limiting illnesses, and their families, to live the best quality of life while they are alive.<sup>[32, 85, 126]</sup> This requires an understanding of the illness itself – and of the symptoms that the person may be experiencing – coupled with the individual's perception of the effects of those symptoms. Many palliative illnesses have complex symptoms due to a combination of the illness itself, illness-modifying treatment and/or comorbidities.

# Section 6: Assessing and managing pain

*'Fear of pain adds to the total impact of pain'*

**Palliative Care Australia**<sup>[127]</sup>

Pain of any origin compromises an individual's ability to function and reduces their overall quality of life.

## Review the differing types of pain:

**Acute or chronic pain** – Pain can be acute (<3 months) or chronic (>3 months). Acute pain may occur concurrently with chronic pain and should be investigated and treated.

For chronic pain, identification of pain patterns helps to establish a treatment regimen.

**Baseline pain** – experienced constantly for more than 12 hours per day.

**Breakthrough (intermittent) pain** – involves transient periods of increased pain

**Incident pain** – flares up during an activity (eg, turning in bed).

**Nociceptive pain** – arises from actual or threatened damage to non-neural tissue and is due to the activation of nociceptors (receptors in skin and deep tissues that are sensitive to potentially noxious stimuli). Nociceptive pain is more likely to respond to conventional analgesics. It can be subdivided into somatic (superficial and deep) and visceral, according to the origin of the nociceptive stimulus.

**Neuropathic pain** – is caused by a lesion or disease of the somatosensory nervous system. It implies that there is some disruption of normal conduction within the nervous system itself and hence is more resistant to opioid analgesia.

Pain means different things to different people. It is important to try to understand what it means to each individual:<sup>[128]</sup>

- Do they simply perceive it as an unpleasant physical sensation?
- Is it perceived to mean that their life is coming to an end?
- Do they feel that it will reduce their capacity – for instance that they will no longer be able to drive themselves?

**Pain is always subjective, and everyone experiences pain differently**

For individuals approaching end-of-life, pain can be due to a range of factors, including:<sup>[128–131]</sup>

- The life-limiting condition
- Treatment protocols
- Resulting weakness or debility
- A comorbid illness.



## Learning Activity:

Why would dysesthesia not be considered pain?

Explain what is meant by the term 'pain is a subjective experience'

What could cause one individual to experience pain from the same illness in a completely different way to another person?

## The multidimensional experience of pain

There is growing recognition that persistent pain is a complex and multidimensional experience stemming from the interrelations among biological, psychological, social, cultural and spiritual factors.<sup>[132]</sup> The effects that pain can have in each of these domains can also be profound:

### The five domains of holistic care



## Cultural Care

Putting pain into words requires a degree of self-awareness and is coloured by the cultural background of the individual.

Cultural pain differences include:<sup>[133]</sup>

- Some people believe that pain results from an imbalance – such as an imbalance between Yin and Yang
- Some cultures believe they should endure pain bravely and serve as a role model, or to improve their standing in life after death
- Some cultures believe pain may be a sign of progress toward recovery
- Some cultures, such as American Indian, Asian, Black, Hispanic, are very stoic regarding pain and may maintain a neutral facial expression despite being in severe pain.

## Physical care

Physiological changes with pain include:<sup>[132, 134]</sup>

- Raised heart rate, pulse, temperature, respiratory rate, blood pressure or sweating
- Abnormal colour of skin, discharge from eyes, nose, vagina, or rectum
- Lesions to oral or rectal mucosa, skin
- Distension of the abdomen, swelling of limbs, swelling of body joints
- Abnormal results on testing urine (eg, presence of blood, leucocytes, glucose)
- Functional decrease in mobility, range of movement, activity, endurance, and increase in fatigue
- Changes in posture-standing, sitting, reclining.

## Social/family care

Pain affects every aspect of the individual's life, including:<sup>[134]</sup>

- Their relationships with others
- Normal daily activities
- Ability to participate in normal activities – including social gatherings.

## Emotional care

Pain is often associated with negative emotions, including:<sup>[132]</sup>

- Depression – There is a strong link between chronic pain and depression, and although this is widely known, depression often remains under-diagnosed in individuals with chronic pain.<sup>[135]</sup> Left undiagnosed, it can lead to exaggerated symptoms, with patients reporting a higher pain intensity and loss of functional ability.<sup>[132]</sup>
- Anxiety
- Anger.

Another challenge may be that people might feel stigmatized when they demonstrate intense emotions like these in the context of their treatment.<sup>[135]</sup>

Stigma can also keep the person from seeking out treatment as they fear that they will be perceived as not coping well enough with the pain, and being labelled a failure.<sup>[136]</sup>

## Spiritual care

Spiritual beliefs can influence:<sup>[132]</sup>

- Lifestyle
- Attitudes
- Feelings about life, pain, and death.

Spirituality and religion may influence the experience of pain and fatigue.

Some religions may believe pain is a part of God's plan, a test of faith, or penance for past sins.<sup>[133]</sup>

When managing pain, particularly pain that is difficult to control, it is important that the person, family, friends, and all healthcare providers collaborate to achieve the best result. For people receiving palliative care, maintaining relationships and continuing normal daily activities are just as important, if not more so, than symptom control.<sup>[24]</sup>



## Learning Activity:

How would you cater for cultural differences when managing an individual's pain?

How can the psychological effects of pain impact on each other to exacerbate an individual's pain?

## Barriers to effective management of pain

Pain experienced by individuals with life-limiting illness, is commonly undertreated. A number of barriers exist that contribute to this situation:<sup>[127, 137–139]</sup>



### System barriers:

- Rules relating to restriction of analgesic prescribing
- A threat of criminal charges for prescribers
- Lack of coordination of care, particularly during the transition from cure to hospice mode
- Lack of availability of opioids in a rural or isolated region.

### Healthcare professionals:

- Lack of awareness of the person's pain
- Lack of time and resources to address pain
- Lack of knowledge about the assessment and management of pain
- Lack of knowledge about the management of side effects of pain medication
- Confusion and concern relating to analgesic tolerance and addiction
- Under-prescribing opioids due to fear of regulatory scrutiny.

### Person and family barriers:

- Fear of addiction
- Fear of side effects of pain medication (eg, drowsiness, unconsciousness)
- Impact of side effects of medication
- Anxiety and depression
- Cultural and spiritual beliefs related to pain and suffering
- Cognitive impairment hindering symptom assessment
- Lack of adherence or understanding of prescribed regimen due to communication difficulties (eg, language, intellect, delirium)
- Failure to report pain.

Individuals, families and healthcare professionals should understand that addiction resulting from analgesics given for pain at the end of life is rare.<sup>[137]</sup>



## Learning Activity:

Why might a person with a life-limiting condition fail to report pain?

What are the reasons that people often fear pain despite effective symptom management that may be available?

## Assessing pain

A comprehensive pain assessment should assess the intensity, distress, and meaning of each pain experienced by the person with a life-limiting illness. It is helpful to use a pain framework such as the following mnemonic:<sup>[140]</sup>

<b>O</b>	<b>Onset of the event</b> <i>'Where is your pain?' 'When did your pain start?'</i>
<b>P</b>	<b>Provocation or palliation</b> Exacerbating/alleviating factors <i>'What makes the pain better or worse?'</i>
<b>Q</b>	<b>Quality of the pain</b> Characteristics of the pain (burning, throbbing, sharp) <i>'What is the pain like?'</i>
<b>R</b>	<b>Radiation</b> Location of the pain <i>'Does it radiate anywhere?'</i>
<b>S</b>	<b>Severity</b> Pain intensity (eg, 1–10) <i>'How would you rate the pain from 1–10?'</i>
<b>T</b>	<b>Timing</b> Temporal component of pain (eg, onset, duration, variation, pattern) including history of the pain (previous response to medications) <i>'How does the pain severity vary over time?'</i>
<b>U</b>	<b>Understanding</b> What is their understanding of the pain? <i>'What is the meaning of this pain to you?'</i>

During the examination look for:

- Tender areas
- Masses
- Areas of abnormal sensation
- Whether a stimulus is provoking the pain and if the patient's response to it is appropriate
- The function of the painful part or system
- The function of the whole person related to their activities of daily living:
  - transfers (lying to sitting to standing)
  - mobility (with and without mobility aids)
  - standing and walking tolerance
  - balance
  - dressing
  - carrying loads.

Other assessments that may inform diagnosis include:

- Mental State Examination (MSE)
- Psychosocial assessment.

Scales for measuring pain severity include:<sup>[35]</sup>

- Categorical or verbal descriptor scales (using descriptors such as no pain, mild, moderate, severe, worst ever pain)
- Numbered scales (0 to 10, 0 to 100)
- Visual analogue scales (simple lines with word anchors at each end)
- Faces pain scales (for people who are unable to use other scales).

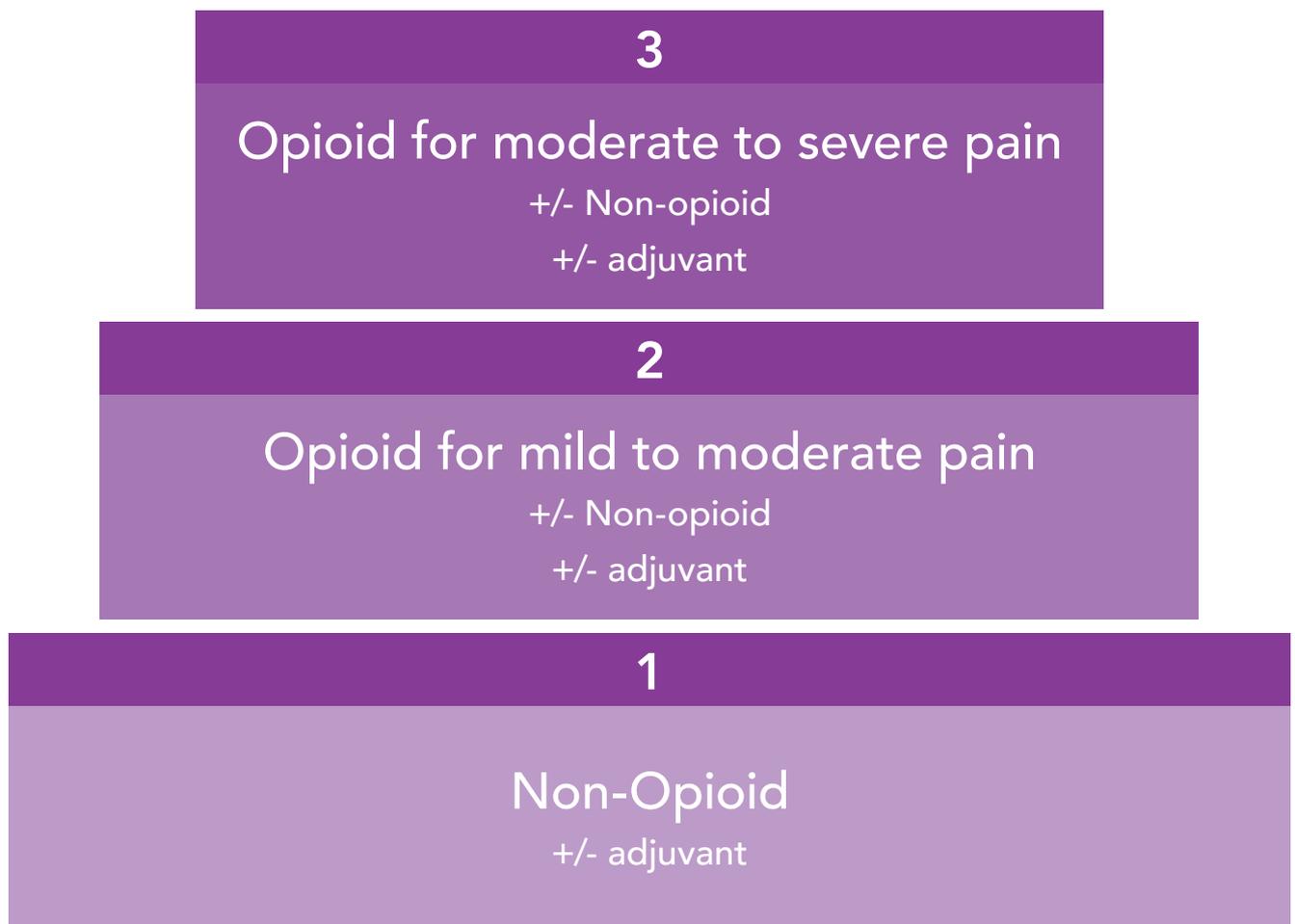
It is essential to document the baseline pain level using a pain assessment tool, then repeat the assessment using the same tool following treatment to monitor the outcome.<sup>[128]</sup>

## Principles of pain management

Important points to remember for pain management include:

- Review pain control regularly
- Provide regular analgesia for persistent pain
- Provide person and carer education
- Report and liaise with the treating team
- Prevent and manage adverse effects.

The World Health Organization three-step analgesic ladder outlines the best practice for effective prescription of analgesics.<sup>[141]</sup>





## Learning Activity:

Why is the oral route the preferred method for analgesics?

### Pain adjuvants

In addition to analgesics, adjuvant medication can enhance the analgesic effects of non-opioids and opioids and have some pain-relieving properties of their own. Adjuvants are drugs whose primary indication is not analgesia, but when used in specific pain situations may be effective as analgesics or co-analgesics. They include drugs used as antineuropathic medications (antidepressants, anticonvulsants and systemic local anaesthetics) and also steroids, bisphosphonates, ketamine, and clonidine.<sup>[142]</sup>

Key points for adjuvants:<sup>[128]</sup>

- Adjuvants should be added when neuropathic or other pain is not fully responsive to opioids – as step 1 analgesics in the World Health Organization analgesic ladder approach to pain management, and most commonly, in conjunction with opioids in treating neuropathic or opioid-resistant pain
- Antidepressants and anticonvulsants provide a small improvement in analgesia for people experiencing neuropathic pain, however this is at the cost of an increase in adverse events
- External beam radiotherapy is an effective treatment for bone pain due to metastases, and may be offered first line along with opioid analgesia
- Bisphosphonates may be used if the therapeutic response is inadequate, but their analgesic effect is not immediate
- Non-Steroidal Anti-Inflammatory Drugs (NSAIDs) are effective analgesics for musculoskeletal pain in cancer
- The analgesic effect of any adjuvant is less in malignant pain than in non-malignant pain.



## Learning Activity:

When should adjuvants be utilised?

What clinical evidence supports the use of an adjuvant?

### Opioids

For people with life-limiting illness, opioids usually provide the best relief for most pain. They are predictable in their effect and the dose can be adjusted precisely. Opioids frequently improve quality of life and allow an increase in activities – however it is often necessary to reassure people about their safety and efficacy.<sup>[143]</sup>

Key points about opioids:<sup>[138]</sup>

- Morphine has been widely recommended due to its efficacy, easy availability, versatility, cost, and the extensive clinical experience of using it in palliative care; however, there is no evidence that it is superior to other opioids
- Morphine, oxycodone, and hydromorphone are clinically similar regarding efficacy and adverse effects

- Choice of opioid is based on specific properties of the drug and preparation (eg, versatility of various routes of administration, availability of sustained and immediate release formulations, cost to the person and the healthcare system)
- Methadone and transdermal preparations are not recommended as first-line strong opioids.

Key considerations when prescribing opioids:<sup>[144]</sup>

- Ability to swallow
- Impaired renal function
- Impaired liver function
- Allergies/intolerance
- Constipation/ileus/bowel obstruction.

#### Before starting opioids:<sup>[145]</sup>

- Is there a treatment to target the cause of pain specifically? – eg, radiotherapy, interventional radiology?
- Should a non-opioid be tried first?
  - If prognosis is many months or years – exhaust non-opioid options first
  - Non-cancer chronic pain
  - Mild pain vs severe pain.
- Consider non-drug management strategies in addition
  - TENS machine, heat/cold pack
  - Allied health – physiotherapy, psychology, spiritual care
- Is the pain unlikely to respond completely to an opioid?
- Consider addition of adjuvant analgesics.

#### When initiating opioids:<sup>[146]</sup>

- Suggested starting doses are oral morphine 30 mg/24 hr in opioid-naïve patients, or 60 mg/24 hr in patients already using a WHO step II opioid
- Doses should be divided into either once or twice daily according to the long-acting morphine preparation used, or divided and given fourth hourly if an immediate release preparation is used
- Initial dose should be based on age and frailty:
  - Young adults: immediate release oral morphine 5 – 10 mg q2h PRN +/- modified release morphine 10mg BD
  - Old/frail adults: immediate release oral morphine 2.5-5mg q2h PRN +/- modified release morphine 5mg BD
- Monitor patients closely to avoid toxicity when starting or changing doses – a pain diary is useful.

#### Side-effects common with opioid analgesics:<sup>[145, 146]</sup>

<b>Constipation</b>	Always give a regular laxative with opioid therapy. Encourage adequate fluid intake and mobility if possible.
<b>Sedation</b>	If excessive sedation, reduce dose by 25 to 50%. For persistent sedation, change to a different opioid.
<b>Nausea and vomiting</b>	Consider giving an antiemetic during initiation of therapy for a few days and then review need. For persistent nausea despite antiemetic therapy, consider changing to different opioid or route of administration.
<b>Respiratory depression</b>	Very rare in carefully adjusting opioid dose against relief of pain.
<b>Cognitive impairment</b>	Patients need to monitor their own reactions and avoid driving or operating machinery until treatment is stable.
<b>Hallucinations and delirium</b>	Change to a different opioid as this is possibly due to build-up of toxic metabolites from the current opioid.
<b>Itching</b>	Consider changing to a different opioid to relieve itch. Antihistamines may be tried.

## Breakthrough pain and opioid titration

Dose increments of at least 25% are usually required when opioids are titrated upwards for poorly controlled pain.<sup>[146]</sup>

If pain is not controlled, but opioids have had some benefit, increase the long-acting background opioid dose by taking the previous 24 hour breakthrough requirements into account.<sup>[143, 145]</sup>

## Opioid rotation and switching

The practice of 'opioid switching' is done to improve analgesia in the minority of patients who do not respond to increasing doses or who have severe adverse effects.<sup>[146]</sup>

When switching opioids, frequent clinical review and reassessment of pain and adverse effects is the safest approach.

Based on studies of opioid switching, it is important to individualise all opioid conversions.

Common reasons for switching between different opioids, (or between routes of administration) are:<sup>[147]</sup>

- Inadequate analgesia – individual variability in response to opioid, hyperalgesia, maximum dose of the opioid is reached, (eg, tramadol, buprenorphine patches)
- Toxicity or intolerable side effects – cognitive dysfunction, drowsiness, myoclonus
- Changing clinical status:
  - Dysphagia, malabsorption, bowel obstruction, development of renal/hepatic failure, concern regarding potential drug abuse
  - Unable to swallow
  - Malabsorption (patch or tablets)
  - Bowel obstruction
  - Renal/hepatic failure.
- Drug interactions
- Financial or drug availability issues – eg, oxycodone is not on PBS for subcutaneous preparations.

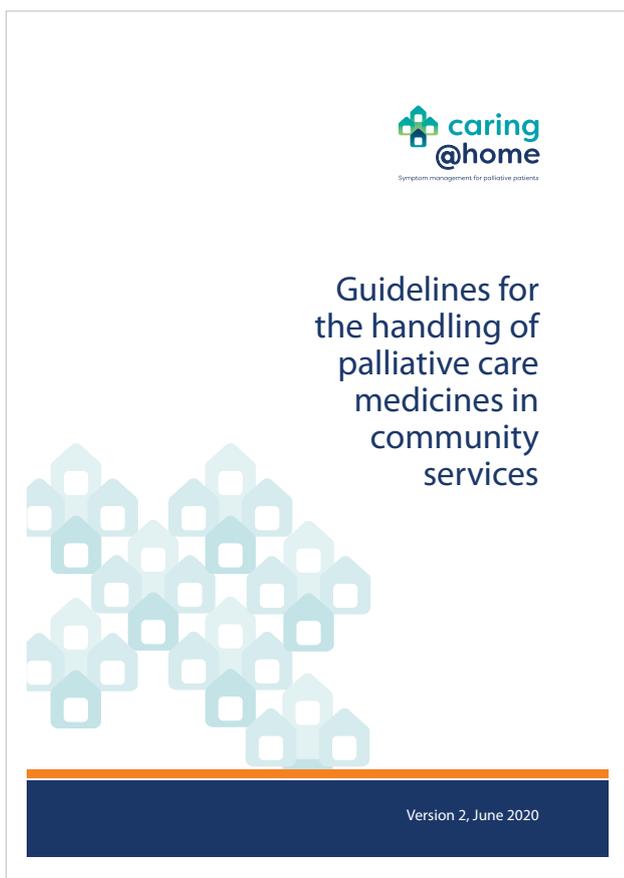
## Opioid conversion

### Opioid calculator for opioid dose conversions

There is wide individual variation in the response to opioids in terms of metabolism, distribution, and receptor dynamics and therefore no single conversion ratio will be applicable to all. <sup>[142, 147]</sup>

Use the [EviQ opioid calculator](#) to assist with estimating equianalgesic doses of opioids. Register for free to access this tool.

Review the [caring@home website](#) and download the 'Guidelines for the handling of palliative care medicines in community services' and ensure you have a copy easily available for your practice.



## Non-pharmacological treatment

When used in conjunction with conventional medicine, non-pharmacological approaches can be effective and well accepted by individuals with life-limiting illness. People may use complementary therapies to gain a therapeutic response and a sense of control.

Complementary therapies can include: <sup>[148–151]</sup>

- Massage
- Heat and cold
- Distraction therapy
- Relaxation
- Reflexology
- Aromatherapy
- Art and music therapy
- Cognitive behavioural therapy (CBT)
- Patient education
- TENS
- Acupuncture.

Complementary therapies work by modifying the sensory input or altering the brain's perception of pain, <sup>[130]</sup> and can be very effective when used in conjunction with pharmacological management.

When complementary therapies like herbs or supplements are taken orally, topically or by some other route, it is important to consider the possibility of pharmacological interactions and side effects.

## Psychological support

The psychological aspects of pain contribute to the person's experience and should be addressed within a holistic pain management approach.<sup>[152]</sup>

Recognising and supporting the person's psychological distress, resolving guilt, fear and unresolved issues, treating depression, counselling, and addressing financial and social concerns can influence their perception of pain and reduce the experience of physical pain.<sup>[130]</sup>

As a GP, you can support individuals with active listening and providing opportunities for them to talk about their pain, concerns and anxieties.<sup>[153]</sup>

## Summary

Pain of any origin compromises an individual's ability to function and reduces their overall quality of life. The prevention and management of pain is an important aspect of palliative care.<sup>[154–156]</sup>

# Section 7: Self-care

Doctors who care for people affected by life-limiting illness are often confronted by human suffering, clinical deterioration, dying and death in ways that they may have never experienced before. The effects of unprocessed emotions and experiences can compromise personal wellbeing and can have negative professional outcomes. This module will explore these issues and examine how reflective writing and mindfulness are essential tools for maintaining self-care in the context of caring for people affected by life-limiting illness.

As a healthcare professional caring for and supporting a person affected by a life-limiting illness, you may witness palliative care recipients' incremental losses of:

- Physical discomfort
- Decreased function
- Loss of professional identity
- Altered family role
- Emotional distress
- Spiritual distress.

You are repeatedly exposed to suffering in all its forms. The effect that this has on you personally, emotionally, and professionally can often go unexpressed and unrecognised.<sup>[157, 158]</sup>

You can also find yourself confronting issues which are unique to palliative care and that are inherently hard to resolve, including:<sup>[157–162]</sup>

- Your own concerns, beliefs, morality, and ethical views about dying and death – which can also trigger a trauma response depending on your own personal experiences
- Clinical anxieties, for instance if there is a perception that a diagnosis was missed or delayed

- Traditional western culture which views death as clinical failure
- Difficulty in deciding how and when to shift from a curative to palliative approach
- Feelings of reluctance to take on complex problems because of time constraints in general practice
- Difficulty dealing with the clinical uncertainty that dying and death, and palliative care in general create
- Feelings of clinical helplessness if you are unable to completely relieve the distress and pain of a person affected by a life-limiting illness or if an outcome was unacceptable
- Caring for people with whom you identify with 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, both with self and the person affected by a life-limiting illness
- Accumulated losses.

Doctors caring for people affected by life-limiting illnesses are at particular risk for compromised wellbeing from a combination of these factors. This is compounded by the nature and intensity of the clinical stressors they face.<sup>[163, 164]</sup> When caring for 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.



## Learning Activity:

Think back to a situation that you have been involved in, which raised confronting issues:  
How did this situation affect you?

What impact did it have on your personally? Professionally?

What steps did you take to manage the situation?

## Impact of accumulated stressors

When working with people affected by a life-limiting illness, stress is often related to the emotional impact of being exposed to compounding human suffering. Accumulated stressors can have emotional and spiritual effects which can compromise personal well-being. Unexamined emotions can lead to burnout, moral distress, and compassion fatigue.<sup>[163, 164]</sup>

### 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.

## Professional boundaries

Professional boundaries allow healthcare professionals and people affected by life-limiting illness to engage safely and effectively in professional relationships. This is especially important where care involves personal and/or intimate contact – or where the doctor has a long-term involvement with the patient such as with people in palliative care. In these situations, the bond between the clinician and person can become strong and the line between a professional relationship and personal relationship can become blurred.

In all our relationships we set limits. Each of us has a boundary around us that defines who we are as individuals. The strength of our boundary depends on our relationship with the other person and on the context of that relationship. As a doctor, you enter the therapeutic relationship with skills and knowledge that include a large amount of personal information about the person in your care. Professional boundaries determine the mutually understood, unspoken, physical, and emotional limits of the relationship that you have with the patient. They also underpin trust, respect, intimacy, and power in the therapeutic relationship.<sup>[165]</sup>

Professional boundaries may become blurred when you identify that you share several similarities and build a strong rapport.

Despite becoming close to people, you need to ensure that you do not become too involved and encounter boundary issues, such as:<sup>[166]</sup>

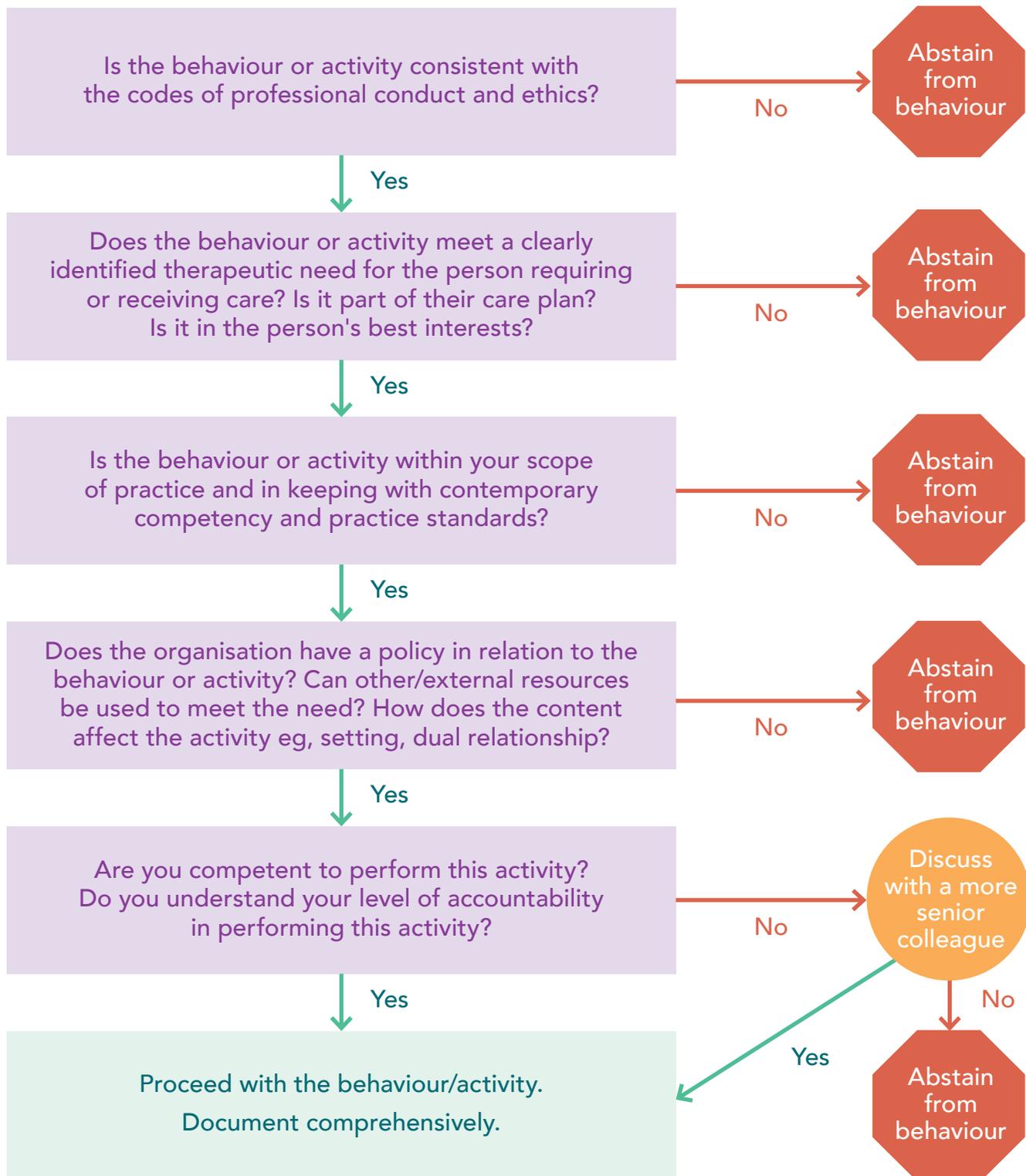
- Boundary crossing
- Boundary violations.

Boundary crossings and violations often begin with innocent behaviour, and one event may be acceptable. However, this can be the start of increasingly problematic behaviours.

The presence of the following behaviours or emotions in healthcare professionals could indicate that professional boundaries have been crossed:<sup>[166, 167]</sup>

- Avoidance
- Increased contact with the patient even when medically unnecessary
- Negative feelings, anger
- Feeling a personal responsibility to save the person
- Feeling that no one else can care for the person the same way.

The following decision-making tool can be beneficial to maintaining professional boundaries:



Adapted from: ANMC (2007) A national framework for the development of decision-making tools for nursing and midwifery practice; College of Registered Nurses of Nova Scotia (2002) Guidelines for Nurse-Client Relationships, Halifax, 5; College of Nurses Ontario (2006) Practice Standard: Therapeuti Nurse-Client Relationship, Toronto, 11.

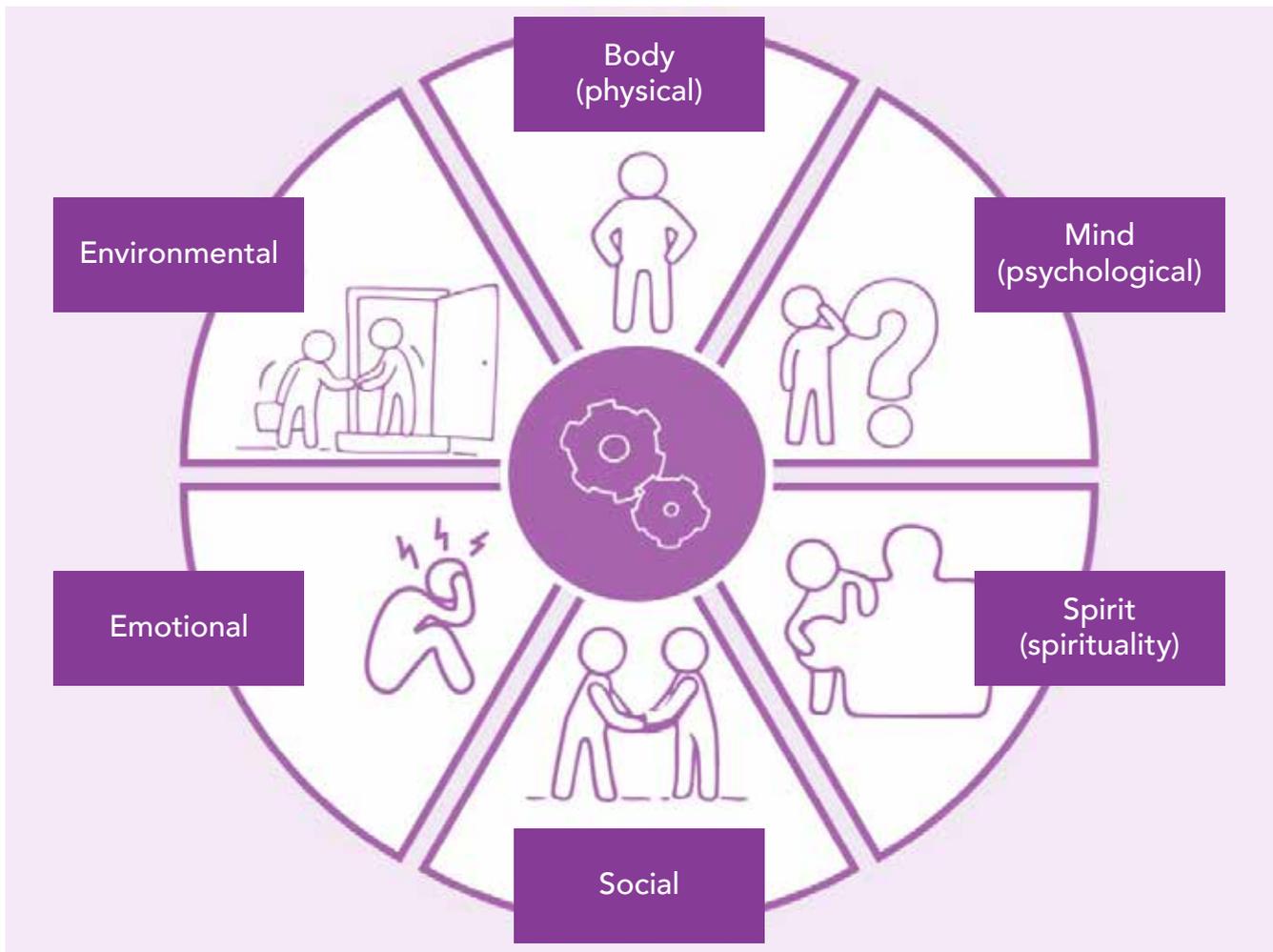
## Adopting self-care strategies

Self-care is any activity that we do deliberately in order to take care of mental, emotional, and physical health.<sup>[164]</sup> Self-care is both a preventative and therapeutic action that helps to improve or maintain overall wellbeing. It involves:<sup>[168]</sup>

- Recognising your limits and setting boundaries
- Establishing and working towards achieving goals and maintaining a work–life balance
- Implementing strategies to provide care and compassion to yourself
- Setting up the foundation for positive mental and physical health
- Accessing support as required
- Undertaking deliberate, self-initiated activity to take care and control of your own wellbeing.

## Self-care assessment

The Wheel of Wellness is a tool that can be used to determine your current need for self-care. There are numerous representations of the Wheel of Wellness, however the model endorsed by the Queensland and New South Wales (NSW) Mental Health Commissions contains the following six spokes:<sup>[169]</sup>



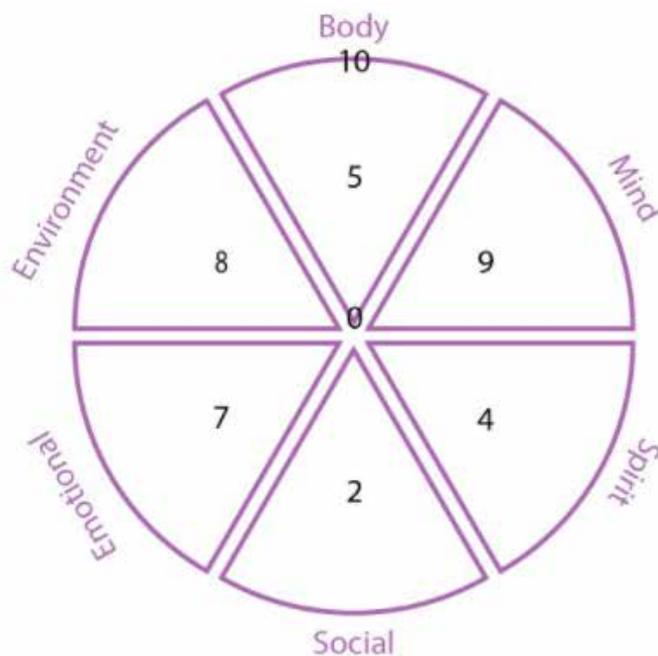
Maintaining balance in our Wellness Wheel requires discipline and continuous effort in the form of self-reflection and personal analysis of how each element is affecting the other elements of our self – much like the spokes on a wheel.



## Learning Activity:

Complete your own Wheel of Wellness

### Assess each area



This approach assumes that you will be happy and fulfilled if you can find the right balance of attention for each spoke – and different areas of your life will need different levels of attention at different times.

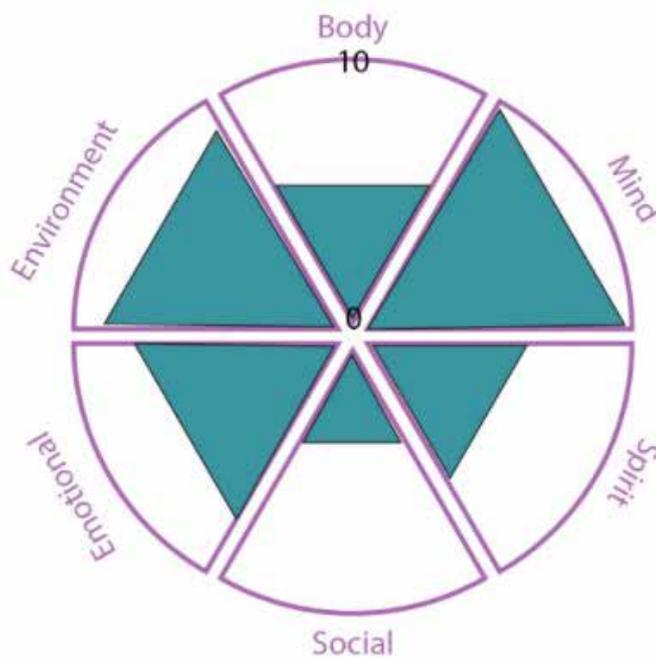
Assess the amount of attention you are currently devoting to each area.

Consider each spoke in turn. On a scale of 0 (low) to 10 (high), write down the amount of attention that you are devoting to that area of your life. Mark each score on the appropriate spoke of your Wheel of Wellness.



## Learning Activity *continued*

### Join up the marks

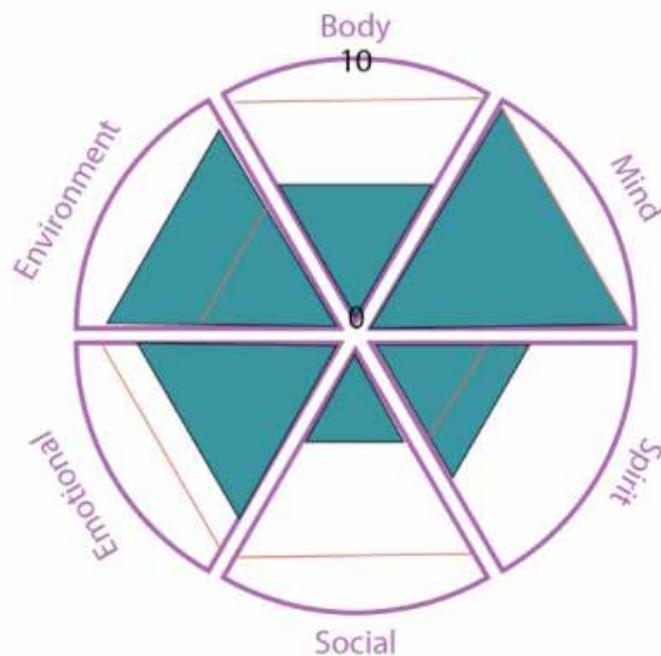


Join up the marks around the circle. Does your Wheel of Wellness look and feel balanced?



## Learning Activity *continued*

### Consider your ideal level



Consider your ideal level in each area of your life. A balanced life does not mean getting 10 in each life area. At any time some areas need more attention and focus than others. Because your time and energy are not in unlimited supply you will need to make choices and compromises around where to focus your attention.

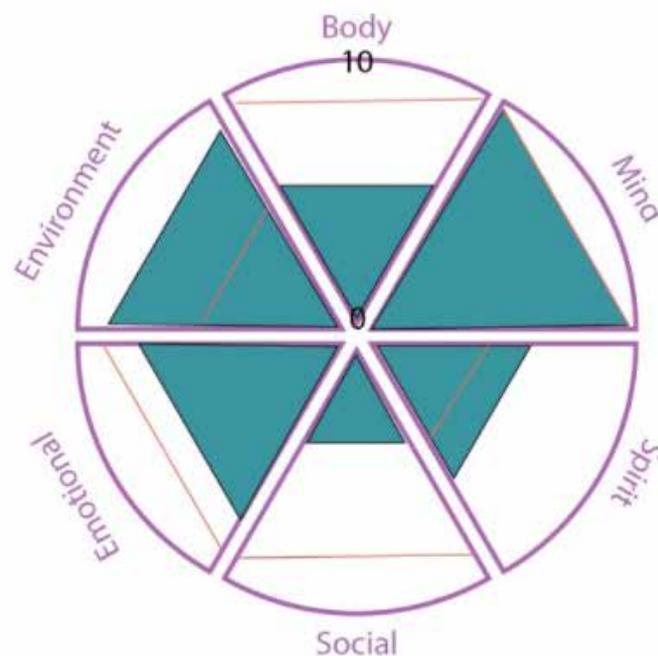
The question is: what would the ideal level of attention be for you in each life area?

Plot the 'ideal' scores around your Wheel of Wellness too. This is represented by the orange lines in the diagram.



## Learning Activity *continued*

### Analyse the gaps



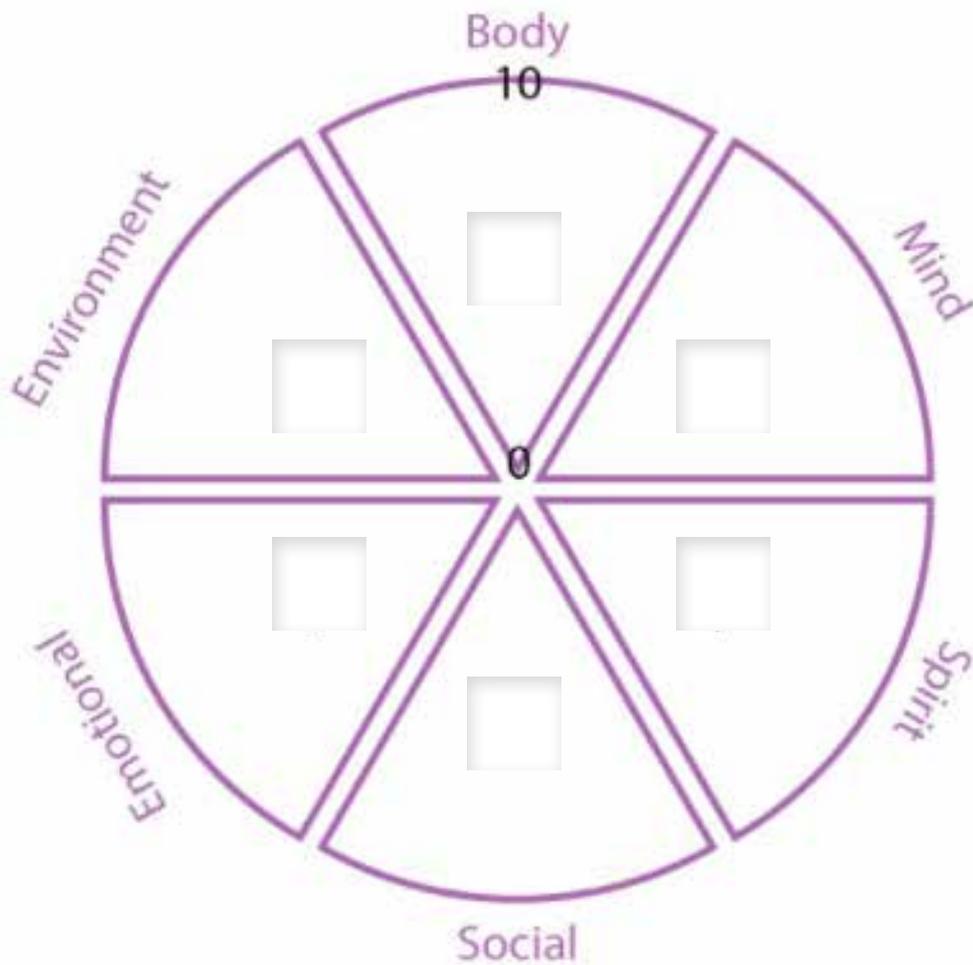
You will now have a visual representation of your current life balance and your ideal life balance. Are there any gaps? These are areas of your life that need attention.

Gaps can also go both ways. There will be areas that are not getting as much attention as you would. There may also be areas where you are putting in more effort than you would ideally like. These areas are draining energy and enthusiasm that may better be directed elsewhere.



## Learning Activity *continued*

Complete your own Wheel of Wellness below.



## Developing your self-care plan

Once you have identified the areas that need attention, it is time to plan the actions needed to work on regaining balance. Starting with the neglected areas, what things do you need to start doing to regain balance? In the areas that currently drain energy and time, what can you stop doing, reprioritise, or delegate to someone else?

Strategies for personal self-care include: <sup>[163, 170–174]</sup>

- Prioritising close relationships including relationships with family and close friends
- Maintaining a healthy lifestyle by ensuring adequate sleep, regular exercise, and time for holidays
- Participating in recreational activities and hobbies
- 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
- Practicing mindfulness
- Pursuing spiritual development
- Maintaining a routine
- Participating in activities that bring personal joy
- Being realistic with time and avoiding overcommitting
- Maintaining a connection with culture, country, and community
- Learning relaxation techniques and practicing them 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.

## What is self-awareness?

Self-awareness is defined as your ability to combine self-knowledge and a dual-awareness of both your own subjective experience and the needs of the individual affected by a life-limiting illness. <sup>[175]</sup>

Healthcare professionals who possess lower levels of self-awareness have a greater likelihood of compassion fatigue and burnout.



### Learning Activity:

Visit the Palliative Care Australia website and view the [Self-Care Matters](#) webpage:

Download the *Self-Care Matters planning tool* and work through the tool to complete your own self-care plan.



**Remember! Revisit the tool regularly to ensure you are staying on-track with your goals and self-caring.**

Self-awareness is the most important factor in your ability to function well in the face of personal and professional stressors.<sup>[175]</sup> Increased self-awareness among healthcare professionals can lead to:<sup>[176, 177]</sup>

- Greater job engagement and compassion satisfaction
- Enhanced self-care
- Improved patient care, outcomes, and satisfaction.

Experienced clinicians should take every opportunity to model good self-care practices, mentor junior staff in good self-care practices and explicitly teach self-care skills.<sup>[178]</sup>

## Reflective practice

Reflective practice is a useful tool for developing a self-care plan, and for reflecting on your clinical practice.

### What is it?

Reflective practice is a way of studying your own experiences and aims to help you learn from a particular practical experience through a personal consideration of the event, the emotions it invoked and the consequences of the experience.<sup>[1]</sup>

View the [PCC4U Core Modules](#) to learn more about reflective practice.



## Reflection: Part 2

Let's re-visit your completed reflection of [questions 1–5 from Section 1](#):

Think back to a moment where you have been involved in the delivery of, or referral to the palliative approach to care and you feel that you may not have delivered the best care possible.

### Part 2:

Complete the reflection for the events that occurred with an honest reflection and review of how you can alter future outcomes.

3. What alternative actions were there?

4. What was the outcome of your actions?

5. Could the situation have been dealt with any better? If so, how?



## Mindfulness

Mindfulness encourages moving away from anxious thoughts to focus your attention exclusively on the present to focus the mind and avoid distractions. Mindfulness means paying attention in a particular way.<sup>[179]</sup>

- On purpose
- In the present moment
- Non-judgmentally.

Mindfulness helps to cultivate a kind, non-judgemental attitude towards yourself and others, which can be important when working with people affected by life-limiting illness.<sup>[179]</sup>

Randomised trials have studied the effects of mindfulness-based interventions and found that the benefits of these interventions include:<sup>[163, 179–181]</sup>

- An enhanced sense of well-being
- Increased empathy
- Decreased anxiety.

There are many forms of mindfulness including:

- Mindful breathing
- Being aware and present in your environment
- Mindfulness in your immediate actions
- Mindful of your emotions.

The benefits of mindfulness include:<sup>[174, 179, 181]</sup>

- Improved focus
- Improved mental and physical health
- Improved resilience.



### Learning Activity:

#### Mindful breathing

- Find somewhere comfortable.
- Sit in an upright but relaxed position and focus on your breathing.
- Pay attention to how it feels, listen to the sound of your breath, and feel your chest expand and contract.
- Do not get frustrated with yourself if distracting thoughts arise. Instead, just be aware that you are getting distracted and gently bring your attention back to your breathing. Aim to do this for at least one minute.



## Self-care resources

### RACGP GP Support Program

The RACGP GP Support Program offers free, confidential specialist advice to help cope with professional and personal stressors impacting areas such as mental health and wellbeing, work performance and personal relationships. The service is available to all RACGP members who are registered medical practitioners at locations across Australia, including in regional and remote areas.

### Doctors' Health Advisory Service

Resources and articles relating to wellbeing, illness prevention and recognising and managing mental health illness for medical professionals are available through each state or territory Doctors' Health Advisory Service (DHAS). Each state or territory DHAS operates a telephone help line providing personal advice to practitioners facing difficulties.

### CRANaplus Bush Support Services

CRANaplus' Bush Support Services provides a free and confidential 24-hour/7-day-a-week telephone counselling service for rural and remote health practitioners. The service is staffed by psychologists, including two Aboriginal psychologists. CRANaplus membership is not required to access the service.

### Beyond Blue

Beyond Blue's support service is available 24 hours/7 days a week by phoning 1300 22 4636 or via webchat 3.00 pm–12.00 am/7 days a week.

### Lifeline

Lifeline provides all Australians experiencing a personal crisis with access to 24-hour crisis support.

### RACGP Aboriginal and Torres Strait Islander Health

The RACGP Aboriginal and Torres Strait Islander Health faculty and the Australian Indigenous Doctors' Association provide support for Aboriginal and Torres Strait Islander doctors.

### Rural Workforce Agencies

Rural Workforce Agencies provide personal and family support for health professionals in rural and remote communities, including orientation programs for new recruits and GP locum relief programs that help prevent burnout.

## Summary

Self-care has the potential to not only minimise the harm from burnout, compassion fatigue, and moral distress but to also promote personal and professional well-being.

Job engagement (marked by efficacy, energy, and involvement in work), compassion satisfaction (the pleasure derived from being able to do one's work well when helping others), and resilience (the ability to respond positively to challenging experiences) are all possible outcomes when your personal well-being is carefully tended.<sup>[163]</sup>

If these qualities are supported and strengthened, the characteristics of the work of caring for people affected by a life-limiting illness can bring personal fulfilment and a sense of professional and personal purpose. From a personal perspective, it can also provide you with a sense of self-efficacy, strengthen your sense of connectedness and idealism, and remind you of the preciousness and fragility of life.<sup>[163]</sup>

# Resources

## Advance Care Planning Australia

The Advance Care Australia website contains validated resources for advance care planning specifically for your state/territory.

## CareSearch

CareSearch provides trustworthy information and evidence-based research about palliative care for people with a life-limiting illness, their families and carers – as well as for the healthcare professionals providing their care

## End of Life Directions for Aged Care (ELDAC)

The ELDAC project aims to improve the care of older Australians. Healthcare professionals and aged care workers can access information, guidance, and resources to support palliative care and advance care planning for older people and their families.

## End-of-life Essentials

Most people in Australia will visit an acute hospital in their last year of life. Many of them will die in hospital. End of life Essentials provides e-learning opportunities and resources for doctors, nurses and allied health professionals to improve the quality and safety of end-of-life care in hospitals.

## End of Life Law

End of Life Law in Australia provides accurate, practical and relevant information to assist you in navigating the challenging legal issues that can arise with end of life decision-making.

## Palliative Care Australia

Palliative Care Australia is the national peak body for palliative care.

## Palliative Care Outcomes Collaboration

PCOC develop frameworks and assessments tools and resources to implement quality palliative care in clinical practice.

## RACGP

The Royal Australian College of Medical Practitioners has a range of state by state information about advance care planning.

## Practice Tools

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

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

<b>PalliAGEDnurse PalliAGEDgp</b>	This app helps nurses and GPs working in residential aged care, community care and general practice to care for older people with palliative care needs.	Download links available at: <a href="https://www.palliaged.com.au/tabid/4351/Default.aspx">https://www.palliaged.com.au/tabid/4351/Default.aspx</a>
<b>PalliMEDS</b>	Developed by NPS Medicinewise for caring@home, this app familiarises primary care prescribers with eight palliative care medicines that have been endorsed by the Australian and New Zealand Society of Palliative Medicine for management of terminal symptoms	Download links available at: <a href="https://www.caringathomeproject.com.au/tabid/5159/Default.aspx">https://www.caringathomeproject.com.au/tabid/5159/Default.aspx</a>
<b>SPICT</b>	This app includes information about the SPICT, advice on how to assess and plan care for people identified with it, and tips on effective communication.	Download links available at: <a href="https://www.spict.org.uk/spictapp/">https://www.spict.org.uk/spictapp/</a>
<b>Vital Talk</b>	The Vital Talk app is a tool to support health professionals to use the communication skills that they have learned in the clinical setting. It provides communication skill tips in the form of virtual 'pocket cards'.	Download links available at: <a href="https://www.vitaltalk.org/vitaltalk-apps/">https://www.vitaltalk.org/vitaltalk-apps/</a>



# References

1. Beverley Joan Taylor, *Reflective Practice for Healthcare Professionals: A Practical Guide*. 3rd edition ed. 2010, Berkshire, England: Open University Press.
2. World Health Organization. *Definition of Palliative Care*. 2017 [cited 2020 31 July 2020]; Available from: <http://www.who.int/cancer/palliative/definition/en/>.
3. Palliative Care Australia, *Guidelines for a Palliative Approach in Residential Aged Care: self directed learning package - manual*. 2013.
4. End-of-life essentials: education for acute hospitals. *Introducing specialist palliative care services*. 2016 March 2018]; Available from: <https://www.caresearch.com.au/caresearch/Portals/0/EoLEssentials/MJA-8-Introducing-specialist-palliative-care-services.pdf>.
5. Elliott, M. and C. Nicholson, *A qualitative study exploring use of the surprise question in the care of older people: perceptions of general practitioners and challenges for practice*. *BMJ Supportive & Palliative Care*, 2017. 7(1): p. 32-38.
6. Vickerstaff, V., N. White, N. Kupeli, and P. Stone, *60 Can the 'surprise question' be used to correctly identify people nearing the end of life?: a review*. *BMJ Supportive & Palliative Care*, 2017. 7(3): p. A371-A371.
7. Palliative Care Australia. *National Palliative Care Standards*. 2018 31 July 2020]; 5th Edition: [Available from: <http://palliativecare.org.au/standards>].
8. Palliative Care Australia. *Palliative Care Service Development Guidelines*. 2018 31 July 2020]; Available from: <https://palliativecare.org.au/quality>.
9. Palliative Care Australia, *Background Report to the Palliative Care Service Development Guidelines, Aspx consulting*, Melbourne. 2018.
10. Higginson, I.J., C. Bausewein, C.C. Reilly, W. Gao, M. Gysels, M. Dzingina, P. McCrone, S. Booth, C.J. Jolley, and J. Moxham, *An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial*. *Lancet Respir Med*, 2014. 2(12): p. 979-87.
11. Murray, S.A., M. Kendall, G. Mitchell, S. Moine, J. Amblàs-Novellas, and K. Boyd, *Palliative care from diagnosis to death*. *BMJ*, 2017. 356.
12. Tassinari, D., F. Drudi, M.C. Monterubbianesi, L. Stocchi, I. Ferioli, A. Marzalani, E. Tamburini, and S. Sartori, *Early Palliative Care in Advanced Oncologic and Non-Oncologic Chronic Diseases: A Systematic Review of Literature*. *Rev Recent Clin Trials*, 2016. 11(1): p. 63-71.
13. Palliative Care Australia, *National Standards Assessment Program. Quality Report 2010-2015*. 2016, Canberra: Palliative Care Australia.
14. Australian Government Department of Health. *What is palliative care?* 2019 31 July 2020]; Available from: <https://www.health.gov.au/health-topics/palliative-care/about-palliative-care/what-is-palliative-care>.
15. Palliative Care Australia. *What is Palliative Care?* 2015 31 July 2020]; Available from: <https://palliativecare.org.au/what-is-palliative-care>.
16. Australian Commission on Safety and Quality in Health Care. *Person-centred care*. 2019 [cited 2020 21 Aug]; Available from: <https://www.safetyandquality.gov.au/our-work/partnering-consumers/person-centred-care>.
17. Ateş, G., A.F. Ebenau, C. Busa, Á. Csikos, J. Hasselaar, B. Jaspers, J. Menten, S. Payne, K. Van Beek, S. Varey, M. Groot, and L. Radbruch, *"Never at ease" - family carers within integrated palliative care: a multinational, mixed method study*. *BMC palliative care*, 2018. 17(1): p. 39-39.
18. CareSearch. *Living with Life-Limiting Illness*. 2018 27 April 2020]; Available from: [https://www.caresearch.com.au/Caresearch/Portals/0/Fact-Sheets/CareSearch\\_FactSheet\\_Living-with-Life-limiting-Illness.pdf](https://www.caresearch.com.au/Caresearch/Portals/0/Fact-Sheets/CareSearch_FactSheet_Living-with-Life-limiting-Illness.pdf).
19. Gawande, A., *Being Mortal: illness, medicine and what matters in the end*. 2014, Great Britain: Profile Books Ltd.
20. CareSearch. *Quality of Life*. 2017 27 April 2020]; Available from: <https://www.caresearch.com.au/caresearch/tabid/1077/Default.aspx>.
21. Palliative Care Australia. *National Palliative Care Standards*. 2018; 5th Edition: [Available from: <http://palliativecare.org.au/standards>].
22. Walbert, T., *Maintaining quality of life near the end of life: hospice in neuro-oncology*. *Neuro-Oncology*, 2018. 20(4): p. 439-440.
23. Sartorius, N., *The Meanings of Health and its Promotion*. *Croatian medical journal*, 2006. 47(4): p. 662-664.
24. Palliative Care Expert Group, *Principles of symptom management*, in *Therapeutic Guidelines: palliative care*. 2016, Therapeutic Guidelines Limited: Melbourne. p. 135-143.
25. Haun, M.W., et al., *Early palliative care for adults with advanced cancer*. *Cochrane Database Syst Review*. 2017. 6: p. Cd011129.
26. Murtagh, F.E.M., C. Bausewein, J. Verne, E.I. Groeneveld, Y.E. Kaloki, and I.J. Higginson, *How many people need palliative care? A study developing and comparing methods for population-based estimates*. *Palliative Medicine*, 2013. 28(1): p. 49-58.
27. Detering, K.M., A.D. Hancock, M.C. Reade, and W. Silvester, *The impact of advance care planning on end of life care in elderly patients: randomised controlled trial*. *BMJ*, 2010. 340.
28. Mitchell, G., J. Tieman, and T. Shelby-James, *Multidisciplinary care planning and teamwork in primary care*. *Medical Journal of Australia*, 2008. 21(188(8Suppl)): p. S61-61.
29. Australian Government. Department of Health. *Find a palliative care service provider*. 2019 03 Aug 2020]; Available from: <https://www.health.gov.au/health-topics/palliative-care/planning-your-palliative-care/find-a-palliative-care-service-provider>.

30. Australian Commission on Safety and Quality in Health Care. *National Safety and Quality Health Service Standards*. 2012; Available from: <https://www.safetyandquality.gov.au/sites/default/files/migrated/NSQHS-Standards-Sept-2012.pdf>.
31. Australian Commission on Safety and Quality in Health Care. *National Consensus Statement: Essential elements for safe and high-quality end-of-life care*. 2015 [cited 2020 04 Aug]; Available from: <https://www.safetyandquality.gov.au/publications-and-resources/resource-library/national-consensus-statement-essential-elements-safe-and-high-quality-end-of-life-care>.
32. Amblàs-Novellas, J., S.A. Murray, J. Espauella, J.C. Martori, R. Oller, M. Martínez-Muñoz, N. Molist, C. Blay, and X. Gómez-Batiste, *Identifying patients with advanced chronic conditions for a progressive palliative care approach: a cross-sectional study of prognostic indicators related to end-of-life trajectories*. *BMJ Open*, 2016. 6(9): p. e012340.
33. Beernaert, K., K. Pardon, L. Van den Block, D. Devroey, M. De Laat, K. Geboes, V. Surmont, L. Deliens, and J. Cohen, *Palliative care needs at different phases in the illness trajectory: a survey study in patients with cancer*. *European Journal of Cancer Care*, 2016. 25: p. 534-543.
34. Skornick-Bouchbinder, M., J. Cohen-Mansfield, and S. Brill, *Trajectories of End of Life: A Systematic Review*. *The Journals of Gerontology: Series B*, 2017. 73(4): p. 564-572.
35. Gardiner, C., C. Ingleton, M. Gott, and T. Ryan, *Exploring the transition from curative care to palliative care: a systematic review of the literature*. *BMJ Supportive & Palliative Care*, 2015. 5(4): p. 335.
36. Downar, J., R. Goldman, R. Pinto, M. Englesakis, and N.K.J. Adhikari, *The "surprise question" for predicting death in seriously ill patients: a systematic review and meta-analysis*. *CMAJ : Canadian Medical Association Journal*, 2017. 189(13): p. E484-E493.
37. Thomas, K. *Principles and materials for The Gold Standards Framework*. 2018 05 Aug 2020]; Available from: <http://www.goldstandardsframework.org.uk/>.
38. Moss, A.H., J. Ganjoo, S. Sharma, J. Gansor, S. Senft, B. Weaner, C. Dalton, K. MacKay, B. Pellegrino, P. Anantharaman, and R. Schmidt, *Utility of the "surprise" question to identify dialysis patients with high mortality*. *Clin J Am Soc Nephrol*, 2008. 3(5): p. 1379-84.
39. Ellershaw, J., S. Dewar, and D. Murphy, *Achieving a good death for all*. *BMJ*, 2010. 341.
40. University of Edinburgh. *SPICT*. 2019 [cited 2020 FEB 27]; Available from: <https://www.spict.org.uk/the-spict/spict-4all/>.
41. Advance Care Planning Australia. *Advance Care Planning Australia*. 2018 05 Aug 2020]; Available from: <https://www.advancecareplanning.org.au/>.
42. Austin Health. *Advance Care Planning*. 2020 05 Aug 2020]; Available from: <https://www.austin.org.au/advancecareplanning#:~:text=Advance%20care%20planning%20is%20a,make%20or%20communicate%20their%20decisions>.
43. Swerissen, H. and S. Duckett, *Dying Well*. 2014: Grattan Institute.
44. Ramanayake, R.P.J.C., G.V.A. Dilanka, and L.W.S.S. Premasiri, *Palliative care; role of family physicians*. *Journal of Family Medicine and Primary Care*, 2016. 5(2): p. 234-237.
45. Palliative Care Expert Group, *Therapeutic Guidelines: palliative care*. 4 ed. 2016, Melbourne: Therapeutic Guidelines Limited.
46. Narayanan, V., B. Bista, and C. Koshy, *'BREAKS' Protocol for Breaking Bad News*. *Indian Journal of Palliative Care*, 2010. 16(2): p. 61-65.
47. Therapeutic Guidelines Ltd. *Communicating with the patient in palliative care*. *Palliative Care* 2016 [cited 2018 4 July]; eTG July 2017 edition:[Available from: [https://tgldcdp.tg.org.au/viewTopic?topicfile=communicating-with-palliative-care-patient&guidelineName=Palliative%20Care#toc\\_d1e47](https://tgldcdp.tg.org.au/viewTopic?topicfile=communicating-with-palliative-care-patient&guidelineName=Palliative%20Care#toc_d1e47)].
48. Ha, J.F. and N. Longnecker, *Doctor-Patient Communication: A Review*. *The Ochsner Journal*, 2010. 10(1): p. 38-43.
49. Kourkouta, L. and I.V. Papatathanasiou, *Communication in Nursing Practice*. *Materia Socio-Medica*, 2014. 26(1): p. 65-67.
50. Ciałkowska-Rysz, A. and T. Dzierżanowski, *Personal fear of death affects the proper process of breaking bad news*. *Archives of Medical Science : AMS*, 2013. 9(1): p. 127-131.
51. Woo, J.A., G. Maytal, and T.A. Stern, *Clinical Challenges to the Delivery of End-of-Life Care*. *Primary care companion to the Journal of clinical psychiatry*, 2006. 8(6): p. 367-372.
52. Patvardhan, C., *Breaking bad news*. *BMJ*, 2005. 330(7500): p. 1131.
53. Buckman, R., *Communications and emotions*. *BMJ*, 2002. 325(7366): p. 672.
54. Griffiths, J., G. Ewing, C. Wilson, M. Connolly, and G. Grande, *Breaking bad news about transitions to dying: A qualitative exploration of the role of the District Nurse*. *Palliative Medicine*, 2015. 29(2): p. 138-146.
55. Clayton, J., P. Butow, M. Tattersall, R. Devine, J. Simpson, G. Aggarwal, K. Clark, D. Currow, L. Elliott, and J. Lacey, *Randomized controlled trial of a prompt list to help advanced cancer patients and their caregivers to ask questions about prognosis and end of life care*. *Journal of Clinical Oncology*, 2007. 25(6): p. 715 - 723.
56. Kaplan, M., *SPIKES: a framework for breaking bad news to patients with cancer*. *Clin J Oncol Nurs*, 2010. 14(4): p. 514-6.
57. prepared

58. Benkel, I., H. Wijk, and U. Molander, *Challenging conversations with terminally ill patients and their loved ones: Strategies to improve giving information in palliative care*. SAGE Open Medicine, 2014. **2**: p. 2050312114532456.
59. Coyle, N., *The Hard Work of Living in the Face of Death*. Journal of Pain and Symptom Management, 2006. **32**(3): p. 266-274.
60. Barnes, J., L. Kroll, O. Burke, J. Lee, A. Jones, and A. Stein, *Qualitative interview study of communication between parents and children about maternal breast cancer*. BMJ, 2000. **321**(7259): p. 479.
61. Moore, C., M. Pengelly, and P. Rauch, *Communicating with children when a parent is dying*, in *Handbook of Communication in Oncology and Palliative Care*, D. Kissane, B. Bultz, and P. Butow, Editors. 2010, OUP Oxford: Oxford.
62. Muriel, A.C., C.W. Moore, L. Baer, E.R. Park, A.B. Kornblith, W. Pirl, H. Prigerson, J. Ing, and P.K. Rauch, *Measuring psychosocial distress and parenting concerns among adults with cancer: the Parenting Concerns Questionnaire*. Cancer, 2012. **118**(22): p. 5671-8.
63. Australian Bureau of Statistics. *Estimates of Aboriginal and Torres Strait Islander Australians*,. 2018 [cited 2020 19 Aug]; Available from: <https://www.abs.gov.au/ausstats/abs@.nsf/mf/3238.0.55.001>.
64. Halm, M.A., R. Evans, A. Wittenberg, and E. Wilgus, *Broadening cultural sensitivity at the end of life: an interprofessional education program incorporating critical reflection*. Holistic Nursing Practice, 2012. **26**(6): p. 335-349.
65. Kemp, C., *Cultural issues in palliative care*. Seminars in Oncology Nursing, 2005. **21**(1): p. 44-52.
66. Wiener, L., D.G. McConnell, L. Latella, and E. Ludi, *Cultural and religious considerations in pediatric palliative care*. Palliative & Supportive Care, 2013. **11**(1): p. 47-67.
67. Taylor, K. and P. Guerin, *Health care and indigenous Australians: cultural safety in practice*. 2010: Palgrave Macmillan.
68. Hughes, F.A. and N.J. Gray, *Cultural safety and the health of adolescents*. BMJ : British Medical Journal, 2003. **327**(7412): p. 457-457.
69. Richardson, S. and T. Williams, *Why is cultural safety essential in health care?* Med Law, 2007. **26**(4): p. 699-707.
70. Ellison-Loschmann, L., *Irihapeti Ramsden*. BMJ : British Medical Journal, 2003. **327**(7412): p. 453-453.
71. Australian Institute of Health and Welfare. *Causes of death. 2020* [cited 2020 19 Aug]; Available from: <https://www.aihw.gov.au/reports/australias-health/causes-of-death>.
72. Australian Institute of Health and Welfare. *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples: 2015*. 2017 09/06/2015 [cited 2018 27/06/2018]; Available from: <https://www.aihw.gov.au/reports/indigenous-health-welfare/indigenous-health-welfare-2015/data>.
73. Durey, A., S.C. Thompson, and M. Wood, *Time to bring down the twin towers in poor Aboriginal hospital care: addressing institutional racism and misunderstandings in communication*. Intern Med J, 2012. **42**(1): p. 17-22.
74. Larson, A., M. Gillies, P.J. Howard, and J. Coffin, *It's enough to make you sick: the impact of racism on the health of Aboriginal Australians*. Aust N Z J Public Health, 2007. **31**(4): p. 322-9.
75. Henry, B.R., S. Houston, and G.H. Mooney, *Institutional racism in Australian healthcare: a plea for decency*. Med J Aust, 2004. **180**(10): p. 517-20.
76. Oliver, S.J., *The role of traditional medicine practice in primary health care within Aboriginal Australia: a review of the literature*. Journal of Ethnobiology and Ethnomedicine, 2013. **9**: p. 46-46.
77. Shahid, S., L. Finn, D. Bessarab, and S.C. Thompson, *Understanding, beliefs and perspectives of Aboriginal people in Western Australia about cancer and its impact on access to cancer services*. BMC Health Services Research, 2009. **9**: p. 132-132.
78. Indigenous Allied Health Australia, *Cultural Responsiveness In Action: An IAHA Framework*. 2015.
79. Palliative Care Australia. *Improving access to quality care at the end of life for Aboriginal and Torres Strait Islander Australians*. 2015; Available from: <http://palliativecare.org.au/wp-content/uploads/2015/08/PCA-Palliative-care-and-Indigenous-Australians-position-statement-updated-16-8-11.pdf>.
80. Butler, M., E. Ratner, E. McCreedy, N. Shippee, and R.L. Kane, *Decision aids for advance care planning: an overview of the state of the science*. Ann Intern Med, 2014. **161**(6): p. 408-18.
81. Thomas, K., B. Lobo, and K. Detering, *Advance care planning in end of life care*. 2017: Oxford University Press.
82. Johnston, N., C. Lovell, W.-M. Liu, M. Chapman, and L. Forbat, *Normalising and planning for death in residential care: findings from a qualitative focus group study of a specialist palliative care intervention*. BMJ Supportive & Palliative Care, 2016.
83. Hudson, P., K. Quinn, B. O'Hanlon, and S. Aranda, *Family meetings in palliative care: Multidisciplinary clinical practice guidelines*. BMC Palliative Care, 2008. **7**(1): p. 12.
84. The University of Queensland and Blue Care Research and Practice Development Centre, *The Palliative Approach Toolkit*. 2012, The University of Queensland: Queensland.
85. Murray, S.A., M. Kendall, K. Boyd, and A. Sheikh, *Illness trajectories and palliative care*. BMJ : British Medical Journal, 2005. **330**(7498): p. 1007-1011.
86. Barraclough, J., *ABC of palliative care: Depression, anxiety, and confusion*. BMJ, 1997. **315**(7119): p. 1365-1368.
87. CareSearch. *Advance Care Planning*. Clinical Evidence 2017 [cited 2019 February 18]; Available from: <https://www.caresearch.com.au/caresearch/tabid/450/Default.aspx>.

88. Advance Care Planning Australia. *Advance Care Planning Australia*. 2018 [cited 2018 March 20]; Available from: <https://www.advancecareplanning.org.au/>.
89. CareSearch. *Advance Care Planning*. 2020 23 April 2020]; Available from: <https://www.caresearch.com.au/caresearch/tabid/450/Default.aspx>.
90. Mullick, A., J. Martin, and L. Sallnow, *An introduction to advance care planning in practice*. BMJ : British Medical Journal, 2013. 347.
91. Detering, K. and J. Clayton, *Advance care planning in Australia*. *Advance Care Planning in End of Life Care*, 2017: p. 195.
92. Commonwealth of Australia. *Planning for end of life*. 2018 [cited 2018 June 17]; Available from: <https://www.myagedcare.gov.au/end-life-care/planning-end-life>.
93. RACGP. *Practice Guides and Tools - Advance Care Planning*. 2018 [cited 2018 June 17]; Available from: <https://www.racgp.org.au/guidelines/advancecareplans>.
94. Australia Centre for Health Law Research. *Legal Overview*. 2017 [cited 2017 May 3]; Available from: <https://end-of-life.qut.edu.au/legal-overview>.
95. Australia Centre for Health Law Research. *End of life law in Australia: Legal overview*. 2019 [cited 2020 19 Aug]; Available from: <https://end-of-life.qut.edu.au/legal-overview>.
96. Dening, K.H., *Advance care planning and people with dementia*. *Advance Care Planning in End of Life Care*, 2017: p. 93.
97. Carter, R.Z., K.M. Detering, W. Silvester, and E. Sutton, *Advance care planning in Australia: what does the law say?* Aust Health Rev, 2015.
98. Australia Centre for Health Law Research. *About this website: Glossary*. 2018 23 Jul 2020]; Available from: <https://end-of-life.qut.edu.au/about/glossary>.
99. World Health Organization. *Definition of Palliative Care*. 2017 31 July 2020]; Available from: <http://www.who.int/cancer/palliative/definition/en/>.
100. Palliative Care Australia. *Palliative Care Service Development Guidelines*. 2018; Available from: [https://palliativecare.org.au/wp-content/uploads/dlm\\_uploads/2018/02/PalliativeCare-Service-Delivery-2018\\_web2.pdf](https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Service-Delivery-2018_web2.pdf).
101. International Association for the Study of Pain. *IASP Terminology*. 2018 2018 [cited 2018 8/10/2018]; The following pain terminology is updated from "Part III: Pain Terms, A Current List with Definitions and Notes on Usage" (pp 209-214) *Classification of Chronic Pain, Second Edition*, IASP Task Force on Taxonomy, edited by H. Merskey and N. Bogduk, IASP Press, Seattle, ©1994.]. Available from: <http://www.iasp-pain.org/Education/Content.aspx?ItemNumber=1698>.
102. Therapeutic Guidelines Ltd, *Fatigue in palliative care*. 2019: Melbourne.
103. Therapeutic Guidelines Ltd, *Gastrointestinal symptoms in palliative care*. 2019: Melbourne.
104. Nazarko, L., *The management of dysphagia in palliative care*. *International Journal of Palliative Nursing*, 2017. 23(4): p. 162-164.
105. palliAGED. *Tips for Careworkers: Dysphagia*. 2019 06FEB2020 ]; Available from: [https://www.palliaged.com.au/Portals/5/Documents/Practice-Tip\\_Sheets/Dysphagia-Careworkers.pdf](https://www.palliaged.com.au/Portals/5/Documents/Practice-Tip_Sheets/Dysphagia-Careworkers.pdf).
106. Fearon, K., F. Strasser, S.D. Anker, I. Bosaeus, E. Bruera, R.L. Fainsinger, A. Jatoi, C. Loprinzi, N. MacDonald, G. Mantovani, M. Davis, M. Muscaritoli, F. Ottery, L. Radbruch, P. Ravasco, D. Walsh, A. Wilcock, S. Kaasa, and V.E. Baracos, *Definition and classification of cancer cachexia: an international consensus*. *Lancet Oncol*, 2011. 12(5): p. 489-95.
107. Suzuki, H., A. Asakawa, H. Amitani, N. Nakamura, and A. Inui, *Cancer cachexia—pathophysiology and management*. *Journal of Gastroenterology*, 2013. 48(5): p. 574-594.
108. Collis, E. and H. Mather, *Nausea and vomiting in palliative care*. *Bmj*, 2015. 351: p. 6249.
109. Ketwaroo, G.A., V. Cheng, and A. Lembo, *Opioid-induced bowel dysfunction*. *Current gastroenterology reports*, 2013. 15(9): p. 344-344.
110. Muller-Lissner, S., G. Bassotti, B. Coffin, A.M. Drewes, H. Breivik, E. Eisenberg, A. Emmanuel, F. Laroche, W. Meissner, and B. Morlion, *Opioid-Induced Constipation and Bowel Dysfunction: A Clinical Guideline*. *Pain Med*, 2017. 18(10): p. 1837-1863.
111. Therapeutic Guidelines Ltd, *Respiratory symptoms in palliative care*. 2019: Melbourne.
112. Sariarslan, H.A., Y.B. Gulhan, D. Unalan, M. Basturk, and S. Delibas, *The relationship of sleep problems to life quality and depression*. *Neurosciences*, 2015. 20(3): p. 236-242.
113. Therapeutic Guidelines Ltd, *Neurological and neuromuscular symptoms in palliative care*. 2019: Melbourne.
114. Therapeutic Guidelines Ltd, *Psychological symptoms in palliative care*. 2019: Melbourne.
115. Therapeutic Guidelines Ltd, *Dermatological symptoms in palliative care*. 2019: Melbourne.
116. Bishurul Hafi, N.A. and N.A. Uvais, *Palliative Dermatology*. *Indian journal of palliative care*, 2018. 24(3): p. 385-386.
117. Kavalieratos, D., J. Corbelli, D. Zhang, J.N. Dionne-Odom, N.C. Ernecoff, J. Hanmer, Z.P. Hoydich, D.Z. Ikejiani, M. Klein-Fedyshin, C. Zimmermann, S.C. Morton, R.M. Arnold, L. Heller, and Y. Schenker, *Association Between Palliative Care and Patient and Caregiver Outcomes: A Systematic Review and Meta-analysis*. *JAMA*, 2016. 316(20): p. 2104-2114.
118. Therapeutic Guidelines Ltd, *Principles of symptom management in palliative care*. 2018: Melbourne.
119. Chang, V., *Approach to symptom assessment in palliative care*. UpToDate, 2015.

120. McIlfratrick, S. and F. Hasson, *Evaluating an holistic assessment tool for palliative care practice*. J Clin Nurs, 2014. **23**(7-8): p. 1064-75.
121. Palliative Care Outcomes Collaboration. *Palliative Care Problem Severity Score (PCPSS)*. 2016 27 July 2020]; Available from: <https://www.uow.edu.au/ahsri/pcoc/aged-care/assessment-forms/>.
122. Palliative Care Outcomes Collaboration. *Symptom Assessment Scale (SAS)*. 2020 15 June 2020]; Available from: <https://www.uow.edu.au/ahsri/pcoc/palliative-care/assessment-forms/>.
123. Palliative Care Outcomes Collaboration. *Functional Assessment in Palliative Care (RUG-ADL & AKPS)*. 2016 [cited 2017 March 3]; Available from: <http://ahsri.uow.edu.au/pcoc/functionassessment/index.html>.
124. CareSearch. *Symptom Management*. Clinical Evidence 2018 [cited 2019 February 14]; Available from: <https://www.caresearch.com.au/caresearch/tabid/1466/Default.aspx>.
125. Mitsuhashi, S., S. Ballou, Z.G. Jiang, W. Hirsch, J. Nee, J. Iturrino, V. Cheng, and A. Lembo, *Characterizing Normal Bowel Frequency and Consistency in a Representative Sample of Adults in the United States (NHANES)*. Am J Gastroenterol, 2018. **113**(1): p. 115-123.
126. Lloyd, A., M. Kendall, J.M. Starr, and S.A. Murray, *Physical, social, psychological and existential trajectories of loss and adaptation towards the end of life for older people living with frailty: a serial interview study*. BMC Geriatrics, 2016. **16**(1): p. 176.
127. Palliative Care Australia. *Learn more about pain management*. 2015; Available from: <https://palliativecarewa.asn.au/wp-content/uploads/Pain-Management.pdf>.
128. CareSearch. *Pain*. Clinical Evidence: Patient Management 2012 [cited 2014 June 12]; Available from: <http://www.caresearch.com.au/caresearch/tabid/746/Default.aspx>.
129. Deravin-Malone, L. and J. Anderson, *Chronic Care Nursing*. 2016: Cambridge University Press.
130. Brant, J., *Strategies to manage pain in palliative care*, in *Palliative care nursing: A guide to practice*, M. O'Connor, S. Lee, and S. Aranda, Editors. 2012, Ausmed Publications: Ascot Vale, Vic.
131. Butler, D.S. and G.L. Moseley, *Explain Pain*. 2013, Adelaide, Australia: Noigroup Publications. 113.
132. Dedeli, O. and G. Kaptan, *Spirituality and Religion in Pain and Pain Management*. Health Psychology Research, 2013. **1**(3): p. e29.
133. Givler, A.M.-F., Patricia A, *Cultural Competence in Pain and Palliative Care*. [Updated 2018 Apr 5]. 2018: StatPearls Publishing.
134. Dueñas, M., B. Ojeda, A. Salazar, J.A. Mico, and I. Failde, *A review of chronic pain impact on patients, their social environment and the health care system*. Journal of Pain Research, 2016. **9**: p. 457-467.
135. Kovanur Sampath, K. and D.E. Roy, *Barriers to identifying mood disorders in clients by New Zealand osteopaths: Findings of a thematic analysis*. International Journal of Osteopathic Medicine, 2018. **28**: p. 4-11.
136. Block, C. and L. Cianfrini, *Neuropsychological and neuroanatomical sequelae of chronic non-malignant pain and opioid analgesia*. NeuroRehabilitation, 2013. **33**(2): p. 343-66.
137. O'Connor, M., S. Lee, and S. Aranda, eds. *Palliative Care Nursing: A guide to practice*. 3 ed. 2012, Ausmed Publications: Ascot Vale, Vic.
138. Palliative Care Australia, *Facts about morphine and other opioids*. 2015: Deakin, ACT.
139. Patrick, D.L., S.L. Ferketich, P.S. Frame, J.J. Harris, C.B. Hendricks, B. Levin, M.P. Link, C. Lustig, J. McLaughlin, L.D. Ried, r.A.T. Turrisi, J. Unützer, S.W. Vernon, and P. National Institutes of Health State-of-the-Science, *National Institutes of Health State-of-the-Science Conference Statement: Symptom Management in Cancer: Pain, Depression, and Fatigue, July 15-17, 2002*. Journal of the National Cancer Institute, 2003. **95**(15): p. 1110-1117.
140. Thomas, S.A., *Spinal stenosis: history and physical examination*. Phys Med Rehabil Clin N Am, 2003. **14**(1): p. 29-39.
141. World Health Organization. *WHO's cancer pain ladder for adults*. Cancer: Palliative Care 2017 [cited 2017 July 30]; Available from: <http://www.who.int/cancer/palliative/painladder/en/>.
142. Lussier, D., A.G. Huskey, and R.K. Portenoy, *Adjuvant Analgesics in Cancer Pain Management*. The Oncologist, 2004. **9**(5): p. 571-591.
143. Palliative Care Expert Group, *Therapeutic Guidelines: palliative care*. 3 ed. 2010, Melbourne: Therapeutic Guidelines Limited.
144. CPCRE. *GP Pain Help App*. 2018 [cited 2018 October 10]; Welcome to the GP Pain Help App, to help GPs manage cancer pain in their patients. ]. Available from: [http://www.gppainhelp.com/Content\\_Hub\\_Choice\\_Opioid.html](http://www.gppainhelp.com/Content_Hub_Choice_Opioid.html)
145. Therapeutic Guidelines Ltd. *Pain: opioid therapy in palliative care*. Palliative Care 2016 [cited 2017 March 27]; Available from: [https://tgldcdp.tg.org.au/viewTopic?topicfile=palliative-care-pain-opioid-therapy#toc\\_d1e47](https://tgldcdp.tg.org.au/viewTopic?topicfile=palliative-care-pain-opioid-therapy#toc_d1e47).
146. CareSearch. *Opioid Analgesics*. Professional Groups: Managing Symptoms 2018 [cited 2018 October 10]; Available from: <https://www.caresearch.com.au/caresearch/tabid/749/Default.aspx>.
147. Drewes, A.M., R.D. Jensen, L.M. Nielsen, J. Droney, L.L. Christrup, L. Arendt-Nielsen, J. Riley, and A. Dahan, *Differences between opioids: pharmacological, experimental, clinical and economical perspectives*. British Journal of Clinical Pharmacology, 2013. **75**(1): p. 60-78.

148. Singh, P. and A. Chaturvedi, *Complementary and Alternative Medicine in Cancer Pain Management: A Systematic Review*. Indian Journal of Palliative Care, 2015. 21(1): p. 105-115.
149. Smith, C.A., C.T. Collins, A.M. Cyna, and C.A. Crowther, *Complementary and alternative therapies for pain management in labour*. Cochrane Database of Systematic Reviews, 2006(4).
150. Chen, L. and A. Michalsen, *Management of chronic pain using complementary and integrative medicine*. BMJ, 2017. 357.
151. CareSearch. *Non Pharmacological Approaches*. Clinical Evidence 2018 [cited 2018 October 10]; Available from: <https://www.caresearch.com.au/caresearch/tabid/751/Default.aspx>.
152. Gorczyca, R., R. Filip, and E. Walczak, *Psychological aspects of pain*. Ann Agric Environ Med, 2013. Spec no. 1: p. 23-7.
153. Boström, B., M. Sandh, D. Lundberg, and B. Fridlund, *Cancer patients' experiences of care related to pain management before and after palliative care referral*. European Journal of Cancer Care, 2004. 13(3): p. 238-245.
154. Niv, D. and S. Kreitler, *Pain and quality of life*. Pain Pract, 2001. 1(2): p. 150-61.
155. McCarberg, B.H., B.D. Nicholson, K.H. Todd, T. Palmer, and L. Penles, *The impact of pain on quality of life and the unmet needs of pain management: results from pain sufferers and physicians participating in an Internet survey*. Am J Ther, 2008. 15(4): p. 312-20.
156. Hassanijirdehi, M., M. Khak, S. Afshari-Mirak, K. Holakouie-Naieni, S. Saadat, T. Taheri, and V. Rahimi-Movaghar, *Evaluation of Pain and Its Effect on Quality of Life and Functioning in Men with Spinal Cord Injury*. The Korean Journal of Pain, 2015. 28(2): p. 129-136.
157. Clode, D., *The Conspiracy of Silence: Emotional health among medical practitioners*, R.A.C.o.G. Practitioners, Editor. 2004, Royal Australian College of General Practitioners.
158. Meier, D.E., A.L. Back, and R.S. Morrison, *The inner life of physicians and care of the seriously ill*. JAMA, 2001. 286(23): p. 3007-14.
159. Lowry, F., *Does doctors' own fear of dying hinder palliative care?* CMAJ, 1997. 157(3): p. 301-2.
160. Shanafelt, T., A. Adjei, and F.L. Meyskens, *When your favorite patient relapses: physician grief and well-being in the practice of oncology*. J Clin Oncol, 2003. 21(13): p. 2616-9.
161. Barrett, L. and P. Yates, *Oncology/haematology nurses: a study of job satisfaction, burnout, and intention to leave the specialty*. Australian Health Review, 2002. 25(3): p. 109-121.
162. Girgis, A. and V. Hansen, *Prevalence and predictors of burnout in the COSA oncology workforce*. 2007.
163. Sanchez-Reilly, S., L.J. Morrison, E. Carey, R. Bernacki, L. O'Neill, J. Kapo, V.S. Periyakoil, and L. Thomas Jde, *Caring for oneself to care for others: physicians and their self-care*. J Support Oncol, 2013. 11(2): p. 75-81.
164. CareSearch. *Self-Care*. 2017 June 06, 2017]; Available from: <https://www.caresearch.com.au/caresearch/tabid/3462/Default.aspx>.
165. Kelley, T.M., *At Personal Risk: Boundary Violations in Professional-Client Relationships*, by Marilyn R. Peterson (Book Review). Journal of comparative family studies., 1994. 25(3): p. 422.
166. CareSearch. *Professional Boundaries*. CareSearch Hubs: Allied Health Hub Home 2013 [cited 2014 June 12]; Available from: <http://www.caresearch.com.au/caresearch/tabid/2752/Default.aspx>.
167. Bird, S., *Managing professional boundaries*. Australian Family Physician, 2013. 42: p. 666-668.
168. Chittenden, E.H. and C.S. Ritchie, *Work-life balancing: challenges and strategies*. J Palliat Med, 2011. 14(7): p. 870-4.
169. Queensland Mental Health Commission. *Wheel of Wellbeing Rolls On*. 2018 20 Aug 2020]; Available from: <https://www.qmhc.qld.gov.au/media-events/news/wheel-of-wellbeing-rolls-on>.
170. Kamal, A., J. Bull, S. Wolf, G. Samsa, K. Ast, K.M. Swetz, T.D. Shanafelt, and A.P. Abernethy, *Burnout among palliative care clinicians in the United States: Results of a national survey*. Journal of Clinical Oncology, 2014. 32(15\_suppl): p. e20530-e20530.
171. RACGP. *Self-care and mental health resources for general practitioners*. 2018 [cited 2018 August 17, 2018]; Available from: <https://www.racgp.org.au/guidelines/advancecareplans>.
172. Bowman, J., *Dealing with job stress: peer support, time management, and self-care are key*. Prof Case Manag, 2007. 12(5): p. 252-3.
173. Shanafelt, T.D., P. Novotny, M.E. Johnson, X. Zhao, D.P. Steensma, M.Q. Lacy, J. Rubin, and J. Sloan, *The well-being and personal wellness promotion strategies of medical oncologists in the North Central Cancer Treatment Group*. Oncology, 2005. 68(1): p. 23-32.
174. Cohen-Katz, J., S.D. Wiley, T. Capuano, D.M. Baker, and S. Shapiro, *The effects of mindfulness-based stress reduction on nurse stress and burnout: a quantitative and qualitative study*. Holist Nurs Pract, 2004. 18(6): p. 302-8.
175. Coster, J.S. and M. Schwebel, *Well-functioning in professional psychologists*. Professional Psychology: Research and Practice, 1997. 28(1): p. 5-13.
176. Novack, D.H., A.L. Suchman, W. Clark, R.M. Epstein, E. Najberg, and C. Kaplan, *Calibrating the physician. Personal awareness and effective patient care. Working Group on Promoting Physician Personal Awareness, American Academy on Physician and Patient*. Jama, 1997. 278(6): p. 502-9.

177. Novack, D.H., R.M. Epstein, and R.H. Paulsen, *Toward creating physician-healers: fostering medical students' self-awareness, personal growth, and well-being*. Acad Med, 1999. **74**(5): p. 516-20.
178. CareSearch. *Burnout*. Information for nurses 2017 16 November 2017]; Available from: <https://www.caresearch.com.au/caresearch/tabid/2179/Default.aspx>.
179. Kabat - Zinn, J., *Mindfulness - Based Interventions in Context: Past, Present, and Future*. Clinical Psychology: Science and Practice, 2006. **10**(2): p. 144-156.
180. Beddoe, A.E. and S.O. Murphy, *Does mindfulness decrease stress and foster empathy among nursing students?* J Nurs Educ, 2004. **43**(7): p. 305-12.
181. Shapiro, S.L., J.A. Astin, S.R. Bishop, and M. Cordova, *Mindfulness-Based Stress Reduction for Health Care Professionals: Results From a Randomized Trial*. International Journal of Stress Management, 2005. **12**(2): p. 164-176.

# Record of Participation

This is to record that

---

Has completed

## PEPA Learning Guide for Medical Practitioners

### Learning Outcomes

After completing the Medical Practitioner Learning Guide you will have a better understanding of:

- The principles of palliative care
- Strategies for communicating with patients and families about prognosis and goals and preferences for care
- Core skills and principles required for GPs when undertaking advance care planning and Advance Directives
- The principles for the management of common symptoms and health concerns associated with life-limiting illnesses.
- The principles for the assessment and management of pain in the palliative care recipient
- Self-care strategies to effectively manage the personal issues related to working in the palliative care field
- Resources to support medical practitioners to provide palliative care.

---

Learning Hours\*

Date completed

Signature





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

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

