

Implementation guide



PCC4U

PALLIATIVE CARE
CURRICULUM FOR
UNDERGRADUATES

Funded by the Australian Government
Department of Health

Student learning resources 2014

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About the PCC4U project

The Palliative Care Curriculum for Undergraduates (PCC4U) project, funded by the Australian Government Department of Health, directly articulates with goals 1, 2 and 5 of the National Palliative Care Strategy 2010.

The PCC4U project aims to promote and sustain the inclusion of the principles and practice of palliative care in all health care training. It supports the inclusion of palliative care through the provision of:

- a suite of evidence-based student and facilitator learning resources
- capacity building and professional development activities.

The learning resources are based upon four core graduate capabilities identified as being integral for health professionals to provide a palliative approach to care for persons with a life-limiting illness. Specifically, undergraduate and entry to practice courses in the health professions should aim to develop graduates who, within the scope of practice of their profession, are able to demonstrate the following capabilities in the context of caring for a person with a life-limiting illness:

- effective communication in the context of an individual's responses to loss and grief, existential challenges, uncertainty and changing goals of care
- appreciation of and respect for the diverse human and clinical responses of each individual throughout their illness trajectory
- understanding of principles for assessment and management of clinical and supportive care needs
- the capacity for reflection and self evaluation of one's professional and personal experiences and their cumulative impact on the self and others.

The PCC4U project learning resources are freely available on the project website www.pcc4u.org. The project team is available to assist with any aspect of using the learning materials. To access support, please contact pcc4u@qut.edu.au. For more information about the project, including governance, the project team and outcomes and achievements, go to www.pcc4u.org.

About the project resources

The PCC4U learning resources were developed in 2005 following a range of consultative activities and evidence reviews. The resources are subject to regular review and update in response to emerging priorities and evidence in palliative care.

PRINCIPLES FOR INCLUDING PALLIATIVE CARE IN UNDERGRADUATE CURRICULA



This publication provides a framework and guiding principles for curriculum design, implementation and evaluation. Content includes:

- graduate capabilities
- core values underpinning the learning and teaching of palliative care
- benchmarks for inclusion of the palliative approach in undergraduate curricula
- teaching, learning and assessment strategies.

PALLIATIVE CARE LEARNING MODULES AND TOPICS

The PCC4U student learning resources contain four student-centred core modules and four focus topics, each covering aspects of palliative care relevant to undergraduate and entry to practice students in the health care professions. Within each module or topic students experience the story of someone facing a life-limiting illness.

The learning modules and topics are available to students online at www.pcc4u.org. The video vignettes are also available on DVD. The modules have been designed to be integrated into a variety of curriculum contexts and delivered via a range of flexible modes. Each module includes a range of active learning activities designed to develop one or more of the graduate capabilities for health professionals in palliative care. These learning activities provide opportunities for students to:

- explore key practice concepts relevant to the capability
- understand the experience of individuals living with a life-limiting condition
- promote critical reflection and apply learning
- consider expert's opinions and experiences of practice in the field
- identify and review current evidence and information resources.

Each module includes key learning tools to achieve these outcomes, including a series of 'thinking points' and a separate video case scenario integrated throughout the module. The video case scenario provides an opportunity to meet an individual with a life-limiting condition at various points in their journey, reflect on the experience of individuals and apply concepts to practice. A selection of expert videos are also available.

Depending on desired learning outcomes, the modules can be used in whole or in part and delivered in a range of different formats including:

- workshop activities
- interactive tutorials
- self-directed learning
- lecture presentations
- group discussions.

This implementation guide provides information about the specific content and components of each module, and aims to support the educator to map and integrate the learning modules within and across their own curriculum.

ONLINE TEACHING AND LEARNING RESOURCE COMPENDIUM

The resource compendium, available at the Teaching and Learning Hub at www.pcc4u.org/teaching-and-learning-hub/ includes a comprehensive and current compilation of resources to support the inclusion of palliative care in health curricula. It includes:

- materials to support the integration of the modules and topics into new and existing health curricula:
 - this implementation guide
 - curriculum blueprint
 - curriculum examples in palliative care
 - simulation scenario
 - interprofessional materials, including audio-visual resources and a multi-professional case scenario
 - workbook
- an option to download videos for embedding into Blackboard, Moodle or other learning management system
- materials to support student learning in palliative care:
 - relevant texts and academic reference materials
 - useful web links
 - audio visual resources
 - popular literature and resources from the arts.

www.pcc4u.org



Using the PCC4U learning modules

CORE MODULES & FOCUS TOPICS

The **core modules** articulate with the graduate capabilities in palliative care.

The core modules are:

- **Module 1:** Principles of palliative care
- **Module 2:** Communicating with people with life-limiting illnesses
- **Module 3:** Palliative assessment & intervention
- **Module 4:** Optimising function in palliative care

The **focus topics** aim to support learning about palliative care in specific populations and contexts.

The focus topics are:

- **Topic 1.** A multidisciplinary approach in palliative care
- **Topic 2.** Caring for Aboriginal people with life-limiting conditions
- **Topic 3.** Caring for children with life-limiting conditions
- **Topic 4.** Culture-centred care of people with life-limiting conditions

STRUCTURE OF THE MODULES AND TOPICS

The modules and topics are organised into **sections**, then into **activities**. It is recommended that students work through the sections in order, as the information contained in each section builds on information that precedes it.

The content contains links to **thinking points**. These are questions related to the content. Click on either the link in the right-hand column or in the text to see the questions.

Each module / topic contains a **video vignette**. The videos are an important part of this learning resource. They show the individual's experiences over time when facing a life-limiting illness, from diagnosis to end-of-life. Thinking points also follow each section of video content. There are also videos of health care professionals providing their advice on palliative care.

Students can copy thinking point questions straight into their notebook using the 'Copy text to notebook' button at the top of the thinking points window. Notes will only be saved until the internet browser is closed. To keep a copy of their notes, students should either copy them into another program or print them.

RESOURCES

This section is located under the module and topic menu on the left side of the website. This includes web links to support student learning, evidence and symptom summaries and a glossary.

HOW TO USE THE PCC4U LEARNING MODULES

This section includes a guide to help students use the learning modules. It describes the structure of the modules, the role of the thinking points questions, use of the notebook and print functions.

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MODULE 1

Principles of palliative care

To provide health care that's relevant to community needs, you need to understand the experiences, preferences and care requirements for people with life-limiting illnesses.

OVERVIEW

MODULE 1: Principles of palliative care will help you develop the knowledge and skills needed to provide quality care, across various health care settings, to people with life-limiting illnesses and their families.

AIMS & OBJECTIVES

You'll develop an understanding of the social and personal experiences of people with life-limiting illnesses and their families. This module will also cover the core principles of palliative care.

After completing this module, you should be able to:

- analyse the impact historical trends have on community perceptions about death, dying and bereavement in contemporary society
- recognise how your own values and beliefs about death and dying affect your responses and interactions with people with life-limiting illnesses and their families
- describe the core principles of palliative care.

SECTION 1

Death & dying in contemporary society

In this section you will:

- reflect on various meanings of death and dying in contemporary society and how they relate to a person's own experiences of dying
- consider how your own values and beliefs may influence how you interact with a person with a life-limiting illness
- consider the diversity of cultural issues and needs associated with death and dying.

ACTIVITY 1: Factors influencing death & dying

In the 20th century Australia, like many western nations, witnessed dramatic changes in terms of:

- how people were cared for when they were dying
- what they died from
- where they died.

Some factors influencing death and dying in Australia today include:

- improved sanitation and hygiene
- industrialisation
- scientific advances in the diagnosis and treatment of disease
- immunisation programs.

Today, people are living longer and are more likely to die from chronic diseases. For example, the most common causes of death in Australia in recent years were cardiovascular disease and cancer. Other important changes are reflected in data indicating that deaths due to dementia and Alzheimer's disease have moved from the seventh leading cause in 1998 to the fourth leading cause in 2007.^[1]

Trends in the management of death and dying in western societies

Some factors that have affected death and dying in western societies include:

- the institutionalisation of death and dying i.e. more people dying in hospitals or long-term care settings
- the professionalisation of many aspects of death and dying, such as the certification of death by the medical profession and the disposal of bodies by the funeral industry
- the increasing use of medical technology to prolong life.

1. Australian Bureau of Statistics. (2007). *Causes of Death Report, Australia*. Retrieved January 18, 2010, from <http://www.abs.gov.au/ausstats/abs@.nsf/Products/9982A795F3C13BE2CA25757C001EF4D9?opendocument>.

THINKING POINTS

1. Think about how death is depicted through the media. Consider television programmes, movies, books and magazines.
 - a) Choose an example and in your notebook describe:
 - who is dying?
 - where are they dying?
 - why are they dying?
 - who is involved in the scene?
 - b) In what ways are the media depictions similar or different to your own experiences or observations of where and how people die and how they react to death?
2. What historical developments have been most influential in shaping attitudes and beliefs about death and dying in western societies in the 20th century? Consider factors such as:
 - scientific advances
 - information technology
 - health care developments
 - demographic changes
 - consumerism.
3. Some commentators argue that modern western society is 'death denying' or 'death avoiding'.

Give some examples that would:

 - a) Support this argument
 - b) Contradict this argument.

In responding to this question, think about issues such as:

 - community and healthcare professionals' perceptions
 - the allocation of healthcare resources
 - the experiences of people with life-limiting illnesses.

ACTIVITY 2: Individual factors influencing death & dying

Various social changes and medical advances have influenced the way death and dying is experienced by people in contemporary western societies.

Other factors that influence how individuals experience dying include:

- age: we tend to see death as something that happens in older age. This can make the death of younger people difficult to understand. It can also mean older people who are dying might receive less support because their death is 'expected'.
- culture: the meaning given to illness, dying and death in different cultures can influence how an individual deals with the experience. For example, culture may influence the family's role at this time, communication patterns, or feelings of optimism or fatalism.
- religion: religious beliefs can influence death rituals and beliefs about the afterlife. For some it may provide a source of meaning, while for others it may create a sense of conflict or distress.

- past experience with death and dying: some people may have no experience with dying, and may be uncertain and fearful of what may occur. Others may be anxious about dying because of the negative experiences of someone they have known or heard about.

Influence of culture

Culture is the 'lens' through which we view the world and interpret or make sense of the experiences of life including illness, dying and death. ^[1]

Culture is a system of interrelated values active enough to influence patterns of thought, behaviours, communication styles and beliefs about life and death. ^[2]

Some important points to consider about culture include:

- culture is a dynamic construct. values and beliefs can change from one generation to the next depending on life experiences.
- cultural groups can vary according to where people live (urban, rural or remote regions), the type of environment and education. It is important not to stereotype a person based on their identified cultural background.
- your personal attitudes and beliefs can block or distort how you are perceived by people from different cultures.

THINKING POINTS

1. Think about how you and your immediate family react and respond to death and dying. What cultural or personal factors influenced the way you or your family reacted when someone close to you died? If you haven't experienced the death of someone close to you, consider how you think it would make you feel.
2. Discuss with others their experiences or observations of:
 - a) Practices associated with death and dying in different cultures, age groups, and religions
 - b) Differences within the same cultural groups.
3. How do you think your own culture, age, and religion influence the way you will provide care

1. Blacker, S. & Raines, J.A. (2004). Working with families facing life-threatening illness in the medical setting. In: J. Berzoff & P. Silverman (Eds.), *Living with dying. A hand book for end-of-life healthcare practitioners*. (pp. 548-570). New York, NY: Columbia University Press.

2. Airhihenbuwa, C. (1995). *Health and Culture: Beyond the western paradigm*. Thousand Oaks, California: Sage Publications.

ACTIVITY 3: Cultural factors influencing death & dying

Cultural safety is a framework developed by Maori nurse, Irahapeti Ramsden in the late 1980s. Cultural safety extends beyond cultural awareness and cultural sensitivity and has at its core the experience of the person receiving care.^[1] Cultural safety principles aim to ensure:

- individuals receive care that meets their cultural needs and promotes feelings of being safe^[1, 2]
- individuals are not afforded less favourable outcomes because they hold a different cultural outlook^[2]
- care provided is regardful of culture^[2]

A culturally safe approach to care requires health professionals to:

- be aware and mindful of their personal attitudes and values towards gender, race, religion and sexuality
- be self-aware and reflect on their practice
- understand post-colonisation
- apply the principles of effective communication and be aware of different styles of communication
- be inclusive
- act respectfully and to empower individuals^[2]
- promote shared respect, meaning, knowledge and experiences.

Unsafe cultural practice occurs when actions diminish, demean or disempower the cultural identity of an individual.^[2]

THINKING POINTS

1. Describe the key elements of cultural safety.
2. What can you do to avoid stereotypes and ensure that you apply the principles of cultural safety to every individual in your care?

1. The Nguyen, H. (2008). Patient-centred care: Cultural safety in indigenous health. *Australian Family Physician*, 37(12), 990-994.

2. Taylor, K. & Guerin, P. (2010). *Health Care and Indigenous Australians: Cultural safety in practice*. Melbourne, VIC: Palgrave Macmillan.

ACTIVITY 4: William's Story

William is a 60-year-old man who grew up in a large family in a regional area of Australia. Over the years, like many of his generation, he has seen amazing improvements in the quality of health care and life expectancy. This is due to such things as the introduction of immunisation, antibiotics and new medical technology.

William has also seen how family structures have changed. He has seen the introduction of aged care facilities to care for frail older people who were previously cared for by their families at home.

William is faced with the possibility that he may be diagnosed with a life-limiting illness. William is concerned about a change in his normal bowel habits and has gone to his GP for advice.



William's story

THINKING POINTS

1. William said he thought he had an outside chance of living to a 'ripe old age' and that he doesn't usually think much about dying.
 - a) How might such beliefs influence how William responds to a diagnosis of a potential life-limiting illness?
 - b) What societal and personal factors may have contributed to William's beliefs? Some factors you might like to consider in some detail include:
 - scientific developments
 - demographic changes
 - William's past experience with death
 - William's age.
2. How might William's cultural background influence his response to his illness?
3. How might this response differ for a person who comes from a different cultural background?
4. What is your immediate reaction to William's situation?
5. What do you think influences your reactions? Consider your:
 - age
 - culture
 - religious beliefs
 - family background and personal experience.

SECTION 2

Caring for people with life-limiting illnesses

In this section you will:

- develop your understanding of the main principles of care for people with life-limiting illnesses
- consider the groups that may benefit from palliative care and how to deliver care to meet people's needs.

ACTIVITY 5: Assessing people's needs

To provide health care that's relevant to community needs, it is important to understand the experiences, preferences and care requirements for people with life-limiting illnesses.

People with advanced cancer and other life-limiting illnesses may experience a variety of needs that can vary in complexity and severity during the illness trajectory.

Common needs and preferences for people with life-limiting illnesses include:

- management of physical symptoms such as pain, weakness, fatigue and dyspnoea
- management of psychological symptoms
- need for social support
- culturally specific needs related to language problems and information disclosure preferences
- need for information about treatment, diagnosis or prognosis
- spiritual and existential concerns including hope, loss of meaning and uncertainty
- financial concerns such as loss of income and medical costs
- legal concerns such as preferences for end-of-life care and advanced care directives.^[1]

A range of assessment tools are available to assist health professionals to undertake a needs assessment.

THINKING POINTS

1. What are some of the common concerns people facing life-limiting illnesses might have?
2. Refer to the [palliative care needs assessment tool](#). Discuss with others:
 - a) The key needs that these guidelines will assess
 - b) How such guidelines can be used in practice.
3. What are some of the physical, psychological and social changes that could make a person with a life-limiting illness feel a loss of control?
4. What are the reasons that people often fear pain and other symptoms even when effective symptom management may be available?

1. Waller, A., Girgis, A., Currow, D. & Lecathelinais, C. (2008). Development and pilot testing of the Palliative Care Needs Assessment Tool (PC-NAT). *Palliative Medicine*, 22(8), 956-964.

ACTIVITY 6: Understanding quality of life

Palliative care is a specialised area of health care that's been developed to respond to the type of needs described in the previous section.

Palliative care was developed in the 1960s after it was recognised that the care provided to people with life-limiting illnesses in institutions (e.g. hospitals) needed to be improved.

There are a number of palliative care definitions. The World Health Organization (WHO) has the most well-known definition. It describes palliative care as:

'... an approach that improves quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.'^[1]

Key points in the WHO approach

- the palliative approach comes early in the course of an illness, not just as end-of-life care.
- there is an emphasis on promoting holistic care to ensure physical, psychological, social and spiritual well-being.
- the family and significant others are included in the care process.
- there is an emphasis on impeccable assessment, early identification of problems and implementation of appropriate treatments.
- disease modifying treatments, such as chemotherapy and radiotherapy, may have a role.
- palliative care can be provided in any setting.
- there is an emphasis on a team approach to care.

Improving the quality of life of patients and their families is a central goal of palliative care. Defining what quality of life means for each person is not a straight forward process. This is because quality of life is:

- multidimensional: many different aspects of a person's life (physical, emotional, social, and spiritual) can be important to his or her quality of life
- subjective: defined and experienced by each person in unique ways
- dynamic: quality of life can change over time.

1. World Health Organization (WHO). (1998). *WHO Definition of Palliative Care*. Retrieved January 25, 2010, from <http://www.who.int/cancer/palliative/definition/en/>.

THINKING POINTS

1. How do you define quality of life?
2. How does your definition compare with those of other students or your family and friends?
3. How might a person's definition of quality of life be similar or different as their illness progresses?
4. Why is it important for health care professionals to understand a person's perception of quality of life and how it changes over time?
5. Assessment and early identification of problems is a feature of palliative care.
 - a) Within the context of your own discipline's scope of practice, give a specific example of a potential problem that you could identify early.
 - b) Describe the process you would use to support early identification of the problem.
5. The World Health Organization's (WHO) definition of palliative care states that 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'.
 - a) Discuss what is meant by 'early in the course of a life-limiting illness'.
 - b) How does the WHO palliative care definition fit with your understanding of, and experience with, the concept of palliative care?

ACTIVITY 7: Ethical issues & end of life

Ethical issues that arise towards the end of life may be complex. Some examples of ethical issues encountered in palliative care are:

- method and timing of conversations with family members around the imminent death of a loved one
- deciding when to withdraw futile treatment options and communicating this to the patient and their family
- advance care planning (this is discussed in detail in Module 4).

Ethical principles which guide actions and responses to these situations are consistent with principles applied in all areas of health care. These principles include:

- beneficence
- self-determination
- confidentiality
- justice and non-maleficence.^[1,2]
- respect
- truth telling
- informed consent

1. Palliative Care Expert Group. (2010). Ethical Issues. In Palliative Care Expert Group, *Therapeutic guidelines: palliative care*. Version 3. Melbourne, VIC: Therapeutic Guidelines Limited.

2. Palliative Care Australia. (2009). *Advance Care Planning Position Statement*. Retrieved September 15, 2010, from [http://www.palliativecare.org.au/Portals/46/PCA Advance Care Planning Position Statement.pdf](http://www.palliativecare.org.au/Portals/46/PCA%20Advance%20Care%20Planning%20Position%20Statement.pdf)

THINKING POINTS

1. Refer to the ethical guidelines which inform your professional practice.
 - a) How would you respond in a situation where a caregiver has asked you not to inform the patient about their illness?
 - b) How do you respond to a patient who tells you that they have 'had enough' and no longer want treatment?
2. Search some recent literature and identify some definitions of the term 'futile treatment'.
3. In what ways could definitions of futility differ between patients and health professionals, and between different health professionals?

ACTIVITY 8: Who needs palliative care?

Palliative care is provided to people, regardless of age, who have life-limiting illnesses. It's not dependent on a specific medical diagnosis, but on a person's needs. It may be beneficial for people with health needs and problems, including:

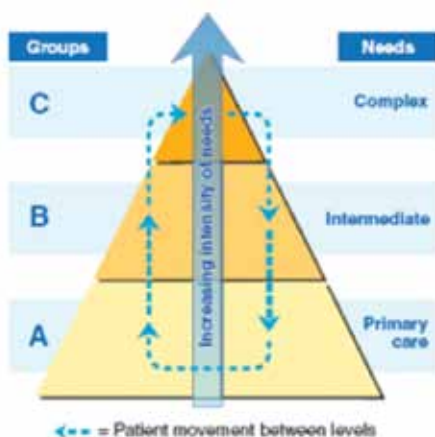
- cancer
- HIV/AIDS
- motor neurone disease
- muscular dystrophy
- cystic fibrosis
- multiple sclerosis
- end-stage dementia
- end-stage respiratory disease
- end-stage cardiac disease
- end-stage liver disease
- end stage renal failure
- older people dying as a consequence of the ageing process
- degenerative conditions or significant deterioration related to ageing.^[1]

There are many factors determining the type of health service provided to people with life-limiting illnesses and their families.

Palliative Care Australia has defined three broad subgroups to illustrate the type of care people need.

1. Commonwealth of Australia. (2010). *National Palliative Care Strategy: A national framework for palliative care service development*. Retrieved August 8, 2012, from <http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-strategy.htm>.

The following diagram is a model of the level of need within the population of individuals with a life-limiting illness.



Remember! A key factor influencing the type of service to provide people with life-limiting illnesses is the intensity of their needs.

Primary care needs

Many people with life-limiting illnesses may have access to their own resources, or have the support of primary health care services that effectively meet their needs. These people may not require specialist palliative care services.

Intermediate needs

Other people may experience occasional problems, such as an exacerbated physical symptom or psychological need that requires more attention than the primary caregivers are able to provide. In these cases, what's needed is access to a specialist palliative care service for advice, while they continue being cared for by their primary health care professional.

Complex needs

There are people who have more complex physical, social, psychological and/or spiritual needs. These people may need specialist practitioners, who work in partnership with primary care providers to develop, implement and evaluate specific care plans. This group will typically benefit from being referred to a specialist palliative care service.^[1]

Key concepts to consider

- All people with life-limiting illnesses have a right to health care that's appropriate to their needs.
- Not everyone with a life-limiting illness will require access to a specialist palliative care service. For many people, care needs can be met by community and personal resources and the support of primary health care services.
- As a health care professional, you are likely to come into contact with people in a variety of settings who may benefit from palliative support. All health care professionals, therefore, need knowledge and skills in providing palliative care.

1. Palliative Care Australia. (2005). *A guide to Palliative Care Service Development: A population based approach*. Retrieved September 15, 2010, from <http://www.palliativecare.org.au/Portals/46/Factsheet - palliative care service development.pdf>.

THINKING POINTS

1. Review Palliative Care Australia's publication Standards for providing quality palliative care for all Australians and identify the key points distinguishing the following definitions:
 - palliative approach
 - specialist palliative care provider.
2. How do you determine who has adequate support and who requires the support of a specialist palliative care service? Consider:
 - a) Issues associated with a person's health needs
 - b) The personal resources and strengths they can draw from.

ACTIVITY 9: William - One year later

It's been one year since William's colonoscopy showed he had stage III colorectal cancer, indicating regional lymph node involvement. Over the past year he had a colon resection and six months of chemotherapy. He has been seeing his GP every two months and has been attending the outpatient colorectal clinic every six months for follow up.

On his 12-month follow up, liver metastases were found. His cancer is now considered stage IV colorectal cancer. Palliative chemotherapy is available in some situations to control such advanced disease. However, William has worsening liver function and is physically too unwell to tolerate chemotherapy.

The surgeon has indicated to William that his prognosis is poor. William and his wife Gladys are at the GP's surgery to discuss what the oncologist from the colorectal clinic has recommended.



William one year later

THINKING POINTS

Think about the principles of palliative care that you've reviewed and how they might apply in William's situation.

1. What do you think are William's and Gladys's main concerns at this time?
2. What are the key messages the GP provides in relation to William's future care? How did the GP communicate these messages?
3. How could you improve on this interaction to ensure William and Gladys get optimal support and information about the role of palliative care?

ACTIVITY 10: William's illness progresses

William has now developed significant pain from his liver metastases and his GP has referred him to a specialist palliative care service. The specialist team keeps in close contact with the GP and his community nurse.

William and his wife are talking to the community nurse and discussing his current needs. Having assessed how he's managing physically, the community nurse recognises that William is becoming less mobile and is increasingly fatigued.

The community nurse begins to explore with William and his wife future options for care as his disease progresses and he becomes physically more frail.



William's illness progresses

THINKING POINTS

1. What factors influence when specialist palliative care would be helpful for people such as William and Gladys?
2. What are some of the decisions that William and Gladys could need to make as William's disease progresses?

SECTION 3

Standards for providing palliative care

In this section you will:

- review Palliative Care Australia's Standards for Providing Quality Palliative Care for all Australians

ACTIVITY 11: Palliative Care Australia's Standards

Palliative Care Australia has standards that describe the dimensions and elements of quality of care for all Australians.

They provide an important framework for all health care professionals involved in caring for people with life-limiting illnesses and their families.^[1]

These standards are based on values and principles of dignity, empowerment, compassion, equity, respect, advocacy, excellence and accountability.

They define standards for health care professionals in generalist or primary care settings and for specialist care. The standards are, therefore, relevant for all health care professionals, not just specialist palliative care services.

Achieving quality palliative care requires access to and use of current evidence. CareSearch is a comprehensive online resource that brings together evidence-based and quality information for many groups within the palliative care community, including students.^[2]

THINKING POINTS

1. Review Standard 1 of Palliative Care Australia's Standards for providing Quality Palliative Care for all Australians. It states that 'care, decision-making and care planning are each based on a respect for the uniqueness of the patient, their caregiver/s and family'. Reflect on the specific strategies that you, as a beginning health care professional, would apply in your practice to meet this standard when caring for people with life-limiting illnesses and their families?
2. Visit the CareSearch website, select 'Constipation' and 'Spirituality' and review the strongest evidence for both of these topics. Write down the key points from these articles.

1. Palliative Care Australia. (2005). *Standards for Providing Quality Palliative Care for all Australians*. Retrieved September 15, 2010, from www.palliativecare.org.au/portals/46/resources/StandardsPalliativeCare.pdf.

2. CareSearch. (2011). *Caresearch Home Page*. Retrieved November 28, 2011, from www.caresearch.com.au.

SECTION 4

Reflections on what you've learnt

1. What key points have you learnt from the activities in this module that will help you in providing care for people with life-limiting illnesses and their families?
2. What specific strategies do you plan to incorporate as a graduate health care professional?
3. Do you see any difficulties using what you've learnt here as part of your practice as a health care professional? If so, what strategies might you use to address these difficulties?



William's Story

A4: WILLIAM'S STORY

▶ 1.32 mins

I've always thought I had good genes; both me mum and dad lived until they were well in their nineties so I thought good outside chance I might live until a ripe old age too. That is until recently, I discovered that when I went to the toilet there was blood on the paper and in the bowl, now he wants me to go and have a colonoscopy, he wants to look up inside the bowel. It's a bit of a worry; you know you don't even think about dying until somebody sends you off for a test like this one. Then you're convinced you're going to have cancer. You're not going to be able to do all the things that you want to do with your life.

A9: WILLIAM – ONE YEAR LATER

▶ 2.49 mins

Doctor: Bill you know from your visit to Dr. Maxwell that they've found the cancer has come back in your liver.

William: Yeh, yeh he said that.

Doctor: What did Dr. Maxwell tell you about what happens from here on in?

William: *Sigh* Well, he told me that the treatment hadn't worked, um and the chemotherapy wouldn't help me anyway. He just couldn't tell me how long I had left. I asked him, he said, he said a few months.

Doctor: Yes

William: *Sigh* So what do I do now, do I just wait around for something to happen. I have so many questions; I mean 'How much pain will I be in?' 'Do I have to go into hospital?' It's too much to think about.

Doctor: Well Dr. Maxwell has sent me the report and I've had a look at the scans. It's quite understandable that you have a lot of questions and a lot of concerns at this time. And It's also important to know that even though the chemotherapy is not going to help you very much at this point, there are a lot of other things that can be done; and I'll be working with a group of skilled health professionals to make sure that things are as good as possible for as long as possible. Would you like me to go through some of the options that are available to you at this time?

William's wife: Yeh that'll be good.

William: Yeh we'd appreciate that.

Doctor: Yeh, well the most important thing is that everyone is an individual but there are some things that can be predicted, some physical and emotional health problems that can arise and it's important for us to keep a very close eye on you to identify those problems early and try to prevent them if we can, but also to try to treat them as early as possible. Bill, is there anything in particular that's worrying you at this time?

William: Well it's hard really, I don't know. I'm worried about Gladys, how she'll cope, and how we'll manage once we get home and I get too sick.

Doctor: Well most people want to be as independent and active as possible for as long as possible. We can engage specialists in medicine, palliative medicine, and palliative nursing, to be able to help you and monitor your progress, they can also identify things and treat them as early as possible. With that support it is possible for most people to stay at home and be active for quite a long time.

William's wife: Okay

William: Well that's better than I thought

William's wife: Yeh, yeh

William: They'll book you straight into a hospital or something, that's good.

A10: HIS ILLNESS PROGRESSES

▶ 2.29 mins

Nurse: So can you just tell me how things have been going for you both since I last saw you.

William: Yeh, not too bad Linda, my appetite's still lousy and I'm in a bit of pain, but you were right those tablets do take the edge right off it, but I don't wanna take that liquid morphine anymore, it makes me too drowsy.

Nurse: Okay so you've got some problems with your appetite and some problems with your pain. The GP, has he been contacting you regularly?

William: Yeh, well I sometimes feel the need to move my medications around a bit, so I just call up the office and make an appointment. The girls are great; they just always seem to be able to fit me in.

Nurse: Do they keep contact?

William: Yeh, there was that social worker that came by last week, she showed us the legal documents to fill in when I get to the point where I can no longer make decisions for myself.

Nurse: Now, I wanted to talk a bit more about your pain and appetite problems, but is there any other sorts of things that you want to talk to me about today?

William: Sighs. Yeh, well look um, I'm unsure as to whether I should go into the hospice or the hospital, when the time comes, when I can no longer be managed from here. Hospital is closer, but everyone says the hospice is great and all the specialists are there on tap. So I just don't know what to do.

Nurse: Have you and Gladys discussed it together?

William: Yeh, look I want to stay at home of course, but the kids have all got their own families and they mostly got work full time, none of them live nearby anyway. So I think when the time comes I should be looked after elsewhere.

Nurse: Well there are a few things we can do. One thing we can do is to increase your services here at home, to you know try and help you stay at home here, but you know if something comes up out of left field, where you're having some problems, you can go into the hospital or into the palliative care unit and hopefully get that sorted out and then possibly come back home again.



MODULE 2

Communicating with people with life-limiting illnesses

Providing support for people with life-limiting illnesses requires you to understand the meaning of the illness and its effects on individuals. It's vital to identify and acknowledge an individual's concerns and sources of distress, and respond to these effectively.

OVERVIEW

MODULE 2: Communicating with people with life-limiting illnesses will help you develop your skills in communicating with people with life-limiting illnesses and their families.

AIMS & OBJECTIVES

After completing this module, you should be able to:

- demonstrate the principles of effective communication when interacting with people with life-limiting illnesses and their families
- identify sources of psychological, social and spiritual support for people with life-limiting illnesses and their families
- recognise how your own values and beliefs about death and dying affect your personal responses and interactions with people with life-limiting illnesses and their families.

SECTION 1

The experience of being diagnosed with a life-limiting illness

In this section you will:

- learn about psychological and existential challenges faced by people with life-limiting illnesses
- learn about the various challenges faced by people with life-limiting illnesses and how different people cope with different challenges.

ACTIVITY 1: The challenges faced

People with life-limiting illnesses experience a range of psychological, social and spiritual challenges. Each person's experience and response will be different. This is because the challenges faced can arise from many different sources, including:

- fear of death and dying
- 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
- feelings of loss of worth
- loss of the sense of dignity
- fears of being a burden or a dependent
- fears of suffering
- concerns about appearance and body image.

Responding to the challenges

People may respond to these challenges in many different ways. For example, some people will express fear or anxiety while others may be sad, withdrawn, depressed, or angry.

Some may express feelings of helplessness, a sense of guilt, or have problems making decisions. Others feel a sense of peace, purpose and contentment with life, or experience that their relationships with family and friends get stronger.

'Existential distress' is a term used to describe the distress people can experience when confronted by their own existence. People may experience existential distress when facing issues of the meaning in life or a threat to their sense of personal worth. They can also experience existential distress if they feel their personal beliefs are being challenged or they suffer feelings of loss.^[1]

1. Yalom, I. (1980). *Existential Psychotherapy*. New York, NY: Basic Books.

THINKING POINTS

1. Consider a person you have cared for who has been diagnosed with a life-limiting illness. What were the main sources of distress for this person and how did you know these were concerns?
2. What are some of the reasons that individuals can respond differently when diagnosed with a life-limiting illness?

ACTIVITY 2: Michelle's story

Michelle is 38 years old and lives with her partner Peter. They have two children aged 9 and 12.

Michelle was diagnosed 2 years ago with triple negative breast cancer, a particularly difficult cancer to treat as it is negative for oestrogen receptors, progesterone receptors and HER2. She had initial treatment but has recently been experiencing a nagging cough and slight breathlessness.

Michelle goes to her GP to get things checked out.



Michelle's story

THINKING POINTS

1. What are some of the fears and concerns that Michelle might experience at this time?
2. What are your immediate personal reactions to Michelle's situation?

SECTION 2

Supportive communication

In this section you will:

- develop your supportive communication skills
- learn how to identify the concerns of people with life-limiting illnesses
- learn how to determine the best ways to respond to the needs and concerns of people with life-limiting illnesses.

ACTIVITY 3: Communication principles

Providing support to people with life-limiting illnesses requires you to use communication skills that enable you to understand the meaning of the illness and its effects on the person. It also requires being able to identify the person's concerns and why he or she may be distressed.

Some people may not be used to discussing personal psychological issues and may find these conversations difficult. There are some general communication strategies that may help facilitate discussion about existential and psychological concerns, and demonstrate respect for the person's individuality.

Table 1 shows key strategies that can be used when communicating with a person with a life-limiting illness and their family. The acronym PREPARED is used to convey these strategies.

TABLE 1

P	Prepare for the discussion, where possible
R	Relate to the person
E	Elicit patient and caregiver preferences
P	Provide information tailored to the individual needs of both patients and their families
A	Acknowledge emotions and concerns
R	(foster) Realistic hope (e.g. peaceful death, support)
E	Encourage questions and further discussions
D	Document

Prepare for the discussion:

- ensure facts about the patient's clinical circumstances are correct
- try to ensure privacy and uninterrupted time for discussion
- mentally prepare
- negotiate who should be present during the discussion e.g. "Is there anyone else you would like to be here with you while we talk?"

Relate to the person:

- develop a rapport
- show empathy, care and compassion during the entire consultation e.g. “This has been a tough time for you and your family...”
- broach the topic in a culturally appropriate and sensitive manner
- make eye contact (if culturally appropriate), sit close to the patient, use appropriate body language, allow silence and time for the patient to express feelings.

Elicit patient & caregiver preferences:

- identify the reason for this consultation and elicit the patient’s expectations
- clarify the patient’s or caregiver’s understanding of their situation and establish how much detail they want to know
- consider cultural and contextual factors influencing information preferences.

Provide information:

Provide information that is tailored to the individual needs of both patients and their families.

- offer to discuss what to expect, in a sensitive manner, giving the patient the option not to discuss it
- give information in small chunks at the person’s pace
- use clear, jargon-free, understandable language
- engage in active listening i.e. attend to the patient fully, reflect what you think they have said e.g. “If I’ve heard you right, you seem to be saying...”
- explain the uncertainty, limitations and unreliability of prognostic and end-of-life information e.g. “I know that often people expect doctors to know what is going to happen, but in truth we can often 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 ...”
- avoid being too exact with timeframes unless in the last few days
- consider the caregiver’s distinct information needs, which may require a separate meeting with the caregiver (provided the patient, if mentally competent, gives consent)
- try to ensure consistency of information and approach provided to different family members, the patient and clinical team members
- use the words ‘death’ and ‘dying’ where appropriate.

Acknowledge emotions & concerns:

- explore and acknowledge the patient’s and caregiver’s fears, concerns and their emotional reaction to the discussion e.g. “What worries you most about...?” or “What is your biggest concern at the moment?”
- be willing to initiate and engage in conversations about what may happen in the future and the dying process e.g. “Do you have any questions or other concerns?”
- respond to the patient’s or caregiver’s distress regarding the discussion, where applicable.

Realistic hope:

- be honest without being blunt or giving more detailed information than desired by the patient
- do not give misleading or false information to try to positively influence a patient’s hope

- reassure the patient that support, treatments and resources are available to control pain and other symptoms, but avoid premature reassurance
- explore and facilitate realistic goals and wishes and ways of coping on a day-to-day basis, where appropriate.

Encourage questions:

- encourage questions and information clarification; be prepared to repeat explanations
- check understanding of what has been discussed and whether the information provided meets the patient's and caregiver's needs
- e.g. "We've spoken about an awful lot just now. It might be useful to summarise what we've said ... Is there anything from that that you don't understand or want me to go over again?"
- leave the door open for topics to be discussed again in the future.

Document:

- write a summary in the medical record of what has been discussed
- speak or write to other key health care providers involved in the patient's care. As a minimum, this should include the patient's general practitioner. ^[1]



Expert Opinion

THINKING POINTS

1. Think about your experience of discussing existential and psychological concerns with patients.
 - a) What aspects of communication are you most comfortable with in this area?
 - b) What aspects of communication do you find challenging?
2. Using the principles described in this section, outline:
 - a) What communication strategies you use most commonly
 - b) What additional strategies you could implement in your practice
3. Watch the expert opinion piece where a General Practitioner is describing some key strategies for communicating challenging news to patients. How well do the medical practitioner's suggestions match the communication strategies identified in this section?

1. 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.
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ACTIVITY 4: Receiving distressing news

Michelle's CT scan shows her cough is caused by spread of the cancer to her lungs.

She also has evidence of metastases in her liver. She attends an appointment with Dr Meredith North, her medical oncologist. Meredith explains the significance of these results and what they mean for her prognosis and further treatment.



Receiving distressing news

THINKING POINTS

1. What do you think would be the main sources of distress for Michelle and Pete at this time?
2. What specific communication strategies did Meredith use to give the news to Michelle and Pete about the progression of her disease?
3. What additional communication strategies could the oncologist use to improve this interaction?

ACTIVITY 5: Understanding palliative treatment

Michelle's bone scan identifies that she also has metastatic deposits on her spine which are the cause of her back pain. Following these results Michelle's medical oncologist referred her to the radiation oncologist and a plan for some palliative radiation therapy has been put into place.

Michelle attends her planning appointment at the radiation therapy department. She sees Jeremy Peters, the radiation therapist, who responds to her questions about palliative radiotherapy. He orientates her to the radiation therapy department and the different types of equipment used in the planning process and the delivery of the radiation therapy.



Understanding palliative treatment

THINKING POINTS

1. What do you think would be the main sources of distress for Michelle at this time?
2. What specific communication strategies did Jeremy use to give the assist Michelle to understand the treatment she was to receive?
3. What additional communication strategies could the radiation therapist use to improve this interaction?

ACTIVITY 6: Michelle's illness progresses

Michelle attends a follow-up appointment with Dr Meredith North, her medical oncologist. She has completed her radiotherapy and has commenced the palliative chemotherapy. She is exhausted and looks unwell.

She is symptomatic with breathlessness and expresses her concern about this. Meredith assesses her breathlessness and develops a management plan with Michelle and Pete. As part of this plan, she introduces the concept of palliative care.



Michelle's illness progresses

THINKING POINTS

1. What do you think would be the main sources of distress for Michelle and Pete at this time?
2. What specific communication strategies did Meredith use to
 - a) Respond to her distress?
 - b) Introduce the concept of palliative care?
3. What additional communication strategies could the oncologist use to improve this interaction?

In this section you will:

- examine how health care professionals can respond effectively to specific concerns of parents about the effect of a life-limiting illness on their children.

ACTIVITY 7: How to communicate with children

Giving children support

Children of parents with life-limiting illnesses can experience stress and need support. When a parent is ill, the child's usual sources of support can often be disrupted.

The following information provides an outline of the factors affecting a child's responses to a parent's diagnosis of a life-limiting illness. The information was developed to inform a training package for health professionals working in this field. These factors are specific to three developmental stages.

The following information can be read in conjunction with the brochure, *What do parents want?* This is a helpful guide for parents with advanced cancer on how to communicate and handle things with their children. ^[1]

Developmental stages

It is recommended that you employ age-appropriate communication with the child. It is important to talk at their level of understanding and take cues from their responses.

1. Children up to 8 years

Younger children are egocentric. Important points to remember about this age group include:

- reinforcing that they are not being blamed for the cancer
- make sure they understand that their behaviour will have no influence on the outcome i.e. not telling them to 'be good' so that the parent can be well
- reassure them that they will always be safe and cared for.

2. Children between 8-12 years

Children in this age group may be concerned that they won't be accepted by their friends and peers and for some, being different for any reason may be distressing. Children in this age group need:

- relevant information aimed specifically for their level of understanding
- to maintain relationships with their peers
- to continue to participate in affirming activities, such as sport
- ongoing opportunities to talk about comments from their peers and how these comments make them feel.

1. Turner, J., Clavarino, A., Yates, P., Hargraves, M., Connors, V. & Hausmann, S. (2007). Development of a resource for parents with advanced cancer: *What do parents want?* *Palliative and Supportive Care*, 5(2), 135-145.

3. Children 12 years and up

Adolescents are particularly vulnerable when a parent is seriously ill. Background tension is likely to be exacerbated. Adolescents need:

- acknowledgement and discussion of changed family roles
- negotiation rather than imposition of domestic tasks
- to maintain their social relationships
- access to specific and relevant information about death and dying
- many opportunities to talk openly about the cancer with their parents.^[2]

Avoiding communication about dying can sometimes cause more worry and keep children from telling others how they feel. However it may also be harmful to confront children with information that they are not ready to take in.

THINKING POINTS

1. What are the main issues for children when a parent has a life-limiting illness?
2. How might these concerns vary depending on the child's age?
3. How would you respond to a parent who is concerned about the effect of their illness on their children?

ACTIVITY 8: Raising concerns

Michelle is receiving her palliative chemotherapy in the day chemotherapy unit. Dawn Matthews, the cancer nurse co-ordinator, visits the unit to see how Michelle and Pete are going. Michelle and Pete raise concerns about telling their children that Michelle's condition is deteriorating. Dawn works through these concerns with them and suggests strategies to help them address these concerns.



Raising concerns

THINKING POINTS

1. What do you think would be the main concerns that Michelle and Pete have about discussing Michelle's prognosis with them?
2. What specific suggestions did Dawn provide to assist Michelle and Pete?
3. What specific communication strategies did Dawn use to provide this advice?
4. What additional strategies could Dawn use to improve this interaction?

2. Turner, J., Clavarino, A., Yates, P., Hargraves, M., Connors, V. & Hausmann, S. (2008). Enhancing the supportive care of parents with advanced cancer: Development of a self-directed educational manual. *European Journal of Cancer*, 12(44), 1625-1631.

SECTION 4

Providing person-centred support

In this section you will:

- expand on the general communication skills that help show support and identify concerns
- review some specific sources of concern or distress and consider communication strategies that may be helpful.

ACTIVITY 9: Understanding sources of distress

People with life-limiting illnesses face many losses which can make them distressed and sad.

Giving people the chance to express how they feel about their losses and concerns can often help them cope. Sometimes, helping people to focus on what's important to them and emphasising what can be done, can also help.

A life-limiting illness affects not only the person with the illness, but his or her family and friends. People with life-limiting illnesses can also become concerned about their appearance and body image and about changing relationships with those close to them, including sexual relationships.

Traditionally, in western societies, 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. As a health care professional, you need to let people with life-limiting illnesses know that you're prepared to talk with them about any concerns they have about these issues.

It's important to understand how the supportive communication skills discussed in the previous section of this module can be used to identify an individual's specific concerns.

The Patient Dignity Inventory (PDI) is an example of an assessment tool designed to help clinicians detect end-of-life dignity-related distress. Using such tools can help to identify the particular sources of a person's distress. This helps caregivers to individualise supportive interventions. ^[1]

THINKING POINTS

1. Review the Patient Dignity Inventory and list the key sources of distress that are assessed by this tool.
2. What are the potential barriers that may hinder discussions between health professionals and patients about their distress?
3. What strategies might a health care professional use to introduce sensitive issues, such as spirituality, intimacy or sexuality?
4. What specific open-ended questions may assist in introducing these topics?

1. Chochinov, H.M., Hassard, T., McClement, S., Hack, T., Kristjanson, L.J., Harlos, M., Sinclair, S. & Murray, A. (2008). The patient dignity inventory: a novel way of measuring dignity-related distress in palliative care. *Journal of Pain & Symptom Management*, 36(6), 559-571.

ACTIVITY 10: Responding to losses

It is now a few months since Michelle was given the news that her cancer had progressed. She has been receiving palliative chemotherapy to help control her disease, but is finding that her personal and social relationships are changing. She has requested an appointment to see Dawn Matthews, the Cancer Care Coordinator, as she is feeling very flat and worried about how she is coping. Dawn arranges for Michelle to see her prior to her scheduled chemotherapy.



Responding to losses

THINKING POINTS

1. Use the Patient Dignity Inventory to identify some of Michelle's sources of distress at this time.
2. What communication strategies does Dawn engage to encourage Michelle to talk about her concerns?
3. What other strategies might be used to support an individual who:
 - a) Expresses concerns about how their illness has affected relationships with people close to them?
 - b) Feel the illness is affecting their personal appearance and body image?
4. As a health care professional, what can you do to help a person, such as Michelle, feel in control when their illness is progressing?
5. Dawn asks Michelle if she would be interested in seeing a psychologist for support. In what circumstances should referral to a psychologist be considered?

In this section you will:

- learn about the essence of spiritual care when looking after someone with a life-limiting illness.

ACTIVITY 11: Understanding spiritual needs

As a health care professional you may at times feel ill-equipped to respond to the spiritual dimension of care. Although you are not expected to have all the answers recognising the importance of spiritual care is paramount.

Spirituality is often seen as being the same as religious beliefs. For some people, spirituality comes from their religious beliefs and commitments.

However it has also been suggested that "spiritual assessment should thus not impose a view, let alone a definition, of spirituality. Instead it should seek to elicit the thoughts, memories and experiences that give coherence to a person's life."^[1]

Undertaking a spiritual assessment

Key criteria for undertaking a spiritual assessment include:

- respect patients' perspectives and do not infringe privacy
- involve all members of the multidisciplinary team to the extent that they are able and willing to contribute
- permit clear documentation of needs, strategic responses to these needs, resources required, and outcomes
- integrate strategies into an overall care plan in ways that are readily understood by all members of the multidisciplinary team
- provide a shared framework for continuity of care between community agencies and inpatient services
- provide a place for religious care but do not conflate spiritual issues with religious practice. While spiritual care in general may be provided by a team, specific religious care is best provided by a person from the same faith community, preferably one willing to participate in the team.

Engaging in spiritual conversations

Giving people with life-limiting illnesses the time to reflect on the meaning and purpose of life and discuss their spiritual distress are important aspects of palliative care. Many supportive communication skills can help.

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

1. Rumbold, B.D. (2007). A Review of spiritual assessment in health care practice. *Medical Journal of Australia*, 186(10), S60-S62. Reproduced with permission.

Spiritual conversations may focus on and clarify questions about:

- identity: who am I in these changing circumstances?
- connectedness: who is my community, where is my place?
- meaning: what's the purpose of my life now?

Following these conversations spiritual care strategies may be developed for each individual. These strategies may involve:

Settings

- identify places where the person feels safe.
- ask the patient 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/patient to explain their rituals and beliefs.
- it is important as the healthcare professional to respect and support these beliefs.
- arrange a visit from an accredited religious practitioner, if requested.
- prepare for end-of-life. Ensure that any specific rituals are well documented.^[1]

THINKING POINTS

1. Reflect on what spirituality means to you. How might this meaning affect your professional responses to people with life-limiting illnesses?
2. Identify specific strategies that might be used to:
 - a) Assess spiritual issues
 - b) Provide spiritual care to people with life-limiting illnesses.

1. Rumbold, B.D. (2007). A Review of spiritual assessment in health care practice. *Medical Journal of Australia*, 186(10), S60-S62. Reproduced with permission.

ACTIVITY 12: Spiritual conversations

Michelle's condition is progressing and she acknowledges that she is dying. James Smith, the palliative care nurse has been asked to visit Michelle and Pete at home to review what support they need in preparing for end of life. During the visit, Michelle talks with James about what dying means and what is important to her at this time. Michelle starts to explore what will happen when she dies.



Spiritual conversations

THINKING POINTS

1. What does Michelle state is important to her at this time?
2. What specific strategies does James use to explore the meaning of illness and dying to Michelle?
3. What specific strategies does James use to respond to
 - a) Michelle's question: 'I am going to die soon aren't I?'
 - b) Michelle's questions about dying?
4. What other strategies would you recommend to:
 - a) Explore the meaning of illness and dying to Michelle?
 - b) Respond to Michelle's questions about dying?

SECTION 6

Support for people at the end stages of life

In this section you will:

- learn about specific concerns people have about the end stages of life and how to provide information and support at this time.

ACTIVITY 13: End-of-life concerns

Providing support and information

The end stage of a person's life can provide some of the most profound and memorable experiences for family members. These moments can provide a time for sharing thoughts and hopes and expressing love and support. It is a time for saying goodbye. However it may also be a time when families experience extreme distress and require a great deal of support from the health care team.

The team needs to provide support and information to the person and their family to minimise distress where possible.

Family and other caregivers often have particular concerns and fears about end-of-life issues.

Family members often want to know what will happen and what they can do to help. They are often concerned that they will not be able to cope with the events. While it's not possible to predict how a person will die, there are some specific strategies that might help provide support to family members.

Several Palliative Care organisations have developed brochures about the dying process. One example of such a brochure is *About the Process of Dying* by Palliative Care Queensland.^[1] It may be a useful tool for health professionals to use when dealing with challenging conversations around death and dying.

THINKING POINTS

1. What might be some of the issues experienced by families and carers in the following end-of-life care settings:
 - hospital
 - home
 - hospice?
2. From the perspective of your own discipline, what specific supportive interventions can you implement as part of end-of-life care?

1. Palliative Care Australia. (2012). *About the Process of Dying*. Retrieved March 26, 2013, from www.palliativecare.org.au/Portals/46/Process-of-dying-FA.pdf

ACTIVITY 14: Preparing for Michelle's death

Michelle's condition has deteriorated and she is now dying. She is being cared for at home, and is now in bed all the time and is semi-conscious. James is visiting the family at home. Pete and James discuss Michelle's imminent death. James prepares Pete and the family around the process of dying and what to expect. He offers ongoing support from the palliative care team at this time and into the bereavement phase.



Preparing for Michelle's death

THINKING POINTS

1. What are Pete's main concerns at this time?
2. How does James help Pete deal with these concerns?
3. What other strategies could you use to provide emotional support to Pete, Michelle and their family at this time?

SECTION 7

Self-care for health care professionals

In this section you will:

- learn how to develop and use self-care strategies to deal with the stresses that arise from working with people with life-limiting illnesses.

ACTIVITY 15: Adopting self-care strategies

Caring for people with life-limiting illnesses may be stressful at times. There are many reasons for caregiver stress:

- your own fears of death and dying
- your own feelings of inadequacy
- your own identification with a person's suffering.

When caring for people with life-limiting illnesses, it's important to have realistic expectations of the degree of support you can provide. It's also important to identify the most suitable sources of support for you; personal and/or professional.



Expert Opinion



Expert Opinion

THINKING POINTS

1. What are some self-care strategies you might use when caring for people with life-limiting illnesses?
2. What strategies can you use to support other members of the health care team?

SECTION 8

Reflections on what you've learnt

1. What have you learnt from this module that will improve your ability to care for people with life-limiting illnesses and their families?
2. What specific strategies are you now going to use as a health care professional?
3. Do you see any difficulties using what you've learnt here as part of your practice as a health care professional? If so, what strategies might you use to address these difficulties?



Michelle's Story

A2: MICHELLE'S STORY

▶ 1.22 mins

Michelle: It was such a shock to hear the doctor say that I had breast cancer.

That was two years ago now, my whole world turned upside down. The initial treatment was really full on, not to mention losing my hair and everything that goes along with chemo, but I got through it all. The cancer responded well to the chemo, and I'm feeling great. My life's balanced again, Pete and I are happy, the kids are great and they're doing so well at school. I love my job, teaching is fantastic, and my boss was brilliant. Everyone has been so supportive. A month or so ago I noticed that I had this nagging cough and lately I've been feeling a bit breathless. I did wonder if the cancer had come back, they said it might, but no, I've just been overdoing it. The kids have been sick; you know it's just a viral thing. Anyway I went to see my GP last week just to have it checked out. She did a whole load of tests. I'm just waiting now to hear back about the results. I'm sure everything will be alright.

A4: RECEIVING DISTRESSING NEWS

▶ 3.01 mins

Doctor: It's lovely to see you again; I just wish it was under better circumstances. I've got your results. We'll talk about that, then if you've got any questions or concerns I'll tend to those as well is that okay?

Michelle: Nods

Doctor: I was hoping to have good news for you today, but unfortunately Michelle your cough's not a virus. I'm really sorry to tell you but the cancer has spread.

Michelle: Cries

Pete: What do you mean?

Doctor: On the CT scans we can see that it has spread to your lungs, that's why you're coughing and that there are a couple of spots in your liver. I know this is not the news that you'd hoped for, I wish I could tell you otherwise. It's a huge shock.

Michelle: I just don't understand, I've been so well and we lead such a healthy lifestyle now. Everything's so good at the moment, this news, it's just devastating.

Doctor: It's really, really tough and you and Pete, you dealt with that first diagnosis just so well with such amazing, incredible determination and you put loads of effort into making sure that you built a healthy lifestyle and that you did everything you could to recover.

Pete: What exactly are you saying? We beat the first cancer, we can do it again. Michelle, she's fit and healthy, she can cope with whatever treatment she needs. We'll get through it alright. Please can you tell us what treatment she can have?

Doctor: Of course Peter, I understand that you need to know what happens next. Are you okay to move on then Michelle? Well the first thing I'd like to do is arrange a bone scan that will give us a lot more information. And our main priority is going to be reducing the size of the cancer in your lungs and in your liver with some chemotherapy.

Pete: Very good, so when can we start this chemo?

Doctor: Well I can try and arrange for the bone scan this afternoon, and then we can meet tomorrow morning to discuss the different options. We should be able to start the treatment as early as next week. I know this is really hard and really a lot to deal with. If you do have questions please ask.

Michelle: Can you still cure this?

Doctor: I wish we could Michelle, but now that the cancer's spread we can't cure it. It's there in your lungs and in your liver, to stop it from spreading further and we'll be looking after your symptoms like your breathlessness, and we'll be trying to give you as much time as you can have with the best possible quality of life.

A5: UNDERSTANDING PALLIATIVE TREATMENT

▶ 2.33 mins

Jeremy (Radiation therapist): Hi Michelle, I'm Jeremy, I'm sorry to see you back here.

Michelle: Yes, it's just the worst news. My breast cancer has spread now; it's in my lungs and my liver. Dr. North sent me for a bone scan and I've just found out it's in my spine. I had back pain but I just thought it was from the gym, I never thought it was something more serious.

Jeremy: I understand this must be very difficult for you, so what's your understanding of what we're going to do today?

Michelle: Dr. Maitland wants me to have some palliative radiotherapy. I don't know what he meant. What is palliative radiotherapy?

Jeremy: Palliative radiotherapy isn't curative, but it's aimed to improve the quality of your life and we give it to relieve symptoms, like your back pain and the treatment will be different too. Now last time you might remember you had the six week course of short daily treatments.

Michelle: Yes.

Jeremy: Well this time the treatment will be different in the length of time that it takes, the dose of the radiation, and the area of the body that will be treated. Now any questions Michelle I'm happy to go over anything at any point if you want me to.

Michelle: Well not really, but will my treatment start today or will we just be planning today?

Jeremy: We'll be planning today but your treatment itself will start at ten o'clock tomorrow, okay.

Michelle: Alright that sounds good, I just remember too much about last time.

Jeremy: Well I can show you through if you want to come inside.

Michelle: That'll be great, thanks.

Michelle and Jeremy walk to the treatment room.

Jeremy: Well here it is, look familiar now?

Michelle: Yep.

Jeremy: So here's the CT scanner. First we'll get you positioned on here. You might remember last time we marked the area with some small tattoos. Well we'll do that again, and that way we can set you in the same position each time.

Michelle: I just hope the treatment helps; I guess I'm just a bit scared.

Jeremy: Well that's perfectly understandable Michelle, but remember you'll have your treatment team around you, if there's any concerns, anytime just ask us and we'll help you if we can. If we can't then we'll find the right person that can.

Michelle: Yep, thank you so much Jeremy, I really appreciate it.

A6: MICHELLE'S ILLNESS PROGRESSES

▶ 3.48 mins

Doctor: You guys look exhausted. How you going Michelle?

Michelle: Not good, I'm not getting any better am I?

Doctor: I'm sorry Michelle, I wish I could say that you were getting better, but your cancer is continuing to spread.

Pete: So, what are we meant to do? I can't just sit back and watch Michelle die.

Doctor: Must be really hard for both of you. Today we need to talk about a management plan and maybe look at some of your goals Michelle. Things that you may or may not want to happen in the future.

Pete: Yeh a plan would be good, we need a plan.

Doctor: We can keep on with some chemotherapy and try to get on top of the cancer in your lungs and your liver. Would you like to know more about that now?

Michelle: Oh yeh, I want to know as much as possible. I need to talk to you about my breathing, it's a lot worse than last time I saw you and I'm really struggling at times. I don't think I can wait for the chemotherapy to work. Is there anything that you can do to help with that now?

Doctor: Yeh, there's a couple of things we can do to make it easier. Can you describe your breathlessness for me?

Michelle: Well its there most of the time now. But a few times it's been really frightening; I couldn't get my breath you know. It's an awful feeling and then I just panic and then that just makes things worse.

Doctor: But not being able to breath is really frightening. Pete it must be scary for you too.

Pete: Yeh it's really hard to see her like this. She had a really bad episode while I was at work and I just feel helpless. What can we do to help her?

Doctor: We're going to put you on some medication today Michelle. We can monitor the dosage and adjust it if we need to. I'd also like to get some input from the palliative care team about how to manage it.

Pete: Palliative care, aren't they the people you see when you're dying.

Doctor: Well that is part of it Pete. They do give end of life care, so it's good for you to meet them and get to know them. The palliative care team is made up of a lot of different types of health professionals. They're there to support you through this really difficult time and they're experts as well in managing symptoms. How would you feel if I made a referral out to them?

Michelle: If you refer me to the palliative team, will I have to stop the chemotherapy?

Doctor: Oh no, not at all. We'll be working closely together, to keep an eye on things, adjusting as we go along.

Michelle: Okay then.

Doctor: Pete?

Pete: Yeh, that's fine.

Doctor: I don't know who you'll see, but they're all really lovely. Have you got any other questions before we move on?

Michelle: Yeh, I do. How long do you think I have to live?

Doctor: That is the hardest question Michelle. Studies that have been done with women who are at the same stage as breast cancer as you are, typically show that survival times are measured in months rather than in years.

Michelle: That's not very long.

Doctor: No, and at this stage, it's impossible to say just exactly how long.

A8: RAISING CONCERNS

▶ 4.17 mins

Nurse: Hi Michelle, hi Pete how are you going?

Michelle: Not bad.

Nurse: What are you looking at there, some diversional therapy for the morning?
Ah the kids, great.

Pete: Just sorting through the photos, we've got so many of the kids; we thought this would be a good time to do it.

Nurse: How are they?

Michelle: Oh they're good thanks. I just want them to remember me as their mum you know. I want them to look at all the pictures and remember all the good times we've shared.

Nurse: It must be really hard to know what to say to them.

Michelle: Yeh, we've tried to protect them from so much, haven't we? Glances at Pete.
Maybe that wasn't the right thing to do.

Pete: We want to do the right thing by them; we just don't know what that is.

Nurse: Well, you know I think, in my experience, I think children often know when something's wrong, so it's often best just to be open and honest with them. You know they can get quite anxious when they don't know what's happening, and then of course when they find out it can be quite a shock for them. It gives you guys a chance also to understand what their worries are and you know how to support them. What do they know about the situation so far?

Michelle: Well not much really, do they? I mean they know the cancer's come back. It's hard to know what to do, you know.

Nurse: Well would you like to come in together? All of you together one day and we can talk about it.

Michelle: Shakes head No.

Nurse: Well maybe we could explore some ideas now, about how best to talk to Ben and Elyse.

Michelle: Yeh, that'd be good.

Nurse: I think it's really important to know that each child might see things a little bit differently, so a really good place to start is to actually find out what they already know. So you need to give them time to talk and to be able to express their feelings. It's really important that they know that its totally okay for them to be open and honest with you, to ask you any questions that they need to ask you and that you are really there to support them. Have they asked you any questions so far?

Pete: Yeh, Ben asked me if you were going to get any better.

Michelle: Yeh, he asked me that one too. He said he's got a friend at school who told him people die if their cancer doesn't go away.

Nurse: What did you say?

Michelle: Well I told him that I really didn't know, and that everyday we hope the cancer will go away.

Nurse: Michelle, do you think the cancer is going to go away?

Michelle: No, Dr. North told me that the treatments couldn't cure it.

Nurse: It might be a good time for you to tell the kids then I think, and start preparing them.

Michelle: Maybe you're right.

Nurse: I think sometimes children also need to know that your cancer's got nothing to do with them, that it's nothing they've done. Do you get a sense that, that could be worrying them?

Michelle: No, not really but we should talk to them more.

Nurse: Let them know how special they are to you guys, how much you love them and maybe also tell them that you're really sad that the cancer has come back.

Michelle: Yeh, we should do that shouldn't we Pete?

Nurse: Pete, they need to know that you're there for them and that life can just go on as normal as possible, so if you can try and keep the usual routines happening, that'd be really helpful. Something else you could do, I don't know if you've thought about it, but you could start a scrapbook for them.

Michelle: I wanted to do that for them, didn't I? I just don't think I've got the strength at the moment.

Nurse: What about a friend? Have you got a friend who could help you with that? Or actually, I could get one of our team to help you out in here. Would you like that?

Michelle: Yeh, that'd be good. I can do it when I come in for chemo.

Nurse: Yes, that'd be a great idea. Look I'll get onto that, arrange that and I'll let you know.

Michelle: Oh wait, I've got one more question. My sister and her husband are going camping with their kids next weekend and they've asked if they can take Ben and Elyse. Do you think that would be a good idea?

Nurse: I think it's a great idea for them to spend time with family and friends that support them; I assume they get on well with their cousins?

Michelle & Pete: Yes.

Nurse: Yeh, then I think it's a great idea. And I think it'll be really good because it will give you guys time to have the weekend together, just the two of you, which might be quite nice.

Michelle: Yeh, thank you so much.

Nurse: So how are you doing Michelle?

Michelle: It's not a good day today. I feel like I'm losing control of everything in my life. I met with my boss last week and its official. I'm on an indefinite leave of absence. I'm absolutely devastated, my job is a huge part of me, and I'm a good teacher. I've made a difference to loads of kids' lives and it's over now and it's finished and my own kids want to spend more time at their friends' houses than they do at ours.

I don't even take them to school anymore, Pete does that. I can't do anything; even walking to the car in the driveway makes me breathless. Sitting in the car just makes this pain so much worse. I don't know. I don't even seem to get my mum hugs anymore. It's just breaking my heart, and then there's Pete. Spending time at his mate's house is clearly more attractive than spending time with me. I can't even remember the last time he gave me a cuddle. Cries

Nurse: You've really been holding on to so much haven't you.

Michelle: I'm really sorry to blurt it out like this. I just really needed to say it out loud and just have a good cry.

Nurse: Yes it's okay.

Michelle: I hope I've left you some tissues.

Nurse: Don't worry about it; I've got plenty out in the cupboard.

You've been through an incredibly tough time Michelle, you've continued to work and be a mum, wife and friend and stay in control of everything. You face some terrible losses Michelle and its okay for you to feel like this. What do you think has been worrying you the most?

Michelle: I just don't know what to do next.

Nurse: Sometimes it's a little bit easier if we break things down into smaller pieces, so the whole situation doesn't seem so overwhelming. So if we did that, what would be top of your list?

Michelle: Pete, Pete and me. We're just drifting apart and I love him so much. I miss the beautiful intimacy; you know, the kisses and the cuddles, just being together.

Nurse: Yes, that special part of a relationship. You guys are really close.

Michelle: I just can't relax with Pete anymore. There are times when I don't even want him to touch me or even see me. I look at myself in the mirror and I don't recognise myself. I mean who am I?

Nurse: Have you been able to tell Pete how you feel?

Michelle: I've tried, the time just never seems right.

Nurse: You can't find the right words either, I suppose. I'm guessing that Pete is finding it really hard to share his feelings with you as well. Maybe we could look at some ways that you and Pete might be able share your thoughts and feelings? Do you have any ideas about what you could do?

Michelle: Something simple, I don't know really. I know I really need to talk to Pete about it. But I just get the sense that he's scared to upset me and he keeps pulling away.

Nurse: Sometimes it might be helpful having someone break the ice for you. Perhaps when you're in next I could have a chat with Pete if you like. I can tell him what we've been talking about and to let him know that you'd really like to be talking to him as well.

Michelle: That would be so good, thank you.

Nurse: Do you think Pete would feel comfortable talking to me?

Michelle: I think so, he trusts you.

Nurse: Okay alright well I'll try and arrange it when you come in next. There are also some really good resources that we have on sexuality and intimacy for women with breast cancer and their partners that you might find really helpful to read. Would you like me to get some of that information?

Michelle: Yes, that'd be good.

Nurse: Michelle it's really, really good that you've been able to talk to me about this, you know. It's such a big burden for you. It's good for you to get it off your chest, I think, at times.

Michelle: Oh yes, I feel so much better. Thank you.

Nurse: It's my pleasure. I've just got one more thought. We have a psychologist on our team. I'm thinking it might be really helpful for you to talk to her she might have some other ideas that might be useful. So perhaps when you come in next if you're still feeling a bit concerned about you and Pete I can go and get her to see you if you like.

Michelle: I think that'd be good. It might be nice to talk about it some more. Thank you.

A12: SPIRITUAL CONVERSATIONS

► 5.15 mins

Michelle: I know I'm dying, I'm scared. I don't know what it all means.

Palliative care nurse: What is it that scares you most?

Michelle: Not being prepared, does that sound weird. You know when you're pregnant you've got nine months to prepare for the birth. You go to information sessions and workshops and everybody wants to tell you their story, good or bad. The point is that they talk to you about it, but no one wants to talk to you about death and I need to talk about it. I am going to die soon, aren't I? I'm not a religious person, neither of us are. We bought the kids up with a set of values that I hope will get them through life.

Palliative care nurse: I'm sure you have, are those values helpful to you now?

Michelle: Definitely, they help me to figure out what's important and what it all means.

Palliative care nurse: So what is important to you right now?

Michelle: My family and friends, I don't think I could get through this without the strength that they give me every day.

Palliative care nurse: A lot of people in your situation feel the same. There's nothing quite like the support of friends and family. Your friends have rallied around, have they?

Michelle: I don't even know where to start; Liz has been bringing me two meals a week, for months now. Paul and Jen take our kids out every week, with their kids. Barb brings me the naughty things, gourmet chocolates and bubbles and even clothes that she's picked up on special. Then there's Meg, Meg she just fits in with wherever I am that day. Sometimes she sits with me and we say nothing, and it's just beautiful. She's so dear to me. I can see that everyone's worried about me; they know I'm going to die soon, but Meg is the only one who will talk to me about it. I think that's why it's been so hard lately. Pete and all my good friends are trying to avoid talking about it. What does it feel like, when I die?

Palliative care nurse: There are certain indications that will let you and the people around you know that death is getting closer.

Michelle: What are they?

Palliative care nurse: You'll start to feel weaker, you'll spend longer periods in bed, you'll be drowsy

and you'll be less aware of what's going on around you.

Michelle: What about the medication and my breathing? What if I can't swallow? How will I take my medication?

Palliative care nurse: We can change the way we give you the medication if we need to. We can use a little machine about this big and what we'll do is we'll put a little needle under your skin; it's just like a pin prick going in. Then we'll attach some tubing from the needle to the syringe with your medication in it. A community nurse will come each day and change the syringe.

Michelle: That sounds good, but what if it all gets too much for Pete to take care of me.

Palliative care nurse: We'll be visiting regularly, reassessing things each day. If at any time you or Pete are having difficulties just let us know, give us a yell and remember we talked about the Palliative care unit, so that's always an option and wherever you are there's a whole team to look after you.

Michelle: Thank you.

Palliative care nurse: I know it's a really difficult time; you've got a huge amount on your plate at the moment Michelle. I'm here to listen and help as much as I can. But remember we've also got pastoral carers and social workers in our team and I can organise for one of them to come and have a chat, if you think that might help.

Michelle: Thank you and I really will let you know if I need more help.

Palliative care nurse: Alright.

A14: PREPARING FOR MICHELLE'S DEATH

► 4.22 mins

Pete: It's so hard to see her like this. I'm really worried about her now. I can't get her to eat anything and she'll only take a few sips of water. Should I be trying harder to get her to eat and drink?

Palliative care nurse: I know this is really tough Pete. Michelle's body is shutting down now so she's probably not interested in eating or drinking. Just keep doing what you've been doing; the mouth swabs, the lip balm, that will keep her mouth moist and comfortable.

Pete: We've been using those mouth swabs you left us. It gives us something to do.

Palliative care nurse: So what's your main concern at the moment?

Pete: The noisy breathing, it started yesterday. I know you mentioned something to me about it a while ago, but I can't remember what exactly or if I should be doing anything about it.

Palliative care nurse: When people get to this stage, the secretions, the fluid builds up in the back of the throat. Michelle's not swallowing anymore so the fluid is there in the back of her throat and it's noisy. It's distressing to listen to I know but it's not distressing for Michelle. We could try some medications but it probably won't stop it completely. The other thing we could try is turning her on her side and making her more comfortable.

Pete: Could we do that before you go?

Palliative care nurse: Sure, let's do that. You know Michelle is deteriorating now. She's probably going to die within a couple of days, maybe a week at the most. She'll probably stay fairly peaceful and just quietly stop breathing eventually.

Pete: I knew that this was coming. Her hands and feet are starting to change colour, just like you said they would. All we can do is hang on to every last second, what else can we do? I feel so helpless.

Palliative care nurse: That's totally understandable Pete. The main thing is that you, Ben and Elyse are able to spend time with Michelle. Just tell her that you love her, be there with her. Even if she's too weak to respond she can hear what you're saying. So how are Ben and Elyse managing with it all?

Pete: They're okay I think, very sad. But they're okay. Elyse especially just wants to be with her mother as much as possible. I came in last night and she was painting Michelle's fingernails pink, chatting about her day at school. Begins to cry I'm so proud of my kids, they're my strength.

Palliative care nurse: You've got a really good bond with your kids, and that's great Pete. The main thing now is that you all spend as much time with Michelle. But you need to get your rest as well. Everything's in place just the way Michelle wanted it to be, you're all here with her at home.

I'll be heading off shortly. You've got my mobile number if you need me. I'll give you a ring later in the day, see how things are going and remember we will be here for you after Michelle dies as well, okay.

Pete: Thanks James, I don't know how I would've coped without you.

Palliative care nurse: Let's go back in and reposition Michelle. We'll get her comfortable.



MODULE 3

Palliative assessment and intervention

To understand a person's symptoms and identify appropriate intervention strategies, a comprehensive, multidimensional approach to assessment is needed.

OVERVIEW

MODULE 3: Palliative assessment and intervention will help you develop the knowledge and skills needed to identify the health needs of people with life-limiting illnesses. The resource will also help you develop your understanding of the principles for managing common clinical problems in palliative care.

AIMS & OBJECTIVES

After completing this module, you should be able to:

- describe the epidemiological and clinical features along the illness trajectories of specific life-limiting illnesses
- explain the principles for assessing common symptoms and health problems associated with life-limiting illnesses
- explain the principles for management of common symptoms and health problems associated with life-limiting illnesses.

SECTION 1

Illness trajectory

In this section you will:

- learn about illness trajectories
- find out how to provide palliative care for different circumstances.

ACTIVITY 1: Life-limiting illnesses

Who is palliative care for?

In Module 1, you learnt that the need for palliative care is not dependent on a specific medical diagnosis, but is applicable to people who have a wide range of progressive and advanced life-limiting illnesses.

The term life-limiting illness is used to describe illnesses where it is expected that death will be a direct consequence of the specified illness. Such illnesses may include, but are not limited to:

- cancer
- heart disease
- chronic obstructive pulmonary disease
- dementia
- heart failure
- neurodegenerative disease
- chronic liver disease
- renal disease.

The palliative approach will also be applicable when caring for frail older people.

Understanding care needs

The needs of people facing life-limiting conditions will vary. Some factors to consider include:

- the nature and level of the person's health and support needs. A holistic approach is recommended where all needs, not only physical needs, are considered
- an individual's strengths and resources for example, social support and coping skills
- an individual's preferences and choices.^[1]

The key focus of this module is to understand specific health needs that are likely to be associated with different life-limiting illnesses. This will help you to develop a plan of care that is centred around the individual's care needs.

1. Palliative Care Australia. (2005). *Standards for Providing Quality Palliative Care for all Australians*. Retrieved September 15, 2010, from <http://www.palliativecare.org.au/portals/46/resources/StandardsPalliativeCare.pdf>.

Illness trajectories

Different life-limiting conditions are associated with different patterns of illness. These patterns, referred to as illness trajectories, indicate the path of a person's experience.

Most life-limiting illnesses, with specific illness trajectories, can follow several possible clinical courses. Often the course is not a series of well-marked events.

For example, following a cancer diagnosis, the goal of treatment for many patients will be curative initially and involve an active treatment plan. For others, their initial diagnosis may indicate advanced disease and the focus may immediately be on controlling progression of the disease and palliative care. Some patients may have a recurrence or progression of their cancer, indicating that it's necessary to reorient from curative to palliative goals of care.

The course of each person's disease and the nature of his or her experience can be influenced by a range of factors. This makes prediction and prognosis a complex process.

Some of the factors influencing the clinical course of a disease include:

- the natural history of the disease itself for example, people with cancer can often remain well and function reasonably for prolonged periods, but experience a sudden decline before death
- presence and nature of co-morbidities for example, people with some chronic diseases may not be able to tolerate some active treatments
- treatment goals and decisions
- access to health services.

It's important to understand the possible clinical course and common experiences for individuals at various points in their illnesses trajectory. This is because:

- throughout the course of a person's illness trajectory, you'll be required to identify interventions appropriate for his or her needs over time
- people diagnosed with life-limiting illnesses often have questions about what's likely to happen to them over the course of their illness. This kind of question needs a clear and honest response from you.

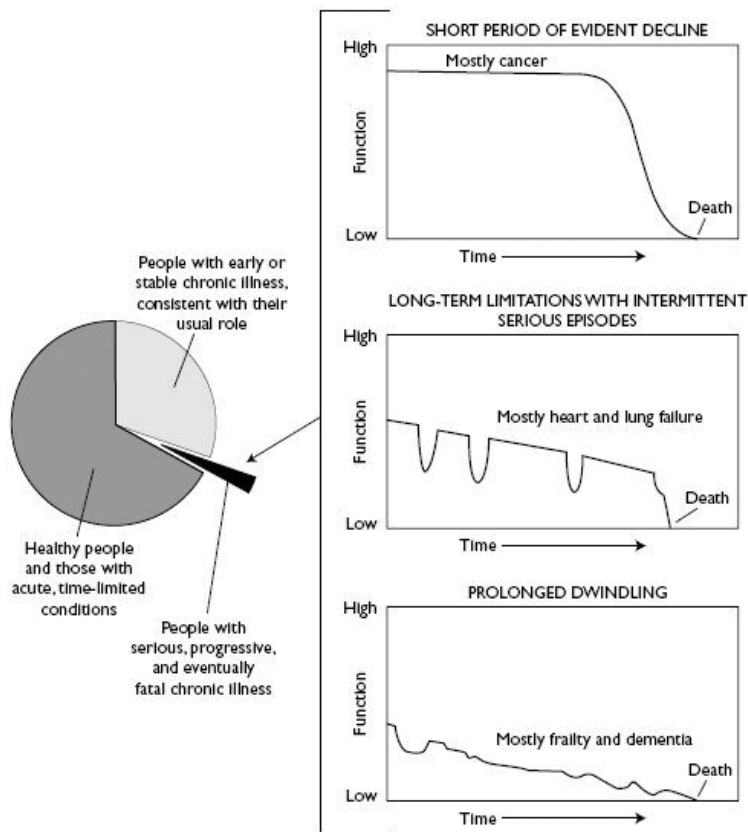
Patterns of change

While each person with a life-limiting illness experiences his or her illness differently, it's possible sometimes to identify patterns of change in the status of his or her health and care needs.

Doing this helps you plan interventions and provide support and information appropriate to each person and his or her family.

The following diagram^[2] shows three typical illness trajectories for patients with progressive chronic illness: cancer, organ failure, and the frail elderly or dementia trajectory. It's important for health professionals to be aware of these trajectories to help them anticipate the individual, multidimensional needs of patients and caregivers and respond appropriately.

2. Lynn, J. & Adamson, D.M. (2003) *Living well at the end of life: adapting health care to serious chronic illness in old age*. Rand Health White Paper WP 137. Retrieved September 15, 2010, from http://www.rand.org/pubs/white_papers/2005/WP137.pdf. Reproduced with permission.



THE FOLLOWING CASE STUDIES ARE TYPICAL EXAMPLES OF EACH OF THE ILLNESS TRAJECTORIES.

Case A - Mostly cancer

A 45 year old woman with breast cancer. Initial diagnosis 10 years ago. Diagnosed with secondary breast cancer 4 years ago and continued to receive a range of anti-cancer treatments. Recently diagnosed with new metastases to the bone and liver. She is suffering from weight loss, loss of appetite and pain. She is increasingly weak and tired. Her condition has been stable for some time, but is likely to deteriorate rapidly.

Case B – Mostly lung and heart failure

A 69 year old man with end-stage heart failure who is experiencing fatigue and increasing shortness of breath on exertion. He has had 3 emergency hospital admissions in the past 12 months. He is concerned about what quality his future holds and when he will die.

Case C – Mostly frailty and dementia

An 85 year old man with COAD, osteoarthritis, early stage 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.

Some key points about illness trajectories

- each phase of an illness trajectory can bring its own particular meanings and challenges for the person with a life-limiting illness. For example, treatment goals for someone with a life-limiting illness, where he or she undergoes a slow functional decline, might focus on maximising function and quality of life.
- knowledge of the likely course of a disease helps predict the illness trajectory and when the condition may, or may not be entering the end phase. For example, a curative treatment for a co-morbid condition may be warranted for a person with a slowly progressive cancer causing limited functional decline.
- understanding the likely course of a disease can help guide clinical assessment and choice of treatment options. For example, it may appear unnecessary to treat aggressively someone with end-stage heart failure who may have pulmonary oedema. However, if it helps the person function and fits in with his or her treatment goals, then such treatment may be appropriate.
- the end-phase of life may become apparent when particular changes in the status of a person's functions or symptom profile occurs. This phase may initiate changes in supportive interventions for the person and their family.

THINKING POINTS

1. Refer to the glossary and review definitions of the following terms:

- life-limiting illness
- illness trajectory
- prognostic factors.

2. Choose one type of cancer (for example, lung cancer) and one non-cancer life-limiting illness (for example, chronic heart failure). Research the literature and answer the following questions:

- a) Identify current epidemiological data relating to incidence and survival rates
- b) Identify classifications, staging, grading and/or prognostic factors
- c) What types of health problems or needs might arise throughout the course of the illness trajectory for these conditions?
- d) How are these trajectories similar or different to that of a frail older person who is dying?

3. Review the Trajectories of Eventually Fatal Illness diagram and the three typical case studies and answer the following questions:

- a) How are these trajectories similar or different to that of a person who is dying as a result of the ageing process?
- b) How might goals of care be influenced by an understanding of illness trajectories?

4. How could you use the data you've found about illness trajectories to assist your clinical decision-making and to provide support to people with life-limiting illnesses and their families?

5. What limitations does the data have in guiding clinical care?

ACTIVITY 2: Herbert's story

Herbert and his wife are self-funded retirees who spend their winter in the north of Australia to escape the cold. On his most recent holiday, Herbert noticed he was much more tired than usual. He seemed to have trouble catching his breath and needed to sleep on extra pillows.

He was diagnosed with systolic heart failure five years ago. His heart failure was initially classified as Class II Heart Failure using the New York Heart Association (NYHA) Classification System.^[1] His condition has been well controlled with medication.



Herbert's story

THINKING POINTS

1. Review the document *Guidelines for the prevention, detection and management of chronic heart failure in Australia (2011)* National Heart Foundation of Australia:

- a) Identify the incidence of heart failure in the Australian population.
- b) How is heart failure classified and what is the relationship between classification and prognostic factors?
- c) What were the clinical indicators that guided the physician's decision to re-classify Herbert's condition as Class III?
- d) What is the possible course of disease progression for someone with Herbert's condition? Consider the following factors:
 - prognosis
 - common symptoms
 - support needs that might arise as his disease progresses
 - other factors that might influence the course of his disease.

2. Within the scope of your own discipline, develop an holistic care plan for Herbert.

3. What does Herbert's statement of "I've got a lot of living to do" indicate about how he might view his disease?

1. Heart Failure Society of America. (2002). *The Stages of Heart Failure – NYHA Classification*. Retrieved September 15, 2010, from http://www.abouthf.org/questions_stages.htm.

SECTION 2

Assessment of common symptoms

In this section you will:

- learn about factors that may contribute to the symptoms of a person with a life-limiting illness
- learn how to understand and assess symptoms.

ACTIVITY 3: Symptom Assessment

The previous section showed that the clinical course of every illness will vary. People with life-limiting illnesses may experience a range of symptoms and clinical problems depending on the underlying pathology of the disease, co-morbidities and other psychological, social, and environmental factors. Preventing, minimising and treating these symptoms is an important component of palliative care and promoting quality of life.

People with life-limiting illnesses can experience a wide range of physical and psychological symptoms.

Some of the most common physical symptoms include:

- fatigue
- pain
- dyspnoea
- anorexia
- constipation. ^[1]

Some of the most common psychological symptoms include:

- emotional distress
- anxiety
- depression. ^[2]

Understanding symptoms

A person's symptoms don't always follow a predictable pattern, although some patterns can be seen and described.

Symptoms are subjective i.e. experienced differently by each person.

Symptoms are multidimensional i.e. having multiple contributing factors and effects.

1. CareSearch. (2009). *Clinical Practice: Physical*. Retrieved September 15, 2010, from <http://www.caresearch.com.au/CareSearch/ClinicalPractice/Physical/tabid/130/Default.aspx>.

2. CareSearch. (2009). *Clinical Practice: Psychological, social, spiritual*. Retrieved September 15, 2010, from <http://www.caresearch.com.au/caresearch/ClinicalPractice/PsychologicalSocialSpiritual/tabid/131/Default.aspx>.

Symptom assessment

Routine assessment of symptoms using recognised assessment tools is a core component of palliative care. There are a range of brief symptom assessment tools that can be used in routine practice to identify symptoms.

The Symptom Assessment Scale (SAS) is widely used within Australian Palliative Care Services. It is one of the recommended assessment tools of the Australian Palliative Care Outcomes Collaboration.^[3]

If you identify that an individual is experiencing a symptom, a comprehensive and multidimensional assessment is required to identify appropriate interventions. This is because each symptom can have different causes, effects and meanings. Your comprehensive assessment provides information needed to develop an individualised management plan.

A comprehensive symptom assessment typically involves evaluation of:

- contributing factors (different causal mechanisms usually require different management responses)
- characteristics of the symptoms, such as: intensity, location, quality, temporal nature, frequency, and associated pattern of disability
- the meaning of the symptom to the person, including beliefs about the symptom and the effect on the person's physical, psychological, and social well-being
- behavioural responses to the symptom, such as the actions that the person is taking to manage or cope with the symptom.

The characteristics of the symptoms help determine causal mechanisms, and help you understand the effect on the person. For example:

- assessment of pain quality allows for a clinical diagnosis of the type of pain and subsequently an appropriate treatment plan
- assessment of the impact of pain helps you determine an appropriate plan to minimise its effects
- assessment of how a person is managing their pain helps you determine treatment preferences and develop an appropriate plan for involving them in their care.

To undertake a comprehensive evaluation of symptoms, you may need to gather clinical data from a range of sources, including:

- interviews
- physical examination
- clinical investigations.

There are a range of comprehensive symptom assessment tools available for use in practice where there is a need to investigate causes and effects of a symptom.

3. Palliative Care Outcomes Collaboration. (2011). *Symptom Assessment Scale*. Retrieved August 7, 2012, from <http://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow115384.pdf>.

THINKING POINTS

1. What does it mean to say that symptoms are subjective?
2. What does it mean to say that symptoms are multidimensional?
3. Describe the clinical history and investigations you would undertake to assess the causes and effects of breathlessness in patients with chronic heart failure?
4. How might the etiology and experiences of breathlessness be similar or different for people with advanced lung cancer?

ACTIVITY 4: Six months later

In Herbert's story, he was introduced as a self-funded retiree with heart failure that had progressed and had been re-classified from Class 11 to Class 111 Heart Failure. It's been six months since Herbert was told that his heart failure was progressing.

His heart failure continues to worsen and he's upset that it's stopping him from spending time with his friends and doing what he enjoys.

He's particularly bothered by his fatigue and his breathing problems. As part of his assessment, Herbert is asked about his appetite. He states that he has a poor appetite and that although he tries to eat he feels that there "isn't much pleasure in it anymore".



Six months later

Think about the physiological, psychological, and environmental factors that may be contributing to Herbert's symptoms.

THINKING POINTS

1. Describe the similarities and differences when undertaking a clinical assessment and investigations for patients with Class I and Class IV Heart Failure. Provide reasons for your answer.
2. What observations do you make from the video that indicate deterioration in Herbert's condition?
3. Consider Herbert's experience with his illness over the past six months.
 - a) Identify the incidence of heart failure in the Australian population.
 - b) How is heart failure classified and what is the relationship between classification and prognostic factors?

4. What are the common symptoms or clinical problems that he may now be experiencing?
5. What are Herbert's psychosocial needs likely to be now that his condition is deteriorating?
6. Consider Herbert's disease and review the pathophysiology of:
 - a) Fatigue
 - b) Loss of appetite.
7. How are the fatigue and loss of appetite impacting on Herbert's quality of life?

ACTIVITY 5: Expert opinion

Note: Answer the Thinking points first before watching the Expert opinion video.



Expert opinion

THINKING POINTS

1. List the key principles for undertaking a multidimensional assessment of the symptoms for people with advanced life-limiting disease.
2. Now watch the video of the palliative care physician by clicking on the Expert opinion icon on the right. The palliative care physician provides key points on assessing symptoms for patients with advanced disease. Compare the points made by the palliative care physician with those you have identified.

ACTIVITY 6: Assessment tools

Guiding clinical assessment

There are many reliable and validated tools available to guide health professionals with symptom assessment.

Assessment tools can be designed to:

- assess multiple symptoms e.g. the Symptom Assessment Scale (SAS).^[1] These tools are useful in routine practice for screening to identify individuals experiencing symptoms.
- guide the assessment of an individual symptom e.g. the Brief Pain Inventory.^[2] These tools enable a more comprehensive assessment to identify causes and effects of symptoms.

1. Palliative Care Outcomes Collaboration. (2011). *Symptom Assessment Scale*. Retrieved August 7, 2012, from <http://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow115384.pdf>.

- identify specific needs in order to provide relevant care/services e.g. The FACIT SP 12 – a spiritual assessment tool.^[3]

One example of a needs assessment tool is the Needs Assessment Tool: Progressive Disease – Cancer (NAT: PD-C).^[4] This tool was developed in conjunction with the The Palliative Care Needs Assessment Guidelines^[5] to facilitate needs based care for people with advanced cancer and their families, including palliative care.

The NAT: PD-C was developed to assist health professionals in matching the types and levels of need experienced by people with advanced cancer with the most appropriate people or services to address those needs. It can be used in both generalist and specialist settings.

THINKING POINTS

1. Visit the International Association for Hospice & Palliative Care website and identify an assessment tool that might be used to assess the symptom of breathlessness.
2. Comment on whether the tool assesses the multiple dimensions of the symptom.
3. Comment on whether the tool assesses the individual's experience of the symptom.
4. Comment on whether the tool is useful for assessing breathlessness associated with different conditions such as chronic heart failure or advanced lung cancer.
5. What advantages and limitations would this assessment tool have in practice? Provide reasons for your answer.

2. Cleeland, C.S., & Ryan, K.M. (1994). Pain assessment: global use of the Brief Pain Inventory. *Ann Acad Med Singapore*, 23(2), 129-38.

3. FACIT. (2007). FACIT -Sp-12: *Spiritual Well Being*. Retrieved September 15, 2010, from <http://www.facit.org/FACITOrg/Questionnaires>.

4. Centre for Health Research and Psycho-oncology. (2009). *Needs Assessment Tool: Progressive Disease – Cancer* (NAT: PD-C). Newcastle, NSW: The Centre for Health Research & Psycho-oncology.

5. Girgis, A., Johnson, C., Currow, D., Waller, A., Kristjanson, L., Mitchell, G., Yates, P., Neil, A., Kelly, B., Tattersall, M., & Bowman, D. (2006). *Palliative Care Needs Assessment Guidelines*. Newcastle, NSW: The Centre for Health Research & Psycho-oncology.

In this section you will:

- find out about the key components of palliative symptom management
- learn how to determine the treatment goals and appropriate interventions for the symptoms of a person with a life-limiting illness.

ACTIVITY 7: Palliative interventions

Sources of evidence

Palliative symptom management must consider evidence in many forms. The randomised controlled trial is usually seen as the gold standard for obtaining evidence about any intervention. However, there are lots of different types and sources of evidence that can inform clinical decision-making.

CareSearch palliative care knowledge network is an online resource consolidating evidence-based and quality information for various groups within the palliative care community.^[1]

It's important to be aware that people with life-limiting illnesses may be seeking complementary or alternative approaches to symptom management.

Comprehensive symptom management

Palliative symptom management may differ depending on a range of factors including the stage of a patient's illness as well as their personal wishes and preferences.

A comprehensive symptom management plan involves:

- a thorough, holistic assessment
- identification of appropriate interventions, based on the assessment
- implementation of the interventions
- ongoing evaluation of outcomes of the interventions.

Effective management typically requires:

- an integrated approach: involves multidimensional symptom assessment and management. For example, pain management may include both opioid analgesia and patient education for relaxation strategies to manage the anxiety related to uncontrolled pain.
- a targeted approach: directed at specific causal mechanisms and factors contributing to the problem. For example, different pharmacological agents might be needed to target different mechanisms or types of pain.
- a tailored approach: suitable for individual circumstances, beliefs and preferences. For example, patients who do not have caregivers or adequate financial resources may require additional support from the multidisciplinary health care team.

1. CareSearch. (2009). *Finding evidence*. Retrieved September 15, 2010, from <http://www.caresearch.com.au/Caresearch/LinkClick.aspx?fileticket=gX28fALIQmw%3d&tabid=62>.

Key components of symptom management in palliative care

EVALUATION

It is important to investigate the underlying cause of symptoms and find out the level of disease progression. This may provide a clearer picture as to whether or not the symptom is reversible or if the individual is entering the terminal phase of their illness.

Interventions may be aimed at alleviating:

1. the causes of the symptom
2. the effects of the symptom.

Some examples are:

- symptoms caused by tumour obstruction may be best managed by endoscopic stenting or surgery
- symptoms caused by oedema, such as raised intracranial pressure, may be best managed with steroids
- symptoms caused by comorbidities such as gastric reflux may be best managed by proton pump inhibitors and/or dietary modifications.

Remember to:

- listen to and accept the description given by the individual
- explore all factors that may be influencing symptom severity.

EXPLANATION AND DISCUSSION

- consider whether new symptoms may trigger discussions around disease progression and end-of-life goals.
- provide clear explanations about the causes of the symptom.
- discuss possible symptom management options based on individual need.
- ensure symptom management plan is consistent with the person's individual goals and preferences for care.
- facilitate family discussion about the symptom management plan.
- involve the multidisciplinary team to ensure an holistic approach.

TAILORING SYMPTOM MANAGEMENT

Develop an individualised symptom management plan. Optimal symptom management requires a multidisciplinary approach.

Consider:

- the applicability of all available treatment options to the individual's clinical and personal circumstances. These treatment options may include:
 - surgical
 - disease modifying (e.g chemotherapy/radiotherapy)
 - pharmacological
 - non-pharmacological
- the benefits vs burdens of treatments from the person's perspective
- the individual and family goals of care and personal preferences.

MONITORING OF PROGRESS

Palliative symptom management requires ongoing monitoring and assessment and often the clinical picture changes quickly. It is important to adopt a proactive approach to symptom management.

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.^[2]

THINKING POINTS

1. Investigate two symptoms of your choice using the following headings:

- a) Underlying causes
- b) Effects on emotional, social and spiritual wellbeing
- c) Pharmacological interventions
- d) Non-pharmacological interventions
- e) Monitoring the effectiveness of interventions.

ACTIVITY 8: His illness progresses

Herbert's heart failure continues to progress. He's been admitted to hospital with pulmonary oedema. While in the hospital his cardiologist puts in a referral to the local specialist palliative care team.

Herbert discusses some of his main symptoms with the palliative care physician, who introduces some possible interventions for managing these symptoms.



His illness progresses

2. Palliative Care Expert Group. (2010). Principles of symptom control. In *Palliative Care Expert Group, Therapeutic guidelines: palliative care. Version 3*. Melbourne, VIC: Therapeutic Guidelines Limited.

THINKING POINTS

1. What symptoms does Herbert describe?
 - a) What are some of the causes of these symptoms?
 - b) What are the treatment goals?
2. The palliative care physician recommends both pharmacological and non-pharmacological interventions for managing Herbert's breathlessness. Identify the supporting evidence and the likely mechanism of action for the following interventions
 - opioids
 - relaxation
 - fans
 - activity pacing
 - oxygen therapy.
3. Herbert expresses some concern about taking morphine for his breathlessness.
 - a) Was the physician's response adequate? Give reasons for your answer.
 - b) What further suggestions do you have for addressing patient concerns about palliative treatments?
4. What other pharmacological agents might be considered to treat Herbert's breathlessness? Provide a rationale for your answer.

ACTIVITY 9: Expert opinion

Note: Answer the Thinking Points first before watching the expert opinion video.



Expert opinion

THINKING POINTS

1. Make a list of the key principles of palliative symptom management that you've learnt about in this section of the module.
2. Now watch the video of the palliative care physician by clicking on the Expert opinion icon on the right. The palliative care physician provides key points on managing symptoms for patients with advanced disease. Compare the points made by the palliative care physician with those you have identified.

SECTION 4

Reflections on what you've learnt

1. What have you learnt from the activities in this module that will help you further improve your ability to care for people with life-limiting illnesses and their families?
2. What specific strategies are you now going to use as a health care professional?
3. Do you see any difficulties using what you've learnt here as part of your practice as a health care professional? If so, what strategies might you use to address these difficulties?



Herbert's Story

A2: HERBERT'S STORY

▶ 1.36 mins

We just got back from our holiday up north; it was earlier than we had planned because when we were travelling I was much more tired than usual. I was struggling to get my breath even when I wasn't doing very much. I've had heart problems for years and a heart attack when I was fifty-five, too much pressure in my job in the bank, after that they told me that I had high blood pressure, that I had to take things easy, change my diet and get a bit more exercise. Despite that the damage must've been done because two years into retirement I had another problem, they said it was heart failure. Now I've always known that apart from a heart transplant that might happen one day. You've got to live a little differently, so I don't overexert myself, and I've got a lot of living to do.

A4: SIX MONTHS LATER

▶ 2.27 mins

Nurse: Bert can you just tell me how you've been feeling the past few days?

Herbert: Not good really, I was better a few days ago, but today not right.

Nurse: That doesn't sound good, can you tell me a bit more about what's been happening?

Herbert: Well it's this damn breathing really. I can't move around the house without puffing, like a steam train. Like I've run up a flight of stairs or something. Of course I haven't but I might've just got up to go to the toilet or something like that.

Nurse: So when you sit back down again, how long does it take you to catch your breath?

Herbert: I try and tell myself breath in and out slowly; one of the physios told me to do that. Partly my own fault, sometimes I try to do too much. Starts off okay, then it catches up with me.

Nurse: It's going to be important to pace yourself and so we'll need to look at some ways in which you can conserve your breathing and conserve your energy. Is there anything that makes you feel better or worse?

Herbert: Most activity really. I'm mostly better sitting down doing nothing, but I find it very hard to do that. Tired, I'm always tired; I go to bed at night, I'm tired. I get up in the morning I'm tired. It's not the sort of tired that sleep seems to do anything for, so frustrating. I'm a man of action. Sitting around doing nothing, drives me mad.

Nurse: That sounds pretty rough. It's fairly common for people with heart failure to have feelings of overwhelming tiredness. How's your appetite going?

Herbert: Poor appetite really, I drive Molly nuts. She tries really hard to accommodate what I feel like eating; but it's partly my own problem. I used to be a meat and potatoes man, now I'm just having snacks. I make myself eat sometimes because of the diabetes but there's not much pleasure in it anymore.

A8: HIS ILLNESS PROGRESSES

▶ 2.15 mins

Doctor: Could you tell me about the main problems you've been having, the main symptoms over the last few weeks?

Herbert: Yes, well I feel pretty low, my heart isn't doing it's job. If I try to do too much I have difficulty catching my breath. I'm starting to lose weight too, because eating isn't much fun anymore, but breathing is the main problem. And well, last week I ended up in here.

Doctor: What about energy levels, can you do everything you want to do?

Herbert: Not really, I feel pretty tired all the time.

Doctor: Let's talk more about your breathlessness then. Specifically, is there anything that makes it better or anything that makes it worse?

Herbert: No, it's often there, even when I don't do too much; but it's much worse when I try to do things or try to walk.

Doctor: I know the nurses have given you the breathing exercises, and they can be very useful. The physiotherapist will come along and help you do those. The other thing of course is morphine. There are lots of studies now that show morphine can help considerably with breathing, we're not sure how it works but it does seem to help patients manage their breathing more and it reduces the sensation of breathlessness. So I would really advise a bit of morphine to see how it goes.

Herbert: I didn't know morphine was the thing to take for breathlessness. Isn't that addictive?

Doctor: Everyone worries about that, but when we use it in specific situations like this addiction isn't a problem. Addiction tends to be a problem when people are using it for psychological reasons or for 'kicks' so to speak. We have no difficulty getting people off morphine, but most people stay on it because they find it so useful for their breathing.

Herbert: Oh... (trails off)



MODULE 4

Optimising function in palliative care

Maintenance of physical, psychological, and social functioning is important to ensure optimal quality of life for people with life-limiting illnesses and their families.

OVERVIEW

MODULE 4: Optimising function in palliative care will help you develop your understanding of how to provide support for people with life-limiting illnesses and their families. In particular, it focuses on issues of loss, establishing goals of care, and understanding the effect of caregiving.

AIMS & OBJECTIVES

After completing this module, you should be able to:

- recognise the different responses and emotions of people living with life-limiting illnesses and their families
- discuss strategies for facilitating collaborative decision-making on care goals with people with life-limiting illnesses and their families
- identify interventions that will optimise physical, psychological and social function for people with life-limiting illnesses and their families
- analyse the effect of caregiving on the family networks of people with life-limiting illnesses
- recognise how your own values and beliefs about death and dying affect your responses and interactions with people with life-limiting illnesses and their families.

SECTION 1

Living with a life-limiting illness - experiencing loss

In this section you will:

- learn about loss and how it affects different people in different ways
- find out how to treat people who are experiencing loss.

IMPORTANT NOTE

This section will explore issues associated with loss and grief and the possible effects on people living with life-limiting illnesses. The issues considered in this section can be very personal. They may trigger emotions for you. These emotions are natural, but please talk to your lecturer or friends if you need to.

If you're working on the activities in a group, it's important to remember the following points:

- privacy and confidentiality are essential
- people's feelings and thoughts must be respected
- people's right not to disclose feelings and thoughts must be respected.

ACTIVITY 1: Responses to loss

Loss is a universal aspect of life-limiting illnesses. People with life-limiting illnesses and their families, caregivers and friends must adapt to the many changes in their lives. They need to cope with loss of health, function, mobility, future potential, and dreams. They also need to cope with death.

The following responses may occur not only at diagnosis. They can occur as the person experiences other changes as his/her disease progresses.

Some common psychological and social responses to loss, include:

- sadness
- anger
- fear
- distress
- despair
- disbelief
- anxiety
- guilt
- worrying thoughts
- sleep disturbances
- social withdrawal
- decreased ability to maintain an organised lifestyle.^[1]

1. Palliative Care Expert Group. (2010). Loss, grief and bereavement. In: *Palliative Care Expert Group, Therapeutic guidelines: palliative care*. Version 3. Melbourne, VIC: Therapeutic Guidelines Limited.

THINKING POINTS

Think of a situation where you have experienced loss. It may be the loss of a relationship, object, or loss of ability to do something you used to be able to do.

1. Write a short paragraph about your loss. Consider the following questions:
 - a) How did the loss make you feel? Consider both the physical and emotional responses you may have experienced.
 - b) How did you deal with your feelings?
 - c) Has thinking about the loss here triggered uncomfortable emotions? If so, what has led you to respond in this way?

Please see your facilitator after the session if you need to talk things through in more detail.

ACTIVITY 2: Bob's story

Bob and his wife Margaret have two children - two girls aged 24 and 27. All the family members live in the same city.

Bob was diagnosed with Motor Neurone Disease 12 months ago. He was working as an electrician, but was forced to retire when he was diagnosed.

Bob talks about how he's adjusted to being diagnosed with Motor Neurone Disease.



Bob's story

THINKING POINTS

1. What are the losses that Bob talks about?
2. What are Bob's reactions to these losses?
3. Refer to the MND Australia publication, Motor neurone disease – aspects of care for the primary health care team. Discuss what other losses Bob might face as his illness progresses?
4. Discuss Bob's response to other people's reactions to his situation
5. Bob states that he found it hard because 'everybody seems to be an expert on what you should be doing'. What strategies can health care professionals use to understand an individual's experience, preferences and goals and to establish effective partnerships with patients and their caregivers?

SECTION 2

Goals of care and Advance Care Planning

In this section you will:

- learn about strategies for establishing goals of care for people with life-limiting illnesses
- find out how to optimise function for people with life-limiting illnesses
- learn about advance care planning in palliative care.

ACTIVITY 3: Establishing goals of care

End-of-life goal setting is a key palliative care skill. Discussions to establish goals of care ideally begin soon after the diagnosis of a life-limiting condition. Health care professionals need to work with the person to develop goals of care that target individual needs, values and preferences. This requires you to have good communication skills.

These skills include:

Listening and enquiring: To begin with, ascertain the individual's level of understanding and reactions to their situation and prognosis. The types of open questions that may be helpful to understand an individual's goals and preferences may be:

- What are you hoping for now?
- What is important to you?
- What do you need to accomplish?
- Who do you need to see in the time that is left? ^[1]

Checking and clarifying: An individual's goals are likely to change as their illness progresses. It is important to state your understanding of the individual's goals and check this with how the individual sees his or her situation.

Two strategies that may be useful when establishing end-of-life goals of care are:

1) Family meetings

A family meeting is a discussion with involved family members and the caring team to exchange information and improve communications. The patient can be included. These meetings provide an opportunity for family members to express and share their feelings within a safe and structured context.

Family meetings:

- require a skilled facilitator
- are offered by the service provider based on individual family need
- promote a proactive approach to care
- may provide a clearer picture of the goals of care to patients and families
- are mutually beneficial.

1. End of Life/Palliative Education Resource Centre. (2009). *Establishing End-of-Life Goals: The Living Will Interview(2nd ed)*. Retrieved September 15, 2010, from http://www.mcw.edu/fastFact/ff_65.htm.

Family meetings are documented in the clinical record to maintain communication among professionals. Record who attended and a clear summary of significant conversations and decisions.

Family meetings are not:

- a platform for clinical debate about a patient's condition
- a tool saved for crisis situations only.

Guidelines have been developed to help health care professionals to conduct effective family meetings. ^[2]

2) Advance Directives

An Advance Directive is a document that:

- contains instructions that consent to, or refuse, specified medical treatments
- clearly states patient care goals and preferences
- may be completed by a legally competent patient or by a legally appointed proxy e.g. enduring power of attorney
- may be completed as part of the advance care planning process
- has legal status
- must be available when the individual's place of care is being changed i.e. admission to hospital from home
- varies according to each Australian state or territory.

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 family liaison. ^[3]

Review Module 2 for the principles of effective communication in palliative care.

THINKING POINTS

1. How would you describe the primary goals of palliative care?
2. How can you assess a person's preference for their care?
3. What are some of the reasons that individuals with life-limiting illnesses may continue to have the goal of cure?
4. How would you as a health care professional respond to the following situations:
 - a) The person's goals may not be consistent with their prognosis
 - b) The care goals conflict with the goals and wishes of their family.
5. In what ways might beliefs and culture influence personal goals and preferences for care?

2. Hudson, P., Quinn, K., O'Hanlon, B. & Aranda, S. (2008). Family meetings in palliative care: Multidisciplinary clinical practice guidelines. *Biomed Central*, 7(12).

3. Palliative Care Australia. (2009). *Advance Care Planning position statement*. Retrieved September 15, 2010, from <http://www.palliativecare.org.au/Portals/46/PCA-Advance Care Planning Position Statement.pdf>.

ACTIVITY 4: Three months later

Bob's illness has progressed over the last three months. He has severe weakness in his arms, but is still able to walk around.

He's been referred to a physiotherapist and occupational therapist to determine what can be done to improve his physical and social functioning. The occupational therapist visits him at home to discuss some modifications to the house.



Three months later

THINKING POINTS

1. Discuss, in detail, how you would determine Bob's goals of care?
2. Bob talks about the benefits of the wheelchair and the seat over the bath, but doesn't wish to go ahead with any major house modifications at this stage. Discuss the following:
 - a) His reasons for delaying the bathroom modifications
 - b) Health care professional responses to situations where a patient may have different opinions about recommendations for care.

ACTIVITY 5: Advance care planning

Advance care planning is an ongoing process which can be constantly reviewed within a changing clinical context. Advance care planning is a term used to describe the process whereby a person thinks about and plans for their future medical care should they become unable to communicate. Advance care planning promotes open and ongoing communication between patients, their families and health care professionals about end of life decisions.^[1]

Engaging in Advance Care Planning Discussions

Advance care planning discussions may be challenging as issues around death and dying emerge. Therefore it is important that the health professionals who are instigating and facilitating these discussions have excellent communication skills.

Key points

- 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 family.

1. Respecting Patient Choices. (2010). *Advance care planning for everyone*. Retrieved September 15, 2010, from http://www.respectingpatientchoices.org.au/index.php?option=com_content&view=article&id=1:advance-care-planning-for-everyone&catid=5&Itemid=2.

- ensure that the caregiver who may be making decisions in the future understands the advance care planning process and the person’s end-of-life goals. ^[2]
- 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. ^[1]
- arrange a family meeting if required.
- document discussions to ensure that all parties are aware.
- complete an advance directive as appropriate.

THINKING POINTS

Visit the Respecting Patient Choices (RPC) website. Review the relevant legislation in conjunction with the RPC Guide to Advance Care Planning.

Answer the following questions:

1. What are the steps that an individual would follow in order to participate in advance care planning?
2. What are the implications of the legislation for you as a health professional?
3. What options would a person have if he/she wanted to:
 - a) Specify his/her wishes in advance
 - b) Appoint someone to act on his/her behalf.

2. 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. *Medical Journal of Australia*, 186(12), S77-108.

SECTION 3

Optimising physical and social function

In this section you will:

- learn how to assess and maintain both the physical and social function of people with life-limiting illnesses
- learn how to determine the resources that will help people with life-limiting illnesses cope with loss of function.

ACTIVITY 6: Assessing & maintaining function

People with life-limiting illnesses may experience a decline in their physical and social function. This can occur over the course of their illness trajectory.

As a health care professional, assessing and maintaining a person's function is important to ensure quality of life is optimised. In palliative care, even the smallest improvements in functional status may be viewed very positively by the patient.

What is functional status?

A person's functional status comprises several dimensions, including:

- cognitive functioning, for example attention, concentration, memory and problem solving
- behavioural functioning, for example undertaking daily activities, such as bathing, dressing, feeding, as well as instrumental activities, such as shopping, cooking and cleaning
- psychological functioning, for example mood, affect, and motivation
- social functioning, for example activities associated with roles at various stages of development.

Assessing functional status

Both clinician assessment and an individual's self-report can be used to assess the patient's functional status. The Australian modified Karnofsky Performance Status (AKPS) scale is one assessment tool that is used by clinicians to assess individual's performance status.^[1]

In selecting a tool for assessing function, it's important that the tool chosen is relevant to the person's care goals. This means that it's important you understand:

- the person's preferences and goals in relation to their function
- the trajectory of a person's illness, and the anticipated progression of their clinical problems.

Once goals of care are identified, consider the following questions to guide your selection of a method for assessing function that is relevant to the person's goals of care.

- does the assessment method measure cognitive, behavioural, psychological, or social aspects of function?
- is this assessment consistent with the person's own goals?

1. Abernethy, A., Shelby-James, T., Fazekasm B., Woods, D. & Currow, D. (2005). The Australia-modified Karnofsky Performance Status (AKPS) scale: a revised scale for contemporary palliative care clinical practice. *BMC Palliative Care*, 4(7), doi: 10.1186/1472-684X-4-7.

- does the assessment method require the person's self-report, or can it be generated by a proxy (caregiver or clinician)?
- is the assessment method practical and feasible for this person's circumstances?
- is the assessment method sensitive enough to pick up changes in a person's function?

THINKING POINTS

Visit one of the palliative care assessment tool websites listed in the resources for this module and identify an assessment tool that might be used to assess the functional status.

1. Comment on the dimensions of functional status that are assessed by the tool.
2. Comment on whether the tool is useful for assessing functional status associated with different conditions, such as neurodegenerative disorders such as Motor Neurone Disease, or advanced cancer.
3. What advantages and limitations would this assessment tool have in practice?

ACTIVITY 7: Exploration

The occupational therapist visits Bob to assess his situation. The therapist explores how Bob's illness has affected his day-to-day functioning.

Bob speaks to the occupational therapist about his physical and social function.



Exploration

THINKING POINTS

Bob identifies the following problems:

- decreased mobility
 - difficulty swallowing
 - difficulty maintaining social contact.
1. How do you identify the personal and social resources that may help a person with a life-limiting illness cope with the loss of physical and social function?
 2. Consider your specific health care discipline. How do you promote physical and social function for the problems Bob has identified? Search relevant literature to identify the evidence to support your answers.
 3. What other health care disciplines might be involved in care planning to help Bob?
 4. How might your care plan complement the care plan proposed by the other health care disciplines?
 5. What strategies would you use to ensure an effective team approach to managing Bob's problems?

SECTION 4

Understanding the impact of caregiving

In this section you will:

- learn about caregivers, their role and the stress they experience when caring for people with life-limiting illnesses
- discover caregivers' basic needs, their positive experiences and the challenges they face
- learn about home care and respite care and when to choose respite care.

ACTIVITY 8: Caregiver needs

Sources of stress for caregivers

A life-limiting illness can impact on the well-being and function of an entire social network. Evidence shows that caregivers who care for people with life-limiting illnesses may be adversely affected if they're not adequately prepared for, or don't have the resources to undertake, the caregiving role.

Sources of stress for caregivers may include:

- uncertainty about treatment
- lack of knowledge about care
- role changes in the family
- strained financial resources
- physical restrictions
- threats to own health, well-being and sense of self
- lack of social support
- fear of being alone
- inability to plan other aspects of their life because of uncertain prognosis
- emotional and physical burnout.

While caring for people with life-limiting illnesses can provide personal and physical challenges for caregivers, many report positive experiences. Many caregivers find there's meaning to their caregiving role and get satisfaction from knowing they're doing a good job. They may also feel closer to the person they are caring for. ^[1]

About home care

For the majority of people with life-limiting illnesses, the preferred place of care, during the course of life-limiting illnesses, is at home. Factors determining the level of community services required to care for a person at home include:

- availability and ability of the caregiver
- the person's physical condition, particularly his or her level of mobility

1. Palliative Care Australia. (2004). *The hardest thing we have ever done - the social impact of caring for terminally ill people in Australia*. Retrieved September 15, 2010, from <http://www.palliativecare.org.au/Portals/9/docs/publications/CaringReport.pdf>.

- the physical environment of the home
- the level of health and social services available
- the nature of the relationship between the ill person and their caregiver.

When to use respite care

There may be periods throughout the course of the life-limiting illness where home care becomes difficult. In these situations, respite care and other support mechanisms should be considered.

Respite care offers the caregiver a break from the caring role. Health care professionals see respite care as a good way of minimising the burden and strain on the caregiver. However, the caregiver and the person receiving care are often uncertain about the offer.

Caresearch also provides useful information about the impact of caregiving. ^[2]

THINKING POINTS

Reflect on Bob's story so far.

1. Identify Margaret's stressors

- Currently
- As Bob's condition deteriorates
- As Bob begins to near the end of life.

2. How would you assess these stressors?

3. What factors might affect Margaret's experiences as caregiver?

ACTIVITY 9: His illness progresses

Bob's condition is deteriorating and he is finding that most day-to-day activities are becoming increasingly difficult. Margaret admits that "it's been very hard" and says, "I know I should be stronger but I can't". She is visibly upset.

The GP explores the options for care and respite with Bob and Margaret.



His illness progresses

2. CareSearch. (2009). *Looking after someone*. Retrieved September 15, 2010, from <http://www.CareSearch.com.au/CareSearch/ForPatientsandFamilies/HowToCare/LookingAfterSomeone/tabid/1108/Default.aspx>.

THINKING POINTS

1. What are Bob's main concerns?
2. How might you respond to these concerns?
3. Discuss some of the reasons that Bob may be concerned about using respite care.
4. What concerns does Margaret express to their GP?
5. What other concerns might caregivers have about caring for a family member at home?
6. Consider your specific health care discipline. What options can you provide to support Bob and Margaret at home?

ACTIVITY 10: BEREAVEMENT

The experience for a caregiver doesn't end when the person he or she is caring for dies. This is a time of major transition and adjustment for the bereaved person. In the period following death, the caregivers may need social and psychological support.

According to the World Health Organization, Palliative care:

- "offers a support system to help the family cope during the person's illness and in the family's bereavement
- uses a team approach to address the needs of people with life-limiting illnesses and their families, including bereavement counselling, if indicated." ^[1]

Palliative Care Australia's Standards for Providing Quality Palliative Care to all Australians identifies the following two criteria for bereavement support provided by primary care providers:

- "information (both verbal and written) on loss and grief and the availability of bereavement support services is routinely provided to family members prior to and after death of the patient
- bereavement risk for caregivers and family members is assessed during the patient's illness and support is offered based on need." ^[2]

Bereavement is an individual experience. There's no standard response to the death of a close family member or friend. For most people, the feelings of loss and grief will wane over time. However, for some, there is the potential for negative effects on the physical and mental health of the bereaved that can last for some time.

As a health professional caring for the dying, you will be involved in the provision of bereavement support to grieving relatives. Identifying risk factors is an integral part of this process. It is important to seek guidance, if necessary, from an experienced member of the multidisciplinary team to ensure that optimal bereavement support is provided.

1. World Health Organization (WHO). (1998). *WHO Definition of Palliative Care*. Retrieved September 15, 2010, from <http://www.who.int/cancer/palliative/definition/en/>.

2. Palliative Care Australia. (2005). *Palliative Care Australia's Standards for Providing Quality Palliative Care to all Australians*. Retrieved September 15, 2010, from <http://www.palliativecare.org.au/Portals/9/docs/publications/Standards.pdf>.

Risk factors for complicated bereavement may include:

- childhood experiences of the bereaved person, including death of a parent, childhood sexual abuse or childhood separation anxiety
- insomnia
- levels of closeness with the deceased, time since death, and relationship with the deceased
- younger age of the deceased
- violent death
- gender of the bereaved person - women show greater grief.

Some patients may be extremely resilient, even when they have multiple risk factors that would suggest possible vulnerability, and so assessment should be individualised. ^[3]

The CareSearch review of the grief and bereavement literature suggests the following key messages:

- expressions of grief can vary widely from person to person. No-one can tell others how they 'should' be grieving.
- most people who experience normal grief reactions do not require specialist counselling.
- for those people who experience normal grief reactions reassurance, acknowledgement of their losses and access to information may be all that is required.
- a proportion of people who grieve may develop complex grief
- a number of options for referral for complicated bereavement exist:
 - specialist bereavement counsellors
 - palliative care services usually offer bereavement follow up to their clients, often based on a risk assessment, and may accept referrals from other sources
 - other mental health professionals with appropriate skills and expertise. ^[4]

THINKING POINTS

Reflect on Bob's complete story and answer the following questions.

1. Identify some factors that might impact on how Margaret copes with Bob's death.
2. What resources are available within your community to help bereaved caregivers? These may be formal and informal.
3. As a health care professional, it's important to understand that the death of patients in your care may have an effect on you. What self-care strategies will you adopt when a person you're caring for has died?

3. CareSearch. (2009). *When to Refer (Bereaved)*. Retrieved June 17, 2010, from <http://www.caresearch.com.au/CareSearch/ProfessionalGroups/GPHome/FollowingUptheBereaved/WhentoReferBereaved/tabid/1190/Default.aspx>. Used with permission.

4. CareSearch. (2010). *Bereavment and grief*. Retrieved June 17, 2010, from <http://www.caresearch.com.au/caresearch/ClinicalPractice/PsychologicalSocialSpiritual/BereavmentandGrief/tabid/1345/Default.aspx>. Used with permission.

SECTION 5

Reflections on what you've learnt

1. What have you learnt from the activities in this module that will help you further improve your ability to care for people with life-limiting illnesses and their families?
2. What specific strategies are you now going to use as a health care professional?
3. Do you see any difficulties using what you've learnt here as part of your practice as a health care professional? If so, what strategies might you use to address these difficulties?



Bob's Story

A2: BOB'S STORY

▶ 2.27 mins

I've been retired for just on twelve months now. I was diagnosed with motor neurone disease and because I was a sparky it was just too dangerous for me to keep on working. My wife and I didn't know what motor neurone disease was, but the neurologist we went to referred us on to the MND association. That was pretty confronting at first. They gave us some brochures that were very frank about what happens; it's a cruel disease. I was really angry for a few weeks and you immediately think 'why me', 'why now'. I didn't take it very well, I really took it out on the family. Everyone's different of course but you've just gotta do what's best for you. I found others that were coming to terms with issues like 'what it's like to not be the bread winner anymore' and you know that sooner or later you're going to have to relinquish some of your responsibilities, but you just can't do everything. These were some of the hardest adjustments I've had to make, but it's hard when you think people just aren't listening to what you want. Everyone seems to be an expert on what you should be doing.

A4: THREE MONTHS LATER

▶ 1.09 mins

Occupational therapist: I just wanted to go over some of the plans we discussed last time I saw you, and see how you're managing with some of the equipment that I brought over, and also the modifications to the house that we discussed.

Bob: Well the chair over the shower is making showering a lot safer and the wheelchair makes it easier if we go out shopping. But I still like to walk though.

Occupational therapist: Have you heard when they're coming to change the bathroom around?

Bob: Well, that's a bit of an issue. I know when you came over and we spoke it seemed like a good idea at the time. But I think it's a lot of expense and bother changing everything around, just to make it easier for me to get in the shower.

Occupational therapist: I guess they're just suggestions and whether you get them done or not is really up to you and Margaret. At the moment you're obviously coping with the shower in the bath but further on down the track you may find it a bit more difficult to use. So maybe what we'll do is reassess as things change.

A7: EXPLORATION

▶ 1.39 mins

Occupational therapist: How is your strength in your arms and legs at the moment?

Bob: The legs are a lot stronger than the arms and I'm a lot better in the mornings than I am in the afternoons.

Occupational therapist: Last time we talked about the tasks you need to do across the day.

Bob: I do try to do that. But some days I just can't do things that I want, when I want and I get angry because I just can't do as many things as I could do last year.

Occupational therapist: What sort of things help you deal with your concerns?

Bob: Well I guess I still really enjoy the friendship of some old blokes I know. But I don't want to be a burden on anyone.

Occupational therapist: Are you managing to get out and maintain some social contact?

Bob: I'm been very self-conscious that my walking is starting to look funny. and if we go any distance and take the chair, you know people look at you. I much rather stay at home. I'm embarrassed to eat in front of anybody other than Margaret. My coordination is bad, sometimes I cough.

Occupational therapist: Are you having trouble swallowing? Is that why you cough?

Bob: Some food just seems to stick.

Occupational therapist: Now might be a good time to see a speech therapist and a dietician then.

Bob: My GP said that this may become necessary.

Occupational therapist: Well it's very individual and it doesn't necessarily mean that you can't continue to eat. It's just very important that you do so safely.

Bob: Okay.

A9: HIS ILLNESS PROGRESSES

▶ 5.14 mins

Doctor: So Bob, how are things at the moment?

Bob: I've been getting very weak. If I have to go any distance I have to use the chair. I can walk a bit, but I'm very slow and my arms are very weak. But its Margaret I'm worried about, look at her. Some days it breaks my heart to see what this is doing to her.

Doctor: Yes. Margaret how are you managing?

Margaret (Bob's wife): It's been very hard. I know I should be stronger but I can't.

Bob: I wonder as I get worse, it's going to be harder for people to understand what I want and I'm going to be totally dependent on them. When I was in the palliative care unit for a few weeks it gave Margaret a rest, and I realised that while you're at home that there's someone there all the time. But in the palliative care unit and in the hospital it's not always going to be like that.

Doctor: It is very hard to adjust to but there are people there twenty-four hours a day whereas Margaret has got to have some sleep at some stage. And they'll never let you get into any real trouble.

Margaret how did you find it when Bob was in respite?

Margaret: Well In some ways it was a real break, especially at night. However Bob didn't like it and he's not keen to go back. I don't know how much longer we can keep going at home.

Doctor: Yes. Bob, what do you think about staying at home?

Bob: Naturally I want to stay at home as long as I can. I know the time will come when I might have to go to the hospital and back to the palliative care unit.

Doctor: Do you think you're getting enough help at home at this stage?

Margaret: There is a constant stream of people coming to our house so I don't know if we need any more. I mean they all want to help. But you do lose your sense of privacy don't you?

Doctor: It does sound like both of you are under a lot of pressure at the moment and I think we need to do something to try and help. I wonder if it might be time to get the OT to come back to your place and just reassess how things are and whether they can provide any extra support for you to might make things easier. Bob how would you feel if we did arrange more time in respite to help Margaret? And Margaret it is very important that you to get some rest so that you can provide help for as long as you possibly can.

Bob: What you think Margaret?

Margaret: I'll keep it in mind, but I'm okay at the moment.



TOPIC 1

Multidisciplinary care

To provide care that is responsive to the complex and multifaceted needs of individuals with a life-limiting illness, it is important to understand the functions and processes associated with a multidisciplinary approach to care.

OVERVIEW

TOPIC 1: A multidisciplinary approach in palliative care will help you develop the skills needed to work effectively within the context of a multidisciplinary team when providing care to people with life-limiting illnesses and their families.

AIMS & OBJECTIVES

After completing this focus topic, you should be able to:

- discuss the key principles and components of an effective multidisciplinary approach in responding to the needs of individuals with life-limiting illnesses
- identify the role of the multidisciplinary team in caring for people with life-limiting illnesses and their families
- analyse the various care contexts and the roles of the multidisciplinary team in caring for people with life-limiting illnesses.

SECTION 1

Principles of a multidisciplinary approach

In this section you will:

- identify the rationale and elements of a multidisciplinary approach in providing care for people with life-limiting illnesses
- develop an understanding of the principles involved in providing multidisciplinary end-of-life care.

ACTIVITY 1: What is a multidisciplinary approach to care?

Individuals with life-limiting illnesses often have complex and multifaceted needs.^[1] In most cases, these needs are best managed using a multidisciplinary approach to care that includes opportunities for multidisciplinary discussions and care planning.^[1, 2, 3, 4, 5] Effective multidisciplinary care embeds collaborative and patient-centred approaches to care planning and provision, and leads to the achievement of care goals that are unlikely to be achieved by health professionals acting in isolation.^[3, 4]

Benefits of a multidisciplinary approach to care include:

- increased patient perception that their care is being managed by a team
- greater likelihood of the delivery of care in accordance with national standards and clinical practice guidelines
- increased patient satisfaction with care
- increased access to information, psychosocial and practical support for patients.^[1, 6]

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1. Kuziemy, C.E., Borycki, E.M., Purkis, M.E., Black, F., Boyle, M., Cloutier-Fisher, D., Fox, L., MacKenzie, P., Syme, A., Tschanz, C., Wainwright, W., Wong, H. & Interprofessional Practices Team. (2009). An interdisciplinary team communication framework and its application to healthcare 'e-teams' systems design. *BMC Medical Informatics and Decision Making*, 9(1), 43-57.
 2. Palliative Care Australia. (2003). *Palliative Care: Service Provision in Australia: A planning guide. 2nd edition*. Retrieved May 30, 2011, from [www.palliativecare.org.au/Portals/9/docs/publications/Planning guide2003.pdf](http://www.palliativecare.org.au/Portals/9/docs/publications/Planning%20guide2003.pdf)
 3. Meier, D.E., Beresford, L. (2008). The palliative care team. *Journal of Palliative Medicine*, 11(5), 677–681.
 4. Mitchell, G., Tieman, J. & Shelby-James, T. (2008). Multidisciplinary care planning and teamwork in primary care. *Medical Journal of Australia*. 21, 188(8 Suppl), S61-4.
 5. Baldwin, P. K., Wittenberg-Lyles, E., Oliver, D.P., Demiris, G. (2011). *An Evaluation of Interdisciplinary Team Training in Hospice Care*. *Journal of Hospice & Palliative Nursing*, 13(3), 172-182, DOI: 10.1097/NJH.0b013e31820b5c16Article.
 6. National Breast and Ovarian Cancer Centre. (2008). *Multidisciplinary care principles for advanced disease: a guide for cancer health professionals*. Surry Hills, NSW: National Breast and Ovarian Cancer Centre.

THINKING POINTS

1. In your own words describe what is meant by multidisciplinary care.
2. Describe an example from your own experience where a multidisciplinary approach to care was provided. In thinking about this example, identify:
 - a) Who was involved
 - b) Why this approach was used
 - c) What benefits were achieved by this approach
 - d) What challenges were associated with this approach.

ACTIVITY 2: Betty's story

Betty is a 79-year-old woman married to Alan, also 79. Betty and Alan have a close family network; their daughter, Cheryl, has two young boys and they see each other regularly.

Two years ago Betty was diagnosed with Stage 3 Chronic Kidney Disease (CKD) following routine tests organised by her GP. Betty has multiple co-morbidities including: diabetes type II, ischemic heart disease and peripheral vascular disease. She also has hypertension and had a myocardial infarction 2 years ago.

Her kidney disease has been fairly stable since diagnosis. Betty has been well managed by her GP in conjunction with the multidisciplinary team at the Kidney clinic.

The renal dietician has been providing nutritional information and support to Betty and Alan, in particular educating them about the impact of certain foods on her kidney function.

For the past month or so, Betty has been experiencing new symptoms. She is lethargic, slightly short of breath, nauseated at times and her legs are oedematous. Betty is concerned about these new symptoms and is seeing her team at the Kidney clinic tomorrow to discuss this.



Betty's story.

THINKING POINTS

1. What does Betty raise as her main concerns?
2. What goals of care might be identified following Betty's discussion?
3. Which health professionals do you think would need to be part of the multidisciplinary team that cares for Betty as her disease progresses?

ACTIVITY 3: Principles of multidisciplinary care

The National Breast and Ovarian Cancer Centre developed multidisciplinary care principles for advanced disease.^[1] These broad principles are relevant across all care settings. Key components of effective multidisciplinary care include:

Patient-defined goals of care

Patients and their nominated caregivers, where appropriate, are involved in decisions about their care.

Includes:

- supporting patients and their caregivers to participate in care planning. This includes explaining the concept of the multidisciplinary care team approach and may or may not include participation in a care planning meeting.
- informing patients and caregivers that their case may be discussed at a team level and with health professionals they have not met, and obtaining patient consent for this.
- providing information to the patient and caregiver.
- a process of establishing goals of care, and re-evaluating treatment and care plans at critical times.
- identification of a designated point of contact and care coordinator.

A team approach

Input from as many professions as required is achieved.

Includes:

- the patient, caregivers, and the patient's general practitioner.
- flexible and evolving membership that reflects the patient's care needs.
- implementing a process to review and audit team functionality.

Ongoing information and communication

Ongoing, timely information and communication is facilitated among all team members, including patients and their nominated caregivers throughout the patient's trajectory.

Includes:

- establishing communication mechanisms and frameworks that facilitate input from all team members.
- contingency planning and forward planning, including advanced care planning.
- support and debriefing opportunities for team members.

1. National Breast and Ovarian Cancer Centre. (2008). *Multidisciplinary care principles for advanced disease: a guide for cancer health professionals*. Surry Hills, NSW: National Breast and Ovarian Cancer Centre.

Standards of care

Provision of care is in accordance with nationally agreed standards.

Includes:

- consistency with national evidence-based recommendations and benchmarks.
- linkages with/referral to specialist and community-based services, including palliative care services. ^[1]

These four principles recognise the importance of:

- the patient and their caregiver involvement in the care planning process.
- care coordination.
- continuity of care. ^[1]

THINKING POINTS

1. Consider the principles and strategies relating to Patient Defined Goals of Care, and Ongoing Information and Communication described in this section. In terms of your own profession, what specific activities can you implement to ensure these principles are demonstrated in a multidisciplinary team context?

SECTION 2

Planning multidisciplinary care

In this section you will:

- consider the application of the multidisciplinary care principles in the provision of palliative care
- identify the roles, responsibilities and outcomes of a multidisciplinary team meeting
- explore factors that influence the functioning and effectiveness of the multidisciplinary team.

ACTIVITY 4: Patient-centred care planning

A plan of care is developed through contributions from all relevant disciplines and is based on a comprehensive assessment of the individual and family. The team works both autonomously and together with individuals, families and caregivers to clarify goals of care and develop a single, co-ordinated, needs-based palliative care plan.^[1, 2, 3] Individual team members work within the evidence base for their specific profession.^[4]

The care planning process may consider:

- current disease status and past medical history, including all co-morbidities
- physical and psychological symptoms
- functional status
- social, cultural, spiritual concerns
- advance care planning preferences.^[5]

Ideally, the multidisciplinary team communicates regularly (at least weekly, more often as required by the clinical situation) to review and evaluate the care plan.^[3, 5]

Family meetings can be conducted to assist with aspects of care planning and provision. Family meetings can also have a significant role in meeting the education and information needs of the patient and caregiver. The Centre for Palliative Care Education and Research website includes an evidence-based resource Family meetings in palliative care: multidisciplinary clinical practice guidelines to guide the planning and implementation of family meetings in palliative care.^[6]

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1. Meier, D.E. & Beresford, L. (2008). The palliative care team. *Journal of Palliative Medicine*, 11(5), 677–681.
 2. Baldwin, P. K., Wittenberg-Lyles, E., Oliver, D.P., Demiris, G. (2011). An Evaluation of Interdisciplinary Team Training in Hospice Care. *Journal of Hospice & Palliative Nursing*. 13(3), 172-182, DOI: 10.1097/NJH.0b013e31820b5c16Article.
 3. National Breast and Ovarian Cancer Centre. (2008). *Multidisciplinary care principles for advanced disease: a guide for cancer health professionals*. Surry Hills, NSW: National Breast and Ovarian Cancer Centre.
 4. Palliative Care Australia. (2005). *Standards for Providing Quality Palliative Care for all Australians*. Retrieved May 30, 2011, from www.palliativecare.org.au/portals/46/resources/StandardsPalliativeCare.pdf.
 5. National Consensus Project for Quality Palliative Care (2009). *Clinical Practice Guidelines for Quality Palliative Care, Second Edition*. Retrieved May 30, 2011, from www.nationalconsensusproject.org.
 6. Hudson, P., Quinn, K., O'Hanlon, B. & Aranda, S. (2009). *Family meetings in palliative care: multidisciplinary clinical practice guidelines*. Retrieved December 9, 2011, from www.centreforpallcare.org/index.php/resources/.

THINKING POINTS

1. When and how can patient and caregiver input be facilitated in the care planning process?
2. What strategies can be used to ensure the contribution of a range of different service providers is optimised when planning multidisciplinary care?

ACTIVITY 5: The multidisciplinary team

There are many functions of the multidisciplinary team in palliative care, including:

- advocating on behalf of the wishes of patients, families and caregivers^[1, 2]
- implementing multiple strategies to address the needs of the individual^[3]
- adapting the team composition accordingly in response to changing needs throughout the disease trajectory^[3]
- utilising the process of advance care planning.^[1]

The composition of the multidisciplinary team can include many members across several professional disciplines including those from other specialties e.g. specialists in pain management, geriatrics and psychiatry. CareSearch has comprehensive web pages on professional groups in palliative care. There are also pages relating to multidisciplinary approaches to care.^[4]

Some of the key attributes of an effective and efficient multidisciplinary team include:

- collaborative practice
- clear communication
- clear definition of tasks and responsibilities
- clear goals, objectives and strategies
- recognition of and respect for the competence and contribution of each team member
- competent leadership
- clear procedures for evaluating the effectiveness of the team
- support for team members as required
- recognition of the contribution of team members' experience .

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1. Palliative Care Expert Group. (2010). Principles of palliative care. In Palliative Care Expert Group *Therapeutic guidelines: palliative care*. Version 3. Melbourne, VIC: Therapeutic Guidelines Limited.
 2. Palliative Care Australia. (2005). *Standards for Providing Quality Palliative Care for all Australians*. Retrieved May 30, 2011, from www.palliativecare.org.au/portals/46/resources/StandardsPalliativeCare.pdf.
 3. Mitchell, G., Tieman, J., Shelby-James, T. (2008). Multidisciplinary care planning and teamwork in primary care. *Medical Journal of Australia*, 21,188(8 Suppl), S61-4.
 4. CareSearch. (2010). *Professional Groups*. Retrieved May 30, 2011, from www.caresearch.com.au/caresearch/ProfessionalGroups/tabid/55/Default.aspx.

Interpersonal skills that may contribute to effective team communication are those around:

- communication and negotiation
- self awareness
- an ability to self reflect
- an ability to apply principles of self care. [5, 6, 7]

THINKING POINTS

1. What are some of the challenges that can impact upon team effectiveness and functioning?
2. What strategies can be used by multidisciplinary team members to ensure:
 - a) Clear definition of tasks and responsibilities
 - b) Recognition of and respect for the contribution of each team member
 - c) Clear communication?
3. What additional strategies can be implemented help a team function effectively?

ACTIVITY 6: The team meeting

Betty has been seen in the CKD clinic and the team meeting takes place a few days later. The team plans to discuss Betty as her kidney disease has now progressed to stage 4.

Leanne has been Betty's Renal Nurse Practitioner since her diagnosis. She is the facilitator of today's meeting.



The team meeting

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5. Baldwin, P. K., Wittenberg-Lyles, E., Oliver, D.P. & Demiris, G. (2011). An Evaluation of Interdisciplinary Team Training in Hospice Care. *Journal of Hospice & Palliative Nursing*, 13(3), 172-182. DOI: 10.1097/NJH.0b013e31820b5c16Article.
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 7. Kuziemy, C.E., Borycki, E.M., Purkis, M.E., Black, F., Boyle, M., Cloutier-Fisher, D., Fox, L., MacKenzie, P., Syme, A., Tschanz, C., Wainwright, W., Wong, H. & Interprofessional Practices Team. (2009). An interdisciplinary team communication framework and its application to healthcare 'e-teams' systems design. *BMC Medical Informatics and Decision Making*, 9 (1), 43- 57.

THINKING POINTS

1. What are the objectives of the team meeting?
2. What is the role of the facilitator of the team meeting?
3. What are the care-planning considerations discussed in the video?

ACTIVITY 7: Ongoing information and communication

The team, through a coordinated approach, has now identified Betty's symptoms and a management plan has been commenced.

The meeting continues with input from other allied health members of the team. Betty's functional and nutritional needs are discussed.



Ongoing information and communication

THINKING POINTS

1. What contribution was made by each team member at the meeting?
2. What examples of collaboration between the team members are demonstrated?
3. What documentation and communication principles are evident:
 - a) Within the team
 - b) To occur following the meeting?
4. What recommendations would you make for improving communication and collaboration between team members?

SECTION 3

Providing multidisciplinary care at the end-of-life

In this section you will:

- increase your understanding of the roles and responsibilities of the multidisciplinary team in providing end-of-life care
- review resources available to support patients, family members and carers at the end of life.

ACTIVITY 8: Betty's disease progresses

Betty's disease has now progressed to stage 5 or end stage kidney disease. Betty is dealing with the knowledge that her condition is deteriorating and that she will die from her disease. She talks about the symptom burden of her disease and highlights the importance of the management plan that has been established by the care team in supporting her and her family through this time.



Betty's disease progresses

THINKING POINTS

1. What are Betty's main concerns now that her disease has progressed?
2. How are her concerns different from those she highlighted in the first scene?
3. What are some of the community and social supports that may help Betty as her disease progresses?
4. How can the roles and responsibilities within the care team change as Betty's disease progresses?

ACTIVITY 9: The team implements an end-of-life care plan

Betty has been very unwell for a few months and has been unable to attend the CKD clinic at the hospital. She is now bed-bound and extremely weak. Leanne has visited her at home in conjunction with the community palliative care team and Betty's GP.

The CKD team are meeting following the recent results that Betty's kidney disease is now end stage.

Betty is experiencing many of the multisystem effects of uremia, including pruritis, nausea, extreme lethargy and weakness, and anaemia. She is also having trouble swallowing her tablets.

The team suggest a case conference to coordinate a plan of care to manage these multiple issues and to ensure that Betty is able to die at home, as she wants to, supported by her GP and the palliative care team.



The team implements an end-of-life care plan

THINKING POINTS

1. Leanne suggests holding a case conference with the GP and the community palliative care team to address Betty's end of life needs. Write an agenda for this case conference - include key priorities and the team member responsible for each.
2. How might the outcomes of this team meeting be communicated to Betty and her family?
3. From the perspective of your own discipline, what role can you have in Betty's care now as her illness has progressed to the end of life care stage?

ACTIVITY 10: Standards of care

One of the principles of providing multidisciplinary care relates to ensuring standards of care are achieved and maintained. A key resource in the provision of end of life care is Palliative Care Australia, (2005), *Standards for Providing Quality Palliative Care for all Australians*.

THINKING POINTS

1. Review the *Standards for Providing Quality Palliative Care for all Australians*, particularly pages 23-40, and identify:
 - a) Those standards that articulate with a multidisciplinary care approach?
 - b) How achievement of the standards can be monitored by the multidisciplinary care team?

ACTIVITY 11: Alan's perspective

Alan reflects on his life with Betty and in particular the past few months where he has taken on more of the caring role for Betty.

He speaks about the care team and their support not only for Betty, but for him and their daughter and grandsons.



Alan's perspective

THINKING POINTS

1. Summarise how each of the following elements have been addressed in Betty's multidisciplinary care planning and provision:
 - a) Involvement of Betty and Alan in care planning
 - b) Continuity of care
 - c) Care coordination.
2. What is the role of the multidisciplinary team following Betty's death?
3. Investigate the bereavement services available in your area. You may find information through the local council, hospital, community centre or palliative care service. Describe the details of services available.

SECTION 4

Reflections on what you've learnt

1. What key points have you learnt from the activities in this module that will help you in providing care for people with life-limiting illnesses and their families?
2. What specific strategies do you plan to incorporate as a graduate health care professional?
3. Do you see any difficulties using what you've learnt here as part of your practice as a health care professional? If so, what strategies might you use to address these difficulties?

TRANSCRIPT TOPIC 1

A multidisciplinary approach in palliative care



Betty's Story

A2: BETTY'S STORY

▶ 1.31 mins

Betty: I'm seventy-nine years old and about two years ago my doctor told me that my kidneys were not working properly. He sent me to a renal specialist and he told me I had stage 3 chronic kidney disease. Now I have diabetes and high blood pressure, but I had no idea that my kidneys were not working, so I'm on a special diet and taking tablets. And Alan, Alan's been so good, making most of the meals. My daughter Cheryl has been popping in from time to time, keep an eye on me, and check up on me and she brings our lovely grandsons, and they certainly cheer me up. The team at the clinic have been very supportive; they've told me that overtime this kidney function will only worsen and I do understand that I'm not going to get better. Actually, I'm worried about what's happening at the moment. I'm tired all the time, my legs are swollen, I feel sick, I can't eat. I think I'll have to talk to Leanne and make a decision about what is going to happen when I'm sicker.

A6: THE TEAM MEETING

▶ 4.30 mins

Gillian (Nephrologist): Well Thanks for coming everyone and Chris is online.

Chris (Clinical Psychologist): Hi all

Leanne (Nurse practitioner): Hi Chris

Gillian (Nephrologist): Let's start with Betty Harrison. Now I saw Betty and Alan last week and things have really deteriorated. Leanne would you like to start?

Leanne (Nurse practitioner): Yeh, Thanks, I am concerned about Betty, her kidney disease has progressed to stage four. So I would like to discuss her symptoms management and end of life care for Betty.

Uh so she's seventy-nine years of age, uh she's a diabetic type 2, she has ischemic heart disease, and had a myocardial infarction about two years ago and has peripheral vascular disease. When we saw her in clinic last week and she had quite a few symptoms including lethargy, oedematous legs, some slight shortness of breath. She was hypertensive and has also been experiencing some nausea in the mornings. So let's start with a review our plan with Betty's management of her co-morbidities and some of these symptoms.

Tony (Pharmacist): Last week we noticed quite a difference in Betty. She raised some concerns about the number of medications she's on; she's starting to get a little bit muddled. So I did a medication review, looked at all her medications, sent her home with a list of them all. I need

to flag though that we're going to need to start withdrawing her medications in the not too distant future and obviously we'll have to do this very carefully given all her co-morbidities.

Gillian: So let's review her medications at each team meeting okay? We'll address those poly-pharmacy issues as they come up.

Tony: That sounds good, but for the new symptoms we've started her on a diuretic and just adjusted the dose of her ace inhibitor as well.

Leanne: Yeh and we've decided to start her on an erythropoietin-stimulating agent. So hopefully this will give her a boost just to help to make her feel a little bit more energetic and less symptomatic with the tiredness.

Tony: So I think we've pretty much got her on the right medications at the moment. I'll see her again in a week or so, and she knows if there are any problems to contact us. Hey Jane!

Leanne: I'd also like to look at some non-pharmacological measures as well and I'll write those into her care plan. So Jane let's talk later about some strategies to help manage Betty's activities and her rest. Are there any more comments/ questions about her symptoms?

Team: No

Leanne: Alright well I'd like to talk about Alan and Betty's emotional wellbeing. Gillian, how was your meeting with them?

Gillian: Well I spoke to them both last week, and talked to them about end of life care and what Betty does and doesn't want. She asked me about dialysis and in particular wanted to know if it might improve her quality of life. So, I spoke to them about her co-morbidities and explained to her that for her dialysis might not extend either quality or the length of her life.

Pamela (Social worker): It's a lot for Betty to take in. How did she respond to that?

Gillian: It was a lot for her to take in and she was quite overwhelmed by the change in her condition. I reassured both of them that there's no rush to make any decisions and that our team will be there to support them through the entire process. She seemed certain by the end of session that she wants conservative management with supportive palliative care at end of life. I'm not concerned about her decision making capacity and I'm fairly confident she's not clinically depressed. But I did refer her to Chris for a psychology review because it gave her a chance to talk about it all. So Chris would you like to fill us in please?

Chris: Hi all, I was able to see them yesterday and Betty was quite settled and as you say she isn't clinically depressed. She does have a good understanding of her situation, we talked about symptom management and her options around palliative care. Betty was quite clear, she doesn't want dialysis and she would like to die at home.

Pamela: Hi Chris, it's Pam here. Sounds like you've had a good session with Betty.

Pamela: In light of these end of life discussions it would be good to see Betty for some advanced care planning, and to explore what's really important to her. And to have it all documented, if that's what she wants. I'm seeing her later this week, and I'm happy to raise it with her. Is everyone okay with that?

Team: Yes

Chris: That sounds good. I'm also happy to see them again, although can I just flag with everyone, I will be on holidays for a few days now. But I'll forward details on who's covering for me

A7: ONGOING INFORMATION AND COMMUNICATION (TEAM MEETING CONTINUED)

▶ 3.36 mins

- Chris:** I'm concerned about the burden of Alan caring for Betty at home. He is very supportive, but he is also quite frail.
- Leanne:** Yeh I agree, Alan is seventy nine he has his own medical problems to worry about. Jane, do you have any thoughts on that?
- Jane (Occupational therapist):** What's Betty's home situation like?
- Leanne:** She lives in a two bedroom unit on the ground floor, there are lot of neighbours who support them.
- Pamela:** Alan and Betty's daughter Cheryl, she lives locally, she's very supportive. She drops in all the time with her two little boys.
- Jane:** Are there any community services going in?
- Pamela:** No, not at the moment. I have offered to arrange for help with the cleaning and the shopping and I've also explained respite care options, you know to help give Alan a break but they're pretty keen to cope on their own.
- Jane:** Yeh and that's pretty understandable isn't it? What about Cheryl, you said she lives locally. How involved is she?
- Pamela:** She's a single mum, she's got two young kids and she works three days a week, so she's a very busy woman. But I'm meeting her at the house later in the week, so I can see how she's going and let you know.
- Jane:** That'll be great. I'm really keen to do an OT function and an ADL assessment in the home, and could we maybe do that as a joint visit with the community palliative care, and that way I can give them some advice about how to deal with lethargy. Has Betty been referred to the community palliative care?
- Leanne:** Yeh, I referred Betty a few weeks ago, and Sue, one of the nurses has been in to see them, and meet them in preparation for when the disease progresses. But we've discussed that and agreed that at this stage we don't really required a lot of input from them, I'm just going to keep Sue up to date with our meetings. But you can organise to meet with her back at the house if you want to.
- Jane:** Okay, well I'll give Sue a call and make it a time when and Alan and Cheryl can be there as well. And then that way I can show them both some strategies to help them deal with care giving tasks and make it a little bit easier for them.
- Leanne:** Um Anna, How is Betty doing from a nutritional point of view?
- Anna (Renal dietician):** Oh she's been managing her diet really well ever since she's been diagnosed. So I've spoken to her about the different food types, about the relevance of protein and potassium in her diet and she seems to be taking all that on board. Um the only thing is her serum phosphate levels, they are a bit higher than they used to be and that's a bit of a concern for me.
- Leanne:** Well I'll organise to get her bloods checked regularly, and I'll keep you updated with the results. I mean we may need to put her on a phosphate binder if her phosphates rise too much and she becomes symptomatic.
- Anna:** Yeh Betty did ask me what will happen once her kidney function gets worse. So I've given her as much information as possible, including the food types that she will have to stop eating and drinking. She seems to be okay with that, I've also given her resources on how to deal

with the nausea, the headache, the itchiness, and the tiredness. Oh I've also gave Alan and Cheryl some new recipes, so hopefully that will take their mind off things for a little bit.

Gillian: That good Anna, sounds like you've covered everything. Well given the change to Betty's situation and our plan to coordinate care to support a home death, let's review Betty again next week and share our assessments. There's a lot going on for them in the next few weeks so please contact Leanne or I if any of you have any concerns.

Leanne: Are there any more comments or questions?

Team: No

Leanne: Okay, well I'll give Betty's GP a call tomorrow and just update him on what we discussed today in our team meeting. He's been really involved in Betty's care and wants to be kept in the loop. So just to prioritise then from today's meeting, the important things about Betty's symptoms are her oedematous legs, her shortness of breath, her lethargy, hypertension (fades out).

A8: BETTY'S ILLNESS PROGRESSES

▶ 1.29 mins

Betty: Things have been awful really, the tablets help but not very much, it's...it's always there. And as for the retched itching, it never stops. I've just had enough of these tablets and I can't... can't even swallow them, I choke every time. I know I'm going to die. I just want to home with my family, I want to be able to have a laugh with them, I...I want to see my gorgeous grandsons before I die, I know I will never ever see them grow up.

The clinic has been so...so good to me and they've listened to what I've said, and try to find every way possible to ease my pain. I couldn't have done this without them. Everything's in order, and all my affairs have been sorted.

I...I do worry about Alan, I don't know how he's going to cope when I die. But I know Cheryl and the boys will look after him.

A9: THE TEAM IMPLEMENTS AN END-OF-LIFE CARE PLAN

▶ 2.04 mins

Leanne: Okay, it's been several months now since we discussed end of life care with Betty and Alan. Betty is now in stage 5 of her kidney disease. Her GFR is 6 and her creatinine is 438. So we've discussed openly with Betty and Alan since the diagnosis and both Betty and Alan are aware that Betty will die soon, so our main goal now is to support Betty at home with her symptoms management and support Alan and Cheryl with this as well.

Chris: So how's Betty doing?

Leanne: Hmm not so well, she has severe pruritus, which is driving her crazy, she's got nausea she's very weak and lethargic. So she's actually having a lot of trouble swallowing her tablets, the palliative care team will have to start a syringe driver soon for the pain I think. Umm so they've actually asked if they could collaborate on her medication management. Uh so I'm going to organise a meeting with the palliative care team and Betty's GP in the next couple of days, so that we can review her care plan and her medication management

Tony: I can provide some input around the subcutaneous medication if necessary.

Leanne: Okay great, Thanks Tony Pamela: I'd like to refer Alan and Cheryl to the bereavement support program, run by the palliative care team.

Anna: I'll also like to check to see if they need any additional nutritional support perhaps at this point.

Leanne: Okay thanks

Chris: Can I also just take this time to remind everyone that Craig our staff counsellor is always available. He could come and have a chat with us as a group or individually if anyone wants.

Leanne: Yeh thanks Chris. Actually last time I spoke with Betty and Alan they asked me to pass on their sincere thanks to the team for the ongoing support over the last two years. And I think they've both progressed well and hopefully we've managed to meet our goal, which is for Betty to die at home with some dignity and some comfort.

A11: ALAN'S PERSPECTIVE

▶ 2.48 mins

I can't help but worry about looking after Betty at home. Not that I told her that. I didn't want to worry her. The team has been great, always keen to help us no matter what the problem; I could not have done without them. Betty's renal team have seen her regularly and the community palliative team sees us now at home. Everything seemed so well planned and coordinated. I still feel on top of things but, with all these people surrounding us and so willing to help. The team arranged for some volunteers to be with Betty when I go out. I don't go much, walk down to our favourite spot, talk with Cheryl and the boys sometimes. I know Betty's had enough now, she's ready to die. She's suffered nausea, she's suffered these terrible itchings; the palliative nurses have some idea of how to manage these things so we're going to try them. I worry about what will happen when all this is over. Will I fall in a heap? When all the team has gone. Those wonderful grandsons, they'll see me through. We had a great life together...



TOPIC 2

Caring for Aboriginal people with life-limiting conditions

To provide quality care for people with life-limiting conditions and their families you need to be able to respond effectively to their specific needs.

OVERVIEW

TOPIC 2: Caring for Aboriginal people with life-limiting conditions will help you develop the knowledge and skills needed to provide quality care, across various health care settings, to Aboriginal people with life-limiting illnesses and their families.

AIMS & OBJECTIVES

This focus topic is based on the core principles of palliative care and is designed to supplement the learning activities in Module 1: Principles of palliative care.

After completing this focus topic, you should be able to:

- identify the practice principles of caring for Aboriginal people with life-limiting illnesses.

SECTION 1

Caring for Aboriginal people with life-limiting illnesses

In this section you will:

- explore the practice principles of caring for Aboriginal people with life-limiting illnesses
- consider how you can ensure the care you provide is culturally safe.

ACTIVITY 1: Tom's story

Tom is a 55 year old Aboriginal man with advanced lung cancer and multiple metastases. He collapses at home, his family call the ambulance and he is admitted to the ward, extremely breathless. His disease is now end stage. Tom's wife Cec and their son Jimmy are with him in the ward.



Tom's story

THINKING POINTS

1. What are some of the communication issues illustrated in the video?
2. Think about your own discipline and identify actions you could take to ensure that the care you will provide to Tom and his family is culturally safe.

ACTIVITY 2: Engaging with Aboriginal communities in providing palliative care

Australian Aboriginality is a broad category within which are embedded many language groups and subcultures. Aboriginal peoples are the Indigenous Australians and should be respected as the traditional custodians of the land. Indigenous Australians make up approximately 2.5% of the total population.^[1]

Factors which may impact on health care provision to Aboriginal people include:

- historical factors such as interactions with European settlers, and detrimental government and healthcare policies & practices.^[1, 4]
- social factors including welfare issues, education and employment.^[2]
- physical and environmental factors including housing, access to safe water and sanitation and necessary services (electricity, phone etc).^[2]

1. Taylor, K. & Guerin, P. (2010). *Health Care and Indigenous Australians: Cultural safety in practice*. Melbourne, VIC: Palgrave Macmillan

2. AIHW. (2011). *The health and welfare of Australia's Aboriginal and Torres Strait Islander people: an overview 2011*. Cat. no. IHW 42. Retrieved December 9, 2011, from www.aihw.gov.au/publication-detail/?id=10737418989

- mortality and morbidity data. The life expectancy gap between Indigenous and non-Indigenous Australians is currently estimated to be 11.5 years for men and 9.7 years for women.^[2] 80% of the mortality gap can be attributed to chronic diseases.^[2] From ages 35-54, the ratio of Indigenous to non-Indigenous death rates is highest for diabetes, diseases of the liver, chronic lower respiratory disease and ischaemic heart disease.^[3] This may make experiences of grief and loss especially profound.

Fundamental to providing culturally safe palliative care to Aboriginal people are three key practice principles. The first of these principles is to engage with Aboriginal organisations and personnel in the planning, provision and monitoring of palliative care to ensure culturally relevant requirements are addressed and preferences of the patient and/or their family are considered.^[4]

Some ways in which you can engage with Aboriginal communities include:

- refer to and establish links with Aboriginal liaison officers and/or Aboriginal health workers - they may be an invaluable resource in hospital and community settings^[1, 4, 5]
- liaise with the appropriate Aboriginal organisations as part of discharge planning.
- refer to Aboriginal Medical Services (AMS), Regional Councils, Aboriginal community health organisations for information as required
- acknowledge the importance of kinship, traditional healers and bush medicines for some individuals.^[4, 5]

THINKING POINTS

1. Consider how each of these factors - historical, social, physical and environmental, mortality and morbidity - can impact on the provision of palliative care for Aboriginal people

ACTIVITY 3: Acknowledging specific needs

Sarah contacts Nancy, the hospital Aboriginal Liaison Officer. They get together for a discussion about Tom's admission. Sarah asks Nancy for some support and advice in how to progress caring for Tom and his family.

Their discussion highlights several key issues to consider when caring for an Aboriginal family. Nancy offers to come and see the family with Sarah.



Acknowledging specific needs

3. AIHW Indigenous observatory. (2011). *Life expectancy*. Retrieved December 9, 2011, from www.aihw.gov.au/indigenous-observatory-life-expectancy/
4. Commonwealth of Australia. (2004). *Providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander Peoples: Resource Kit*. Retrieved December 9, 2011, from www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-pubs-indig-resource.htm
5. McGrath, P. (2010). The Living Model: An Australian model for Aboriginal palliative care service delivery with international implications. *Journal of Palliative Care*, 26(1), 59-64.

THINKING POINTS

1. Nancy says: “We need to take our cues from the family”. What does this mean?
2. Nancy mentions to Sarah that the local Aboriginal Medical Service might be a good resource in terms of locating a traditional healer. Go to the website [Australian Indigenous HealthInfoNet](#) and move through the sections about health systems/health workers/organisations and find your local Aboriginal Medical Service on the map. Identify the key elements of their service.

ACTIVITY 4: Communication principles when caring for Aboriginal people

The second key practice principle when caring for Aboriginal people is to communicate with the individual, their family and community and Aboriginal Health Workers in a sensitive way that values cultural safety.^[1]

Such communication can require you to:

- ensure that the right information is being shared with the right people^[2]
- identify the nationhood of the Aboriginal individual
- check with the individual and their family about what is appropriate to talk about
- consider culturally safe communication strategies relevant to the individual and their family e.g. teleconferences, family meetings and translators
- allocate an appropriate amount of time to facilitate meaningful discussions
- start interactions simply ‘having a yarn’ and allow the conversation to progress slowly to the point at hand and at the same time incorporate patient and family education
- confirm that information has been understood.
- avoid using medical jargon
- complete a comprehensive, holistic clinical assessment
- identify, respond to and document specific cultural and spiritual needs, ceremonies or practices, including post death
- support families who have large numbers of visitors. Consider moving the individual to a larger room near the ward entrance.^[1, 2, 3]

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1. Commonwealth of Australia. (2004). *Providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander Peoples Resource Kit*. Retrieved December 9, 2011, from www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-pubs-indig-resource.htm.
 2. McGrath, P. (2010). The Living Model: An Australian model for Aboriginal palliative care service delivery with international implications. *Journal of Palliative Care*, 26(1), 59-64.
 3. Taylor, K. & Guerin, P. (2010). *Health Care and Indigenous Australians: Cultural safety in practice*. Melbourne, VIC: Palgrave Macmillan.

THINKING POINTS

1. 'Yarning' allows the longer narrative to be told.
 - a) What is your understanding of 'yarning'?
 - b) What is its relevance in end-of-life care?
2. Refer to the communication principles on pages 20 and 21 in the Indigenous Palliative Care Resource Kit – Practice Principles. Describe specific strategies you might use to apply these principles in practice.

ACTIVITY 5: Communicating with Tom's family

Sarah and Nancy return to the bedside. Tom is now very unwell and is now extremely breathless. The family are pleased to see Nancy. Sarah is concerned about Tom's symptoms.



Communicating with Tom's Family

THINKING POINTS

1. What strategies are demonstrated by Nancy at the beginning of the scene to facilitate effective communication with Tom?
2. What recommendations would you make to improve communication by Nancy and Sarah?
3. What are the key needs and concerns likely to be for Tom and his family as they face Tom's imminent death in the hospital? Provide evidence for your answer.
4. Jimmy states that "Dad knows he's not going to make it back to country to die." Based on this scene, what are some of the reasons that Tom may want to return to country to die?

ACTIVITY 6: Building capacity

The third practice principle is to provide information or training to all personnel to enable the provision of culturally safe palliative care to Aboriginal peoples.^[1]

Consider the following:

- all health care staff, including non direct care workers, should complete cultural safety training^[1]
- non-Indigenous Australians must increase their knowledge and understanding of the correlation between historical events, political agendas, economics and ill health

1. Commonwealth of Australia. (2004). *Providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander Peoples: Resource Kit*. Retrieved December 9, 2011, from www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-pubs-indig-resource.htm.

- building workplace relationships and partnerships with Aboriginal Health workers/ indigenous liaison officers to enhance the practical knowledge of staff in regards to providing culturally safe care ^[2]
- sourcing culturally appropriate education materials
- the Centre for Cultural Competence Australia (www.ccca.com.au/) provides training and development to individuals and organisations in the field of Aboriginal and Torres Strait Islander Cultural Competence
- closing the gap in health outcomes between Indigenous and non-Indigenous Australians is currently a key priority within Australia. ^[3]

THINKING POINTS

1. What resources are available to support health professionals maintain a culturally safe environment when caring for Aboriginal people?
2. How do you determine if the care you are providing is culturally safe?

SECTION 2

Reflections on what you've learnt

1. What key points have you learnt from the activities in this module that will help you in providing care for people with life-limiting illnesses and their families?
2. What specific strategies do you plan to incorporate as a graduate health care professional?
3. Do you see any difficulties using what you've learnt here as part of your practice as a health care professional? If so, what strategies might you use to address these difficulties?

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2. Queensland Government. (2011). *Sad news, sorry business. Guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying*. Retrieved December 9, 2011, from www.health.qld.gov.au/atsihealth/documents/sorry_business.pdf.
 3. Australian Indigenous HealthInfoNet. (2011). *Closing the gap*. Retrieved December 9, 2011, from www.healthinonet.ecu.edu.au/closing-the-gap.



Tom's Story

A1: TOM'S STORY

▶ 2.16 mins

Cec (Tom's wife): Tom, Tom the ambulance is coming to take you to hospital!

Jimmy (son): Mum, mum what happened?

Cec: He couldn't sleep, he was hot and sweaty, couldn't keep still, he got up to go to the toilet. I heard a crash. He just fell.

Jimmy: Dad, dad you okay old mate?

Tom: Yeh! Yeh, I'm alright!

Jimmy: Okay, okay everything's fine dad. The ambulance is coming, we're all here.

In hospital

Sarah (Nurse): Hi Tom, what have you been up to then? Having a bit of excitement to start your day? What happened this morning Tom?

Tom: I was on the way to the toilet and next thing I knew I was on the floor. Felt I couldn't get my breath.

Sarah: You must've both got a fright. What happened just before you fell?

Tom: Not sure, just remember being on the floor.

Sarah: That's okay Tom, we'll have a look at everything and see if we can find out what's going on. You've been coming to the hospital for some time now, haven't you? How long's it been?

Cec: Yeh, it's been a while now hey, over a year now.

Sarah: What's your biggest worry at the moment?

Tom: I'm okay really. I've got the family coming around to help Cec, which is a good thing.

Sarah: Tom, I can see a difference in you since we saw you last and I can see that you're in pain and that you seem to be having trouble breathing. Tom I'd like to talk to you about some medications we can use to help manage your pain and breathing. How would you feel about having a chat about that? Perhaps there's someone else you'd like to be here while we talk about these things? Or I can ask Nancy our Aboriginal liaison officer to come in? Tom nods Okay Tom, I'll let you rest now and I'll come back in a little while. Here's your call button, I'm just going to put it right there, if you need me just call, just press it okay. Alright, I'll be back soon.

A3: ACKNOWLEDGING SPECIFIC NEEDS

▶ 1.40 mins

Sarah: Tom's back in with us following a collapse this morning. I started admitting him, but he just wasn't comfortable talking to me about this last episode. Actually I felt really uncomfortable and I didn't really know what to say.

Nancy (Aboriginal liaison officer): What's the biggest concern about Tom at the moment?

Sarah: He's in a lot of pain, and he's having trouble breathing. I mentioned that I'd like to try some tablets to try and help manage his symptoms but he just stopped engaging with me. I don't know why?

Nancy: Well he's probably worried about a lot of things at the moment. I think first and foremost we need to let him settle in with the family and he's also likely to be sensing something is really different this time.

Sarah: Absolutely, it's been documented that his condition has been deteriorating by his team. They've also mentioned that his prognosis is very poor. That has also been discussed with his family.

Nancy: And I'm sure Tom and his family are really aware of that.

Nurse: Absolutely, he has definitely deteriorated since I saw him last. I'm really worried about his symptoms; they need to be managed properly.

Nancy: Yes, we do need to be mindful though that Tom may want to use a traditional healer or he may want to use some traditional medicines.

Sarah: Oh okay, I don't really know much about that so what would I need to do to arrange for that to happen.

Nancy: Importantly we need to take the cues from the family first. They may already be dealing with some traditional medicine or some healers. If not though we can always contact the local Aboriginal medical service and see if they're dealing with any traditional healers at the moment, but importantly we need to take the cues from the family first.

Sarah: Yes.

Nancy: Should we go and see him?

A5: COMMUNICATING WITH TOM'S FAMILY

▶ 3.40 mins

Nancy: Hey Tom, good to see you. How you doing Cec? Good to see you Jimmy. You been alright Uncle, you been up to country lately?

Tom: We was up there a month or two ago, that right Cec, yeh.

Cec: Yeh, about that.

Nancy: How's all the mob?

Tom: They're all good.

Nancy: Now Uncle, I hear that you've been talking to Sarah the nurse and she's told me that you're in a little bit of pain, and that you're breathless.

Tom: Yeh, I don't want them to put me on that morphine. Remember Cec when they gave it to Aunty Joyce. That morphine, made her real drowsy. She couldn't even speak and then she died the next day.

I'm not staying here, we can manage at home. Anyway I want to see Uncle Joe!

Jimmy: Yeh that's okay Dad, I'll talk to Uncle Joe. I'll get him to come have a yarn, okay. But let's listen to what Sarah has to say first hey.

Sarah: Tom it's understandable that your experience with Aunty Joyce would make you cautious about morphine. We would use a small amount to help manage your pain and breathing without making you drowsy. From what you're saying, it's really important for you to be awake and not drowsy, is that right?

Tom: Yep, not drowsy. I want to be awake so I can have a yarn with everybody, keep in control. That's what this is all about isn't it?

Sarah: Let me look at this brochure with you, it's good. It tells you all about morphine and how it might help you. It helps explain the medical jargon. Let's go through it together. Fades out
Okay so Tom does that make a little more sense now about why we're wanting to use morphine to help control your pain and breathing? Why don't you have a yarn with your family? I'll have a chat with the doctors now. I'll come back and we can talk about anything that you need to.

Jimmy: Hey Sarah, I'll start tracking down Uncle Joe.

Sarah: Who's Uncle Joe?

Jimmy: Uncle Joe is an elder back in country; he's what you call our traditional healer. It's really important that he's part of all the decisions that are made.

Sarah: Does he need to come down here, or can we get him on the phone?

Jimmy: Oh, I can get him on the phone.

Sarah: Okay well I can try and set up a family meeting via tele-conference. Would that be okay?

Jimmy: Yeh, no worries. Thanks Sarah.

Sarah: Jimmy I was wondering if you'd like us to move your dad into a single room, up near the entrance of the ward. There's a big area there where your whole family can wait and probably visit your dad in larger numbers than just the usual two visitors at a time policy.

Jimmy: Sounds great, thank you.

Sarah: Okay, is there anything else that you need right now?

Jimmy: Dad knows that he's not going to make it back to country to die. I really do think he needs to share his stories with the folks back home. I think he really needs to say his final goodbyes, it's really important.



TOPIC 3

Caring for children with life-limiting conditions

To provide care that is responsive to the specific needs of children with life-limiting conditions and their families, it is important to understand the social, personal and illness experiences of individuals facing such a condition and how the principles of palliative care can be applied to support children and their families.

OVERVIEW

TOPIC 3: Caring for children with life-limiting conditions will help you develop the knowledge and skills needed to provide care, across various health care settings, to children with life-limiting conditions and their families.

AIMS & OBJECTIVES

After completing this focus topic, you should be able to:

- discuss the key principles associated with caring for children with life-limiting conditions and their families
- describe the process of assessment and management of children with a life-limiting illness and their families, through an interdisciplinary approach to care
- identify strategies to facilitate coordination of care for children with a life-limiting condition, their families and their communities.

SECTION 1

Understanding needs of children with life-limiting conditions and their families

In this section you will:

- review key principles for responding to the needs of children with life-limiting conditions and their families
- review illness trajectories and their implications for children with life-limiting conditions
- learn about loss and bereavement in the context of children and their families.

ACTIVITY 1: Impact of life-limiting conditions

Life-limiting conditions in childhood

Life-limiting conditions in children can include a varied and diverse range of health disorders, including:

- genetic or congenital disorders
- neurological disorders
- cancers, brain tumours, solid tumours
- respiratory disorders
- gastrointestinal disorders
- cardiovascular disorders
- metabolic disorders
- renal diseases
- immunological disorders. ^[1]

These conditions can be divided into four broad groups that are associated with differing trajectories:

- life-limiting conditions for which treatment may be feasible but can fail e.g., cancer
- conditions where there may be long periods of treatment aimed at prolonging life, though life is ultimately limited e.g., complex cardiac disease
- progressive conditions with no curative options e.g., neurodegenerative disorders such as Batten's Disease, Spinal Muscular Atrophy type 1
- irreversible conditions causing disability leading to possible health complications and likely life threatening implications e.g., severe cerebral palsy with complex medical conditions. ^[2]

Illness trajectories for children with life-limiting conditions are often uncertain, as medical advances are rapidly altering outcomes. This uncertainty can cause significant distress for children and their families. It can also defer appropriate early referral to a palliative care service. ^[3]

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1. Feudtner, C., Kang, T.I., Hexem, K.R., Friedrichsdorf, S.J., Osenga, K., Siden, H., Friebert, S.E., Hays, R.M., Dussel, V. & Wolfe, J. (2011). Pediatric Palliative Care Patients: A Prospective Multicenter Cohort Study. *Pediatrics*, 127(6), 1094-1101.
 2. Association for Children's Palliative Care (ACT). (2009). *A Guide to the Development of Children's Palliative Care Services*, Bristol, UK: Author.
 3. Davies, B., Sehring, S.A., Partridge, J.C., Cooper, B.A., Hughes, A., Philp, J.C., Amidi-Nouri, A. & Kramer, R.F. (2008). Barriers to Palliative Care for Children: Perceptions of Pediatric Health Care Providers. *Pediatrics*, 121(2), 282-288.

Impact of life-limiting conditions

Life-limiting conditions impact physically, emotionally, spiritually and socially on children and their families. The impact of life-limiting conditions often extends to friends, schools and communities. [4-6]

For example, some life-limiting conditions are associated with symptoms such as pain. These symptoms can affect the child's ability to attend school and socialise with other children, with parents and carers becoming children's main social contacts. [2] Isolation at different stages of a child's life may affect their physical, psychological, cognitive and social development. [7] Older children who have absences from school often report anxiety about their academic performance. [8] Children can also be affected by altered self-image, often causing them to strive for normality. [9]

A child's experience of living with a life-limiting condition is influenced by their age and developmental stage. It is important to assess each child's understanding of their illness, as a range of factors including personal experience with illness can influence their experience. The following box summarises common features of the child's concept of death at different ages, although it is important to consider this as a guide as considerable variation can exist.

TABLE 1 Children's age related understanding of death and dying

Age 0 - 2 years:

- sees death as separation or abandonment
- has no cognitive understanding of death
- feels despair from disruption of caretaking

Age 2 - 6 years:

- often believes that death is reversible, temporary
- may perceive death as a punishment
- engages in magical thinking that wishes come true - may feel guilt for negative feelings toward the person who died, and think that was the cause of death

Age 6 - 11 years:

- shows gradual understanding of irreversibility and finality of death
- demonstrates concrete reasoning with ability to comprehend cause and effect relationship

Age 11 years or older:

- understands that death is irreversible, universal, and inevitable
- has abstract and philosophical thinking

Source: Medline Plus, National Institutes of Health. Accessed March 31, 2013 from www.nlm.nih.gov/medlineplus/ency/article/001909.htm [10]

4. Palliative Care Australia. (2005). *A Guide to Palliative Care Service Development: A population based approach*. Retrieved October 20, 2012, from [www.palliativecare.org.au/Portals/46/A guide to palliative care service development - a population based approach.pdf](http://www.palliativecare.org.au/Portals/46/A%20guide%20to%20palliative%20care%20service%20development%20-%20a%20population%20based%20approach.pdf)
5. Palliative Care Australia. (2010). *Journeys: Palliative Care for Children and Teenagers*. Retrieved October 15, 2012, from [http://www.palliativecare.org.au/Portals/46/JOURNEYS/Journeys 2010 full document.pdf](http://www.palliativecare.org.au/Portals/46/JOURNEYS/Journeys%202010%20full%20document.pdf)
6. Kuhlthau, K., Kristen Smith, H., Yucel, R. & Perrin, J.M. (2005). *Financial Burden for Families of Children with Special Health Care Needs*. *Maternal and Child Health Journal*, 9(2), 207-218.
7. Howe, C. (2009). *Peer Groups and Children's Development : Psychological and Educational Perspectives*, Chichester, UK: Wiley-Blackwell.
8. Li, H., Chung, O. & Chiu, S. (2010). The impact of cancer on children's physical, emotional and psychosocial well-being. *Cancer Nursing*, 33(1), 47-54.

Children with life-limiting conditions can experience needs across many domains of health, requiring a comprehensive assessment approach, using language and techniques appropriate to their development stage. Key areas for assessment include:

- physical concerns
 - identify pain or other symptoms, using strategies that are age or developmental stage appropriate
- psychosocial concerns
 - identify the child's and family's fears and concerns
 - identify coping and communication styles
 - discuss previous experiences with death, dying or other traumatic life events
 - assess resources for bereavement support
- spiritual concerns
 - discuss spiritual needs
- planning for end of life care
 - identify decision makers
 - discuss anticipated illness trajectory
 - identify goals of care
 - consider concerns near end of life
 - consider acute resuscitation plan if appropriate
- practical concerns
 - plan communication and coordination of health care team
 - identify child and family preferences for location of care
 - discuss child's home or school environment
 - assess child's current and future functional status
 - identify possible financial consideration on family.^[11]

THINKING POINTS

1. Consider the following conditions and for each, describe possible illness trajectories:

- a) Spinal Muscular Atrophy type 1
- b) Infantile Batters disease.

2. In what ways does a child's developmental stage influence their understanding of death and dying?

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9. Taylor, R.M., Pearce, S., Gibson, F., Fern, L. & Whelan, J. (2013). Developing a conceptual model of teenage and young adult experiences of cancer through meta-synthesis. *International Journal of Nursing Studies*, 50(6), 832-846.
10. Medline Plus. (2013). *Discussing Death with Children*. Retrieved March 31, 2013, from <http://www.nlm.nih.gov/medlineplus/ency/article/001909.htm>
11. Himelstein, B.P., Hilden, J.M., Boldt, A.M. & Weissman, D. (2004). Pediatric Palliative Care. *New England Journal of Medicine*, 350(17), 1752-1762.

ACTIVITY 2: The family's experience of their child's life-limiting illness

Parents can experience a wide range of concerns including:

- fear, anxiety and stress associated with observing their child's distress and the loss of their child
- financial burden associated with medical management, equipment and transport costs, as well as absences from employment
- a decline in parental physical health due to stress and increased workload associated with medical management responsibilities, relationships and lack of time for themselves.

Siblings of children with life-limiting conditions can also be affected. The sibling's experiences can include:

- increased responsibilities
- stress from upheaval of family routine and dynamics
- feelings of anxiety through concern for sibling who is unwell as well as separation from parents
- feelings of guilt about thoughts they may have towards their sister or brother
- feelings of embarrassment about being seen in public with their unwell or disabled sibling.^[1, 2]

Grief and bereavement

The death of a child is one of the most stressful situations a family can face. For parents, feelings of grief and loss can start well before the child has died.^[3] Responses to the death of a child will vary. Some parents and siblings can experience grief that continues long after the death of a child. For many, this is a normal response to a significant loss and the continuing bonds that parents have with their child even after the child's death. Other individuals can experience a more complicated grief. For some, this complicated grief will require additional professional supports.^[4] Grief and loss is often experienced also by grandparents, friends, community and health professionals involved in the child's care. Grandparents can experience grief both from the loss of their grandchild and from seeing their own child experience loss.^[5]

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1. Newton, A.S., Wolgemuth, A., Gallivan, J. & Wrightson, D. (2010). Providing support to siblings of hospitalised children. *Journal of Paediatrics and Child Health*, 46(3), 72-75.
 2. Abrams, M. (2009). The Well Sibling: Challenges and Possibilities. *American Journal of Psychotherapy*, 63(4), 305-317.
 3. Kars, M.C., Grypdonck, M.H., de Korte-Verhoef, M.C., Kamps, W.A., Meijer-van den Bergh, E.M., Verkerk, M.A. & van Delden, J.J. (2011). Parental experience at the end-of-life in children with cancer: 'preservation' and 'letting go' in relation to loss. *Support Care Cancer*, 19(1), 27-35.
 4. Rosenberg, A.R., Baker, K.S., Syrjala, K. & Wolfe, J.(2012). Systematic review of psychosocial morbidities among bereaved parents of children with cancer. *Pediatric Blood & Cancer*, 58(4), 503-512.
 5. Ponzetti, J. (1992). Bereaved Families - A comparison of parents and grandparents - reactions to the death of a child. *Omega - Journal of Death and Dying*, 25(1), 63-71.

THINKING POINTS

1. Consider the impact of long-term medical management for a child with a life-limiting illness. In what ways might this impact on the child:
 - a) Physically
 - b) Emotionally
 - c) Spiritually
 - d) Socially?
2. What are some of the ways feelings of grief might be experienced by parents?

ACTIVITY 3: Emily's story

Emily is a 10 year old girl who was diagnosed at birth with a congenital heart defect. Her parents were informed soon after birth she had Hypoplastic Left Heart Syndrome. The Paediatric Cardiology Team were involved in Emily's care upon diagnosis. Emily was not suitable for a heart transplant according to the national criteria. Emily had numerous reconstructive surgical procedures until the age of 9 when Emily's condition deteriorated and further surgical procedures were not possible.

Emily lives with her parents and younger siblings on a cattle property in rural Australia. Emily's parents work on the property and Emily's mother has recently obtained work in the nearest town to assist the family financially.



Emily's story

THINKING POINTS

1. Identify the stressors that Emily's parents might currently be dealing with:
 - a) Physically
 - b) Psychosocially
 - c) Financially
 - d) Spiritually.
2. What are Emily's current physical concerns?
3. Identify the additional concerns for children with a life-limiting illness and their families who live in rural and remote areas.

ACTIVITY 4: Paediatric palliative care concepts

Definition and standards in paediatric palliative care

The World Health Organisation's definition for paediatric palliative care includes the principles of:

- palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family
- it begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease
- health providers must evaluate and alleviate a child's physical, psychological, and social distress
- effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited
- it can be provided in tertiary care facilities, in community health centres and in children's homes.^[1]

Palliative care standards^[2] for children remain the same as they do for adults, with some care priorities that have particular significance including:

- involving the whole family in the child's care
- involving allied health professionals with specialised skills
- supporting families to care for their sick child as well as other siblings
- individualising responses to the child's care needs.^[3]

Some unique aspects of palliative care for children include:

- smaller number of children requiring palliative care
- wider, more diverse range of conditions
- each child's developmental factors need to be considered with their care
- different physiology and pharmacokinetics
- parents often involved in decision making
- siblings require developmental appropriate individualised support
- child's life-limiting illness has profound effects on all aspects of family life
- most children with life-limiting conditions are cared for at home
- the death of a child has profound and prolonged effects on family members and family life, as connections with the child continue after the child's death.^[4, 5]

Children with a life-limiting illness can have disabilities that have a compounding effect on their specific palliative care needs.

1. World Health Organisation. (1998). *WHO Definition of Palliative Care for Children*. Retrieved May 23, 2012, from <http://www.who.int/cancer/palliative/definition/en/>.

2. Palliative Care Australia. (2005). *Standards for providing quality palliative care for all Australians*. Retrieved November 6, 2012, from www.palliativecare.org.au/portals/46/resources/StandardsPalliativeCare.pdf.

3. Palliative Care Australia. (2010). *Journeys: Palliative Care for Children and Teenagers*. Retrieved October 15, 2012, from [www.palliativecare.org.au/Portals/46/JOURNEYS/Journeys 2010 full document.pdf](http://www.palliativecare.org.au/Portals/46/JOURNEYS/Journeys%202010%20full%20document.pdf).

4. Caresearch. (2010). *Paediatrics*. Retrieved November 17, 2012, from <http://www.caresearch.com.au/caresearch/tabid/737/Default.aspx>.

5. Royal Children's Hospital Melbourne. (2010). *Palliative Care: Paediatrics*. Retrieved October 18, 2012, from http://www.rch.org.au/rch_palliative/About_palliative_care/.

THINKING POINTS

1. List key physiological differences between children and adults that can have implications when caring for a child with a life-limiting illness.
2. In the context of your own discipline, list examples of how you would apply the following principles of paediatric palliative care in your practice:
 - a) Providing a family centred approach to care
 - b) Providing care based on each child's developmental needs.

SECTION 2

Principles of care for children with a life-limiting illness

In this section you will:

- develop communication skills to enable you to respond effectively to children with life-limiting conditions and their families
- learn about principles for the assessment and management of children with a life-limiting condition
- explore principles for coordinating care of children with life-limiting conditions and their family through a collaborative approach.

ACTIVITY 5: Communication with children and their families

Communication with children with a life-limiting condition

Like adults, children often have questions about their illness, care and dying. It is important that responses to questions are open, honest and age appropriate. Age appropriate communication with children and adolescents assists with acceptance of their condition, management of symptoms and preparation for dying. Involving adolescents in conversations and in their own care planning creates trust with health professionals. ^[1]

Age, individual developmental stages and possible neurological impairments need to be considered when communicating with children. Communication should be directed at the child though, depending on age, communication about care could also be through parents. Consider all family members who need to be involved when discussing aspects of the child's care. ^[2]

Strategies when talking to children include:

- tailor communication to meet the child's developmental stage ^[3]
- use age appropriate methods of communication such as drawings, books, action based toys ^[4]
- be honest and maintain trust, be clear with responses to questions
- take time to be together and communicate, not just about their illness
- allow children to have a break away from family and carers
- be prepared to listen to and revisit conversations about care. ^[5]

1. Wiener, L., Zadeh, S., Battles, H., Baird, K., Ballard, E., Osherow, J. & Pao, M. (2012). Allowing Adolescents and Young Adults to Plan Their End-of-Life Care. *Pediatrics*, 130(5), 897-905.

2. CareSearch. (2011). *Communicating with Health Professionals*. Retrieved December 6, 2012, from <http://www.caresearch.com.au/caresearch/tabid/1107/Default.aspx>.

3. Zwaanswijk, M., Bates, K., van Dulmen, S., Hoogerbrugge, P.M., Kamps, W.A., Beishuizen, A. & Bensing, J.M. (2011). Communicating with child patients in pediatric oncology consultations: a vignette study on child patients', parents', and survivors' communication preferences. *Psycho-Oncology*, 20(3), 269-277.

4. Rollins, J.A. (2005). Tell me about it: drawing as a communication tool for children with cancer. *Journal of Pediatric Oncology Nursing*, 22(4), 203-221.

5. Turner, J., Clavarino, A., Yates, P., Hargraves, M., Connors, V. & Hausmann, S. (2007). Development of a resource for parents with advanced cancer: What do parents want? *Palliative and Supportive Care*, 5(2), 135-145.

Communication with family

Parents of children with life-limiting conditions report that communication difficulties with health professionals about death are amongst the most stressful situations experienced.^[6] Conversations about care, choices and advanced planning are vital to ensure families are part of the plan of care. When talking with children with a life-limiting condition and their parents together, it can be difficult to assess each person's level of understanding, as neither may want to openly acknowledge how sick the child may be.^[7]

Specific considerations when talking to families around the time of death of a child include:

- plan the conversations in advance, taking into account timing and environment
- assess prior knowledge and what is needed to be discussed
- be clear, concise and empathetic when delivering information about the child's condition
- allow silence and acknowledge emotions
- plan for future meetings or discussions to allow families time to go away and consider the conversation.^[8]

Communication with siblings and friends

The level of understanding of death and dying for children with a life-limiting illness may be different to other children their age. This understanding develops from inclusion in conversations about their illness and management, and their experience of seeing other children they know die.^[7] Age appropriate conversations around death and dying are required for siblings and friends of the child with a life-limiting condition. Often parents and carers are dealing with their own grief. They may require assistance from members of the palliative care team to facilitate such discussions.^[9]

Siblings can benefit from:

- being included in family conversations
- being provided with education about their sibling's condition
- having time allocated to discuss concerns with health professionals
- connecting with support groups or other children who are dealing with similar circumstances
- being shown personal interest in them as individuals
- being encouraged to express emotions such as sadness and anger
- having these feelings and emotions normalised^[10, 11]
- being allowed to spend time with their sibling who is ill
- receiving reassurance about their own health.

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6. Sandler, I. (2004). Parental grief and palliative care require attention. *Pediatric and Adolescent Medicine*, 158(6), 590-591.
 7. Bluebond-Langner, M., Belasco, J. & DeMesquita Wanda, M. (2010). "I want to live, until I don't want to live anymore": Involving children with life threatening and life-shortening illnesses in decision making about care and treatment. *The Nursing Clinics of North America*, 45(3), 329.
 8. Klick, J.C. & Hauer, J. (2010). Pediatric Palliative Care. *Current Problems in Pediatric and Adolescent Health Care*, 40(6), 120-151.
 9. Carlile, M. (2012). Understanding grief and bereavement in the palliative care setting. In M. O'Connor, S. Lee, & S.Aranda, (Eds.) *Palliative care nursing: A guide to practice*, (pp. 271-289), Ascot Vale, VIC: Ausmed Publications.
 10. Abrams, M. (2009). The Well Sibling: Challenges and Possibilities. *American Journal of Psychotherapy*, 63(4), 305-17.
 11. Brown, E., Warr, B. & Smallman, A. (2007). *Supporting the Child and the Family in Paediatric Palliative Care*, London, UK: Jessica Kingsley Publishers.

THINKING POINTS

1. Describe how communication strategies are similar and/or different for a child with a life-limiting illness who is 13 years of age compared to 5 years of age, when assessing their understanding of palliative care, death and dying.
2. List common euphemisms that might be used when speaking about someone who has died, such as 'going to have a long sleep'. How might a young child misconstrue these terms?
3. When supporting parents through their child's illness, describe the key communication strategies that you would use in practice.

ACTIVITY 6: Emily's review

For Emily to be assessed by the general practitioner, she and her mother need to travel approximately 60 km over dirt and bitumen roads. Emily finds this tiring and increases pain and breathlessness that she experiences.

Margaret is a general practitioner who has been caring for Emily since her birth 10 years ago. As with many rural communities, she is acquainted with Emily's family.



Emily's review

THINKING POINTS

1. Describe how Emily's age and life experience has influenced her understanding of death.
2. List the specific communication strategies Margaret used to introduce the concept of palliative care.
3. Describe additional communication strategies Margaret could use to improve this interaction.

ACTIVITY 7: Collaborative approaches to care

Service delivery models for children with life-limiting conditions

Paediatric palliative care is a highly specialised area of health care. A collaborative approach to care and decision-making is required to effectively respond to the complex needs of children and their families and enable ongoing support across the illness trajectory and outside of specialist settings.^[1, 2] The transition to palliative care can be an especially difficult time. Coordination of care between acute and palliative care services is very important.

1. Monterosso, L. & De Graves, S. (2012). Paediatric Palliative Care. In M. O'Connor, S. Lee, & S.Aranda, (Eds.) *Palliative care nursing: A guide to practice*, (pp. 355-377), Ascot Vale, VIC: Ausmed Publications.
2. Lyndes, K.A., Fitchett, G., Berlinger, N., Cadge, W., Misasi, J. & Flanagan, E. (2012). A Survey of Chaplains' Roles in Pediatric Palliative Care: Integral Members of the Team. *Journal of Health Care Chaplaincy*, 18(1-2), 74-93.

Shared care models are commonly used in paediatric care. These models highlight the joint role that primary care health professionals and specialist care health professionals play in caring for a child with life-limiting conditions. Shared care models are especially important for children and families living in rural and remote settings. Some strategies that can support a shared care approach include:

- basic
 - communication between professionals through letter and health record forms
- liaison
 - care coordinator liaises between specialist health team and primary health professional
- shared care record card
 - document carried by patient between primary and secondary health professionals
- technology-assisted shared care
 - Personally Controlled Electronic Health (eHealth) Records
 - video-conferencing.^[3]

Coordination of care

Effective coordination of the multiple services and health care providers involved in the child's care is critical.^[4] Key elements of a coordinated service delivery model for children with life-limiting conditions are included in the following table.^[5]

TABLE 2 Coordinated Service Delivery of Care

Integrate service across the continuum of care

- deliver a comprehensive service with a family-centred care approach
- allow families to make informed choices about care of their children
- coordinate and integrate paediatric palliative care services
- focus on delivering care that best meets needs of children and families
- integrate all aspects of care under same goals
- offer interdisciplinary holistic services

Provide appropriate home-based support

- provide infrastructure to give families the option of caring for children at home
- provide access to palliative care services and resources
- ensure adequate respite facilities when required
- recommend appropriate community support organisation

Provide a coordinated, flexible and responsive program

- allow for flexibility of care needs for children and their families, between home, hospital and palliative care service
- promote coordination and continuity of care through a collaborative approach from health professionals and community based palliative care services

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3. Hickman, M., Drummond, N. & Grimshaw, J. (1994). A taxonomy of shared care for chronic disease. *Journal of Public Health Medicine*, 16(4), 447-454.
 4. Stille, C. & Antonelli, R. (2004). Coordination care children special health care needs. *Current Opinion in Pediatrics*, 16, 700-705.
 5. Australian Government Department of Health and Ageing. (2003). *Paediatric Palliative Care Service Model Review Final Report*, Canberra, ACT: Rural Health and Palliative Care Branch, Australian Government Department of Health and Ageing

Improve access to services for rural communities

- identify strategies to overcome isolation that causes problems with accessibility, costs, travel, disruption to home life and more
- recruit and train clinical and non-clinical service providers in rural and remote regions
- facilitate regular telecommunication links with palliative care services for families living rural and remotely
- develop specific strategies to provide support to communities through online and phone services
- paediatric palliative care service may have a 24 hour phone service call point

Improve the interfaces with other related sectors

- strengthen links between paediatric palliative care services and disability and education sectors
- integrate paediatric and adult palliative care services

Provide additional respite care

- offer respite service as an integral component of paediatric palliative care and used to supplement home based care
- allow flexibility and choice in types of respite including, short break respite, external respite for children and adolescents and emergency respite
- provide both in-home respite and out-of-home respite, particularly for families caring for children with high degrees of disability and dependence

Develop and implement educational programs

- assist and provide appropriate education for children and families to understand what palliative care is and how it can assist them
- provide palliative care training and education for generalist workforces, particularly for those in rural and remote areas
- ensure formal training, feedback and a means of challenging current practices of paediatric health professionals in their thinking about paediatric palliative care

Increase professional development

- provide paediatric specific clinical support and professional development opportunities for health professionals working in palliative care

Increase evidence-based research to support clinical best evidence

- support more research in paediatric palliative care

Establish a family advocacy program

- establish effective advocacy programs to ensure the needs of children and their families are identified and addressed within the paediatric palliative care service delivery framework

THINKING POINTS

1. List health professionals who can be involved and the role they would play in care of a child with a life-limiting illness and their family.
2. Describe strategies for ensuring coordination of care for a child with a life-limiting condition.

SECTION 3

Supportive care interventions

In this section you will:

- identify key principles and components of support to children with a life-limiting illness and their families
- reflect upon the importance of individualised education about ongoing management and care of children with a life-limiting illness, their families and communities.

ACTIVITY 8: Supportive approaches to care

Assessment and management of symptoms and quality of life

Symptoms can manifest differently in children when compared to adults. Children may also have different psychological, behavioural and social responses to symptoms. As a child's body grows and develops rapidly, frequent assessment and updating of management strategies is required. Symptoms and the subsequent management can interfere with children's normal development.

Fatigue can impact on a child's ability to socialise and add to their feelings of social isolation.^[1, 2] Management of pain and other symptoms at end of life can impact on the parent's grief and ability to move forward.^[3]

Self-report is recognised as the gold standard when assessing symptoms and quality of life for adults. Children's self-report of their needs and experiences is also important, although the way such assessment is conducted needs to take into account the unique characteristics of the child. The observations of family members and health professionals are integral to identify the child's needs especially where children are too young or unable to communicate effectively how they feel.

^[4] Symptoms that can be experienced by children with life-limiting conditions include:

- pain
- dyspnoea/cough
- fatigue
- poor appetite
- nausea and vomiting
- constipation/diarrhoea
- change in sleeping patterns^[5]
- deteriorating ability to swallow
- fever

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1. Taylor, R.M., Pearce, S., Gibson, F., Fern, L. & Whelan, J. (2013). Developing a conceptual model of teenage and young adult experiences of cancer through meta-synthesis. *International Journal of Nursing Studies*, 50(6), 832-846.
 2. Ruland, C.M., Hamilton, G.A. & Schjødt-Osmo, B. (2009). The Complexity of Symptoms and Problems Experienced in Children with Cancer: A Review of the Literature. *Journal of pain and symptom management*, 37(3), 403-418.
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- anxiety
- seizures
- irritability/agitation.

Management of symptoms requires:

- careful assessment
- identification of contributing factors
- tailoring of pharmacological and non-pharmacological strategies to the child's needs
- ongoing evaluation and monitoring.
- pain and symptom management in children with life-limiting conditions is especially complex due to the unique biological, pharmacokinetic, psychosocial, and spiritual factors associated with a person's growth and development. For example, measurement of pain for infants, younger children and children with neurological impairment, is more accurate through non-verbal assessment and through observing changes in their body and behaviour.^[6]
- in older children and adolescents, using a scale to self-report pain can be an effective tool. A systematic review of tools used found the effectiveness of tools depends on the child's age, purpose of using the tool, questions asked and implementation of the tool.^[7]
- children's metabolic rates and physical size require specific dosing protocols for medications and regular review for the pharmaceutical management of pain. Consultation with a specialist pain health professional or paediatric palliative care service is recommended if there is any unfamiliarity in paediatric dosages.^[5]

THINKING POINTS

1. Describe an approach to assess pain in a 4 year old child with a life-limiting condition.

ACTIVITY 9: Emily's case conference

Margaret has organised a case conference via videoconferencing with the Paediatric Cardiology Team and Paediatric Palliative Care Service. Both services are located in a large metropolitan hospital.

The Paediatric Cardiology Team has been involved with Emily's care since her birth. Emily's medical records were sent through to the Paediatric Palliative Care Service prior to the meeting for review.



Emily's case conference

6. Nilsson, S., Finnström, B. & Kokinsky, E.V.A. (2008). The FLACC behavioral scale for procedural pain assessment in children aged 5-16years. *Pediatric Anesthesia*, 18(8), 767-774.
7. Cohen, L.L., Lemanek, K., Blount, R.L., Dahlquist, L.M., Lim, C.S., Palermo, T.M., McKenna, K.D. & Weiss, K.E. (2008). Evidence-based Assessment of Pediatric Pain. *Journal of Pediatric Psychology*, 33(9), 939-955.

THINKING POINTS

1. List the aspects of Emily's care that were identified at the case conference.
2. From the perspective of your discipline, describe interventions you could use to assist Emily to manage her increasing breathlessness.
3. How could other disciplines be involved in Emily's case conference?
4. What advantages could there be in Emily's case to embedding Advanced Care Directives into Personally Controlled Electronic Health (eHealth) Records?

ACTIVITY 10: Psychosocial and spiritual support for children

Psychosocial and spiritual assessment includes assessment of:

- the child's developmental stage
- the child's experience of emotional symptoms
- the effectiveness of communication channels between the child, family and health care team
- practical factors effecting the family, including financial and living situation and social support
- the child's religious or spiritual backgrounds and beliefs. ^[1]

Adolescents have unique support needs as the dynamics involving the adolescent, their family and health professionals change. Psychosocial, hormonal changes, cognitive and physical growth and developmental changes occur in teenagers and adolescents that require unique care and communication. Transitioning adolescents to adult care facilities requires careful planning between adolescents, families and health professional teams. ^[2] Strategies that assist with a successful transition of care to adult centres include:

- health care transition plan in early adolescence
- transition policy agreed upon by members of the health care team
- preparation period and educational program for adolescent and family
- network of palliative care services and youth and adult services
- liaison personal for paediatric and adult services. ^[3]

Children are cared for in a variety of settings including at home, hospice (in some states and territories) and acute care facilities. When children are cared for away from home, parents require unrestricted visiting, clear communication with staff and involvement in decision-making. ^[4]

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1. McSherry, M., Kehoe, K., Carroll, J.M., Kang, T.I. & Rourke, M.T. (2007). Psychosocial and Spiritual Needs of Children Living with a Life-Limiting Illness. *Pediatric Clinics of North America*, 54(5), 609-629.
 2. Steinbeck, K., Masterson, L. & Sturrock, T. (2007). Adolescent appropriate care in an adult hospital: the use of a youth care plan. *Australian Journal of Advanced Nursing*, 24(3), 49-53.
 3. McDonagh, J.E. & Kelly, D.A. (2003). Transitioning care of the pediatric recipient to adult caregivers. *Pediatric Clinics of North America*, 50(6), 1561-1583.
 4. Meert, K., Schim, S. & Briller, S. (2011). Parental bereavement needs in the pediatric intensive care unit: review of available measures. *Journal of Palliative Medicine*, 14(8), 951-64.

THINKING POINTS

1. What strategies might you use to identify the spiritual needs of a 7 year old child?
2. List some of the unique features of adolescence that could influence how they respond to a life-limiting illness.
3. What strategies might you suggest to a teenager with a compromised immune system to maintain contact with friends?

ACTIVITY 11: Psychosocial and spiritual support for families and community

Family structures and households today are diverse. Health professionals need to understand circumstances unique to each family. Parents need to feel they can trust and access the health care team, be able to ask questions and be kept informed about their child's progress.^[1] Parents can also have different perspectives and needs from each other, so it is important to respond to individual needs.

Caring for a child with life-limiting conditions can be physically and emotionally exhausting, often for an extended period of time. Strategies should be offered to assist parents and carers to deal with this level of stress, including:

- psycho-educational programs highlighting the positive aspects of caring
- education for pain and symptom management
- counselling and support group involvement
- behavioural sleep intervention
- involvement in group educational programs
- telephone support service
- psychosocial support^[2]
- educational programs to teach parents and carers how to assist with physical aspects of care
- environmental adaptations and home modifications to assist with care
- respite services
- continued contact with friends, community and interest groups.

Psychosocial support for parents involves recognising the meaning and impact of their impending loss. It also involves engaging with parents about their thoughts and feelings as they provide end of life care to their child. Parents who have lost a child have described valuing health professionals who:

- approached them on a human level
- acknowledged their impending loss
- initiated conversations that enabled parents to share their thoughts and feelings
- if desired, enabled social support from other parents who shared similar experiences.^[3]

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1. Monterosso, L., Kristjanson, L. & Phillips, M. (2009). The supportive and palliative care needs of Australian families of children who die from cancer. *Palliative Medicine*, 23(6), 526-536.
 2. Hudson, P., Remedios, C. & Thomas, K. (2010). A systematic review of psychosocial interventions for family carers of palliative care patients. *BMC Palliative Care*, 9(1), 17.
 3. Forster, E.M. (2012). *Parent and staff perceptions of bereavement support surrounding loss of a child*, Brisbane, QLD: The University of Queensland.

Guilt can be experienced and acting out, attention seeking and becoming withdrawn are behaviours that can be displayed by siblings of children with a life-limiting illness. Stress in siblings can be reduced if they are supported, prepared for their sibling's death and have close family relationships. ^[4]

Grandparents can be a supportive lifeline for families. Strategies to assist grandparents include:

- providing access to education and information regarding their grandchild's condition
- supporting communication between grandparents and their adult children
- referral to support groups or workshops specifically tailored to grandparent perspectives. ^[5]

Respite or short breaks can be beneficial for both children and their families by assisting to prevent carer burden. ^[6] Respite can be provided in the form of direct respite where children are cared for either at or away from home, or indirect respite where support workers assist with domestic chores and babysitting of siblings. ^[7] Respite services for children often meet specific needs such as education, play and social interaction that assists to reach developmental milestones. For adolescents transitioning to adult respite services, extra activities required for development need to be identified.

Community support

Bereaved parents can become quite isolated as other families with children may inadvertently avoid them and avoid discussing the deceased child - sometimes because they don't know what to say. Communities and schools can offer much needed support to families. Communities as a collective can experience grief both privately and publically ^[8], which may require support on a larger scale. Myths and inaccurate information can be passed around a school or community. Leaders and teachers should be supported, with permission from the family. Education and support can assist with developing an appropriate awareness and understanding within a specific community setting. ^[9]

Follow up after a child's death

Parents are at an increased risk of psychological distress and complicated grief following the death of their child. ^[4] As well as careful communication during a child's palliative care, it is useful to arrange professional bereavement follow up after a child's death to allow parents to:

- ask questions
- talk about illness, death, coping
- talk about events around time of death
- discuss post mortem findings if warranted
- discuss further support.

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4. McSherry, M., Kehoe, K., Carroll, J.M., Kang, T.I. & Rourke, M.T. (2007). Psychosocial and Spiritual Needs of Children Living with a Life-Limiting Illness. *Pediatric Clinics of North America*, 54(5), 609-629.
 5. Lee, M. & Gardner, J.E. (2010). Grandparents' Involvement and Support in Families with Children with Disabilities. *Educational Gerontology*, 36(6), 467-499.
 6. Association for Children's Palliative Care (ACT). (2009). *A Guide to the Development of Children's Palliative Care Services*, Bristol, UK: Author.
 7. WA Cancer & Palliative Care Network: Paediatric Palliative Care Reference Group. (2010). *About Respite: information for families, Paediatric Palliative Care Program, Princess Margaret Hospital*. Retrieved January 16, 2012, from www.healthnetworks.health.wa.gov.au/cancer/docs/Respite_Information_for_Families.pdf.
 8. National Association for Loss and Grief (Vic). (2010). *Living with life's losses*, Victoria: National Association for Loss and Grief (Vic) Inc. Retrieved March 22, 2012, from www.nalagvic.org.au/documents/NALAG_LivingwithLifesLosses.pdf.
 9. Holland, J. (2008). How schools can support children who experience loss and death. *British Journal of Guidance & Counselling*, 36(4), 411-424.

THINKING POINTS

1. List
 - a) The advantages, and
 - b) Potential challenges associated with providing respite for a child with a life-limiting illness.
2. Describe supportive strategies you would implement for parents following the death of their child.

ACTIVITY 12: Emily's progression

Emily is now 12 and her health has continued to decline over the past 18 months. Emily's extended family, friends and school community have continued to be supportive.



Emily's progression

THINKING POINTS

1. List the information and education you would provide to Emily's school teacher prior to Emily visiting the school.
2. As Emily's illness progresses, her younger sibling, who is 8 years of age, asks you directly if Emily is going to die. As the health professional involved in Emily's care, how could you respond to this question?
3. Discuss strategies that could be implemented before and after Emily's death to help Emily's siblings deal with their loss.
4. Emily's mother spoke openly when Emily asked about her grandmother looking down from her star. In what further ways might Emily's spiritual needs be supported?

ACTIVITY 13: Self-care for health professionals

As children with life-limiting conditions are often under the care of health professionals for many years the end-of-life phase and the death of a child can be distressing for health professionals.^[1] An opportunity for family and health professionals to talk in a safe environment can have lasting positive effects.^[2] Self-care strategies are described in PCC4U Module 2. www.pcc4u.org

1. Baverstock, A. & Finlay, F. (2008). What can we learn from the experiences of consultants around the time of a child's death? *Child: Care, Health and Development*, 34(6), 732-739.
2. Bateman, S.T., Dixon, R. & Trozzi, M. (2012). The Wrap-Up: A Unique Forum To Support Pediatric Residents When Faced with the Death of a Child. *Journal of Palliative Medicine*, 15(12), 1329-1334.

THINKING POINTS

1. Reflect on how caring for a child with a life-limiting illness might affect you personally.
2. What strategies would you use to promote self-care?

SECTION 4

Reflections on what you've learnt

1. What key points have you learnt from the activities in this module that will help you in providing care for children with life-limiting conditions and their families?
2. What specific strategies do you plan to incorporate as a graduate health care professional?
3. Do you see any difficulties using what you have learnt here as part of your practice as a health care professional? If so, what strategies might you use to address these difficulties?



Emily's Story

A3: EMILY'S STORY

▶ 1.34 mins

Jacob: You're feeding the dog Ryan.

Ryan: No I'm not. I did it last night.

Jacob: Yeh, but if you do it last night then you do it in the morning as well.

Melissa: Ryan, you're feeding the dog. Jacob, can you get upstairs and clean your teeth and get ready for school as quickly as possible.

Jacob: But I've got to eat my breakfast.

Melissa: After you've finished your breakfast then okay.

Melissa: (to Robert) Emily had a really really bad night last night. She is a lot paler than usual. She's really keen to go to school today but this breathing has got me really worried.

Robert: Yeh, you're right, she's not looking too good.

Robert: You breathin' a bit hard today Princess?

Emily nods.

Melissa: I am going to have to take her in to town to see the doc.

Robert: Okay love, look that heifer's got into Darren's paddock again. You right to take the boys to the school bus?

Melissa: Yeh, yeh – of course. See you this arv.

Robert: Righto, drive safely. (To Emily) Love ya princess. (To sons) Boys, behave for your mother. Okay? Righto. See you gang. Have a good day.

Melissa: Bye.

Jacob: See you dad.

Ryan: You're feeding the dog.

Melissa, Emily, Jacob and Ryan in the car.

Melissa: OK boys, school bus is here. I'll pick you up at usual time this afternoon. Okay?

Jacob & Ryan: Okay, see you mum.

Melissa: Be good. See you.

Melissa: (to Emily) You alright in the back there darling? It's not going to be long.

Margaret: Hi Emily, come in and have a seat.

Margaret: So Emily, you sound as though you are having trouble breathing today.

Emily: I couldn't sleep last night and it hurts to breathe in too much. I really wanted to go to school today but Mum said I am not allowed to.

Melissa: Emily has been going to school lately but on Monday when she came home she looked so pale and she just wasn't at all herself. By yesterday she was having trouble breathing when she was talking. It's bad, like the last time she was unwell but it just seems to have happened so much faster this time. She is using oxygen like you suggested for when her breathing gets like this and when she uses it she does seem to be a bit better.

Margaret: I am glad to hear that the oxygen has helped. Emily, I see that you used your walker to come in today. Does it help with your breathing when you are walking for longer distances?

Emily: I have to walk slowly and sometimes I feel dizzy.

Margaret: It's good that you have found it helpful. Right, well, I think I'll have a listen to your chest.

Margaret: Emily, it looks and sounds as though your heart is having trouble pumping the blood around your body today, which is why you are having trouble breathing. I'll have a look and see what other medications we can use and I'll speak to Dr Greg from your cardiology team. I think I'll also speak to another team in Brisbane, they work specifically with children, and see if we can help with your shortness of breath. They're called the paediatric palliative care team.

Emily: I know the palliative care team! That's just for old people! Like Grandma in the hospital before she died.

Margaret: Well, palliative care teams work with people of all ages, not just when they are dying. They help you to do the things that matter to you when you are getting more unwell. (Pause) You remember a while ago I spoke with you about how one day your heart might not be strong enough and we might need some additional help to keep you comfortable? Well, Emily we are worried now that you are getting sicker more often and we know that your heart is getting weaker and weaker. Together with the Brisbane team our aim is to keep your heart working as well as it can and to keep you comfortable no matter what....

Melissa: Does this mean we are going to have to drive to Brisbane? I don't think that Emily can handle that drive and Robert is just so busy and then there's the boys and the farm and..

Margaret: No. I can speak with the team in Brisbane by organising a meeting via the computer. Just like everyone's there in the room with you. For now I think it's important that you stay home from school and keep using the oxygen when you need to. I will give you a call after I have spoken to the teams in Brisbane and I'll organise a time for you to speak to Chenoa, she's the nurse with the paediatric palliative care service. She is in a similar role to Hannah but for palliative care instead of cardiac. Chenoa and the doctor with the team are incredibly knowledgeable and they love working with kids. I think you will find them to be a great help and you can ask them any questions you may have. (Pauses) I know this is a lot to take in....but,well...how do you feel about this as a plan?

Melissa & Emily: Okay.

Melissa and Emily in car.

Melissa: We should just make it in time to pick up your brothers.

Hannah: Can you hear me Margaret?

Margaret: Oh hello, there you are! Well done Hannah. Can everyone see and hear us all the way out there?

Hannah: We can hear you loud and clear.

Margaret: Hi everyone, and our thanks for agreeing to meet with myself, Di, our Director of Nursing, and Alan from the Royal Flying Doctor Service to discuss Emily's case today. I'm very keen to hear any suggestions you may have about Emily's management and ongoing care.

Hannah: Good morning Margaret. I believe you know Greg and Ben from the Paediatric Cardiology team.

Greg & Ben: Hello.

Margaret: Yes hello again!

Hannah: And I'd like to introduce you to Chenoa from the Paediatric Palliative Care Service.

Chenoa: Thanks Hannah. With me here today is Amanda our Paediatric Palliative Consultant and Tuyen, our Social Worker.

Amanda: Hello.

Chenoa: Amanda would you like to take it from here?

Amanda: Hi Margaret, I am sorry to hear that Emily is unable to have more surgery and that she is not able to have a heart transplant. As you know, our team would like to work with you and the cardiology team to give her the best quality of life we can, and also to support the family as much as we can. One area we'd like to focus on is pain management and other symptoms. Are any of these an issue for Emily?

Margaret: She is having increasing difficulty breathing.

Amanda: I see here that Emily already uses oxygen at home when she is breathless. Does Emily also have a portable oxygen cylinder that she can use when she is away from the house?

Margaret: Well, Emily had an exacerbation of her condition about 6 months ago, which is when we first ordered the oxygen. Her breathlessness seemed to settle down for quite a few months after that. I was surprised at how soon it is now since her last episode. She has recommenced using the oxygen this week with moderate effectiveness. I would like to organise a mobile oxygen cylinder, because they mentioned on their visit that it helps Emily when she uses oxygen. She has two large standing cylinders because they live out of town and often rely on a generator or solar power.

I know Emily is keen to get back to school to see her friends. It would be helpful for the palliative care team to connect with school about the care of the oxygen equipment.

Tuyen: What about Emily's parents? How are they coping with things?

Margaret: Emily's parents own a large cattle property out of town. Robert works 7 days a week on the property and Melissa has had to get a job in town 2 days a week to help them financially. They also have two other children, Jacob and Ryan who are 6 and 8 years old. They can be a bit of a handful.

Emily has had quite a bit of time away from school lately and I know that Melissa has been helping with her school work as well. When they came in yesterday, Melissa looked tired and physically run down. To be honest I don't know how Dad is coping. I never see him and I rarely get the chance to ask Melissa when she brings Emily in to see me...even how she is managing all of this to be honest. I would really like to assess this properly and see if we can provide some support financially as well as emotionally.

Tuyen: Margaret, I will talk to Chenoa and Hannah. We will discuss what further assistance and financial support might be available. It is often what we see; as you describe, the dad is busy trying to financially support the family and it can be difficult to get his perspective. We can connect with them at home with an adult's only conversation to explore some of their shared and individual concerns.

Amanda: Margaret, have you had a conversation with Emily and her family that her condition will deteriorate? I realize this can be difficult to do and she may have periods of stability but it is likely they will see a steady decline. The time frame we are dealing with in terms of life expectancy is still uncertain.

As you know with complex heart disease, it is possible that Emily could have a cardiac episode or even an infection such as influenza within the next 12 months and not recover. It will be important now to manage both her physical symptoms, such as pain and shortness of breath, as well as provide practical and emotional support.

It would also be a good idea to discuss a plan about what to do if Emily should have a sudden deterioration. This could include a sudden worsening of her symptoms, as well as an arrhythmia, which could cause a very sudden decline and possibly even sudden death. We have developed a resuscitation plan to assist with this discussion, and would be happy to share this with you. Again, I acknowledge this will be a very tough series of conversations for you to have with the family.

Margaret: Yes, it is a very difficult time. I mentioned to Emily and Melissa that I would be including the paediatric palliative care service in her care and explained what that means. Emily was upset by this. I explained to her what you do as a service. I haven't spoken to them directly about Emily's condition deteriorating and what that may include but I am sure they are very aware of it. I have found it hard to discuss. I am not really sure what to say to them. From the things that Emily has been saying recently, I think she knows she is going to die but doesn't seem to want to talk about it in front of her mum. I get the same feeling that Melissa doesn't want to admit it in front of Emily.

Chenoa: Yes it is hard to discuss but it is an important conversation to have. It is actually not uncommon for parents or children to understand the seriousness of the illness and know that death will happen, but they just don't like discussing it. We will set up a family meeting on line with you, Emily and Melissa. We would like it if you could organise it so that Robert can be involved as well and then we can all sit together and discuss what is likely to happen and what steps to take.

Margaret: Well that sounds like a great approach and I'm sure we all look forward to meeting and planning together again soon...

A12: EMILY'S PROGRESSION

▶ 1.02 mins

Emily: Mum, have a look at the funny email that Chenoa sent me for my birthday.

Melissa: Well you don't turn twelve every day, do you? That is a funny birthday message. When you reply to Chenoa, tell her thank you and that we have spoken to your teacher and we've organised for you to visit your school friends tomorrow. You can go in your wheelchair and we will attach the portable oxygen.

Emily: Mum, there was also a birthday card from Pop today. Do you think Grandma is looking down from her star and wishing me a happy birthday too?

Melissa: I am sure she is darling.

Emily: Go away brats!



TOPIC 4

Culture-centred care of people with life-limiting conditions

To provide appropriate care that responds to the specific needs of people with life-limiting conditions, it is important to recognise cultural considerations associated with end-of-life and bereavement.

OVERVIEW

TOPIC 4: Culture-centred care of people with life-limiting conditions will provide an opportunity to develop knowledge and skills associated with providing culturally appropriate care for people with life-limiting conditions.

AIMS & OBJECTIVES

This focus topic is based on the core principles of palliative care and is designed to supplement the learning activities in Module 1: Principles of palliative care.

After completing this focus topic, you should be able to:

- understand the role of culture in contributing to individual's experiences of living with a life-limiting condition
- apply principles of culturally centred care when caring for people with life-limiting conditions.

SECTION 1

Diversity in contemporary Australian society

In this section you will:

- examine the diversity of Australian populations requiring palliative care
- consider key concepts associated with cultural competence and culturally safety.

ACTIVITY 1: Diversity in Australia health care

Diversity is what makes an individual or group unique. Diversity is not just associated with one's ethnic background. Diversity can be reflected in a number of ways including:

- ethnicity and race
- language
- gender
- sexual orientation
- age and generation
- socioeconomic status
- religion, faith and other beliefs. ^[1]

This diversity means that health care professionals need an understanding of how social and cultural background can influence health beliefs and practices, including beliefs about dying, death and bereavement. For example, specific populations who can have unique social and cultural backgrounds that shape health responses include:

- multicultural groups
- Aboriginal peoples
- Torres Strait Islander peoples
- refugees and asylum seekers
- Gay, Lesbian, Bisexual, Transgender, Intersex and Queer (GLBTIQ)
- older people
- children
- people who are deaf, Deaf or hearing impaired
- people with dementia
- people with physical disabilities
- people with intellectual disabilities
- people living in rural and remote areas
- people living alone
- homeless people
- prisoners
- religious and faith groups and other beliefs. ^[2,3]

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1. Dreachslin, J., Gilbert, M., & Malone, B. (2012). *Diversity and Cultural Competence in Health Care : A systems approach* (1 ed.). Hoboken, NJ: Wiley.
 2. CareSearch. (2008). Specific Populations. *Clinical Evidence*. Retrieved August 1, 2013, from <http://www.caresearch.com.au/caresearch/tabid/115/Default.aspx>
 3. Queensland Health Multicultural Services. (2012). *Guidelines for multicultural health policy implementation*. Retrieved from <http://www.health.qld.gov.au/qhpolicy/docs/gdl/qh-gdl-080.pdf>

It is important not to assume a person's preferences on the basis of their cultural background. Individualised discussion needs to occur between health professionals and a person about their end-of-life care. ^[4] People's experiences and responses at end-of-life can be shaped by our cultural background. For example, many of the following experiences can be influenced by culture:

- language and communication styles
- expectations of roles and relationships
- beliefs about ill health
- previous interactions with health care professionals/system
- preferred foods
- preferred methods of decision-making
- practices in relation to family involvement in care
- religion, faith groups and other beliefs
- preferences for involvement of clergy
- practices/rituals leading up to end-of-life
- preferences for life support and advance directives
- meaning of suffering
- expression of pain and other symptoms
- attitudes and practices relating to pain relief medications including opioids
- preferred place of death
- meaning of life, death, dying and grief
- practices relating to immediate care after death
- preferences for autopsy and organ donation
- beliefs about what happens to the body after death eg, burial or cremation
- grief and bereavement responses ^[5,6]
- practices relating to new experimental therapies in clinical trials
- practices relating to use of complementary and alternative medicines.

THINKING POINTS

1. Think about someone you have cared for from one of the groups listed in the section above. What cultural considerations were associated with caring for them?
2. What were things you could have done to improve the situation?

4. Halm, M. A., Evans, R., Wittenberg, A., & Wilgus, E. (2012). Broadening cultural sensitivity at the end of life: an interprofessional education program incorporating critical reflection. *Holistic Nursing Practice*, 26(6), 335-349.

5. Kemp, C. (2005). Cultural issues in palliative care. *Seminars in Oncology Nursing*, 21(1), 44-52.

6. Wiener, L., McConnell, D. G., Latella, L., & Ludi, E. (2013). Cultural and religious considerations in pediatric palliative care. *Palliative & Supportive Care*, 11(1), 47-67.

ACTIVITY 2: Culturally diverse populations in Australia

Multicultural Australia

Australia is a multicultural society with almost a third (30.2%) of the population born overseas. The most common countries of birth of people born overseas living within Australia include England, New Zealand, China, India and Italy.^[1]

Cultural and linguistic diversity refers to different cultures and language groups represented within a society. In Australia a quarter of households speak languages other than English at home. Other common languages spoken in Australian households include Mandarin, Italian, Arabic, Cantonese and Greek.^[1] Culture does not mean the ethnic group from which a person comes. Rather culture refers to their beliefs, morals, values and attitudes that might arise from a culture group.^[2]

Cultural safety

Cultural safety creates a safe environment without risk of assault, challenge of who they are or what they need whilst promoting shared respect, shared meaning, knowledge and experience.^[3] Cultural safety looks at a person as an individual rather than the country or ethnic group they originate from. It is an approach to care that protects them from physical, psychological, social and environmental harm.^[4]

For example, a culturally safe health care service should include:

- welcoming environment including the staff
- orientation to service & staff
- honest open communication
- culturally diverse staff
- enabling interactions
- access to language interpreters
- ongoing training for care staff about cultures, diversity within, and languages of, people they are caring for
- encouragement of self-reflection
- literature and signs in languages reflecting people cared for.^[5]

If uncertain about a person's culture or belief, don't be afraid to ask questions in a respectful way, of the person, family or liaison staff member. For example "Good Morning Mrs Bahram, I was wondering about a few things, could I ask you about them". Accessing information from programs such as Partners in Culturally Appropriate Care (PICAC) can assist health care services and professionals with education and training in culturally appropriate care.^[6]

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 2. Culture. (2013). In *Oxford Dictionaries*. Retrieved from <http://oxforddictionaries.com/definition/english/culture?q=culture>.
 3. Williams, R. (1999). Cultural safety-what does it mean for our work practice? *Australian and New Zealand Journal of Public Health*, 23(2), 213-214.
 4. Papps, E., & Ramsden, I. (1996). Cultural Safety in Nursing: the New Zealand experience. *International Journal for Quality in Health Care*, 8(5), 491-497.
 5. Anderson, L. M., Scrimshaw, S. C., Fullilove, M. T., Fielding, J. E., & Normand, J. (2003). Culturally competent healthcare systems: A systematic review. *American Journal of Preventive Medicine*, 24(3), 68-79.
 6. Partners in Culturally Appropriate Care (PICAC) Program. (2012). Support for people with special needs. *Aged Care*. Retrieved October 22, 2013, from <http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-specneed-picac.htm>

Cultural Competence

Cultural competence refers to behaviours, attitudes and policies that come together in a system or network that enable working effectively with people from diverse cultures. This competence is based on positive two-way cultural interactions that recognise advanced verbal and non-verbal communication skills. For example, information can be exchanged by simply using resources or even drawing diagrams, to draw on visual, auditory and kinaesthetic senses.

Rather than stereotyping, cultural competence respects other cultures while gaining an understanding of cultures including your own through self-reflection. Cultural competence skills are developed through awareness, ongoing encounters, evaluation of encounters, observation and positive participation with people from other cultures. Simply speaking the same language as the patient does not render health care staff to be culturally competent.

Health professionals risk stereotyping a person by trying to care for them based on culture and the beliefs about that culture.^[7] A person's own life experiences and beliefs need to be considered. A person from a particular ethnic cultural group may identify a little or a lot with that culture depending on level of acculturation.^[8] Acculturation explains cultural changes that occur when members of cultural groups adopt beliefs and behaviours of another cultural group.

Cultural competence in health care requires specific practice knowledge, communication, skills, attitudes and behaviours, relating to:

- their history eg. global, local
- communication styles, verbal and non-verbal
- disclosure and consent
- decision making including how and when the person and family are involved
- individual's worries
- concepts of disease, pain and other symptoms
- attitudes to medication and nutrition
- spirituality and religion
- concepts of life cycle, including end-of-life
- customs surrounding end-of-life, burial or cremation and grief.^[8]

However cultural competence respects the diversity within cultural groups, and supports an approach to care that seeks to understand and respond to individuals within the context of their culture.

THINKING POINTS

1. Reflect on your own culture. What are your beliefs? How do you respond when your beliefs are not consistent with others?
2. In your own words, describe the differences and similarities between cultural competence and cultural safety.

7. Waxler-Morrison, N., Anderson, J., Richardson, E., & Chambers, N. (2005). *Cross-Cultural Caring: A Handbook for Health Professionals* (2nd ed.). Vancouver, Canada: UBC Press.

8. Lickiss, J. (2003). Approaching death in multicultural Australia. *The Medical Journal of Australia*, 179, S14-S16.

ACTIVITY 3: Amy's story

Lan migrated to Australia with her parents Yi Ming and Mei when she was 18 years of age. Lan adopted the English name Amy soon after arriving in Australia. Amy married in her early 20s, had a son Erik and divorced from her husband when Erik was 6 yrs of age. Amy took on the responsibility of raising Erik with the assistance of Yi Ming and Mei.

Amy is now 59 years of age and works full time in a fruit canning factory. She has good friends from her workplace, neighbourhood and community.

Amy speaks both English and her traditional language. Amy lives with her son Erik and her mother Mei, who moved in with them after her husband died 12 years ago. Amy's mother Mei is now in her 80's and speaks limited words in English.

Erik speaks English both in and outside of his home with limited ability to speak Amy's traditional language. Erik met Samantha at the engineering company that he works for; they have been dating for the past 5 months.

Recently Erik has noticed that his mother has trouble finding words and sometimes repeats herself during a conversation. He has also noticed that she doesn't seem to be able to concentrate for long and missed paying the phone bill two months in a row, which is very unlike her. Erik asked her about it but she shrugged it off, saying she has been feeling stressed from work.



Amy's story

THINKING POINTS

1. Amy's family makes an appointment with you to discuss their concerns about Amy's memory and change in behaviour. Discuss what advice you would give them.

SECTION 2

Culture-centred communication

In this section you will:

- review principles for communicating with people with a life-limiting condition from a culturally and linguistically diverse background
- examine the role of professional interpreters in supporting effective communication in palliative care settings
- learn what resources are available to assist communication with a person from a culturally and linguistically diverse background.

ACTIVITY 4: Intercultural communication principles

If you have not already completed the PCC4U module *Communicating with people with life-limiting illnesses*, please go to this module now and review the key principles for communication in palliative care.

Intercultural communication shares information between people of different cultures where language, nationality, ethnicity, values and customs differ. Communication between people from different cultures can be challenging due to possible misunderstanding of words and phrases. Some cultures rely more on behaviours rather than words and phrases than others. This requires health professionals to consider alternative strategies to verbal or written communication.^[1]

When communicating with a person from a culturally and linguistically diverse background where English is their second language, some additional considerations are listed below. Whilst communicating in ways which would not be considered patronising or disrespectful, consider the following:

- who is present
- being aware of gender and age implications
- asking the person about their understanding of the situation
- avoiding jargon and acronyms used in the workplace
- describing medical terminology
- using visual aids to support understanding
- slowing down your body language and speech
- using plain language
- repeating important information
- addressing things, one at a time
- asking the person about their worries or concerns
- asking the person their thoughts / understanding of the situation.

Observe the tone of voice and nonverbal gestures used, as words account for only a portion of communication. Some cultures convey messages largely through body movements, gestures, posture, tone of voice and expressions. The use of silence, eye contact, touch, space and

1. Novinger, T. (2001). *Intercultural communication: a practical guide*. Austin, Texas: University of Texas Press

distance can all have different meanings and significance within a culture.^[2] For this reason it is important to use a number of sources of observation to confirm the person's understanding, as well as asking the person.

Showing compassion, kindness and respect for cultural differences to a person and their family will foster trust and open communication.^[3]

Working with interpreters

People who speak little or no English require a medical interpreter to convey a prognosis and information for health professionals. Trained interpreters are used to speak to medical staff and understand some of the medical terms used.^[4] They can also assist the health care professional to understand the person's wishes and questions, especially when completing an advance care plan.^[5] Medical interpreters providing face-to-face, video conferencing or over the phone interpretation is available through services in Australia.

Not all interpreters will have skills in conveying bad news. Information can be altered or poor prognosis not interpreted at all in delivering messages. Confidentiality can also be an issue where they are a part of a small community or they know the person and their family.^[6]

It is not uncommon for a person to request that someone they know act as interpreter. It is advisable however, that where possible family and friends are not used as interpreters as they may feel constrained or uncomfortable at the nature of the discussion. Where a medical interpreter is not available, questions should be asked to determine the person most suitable to interpret. Children should not be used as interpreters as they may misunderstand what is being said which could be harmful to them.^[7] Asking a person who has not been professionally trained as a medical interpreter can cause:

- inaccuracies in information given due to lack of knowledge of medical concepts and terminology
- altered or distorted information being portrayed and suppression of information possibly related to 'truth telling'
- breach of confidentiality
- invalid consent.^[8]

Professional medical interpreters should be present when information is given or required from a person whose English is their second language, including:

- during admission, assessments and development of management plans

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2. Huang, M., Yates, P., & Prior, D. (2009). Accommodating the Diverse Cultural Needs of Cancer Patients and Their Families in Palliative Care. *Cancer Nursing*, 32(1), 12-21.
 3. Sharma, R. K., & Dy, S. M. (2011). Cross-Cultural Communication and Use of the Family Meeting in Palliative Care. *American Journal of Hospice and Palliative Medicine*, 28(6), 437-444.
 4. CareSearch. (2012). Multicultural. *Clinical Evidence*. Retrieved September 11, 2013, from <http://www.caresearch.com.au/caresearch/tabid/229/Default.aspx>
 5. Anderson, L. M., Scrimshaw, S. C., Fullilove, M. T., Fielding, J. E., & Normand, J. (2003). Culturally competent healthcare systems: A systematic review. *American Journal of Preventive Medicine*, 24(3), 68-79.
 6. Broom, A., Good, P., Kirby, E., & Lwin, Z. (2013). Negotiating palliative care in the context of culturally and linguistically diverse patients. *Internal Medicine Journal*, 43(9), 1043-1046.
 7. Queensland Health. (2012). *Literature review: Best practice multicultural policy implementation*. Retrieved from <http://www.health.qld.gov.au/qhpolicy/docs/gdl/qh-gdl-080-att-b.pdf>
 8. Ministry of Health NSW. (2006). *Interpreters - Standard Procedures for Working with Health Care Interpreters*. Policy Directive Retrieved from http://www0.health.nsw.gov.au/policies/pd/2006/pdf/PD2006_053.pdf

- explaining procedures, medical information and medication
- consenting for operations, procedures, treatments and research
- identifying correct person, procedure and procedure site
- giving prognostic information and bad news
- counselling
- during family meetings and case conferences. ^[8]

When engaging an interpreter to assist with communication, consider the following principles when holding the meeting:

- informing the interpreter service of the nature of the meeting, gender and/or age preference, especially if sensitive matters will be discussed, and brief information on the person's condition
- speaking with the interpreter prior to the meeting to gauge their understanding of the terminology and concepts that will be mentioned during the conversation
- allowing time for the interpreter to briefly meet with the person and their family prior to the meeting
- using plain language when discussing care, for example a phrase such as "you may want to spend time with your family now" can be confusing and may be lost in translation
- including everyone one involved in the conversation rather than only looking at the interpreter
- avoiding long speech segments and highly technical language
- clarifying information with the interpreter regularly throughout the conversation
- asking the person and their family about their understanding and thoughts on new information and allowing time for a response
- allowing time at the end of the meeting for any questions or concerns to be raised offering counselling or debriefing to the interpreter after the meeting if the nature of the conversation was particularly distressing. ^[6,9,10]

Assisted communication

Cue cards can be useful when communicating basic terms and concepts with people who have trouble communicating in English. Terms such as pain, toilet, drink, happy and sad can be conveyed on a cue card with an image and a word. A wide range of medical cue cards are available on the Eastern Health website. ^[11] Take care to ensure these cue cards are able to be read and understood by people who may have visual or cognitive impairments.

Brochures and resources containing information in languages specific to the person with a life-limiting condition can be useful to assist with care and for educational purposes. Multilingual resources with information on palliative/end-of-life care, symptoms and management are available on the Palliative Care Australia website. ^[12] Short videos relating to palliative care spoken in Greek, Italian and Cantonese are available on the CareSearch website. ^[4]

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9. Butow, P. N., Sze, M., Eisenbruch, M., Bell, M. L., Aldridge, L. J., Abdo, S., Tanious, M., Dong, S., Iedema, R., Vardy, J., Hui, R., Boyle, F., Liauw, W., & Goldstein, D. (2013). Should culture affect practice? A comparison of prognostic discussions in consultations with immigrant versus native-born cancer patients. *Patient Education and Counseling*, 92(2), 246-252.
 10. Australian Institute of Interpreters & Translators (AUSIT). (2007). *AUSIT Guidelines for Health Professionals Working with Interpreters*. Retrieved from http://ausit.org/AUSIT/Documents/Guidelines_For_Health_Professionals.pdf
 11. Hiruy, K., & Mwanri, L. (2013). End-of-life experiences and expectations of Africans in Australia: Cultural implications for palliative and hospice care. *Nursing Ethics (Online)*. Retrieved from <http://nej.sagepub.com/content/early/2013/03/04/0969733012475252.abstract>
 12. Palliative Care Australia. (2012). *Multilingual resources*. Resources. Retrieved September 11, 2013, from <http://www.palliativecare.org.au/Resources/Multilingualresources.aspx>

THINKING POINTS

1. Consider the principles when communicating with a person whose second language is English. Outline strategies you would use to:
 - a) Say good morning and ask how they are feeling
 - b) Explain how and why vital signs are taken
 - c) Explain the goals of palliative care as opposed to active treatment
 - d) Explain an Advanced Health Directive order.
2. Consider a scenario that requires an interpreter to be involved. What information would you give to the interpreter prior to commencing the interview with the person with a life-limiting condition?

ACTIVITY 5: Decision making and care planning

Including family and community in decision making

Western societies typically place high value on the right of individuals to make their own decisions and have choices about what will happen to them at end-of-life. Information about diagnosis, treatment options, decision making and future planning is typically given early in the course of illness management. In other cultures, the person's place as part of a family and community is emphasised. Decisions relating to marriage selection, career choices and medical care can require greater involvement of the family and wider community.^[1] In some cultures, several family members may have a role to play in the care of the person.^[2]

On admission and prior to discussing care with the person with a life-limiting condition and their family, identify the preferred person/s to direct questions and information to. In some cultures the gender of the person with a life-limiting condition influences the member of the community included in the discussions, with discussions only occurring with other members of the same sex.^[3]

A cultural framework should be considered when discussing care with the person with a life-limiting condition and their family, with attention to:

- 'truth telling' when providing medical information
- asking about preferences regarding cultural beliefs about death and dying
- exploring family's preferred role in decision making
- deliberation and decision making in the context of cultural beliefs related to respect for authority, respect for elders, spirituality and trust^[4]

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1. Chater, K., & Tsai, C. (2008). Palliative care in a multicultural society: a challenge for Western ethics. *Australian Journal of Advanced Nursing* (Online), 26(2), 95-100. Retrieved from http://www.ajan.com.au/Vol26/26-2_Chater
 2. Hiruy, K., & Mwanri, L. (2013). End-of-life experiences and expectations of Africans in Australia: Cultural implications for palliative and hospice care. *Nursing Ethics* (Online). Retrieved from <http://nej.sagepub.com/content/early/2013/03/04/0969733012475252.abstract>
 3. Shahid, S., Bessarab, D., van Schaik, K. D., Aoun, S. M., & Thompson, S. C. (2013). Improving palliative care outcomes for Aboriginal Australians: service providers' perspectives. *BMC Palliative Care*, 12(26).
 4. Sharma, R. K., & Dy, S. M. (2011). Cross-Cultural Communication and Use of the Family Meeting in Palliative Care. *American Journal of Hospice and Palliative Medicine*, 28(6), 437-444.

- preferences for ongoing treatment
- what quality of life means to them.

Collusion, disclosure and ‘truth telling’

Preferences for information giving, relating to diagnosis and prognosis, can be influenced by culture. For example, withholding information can occur in some cultures that hold beliefs that giving a person bad news can be emotionally harmful and may hasten death.^[5, 4] Reasons for non-disclosure include the belief that discussion of serious illness and death:

- is disrespectful or impolite
- may cause depression or anxiety in the person with a life-limiting condition
- may cause the person with a life-limiting condition to lose hope
- can make death or terminal illness real because of the power of the spoken word.^[6]

Collusion between family and physicians can be deeply rooted in some cultural practices, where both parties act to conceal the seriousness of the illness from the person with a life-limiting condition.^[7] Strategies to reduce collusion include:

- the person with a life-limiting to decide the level of information they want^[7]
- providing information to families about the stages of the life-limiting condition and the ability to discuss progressing symptoms
- acknowledging with care teams that collusion is a possibility
- providing education to care teams about collusion, why this happens and the negative/positive impacts this may have on people with a life-limiting condition.

THINKING POINTS

1. Discuss the impact that withholding truth about the person’s condition can have:

- a) On a person with a life-limiting condition
- b) On their family
- c) On you.

2. How is collective decision making accommodated in health care?

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5. Wiener, L., McConnell, D. G., Latella, L., & Ludi, E. (2013). Cultural and religious considerations in pediatric palliative care. *Palliative & Supportive Care*, 11(1), 47-67.
 6. Searight, H. R., & Gafford, J. (2005). Cultural diversity at the end of life: Issues and guidelines for family physicians. *American Family Physician*, 71(3), 515-522.
 7. Low, J., Kiow, S., Main, N., Luan, K., Sun, P., & Lim, M. (2009). Reducing Collusion Between Family Members and Clinicians of Patients Referred to the Palliative Care Team. *The Permanente Journal*, 13(4), 11-15.

ACTIVITY 6: Amy is admitted to an aged care facility

Six years ago Amy was diagnosed with early onset probable Alzheimer's disease. At the time of diagnosis, Amy, Mei and Erik met with Amy's General Practitioner who explained the likely progression of the disease and informed them that Amy's life expectancy was expected to be up to 10 years.

Amy was able to continue working for another year after her diagnosis, went part time for six months and then retired early when she was no longer able to keep up with work demands.

Over the past 12 months Amy's memory and ability to perform familiar tasks independently have declined more quickly. She is often anxious or argumentative, can no longer wash or dress herself, wakes up at night and wanders about, and has recently developed urinary incontinence. Mei and Erik have been caring for Amy at home.

Despite assistance with Amy's care by home care services twice a week, Mei and Erik are finding that Amy has become more difficult to care for. The changes have been distressing for Amy and also for both Mei and Erik. Erik is struggling to keep up at work and care for both his grandmother, now almost 90, and his mother. He has been sleeping poorly, complaining of headaches and becomes tearful easily.

Mei and Erik are now unable to cope with Amy at home any longer. Amy has been re-assessed by the Aged Care Assessment Team and it has been determined that Amy is eligible for high-level care. After much consideration, Mei and Erik have made the difficult decision to admit Amy to an aged care facility. Mei finds this particularly distressing as she believes it is her role to care for Amy at home.



Amy's is admitted to an aged care facility

THINKING POINTS

1. What are some of the fears and concerns that Erik and Mei might be facing as carers, while caring for Amy at home.
2. What information would you provide the medical interpreter with, prior to her first meeting with Amy, Erik and Mei at the Aged Care facility?

SECTION 3

Providing person-centred care

In this section you will:

- identify common barriers to care for people with a life-limiting condition from a culturally diverse background
- learn about cultural attitudes, beliefs and meanings of health, illness and symptoms
- recognise culturally unique aspects of care provision at end-of-life.

ACTIVITY 7: Access to services and care

People from culturally and linguistically diverse backgrounds can be less likely to access and use end-of-life services compared to other groups.^[1] Common barriers to accessing services include:

- it's a family business / responsibility
- lack of knowledge and information about services available
- lower socioeconomic status
- lack of confidence to seek services and individual care needs
- social isolation
- complexity of the health care system
- communication barriers
- attitudes to seeking or receiving help
- beliefs that it is rude to respond or say no to a medical officer
- programs offered that are not culturally relevant
- past negative experience, particularly for migrants who previously experienced trauma or torture.^[2, 1, 3]

People from a culturally diverse background are more likely to access services and comply with treatment when there is sensitivity shown by the health care staff and service. If necessary refer back to cultural competence in Activity 2 of this module.^[4, 1]

Factors to be considered when caring for culturally and linguistically diverse people with a life-limiting condition and their family include:

- the person's understanding of life cycle / journey
- the person/family understanding of symptoms
- the person/family understanding of anatomy and bodily functions

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1. Evans, N., Menaca, A., Koffman, J., Harding, R., Higginson, I., Pool, R., & Gysels, M. (2012). Cultural Competence in End-of-Life Care: Terms, Definitions, and Conceptual Models from the British Literature. *Journal of Palliative Medicine*, 15(7), 812-820.
 2. Wiener, L., McConnell, D. G., Latella, L., & Ludi, E. (2013). Cultural and religious considerations in pediatric palliative care. *Palliative & Supportive Care*, 11(1), 47-67.
 3. Migrant Information Centre. (2009). *Palliative Care for Culturally & Linguistically Diverse Communities*. Retrieved from http://www.miceastmelb.com.au/documents/pdaproject/Palliative_care_resource_for_workersAug2009.pdf
 4. Broom, A., Good, P., Kirby, E., & Lwin, Z. (2013). Negotiating palliative care in the context of culturally and linguistically diverse patients. *Internal Medicine Journal*, 43(9), 1043-1046.

- the person/family understanding of appropriate treatment
- optimal communication patterns
- autonomy and self-efficacy
- gender roles
- family involvement/inclusion or exclusion
- pain expression and management
- diets and dietary practices
- concepts of end-of-life / death and dying
- expectations of health professionals^[5, 6]
- preferred location for care
- institutionalised racism in terms of policies and procedures that do not support cultural diversity
- personalised / Individual racism.

THINKING POINTS

1. List strategies that could be used to increase the uptake of health care services by people from culturally and linguistically diverse backgrounds.
2. Discuss education and support that would ensure that everyone's cultural safety is met.

ACTIVITY 8: Symptom Management

Understanding of health, illness, symptoms and pain

The concept of health and illness is viewed differently between cultures.^[1] Similarly, culture and society influences an individual's perception of illness, symptoms and pain through shared behaviours, customs and beliefs.

Cultures can attribute health, illness and death to natural or supernatural causes.^[2] Some people can have a cultural belief that pain is a punishment for past wrongdoings.^[3] Other cultures believe that pain needs to be tolerated for access to heaven to be granted.^[4]

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5. Dreachslin, J., Gilbert, M., & Malone, B. (2012). *Diversity and Cultural Competence in Health Care : A systems approach* (1 ed.). Hoboken: Wiley.
 6. Huang, M., Yates, P., & Prior, D. (2009). Accommodating the Diverse Cultural Needs of Cancer Patients and Their Families in Palliative Care. *Cancer Nursing*, 32(1), 12-21.

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1. Ballantyne, P. J., Mirza, R. M., Austin, Z., Boon, H. S., & Fisher, J. E. (2011). Becoming Old as a 'Pharmaceutical Person': Negotiation of Health and Medicines among Ethnoculturally Diverse Older Adults. *Canadian Journal on Aging*, 30(2), 169-184.
 2. Wasti, S. P., Randall, J., Simkhada, P., & van Teijlingen, E. (2011). In what way do Nepalese cultural factors affect adherence to antiretroviral treatment in Nepal? *Health Science Journal*, 5(1), 37-47.
 3. Arnold, R. (2007). Why Patients Do Not Take Their Opioids: Fast facts and concepts. *End of Life / Palliative Education Resource Center*. Retrieved from http://www.eperc.mcw.edu/EPEC/FastFactsIndex/ff_083.htm
 4. Wiener, L., McConnell, D. G., Latella, L., & Ludi, E. (2013). Cultural and religious considerations in pediatric palliative care. *Palliative & Supportive Care*, 11(1), 47-67.

Management and provision of care

Severity of pain and other symptoms can be under reported depending on the belief people hold about their attribution. Effective management of pain and other symptoms in people with a life-limiting condition requires discussion, comprehensive assessment, monitoring and the use of pharmacological and non-pharmacological management. ^[5]

Depending on the persons understanding of the cause of pain and other symptoms, traditional management can include swimming in healing waters, making promises to their God or deity, giving offerings or sacrificing animals. ^[4,2] Rituals can be held to remove evil spirits from the body and mind and can include the use of amulets, special clothes, herbs and traditional remedies. ^[4]

In some cultures, management of illness and symptoms can involve the use of foods, natural products, traditional medicinal herbs and traditional healers. Familiarity and trust may be built over a long period of time and connection between individuals and their traditional healer. ^[1] While traditional healers and herbal medicines are often easily accessible in some cultures, this may not be the case in Australia with traditional healers and treatments possibly more difficult to access.

Effective communication and explanation of available management options is imperative to allow people with a life-limiting condition and their family to make informed decisions. ^[6] Information regarding medication and management options need to be in a format and language that the person and their families can clearly understand and is culturally appropriate. ^[7]

Cultural values can also influence beliefs about who provides care for a person. In some cultures, shame, embarrassment and a perceived loss of self-respect can be experienced if a person is cared for by a member of the opposite sex. ^[8] Some people in cultures do not recognise a person of the opposite gender, impeding therapeutic communication.

THINKING POINTS

1. Select one cultural group. Review some literature to describe the common traditional beliefs held about pain and other symptoms within that cultural group.
2. What are your cultural beliefs about this?
3. How would you take these beliefs into consideration in your practice?

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5. Lanken, P. N., Terry, P. B., DeLisser, H. M., Fahy, B. F., Hansen-Flaschen, J., Heffner, J. E., Levy, M., Mularski, R. A., Osborne, M. L., Prendergast, T. J., Rocker, G., Sibbald, W. J., Wilfond, B., & Yankaskas, J. R. (2008). An Official American Thoracic Society Clinical Policy Statement: Palliative Care for Patients with Respiratory Diseases and Critical Illnesses. *American Journal of Respiratory and Critical Care Medicine*, 177(8), 912-927.
 6. Palliative Care Expert Group (Ed.). (2010). *Therapeutic guidelines: palliative care* (3 ed.). Melbourne: Therapeutic Guidelines Limited.
 7. Queensland Health. (2012). *Literature review: Best practice multicultural policy implementation*. Retrieved from <http://www.health.qld.gov.au/qhpolicy/docs/gdl/qh-gdl-080-att-b.pdf>
 8. Shahid, S., Bessarab, D., van Schaik, K. D., Aoun, S. M., & Thompson, S. C. (2013). Improving palliative care outcomes for Aboriginal Australians: service providers' perspectives. *BMC Palliative Care*, 12(26).

ACTIVITY 9: Cultural and individual differences

Amy has settled in to the aged care facility. A family meeting was held within the first week of Amy's arrival. Mei and Erik met with members of the health care team and a medical interpreter. During the meeting, management of Amy's symptoms and quality of life was discussed. Despite time allocated for Mei and Erik to ask questions during the meeting, Mei did not feel comfortable to speak up at this time and sat silently in the room. Erik worried that the information about his mother's deteriorating condition was very difficult for Mei to listen to and accept.

Mei comes every morning to visit Amy and helps with her care. The change in Amy's condition upsets Mei and she finds it difficult to understand that it is a purely biophysical condition. Mei has always placed a small piece of Jade under Amy's pillow to ward off evil spirits and to assist with healing. She continues to do this.

Each morning at home, Mei gets up and prepares food to take to Amy when she visits her. It is important to Mei and Erik that Amy's friends and community are allowed to visit Amy when they would like to and they have asked the facility to accommodate for this. Erik visits his mum each afternoon after work and takes Mei back home with him when he leaves.



Cultural and individual differences

THINKING POINTS

1. Discuss how staff attitudes about Amy, Mei and Erik's cultural practices would:
 - a) Affect care provided to Amy and her family
 - b) Impact on Amy and her family's psychological well-being
2. What strategies could be used to educate health care professionals about cultural competence?

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1. Sun, D., Li, S., Liu, Y., Zhang, Y., Mei, R., & Yang, M. (2013). Differences in the origin of philosophy between Chinese medicine and western medicine: Exploration of the holistic advantages of Chinese medicine. *Chinese Journal of Integrative Medicine*, 19(9), 706-711.
 2. Wiener, L., McConnell, D. G., Latella, L., & Ludi, E. (2013). Cultural and religious considerations in pediatric palliative care. *Palliative & Supportive Care*, 11(1), 47-67.

ACTIVITY 10: Understanding spiritual needs and sources of distress

Spiritual and religious beliefs

Western societies tend to place some emphasis on biomedical aspects of end-of-life care. Some other cultures place more emphasis on the more holistic and spiritual aspects of care.^[1] These beliefs can influence the way people seek assistance, make choices about their management and care and ultimately where they would like to die.

Discussion should be held with the person with a life-limiting condition and their family to understand preferences for spiritual care. People from some cultural backgrounds can interpret the involvement of spiritual care workers as an impending sign that they are near death.^[2]

Grief and bereavement

The meaning of grief, what is grieved for and the way people grieve varies among individuals and within cultures. While grieving is a natural process, questioning a person about their grief may signify to them that their grief is irrational.^[2]

Grief is expressed differently by people for a variety of reasons. People from some cultures may display their grief openly and even publically by crying and wailing, where for people from other cultures may remain calm and appear stoic.^[2]

In cultures where eating traditional food and gathering to eat with family, friends and community are important, people may express sadness at a loss of appetite.^[3] The practice of artificial nutritional feeding as a life sustaining measure in people with a life-limiting condition occurs at a higher rate in some cultures compared to others. This may be due to importance that food plays in some communities.^[4] Effective communication about a person's body preparing itself for the end of life is required. Discussing changes in the body through the last weeks and days can help families when changes occur. If there are concerns about nutrition and hydration supplements you could explain that preparation for end-of-life does not require much sustenance.

THINKING POINTS

1. What issues should be considered in deciding whether artificial nutrition has a role in a person's care at end-of-life?
2. How does your culture grieve?

3. Anngela-Cole, L., & Busch, M. (2011). Stress and Grief Among Family Caregivers of Older Adults With Cancer: A Multicultural Comparison From Hawaii. *Journal of Social Work in End-Of-Life & Palliative Care*, 7(4), 318-337.

4. Connolly, A., Sampson, E. L., & Purandare, N. (2012). End-of-Life Care for People with Dementia from Ethnic Minority Groups: A Systematic Review. *Journal of the American Geriatrics Society*, 60(2), 351-360.

SECTION 4

Support for people from culturally diverse backgrounds at end stages of life

In this section you will:

- learn about concerns people from diverse cultures have about the end stages of life
- reflect on customs and beliefs surrounding death, burial and cremation.

ACTIVITY 11: End-of-life care

End-of-life care planning

End-of-life care planning and decision making may include and respect the wishes of the individual, the family and the community.^[1] However in many countries, advance care planning and health directives are not a standard practice. Decisions about life sustaining measures or withholding treatment may be difficult for caregivers and relatives.^[2] Parents, families and carers of children with a life-limiting condition may find it particularly difficult to speak truthfully and openly to children about their illness.^[3]

While advanced care plans and health directives are not standard in many countries, when a palliative diagnosis is made, a referral should be made to a palliative care specialist service for discussion. Through open conversations in plain English, discussions should be used as a way of identifying to medical staff the social or cultural pathways, important to the person with a life-limiting condition and their family.

End-of-life care

Any culture can see the health system as intruders, taking loved ones away. In some cultures death is considered to be a natural part of the life cycle while others may see it as unnatural and a sign of weakness. These underpinning beliefs can influence the way people would like to say goodbye to their families and communities at end-of-life. Some people will insist that many family and community members are given the opportunity to say goodbye, where others want discretion so as not to draw attention to them or their illness.^[3]

The preference for the place to receive end-of-life care and to die varies between individuals. For some cultures the importance exists in remaining with the family or returning to their origins to die. Where family and community support is strong, the desire for the provision of in home care is strong. For others the choice may be a care facility.^[2] Many beliefs exist around the time and place of death. Some believe that dying and death that occurs at home is a sign of bad luck, where others believe that a person's soul will be lost for ever if they die away from their home.^[3]

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1. Graham, N., Gwyther, L., Tiso, T., & Harding, R. (2013). Traditional healers' views of the required processes for a "good death" among xhosa patients pre- and post-death. *Journal of Pain & Symptom Management*, 46(3), 386-394.
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Customs surrounding death, burial or cremation and bereavement, rituals

Strong community involvement may be pivotal to a person's culture. A person's care can involve and be carried out by family, relatives and people in the surrounding community. Members of the community also celebrate and mourn together. ^[4] Prior to and at the time of death, families may want to carry out cultural or religious ceremonies or rituals. These ceremonies and rituals can include family members bathing and dressing the person after death. ^[5]

Provisions need to be given to allow physical space and noise to occur without disrupting other people being cared for. Additional support for care workers may be required to identify and manage the often multiple needs of all persons involved. ^[6] Acceptance by health professionals and care staff of cultural difference and practices occurs through education, communicating directly with people and their family, and recognising and respecting their individual beliefs surrounding customs, rituals and preferences. ^[7]

THINKING POINTS

1. Describe ways that you would accommodate requests for visits from a large number of family and community members in the journey to the end-of-life.
2. Is this similar to your culture?

ACTIVITY 12: Support for Amy's family at end-of-life

It is now 3 years on and Amy has entered the advanced stage of early onset probable Alzheimer's. Dr Romano Sayer completed his training and is now a General Medical Practitioner who works at a nearby clinic. Romano is Amy's primary physician and has been overseeing her medical care for the past 6 months. When it was obvious that Amy was not improving, a family meeting was held and with the assistance of an interpreter, Romano informed Mei and Erik that Amy's health was declining and that she was entering the end stages of her life.

Amy died this morning with Mei, Erik and Samantha by her bedside.



Support for Amy's family at end-of-life

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5. Kobler, K., Limbo, R., & Kavanaugh, K. (2007). Meaningful Moments: The Use of Ritual in Perinatal and Pediatric Death. *The American Journal of Maternal/Child Nursing*, 32(5), 288-295.
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7. Halm, M. A., Evans, R., Wittenberg, A., & Wilgus, E. (2012). Broadening cultural sensitivity at the end of life: an interprofessional education program incorporating critical reflection. *Holistic Nursing Practice*, 26(6), 335-349.

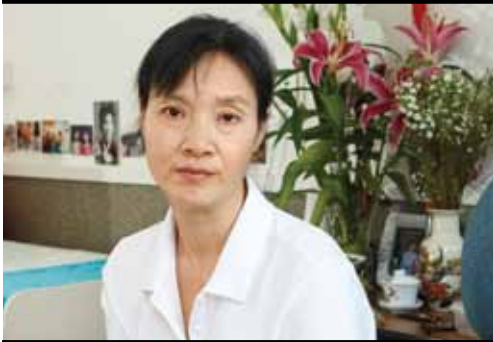
THINKING POINTS

1. What should be considered when preparing for the family meeting to support Erik and Mei for Amy's passing?
2. Discuss various cultural ceremonies and rituals that may be practiced around the time of a person's death.
3. What might be some of the reasons that Dr Sayer would use the term 'passed away' rather than died?

SECTION 5

Reflections on what you've learnt

1. What key points have you learnt from the activities in this module that will help you in providing care for culturally and linguistically diverse people and their families?
2. What specific strategies do you plan to incorporate as a graduate health care professional?
3. Do you see any difficulties using what you have learnt here as part of your practice as a health care professional? If so, what strategies might you use to address these difficulties?



Amy's Story

A3: AMY'S STORY

▶ 1.14 mins

Amy's co-worker: So is your mum going to finally get to meet Samantha tonight?

Amy: Who?

Amy's co-worker: Eric's girlfriend, Samantha, that's her name isn't it?

Amy: Oh yes, I think she's going to see my mum tonight, should be interesting

Amy's co-worker: Are you okay? You haven't seemed yourself lately

Amy: Yeh, I'm okay. I'm just a bit tired

Scene Break

▶ 1.47 mins

Amy: *Chinese* Mum, what are you cooking? It smells delicious!

Amy's mum: *Chinese* You are back! I'm cooking dumplings. They should be ready soon. I hope they taste good and she likes them

Amy: *Chinese* Huh? Why are you cooking dumplings? Who are you talking about?

Amy's mum: *Chinese* Have you forgotten already? Eric is bringing his new girlfriend over.

Amy: *Chinese* Oh yes! I forgot about that. Hey mum, I think Eric is a bit nervous about bringing his girlfriend to meet us

Amy's mum: *Chinese* Yes, yes I think I agree

Amy: *Chinese* I feel a bit tired and I want to have a rest, is that okay?

Amy's mum: *Chinese* Okay, Okay

Amy: *Chinese* oh mum, you've been working so hard. I'll go now

Scene Break

Eric: *Chinese* Grandma! This is my girlfriend, Samantha

Grandma: *Chinese* Welcome, welcome, welcome

Samantha: Hi, it's nice to meet you

Eric: She says hello.

Grandma: *Chinese* Hello – Thank you

Eric: *Chinese* Grandma, where's mum?
Grandma: *Chinese* In her room having a rest
Eric: *Chinese*Ma? Mum?
Amy (mum): I'm so sorry Eric, I was just sitting down. Hello, Sandra?
Eric: Samantha mum, Samantha
Samantha: It's nice to meet you
Amy (mum): Nice to meet you too, have a seat, please

A6: AMY'S ADMISSION TO AN AGED CARE FACILITY

▶ 2.52 mins

Eric: *Chinese* Mum, you sit there, Grandma you sit there
Nurse Unit Manager: it's great to finally meet you all. As I said, my name is Misha and I'm the nurse unit manager here. I believe you met Liv Katherine last week and she showed you around the facility and gave you some information?
Eric: Uh, yes...I did, thank you. I'm Sorry, I have to go off to work very soon
Grandma: *Chinese* What is she saying? Tell her that your mum likes to watch midday TV everyday
Amy (mum): Yes! I want to watch TV. Mum, I want you to watch with me
Grandma: *Chinese* Yes, yes
Eric: My grandmother is anxious, it's a difficult time for her because she's traditionally took care of my mum, so seeing her here is very difficult for her
Grandma: *Chinese* You have to tell her to remember that your mum likes to watch TV
Eric: My mother enjoys watching the afternoon movie and um my grandmother often watch it with her, um but uh well, they do it together
Nurse Unit Manager: Great, well I'll make sure we'll finish up in time so she can watch the midday movie. Hello Amy, I'm Misha and I'm gonna be helping look after you while you're here with us
Amy: Are you going to show me now?
Nurse Unit Manager: I'm Misha, and I'm going to talk to you for a little while then I'm going to take you to your new room
Eric: She is welcoming us. Her name is Misha and she is the Nurse Unit Manager here
Grandma: Okay, Okay
Nurse Unit Manager: And this is Jing Jing, she's our medical interpreter today
Medical Interpreter: *Chinese* Hello, my name is Jing Jing and I'm a medical interpreter. I will help Misha to provide for you the information you need
Nurse Unit Manager: I will need to ask you some questions to get some information to help best care for you, I will also tell you a little bit about our facility, please ask if there is anything that you are unsure of
Medical Interpreter: *Chinese* Misha will ask you a few questions so that she can get the information she needs to best care for Amy. Then she will give you some information about this facility. If you have any questions just ask

Grandma: *Chinese* Thank you

Nurse Unit Manager: Who's the best person to be answering these questions?

Medical Interpreter: * Chinese*who is the best person to be answering these questions?

Eric: Well I can answer some of the questions, but my grandmother took care of my mum a lot so we'll both answer them

Nurse Unit Manager: Great, well let's get started.

A9: CULTURAL AND INDIVIDUAL DIFFERENCES

▶ 4.18 mins

Amy: Ling Li have you finished your school work already? Did you come straight home?

Eric: It's me mum, it's me Eric

Amy: Oh...Eric *Chinese* My son...

Nurse Unit Manager: Hi Amy, I like you to meet Dr Romano Sayer, he's a medical intern who will be working here in the next couple of months

Eric: He is a new Doctor

Amy: Oh...

Nurse Unit Manager: I'll come back and talk to you all later

Worker: Hey Misha, quick question, I'm taking a meal down to Amy's room. I don't understand why we do this each day, whenever I go in there there's always a bowl of food that her mum's brought in and she doesn't even always eat that

Nurse Unit Manager: Yeh, Mei makes food for Amy everyday and brings it into her, I know she doesn't always eat it. But it's not just about the food itself, many cultures bring in food in the same way others bring in flowers. I know in my family, if someone didn't bring food to us when we're sick, we would think we were being uncared for.

Worker: Really?

Nurse Unit Manager: Yes. Although despite the cultural differences, it's important to treat Amy as an individual, take a meal to her and she can choose what she wants to eat.

Worker: Okay, I will

Worker: Hey Misha, could you clarify something for me. Now, I noticed that Amy's mum Le Mei keeps a piece of jade under Amy's pillow, but she also wears a cross around her neck. Now, what exactly does she believe in?

Nurse Unit Manager: I certainly don't have one set of beliefs, do you?

Worker: No, not really

Nurse Unit Manager: Well just like you and me, Amy, Mei, and Eric are individuals. They're likely to have a mix of traditional and non-traditional beliefs and customs. You're actually asking the wrong person if you want to know exactly what they believe. You need to speak to them, ask them directly

Worker: Okay, okay, I get it

Nurse Unit Manager: Hi Tev, I was just in Amy's room and I noticed the manual handling chart wasn't there.

Nurse: Yeh, I have it here. I'm just returning it. Listen, she is quite unsteady on her feet, she'll require some assistance with walking and transferring. I went to go in earlier, but she had a room full of visitors – AGAIN – I don't know what they were saying when they don't speak in English.

Nurse Unit Manager: I've often heard you talk about your family, it sounds like you must have a big group when you get together. Do you all speak in English then?

Nurse: No, rarely

Nurse Unit Manager: Well, just like you. When Amy's family and community come together, I'm sure they communicate in a way that they all feel comfortable

Nurse: Yeh, I guess

Nurse Unit Manager: Remember also, this is a difficult time for them, as Amy's condition has deteriorated. So I'm sure it helps them cope a little more with what's happening. Even though language might seem like a barrier at times, if you talk to people as individuals, share your concerns, get to know them. The differences aren't that important.

Nurse: Yeh, okay, good point.

Nurse Unit Manager: Okay, see you later

Nurse: Alright, see ya

A12: SUPPORT FOR AMY'S FAMILY AT END-OF-LIFE

▶ 1.18 mins

Grandma: *Chinese* Amy, my Amy, Amy...Amy, wake up Amy, wake up, don't leave me, I don't want you to leave.

Doctor: Eric, I need to go and see a few people now. Please take as much time as you want and let the staff know if there is anything that we can do

Eric: Thank you Romano

Nurse: Hi Dr Sayer what's happened?

Doctor: Amy's passed away this morning

Nurse: Who's in there now? And why are they being so loud?

Doctor: It's Amy's family, friends and community. Think about the people you've seen grieving, have they all grieved in the same way?

Nurse: No, they haven't

Doctor: And just like everyone else who grieves, they are individuals and they grieving in their own way

