

Workbook



PCC4U

PALLIATIVE CARE
CURRICULUM FOR
UNDERGRADUATES

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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.

ACTIVITY 1: Factors influencing death & dying**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

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?

ACTIVITY 3: Cultural factors influencing death & dying

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?

ACTIVITY 4: 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.

ACTIVITY 5: Assessing people's needs

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?

ACTIVITY 6: Understanding quality of life

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

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?

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



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



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?

ACTIVITY 11: Palliative Care Australia's Standards**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.



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

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: The challenges faced

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



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?

ACTIVITY 3: Communication principles



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?

ACTIVITY 4: 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



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



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?

ACTIVITY 7: How to communicate with children

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



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?

ACTIVITY 9: Understanding sources of distress**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?

ACTIVITY 10: 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?

ACTIVITY 11: Understanding spiritual needs

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.

ACTIVITY 12: 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?

ACTIVITY 13: End-of-life concerns**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?

ACTIVITY 14: 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?

ACTIVITY 15: Adopting self-care strategies



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?



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.

ACTIVITY 1: Life-limiting illnesses

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



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?

ACTIVITY 3: Symptom Assessment

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



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



THINKING POINTS

1. List the key principles for undertaking a multidimensional assessment of the symptoms for people with advanced life-limiting disease.

2. Watch the video of the palliative care physician. 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.

ACTIVITY 6: Assessment tools

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.

ACTIVITY 7: Palliative interventions

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



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



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. Watch the video of the palliative care physician by clicking on the Expert opinion icon. 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.



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

ACTIVITY 1: Responses to loss

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



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?

ACTIVITY 3: Establishing goals of 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?

ACTIVITY 4: 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

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.

ACTIVITY 6: Assessing & maintaining 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**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?

ACTIVITY 8: Caregiver needs

THINKING POINTS

Reflect on Bob's story so far.

1. Identify Margaret's stressors a) Currently

b) As Bob's condition deteriorates

c) 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



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

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?



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.

ACTIVITY 1: What is a multidisciplinary approach to care?

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



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 4: Patient-centred care planning**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**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's team plans to discuss Betty as her kidney disease has now progressed to stage 4

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

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

ACTIVITY 8: 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



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

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



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.



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 module, 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

ACTIVITY 1: 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

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



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](http://www.australianindigenoushealthinfo.net) 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

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



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

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?



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

ACTIVITY 1: Impact of life-limiting conditions

THINKING POINTS

1. Consider the following conditions and for each, describe possible illness trajectories:

a) Spinal Muscular Atrophy type 1

b) Infantile Battens disease.

2. In what ways does a child's developmental stage influence their understanding of death and dying?

ACTIVITY 2: The family's experience of their child's life-limiting illness

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



THINKING POINTS

1. Identify the stressors that Emily's parents might currently be dealing with:

a) Physically

b) Emotionally

c) Spiritually

d) Socially?

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

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

ACTIVITY 5: Communication with children and their families

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



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

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.

ACTIVITY 8: Supportive approaches to care

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



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

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

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



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

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?



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 module, 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

ACTIVITY 1: Diversity in Australia health care

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?

ACTIVITY 2: Culturally diverse populations in Australia

THINKING POINTS

1. Reflect on your own culture. What are your beliefs? How do you respond when your beliefs are not consistent with others?

ACTIVITY 4: Intercultural communication principles**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

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?

ACTIVITY 6: Amy 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?

ACTIVITY 7: Access to services and care**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**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?

ACTIVITY 9: 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?

ACTIVITY 10: Understanding spiritual needs and sources of distress

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?

SECTION 4

Support for people from culturally diverse backgrounds at end stages of life

ACTIVITY 11: End-of-life care

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



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?

