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.

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.

---

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 fraility 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.

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?

---

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.

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.

---

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”.

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). 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. These tools enable a more comprehensive assessment to identify causes and effects of symptoms.

---

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.

---


SECTION 3  Evidence-based symptom management

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.

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

## 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?
A2: HERBERT’S STORY

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

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

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)