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 For example, some people will express fear or anxiety while others may be sad, withdrawn, depressed, or angry.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]

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>
<thead>
<tr>
<th>TABLE 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>P Prepare for the discussion, where possible</td>
</tr>
<tr>
<td>R Relate to the person</td>
</tr>
<tr>
<td>E Elicit patient and caregiver preferences</td>
</tr>
<tr>
<td>P Provide information tailored to the individual needs of both patients and their families</td>
</tr>
<tr>
<td>A Acknowledge emotions and concerns</td>
</tr>
<tr>
<td>R (foster) Realistic hope (e.g. peaceful death, support)</td>
</tr>
<tr>
<td>E Encourage questions and further discussions</td>
</tr>
<tr>
<td>D Document</td>
</tr>
</tbody>
</table>

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?

   Reproduced with permission.
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.

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.

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.

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?
SECTION 3 Communicating with children

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.

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. 

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.

**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?

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?

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

<table>
<thead>
<tr>
<th>THINKING POINTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Use the Patient Dignity Inventory to identify some of Michelle’s sources of distress at this time.</td>
</tr>
<tr>
<td>2. What communication strategies does Dawn engage to encourage Michelle to talk about her concerns?</td>
</tr>
<tr>
<td>3. What other strategies might be used to support an individual who:</td>
</tr>
<tr>
<td>a) Expresses concerns about how their illness has affected relationships with people close to them?</td>
</tr>
<tr>
<td>b) Feel the illness is affecting their personal appearance and body image?</td>
</tr>
<tr>
<td>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?</td>
</tr>
<tr>
<td>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?</td>
</tr>
</tbody>
</table>
SECTION 5  The spiritual dimension of care

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.

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.

---

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.

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?

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

<table>
<thead>
<tr>
<th>THINKING POINTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What are Pete’s main concerns at this time?</td>
</tr>
<tr>
<td>2. How does James help Pete deal with these concerns?</td>
</tr>
<tr>
<td>3. What other strategies could you use to provide emotional support to Pete, Michelle and their family at this time?</td>
</tr>
</tbody>
</table>
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?
A2: MICHELLE’S STORY

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

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

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, thankyou 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**

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 it’s 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: 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.
A10: RESPONDING TO LOSSES

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 it’s 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 it’s 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

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.