

Topic 3: Workbook

Caring for children with life-limiting illnesses



To provide care that is responsive to the specific needs of children with life-limiting illnesses 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 illnesses will help you develop the knowledge and skills needed to provide care, across various health care settings, to children with life-limiting illnesses and their families.

Aims and objectives

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

- Discuss the key principles associated with caring for children with life-limiting illnesses 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 illness, their families and their communities.



Topic 3: Workbook

Section 1: Understanding needs of children with life-limiting illnesses and their families

Activity 1: Impact of life-limiting illnesses

Thinking Points

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

- Spinal Muscular Atrophy type 1

- Infantile Batters disease.

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

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:

- Physically

- Emotionally

- Spiritually

- Socially?

 **Thinking Points** *continued*

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:

- Physically

- Psychosocially

- Financially

- Spiritually.

 **Thinking Points** *continued*

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:

- Providing a family-centred approach to care

- Providing care based on each child's developmental needs.

Topic 3: Workbook

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 five-years-of-age, when assessing their understanding of palliative care, dying and death.
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 illness.

Topic 3: Workbook

Section 3: Supportive care interventions

Activity 8: Supportive approaches to care

Thinking Points

1. Describe an approach to assess pain in a four-year-old child with a life-limiting illness.

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 profession, describe interventions you could use to assist Emily to manage her increasing breathlessness.
3. How could other professions be involved in Emily's case conference?
4. What advantages could there be in Emily's case to embedding advance care planning information into personally controlled electronic health (MyHealth) records?

Activity 10: Psychosocial and spiritual support for children

Thinking Points

1. What strategies might you use to identify the spiritual needs of a seven-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 the advantages and 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 eight-years-old, 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 3: Workbook

Section 4: Reflections on what you have learnt



It is essential for all healthcare professionals to develop the capacity for reflection and self-evaluation of their professional and personal experiences, and to consider how this can impact on themselves and others.

Consider the focus topic you have just completed and reflect on the following questions to assist with your ongoing development:

1. What key points have you learnt from the activities in this module that will help you in providing care for children with life-limiting illnesses and their families?

2. What specific strategies do you plan to incorporate as a graduate health care professional?

3. Do you see any difficulties using what you have learnt here as part of your practice as a health care professional? If so, what strategies might you use to address these difficulties?