



## 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?

