



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

In this section you will:

- review key principles for responding to the needs of children with life-limiting conditions and their families
- review illness trajectories and their implications for children with life-limiting conditions
- learn about loss and bereavement in the context of children and their families.

ACTIVITY 1: Impact of life-limiting conditions

Life-limiting conditions in childhood

Life-limiting conditions in children can include a varied and diverse range of health disorders, including:

- genetic or congenital disorders
- neurological disorders
- cancers, brain tumours, solid tumours
- respiratory disorders
- gastrointestinal disorders
- cardiovascular disorders
- metabolic disorders
- renal diseases
- immunological disorders. ^[1]

These conditions can be divided into four broad groups that are associated with differing trajectories:

- life-limiting conditions for which treatment may be feasible but can fail e.g., cancer
- conditions where there may be long periods of treatment aimed at prolonging life, though life is ultimately limited e.g., complex cardiac disease
- progressive conditions with no curative options e.g., neurodegenerative disorders such as Batten's Disease, Spinal Muscular Atrophy type 1
- irreversible conditions causing disability leading to possible health complications and likely life threatening implications e.g., severe cerebral palsy with complex medical conditions. ^[2]

Illness trajectories for children with life-limiting conditions are often uncertain, as medical advances are rapidly altering outcomes. This uncertainty can cause significant distress for children and their families. It can also defer appropriate early referral to a palliative care service. ^[3]

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1. Feudtner, C., Kang, T.I., Hexem, K.R., Friedrichsdorf, S.J., Osenga, K., Siden, H., Friebert, S.E., Hays, R.M., Dussel, V. & Wolfe, J. (2011). Pediatric Palliative Care Patients: A Prospective Multicenter Cohort Study. *Pediatrics*, 127(6), 1094-1101.
 2. Association for Children's Palliative Care (ACT). (2009). *A Guide to the Development of Children's Palliative Care Services*, Bristol, UK: Author.
 3. Davies, B., Sehring, S.A., Partridge, J.C., Cooper, B.A., Hughes, A., Philp, J.C., Amidi-Nouri, A. & Kramer, R.F. (2008). Barriers to Palliative Care for Children: Perceptions of Pediatric Health Care Providers. *Pediatrics*, 121(2), 282-288.

Impact of life-limiting conditions

Life-limiting conditions impact physically, emotionally, spiritually and socially on children and their families. The impact of life-limiting conditions often extends to friends, schools and communities. [4-6]

For example, some life-limiting conditions are associated with symptoms such as pain. These symptoms can affect the child's ability to attend school and socialise with other children, with parents and carers becoming children's main social contacts. [2] Isolation at different stages of a child's life may affect their physical, psychological, cognitive and social development. [7] Older children who have absences from school often report anxiety about their academic performance. [8] Children can also be affected by altered self-image, often causing them to strive for normality. [9]

A child's experience of living with a life-limiting condition is influenced by their age and developmental stage. It is important to assess each child's understanding of their illness, as a range of factors including personal experience with illness can influence their experience. The following box summarises common features of the child's concept of death at different ages, although it is important to consider this as a guide as considerable variation can exist.

TABLE 1 Children's age related understanding of death and dying

Age 0 - 2 years:

- sees death as separation or abandonment
- has no cognitive understanding of death
- feels despair from disruption of caretaking

Age 2 - 6 years:

- often believes that death is reversible, temporary
- may perceive death as a punishment
- engages in magical thinking that wishes come true - may feel guilt for negative feelings toward the person who died, and think that was the cause of death

Age 6 - 11 years:

- shows gradual understanding of irreversibility and finality of death
- demonstrates concrete reasoning with ability to comprehend cause and effect relationship

Age 11 years or older:

- understands that death is irreversible, universal, and inevitable
- has abstract and philosophical thinking

Source: Medline Plus, National Institutes of Health. Accessed March 31, 2013 from www.nlm.nih.gov/medlineplus/ency/article/001909.htm [10]

4. Palliative Care Australia. (2005). *A Guide to Palliative Care Service Development: A population based approach*. Retrieved October 20, 2012, from [www.palliativecare.org.au/Portals/46/A guide to palliative care service development - a population based approach.pdf](http://www.palliativecare.org.au/Portals/46/A%20guide%20to%20palliative%20care%20service%20development%20-%20a%20population%20based%20approach.pdf)
5. Palliative Care Australia. (2010). *Journeys: Palliative Care for Children and Teenagers*. Retrieved October 15, 2012, from [http://www.palliativecare.org.au/Portals/46/JOURNEYS/Journeys 2010 full document.pdf](http://www.palliativecare.org.au/Portals/46/JOURNEYS/Journeys%202010%20full%20document.pdf)
6. Kuhlthau, K., Kristen Smith, H., Yucel, R. & Perrin, J.M. (2005). *Financial Burden for Families of Children with Special Health Care Needs*. *Maternal and Child Health Journal*, 9(2), 207-218.
7. Howe, C. (2009). *Peer Groups and Children's Development : Psychological and Educational Perspectives*, Chichester, UK: Wiley-Blackwell.
8. Li, H., Chung, O. & Chiu, S. (2010). The impact of cancer on children's physical, emotional and psychosocial well-being. *Cancer Nursing*, 33(1), 47-54.

Children with life-limiting conditions can experience needs across many domains of health, requiring a comprehensive assessment approach, using language and techniques appropriate to their development stage. Key areas for assessment include:

- physical concerns
 - identify pain or other symptoms, using strategies that are age or developmental stage appropriate
- psychosocial concerns
 - identify the child's and family's fears and concerns
 - identify coping and communication styles
 - discuss previous experiences with death, dying or other traumatic life events
 - assess resources for bereavement support
- spiritual concerns
 - discuss spiritual needs
- planning for end of life care
 - identify decision makers
 - discuss anticipated illness trajectory
 - identify goals of care
 - consider concerns near end of life
 - consider acute resuscitation plan if appropriate
- practical concerns
 - plan communication and coordination of health care team
 - identify child and family preferences for location of care
 - discuss child's home or school environment
 - assess child's current and future functional status
 - identify possible financial consideration on family.^[11]

THINKING POINTS

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

- a) Spinal Muscular Atrophy type 1
- b) Infantile Batters disease.

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

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- 9. Taylor, R.M., Pearce, S., Gibson, F., Fern, L. & Whelan, J. (2013). Developing a conceptual model of teenage and young adult experiences of cancer through meta-synthesis. *International Journal of Nursing Studies*, 50(6), 832-846.
 - 10. Medline Plus. (2013). *Discussing Death with Children*. Retrieved March 31, 2013, from <http://www.nlm.nih.gov/medlineplus/ency/article/001909.htm>
 - 11. Himelstein, B.P., Hilden, J.M., Boldt, A.M. & Weissman, D. (2004). Pediatric Palliative Care. *New England Journal of Medicine*, 350(17), 1752-1762.

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

Parents can experience a wide range of concerns including:

- fear, anxiety and stress associated with observing their child's distress and the loss of their child
- financial burden associated with medical management, equipment and transport costs, as well as absences from employment
- a decline in parental physical health due to stress and increased workload associated with medical management responsibilities, relationships and lack of time for themselves.

Siblings of children with life-limiting conditions can also be affected. The sibling's experiences can include:

- increased responsibilities
- stress from upheaval of family routine and dynamics
- feelings of anxiety through concern for sibling who is unwell as well as separation from parents
- feelings of guilt about thoughts they may have towards their sister or brother
- feelings of embarrassment about being seen in public with their unwell or disabled sibling.^[1, 2]

Grief and bereavement

The death of a child is one of the most stressful situations a family can face. For parents, feelings of grief and loss can start well before the child has died.^[3] Responses to the death of a child will vary. Some parents and siblings can experience grief that continues long after the death of a child. For many, this is a normal response to a significant loss and the continuing bonds that parents have with their child even after the child's death. Other individuals can experience a more complicated grief. For some, this complicated grief will require additional professional supports.^[4] Grief and loss is often experienced also by grandparents, friends, community and health professionals involved in the child's care. Grandparents can experience grief both from the loss of their grandchild and from seeing their own child experience loss.^[5]

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1. Newton, A.S., Wolgemuth, A., Gallivan, J. & Wrightson, D. (2010). Providing support to siblings of hospitalised children. *Journal of Paediatrics and Child Health*, 46(3), 72-75.
 2. Abrams, M. (2009). The Well Sibling: Challenges and Possibilities. *American Journal of Psychotherapy*, 63(4), 305-317.
 3. Kars, M.C., Grypdonck, M.H., de Korte-Verhoef, M.C., Kamps, W.A., Meijer-van den Bergh, E.M., Verkerk, M.A. & van Delden, J.J. (2011). Parental experience at the end-of-life in children with cancer: 'preservation' and 'letting go' in relation to loss. *Support Care Cancer*, 19(1), 27-35.
 4. Rosenberg, A.R., Baker, K.S., Syrjala, K. & Wolfe, J.(2012). Systematic review of psychosocial morbidities among bereaved parents of children with cancer. *Pediatric Blood & Cancer*, 58(4), 503-512.
 5. Ponzetti, J. (1992). Bereaved Families - A comparison of parents and grandparents - reactions to the death of a child. *Omega - Journal of Death and Dying*, 25(1), 63-71.

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

Emily is a 10 year old girl who was diagnosed at birth with a congenital heart defect. Her parents were informed soon after birth she had Hypoplastic Left Heart Syndrome. The Paediatric Cardiology Team were involved in Emily's care upon diagnosis. Emily was not suitable for a heart transplant according to the national criteria. Emily had numerous reconstructive surgical procedures until the age of 9 when Emily's condition deteriorated and further surgical procedures were not possible.

Emily lives with her parents and younger siblings on a cattle property in rural Australia. Emily's parents work on the property and Emily's mother has recently obtained work in the nearest town to assist the family financially.



Emily's story

THINKING POINTS

1. Identify the stressors that Emily's parents might currently be dealing with:
 - a) Physically
 - b) Psychosocially
 - c) Financially
 - d) Spiritually.
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

Definition and standards in paediatric palliative care

The World Health Organisation's definition for paediatric palliative care includes the principles of:

- palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family
- it begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease
- health providers must evaluate and alleviate a child's physical, psychological, and social distress
- effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited
- it can be provided in tertiary care facilities, in community health centres and in children's homes.^[1]

Palliative care standards^[2] for children remain the same as they do for adults, with some care priorities that have particular significance including:

- involving the whole family in the child's care
- involving allied health professionals with specialised skills
- supporting families to care for their sick child as well as other siblings
- individualising responses to the child's care needs.^[3]

Some unique aspects of palliative care for children include:

- smaller number of children requiring palliative care
- wider, more diverse range of conditions
- each child's developmental factors need to be considered with their care
- different physiology and pharmacokinetics
- parents often involved in decision making
- siblings require developmental appropriate individualised support
- child's life-limiting illness has profound effects on all aspects of family life
- most children with life-limiting conditions are cared for at home
- the death of a child has profound and prolonged effects on family members and family life, as connections with the child continue after the child's death.^[4, 5]

Children with a life-limiting illness can have disabilities that have a compounding effect on their specific palliative care needs.

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1. World Health Organisation. (1998). *WHO Definition of Palliative Care for Children*. Retrieved May 23, 2012, from <http://www.who.int/cancer/palliative/definition/en/>.
 2. Palliative Care Australia. (2005). *Standards for providing quality palliative care for all Australians*. Retrieved November 6, 2012, from www.palliativecare.org.au/portals/46/resources/StandardsPalliativeCare.pdf.
 3. Palliative Care Australia. (2010). *Journeys: Palliative Care for Children and Teenagers*. Retrieved October 15, 2012, from www.palliativecare.org.au/Portals/46/JOURNEYS/Journeys2010fulldocument.pdf.
 4. Caresearch. (2010). *Paediatrics*. Retrieved November 17, 2012, from <http://www.caresearch.com.au/caresearch/tabid/737/Default.aspx>.
 5. Royal Children's Hospital Melbourne. (2010). *Palliative Care: Paediatrics*. Retrieved October 18, 2012, from http://www.rch.org.au/rch_palliative/About_palliative_care/.

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

In this section you will:

- develop communication skills to enable you to respond effectively to children with life-limiting conditions and their families
- learn about principles for the assessment and management of children with a life-limiting condition
- explore principles for coordinating care of children with life-limiting conditions and their family through a collaborative approach.

ACTIVITY 5: Communication with children and their families

Communication with children with a life-limiting condition

Like adults, children often have questions about their illness, care and dying. It is important that responses to questions are open, honest and age appropriate. Age appropriate communication with children and adolescents assists with acceptance of their condition, management of symptoms and preparation for dying. Involving adolescents in conversations and in their own care planning creates trust with health professionals. ^[1]

Age, individual developmental stages and possible neurological impairments need to be considered when communicating with children. Communication should be directed at the child though, depending on age, communication about care could also be through parents. Consider all family members who need to be involved when discussing aspects of the child's care. ^[2]

Strategies when talking to children include:

- tailor communication to meet the child's developmental stage ^[3]
- use age appropriate methods of communication such as drawings, books, action based toys ^[4]
- be honest and maintain trust, be clear with responses to questions
- take time to be together and communicate, not just about their illness
- allow children to have a break away from family and carers
- be prepared to listen to and revisit conversations about care. ^[5]

1. Wiener, L., Zadeh, S., Battles, H., Baird, K., Ballard, E., Osherow, J. & Pao, M. (2012). Allowing Adolescents and Young Adults to Plan Their End-of-Life Care. *Pediatrics*, 130(5), 897-905.

2. CareSearch. (2011). *Communicating with Health Professionals*. Retrieved December 6, 2012, from <http://www.caresearch.com.au/caresearch/tabid/1107/Default.aspx>.

3. Zwaanswijk, M., Bates, K., van Dulmen, S., Hoogerbrugge, P.M., Kamps, W.A., Beishuizen, A. & Bensing, J.M. (2011). Communicating with child patients in pediatric oncology consultations: a vignette study on child patients', parents', and survivors' communication preferences. *Psycho-Oncology*, 20(3), 269-277.

4. Rollins, J.A. (2005). Tell me about it: drawing as a communication tool for children with cancer. *Journal of Pediatric Oncology Nursing*, 22(4), 203-221.

5. Turner, J., Clavarino, A., Yates, P., Hargraves, M., Connors, V. & Hausmann, S. (2007). Development of a resource for parents with advanced cancer: What do parents want? *Palliative and Supportive Care*, 5(2), 135-145.

Communication with family

Parents of children with life-limiting conditions report that communication difficulties with health professionals about death are amongst the most stressful situations experienced.^[6] Conversations about care, choices and advanced planning are vital to ensure families are part of the plan of care. When talking with children with a life-limiting condition and their parents together, it can be difficult to assess each person's level of understanding, as neither may want to openly acknowledge how sick the child may be.^[7]

Specific considerations when talking to families around the time of death of a child include:

- plan the conversations in advance, taking into account timing and environment
- assess prior knowledge and what is needed to be discussed
- be clear, concise and empathetic when delivering information about the child's condition
- allow silence and acknowledge emotions
- plan for future meetings or discussions to allow families time to go away and consider the conversation.^[8]

Communication with siblings and friends

The level of understanding of death and dying for children with a life-limiting illness may be different to other children their age. This understanding develops from inclusion in conversations about their illness and management, and their experience of seeing other children they know die.^[7] Age appropriate conversations around death and dying are required for siblings and friends of the child with a life-limiting condition. Often parents and carers are dealing with their own grief. They may require assistance from members of the palliative care team to facilitate such discussions.^[9]

Siblings can benefit from:

- being included in family conversations
- being provided with education about their sibling's condition
- having time allocated to discuss concerns with health professionals
- connecting with support groups or other children who are dealing with similar circumstances
- being shown personal interest in them as individuals
- being encouraged to express emotions such as sadness and anger
- having these feelings and emotions normalised^[10, 11]
- being allowed to spend time with their sibling who is ill
- receiving reassurance about their own health.

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6. Sandler, I. (2004). Parental grief and palliative care require attention. *Pediatric and Adolescent Medicine*, 158(6), 590-591.
 7. Bluebond-Langner, M., Belasco, J. & DeMesquita Wanda, M. (2010). "I want to live, until I don't want to live anymore": Involving children with life threatening and life-shortening illnesses in decision making about care and treatment. *The Nursing Clinics of North America*, 45(3), 329.
 8. Klick, J.C. & Hauer, J. (2010). Pediatric Palliative Care. *Current Problems in Pediatric and Adolescent Health Care*, 40(6), 120-151.
 9. Carlile, M. (2012). Understanding grief and bereavement in the palliative care setting. In M. O'Connor, S. Lee, & S.Aranda, (Eds.) *Palliative care nursing: A guide to practice*, (pp. 271-289), Ascot Vale, VIC: Ausmed Publications.
 10. Abrams, M. (2009). The Well Sibling: Challenges and Possibilities. *American Journal of Psychotherapy*, 63(4), 305-17.
 11. Brown, E., Warr, B. & Smallman, A. (2007). *Supporting the Child and the Family in Paediatric Palliative Care*, London, UK: Jessica Kingsley Publishers.

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

For Emily to be assessed by the general practitioner, she and her mother need to travel approximately 60 km over dirt and bitumen roads. Emily finds this tiring and increases pain and breathlessness that she experiences.

Margaret is a general practitioner who has been caring for Emily since her birth 10 years ago. As with many rural communities, she is acquainted with Emily's family.



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

Service delivery models for children with life-limiting conditions

Paediatric palliative care is a highly specialised area of health care. A collaborative approach to care and decision-making is required to effectively respond to the complex needs of children and their families and enable ongoing support across the illness trajectory and outside of specialist settings.^[1, 2] The transition to palliative care can be an especially difficult time. Coordination of care between acute and palliative care services is very important.

1. Monterosso, L. & De Graves, S. (2012). Paediatric Palliative Care. In M. O'Connor, S. Lee, & S.Aranda, (Eds.) *Palliative care nursing: A guide to practice*, (pp. 355-377), Ascot Vale, VIC: Ausmed Publications.
2. Lyndes, K.A., Fitchett, G., Berlinger, N., Cadge, W., Misasi, J. & Flanagan, E. (2012). A Survey of Chaplains' Roles in Pediatric Palliative Care: Integral Members of the Team. *Journal of Health Care Chaplaincy*, 18(1-2), 74-93.

Shared care models are commonly used in paediatric care. These models highlight the joint role that primary care health professionals and specialist care health professionals play in caring for a child with life-limiting conditions. Shared care models are especially important for children and families living in rural and remote settings. Some strategies that can support a shared care approach include:

- basic
 - communication between professionals through letter and health record forms
- liaison
 - care coordinator liaises between specialist health team and primary health professional
- shared care record card
 - document carried by patient between primary and secondary health professionals
- technology-assisted shared care
 - Personally Controlled Electronic Health (eHealth) Records
 - video-conferencing.^[3]

Coordination of care

Effective coordination of the multiple services and health care providers involved in the child's care is critical.^[4] Key elements of a coordinated service delivery model for children with life-limiting conditions are included in the following table.^[5]

TABLE 2 Coordinated Service Delivery of Care

Integrate service across the continuum of care

- deliver a comprehensive service with a family-centred care approach
- allow families to make informed choices about care of their children
- coordinate and integrate paediatric palliative care services
- focus on delivering care that best meets needs of children and families
- integrate all aspects of care under same goals
- offer interdisciplinary holistic services

Provide appropriate home-based support

- provide infrastructure to give families the option of caring for children at home
- provide access to palliative care services and resources
- ensure adequate respite facilities when required
- recommend appropriate community support organisation

Provide a coordinated, flexible and responsive program

- allow for flexibility of care needs for children and their families, between home, hospital and palliative care service
- promote coordination and continuity of care through a collaborative approach from health professionals and community based palliative care services

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3. Hickman, M., Drummond, N. & Grimshaw, J. (1994). A taxonomy of shared care for chronic disease. *Journal of Public Health Medicine*, 16(4), 447-454.
 4. Stille, C. & Antonelli, R. (2004). Coordination care children special health care needs. *Current Opinion in Pediatrics*, 16, 700-705.
 5. Australian Government Department of Health and Ageing. (2003). *Paediatric Palliative Care Service Model Review Final Report*, Canberra, ACT: Rural Health and Palliative Care Branch, Australian Government Department of Health and Ageing

Improve access to services for rural communities

- identify strategies to overcome isolation that causes problems with accessibility, costs, travel, disruption to home life and more
- recruit and train clinical and non-clinical service providers in rural and remote regions
- facilitate regular telecommunication links with palliative care services for families living rural and remotely
- develop specific strategies to provide support to communities through online and phone services
- paediatric palliative care service may have a 24 hour phone service call point

Improve the interfaces with other related sectors

- strengthen links between paediatric palliative care services and disability and education sectors
- integrate paediatric and adult palliative care services

Provide additional respite care

- offer respite service as an integral component of paediatric palliative care and used to supplement home based care
- allow flexibility and choice in types of respite including, short break respite, external respite for children and adolescents and emergency respite
- provide both in-home respite and out-of-home respite, particularly for families caring for children with high degrees of disability and dependence

Develop and implement educational programs

- assist and provide appropriate education for children and families to understand what palliative care is and how it can assist them
- provide palliative care training and education for generalist workforces, particularly for those in rural and remote areas
- ensure formal training, feedback and a means of challenging current practices of paediatric health professionals in their thinking about paediatric palliative care

Increase professional development

- provide paediatric specific clinical support and professional development opportunities for health professionals working in palliative care

Increase evidence-based research to support clinical best evidence

- support more research in paediatric palliative care

Establish a family advocacy program

- establish effective advocacy programs to ensure the needs of children and their families are identified and addressed within the paediatric palliative care service delivery framework

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.

SECTION 3

Supportive care interventions

In this section you will:

- identify key principles and components of support to children with a life-limiting illness and their families
- reflect upon the importance of individualised education about ongoing management and care of children with a life-limiting illness, their families and communities.

ACTIVITY 8: Supportive approaches to care

Assessment and management of symptoms and quality of life

Symptoms can manifest differently in children when compared to adults. Children may also have different psychological, behavioural and social responses to symptoms. As a child's body grows and develops rapidly, frequent assessment and updating of management strategies is required. Symptoms and the subsequent management can interfere with children's normal development.

Fatigue can impact on a child's ability to socialise and add to their feelings of social isolation.^[1, 2] Management of pain and other symptoms at end of life can impact on the parent's grief and ability to move forward.^[3]

Self-report is recognised as the gold standard when assessing symptoms and quality of life for adults. Children's self-report of their needs and experiences is also important, although the way such assessment is conducted needs to take into account the unique characteristics of the child. The observations of family members and health professionals are integral to identify the child's needs especially where children are too young or unable to communicate effectively how they feel.

^[4] Symptoms that can be experienced by children with life-limiting conditions include:

- pain
- dyspnoea/cough
- fatigue
- poor appetite
- nausea and vomiting
- constipation/diarrhoea
- change in sleeping patterns^[5]
- deteriorating ability to swallow
- fever

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1. Taylor, R.M., Pearce, S., Gibson, F., Fern, L. & Whelan, J. (2013). Developing a conceptual model of teenage and young adult experiences of cancer through meta-synthesis. *International Journal of Nursing Studies*, 50(6), 832-846.
 2. Ruland, C.M., Hamilton, G.A. & Schjødt-Osmo, B. (2009). The Complexity of Symptoms and Problems Experienced in Children with Cancer: A Review of the Literature. *Journal of pain and symptom management*, 37(3), 403-418.
 3. Bruce, M.(2006). A systematic and conceptual review of posttraumatic stress in childhood cancer survivors and their parents. *Clinical Psychology Review*, 26(3), 233-256.
 4. Klassen, A., Anthony, S., Khan, A., Sung, L. & Klaassen, R. (2011). Identifying determinants of quality of life of children with cancer and childhood cancer survivors: a systematic review. *Supportive Care in Cancer*, 19(9), 1275-1287.
 5. Shaw, T.M.(2012). Pediatric Palliative Pain and Symptom Management. *Pediatric Annals*, 41(8), 329-334.

- anxiety
- seizures
- irritability/agitation.

Management of symptoms requires:

- careful assessment
- identification of contributing factors
- tailoring of pharmacological and non-pharmacological strategies to the child's needs
- ongoing evaluation and monitoring.
- pain and symptom management in children with life-limiting conditions is especially complex due to the unique biological, pharmacokinetic, psychosocial, and spiritual factors associated with a person's growth and development. For example, measurement of pain for infants, younger children and children with neurological impairment, is more accurate through non-verbal assessment and through observing changes in their body and behaviour.^[6]
- in older children and adolescents, using a scale to self-report pain can be an effective tool. A systematic review of tools used found the effectiveness of tools depends on the child's age, purpose of using the tool, questions asked and implementation of the tool.^[7]
- children's metabolic rates and physical size require specific dosing protocols for medications and regular review for the pharmaceutical management of pain. Consultation with a specialist pain health professional or paediatric palliative care service is recommended if there is any unfamiliarity in paediatric dosages.^[5]

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

Margaret has organised a case conference via videoconferencing with the Paediatric Cardiology Team and Paediatric Palliative Care Service. Both services are located in a large metropolitan hospital.

The Paediatric Cardiology Team has been involved with Emily's care since her birth. Emily's medical records were sent through to the Paediatric Palliative Care Service prior to the meeting for review.



Emily's case conference

6. Nilsson, S., Finnström, B. & Kokinsky, E.V.A. (2008). The FLACC behavioral scale for procedural pain assessment in children aged 5-16years. *Pediatric Anesthesia*, 18(8), 767-774.
7. Cohen, L.L., Lemanek, K., Blount, R.L., Dahlquist, L.M., Lim, C.S., Palermo, T.M., McKenna, K.D. & Weiss, K.E. (2008). Evidence-based Assessment of Pediatric Pain. *Journal of Pediatric Psychology*, 33(9), 939-955.

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

Psychosocial and spiritual assessment includes assessment of:

- the child's developmental stage
- the child's experience of emotional symptoms
- the effectiveness of communication channels between the child, family and health care team
- practical factors effecting the family, including financial and living situation and social support
- the child's religious or spiritual backgrounds and beliefs. ^[1]

Adolescents have unique support needs as the dynamics involving the adolescent, their family and health professionals change. Psychosocial, hormonal changes, cognitive and physical growth and developmental changes occur in teenagers and adolescents that require unique care and communication. Transitioning adolescents to adult care facilities requires careful planning between adolescents, families and health professional teams. ^[2] Strategies that assist with a successful transition of care to adult centres include:

- health care transition plan in early adolescence
- transition policy agreed upon by members of the health care team
- preparation period and educational program for adolescent and family
- network of palliative care services and youth and adult services
- liaison personal for paediatric and adult services. ^[3]

Children are cared for in a variety of settings including at home, hospice (in some states and territories) and acute care facilities. When children are cared for away from home, parents require unrestricted visiting, clear communication with staff and involvement in decision-making. ^[4]

1. McSherry, M., Kehoe, K., Carroll, J.M., Kang, T.I. & Rourke, M.T. (2007). Psychosocial and Spiritual Needs of Children Living with a Life-Limiting Illness. *Pediatric Clinics of North America*, 54(5), 609-629.

2. Steinbeck, K., Masterson, L. & Sturrock, T. (2007). Adolescent appropriate care in an adult hospital: the use of a youth care plan. *Australian Journal of Advanced Nursing*, 24(3), 49-53.

3. McDonagh, J.E. & Kelly, D.A. (2003). Transitioning care of the pediatric recipient to adult caregivers. *Pediatric Clinics of North America*, 50(6), 1561-1583.

4. Meert, K., Schim, S. & Briller, S. (2011). Parental bereavement needs in the pediatric intensive care unit: review of available measures. *Journal of Palliative Medicine*, 14(8), 951-64.

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

Family structures and households today are diverse. Health professionals need to understand circumstances unique to each family. Parents need to feel they can trust and access the health care team, be able to ask questions and be kept informed about their child's progress.^[1] Parents can also have different perspectives and needs from each other, so it is important to respond to individual needs.

Caring for a child with life-limiting conditions can be physically and emotionally exhausting, often for an extended period of time. Strategies should be offered to assist parents and carers to deal with this level of stress, including:

- psycho-educational programs highlighting the positive aspects of caring
- education for pain and symptom management
- counselling and support group involvement
- behavioural sleep intervention
- involvement in group educational programs
- telephone support service
- psychosocial support^[2]
- educational programs to teach parents and carers how to assist with physical aspects of care
- environmental adaptations and home modifications to assist with care
- respite services
- continued contact with friends, community and interest groups.

Psychosocial support for parents involves recognising the meaning and impact of their impending loss. It also involves engaging with parents about their thoughts and feelings as they provide end of life care to their child. Parents who have lost a child have described valuing health professionals who:

- approached them on a human level
- acknowledged their impending loss
- initiated conversations that enabled parents to share their thoughts and feelings
- if desired, enabled social support from other parents who shared similar experiences.^[3]

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1. Monterosso, L., Kristjanson, L. & Phillips, M. (2009). The supportive and palliative care needs of Australian families of children who die from cancer. *Palliative Medicine*, 23(6), 526-536.
 2. Hudson, P., Remedios, C. & Thomas, K. (2010). A systematic review of psychosocial interventions for family carers of palliative care patients. *BMC Palliative Care*, 9(1), 17.
 3. Forster, E.M. (2012). *Parent and staff perceptions of bereavement support surrounding loss of a child*, Brisbane, QLD: The University of Queensland.

Guilt can be experienced and acting out, attention seeking and becoming withdrawn are behaviours that can be displayed by siblings of children with a life-limiting illness. Stress in siblings can be reduced if they are supported, prepared for their sibling's death and have close family relationships. ^[4]

Grandparents can be a supportive lifeline for families. Strategies to assist grandparents include:

- providing access to education and information regarding their grandchild's condition
- supporting communication between grandparents and their adult children
- referral to support groups or workshops specifically tailored to grandparent perspectives. ^[5]

Respite or short breaks can be beneficial for both children and their families by assisting to prevent carer burden. ^[6] Respite can be provided in the form of direct respite where children are cared for either at or away from home, or indirect respite where support workers assist with domestic chores and babysitting of siblings. ^[7] Respite services for children often meet specific needs such as education, play and social interaction that assists to reach developmental milestones. For adolescents transitioning to adult respite services, extra activities required for development need to be identified.

Community support

Bereaved parents can become quite isolated as other families with children may inadvertently avoid them and avoid discussing the deceased child - sometimes because they don't know what to say. Communities and schools can offer much needed support to families. Communities as a collective can experience grief both privately and publically ^[8], which may require support on a larger scale. Myths and inaccurate information can be passed around a school or community. Leaders and teachers should be supported, with permission from the family. Education and support can assist with developing an appropriate awareness and understanding within a specific community setting. ^[9]

Follow up after a child's death

Parents are at an increased risk of psychological distress and complicated grief following the death of their child. ^[4] As well as careful communication during a child's palliative care, it is useful to arrange professional bereavement follow up after a child's death to allow parents to:

- ask questions
- talk about illness, death, coping
- talk about events around time of death
- discuss post mortem findings if warranted
- discuss further support.

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4. McSherry, M., Kehoe, K., Carroll, J.M., Kang, T.I. & Rourke, M.T. (2007). Psychosocial and Spiritual Needs of Children Living with a Life-Limiting Illness. *Pediatric Clinics of North America*, 54(5), 609-629.
 5. Lee, M. & Gardner, J.E. (2010). Grandparents' Involvement and Support in Families with Children with Disabilities. *Educational Gerontology*, 36(6), 467-499.
 6. Association for Children's Palliative Care (ACT). (2009). *A Guide to the Development of Children's Palliative Care Services*, Bristol, UK: Author.
 7. WA Cancer & Palliative Care Network: Paediatric Palliative Care Reference Group. (2010). *About Respite: information for families, Paediatric Palliative Care Program, Princess Margaret Hospital*. Retrieved January 16, 2012, from www.healthnetworks.health.wa.gov.au/cancer/docs/Respite_Information_for_Families.pdf.
 8. National Association for Loss and Grief (Vic). (2010). *Living with life's losses*, Victoria: National Association for Loss and Grief (Vic) Inc. Retrieved March 22, 2012, from www.nalagvic.org.au/documents/NALAG_LivingwithLifesLosses.pdf.
 9. Holland, J. (2008). How schools can support children who experience loss and death. *British Journal of Guidance & Counselling*, 36(4), 411-424.

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

Emily is now 12 and her health has continued to decline over the past 18 months. Emily's extended family, friends and school community have continued to be supportive.



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

As children with life-limiting conditions are often under the care of health professionals for many years the end-of-life phase and the death of a child can be distressing for health professionals.^[1] An opportunity for family and health professionals to talk in a safe environment can have lasting positive effects.^[2] Self-care strategies are described in PCC4U Module 2. www.pcc4u.org

1. Baverstock, A. & Finlay, F. (2008). What can we learn from the experiences of consultants around the time of a child's death? *Child: Care, Health and Development*, 34(6), 732-739.
2. Bateman, S.T., Dixon, R. & Trozzi, M. (2012). The Wrap-Up: A Unique Forum To Support Pediatric Residents When Faced with the Death of a Child. *Journal of Palliative Medicine*, 15(12), 1329-1334.

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?

SECTION 4

Reflections on what you've learnt

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 conditions 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?



Emily's Story

A3: EMILY'S STORY

▶ 1.34 mins

- Jacob:** You're feeding the dog Ryan.
- Ryan:** No I'm not. I did it last night.
- Jacob:** Yeh, but if you do it last night then you do it in the morning as well.
- Melissa:** Ryan, you're feeding the dog. Jacob, can you get upstairs and clean your teeth and get ready for school as quickly as possible.
- Jacob:** But I've got to eat my breakfast.
- Melissa:** After you've finished your breakfast then okay.
- Melissa:** (to Robert) Emily had a really really bad night last night. She is a lot paler than usual. She's really keen to go to school today but this breathing has got me really worried.
- Robert:** Yeh, you're right, she's not looking too good.
- Robert:** You breathin' a bit hard today Princess?
- Emily nods.
- Melissa:** I am going to have to take her in to town to see the doc.
- Robert:** Okay love, look that heifer's got into Darren's paddock again. You right to take the boys to the school bus?
- Melissa:** Yeh, yeh – of course. See you this arv.
- Robert:** Righto, drive safely. (To Emily) Love ya princess. (To sons) Boys, behave for your mother. Okay? Righto. See you gang. Have a good day.
- Melissa:** Bye.
- Jacob:** See you dad.
- Ryan:** You're feeding the dog.
- Melissa, Emily, Jacob and Ryan in the car.
- Melissa:** OK boys, school bus is here. I'll pick you up at usual time this afternoon. Okay?
- Jacob & Ryan:** Okay, see you mum.
- Melissa:** Be good. See you.
- Melissa:** (to Emily) You alright in the back there darling? It's not going to be long.

Margaret: Hi Emily, come in and have a seat.

Margaret: So Emily, you sound as though you are having trouble breathing today.

Emily: I couldn't sleep last night and it hurts to breathe in too much. I really wanted to go to school today but Mum said I am not allowed to.

Melissa: Emily has been going to school lately but on Monday when she came home she looked so pale and she just wasn't at all herself. By yesterday she was having trouble breathing when she was talking. It's bad, like the last time she was unwell but it just seems to have happened so much faster this time. She is using oxygen like you suggested for when her breathing gets like this and when she uses it she does seem to be a bit better.

Margaret: I am glad to hear that the oxygen has helped. Emily, I see that you used your walker to come in today. Does it help with your breathing when you are walking for longer distances?

Emily: I have to walk slowly and sometimes I feel dizzy.

Margaret: It's good that you have found it helpful. Right, well, I think I'll have a listen to your chest.

Margaret: Emily, it looks and sounds as though your heart is having trouble pumping the blood around your body today, which is why you are having trouble breathing. I'll have a look and see what other medications we can use and I'll speak to Dr Greg from your cardiology team. I think I'll also speak to another team in Brisbane, they work specifically with children, and see if we can help with your shortness of breath. They're called the paediatric palliative care team.

Emily: I know the palliative care team! That's just for old people! Like Grandma in the hospital before she died.

Margaret: Well, palliative care teams work with people of all ages, not just when they are dying. They help you to do the things that matter to you when you are getting more unwell. (Pause) You remember a while ago I spoke with you about how one day your heart might not be strong enough and we might need some additional help to keep you comfortable? Well, Emily we are worried now that you are getting sicker more often and we know that your heart is getting weaker and weaker. Together with the Brisbane team our aim is to keep your heart working as well as it can and to keep you comfortable no matter what....

Melissa: Does this mean we are going to have to drive to Brisbane? I don't think that Emily can handle that drive and Robert is just so busy and then there's the boys and the farm and..

Margaret: No. I can speak with the team in Brisbane by organising a meeting via the computer. Just like everyone's there in the room with you. For now I think it's important that you stay home from school and keep using the oxygen when you need to. I will give you a call after I have spoken to the teams in Brisbane and I'll organise a time for you to speak to Chenoa, she's the nurse with the paediatric palliative care service. She is in a similar role to Hannah but for palliative care instead of cardiac. Chenoa and the doctor with the team are incredibly knowledgeable and they love working with kids. I think you will find them to be a great help and you can ask them any questions you may have. (Pauses) I know this is a lot to take in....but,well...how do you feel about this as a plan?

Melissa & Emily: Okay.

Melissa and Emily in car.

Melissa: We should just make it in time to pick up your brothers.

Hannah: Can you hear me Margaret?

Margaret: Oh hello, there you are! Well done Hannah. Can everyone see and hear us all the way out there?

Hannah: We can hear you loud and clear.

Margaret: Hi everyone, and our thanks for agreeing to meet with myself, Di, our Director of Nursing, and Alan from the Royal Flying Doctor Service to discuss Emily's case today. I'm very keen to hear any suggestions you may have about Emily's management and ongoing care.

Hannah: Good morning Margaret. I believe you know Greg and Ben from the Paediatric Cardiology team.

Greg & Ben: Hello.

Margaret: Yes hello again!

Hannah: And I'd like to introduce you to Chenoa from the Paediatric Palliative Care Service.

Chenoa: Thanks Hannah. With me here today is Amanda our Paediatric Palliative Consultant and Tuyen, our Social Worker.

Amanda: Hello.

Chenoa: Amanda would you like to take it from here?

Amanda: Hi Margaret, I am sorry to hear that Emily is unable to have more surgery and that she is not able to have a heart transplant. As you know, our team would like to work with you and the cardiology team to give her the best quality of life we can, and also to support the family as much as we can. One area we'd like to focus on is pain management and other symptoms. Are any of these an issue for Emily?

Margaret: She is having increasing difficulty breathing.

Amanda: I see here that Emily already uses oxygen at home when she is breathless. Does Emily also have a portable oxygen cylinder that she can use when she is away from the house?

Margaret: Well, Emily had an exacerbation of her condition about 6 months ago, which is when we first ordered the oxygen. Her breathlessness seemed to settle down for quite a few months after that. I was surprised at how soon it is now since her last episode. She has recommenced using the oxygen this week with moderate effectiveness. I would like to organise a mobile oxygen cylinder, because they mentioned on their visit that it helps Emily when she uses oxygen. She has two large standing cylinders because they live out of town and often rely on a generator or solar power.

I know Emily is keen to get back to school to see her friends. It would be helpful for the palliative care team to connect with school about the care of the oxygen equipment.

Tuyen: What about Emily's parents? How are they coping with things?

Margaret: Emily's parents own a large cattle property out of town. Robert works 7 days a week on the property and Melissa has had to get a job in town 2 days a week to help them financially. They also have two other children, Jacob and Ryan who are 6 and 8 years old. They can be a bit of a handful.

Emily has had quite a bit of time away from school lately and I know that Melissa has been helping with her school work as well. When they came in yesterday, Melissa looked tired and physically run down. To be honest I don't know how Dad is coping. I never see him and I rarely get the chance to ask Melissa when she brings Emily in to see me...even how she is managing all of this to be honest. I would really like to assess this properly and see if we can provide some support financially as well as emotionally.

Tuyen: Margaret, I will talk to Chenoa and Hannah. We will discuss what further assistance and financial support might be available. It is often what we see; as you describe, the dad is busy trying to financially support the family and it can be difficult to get his perspective. We can connect with them at home with an adult's only conversation to explore some of their shared and individual concerns.

Amanda: Margaret, have you had a conversation with Emily and her family that her condition will deteriorate? I realize this can be difficult to do and she may have periods of stability but it is likely they will see a steady decline. The time frame we are dealing with in terms of life expectancy is still uncertain.

As you know with complex heart disease, it is possible that Emily could have a cardiac episode or even an infection such as influenza within the next 12 months and not recover. It will be important now to manage both her physical symptoms, such as pain and shortness of breath, as well as provide practical and emotional support.

It would also be a good idea to discuss a plan about what to do if Emily should have a sudden deterioration. This could include a sudden worsening of her symptoms, as well as an arrhythmia, which could cause a very sudden decline and possibly even sudden death. We have developed a resuscitation plan to assist with this discussion, and would be happy to share this with you. Again, I acknowledge this will be a very tough series of conversations for you to have with the family.

Margaret: Yes, it is a very difficult time. I mentioned to Emily and Melissa that I would be including the paediatric palliative care service in her care and explained what that means. Emily was upset by this. I explained to her what you do as a service. I haven't spoken to them directly about Emily's condition deteriorating and what that may include but I am sure they are very aware of it. I have found it hard to discuss. I am not really sure what to say to them. From the things that Emily has been saying recently, I think she knows she is going to die but doesn't seem to want to talk about it in front of her mum. I get the same feeling that Melissa doesn't want to admit it in front of Emily.

Chenoa: Yes it is hard to discuss but it is an important conversation to have. It is actually not uncommon for parents or children to understand the seriousness of the illness and know that death will happen, but they just don't like discussing it. We will set up a family meeting on line with you, Emily and Melissa. We would like it if you could organise it so that Robert can be involved as well and then we can all sit together and discuss what is likely to happen and what steps to take.

Margaret: Well that sounds like a great approach and I'm sure we all look forward to meeting and planning together again soon...

A12: EMILY'S PROGRESSION

▶ 1.02 mins

Emily: Mum, have a look at the funny email that Chenoa sent me for my birthday.

Melissa: Well you don't turn twelve every day, do you? That is a funny birthday message. When you reply to Chenoa, tell her thank you and that we have spoken to your teacher and we've organised for you to visit your school friends tomorrow. You can go in your wheelchair and we will attach the portable oxygen.

Emily: Mum, there was also a birthday card from Pop today. Do you think Grandma is looking down from her star and wishing me a happy birthday too?

Melissa: I am sure she is darling.

Emily: Go away brats!