

PSYCHOLOGY WORKS Fact Sheet: Pediatric Palliative Care

What is Pediatric Palliative Care?

Pediatric palliative care is an active and comprehensive care approach embracing physical, emotional, social, and spiritual well-being. It focuses on enhancing the quality of life for a child or adolescent and their entire family throughout the course of a life-limiting or life-threatening illness. Life-limiting or life-threatening illnesses can be broadly divided into four categories: diagnoses which are life-threatening in nature and curative treatments may or may not be effective (e.g., cancer), diseases with a high likelihood of premature death (e.g., cystic fibrosis), chronic progressive illnesses without a cure (e.g., Batten disease), and diseases that are irreversible but non-progressive which have complications likely to lead to premature death (e.g., severe cerebral palsy). Different from end-of-life care and hospice services, pediatric palliative care is a more broad-ranging service which can be accessed from the time a child receives a relevant diagnosis. It can therefore be utilized throughout a child or adolescent's life journey including alongside curative or life-prolonging approaches as well as with end-of-life care or hospice should a condition progress and death become imminent.

Palliative care is often provided through an interdisciplinary team, which may include a number of professionals such as physicians, nurse practitioners, social workers, pharmacists, and psychologists. This approach can help to mitigate gaps in care while addressing a number of symptoms common for children and adolescents with life-limiting and life-threatening illnesses. Supports may be related (and are not limited) to: effective communication, psychological well-being, spiritual care, decision making, comprehensive pain and symptom control, and grief and bereavement support.

What is Psychology's Role in Pediatric Palliative Care?

The journey with a life-limiting or life-threatening illness can be long, complex, and challenging for the child or adolescent as well as their family. The stress or trauma of the situation can have many impacts on one's well-being, such as increased tension, strained relationships, and increased emotional vulnerability. Psychologists can help address a number of child or adolescent and family needs and goals, ultimately aiming to improve the quality of life of children and adolescents with a life-limiting or life-threatening condition and their families. For example, they may help children and adolescents and their families with:

- Promoting coping skills and adjustment to a diagnosis and related emotions
- Treatment of co-occurring mood, anxiety, and trauma- and stressor-related disorders
- Supporting children, adolescents, and families in a more structured way to problem solve and make difficult decisions
- Talking to children, adolescents, and families about death and related beliefs and wishes
- Supporting children and adolescents' ability to communicate their beliefs and wishes to their families and other members of their interdisciplinary care teams, and assisting them in asking any questions that will support their journey



- Managing pain (e.g., through imagery or relaxation techniques)
- Providing parenting guidance and education related to parenting a child or adolescent with a life-limiting or life-threatening condition, or parenting siblings
- Preparing for the child or adolescent's death (e.g., anticipatory grief, completing meaningful activities related to their loved one)
- Coping with loss, grief, bereavement for parents and siblings

In these situations, psychologists use a variety of therapies such as:

- Cognitive and behavioural therapy, which may help to challenge or alter maladaptive patterns of thinking and behaving, promote healthy and adaptive ways of thinking and behaving, and foster effective coping strategies
- Relaxation therapies, which may help to reduce arousal and improve sleep
- Interpersonal therapy, which may help individuals examine and better cope with relational difficulties
- Existential therapy, which may help the individual to explore their sense of being-in-the-world, increase their self-awareness, and find meaning in their life

The therapeutic approach will vary depending on the individual person, family, and their needs or goals.

Developmental Considerations in Pediatric Palliative Care

Children and adolescents are in a process of physical, emotional, cognitive, and spiritual development. Depending on their developmental stage, they have different skills and different emotional, physical, and developmental needs. A child or adolescent's cognitive development and age can also impact their understanding of concepts such as their illness, prognosis, emotional experiences, and death. It is therefore important to recognize the unique issues and needs arising within the context of palliative care of children and adolescents.

- Children and adolescents communicate differently and depending on their stage of development, have a different understanding of illness, death, and dying. A child or adolescent's concept of illness and dying continues to evolve over time and is influenced by many factors (e.g., religion, cultural beliefs, patterns of coping, disease experience, previous experience with loss or death, and emotions associated with grief).
- Children and adolescents are members of many communities, including families, neighbourhoods, and schools. Their continuing role in these communities should be incorporated into their life journey despite their condition. Some life-limiting or life-threatening illnesses may require that children miss out on typical childhood experiences and aspects of development. For example, these children may spend more time with adults compared to their peers. It is essential, as much as possible, that they have ongoing opportunities to participate in normative academic and social interactions with their peers.
- Children and adolescents are often less able to advocate for themselves and often rely on family members to make decisions on their behalf.



You can consult with a registered psychologist to find out if psychological interventions might be of help to you. Provincial, territorial, and some municipal associations of psychology may make available a referral list of practicing psychologists that can be searched for appropriate services. For the names and coordinates of provincial and territorial associations of psychology, go to <https://cpa.ca/public/whatisapyschologist/PTassociations/>.

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Your opinion matters! Please contact us with any questions or comments about any of the **PSYCHOLOGY WORKS** Fact Sheets: factsheets@cpa.ca

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