



"Psychology Works" Fact Sheet: Paediatric Palliative Care

What is Paediatric Palliative Care?

Paediatric palliative care focuses on the provision of active and total care (embracing physical, emotional, social, and spiritual elements) to children living with life-limiting or life-threatening illnesses. It focuses on enhancing the quality of life for the child and entire family throughout the child's illness and life journey. Palliative care goals and life-prolonging goals can be pursued simultaneously. When a child dies from a sudden or prolonged illness, bereaved parents and siblings benefit from continued emotional support.

How can psychology help?

Child psychologists receive specialized training in understanding a child's normal development. Because children and adolescents are in the process of physical, emotional, cognitive, and spiritual development, their understanding of illness, death and dying will depend on their developmental age. Psychologists can complement palliative care services for children by facilitating discussions with the child about their illness and prognosis, treating emotional symptoms, and improving overall quality of life.

Attention to the family is also an essential aspect of supportive care when the patient is a child. Caring for a child with a life-threatening illness is a complex and emotionally difficult challenge that impacts the well-being of all family members. Bereaved parents are at risk of developing a more severe, complex, or prolonged form of grief that impairs functioning. Psychologists can also help provide support and treatment for siblings and parents who are anticipating this loss or are grieving it afterwards.

What psychological treatments are effective?

Psychologists can provide individual, family, or group psychotherapy to address a number of end-of-life and bereavement issues that arise for the child, parents or siblings. They can help in the following ways:

Promoting Coping Skills and Adjustment. Psychology can help the child and family to cope with distress and a range of difficult emotions (e.g., fear, anger, anxiety, depression, grief, helplessness, and hopelessness). The intense physical, emotional, social, and economic demands placed on a family caring for a child at home, or during prolonged and/or repeated hospitalizations, can be extremely stressful. The stress and trauma of the situation often increase tension and emotional vulnerability. Siblings often feel on the "side lines" during the child's illness and may act out behaviourally or may internalize strong emotions (e.g., sadness, anger, and jealousy). Encouraging individual family members to seek support outside of the family circle can ease this burden and strengthen the family's individual members, who can then be more available, emotionally and physically, for one another.



Treatment of Mood and Anxiety Disorders. Psychologists can provide empirically supported treatments for disorders that commonly arise secondary to experiencing a life-limiting illness. The psychological support provided to parents prior to and following the death has been linked to the healthy adaptation for families mourning the death. Psychologists can provide a variety of helpful therapies:

- Relaxation Therapies may help to reduce anticipatory anxiety, pain and improve sleep.
- Cognitive and/or Behavioural Therapy may help to challenge or alter maladaptive patterns of thinking and behaving, to improve mood, promote healthy and adaptive ways of thinking and behaving, and to foster effective coping strategies.
- Interpersonal Therapy may help individuals to examine social factors and current difficulties in their relationships. Interpersonal Therapy may assist the individual/family to communicate their needs and emotions more effectively within current relationships.

Talking to Children about Death. Psychologists can work with parents on how to talk with their children about death and dying. A variety of communication strategies can be used to talk to children about death and facilitate the understanding of death in an age-appropriate manner. In addition, psychology can support families to examine family beliefs about death and dying.

Making Difficult Decisions. Psychology can provide support and assistance with problem solving around practical concerns (e.g., financial issues, household functioning, and supporting loved ones). Some psychological interventions involve structured assistance in setting priorities, breaking problems down into manageable parts, and identifying (and implementing) possible solutions. This structured assistance may be useful when making difficult decisions regarding medical treatment (e.g., foregoing potentially life-sustaining treatments, implementing a DNR order, ending life support).

Parenting Skills Enhancement. Parents often benefit from specific behavioral strategies and tools to address the special needs of a child with a life-threatening condition. Such interventions also may be useful with siblings who are showing signs of behavioral maladjustment.

Preparing for the Child's Death. The family may benefit from psychological support regarding anticipatory grief when the child's death is inevitable. Additionally, psychology can be involved in assisting the child and family to prepare for death by participating in rites and rituals that are important to the family, and/or in life closure, gift giving, legacies, and other meaningful activities.

Complicated Grief Therapy. Parents who experience the death of a child may be at risk of experiencing a form of grief that is more severe, prolonged, and debilitating due to the nature of this loss. Specialized grief therapy can target symptoms that resemble depression or post-traumatic stress disorder. Among the aims is to help facilitate a transformational process that often involves a re-evaluation of self, life priorities, and relationships in order to move forward in life in a meaningful way without their deceased child. Surviving siblings may also have a variety of psychosocial difficulties after the death (e.g., feelings of isolation, guilt, sleep problems, separation anxiety). It often is helpful for surviving siblings to have support in adjusting to their new family role and in dealing with their grief.



Where do I go for more information?

For Parents:

When Your Child Dies. Tools for Mending Parents' Broken Hearts. Avril Negel and Randie Clark. New Horizon Press, 2012.

Preparing the Children. Information and Ideas for Families Facing Serious Illness and Death, Revised Edition. Kathy Nussbaum, Gifts of Hope, 2012.

For Young Children (explaining death):

Waterbugs and Dragonflies. Doris Stickney. Pilgrim Press, 1997.

Gentle Willow. A Story for Children about Dying. Joyce Mills. Magination Press, 2004.

Adolescents:

Healing your grieving heart for teens. Alan Wolfelt. Companion Press, 2001.

Helping teens cope with death. The Dougy Center, National Center for Grieving Children & Families, 2004.

For Professionals:

CBT for Chronic Illness and Palliative Care: A Workbook and Toolkit. Sage, Sowden, Chorlton, and Edeleanu. John Wiley and Sons Ltd, 2008.

Complicated Grief: Scientific Foundations for Health Care Professionals. Stroebe, Schut, and VanDen Bout. Routledge, 2013.

Parenting after the Death of a Child: A Practitioner's Guide. Buckle and Fleming. Routledge, 2011.

This fact sheet has been prepared for the Canadian Psychological Association by Danielle Cataudella, Psy.D., C. Psych; and Cathy Maan, Ph.D., C. Psych.

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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

Canadian Psychological Association
141 Laurier Avenue West, Suite 702
Ottawa, Ontario K1P 5J3
Tel: 613-237-2144
Toll free (in Canada): 1-888-472-0657