

Facts & Resources: Pediatric Palliative, End-of-Life, and Bereavement Care

Overview

According to a landmark report from the Institute of Medicine, the goal for children and families facing life-threatening disease should be to create a healthcare system “that people can trust to provide competent, consistent, and compassionate care...and that families can count on for support and solace as they experience a loved one’s grave illness or death.”¹ Coping with experiences at the end of life are even more difficult when the patient is a child or young person. Some of the factors that make it harder include:

- Children’s developmental levels change over time, even if a young person is seriously ill. As a child’s intellectual, emotional and social skills develop, it is important to change the types of support and ways care providers communicate with the child and family.
- Families frequently need to travel far from home for treatment, removing patients and families from normal support networks. Long stays away from home disrupt the child’s school and parents’ employment, taking a toll on family relationships, siblings and other loved ones. A family’s financial situation can be affected adding to the difficulties of the situation.
- Medical decisions for children are made by adults. Poor communication, guilt and expectations of other people often cause adults to make healthcare choices focused only on prolonging life at all costs without considering the quality of life and options for comfort-oriented care.
- There continue to be misunderstandings among healthcare professionals, policy makers and the general public that palliative care is only useful when all efforts for a cure are unsuccessful.
- It is difficult to talk about children dying. Physicians, nurses and other care professionals often wait too long before having these important discussions with children and their families. This delay often prevents children and families from receiving beneficial palliative care and hospice services that could improve their quality of life.

What type of care might be best?

Palliative care, also known as comfort care, should begin immediately when any child receives a diagnosis of a life-threatening condition. Palliative care should continue throughout treatment and all the way through the end of life.

The goals of palliative care are to:

- Minimize the pain from a life-threatening disease, like cancer, and make the person as comfortable as possible at all times
- Provide care and support for the physical, emotional, developmental, spiritual and practical needs of a patient and family

End-of-life care focuses on the special needs a patient and family have when facing death. It's important to educate families about options for care and help them make informed decisions. This special kind of care may be provided by a hospice or special care program.

Shared decision-making makes sure that healthcare providers fully inform and involve parents in decisions that must be made. Communication between families and care providers must be understandable and culturally sensitive. The patient should be involved to whatever extent possible.

Bereavement care provides the family with a coordinated program involving professionals, volunteers, family and community support systems that meets their needs. In the days, months, and years following a child's death, physicians, nurses, social workers and hospice staff can stay meaningfully involved with the family. Abruptly ending contact with grieving families may feel like abandonment.

How do cultural issues impact care?

Ethnic and cultural factors can have a strong influence on the way a patient and family reacts to cancer and other life-threatening illnesses. It's especially important to pay attention to the values, spiritual traditions, customs and relationships in a family facing the end of a child's life. Culturally competent care includes awareness of and respect for the many aspects of cultural diversity such as:

- Definition of "family" (nuclear, extended, families of choice)
- Views of gender roles and child-rearing practices
- Communication patterns (such as direct versus indirect and the role of nonverbal communication) cultural influences on advance care planning, treatment choices and disclosure
- Religious and spiritual belief systems
- Ideas about physician authority
- Views of suffering and the afterlife

How can we help siblings cope?

When a brother or sister dies, the surviving siblings may suffer from low self esteem, school problems, feelings of isolation, anxiety, depression and anger, as well as other problems that will come up later in life. It's important to provide siblings with grief support throughout the course of an illness and following the death of a loved one.

Offering such support to children may help them avoid serious mental health issues later in life. Specific ways to help a child deal with the chronic illness or death of a sibling include:

- Be honest and provide siblings with information that is truthful
- Involve youngsters in caring for their ill sibling
- Offer social support through therapy, support groups, camps, and other ways that allow children to express their feelings

Resources for Pediatric End-of-Life and Bereavement Care

**Indicates organizations serving as national partners to the ITVS Community Engagement Campaign for A LION IN THE HOUSE*

Bereaved Parents Self-Help Group, <http://www.bereavedparentsusa.org>

Bereaved Parents of the USA (BP/USA) is a national non-profit self-help group that offers support, understanding, compassion and hope to bereaved parents, grandparents and siblings struggling to rebuild their lives after the death of their children, grandchildren or siblings.

Caring Connections, <http://www.caringinfo.org>

Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO), is a national consumer engagement initiative to improve care at the end of life, supported by a grant from The Robert Wood Johnson Foundation. Caring Connections provides free resources to the general public on a range of topics.

Children's Hospice International, <http://www.chionline.org>

Children's Hospice International (CHI), a non-profit organization, was founded in 1983. CHI provides education, training and technical assistance to those who care for children with life-threatening conditions and their families.

Compassionate Friends Self-Help Group, <http://www.compassionatefriends.org>

The mission of The Compassionate Friends is to assist families toward the positive resolution of grief following the death of a child of any age and to provide information to help others be supportive.

Education in Palliative & End of Life Care, <http://www.epec.net/EPEC/webpages/index.cfm>

The Education in Palliative & End of Life Care (EPEC) Project mission is to educate all healthcare professionals on the essential clinical competencies in palliative care.

End of Life Nursing Education Consortium, <http://www.aacn.nche.edu/ELNEC/>

The End-of-Life Nursing Education Consortium (ELNEC) is a national education initiative to improve end-of-life care in the United States. The project provides training for undergraduate and graduate nursing faculty, CE providers, staff development educators, pediatric and oncology-specialty nurses, and other nurses in end-of-life care so they can teach this essential information to nursing students and practicing nurses.

Growth House, <http://www.growthhouse.org>

Growth House, Inc. provides an award-winning portal as an international gateway to resources for life-threatening illness and end of life care. Their primary mission is to improve the quality of compassionate care for people who are dying through public education and global professional collaboration. The search engine gives you access to the Internet's most comprehensive collection of reviewed resources for end-of-life care.

Healing the Loss, <http://www.griefsong.com>

GRIEFSONG offers a unique area where you can share titles and lyrics of songs that have touched you or strengthened you and even your original lyrics and poetry that speaks of the connections to your loved one.

Hospice and Palliative Nurses Association, <http://www.hpna.org>

Established in 1986, the Hospice and Palliative Nurses Association (HPNA) is the nation's largest and oldest professional nursing organization dedicated to promoting excellence in pain management and end-of-life care.

Initiative for Pediatric Palliative Care, <http://www.ippcweb.org>

The Initiative for Pediatric Palliative Care (IPPC) is both an education and a quality improvement effort, aimed at enhancing family-centered care for children living with life-threatening conditions. IPPC's comprehensive, interdisciplinary curriculum addresses knowledge, attitudes and skills that health care professionals need in order to better serve children and families.

KIDSAID (2 Kids, 4 Kids, By Kids), <http://www.kidsaid.com>

KIDSAID is a safe place for kids to share and to help each other deal with grief about any of their losses. It's a place to share and deal with feelings, to show artwork and stories, to talk about pets and to meet with one's peers.

Parent Online Resource Guide, <http://www.PartnershipForParents.org>

PartnershipForParents.org is a national website for parents of seriously ill children sponsored by the Children's Hospice and Palliative Care Coalition. The website offers practical information, resources and support for parents whose children are receiving

A Lion in the House

a film by Steven Bognar and Julia Reichert

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curative treatment, palliative or end-of-life care. The site also includes information for families grieving the loss of a child.

***The National Center of Medical Home Initiatives,** <http://www.medicalhomeinfo.org>

The National Center of Medical Home Initiatives for Children with Special Needs provides support to physicians, families, and other medical and non-medical providers who care for children with special needs so that they have access to a medical home.

***The National Hospice and Palliative Care Organization,** www.nhpco.org

The National Hospice and Palliative Care Organization (NHPCO) is the largest nonprofit organization representing hospice and palliative care programs and professionals in the United States. The organization is committed to improving end-of-life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people dying in America and their loved ones.

¹ When Children Die: Improving Palliative and End of Life Care for Children and their Families, Institute of Medicine, Editors: Marilyn Field and Richard, National Academies Press, 2003. **Read or purchase the report at**

<http://www.iom.edu/CMS/3740/4483.aspx>

Although dying is a part of life, a child's death, in a very real sense, is unnatural and has a devastating and enduring impact. Over the past century such deaths have been significantly reduced by socioeconomic, public health, and medical advances in developed countries such as the United States. Nonetheless, over 50,000 children die each year.

This facts and resources sheet about Pediatric End of Life and Bereavement Care is a resource produced by the ITVS Community Engagement Campaign for A LION IN THE HOUSE, a documentary series coming to public television on PBS/Independent Lens, June 21st & 22nd, 2006. The Campaign offers organizations, individuals and public television station partners opportunities to get involved in events that will: strengthen local care networks, educate the community, and increase local capacity to address the needs of patients and families, especially in overcoming barriers to care for underserved populations. Learn more about what's going on in your community and how to get connected.

For more information: www.itvs.org/outreach/lioninthehouse

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