



PALLIATIVE CARE FACT SHEET

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The term Pediatric Palliative Care can provide confusion for many families. Often when we hear the term palliation in pediatrics our first thoughts turn to cancer. However, palliative medicine principles are increasingly becoming an integral part of the care provided to children living with a variety of life-threatening illness. Traditionally physicians waited until a child was no longer appropriate for curative therapy i.e. “dying” before introducing palliative care. However, children with complex life-threatening illness are at risk of premature death. Determining when such a child may die is extremely unpredictable. It is not practical to view initiation of palliative services based on “time to death.” The American Academy of Pediatrics and the World Health Organization have advocated a more integrated view of palliative care “in which components of palliative care are offered at diagnosis and continued throughout the course of illness, whether the outcome ends in cure or death.”

Pediatric Palliative Care can be viewed as both a philosophy of care and an organized program for delivering care to children with life-threatening conditions. Although most associate palliative care with issues surrounding the end of life, the intent of palliative care is to assist a child and family to live to the fullest extent possible. It seeks to fill the gaps in care which arise during the course of caring for children with a complex life-threatening illness. This care focuses on enhancing quality of life for the child and family, minimizing suffering, optimizing function, and providing timely and accurate information regarding the disease.

The central element of Pediatric Palliative Care is the recognition that the child and the family are the unit of care. An emphasis on symptom management (pain, irritability, nausea, etc.) is coupled with psychosocial and spiritual support for the child/family. Palliative care hopes to promote clear and culturally sensitive communication between the child, family and their primary care givers to assist the families in understanding the diagnosis, prognosis and benefits/burdens of treatment options. Goals for care, as defined by the child and family, are outlined and communicated to all care providers. There exists a need to anticipate the course of the illness and plan for changes in health status. The child’s developmental and decision-making capacity is assessed and an opportunity is afforded for the child to share in decision making and care planning with the family and physician. Most importantly, palliative care includes a clearly identified team member responsible for coordinating care and assuring that changing needs and goals of the child and family are met. Respite and bereavement care remain the final pieces of palliative care.

Ask your primary care physician and/or neurologist about pediatric palliative care teams in your geographic area.

Internet resources for Pediatric Palliative Care:

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

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

Children's Project on Palliative/Hospice Services (ChiPPS):
<http://www.nhpco.org/i4a/pages/index.cfm?pageid=3409>

The Association for Children with Life-Threatening or Terminal Conditions and their Families:
<http://www.act.org.uk/act/start.asp>

The Canadian Network of Palliative Care for Children: <http://cnpcc.ca/>

National Public Radio program on Pediatric Palliative Care aired on August 9, 2006 which can be accessed at <http://www.npr.org>
Search pediatric palliative care.

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