



Precepts of Palliative Care for Children, Adolescents and Their Families



**National
Association of
Neonatal
Nurses**



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*A national coalition to improve
care and caring near the end of life*

Palliative care for children* and their families involves the comprehensive management of physical, psychological, social, spiritual and existential needs. It is a suitable approach to care for children who are born with serious medical conditions as well as those who develop such illnesses at a later stage of childhood or adolescence. Although palliative care may be an appropriate part of the treatment of any complex or serious illness or injury, it is vital in the care of life-threatening and incurable progressive conditions.

Palliative care affirms life and regards dying as a process that is a profoundly personal experience for the child and family. Palliative care is family-centered, with the goal of achieving the best possible quality of life and relief of suffering—physical, psychological, social, emotional and spiritual. Palliative care focuses on the control of symptoms and restoration of functional capacity while remaining sensitive to personal, family, cultural and religious values, beliefs and practices. Because the death of a child is considered premature and untimely, life-threatening illness and death are rarely expected for a child and are devastating and life-altering events for the family. As a society, we often do not know how to respond to the death of a child and therefore have few established social norms to help a family cope with the loss of a child.

Palliative care can coexist with potentially curative or life-extending modes of treatment based on the identified goals of care. The intensity and range of palliative interventions may increase as illness progresses and the complexity of care and needs of the child and family increase. At the same time, services and guidance are offered to families to help them make decisions regarding possible goals of care, treatment options and settings for care.

The medical, developmental and psychosocial needs of the seriously ill child are often fundamentally differ-

ent from those of adults with the same or similar diagnoses; the illness trajectory is more unpredictable and the impact on the family is more intense and broader in scope. Also, decision-making involves the parent or guardian as surrogate and often takes place under conditions of uncertainty. As a result, treatment plans for children are more likely to include continuation of potentially life-prolonging interventions such as chemotherapy, nutritional support, radiation and administration of blood products.

Palliative care requires an interdisciplinary team working as an integrated unit that includes physicians, nurses, psychologists, developmental specialists, child life specialists, pharmacists, pastoral caregivers, social workers, ancillary staff, volunteers and family members. Palliative care has become an area of special expertise within many disciplines. However, advances in palliative care have not yet been integrated effectively into standard pediatric and adolescent clinical practice. Therefore, the precepts of palliation should be a basic component of the attitudes, knowledge base and practice skills of all health care professionals. To achieve this, the principles, goals, core knowledge and skills of palliative care must be included in the initial education and training of physicians, nurses, social workers and other health professionals, as well as within their continuing education programs.

*Throughout the rest of this document, we use the term “children” to encompass birth to adolescence.



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Respecting Patient Goals, Preferences, and Choices

Palliative Care:

- Emphasizes family-centered care and addresses the child's needs in the context of the child's physical condition, developmental stage, family and community.
- Recognizes that the family constellation is defined by the child, the family, and their culture and beliefs, and encourages child and family involvement in planning and providing care.
- Identifies and honors the preferences of the child and family through careful attention to their values, goals and priorities as well as their cultural and spiritual perspectives.
- Assists the child and family in establishing goals of care by facilitating their understanding of the diagnosis and prognosis, clarifying priorities and providing an opportunity to collaborate with providers on the creation of a care plan. This process takes into account the child's developmental stage, chronological age and the family's wishes.
- Respects the roles of parent or surrogate by presenting a model of shared decision-making.
- Strives to meet the child's and family's preferences about care settings, living situations and services, recognizing the uniqueness of these preferences and

assisting the family to work through any barriers to achieving their goals.

- Encourages advance care planning through ongoing dialogue among health care professionals, the child and family.

Comprehensive Caring

Palliative Care:

- Responds to the inherent human suffering and grief associated with living with serious illness and life-threatening conditions.
- Appreciates differences among children and families regarding the meaning of their experience; for some children and families, this experience can be a period for inner growth.
- Places a high priority on physical comfort and functional capacity, including, but not limited to, expert management of pain and other symptoms, diagnosis and treatment of psychological and spiritual distress, and assistance in remaining as independent as possible, if so desired.
- Provides comprehensive interventions and support to help the child and family adapt to living with serious illness and/or life-threatening conditions.
- Alleviates isolation through a commitment to non-abandonment, ongoing communication and sustaining relationships.
- Assists with reaffirmation of the child's life and the parents' role in that life as well as helping to bring about completion and closure within the context of family culture and values.
- Extends support beyond the life span of the child to assist the family and others in their bereavement through ongoing support, guidance and remembrance.

Using the Strengths of Interdisciplinary Resources

Palliative Care:

- Requires an interdisciplinary team of knowledgeable, skilled and experienced pediatric health care professionals, who are provided the opportunity for ongoing education, professional support and development.
- Includes a clearly identified, accessible and accountable individual or team responsible for coordinating care to ensure that changing needs and goals are met and to facilitate continuity of care and ongoing communication among team members, the child and the family.
- Incorporates the full array of interinstitutional and community resources (e.g., schools, hospitals, home care, hospice) and promotes a seamless transition between institutions/settings and services.
- Determines what services are available for the child and family and that the hospice/palliative care staff are knowledgeable about the unique needs of the seriously ill child and the family.

Acknowledging and Addressing Caregiver Concerns

Palliative Care:

- Recognizes that the well-being of seriously ill or injured children and that of their family caregivers are intertwined.
- Appreciates the substantial physical, emotional and economic demands placed on a family caring for the child at home, or during prolonged and/or repeated hospitalizations as they attempt to fulfill caregiving responsibilities and to meet the entire family's needs.
- Provides concrete supportive services to caregivers such as respite care, and around-the-clock availability of expert advice and support by telephone, grief counseling, personal care assistance and referral to community resources.
- Anticipates that some family caregivers may be at high risk for fatigue, physical illness and emotional distress and considers the special needs of these caregivers in planning and delivering services.
- Recognizes and addresses the economic costs of caregiving including loss of income and non-reimbursable expenses.
- Acknowledges that family grief begins during the child's illness and continues after a child dies.



Building Systems and Mechanisms of Support

Palliative Care:

- Requires an environment that supports innovation, research, education and dissemination of best practices and models of care.
- Needs an infrastructure that promotes the philosophy and practice of pediatric palliative care.
- Relies on the formulation of responsible policies and regulations by institutions and by state and federal governments.
- Promotes equitable and timely access to the full array of interdisciplinary services necessary to meet the multidimensional needs of patients and their caregivers.
- Demands ongoing evaluation including the development of evidence-based standards, guidelines and outcome measures.
- Assures that mechanisms are in place at all levels (e.g., systems, direct care services) to guarantee accountability in the provision of care.
- Requires appropriate financing including the development of new methods of reimbursement within the context of a changing health care financing system.



This document was adapted from the Precepts of Palliative Care, originally developed by the *Last Acts* Palliative Care Task Force in December 1997. The following individuals reviewed or contributed to the creation of this version for a pediatric professional audience:

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