



## Talking Points: Pediatric Palliative Care & PCHETA

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The goal of pediatric palliative care is to optimize quality of life and well being of children with life-threatening illnesses and their families by anticipating, preventing, and treating suffering in all its forms. When a child is diagnosed with a serious illness, the entire family is affected, so pediatric palliative care also includes a focus on the well-being of the siblings and parents. Delivered throughout the continuum of illness, palliative care addresses physical, intellectual, emotional, social and spiritual needs. These services are available concurrently with, or independent of, curative and life-prolonging care and other medical services.

There is growing evidence to suggest palliative care increases patient and family satisfaction, improves symptom control, enhances quality of life for patients and families, reduces the burden of care felt by parents, decreases health care utilization, lengthens survival, maximizes (leverages) health care dollars, and can help prevent parent regret in the years that follow the child's death.

### **Pediatric Palliative Care Improves Quality of Life and Quality of Care for Children and Families**

- **Adding a critical (essential, vital) layer of support:** Palliative Care strives to ease the burden of difficult illnesses, using a family-centered approach that promotes healing and comfort. Palliative care treats children and their family members as integral members of the care team and remains engaged in the consultation process to help each family maximize the quality of each day.
- **Team-based comprehensive care:** The goal of pediatric palliative care is to partner with patients, families and the primary care team to develop a collaborative plan of care that will meet the needs and goals of the child and family. This unique subspecialty provides care through an inter-disciplinary team of doctors, nurses, social workers, child life specialists, chaplains, volunteers, expressive therapists, integrative providers, and psychologists. The palliative care team focuses on comfort and quality of life for patients and works alongside the primary health care team while they focus on the treatment of the underlying illnesses. Often times, the palliative care team helps coordinate the child's specialists across settings and bridge communication gaps that may exist between these specialists.
- **Surviving and thriving:** Pediatric palliative care is appropriate at any age (including prenatally, infancy, childhood, adolescents and young adulthood) or stage of a life-threatening illness such as cancer, muscular dystrophy, cystic fibrosis or congenital heart disease. Recognizing palliative care's benefit to children and their families, the American Academy of Pediatrics and the Institute of Medicine have called for integration of early pediatric palliative care as an essential aspect of providing optimal treatment, beginning at the time of diagnosis and continuing along the child's course of care.

### **Expanding Access for Families to Integrated Pediatric Palliative Care**

Access to pediatric palliative care is improving, but must be expanded. The number of pediatric palliative care teams in ambulatory, hospital and home settings is on the rise, but the level of services and staffing available varies considerably across the country and are generally inadequate to meet increasing demands.

### **Palliative Care and Hospice Education and Training Act, H.R. 3119 and S. 2748**

Through advocacy efforts, the Patient Quality of Life Coalition is focused on expanding workforce training and access to integrated palliative care services for all adults and children facing serious illness—at any age or stage—so these patients and families can benefit from the most comprehensive care possible.

- *Palliative Care and Hospice Education and Training Act, H.R. 3119 and S. 2748:* Palliative care improves quality, controls cost, and enhances patient and family satisfaction for the rapidly expanding population of individuals with serious or life-threatening illness. This act establishes Palliative Care and Hospice Education Centers to improve the training of health professionals, establishes a national campaign to inform patients, families and health professionals about the benefits of palliative care and the services, and directs expanded NIH funds to improve the delivery of palliative care to patients with serious illnesses.