

Improving Quality of Life for Children with Cancer



Cancer is the leading cause of death by disease in the United States for children ages 1-19, with more than 15,000 children facing a diagnosis this year. Research has improved treatments and boosted survival in some types of pediatric cancer, but treatment toxicities still cause a majority of children to experience distressing side effects and late effects—conditions that often cause significant suffering that continues into adulthood and can last a lifetime. Additional scientific research is essential to drive advances in childhood cancers that remain deadly, and to improve quality of life and minimized symptoms for the more than 420,000 childhood and adolescent cancer survivors living in the U.S. today.

Pediatric Palliative Care Improves Quality of Life for Children and Families

- **Adding an extra layer of support:** For most children and their families, treating the pain, stress and other symptoms of cancer is as important as treating the disease. Consequently, pairing pediatric palliative care with delivery of anti-cancer therapies has emerged as the model for optimal comprehensive care that focuses on the quality of life for the child and family as an essential aspect of managing the disease.
- **Team-based comprehensive care:** Pediatric palliative care is provided by a team of doctors, nurses, social workers, child life specialists, and others who partner with a child's oncologists and other clinicians to relieve the child's symptoms, help with communication and coordination of care, and ensure the child and family have the physical, emotional and mental strength to carry on with daily life.
- **Surviving and thriving:** Pediatric palliative care is appropriate at any age or stage of disease, and can be provided along with treatments meant to cure. Recognizing palliative care's benefit to children and their families, the American Academy of Pediatrics has 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.

Quality of Life Campaign: 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 and hospital settings is on the rise, but the level of services and staffing available varies considerably across the country.

ACS CAN's Quality of Life Campaign (fightcancer.org/qualityoflife), in partnership with the ACS CAN-led Patient Quality of Life Coalition, is focused on expanding workforce training and patient 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. ACS CAN is advancing important legislation to improve patient access to palliative care services:

Palliative Care and Hospice Education and Training Act (PCHETA), H.R. 647/S. 2080: This bill 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.