Pediatric Palliative Care: Opportunities for Health Plans

What is Palliative Care?

Only about one in four Americans is familiar with the term palliative care according to a survey released in March 2011.1 A common misconception is that all curative treatment must cease once palliative care is initiated. For parents with children who are critically ill, the choice to forgo restorative care can be extremely difficult, and many parents are reluctant to discuss hospice or palliative care with their child’s health care providers. Yet palliative care does not require that therapeutic care be terminated but is defined as a “focus of care integrated in all phases of life and as a set of interventions aimed at easing suffering associated with life-threatening conditions.”2 Palliative care goes beyond traditional treatments like pain medication and increases patients’ quality of life by helping them to remain comfortable and engaging them and their families in emotional support networks.

The etiology and treatment of diseases and life-threatening conditions are not the same in children and adults, therefore pediatric and adult palliative care also differ, yet the delivery of care in a team approach is generally consistent. Due to the wide variation in pediatric diagnoses3, the use of coordinated teams of physicians, family members, case managers, social workers, art therapists and others to administer palliative care so that it best fits the patient’s specific needs is especially important.

There is currently a lack of evidence on the cost effectiveness of pediatric palliative care. However, studies of adult palliative care have indicated that it is cost effective,4,5 so there may be potential cost savings in providing palliative care to children. Also, because the use of palliative care teams results in higher quality of life,6 palliative care for children can be an opportunity for health plans to improve care for children who are at the end of their lives. While pediatric palliative care is an emerging field, there are programs and initiatives underway that provide children with care that will help them remain comfortable as they battle life-threatening illnesses.

What is your health plan or organization doing to support pediatric palliative care? Tell us about it!

Palliative Care Programs

Aetna Compassionate Care Program

Aetna developed the Aetna Compassionate Care Program for members confronting advanced stage illness. The program serves members of any age including children and adolescents who are battling life-threatening illness. The goal of Compassionate Care is to help patients and their families navigate serious illness and prepare them for the final stages of life if necessary. The Compassionate Care Program includes access to nurses who are extensively trained in palliative care coordination and access to a website and tools specially designed to provide information to patients and their loved ones to help manage their conditions and improve quality of life. Hospice and palliative care options can be obtained without forgoing curative treatment. An early
evaluation of this program found that patients were satisfied and that the program helped to save money. Visit the Compassionate Care Program website for more information.

New York’s Care at Home Program

New York State runs an innovative program that allows children to obtain the care they need to keep them comfortable while they fight a life-threatening illness or terminal disease. New York has operated a 1915(c) Medicaid waiver called Care at Home I/II since 1985. In 2008 amendments were made to provide access to palliative care services similar to Medicaid programs in FL, CO and CA. A child who is eligible for Medicaid when waiving parental income can utilize the Care at Home I/II program if the child is determined medically eligible by nurses employed by the state. The program allows children who are physically disabled and require at least a nursing home level of care to remain at home with their parents or guardians instead of at a facility. In addition to regular state plan services, the program provides respite care, case management, home and vehicle modifications, and now provides palliative care services to children and their family members. There are 5 palliative care services that are available for children and their families: family palliative care education, pain and symptom management, bereavement services for the child and family, massage therapy and expressive therapy. The State is in the process of approving providers of palliative care services and enrolling children to receive them.

Medicaid/CHIP

The Affordable Care Act (ACA) includes a provision that requires state Medicaid and Children’s Health Insurance Program (CHIP) programs to continue reimbursing for all medically necessary coverable services, including curative treatment, even after choosing to receive hospice. This section of the law (2302) will prevent many parents and caregivers from having to make the difficult decision to stop treatment in order for the child to receive care that lets them remain comfortable during the last six months of life.

The Supportive Care Program

The Supportive Care Program at The Children’s Hospital of Pittsburgh offers a comprehensive bereavement program that provides supportive and palliative care to patients and families facing life-threatening illnesses or injuries. The program includes pain and symptom management, assistance with decision-making, end-of-life care and bereavement support to help optimize quality of life and comfort at every stage of illness. The program is the only pediatric palliative care program in Western Pennsylvania and one of three in the state of Pennsylvania. The program has the distinction of being one of three Centers of Excellence for pediatric palliative care in Pennsylvania. The Supportive Care Program is funded in part by the Highmark Foundation.

Pediatric Palliative Care Resources

Children’s Hospice International

Children’s Hospice International (CHI) is an organization dedicated to incorporating hospice concepts into pediatrics. Children’s Hospice International believes that no parent should ever have to choose between hospice care and hope for a cure, which is why CHI developed the Children’s Program for All-inclusive Coordinated Care (CHI-PACC) in partnership with U.S. Congress and
Centers for Medicare and Medicaid Services (CMS). CHI partners with and supports CMS' work with states to offer a version of the CHI-PACC model to children in the Medicaid and CHIP programs. CHI-PACC goes beyond hospice and palliative care by incorporating the critical components of each type of care with curative treatment from time of diagnosis throughout the entire continuum of care, regardless of whether that care is delivered in the home, hospital, or other appropriate facility. While certain state Medicaid waiver programs provide some of the CHI-PACC Program Services, none provide the full services of the gold standard of CHI-PACC. A bill has recently been introduced in Congress that would allow states to elect CHI-PACC as a state plan option through Medicaid. While currently the CHI-PACC model is moving forward primarily through Medicaid, CHI welcomes discussions with health plans interested in implementing the CHI-PACC, or a similar model, into their benefits programs.

The Initiative for Pediatric Palliative Care

The Initiative for Pediatric Palliative Care (IPPC) is a unique program that brings health care professionals and specialists together with families of critically ill children in retreat settings. These retreats allow physicians, social workers, child life specialists and other professionals to learn side by side about innovative ways of delivering pediatric palliative care. The IPPC collaborates with leading hospitals to develop and implement quality improvement projects and to pilot test the IPPC curriculum. Some of these hospitals include: The Children’s Hospital of Boston/Dana-Farber Cancer Institute, The Children’s Hospital of Philadelphia, Johns Hopkins Children’s Center and Vanderbilt University Medical Center. The IPPC is funded in part by the Aetna Foundation.

The American Academy of Pediatrics

The American Academy of Pediatrics (AAP) outlines their recommendations for pediatric palliative care in the policy brief, “Palliative Care for Children.” This brief recommends that a child who is given a diagnosis of a potentially life-threatening condition receive a palliative care consultation immediately, and that care should continue throughout the course of the illness, regardless of the outcome. Additionally, the brief provides recommendations for standards in pediatric palliative care. It also includes resources for providers and details about how adult palliative care differs from pediatric palliative care.

1 Andrews M. “Demand Grows for Palliative Care.” Kaiser Health News, March 29, 2011