

**FAST FACTS AND CONCEPTS #442**  
**PEDIATRIC SUBTOPIC #1.2\*****DESCRIBING PEDIATRIC PALLIATIVE CARE CONCEPTS TO PATIENTS AND FAMILIES**  
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**Background** Introducing pediatric palliative care can present unique challenges within a healthcare setting that focuses primarily on cure. Barriers to pediatric palliative care access include: limited availability of pediatric palliative care services (1-3); varying degrees of readiness among children, families, and their healthcare teams (4,5); misconceptions about palliative care availability alongside pursuit of curative therapy (6); and assumptions around the definitions of “palliative care” and how it relates to “hospice” and end-of-life care (7,8). Various organizations endorse early, integrated access to pediatric palliative care as a standard of care beginning at the time of serious illness diagnosis and regardless of prognosis (9,10). Most children and adolescents with serious illness do not receive palliative care services, despite evidence that many of them survive more than one year beyond palliative care consultation (11). The following pediatric palliative care concepts are meant to facilitate understanding and foster earlier referrals and acceptance of palliative care toward overcoming the challenges of integrating pediatric palliative care into the care of any child or adolescent with serious illness.

**Centering Discussions with Families**

- *Introducing Palliative Care:* Introduce palliative care teams as interprofessional specialists in symptom management and psychosocial adaptation who will work alongside the existing team (see suggested phrasing below). This language conveys collaboration among teams as well as the breadth of palliative care resources and expertise (12-14).
- *Symptom Assessment and Intervention:* Symptoms of serious illness include pain, anxiety, difficulty breathing, nausea, and much more that can greatly alter a child’s quality of life. Complex symptom management, with a deep toolbox that combines pharmacologic and non-pharmacologic approaches, is one of the core tasks of pediatric palliative care in providing an additional layer of support (10).
- *Social, Emotional, and Spiritual Assessment and Intervention:* Life-sustaining therapies may result in prolonged hospitalizations, financial hardships, disruption of parenting well siblings, and prognostic uncertainty, all of which can take a significant toll on the family unit. Identifying cultural and spiritual needs and values provides individualized palliative care to better support quality of life for the family.
- *Compassionate and Honest Communication:* Resources dedicated to facilitating effective and therapeutic communication can be especially helpful for children and families facing a potentially life-threatening or life-limiting illness. Interprofessional team members have special expertise in engaging in clear and forthright discussions (8,10,12) and can support families and clinicians during challenging yet important conversations (e.g., processing grief along with hope) (15,16).
- *Patient and Family-Centered Care and Decision Making:* Palliative care teams form long-term partnerships with families founded on respect, providing opportunities to elicit preferences and priorities for goals of care. Ongoing dialogue at regular intervals or during acute exacerbations with attention to shared decision-making will ensure treatment goals are congruent with patient/family preferences and facilitate ongoing dialogue about advance care planning (10,12,14,17).
- *End-of-life Care:* End-of-life care is a key component of pediatric palliative care provision. Team members provide grief/bereavement support to patients, families, and siblings, including developmentally appropriate anticipatory grief support and guidance for meaning-making and legacy activities while transitioning toward end-of-life and/or hospice care and beyond (18).

**Sample Script for Introducing Palliative Care:** “We recommend a specialized, interprofessional team available to support your child and family throughout this illness, called the pediatric palliative care team. This team focuses on symptom relief and promotion of comfort and quality of life during treatment while supporting patient/family values. They will partner with your current team of specialists to provide an added layer of support and help make sure we are considering all of your child’s and your family’s needs while providing individualized care that aligns with your goals.”

**Summary** Pediatric palliative care teams provide an additional layer of continuity and support to children and families throughout the course of any serious illness. The above concepts offer support to a child’s

primary medical team who play an instrumental role in educating patients and families about palliative care and fostering appropriate and timely integration of pediatric palliative care services.

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\*Connotes Pediatric Fast Fact Topic #1 – Role of Palliative Care; 2<sup>nd</sup> article on this topic.

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