

How to Talk with Families about “Palliative Care”

Palliative Care is an option to offer an added layer of support to a child and family when the child is seriously ill with a complex or life-threatening illness. Palliative Care can be introduced at any time throughout the course of care, but earlier referrals provide optimal support. Introducing Palliative Care allows for the opportunity for an early partnership and the building of a relationship to pave the way for hospice care. Palliative Care helps the child and family gain the strength to carry on with daily life and the often challenging tasks of managing the demands of a complex illness. Rising above fears to have the discussion about the need for Palliative Care permits the professional to provide help for a patient earlier. The child, parents and siblings often embrace the added layer of support offered by a Palliative Care team quickly.

Palliative care is:

- Focused on enhancing quality of life for a child and family, while minimizing suffering and optimizing function
- Focused on providing relief from the symptoms, pain and stress of a serious illness, whatever the diagnosis
- Intended to guide and assist a child/family in making decisions aligned with their identified goals of care
- Provided by an interdisciplinary team that works with the child, family and the child’s doctors to provide an extra layer of support
- Appropriate at any age and any stage in a serious illness, and can be provided in conjunction with disease-modifying treatment
- Assistance with improving coordination of care and communication with health care provider
- Tailored to meet the needs of each individual patient

If you answer “yes” to any of these questions below, it may be the right time to start a conversation about a referral to Palliative Care with the child and parents.

- Does this child have a life-threatening or life-limiting illness and is continuing to pursue medical treatment options?
- Is a cure possible, but may not be attainable?
- Is there no known cure but treatment may prolong quality and/or quantity of life?
- Is this a serious illness where the child is vulnerable to life-limiting complications?

Suggested conversation starters:

Begin with a cautionary statement

- “I want to talk with you about a sensitive but important subject that may be difficult to hear. It is important to discuss so you can get all of the support needed for you and (name of child) during this time”

Allow room for a choice to have the conversation with words like “I wonder if...”

- “I wonder if we can talk today about a referral to Palliative Care so that you and (child’s name) have all the help available as we navigate the course of this difficult illness together”

Provide what you know directly and honestly

- What the Palliative Care team offers and why you are suggesting this now

For more information or help finding pediatric palliative care, please visit the Pediatric Palliative Care Coalition website, www.ppcc-pa.org, or email info@ppcc-pa.org.

