How your Family Can Talk about "Palliative Care"

When your child is seriously ill with a complex or life-threatening illness, Palliative Care is an option to offer an added layer of support to your child and family. 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 your 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 your fears to have the discussion about the need for Palliative Care permits you and your family to get help for your child earlier. Your child and family often embrace the added layer of support offered by a Palliative Care team quickly.

Palliative care is:

- Focused on enhancing quality of life for your 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 your child/family in making decisions aligned with your identified goals of care
- Provided by an interdisciplinary team that works with your child, family and your 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 providers
- Tailored to meet the needs of your child

If you answer "yes" to any of these questions below, it may be the right time for your family to start a conversation about a referral to Palliative Care.

- Does your 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 your child is vulnerable to life-limiting complications?

Suggested conversation starters:

Begin with a cautionary statement

"It is very difficult for our family to talk about Palliative Care, but we think it's time to learn how we can get the support needed for our family 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 what Palliative Care can offer so that our family and (child's name) have all the help available as we navigate the course of this difficult illness together"

Can you we talk about:

■ What the Palliative Care team offers and why now may be a good time to start the conversation

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.

