

How to Talk with Families about “Hospice”

“I wish hospice would have been contacted sooner.”

This is a common reflection of family members when discussing the care of their child.

We share the common goal of providing possible help for the child and family during this difficult time. Rising above personal fears and bringing up the subject of “HOSPICE” allows the professional to provide a patient a unique level of help and guidance. Hospice care provides the clinical expertise, support and companionship needed during a most difficult journey. Parents, siblings, and other loved ones may be better assisted after the death of a child when they have had the added layer of support that hospice can offer. The guide below is intended to help introduce the hospice concept.

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

- Is it possible that this child will die prematurely due to a life-limiting illness?
- Is it possible that this child will die within a year?
- Is it possible that this child will die during this episode of care?
- Do you know what the child’s and family’s wishes are for the end of life?

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 yet 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 what hospice can offer 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

- While hospice can provide valuable care, some people are frightened by the word “hospice”
- Insurance plans ask the physician to give a prognosis of 6 months or less when referring to hospice
- Prognosis for children can be unpredictable, and it is important for others to know we are not giving up
- State insurance plans like Medical Assistance allow for both curative care and hospice care to be covered at the same time

Here is what you can expect from the hospice team

- Hospice will partner with you to care for your whole family, not just (child’s name)
- Services available will meet your individual needs, but can include:
 - 24-hour phone support by a registered nurse and visits as needed
 - The hospice team collaborates with your physician’s office regularly
 - A social worker assigned to help you look for additional resources and add additional support
 - Spiritual support as needed and desired
 - Nurses’ aides to help with personal care
 - Medications and equipment related to the illness are paid for by hospice
- Your local hospice can offer additional information regarding additional support in the home

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

