

How your Family Can Talk about “Hospice”

“I wish we would have contacted hospice sooner.”

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

Families can seek help for their child during this difficult time. Rising above your fears and bringing up the subject of “HOSPICE” allows your family to get your child a unique level of help and guidance. Hospice care provides the clinical expertise, support and companionship needed during a most difficult journey. With the added layer of support that hospice can offer, your family – parents, siblings, and other loved ones – may be better assisted in their coping after the death of a child. The guide below is intended to help you introduce the hospice concept.

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 Hospice.

- Is it possible that your child will die prematurely due to a life-limiting illness?
- Is it possible that your child will die within a year?
- Is it possible that your 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

- “It is very difficult for our family to talk about Hospice, but we think it’s time to learn how we can get all of 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 hospice 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 the following:

- We know hospice can provide valuable care, but the word “hospice” is frightening; can you tell us more about it?
- Are there restrictions by insurance plans (i.e., do we need to ask the physician to give a prognosis of a certain timeframe 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; can they be covered at the same time?

Can you let us know what we can expect from the hospice team?

- Many hospices provide the following services; it is important to check with your team for what levels of support are available.
 - 24-hour phone support by a registered nurse and visits, as needed
 - Regular collaboration of the hospice team with your physician’s office
 - A social worker assigned to us for additional resources and additional support
 - Spiritual support as needed and desired
 - Nurses’ aides to help with personal care
 - Medications and equipment related to the illness paid for by hospice
- Can your local hospice 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.

