Introduction to Pallitative Care

Learning Objectives

After reviewing this Guide you will be able to:

- Recognize how palliative care can help your child and family
- Address concerns and preconceived notions about palliative care
- Understand how to request and advocate for palliative care support

Introduction

Making Each Day the Best it Can Be

If you are curious about pediatric palliative care (PPC), it's likely that someone on the medical team has introduced the term to you or has suggested a palliative care consult. Or perhaps another parent has mentioned or recommended pediatric palliative care.

Sometimes families hesitate to consider palliative care for their child. This is usually because they have confused it with hospice care or believe that palliative care is only related to end of life. But palliative care is not hospice care, although it may include hospice care near the end of life.

The main goal of PPC is to address symptoms of physical and/or emotional suffering, such as pain or anxiety, throughout the illness journey. However, palliative care actually is much broader. Palliative clinicians consider the whole child and family. They help with clarifying care goals and, as necessary, reconsidering the goals if your child's condition progresses. They help to coordinate the care and can act as a liaison with other clinicians on the team. They are a sounding board for considering different treatment options and their benefits and burdens. Many provide consistency across settings and over months or years, ensuring that the focus is on living each day as well as possible for as long as possible.

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For all of these reasons palliative care can be offered at the same time as treatment of an illness: sometimes at diagnosis, sometimes as an illness progresses with more complicated decisions, and sometimes when the family is facing or thinking about end of life.

To learn more about the differences between palliative care and hospice care, see the CPN guide "Palliative Care and Hospice Care: Understanding the Differences."

An Interdisciplinary Practice that Aims to Relieve Physical, Emotional, and Spiritual Distress

The PPC team might be made up of physicians, nurses and nurse practitioners, social workers, spiritual care providers, child-life specialists, integrative therapists and others who listen well to what your needs are and help you advocate for your child and family. Some primary care providers or specialists may feel equipped to have these discussions with you. However, a dedicated PPC team, if available, may offer more comprehensive support.

Your Relationship with the PPC Team

Open and direct communication with the care team is very important. Palliative care clinicians understand that parents know their child best. They recognize that your child is part of a family system with its own culture, values and beliefs. They consider you the expert on your child and respect your knowledge. Your understanding of your child and how they are being affected by the condition, together with the clinicians' understanding of your family's goals, helps the team make recommendations for the care plan.

Of course, you will have questions and concerns. You may feel overwhelmed by uncertainty. Questions like "Am I doing what's best for my child?" "Will my child survive?" and "How will our family get through this?" are hard to consider. It may feel intimidating or uncomfortable to bring your thoughts and questions to your friends, family or even to your child's medical team. Your conversations, and the support of the palliative care team over time, often bring increased clarity and can make you feel more confident as you care for your child.

What to Expect

A palliative care consult begins with the clinicians listening to the caregivers. They will ask about your child before and after diagnosis, questions such as:

What is your understanding of the illness?

What does quality of life mean to you?

What are your hopes? Your fears?

When you have faced difficult times in the past, what has helped you get through them? (Family, faith, community, etc.)

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Caregivers can help to build the relationship by expressing interest in how to work with the palliative care team. Some questions to ask are:

How is palliative care different from social work or child-life specialist work?

How will you work with the other specialists?

When is it appropriate for me to ask you for help, and how will I reach you?

Based on your answers, the team will offer suggestions to keep your child as comfortable and active as possible. They will provide support such as:

- Expert treatment of physical pain, emotional pain and spiritual distress
- Guidance about issues and decisions that you may face
- Ways to help your child understand and cope with their condition, if appropriate
- Support for siblings, extended family and community
- Access to spiritual care and integrative therapies such as massage, Reiki, music, art therapy
- Resources for addressing hardships: financial, housing, transportation, etc.

Shared Decision-Making

Over the course of your child's illness you will be asked to consider options for treatments and to make decisions with clinicians. The palliative care team is a sounding board to explore these options and consider the benefits and burdens. Because they focus on the whole child and family, they can be effective facilitators of conversations with any or all members of your team, including subspecialists, about your goals and what is and isn't working. They can then help you decide which recommended treatments might be most beneficial, given your child's condition and your family goals. Team members can also help clarify what the next steps should be (including proceeding—or not—with the proposed treatments).

Over time the clinicians may suggest revisiting your goals, or re-considering interventions as circumstances change. These conversations can help families to minimize any future regrets they may fear.

Support for the Whole Family

Family members often experience grief and a sense of loss that begins as early as diagnosis. Any or all family members may have questions ("Why me?" "Why my child?" "Why my sibling?"). And, each will have these experiences in their own way and in their own time. The PPC team will work with you to address concerns about your other children and parenting partner if you have one. They will advise you on how to manage work and family demands. They may connect you with additional resources in your community.

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Some of the other supports you once relied on, such as friend groups or faith practices, may feel different now. Palliative care specialists can help you explore and validate your feelings without judgment. They will help you work through these complicated feelings and find the supports you need.

Requesting Palliative Care

A physician, nurse, social worker or chaplain can help with a palliative referral, but some clinicians may not be aware that a team is available. Others may not think to mention palliative care, because they also confuse it with hospice. If a team is not available, there are many clinicians who are not formally trained in palliative care but incorporate palliative practice into their treatment. Do not hesitate to ask for a consult.

Conclusion

Your palliative care providers can provide consistency across settings and over months or years. They can be among your greatest supporters in advocating for your child, helping you in making decisions consistent with your goals of care. For many caregivers, palliative care makes all the difference in the quality of the illness journey—and not just for the patient. For more information and to hear families and clinicians talk about palliative care (pediatric care in particular) visit CourageousParentsNetwork.org.