Introduction to Pediatric Palliative Care





INTRODUCTION

Making each day the best it can be

If you are curious about palliative care, 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 (PPC).

Sometimes families hesitate to consider PPC. They confuse it with hospice care, or believe that palliative care is only related to end of life. Pediatric palliative care is not hospice care, although it may include hospice care near the end of life. PPC focuses on making each day as good as it can be—whatever that means to your child and family. 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 you are facing or thinking about end of life. The PPC team can likely follow your child's care across settings— at the clinic or hospital, and home.

To learn more about the differences between PPC and hospice care, see the CPN guide "Palliative Care and Hospice Care: Understanding the Differences": https://courageousparentsnetwork.org/guides/understanding-palliative-care-and-hospice-care.

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An interdisciplinary practice that aims to relieve physical, emotional, spiritual distress

The main goal of PPC is to address symptoms of physical and/or psychosocial suffering, and to support the needs of the whole family. The PPC team members are experts in communicating with families whose child has a serious illness. They can also help you advocate for your priorities in your child's care and facilitate conversations. For example a palliative care provider may help convene, or participate in, interdisciplinary team meetings to support you. These meetings can help everyone clarify the goals of care to identify what is and isn't working and plan what the next steps are so that everyone feels they are "on the same team."

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—not just for your child, but for your entire 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 services.

Your relationship with the PPC Team

With many worries and often few clear answers, parents 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 with the palliative care team, often help build confidence and clarity as you care for your child.

COMMUNICATING AND COLLABORATING

Open and direct communication with the care team is very important. Palliative care providers 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. Your understanding of the illness and knowledge about your child help clinicians come together to make recommendations for the plan of care.

What to expect

The PPC team will ask about your child as a person before and after diagnosis, and about your family. Learning the "big picture" helps the team better understand and support your needs and goals.

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You can begin to build the relationship by expressing your own thoughts and concerns. Here are some questions you may wish to ask directly at your first palliative care team meeting:

- What is palliative care? How is it different from social work or child-life specialist work?
- How will you work with my child's other specialists?
- When is it appropriate for me to ask you for help, and how will I reach you?

The PC team may also ask you some questions, such as:

- What is your understanding of your child's illness?
- What is quality of life for your child and your family?
- What are your hopes for your child and family?
- What are your fears?
- When you have faced difficult times in the past, what has helped you get through them?Family, faith, community?

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 his/her illness
- 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 life you will be asked to consider options for treatments and to make a number of decisions with clinicians. The palliative care team is a sounding board to explore these options and consider the benefits and burdens. They can help you decide what is most important, given your child's condition and your family goals. This may mean proceeding—or not—with proposed treatments. Over time they also may suggest revisiting your goals or re-considering interventions as circumstances change. This can help you feel more confident and minimize any future regrets.

SUPPORT FOR THE WHOLE CHILD AND FAMILY

The PPC team will work with you to address concerns about how to manage work and family demands. They may connect you with additional resources in your community.

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Family members often experience anticipatory grief and a sense of loss that begins as early as diagnosis. You may have questions ("Why me?" "Why my child?"). Some of the 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 support you need.

Requesting palliative care for your child and family

If your child's medical team does not refer you for PPC, you can ask for it. Some providers may not be aware that a palliative care team is available. It may be helpful to have a team involved that is not directly responsible for the interventions or management of your child's care and may more easily see the whole picture. You can ask your physician, nurse, social worker or chaplain for help in locating PPC resources. You can also search palliative care options within your hospital or region.



CONCLUSION

A critical resource as you advocate for your child

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 and ensuring the focus is on living each day as well as possible.