

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 palliative care, because they confuse it with hospice care, or believe that it is only related to end of life. But that is not the case. *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.**

It is given 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.

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An interdisciplinary practice that aims to relieve physical and/or emotional distress

The main goal of PPC is to address symptoms of physical and/or emotional distress, such as pain or anxiety. The PPC team helps to coordinate your child's care and can act as a liaison between you and the other clinicians (and, really, everyone who is involved with this illness journey). They are experts in communicating with families whose child has a serious illness.

Depending on your child's and family's needs, the PPC team can be made up of physicians, nurses and nurse practitioners, social workers, child-life specialists, integrative therapists and other providers who listen 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, if available, a dedicated PPC team may offer more comprehensive services. You should not hesitate to ask.

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. Palliative care providers understand and are there to listen. Your conversations, and their support, can bring the clarity you need to feel more confident 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 your family system and of a larger community that may include school and friends. Your understanding of the illness and perception of how your child is doing help specialists come together to make recommendations for the plan of care.

What to expect

The PPC team will ask about your child as a person and about your family. They want to get as much insight as possible about all of you, so that they can better understand and support your needs and goals. If relevant, the team will also want to learn about your child's life before the diagnosis: his or her likes, dislikes, interests and place within the family. The “big picture” helps the team relate to your child and whole family unit.

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The team members will offer suggestions to keep your child as comfortable and active as possible. Working alongside the primary providers, the PPC specialists employ their multidisciplinary approach to managing symptoms such as pain and distress. The team will also support your entire family's physical, emotional and spiritual wellbeing.

Some examples:

- Expert treatment of pain and emotional distress
- Guidance around important decisions you may encounter
- Age-appropriate help for your child in understanding and coping with their illness
- Support for siblings and other loved ones
- Integrative treatments, such as massage, Reiki, music and/or art therapy
- Resources for coping with trauma, financial issues and other related concerns

● **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. The palliative care team is a sounding board to help you talk about your hopes and worries.

They will support you in exploring options and anticipating the benefits and burdens of interventions. They can help you figure out what is most important to you and your child as you face treatment options—including the option to forgo interventions. Establishing and sharing your goals of care allows for decisions that work with your family's values. Coming back to the goals of care, and re-considering them as circumstances change, will help you feel more confident and minimize any future regret that you may feel.

PCC providers can also coordinate your child's care and facilitate conversations with the larger team about your concerns for your child and family. For example, a palliative care provider may convene interdisciplinary team meetings. These meetings can help the entire team, and you, identify any possible gaps in your child's care.

● **SUPPORT FOR THE WHOLE CHILD AND FAMILY**

In addition to worrying about your sick child, you may also have concerns about your other children, marriage or parenting partnership, and how to keep up with work and friends. The PPC team looks at your child and family across settings—not just at the clinic or hospital, but also in the home. Through documentation, phone calls and facilitating team/family meetings, they will strive to bring together, with you, those who can help make the best-informed decisions regarding the care of your child. As they get to know you in all of these settings, they are also able to offer support for each family member as they consider what it means to understand, accept and cope with this very stressful set of circumstances.

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● SELF-CONSIDERATION AND CARE

Primary caregivers, even if they are sharing responsibility with a parenting partner, often face emotional and spiritual challenges. These are deeply personal and may arise suddenly or unexpectedly. You may experience 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 supports 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. Some may not appreciate that it is helpful for the family to have a team involved that is not directly responsible for the interventions or management of the child’s care. But being one step removed allows the palliative care team to see the whole picture, and support the family accordingly.

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 state Department of Public Health.



CONCLUSION

A critical resource as you advocate for your child

Your palliative care providers remain with you through your child’s entire illness, however long or short, and sometimes beyond. They can be among your greatest supports in advocating for your child.

Once these relationships are established, parents often report that they wish they had been referred earlier. For this reason, Courageous Parents Network encourages all families to investigate and request a palliative care consult, if one has not been offered.