

# Introducing Families to Pediatric Palliative Care



## LEARNING OBJECTIVES

After reviewing this Guide you will be able to:

- Distinguish between palliative care and hospice care in a family conversation
- Illustrate the value of palliative care for a patient family
- Formulate a personal approach to introducing palliative care and corresponding CPN resources

## EDUCATING YOURSELF

Pediatric palliative care is frequently confused with end of life or hospice care. Clinicians considering a palliative care referral may be fearful of upsetting a patient family, anticipating that family members will believe that they are being abandoned; that all treatment options have been exhausted; that the team has given up; that the child's death is imminent. Explaining the differences between palliative care and hospice care can be very helpful.

*Palliative care* is a resource for anyone living with a serious illness. The term “palliative care” refers to a wide range of treatments and interventions that complement the disease-directed care, addressing physical, emotional and spiritual symptoms. It includes support for the sick child and the entire family.

Palliative care can be helpful as early as diagnosis and at almost any point during the illness. While end-of-life care is part of the palliative care skill set, most children receiving palliative

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care are not actively dying. The goal of palliative care is that a child may live as well as possible for as long as possible. It is helpful to think of, and communicate, that children receiving this care are actively living, with a serious medical condition.

Whatever treatments are being discussed, sometimes the most important intervention is listening to the family. Pediatric palliative care clinicians get to know the child and family by listening to their story and exploring fears, values, worries and hopes. Listening enables the care team members to develop trust and a relationship with the family, allowing them to support the family with coping and decision-making.

Pediatric palliative care clinicians typically follow the family through changes in the child's health status, helping caregivers to understand, consider and choose treatment options. They do not displace the primary medical team; they work as consultants to the family and the team.

*Hospice care* is an extension of palliative care and focuses on end of life. For hospice enrollment, and to qualify for insurance coverage (private or Medicaid), a physician must certify that the child may die within the next six months if the disease follows its natural progression; however, this time limit can and often is renewed, especially because with children there is often much uncertainty about their prognosis or disease trajectory.

Hospice care is delivered through a specialized interdisciplinary team of professionals and hospice volunteers. Hospice most often provides care in the home, with members of the team coming for scheduled visits. Hospice pays for and secures any medication or equipment related to comfort, often delivering them to your home. Therefore, all medications, durable medical equipment and medical supplies that are related to non-curative treatments are covered and managed by hospice.

## HOW PALLIATIVE CARE HELPS

Providers and families find that palliative care specialists can help to:

- Clarify the family's values and care goals for their child
- Facilitate communication and decision-making among the family members, primary providers and subspecialists. This is especially important, as fragmentation in the patient's care can be difficult and bewildering for everyone involved
- Provide an opportunity to think through medical decisions in the context of what is important to the family
- Focus attention on quality of life as defined by the family, which involves symptom management and alleviating suffering

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## WHEN TO INTRODUCE PALLIATIVE CARE

Many families regard their PPC providers as a lifeline—and they wish that they had known about, or agreed to, this support earlier. Examples of appropriate times to recommend palliative care include:

- When the family has recently received a serious, life-threatening diagnosis
- If the child is experiencing a decline in a chronic condition or has had a lengthy or complicated medical course where the outcome is uncertain
- If the child has had repeated hospitalizations and setbacks with a declining baseline
- If the focus of care has shifted from disease-directed treatment to treatments that promote comfort and relief from suffering
- As the family begins to consider planning for end of life

## SCRIPTS

### ● Introducing Palliative Care

In your own voice, you might use language like this for describing palliative care and recommending a consult:

“May I talk with you about something I think would be beneficial for your child? There is a consult team that helps families like yours when they face decisions that involve a lot of uncertainty. They would work with you and our team to provide support and sometimes clarity around tough issues. I think it is a good time to arrange such a consultation.”

OR

“Have you ever heard the term palliative care? Many people have not, and some believe it is just for the end of life, but it is not. Palliative care is appropriate when families face decisions that involve a lot of uncertainty. The palliative care team would spend time learning about your child and family. They may help with symptom management or advocating for your child’s needs. They would help to provide continuity as your child moves within the hospital, or is in an outpatient clinic or at home. I believe that you would benefit from a palliative care consult. I’ve asked the team to come by and meet you later today.”

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## ● **Introducing a family to CPN**

It is well known that parents greatly value the experience of other families. In many cases, it is difficult for families to connect to much-needed peer perspectives. Some join disease groups and participate in their programs; others prefer to be anonymous or private—but value hearing from other families nevertheless. Courageous Parents Network supports connection to other families' experience through a wealth of resources: videos, podcasts, downloadable guides, events and more.

You might use language like this to introduce a patient family to CPN:

“You might like to hear from other parents whose child and family were helped by palliative care. Courageous Parents Network is a nonprofit that offers videos, downloadable guides, podcasts, and events featuring parents and professionals, to help families see and feel that they are not alone. They have a website and a mobile app.

“Even though each family is unique, they often face similar challenges and experience similar feelings. The CPN families share a serious illness with much uncertainty ahead. Their sharing of experiences and perspectives might really be helpful to you.”

## ● **Introducing a colleague to CPN**

You might also be in a position to suggest a consult for a colleague's patient family, using language like this:

“I've heard that you have a challenging patient family with a serious illness and lots of uncertainty. In a recent case it was helpful for me to look at Courageous Parents Network, a nonprofit organization with a website and a mobile app that include professionally produced videos, podcasts, events, downloadable guides and other tools that feature families and clinicians sharing their experience and perspectives. These resources are reviewed by medical professionals and can be used to educate families and ourselves.”

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## BEING “PALLIATIVE-AWARE”

Not all hospitals or communities have palliative care specialists. It still is possible for you and colleagues to learn about palliative care principles and practices, and to offer this additional support to families.

Palliative-aware practices include:

- Tending to and appreciating the whole person: physical, emotional, spiritual care of the child and family
- Encouraging parents/caregivers to share their expertise about their child and family when considering, together, the benefits and burdens of interventions; e.g., medications, surgical procedure, clinical trial
- Using the interdisciplinary team (child-life, social work, chaplain, music/art therapists) to provide ideas and possible interventions for pain and other symptom relief and management

## RESOURCES FOR FAMILIES

Resources appropriate to use at bedside, in family meetings, or as a follow-up to offer additional support, include:

### **Courageous Parents Network Unit: “How Palliative Care Helps”**

Includes videos, guides and other information to introduce palliative care and provide family and clinician perspectives on its value

<https://courageousparentsnetwork.org/topics/how-palliative-care-helps>

These downloadable guides, found within the unit, are popular and especially recommended for sharing with families:

### **“Introduction to Pediatric Palliative Care”**

<https://courageousparentsnetwork.org/guides/introduction-to-pediatric-palliative-care>

### **“Understanding Palliative Care and Hospice”**

<https://courageousparentsnetwork.org/guides/understanding-palliative-care-and-hospice-care>

Note: This guide is also available as an interactive Pathway, found in the CPN Clinician Portal.

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## ADDITIONAL RESOURCES FOR CLINICIANS

### **Courageous Parents Network Referral Card**

Order (free) cards to introduce families to CPN

<https://courageousparentsnetwork.org/providers/referral-request-form/>

### **“Introducing Palliative Care to Pediatric Patients and Families”**

Interactive learning session designed for clinicians educating colleagues on the concepts of palliative care

<https://api.courageousparentsnetwork.org/app/uploads/2020/02/CPN-Palliative-Care.pdf>

The full set of teaching modules, created in a collaboration between Courageous Parents Network, Cleveland Clinic and MassGeneral Hospital for Children, can be found here:

### **“The Power of the Family Voice: Using Courageous Parents to Teach Clinicians”**

<https://courageousparentsnetwork.org/guides/teaching-modules>



## CONCLUSION

Families caring for a child with a serious illness face uncertainty, difficult decisions, and the reality of their lives being forever changed. The feelings of isolation, anger, fear and love may be overwhelming. Knowing palliative care principles, or partnering with a pediatric palliative care team, can help with many of the most prevalent stressors: pain and symptom management; parents’ relationship and sibling support; values clarification and communication; advance care planning and anticipating end of life. In addition, many clinicians find that the addition of a palliative care team brings the family—and other members of the medical team—a sense of greater control and confidence in their ability to care for a child.