

# Introducing Families to Courageous Parents Network



## Learning Objectives

**After reviewing this Guide you will be able to:**

- Identify appropriate opportunities to introduce families to Courageous Parents Network
- Evaluate resources for self-education and educating colleagues on topics relating to the lived family experience

## Why Do Pediatric Clinicians Value Courageous Parents Network

Clinicians and families both struggle when a child is facing a serious medical condition. Families must learn to navigate a bewildering new world of the medical “system,” engage with a host of new medical specialists, find the support they need to make difficult choices, and learn how to communicate their evolving philosophy of care—all in the absence of prior experience to guide them. Providers have medical knowledge and experience in patient care, but many do not have sufficient access to the family’s lived experience. Each party benefits from learning to effectively communicate with the other.

### **Caregivers want information and validation**

In addition to their providers, there is no one that caregivers trust more than other caregivers. Learning how families are facing, or have faced, similar challenges can help clarify for families what they do or don’t want—whether that is by relating to and leaning in towards something they see, read or hear, or by reacting against and leaning away. Courageous Parents Network resources are designed to support the caregiver’s exploration at their own pace, in privacy and with no particular burden to engage.

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## Clinicians want to be the best possible resource to their patient families—and colleagues

Just as families learn from their peers, so too can clinicians use CPN resources to become better positioned to support the families whose child they care for, whether or not the family visits CPN. They report that they regularly utilize CPN resources to gain insight into the family experience and as a tool for educating colleagues and peers.

### CPN Resources

Most of CPN content is organized in units around topics and themes common to the lived family experience. This content includes

- Short **videos** of parents, siblings, clinicians and extended family members speaking to their experiences and perspectives on living with, caring for, and in some cases grieving a child (or children). Topics include anticipatory grief, understanding baseline, interventions, sibling and self-care, advance care planning and end of life. The value of palliative care is a theme woven through these conversations.
- **Handouts/downloadable guides** offering practice advice and support around important topics such as understanding baseline, shared decision-making, siblings, clinical trial, transitioning to adulthood, out-of-home placement, anticipating end of life, palliative and hospice care, and more.
- The **CPN blog**, written and guest-written by members of the CPN community.
- **Pathways**, digital learning experiences that integrate text, videos, blogs, downloadable guides and podcasts.
- **Clinician Portal**, the section of the site designed and devoted to clinician needs and education.

### Which Families Can Benefit From CPN Resources?

Any family whose child has a serious medical condition, even those whose diagnosis or prognosis is unclear, will be able to relate to the experiences of other families shared on CPN. They likely will have difficult decisions to make regarding goals of care, medical interventions and more. They will be concerned about the impact of the child's illness on the caregiving relationship and on siblings.

In all cases, however, providers should be aware that not every family will be comfortable with every topic.

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## The Optimal Time(s) to Introduce CPN

**At diagnosis, with caveats:** With notable exceptions, parents receiving a diagnosis will have many concerns and their initial focus will be on treatment and cure. If appropriate, Courageous Parents Network may be a resource to mention with emphasis on practical information, such as navigating the hospital, goals of care, and shared decision-making.

**Along the way:** Within each clinician role other opportunities will present themselves. Whenever a family voices a sense of isolation, anticipatory grief, or feeling out of control and frightened for their child's future, hearing from other families and/or providers may help.

**At a critical decision point:** When a family is faced with having to make choices about medical interventions such as G-tube, tracheostomy, spinal fusion surgery, experimental treatments, clinical trials or even out-of-home placement, hearing how other families have navigated different choices can be helpful.

When the answer to what is sometimes called the “**Surprise Question**” (“Would you be surprised if this child died in the next year?”) is NO. While the question does not provide prognostic accuracy in pediatrics to the degree that it does in adult medicine, it is still a useful screening tool for identifying when a child and family are facing ongoing complexity and requisite decision-making.

At any time the clinician is considering a **referral to palliative care**. Courageous Parents Network strongly endorses the value of pediatric palliative care (PPC). CPN resources carefully address the differences between palliative care and hospice, and illustrate the benefit Network families have enjoyed as a result of their PPC experience.

## Scripts for Introducing Courageous Parents Network

Using the family's expressed concerns may offer you an entry point to introduce CPN. You might say:

“Even though each family is unique, they often face similar challenges and experience similar feelings. I have heard parents say that there is no one they trust more to give them advice and perspective than other parents.”

“Courageous Parents Network is a nonprofit with a website, mobile app, blog and live streamed events featuring families and clinicians talking about some of the topics we are discussing. Their sharing of experiences and perspectives might really be helpful to you.”

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## Conclusion

Nothing can replace the human interaction with clinicians that a child and family cherish. However, it truly takes a village to care for the child and family when there is a serious medical condition. CPN is honored to be a part of that village, offering family and clinician voices to help reduce isolation and support insight and reflection.