

Introducing Families to CPN



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 Need to Know about 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 medical 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; however, they may not have as much insight into the family’s lived experience. We need a language that works for all the partners in the illness journey.

1. We know that in addition to their providers, **there is no one that parents trust more than other parents.**

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.

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**COURAGEOUS
PARENTS
NETWORK**

On the CPN platforms (web and mobile) they can browse and search at their own pace and in their own time, with no burden to engage with anyone else, and in absolute privacy if they so wish.

2. **Just as families learn from their peers, so too can clinicians use CPN resources to deepen their understanding in ways that will help navigate challenges.** That is, we become better positioned to support the families whose child we care for, whether or not the family visits CPN.
3. CPN presents many different family and clinician perspectives to emphasize that there are no right or wrong answers—only what works with the family’s goals and values, and what makes the best sense for their child.

What are the CPN Resources?

CPN is a digital platform (web and mobile) for learning, sharing and story-telling. Its resources include:

- More than 500 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) with a serious illness. Topics include palliative care, working with the medical team, interventions, advance care planning and end of life.
- **Handouts/downloadable guides** offering practice advice and support around important topics; e.g., understanding baseline, managing pain, palliative and hospice care, transitioning to adulthood, exploring out-of-home placement.
- **Units** of CPN content organized around topics and themes common to the lived family experience. Units include: downloadable guides, videos, podcasts, blog posts, and pathways organized by topic; e.g., clinical trial, siblings, shared decision-making, bereavement.
- **Pathways**, digital learning experiences that integrate text, videos, blogs, downloadable guides and podcasts.
- The **CPN blog**, written and guest-written by members of the CPN community.
- **Clinician Portal**, the section of the site designed and devoted to clinician needs and education.

How do Clinicians Use CPN?

Findings from surveys of clinicians who use Courageous Parents Network indicate that CPN has helped all or some of their patient families who use the resources to:

- Feel more confident in caring for their child
- Cope with fear and anxiety
- Be more comfortable in communicating with clinicians

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A significant number of clinicians also use CPN for their own education and/or to educate colleagues. Clinicians using CPN for this purpose report that CPN has helped them:

- Be a better resource for families
- Educate themselves about the family experience

Which Families Should Be Introduced to CPN?

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 parenting relationship and on siblings.

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

When is the Right Time to Introduce CPN?

- At the time of diagnosis: Right from the time of a child's diagnosis with a serious medical condition, parents are plunged into a new difficult world and face a range of new emotions and challenging conversations and decisions. Including CPN among the resources you provide to a family at that time is appropriate.
- Along the way: Within each provider 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. 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.

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In particular, CPN looks gently but honestly at the often-unspoken, but ever present, questions and concerns that parents and providers have about end of life.

The family videos, podcasts and blogs can be an enlightening resource when questions arise about:

- Continuing to pursue curative or life-extending treatments
- Including the child and siblings in conversations about what end of life will look like
- Understanding medical orders and making advance care decision regarding resuscitation interventions
- Preparing for and anticipating end of life; bereavement; what end of life looks like for the family

Scripts

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

"Many families whose child has a serious medical problem have faced similar struggles. I have heard parents say that there is no one they trust more than other parents."

"That's what Courageous Parents Network is. It's by parents like you, for parents. Courageous Parents Network is a website and mobile app that has a parent blog, guides, and lots of video interviews and podcasts with parents, as well as with a few clinicians."

"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."

Recommending the website or perhaps showing them the app on your phone will let families know that CPN is a trusted, free, easily accessible resource that is available 24/7.

Conclusion

Nothing can replace the human interaction with clinicians that a child and family cherish. We know however it truly takes a village to care for the child with a serious illness and the family. CPN is honored to be a part of that village- offering parent, sibling and clinician voices to support families, help them feel less isolated and more empowered.

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Resources for Clinicians



Courageous Parents Network Referral Card

Order (free) cards to introduce families to CPN

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

Resources for Families:

Videos



Who We Are

<https://courageousparentsnetwork.org/videos/who-we-are>

What We Do

<https://courageousparentsnetwork.org/about/what-we-do>



Downloadable Guides

<https://courageousparentsnetwork.org/guides>

- Introducing Families to CPN
- CPN FAQ Sheet
- Printable CPN Info Sheet
- Understanding the Lived Family Experience
- Introducing Families to Palliative Care
- The Pediatrician's Role in Serious Illness
- Understanding Palliative Care and Hospice Care
- In Case of an Emergency... here is what others need to know about my child's care.
- Introduction to Pediatric Palliative Care
- What is Anticipatory Grief?
- Care Plan Book
- Navigating the Hospital
- Understanding Baseline
- Family Meeting: Being Prepared
- Communicating Effectively and Compassionately to Help Siblings Cope
- Strengthening Your Parenting Partnership
- Self Care: A Parent's Guide to Taking Care of Yourself (as well as Your Child)
- For Grandparents and Extended Family of Children with Serious Illness
- Managing Pain in Children with Complex Chronic Conditions
- Medical Orders
- Scoliosis and Spine / Spinal Surgery: Facts and Decision-Making
- What is Tube Feeding?
- Considering Tracheostomy
- Evaluating the Clinical Trial Option: A guide to CPN Resources
- Clinical Trial Unit: Questions to Consider
- Glossary: Understanding Clinical Trial Terms
- Guide to Informed Consent
- Planning Transition from Pediatric to Adult Providers for the Fully-Dependent Child
- Exploring Out-of-Home Placement
- Considerations for Guardianship & Medical Decision-Making
- End-of-Life Guide Part 1: Preparing
- End-of-Life Guide Part 2: What to Expect
- Understanding and Managing Nutritional Needs at End of Life
- Making Critical Care Choices: A Guide
- Facing End of Life Bibliography
- Bereavement Bibliography
- Supporting the Surviving Siblings
- Guide for Writing as Healing