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 resources
- Evaluate resources for self-education and educating colleagues on topics relating to the lived family experience

The Value of Anticipatory Guidance

Clinicians and families both struggle when a child faces a serious medical condition. Parents must learn to navigate a bewildering new world of the medical "system," engage with a host of new medical specialists, become familiar with the concept and symptoms of anticipatory grief, 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, or understanding of, the family's lived experience and spectrum of psycho-social and emotional needs. Each party can benefit from learning to effectively communicate with the other.

Caregivers Want Information and Validation

After the medical team, there is no one that caregivers trust more than their peers. Learning how other parents are facing (or have faced) similar challenges can help clarify for families what they do or don't want. They may use an insight to lean towards something they see, read or hear, or to react against it and lean 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. The resources are organized so that users can easily locate relevant content for the current stage in their illness

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journey, with the option to look ahead for information and guidance on what they might anticipate in the future.

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 and provide more family-centered care. In fact, clinicians regularly report that they turn to these resources to gain insight into the family experience and as a tool for educating colleagues and peers.

Courageous Parents Network Resources

All Courageous Parents Network programming and content is designed around topics and themes common to the lived family experience. The organization website, CourageousParentsNetwork.org, presents most of CPN's assets in a collection of digital experiences:

- Information about the organization itself
- Topic-specific portals, or initiatives, based on families' circumstances, full of content and related resources (videos, blog posts, downloadable guides)
  - *Navigating Medical Complexity*, to orient and guide families and others navigating a serious pediatric medical condition
    - Evaluating the Clinical Trial Option
  - *NeuroJourney*, dedicated to the specific medical and psychosocial needs and interests of families whose child has severe neurological impairment (SNI)
  - *Coping with Loss*, to encourage and reassure bereaved family members by offering perspectives on loss and grief
- Resources shared across the initiatives: Media Library, CPN Events, parent- and clinician-authored Blog
- Private site specifically for clinicians and educators

Which and When: Introducing CPN Resources

Any family whose child has a serious medical condition, even if the diagnosis or prognosis is unclear, will be able to relate to the experiences of other families shared across the CPN platform. They will likely be experiencing anticipatory grief. They will likely 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 siblings and on their relationships

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with others. In all cases, clinicians should be aware that not every family will be comfortable with every topic. Courageous Parents Network suggests that the initial introduction be to a particular topic that is relevant to the expressed need or the point of care. For example:

At diagnosis, parents will have many questions and concerns. Their initial focus will likely be on treatment and cure (if possible). Where appropriate, Courageous Parents Network may be a resource to mention, with emphasis on practical information from Navigating Medical Complexity, such as anticipatory grief, navigating the hospital, goals of care, and shared decision-making. (These and many more specific topics are also available in the NeuroJourney portal.)

Along the way, 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. 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. Similarly, the parents may be concerned about the impact of the illness on the siblings, for which direction to CPN's Siblings topic would be responsive.

Courageous Parents Network suggests that introduction is particularly appropriate at any time when the clinician is considering a referral to pediatric palliative care (PPC). CPN's strong endorsement of PPC is evident in every resource the organization produces. Especially if the family is wary and may be confusing palliative care with hospice care, CPN's specific section on palliative care, featuring parents talking about how PPC has supported them, can be an effective way to introduce parents to what palliative care is and how it helps.

Script for Introducing Courageous Parents Network

Using the family's expressed concerns may offer you an entry point to introduce CPN resources. 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 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

In addition to their clinicians, families need and want to hear from others who have traveled the path of serious pediatric illness. Courageous Parents Network offers access to voices they might otherwise never hear, to perspectives they might otherwise never encounter. This access gives parents assurance that they are not alone, and confidence to accompany and advocate for their child.