F.A.Q.

Introducing Courageous Parents Network





What is Courageous Parents Network?

Courageous Parents Network (CPN) is a nonprofit organization and a digital web, mobile) platform designed to support families of seriously ill children and the providers who care for them. All of this content is offered free of charge, 24/7, and is easily accessible on all devices (computer, phone, tablet).

- More than 500 videos and podcasts of families and providers discussing a wide range of subjects, from diagnosis to family care to advance care planning to bereavement.
- Downloadable guides to help families navigate the care "system" and important decisions; podcasts; curated modules on topics of particular interest; and a blog.
- *Provider Portal*, a provider-only section of *CPN that includes content* on best practices in communicating and shared decision-making, and a Video Search Tool for easy, convenient identification of materials to share with patients and colleagues.

Who should know about CPN?

Many providers introduce CPN to families as a way to increase their confidence and resilience, as they see that others have experienced what they're going through--and survived. If you are a PCP or specialist working with a family at any stage of the illness journey, encouraging caregivers to hear family and provider perspectives can be a gentle way to approach important discussions and challenges.

- At the time of diagnosis, to help the family adjust to their new reality.
- Along the way, to help with isolation, anticipatory grief, fear, sibling and relationship support.
- At a critical decision-point, to learn how others have navigated the choices.

CPN is also an effective tool for self-education and for in-service education and discussion.

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How should I introduce CPN to a family?

The *Provider Portal* offers details and scripts for initiating these conversations. Here is a way to begin:

"Many families whose child has a serious medical problem have faced similar struggles. They have taught us that it can be helpful to hear about others' experiences. Would it be helpful to you to learn how other families have thought about this?"

Where should we start?

We have identified three primary family priorities:

- To make good, informed decisions, consistent with the family's values.
- To support the entire family.
- To connect caregivers to the perspective of others.

They are represented by buttons that link to views of related content. Content can also be found by medium (video, podcast, guide, blog, etc.) and by diagnosis. Search and, in the *Provider Portal*, a Video Search Tool are also available.

CPN Content

How trustworthy is this content?

CPN is governed by a board of directors that includes medical professionals and parents, and is overseen by a Medical Advisory Board that reviews and vets the content.

What if my patient family isn't ready to see everything on the CPN site?

CPN doesn't shy away from the difficult topics, and we don't force any content on users. If caregivers aren't ready, you can simply provide links or download material that is appropriate to their situation. Beginning with a *Guided Pathway (digital modules of topic-specific, curated content)* is another, more focused way to introduce CPN.

What if my patient's condition is not one featured in the Diagnoses section?

CPN's philosophy is that many issues and challenges that families (and providers) face are relevant to all. While we continue to build out the diagnoses, focusing there isn't necessarily the only or best way to support a family.

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Do you offer content in other languages?

CPN videos are available with subtitles on YouTube. The Guides and Guided Pathways have been translated to Spanish by native speakers and can be found via *En Espanol* in the primary navigation.

Do you accept contributions from patient families?

Yes! Family perspectives are very important—and families also can find healing in sharing their stories. There are many different ways to contribute: video, blog post, podcast, etc. If you have a family interested in working with CPN, please ask them to contact us at connect@courageousparentsnetwork.org. We also welcome perspectives from providers; contact information is the same.

CPN Community

What else does CPN do?

Provider education is a growing, part of the CPN's program. All bereaved parents and/or pediatric palliative care providers, we think we speak with a unique combination of compassion and authority!

We are proud to have partnered with two major children's hospitals in the creation of a medical education curriculum now being utilized in residency programs across North America.

Our staff is available for rounds or workshops about the lived experience of patient families, on a host of topics. We also speak to biopharmaceutical companies and industry groups; and we lead or participate in workshops, panels, presentations and online events. For more information about this, see the *Speaking Engagements* page of courageousparentsnetwork.org.

And, CPN is active in the pediatric palliative care (PPC) advocacy movement, raising awareness of PPC through membership in coalitions, participation in events, and contributions of intellectual capital (articles, op eds, etc.).