

Courageous Parents Network Offers Digital Tools to Guide You, No Matter Where You are in the Care Journey

Caring for a child with a rare disease can feel overwhelming, as you navigate complex medical needs, changing abilities, and deep emotional challenges. [Courageous Parents Network](#) offers resources for families facing serious childhood illness, with guidance for today and what lies ahead, plus a [Media Library](#), [blog](#), and [events](#) designed to connect and support you. Wherever you are in your journey, you are not alone.

Here's how it can help:

[Navigating Medical Complexity](#)

Rare diseases often involves frequent decisions about seizures, feeding, mobility, and care coordination. This tool offers videos, guides, and practical resources organized into phases—[Orienting](#), [Navigating](#), and [Moving Forward](#)—to help you better understand what to expect and how to advocate for your child.

[NeuroJourney](#)

Designed for specifically for families of children with severe neurological conditions, this tool offers resources organized through four phases - [Adapting to Diagnosis](#), [Building Strengths](#), [Adjusting to Changes](#), and [Navigating Decline](#) – to help you to locate where you are in the care journey. The tool explores the interconnected relationship of the brain and body systems helping parents anticipate what medical complications may be part of their child's life and explore the emotions that often accompany changes in baseline. NeuroJourney, explained in [this video](#), is available in 5 languages and audio formats.

[Coping with Loss](#)

Created for bereaved families, Coping with Loss offers perspectives on loss and grief from families and clinicians of the CPN network. This digital tool is also organized into sections—[Understanding Grief](#), [Coping with Loss](#), and [Maintaining Connection](#)—with complementary resources and perspectives from families and caregivers on topics such as identity, caring for the siblings and continuing your bond with your child.

[For Clinicians and Care Teams](#)

If you're working with a family, [this portal](#) can help you better understand the lived experience. It includes parent voices and tools to support more compassionate, coordinated care.