

# Introducing Families to Navigating Medical Complexity



## Learning Objectives

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

- Articulate the value of Navigating Medical Complexity and its potential use in clinical training settings
- Identify appropriate opportunities to introduce the tool to families whose child has medical complexity

## Introduction

Families whose child has medical complexity encounter both medical issues and daunting physical, social and emotional challenges. Courageous Parents Network addresses many of the former (medical) in the section NeuroJourney, where changes in the central nervous system and how they affect other bodily systems are discussed in detail. Both NeuroJourney and Navigating Medical Complexity represent psychosocial topics which are the focus of this section and offer much more detail.

Navigating Medical Complexity topics are staged along phases as they commonly occur in the family experience:

**Orienting** – Collecting information and building a foundation of support as the journey begins

**Navigating** – Maximizing resiliency and making decisions that work for the child and family

**Moving Forward** – Adapting to the child's evolving baseline and re-orienting goals

The clinician and the patient family will find that this map of experience is fluid, with topics overlapping the phases. Parent and clinician commentary and perspective serve to normalize the experience, build a sense of agency and confidence, and help mitigate the sense of isolation that families so often encounter.

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## Suggestions for Introducing Navigating Medical Complexity

There is no one optimal time to introduce a family to this tool. A clinician might consider doing so:

- At the time of diagnosis, or shortly thereafter, if there is a sense that the caregivers will be prepared to confront some of the difficult topics discussed. Focusing on a single phase, or a certain aspect of a phase, might be helpful
- Along the way, as circumstances change and opportunities present themselves—especially when there is a change in the child’s baseline
- At a critical decision point about a medical intervention, such as introducing a feeding tube or mechanical ventilation
- As end of life approaches, as a gentle way to present material the family may desire but hesitate to request

## Scripts

Using the family’s expressed concerns may offer an entry point to introduce this material. You might say something like:

“Even though each family is unique, parents often face similar challenges and experience similar feelings when their child has a serious medical condition. There is an online resource that explains many of the challenges parents and their child may encounter. It was designed by families and clinicians who appreciate the emotions and all the planning that parents need to do. It may be helpful to you as a reminder of topics we are discussing. You can also use it to look ahead and see what else might be coming up for you to think about, or us to discuss.”

“[We can start by looking at the tool together, would you like to do so?] [You might like to take a look at it by yourself, see if it works for you. And if you have questions, we can talk them through together.]”

“The nonprofit behind this tool, Courageous Parents Network, has a worksheet where you can keep track of your thoughts, reactions, ideas and questions. It also provides some prompting questions for you to consider. Would you like to see that?”

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## Conclusion

Navigating Medical Complexity was developed in the spirit of offering anticipatory guidance to families (and their clinicians) facing extraordinarily difficult circumstances. It is a resource that will grow over time, as more topics are uncovered and more needs are expressed. Courageous Parents Network invites you to share your feedback at: [Connect@CourageousParentsNetwork.org](mailto:Connect@CourageousParentsNetwork.org).

[www.medicalcomplexity.org](http://www.medicalcomplexity.org)

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