

Tools and Resources for Families and Clinicians Caring for a Child with Severe Neurologic Impairment (SNI)

The Arc of a Life

Severe Neurologic Impairment is a complex condition, and it comes without a roadmap for families and others caring for a child. NeuroJourney is an educational resource and reference that presents many aspects of the SNI disease trajectory in a series of phases—the arc of a life—to help parents and other caregivers navigate the present and prepare for the future. Medical topics are discussed through the lens of changes in the central nervous system and how they affect many bodily systems. Psychosocial topics are also represented, along with commentary that brings in a holistic, palliative point of view.



Adapting to Diagnosis

Collecting information, care and support as issues emerge for the child and your journey begins.

Building Strengths

Maximizing the child's core skills and family resiliency to develop a foundation for the journey.

Adjusting to Changes

Making decisions and adapting to the child's evolving baseline throughout the journey.

Navigating Decline

Re-orienting goals and finding support alongside declines in the child's condition, preparing you for the end of your child's journey.

A Flexible Educational Resource

NeuroJourney supports parents in:

- Understanding interconnected medical considerations
- Building their child's care team
- Reflecting on goals of care and decisions they may encounter
- Communicating with clinicians, family and others

Clinicians employ NeuroJourney in:

- Speaking with parents about the interconnectedness of medical considerations as changes in the central nervous system affect other bodily systems
- Preparing caregivers with anticipatory guidance for the medical, emotional and social issues they may encounter
- Encouraging shared decision-making
- Training clinicians with emphasis on palliative care and palliative-aware practice

Collaboration of Courageous Parents Network and Pediatric Specialists

NeuroJourney is an initiative of Courageous Parents Network, created in partnership with Julie Hauer, MD FAAHPM; and Rachel Thienprayoon, MD MSCS FAAHPM FAAP, Cincinnati Children's Hospital; with significant contributions from advising medical reviewers, parent authors, and content editors.

“It is challenging enough for us as pediatric providers to understand the full scope of caring for a child with Severe Neurological Impairment, let alone the experience of families wading in these waters. I believe NeuroJourney will serve as a valuable long-term resource for our families: it combines a comprehensive medical overview provided by experts in SNI coupled with the practical consideration of caregivers who have already walked the walk with their own children.”

P. Galen DiDomizio, MD
 Medical College of Wisconsin, Assistant Professor of Pediatrics, Complex Care

Medical Considerations

Adapting to Diagnosis	Building Strengths	Adjusting to Changes	Navigating Decline
Collecting information, care and support as issues emerge for your child and your journey begins.	Maximizing your child's core skills and family resiliency to develop a foundation for the journey.	Making decisions and adapting to your child's evolving baseline throughout the journey.	Re-orienting goals and finding support alongside declines in your child's condition, preparing you for the end of your child's journey.
	Endocrine		
Gastrointestinal			
	Irritability and Pain		
Muscular-Skeletal			
Neurology			
Nutrition and Growth			
Pulmonary			
	Sleep		
	Urology		

Social and Emotional Considerations

Adapting to Diagnosis	Building Strengths	Adjusting to Changes	Navigating Decline
Collecting information, care and support as issues emerge for your child and your journey begins.	Maximizing your child's core skills and family resiliency to develop a foundation for the journey.	Making decisions and adapting to your child's evolving baseline throughout the journey.	Re-orienting goals and finding support alongside declines in your child's condition, preparing you for the end of your child's journey.
Goals of Care			
Anticipatory Grief			
Communicating the Diagnosis			
	Guilt and Regret		
	Partnership and Marriage		
Family Planning			
	Caregiver Well-being		
Supporting the Siblings			Siblings at End of Life
	Extended Family and Friends		
Spirituality and Faith			
Financial Planning			
Work			
	Out-of-Home Placement		
		Transition to Adulthood	
			Advance Care Planning and End of Life

More Information

To schedule a virtual or in-person presentation, please contact Courageous Parents Network at connect@courageousparentsnetwork.org.