Introducing Families to NeuroJourney

Learning Objectives

After reviewing this Guide you will be able to:

- Articulate the value of NeuroJourney and its potential use in clinical and clinical training settings
- Identify appropriate opportunities to introduce NeuroJourney to caregiver families caring for a child with Severe Neurological Impairment (SNI)

What Pediatric Clinicians Need to Know about NeuroJourney

SNI is a phrase used to describe a group of conditions, or disorders, that affect the central nervous system. Categories of SNI include metabolic neurodegenerative disorders, genetic conditions and syndromes, developmental epileptic encephalopathy and seizure disorders, and brain malformations, infections, and injuries. As they progress, these conditions commonly result in problems with motor skills, cognitive skills, and other medical complexity.

Families of a child with SNI typically encounter both medical issues and daunting physical, social and emotional challenges—all without an integrated way to understand what is occurring and what might occur. Acknowledging that a child with SNI may have a shorter life, NeuroJourney is an educational resource that seeks to help parents and other caregivers consider that life as a full arc. This digital tool 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 considerations are staged along these phases as they commonly occur, discussed through the lens of changes in the central nervous system and how they affect other bodily systems. Psychosocial topics are also represented, along with commentary that brings in a holistic, palliative point of view.

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NeuroJourney Phases

- Adapting to Diagnosis and building support
- Building Strengths to establish baseline and care for the child
- Adjusting to Changes as they occur along the arc of a life
- Navigating Decline as end of life approaches

Adapting to Diagnosis

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

Building Strengths

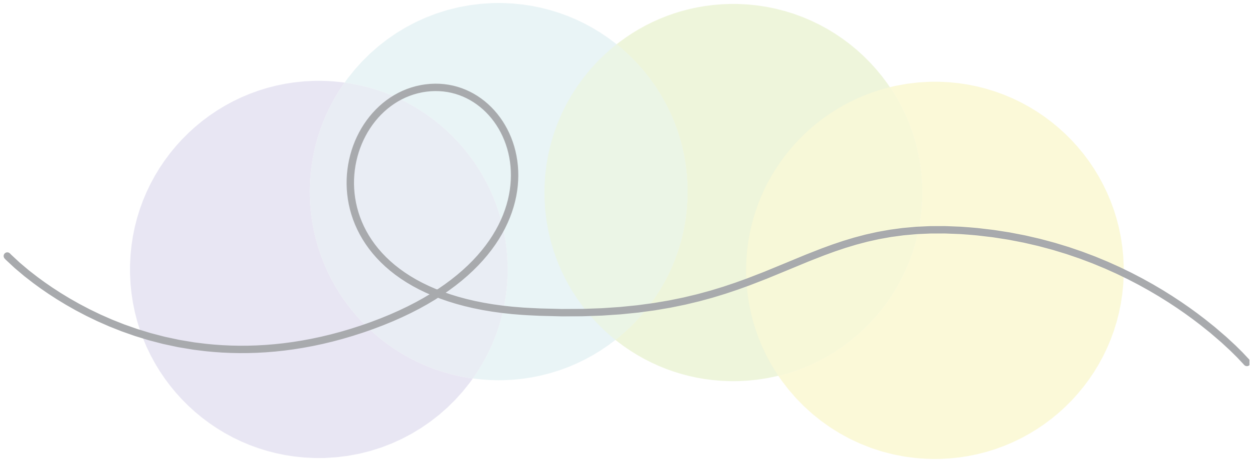
Maximizing the child's core skills and family resiliency to develop a foundation for the journey.

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.



NeuroJourney Arc of a Life

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Medical Considerations and Psychosocial Topics

NeuroJourney was 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.

Medical Considerations

Adapting to Diagnosis
Collecting information, care and support as issues emerge for your child and your journey begins.

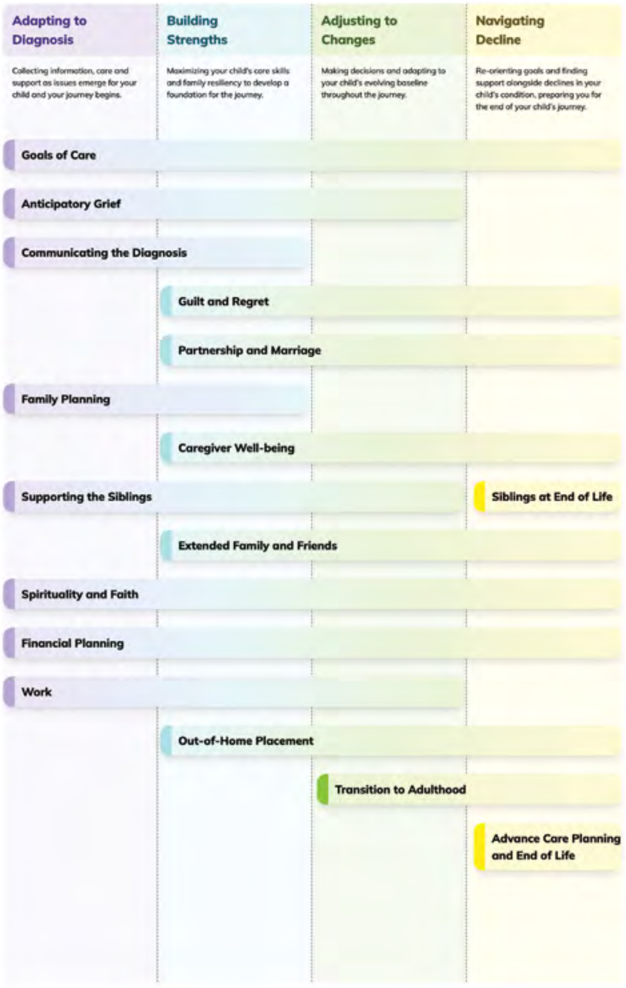
Building Strengths
Maximizing your child's core skills and family resiliency to develop a foundation for the journey.

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

Navigating Decline
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 & Emotional Considerations



Adapting to Diagnosis
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Building Strengths
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Adjusting to Changes
Making decisions and adapting to your child's evolving baseline throughout the journey.

Navigating Decline
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

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Using NeuroJourney Content

NeuroJourney is used by clinicians in explaining medical considerations, offering anticipatory guidance, and training clinicians with emphasis on palliative care and palliative-aware practice. This resource can also be used to support parents in

- Building their child's care team
- Understanding interconnected medical considerations
- Reflecting on goals of care
- Communicating about the child's condition with clinicians, family and others

Suggestions for Introducing NeuroJourney

There is no one optimal time to introduce NeuroJourney to a family. 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. The commentary in the medical chapters, and the psychosocial topics especially, are designed to help build a sense of agency and confidence
- 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 NeuroJourney. You might say something like the following:

> "Even though each family is unique, parents often face similar challenges and experience similar feelings when their child has neurological impairment. There is an online resource, NeuroJourney, that explains many of the challenges parents and their child may encounter.
>
> "NeuroJourney was designed by physicians and families that understand how complicated the medical issues are and what to expect. They also appreciate the emotions and all the planning that families need to do for their child and family. NeuroJourney might 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 us to discuss.

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

"The nonprofit behind NeuroJourney, 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?"

Conclusion

NeuroJourney was developed in the spirit of offering anticipatory guidance to families (and their clinicians) facing extraordinarily the 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.

Example: Integration of NeuroJourney within Outpatient Documentation

In the following example, the clinician has completed clinical documentation for John, a child with severe neurological impairment. In the After Visit Summary, the clinician described the recommendations and hyperlinked the page within NeuroJourney relevant to that topic.

AVS: Changes made Wed 1/3/2024

- Medications reviewed and updated.

- I introduced John's family to the Center for Complex and Rare Diseases covering our role in transitional care management, complex care coordination and symptom management. We made a shared decision to enroll.

- I introduced the concept of chronic neuropathic pain and we started gabapentin and clonidine as follows:
    - Start Gabapentin 0.3 mL (15 mg total) by G-tube route 3 (three) times a day for 7 days, THEN 0.6 mL (30 mg total) 3 (three) times a day for 7 days starting on 1/10, THEN 1 mL (50 mg total) 3 (three) times a day starting on 1/17. This is a medication that we will increase weekly unless John experiences side effects such as nystagmus, persistent sedation, tremor, ataxia, swelling.
    - Give clonidine 0.4 mL (8 mcg total) by G-tube route every 6 (six) hours as needed for breakthrough episodes that suggest autonomic storm events (suggested by facial flushing, muscle stiffening and tremors, hyperthermia) or central neuropathic pain (irritability to touch, noise, temperature change, tube feeding, gas), and insomnia. Hold for heartrate < 60.
    - I gave you a copy of Julie Hauer's Book.
    - We discussed the Courageous Parents Network's NeuroJourney, NeuroJourney.
    - You can read more here Irritability and Pain | NeuroJourney.

- We talked about motility, slow transit constipation and added senna to John's bowel plan as follows:
    - Senna 5 mL (8.8 mg total) by G-tube route Once Daily. May titrate from 2.5ml (4.4mg) to 5ml (8.8mg) to maintain daily bowel movements.
    - Continue using Miralax as ordered.
    - You can read more at Motility, Constipation and Diarrhea | NeuroJourney.

- We talked about sleep. John has issues with sleep disruption. He sleeps a lot during the day and is up more overnight. There are times when he is awake for more than a day. You can use clonidine prn to help with sleep. You can read more about sleep here Sleep | NeuroJourney.

- We discussed referrals needed and I referred John to pediatric cardiology, hematology, and genetics to establish care.

- Complex care to see John on 1/10 at 10:00 am coordinated with pulmonology and PMR in person.

NeuroJourney