Transitioning from childhood and adolescence to adulthood

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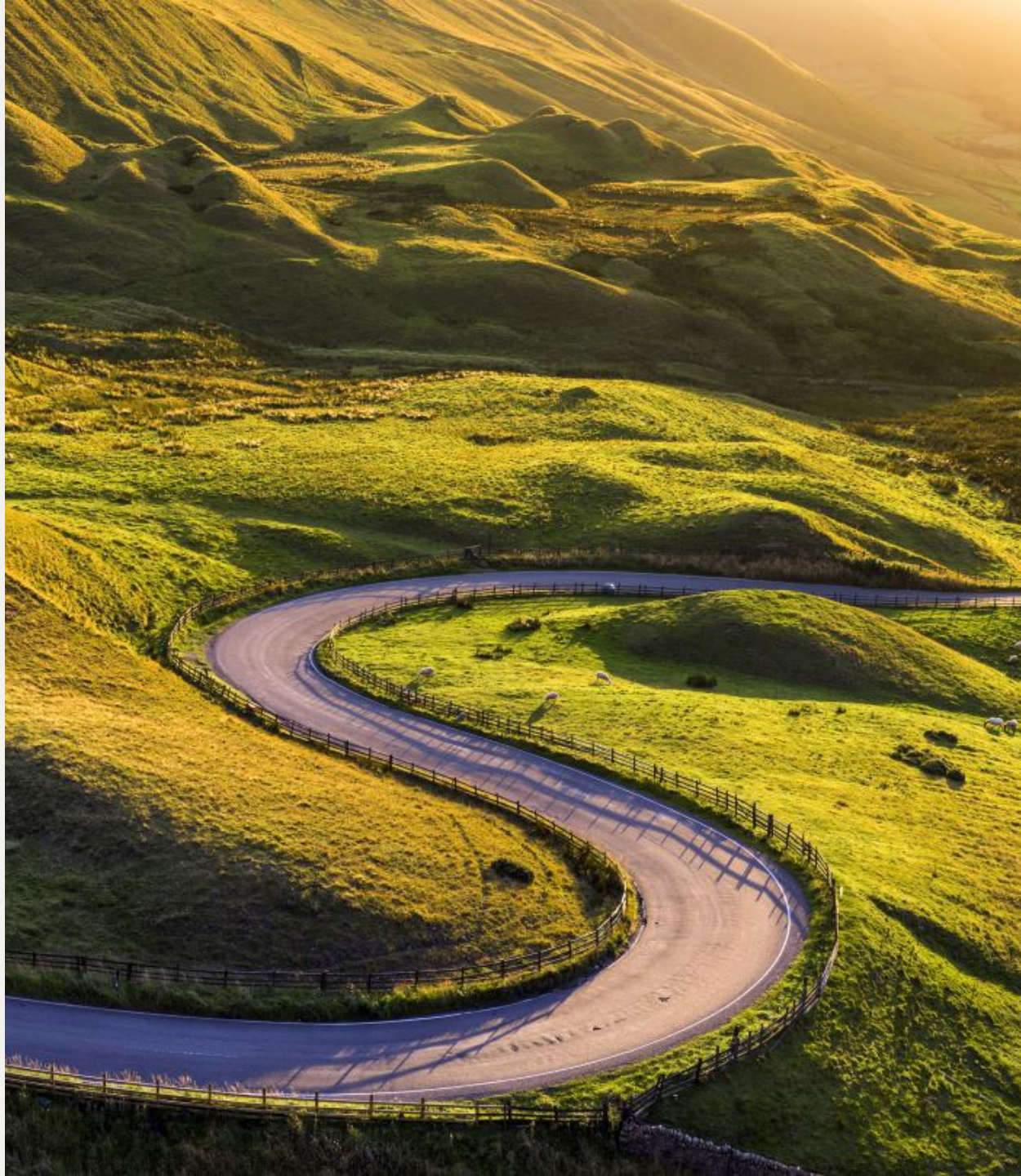

Disclosures

No disclosures to report.

Agenda

- What is transition?
- Planning for transition
- Unique needs for children with neuroinflammatory disease

What is transition?

A Journey

- Process of providing age and developmentally appropriate education and support to plan for the future
- Family centered pediatric care → individual centered adult care
- Empowering young people

Why Plan for Transition?

Pediatric neurology as a medical home

Prevent gaps in care

Allow time and preparation to build confidence

Improve social and psychological outcomes

Understand legal and financial implications

Ensure management of comorbidities

Identify touch point for questions or emergencies

August 23, 2016; 87 (8) CONTEMPORARY ISSUES

The neurologist's role in supporting transition to adult health care

A consensus statement

- Assess self-management skills at age 12.
- Discuss the expectation of transition by age 13.
- Discuss youth's expected legal competency by age 14.

- Yearly session topics
  - medical condition
  - medications and side effects
  - signs and symptoms of concern
  - genetic counseling and reproductive implications
  - puberty and sexuality
  - driving, alcohol, substance use
  - emotional/psychological concerns

- Identify adult provider(s) for the neurologic condition(s) before the anticipated time of transfer.
- Directly communicate with adult provider(s) to ensure an appointment is made and kept.

Brown et al. The neurologist's role in supporting transition to adult health care: A consensus statement. Neurology. 2016 Aug 23;87(8):835-40.

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The neurologist's role in supporting transition to adult health care

A consensus statement

By age 14, develop a transition plan

- Youth
- caregiver(s)
- other health care providers
- school personnel
- vocational professionals
- community services providers
- legal services (as needed)

Plan addresses health care, finance, legal concerns, primary care, other specialty care, education, employment, housing, and community services.

Summary of all health care issues:

- assessment of the youth's understanding of his or her neurologic diagnosis and management (including prognosis and any reproductive implications of the diagnosis)
- goals and preferences for adult service requirements
- timing of the transition to an adult provider of neurologic care
- any necessary additional testing or assessments to be completed before transfer
- emergency plans
- advanced plan of care (e.g., medical power of attorney, living will, do not resuscitate order)

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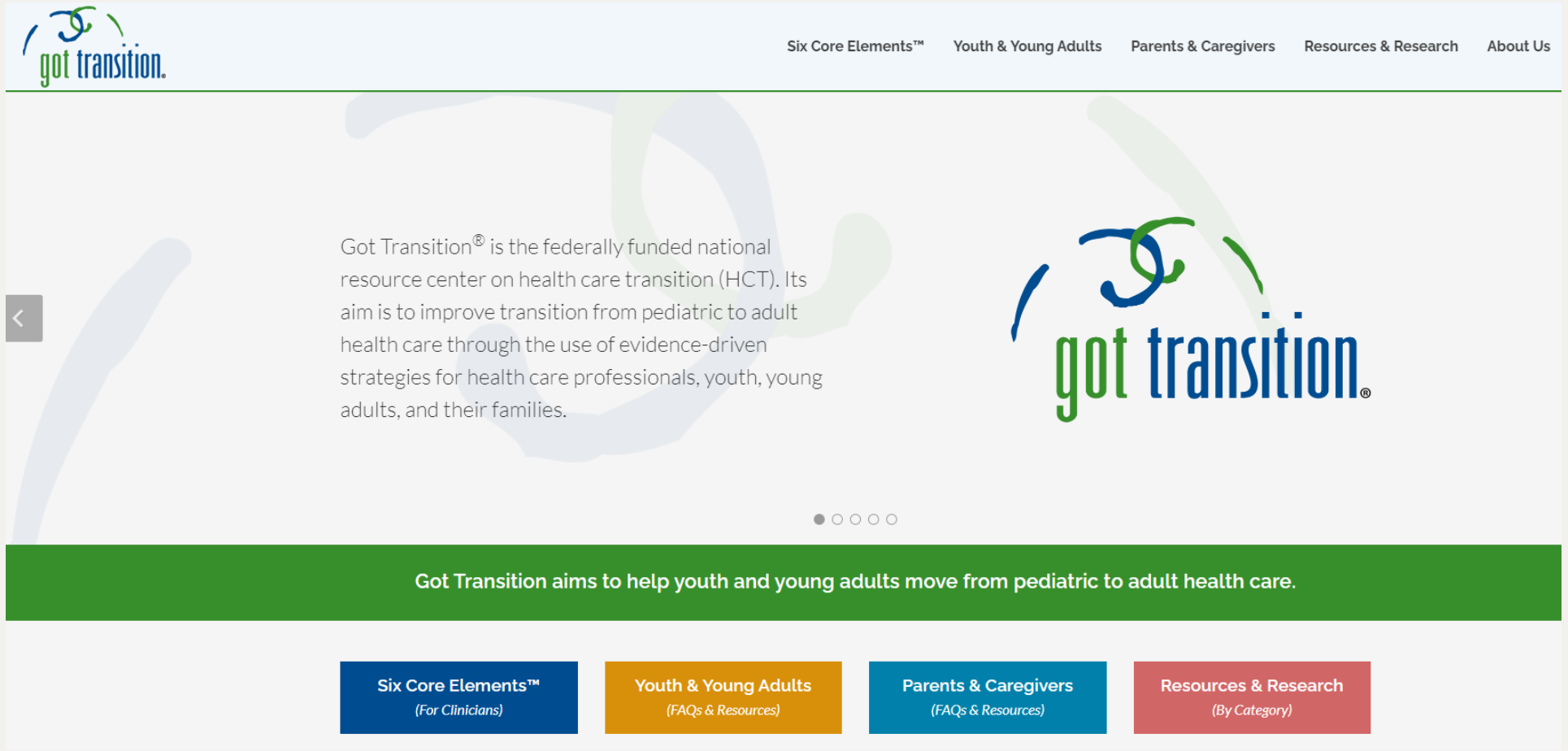


- Transition Readiness Assessment for youth

https://gottransition.org/6ce/leaving-readiness-assessment-youth

- Transition Readiness Assessment for parents/caregivers

https://gottransition.org/6ce/leaving-readiness-assessment-parent

Transition Readiness Assessment Questionnaire (TRAQ)

- Quick
- Valid
- Not disease specific

Wood et al. The Transition Readiness Assessment Questionnaire (TRAQ): its factor structure, reliability, and validity. Acad Pediatr. 2014 Jul-Aug;14(4):415-22.

Transition Readiness Assessment Questionnaire 5.0

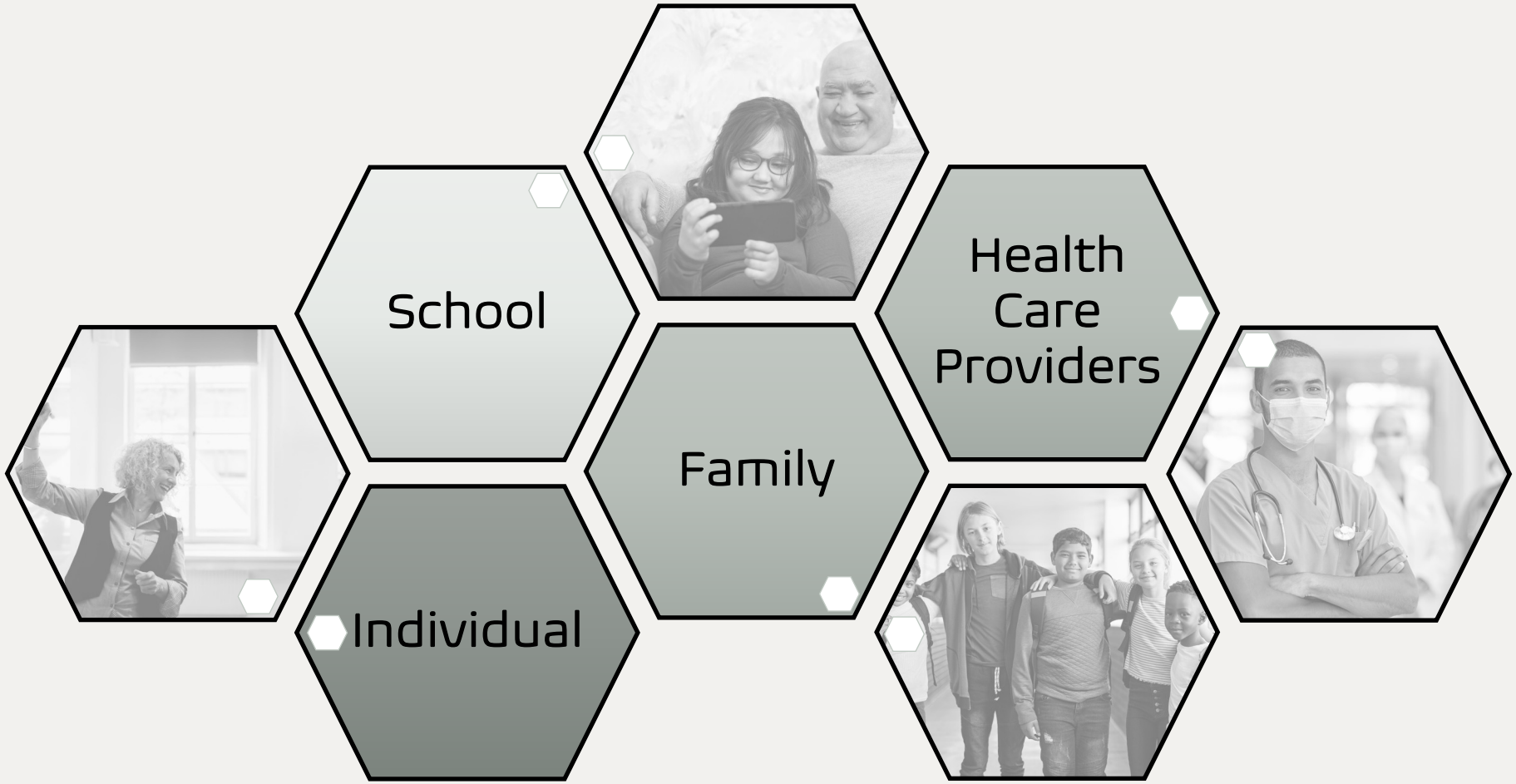
Directions: Please check the box that best describes your skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.

	No, I do not know how	No, but I want to learn	Yes, I am learning to do this	Yes, I started doing this	Yes, I always do this when I need to
	1	2	3	4	5
Managing Medications					
1. Do you fill a prescription if you need to?					
2. Do you know what to do if you are having a bad reaction to your medications?					
3. Do you take medications correctly and on your own?					
4. Do you reorder medications before they run out?					
Appointment Keeping					
5. Do you call the doctor's office to make an appointment?					
6. Do you follow-up on any referral for tests or check-ups or labs?					
7. Do you arrange for your ride to medical appointments?					
8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?					
9. Do you apply for health insurance if you lose your current coverage?					
10. Do you know what your health insurance covers?					
11. Do you manage your money & budget household expenses (For example: use checking/debit card)?					
Tracking Health Issues					
12. Do you fill out the medical history form, including a list of your allergies?					
13. Do you keep a calendar or list of medical and other appointments?					
14. Do you make a list of questions before the doctor's visit?					
15. Do you get financial help with school or work?					
Talking with Providers					
16. Do you tell the doctor or nurse what you are feeling?					
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?					
Managing Daily Activities					
18. Do you help plan or prepare meals/food?					
19. Do you keep home/room clean or clean-up after meals?					
20. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?					

Formalize Your Journey

12 -13 years	Phase 1	• Transition of medical care: What is it and why it matters • Explain your diagnosis: Explain your diagnosis (to peers, school) • Knowing medications and what they are used for
14 – 15 years	Phase 2	• Carrying an insurance card • Create an 'About Me' fact sheet for emergencies/new providers • Explain family medical history • When to get emergency care
16 – 17 years	Phase 3	• Making decisions as an adult • How to make an appointment • Refilling Medication
17 – 18 years	Phase 4	• Goals for adult care (where to transition care) • Create a medical summary • NI Clinic to make referrals for therapy and subspcialty referrals, update medications, transfer of records to adult provider • First appointment with adult provider • Graduation from clinic!
18+ years	Phase 5	• Seeing your adult provider • Transfer of care to adult provider

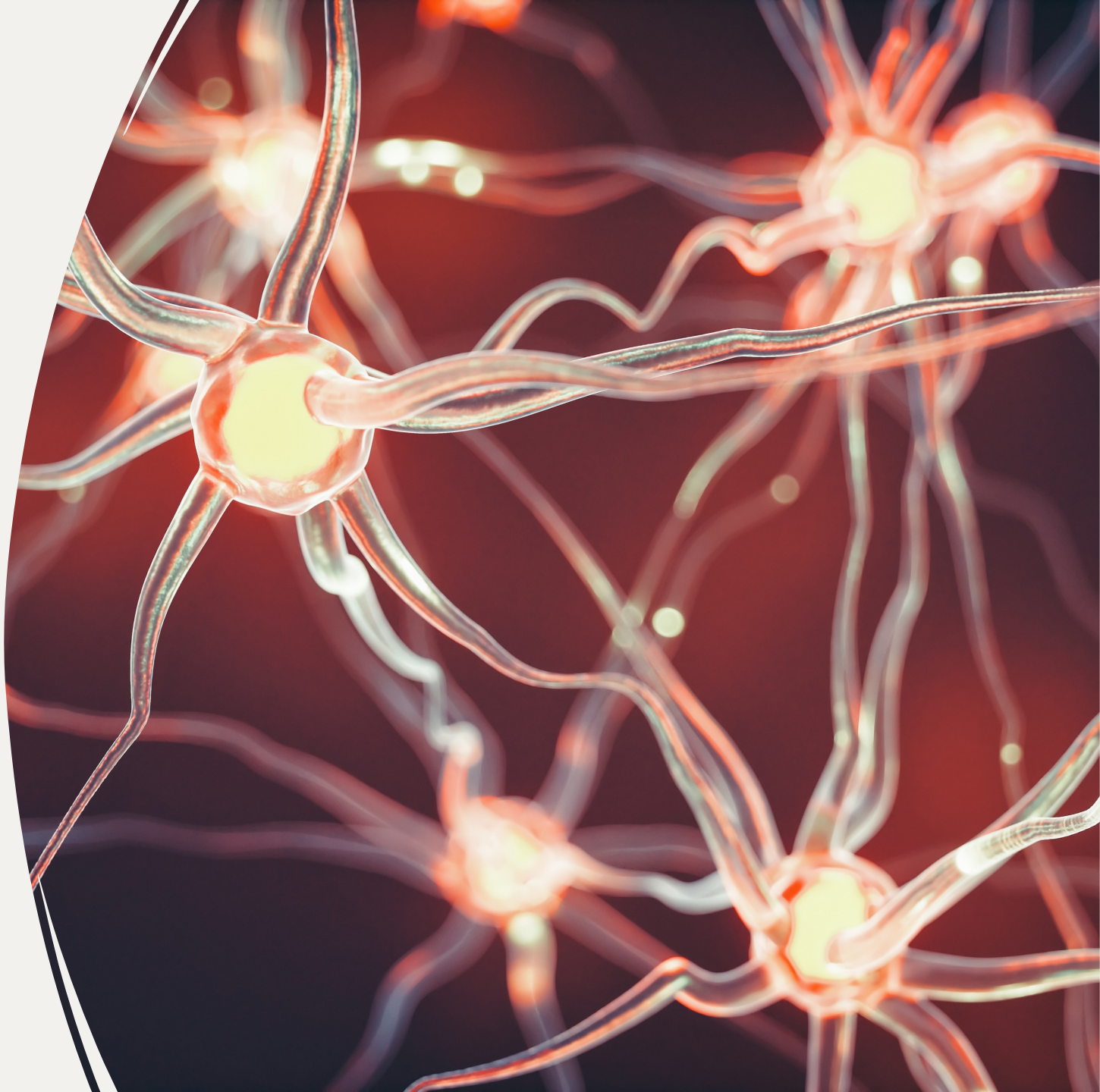
Transition Team



Each transition journey will be unique.

We need to meet families where they are and modify their transition plan over time.

Unique needs for children with neuroinflammatory disease







Legal Logistical Physical Mental Emotional

- Adolescent brain development: emotional, decision making, puberty and hormones
- Increased independence and desire to "feel normal"
- Psychiatric comorbidities
- Cognitive side effects of medications
- Time away from daily activities for medical appointments and care
- Multiple subspecialties
- Need to transition to community supports, especially psychosocial and interdisciplinary supports
- Advocacy resources for continuing school or entering the work force

Empowering young people

- Be transparent about differences in adult care culture
- Identify your child's unique needs
- Transition primary care provider before subspecialty transfer
- Graduated independence
- Have a Transition Plan Document

Summary

It’s a journey.

Graduated autonomy and practice with guidance.

Start early.

Formalize a transition plan.

Utilize your team.

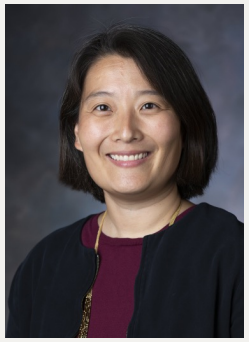
Family, friends, school, medical team

Individualized experience.

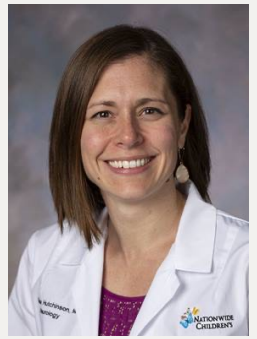
Empower independence.

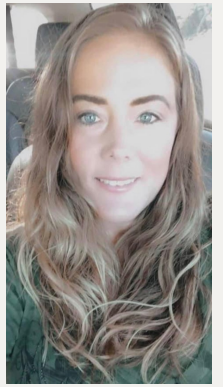
NCH Neuroimmune Team





Neuroimmunology Clinic
Nationwide Children's Hospital

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