Guidelines for Transitioning Patients to Adult Neurology Care

Introduction

Our pediatric neurology team is specialized in the care of infants, children and teens with neurological disorders. Some patients seen in our clinic will not need to see a neurologist when they become adults. Many patients will require ongoing care from a neurologist after they become adults, and we have developed these guidelines to guide this process.

What is Transition?

Transition refers to BOTH the transition of decision-making and other rights and responsibilities from caregivers to the patient AND the transfer of care from a pediatric to an adult provider.

Core Beliefs

Transition requires collaboration between the patient, the family/caregivers and our entire team. We are committed to supporting a smooth transition from adolescence into young adulthood.

This includes a clear and deliberate:

- Transition from an approach focused on talking with the parent(s)/guardian of a younger child to an approach focused on talking directly with the young adult who is responsible for his/her own decisions and self-care.

- The eventual Transfer of care to an adult neurology provider, including transfer of medical information from our setting to the adult practice. We will make every effort to help coordinate this transfer of care to the patient’s chosen adult neurology practice.

Timeline for Discussion, Planning, Preparation and Action

- Between the ages of 14-16 years of age, a beginning discussion about readiness for transition will occur.

- By age 18 years of age, young adults who are able will be fully involved in their own care, with adjustments made as needed for youth with intellectual disabilities or special healthcare needs.

- Between 18 and 21 years of age most young adults seen in our clinics will transfer to an adult neurologist.

- We honor the preferences of the patient and family regarding the best time for transfer of care.

Message to the Teen/Young Adult

We want you to have a lifetime of the best health you can have!

At 18 years of age, you become an adult, both medically and legally...

What does this mean for you?

Starting around age 14, we will begin the process of preparing you for this transition from “pediatric” care where your caregivers make decisions about you, to “adult” care where you make decisions.

During this process, we will:

- Teach and answer your questions.

- Spend more time with you alone during clinic visits when appropriate.

- Ask you to take on more responsibility for your care as you grow closer to reaching adulthood.

How do we protect your privacy once you are legally an adult?

Our approach to the care of young adults age 18 and older meets federal and state legal privacy requirements making the young adult the sole decision-maker about their care, and about the sharing of personal health information. Exceptions to this approach require legally valid, signed consent of the young adult, a custodial care or power of attorney document, or an adjudicated guardianship arrangement.