



THE NEUROLOGIST'S ROLE IN SUPPORTING TRANSITION TO ADULT HEALTH CARE

EIGHT COMMON PRINCIPLES



According to the U.S. Census Bureau, 18 million U.S. adolescents age 18-21 are moving into adulthood and will need to transition from pediatric to adult-centered health care. Appropriate planning of a youth's transition may assist in preventing gaps in care (Brown et al 2016), particularly when the individual has complex medical needs. In cases where the adolescent lives with a neurologic condition, the child neurologist plays an important role in ensuring that the transition from pediatric to adult care is successful. Providers of neurologic care should start transition discussions early, in partnership with families, and guide their patients' transition planning processes.

To help make transitioning to adult health care a reality for patients and families with neurologic conditions, the Child Neurology Foundation (CNF) convened a multidisciplinary panel

to develop the steps needed to ensure a complete and effective transition. CNF's panel developed 8 Common Principles that were then featured in a 2016 consensus statement published in the journal *Neurology*. This statement was endorsed by the American Academy of Neurology, the Child Neurology Society, the American Epilepsy Society, and the American Academy of Pediatrics. The authors of the consensus statement believe that the 8 Common Principles apply to a broad spectrum of neurologic conditions.

After publication, CNF set out to create tools that matched up with each of the 8 Common Principles. The tools are meant to help providers use the Principles in their practices and to help families communicate with providers around their child's transition needs and goals.



MAKING THE SWITCH: The child neurology team, in collaboration with the youth and caregivers, should help identify appropriate adult providers for the neurologic conditions before the anticipated time of transfer.



The 8 Common Principles and related tools are outlined as follows and can all be found on CNF's website, www.childneurologyfoundation.org/transitions



1. EXPECTATION OF TRANSITION

The first Principle highlights the expectation of transition. Ideally, the child neurology team will begin discussion about the expectation of transitioning with patients and caregivers no later than the youth's 13th birthday. Beginning the discussion early will give patients and their caregivers ample time to prepare for the need to transition out of pediatric care into adult care. To document and make this expectation clear, it is helpful to have an office **Transition Policy** that outlines the child neurology practice's approach to transitions as well as a **Transitions Checklist** which can be followed throughout the subsequent years.



2. YEARLY SELF-MANAGEMENT ASSESSMENT

The second Principle recommends that the child neurology team assess the youth's self-management skills starting at age 12 and will continue annually. Self-assessments should be entered into the youth's medical records. Youth with intellectual disabilities should not be excluded from this process, as many may be able to develop limited self-

management skills. However, in cases of a severe neurologic conditions in which self-management skills do not change, an annual reassessment may not be necessary. **Self-Care Assessment (Youth/Young Adult)** and **Self-Care Assessment (Parents/Caregivers)** tools can assist with this Principle.



3. ANNUAL DISCUSSION OF MEDICAL CONDITION AND AGE-APPROPRIATE CONCERNS

The child neurology team talks with each youth and his or her caregiver(s) about transition planning and transfer readiness at least annually at scheduled visits, beginning at age 13 years. At yearly scheduled visits, the neurologist should address (1) the youth's medical condition; (2) current medications and potential side effects; (3) signs and symptoms of concern; (4) genetic counseling and reproductive implications of the condition; (5) issues of puberty and sexuality; (6) driving, alcohol and substance use and (7) emotional/psychological concerns and wellness. The child neurology team should drive this discussion and continue to discuss the eventual transfer to adult care. In an ideal situation, these discussions take place separately from regularly scheduled visits.



4. EVALUATION OF LEGAL COMPETENCY

By the age of 14, the child neurology team should initiate discussion with the youth and their caregivers regarding the youth's expected legal competency (whether there is a need for legal guardianship and powers of attorney) in the medical record. If the youth's expected legal competency is unclear, an assessment of that capacity should be made annually. Some youth with cognitive limitations will require legal guardianship and powers of attorney to be established, preferably as soon as they reach the age of majority in their state. It's important to know that the process of obtaining legal guardianship can be expensive and time-consuming. However, social workers, IEP team members, and community-based support services may be helpful throughout the guardianship process.



5. ANNUAL REVIEW OF TRANSITION OF CARE PLAN

The child neurology team should assure that a transition plan that meets the comprehensive needs of the youth is developed in collaboration with the youth, caregiver(s), other health care providers, school personnel, vocational professionals, community services providers, and legal services (as needed). The plan addresses health care finance and legal concerns, primary care, other specialty care, education to employment, housing, and community services. It usually makes sense to transition from all pediatric subspecialists to adult care at the same time; this is most likely to be achieved when the various pediatric health care providers plan together. A pediatrician or family practitioner, acting as a medical home, may coordinate and maintain the comprehensive transition plan. The comprehensive transition plan should identify the youth's goals and barriers or obstacles to these goals. The **Plan of Care** tool can help with this Principle.



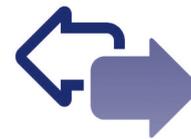
6. CHILD NEUROLOGY TEAM RESPONSIBILITIES

The child neurology team should develop and verify the neurologic component of the plan of care and update it annually. This should include a specific summary of all health care issues; a summary of the youth's and caregiver's goals for adult service requirements; the planned timing of the transition to an adult provider of neurologic care; any necessary additional testing or assessments to be completed before transfer; current assessment of the youth's understanding of his or her neurologic diagnosis and management (including prognosis and any reproductive implications of the diagnosis); and emergency plans and the youth's advanced plan of care (e.g., medical power of attorney, living will, do not resuscitate order). For those with profound cognitive disability, plans for establishing guardianship are also included. The **Plan of Care** tool can also help with this Principle.



7. IDENTIFICATION OF ADULT PROVIDER

One of the central challenges in the medical transition of youth with neurologic conditions is the identification of an appropriate adult provider. Therefore, the child neurology team, in collaboration with the youth and caregiver(s), should identify an appropriate adult provider(s) for the neurologic condition(s) before the anticipated time of transfer. Difficulties in identifying an adult provider should be considered. These include the possibility of an adult provider being uncomfortable accepting patients with intellectual or behavioral challenges, as well as treating patients with rare childhood-onset disorders, and those with inadequate health insurance coverage. When an adult health care provider is identified, the child neurology team should forward a **Transitions Package** that includes a **Transfer Letter** to the adult provider, **Self-Care Assessments**, **Plans of Care**, and a **Medical Summary**. An updated copy of this document should be routinely provided to the youth and caregiver. Identifying an adult provider should take place 1 to 2 years in advance of the actual transfer. If an adult health care provider is not identified before the planned time or age for transfer or transfer is delayed because of extenuating circumstances such as an acute event, the child neurology team is responsible for continuing to assure the youth receives adequate care.



8. TRANSFER COMPLETE

The child neurology team directly communicates with the appropriate, identified adult provider(s) to ensure that the identified provider agrees to accept the patient and an appointment is made and kept. The child neurology team documents the youth's transfer into the medical record. The child neurology team is responsible for confirming that the transfer has been completed and adult care is established. Adult health care providers may be more open to accepting patients with neurologic conditions if they are assured of direct access to the pediatric provider should questions arise. Note: There are some youth with neurologic disorders who are not expected to live into adulthood. Transition to an adult health care provider may not be appropriate in these cases, although child neurologists may still adapt their practice with these patients to maximize skills such as self-management and independence. Conversely, some children are treated by adult neurologists; a pediatric-friendly, family-based approach should evolve to an adult model as developmentally appropriate for the patient. In both of these cases, the common principles may help to identify areas of focus for such adaptation.

It's important to remember that transitioning from pediatric care to adult care should be thought of as a process, not an event. Using the 8 Common Principles to guide the transition process can ensure that it goes as smoothly as possible. •

To read the entire consensus statement and to view and download all transition tools developed by the Child Neurology Foundation, visit www.childneurologyfoundation.org/transitions.