

# BOSTON MEDICAL CENTER'S COMPREHENSIVE EPILEPSY CENTER

## GUIDELINES FOR TRANSITIONING PATIENTS TO ADULT-ORIENTED EPILEPSY CARE

MISSION STATEMENT: BOSTON MEDICAL CENTER'S COMPREHENSIVE EPILEPSY CARE PROGRAM SEEKS TO MAXIMIZE EACH PATIENT'S POTENTIAL TO PARTICIPATE IN THEIR HEALTH CARE DECISION MAKING AND ABILITY TO NAVIGATE THE HEALTH CARE SYSTEM. OUR GOAL IS TO RESPECT THE AUTONOMY OF EACH INDIVIDUAL AND PROVIDE THE EDUCATION AND SUPPORT NECESSARY FOR THEM TO THRIVE.

### BACKGROUND OF NEED FOR TRANSITIONING:

Boston Medical Center, child neurology/epilepsy program is committed to helping our patients make a smooth transition from pediatric to adult-oriented health care. This process involves working with youth and their families to prepare for the change from a "pediatric" model of care where parents make most decisions to an "adult" model of care where youth take full responsibility for decision-making. This means that we will spend time during the visit with the teen without the parents present in order to assist them in setting health priorities and supporting them in becoming more independent with their own health care. The epilepsy team at Boston Medical Center will evaluate adolescents and young adults for transition readiness yearly and will provide education that is tailored to the youth's ability.

At age 18, youth legally become adults. We respect that many of our young adult patient choose to continue to involve their families in health care decisions. However, we will no longer be able to discuss anything with parents about care or share any personal health information without the young adult's written consent, which we have at the clinic. If the youth has a condition that prevents him/her from making health care decisions, we encourage parents/caregivers to consider options for supported decision-making (legal guardianship).

Health care providers have an important role in planning and coordinating the successful transition from the pediatric to adult health care system for youth with epilepsy. Planning and

education around transition should start early, between ages 12 and 14 years of age. A successful transitioning plan requires care coordination among health care, educational, vocational, and community services providers. When done properly, a good plan will maximize the youth's ability to direct their healthcare needs and may prevent lapses in care and/or health crises for youth with epilepsy. Adolescents whose neurologic conditions result in cognitive or physical disability and their families may need supplemental support during this transition. (Neurology® 2016;87:1–6)

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**DEFINITION of ADULT-ORIENTED CARE:**

*Around age 14 years, our clinicians will begin to guide the teen toward becoming more responsible for their health care. Each teen will be educated about this process at their own pace depending on their needs.*

*The first step in moving toward adult-oriented care is for the clinician to have time talking to the teen or young adult without their parent in the room for a portion of the visit. This allows time for the clinician and patient to develop a better understanding of the youth's concerns, questions, and abilities. Over time, we will guide you through gaining more independence in managing your medications, understanding how to reach your care providers for medical concerns, and knowing how best to control your seizures.*

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**OPTIONS FOR LOCATION OF RECEIVING ADULT-ORIENTED EPILEPSY CARE:**

The Comprehensive Epilepsy Center at Boston Medical Center serves patients of all ages. Once you are a patient at Boston Medical Center, you will have access to the pediatric and adult epilepsy teams. For some, they may wish to receive adult oriented-epilepsy care in the Adult Epilepsy Clinic at 18 or 22 years; the adult epilepsy center is located on Shapiro 7. For others, they may need a more gradual transition from the pediatric to adult epilepsy teams and can receive adult-oriented epilepsy outpatient care from their pediatric epilepsy physician beginning at age 18 years. Before 22 years, however, we recommend a consult with one of the adult epilepsy physicians. Although outpatient epilepsy care can be provided in the pediatric epilepsy clinic beyond age 22 years, persons who need to be

admitted to the hospital will be under the care of the adult epilepsy inpatient team. The pediatric and adult epilepsy teams conference together whenever there is a shared patient.

TIME LINE

<b>AGE</b>	<b>GOAL</b>	<b>Responsible Team Member</b>
<b>12-14 years</b>	<i>Begin to encourage patient to ask more questions about their health</i>	<i>Pediatric Epilepsy Center Care Providers</i>
<b>14 years</b>	<i>Review the transition guidelines with patient and family</i>	<i>Pediatric Epilepsy Center Care Providers</i>
<b>14 years</b>	<i>Discuss what it means to receive adult-oriented care</i>	<i>Pediatric Epilepsy Center Care Providers</i>
<b>14 years-transition</b>	<i>Assess Transition Readiness yearly</i>	<i>Pediatric Epilepsy Center Care Providers and Patient/Family</i>
<b>14 years-</b>	<i>Develop comprehensive care plan that includes goals for transitioning</i>	<i>Patient, Family, Epilepsy Center, Primary Care</i>
<b>14 years</b>	Share care plan with the school and other important community providers	Patient, Family, Epilepsy Center, Primary Care
<b>15+ years</b>	<b>Plan for independence</b> <ul style="list-style-type: none"> <li>• Self-medication, maintain calendar, report need for prescriptions, pill box</li> <li>• Discuss driving if appropriate (based on state laws)</li> <li>• Encourage good health practices: discuss exercise, sleep, alcohol, drugs, sexuality (planned pregnancies)</li> </ul>	Patient, Family, Epilepsy Center, Primary Care

	<ul style="list-style-type: none"> <li>• Compliance issues (breakthrough seizures, implications on driving license, SUDEP)</li> <li>• Query for mood and sleep problems</li> <li>• Know emergency care plan</li> </ul>	
<b>16-17 years</b>	Identify a primary care provider who can provide adult-oriented care	Patient, Family, Primary Care
<b>16-17 years</b>	Identify the neurologist who will provide adult-oriented care. If care is to be provided by a pediatric neurologist/epileptologist define age or other reasons for transitioning to an adult neurologist/epileptologist	Patient, Family, Epilepsy Center
<b>16 years</b>	Consider neuropsychological evaluation and need for legal guardianship	Epilepsy Center, Primary Care
<b>16-17 years</b>	Discuss career and education goals beyond high school	Patient, Family, Epilepsy Center, Primary Care
<b>17 years</b>	Discuss safety for independent or supported living	Epilepsy Center, Primary Care
<b>17.5 years</b>	Introduction/Consult with Adult Epilepsy Team	Epilepsy Center
<b>17.5 years</b>	Share care plan with health care providers, current and future	Patient, Family, Epilepsy Center, Primary Care
<b>18 years</b>	Obtain consent from young adult to share information with family if desired; ensure legal guardianship where appropriate	Patient, Family, Epilepsy Center, Primary Care