Transitions from Pediatric Care to an Adult Health Care System
YOUR KIDS ARE GROWING UP: WHAT’S NEXT?
FROM THE EPILEPSY FOUNDATION

This webinar is for educational purposes and does not take the place of *individual* medical advice.
SPEAKERS

• Patricia Osborne Shafer, RN, MN- *Moderator*
  • Senior Director, Health Information and Resources and Associate Editor of epilepsy.com, Epilepsy Foundation
  • Epilepsy Nurse Specialist, Beth Israel Deaconess Medical Center, Boston Massachusetts

• Angel Hernandez, MD
  • Chief of the Division of Neurosciences, Helen DeVos Children’s Hospital, Grand Rapids, Michigan

• John Stern, MD
  • Professor of Neurology, Seizure Disorders Center and Reed Neurological Research Center, UCLA Neurology at the David Geffen School of Medicine, Los Angeles, California
PREPARING OUR YOUTH FOR LIFE AS AN ADULT WITH EPILEPSY: KEY ISSUES

• What needs does your child have?
• How do you find a new epilepsy team?
• What other supports might he or she need?
• How do you and your child transition to a new health care system? What can I expect?
PREPARING OUR YOUTH FOR LIFE AS AN ADULT WITH EPILEPSY: SCENARIOS

• 14 year old male with new onset seizures at night only. Not on medications yet.
• 16 year old female with juvenile myoclonic epilepsy. Currently controlled with sodium valproate.
• 19 year old female with focal seizures, not controlled after many trials with seizure medicines. Some cognitive and social problems interfering with college, work and peers. Wants to have children some day.
WHAT IS THE TRANSITION PROCESS IN EPILEPSY?
TALK ABOUT EXPECTATIONS FOR TRANSITION

Start after age 13

• Involves parents, guardians, youth and health care providers
• Consider spectrum of epilepsy, age of onset and possible outlook
• Current and future impact of epilepsy on quality of life critical
ASSESS YOUTH’S SELF-MANAGEMENT SKILLS

• Managing treatments
  • Ability to manage independently and safely
  • Complexity of regimens
  • Understanding drug interactions
  • Recognizing side effects

• Trigger management
  • Recognize triggers
  • Modify lifestyle or habits

• Talk About It

• Staying safe
  • Assessing risks
  • Knowing first aid and developing plans
  • Appropriate precautions

• Aiming for Zero Seizures
  • Knowing risks of seizures and treatments
  • Goals for seizures, quality of life and safety
  • Set priorities
PHASE IN TRANSITION PLANNING

- Together, providers, youth and parents identify issues
- Develop plan to address over the teen years
- Set milestones, revise yearly

Examples of Phased Planning

Series 1
Series 2
Series 3
Start by age 14

- Assess competency, decision-making, and readiness for independence
- What is outlook given type of epilepsy, other neurological or developmental issues?
- Is testing needed?
- Who does testing?
DEVELOP TRANSITION PLAN FOR COMPREHENSIVE CARE

By age 14

• Include epilepsy and other health care and support services
• Who else should be involved? (teachers, vocational or guidance counselors, mental health supports, funding agencies)
• What supports, systems, and insurance are available?
• Where are the gaps?
VERIFY THE NEUROLOGICAL ISSUES

Yearly

• What type of seizures and what is the outlook?
• Other neurological or associated problems – what impact will they have on transition?
• How does neurological problems affect a youth’s function? (walking, talking, driving, learning, relating,...)
IDENTIFY AN ADULT PROVIDER OR TEAM

Before anticipated change

• Consider type of providers
  • Does youth need an epilepsy team or single provider?

• Epilepsy specialist or generalist?

• Neuropsychology, social work, psychiatry, academic supports Vocational, physical, speech, or occupational therapy
IDENTIFY AN ADULT PROVIDER OR TEAM

Before anticipated change

• Will they take your insurance?

• What is the process involved?

• Role of primary care provider in organizing and/or supporting need for care?

• Is provider or team accessible?
MOVING INTO ADULT HEALTH CARE: A DIFFERENT PERSPECTIVE
REALISTIC EXPECTATIONS AND PRIORITIES

• What are priorities of the teen and parents? Are these similar? Realistic for age and health?
  • School, drive, work, safety, dating, pregnancy?
  • Where does seizure control fit?

• How should these be prioritized when moving into the adult health care system?
  • Do seizures need to be re-evaluated or change in medications first?
  • Do medical changes come before work?

• Consider consult with desired provider or team before changing providers to see if priorities and expectations match.
CRITICAL SELF-MANAGEMENT SKILLS FOR EPILEPSY CARE

• How much help does the teen need? Are skills new to them? Are they able to communicate with the team, develop trust? Can they talk about seizures?

“I have epilepsy and I’d like to #ShareMySeizure with you.”
FACTORS INFLUENCING DECISION MAKING AND CARE

- Role of person with epilepsy – willingness and ability to make decisions
- Cognitive function and emotional health
- Role of family – does teen want them involved, who, and to what extent?
- Social and living environment
  - Alone, roommates, family, school environment?
  - Social isolation? Friends available to help?
  - Other community supports
TYPES OF PROVIDERS

• Male with new onset seizures at night only. Not on medications yet.
  • Depends on status at time of transition. Have seizures resolved or persisted?

• Female with juvenile myoclonic epilepsy. Currently controlled with sodium valproate. Wants children
  • Epilepsy team - MD for change of medications, RN, SW for education/counseling; OB family planning

• Female with focal seizures, not controlled. Some cognitive and social problems interfering with college, work and peers.
  • Comprehensive epilepsy team
  • Consider surgery, devices, other treatments
NEUROLOGICAL CONCERNS FROM AN ADULT EPILEPTOLOGIST

• Have seizures changed over the teen years and what is the outlook?
• Any changes in brain imaging or EEG that need further attention?
• Any changes in neuropsychological function that may be related to epilepsy or medicines?
• Associated problems with an epilepsy syndrome or other health problems
FINDING PROVIDERS

- National Association of Epilepsy Centers (NAEC)
  - [https://www.naec-epilepsy.org/](https://www.naec-epilepsy.org/)
  - Accredited epilepsy centers
  - Does not include all epilepsy centers

- American Epilepsy Society (AES)
  - [https://my.aesnet.org/Find aDoctor](https://my.aesnet.org/Find aDoctor)
  - Database of members of AES physicians

24/7 Helpline

Help • Hope • Support

How Can You Contact Us?
You can speak with trained information specialists on our Epilepsy & Seizures 24/7 Helpline at any time by calling:

**Our Toll-Free Helpline: 1-800-332-1000**
(EN ESPAÑOL 1-866-748-8008)

Calls are answered 24 hours a day, 7 days a week

ASK A QUESTION ONLINE

NOTE: Please be aware that the Epilepsy & Seizures 24/7 Helpline is an information and referral line and is not staffed by clinical professionals. We do not provide medical services, diagnosis, treatment recommendations or laboratory test analysis. Our staff can only provide information based upon published materials that have been approved by the Foundation’s Professional Advisory Board and we make referrals to independent resources.

Search for Resources

Search for epilepsy resources in your area.
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Please visit epilepsy.com for more information on youth and families living with epilepsy.