

The National Coordinating Center for Epilepsy has developed the Strengthen & Enhance Epilepsy Knowledge Training as a resource to help build capacity and start conversations amongst medical residents, school nurses, social workers, community health workers, and public health professionals regarding the care of children and youth with epilepsy. This training is intended to be self-guided or facilitated as a Lunch and Learn opportunity to encourage discussion in a short 30-minute presentation. This training consists of a pre-recorded didactic lecture presentation, presenter slides, and a case study for the facilitator.

Facilitated Lunch and Learn - Strengthen & Enhance Epilepsy Knowledge Training

Instructions: The story below presents an example of the complexities and nuances associated with various epileptic syndromes, from the perspective of a pediatric clinician/medical home. It is recommended that this story be presented and discussed during the Lunch and Learn series. Refer to the discussion questions and possible answers in the module slides to guide the discussion.

Case:

An 18-year-old with epilepsy since the age of 4 returns to her pediatric neurologist for a follow-up visit. She currently has well-controlled epilepsy for the past 12 months and she has no other chronic medical conditions. She has not seen her general pediatrician for 2 years and when her mother called the pediatrician's office about updating her immunizations, she was informed that they needed to find an adult doctor as her pediatrician's practice does not see people over 18 years old.

She came today with her mother as usual. However, she is worried that she will need to find an adult neurologist as she is planning to leave home for college located 1 hour from her home in a few weeks and wonders how she will get her medications from her mother in college.

Case Study Questions & Answers

Use the questions below to guide conversation following the story. Possible answers are bulleted below each question. The responses are by no means exhaustive.

1) What kind of planning for her transition to adult health care should have happened prior to this visit with either the general pediatrician or pediatric neurologist?

Suggested Answers:

- a) There should have been visits in which the young adult and her general pediatrician or pediatric neurologist met without her mother beginning around the age of 14. This would have given the young adult a chance to build her autonomy and enhance her comfortability to answer questions on her own. The general pediatrician should have begun to speak and interface directly with her around the age of 14 even when the parents are in the visit explaining to the parents that they can answer if she does not know the answer or encourage them to help provide guidance.
- b) A discussion of the practice's policy on when she needs to move to an adult practice and how the practice will help her gain the skills, she needs to manage her own health. Ideally this should be first mentioned between the ages of 12-14 years old.
- c) The practice could have offered a health care skills assessment (eg, knowing her medications and how to get them refilled, how to make an appointment, knowing when to go to an emergency room,

understand her insurance, etc) and educational information on how to manage her health and health care.

- d) The general pediatrician/neurologist should have held a discussion with the young adult and her caregiver to create a medical summary and a health care transition plan (including a seizure action plan and goals to transition to college and an adult practice). It would be updated to share with her new adult physician when she transfers to their care.
 - i) Discuss who and how to tell others about her epilepsy (eg, schoolteachers, friends, teammates, etc)
 - ii) Discuss and plan when to transfer her care to an adult primary care physician first and then to an adult neurologist.
- e) The general pediatrician/neurologist should have held a discussion with the young adult before the age of 18 about what it means to legally be an adult at the age of 18, especially for the confidentiality of her medical records and that her parents should not be in the visit with her unless she consents to them being present. The pediatrician and the pediatric neurologist should practice an adult model of care at age 18 to prepare her for being seen as an adult in an adult health care setting.
- f) The general pediatrician/neurologist should discuss seeing a gynecologist and the interaction between oral contraceptives and anti-epileptic medications.

2) What key issues and skills should her pediatric practice address now that she will be going to college in a few weeks?

Suggested Answers:

- a) A skills assessment should be completed to help concentrate on helping the young adult understand her medications and learn how to fill her prescriptions while away for school (eg, where is the nearest pharmacy? How will she pick them up-does she have a car? Does she know when and how to contact your office if she needs more medication?).
- b) A medical summary and emergency care plan should be created or updated in collaboration with the young adult
 - i) Discuss all those who should receive a copy of her medical summary and emergency care plan.
- c) Discuss what she needs to do when she gets to college (eg, find and talk to the disability student office about any needed accommodations, know where student health is located, how to access behavioral health on campus, what is the nearest emergency room, etc).
 - i) Learn about her insurance coverage and how long she is covered on her parent's medical plan?
 - ii) Clarify whether the college health system accepts her insurance?
 - iii) Verify if her current physician is in a health system that has a health care location near her college for sharing of her medical records.
- d) Now that she is 18 years old, it is appropriate for the young adult's confidentiality that the practice use an adult model of care and there be a discussion without her mother in the room about being seen alone for her privacy.
- e) Discuss the change to an adult primary care physician and the different role that the adult primary care physician will have in her care. Discuss her preferences for her new physician and offer suggestions of adult physicians. Discuss if she has a gynecologist and the issue of birth control.
- f) After finding an adult primary care physician, discuss that, at a future visit, she will need to transition to an adult neurologist and offer suggestions after listening to her preferences.

3) What is an adult model of care?

Suggested Answers:

- a) The adult model of care (AMC) places emerging adults in the center of their care acknowledging that adults are primarily responsible for their own health care. At the age of 18, the young adult is legally an adult who has control of her health decisions and medical records. She must give permission for others to be on a medical visit or see her medical records. This approach should be discussed with her parents to remind them of her new legal status as an adult at age 18.

4) Should you ask the mother to leave the room?

Suggested Answers:

- a) Unless there is legal shared decision-making or guardianship documentation in force, it is appropriate for the young adult's confidentiality that there be a discussion with her without her mother in the room about if she wants to be seen alone.
 - i) If yes, how would you handle asking her mother to leave the room?

Suggested answer:

- (1) Explain the practice's policy around age 18 and the legal ramifications of her daughter being an adult and ask her to step out for a moment so you can speak with her daughter alone. Remind her that she will always be an important support daughter should learn to manage her own health and learn how ask her support team for assistance.

5) Who should be a part of her support team in college?

Suggested Answers:

- a) The main point is that her physician discusses this to remind her she has a support system who she can call on to assist her. She is not alone in her new college environment.
 - i) Some ideas are parents, siblings, high school and new college friends or team and club mates, counselors, school nurse, new college roommates, etc.

If you have any questions regarding epilepsy or this facilitated mini training, please contact:
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