

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 module slides to help guide the discussion.

Arianna is a 16-year-old Hispanic female who presents for a sports physical for soccer. She has a history of juvenile myoclonic epilepsy that has been well-controlled lately. She takes lamotrigine twice a day and her last seizure was 6 months ago. Her typical seizures are myoclonic jerks in the morning where she will drop her beverage and she has had 3 generalized tonic-clonic seizures in her life. Arianna also had infrequent absence seizures in middle school. In the past she has not needed rescue medications, however, she has a seizure action plan that recommends intranasal midazolam be administered if a seizure of more than 5 minutes occurs. She is asking about attending a sleep away soccer camp in a rural part of her state for a week this summer and is excited about the possibility because many of her high school teammates attended last year.

Arianna's mother expresses apprehension about her attending camp given her epilepsy. However, Arianna is concerned that if she doesn't attend, she may not be promoted to the Varsity team this year. She feels that her parents are overprotective of her compared to her siblings and expresses frustration that this is related to her epilepsy. She also expresses excitement about getting her learner's permit and driving soon.

The clinic medical assistant mentions that when doing medication reconciliation her mother declined a refill for her intranasal midazolam rescue medication because it is "expensive and she has never needed it".

### 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 might be the concerns regarding Arianna attending sleepaway camp? What would be the benefits? What activity limitations or precautions might be necessary? Specifically, her mother asks about swimming.**

*Suggested Answers:*

- a) Arianna's mother likely has a number of concerns related to Arianna's safety attending sleepaway camp, such concerns could include medication compliance, supervision by individuals not as familiar with Arianna and her seizure history as her family and friends, capability and comfort of staff responding to a seizure emergency, and possibility of situations that could lower the seizure threshold, such as sleep deprivation.
  - i) The potential benefits of attending camp are numerous. Attending may allow for opportunities for learning, team building, socialization, and physical activity to promote health. It is important to make sure that children and youth with epilepsy (CYE) are treated like the children and youth that they are. They are first and foremost individuals, who happen to have a chronic medical condition which does not define who they are.
- b) It is feasible for CYE to safely participate in summer camp. There are some steps that can help to enhance participation in camp, such as, a discussion with their neurologist to ensure that the camper is on a stable dose of medication. Also, check to see if there are any recommended adjustments in the medication plan. Lastly, be sure to contact the neurologist if there are side effects during a medication change that could interfere with typical daily activities, and ultimately, with participation in camp.
- c) Facilitate a conversation between the camper and camp staff regarding how seizures present, potential triggers, how to respond to different seizures, medication management, activity limitations and acceptable activities, to improve the comfort of all involved.
- d) Encourage family/camper to review camp policies and discuss instructions well in advance of starting camp regarding expected routine and camp policies about medication administration/storage. Such preparation can help ease potential anxiety of receiving information at the last minute. Ensure that a seizure action plan is completed and submitted to the camp in advance of the start date. Make sure the camper knows the importance of taking medications as instructed and knows what to do if a dose is missed.
- e) Patients with epilepsy are generally cautioned against activities where a fall could lead to significant injury, such as climbing. However, with proper safety equipment, precautions, and supervision, such activities could be considered for some campers. Generally, individuals with epilepsy should be seizure-free for over 1 year before considering higher-risk recreational activities like scuba diving, rock climbing, and motorsports.
- f) When it comes to water safety, CYE should never swim alone. A seizure occurring in water can lead to drowning. A child with a history of seizures should be supervised by

a person who is capable of swimming and can provide emergency assistance if needed. Showers are recommended instead of baths. Normal water safety precautions are advised (ie, personal floating devices (PFDs) for water sports, etc)

**2) Does Arianna require seizure rescue medication? Are there any concerns about her having this at camp? (Consider: Is it a controlled substance? Refrigeration? Self-administration?)**

*Suggested Answers:*

- a) A rescue medication is indicated for Arianna, who has a history of generalized tonic-clonic seizures. While her seizures have self-resolved within a few minutes in the past, epilepsy is unpredictable, and she is still at risk for having prolonged or frequent seizures.
- b) Abortive seizure rescue medications are benzodiazepines, examples include diazepam, midazolam, clonazepam, and lorazepam.
- c) Benzodiazepines are a schedule IV drug and a controlled substance. Like at schools, these medications should be kept at the camp medical office. These should not be carried by the CYE.
- d) Since these medications are typically used for generalized tonic-clonic seizures over 5 minutes or clusters of seizures, the CYE would likely be unable to self-administer the medication.
- e) It is important to remember that seizures can present in many different ways and seizure action plans can vary significantly among individuals. It is important to encourage CYE and caregivers to work with their neurologists to produce clearly documented seizure action plans that can be readily available by camp staff and school staff alike. The Epilepsy Foundation has a site with resources specifically for camp preparedness, including fillable seizure action plans (SAP), medical supplement form, seizure diary, and camp checklist: [Resources and Seizure Action Plans for Summer Camp | Epilepsy Foundation](#).

**3) Demonstrate how you might engage in shared decision making with Arianna and her mom, helping to address her mom's concerns, while helping mom see how Arianna could safely be more independent.**

*Suggested Answers:*

- a) As a teenager, Arianna is likely seeking more independence and her mother's concerns over her safety could possibly lead to frustration in Arianna and tension in their relationship. Offering some ideas for Arianna to take steps towards achieving more independence and autonomy in her medical care may be helpful. Perhaps Arianna can begin to use an app on her phone to help her to track when she has taken her medication and provide reminders if she forgets. She can demonstrate maturity and responsibility that may lead to her family gaining more peace of mind and offering more independence. She may be able to use apps to track her seizures as well, maintaining some independence while providing her caregivers insight into her seizure frequency.
- b) Primarily engage with Arianna and encourage her to answer questions/develop plans first with caregiver's input as she becomes more autonomous.
  - i) The American Academy of Pediatrics outlines a [4-Step Framework for Shared Decision-making in Pediatrics](#).

**4) Are there concerns regarding Arianna driving? What are some safety factors to discuss?**

*Suggested Answer:*

- a) If a driver has a seizure, their life, and the lives of others on the road can be put in jeopardy. The laws of each state differ in restrictions and limitations placed on drivers with epilepsy. It is important for patients and physicians to know the relevant laws in their state. In most circumstances, the Department of Motor Vehicles, not the physician, makes the decisions on driving. People with epilepsy are legally obligated to report seizures to the DMV, and to disclose any history of epilepsy when applying for or renewing a driver's license.

**5) Discuss the risks and benefits of having rescue medication. What resources might be available to help Arianna's family with the cost associated with the medication?**

*Suggested Answers:*

- a) The longer a seizure lasts, the more difficult it can become to stop. The intended benefit is to prevent longer or more frequent seizures from progressing to status epilepticus.
- b) Potential risks include the side effect profile of benzodiazepines (sedation, respiratory depression, etc.), cost and ability to obtain, some routes of administration, and the potential for heightened stress and anxiety among CYE and/or caregivers about having the medication ready and when to administer.
- c) There are several forms of benzodiazepines that can be utilized for seizure abortive medications. Rectal diazepam has been a common formulation; however, the route of administration can be burdensome and uncomfortable. Some medications, such as oral dissolvable clonazepam, can be administered inside the cheek, however, it is important to be cautious not to place a finger beyond the teeth, as an unexpected bite could occur. Furthermore, some patients may drool or have foaming of saliva during seizures, and the absorption of the medication could be compromised and potential for choking could be a concern. More recently, there are FDA approved nasal formulations of diazepam (6 years +) and midazolam (12 years +) for seizure clusters. Given that these formulations are newer, there is no available generic and cost may present a concern. However, both formulations have patients' savings programs.
- d) Patients may also be eligible for state insurance programs based upon medical conditions that may also help cover additional medical costs.

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

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