



How to Support a Child or Teen with Epilepsy

Most children and teens with epilepsy (</English/health-issues/conditions/seizures/Pages/Seizures-and-Epilepsy-in-Children.aspx>) live full, active lives that include school, friends, sports and other activities. How much epilepsy interrupts a child's life depends upon the kind of epilepsy, the success of treatment (</English/health-issues/conditions/seizures/Pages/Epilepsy-in-Children-Diagnosis-and-Treatment.aspx>) and many other factors. Talk with your child's doctor about safely participating in activities.



As your child grows, help them become more independent. Driving, college, career, marriage and raising a family certainly are possible for the vast majority of people with epilepsy. (See, *"Teen to Teen: Managing Seizures While Figuring Out New Life Situations,"* below.)

Tips to encourage & support your child with epilepsy

- Learn as much as you can about epilepsy. Discuss epilepsy openly and honestly with your child. Also help your child talk openly and honestly with others (</English/health-issues/conditions/seizures/Pages/Talking-About-Epilepsy-with-Children,-Family-and-Friends.aspx>) about epilepsy.
- Avoid saying things that could make your child feel like a problem or burden. Be positive and praise (</English/ages-stages/gradeschool/Pages/Helping-Your-Child-Develop-A-Healthy-Sense-of-Self-Esteem.aspx>) your child's success.
- Encourage sports, hobbies and other interests. Help your child make friends (</English/family-life/power-of-play/Pages/What-Parents-Can-Do-to-Support-Friendships.aspx>). Continue family activities and traditions.
- Make time for yourself without feeling guilty. Respite (<https://www.epilepsy.com/stories/respice-care-lending-hand-caregivers>) allows you to take care of yourself so that you are physically and mentally better able to care for your child.
- Build a support network for you and your child. Resources are available through the Epilepsy Foundation (<http://www.epilepsy.com/affiliates>), Parent to Parent-USA, (<http://www.p2pusa.org/>) Parent Training and Information Centers (<http://www.parentcenterhub.org/find-your-center/>) and Family Voices: Family-to-Family Health Information Centers (<http://www.familyvoices.org/>).
- Establish routines. Routines, schedules and structure are what keep all busy families going. Schedule a regular time for homework.
- Have your child take medication at the same time every day. Involve them in taking charge of their medications.
- Make sure your child gets enough sleep (</English/healthy-living/emotional-wellness/Pages/Sleep-and-Mental-Health.aspx>) to lower the risk of seizures (</English/health-issues/conditions/seizures/Pages/Seizures-and-Epilepsy-in-Children.aspx>).



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Infants & toddlers with epilepsy

Seizures occur most frequently during the first few years of life. This is a time when the brain is going through its most dramatic growth and changes. Recognizing and treating seizures as early as possible can help avoid learning and developmental delays (</English/ages-stages/toddler/Pages/Assessing-Developmental-Delays.aspx>).

However, diagnosing seizures in infants can be difficult. They cannot communicate what they are feeling after a seizure or during medical tests. As a parent or caregiver, your observations are key. They are especially valuable and necessary for doctor's to effectively treat infants and toddlers with epilepsy.

Finding child care for infants & toddlers with epilepsy

One of the biggest challenges parents of infants or toddlers with epilepsy can face is child care. Some child care centers may not admit children with epilepsy. Some refuse to give them emergency anti-seizure medication, even though they may be required to do so by the Americans with Disabilities Act (</English/health-issues/conditions/learning-disabilities/Pages/Your-Right-to-Special-Services.aspx>). Your local Epilepsy Foundation can provide information about laws and resources in your area. See here for more information (<http://www.epilepsy.com/learn/seizures-youth/about-newborns-and-infants>).

School-age children with epilepsy

When children are older, having epilepsy can impact many parts of their lives. This includes how well they do in school, what sports they can play and how they are treated by friends. The more you can do to help their child lead an active, normal life, the better.

As with all school-age children, it is best to establish routines and set clear rules and limits. Sometimes, parents worry that upsetting a child with epilepsy can lead to a seizure. Usually, if you stay calm and your child is old enough to understand why you are stopping a certain behavior, it should not increase the risk of a seizure. Talk with your child's doctor if you have concerns about the best way to discipline (</english/family-life/family-dynamics/communication-discipline/Pages/default.aspx>).

Teens with epilepsy

The preteen and early teen years are difficult for everyone. It is a time of great change, new challenges and some dangerous temptations. For adolescents with epilepsy, the risks and insecurities of this age are increased. It is important to talk as openly as possible with your teen about epilepsy and any other concerns.

- **Dating.** This is a normal part of teen life, but it's far from easy. A first date can be nerve-wracking under the best of circumstances, but epilepsy just adds another twist. Teens often worry about how much and how soon they should tell their date about their epilepsy. They also worry about rejection. Here are some dating tips and ideas (<http://www.epilepsy.com/learn/age-groups/youth/dating/to>) to share with your teen.
- **Puberty.** Changing bodies affect how children look, feel and think. Changes in hormones can also affect seizures and medication needs, especially for girls. Sometimes, teens need to change in the amount or type of medication they are taking based on behavioral changes, for example.
- **Social life.** Having friends and fitting in may seem to be all a teen thinks about. Being "different" in any way, such as having epilepsy, is not easy. While parents can't make their child "popular," they can help their child understand that having a few good friends is actually more important than having a lot of casual acquaintances. Teens should be encouraged to talk about epilepsy with their friends.
- **Substance abuse.** Alcohol and drugs are dangerous for all children. This is even more true for children who are prone to seizures and may be taking medication for epilepsy. Discuss the risks with your child. Then talk some more, and encourage your child's doctor and others your child respects to talk to them, too. Even if it seems like your child is not paying attention, the message may eventually sink in. Discuss not only the risks, but also ways to get out of uncomfortable situations.



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- **Responsibility.** This is the time when teens are learning to be more independent and that their actions have consequences. If a teen gets epilepsy at this age, it could affect their independence for a while. As a teen begins to spend more time away from home, they will need to start taking on some new responsibilities. Work with your child and doctor to figure out the best way to organize and monitor their condition when they are away from home. When teens learn to drive, parents will need to check their local state driving laws (<http://www.epilepsy.com/driving-laws>).

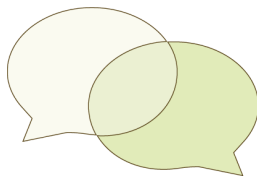
Helping teens with epilepsy transition to adult health care

Parents and medical professionals should work as a team to prepare kids for their move into adulthood and help them transition (</English/family-life/health-management/Pages/How-to-Prepare-for-a-Move-to-a-Doctor-Who-Cares-for-Adults.aspx>) into managing their health condition. This will include responsibilities such as:

- Keeping track of medications
- Refilling prescriptions
- Making doctor appointments
- Asking questions of the medical team, etc.

For more information and resources on building a care notebook, click here

(<https://www.medicalhomeportal.org/living-with-child/caring-for-children-with-special-health-care-needs/managing-and-coordinating-care/care-notebook>).



Teen to Teen

Managing Seizures While Figuring Out New Life Situations

By: Amber Sorenson, MA

There were several times during my childhood that I had "fainting spells." These may have been seizures, but I wasn't officially diagnosed with epilepsy until age 21. By then, I had experienced two **tonic-clonic seizures** (</English/health-issues/conditions/seizures/Pages/Seizures-and-Epilepsy-in-Children.aspx>) during a relatively short time frame while studying abroad in England. Although I wasn't aware of it until a few years before my diagnosis, I was at an increased risk for epilepsy because I had experienced significant **head trauma** (</English/health-issues/injuries-emergencies/Pages/Head-Injury.aspx>) as an infant.



In England, after numerous imaging tests, ER visits and trips to the neurologist, I started on levetiracetam. This is one of the most common anti-seizure medications. I also learned a lot about the importance of **self-care** (</English/healthy-living/emotional-wellness/Building-Resilience/Pages/healthy-self-care-for-teens-how-families-can-help.aspx>) to help lower the risk for breakthrough seizures. For me, this meant getting enough sleep, keeping stress to a minimum (easier said than done!) and perhaps most importantly, taking my medication as prescribed.

Eventually, I returned to the U.S. I graduated with my bachelor's degree, went on to graduate school and earned a master's degree. I was seizure-free for over three years. Then, after the first week of my first full-time job and a big move, I had another tonic-clonic seizure. It was the first one I'd had in years. I hadn't missed taking any medication



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My levetiracetam dose was adjusted, but I continued to have seizures over the next year—roughly one every 3 to 4 months. Despite every medication adjustment, I was left unable to drive for the better part of my first year out of school. I had to rely a lot on help from others to do things like getting to work or getting groceries.

Since I had been seizure-free for so long, having them so frequently that first year "on my own" left me with a lot of uncertainty. My primary care provider started me on some anxiety medication. I tried a few different kinds over the next year. Mental health issues like **anxiety** (https://effectivehealthcare.ahrq.gov/sites/default/files/nt_docs/anxiety-adolescents-topic-brief.pdf) and depression are heightened among people with epilepsy. But I think that can especially be the case for **teenagers** (<https://www.epilepsy.com/parents-and-caregivers/teens>) and young adults trying to figure out new life situations on top of having seizures.

I also started seeing a therapist. I highly recommend this, especially for anyone facing seizures that seem difficult to control with medication alone. For teens and young adults, in particular, therapy is a great means to just talk about anything and everything, which can help lower stress levels.

After my most recent seizure (the first one that happened in a public place), I got a medical ID bracelet. Although I already had medical ID set up on my phone, this gives me a bit more peace of mind if I'm out and about, on my own.

Amber Sorenson, MA, serves as a Young Adult Council member of the American Academy of Pediatrics' National Coordinating Center for Epilepsy, and as a Patient Experience Bureau member and Transition Expert Panel member for the Child Neurology Foundation. In addition to serving in advocacy roles for those living with epilepsy, she has authored several publications on the effects of pediatric abusive head trauma on families.

Explaining epilepsy to teachers & friends

Help others in your child's life understand epilepsy. Make sure others know what to do if your child has a seizure (/English/health-issues/conditions/seizures/Pages/Seizure-First-Aid-for-Children.aspx). This will help keep your child safe, feel more comfortable and do better in school (/English/health-issues/conditions/seizures/Pages/Children-with-Epilepsy-at-School.aspx). By talking openly and honestly about epilepsy, parents reduce some of the stigma and fear about it.

More information

- Seizures and Epilepsy in Children (/English/health-issues/conditions/seizures/Pages/Seizures-and-Epilepsy-in-Children.aspx)
- Epilepsy in Children: Diagnosis & Treatment (/English/health-issues/conditions/seizures/Pages/Epilepsy-in-Children-Diagnosis-and-Treatment.aspx)
- Children With Epilepsy at School (/English/health-issues/conditions/seizures/Pages/Children-with-Epilepsy-at-School.aspx)
- What is a Child Neurologist? (/English/family-life/health-management/pediatric-specialists/Pages/What-is-a-Child-Neurologist.aspx)
- Young Adults With Epilepsy Share Their Stories (<https://www.aap.org/en/patient-care/epilepsy/young-adults-with-epilepsy-share-their-story/>) (National Coordinating Center for Epilepsy)
- Epilepsy Foundation (<http://www.epilepsy.com/>)

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