



H.O.P.E.
MENTORING PROGRAM™

Helping Other People with Epilepsy



Seizures in the Teen Years



EPILEPSY
FOUNDATION®

Not another moment lost to seizures™

About the Epilepsy Foundation

The Foundation's mission is to ensure that people with epilepsy have access to all life experiences and to prevent, control and cure epilepsy through research, education, advocacy and services.

The Foundation offers information and assistance to people of all ages who are living with epilepsy, and their families, through its Epilepsy Resource Center.

The Epilepsy Foundation's H.O.P.E. (Helping Other People with Epilepsy) Mentoring Program offers mentoring and presentations on epilepsy to individuals, families and in community living settings.

To find out more about the H.O.P.E. Mentoring Program or the name of a participating Epilepsy Foundation near you, call 1-877-467-3496, or visit www.epilepsyfoundation.org

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This pamphlet provides general information about epilepsy to the public. It is not medical advice. People with epilepsy should not make changes in treatment or activities based on this information without first consulting a physician.



Thirteen-year-old Mary has staring spells called absence seizures. She sometimes has muscle jerks of the arms, called myoclonic seizures. The episodes come on abruptly and without warning. At first, her parents were unsure what exactly this behavior was, and thought she was just acting out. But after tests a different diagnosis was made: Mary was having seizures because she had epilepsy.

Teenagers and Seizures

Being a teenager is an adventure. From driving to dating, sports to activities, homework to that first job, teenagers face big challenges.

Teens who have epilepsy (also known as seizure disorders) face other big challenges, too. Like explaining seizures to other people. Wondering how their friends are going to react. Never knowing when the next seizure's going to happen.

A big challenge is the fact that other teens may not know much about epilepsy. Seizures can look strange sometimes—and that can be a problem, too.

Nobody wants to be different, but sometimes there are differences that affect people's lives—and people just have to deal with it.

Dealing with epilepsy is a challenge—for teens with the condition and their friends. Answering some of the questions that teens have is what this pamphlet is all about. We hope it helps.

Tell Us Why

Q. Why did epilepsy happen to me?

That's hard to say. Often, the doctors can't come up with a reason. Some things that can lead to epilepsy are: problems in development before birth, severe infections that involve the brain, a severe head injury, certain genetic factors. But that doesn't mean that your epilepsy was caused by any of these things.

Q. Will I always have it?

That depends. Some people find that seizures go into remission after a few years. Others will continue to have seizures unless they take meds to prevent them.

FAST FACTS ABOUT EPILEPSY AND TEENS

- *One in 100 teenagers has epilepsy (a seizure disorder).*
- *It's a condition in the brain that sometimes makes people have seizures.*
- *Anyone, at any age, can develop epilepsy. But it is NOT contagious.*
- *Often, there's no known cause.*
- *Teens with epilepsy take medication to prevent seizures. Some use other kinds of treatment.*
- *Some teens have lots of seizures. Some have very few or none at all.*
- *Teens with epilepsy play sports, hang out and go to regular schools.*
- *Teens with epilepsy want to be treated just like everyone else.*

Q. Is there a cure for epilepsy?

Not yet. Medications don't cure epilepsy the way an antibiotic can cure an infection. They only work if they're taken regularly. That doesn't mean you'll have to take them for the rest of your life. After a while you and your doctor may decide that slowly discontinuing your meds is worth a try. But that's something only your doctor can advise you about.

***NEVER STOP MEDS ON YOUR OWN.
YOU'D RISK A BAD SEIZURE.***

Q. I take epilepsy meds and others, too. Sometimes it's hard to remember what I've taken.

Time to get organized. That's your best bet to keep track of medication. You could get a watch or a pillbox, or even a PDA with an alarm and set it for each time you have to take a pill.

FAST FACTS ABOUT SEIZURES

- *Seizures can make you stop and stare.*
- *Seizures can make you wander around as if you were totally out of it.*
- *Seizures can make your muscles jerk.*
- *Seizures can make you fall suddenly to the ground.*
- *Seizures are usually over in seconds or minutes.*
- *Seizures can make your arms and legs shake.*
- *Seizures are not likely to hurt your brain or your intelligence.*

Q. Is there any other way to treat epilepsy?

Surgery to remove a small area of the brain may work for some people. Brain stimulation via a large nerve in your neck (vagus nerve stimulation, or VNS, therapy) may help.

There's also a weird diet (lots of fat, hardly any carbs—forget the pizza and the bread—and no sugar) that helps little kids with seizures. But it's not a do-it-yourself diet. It's called the ketogenic diet. It's serious medicine and you have to be really disciplined to make it work.

Q. I worry about having a seizure. Suppose nobody knows how to help me?

You can make sure your friends know. If you have the kind of seizure where you fall and shake, tell them to clear things out of your way, put something soft and flat under your head, and turn you on your side to prevent choking. That's pretty straightforward.

If you have the kind of seizure where you seem to be totally out of it, tell your friends to look out for you, to block the way to hazards like a busy street if that's where you seem to be heading, to explain to others what's happening and to stay cool, and to stay with you until you're back to normal. That's pretty straightforward, too.

Lots of people with seizures wear I.D. bracelets that say "Epilepsy" or "Seizure Disorder." It helps other people who may not know you recognize what's happening when you have a seizure and do the right thing for you.



Sixteen-year-old Josh and his family have experienced a roller coaster of emotions throughout his year of frequent, uncontrolled seizures. At the beginning, they did not know how to help him during a seizure.

Q. I met someone I really like, but I don't know when to tell him I have epilepsy. When's the best time?

It depends how often you have seizures. If you have them quite often, you're going to want him to know early on what to expect and what to do. Think of the shock if he didn't know. That's liable to be a bigger turn off than your careful explanation.

If you have very few seizures or none at all, you could probably wait until the relationship is more solid. Either way, there's no guarantee that he'll respond well. But if he doesn't, at least you will know whether he's worthy of your friendship.

Q. Will I be able to get my driver's license?

Yes, if you are not having any seizures that make you black out or lose control of what you're doing. How long you have to be seizure-free before you can drive depends on which state you are living in. The time ranges from three months to a year. You also have to make a real commitment to take your meds every day, on time, so you don't risk having a seizure on the road.

Q. I've had a couple of seizures but I don't want to tell my doctor because I'm afraid I'll lose my license.

If you don't tell the doctor, you're missing a chance to adjust your meds so you won't have more seizures. The bigger risk is that you'll have a seizure while driving. While it's tough not being able to drive for a while, you don't want to risk having a bad accident that hurts you or someone else.

Q. If I lose my license because of seizures, can I ever get it back?

Yes. Once you have been seizure-free (really seizure-free) for however long your state requires, you can re-apply and get your license back.

Q. There's alcohol and sometimes drugs at parties. It makes me feel really different to always say no. How would they affect my seizures?

Using either is a real risk, because both are against the law and you could get caught. You don't want that kind of trouble. Besides, mixing street drugs with epilepsy meds is



Fourteen-year-old Leslie was diagnosed with epilepsy and responded well to medication at first. But once she hit adolescence, her seizures became more frequent. Throughout this time, Leslie kept going to school, and kept up with her studies, like a silent warrior. Leslie has tried several other medical options to reduce her seizures. Today, she has fewer side effects and fewer seizures.

even riskier. Some illegal drugs—cocaine, for example—can cause seizures in people who don't even have epilepsy.

Other illegal substances, like pot, may contain all kinds of additives that could be harmful to you. As for alcohol, it's unlikely to cause a seizure immediately, but it may the following day. Remember, just one seizure can set you back on qualifying for a driver's license.

Q. Will I be able to go to college? Get a job?

Yes, to both. If your high school grades are good enough to get you into college if you didn't have epilepsy, there's no reason to think that having epilepsy would be a barrier.

Sometimes, the meds might affect how quickly you can complete tests and similar projects. In most cases, you should be able to work with the college administration to

take a lighter credit load and even have extra time to complete your work.

The key to getting a job is to have marketable skills and some work experience. Try building a resume with part time jobs while you're still in high school and at college, or do some volunteering or community service. Sometimes volunteer jobs can become permanent ones.

Q. Will I be able to have children? Will they have epilepsy?

Chances are good that you will be able to have children, just like anyone else, and chances are they will not have epilepsy. There are genetic factors in epilepsy, but it's not inherited as predictably as curly hair or blue eyes.

Q. My parents don't want me to play sports. They think it'll make the seizures worse. But I really want to. How can I make them see how important this is to me?

Have you tried raising this question with your doctor? He or she could be a good ally—depending on the sport and how your seizures affect you. Most teens with epilepsy should be able to run track and play basketball or tennis or other sports with no problems.

Swimming alone is not a good idea, at any time for any one. Swimming with others who know you have epilepsy and are good enough swimmers to help you if you should have a seizure is a better plan.

Protective helmets can reduce the risk of head injury from cycling, baseball and football, although not completely. Helping parents let

go is never easy, and it's especially tough when a teenager has a medical problem. Perhaps you can convince them to let you try and see how things go.

Q. Ever since I started having seizures I've felt very down and sad. I worry all the time about having seizures. Nothing seems like fun any more. Could the seizures be doing that, or is it just because I hate having epilepsy?

It could be a combination of both. It could also be the medicines. Tell your parents how you're feeling and see if you can get an appointment with your doctor to find out what is causing you to feel this way. A change in medicine might help. Depression and anxiety are not things to ignore. They can be treated successfully.

Q. I think I'm more likely to have seizures when I'm really stressed or tired. Is that possible?

Yes, being under stress or not getting enough sleep can trigger seizures in some people. All nighters are not a good idea when you have epilepsy. That doesn't mean you have to nap all the time, just get an average amount of sleep to feel rested.

Q. Someone told me flashing lights or even video games can cause seizures. Is that right? I really like the games, and I've never had a seizure when playing them. What's the story?

Some people are what's called photosensitive, which means they may have seizures if a light flashing at a certain rate is shined in their eyes or they look at flashing images of light and dark.

If you've had an EEG test, they probably did a photosensitivity test as well, using a light, to see if your EEG would respond. If you didn't have a seizure, or there were no telltale signs on your EEG, then flashing lights or flashing video game images may not be a problem for you.

Q. When I asked the doctor about the kind of epilepsy I had, she told me a lot of long words. How can I find out more about it?

The Epilepsy Foundation's website, www.epilepsyfoundation.org has a lot of information about types of epilepsy and types of seizures—no, they're not the same thing. A section of the site, called E2R (which stands for Entitled to Respect) has additional information for teens, and there's a teen discussion group under the heading of eCommunities where you can interact with other teens.

Some local Epilepsy Foundations have teen groups where you can get to know others who are living with seizures.

Epilepsy 101

Epilepsy is an underlying condition in the brain that from time to time produces electrical disturbances that affect awareness, movement, sensations or behavior. The electrical disturbances are called seizures.

Seizures can be partial (where only part of the brain is affected) or generalized (where a wave of energy affects the whole brain at once). On the right is a list of how these different types of seizures typically affect people.

Common Symptoms

SIMPLE PARTIAL SEIZURES

- *Jamais vu (familiar things suddenly seem unfamiliar)*
- *Trembling that moves up one side of the body*
- *Déjà vu (unfamiliar things suddenly seem familiar)*
- *Out of body experiences*
- *Sudden shifts in mood*
- *Unexplained anger or fear*
- *Disturbed speech*

COMPLEX PARTIAL SEIZURES

- *Lip smacking*
- *Swallowing*
- *Picking at clothes*
- *Wandering*
- *Lost time*
- *Lack of response to others*
- *Senseless, clumsy movements*
- *Repeating phrases*
- *Taking off clothes*
- *Unaware of danger or pain*
- *“Sleepwalking” appearance*

GENERALIZED SEIZURES

- *Convulsions*
- *Sudden falls*
- *Brief blackouts, staring*
- *Sudden muscle jerks*

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