



A Gillette Guide

Life StagesSM
for
Preteens and Early Teens with Epilepsy

Life StagesSM

for

Preteens and Early Teens with Epilepsy

Your body is changing. Your mind is maturing. You're moving on to middle school, junior high or high school. Having epilepsy can influence how those changes affect you. At the same time, some of those life changes might trigger shifts in your seizure activity or lead you to make treatment adjustments.

This booklet from Gillette Children's Specialty Healthcare addresses questions that people who have seizures ask as they approach and enter their teenage years. You might find it helpful to discuss the information with family members, friends and health-care providers.



Information to Have on Hand

To help make sure you receive proper health care and inform others about your needs, keep the following materials in an easy-to-find location (on your family's refrigerator, for example):

- Name and description of your seizure type
- Descriptions of how you might appear or behave during a seizure
- A plan that tells other people what to do if you have a seizure
- Information about your medicines, including:
 - What to do if you miss a dose
 - Potential side effects
 - What to do if side effects occur
- A calendar (or some other tool) for tracking when you:
 - Have seizures
 - Take medicines
 - Experience side effects from medicines
- A list of phone numbers to call for help under various circumstances

Your Gillette neurology care team can help you gather this information.



Q&A Common Questions

Stephanie, who has epilepsy, volunteers with other teens at her church.

Telling Others

Who should know that I have epilepsy?

If people know that you have epilepsy, they're better prepared to respond if they see you have a seizure. So, talk about your epilepsy with people you see often, including:

At School

- Friends
- Teachers
- School nurses
- Coaches and activity leaders
- Bus drivers
- The principal or vice principal

Elsewhere

- Coaches, leaders, teammates and others involved with you in community organizations, such as sports teams and Scout troops
- Employers (including people who hire you to babysit, mow lawns, etc.) and co-workers
- Leaders and members of your religious institutions

Your decisions to share information about your epilepsy might depend on the type and frequency of your seizures. For example, if your seizures always happen during sleep, you might discuss them with people outside your family only when you sleep away from your home.

Staying Healthy

How might puberty affect my seizures?

Hormone and growth changes during puberty can have several possible effects on people who have epilepsy:

- Some people's seizures subside or stabilize.
- Some people's seizures get more intense or harder to control.
- Some girls start to experience catamenial epilepsy — fluctuations in seizure activity that correspond with their menstrual cycles.

Do I need to adjust my medicines?

Now is a good time to review your medicines with your health-care providers. Changes might be necessary because:

- Medicine dosages often depend on a person's weight, and growth spurts are common during adolescence.
- If you start taking other medicines (such as some antibiotics or medicines containing hormones), your seizure medicines might affect you differently than they did before.

Am I eating right and getting enough sleep?

Your school days might start earlier than they did before, and you might stay up late more often. It might be hard to stick to a regular meal schedule. Nevertheless, diet and sleep should be high priorities for you. Your seizures might become more frequent or intense if you don't eat well or get enough rest.

How can I keep my bones healthy?

When you eat away from home, be sure you select foods containing calcium, which helps strengthen your bones. Some seizure medicines can interfere with your body's ability to absorb calcium. Therefore, your health-care providers also might recommend:

- Calcium supplements
- Bone-age testing to help evaluate the health of your bones
- Bone-strengthening activities, especially if you use a wheelchair

Should I take vitamin supplements?

Some seizure medicines can lower the levels of important vitamins and minerals in your body. Your health-care providers might recommend compensating for that effect by taking vitamin supplements.

Can I use over-the-counter medicines and nutritional products (such as herbs)?

Your friends might recommend products they use for pain relief or general wellness. But some of those products might interfere with your epilepsy medicines or trigger changes in your seizure activity. Before taking any medicines or supplements, discuss them with a health-care provider or pharmacist.

Will alcohol or illegal drugs affect my seizures?

Alcohol and other drugs can cause seizures, even in people who don't have epilepsy. So, using such substances might be more dangerous for you than it is for others. Drinking alcohol or taking illegal drugs might trigger a rise in the number of seizures you have, make your seizures last longer, or increase their intensity.

How can I maintain good mental health and emotional well-being?

Mood swings are common among people your age. If your emotions become particularly intense, reasons might include:

- You're concerned that having epilepsy makes it difficult to fit in with other kids.
- A seizure medicine seems to cause changes in your mood. If this happens after you start taking a new medicine, contact your Gillette neurology care team.
- You're experiencing a mood disorder, such as anxiety or depression.

Even if you don't feel you're having severe emotional problems, you might find it helpful to meet with a counselor or psychologist. Getting professional advice now might help you better understand how to respond if you face emotional struggles in the future.

Going to School

What happens if I have a seizure at school?

Whenever you enter a new school, you and your family should work with the school's nursing staff to develop a seizure action plan. The plan tells teachers and other staff members what to do if you have a seizure at school. Make sure your seizure action plan stays up to date and always reflects your current medical needs.

Will epilepsy affect my schoolwork?

If you're starting middle school, junior high or high school, your studies are probably going to require more planning and independent work than they did before. When those demands rise, some people who have epilepsy start to experience learning difficulties. To prepare for new schooling needs, now might be a good time to:

- Create a more structured study schedule for yourself
- Ask your school district about its academic support services

Should I start planning for my future?

If your school system has set up an individualized education program (IEP) for you, by the time you're 14 it must include a transition plan to help you prepare for adult life. Your transition plan might call for you to receive services that can help you:

- Prepare for employment and find jobs
- Get ready to live outside your family's home
- Continue your education after high school
- Become involved in your community
- Improve skills — such as cooking, cleaning and getting dressed — that you'll need to live independently and take care of yourself

You're allowed — and encouraged — to attend meetings about your IEP. By helping to create your transition plan, you can make sure it reflects your abilities, interests, goals and dreams.

Socializing

Will I have trouble fitting in with other kids?

As you enter your teenage years, it's natural to want to make new friends and spend more time with people your own age. If epilepsy keeps you from participating in some activities that other kids enjoy, look for alternatives that interest you. Possibilities include:

- Music and arts activities, such as bands or theater productions
- Scouting programs
- Community recreation programs
- Youth-group activities within religious institutions
- Volunteer or service opportunities

Getting involved in organized activities gives you a way to meet people who share your interests and values.

Does epilepsy affect friendships and dating?

People who have epilepsy develop the same kinds of relationships as anyone else. It's important that people close to you know about your epilepsy, however, in case you have a seizure while you're with any of them. You might worry that sharing such information will change the way people feel about you. If starting conversations about your seizures makes you nervous, consider discussing your concerns — or practicing what you want to say — with a family member, counselor or health-care provider.

Living Your Life

Do I have to be cautious about anything at home?

Depending on the type and frequency of your seizures, some safety precautions during daily routines might be wise. For example:

- Taking showers, rather than baths, can decrease your risk of drowning during a seizure.
- Keeping the bathroom door unlocked makes it easier for someone to help you if you have a seizure while you're inside. To maintain your privacy, you might come up with an alternate system — using an "occupied" sign, for example — to stop family members from disturbing you while you're using the room.

Can I participate in sports and physical recreation?

Most people who have seizures can be physically active. (In fact, some Olympians and professional athletes have epilepsy.) Your restrictions depend on the nature of your seizures. Some activities, however, call for precautions:

■ Swimming

Never swim alone. Make sure someone nearby knows you have epilepsy. Swimming in a clear pool is safer than swimming in a lake.

■ Using bikes, scooters, skates, skateboards and skis

Always wear helmets and other recommended protective equipment. You might want to ride only on trails or in other areas that don't have automotive traffic.

If you sometimes lose consciousness or can't control your movements during seizures, you might have to restrict your activities more than other people do. For instance, activities that could cause dangerous falls — such as rock climbing or some gymnastics events — might be unsafe for you.

Can I sleep overnight at a friend's house?

Talk with your family about whether a sleepover is a good idea for you. If you've demonstrated that you regularly take your seizure medicines and get enough sleep, you might be ready to stay overnight at a friend's house. You should, however, discuss your epilepsy with your friend's family to make sure they know what to do if you have a seizure while you're at their home.

Will I be allowed to drive a car?

In most states, people can receive a driver's license if they've been free of seizures for a length of time (usually three to 12 months, depending on the state). If you have questions or concerns about driving, talk to a health-care provider.



More Questions?

Call Gillette Nursing Triage at 651-229-3890 and ask to speak to one of our neurology nurse practitioners.

Our Mission

Gillette meets the special health-care needs of people — primarily children and teens — who have disabilities. Our mission is to help those we serve realize greater well-being, independence and enjoyment in life.

We combine medical, nursing, therapeutic, technical, psychosocial and other expertise in family-centered programs. We provide services at our clinics, in our hospital and throughout the region, in response to community needs and often in collaboration with other organizations. We seek to build community partnerships that help continue our mission and enhance care for people who have disabilities.



**Gillette
Children's**

Specialty Healthcare

St. Paul (Main) Campus
200 University Avenue East
St. Paul, MN 55101
651-291-2848
800-719-4040 (toll-free)

Duluth Clinic
Lakewalk Center
1420 London Road
Duluth, MN 55805
218-728-6160
800-903-7111 (toll-free)

Burnsville Clinic
305 East Nicollet Boulevard
Burnsville, MN 55337
952-223-3400
866-881-7386 (toll-free)

Minnetonka Clinic
6060 Clearwater Drive
Minnetonka, MN 55343
952-936-0977
800-277-1250 (toll-free)

Mobile Outreach Clinic
For locations and schedules:
651-634-1938
800-578-4266 (toll-free)
www.gillettechildrens.org



**Gillette
Lifetime**

Specialty Healthcare

St. Paul – Phalen Clinic
435 Phalen Boulevard
St. Paul, MN 55130
651-636-9443
800-578-4266 (toll-free)

www.gillettechildrens.org