
Epilepsy: 10 Things Patients & Family Members Should Know

1. Seizure Disorder = Epilepsy (but not all seizures are epilepsy)

Epilepsy is a brain condition that causes seizures. Some doctors might use the term “seizure disorder” instead of epilepsy. A seizure is a brief change in how you act, feel, or move. When a seizure happens, you can’t control these changes in your body.

The brain is made up of cells called neurons. Neurons work by sending electrical signals. With epilepsy, sometimes too many neurons fire at once. This causes a seizure.

There are some seizures, though, that are not considered epilepsy. This includes...

- a seizure caused by fever
- a seizure caused by low blood sugar
- a seizure that comes right after a brain injury
- a seizure following alcohol abuse
- a seizure caused by certain drugs

Another type of seizure that’s not epilepsy is a **psychogenic nonepileptic seizure** (PNES). These seizures are not caused by an electrical problem in the brain. Instead, they are caused by stress, often from something bad that happened in the past. Treatment for PNES is very different from treatment for epilepsy.

There are also many things that can look like seizures but aren’t. This includes...

- fainting
- sleep disorders
- panic attacks
- migraines
- strokes or mini strokes

...and many other conditions.

2. There are many types of seizures and many types of epilepsy.

Epilepsy is not a single condition. It is a general term for over 60 different conditions. There are also about 30 different types of seizures. Seizures can involve a wide range of symptoms. Most often, they start suddenly and end after a minute or two. Tell your neurologist about any brief episodes you’ve had that involved any of these symptoms:

- loss of consciousness (blacking out)
- not responding to others
- not remembering what just happened
- confusion
- falling for no reason
- staring, chewing, or unusual eye movements
- fumbling with objects, picking at clothes
- wandering around in a daze
- sudden fear for no reason
- déjà vu (feeling where everything seems strangely familiar)
- seeing, hearing, smelling, or tasting something that's not there
- numbness or tingling
- trouble with thinking or speaking
- strange feelings that are hard to describe
- movement you can't control
 - stiffening
 - jerking, shaking, or twitching
 - sudden drop of the head
 - movements that have no purpose

If any of these episodes are seizures, ask your doctor what type they are. Also be sure to ask your neurologist what type of epilepsy you have. The more you know about your condition, the better you can manage it. Knowing more about your specific epilepsy type can help you...

- talk about it with others
- find out more about it at the library, on the Internet, or through Epilepsy Foundation of Michigan
- understand your treatment options
- plan for the future

Many tools can be used to help doctors understand your epilepsy. Ask your doctor about...

- routine EEG
- ambulatory EEG
- video-EEG monitoring
- keeping a seizure diary and videotaping seizures
- blood tests
- sleep studies
- MRI
- other neuroimaging technologies

Sometimes, a neurologist may not know exactly what type of epilepsy you have. Even so, you have the right to hear everything your doctor *does* know about your condition.

3. The goal of epilepsy treatment is “No seizures and no side effects.”

You and your neurologist should always be working toward this goal. This includes telling your neurologist about...

- any side effects you're having
- any seizures you've had, including...
 - seizures you think of as “minor”
 - other episodes that *might be* seizures (but you're not sure)
- any other medicines you're taking (some can affect how your epilepsy drugs work)
- any seizure patterns, triggers, or warnings you've noticed
- any problems you've had getting your medicine or paying for it
- any changes in the medicine your pharmacist gives you

You should see an epileptologist (a neurologist who specializes in epilepsy) to talk about other treatment options if...

- you've tried two medicines for epilepsy, and you're still having seizures
- you've seen a general neurologist for a year, and you're still having seizures

Other treatments include...

Epilepsy Surgery

- mostly for people whose seizures start in one part of the brain
- usually, a part of the brain is removed or disconnected
- may offer the best chance of becoming seizure free
- risk of serious problems is low but should be discussed with doctor

Responsive Neurostimulation (RNS)

- device embedded in skull and connected to one or two electrodes on the brain
- continuously monitors electrical activity in the brain
- delivers electrical stimulation when onset of seizure is detected
- may stop some seizures before they start
- can be used for people with one or two seizure foci

Vagus Nerve Stimulator (VNS)

- device implanted under the skin on the chest
- wires connect to the vagus nerve in the neck
- brain gets electrical stimulation every 5 minutes or so
- can make seizures happen less often or make them less severe
- magnet can be used to stop or shorten a seizure that has already begun
- people with the VNS usually don't become seizure free

Ketogenic Diet

- high-fat, low-carb diet that can sometimes reduce or stop seizures
- must be closely monitored by a doctor and a dietician
- can be hard to follow and is used mostly in young children

There are other treatment options as well, but less is known about how safe and effective they are.

4. You have some control over your seizures and your health.

With epilepsy, seizures are hard to predict. Much of what happens is beyond your control. There are things you can do, however, to have fewer seizures and better health. Here are some examples:

- Keep a seizure diary, and avoid seizure triggers
- Have a regular sleep schedule, with at least 8 hours of sleep each night
- Reduce your stress
- Take your medicines as prescribed
- Exercise and eat healthy foods
- Avoid alcohol

If you're having trouble with any of these behaviors, talk to your healthcare team. They may be able to help.

5. Women with epilepsy face unique issues.

- Female hormones can affect seizure patterns.
- Women with epilepsy are at higher risk for certain reproductive problems.
- Some epilepsy drugs can...
 - interfere with birth control pills
 - increase the risk of birth defects
 - weaken bones
- Women are more likely to have psychogenic nonepileptic seizures than men.
- Women with epilepsy can have healthy babies, but there are some risks.

Your neurologist should be aware of these issues and able to address them.

6. Memory problems are common in people with epilepsy.

In people with epilepsy, memory and thinking can be affected by...

- side effects of antiseizure drugs
- seizures
- changes in the structure of the brain
- changes in how the brain works

Seeing a neuropsychologist may help you learn more about your memory problems. It can also give you ideas on how to cope with them. Be sure to share your memory concerns with your doctors as well. Medicine changes or further testing may be needed.

7. Depression is a common, serious, and treatable problem in people with epilepsy.

It's normal to feel sad once in a while. When this feeling doesn't go away, though, it could be depression. Depression is a serious medical problem that requires treatment. About 3 out of 10 people with epilepsy have depression. Depression can...

- cause stress
- cause sleep problems
- make it harder to think, concentrate, or remember things
- make it harder for you to take your medicines
- make you have more seizures
- lead to risky behaviors
- lead to suicide

If you think you might have depression, tell your doctor. There are medicines for depression that can be safely taken by people with epilepsy. Talking with a therapist can also help.

8. People with epilepsy can succeed in school and the workplace.

If epilepsy is causing problems in school or at work, Epilepsy Foundation of Michigan can help. Here are some things we can do...

In School

- train school staff on how to recognize seizures and provide first aid
- train parents and teachers on how epilepsy can affect learning
- teach other students about epilepsy
- make sure the child gets needed services
- help the child build social skills

At Work

- teach you about your rights
- suggest job accommodations
- help you to address employer fears about epilepsy
- connect you with job training and placement programs
- help you explore ideas for new careers

9. There are risks that go along with epilepsy, but you can lower these risks.

Epilepsy can cause injury, other health problems, or, in rare cases, death. Here are some things that can happen with epilepsy:

- Chronic health problems
 - depression
 - obesity
 - bone loss
 - reproductive disorders
- Injuries from seizures
 - muscle, bone, and joint injuries
 - burns
 - cuts and bruises
 - brain injury
- Car accidents
- Drowning
- Injury or death from seizures that won't stop (status epilepticus)
- SUDEP (Sudden Unexpected Death in Epilepsy)

Ask your doctor about these risks and how to lower them. Some basic safety precautions, healthy habits, and treatment changes can help. This can allow you to focus on your goals rather than your fears.

10. You are not alone.

One out of 26 Americans will have epilepsy at some point in their lives. You don't have to deal with this condition on your own. Epilepsy Foundation of Michigan offers programs where you can...

- learn from experts about epilepsy and other topics
- get one-on-one help with managing epilepsy
- meet others with epilepsy who have ideas and experiences to share

It's ok to ask for help. Please call us or visit our website to learn more.

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