EPILEPSY FOUNDATION®

Not another moment lost to seizures®

Everyday Life Information for Adults with Epilepsy and Seizure Disorders

About the Epilepsy Foundation

The Epilepsy Foundation is the national voluntary agency solely dedicated to the welfare of the more than three million people with epilepsy in the U.S. and their families. The organization works to ensure that people with seizures are able to participate in all life experiences; and to prevent, control and cure epilepsy through services, education, advocacy and research. In addition to programs conducted at the national level, people with epilepsy are also served by local Epilepsy Foundation affiliates across the country.

If you have any questions about epilepsy and seizure disorders, living with epilepsy, or helping a friend or family member who has epilepsy, please visit us on the Web at www.EpilepsyFoundation.org or call 800-332-1000. Our Web site has information about the disorder, offers opportunities to network with others touched by epilepsy through our eCommunities forums and Web events. You can also subscribe to our bi-monthly magazine *EpilepsyUSA*. Each issue contains exciting developments for people affected by seizure disorders—new treatments and medicines, ground-breaking research, safety tips, personal stories, advice for parents and much, much more—all delivered right to your door.

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People with Epilepsy Are Just Like People Without Epilepsy

People with epilepsy and/or seizure disorders are pretty much just like people without epilepsy or seizure disorders except that every once in a while they have a little electrical storm in their brain. Some people have more of these electrical storms while some have fewer, and some are bigger storms than others, but altogether, about 1 out of every 100 people has epilepsy. That means that more than 3 million Americans and more than 50 million people around the world have it.

Just remember that if you, or a friend or loved one, has epilepsy, they have it, it doesn't have them. It's not who they are, it's just a medical condition they have. It doesn't define them, and they shouldn't call themselves an epileptic. They're a person with epilepsy, because they're a person first, last and always.

To Start at the Beginning: A Little Bit About Epilepsy

Seizures (some people might call them fits or spells) are different from one person to another. One person's seizure might just cause them to stare for a little while. Another person might stutter, pick at his or her clothes, or walk around in circles. A third person might suddenly start shaking all over and fall down.

Different people have different types of seizures and some people might have more than one type. Just remember that seizures are not any sort of mental illness, and epilepsy does not make you any less intelligent than other people or change the way you look.

And just like there are different types of seizures and epilepsy, there are different types of treatments. Some people might take medicine, while others might have something implanted in their body, and others might have brain surgery or some other sort of treatment altogether.

Just remember that no matter what type of seizure you have, you can still have a good, full life and do many of the same things that other people do like go to school, date, have a job, get married, and have children.

Different people have different types of epilepsy and seizures, so not everything in this brochure will apply to everyone. Your doctor is always your best guide to what you can and cannot do, and for what is best for you. You should always discuss any major decisions regarding your health with your doctor.

You should not be afraid to discuss things with your doctor. Your goal for your treatment should be that you won't have any seizures and you won't have any side effects. This is not always possible, but it is something that you and your doctor should try to achieve for you.

A few terms to know:

Breakthrough seizures are seizures that happen suddenly and unexpectedly after you've not had a seizure for a while. They break through the control you've had over your seizures and epilepsy.

Controlled epilepsy means that you have epilepsy, but because of your drugs and/or other treatments, you don't have seizures and haven't had any in a while.

A ***seizure trigger*** is something that causes you to have a seizure. Different people have different seizure triggers. For instance, some people are photosensitive and might have a seizure when they see flashing lights.

Living Well with Epilepsy

If you've just been diagnosed with epilepsy, you might have to make some adjustments in how you live. Chances are, though, that you'll still be able to live just like anyone else.

Epilepsy Treatments

There are a lot of different types of epilepsy. There are also a lot of different types of treatments for people with epilepsy. For instance, there are dozens of medicines your doctor might try you on one at a time, or in combination with others. There's also the Vagus Nerve Stimulator, which is put into your body and uses electricity to try to stop seizures either before they happen, or while they happen. And of course there's brain surgery. Surgery should be considered when several medicines have been tried at good dosages over a period of about 2-3 years. If your seizures continue it is important to request a referral to a specialized epilepsy center where a more comprehensive evaluation of your epilepsy can be undertaken.

Not every type of treatment is right for every different person. And some treatments work only with certain types of epilepsy.

The important thing is to talk with your doctor and be honest. Let him or her know what's happening with you, what sort of side effects you're having, how many seizures you're having, what your seizures are like, as well as anything else you might find important.

Increasing Your Quality of Life when Living with Epilepsy

Getting a Job/Making a Living

People with epilepsy have all sorts of different types of jobs. Some are lawyers or doctors. Others work in offices, stores or restaurants.

Some of these people with epilepsy have complete seizure control while others still have seizures frequently or occasionally. The most important things are to find a job you're qualified for and good at, and to make a good impression.

Because of the Americans with Disabilities Act (ADA) and other related laws, you don't have to tell a potential employer you have epilepsy. The employer isn't even allowed to ask, in fact. But if you do choose to tell them about your condition, you should make sure they know that it won't affect how you do your job.

Healthy Living is Good for People with

Epilepsy, Exercise and Sports

Eating well and exercising is as good for people with epilepsy as it is for other people. Before you start any sports or exercise programs, you should discuss them with your doctor. This will let the two of you think about the risks and what you can do to lessen the risks.

There are dozens of activities that people with epilepsy can enjoy. You should probably let the people you are playing with know what to do if you have a seizure, especially if your seizures aren't controlled. You should also know that although everyone should wear a helmet when skating or biking, it is even more important for people with epilepsy to do so.

There are also some sports that would be dangerous if you had a seizure while you are participating in them. These sports include swimming, waterskiing, scuba diving, skydiving and horseback riding. With the exception of simple swimming, which you can do with a buddy who is a good swimmer, you should only try these sports if you have long-term, complete seizure control and you've discussed them with your doctor.

Epilepsy and Diet

No particular food or diet has been found to cause or prevent seizures in adults. It is important, however, to eat balanced meals at regular times. Some adults with epilepsy respond favorably to the ketogenic diet, modified Atkins diet, or low glycemic index treatment. You should consult with your neurologist about these dietary options.

There's no proof that any sorts of herbal remedies, natural curatives, or massive doses of vitamins will help people with epilepsy. And, just like other people, if you want to go on a diet, you should talk it over with your doctor first. You should also let him know how it goes, since how

much you weigh directly effects your medication dos
medications if you weigh less. But, if you suddenly g
should discuss it with your doctor, since it could be

Epilepsy and Sleeping

Not sleeping enough is a seizure trigger for m
setup and keep a regular sleep schedule that ensur
drowsy and tired all of the time, you should talk ab
of your epilepsy medications.

Epilepsy, Drinking and Drugs

All types of alcohol, including beer, wine and
interact very badly with a number of epilepsy me
discuss it with your doctor first.

Illegal drugs are even more harmful. They c
can cause seizures in people who don't have epil

They can interact badly—or even fatally—
ated with all sorts of unknown things, some of
being mixed with.

Avoiding Depression

If you have epilepsy you are at greater risk
epilepsy medications make you even more like

sages and you might require lesser quantities of
gain or lose a lot of weight without trying to, you
a side effect from your medication.

any people with epilepsy. You should try to
es you sleep enough on a regular basis. If you feel
bout it with your doctor. It could be a side effect

l liquor, are known seizure triggers. They also
edications. If you plan on drinking at all, you should

an cause seizures in people who have epilepsy. They
epsy. They can kill you.
with your epilepsy medications. And they are cre-
which can kill you even without the drugs they're

k of becoming depressed than other people. Some
ely to become depressed and, possibly, suicidal.

Avoiding Depression cont.

It is important for you and your loved ones to be aware of this and to know what to look out for.

Signs of depression include feeling tired, sad, depressed or hopeless; sleeping poorly or all of the time; being unable to concentrate or finish a task; or thinking about committing suicide.

If you think you are depressed or suicidal, it is very important to talk to your doctor as soon as possible. Do not stop your medications suddenly or without talking with your doctor first.

Some other things you can do to help ease your depression are to get help as soon as possible. You should find someone to talk to about how you're feeling. You can do this by becoming involved with a support or self-help group. You can often find such a group by contacting your local Epilepsy Foundation affiliate. You can also get counseling or explore other options your doctor might tell you about.

Depression can be more harmful than epilepsy is, so it is important to do something about it immediately.

You should also know that mood swings can also be caused by seizures (some seizures present partly with sudden mood changes) and epilepsy drugs. So if you have sudden bouts of anger, sadness or worry, you should tell your doctor about it. A change in medication might be all that is needed.

Other things that can help with depression include exercise and relaxation and stress reduction techniques. You can find books about these things in bookstores and at the library.

If you have so many seizures you can't work, or if your seizure disorder and another condition make you completely disabled, you might be able to qualify for financial assistance. For more information on such options, contact your local social security office or Epilepsy Foundation affiliate.

Building a Family

Most people with epilepsy are physically able to have sexual relations and have children.

Sometimes men or women with epilepsy might have decreased sex drives. Some men with epilepsy might experience impotence. These things might be due to their medications.

Sometimes people with epilepsy are afraid that sexual excitement might cause a seizure. But there has been no indication that this is the case.

If you are a woman and either want to have children or want to take birth control, you should discuss this with your doctor. Some birth control pills do not interact well with seizure medications, while other options might harm your chance of later having children.

If you decide to become pregnant, you should also discuss your treatment and any associated risk with your doctor. Although women with epilepsy have a greater than normal chance of having babies with birth defects, more than 90 percent of babies born to women with epilepsy are normal and healthy. There is a slightly greater than average chance that a baby born to a father and/or mother with epilepsy will also have epilepsy—but most such children do *not* have epilepsy.

Q: Does having epilepsy make it harder to get pregnant?

A: Women with epilepsy are less likely to become pregnant than women without epilepsy. Doctors have identified several problems associated with epilepsy that could impede your ability to become pregnant. Despite this, most women with epilepsy are able to conceive and give birth to normal, healthy children.

Getting a Driver's License

Having a driver's license is very important to a lot of people these days. For a lot of teenagers, getting their license is a rite of passage.

But the truth is that you shouldn't get a license until it is safe for you to do so. No matter how aggravating and difficult it is to live without a driver's license—particularly in an area that does not have a good public transportation—your safety and the safety of others is most important.

You will be able to get a driver's license in most states when you have been seizure-free for six months to a year. In other states, your doctor will need to sign a statement that says your seizures are under control before you can get a license. The exact rules for getting a driver's license vary from state to state, so you need to find out what they are in your area to know for sure.

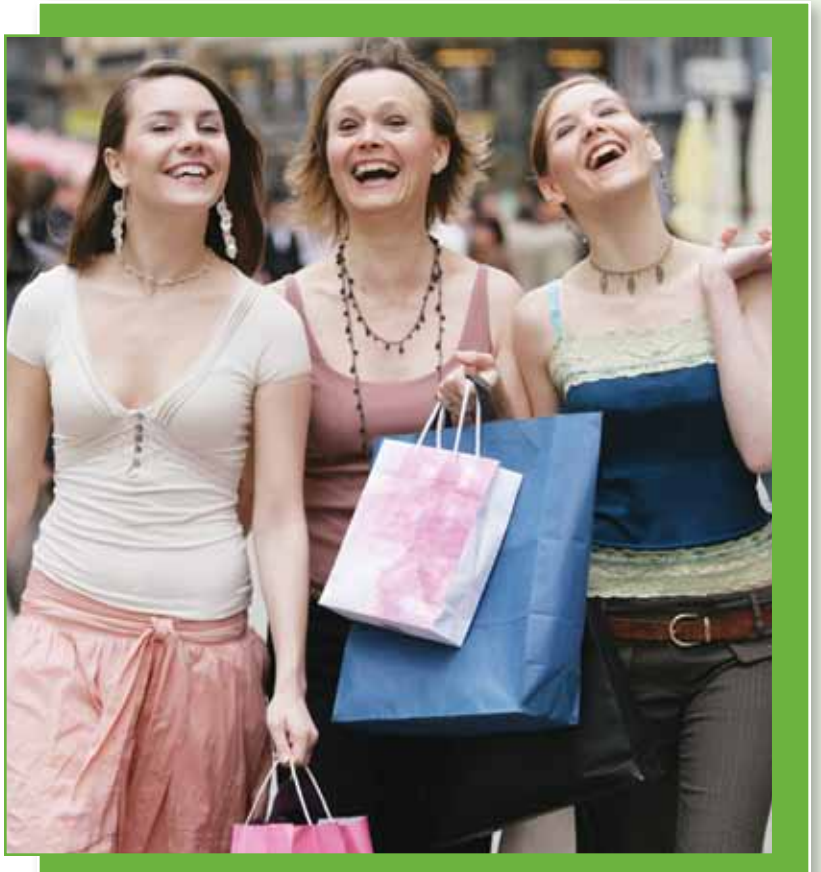
Your insurance will not cover you if you are in an accident when you are driving illegally. But, more importantly, if you have a seizure while you are driving, you can hurt or kill someone.

That is why it is so very important to make sure your seizures are under control before you start, or continue, driving.

Helping Memory

Some people with epilepsy have trouble remembering things. They might remember things from long ago, but have trouble remembering things that just happened.

If you find this happening to you, you should talk to your doctor about it. It might be a side effect from a drug you are on. In the meantime, you should do things to help yourself. For instance, making lists of things you plan to do might help, as might taking notes at work, or during phone conversations. Using a calendar to keep track of appointments and special dates is also frequently helpful. Pill organizers can help you keep track of when to take your medicines. And taking notes about how to do new things can also help.



Lifestyle tips:

- Epilepsy doesn't control you or your life, no matter how much it might sometimes seem like that.
- Educate yourself about your type of seizure.
- Educate others about your seizures to help them see that it's likely not nearly as big a deal as they might've thought at first and they'll realize just how little a part of you it is, and just how much more to you there is than your epilepsy.
- Keep yourself active and busy. If you can hold a job, get a job. If you can't, volunteer to help others or find some hobbies. The busier you are, the less time you'll have for self-pity and the better you'll feel.
- Avoid self-pity. Focus on the good things in life—on your friends and family and those who care about you, and on all that you do for others, and on all that you can do.
- Think about the good things that happen every day. Focus on the happy times. Writing a list of these things including things like, "Good friends like [insert name]," "No seizures today/this week/this month," "a

stranger stopped to help me when something bad happened" can help you make it through the bad times.

- Keeping busy with hobbies and volunteering with local organizations not only keeps you thinking positively, they'll help you make friends and keep your mind off the bad things and the bad times.
- Find the funny. Focusing on funny things and keeping your sense of humor will help you make it through any setbacks.
- Find a good doctor or team of doctors that you can talk to and trust.
- Follow your doctor's orders and take the best care of yourself that you can. Exercise if and how you can.
- Find a good drug store. Good pharmacists care and can help you a lot, too.
- Try to live as independently as you can.
- Try not to worry all the time about having a seizure. Don't let those fears keep you at home.
- Wear a medic alert identification and keep a first-aid card in your wallet so people will know what to do if you have a seizure.
- Chances are very, very low that you will die during a seizure. Very, very slight. So don't worry about it. Live for this day, for this moment, and make all you can of the time you have just like everyone else on the planet does.
- Don't let mean people hurt you. They're often mean because they feel so badly about themselves. When they're mean to you, chances are, it's their way of saying they think you're better than they are.
- We're all here in this world for a reason, so find your reason and live up to your fullest potential.
- Never, ever forget you're a normal person who happens to have a treatable medical condition. In every important aspect of your life you are just like everyone else, with just as much to offer the world, and just as much right to a happy and full life.
- Be happy. Don't worry.

To find out about other services in your community, contact your local Epilepsy Foundation or the Epilepsy Foundation's national office at 800-332-1000 or visit www.epilepsyfoundation.org

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