



Living with Epilepsy

Amber Specialty Pharmacy has expertise in the management and treatment of epilepsy, including complex epileptic conditions like Dravet and Lennox-Gastauts syndromes. Today's epilepsy medications help reduce seizure frequency and intensity in children and adults. To live life fully and completely, it is important to look at the whole picture. We have compiled information to address many overall health needs of patients and caregivers dealing with epilepsy. This material includes helpful tips on sleep, exercise, social activities, career, driving, travel and more. In addition, we have provided you with a comprehensive look at nutritional care and epilepsy.



Take Your Medicine

It's important for people with epilepsy to take the right dose of their medicine on the right schedule. Staying consistent with your medication is also called staying adherent or compliant. Seizure medicine is usually more effective at stopping and preventing seizures when it's taken regularly. Do not stop taking your medicine or make any changes to your medication without talking with your doctor or pharmacist.

Know Your Triggers

Knowing your seizure triggers can help manage epilepsy. If you have a seizure disorder and you understand your triggers, it's easier to plan ahead. You can maybe avoid certain situations or make adjustments based on how your body reacts to triggers. Sometimes triggers are unavoidable. If that's the case, people who know their seizure triggers may be better prepared to respond.

Prioritize Sleep

Sleep is often related to seizures. If you are getting too much sleep, not enough sleep, or if you don't have a consistent sleep schedule, you may notice more frequent seizures. Try developing a regular sleep pattern. Once you get into a routine, it's best to stick with it, even on the weekends.



Reduce Stress

High levels of stress may lead to more seizures. While it's not always possible to remove stress from your life, there are several ways to effectively manage it. Breathing exercises, listening to music, exercise and fresh air are a few ways to lower your stress levels. Finding healthy outlets to reduce stress is an important part of managing epilepsy.

Make Healthy Choices

A healthy lifestyle often helps people with epilepsy cope with their condition. Eating balanced, nutritious meals and exercising regularly may improve your seizure management. Exercise can potentially lower your risk of seizures, boost your mood, and keep your body healthy and strong. While exercise is generally recommended, people with epilepsy should avoid hyperventilating, getting too tired, or overheating, which may trigger a seizure. Talk to your doctor about exercise and how it may affect epilepsy.

Keep a Journal

Seizure disorders affect everyone differently. One of the best ways to understand how epilepsy affects you is to keep a journal. Write down when seizures occur, how long they last, what may have triggered the seizure, what medication you take, medication side effects, and anything else that may be related to your seizure disorder. It can be helpful to bring your seizure journal to medical appointments and share this information with your doctor.

Epilepsy and Your Social Life

It's not uncommon for people with epilepsy to deal with social anxiety. Some people with seizure disorders feel embarrassed and worry about having a seizure in public. This can make parties, concerts, dates and other social events more stressful and less fun. Overall, you can have epilepsy and enjoy social activities without worry. There are some environments, however, that may increase the chances of a

Epilepsy and Your Social Life continued...

seizure event. Theme parks and carnivals, for example, may pose additional risks for you. Before entering a ride, ask the operator about any potential triggers.

You may be more comfortable in social situations if you prepare in advance. Find out if there will be epilepsy triggers, such as strobe lights at a concert, and talk to your friends and companions about what to do in the event of a seizure.

When considering a lifestyle that involves alcohol consumption, talk to your doctor or pharmacist about potential medication side effects. You should be mindful that alcohol and hangovers can be seizure triggers. A night of drinking may also throw off regular sleep patterns, which could trigger a seizure.

Epilepsy and Exercise

Exercise is important to maintain good health and wellbeing. People with seizure disorders can often participate in most forms of exercise without additional risk. If you have epilepsy, you should always talk with your doctor before starting a new sport or exercise program. Ask specific questions about precautions you should take when exercising to avoid getting too tired, hyperventilating or activating other seizure triggers.

As a general rule, use good judgement when it comes to exercise and epilepsy. For example, someone with epilepsy may want to avoid biking along busy streets or ride with another person who could get help during a seizure. It may be a good idea for you to exercise with a partner. An exercise buddy can help you stay safe if a seizure occurs. Before starting any new activity, you should talk to your doctor.

Combat sports and other contact sports that could cause head injuries are usually not recommended for people with epilepsy. Boxing and football are sports that could be especially risky if you have a seizure disorder.

Epilepsy and School

As a parent, one of the best ways to help your child succeed in school is to be involved. If your child has epilepsy, it can be especially important. Talk with the school to make sure teachers and staff members understand your child's condition. Ask your child about his or her grades and offer support in subjects that may need a little extra help.

When it comes to extracurricular activities, epilepsy usually doesn't interfere. Most sports, clubs and activities are fine and can help your child build friendships and develop social skills. You may need to consider extra precautions for sporting activities to help your child avoid overheating or other seizure triggers. Your child's coaches, sponsors and teachers should know how to respond if a seizure does occur. If you have questions about how your child's epilepsy may affect their participation in a certain activity, talk with your child's physician.

Help your child understand his or her condition, even from a young age. They will likely have to explain their condition to others. Help them learn about their seizures and teach them how to manage their condition.

Epilepsy and Your Career

Epilepsy will not necessarily affect your career goals or professional life. Your career options may depend on how often you have seizures and how severe your seizures are. When seizures are controlled and you understand your patterns and triggers, it's easier to develop a work routine.

Seizure disorders may prevent you from working in certain jobs or career fields. Use caution or consider other areas of work if a seizure could put you or other people at risk. If you have questions about epilepsy in your workplace, talk to your human resource manager or your doctor. There are also resources to learn more about disability benefits and epilepsy at www.DisabilityBenefitsHelp.org.

Epilepsy and Driving

Epilepsy may make it difficult for you to get a driver's license. Driving requirements are different in each state but in general, all drivers must be a minimum age and pass both a written exam and a driving test. Drivers cannot have a medical condition that would make it unsafe to operate a vehicle. In some cases, epilepsy is a medical condition that may prevent a person from driving.

To get a driver's license, you often have to be seizure-free for a certain amount of time. Your application for a driver's license will likely be reviewed by the department of motor

Epilepsy and Driving continued...

vehicles (DMV). The DMV may also consult with the state's medical board. In some cases, you are able to drive under specific conditions, such as during daylight hours only or within a certain radius. If your driver's license application is rejected, you can appeal to a medical advisory board.

Epilepsy and Travel

If you are traveling with epilepsy or you are traveling with someone who has epilepsy, make sure to bring enough medication to last the entire trip. Get pill containers designed to organize medications by day and by dose. Check the latch on the pill container to make sure it closes

tightly and won't open during travel. Bring a copy of important medical information. For longer trips, look into travel insurance options. Plan for how you will respond if a seizure occurs.

If you are going through an airport, be sure to check the most recent Travel Security Administration (TSA) guidelines on traveling with medication. Amber Pharmacy recommends keeping your medication in the appropriate containers with the prescription number showing. You may also want to keep all your medication in your carry-on luggage in case you need to access it during the flight or your checked baggage is lost.

Overall Health and Well-being

People diagnosed with epilepsy may notice other areas of their health are affected, even if it seems unrelated to their seizure disorder. Improving your overall health and well-being can have a tremendous positive impact on epilepsy management. You don't have to make drastic lifestyle changes to be successful. Improving your health and wellness is a journey. Celebrate small victories and start moving toward a healthier lifestyle one day at a time.

Get involved

People who try new things and build a strong social network often have better overall health. Make new friends, volunteer and get involved in your community. The challenges of living with epilepsy can be easier when surrounded by a good support group. Support networks are often a great way to connect with people who understand seizure disorders. Whether it's online or in person, many people find strength and encouragement through epilepsy support groups.



If you witness someone having a seizure:

Stay calm

If you witness a seizure, it's important that you remain calm and offer basic seizure first aid.

Check the area

Make sure that the area is safe for you and the person having a seizure. Move any furniture or potentially dangerous items.

Turn them on their side

Carefully turn the person seizing on his or her side.

Loosen tight clothing

Loosen any tight clothing items around the seizing person's neck, such as ties or shirt collars.

Look for an ID bracelet

Look for a medical ID bracelet or other accessory that identifies specific medical needs. This may help you understand the person's medical history and respond appropriately.

Note the time

Take note of what time the seizure begins and when it ends. If a seizure lasts for longer than five minutes, call an ambulance.

Do not restrain them

Do not hold a person down during a seizure or try to restrain his or her movements. Do not put anything in his or her mouth. Place a pillow or cushion underneath the seizing person's head.

Stay with them

Stay with the person having a seizure until he or she has fully recovered. Gently help the person into a recovery position, resting on one side, and wait for breathing to return to normal. Carefully check the person's mouth to make sure nothing is blocking the airway.

Call 911 if:

- ▶ The person is injured during the seizure.
- ▶ The seizure lasts longer than five minutes.
- ▶ The person has never had a seizure before.
- ▶ The person has trouble breathing or waking up.
- ▶ There is a second seizure shortly after the first one.
- ▶ The person has another health condition, such as diabetes or pregnancy.

Nutrition Care for Epilepsy

A balanced diet keeps your body functioning at its best.

Managing your diet and nutrition can make it easier to manage epilepsy. Though most individuals with a seizure disorder have no issues with food sensitivity, some people may have specific food triggers. Some people have found that dietary supplements and other alterations to their diet can help control seizures. One diet that has been effective for many people is the ketogenic diet.

Talk to a registered dietitian, pharmacist or physician about potential food and drug interactions. Grapefruit, grapefruit juice and pomegranate juice might make medication side effects more likely to occur because these fruits can interact with your medications.

Safe Food Preparation with Epilepsy

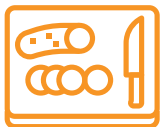
Kitchens can create numerous hazards for people with epilepsy. However, a seizure disorder doesn't have to restrict your ability to prepare food. Make cooking with epilepsy safer with these simple changes around your kitchen.



Try to avoid lifting heavy pans, slide them as much as possible.



If possible, make sure someone else is around when cooking.



Buy pre-chopped fruits, vegetables or meats.



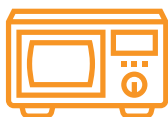
Invest in chairs with armrests to avoid falls.



Use a food processor to avoid knives.



When drinking hot liquids, always use lids.



Cook with a microwave or crockpot instead of a stove.



Purchase healthy pre-made meals from your local grocery store, and consult a registered dietitian.

The Ketogenic (Keto) Diet

The ketogenic diet is often recommended for epilepsy patients because it effectively reduces seizures in some cases. There are variations of the ketogenic diet, or keto diet, but it's essentially a high fat, moderate protein, low carbohydrate diet. Eating "keto" may help control seizures in some children and adult epilepsy patients. Be sure to discuss the ketogenic diet with your doctor before trying it. The keto diet will be initiated under your doctor's supervision. The ketogenic diet changes the way your body uses energy, which leads to a state of ketosis.

Ketosis is when your body uses fat as an energy source, instead of using carbohydrates or glucose. A state of ketosis has been linked to various therapeutic benefits for some people, including those with epilepsy. Some people on the keto diet also practice "intermittent fasting," which can help in reaching ketosis. Intermittent fasting is a cycle between eating and fasting or abstaining from food.

One common recommendation for people with epilepsy is to reduce the amount of sugar and sweets they consume. Reducing or eliminating sugar intake is part of the ketogenic diet. If you're eating keto, you'll probably have to say no to sugar, including natural sugars from fruits and vegetables.

After speaking with your doctor, you may be able to ease off the ketogenic diet after three to five years of seizure control. In some cases, people with seizure disorders continue to practice eating keto because of personal preference or a doctor's recommendation.



Fat
70%

Protein
25%

Carbs
5%

The ketogenic diet can be rather challenging, especially when a person is adjusting to a new nutrition plan. It's important to connect with a registered dietitian during this transition. For the latest information about the ketogenic diet, visit the Charlie Foundation website.

Before making any diet and nutrition changes, consult with a registered dietitian or a physician.

Drink plenty of water. It's important to stay hydrated because both overheating and dehydration can trigger seizures.

Amber Specialty Pharmacy is here to help.

We offer guidance and support through our dedicated team of healthcare experts. Pharmacists are available 24/7 to assist you when you have questions. Our Registered Nurse and Registered Dietitian offer personalized consultations to assist you with any medically-based questions and nutritional care.

This information is intended for educational purposes only. The material is not a substitute for professional help or medical diagnosis. It is important that you consult a medical professional if this information leads you to believe there is a concern for you or your patient(s). The diagnosis and treatment of all physical and/or psychological disorders requires a trained professional.