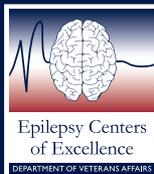




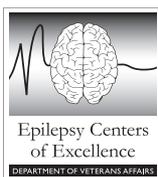
self-management in epilepsy

a guide for
healthcare professionals



This booklet is designed to help epilepsy care providers counsel patients about managing medications, staying safe and living a healthy lifestyle. It is written in the second person so the provider can make comments directly to the patient. Providers can select the items they believe are most important for a specific patient.

They can also give the booklet to the patient to take home.



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Managing Medications

- The standard treatment for epilepsy is the use of anti-seizure drugs.
- About 60-70% of patients with epilepsy can achieve seizure control with medication.
- The type of drug prescribed depends on many things: seizure type and frequency, age, general health, and other medical problems.

Side Effects of Anti-Seizure Drugs

- Every drug has the potential to cause side effects.
- The goal of anti-seizure drugs is to control seizures with no drug side effects.
- Side effects seen with anti-seizure drugs often depend on the dose, type of medication, and length of treatment.
- Anti-seizure drugs are usually started at low doses and are increased slowly to make the adjustment easier.
- Side effects have a tendency to be less severe over time as individuals adjust to the medication.
- Some side effects are mild and resolve in time. Others side effects can be quite serious and may become more severe with time which will require that you come off the drug.
- Common side effects that you should report to your health care provider but may not require you to stop the anti-seizure medication include blurred or double vision, fatigue, sleepiness, unsteadiness, stomach upset, weight changes, and tremor. These side effects are more common an hour or two after a dose.
- More serious side effects of anti-seizure medications include skin rash, low blood cell counts, liver problems, osteoporosis, and thoughts of harming oneself. Please talk to your health care provider about your risk for these serious side effects.
- It is important to inform your provider of **any** side effects you may experience.

Duration of Drug Management

- Each person with epilepsy is different. Your type of epilepsy and how long you have been seizure-free helps determine whether lifelong drug therapy is indicated.
- Some people need to continue medication for the rest of their lives, but other people may not need to. Please speak to your health care provider regarding how long you may need to be on anti-seizure drugs.
- If the decision is made to come off of medication, you will slowly and cautiously decrease your anti-seizure medications over weeks to months. Never abruptly stop your medications.

Missed Doses

- Most anti-seizure drugs are scheduled every twelve hours, but some are scheduled once a day and others three times a day.
- If you take a drug once a day, missing one dose of medication puts you at higher risk of having a seizure.
- If you forget a dose, take it just as soon as you remember, but not if it is already time for your next dose (take your next dose as regularly scheduled).
- Do not double up on your doses or manipulate the dose unless guided by your health care provider.
- The more doses you miss, the greater your risk for having a seizure.

Tips to Improve Seizure Control

- Take medications exactly as prescribed.
- Develop a routine and take your medications at the same time every day.
- Use a medication organizer that separates pills by day of the week and time of day. This helps you determine if you've missed a dose.
- Get creative! Use an alarm on your watch or phone. For those with smartphones, there are apps that remind you to take your pills, and also show you the name and pill shape/color/size of your medication.
- Ask your provider to write down any special instructions about your medication and what specific side effects you can expect.
- Keep all clinic visits. Be sure to write down any questions or concerns you have and bring them to your appointment.
- Always inform your health care provider of all other prescription drugs, over-the-counter drugs, or herbal remedies you are taking. Anti-seizure drugs can interact with other drugs and supplements. Mixing them can be dangerous.

- Inform your health care provider of any alcohol and recreational drug use.
- Never stop taking your anti-seizure drug without the guidance of a neurology provider.
- Be careful not to let your prescription run out. Stopping an anti-seizure drug abruptly can raise your seizure risk. Do not wait until you are low or out of medication before refilling your prescription.
- Confirm that your medication looks the same when you pick up your refills **before** you leave the pharmacy.
- If you receive your medication in the mail, be sure to notify the pharmacy and your provider as soon as possible if your medications look different.
- Know if you are taking generic or brand name of medication. If your medication is changed to a generic version, your provider may want to check a blood level to ensure you're on the right dose.
- Try to keep at least a two week supply of medication available at all times.
- If possible, keep an "emergency" supply at work or in your car in case you cannot make it home in time for your next dose.
- Get your labs drawn as requested by your provider. One of these labs may be a "drug level." This measures the amount of medication in your blood stream. The drug level along with your seizure frequency and your report of any side effects can guide your health care provider in making decisions about medication adjustments.

Commonly Used Anti-Seizure-Drugs

Therapeutic blood levels have only been listed for those anti-seizure drugs that have well established and recognized therapeutic levels.

CARBAMAZEPINE (TEGRETOL)

Indications	· For the treatment of partial onset (focal) seizures with or without secondary generalization
Common side effects	· Feeling sleepy · Dizziness · Blurred vision/double vision · Headache · Stomach upset
Potentially life-threatening side effects	· Skin rashes, including Stevens-Johnson Syndrome · Low blood sodium · Liver problems · Bone marrow suppression and other blood disorders
Average adult daily dose	· 400 mg–1200 mg
Therapeutic blood level	· 4–12 mcg/mL

CLOBAZAM (ONFI)

Indications	<ul style="list-style-type: none">· The FDA-approved indication is for the treatment of seizures associated with Lennox-Gastaut Syndrome but the medication is used as an add-on medication for all seizures types.
Common side effects	<ul style="list-style-type: none">· Feeling Sleepy· Drooling· Dizziness· Feeling off balance· Agitation and aggressive behavior
Potentially life-threatening side effects	<ul style="list-style-type: none">· Skin rashes, including Stevens-Johnson Syndrome
Average adult daily dose	<ul style="list-style-type: none">· 20 mg–40 mg

ESLICARBAZEPINE (APTIOM)

Indications	<ul style="list-style-type: none">· For the treatment of partial onset (focal) seizures with or without secondary generalization
Common side effects	<ul style="list-style-type: none">· Feeling sleepy· Dizziness· Blurred vision/double vision· Headache· Stomach upset
Potentially life-threatening side effects	<ul style="list-style-type: none">· Skin rashes, including Stevens-Johnson Syndrome· Low blood sodium· Liver problems· Bone marrow suppression and other blood disorders
Average adult daily dose	<ul style="list-style-type: none">· 800 mg–1200 mg

ETHOSUXIMIDE (ZARONTIN)

Indications	<ul style="list-style-type: none">· For absence seizures only
Common side effects	<ul style="list-style-type: none">· Stomach upset with nausea and vomiting, loss of appetite, diarrhea· Feeling sleepy· Headache· Dizziness· Hyperactivity
Potentially life-threatening side effects	<ul style="list-style-type: none">· Skin rashes, including Stevens-Johnson Syndrome· Bone marrow suppression or other blood disorders· Depression and suicidal thoughts
Average adult daily dose	<ul style="list-style-type: none">· 500 mg–1500 mg
Therapeutic blood level	<ul style="list-style-type: none">· 40–100 mcg/mL

FELBAMATE (FELBATOL)

Indications	· For partial onset (focal) epilepsy and primary generalized epilepsy
Common side effects	· Insomnia · Feeling sleepy · Stomach upset with loss of appetite · Weight loss · Headache
Potentially life-threatening side effects	· Bone marrow suppression and other blood disorders · Liver problems
Average adult daily dose	· 1200 mg–3600 mg
Therapeutic blood level	· 30–60 mcg/mL

GABAPENTIN (NEURONTIN)

Indications	· For the treatment of partial onset (focal) seizures with or without secondary generalization
Common side effects	· Feeling sleepy · Dizziness · Feeling off balance · Swelling of the lower extremities · Weight gain
Potentially life-threatening side effects	· None documented
Average adult daily dose	· 900 mg–4800 mg
Therapeutic blood level	· 2–20 mcg/mL

LACOSAMIDE (VIMPAT)

Indications	· For the treatment of partial onset (focal) seizures with or without secondary generalization
Common side effects	· Dizziness · Headache · Feeling off balance · Nausea and vomiting · Double vision
Potentially life-threatening side effects	· Increased PR interval (heart arrhythmias) · Second degree and complete AV block (heart conduction abnormalities)
Average adult daily dose	· 200 mg–400 mg

LAMOTRIGINE (LAMICTAL)

Indications	<ul style="list-style-type: none">· For the treatment of partial onset (focal) seizures with or without secondary generalization· Also used for treatment of primary generalized epilepsy
Common side effects	<ul style="list-style-type: none">· Insomnia, feeling sleepy is less likely compared to other seizure medications· Headache· Dizziness· Tremor· Feeling off balance· Vivid dreams
Potentially life-threatening side effects	<ul style="list-style-type: none">· Skin rashes, including Stevens-Johnson Syndrome
Average adult daily dose	<ul style="list-style-type: none">· 200 mg–600 mg
Therapeutic blood level	<ul style="list-style-type: none">· 2.5–15 mcg/mL

LEVETIRACETAM (KEPPRA)

Indications	<ul style="list-style-type: none">· For the treatment of partial onset (focal) seizures with or without secondary generalization· Also used for treatment of primary generalized epilepsy
Common side effects	<ul style="list-style-type: none">· Increased sleepiness· Dizziness· Mood disturbances including depression, suicidal thoughts, irritability with aggression, agitation
Potentially life-threatening side effects	<ul style="list-style-type: none">· Skin rashes, including Stevens-Johnson Syndrome· Bone marrow suppression and other blood disorders· Depression with suicidal thoughts
Average adult daily dose	<ul style="list-style-type: none">· 1000 mg–3000 mg
Therapeutic blood level	<ul style="list-style-type: none">· 12–46 mcg/mL

OXCARBAZEPINE (TRILEPTAL)

Indications	<ul style="list-style-type: none">· For the treatment of partial onset (focal) seizures with or without secondary generalization
Common side effects	<ul style="list-style-type: none">· Increased sleepiness· Dizziness· Feeling off balance· Blurred vision· Double vision· Stomach upset with nausea and vomiting
Potentially life-threatening side effects	<ul style="list-style-type: none">· Skin rashes, including Stevens-Johnson Syndrome· Bone marrow suppression and other blood disorders· Low blood sodium
Average adult daily dose	<ul style="list-style-type: none">· 600 mg–2400 mg
Therapeutic blood level	<ul style="list-style-type: none">· 3–35 mcg/mL

PERAMPANEL (FYCOMPA)

Indications	<ul style="list-style-type: none">· Add-on therapy for the treatment of partial onset (focal) seizures with or without secondary generalization
Common side effects	<ul style="list-style-type: none">· Increased sleepiness· Dizziness· Weight gain
Potentially life-threatening side effects	<ul style="list-style-type: none">· Serious psychiatric and behavioral issues including aggression, hostility, irritability, anger, thoughts of suicide
Average adult daily dose	<ul style="list-style-type: none">· 8 mg–12 mg

PHENOBARBITAL

Indications	<ul style="list-style-type: none">· For the treatment of partial onset (focal) seizures with or without secondary generalization
Common side effects	<ul style="list-style-type: none">· Increased sleepiness· Cognitive impairment· Mood changes· Altered sleep cycles
Potentially life-threatening side effects	<ul style="list-style-type: none">· Skin rashes, including Stevens-Johnson Syndrome· Liver problems· Tolerance of and dependence on medications
Average adult daily dose	<ul style="list-style-type: none">· 60 mg–200 mg
Therapeutic blood level	<ul style="list-style-type: none">· 20–40 mcg/mL

PHENYTOIN (DILANTIN)

Indications	<ul style="list-style-type: none">· For the treatment of partial onset (focal) seizures with or without secondary generalization· Also used for treatment of primary generalized epilepsy· Can be given intravenously in the hospital to rapidly control active seizures. If the drug is given by IV, Cerebyx (fosphenytoin) is preferred
Common side effects	<ul style="list-style-type: none">· Increased sleepiness· Cognitive impairment· Gum thickening (gingival hyperplasia)· Stomach upset with nausea and vomiting· Feeling off balance· Dizziness· Blurred vision· Double vision
Potentially life-threatening side effects	<ul style="list-style-type: none">· Skin rashes, including Stevens-Johnson Syndrome· Bone marrow suppression and other blood disorders· Liver problems· Long term Phenytoin use may cause decreased sensation in the lower extremities (peripheral neuropathy)
Average adult daily dose	<ul style="list-style-type: none">· 300 mg–600 mg
Therapeutic blood level	<ul style="list-style-type: none">· 10–20 mcg/mL

PREGABALIN (LYRICA)

Indications · Add-on therapy for the treatment of partial onset (focal) seizures with or without secondary generalization

Common side effects

- Increased sleepiness
- Cognitive impairment
- Dizziness
- Feeling off balance
- Blurry vision
- Double vision
- Increased appetite and weight gain
- Swelling of the lower extremities

Potentially life-threatening side effects · Skin rashes, including Stevens-Johnson Syndrome

Average adult daily dose · 150 mg–600 mg

TIAGABINE (GABITRIL)

Indications · Add-on therapy for the treatment of partial onset (focal) seizures with or without secondary generalization

Common side effects

- Increased sleepiness
- Cognitive impairment
- Dizziness
- Feeling off balance
- Blurry vision
- Double vision

Potentially life-threatening side effects · Skin rashes, including Stevens-Johnson Syndrome

Average adult daily dose · 32 mg–56 mg

TOPIRAMATE (TOPAMAX)

Indications

- For the treatment of partial onset (focal) seizures with or without secondary generalization
- Also used for treatment of primary generalized epilepsy

Common side effects

- Increased sleepiness
- Cognitive impairment/difficulty concentrating
- Decreased speech, impairment of ability to recall words
- Anxiety/nervousness
- Tremor
- Paresthesias
- Weight loss

Potentially life-threatening side effects

- Skin rashes
- Kidney stones
- Acute closure in narrow angle glaucoma

Average adult daily dose · 100 mg–400 mg

Therapeutic blood level · 2–20 mcg/mL

VALPROATE (DEPAKOTE)

Indications	<ul style="list-style-type: none">· For the treatment of partial onset (focal) seizures with or without secondary generalization· Also used for treatment of primary generalized epilepsy
Common side effects	<ul style="list-style-type: none">· Increased sleepiness· Cognitive impairment· Dizziness· Feeling off balance· Blurry vision· Double vision· Tremors· Stomach upset with nausea and vomiting· Appetite stimulation with weight gain· Hair loss
Potentially life-threatening side effects	<ul style="list-style-type: none">· Skin rashes, including Stevens-Johnson Syndrome· Liver problems· Bone marrow suppression and other blood disorders such as decreased platelet count· Pancreatitis
Average adult daily dose	<ul style="list-style-type: none">· 1000 mg–3500 mg
Therapeutic blood level	<ul style="list-style-type: none">· 50–100 mcg/mL

VIGABATRIN (SABRIL)

Indications	<ul style="list-style-type: none">· Add-on therapy for the treatment of partial onset (focal) seizures with or without secondary generalization
Common side effects	<ul style="list-style-type: none">· Increased sleepiness· Weight gain· Tremor· Blurry vision
Potentially life-threatening side effects	<ul style="list-style-type: none">· Progressive and permanent peripheral vision loss
Average adult daily dose	<ul style="list-style-type: none">· 2000 mg–3000 mg

ZONISAMIDE (ZONEGRAN)

Indications · Add-on therapy for the treatment of partial onset (focal) seizures with or without secondary generalization

Common side effects · Increased sleepiness
· Cognitive impairment and difficulty concentrating
· Depression
· Feeling off balance

Potentially life-threatening side effects · Skin rashes, including Stevens-Johnson Syndrome
· Kidney stones
· Weight loss
· Bone marrow suppression and other blood disorders

Average adult daily dose · 100 mg–600 mg

Therapeutic blood level · 10–40 mcg/mL

Safety Issues

For the Person Witnessing a Convulsive Seizure

- Protect from injury—place something soft and flat under the person's head.
- Gently roll the person onto his or her side.
- Loosen anything tight around the neck, remove eye glasses.
- Time the seizure.
- **Do not** restrain the person or grab hold of or shout at the person.
- **Do not** put anything in the mouth.
- Stay calm, let the seizure take its course.
- After the seizure, talk to the person reassuringly.

For the Person Witnessing a Non-Convulsive Seizure

- Stay with the person and let the seizure take its course.
- Time the seizure.
- Gently guide the person away from dangerous situations like crossing the street.
- Stay with the person until he or she gets back to normal.
- Calmly reassure the person.

For the Person with Seizures

- Wear a medical ID bracelet or necklace that says you have epilepsy.
- Take your medicine on time, everyday (a pillbox may help you remember).
- Try to get enough sleep.
- Avoid using alcohol and illegal drugs. Both can cause seizures.
- If you have a warning before a seizure, let someone nearby know and move to a safe place.
- Carry a cell phone so you can contact family or friends.

Most seizures last only a couple of minutes and don't require calling 911 or going to the emergency room. See what your doctor says about how to handle your seizures. In general your friends and family should call 911 if:

- You don't start breathing normally after the seizure.
- You've been severely hurt in some way.
- You had the seizure in water.
- Your seizure lasted more than 5 minutes.
- You had another seizure right after the first one without waking up between seizures.
- You're pregnant.
- You have diabetes or other serious illness.

Home Safety Tips

- Avoid space heaters that can tip over.
- Put guards around the fireplace or preferably close fireplace screens while a fire is burning.
- Carpet the floors in your house or apartment with heavy pile and thick under padding.
- Pad sharp corners of tables and other furniture; buy furniture with rounded corners; catalogs for baby and toddler supplies offer special padding in many shapes and sizes.
- Don't smoke or light fires when you're alone.
- Don't carry hot items or lighted candles around the house.
- Use curling irons or clothing irons with automatic shut off switches to prevent burns.
- Use chairs with arms to prevent falling.
- Use long heavy duty oven mitts or holders when reaching into a hot oven.
- Use a microwave for most of your cooking.
- Use the stove only when someone else is home. Serve hot things directly from the stove onto plates.
- Use plastic or paper plates and drinking cups instead of china or glass.
- Use cups with lids so you don't get burns from spilling hot liquids.
- Carve meat or poultry with a regular knife, not an electric one or an electric slicer.
- If you mow the lawn, use a mower with a "dead man's handle" which stops running if you stop holding the handle.

- If you use a circular saw or other kind of electric-powered saw, make sure it has hand protection. Make sure it stops when you stop holding it.
- At barbecues, ask someone else to do the grilling.

Parenting by the Person with Epilepsy

- When feeding your baby, sit on the floor or keep the baby snug in a stroller or steady infant seat to avoid injury to the baby in case you have a seizure.
- Dress, change and sponge-bath the baby on the floor using a changing pad.
- At home, keep the baby in the playpen or play yard.
- Always keep your epilepsy medications (and other medications) where your child can't get at them.
- Do not bathe your baby unsupervised.

Educating Your Children about Epilepsy

As your child grows, he or she may ask about your seizures.

- Use words the child can understand.
- Tell your child that you will be okay, but you may need help sometimes.
- Show your child how to get another adult to help, or to call 911 if you don't wake up after a seizure
- If you're calm, your child will be too.
- Remember that life doesn't stop because of seizures. Life goes on and, with a little planning, it will go on safely for you and your family.

Bathroom Safety

- Hang bathroom doors to open outwards instead of inwards so that if you fall against the door it can still be opened.
- Put extra padding under carpeting in the bathroom.
- Hang an "occupied" sign on the outside handle of the bathroom door instead of locking it.
- Routinely check that the bathroom drain works properly before taking a bath or shower.
- If you fall during seizures, consider using a shower or tub seat with a safety strap.
- Install non-skid strips in the tub.

- Use a hand held shower nozzle while seated in the tub or shower.
- Install tub rails or grab bars.
- Place protective covering on faucets, edges of countertops and heating units or radiators
- Set water temperature low so that you won't be burned if you lose consciousness while hot water is running.
- Avoid using electrical appliances such as a hair dryer or electric razor in the bathroom or near water.
- Use shatterproof glass for mirrors and shower doors.

Driving/Transportation Safety

- Don't drive unless you have a valid license. Follow your health care provider's advice about when you may resume driving.
- Don't drive if you've been having seizures. Know your state's law regarding when you can return to driving after having a seizure.
- If you can't drive because you're still having seizures, see if there are special bus or taxi services for people with disabilities.
- If you choose to ride a bike, protect yourself with a helmet, knee pads and elbow pads. Keep to side roads as much as possible.
- If you're waiting for a bus or a subway train, stand back from the road or the edge of the subway platform so you don't get hurt if you fall.
- If you have seizures often and can't get around any other way, a taxi may be the best choice. Your safety is worth the extra cost.
- Stay away from long steep escalators. Take an elevator instead.

Employment Safety

- Avoid work that involves heights, heavy machinery, extreme heat, fire, or molten material, or being over water.
- Use safety guards and automatic shut-offs if working with machinery or power tools.
- If using machinery, wear appropriate gloves, safety glasses, boots, and the like.
- Keep consistent work hours to maintain a healthy lifestyle and to avoid sleep deprivation.
- Learn coping methods to manage stress.
- Make sure that co-workers know appropriate first aid for seizures.

Safety Outdoors

- When you exercise, take lots of breaks. Don't get overheated.
- Taking up a new sport? Get to know the sport ahead of time. Ask yourself: would I get hurt doing this if I have a seizure?
- The buddy system is best for skiing and swimming safely. You may need extra help if you have a seizure on a snowy mountain or in a pool.
- Always use protective gear (helmets, knee pads, etc.) when playing sports.

Lifestyle Management: Health and Wellness

Be proactive about being healthy. Eating a healthy diet, exercising regularly, getting regular sleep, and managing stress are all tied into wellness. It is also important to avoid smoking and street or illegal drugs.

Research shows that people who take care of themselves and engage in healthy behaviors are more productive, are less likely to suffer from depression, and more likely to live a longer life. For people with epilepsy, being healthy can lead to better seizure control.

Eating Well

- Being a healthy, normal weight helps prevent many diseases such as heart disease, diabetes, high blood pressure, and certain cancers. Keeping your body healthy can also prevent unnecessary stress that may trigger seizures.
- Load up on fruits and vegetables (the USDA recommends at least 5 servings/day)
- Protein is essential for our bodies, we just don't need too much of it. Only $\frac{1}{4}$ of your plate should be protein. The protein you eat should be lean protein such as chicken, fish, tofu, lean beef or pork.
- Eat at least 2 servings of fish per week. Seafood is a good lean source of protein. Many fish, such as salmon and tuna have omega-3 fatty acids that have been linked to improving heart health and brain function.
- Not all fat is bad. Some fats such as unsaturated fat in olive oil and canola oil can help reduce "bad" cholesterol levels.
- Be a smart shopper. Plan meals and make lists before you go to the grocery store. Do not shop at the store when you are hungry because that can lead to impulsive purchases.
- Learn to read food labels.
- Eating well is not about deprivation. Studies show that depriving yourself of foods you love can lead to overeating later. Eat everything in moderation. If you're going to have a piece of cake, eat a smaller lunch or exercise a little longer.

Stop Smoking

- We do not know how smoking tobacco affects seizure control. However, people with epilepsy are at increased risk of injury or death from fire caused by cigarettes.
- Smoking causes harm to nearly every organ of the body, causing many diseases, and affects the health of smokers in general.
- Quitting smoking has immediate as well as long-term benefits for you and your loved ones.
- Don't give up on quitting. No matter how long you've smoked or how many times you've tried to quit, you can be smoke free.
- Smoking persists as one of the VA's biggest public health challenges. Many veterans began using tobacco while in the military. The rate of smoking among Veterans in the VA health care system is higher than among the US population.
- Approximately 70% of smokers want to quit. Even the most motivated individuals may try to quit 5-6 times before they are successful.
- To help Veterans quit smoking, the VA offers:
 - ▶ Individual counseling
 - ▶ Prescriptions for nicotine replacement therapies such as nicotine patch/gum, or other medications
 - ▶ Smoking cessation programs

Alcohol and Drugs

- Large amounts of alcohol may raise the risk of seizures and may even cause seizures.
- When you drink alcohol, it temporarily reduces your risk of seizures for a few hours but then the risk increases as the alcohol leaves your body. This is why people who drink heavily, even though they may not have epilepsy, may experience seizures after periods of binge drinking.
- When it comes to "social drinking," that is, having 1-2 drinks during an evening, the risk for seizure in a person with epilepsy can vary from person to person.
- Using illegal drugs such as cocaine, crack, PCP and speed is especially dangerous when you have epilepsy. Some of the impurities or additives to illegal drugs can cause seizures and some illegal drugs may have unpredictable or dangerous interactions with prescription medications.
- In terms of marijuana, there have been case reports that marijuana may decrease seizures. However, there is not enough research to validate this claim.

Exercise

- For people with seizures, getting regular exercises can make you feel good and it also fights depression. It can help keep you at a reasonable weight and make you feel and look your best which can build self-confidence and self-esteem.
- Be as physically active as possible. This means walking as much as possible instead of driving, taking the stairs instead of the elevator, going for a walk instead of watching TV, and having a regular workout routine.
- Always discuss new exercise routines with your epilepsy provider.
- If your seizures are not completely controlled, you should think carefully about participating in activities such as swimming, climbing, cycling, skiing, etc. If you decide to continue with these activities, you should take extra precautions to protect yourself if you have a seizure during the activity. Please see the section on **Safety Outdoors** for more tips on how to be safe when doing these activities.
- Adults should engage in at least 2.5 hours a week of moderate-intensity or 1.5 hours a week of vigorous-intensity aerobic physical activity.
 - ▶ *Mild intensity activities:* Slow walking. These activities do not cause much of a sweat or cause you to have trouble catching your breath
 - ▶ *Moderate intensity activities:* Fast walking. These activities cause your heart to beat faster. This may cause light sweating but should never cause you to be “out of breath” or exhausted.
 - ▶ *Vigorous intensity activities:* These cause your heart to beat fast. With these activities you will sweat heavily and breathe heavily.

Exercise should be FUN! Some ideas include:

- Go walking with others. Start a walking club in your neighborhood.
- Dance
- Get the whole family involved in some physical activity like walking in the park
- Find a beginner’s exercise class that you might enjoy
- Do housework to music
- Try a new sport or activity
- Do yoga or tai chi with friends or family
- Check out your local community center for upcoming events
- Play golf — carry your clubs to burn more calories or use a pull-cart.

Getting Regular Sleep

- People with epilepsy need the same amount of sleep as everyone else. There is no need to take extra naps or go to bed early.
- If you have epilepsy and you feel that you need an excessive amount of sleep, or you feel tired and sleepy all the time, this could mean that your medications need to be adjusted or that you are depressed. Your dose of medication could be too high, or you can be taking your medication at the wrong time of day. Consult your epilepsy health care team.
- Getting good sleep is important. Being sleep deprived (all-night study sessions, a series of late nights) or an overall lack of sleep can greatly raise the risk of seizures. In fact, sleep deprivation is one of the “activating” techniques physicians use to trigger a seizure during an EEG study.
- The following tips have been shown to help promote regular sleep:
 - ▶ Use your bed only for sleep or sex, no TV
 - ▶ If you don’t fall asleep within 30 minutes of going to bed, get up
 - ▶ Relax before bedtime (listen to music, take a bath, read a book)
 - ▶ Have a regular bedtime and rising time
 - ▶ Limit naps
 - ▶ Increase regular exercise
 - ▶ Avoid caffeine and other stimulants before bedtime
 - ▶ Limit alcohol use
 - ▶ Sleep in a cool, dark, quiet room

Identifying Seizure Triggers

- Seizures are rarely predictable and many people may not know what exactly causes their seizure on a given day, but they may suspect certain things increase the likelihood of seizures.
- The most common trigger for a seizure is missing a dose of medication. Epilepsy medications work best when there is a steady level of medicine in your blood.
- Other triggers may include:
 - ▶ Excessive use of or sudden withdrawal from alcohol
 - ▶ Adding or removing other prescription medications
 - ▶ Acute illness such as the common cold
 - ▶ Other medical issues such as low sodium levels, low blood sugar
 - ▶ Emotional stress leading to anxiety, worry, anger
 - ▶ Fatigue and chronic sleep loss
 - ▶ Flickering lights
 - ▶ Hormone cycles
- Knowing your triggers can help you manage your epilepsy. Keep a daily log to improve your awareness of what your seizure triggers are.
- You can choose to keep track of your seizures and seizure triggers on a paper calendar. There are also online tools and smartphone apps to help you track seizures.
- *Seizure Tracker* (www.SeizureTracker.com) - This is an online tool to help patients log and track seizure activity, appointments, and medication schedules through a simple calendar interface from their computer or mobile phone.

Smartphone and Tablet Apps

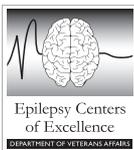
- *Epilepsy Society* app (Android OS, iOS) - Developed by the Epilepsy Society, this app includes medication reminders, medication lists, first aid information for seizures, and a seizure diary to track events, triggers, and medication side effects.
- *Seizure Tracker* app (iPhone/iPad) - Similar to the seizure tracker website described above.
- *My Epilepsy Diary* (Android OS, iOS) - Developed by the Epilepsy Foundation.

Managing Stress

- Stress can contribute to poor seizure control. It is important that you learn techniques to manage your stress when you start feeling overwhelmed, angry, or anxious.
- Techniques for managing stress include:
 - ▶ Body and mental relaxation
 - ▶ Positive thinking
 - ▶ Problem solving
 - ▶ Anger control
 - ▶ Time management
 - ▶ Exercise
- Activities to help distract or soothe yourself:
 - ▶ Listening to music
 - ▶ Getting together with a friend
 - ▶ Reading a good book
 - ▶ Watching a movie
 - ▶ Spiritual activity such as prayer
 - ▶ Yoga
 - ▶ Meditation
 - ▶ Taking a nap
 - ▶ Keeping a journal or diary
 - ▶ Expressing yourself creatively
 - ▶ Doing a hobby

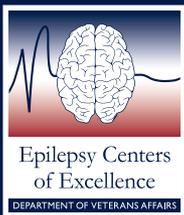
Resources

- **American Epilepsy Society:** www.aesnet.org
- **The Anita Kaufmann Foundation:** www.akfus.org
- **Center for Disease Control. *Smoking and Tobacco Use:***
www.cdc.gov/tobacco/
- **Cleveland Clinic. *Epilepsy Patient Education:***
my.clevelandclinic.org/services/neurological_institute/epilepsy/patient-education
- **Citizens United for Research in Epilepsy (CURE):**
www.CUREepilepsy.org
- **Epilepsy Foundation:** www.epilepsy.com/learn
- Lawhorne-Scott, C., and Philpott, D. (2013). *Military mental health care: A guide for service members, veterans, families, and community.* Lanham, Md.: Rowman & Littlefield.
- **Mayo Clinic. *Epilepsy Patient Care and Health Information:***
www.mayoclinic.org/diseases-conditions/epilepsy/home/ovc-20117206
- **My Seizures, Know More:** www.myseizuresknowmore.com
- **National Association of Epilepsy Centers:** www.naec-epilepsy.org
- **Seizure Tracker:** www.SeizureTracker.com
- **VA Epilepsy Centers of Excellence. *Patient Education:***
www.epilepsy.va.gov/Patient_Education.asp



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