Self-Management for Veterans with Epilepsy

Developed by
VA Epilepsy Centers of Excellence
Nursing Committee

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Understanding Epilepsy

Epilepsy is the medical term for someone who has more than one seizure or has one seizure and is likely to have another. Seizures happen because of a brief, electrical storm in the brain that can alter the way messages are sent between neurons. These abnormal firings can cause sudden changes in behavior, movement, sensation, or consciousness.

People with epilepsy can still live active and productive lives! Appropriate medical treatments, safety management, and coping strategies can allow those with epilepsy to increase their quality of life. We will talk about a few tactics here.

Identifying Seizure Triggers

People with epilepsy find that keeping a seizure journal can help them understand more fully why seizures occur at certain times. Women with catamenial epilepsy may notice that their seizures occur more often at a certain stage of their menstrual cycle, such as a few days before their period. Some women have seizures at other stages of their menstrual cycle. For instance, some women with catamenial seizures have noticed that the drop in their progesterone just before their period starts and the rise in estrogen during ovulation may be triggers for seizures. Other common seizure triggers include missed sleep and alcohol use, which can lower seizure threshold and increase likelihood of a seizure. Keeping a thorough record of the behaviors the person experiences before their seizures can help identify what triggers to avoid. This lends understanding for how to better manage their epilepsy.

Antiseizure Medications

Epilepsy is usually treated with antiseizure medications (ASMs). ASMs do not cure epilepsy, but they control seizure activity. The ASM you are given is chosen based on several factors—primarily your seizure type. Additionally, your age, overall health, and other medical problems are taken into account.

Controlling Seizures

The provider, with the patient's input, will balance the amount of seizure control with the side effects of the medicine chosen: It is often a fine balance when your provider is choosing the correct dosage of your ASM, and communication is crucial between provider and patient. ASMs can control seizures in most people who take them consistently and as prescribed.

ASM Side Effects

All ASMs can cause side effects. They can also affect other medicines you are taking, including vitamins, herbals, or other medicines you buy on your own. Be sure to tell you provider about all of these other medicines. The most common side effects of ASMs are tiredness, sleepiness, nausea, dizziness, weight gain or loss, blurred or double vision, mood changes, and sexual side effects. Let your provider know right away if your ASM causes a rash as this can be a sign of a serious allergic reaction. Your provider will help you manage each side effect or alter your ASM. It is your responsibility to call your provider right away if you are worried.

“How long will I be on antiseizure medicine?”

Each person with epilepsy is unique: Your type of epilepsy and how long you have been seizure-free helps determine whether lifelong drug therapy is needed. It is important that you discuss your goals of treatment with your health care provider. Have regular conversations about seizure self-management, including how to order medications, manage missed medications, breakthrough seizures, your seizure triggers, and side effects of medications.

How to Manage Timely Ordering of Your ASMs

You’re in charge of having success with your antiseizure medications. Order your antiseizure medications on time—don’t wait until you have one pill left. Use a calendar on your refrigerator to circle the date you need to order, leaving time for shipping. Make sure you have adequate refills. If you experience an issue refilling your medication, contact your provider as soon as possible to prevent missed doses that can lead to seizures.

If You Missed a Dose

In general, if you missed a dose, try to take it as soon as you remember, but not if it’s too close to the time of your next dose. Do not take a double dose without being told to do so. The more doses you miss, the greater your risk of having a breakthrough seizure. Contact your provider or pharmacist with questions about missed doses or changes to the timing of your medication. Use a pill box, reminder app, or calendar to ensure you are taking your medications on time. If you have trouble remembering to take your ASM twice a day, ask your provider if changing to an extended-release version, which can be taken once a day, is an option.

Epilepsy Education Helps Our Families and Caregivers

Caring for a person with epilepsy can be stressful, but, if caregivers learn about epilepsy, they can help minimize their loved one's anxiety surrounding their epilepsy. Important things for our families and caregivers to learn about are types of seizures, seizure triggers, seizure first aid, antiseizure medications, and other helpful strategies.

It's a good idea to invite your caregiver or family member to your medical appointments. Often, they ask good questions that you might not think of asking. They can help you remember information discussed at your visit. Also, they can take notes for you to review after your appointment.

Epilepsy's Impact on Family and Caregivers

The daily routine of caring for someone with epilepsy can be emotionally draining. It is important that caregivers do not neglect themselves.
Stress relieving exercises such as deep breathing, meditation, yoga, or taking a walk can decrease stress. Finding a support group for caregivers can be another way to relieve stress. If you are experiencing caregiver burnout, ask to speak to a social worker or therapist who can suggest other helpful ways to decrease stress.

Relationship with Family

When epilepsy is first diagnosed, members of your family may experience a range of emotions such as fear, helplessness, guilt, overprotection, depression, resentment, embarrassment, or jealousy. Discussing these feeling as a family and with your health care team may be helpful. People with epilepsy and their families can create and maintain positive relationships through learning about how to manage epilepsy together. Also, keeping open channels of communication with each other is vital.

Epilepsy's Impact on You

Memory and Thinking Problems

Some people with epilepsy may never experience memory or thinking problems. Others may have problems depending on the seizure type and frequency. Problems can include trouble with memory, attention and concentration, difficulty finding the right words, or other problems with mental functioning. Some antiseizure medications may affect memory or cause slowed thinking as a side effect. Your health care team can help you develop strategies to improve your mental function.

Tips to improve your memory:

- Follow a set routine.
- Use pictures as visual aids.
- Use a pill box to help you remember to take your medications. Ask your VA pharmacist to provide a pill box for you.
- Set a daily reminder on your cell phone to take your medication. Set reminders for your appointments.
- Use sticky notes around the house.
- Ask family members/caregivers/friends to provide reminders.
- Participate in memory training programs, such as HOBSCOTCH (**HOBSCOTCH.org**).

Sleep

Epilepsy affects your sleep and, in turn, your memory. During sleep our brains process information and experiences. Concentration and memory are lessened when you do not sleep well.
Regular seizures during sleep can have a significant impact on daytime functioning and memory. When a seizure or seizures happen during sleep, they disrupt the sleep patterns for the rest of the night, leaving the person feeling unrefreshed, drowsy, and tired in the morning (and during the day). Your hypothalamus-pituitary-adrenal system is impaired with chronic sleep loss, which will contribute to memory deficits. Sleep disorders are more common in people with epilepsy.

The Epilepsy Centers of Excellence suggests a referral to a sleep specialist to rule out a sleep disorder such as sleep apnea. The effect of sleep loss is huge on memory retrieval, storage, and retention. Sleep loss could thus affect the resiliency of your stress response. This may accelerate the development of metabolic and cognitive consequences of cortisol excess. Simply stated, higher serum cortisol is associated with lower brain volumes and impaired memory, so protect your sleep.

Tips to improve your sleep:

- Use your bed only for sleep or sex. Avoid watching tv or using electronic devices in bed.
- If you don’t fall asleep within 30 minutes of going to bed, get up and do something relaxing until you feel tired.
- Relax before bedtime (listen to music, take a warm shower, read a book).
- Don’t take your worries to bed.
- Get up and go to bed at the same time every morning and evening.
- Limit naps.

- Engage in regular exercise and refrain from exercising 2 hours before bedtime.
- Avoid stimulants such as caffeine, nicotine, and chocolate before bedtime.
- Sleep in a cool, dark, quiet room.

Alcohol and Drugs

- Large amounts of alcohol may raise the risk of seizures and may even cause seizures.
- When it comes to "social drinking," that is, having 1-2 drinks during an evening, the risk for seizure in a person with epilepsy varies from person to person.
- Using illegal drugs is especially dangerous when you have epilepsy. Some of the impurities or additives to illegal drugs can cause seizures. Some illegal drugs may have unpredictable or dangerous interactions with your prescription and over-the-counter medications.

Improving Epilepsy Management

Recreational Activities and Exercise

Maintaining a healthy, active lifestyle can improve seizure control. However, since seizures can happen at any time, it is important to be safe during recreational activities. For people with seizures, getting regular exercise can make you feel better. Exercise also fights depression. It can help keep you at a healthy weight and make you feel and look your best, which can build self-confidence and self-esteem.

Some tips include:

- 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. Use the buddy system when possible. Try not to go alone.
- When you exercise, take a lot of breaks so you don't get overheated. Drink a lot of water to prevent dehydration.
- Exercise on soft surfaces like grass, mats, or wood chips, if able.
- Check with your epilepsy provider before engaging in contact sports.
- Wear a life vest when you are on or close to water.
- Wear head protection when playing contact sports, or when there is an added risk of falling or head injuries.
- 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.
- 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.

Nutrition

Eating a healthy diet is important for fitness and wellness and will improve your heart health. There are no specific foods that generally trigger seizures. A healthy body, of course, means a healthy brain. Mind health reduces the stress surrounding seizures. Your provider can refer you to a nutritionist to assist with your particular dietary needs. A modified ketogenic or Atkins diet can aid in management of your epilepsy.

Home Safety

- 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.
- 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 or grill only when someone else is home.
- Use plastic or paper plates and drinking cups instead of 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 barbeques, ask someone else to do the grilling.

Driving Safety

- Don’t drive without a valid license.
- Follow your healthcare provider’s advice about when to resume driving.
- Know your state’s law regarding driving after having a seizure.

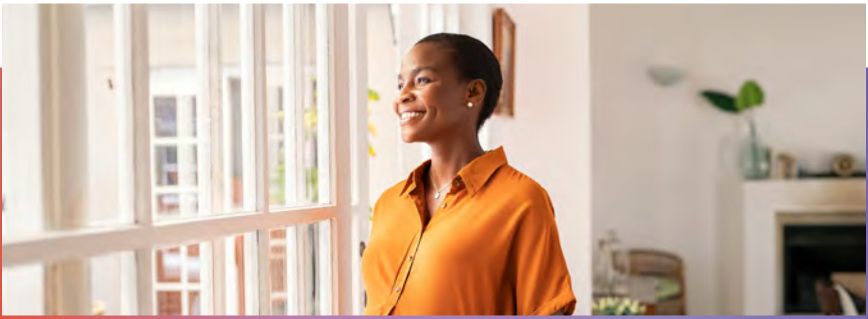
Mental Health Management

“How do I know what is normal and when to ask for help?”

People with epilepsy sometimes experience mood problems or increased stress and forget to ask for help. These changes in mood can affect their activities and their sense of having a quality life. These feelings may occur at different times, or around the time of a seizure. Some people may just feel more irritable, while others may become depressed.

There are different ways to treat mood conditions. If you find that certain behaviors or emotions trigger your seizures, your provider can help with referrals to other specialists, as well as medications. If you start a new medicine for your mood, your provider may need to adjust the dose to account for medicine interactions with your ASMs.

Mood can be addressed by psychotherapy, individual and family counseling, or epilepsy support groups. If you have mood changes or are feeling depressed, speak with your epilepsy care team. By listening to these professionals and volunteers, you may learn new ways to deal with the stress of epilepsy. Talking openly with your provider, who is experienced with finding solutions, will help you find ways to cope well with your disease.



Stress Management

Stress can trigger seizures. There are several excellent ways to destress:

- Body relaxation techniques
- Positive thinking
- Anger management
- Time management
- Music therapy
- Art therapy
- Meeting with a friend
- Volunteering with a service group
- Reading or listening to a good book
- Watching a movie
- Prayer and other spiritual fuel
- Exercising
- Taking time for meditation
- Power naps
- Keeping a journal

Attitudes and Stigmas

As common as epilepsy is, there are still many myths and stigmas about it. In the past, people with epilepsy were labeled as being possessed or being punished. Concurrently, in some cultures, epilepsy is considered a gift, and this can cause family to be resistant to "treat" the gift that their loved one has. Today, people with epilepsy continue to feel that they are treated as being "different," despite modern medicine, technology, and public education. At the end of this booklet, you will find multiple resources for educating yourself and others about how to empower those with epilepsy.

Epilepsy Support

Make Ties with Others

Embarrassment about having seizures may make you feel uncomfortable and insecure around others or tempted to isolate yourself. Because support is essential to managing epilepsy, it can be beneficial to reach out to others and establish a solid support community. When you do have feelings of loneliness or isolation, communicate with your health care team and try to focus on the more manageable aspects of your condition. For instance, take your medications as prescribed and strive to live a healthy lifestyle. These tips are ways you can manage a complicated disease.

Social Media

Along with the usual forms of friends and support groups in your community, you can find support online. Reputable social media networks can offer a powerful communication tool for epilepsy patients, where you can share with others who have the same concerns as you. By speaking up about issues, you help both yourself and others with your shared experiences. You become both the learner and the mentor!

www.patientslikeme.com

Employment

You may also have trouble finding and keeping a job. Remember that these problems are *not* your fault. There are things you can do to manage the controllable aspects of epilepsy, such as reaching out and finding agencies that know the laws of employing those with medical conditions. There are resources at the end of this booklet to assist you with employment success.

Additional Resources

Mental Health Management

The Epilepsy Foundation provides a useful tool for screening for depression and other neurological disorders associated with epilepsy. The Neurological Disorders Depression Inventory for Epilepsy (NDDI-E) Screening Tool is a confidential questionnaire that generates a score at the completion of the questionnaire. Your score will help your physician determine what necessary steps to take in your treatment. More information about the NDDI-E can be found at the below webpage. Just highlight the address, and press "ctrl" on your keyboard and left click your mouse to see an information page for this tool.

www.myamericannurse.com/wp-content/uploads/2019/07/CE-Epilepsy-Screening-Tools.pdf

Epilepsy and Families/Caregivers

Online support is available for individuals with epilepsy and those caring for them. Online communities provide forums, group chats, blogs, and other useful information for individuals with epilepsy. To find out more, just highlight, copy, and paste the following site in your browser:

www.epilepsy.com/connect

Socioeconomic Factors

To find out more about epilepsy and employment, the Epilepsy Foundation's forum on epilepsy and employment is a useful resource developed specifically for individuals with epilepsy. This forum contains topics such as discrimination, career changes, disability benefits, etc. For more information, highlight, copy, and paste the following sites in your browser:
Employment Help with Epilepsy | Epilepsy Foundation

Additional Websites

www.epilepsy.com/learn/about-epilepsy-basics
www.cdc.gov/epilepsy
www.managingepilepsywell.org

Veterans Crisis Line
DIAL 988 then PRESS 1

Epilepsy Centers of Excellence
Department of Veterans Affairs

email: **ECoE@va.gov**

www.epilepsy.va.gov

U.S. Department of Veterans Affairs
Veterans Health Administration