

Self-Management Strategies in Epilepsy

Self-management skills can help people take control of their health and better manage their day-to-day challenges.

Thank you to the Epilepsy Foundation of America and the Managing Epilepsy Well Network for the information and tools listed in this document.

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Self-Management Strategies in Epilepsy

Managing a condition like epilepsy can be complex and frustrating at times. Seizures can make it challenging to work, go to school, drive, and take part in social activities. Sometimes epilepsy treatment makes these activities harder, too. Self-management skills can help people take control of their health and better manage their day-to-day challenges.

Self-management does not mean that people manage their health alone. Self-management requires an active partnership between a person with epilepsy, their support network, and their health care provider(s). Each one plays an important role in epilepsy self-management.

Epilepsy self-management encompasses three broad areas:

Treatment Management

Medication schedules, keeping clinic appointments, and communicating with health care professionals.

Seizure Management

Recognizing and avoiding seizure triggers whenever possible and keeping track of seizures.

Lifestyle Management

Getting adequate sleep, reducing stress, and maintaining social support networks.

Tracking Seizures

Diagnose Seizures



Seizures can look and feel different from one person to the next. A first-person report of what is going on will help the doctor tell if the events are seizures or not. And figure out what kind of seizure it is. Knowing the seizure type will help you and your family know: how to respond to a seizure, what to be concerned about, what NOT to worry about, and when to get emergency help.

Choose Treatments



Not all seizure medicines work for all types of seizures. Some are better for focal seizures than for generalized ones or in people with a specific epilepsy syndrome. Knowing the seizure type will help everyone decide which medicine or treatment to try.

Know if Treatment Works



Track if seizures happen less often or have changed after a new medicine or treatment is started. If seizures continue or get worse, this information will also help you and your team decide when to try a different treatment.

Identify and Manage Side Effects



Tracking side effects of medicines on seizure calendars can help you and your doctor know how you are tolerating the drug. See if side effects get better over time or go away when a dose is changed. If side effects don't go away, it's one more piece of information to use when deciding if other treatments should be tried.

Identify Triggers and Modify Lifestyle



Writing down when seizures occur and what happened around that time helps you recognize possible triggers. You may notice a pattern, such as seizures that occur only at a specific time of day. Or you can see if certain factors occur around the time of your seizures, such as not sleeping well, being sick with fever or illness, stress, or missing medicines. Use this information to make changes and help you get better seizure control.

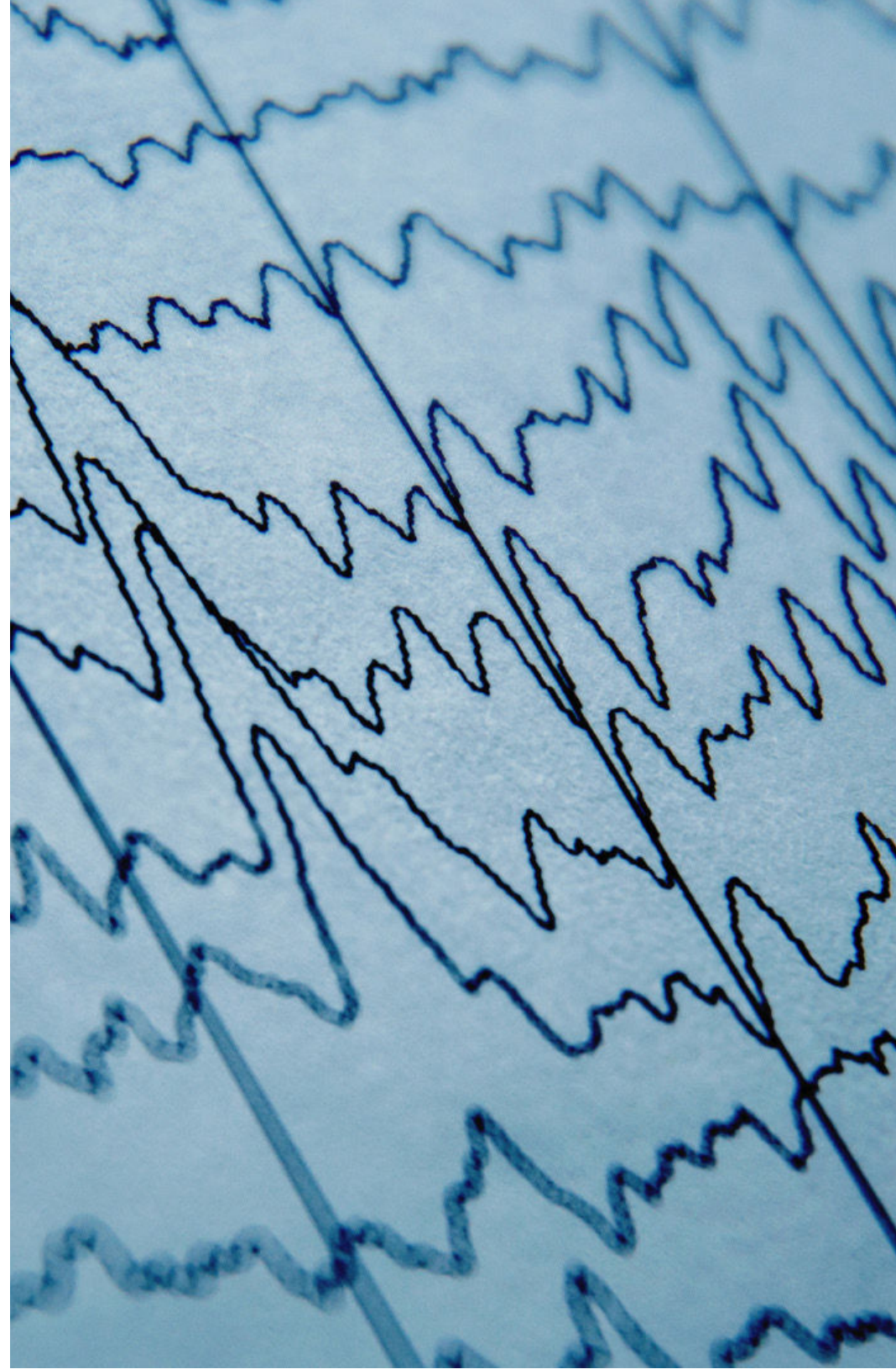
Managing Triggers

Once you start tracking your seizures, you may find that your seizures occur in a pattern or in certain situations.

Avoiding these patterns can help lessen the chance that a seizure may happen.

Remember that not all people with epilepsy have seizure triggers, and for those that do, triggers might be different from person to person. In other words, not all persons whose seizures can be triggered have the same seizure triggers.

Triggers may be different from one person to the next. For example, seizures may occur only during sleep or when waking up. Some women may notice that they are more likely to have a seizure during certain parts of their menstrual cycle, while other people may notice seizures more often at times of high stress.



Common Seizure Triggers

Missed Medication

Menstrual Cycle

Sleep Deprivation

Nutritional Factors

Stress

Over-the-Counter
Medicines

Alcohol

Flashing Lights

Drug Abuse

Communication with your Healthcare Team

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Talking with your doctor goes both ways. You want answers, but the doctor and other members of the healthcare team need information from you too! What you can tell your doctor and team is important to get the right diagnosis and care! Here are a few things to consider when talking to and sharing information with your healthcare team.

Look at your role on the healthcare team:

The traditional approach to medical care is that the patient answers questions, and the doctor or other healthcare professional recommends the treatment. However, patient-centered and self-management approaches stress the central role of the patient and family on the healthcare team. These approaches are very important when people are coping with a health problem over time.

Keep in mind that epilepsy is often 'invisible' to healthcare providers - seizures and other problems can't be easily seen or diagnosed during an office visit. **You, the person with epilepsy, and your family members are central to what is going on.**

Don't be afraid to ask questions.



People work together best when they know what to expect from each other. Learn to ask questions about your role, your doctor's role, and what to expect from each other.

Some of these questions should be discussed early on in your treatment. However, your doctor may not be able to answer whether new treatments are appropriate for you until he or she gets to know you and finds out more about your seizures.



Learn how to talk about new ideas or treatments, other people who should be part of your team, and other concerns you may have.

Responding to Seizure Emergencies

A seizure is considered an emergency when it lasts a long time or when seizures occur close together and the person doesn't recover between seizures. Just like there are different types of seizures, there are also different types of emergencies.

Convulsive status epilepticus

This term is used to describe the more common form of an emergency situation that can occur with prolonged or repeated tonic-clonic (also called convulsive or grand mal) seizures. Most tonic-clonic seizures end normally in 1 to 2 minutes, but they may have post-ictal (or after-effects) symptoms for much longer. This makes it hard to tell when a seizure begins and ends.



Status epilepticus occurs when:

- The active part of a tonic-clonic seizure lasts 5 minutes or longer.
- A person goes into a second seizure without recovering consciousness from the first one.
- If a person is having repeated seizures for 30 minutes or longer.

Convulsive status epilepticus requires emergency treatment by trained medical personnel in a hospital setting. EEG testing may be needed to monitor the seizures and how a person responds to treatment. This situation can be life-threatening and getting treatment started fast is vital.

The outlook for convulsive status epilepticus may vary depending on the cause of the emergency and if other medical problems or complications occur.

Nonconvulsive status epilepticus

This term is used to describe long or repeated absence or complex partial seizures.

- The person may be confused or not fully aware of what is going on, but they are not 'unconscious', like in a tonic-clonic seizure.
- These situations can be harder to recognize than convulsive seizures. Symptoms are more subtle and it's hard to tell seizure symptoms from the recovery period.
- There is no consistent time frame on when these seizures are called an emergency. It depends in part on how long a person's typical seizures are and how often they occur.

When nonconvulsive status epilepticus occurs or is suspected, emergency medical treatment in a hospital setting is needed. EEG testing may be needed to confirm the diagnosis first. People with this type of status are also at risk for convulsive status epilepticus, thus quick treatment is required.

Acute repetitive seizures or clusters

Seizures of any type may occur in groups or clusters over a number of hours or days. A person usually recovers between seizures and the clusters will end on their own.

People can be at risk for repeated clusters or status epilepticus if:

- Seizure clusters last longer than normal.
- Seizures occur closer together.
- A person doesn't recover as well between seizures or clusters.
- The rescue medicines given to stop the clusters don't work.

If a person can recognize seizure clusters or acute repetitive seizures easily enough, they can often be treated outside of a hospital setting. Ideally, this early treatment will prevent the need for hospital treatment. However, if out-of-hospital treatments don't work and seizures continue or complications occur, emergency medical treatment will be needed.

Epilepsy and Mental Health

Epilepsy and Mental Health conditions are co-occurring conditions that greatly impact each other. Being aware of each individual condition and how they interact together affects your overall well-being. Below are four strategies to be aware of as you manage both conditions.

1 Stay Informed on Treatment Strategies

- Be aware of medication side effects.
- Use useful medication reminders and dispense options.
- Be informed of the timeline and projected progress made by treatment strategies.

2 Identify Coping Mechanisms for Double Stigma

Double stigma is the result when two highly stigmatized conditions sensitive to cultural themes occur in the same individual, such as epilepsy and mental health.

- Inform yourself of accurate information related to epilepsy and mental health.
- Include your support network in how you practice self-care.

3 Seek Professional Support

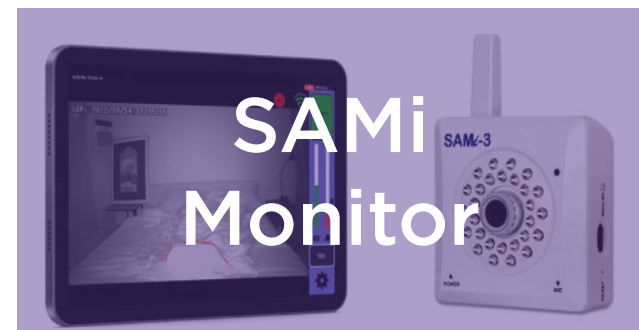
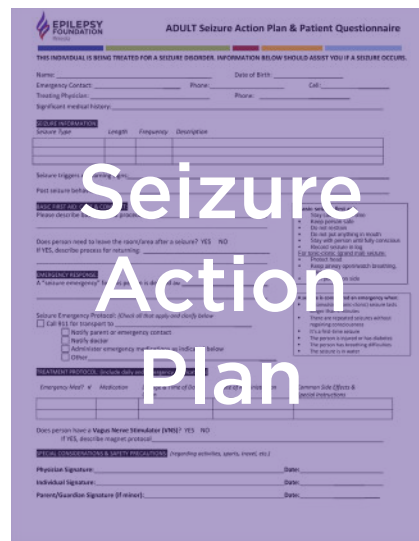
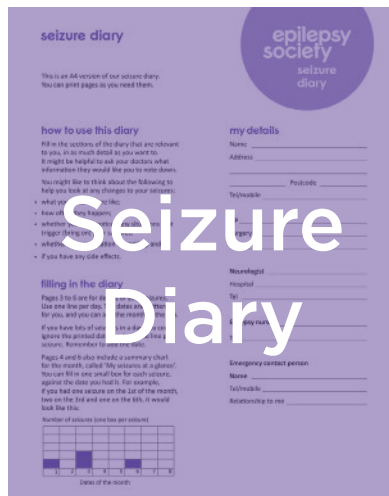
- Talk with your epilepsy provider for a mental health provider referral.
- [Connect with the Epilepsy Foundation of Minnesota](#) for a mental health provider referral and additional resources.

4 Join Social Groups

- Identify a trusted group within your community to connect with.
- [Join a connect group](#) through the Epilepsy Foundation of Minnesota
- [Join a group](#) through the National Alliance of Mental Illness – Minnesota.

Useful Tools and Devices

Click on an image below to learn more.



Citations: epilepsy.com, managingepilepsywell.org/self-management

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