MODULE 3: EPILEPSY SUPPORT AND NON-MEDICATION MANAGEMENT
## TABLE OF CONTENTS

- Epilepsy Management Includes More Than Medication .................3
- Build Your Epilepsy IQ: Common Epilepsy Terms .........................4
- Epilepsy Safety ........................................................................11
- Living With Epilepsy – Quality of Life .......................................14
- Epilepsy Self-Management: Managing Lifestyle and Wellness ........16
- Building Your Epilepsy Community of Support ............................18
- References .............................................................................22

### Handouts

- Who to Contact for Help With Quality-of-Life Issues ...............24
- Epilepsy Educational Resources and Support Groups ..............25-27
- Frequently Asked Questions and Answers ..............................28-31
- Healthcare Lingo .....................................................................32-33
- Seizure Action Plan for Adults ..............................................34-38
- Seizure Action Plan for Teens .................................................39-44
Epilepsy Management Includes More Than Medication

Taking your antiepileptic drugs (AEDs) is an important part of epilepsy management.° Living well with epilepsy means that you will need to do more than take your medications regularly.

5 Keys to Empowerment

- Build your epilepsy IQ
- Manage lifestyle and wellness
- Establish a community of support
- Live safely with epilepsy
- Improve your quality of life

Self-management of epilepsy is an important part of your care.°° Self-management means taking responsibility for your own behavior and well-being. It also means managing your own day-to-day health.
Build Your Epilepsy IQ: Common Epilepsy Terms

Building your epilepsy IQ means learning about all the ways that epilepsy affects your life. Epilepsy affects each person differently. What is most important about how epilepsy affects your life? Think about what is most important to you as you develop self-management tools to help manage your seizures. The goal of epilepsy self-management is to live the best life possible while managing the disease. Learning more about common epilepsy terms can help you build your epilepsy IQ and self-management skills.

Seizure Triggers

Seizure triggers are specific things that may cause your seizures. Triggers are different for each person with epilepsy. If you know what your seizure triggers are, then you can try to avoid them.

A seizure trigger is something that happens regularly before seizures. Here are some common seizure triggers:

- Missed dose of AED
- Lack of sleep or disrupted sleep
- Illness (with or without a fever)
- Alcohol or illegal drug use
- Stress
- Flashing bright lights
- Certain foods
- Skipped meals (low blood sugar)
- Hormonal changes in women
- Medicines that interfere with AEDs
- Too much caffeine
- Not drinking enough liquids

You may already know what your seizure triggers are. If so, you might want to share this information with your family, friends, coworkers, and healthcare professionals so they can help you avoid your triggers.
If you don’t know what your seizure triggers are, try to remember what you were doing before you had a seizure. Here are some ideas to think about:

- Where were you?
- Were there flashing lights or anything else going on around you that may have triggered the seizure?
- How did you sleep the night before?
- Were you feeling extra stress around the time of the seizure?
- What did you eat or drink that day?

If you can remember what was happening right before you have a seizure, you can write this down on your seizure diary each time you have a seizure. If someone was with you when you had a seizure, ask if the person remembers anything that might have triggered the seizure. You and your healthcare professional might be able to figure out what your seizure triggers are by looking at your notes.
Aura

An aura is a warning that some people may have before a seizure. Not everyone with epilepsy has an aura. For people who do have an aura, it may be hard to describe. An aura can be a change in feeling, sensation, thought, or behavior. If you have an aura, it could be the same each time you have a seizure, or it could be one of the warning signs mentioned. An aura may actually be a seizure for some people with epilepsy.

Some people have physical changes before a seizure, such as:

- Dizziness
- Lightheadedness
- Headache
- Feeling sick to your stomach, or having other stomach problems
- Numbness or tingling in a part of the body
Risk Factors
Risk factors are something that can make a person more likely to have epilepsy. Not everyone who has epilepsy has risk factors. Here are some risk factors for adults with epilepsy:

- Alzheimer’s disease
- Autism
- Brain injuries, tumors, infections, or bleeding
- Stroke (blocked blood vessel in the brain)
- Family history of epilepsy
- Family history of seizures that happen during a fever
- Use of illegal drugs such as cocaine

Drug-resistant Epilepsy
Drug-resistant epilepsy means that after trying either 2 different types of AED medications alone or after trying 2 different combinations of AED medications, you continue to have seizures.
Status Epilepticus
Status epilepticus is a series of continuous seizures that last over a period of time and may cause brain injury.¹⁷

Any seizure that causes muscle contractions and lasts more than 5 minutes should be considered a medical emergency, and someone should call 911.¹⁷

In some people, status epilepticus is caused by something happening in the brain, such as a brain tumor or a brain infection. In other people, there is no known cause.¹⁷

Sudden Unexpected Death in Epilepsy (SUDEP)
SUDEP is a sudden unexpected death related to epilepsy. It is not caused by drowning or another type of accident that could lead to death while having a seizure. SUDEP can happen with or without a seizure.¹⁸

SUDEP might be hard to talk about, but knowing that it could happen is an important part of prevention.¹⁸

Facts About SUDEP
Here are some facts about SUDEP:

- About 1 in 1000 adults with epilepsy die of SUDEP each year¹⁹
- Frequent seizures, especially generalized tonic-clonic seizures, are the greatest risk factor for SUDEP¹⁹
- Most common epilepsy-related cause of death that is not due to physical injury¹⁸
- Happens more often in people with epilepsy who could be treated with surgery¹⁸
- Among neurologic conditions, SUDEP ranks second, after stroke, in years of potential life lost¹⁸
Risk Factors for SUDEP

Here are the known risk factors for SUDEP:

- Male gender
- Age between 20 and 40 years
- Longer duration of epilepsy
- Frequent uncontrolled seizures
- Nighttime seizures
- Seizures that happen in bed
- Frequent generalized tonic-clonic seizures

You may want to talk to your epilepsy doctor about your potential risk of SUDEP.
Preventing SUDEP

Doctors and researchers are studying SUDEP to learn more about it. It is not known yet if SUDEP can be prevented.\(^8\)

These SUDEP prevention tips are especially important if you have generalized tonic-clonic seizures. Some people at high risk of SUDEP might wear a seizure monitoring device while sleeping.\(^8\)
Epilepsy Safety

Being safe while living with epilepsy is very important. During a seizure, you may fall, lose consciousness, or have muscle movements that you can’t control.

These can put you at risk for:
- Bruises
- Burns
- Cuts
- Breaking a bone
- Head injuries
- Drowning

Certain situations carry extra risk for someone with epilepsy, such as:

- Heights
- Traffic
- Water
- Source of heat
- Source of electricity

Planning for Safety

You need to plan for your own safety in case a seizure happens. Think about safety at home, safety in the workplace, and how people around you can help you stay safe. Here are some things you can do no matter where you are:

- Wear a medical ID bracelet that says you have epilepsy
- If you have an aura or any kind of warning before you have a seizure, let someone near you know and move to a safe place
- Carry a cell phone so you can contact family or friends
Safety at Home

How have you prepared for a seizure emergency in your home? Some ideas to stay safe at home include:

- Don't smoke or light candles or fires when you're home alone.
- Install non-skid strips in the bathtub or shower.
- Carpet floors with heavy pile and thick carpeting.
- Use microwave for most of your cooking, or only use stove when someone else is home.
- Buy furniture with rounded corners or pad sharp corners.
- Use plastic or paper instead of china or glass.

What other things can you do to make your home more safe?

Safety in the Workplace

How have you prepared for a seizure emergency in your workplace? Here are some ideas about safety in the workplace:

- Make sure that coworkers know what to do if you have a seizure.
- Avoid work that involves heights, being over water, using heavy machinery, or being exposed to extreme heat or fire.
- Try to keep regular work hours and a regular sleep schedule to maintain a healthy lifestyle.
- Use safety guards and other automatic shutoffs if working with machinery or power tools.

What other things can you do to make your workplace more safe?
Educating Others About Epilepsy Safety

Make a list of people who need to know about your seizures, including family, friends, and coworkers.

Create a seizure action plan in case any of these people need to help you when you have a seizure. This plan will tell people what to do when you have a seizure and includes how to help you after the seizure, who to call, your doctor’s name, your medications, and lots of other information. Seizure action plans for adults and older teenagers are available at the end of this module, after the handouts. Both seizure action plans can also be downloaded from the Exploring Epilepsy website.

Seizure first aid classes are complimentary through the Epilepsy Foundation. Contact your local chapter.
Living With Epilepsy – Quality of Life

Impact of Epilepsy on Quality of Life

Epilepsy is about more than having seizures. Living with epilepsy can affect your quality of life. Quality of life is your sense of well-being that comes from how satisfied you are with your roles, activities, goals, and opportunities in life.\(^6\)

Here are some specific ways that your quality of life may be affected if your seizures are not controlled:

- Your ability to work\(^3\)
- Your ability to drive\(^3\)
- How productive you are at work, home, or school\(^6\)
- Your ability to live independently\(^3\)
- How you function in family, social, and romantic relationships\(^6\)
- Feeling embarrassed about having a seizure in public\(^3\)
- Feeling depressed or anxious\(^3\)

People with epilepsy who are seizure free have about the same quality of life as people without epilepsy.\(^2\)
Who to Contact for Help With Quality-of-Life Issues

Part of epilepsy self-management is learning how to improve your quality of life. In addition to your healthcare team, there are other people in your community who can help you navigate this journey. 

Here are some ways of finding help:

**Community Services**
- State and local Epilepsy Foundation affiliates
- Local nonprofit organizations that help patients with chronic conditions
- Social workers

**Employment**
- The human resources department where you work
- Vocational training programs
- Government agencies

**Transportation**
- Local department of motor vehicles
- Local transportation agencies
- Social service organizations
- Government agencies

**Housing**
- Social service organizations
- Nonprofit organizations, including faith-based organizations
- Government agencies

**Social Support**
- Psychologists, social workers, or other behavioral specialists
- State and local Epilepsy Foundation affiliates
- Faith-based organizations

**Education**
- Individualized education programs
- Cognitive testing and educational assistance
Epilepsy Self-Management: Managing Lifestyle and Wellness

Managing your lifestyle and improving your overall wellness can be just as important as taking your AEDs regularly to help control seizures. Making a commitment to the treatment plan, including both medication and non-medication therapies, can help you live well with epilepsy.\(^4,6\)

Let’s talk about some lifestyle changes that may help control your seizures and improve your quality of life.\(^4,6,15,23,24\)

Reduce Stress

For some people with epilepsy, stress can be a seizure trigger. People who experience stress can feel overwhelmed, anxious, or angry. Reducing stress may reduce the number of seizures you have. Some ways to reduce stress include yoga and meditation.\(^4,6\)

Practice Good Sleep Hygiene

Sleep is important for your overall well-being. Lack of sleep is a seizure trigger for some people. Good sleep hygiene means more than just getting enough sleep each night. It also means you should go to bed and get up at about the same time. Sleep in a cool, dark, quiet room. Try not to look at your smartphone, TV, or other electronic devices right before you go to bed. Avoid caffeine before bedtime.\(^4,24\)

Eat Healthy Foods

Proper nutrition (what you eat each day) may improve your overall well-being and may help with better seizure control.\(^4,6\) Try to eat regularly throughout the day so your blood sugar doesn’t get too low. Low blood sugar is a seizure trigger for some people.\(^10\) Choose healthy foods.\(^4\)

There are some specific diets that can help some people with epilepsy.\(^6\) For example, the ketogenic diet is a special high-fat, low-carbohydrate diet that may be prescribed by your doctor. Along with medication, the ketogenic diet may help control seizures for some people with epilepsy.\(^37\) You should talk to your healthcare team before making changes to your diet.\(^6\)
Let's review some lifestyle changes that may help control your seizures and improve your quality of life:

- Try to reduce stress; you may want to try yoga, meditation, or other methods of stress relief.
- Get enough sleep and follow a regular sleep schedule.
- Eat healthy foods.
- Exercise regularly.
- Talk to a therapist about how to include lifestyle changes in your daily routine.

**Exercise Regularly**

Regular exercise can help some people with epilepsy have fewer seizures. Exercise can also improve your ability to pay attention, your mood, and your overall health. Talk to your healthcare team before starting a new exercise program, because exercise may also be a seizure trigger for some people with epilepsy. Also, think about how to keep yourself safe in case you have a seizure while you exercise.

**Talk to a Therapist**

You might find it helpful to talk to a psychologist or a social worker about how epilepsy impacts your daily life. A therapist can help you figure out how to include lifestyle changes in your daily routine.
Building Your Epilepsy Community of Support

Members of Your Community of Support

Your Healthcare Team

Remember that you are the most important member of your healthcare team. Other members of your healthcare team can help you in different ways.

Your Friends, Family Members, and Other Caregivers

Your friends, family members, and other caregivers can also support you. They can help you with self-management of epilepsy, such as making sure you get enough sleep, eat healthy, and are safe at home.

Your Coworkers

Your coworkers can support you by making sure you are safe at work.

Other People With Epilepsy

Talking to other people living with epilepsy may be very helpful. Only another person with epilepsy can really understand how you feel and what you’re dealing with. You might want to join:

- Online epilepsy support groups
- In-person epilepsy support groups
Support groups can help you in a lot of ways:

- Feeling more comfortable with your epilepsy diagnosis
- Taking your AEDs regularly
- Keeping track of your seizures
- Finding ways to talk to your healthcare team about your seizures, medications, or other issues
- Helping you feel like you have more control over epilepsy
- Helping you live well with epilepsy
Online Support Groups

Online support groups might also be called online communities. Here are some recommended, well-known, education-based online communities for people with epilepsy:

**Epilepsy Foundation**
- Community Forums are online discussion groups for specific topics, such as medication issues, women with epilepsy, or epilepsy and college.
- Chat Room is a way you can share experiences, questions, or concerns about epilepsy and seizures.

**Patients Like Me (Epilepsy Community)**
- You can see what epilepsy medications other people have tried, how well the medications work for them, and what side effects people have.
- You can see what other problems (symptoms) people have, like feeling tired or having trouble sleeping.

**WebEase**
- Ease stands for “Epilepsy Awareness, Support, and Education”.
- Free online self-management program for people with epilepsy.
- Has 3 modules (medication management, stress management, sleep management) you can use to set goals and create a personal plan to get better control over your epilepsy.

**Living Well With Epilepsy**
- An online community created by a woman with epilepsy.
- Share stories about epilepsy with other people like you.
- Learn more about how to live well with epilepsy.
Social Media Platforms

Some people with epilepsy might enjoy being part of a social network. My Epilepsy Team is a social network and online support group for people living with epilepsy. It’s like Facebook for people with epilepsy.

In-person Support Groups

Some people with epilepsy might like being part of online communities. For other people, it might feel good to have an in-person local support group. The Epilepsy Foundation is a good way to find support groups that give you a chance to meet other people with epilepsy. There might be different types of groups you can join in your local community:

- Support groups for families
- Support groups for older teenagers
- Support groups for families

You might want to join both online and local support groups. It may take some time to try different support groups to see which type works best for you.
References


Who to Contact for Help With Quality-of-Life Issues

Part of epilepsy self-management is learning how to improve your quality of life. In addition to your healthcare team, there are other people in your community who can help you navigate this journey. Here are some ways of finding help:

Community Services
- State and local Epilepsy Foundation affiliates
- Local nonprofit organizations that help patients with chronic conditions
- Social workers

Employment
- The human resources department where you work
- Vocational training programs
- Government agencies

Transportation
- Local department of motor vehicles
- Local transportation agencies
- Social service organizations
- Government agencies

Housing
- Social service organizations
- Nonprofit organizations, including faith-based organizations
- Government agencies

Social Support
- Psychologists, social workers, or other behavioral specialists
- State and local Epilepsy Foundation affiliates
- Faith-based organizations

Education
- Individualized education programs
- Cognitive testing and educational assistance

Reference
Epilepsy Educational Resources and Support Groups

Educational Resources
Here are some recommended, well-known, websites where you can learn more about epilepsy:

- Centers for Disease Control and Prevention (https://www.cdc.gov/epilepsy/index.html)
- CURE – Citizens United for Research in Epilepsy (http://cureepilepsy.org/)
- Epilepsy Birth Control Registry (http://www.epilepsybirthcontrolregistry.org/)
- Epilepsy Action (https://www.epilepsy.org.uk/)
- Epilepsy Foundation (http://www.epilepsy.com/)
- National Association of Epilepsy Centers (http://www.naec-epilepsy.org/)
Online Support Groups
Here are some recommended, well-known online communities for people with epilepsy:

**Epilepsy Foundation** (http://www.epilepsy.com/)
- Community Forums within the Epilepsy Foundation are online discussion groups for specific topics, such as medication issues, women with epilepsy, or epilepsy and college (http://www.epilepsy.com/forum-topics)
- Chat Room is a way you can share experiences, questions, or concerns about epilepsy and seizures (http://www.epilepsy.com/connect/chat)

**Patients Like Me (Epilepsy Community)** (https://www.patientslikeme.com/conditions/3)
- You can see what epilepsy medications other people have tried, how well the medications work for them, and what side effects people have
- You can see what other problems (symptoms) people have, like feeling tired or having trouble sleeping

**WebEase** (https://www.webease.org/)
- Ease stands for “Epilepsy Awareness, Support, and Education”
- Free online self-management program for people with epilepsy
- Has 3 modules (medication management, stress management, sleep management) you can use to set goals and create a personal plan to get better control over your epilepsy

**Living Well With Epilepsy** (http://livingwellwiththeepilepsy.com/epilepsy-101)
- An online community created by a woman with epilepsy
- Share stories about epilepsy with other people like you
- Learn more about how to live well with epilepsy
Social Media Platforms

Some people with epilepsy might enjoy being part of a social network. My Epilepsy Team is a social network and online support group for people living with epilepsy. It’s like Facebook for people with epilepsy. (https://www.myepilepsyteam.com/)

In-person Support Groups

Some people with epilepsy might like being part of online communities. For other people, it might feel good to have an in-person local support group. The Epilepsy Foundation is a good way to find local support groups that give you a chance to meet other people with epilepsy who live in your area. Go to www.epilepsy.com and click “Find us in your area” and you can choose a state or enter your zip code. There might be different types of groups you can join in your local community:

- Support groups for adults
- Support groups for older teenagers
- Support groups for families

You might want to join both online and local support groups. It may take some time to try different support groups to see which type works best for you.
Frequently Asked Questions and Answers

Where Can I Find Out More Information About Epilepsy?

There are many websites for epilepsy information.

- Centers for Disease Control and Prevention (https://www.cdc.gov/epilepsy/index.html)¹
- Epilepsy Action (https://www.epilepsy.org.uk/)²
- Epilepsy Foundation (http://www.epilepsy.com/)³
- National Association of Epilepsy Centers (http://www.naec-epilepsy.org/)⁴

If you go to the Epilepsy Foundation website, you can search for local support groups in your area.

Where Can I Find Support From Other People with Epilepsy?

You may be able to find a local Epilepsy Foundation support group.

There are also many online support groups for people with epilepsy. Here are some trustworthy online communities:

- The Epilepsy Foundation has online community forum (http://www.epilepsy.com/forum-topics)⁵ and also a chat room (http://www.epilepsy.com/connect/chat)⁶
- Patients Like Me (Epilepsy Community) (https://www.patientslikeme.com/conditions/3)⁷
- WebEase (https://www.webease.org/)⁸
- Living Well With Epilepsy (http://livingwellwithepilepsy.com/epilepsy-101)⁹
- My Epilepsy Team (https://www.myepilepsyteam.com/)¹⁰
How Can I Talk to My Family About Epilepsy?

Epilepsy affects not only you, but also your family members as well. They need to know how to help you when you have a seizure. All members of your family should know what to do, and what not to do, when you have a seizure. You can create a seizure action plan and talk about it with your family. You can also practice what to do when a seizure happens, the way you might have a fire drill. Your family members might also be able to help you manage your epilepsy by helping you make sure you take your medicine and assisting with lifestyle management. Talk to your family about what it’s like for you when you have a seizure. Ask them what questions they have. The Epilepsy Foundation website has more information about talking to your family (http://www.epilepsy.com/article/2014/12/epilepsy-and-family).

How Can I Talk to My Friends About Epilepsy?

Even though you might feel nervous talking about your epilepsy, or feel like you want to hide your epilepsy, it’s important to tell your friends. If you have a seizure, your friends will need to know what to do to help you. Also, your friends will probably want to support you. Pick a time and place when you’re comfortable and won’t be interrupted. You might want to use a conversation starter, such as “Did I ever tell you why I take medicine every day? It’s because I have epilepsy and the medicine helps prevent seizures.” The Epilepsy Foundation website has other conversation starters that might be helpful (http://www.epilepsy.com/learn/age-groups/youth/talking-about-epilepsy/talking-friends-and-family).

What About Dating?

Dating is hard for anyone, and it can be doubly hard to decide when to tell someone you are in a relationship with that you have epilepsy. If your seizures are well controlled, you may want to wait until you feel comfortable with the other person before talking about your epilepsy. If your seizures are not well controlled, you might want to talk about your epilepsy sooner rather than later. Either way, if you are spending a lot of time with someone, you probably want to talk about your epilepsy so they know what is happening if you have a seizure and what they can do to help keep you safe. The Epilepsy Foundation website has more information about dating (http://www.epilepsy.com/learn/age-groups/youth/dating). You could also talk to other people with epilepsy about how they handle dating situations. Psychologists and social workers might be able to provide tips about how to talk to people you are dating about your epilepsy.
**Status Epilepticus and SUDEP**

**Is status epilepticus the same thing as SUDEP?**
No. Status epilepticus is a prolonged, severe seizure that can cause brain injury. SUDEP is a sudden unexpected death related to epilepsy. SUDEP can happen with or without a seizure.

**Can status epilepticus lead to death?**
It can lead to death, but it does not always lead to death.

**Can SUDEP affect anyone with epilepsy?**
SUDEP can affect anyone with epilepsy, but people with generalized tonic-clonic seizures are at the greatest risk of SUDEP.

**How can I prevent SUDEP?**
The best way to prevent SUDEP is to take your AEDs regularly to help control your seizures. Here are some other things you can do:

- Do not sleep face down
- Talk to your doctor about whether surgery for epilepsy is an option for you
References

HEALTHCARE LINGO

**Antiepileptic drugs (AEDs)**
Medicines to treat seizures. Also called antiepileptic medications, anticonvulsants, antiseizure drugs.\(^1\)

**Aura**
A warning that you have before a seizure, or an actual seizure. An aura might be a change in a sensation, such as your sense of smell, taste, or sight. Or it could be a physical change, such as feeling lightheaded or dizzy.\(^2-4\)

**Ketogenic diet**
A special high-fat, low-carbohydrate diet that may be prescribed by your doctor in addition to medications to help control seizures.\(^5\)

**Lifestyle factors**
These are things like getting enough sleep, exercising regularly, and decreasing stress that might help you manage your epilepsy.\(^6\)

**Neuron**
A nerve cell. Nerve cells communicate with each other in the brain and can send messages to other parts of the body.\(^7\)

**Neurologic**
Relating to neurons (nerve cells).\(^7\)

**Quality of life**
Your sense of well-being. Your sense of well-being comes from how satisfied you are with your roles, activities, goals, and opportunities in life.\(^8\)

**Seizure frequency**
How often you have seizures.

**Seizure triggers**
Factors that might cause your seizures, such as stress or lack of sleep.\(^8\)

**Self-management**
Taking responsibility for your own behavior and well-being, and managing your own day-to-day health.\(^9\)

**Status epilepticus**
A prolonged, severe seizure that can cause brain injury. Any seizure that causes muscle contractions and lasts more than 5 minutes can be a medical emergency, and someone should call 911.\(^10\)

**SUDEP**
Sudden unexpected death related to epilepsy. It is not caused by drowning or another type of accident that could lead to death while having a seizure. SUDEP can happen with or without a seizure.\(^11\)
References


Seizure Action Plan for Adults

What Is a Seizure Action Plan?
A Seizure Action Plan is a form that tells other people how to help after you have a seizure. Your Seizure Action Plan will tell people what to do when you have a seizure, who to call, your doctor’s name, your medications, when to call 911, and lots of other information.¹

Why Should I Use a Seizure Action Plan?
A Seizure Action Plan will allow your community of support, including your family members, friends, and coworkers, to help you after you have a seizure by following steps you’ve created.¹

How Do I Use a Seizure Action Plan?

- Fill out as much information as you can in the Seizure Action Plan form¹
- Work with your healthcare provider who helps manage your epilepsy to fill out any information that you don’t know. For example, you might need your healthcare provider’s help with the following sections¹:
  - When Seizures Require Additional Help
  - As-needed Treatments
  - Special Instructions
- You and your healthcare provider should both sign and date the Seizure Action Plan at the bottom of the form after the plan is completed
- Review your Seizure Action Plan with your healthcare team and family, friends, and coworkers at least once a year (or more often if your seizures or your treatment changes) ¹
• Make a list of people who need to know about your seizures, including family, friends, and coworkers\(^1\)

• Give each person a copy of your completed Seizure Action Plan\(^1\)

• Keep a copy in a central place in your home\(^1\)

• Keep a copy of your Seizure Action Plan with you (in your purse, pocket, wallet, or backpack)\(^1\)

Remember that seizure first aid classes are complimentary through the Epilepsy Foundation. Contact your local chapter.\(^2\)
**Adult Seizure Action Plan**

This person is being treated for a seizure disorder. The information below may be helpful if you are present when the person has a seizure, or as the person is recovering.

<table>
<thead>
<tr>
<th>Name</th>
<th>Address</th>
<th>Date of birth</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>First Emergency Contact Name</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Second Emergency Contact Name</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Important Medical History**

<table>
<thead>
<tr>
<th>My Seizure Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seizure Type</td>
</tr>
<tr>
<td>--------------</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Seizure Triggers or Warning Signs</th>
<th>Usual Response After a Seizure</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Daily Seizure Medications**

<table>
<thead>
<tr>
<th>Medication Name (brand name and generic name)</th>
<th>Medication Dose (how many milligrams, or mg, in each pill)</th>
<th>How Many Pills Do You Take and How Many Times Per Day (instructions on the prescription bottle)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Other Seizure Treatments

<table>
<thead>
<tr>
<th>Type of Device (such as a vagus nerve stimulator)</th>
<th>Model</th>
<th>Serial Number</th>
<th>Date Implanted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nutritional Therapy (type of dietary therapy and date started)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Any Other Type of Therapy or Special Instructions

Basic First Aid

- Keep calm, provide reassurance, remove bystanders
- Keep person safe, remove objects around them, do not restrain
- Time the seizure, observe what happens, write down what happens
- Stay with the person until they recover from the seizure
- Other care needed for this person:

Additional ways to help during a convulsive (tonic-clonic) seizure:

- Protect person’s head
- Keep airway open, make sure nothing is in mouth, watch breathing
- Turn person on side, if possible

When Seizures Require Additional Help

<table>
<thead>
<tr>
<th>Type of Emergency for This Person (for example, a long seizure, clusters of seizures, or repeated seizures)</th>
<th>Description</th>
<th>What to Do</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
As-needed Treatments

<table>
<thead>
<tr>
<th>Treatment Name (for example, vagus nerve stimulator [VNS] magnet, specific medication)</th>
<th>When to Give</th>
<th>Amount to Give</th>
<th>How to Give</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Call 911 or Seek Emergency Help In Any of the Following Situations

- Generalized seizure that lasts longer than 5 minutes, unless otherwise noted on this form in the "When Seizures Require Additional Help" section above
- 2 or more seizures without recovering between seizures
- If “As-needed” treatments listed on this form don’t work
- Injury occurs or is suspected, or seizure occurs in water
- Breathing, heart rate, or behavior doesn’t return to normal
- Unexplained fever or pain that happens hours or a few days after seizure
- Other emergency care needed for this person:

Healthcare Contacts

<table>
<thead>
<tr>
<th>Healthcare Contacts</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epilepsy Doctor</td>
<td></td>
</tr>
<tr>
<td>Primary Care or Other Healthcare Provider</td>
<td></td>
</tr>
<tr>
<td>Preferred Hospital</td>
<td></td>
</tr>
<tr>
<td>Pharmacy</td>
<td></td>
</tr>
</tbody>
</table>

Special Instructions

My Signature

<table>
<thead>
<tr>
<th>Date</th>
<th>Healthcare Provider Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date</td>
<td></td>
</tr>
</tbody>
</table>

Seizure Action Plan for Teens

What Is a Seizure Action Plan?
A Seizure Action Plan is a form that tells other people how to help after you have a seizure. Your Seizure Action Plan will tell people what to do when you have a seizure, who to call, your doctor’s name, your medications, when to call 911, and lots of other information.¹

Why Should I Use a Seizure Action Plan?
A Seizure Action Plan will allow your family, friends, and people at school to help you after you have a seizure by following steps you’ve created.¹

How Do I Use a Seizure Action Plan?
- Work with your parent or guardian to fill out as much information as you can in the Seizure Action Plan form¹
- Work with your healthcare provider who helps manage your epilepsy to fill out any information that you or your parent or guardian don’t know. For example, you might need your healthcare provider’s help with the following sections¹:
  - When Seizures Require Additional Help
  - As-needed Treatments
  - Special Instructions
- Your parent or guardian and your healthcare provider should both sign and date the Seizure Action Plan at the bottom of the form after the plan is completed
- Review your Seizure Action Plan with your healthcare team and family, friends, and school personnel at least once a year (or more often if your seizures or your treatment changes)¹
• Make a list of people who need to know about your seizures, including family, friends, and school personnel

• Give each person a copy of your completed Seizure Action Plan

• Keep a copy in a central place in your home

• Keep a copy of your Seizure Action Plan with you (in your backpack, pocket, wallet, or purse)

Remember that seizure first aid classes are complimentary through the Epilepsy Foundation. Contact your local chapter.
### Teen Seizure Action Plan³,⁴

This person is being treated for a seizure disorder. The information below may be helpful if you are present when the person has a seizure, or as the person is recovering.

<table>
<thead>
<tr>
<th>Name</th>
<th>Address</th>
<th>Date of birth</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Parent/Guardian Emergency Contact Name</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other Emergency Contact Name</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Important Medical History**

**My Seizure Information**

<table>
<thead>
<tr>
<th>Seizure Type</th>
<th>Length</th>
<th>Frequency</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Seizure Triggers or Warning Signs**

<table>
<thead>
<tr>
<th>Seizure Triggers or Warning Signs</th>
<th>Usual Response After a Seizure</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Daily Seizure Medications**

<table>
<thead>
<tr>
<th>Medication Name (brand name and generic name)</th>
<th>Medication Dose (how many milligrams, or mg, in each pill)</th>
<th>How Many Pills Do You Take and How Many Times Per Day (instructions on the prescription bottle)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Other Seizure Treatments

<table>
<thead>
<tr>
<th>Type of Device (such as a vagus nerve stimulator)</th>
<th>Model</th>
<th>Serial Number</th>
<th>Date Implanted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nutritional Therapy (type of dietary therapy and date started)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Any Other Type of Therapy or Special Instructions

Basic First Aid

- Keep calm, provide reassurance, remove bystanders
- Keep person safe, remove objects around them, do not restrain
- Time the seizure, observe what happens, write down what happens
- Stay with the person until they recover from the seizure
- Other care needed for this person:

Additional ways to help during a convulsive (tonic-clonic) seizure:

- Protect person’s head
- Keep airway open, make sure nothing is in mouth, watch breathing
- Turn person on side, if possible

When Seizures Require Additional Help

<table>
<thead>
<tr>
<th>Type of Emergency for This Person (for example, a long seizure, clusters of seizures, or repeated seizures)</th>
<th>Description</th>
<th>What to Do</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Seizure Emergency Protocol at School
A seizure emergency for this student is defined as:

Seizure Emergency Protocol
(Check all that apply and add instructions as needed)

- Contact school nurse at:
- Call 911 for transport to:
- Notify parent/guardian or emergency contact
- Administer emergency medications as noted above
- Notify healthcare professional
- Other:

Special Instructions
For example, if the seizure occurs in school, does the person need to leave the classroom after a seizure?

- Yes
- No

If YES, describe process for returning to classroom:

List any special considerations and precautions for school activities, sports, trips, etc:

As-needed Treatments
<table>
<thead>
<tr>
<th>Treatment Name</th>
<th>When to Give</th>
<th>Amount to Give</th>
<th>How to Give</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Call 911 or Seek Emergency Help In Any of the Following Situations

- Generalized seizure that lasts longer than 5 minutes, unless otherwise noted on this form in the “When Seizures Require Additional Help” section above
- 2 or more seizures without recovering between seizures
- If “As-needed” treatments listed on this form don’t work
- Injury occurs or is suspected, or seizure occurs in water
- Breathing, heart rate, or behavior doesn’t return to normal
- Unexplained fever or pain that happens hours or a few days after seizure
- Other emergency care needed for this person:

Healthcare Contacts

<table>
<thead>
<tr>
<th>Healthcare Contact</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epilepsy Doctor</td>
<td></td>
</tr>
<tr>
<td>Primary Care or Other Healthcare Provider</td>
<td></td>
</tr>
<tr>
<td>Preferred Hospital</td>
<td></td>
</tr>
<tr>
<td>Pharmacy</td>
<td></td>
</tr>
</tbody>
</table>

Parent/Guardian Signature

<table>
<thead>
<tr>
<th>Date</th>
</tr>
</thead>
</table>

Healthcare Provider Signature

<table>
<thead>
<tr>
<th>Date</th>
</tr>
</thead>
</table>