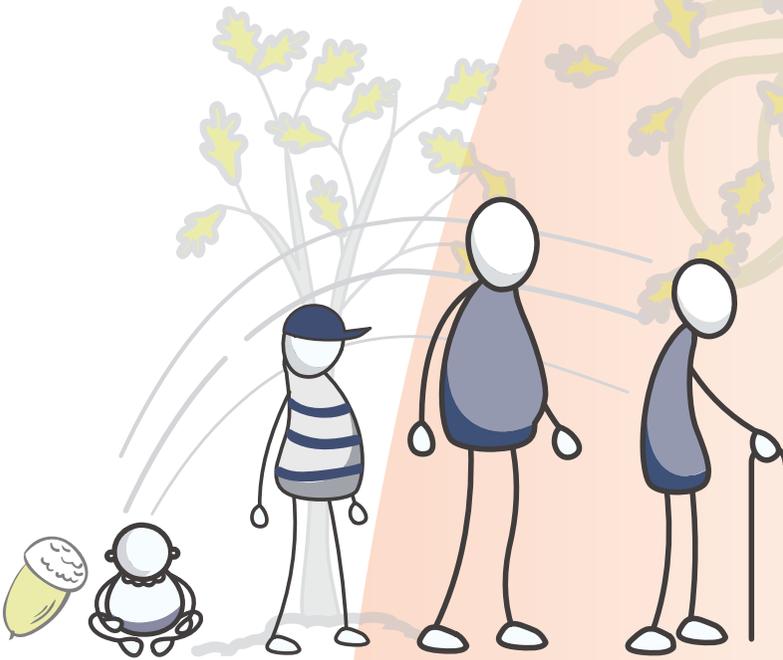


TRANSITIONS OF CARE IN EPILEPSY

**A Patient Guide for
Adults & the Elderly:
Epilepsy Considerations**

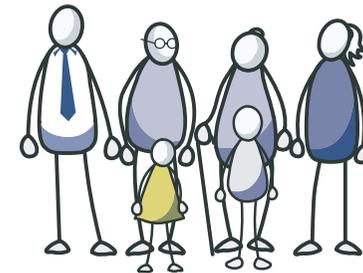


Module 3 in this series is
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TRANSITIONS OF CARE IN EPILEPSY

A Patient Guide for Adults & the Elderly: Epilepsy Considerations



The Transitions in Epilepsy series includes

Module 1: A Guide for Parents & Caregivers

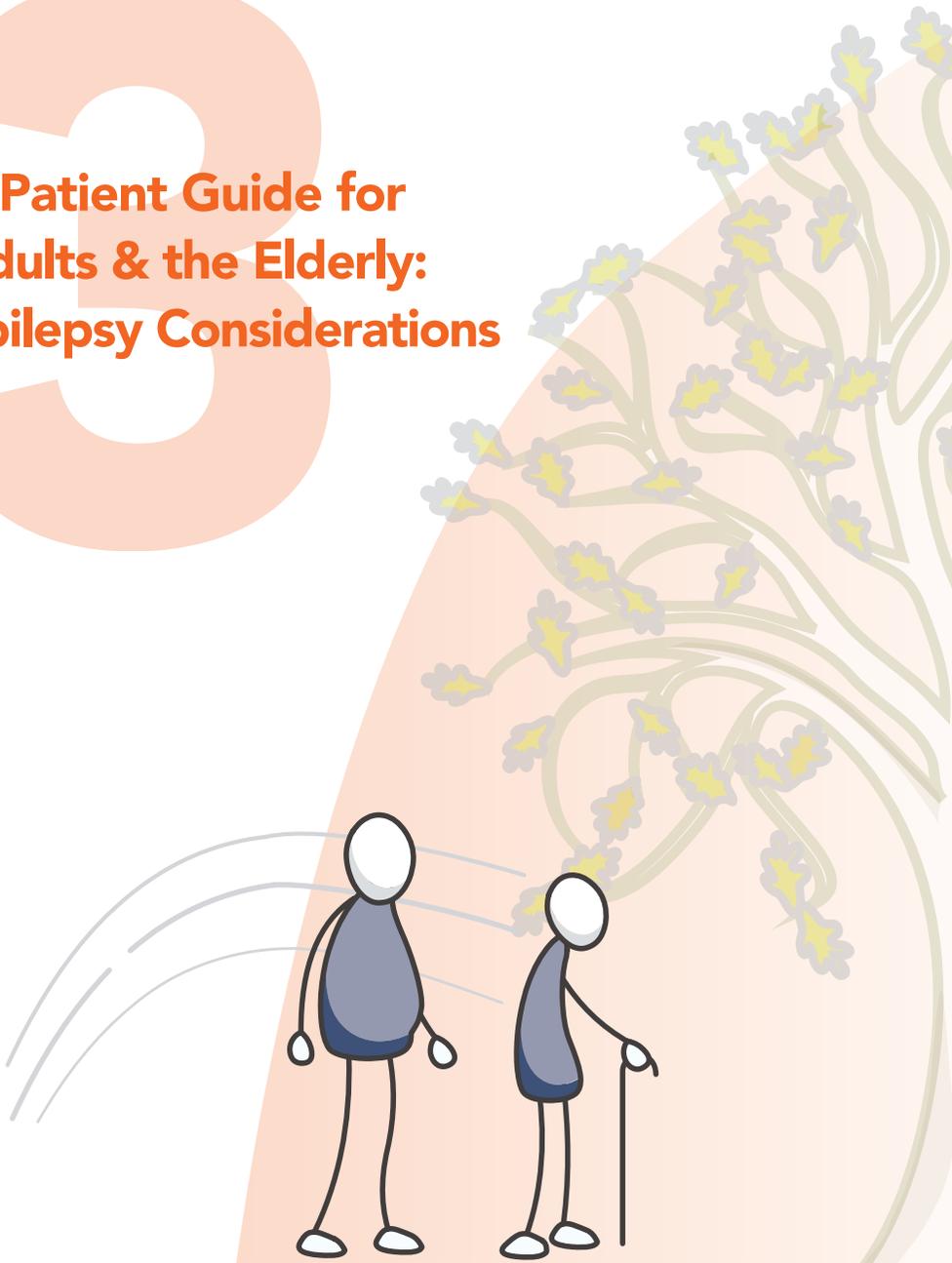
**Module 2: A Patient Guide for Teens & Young Adults:
*What's Your Plan?***

**Module 3: A Patient Guide for Adults & the Elderly:
Epilepsy Considerations**

To access all 3 modules in this series, please request copies from your epilepsy health care provider.

3

A Patient Guide for Adults & the Elderly: Epilepsy Considerations



Disclaimer: This educational publication is intended to serve as a detailed, but not all-inclusive, patient-focused summary of selected topics related to epilepsy. The authors have taken care to ensure that the content herein is correct and compatible with AMA style and generally accepted good publishing practices at the time of printing. Nevertheless, as new information becomes available, changes in medical approaches become necessary. This material is for informational purposes only. It does not replace the advice or counsel of a doctor or health care professional. Readers should consult with, and rely only on the advice of, their physician or health care professional. The authors, editors, and Supernus Pharmaceuticals, Inc. disclaim responsibility for any liability, loss, injury, or damage incurred as a consequence, directly or indirectly, of the use and/or application of any content contained herein.

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Welcome, friends!



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Epilepsy, a seizure disorder, is a common brain condition that affects individuals of all ages. Having a seizure can be a scary experience and learning how to manage epilepsy appropriately may require significant time and effort throughout life. The purpose of our educational series is to describe the changes that people with epilepsy experience throughout the stages of their lives. By addressing medical, psychosocial, educational, and employment needs, this booklet will help individuals successfully manage transitions in epilepsy.

This is the third of 3 modules in the *Transitions of Care in Epilepsy* series

Module 3 examines concerns related to epilepsy care for **adults and seniors**. These issues often revolve around employment and major life events such as marriage, raising children, and retirement. As an adult with epilepsy, you may wonder if you will be able to work, what types of jobs are available to you, or if you should be concerned about workplace discrimination. You may also be uneasy about your ability to manage long-term relationships or start a family. If you are a senior, you may worry about financial planning, health insurance coverage, and the potential need for a caregiver as you age with epilepsy. This section addresses these concerns.

**We hope readers find this educational series
helpful and informative!**

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ADULT EPILEPSY CONSIDERATIONS

Can adults become epileptic?

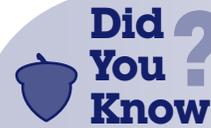
Epilepsy is a chronic disease that is marked by unpredictable seizures. About 2.4 million adults in the United States have epilepsy. For some people, epilepsy may be a lifelong condition that begins in childhood, whereas others are first diagnosed with epilepsy as adults. Seizures can happen at any time in your life. In fact, the first occurrence of a seizure is common in people older than 65 years of age.

If you have your first seizure as an adult, your doctor will perform tests to determine if they are epileptic in nature or if they are “symptomatic from a reversible cause,” such as low blood sugar or alcohol withdrawal. Detection of recurrent seizures or a tendency to experience recurrent epileptic seizures is required to diagnose epilepsy.

If you are diagnosed with new-onset epilepsy as an adult, you may have to deal with many of the issues discussed in this module. Your current doctor can help you identify a specialist to manage your new-onset epilepsy.



What can I do to prevent seizures?

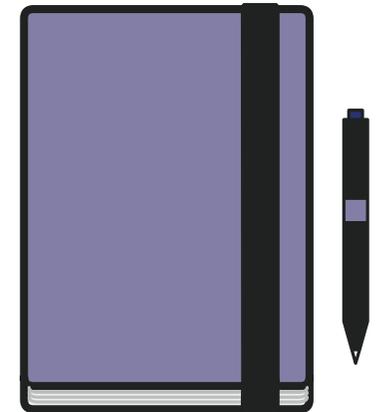


If you have epilepsy, you should look for ways to self-manage your condition to decrease seizures and improve your overall health.

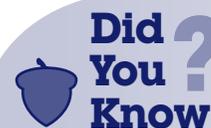
Visits with your neurologist are extremely important to your epilepsy management. During these visits, your doctor may discuss tests you may need from time to time (such as blood tests), how to take your medicine correctly, and how to avoid triggers that can increase your seizure risk. When visiting your doctor, ask questions about your medicine, directions for their use, and possible side effects.

Keep a seizure diary as part of self-care. Documenting your seizures in a seizure diary is a key part of self-care that will help you and your doctors keep track of:

- How well your seizures are controlled
- Any problems you may have taking your medicine
- Whether you might need to change the dose of your seizure medicine
- Whether your medicine or seizures may be interfering with your daily activity



Typically, people with epilepsy who keep seizure diaries are more satisfied with their epilepsy treatment. These days, documenting your seizures is very easy. The Epilepsy Foundation provides a mobile app called *My Seizure Diary*, that can help you track seizures, manage medicines, identify potential triggers, and communicate with your doctor. Online or mobile versions, such as Seizure Tracker, exist and can be useful to record your seizures.



“My Seizure Diary” can be found at the following Epilepsy Foundation URL: <http://www.epilepsy.com/living-epilepsy/epilepsy-foundation-my-seizure-diary>.

How does sleep affect my epilepsy?

Sleep quality is important in adults with epilepsy.



You may be at higher risk for seizures if you do not get enough sleep.

Some antiseizure medicines may interfere with your ability to sleep well because they may make you tired, crave naps, or cause insomnia at night. You can work with your doctor to adjust the timing of when to take your medicines such as in the morning for drugs that cause insomnia or at bedtime for those that cause sedation. Long-acting or slow-release medicines also may be helpful.

Lifestyle changes that can help you get enough sleep include:

- Making your bedroom quiet and dark
- Not using your bed to watch TV or read
- Going to bed and waking up at the same time each day
- Not eating late at night
- Not exercising shortly before bedtime
- Not using or turning off your electronics before bedtime
- Not drinking caffeine at least 6 hours before bedtime
- Taking a warm shower before bedtime
- Doing activities such as relaxation exercises or meditation before going to bed



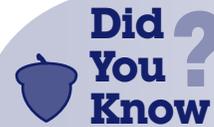
Remember to discuss any sleep problems you have with your doctor before starting over-the-counter medicines.

Stress

Epilepsy self-care also includes reducing stress and exercising regularly. Using relaxation techniques such as meditation and yoga can lower your stress levels and improve seizure control. Regular exercise (as appropriate, see below) can:

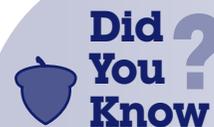
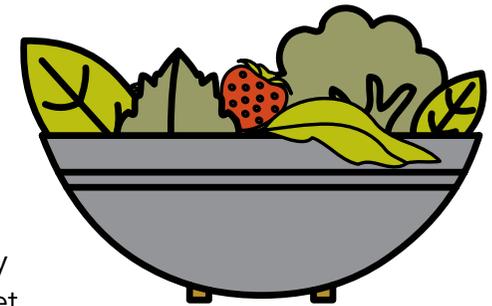
- Improve seizure control
- Reduce side effects of certain medicines
- Improve your sleep
- Improve your mental health
- Improve your overall quality of life

Diet



A healthy diet may play a role in controlling seizures.

Eating unhealthy foods or going long periods without eating may increase your seizure risk. Anecdotal reports have shown that cooking and eating foods with better nutritional content may improve seizure control. If your seizures are uncontrolled with medicines, your doctor may recommend you try a special diet known as the ketogenic diet.



The modified Atkins diet may be recommended for adults with epilepsy. The modified Atkins diet (often abbreviated as “MAD”) is a change to the traditional “classic” ketogenic diet recommended for children in order to make it less restrictive.

Does having epilepsy affect my mental health?



Studies suggest that 20% to 60% of people with epilepsy may also have mental health disorders.

Antiseizure medicines may be the cause of some of these conditions. Mental health disorders can include depression, anxiety, aggression, and/or emotional instability.

- Medicines, such as carbamazepine, levetiracetam, or phenytoin, may alter depressive symptoms.

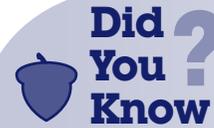


Depression and anxiety are common among people with epilepsy, especially women.

Some symptoms of mental health disorders include anxiety, depression, irritation, fearfulness, panic, sleep problems, sexual dysfunction, or pain (for example, headache, backache). If you experience any of these symptoms, discuss them with your doctor.

There are many approaches to treating mental health disorders, including medicine. Some of these medicines may cause seizures or interact with your antiseizure medicine. Because of this, your doctor may start a medicine for your mental health disorder at a lower dose and increase the dose very slowly.

If you have depression, your doctor may prescribe an **antidepressant**. Antidepressants may be safe to use in people with epilepsy.

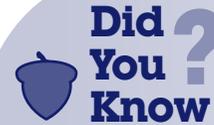


Counseling is available to help you deal with mental health issues. Ask your doctor to suggest where you can go.

During counseling sessions, you may explain your feelings, receive education about your moods and behaviors, or learn new ways of thinking about your problems. Some counseling sessions may include your family members in order to discuss issues that may potentially contribute to your mental health disorder.

Neurologic disabilities and epilepsy

People with neurologic disabilities also may have epilepsy. Epilepsy can be more severe and unresponsive to treatment in people who have an advanced neurologic disability.



Caregivers play an important role in the lives of people with neurologic disabilities and epilepsy. Caregivers may include parents, group home staff, and health care workers.

People with both neurologic disabilities and epilepsy may require frequent hospitalizations. Careful planning and preventative actions may decrease the number of these hospitalizations.

If you must go to the hospital to manage a seizure, you will want to be able to provide an accurate medical history. People with both neurologic disabilities and epilepsy may not always be able to communicate effectively with hospital health care workers. During the discharge process from the hospital, you and your caregiver should make sure to receive clear instructions and explanations regarding any changes in medicines. Your neurologist should be notified immediately of any changes.

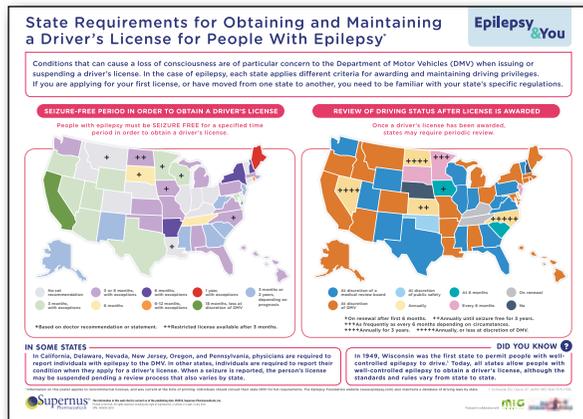
Am I able to drive if I have epilepsy?



More than 60% of people with epilepsy have concerns about driving, and more than 50% of people with epilepsy worry about losing their independence.

Having a job, socializing, and feeling self-confident may depend on your ability to drive.

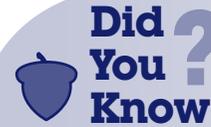
- If you are not able to drive because of your epilepsy, you may feel as if you have less independence and control.
- You may have to rely on public transportation or other people to drive you. It may be necessary to search for jobs that are located within walking distance to you or that are accessible by public transportation.



A person with epilepsy who drives is at an increased risk of being in a car accident. Having a seizure that impairs awareness or motor control while driving is very dangerous, so driving rules for people with epilepsy focus on keeping everyone, including you, safe on the road.

If your seizures are well controlled, you can drive in the United States as well as in many other countries. However, you are only able to obtain driving privileges after authorities review your condition. Depending on the severity of your epilepsy, you may be allowed to drive with certain restrictions. Some examples of restrictions include driving only during the daytime, driving only to and from work, driving within a specific distance from your home, or driving only during emergencies. If you are at high risk for active seizures, you may face more restrictions on your driving.

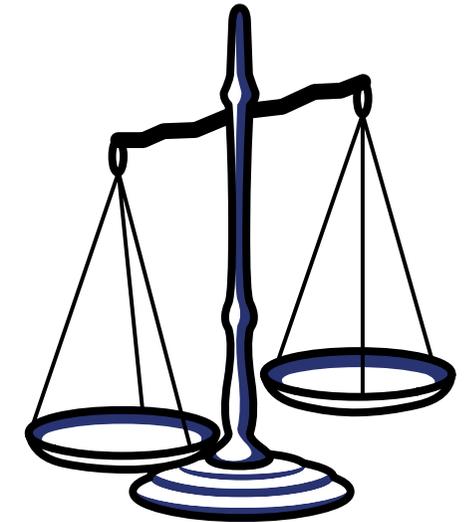
Most states within the United States look at the seizure-free period to determine if you are allowed to drive. The seizure-free period is a period of time during which you have not had any seizures. Please check your state's rules as they relate to driving and seizures.



Depending on the state, the required seizure-free period for driving ranges from 3 to 12 months. Some states also consider recommendations from your doctor when deciding if you can drive.

Specific situations may allow you to receive driving privileges even if you do not meet the usual seizure-free period set by your state. These situations include:

- Seizures that were caused by changes in your medicine
- Seizures that do not cause changes in your awareness
- Seizures that consistently begin with long auras that allow you time to pull over
- Seizures caused by a disease or provocation that should not happen again



Some situations may require you to have a longer seizure-free period before you can receive driving privileges. Examples of these situations include:

- Not taking your medicine as prescribed
- Drinking alcohol excessively or abusing drugs
- Being diagnosed with a brain disease or another disease that is not treatable
- Having more frequent seizures recently
- Not knowing that a seizure has happened, that is, you do not know if you are truly seizure free
- Having a history of crashing because of seizures
- Having a bad driving record

When applying for a driver's license, you must report that you have epilepsy. Not reporting this information puts you and other people at risk. In fact, self-reporting of seizures is required by law. Six US states require your doctor to report your diagnosis of epilepsy to the motor vehicle administration. These states are California, Delaware, Nevada, New Jersey, Oregon, and Pennsylvania. In other states, your doctor may report that you have epilepsy if he or she believes that the condition may influence your driving and safety on the road.

If your doctor recently stopped one of your antiseizure medicines, you should stop driving for some time so you can see how the change affects you. Stopping or taking lower doses of your antiseizure medicine puts you at risk for a seizure. The state of Maine specifically requires people with epilepsy to stop driving if an antiseizure medicine was recently discontinued.



Did You Know?

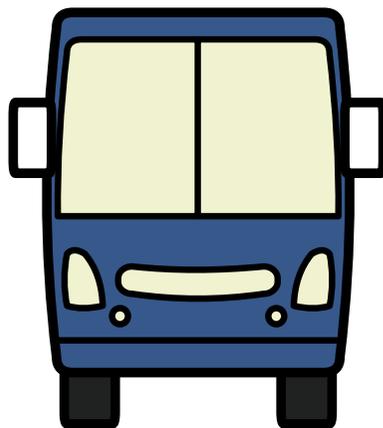
About 30% of people with epilepsy will have a seizure within 1 year of stopping an antiseizure medicine.

Can I get driving privileges for a commercial vehicle?

Laws regarding driving commercial vehicles are different from laws for personal vehicles.

Obtaining driving privileges for **commercial vehicles** is more difficult for people with epilepsy, and the rules are stricter.

Commercial vehicles are used to transport people or goods for businesses. You may qualify for a commercial driver's license only if your seizures are well controlled. Some qualifying criteria consist of a seizure-free period of at least 8 years and a stable antiseizure medicine regimen for at least 2 years. If you receive a commercial driver's license, you may have to renew it every year.



Can I drive outside the United States?

Canada

In Canada, you are able to drive as long as you meet the country's qualifications. The seizure-free period is set at 6 months, and you should not experience any drowsiness from your medicine. Any new seizures should be reported.

Europe

In the United Kingdom, the seizure-free period is 1 year. People with epilepsy who have seizures during the night may qualify for driving privileges if they show that all their seizures occurred during the night for the past year. People who meet driving regulations in the United Kingdom and have a license can also drive in many other European countries. When visiting any European country, make sure to check that you meet their medical standards for driving.

If you plan to travel outside the United States, check your destination's driving laws for people with epilepsy.

What if I am not able to drive?

If you are not able to drive because of epilepsy, other transportation options exist. You can carpool with co-workers or friends or use public transportation.



Did You Know?

Paratransit services may be available if you cannot use public transportation. Paratransit services will pick you up at your home. Ask your health care provider or caregiver to help decide if paratransit services may be right for you. You can receive more information about paratransit services by contacting your area's transit authority.





People who cannot safely use public transportation because of their epilepsy or those who cannot walk to and from a bus stop may qualify for paratransit services. For example, paratransit services are a good option for people whose frequent seizures may put them in danger while waiting for a bus at a busy intersection. You can receive more information about paratransit services by contacting your area's transit authority. When applying for this service, be prepared to describe your epilepsy and how it prevents you from using public transportation and provide notes from your doctor.

Currently, several major companies are developing self-driving cars. In the future, these types of cars may be a potential solution for people with epilepsy who are not able to drive.

When using public transportation, you have the right to reasonable accommodations under the **Americans with Disabilities Act (ADA)** of 1990. For example, buses need to provide seat belts to people with frequent seizures to help prevent injuries. You may file an ADA complaint with the Department of Justice if you do not receive a reasonable accommodation.

Can I work if I have epilepsy?

Many people with epilepsy are able to work.



In the United States, unemployment for people with epilepsy ranges from 12% to 50%. This range is wide and may depend on how often seizures occur.

When looking for a job you may want to consider:

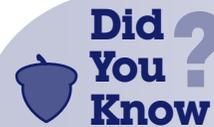
- If you are able to perform specific tasks
- If you need any additional training

Having a supportive family and self-determination may help you with your job search process. People with epilepsy have a higher chance of having a job if they have a higher level of education, more motivation, and a diagnosis of **generalized (rather than focal) epilepsy**.



Most adults view people with epilepsy positively. Over the past decade, public perceptions of epilepsy have improved, and most adults think that people with epilepsy can lead normal lives and work 40 hours per week.

What are my employment rights?



The ADA, a federal law, and the **Equal Employment Opportunity Commission (EEOC)** provide information on your employment rights.

The ADA protects individuals from discrimination based on a disability, such as epilepsy, when they are looking for a job at a company or organization that employs at least 15 people. These companies and organizations are required to make arrangements for you to successfully complete job tasks.

- The only situation where the ADA does not require arrangements to be made is when these arrangements are too difficult or expensive, or cause safety or health risks for others.

The EEOC is an organization that provides support to people with epilepsy in the workplace. It makes sure that companies and organizations follow the law and do not discriminate against a job applicant or employee based on a disability such as epilepsy.

- If you experience discrimination, the EEOC can investigate and, if necessary, file a lawsuit against that institution.

As part of the hiring process, an organization or company may require you to complete a health screening.

- You do not have to tell your new organization or company about your condition unless having epilepsy would directly impact your work.
- The company can ask you to describe or show them how you would do specific job tasks if necessary.

It is recommended that you tell select co-workers (for example, your manager) about your condition after starting a new job.

- If your seizures are frequent, you may need to teach your co-workers and supervisors about epilepsy and seizure care. This may prevent misunderstandings and answer any questions your co-workers may have about your condition.
- If you struggle to complete tasks at your current job because of epilepsy, you may want to consider training for another job or profession.

What types of jobs can I do with epilepsy?

Your doctors and/or neurologists can give you advice on selecting the types of professions or jobs for you depending on the type of epilepsy you have and how frequently seizures occur. They can counsel you on how specific epilepsy symptoms may affect your performance at a specific job.



Did You Know?

About 50% of people who are newly diagnosed with epilepsy experience full seizure control with medicines and about 20% to 30% of people get sufficient control of seizures so that they are able to fully function at work.

You should carefully read through the requirements of a position before applying or accepting an offer. For certain jobs you may have to consider restrictions and standards specific to patients with epilepsy. These include:

- Drivers
- Pilots
- Military service
- Law enforcement service



As an employed person with epilepsy you may need to:

- Adjust your work style or request special arrangements if you experience potential after effects of a seizure, such as problems with memory and time management.
- If you have memory problems, write down instructions and deadlines on a piece of paper as a future reminder.

Can I serve in the military?

As an adult with epilepsy, joining the military may not be possible.

- Only people with epilepsy who have not had any seizures from the age of 5 years or who have been seizure free without medicine for 5 years can apply for military service.



Did You Know?

The military can send its members anywhere in the world, and some of the locations do not have access to doctors and/or medical care.

If you develop epilepsy while in the military, fully controlling your seizures with medicine is important to remain an active member.



Managing work stress

Keep in mind that managing stress at work is key because stress can cause or worsen seizures. At work, you may feel stressed for many reasons including a heavy workload, short deadlines, and conflicts with co-workers. If you feel stressed, talk with your manager about changing your work schedule. Certain techniques and exercises can reduce your stress at work.

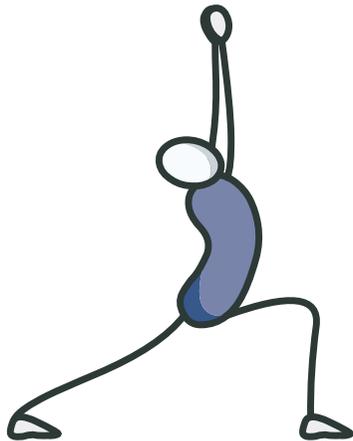


FAST FACT



About 80% of people with epilepsy who use relaxation techniques and exercises believe that these activities have helped them control their seizures.

Practicing meditation or yoga can lower the number of seizures you have and possibly improve your quality of life. Also, surrounding yourself with supportive people may allow you to exert more control over your life and handle stressful situations better.



Financial costs of epilepsy

Treating epilepsy can be expensive. In the United States, costs may range from \$1,000 to \$20,000 per person per year. These numbers represent the total cost of care and do not include how much your health insurance may cover versus how much you may need to pay out of pocket.

Health insurance

As you transition from one job to another, ensuring continuous health care coverage is essential. Many employers provide health insurance. If you do not have a job or your company does not provide health insurance, finding inexpensive insurance may be difficult.



When switching jobs, study your new employer's options for health insurance. Make sure you evaluate the different copays, premiums, deductibles, prescription drug coverage, and **physician networks** before selecting a health plan that meets your needs. If your company does not provide health insurance, you may find insurance on the private insurance marketplace.

Understanding prescription drug coverage is important when selecting your health insurance plan.

- Make sure that your new health insurance plan covers the antiseizure medicines that you are taking.

Some health insurance plans may not cover newer antiseizure medicines, which may cost anywhere from \$350 to \$500 per month per prescription.

People who do not have health insurance may be eligible for health insurance through Medicaid, depending on their level of income.

- Depending on the state where you live, you may still pay a small amount of money for certain doctor's visits. Medicaid also may pay for necessary prescription drugs.

You should understand coverage under the new health insurance policy when switching jobs.

Disability benefits

Disability benefits may be available to you if you are unable to work. Work with your doctor to see if you qualify to receive these benefits. When applying for disability benefits, you may need to provide the following information:

- The type of seizures you have
- Current and previous medicines that are or were used for your epilepsy treatment and how well they worked
- Detailed information on your seizures, such as how often they occur, how long they last, and the effects they have on you

Typically, if you continue to have seizures for more than 3 months while taking appropriate medicines, you may qualify for disability benefits.

Your first application for disability benefits may be rejected. Being persistent is important, and you may need the services of a lawyer to appeal the rejection.

- National organizations such as the National Legal Advocacy Department or local chapters of the Epilepsy Foundation can help you find a private or public lawyer.
- Working with a lawyer may help get your application for disability benefits approved. You have the option to hire a private lawyer.

FAST FACT

Once your application is approved, your benefits will be paid from the date when your disability was established.

How can epilepsy impact my marriage and family planning?

As an adult with epilepsy, you may have general concerns about entering a committed relationship, getting married, and raising a family. Compared with adults without epilepsy, adults with epilepsy are less likely to get married, and more people with epilepsy, especially women, get divorced. Society's negative attitudes and beliefs, called **stigma**, about people with epilepsy may be behind this historical trend.

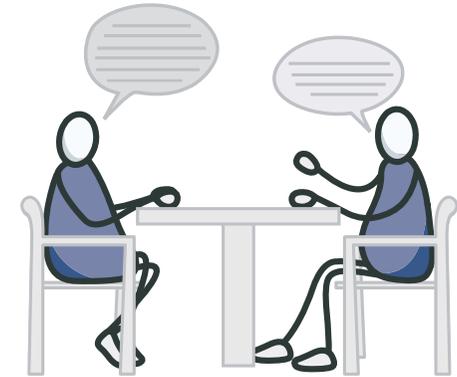


Did You Know?

A large number of adults in the general population believe that people with epilepsy can have successful relationships and raise children. These adults are also more open-minded about their own children dating people with epilepsy.

You may be afraid to tell your partner about your epilepsy because you are unsure how it may affect your relationship.

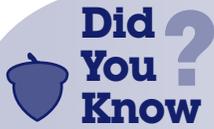
- Before entering a committed relationship, telling your partner about your epilepsy is essential.



What about contraception options?

Many people with epilepsy are able to have children and raise families. Family planning may be an important concern for you as an adult with epilepsy. Women with epilepsy should understand that many antiseizure medicines, such as carbamazepine, oxcarbazepine, topiramate, phenobarbital, and phenytoin, interact with birth control pills.



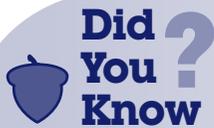


Oral birth control pills often are not the best birth control method for women with epilepsy.

Birth control pills may alter blood levels of epilepsy medicines and make them less effective in managing seizures.

- You may want to consider other methods for preventing pregnancy that do not interact with antiseizure medicines such as medroxyprogesterone injections and **intrauterine devices (IUDs)**.
- You also can use birth control methods, such as condoms, that do not have any medicines.

Before starting any birth control methods, you should discuss potential options with your neurologist.



For women with epilepsy, careful planning is necessary for a successful pregnancy.

Can I have children?

Although you have epilepsy and may be taking antiseizure medicines, you can still experience a normal pregnancy. Most women do not experience any changes in how often their seizures occur during pregnancy. For those with increased seizures, it may be the result of hormonal changes in your body due to pregnancy. You should discuss your antiseizure care plan with your doctor before becoming pregnant.



During pregnancy your doctor may:

- Recommend that you use only 1 medicine to manage seizures during pregnancy even if you have been using several medicines to control your epilepsy before your pregnancy.
- Tell you to take a lower dose(s) of your antiseizure medicine(s).
- Need to measure blood levels of certain antiseizure medicines.



During pregnancy, you may be concerned that unexpected seizures may harm you or your baby.

- You may fall during an active seizure.
- Seizures that happen while delivering a baby may increase your delivery time and cause your baby to have problems getting enough oxygen and nutrients.
- Overall, women with epilepsy are no different than other women when it comes to the occurrence of early birth, diabetes during pregnancy, miscarriages, or a newborn baby being admitted to an intensive care unit.

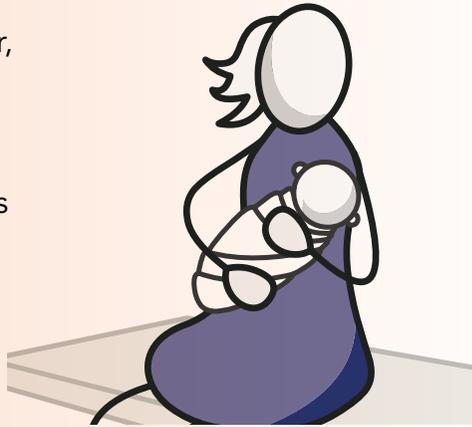
Some antiseizure medicines can cause birth defects if taken during pregnancy.

You should avoid taking valproate as well as potentially other antiseizure medicine during pregnancy. Discuss with your health care provider before taking any antiseizure medicines during pregnancy.

Limited information is available on the safety of newer antiseizure medicines in pregnancy. Pregnant women should discuss taking supplements such as folic acid with their health care provider.

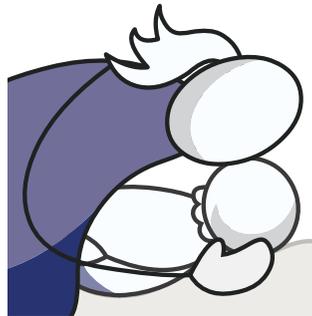
Breastfeeding

Breastfeeding has numerous benefits for a baby and the mother, but you may be concerned with exposing your baby to your antiseizure medicines while breastfeeding. Breast milk contains growth factors and antibodies that can improve baby's health. Breastfeeding also helps a woman bond with her baby. But breastfeeding can expose your baby to antiseizure medicines that you take. If you are taking antiseizure medicine, you should talk with your health care provider about these concerns.



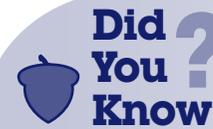
What about raising my children?

Careful planning is necessary for people with epilepsy to raise children safely. If you are a parent with epilepsy, you may have concerns about raising children especially if your seizures remain uncontrolled despite medicine therapy. Your main concerns may focus on preventing accidents that could harm your children and taking care of your child during an active seizure.



If you are a parent with epilepsy who has young children, you can implement several routines to keep them safer in case you have an active seizure. These include:

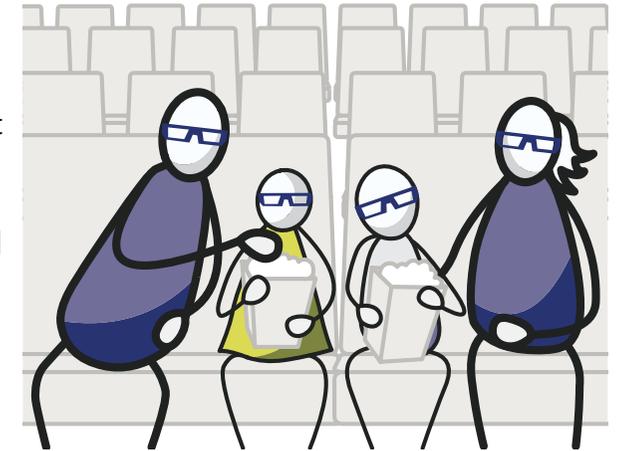
- Dressing and changing your baby on the floor
- Washing your baby with a sponge instead of in a tub with water
- Carrying your baby in a padded bassinet
- Feeding your baby in a low high chair or on the floor surrounded by cushions
- Telling your child to stay nearby when you have an active seizure



Support from family and outside support programs can help decrease your stress about parenting.

Being a single parent is especially challenging if you have epilepsy. Reaching out to support programs and your family can help you reduce stress associated with single parenting while dealing with your epilepsy.

If you have difficulties with parenting, you may want to let others know. This may include contacting your family members, doctors, and/or support programs. Your doctors, including your child's pediatrician, need to be aware of any difficulties you are having with parenting. Discussions with other people who have epilepsy and are raising children can help you understand and manage potential parenting problems.



What about child custody?

In the case of divorce, you cannot be denied child custody based only on your epilepsy diagnosis.

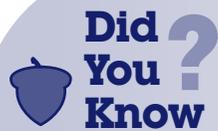
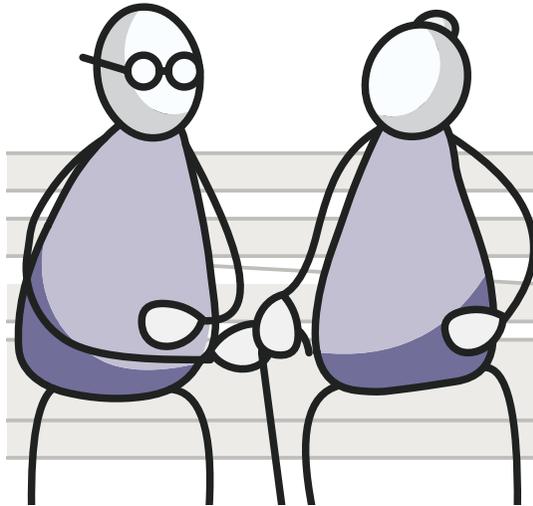
- The main concern during custody cases is the safety and best interests of your child; therefore, the courts may look closer at the details of your epilepsy.
 - These details may include the type of seizures you have, how well your seizures are managed with medicine, how often seizures occur, what happens to you after an active seizure, and how reliable you are about taking your prescribed medicine.
- Your neurologist may provide additional information about your epilepsy and your ability to take care of a child.
- Courts may look at how your epilepsy affects your child.

Children do not have any negative psychological effects after seeing an active seizure. Additionally, children who are aware of a parent's epilepsy handle situations involving seizures better than children who do not know about the condition, so it is important for you to let your child know about your epilepsy. Many people with active seizures can successfully take care of a child by implementing minor changes to daily activities. You should make sure to tell the court how you changed childcare activities to increase the safety of your child.

Epilepsy in later life: What should I know?

The incidence of epilepsy increases in people who are 65 to 69 years of age and increases even more in those 80 years of age and older.

The exact causes of new-onset epilepsy in older people are unknown in many cases, but stroke, head injury, Alzheimer's disease, a brain tumor, and alcoholism all increase the risk for epilepsy.

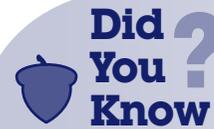


Older people have a higher risk for diseases involving the brain and its blood vessels, sometimes called **cerebrovascular diseases** (stroke), and are at a higher risk for **Alzheimer's disease** and **brain tumors**. These diseases can contribute to the development of epilepsy.

Symptoms of epilepsy in elderly people may include:

- Confusion
- Memory problems
- Falls
- Dizziness
- Numbness

As an older adult, you may think that these symptoms are present just because you are getting older and that falling down and shaking is necessary to have a seizure. Often, confusion or feeling dazed is a symptom of the most common seizure type, a **focal impaired awareness seizure**, also known as a complex partial seizure. If you notice any of the symptoms mentioned, make sure to discuss them with your doctor.



A family member or caregiver can be taught how to manage your seizure episodes at home.

As an older adult with epilepsy, it's important that your doctor assess your antiseizure medicines for potential side effects.

- Later in life, your kidneys and liver may slow down or prevent the removal of medicine from your body.

Because older people can have other diseases in addition to epilepsy, medicine for these diseases may interact with antiseizure medicines. Antiseizure medicine may negatively influence thinking and other mental health problems such as depression or anxiety.

- Your doctor may start you on a lower dose of an antiseizure medicine and increase the dose very slowly to avoid side effects.
- Ideally, 1 antiseizure medicine should control your seizures, but sometimes your doctor may need to start you on a second if the first medicine is not working well for you.

You should tell your doctor about all the medicines and supplements you take so that he or she can evaluate if you need to change or stop certain medicines.

- Your doctor needs to know about your alcohol use, too. Alcohol can interact with your antiseizure medicines, causing seizures. Drinking alcohol in large amounts or suddenly stopping consumption of alcohol may trigger seizures.

Finally, make sure to have regular appointments with your doctor or neurologist to monitor your epilepsy. With the right treatment and monitoring, you may be able to live a healthy and independent lifestyle as an older adult.

Does epilepsy weaken my bones or increase my risk for falling?

Antiseizure medicine can influence your balance and ability to walk. Some antiseizure medicines may cause your bones to be weaker and change the level of vitamin D in your body.

- Vitamin D helps your body absorb calcium and makes your bones stronger.
- Certain antiseizure medicines may contribute to reducing the amount of vitamin D in your body, which, in turn, may make your bones weaker and cause osteoporosis. You should discuss the impact of your antiseizure medicine on bone health with your health care provider.



The risk for osteoporosis is especially high with certain medicines.

- Falling during active seizures is also puts you at risk for broken bones. Your doctor may prescribe a medicine to strengthen your bones.
- If you are not able to walk without help, you may need to make changes to your home or other spaces that you live in such as a vacation home.
- Make sure that carpets and rugs on floors have skid-proof backing to prevent them from moving around. Installing grab bars near the tub, shower, and toilet may help you prevent falls.
- If you have stairs in your home, they should have sturdy handrails on each side and secure carpeting.
- You may need an alert system in case you fall.

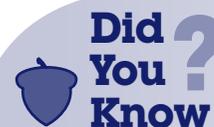
How can I protect my bones?

Although antiseizure medicines may weaken your bones, taking them is important for controlling seizures. To protect your bones, you can implement the following changes:

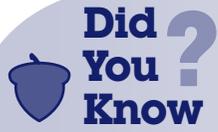
- Eat a diet that contains enough calcium. If you don't ingest enough calcium, you may need to take a calcium supplement.
- To strengthen your bones, do weight-bearing exercises in which your feet or legs support the weight of your body.
- Get enough sun exposure, but in safe amounts, as sunlight is an important source of vitamin D.
- Make sure that your doctor checks your blood levels of vitamin D.
- If you are over 50 years of age, your doctor may check your bone health by using a DXA bone density scan. Your doctor may prescribe a medicine for bone protection based on the results of the scan.

Can menopause affect my epilepsy?

Menopause may influence how often seizures occur. If you are a woman undergoing menopause, you may be prescribed **hormone replacement therapy**. Hormone replacement therapy may help with hot flashes and mood swings that appear during menopause because your body stops making natural hormones. Hormone replacement therapy usually contains estrogen, and some therapies have both estrogen and progesterone. Estrogen may make seizures more likely to occur for a minority of women. If you experience more frequent seizures after starting hormone replacement therapy, talk with your doctor about other available options. Estrogen and other hormonal therapies can lower the levels of some antiseizure medicines, so before you start on any hormone replacement therapy, remember to let your neurologist know.



During menopause, about 40% of women with epilepsy have more seizures, whereas about 27% of women have fewer seizures.



Having an active lifestyle may lower your risk for seizures.

Does epilepsy impact my exercise and daily activity?

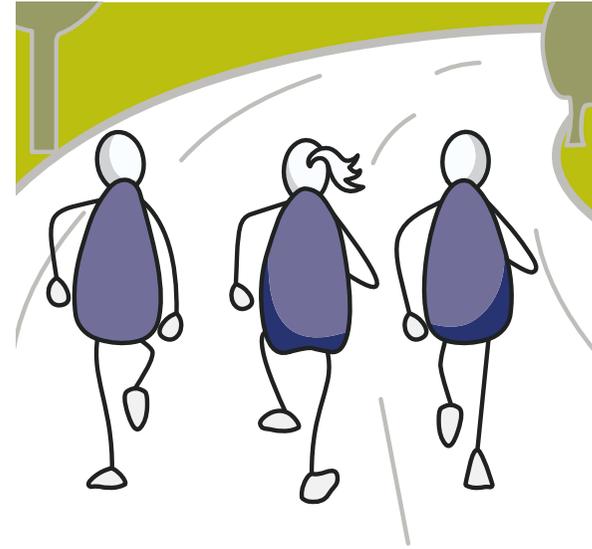
Staying active and exercising improves mental, emotional, and physical well-being in adults of all ages. You should lead an active lifestyle even when you are reaching your older years because being fit may lower your seizure risk.

Epilepsy should not be a barrier to enjoying exercise and playing sports. In fact, most people with epilepsy can safely exercise, even if their seizures are not fully controlled, as long as simple safety precautions are taken. For example, if you enjoy downhill skiing, consider using beginner or intermediate trails, skiing with a companion, and using a harness on a ski lift if you have frequent active seizures.

If you are just beginning your exercise regimen, exercise only for a short period of time initially and work your way up to longer periods of exercise. Remember to take frequent breaks and drink plenty of fluids. Always wear a medic alert bracelet or necklace and carry a cell phone with you. Save emergency phone and contact numbers in your phone so that you can reach them easily and faster if you have a seizure while exercising. Apps are available that can store such important information and make it readily accessible to others in an emergency.



You should always wear a medic alert bracelet or necklace and carry a cell phone with you.



Although people with epilepsy can participate in most activities, those that are extremely dangerous should be avoided. Some of these include scuba diving, rock climbing, skydiving, and hang gliding. Having a seizure while participating in these activities may lead to injury and possibly death.

Recommended safety precautions based on physical activity.

Activity	Safety precautions
Biking	<ul style="list-style-type: none"> ▲ Ride with a companion ▲ Avoid busy streets ▲ Ride your bike on bike paths or quiet streets ▲ Wear a helmet
Exercising in a fitness facility	<ul style="list-style-type: none"> ▲ Exercise with a companion ▲ Do not use a treadmill alone, instead run on a track
Participating in water sports	<ul style="list-style-type: none"> ▲ Swim with a companion ▲ Wear a life vest near the water ▲ Wear a medic alert bracelet or necklace ▲ Inform a person participating or observing a water activity about your epilepsy, especially if this person knows basic lifesaving techniques
Walking	<ul style="list-style-type: none"> ▲ Avoid busy streets ▲ Walk with a companion

When should I consider involving a caregiver?

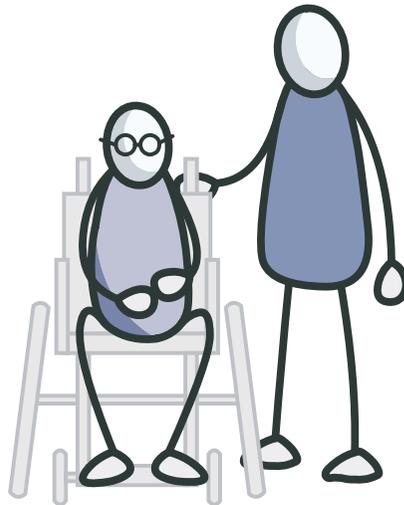


You may need a caregiver if you are not able to complete daily activities independently.

If you are an older person with epilepsy, you can live independently. Sometimes, family members may become concerned and overprotective if you are older and have an epilepsy diagnosis. Even though they have your best intentions at heart, they may encourage you to become more dependent on them. If you desire to live independently, you can use technology such as portable phones or pagers to stay in touch with your family. You also can use these devices to call your family or an emergency number for help.

If you want to live alone, you may need to make some changes to make your home safer:

- If you need to, move to a home or apartment that does not require you to use stairs.
- Make sure your home has carpeted floors so that you have access to softer surfaces during seizures.
- Install padding on your furniture and around the corners of tables to prevent any injuries during seizures.



If you are not able to complete daily activities independently, you may need a caregiver.

- Your caregiver can help you adhere to your antiseizure medicine regimen and can attend your doctor's appointments with you.

Make sure that your caregiver knows the type of seizures you have because he or she must administer appropriate first aid when they occur. Encourage your caregiver to take proper care of themselves as well.

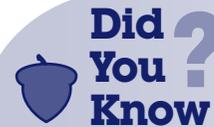
What caregivers of adults with epilepsy should consider

For caregivers, stress is common and often related to:

- Financial problems
- Handling behavior and mood problems of people with neurologic disabilities and epilepsy
- Helping with daily life activities such as bathing and assisting with bladder problems and stiff muscles in these individuals.

If you are a caregiver for a person with neurologic disabilities and epilepsy, consider contacting social services and a support group to help manage your stress.

My financial planning



Careful financial planning is especially important if you have epilepsy.

People with epilepsy should focus on financial planning and think about budgeting and savings, retirement planning, choosing life insurance, and creating a will.

- When planning your finances, you should consider the status of your epilepsy. How long have you had epilepsy? How does epilepsy affect your health? How much does your epilepsy care costs affect your finances?
- Hiring an accountant or attorney may help with financial planning, but make sure to tell them that you have epilepsy.
- Standard legal documents do not discuss the effects of epilepsy on your life, so the attorney or accountant should know about this condition when giving you financial advice or drafting legal documents.

An attorney can give you important advice with regard to financial planning. Your attorney:

- May recommend that you have **umbrella coverage**, which is maximum personal excess liability insurance coverage, if you have driving privileges.
- Can discuss with you how to protect your wealth and home from lawsuits, which is called **asset protection**.



Remember:

Before you sign any legal documents, obtain a note from your neurologist about the date of your last seizure. This documentation will show that you were conscious and not disoriented while signing legal documents. Keep all documentation for your records.

Additional legal terms to understand as an older adult with epilepsy

- A **power of attorney** allows a person that you select to oversee your legal, tax, and financial matters when you are no longer able to do it.
- A **Health Insurance Portability and Accountability Act (HIPAA)** release document allows other people to see your medical records. You will specify which individuals, called HIPAA representatives, have access to your records. For example, you may sign this document to allow your family to monitor your medical status and treatment. HIPAA representatives can only see your records; they cannot make any decisions about your treatment.
- A **health care proxy** or medical power of attorney gives individuals, including family members, permission to make decisions about your medical treatment.
- A **living will** is a document that explains your health care wishes in situations when you are alive but unable to provide consent for medical care. For example, the document may state that you would like an experimental treatment if your condition gets worse.

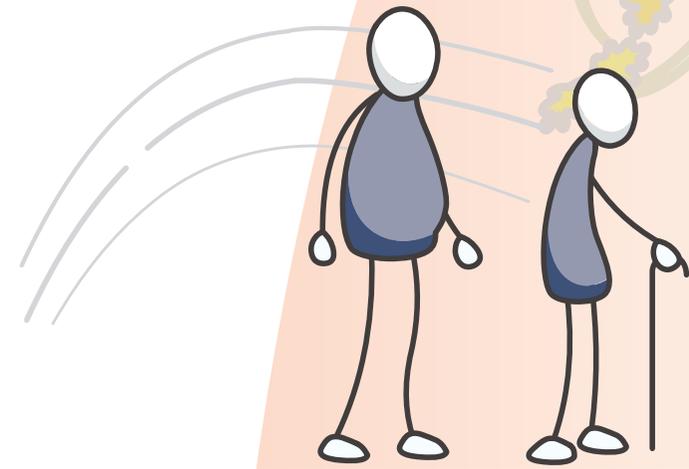


CONCLUSION

Transitioning through various stages of adulthood is challenging for most adults and even more so for people with epilepsy. The goal of this publication is to provide people with epilepsy at any stage, and their families and caregivers, with a valuable resource that can be consulted time and again. Having tools and resources at your disposal can help you and your caregivers with your transitions of care in epilepsy.



LIST OF TERMS USED THROUGHOUT THIS EDUCATIONAL SERIES



LIST OF TERMS

Adherence: taking medicines exactly as instructed by a health care provider

Americans with Disabilities Act (ADA): passed in 1990, this act protects people against discrimination based on a disability, such as epilepsy, when looking for a job at a company or organization that employs at least 15 people; these companies are required to make arrangements for people with disabilities to complete job tasks

Antidepressant: medicine used to treat major depressive disorder

Antipsychotic medicine: medicine used in schizophrenia

Asset protection: protecting your wealth and home from lawsuits

Aura: a perceptual disturbance experienced by a person with epilepsy

Bone mineral density: a test that measures the amount of calcium in a person's bones using x-rays

Copayment or coinsurance: set amounts of money that a person must pay each time he or she sees a doctor or seeks health services

Deductible: a set amount of the fees for service that a person must pay before the health insurance company starts paying for medical care

Electroencephalogram (EEG): is a test that measures and records the electrical activity of your brain

Epilepsy: a seizure disorder that affects individuals of all ages

Equal Employment Opportunity Commission (EEOC): an organization that provides support to people with epilepsy in the workplace and ensures that companies and organizations follow the law and do not discriminate against a job applicant or employee based on a disability such as epilepsy

Exclusive provider organization (EPO): an insurance plan that allows a person to select 1 doctor from a smaller network and charges additional fees when seeing a specialist out of network

Focal impaired awareness seizure: also known as complex partial seizure this is considered the most common form of epilepsy in adults, it involves abnormal regional discharges of electrical activity in the brain

Generalized epilepsy: types of epilepsy characterized by seizures affecting both sides of the brain that can result in a loss of consciousness

Guardianship: a legal option that gives the right to make legal decisions about an adult (someone older than age 18 years in most states) to another trusted individual when the adult is not capable of making decisions on their own

Health care proxy: an adult with the authority to provide health information or make health care decisions for another adult if the adult is not able to speak for him or herself

Health maintenance organization (HMO): an insurance plan in which the primary care provider refers a person to see specialists, such as a neurologist

Hormone replacement therapy: medical treatment used to relieve discomfort caused by the lack of estrogen and progesterone hormones in menopausal women

Intrauterine devices (IUDs): a small plastic T-shaped device inserted in the uterus to prevent pregnancy

Ketogenic diet: prescribed by a doctor, this high-fat, low-carbohydrate diet requires strict tracking of calories, fluids, and proteins

Legal competency: being able to make independent decisions

Living will: a document that explains a person's health care wishes in situations when he or she is alive but unable to provide consent for medical care

Magnetic resonance imaging (MRI): is a test that uses a magnetic field and pulses of radio wave energy to make pictures of organs and structures inside the body

Mail order pharmacy: pharmacies that can mail prescription medicines directly to a person's home

Medical home: refers to a doctor's office or clinic that connects all of a patient's health care providers

Menopause: the absence of menstrual periods for 12 consecutive months

Modified Atkins diet: a diet with no restrictions or limits on fluids, calories, or protein but requires carbohydrates to be counted and monitored; usually requires less doctor involvement

Neurologist: a specialist who treats diseases related to the nervous system, including epilepsy

Nonadherence: not taking medicine as prescribed, including taking too much or too little, taking it at the wrong times, or forgetting altogether

Nurse Practitioner (NP)/Advanced Practice Nurse: a registered nurse with advanced training who usually works with a pediatrician, neurologist, or epileptologist

Out-of-pocket maximum: the limit on the amount a person will pay for his or her medical needs before the insurance company pays for the rest

Paratransit services: transportation services available for people with disabilities who are unable to access mass transit

Physician Assistant (PA): a health care professional who is trained to practice medicine as part of a team with a physician

Point of service (POS): an insurance plan that allows a person to see a doctor who is in the network, but charges additional fees when seeing a specialist out of network

LIST OF TERMS

Power of attorney: a legal option that gives a person's right to legal decision making to another person

Preferred provider organization (PPO): an insurance plan that allows a person to see any doctor who participates in the insurance plan's network without a referral, but charges additional fees when seeing doctors out of the network

Premium: a set amount that a person pays each month for a health care plan

Stigma: a mark of disgrace or shame felt by people with characteristics considered socially unfavorable

Symptoms: a physical or mental feature or sensation indicating a condition of disease

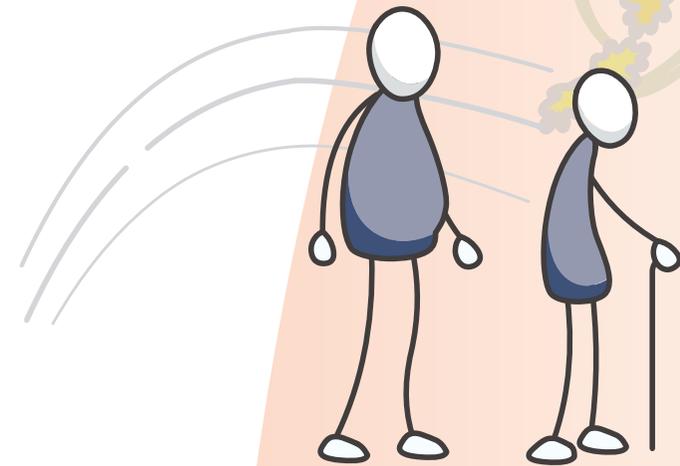
Transition: a "purposeful planned process" that addresses the medical, psychosocial, educational, and/or employment needs of young people with chronic physical and medical conditions as they move from child-centered to adult-focused health care systems

Triggers: refers to situations that bring on a seizure

Umbrella coverage: maximum personal excess liability insurance coverage

Vagus nerve stimulation: a medical treatment in which electrical impulses are sent to the vagus nerve

ADDITIONAL TOOLS AND RESOURCES FOR FURTHER READING



ADDITIONAL TOOLS AND RESOURCES

MODULE 3:

Centers for Disease Control and Prevention

Epilepsy and seizures in older adults

<https://www.cdc.gov/features/epilepsy-older-adults/index.html>

Epilepsy Foundation

Background on epilepsy

<http://www.epilepsy.com/learn/epilepsy-101/what-epilepsy>

Background on seizures

<http://www.epilepsy.com/learn/epilepsy-101/what-seizure>

Caregivers

<http://www.epilepsy.com/learn/age-groups/seniors-and-epilepsy/caregivers>

Exercise and sports

<http://www.epilepsy.com/get-help/staying-safe/safety-exercise-and-sports>

Living independently

<http://www.epilepsy.com/learn/age-groups/seniors-and-epilepsy/living-independently>

Moods and behavior

<http://www.epilepsy.com/learn/impact/moods-and-behavior>

Nutrition

<http://www.epilepsy.com/learn/triggers-seizures/nutritional-deficiencies>

Transportation

<http://www.epilepsy.com/get-help/services-and-support/transportation>

Epilepsy Society

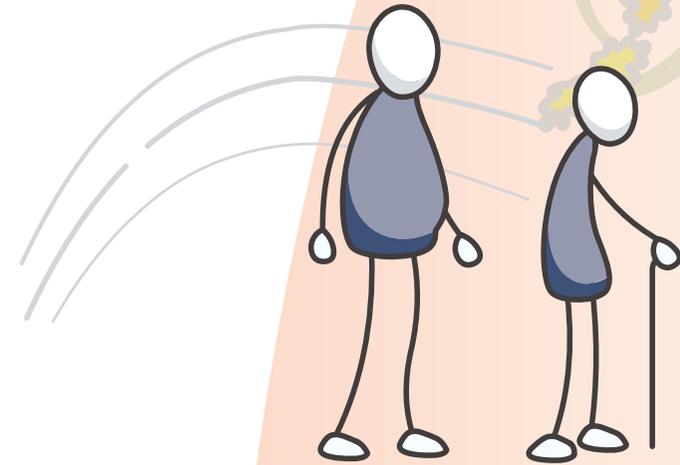
Epilepsy in later life

<https://www.epilepsysociety.org.uk/treatment-and-care-people-later-life#.WXj-ITyuCg>

Menopause and epilepsy

<https://www.epilepsysociety.org.uk/menopause-and-epilepsy#.WXj-uYTyuCg>

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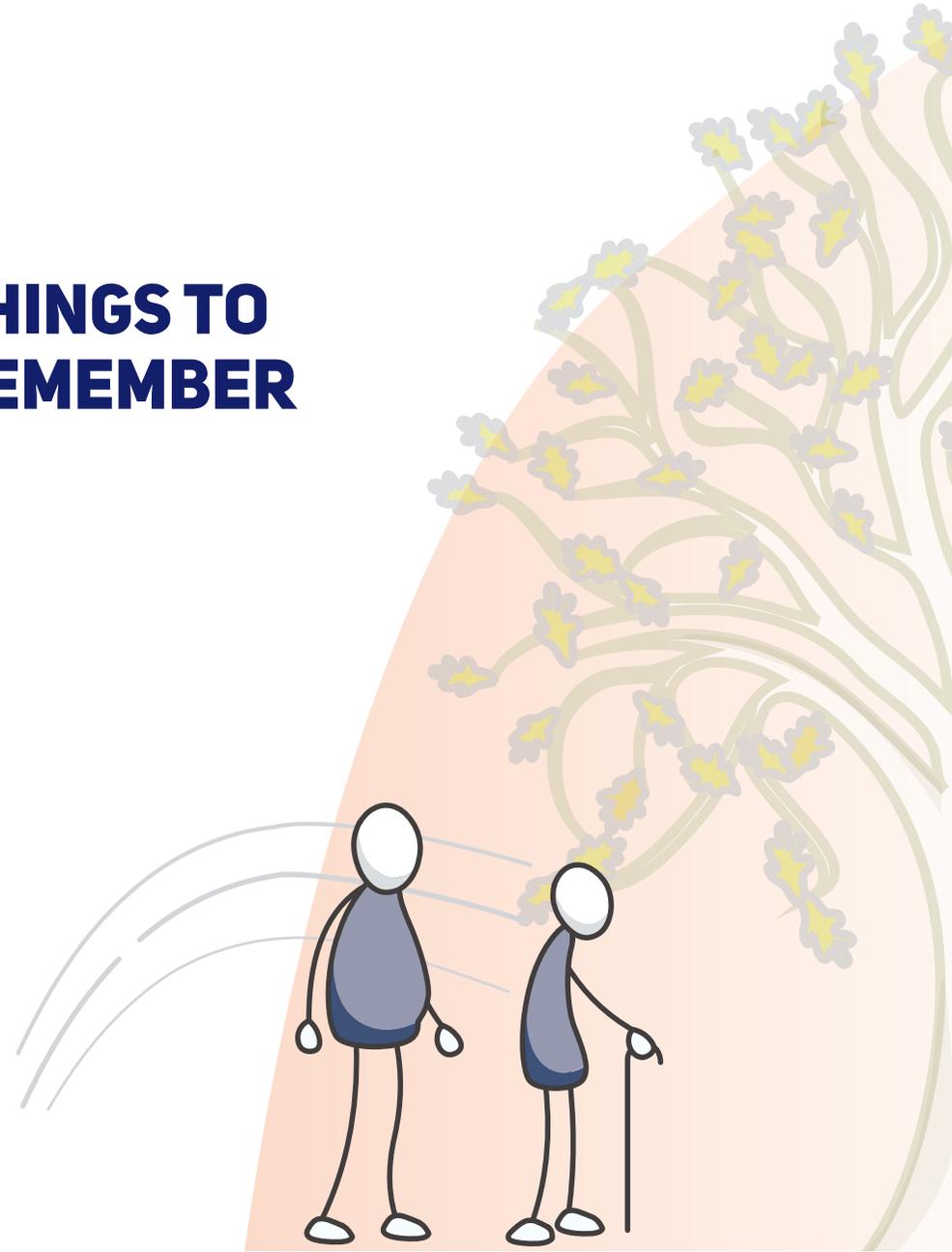


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THINGS TO REMEMBER



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Epilepsy & You



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