

EPILEPSY & YOU
BROCHURES 1-4 & HOLDER

EPILEPSY & YOU
BROCHURES 5-8 & HOLDER

TRANSITIONS OF CARE
IN EPILEPSY

EPILEPSY 50 FACTS

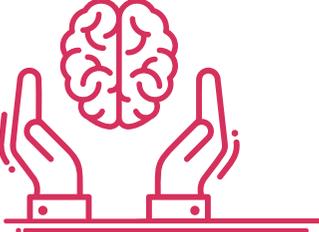
EPILEPSY PATIENT PRIMER

EPILEPSY RESOURCES

PROVIDED BY

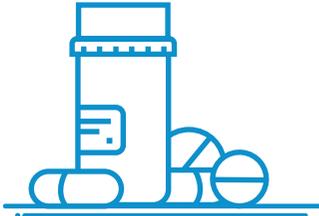


1 Preventive Care & Taking Control of Your Day



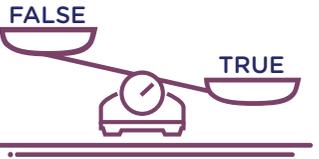
Epilepsy & You

2 Taking Your Epilepsy Medicine



Epilepsy & You

3 Epilepsy: Myths & Facts



Epilepsy & You

4 Managing Your Social Life



Epilepsy & You

Epilepsy is an intrusive illness that can disrupt your life, and even the lives of your family and friends. While antiepileptic medicines can be effective for reducing seizure frequency, achievement of your treatment goals often relies on optimal lifestyle management.

Fast Fact
Epilepsy self-management is a process by which people with epilepsy can modify their behavior and lifestyle to help improve seizure control.

Knowledge about your personal condition (for example, your specific condition, seizure type, and triggers) and treatment options can help you and your healthcare team craft a self-management plan to help you achieve and maintain your lifestyle goals.

Online resources that offer tips and tools for self-management include:
managingepilepsywell.org
www.webase.org

Our Understanding of Epilepsy Has a Timeline

FACT: Originally thought of as a mystical disorder, epilepsy is now understood as a medical condition and many of the false notions about it have been dispelled. Despite this progress, epilepsy is still sometimes misunderstood.

Ancient Times	1800s	1929	1968	1990	Today
Epilepsy is one of the few medical conditions to be recognized by medical writers of the ancient world.	Some of the terminology of epilepsy were first identified/used, including: • "grand mal" for seizures with consciousness and loss of consciousness • "petit mal" for slight seizures • absence for seizures without physical symptoms, but that caused mental confusion or inability to respond later in real life (absence seizures (known today as "stares epileptiques"))	The German experimentalist introduced a method for recording electrical activity in the brain. This technology became an electroencephalogram, or EEG—remains key in the diagnosis of seizures.	The Epilepsy Foundation was formed, dedicated to sharing information and promoting health and well-being for people with epilepsy.	The Americans with Disabilities Act (ADA) was signed into law, protecting the rights of people with chronic conditions, such as epilepsy, seeking equal employment.	Despite progress, people with epilepsy may still experience stigma that can impact relationships with family, friends, and coworkers.

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It is important to work with your healthcare team to identify and understand your personal goals, and review these goals anytime a medicine is added, modified, or deleted from your treatment plan.

Helpful Hints:

- Have a clear understanding of your seizure goals and how medicines can help achieve those goals.
 - If a medicine is being added or switched, understand why.
 - If a dose is being changed, understand why and ask about potential side effects.
- During office visits, discuss any side effects you have even if you don't think they are related to your medicine.
 - Tell your healthcare team about any changes in your overall health (for example, changes in your weight, mood, or eating habits).

DID YOU KNOW?
You and your healthcare team can work together to address any medicine concerns or work/school challenges, or to help improve adherence to your prescribed medicines.

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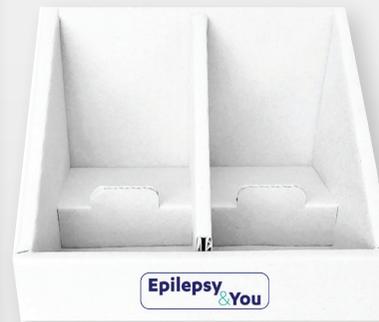
Additional resources

The Managing Epilepsy Well (MEW) Network is a collaboration between the CDC and various academic centers to promote epilepsy self-management. Individual MEW activities may be available in your community or online, including:

- Home-Based Self-Management and Cognitive Training Changes Lives (HOBS/COTCH)
- Management Information & Decision Support Epilepsy Tool (MINDSET)
- Program for Active Consumer Engagement in Self-Management (PACE) in epilepsy
- Personalized Internet Assisted Unobserved Self-Management of Epilepsy (PASSIE)
- Self-Management for people with epilepsy and a history of negative health events (SMART)
- Targeted Self-Management for Epilepsy and Mental Illness (TIMES)
- Web Epilepsy, Awareness, Support, and Education (WebEASE)
- Youth, Epilepsy, and Successful Self-Management (YESS)

Holidays are a busy time of the year. The stress and potential loss of sleep during this time can be a seizure trigger for some. If you are concerned about increased seizure activity around the holidays, consider:

- Managing your time and activities during the day (shopping, cooking, parties), leaving plenty of time for rest
- Limiting alcohol consumption
- Increasing exercise time to help relieve stress



5 Epilepsy & Your Job

Epilepsy & You

6 Family Planning & Epilepsy

Epilepsy & You

7 Children & Epilepsy

Epilepsy & You

8 Seniors & Epilepsy

Epilepsy & You

Adults with epilepsy might worry about their ability to find and keep a job. But having epilepsy does not mean you are not able to work. In fact, most jobs are suitable for people with well-controlled epilepsy.

Epilepsy & Your Job

DID YOU KNOW? Some people with epilepsy are not able to work due to their seizures or related medical conditions. These people can consider applying for disability benefits after a doctor has evaluated their medical status and has formally notified the appropriate agencies. The criteria for disability are complex, and should be discussed with your healthcare provider.

A number of factors can affect your ability to find a job and perform it successfully. These include:

- Your seizure type (focal or generalized onset) and level of seizure control
- How your epilepsy or your medicines affect your thinking and memory
- Depression, anxiety, or social isolation you may experience because of your epilepsy

Adolescence (continued)

Adolescence is also a time when people begin planning for higher education, careers, and marriage. These important life goals can be hindered by poorly controlled epilepsy. Adolescents and young adults with epilepsy often report feeling sad, irritable, and anxious. They may also lack confidence due to their condition. It's important to offer support when your teen is facing these challenges. The CDC offers a resource called "You Are Not Alone" for parents of teens who have epilepsy. Access it at: cdc.gov/epilepsy/toolkit/

Starting college

Helpful Hints: Here are some things to consider for young adults with epilepsy who are starting college:

- When you enroll in a school, provide your health records and confirm they are kept on file
- Familiarize yourself with the school's health center. Some health centers may have less flexible hours and provide more general health services.
- If you choose insurance through the school, be sure to know the policy on doctor visits off-campus and during breaks and holidays

Women with epilepsy may be concerned with:

- The safety of their medicines during pregnancy
- Potential complications during and after pregnancy for both mother and baby
- Labor and delivery

DID YOU KNOW? Many women with epilepsy find support groups to be helpful. Talk with your neurologist about available resources in your community or online.

Helpful Hints: Your gynecologist/obstetrician and neurologist should both be involved in your care and review your medicines before you try to become pregnant.

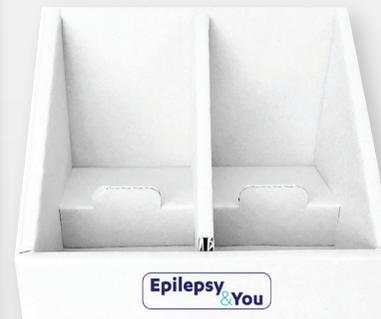
Prior to becoming pregnant, counseling can help provide insight into the changes that occur during and after pregnancy. This information can help you understand:

- Whether your seizures can be effectively controlled with only one medication to minimize exposure to the fetus
- Changes that happen during pregnancy that may affect seizure control
- Whether certain medicines for seizure control are safe or appropriate for use during and after pregnancy
- Risk associated with labor and delivery

Residents

In a recent survey, about two-thirds of nursing home residents said they were being treated with an antidepressant. Adults who need to reside in a nursing home should discuss their health goals and quality of life expectations with their healthcare team.

To help prepare for visits with your doctor, write your questions down before the appointment. If a doctor is talking to you about epilepsy and uses a word you don't know, don't hesitate to ask what it means.



MODULE 1

TRANSITIONS OF CARE IN EPILEPSY

A Guide for Parents & Caregivers

Module 1 in this series is provided as an educational service by

MODULE 2

TRANSITIONS OF CARE IN EPILEPSY

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

Module 2 in this series is provided as an educational service by

MODULE 3

TRANSITIONS OF CARE IN EPILEPSY

A Patient Guide for Adults & the Elderly: Epilepsy Considerations

Module 3 in this series is provided as an educational service by



Did You Know? Talk with your child about all the ways you should and things you should not do to affect seizure risk as they know how to make healthy choices with their peers.

Did You Know? Many high school students are disoriented about epilepsy, adding to the "foggy" associated with the condition. Some areas are responsible for that people with epilepsy often during seizures and before the seizure's ending.

Did You Know? Some young people with epilepsy may have additional concerns that make the transition to adulthood more difficult. For example, children with epilepsy may have physical limitations, learning difficulties, behavioral problems, or mental health issues that children without epilepsy don't have.

Did You Know? For these reasons, young adults with a disability must receive a sufficient amount of support during the time of transition to adult medical care.

When should I start planning for my child's transition to adulthood?

The first discussions about the transition to adult care for epilepsy should happen around 12 to 16 years of age. Starting the conversation early gives you and your child plenty of time to move from fully family-focused care to a more independent epilepsy treatment experience. For children with disabilities or other special needs, discussions about transition may begin before the age of 12. Young adults may start seeing an adult neurologist toward the end of adolescence, around age 16 to 17 years, but this age may vary among families and doctors.

Did You Know? The American Academy of Pediatrics suggests that young people should be encouraged to use their mobile devices to help them stay safe. They should use the app to report seizures, which is a free app available at www.aap.org.

Source: East Tennessee State University Department of Pediatrics. <http://www.etsu.edu>.

Final tips

Refer to the Resource section found at the end of this booklet for some select websites and resources to help with your transition.

Here are some basic steps you can take to start your transition:

- Schedule your next doctor's appointments.
- Start to speak with your doctor on your own without your parents or caregiver.
- Practice ordering your prescription refills and following your treatment plan on your own.
- Keep your seizure diary up-to-date and record any side effects you may experience from your medicine.
- Keep a list of questions you want to discuss with your doctor or nurse between appointments.
- If you are planning to attend college, review the considerations in the "Going to college" section starting on page 23.

CONCLUSION

Transitioning through various stages of adulthood is challenging for most adults and even more so for people with epilepsy. The goal of the education 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. Additional information and resources can be accessed by consulting the following final 3 sections in this publication. Working tools and resources at your disposal can help you and your caregivers with your transitions of care in epilepsy.

These simple tips will help you and all those around you manage your epilepsy more easily and get you off to a good start on the road to independence and achieving your future goals.

Did You Know? Staying on active epilepsy drug lowers your risk for seizure.

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 seizure 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, along with a companion, and using a harness on a ski lift if you have frequent falls.

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 medical alert bracelet or necklace and carry a phone with you. Save emergency phone and contact numbers in your phone so that you can reach them easily and faster. You have a seizure while exercising. Apps are available that can obtain such important information and make it readily accessible to obtain it in an emergency.

Did You Know? You should always wear a medical alert bracelet or necklace and carry a cell phone with you.

Recommended safety precautions based on physical activity:

Activity	Safety precautions
Biking	• Ride with a companion • Avoid busy streets • Ride your bike on bike paths or quiet streets • Wear a helmet
Exercising in a fitness facility	• Exercise with a companion • Do not use a treadmill alone, instead run on a track
Participating in water sports	• Swim with a companion • Wear a life vest near the water • Wear a medical alert bracelet or necklace • Tell others a person participating or observing a water activity about your epilepsy especially if the person knows basic lifesaving techniques • Avoid heavy drinks
Walking	• Walk with a companion

LIFE WITH EPILEPSY:

50 FACTS™

& MORE

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 Pharmaceuticals

Specific centers in your brain are responsible for controlling voluntary processes (like telling your hand to pick up a pencil, or solving a math equation "in your head"). Other brain centers control involuntary processes (like digesting food, controlling your breathing and heart rate), but they all rely on the same signaling actions. Depending on the type of epilepsy you have, one or more of these brain centers may function differently during a seizure, and cause different effects or symptoms:

- **Prefrontal cortex:** involved with processes that impact behavior and personality
- **Motor cortex:** involved with control and coordination of muscle movement (like telling your hand to pick up a pencil)
- **Sensory cortex:** involved with your understanding of sensations from skin, muscle joints, and organs
- **Visual cortex:** involved with converting information from the eyes into images we understand
- **Speech centers:** involved with interpreting spoken and written language, and with speech
- **Hearing centers:** involved with interpreting sound so that we can understand words and melodies
- **Cerebellum:** involved with coordination of skeletal muscle function
- **Brain stem:** connects the brain and the spinal cord

Neurons located in different areas of the brain are dedicated to controlling specific functions.

FACT 4

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What did I learn from my EEG, imaging, and sleep studies?

FACT 11 About 150,000 new cases of epilepsy are diagnosed each year in the United States.

The first time you had a seizure, your doctor may have ordered a test that used electrodes or a cap placed on your head to record the electrical activity in your brain. This test is called an electroencephalogram (EEG). It detects the intensity of electrical activity in different areas of your brain, and records them on a paper or digital chart. This helps the doctor see where any irregular electrical activity in the brain may be occurring.

An EEG finding of irregular electrical activity can help the doctor diagnose epilepsy and find the part of the brain where seizures start.

DID YOU KNOW?
 The EEG test uses the same recording principle as the electrocardiogram (ECG), which records electrical activity in the heart.

An EEG reads electrical signals in the brain.

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FACT 49 In the United States, more people have epilepsy than autism spectrum disorders, cerebral palsy, multiple sclerosis, and Parkinson's disease combined.

Hormone replacement therapy (HRT), which is used to treat symptoms of menopause, also can affect epilepsy. Hormone replacement therapy consists of giving either estrogen alone or both estrogen and progesterone. During the time of menopause and HRT use, dose adjustments may be needed for women taking antiepileptic medicines.

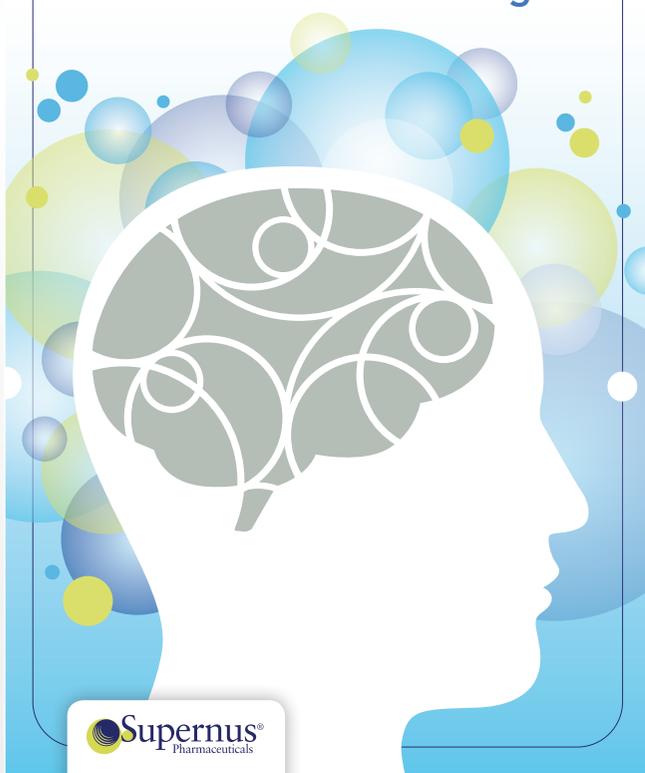
SECTION 13

TALKING with your HEALTHCARE PROVIDER

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Living with Epilepsy

Information & Insights

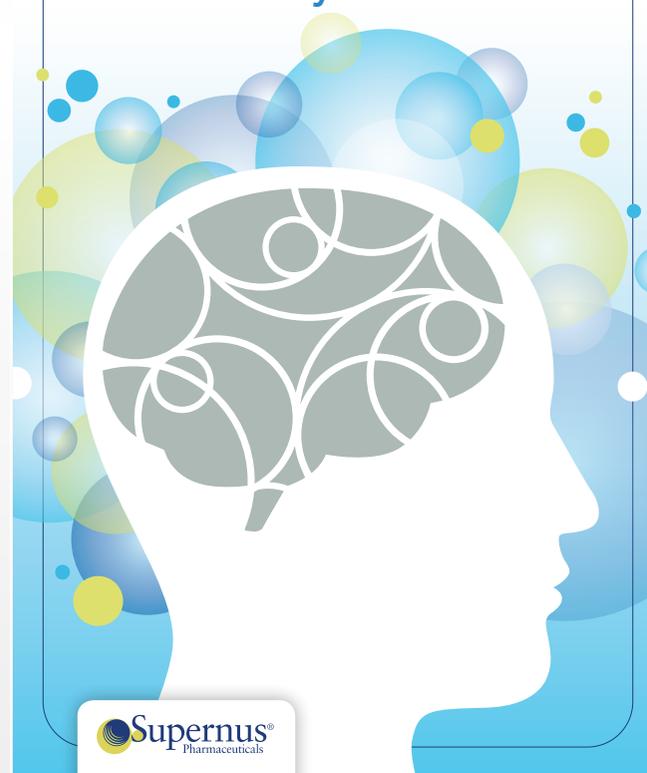


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Información y conocimientos



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Understanding Epilepsy

How Is Epilepsy Diagnosed?

Any seizure is a cause for concern. However, having a single seizure does not mean that a person has epilepsy. Doctors consider the history and nature of a person's seizures in diagnosing epilepsy.

When a person has a seizure for the first time, doctors review his or her **medical history**. They also perform exams on the **body and the brain**, and usually order **laboratory tests**. Doctors use this information to see if there were earlier events that may have been seizures, or if there are risk factors that can be changed to prevent future seizures.

Some questions your doctor may ask about your seizures to find out if they are caused by epilepsy are shown below. **Your doctor may also ask these questions during follow-up care visits.**

- Were there any possible events that may have caused the seizure?
- What happened during the seizure?
- How long did the seizure last?
- What was the first sign that you may have been having a seizure?
- Does anyone in your family have seizures?
- How did the seizure end—slowly or very quickly?
- How did you feel after the seizure—were there any problems afterwards (confusion, muscle aches, bitten tongue)?

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Medicine Adherence & Seizure Prevention

The Importance of Taking Medicine as Prescribed

Taking the right amount of medicine at the right time is called **medicine adherence**. Poor medicine adherence can increase your risk of having seizures.

You can improve your adherence with medicines prescribed for your epilepsy by:

- Knowing about epilepsy and the importance of medicine for managing seizures
- Always checking with your healthcare provider before taking any other medicines

Use daily reminder tools to help you remember to take your medicine, such as daily pill boxes or calendars and electronic reminders. A simple dosing schedule can help improve your adherence.

- Talking with your doctor about any side effects that are bothering you
- Filling and refilling your prescriptions on time. If possible, try to reduce your number of trips to the pharmacy

If you have trouble remembering to take your medicine, talk with your doctor about medicines that can be taken in fewer doses—sometimes just once a day.

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Tipos de convulsiones

Tipos de crisis epilépticas y sus síntomas

Crisis generalizadas	Crisis tónico-clónicas	<ul style="list-style-type: none"> Parálisis repentina del conocimiento con caída al suelo Contracciones musculares en ambos lados del cuerpo Posibles dificultades respiratorias breves 	<ul style="list-style-type: none"> Puede incoordinación ocular o focal Recuperación lenta después de la crisis, con cierto grado de confusión que puede durar varias horas Posibles calambos, fatiga y dolor muscular (principal) después de la crisis
	Crisis de ausencia	<ul style="list-style-type: none"> La crisis comienza y termina repentinamente Prácticamente pérdida del conocimiento (puede ser tan breve como caer al suelo) 	<ul style="list-style-type: none"> Muscle fija, perdida, como si la persona se fuera despierta Las crisis pueden producirse varias veces al día Una vez finalizada la crisis, generalmente no hay entumecimiento
	Crisis atónica	<ul style="list-style-type: none"> Respuesta muscular repentina Cabeza caída 	<ul style="list-style-type: none"> Parálisis postural En ocasiones se utiliza un protector cefálico
	Crisis mioclónicas	<ul style="list-style-type: none"> Movimientos musculares involuntarios 	<ul style="list-style-type: none"> Pueden producirse como episodios únicos o múltiples Pueden afectar a uno o ambos lados del cuerpo
Crisis parciales	Simples	<ul style="list-style-type: none"> Se pérdida o alteraciones de conciencia 	<ul style="list-style-type: none"> Movimientos incoordinados, percepción de olores o sensaciones musculares o fuertes, síntomas de entumecimiento o adormecimiento
	Complejas	<ul style="list-style-type: none"> Los mismos posibles síntomas de las crisis simples 	<ul style="list-style-type: none"> Pérdida o alteraciones de conciencia (pérdida de memoria o cambios de comportamiento)
	Con generalización secundaria	<ul style="list-style-type: none"> La crisis comienza en un lado del cuerpo pero evoluciona a ambos lados 	