



# EPILEPSY

A GUIDE FOR PATIENTS AND FAMILIES



Featuring John O'Hurley



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## A GUIDE FOR PATIENTS AND FAMILIES

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American Academy of Neurology

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The guidebook author is Stephen Braun and the DVD script writer is Deborah Gobble. Complete disclosure information on the physician experts who participated in this program (Dr. Gregory Cascino and Dr. Daniel Hoch) is available at AAN.com.

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## INTRODUCTION

More than 3,000 years ago, people recognized the behaviors that today we know are caused by a brain disorder called *epilepsy*. Epilepsy is more common than most people think. About 2 million people of all ages in the US have epilepsy. And as many as 1 in 26 people will develop epilepsy at some point in their lifetime.

Epilepsy is a serious medical condition. But today, many people can manage epilepsy and live well, just as others learn to live well with other long-term medical conditions. Epilepsy does not have to rule your life!

As many as 2 of every 3 people newly diagnosed with epilepsy are likely to have their seizures become well-controlled by using epilepsy medicines. And medicines and other types of treatments can help people with epilepsy no matter when they were diagnosed.

A key is to get help early and work with health care providers, for example, neurologists, who specialize in treating epilepsy. This kind of partnership can help you take full advantage of the many treatment options that exist today. These treatments can often reduce, or sometimes even eliminate, seizures.

Some people with epilepsy, however, continue to face misunderstandings about their condition. As a result, they can face discrimination in education and employment. Fortunately, more and more people are learning the truth about epilepsy—it is a medical condition that can usually be well-managed with treatment.

This booklet and DVD program will help you:

- Learn more about the different types of epilepsy
- Learn about available treatment options
- Take positive steps to be healthy, both physically and emotionally

### DID YOU KNOW?

Neurologists are medical doctors who specialize in disorders of the brain and nerves. They are the specialists who most often treat people with epilepsy.





## WHAT IS EPILEPSY?

Epilepsy is a problem in the brain that causes seizures to occur without warning. A seizure is like an “electrical storm” in the brain. During a seizure, the normal pattern of activity in the brain is temporarily disturbed. Brain cells begin to fire abnormally.

Many things can cause seizures, including injuries, fevers, and many types of diseases. Epilepsy is the name for a group of medical conditions that cause seizures. There are more than 25 kinds of epilepsy. Each kind is caused by a different type of brain disorder.

There are also many types of epileptic seizures. Seizures can be experienced as strange sensations, emotions, behaviors, convulsions, altered awareness, or inability to respond. Some people may experience unusual sensations before a seizure. These warning sensations are called *auras*.

### DID YOU KNOW?

Epilepsy is the 4th-most common neurological disorder in the US.



### DID YOU KNOW?

Having a seizure does not mean a person has epilepsy. Many people have a single seizure in their lifetime, because of an injury, illness, or fever. This is not epilepsy. Only when a person has had two or more unprovoked seizures is he or she considered to have epilepsy.

Usually an epileptic seizure lasts only a minute or two. After the seizure a person may feel tired and dazed. Some seizures are not obvious. They may consist of only a sensation or unusual feeling that is not noticed by others. Or a person may simply seem “out of it” for a brief time, and then resume what she or he was doing.

### DID YOU KNOW?

**There are 2 major types of seizures:** *focal* seizures and *generalized* seizures. The type is determined by how the seizures start.

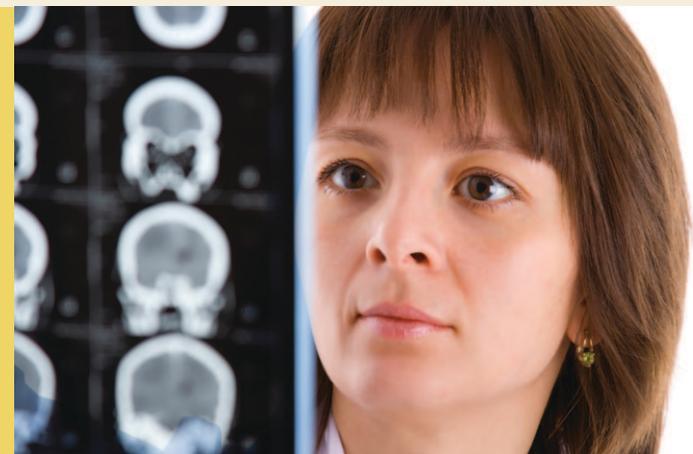
- *Focal* seizures (also called *partial seizures*) begin in just one part of the brain. The feelings or sensations a person may have during a focal seizure depend on which part of the brain is affected. Partial seizures may spread to affect both sides of the brain.
- *Generalized* seizures result from abnormal brain cell activity on both sides of the brain at once. These seizures may cause momentary stares, loss of consciousness, falls, or massive muscle spasms.

## WHAT CAUSES EPILEPTIC SEIZURES?

The human brain is so complicated that many things can make it “act up” and produce seizures. Some seizures occur because the brain’s “wiring”—the connections between brain cells—is not normal. Seizures may also arise from an area of the brain that has been injured in the past or is not working normally for some reason. This can happen for a number of reasons including head injury, tumors, strokes, or Alzheimer’s disease.

Sometimes epilepsy runs in families and is caused by genetic influences. But about half of all seizures have no known cause. Scientists are still learning about the many things that can cause epilepsy.

While there is currently no cure for epilepsy, for some people the seizures can stop. Children may “grow out of” their seizures naturally, whether they take medications or not. In one study, children with epilepsy of an unknown cause had a 68% to 92% chance of becoming seizure-free 20 years after they were diagnosed.



### DID YOU KNOW?

Some famous people who have had seizures:

- Supreme Court Chief Justice John Roberts
- Margaux Hemingway
- Danny Glover
- Leo Tolstoy
- Neil Young
- Tchaikovsky

Patients with uncontrolled epilepsy have a higher risk for other problems such as injuries, accidents, emotional or mood disorders, and, rarely, sudden death. But many people's seizures can become well-controlled by using available treatments. The important thing is to work closely with a neurologist, carefully follow all treatment advice, and do everything you can to be as healthy as possible.

## HOW IS EPILEPSY DIAGNOSED?

Seizures rarely happen in the presence of a health care provider. To figure out if a seizure is due to epilepsy, several kinds of tests can be used. A detailed medical history is still one of the best ways that a health care provider can tell whether a person has epilepsy and, if so, what type of epilepsy he or she has. Since many people who have a seizure can't remember the seizure itself, it's important for somebody close to the person to give an account of the seizure.

A test called an EEG may be used to diagnose epilepsy, or determine the type. An EEG measures the electrical activity of the brain. Sometimes a person with epilepsy will have abnormal patterns of brain waves—an epilepsy "fingerprint." This can help pin down a diagnosis. But an EEG, by itself, may not be enough to confirm a diagnosis. That's because not everyone who has epilepsy has an abnormal EEG. And some people who never have seizures *do* show abnormal brain wave patterns.



*"Epilepsy is what I have, not who I am."*

*—Anonymous patient*

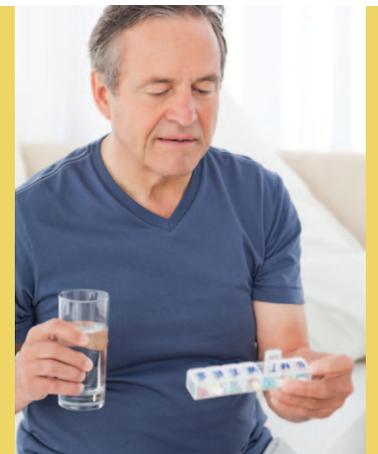
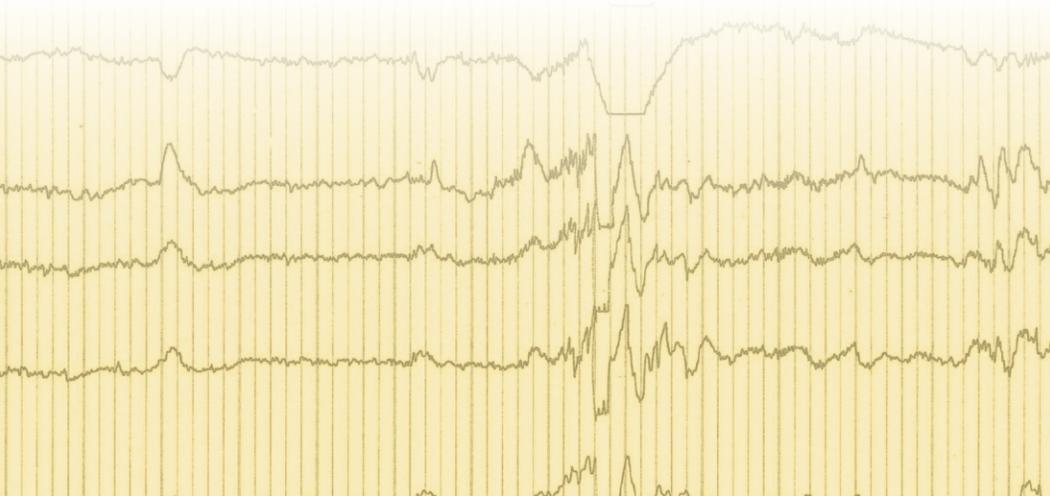
## MEDICINES FOR EPILEPSY

Other kinds of brain scans can help pinpoint where in the brain seizures begin. Some scans (CT scan, MRI) can also detect tumors, cysts, or other problems with the brain that might be causing seizures.

Blood tests are sometimes used to look for underlying problems that can cause seizures, such as infections, lead poisoning, anemia, or genetic issues. Having a clear diagnosis of epilepsy, even if the underlying cause is unknown, is the key first step to finding effective ways to control the seizures.

There are many ways to treat epilepsy. Seizures can be reduced or eliminated in about 80% of people with epilepsy. The most common treatment for epilepsy is the use of medicines. More than 20 kinds of anti-seizure medicines are now available. Which medicine your health care provider recommends will depend on many factors, including the type of seizures you have, your lifestyle, your age, and whether you take other kinds of medications.

Your health care provider or neurologist will work with you to determine if an anti-seizure medicine is right for you. It may take some “experimenting” to find one that works best for you. In some patients, seizures can be best controlled by combining two or more medicines.



## GETTING THE MOST FROM EPILEPSY MEDICINES

Between one-third and two-thirds of people with epilepsy do not closely follow the treatment plans recommended by their health care provider. Taking your medicines exactly as prescribed is key: take the right dose, at the right time, and carefully follow other directions, such as whether or not to take a medicine with food. The more closely you stick with your treatment plan, the better your chances of reducing or eliminating your seizures.

Talk to your neurologist or other health care provider if you are having difficulty keeping track of your medicines, or taking them as directed. Good communication with your health care provider is an important step in helping to get your seizures under control.



## SURGERY FOR EPILEPSY

When seizures cannot be controlled by medicines, surgery may provide another option for some patients. Surgery is typically not the first treatment option. It is usually considered only after at least 2 or 3 medicines have been tried without success.

For those patients who are candidates for surgery, a common technique is to remove the small area of the brain where seizures start. In general, people have a better chance of becoming seizure-free after surgery if doctors can figure out where the seizures are beginning.

Your health care provider will help you decide if you are a good candidate for epilepsy surgery. If you are a good candidate, it is best if surgery is done as soon as possible after the determination has been made.



## OTHER TREATMENT OPTIONS FOR EPILEPSY

In addition to medicines and surgery, two other treatments may help people with certain kinds of epilepsy who do not respond adequately to medicines.

### VAGUS NERVE STIMULATION

The large vagus nerve connects parts of the brain to body organs such as the “voice box,” the heart, and the stomach. Stimulating this nerve has been found to reduce epilepsy seizures in some people by 20% to 40%. In 1997, the US Food and Drug Administration approved the use of vagus nerve stimulators for treating teens and adults whose seizures were not well-controlled by medicines.

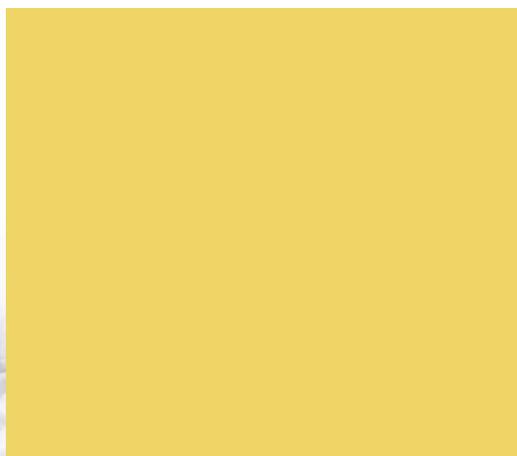
The stimulator is a small battery-powered device that is implanted under the skin of the chest, much like a pacemaker. It is connected to the vagus nerve in the lower neck. The device delivers short bursts of electricity to the vagus nerve, which in turn influences the brain. The stimulation can be either continuous, or it can be controlled by the patient if she or he feels that a seizure may be about to happen.



### SPECIAL DIET

Studies show that some people may have fewer seizures if they follow a strict diet—high in fats and low in sugary or starchy foods (these foods are called carbohydrates).

Originally developed almost a century ago, this diet forces the body to burn fats for calories. When this happens, the body produces substances called *ketones*, which is why this treatment is called a “ketogenic diet.” The diet is not usually used for more than 2 to 3 years to avoid any harmful effects on growth or development if used with children. It requires a lot of motivation and close supervision. Nonetheless, a ketogenic diet may provide a real option for those who do not respond to medicines or other treatments.



## HELPING SOMEONE WHO IS HAVING A SEIZURE

It's important for those close to someone with epilepsy to know what to do if the person has a seizure. It's also important for the person who has epilepsy to talk clearly with others in advance about what to do in the case of a seizure. Many people have mistaken ideas about how to help. For example, some think they should put something in the person's mouth to protect the tongue from being bitten. This is not necessary—it can actually harm the person having a seizure.

According to the National Institutes of Health, here are the steps to take if someone is having a seizure:

- Roll the person on his or her side to prevent choking on fluids or vomit.
- Cushion the person's head.
- Loosen any tight clothing around the neck.
- Keep the person's airway open. If necessary, grip the person's jaw gently and tilt her or his head back.
- Do NOT restrict the person from moving, unless he or she is in danger.
- Do NOT put anything into the person's mouth, not even medicine or liquid, unless instructed by a health care provider.
- Remove any sharp or solid objects that the person might hit during the seizure.
- Note how long the seizure lasts and what symptoms occurred, so you can tell a doctor or emergency personnel if necessary.
- Stay with the person until the seizure ends.
- Call 911 if the person injures her- or himself, if the person stops breathing, or if you have any other reason to feel you cannot handle the situation on your own.

In Case of Emergency

Name \_\_\_\_\_

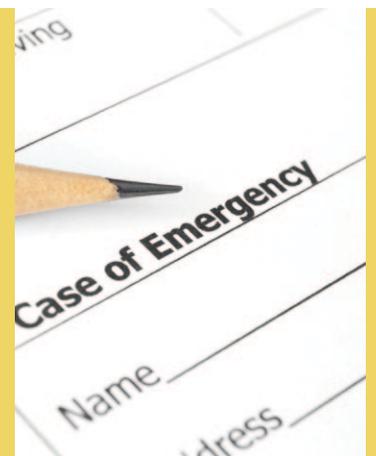




## PLANNING AHEAD

You should work with a health care provider to make a “seizure plan.” This is a list of things to do, both for yourself and for any relatives or caregivers who are likely to be around you. Here are some things a seizure plan might suggest:

- Wear a bracelet or other ID with your medical information on it.
- Consider keeping a seizure or epilepsy diary (see page 35 for a sample diary).
- Organize emergency contact numbers.
- Learn to recognize auras and other warning signs of a seizure, and take steps to move to safe locations or positions.
- Learn your own seizure triggers (for example, lack of sleep, alcohol, stress, or hormone changes related to a menstrual period).
- Safety-proof your environment (pad sharp corners, use barriers to protect against hazards such as heights, pools, bodies of water, fireplaces, etc.).
- Review your plan with relatives or caregivers of children.





## LIVING WELL WITH EPILEPSY

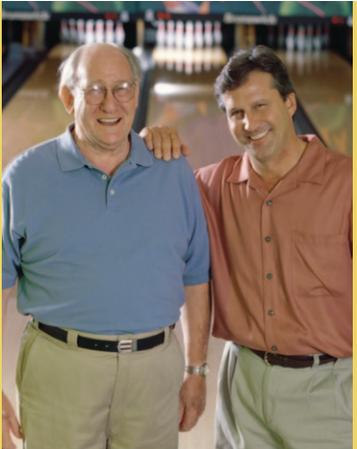
Having epilepsy can be challenging. It can affect schoolwork, mood, relationships, and your ability to work and drive. But there are many ways you can address these challenges. Here are some tips for ways to cope with some of the more common non-medical aspects of epilepsy:

### RECREATIONAL ACTIVITIES

People with epilepsy should avoid sports or recreational activities that would be extremely dangerous if a seizure occurred, like skydiving or motor racing. But people with epilepsy can enjoy many sports such as volleyball, bowling, baseball and softball, basketball, and others using normal protective gear. In fact, some evidence shows that regular exercise can improve seizure control in some people. Talk with your health care provider before starting any new sport or recreational activity.

### DID YOU KNOW?

The American Academy of Neurology warns all people, not just those with epilepsy, about the dangers of sports such as boxing and some martial arts that involve intentional blows to the head.



## BEHAVIOR AND EMOTIONS

People with epilepsy may have difficulty adjusting to their condition or the way other people react to them. Children can be teased, bullied, or avoided. Adults may find that people distance themselves or react negatively when they learn the person has epilepsy. These kinds of situations can lead to an increased risk of poor self-esteem or even depression. People with epilepsy may have a higher risk for depression because the parts of the brain that control mood may be affected.

Behavioral or emotional difficulties can be handled in many ways. Both the person with epilepsy and those around him or her need to learn to accept and live with the possibility of seizures, without blame or embarrassment. Counseling services of many kinds can help people with epilepsy and their family members share their feelings, learn from each other, and work through any misunderstandings or conflicts that might develop.

Sometimes, medication may be helpful in improving mood. If you or a loved one is having emotional problems, talk to a health care provider. She or he can usually suggest other professionals who can help. (Many cities have local chapters of an epilepsy organization that can provide help and guidance. See the Resources section on page 31.)

## DRIVING

Most states require people with epilepsy to demonstrate that they have gone a specific length of time without a seizure to obtain or reinstate a driver's license. This restriction of independence can be difficult to deal with, and may affect choices of where to live or work. But many people with well-controlled epilepsy do drive safely. It is important to learn about the laws of your own state, and how you can meet whatever requirements exist. Of course, alternatives to driving may exist in your city or town. Check out the availability of buses, taxis, trains, or other types of transportation.



## EDUCATION

Several things can make schoolwork or studying harder for people with epilepsy. Some epilepsy medicines can make it harder to concentrate or remember things. Also, some types of epilepsy are associated with learning problems due to underlying brain dysfunction. Students with epilepsy may be entitled to extra help, or extra time with schoolwork.

By law, people with epilepsy in the United States cannot be denied employment or education because of their seizures. Still, people with epilepsy may face barriers at school or work. It's important to know your rights, stand up for yourself, and work to overcome ignorance on the part of others. For example, teachers should be told what to do if a child has a seizure, and parents should work with the school system to find reasonable ways to accommodate any special needs their child may have.



## PREGNANCY AND MOTHERHOOD

According to American Academy of Neurology guidelines, most women with epilepsy can become pregnant and have healthy babies ([AAN.com/view/EpilepsyPregnancy](http://AAN.com/view/EpilepsyPregnancy)). Women with epilepsy do not have substantially higher risk of having complications during labor and delivery. If a woman is seizure-free for 9 months before she becomes pregnant, it's likely that she will not have any seizures during the pregnancy.

Women who are thinking about becoming pregnant should talk with their health care provider well before the pregnancy, because some epilepsy medicines are known to increase the risk of birth defects. Your health care provider can help you take steps to promote a healthy pregnancy, such as taking prenatal vitamins and folic acid.



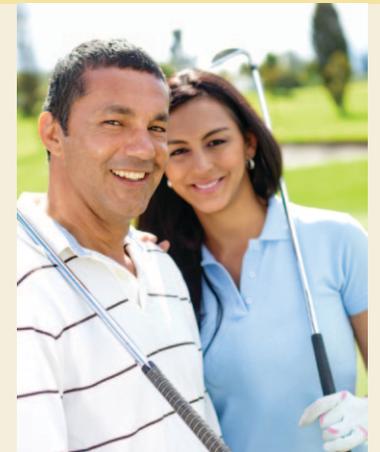
## REAL CHOICES, REAL HOPE

You've learned in this booklet and DVD program that people with epilepsy can live well with their condition. In fact, many people with epilepsy can realistically hope to control their seizures. Remember that you are not alone—millions of people have epilepsy. Organizations and support groups exist in nearly every city and are ready to help you learn more and cope better with your condition.

Medical advances in the past two decades have led to a better understanding of epilepsy and seizures. Advanced brain scans and other techniques allow better diagnosis and treatment planning. Many medicines, surgical techniques, and other treatments can control seizures for most people with epilepsy.

Working closely with a neurologist will help you manage your epilepsy. You should take steps to improve your overall health: exercise regularly, eat well, get enough sleep, and avoid known seizure triggers. You can control your epilepsy, rather than letting it control you!

By learning more about epilepsy and how it can be managed, you've taken the first steps toward living well with this common medical condition. Please refer to page 31 for additional resource information.



## SEIZURE DIARIES AND OTHER TRACKING OPTIONS

One of the most important tools your neurologist or health care provider has to help you manage your epilepsy is one that *you* provide: a record of your day-to-day experiences. “Seizure diaries” provide essential information about the type, timing, and duration of seizures, as well as possible triggers.

Many types of seizure diaries exist. A print version is available on page 35. In addition, there are a number of online diaries and even apps for mobile devices such as an iPhone® or iPad®. See the Resources list opposite for websites that offer online seizure-tracking tools or apps.

## RESOURCES

**American Academy of Neurology**  
AAN.com

**American Brain Foundation**  
CureBrainDisease.org

**Neurology Now® Magazine**  
NeurologyNow.com

**American Epilepsy Society**  
aesnet.org

**Citizens United for Research in Epilepsy (CURE)**  
CUREepilepsy.org

**Epilepsy Foundation**  
epilepsyfoundation.org

**Epilepsy Therapy Project (source of online seizure diary)**  
epilepsy.com

**National Institute of Neurological Disorders and Stroke  
Epilepsy Information Page**  
<http://www.ninds.nih.gov/disorders/epilepsy/epilepsy.htm>

**Seizure Tracker**  
seizuretracker.com

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### **American Academy of Neurology**

The American Academy of Neurology (AAN), established in 1948, is an international professional association of more than 25,000 neurologists and neuroscience professionals dedicated to promoting the highest quality patient-centered neurologic care. A neurologist is a doctor with specialized training in diagnosing, treating, and managing disorders of the brain and nervous system, such as epilepsy, Alzheimer's disease, multiple sclerosis, stroke, and Parkinson's disease.

For more information visit [AAN.com](http://AAN.com).



### **American Brain Foundation**

The American Brain Foundation, the foundation of the American Academy of Neurology, is an independent organization that aims to become the world's leader in raising money to cure brain diseases, such as epilepsy, Alzheimer's disease, stroke, Parkinson's disease, and autism. These diseases affect more than 50 million people in the United States alone.

For more information on how you can help cure brain disease visit [CureBrainDisease.org](http://CureBrainDisease.org).



## Funding Support

### **Sunovion Pharmaceuticals Inc.**

Sunovion is a research-based pharmaceutical company dedicated to discovering, developing and commercializing scientifically advanced therapeutic products that are focused on helping patients suffering from central nervous system and respiratory disorders, as well as other illnesses.

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# Credits

*Epilepsy: A Guide for Patients and Families* was made possible through the expertise, funding, time, and efforts of many contributors. Special gratitude to:

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**American Brain Foundation**

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### Funding Support

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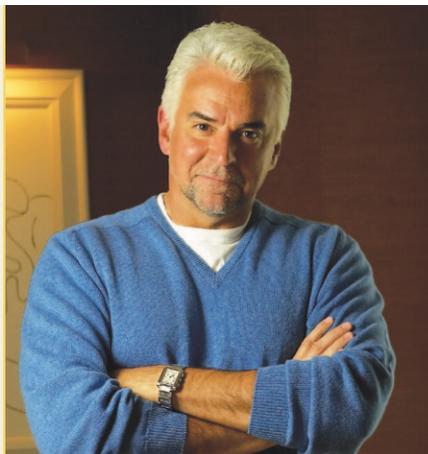
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Special thanks to: **John O’Hurley**

*Mr. O’Hurley lost his teenaged sister to complications of epilepsy.*



# SEIZURE DIARY

Make copies of this form and use it to keep track of any seizures you have. You can bring the forms to your next visit with your neurologist.

Date of seizure: \_\_\_\_\_

Time of day: \_\_\_\_\_

Length of seizure: \_\_\_\_\_

### Possible triggers:

- Medication change (describe) \_\_\_\_\_
- Overtired/lack of sleep
- Alcohol or drug use
- Change of diet or eating pattern
- Emotional stress
- Bright or flashing lights
- Menstrual period
- Fever
- Illness (describe) \_\_\_\_\_

Draw a line on the “Thermometer” to show how severe you feel your seizure was. 10 is most severe; 1 is least severe.

### Description of seizure:

- Aura
- Muscle twitches (describe) \_\_\_\_\_
- Muscle stiffness (describe) \_\_\_\_\_
- Loss of consciousness
- Loss of ability to communicate
- Loss of urine or bowel control
- Altered perceptions
- Other (describe) \_\_\_\_\_



# EPILEPSY

A GUIDE FOR PATIENTS AND FAMILIES



More than 3,000 years ago, people recognized the behaviors that today we know are caused by a brain disorder called epilepsy. About 2 million people of all ages in the US have this condition.

With proper treatment, people with epilepsy now can manage their condition and live well. Having epilepsy does not necessarily have to limit what you do or how you live your life!

Today, as many as 2 of every 3 people who are newly diagnosed with epilepsy are likely to have their seizures become well-controlled with treatment. A key is to get help early and work with your neurologist.

*This booklet and DVD program will help you:*

- Learn more about the different types of epilepsy
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- Take positive steps to be healthy, both physically and emotionally

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PMRC#: STE005-13