

# Living With Epilepsy

A guide to  
understanding  
and managing  
life with epilepsy

# Shining Stars

who didn't let epilepsy keep them down<sup>1</sup>

Alexander the Great

Napoleon

Danny Glover

Florence Griffith Joyner

Julius Caesar

James Madison

Truman Capote

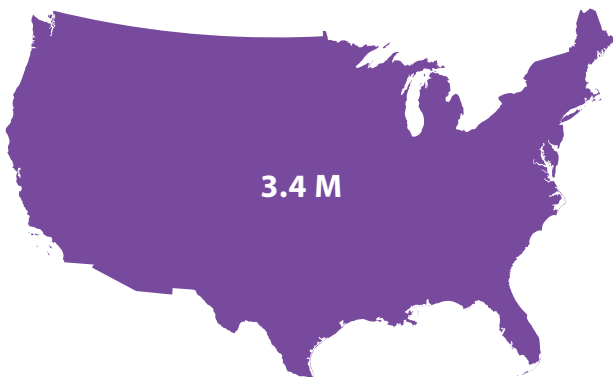
Prince

Neil Young

I have epilepsy, but  
it doesn't have me.



If you have epilepsy, you are not alone.




About 3.4 million people in the United States have epilepsy.<sup>2</sup> It is important to remember that many of these people lead full, active lives.

The goal of this book is to help you understand that:

- Learning and talking about your epilepsy can help you cope
- There are many options to consider in the management of epilepsy
- Epilepsy is just one part of who you are

Use this book as a resource to help you play a more active role in making decisions about your treatment. It may also help you talk about your epilepsy with health care providers, family, friends, and coworkers.



“Challenges are what make  
life interesting and  
overcoming them is what  
makes life meaningful.”  
—Joshua Marine<sup>3</sup>

Actor portrayal

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# Section One

# About Epilepsy

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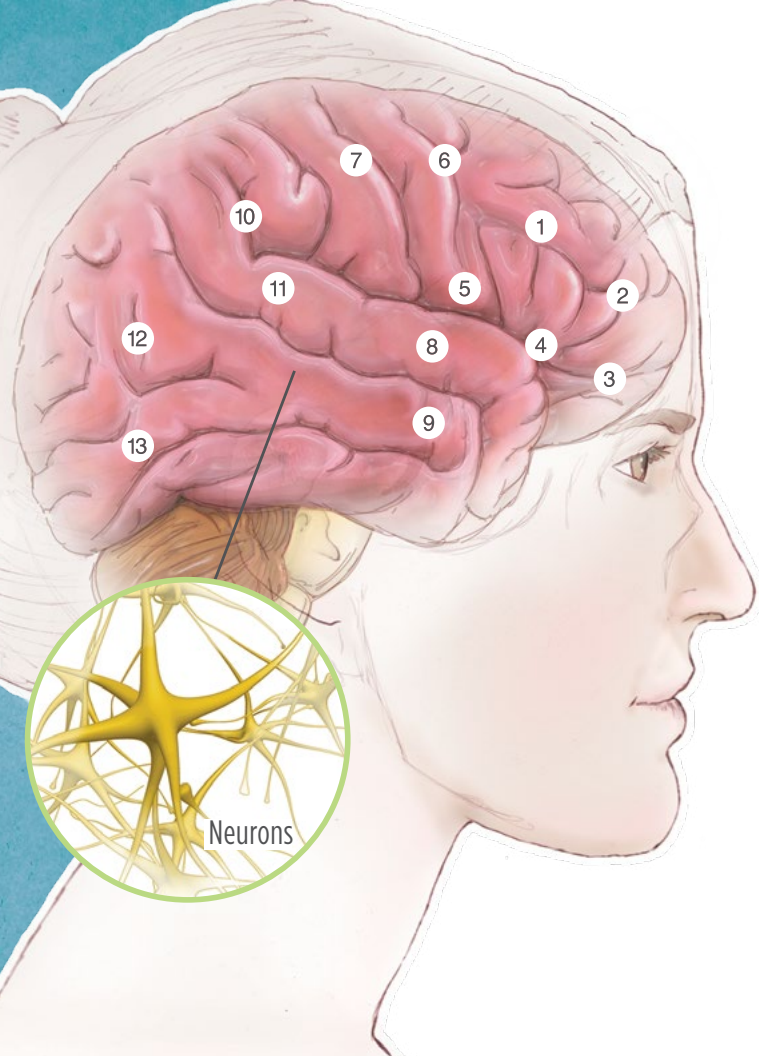
## What Is Epilepsy?

Did you know that  
**1** in every **26**  
people in the United  
States will suffer from  
epilepsy at some time  
in his or her life?<sup>7</sup>

[ Epilepsy is diagnosed in  
people of all ages and races.<sup>4</sup> ]

Epilepsy is a disease involving the brain that causes people to have multiple, unprovoked, seizures.<sup>5</sup> A seizure is a brief electrical “storm” in the brain. This is what happens<sup>6</sup>:

- The normal pattern of electrical activity in the brain is temporarily disturbed
- Brain cells begin to fire rapidly in an abnormal way
- This abnormal activity changes how the body moves and functions



A seizure can involve the entire brain or just part of the brain. Specific seizure symptoms depend on what part of the brain is affected.<sup>6</sup>

Abilities controlled by specific parts of the brain<sup>8</sup>:

- |                |                         |
|----------------|-------------------------|
| 1 Personality  | 8 Smell                 |
| 2 Organization | 9 Virtual memory        |
| 3 Reasoning    | 10 Speech understanding |
| 4 Speech area  | 11 Hearing              |
| 5 Writing      | 12 Vision               |
| 6 Movement     | 13 Visual processing    |
| 7 Sensory      |                         |

Brain functions depend on electrical signals passing between nerve cells called neurons.<sup>6</sup>



### What causes seizures?

Seizures result from a temporary disruption in the communication between nerve cells.<sup>9</sup> This disruption can be provoked or unprovoked.<sup>10</sup>

In about **50%** of people who have epilepsy, the cause is unknown.<sup>11</sup>

### Unprovoked seizures<sup>10</sup>

Unprovoked seizures, by definition, occur in the absence of clear causes or more than a few days after a brain injury or incident, such as a stroke or brain hemorrhage.

### Provoked seizure causes<sup>10\*</sup>:

- Birth trauma
- Withdrawal syndromes (ethanol, benzodiazepines, others)
- Head or brain trauma
- Stroke
- Tumors
- Missing doses of prescribed antiepileptic medications

\*Not an inclusive list.



# Types of Seizures

[ The kind of seizure a person has depends on which part, and how much, of the brain is affected.<sup>12</sup> ]

People can have more than one type of seizure. Seizures fall into 2 general groups<sup>12</sup>:

- **Focal:** results from an electrical discharge that involves one side of the brain
- **Generalized:** results from an electrical discharge that involves both sides of the brain at the same time

## Aura

An aura is an unusual feeling or movement felt around the time a seizure occurs<sup>13</sup>

## Focal seizures

VS

## Generalized seizures

### Focal aware (simple)<sup>14</sup>

- No loss of consciousness
- Unusual feelings or sensations

### Focal impaired awareness (complex)<sup>15</sup>

- Loss of consciousness or no awareness of surroundings
- Strange, repeated behaviors, such as lip smacking, rubbing of the hands, picking at clothes or fumbling

### Tonic-clonic (grand mal)<sup>16</sup>

- Loss of consciousness
- Body stiffens, jerks, and convulses
- Episodes last 1 to 3 minutes

### Absence (petit mal)<sup>17</sup>


- Lapses in awareness
- Staring blankly into space
- Eyes may roll back in the head
- Episodes last only a few seconds

### Atonic (drop attack)<sup>18</sup>

- Not fully aware during the seizure
- Sudden and complete loss of normal muscle tone
- Head may drop or body may collapse
- Episodes typically last less than 15 seconds

## Questions You May Want to Ask Your Health Care Provider About Epilepsy and Seizures

- Is the cause of my epilepsy known?
- What type of seizure do I have?
- What should others do when I'm having a seizure?
- Can you recommend an epilepsy support group?



What other questions do you have for your health care provider?

Enter Your Questions in the Box Below

## Fill Out This Information and Share It With Your Health Care Provider

A seizure journal will help prepare you to answer questions health care providers typically ask.

Date of seizure

Time of day

Signs or symptoms

Part(s) of body affected

Possible triggers

Seizure length

Seizure severity

Aura(s)?

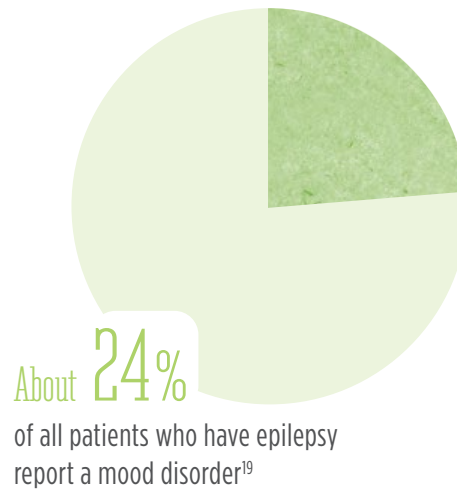
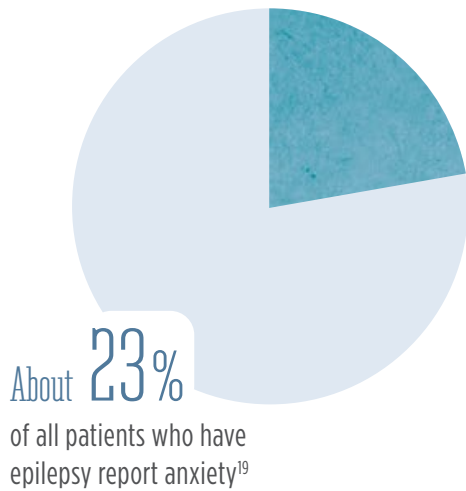
Once you're done filling out this page, save it or take a screenshot, and email it to your health care provider. He or she can use it to determine how well you're doing and whether any adjustments need to be made to your treatment plan.



# Emotional Challenges

[ Sometimes, epilepsy isn't only about seizures. ]

Living with epilepsy can be difficult. Many people don't realize that it has been shown that someone with epilepsy is more likely to experience a psychiatric condition than someone without epilepsy.<sup>19</sup> These psychiatric conditions include anxiety and mood disorders. If epilepsy leaves you feeling not quite like yourself, know that you are not alone.



## Anxiety

Feelings of anxiety are common in people with epilepsy. Anxiety may be overwhelming, and it can have a dramatic impact on your day to day activities.<sup>20</sup> Medicines used to treat seizures can also increase feelings of anxiety.<sup>20</sup>

## Mood Disorders

Mood disorders such as depression have been shown to be the most common psychiatric condition diagnosed in people with epilepsy.<sup>21</sup> Living with the possibility of seizures may make you feel scared and sad. Mood disorders can make you feel that you no longer like doing the things that you used to enjoy.<sup>22</sup>





# Your Epilepsy Specialist Team

[ Both the diagnosis and treatment of epilepsy can be a challenge. ]

Some health care professionals have more training and experience in the treatment of epilepsy. These specialists may include:

**Neurologist**  
(noo-ROL-oh-jist)  
a doctor who specializes in diseases of the brain, spinal cord, and nerves<sup>23</sup>

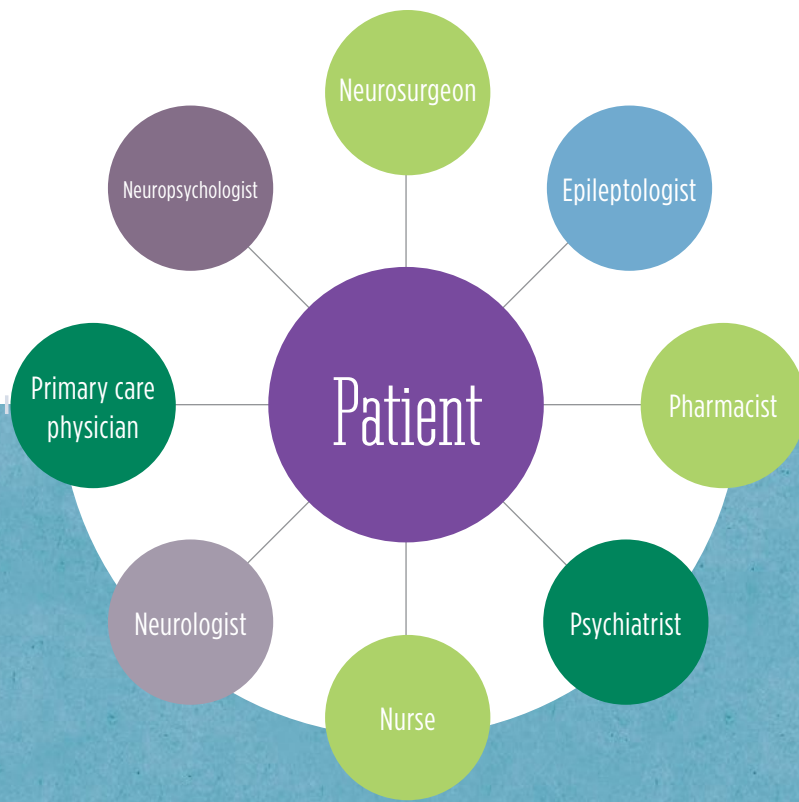
**Epileptologist**  
(EH-pih-lep-TOL-oh-jist)  
a neurologist with advanced training in epilepsy<sup>24</sup>

**Neuroendocrine specialist**  
(NOO-roh-EN-doh-krin)  
a neurologist with advanced training in hormone disorders that affect the brain<sup>24</sup>

**Neurosurgeon**  
(NOO-roh-sur-juhn)  
a surgeon who diagnoses and treats diseases of the brain, spinal cord, and nerves<sup>25</sup>



# Your Health Care Team



Diagnosing and treating epilepsy may require the skills of many health care professionals.<sup>26</sup>

Working together, you may create a treatment plan tailored to meet your personal goals.



# Your Health Care Team

## Talking With Your Health Care Provider

Be an active member of your health care team by preparing for your appointments:

- Have a list of questions with the 3 or 4 most important at the top<sup>27</sup>
- Ask a family member or friend to come to your appointments to listen and take notes<sup>27</sup>
- Bring important health information, such as medical records, x-ray films, test results, a list of medicines you take, your seizure journal if you keep one, and any information your doctor may have requested<sup>27</sup>
- Stay focused on what you want to discuss in order to maximize the time you have with your health care provider
- Don't be afraid to tell your health care provider what you are really thinking and feeling. The more honest you are, the more your doctor can understand what treatments might help you
- Ask your health care provider to draw pictures to help explain something
- Ask your health care provider for educational materials that you can take home



Actor portrayals



# Treatment

[ Understand your treatment options. ]

## Medicine

Medicine is the most common form of treatment for epilepsy.<sup>28</sup> Epilepsy medicines may be called<sup>29,30</sup>:

- AEDs (antiepileptic drugs)
- Anticonvulsants
- Antiseizure medicines

## Choosing a Medicine

Today there are more than 20 different antiseizure medicines. The choice of medicine is specific to the patient and depends on many different factors, including<sup>6</sup>:

- Type of seizure
- Frequency of seizures
- Age and lifestyle
- Potential for pregnancy\*

## Finding What Works For You

It may take time to find a treatment plan that works for you. Be patient and remember to:

- Take your medicine exactly as prescribed
- Tell your health care provider about any new seizures or side effects that you may experience



## Changing or Stopping Medicine

Always talk with your health care provider before you do anything different with your medicine.

\*Remember that it is important to talk to your health care provider before planning a pregnancy.



Eat better,  
feel better.

## Dietary Restriction Strategies

In addition to your medication, following a ketogenic diet may help to control seizures in some people with epilepsy.<sup>31</sup>

The ketogenic diet is a high-fat, low carbohydrate diet. When carbohydrates are not available to the body for fuel, fat becomes the primary fuel instead. When the body uses fat for its source of energy, ketones are formed. Higher ketone levels in the body may help improve seizure control.<sup>31</sup>


Ask your health care provider if changing your diet could help reduce the frequency of your seizures.

## Surgery

Surgery may be an option for people whose seizures are not adequately controlled with medications, dietary therapy, or implanted devices.<sup>32</sup> Surgery may involve<sup>33</sup>:

- Removing the area of the brain causing the seizures
- Blocking the nerve pathway of the seizures

Treatment with surgery is not for everyone. Your health care provider can determine if you're a good candidate for surgery. Keep in mind: surgery does not guarantee that you will be seizure-free or won't have to take medicine anymore.<sup>33</sup>



About 50% of people gain  
control of their seizures  
with medication.<sup>28</sup>

# Section Two

# Managing Life With Epilepsy



## Tips for Seizure Control

[ An important part of the management  
of your treatment plan is you! ]

To help your treatment be as effective as possible:

- Remember to take your medicine<sup>34</sup>
- Avoid seizure triggers<sup>35</sup>
  - Manage your stress
  - Get enough sleep



## Remember Your Medicine

For your medicine to work properly, you need to take it regularly unless directed by your health care provider. Even if you haven't had a seizure recently, do not skip a dose or stop taking your medicine. Missing a dose could cause serious problems, including triggering a seizure.<sup>34</sup>

## Avoid Seizure Triggers

A seizure trigger is something that can cause you to have a seizure. Common triggers include:

- Missing a dose of antiseizure medicine<sup>34</sup>
- Stress<sup>35</sup>
- Dehydration<sup>36</sup>
- Lack of sleep or extreme fatigue<sup>35</sup>
- Being sensitive to bright lights<sup>35</sup>
- Playing video games<sup>37</sup>



It feels great to have family members and caregivers on your team.

## Get Enough Sleep

To help you get enough sleep:

- Have a set time to go to bed and wake up
- Sleep in a dark, quiet room at a comfortable temperature
- Avoid or limit naps, or take naps earlier in the afternoon
- Avoid caffeine, alcohol, and tobacco before bedtime

## Manage Your Stress

To help manage your stress:

- Exercise for 30 minutes every day (see [Safety While Exercising](#) section)
- Take care of any new health problems
- Say no to new tasks that may overburden you
- Stay in touch with people who give you support
- See a professional counselor if you feel overwhelmed

## Find Support

Talking to people close to you about your epilepsy can be helpful. Plus, it's likely that they want to know and would like to help. When you are ready to tell someone, it may help to:

- Pick a quiet, comfortable place
- Allow enough time so you don't feel rushed
- Share this booklet or other printed materials about epilepsy



## Safety Tips

Consider purchasing a seizure detection device that can let someone know when a seizure occurs.<sup>38</sup>

- Certain devices can detect the repeated shaking movements that occur during a seizure
- When a seizure is detected by the device, caregivers are notified
- If a seizure occurs without big movements, it may not be detected by a seizure detection device

### Safety at Home<sup>39</sup>

The home is the most common place for seizure-related accidents. Here are a few tips to make your home as safe as possible:

- Use shatterproof glass for mirrors
- Avoid glass tables
- Install wall-to-wall carpeting or soft flooring when possible to cushion a potential fall
- Add padded covers to faucet handles, nozzles, and countertop edges
- Try to avoid clutter in rooms to allow room for a safe fall
- Have a way to call for help when you are alone, such as an alarm system, medic alert, or other safety device



Actor portrayal



Actor portrayals

## Kitchen Safety<sup>40</sup>

- Use a microwave oven instead of the stovetop
- Use a food processor instead of a knife
- Use unbreakable dishes
- For meals with a lot of preparation, try to cook when someone else is home

## Safety Tips

### Bathroom Safety<sup>39</sup>

- Try hanging an “Occupied” sign on the bathroom door instead of locking it, and have the door swing outward so that it won’t block someone from coming in to help you if you do fall while in the bathroom
- Use an electric razor instead of a straight edge
- Take showers instead of baths
- Make sure your shower drains properly to avoid water pooling
- Install tub rails or grab bars

### Safety While Sleeping<sup>41</sup>

It may seem like your bed would be a good place to have a seizure since you don’t have as high a risk of falling, but sleeping presents its own set of risks for people living with epilepsy. You can reduce these risks by:

- Sleeping on your back to avoid possible suffocation
- Removing dangerous items from around your bed
- Sleeping on a low bed or with the mattress on the floor
- Limiting the number of pillows in your bed



## Safety While Exercising<sup>42</sup>

Tips for exercise safety:

Being active and exercising is a great way for anyone to stay healthy and manage stress, but it is especially important for people living with epilepsy.

If your seizures are uncontrolled, avoid dangerous activities like scuba diving, rock climbing, skydiving, hang gliding, and mountain climbing that could result in injury, or even death, if a seizure occurs while participating.

- Recruit a buddy to exercise with you
- Bike with friends, and avoid busy streets. Make sure that everyone is wearing a helmet
- If going for a long walk, take a cell phone with a GPS locator
- Take frequent breaks and drink plenty of fluids
- Always wear a medic alert bracelet and carry a medic alert card

## Safety Behind the Wheel

People with epilepsy may be able to drive as long as their seizures are controlled and they meet the licensing requirements of their state.<sup>43</sup> If you'd like to drive:

- Find out about your state's laws about driving and epilepsy
- Ask your doctor if it is okay for you to drive and, if not, what steps you can take to be able to drive in the future
- Keep up with regular medical visits and take your medication as prescribed to make sure that your seizures remain controlled

In most states, people who have epilepsy need to present proof that they have been seizure-free for a certain time before they can be issued a driver's license. Visit [www.epilepsy.com/driving-laws](http://www.epilepsy.com/driving-laws) to find out more information about your state's laws concerning driving and epilepsy.<sup>43</sup>





## Seizure Drills<sup>44</sup>

[ Reduce the fear of unexpected seizures by holding seizure drills with your friends and family. ]

A time to practice what to do if a seizure occurs will help everyone to feel more comfortable and prepared in the event of a seizure. Here are a few important things someone can do to help during a seizure:

- Stay calm
- Time the seizure
- Turn the person gently to one side to keep the airway clear and to allow any fluid to flow out of the mouth
- Place something soft under the head
- Loosen anything around the neck
- Move any hard or sharp objects away from the person
- Stay with the person until the seizure ends naturally
- Watch the person for any signs of confusion



## Seizure First Aid<sup>45</sup>

[ Certain seizures require emergency medical attention. ]

Tell those around you to call an ambulance if:

- Your seizure lasts longer than 5 minutes
- You become injured during a seizure
- Your breathing becomes difficult
- You have multiple seizures in a row without regaining consciousness between seizures
- The seizure is different from your usual seizure
- Your seizure occurs in water



# Good to Know

[ You can do what you love! ]

## Know Your Legal Rights

You are protected from job discrimination and job loss by 2 important federal laws<sup>46</sup>:

- Americans with Disabilities Act (ADA)
- Family and Medical Leave Act (FMLA)

According to these laws, people cannot be denied employment or education because of their seizures.<sup>46</sup> However, people with epilepsy may still face some obstacles. A good strategy to overcome them is to know your rights ahead of time so you are prepared to stand up for yourself if necessary.

You can learn more about these laws on the Internet at:

- [www.ada.gov](http://www.ada.gov), for the Americans with Disabilities Act
- [www.dol.gov/whd/fmla](http://www.dol.gov/whd/fmla), for the Family and Medical Leave Act



# Continue Learning

[ Use these resources to learn more about epilepsy and treatment options, to connect with other people with epilepsy, and to take part in epilepsy advocacy. ]

American Academy of Neurology  
[www.aan.com](http://www.aan.com)

American Epilepsy Society (AES)  
[www.aesnet.org](http://www.aesnet.org)

Centers for Disease Control and Prevention (CDC)  
[www.cdc.gov/epilepsy](http://www.cdc.gov/epilepsy)

CURE: Citizens United for Research in Epilepsy  
[www.cureepilepsy.org](http://www.cureepilepsy.org)

Epilepsy Foundation  
[www.epilepsy.com](http://www.epilepsy.com)

National Council on Patient Information and Education  
[www.talkaboutrx.org](http://www.talkaboutrx.org)

National Institute of Neurological Disorders and Stroke (NINDS)  
[www.ninds.nih.gov](http://www.ninds.nih.gov)

## sunovion answers

Call us at: 1-844-427-8466  
8 AM to 8 PM EST Monday through Friday


Your journey can be complex and often overwhelming, but the support you get doesn't need to be. You have questions, and that's why we created Sunovion Answers for you.

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