



**EPILEPSY FOUNDATION**<sup>®</sup>  
*Not another moment lost to seizures*<sup>™</sup>

[www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)

1-800-332-1000

## **BEING A WOMAN**

Making it Work



**EPILEPSY  
FOUNDATION**<sup>®</sup>  
*Not another moment lost to seizures*<sup>™</sup>

***Taking Care of You***  
*How women with epilepsy  
are looking after their health  
and tackling tough issues.*



## INTRODUCTION

If you're reading this, you may be a mom who has epilepsy.

Or perhaps you're one of more than one million American women with epilepsy who are of child bearing age. Perhaps you're wondering whether you should have a child. You're wondering how you would cope with pregnancy and all the demands of motherhood. Maybe you're wondering how your epilepsy would affect your child's life.

There are no easy answers to these questions. But moms and moms-to-be can take comfort in the knowledge that thousands and thousands of women with epilepsy are looking after their own health, raising their children—and making it work.

This publication is about how epilepsy affects women. It's also about how epilepsy affects childbearing and raising a family. It's about ways to deal with some of the issues that come up along the way. It's about how having a plan can help you manage the unexpected.

We've divided the information into two booklets: *Being a Woman* and *Being a Mom*.

You may have to do both to make it work.

We hope you find this material helpful. It's based on what the experts tell us about epilepsy and what moms with epilepsy tell us about their lives, their kids, their challenges and their victories.

The Epilepsy Foundation thanks all those moms who've shared their experiences and the caring professional people who've offered advice.

As we all know, no matter how hard we try, there are no perfect mothers. There are no perfect families.

### Taking Care of You 3

EPILEPSY AND YOU	4
YOUR DOCTOR AND YOU	10
TREATMENT AND YOU	14
EPILEPSY AND SEXUAL FUNCTION	29
PREGNANCY AND YOU	30
MENOPAUSE: WHEN TOMORROW COMES	37
SAFETY AND YOU	39
EMPLOYMENT AND YOU	43
DRIVING AND YOU	45
RESEARCHING YOUR ISSUES	47

Every woman's situation is a little different and may require different approaches from the ones offered here.

Raising children is an exciting, often scary, mix of joy, worry, and the unexpected. Epilepsy adds one more element to the mix. But it doesn't change the basics. Like mothers everywhere, women with epilepsy are doing everything they can for their children. Most of all, they want to help them grow into confident, compassionate, independent young people. And they will.

### ACKNOWLEDGMENTS:

This product was produced through a grant from Medtronic Foundation.

©2008 Epilepsy Foundation of America, Inc.

*This information is intended to provide accurate, general information as of the date of publication. Indications for all drugs and treatment alternatives described herein have been recommended in the medical literature and reflect the practices of experts in epilepsy. This information is not intended to be medical advice or to substitute for the judgment of the physician on treatment in the individual circumstance. Please consult your health care provider for more detail and more recent information for additional information on drug uses, contraindications, and dosages.*



## Taking Care of You

As a woman with epilepsy, your health has to come first. Being well and feeling well helps you to be the kind of mom you want to be for yourself and your family.

**Taking care of you** means learning as much as you can about the kind of epilepsy you have and what you can do to limit its effects.

**Taking care of you** means finding a doctor you like and trust who listens to you and values you as a person.

**Taking care of you** means learning about your seizure meds, their effects, and what other treatment methods may be out there.

**Taking care of you** means building self esteem and building self confidence in your relationships inside and outside the family.

## EPILEPSY AND YOU

"I got encephalitis in '78, which led to epilepsy. I have one or two seizures lasting about 30 seconds each day."



As a woman with epilepsy, you already know quite a lot about it. You know the type of seizure you have. You know how it affects your life. You know how your epilepsy is being treated. And you may know all too well the many medicines that are used to prevent seizures. As one woman said: "I've been on all of them at one time or another."

If you've been researching epilepsy, you may already have learned a good deal more, especially from books, and on the Internet through [epilepsyfoundation.org](https://www.epilepsyfoundation.org) and other sites. You may already know that there are several types of seizures, different types of epilepsy, and that all seizures, no matter what form they take or what triggers them, are caused by sudden changes in how the nerve cells (neurons) function in your brain. But just to recap:

## About seizures

When they're working properly, your brain cells send each other millions of messages through tiny electrical signals. These signals turn on and off, off and on, trillions of times a day. Sometimes, if you have epilepsy, the "off" signals don't work. When that happens, some cells keep firing until a wave of electrical energy sweeps through all or part of your brain. What happens next depends on how much of your brain is affected and in what part of your brain the disturbance takes place.

**Generalized seizures.** If your whole brain is affected by the electrical surge, the seizure is called generalized. There are different kinds of *generalized* seizures, but most people know the most common one. It's the type of seizure everyone associates with epilepsy—the type that causes a person to stop, stare, cry out, fall unconscious, stiffen, and then shake for two to three minutes. It used to be called *grand mal* and lots of people still use that name. But the medical name for it is a *generalized tonic-clonic* seizure.

It's called *generalized* because the discharge in the brain that's causing the seizure affects the whole brain at once. *Tonic* because that's the medical term for the way the body stiffens at the beginning of the seizure. And *clonic* because that's what doctors call the jerking movements that follow.

**Other generalized seizures.** Other generalized seizures can be brief stares (called *petit mal* or *absence*), sudden muscle jerks (*myoclonic* seizures), sudden falls (*drop attacks*), or, in babies, clusters of muscle jerks (*infantile spasms*).

**Partial seizures.** But maybe your seizures are quite different from the ones described above. Perhaps you have *partial* seizures. That's the name for seizures that begin and stay in just one part of your brain. Partial seizures

can be *simple* or *complex*. The main difference between them is whether or not you stay awake and aware during the seizure.

**Simple partial seizures.** A *simple partial* seizure may give you strange feelings and make you unable to speak or understand what other people are saying for a short time. Simple partial seizures may produce jerking movements on one side of your body, or affect your emotions. Your sense of smell, hearing, touch, or vision may be affected. However, you'll stay awake and aware of your surroundings while the seizure is taking place.

**Complex partial seizures.** A *complex partial* seizure clouds your awareness. People who have complex partial seizures typically black out but don't fall. They may mumble, pick at clothes, wander, move things around in an aimless kind of way. No matter what they do, they are completely unaware of time or place or what they're doing during the seizure. Complex partial seizures generally last two to three minutes. As the seizure ends, awareness slowly returns. Complex partial seizures are the most common type of epilepsy in adults. They may be caused by an early injury to the brain.

**Partial seizures secondarily generalized.** Sometimes, a seizure will start out as a partial seizure and then spread to become a generalized seizure. Doctors call this a *partial seizure secondarily generalized*.

*More information about seizure types and symptoms is available on the Epilepsy Foundation's website ([www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)).*

## About types of epilepsy

Although everyone with epilepsy is susceptible to seizures, there are differences in how, when—and sometimes even why—seizures happen. When these differences form patterns that happen over and over again, they are divided into various types of epilepsy. People who have generalized tonic clonic seizures of no known cause are said to have primary generalized epilepsy. People who have partial seizures are said to have partial epilepsy. Partial seizures that always start in the temporal lobe area of your brain may be called temporal lobe epilepsy. Some of the special types of epilepsy are more likely to affect women. For example:

### Catamenial epilepsy

This is a type of epilepsy that affects women only. It is linked to the rise and fall of a woman's hormones during her childbearing years. The name catamenial comes from a couple of Greek words that mean, roughly, "by the month." Catamenial epilepsy makes women susceptible to seizures at certain points of their menstrual cycles. Some women have seizures at the time of their periods, or just before or after a period, or at the time of ovulation.

**A hormonal effect.** Seizures associated with catamenial epilepsy are related to changes in women's hormones. All women of childbearing age have hormone levels that go up and down during the month. Studies show that, if you have catamenial epilepsy, one major hormone (estrogen) makes seizures more likely to happen. Another hormone (progesterone) seems to have an anti-seizure effect.

**Keeping track.** If you've noticed that your seizures happen around the same time every month, start keeping a calendar. Track your seizures and your menstrual cycles over a three to four month period. See if there's any

connection between when you have seizures and when you have your period.

If you see a pattern, and that pattern shows that you're having seizures around the same time every month, take the calendar to your next doctor's appointment. Show your doctor or nurse practitioner what you've found. Your health care team may make some adjustments in what kind or how much medication you take, and when you take it, to avoid these hormone-related seizures.

*The most common patterns are for seizures to happen around the time of your period, around the time of ovulation, or during the second half of your cycle.*

## Photosensitivity

Being photosensitive means you may have seizures that can be triggered by intense flashing lights or alternating flashes of color. EEG tests are routine after someone has a first seizure. They help the medical team that's trying to find out what caused it. One of the tests that most people have during an EEG test flashes an intense, bright light to see whether your brain responds with the typical patterns that indicate epilepsy. If you had a seizure or seizure-like discharges in your brain during your EEG tests, chances are you are photosensitive. If not, you may not be affected by lights at all.

*The type of light most likely to trigger seizures flashes at between 5 to 30 flashes per second (Hertz). Children and teens are more susceptible to the effects of flashing lights than adults. Women may be slightly more likely than men to be photosensitive.*

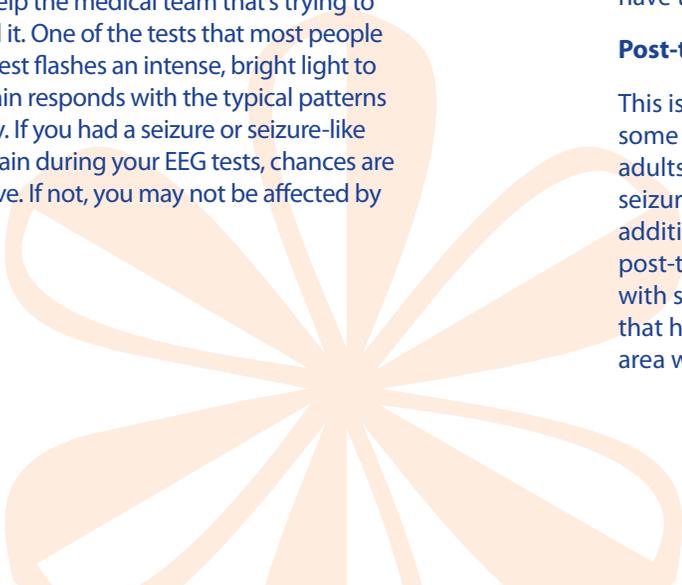
## Juvenile myoclonic epilepsy (JME)

If you have this common condition, it probably started in your teen years, perhaps after several years of having the momentary stares typical of childhood absence epilepsy.

JME is the most common form of generalized epilepsy. It produces generalized seizures, often on awakening. It sometimes includes sudden uncontrolled muscle jerks (myoclonic jerks). We all experience these sudden jerks occasionally, especially when falling asleep. People with JME have them more often, and during waking hours.

## Post-traumatic epilepsy

This is the kind of epilepsy that develops following some kind of injury to the brain. It's more common in adults. It typically produces simple or complex partial seizures (see above) that start in the injured area. In addition to standard treatment with anti-seizure drugs, post-traumatic epilepsy may be successfully treated with surgery. The surgery removes the part of the brain that has been damaged and can be shown to be the area where the seizures start.



## YOUR DOCTOR AND YOU

“I was going to a top neuro with a reputation for treating women with epilepsy and I only just found out I have catamenial epilepsy. Now I use him only as a pharmacist, to get my meds. I looked up docs on Google and found a great specialist.”

“I have a great relationship with my health care provider. But, I do have an insurance problem. They won't cover seizures for a year. I couldn't get private insurance at all.”



Finding the right doctor is a bit like finding the right mate. What sort of person and relationship are you looking for? It goes without saying that you want a physician who has kept up with the latest research findings, who knows about new treatments and who isn't reluctant to suggest a change if what you're currently taking isn't working. You may be looking for some other valuable qualities as well:

### **Wanted: A good listener**

Many women (and probably men, too) put “a good listener” at the top of their ideal doctor list. They're looking for a physician who listens to their issues and responds to their concerns. Although this sounds basic, in today's world of tightly scheduled appointments and limited time, the physician who takes the time to listen, who takes concerns seriously, and who treats the whole person is a real find.

### **Wanted: Partnership and mutual respect**

Successful treatment of epilepsy today is not just a top-down matter, even from the best of listeners and most up to date physicians. It comes from a real partnership between physician and patient. In this partnership, the physician listens to and respects the patient. The patient not only listens to and respects the physician, but takes active steps to be informed. Being informed means tracking what is happening to your body and taking an active interest in your care and decisions about your care. Writing down questions and taking them to medical appointments helps focus attention on what's important and makes the most of limited time with the doctor.

*Most physicians today welcome an informed person—it makes it much more likely that treatment plans will be followed and be successful.*

### **When you've got questions**

Sometimes women worry that the doctor won't like it if they raise questions based on material from the Internet or a magazine, or something that they've found in an Epilepsy Foundation publication. Occasionally, this might happen. However, good doctors don't feel threatened by informed patients. Good doctors will take time to see whether what their patients are suggesting is relevant to their treatment.

## Building a team approach

Partnership also involves the rest of the health care team. In today's medicine, the physician may be supported by nurses, nurse practitioners, and other health professionals. All of them can be valuable allies in all aspects of your health care, especially when you cannot see the physician or you have a question that they can answer before your appointment.

## Getting a second opinion

Unfortunately, health care partnerships, like marriages, don't always have happy endings. Occasionally, there has to be a divorce. Occasionally, you may decide you have to entrust your care to another physician.

## Why look elsewhere?

Poor communication, perceived lack of attention, poor seizure control or a high level of side effects—all of these things may be affecting your quality of life. If you don't feel you are getting the care you need, or that your concerns about your care are not being met, or even if a major change—such as surgery—is being proposed, the first step is to get a second opinion from an equally qualified physician.

## Finding Dr. Right

Where can he or she be found? Teaching hospitals or prominent, respected hospitals in major cities have neurology departments and lists of neurologists with treating privileges at those hospitals. That's one place to look. While many physicians can provide care for epilepsy, a neurologist has special training in all aspects of brain function and should be on your list of physicians to see, even if your regular doctor is not a neurologist.

Another place to look: the Epilepsy Foundation's website has a "Find a Doctor" feature. It lists neurologists nationwide who specialize in the treatment of epilepsy and shows how to get in touch with them. These physicians are all members of the professional American Epilepsy Society, which holds annual scientific meetings and promotes medical education about epilepsy.

*The Epilepsy Foundation has affiliates in many cities nationwide. Volunteers or staff of these local groups can usually provide a list of local physicians with a special interest in epilepsy. (To find an affiliate, go to the main website and click on Your Local Foundation.)*



## TREATMENT AND YOU: MEDICATIONS

"I've had epilepsy since the age of 12. My seizures now are very well controlled. I've had to change meds from time to time. My kids hadn't seen me have a seizure, but when I changed meds, I went into status. Then the kids saw for the first time."

"My greatest challenge is the side effects of the medicines. Sometimes I feel like I have ADD and memory loss."



Approximately one million American women with epilepsy take seizure-preventing drugs every day. Even when other treatments (surgery, brain stimulation, or diet) are tried, the epilepsy meds still have to be taken, at least for a while. More than 20 medications, also called anticonvulsants or antiepileptic drugs, are currently available to treat epilepsy. As a group, these drugs are fifth among the most prescribed medication in the United States. More than 56 million prescriptions are filled in a typical year.

Some epilepsy drugs, such as phenobarbital, phenytoin (brand names: Dilantin, Phenytek), carbamazepine (Tegretol, Tegretol XR, Carbatrol), primidone (Mysoline), and valproate (Depakene, Depakote) have been in use for many years. Others are much newer.

The following generic (brand name) medications may be prescribed for epilepsy:

*Carbamazepine (Tegretol, Tegretol XR, Carbatrol)*

*Clonazepam (Klonopin)*

*Ethosuximide (Zarontin)*

*Felbamate (Felbatol)*

*Gabapentin (Neurontin)*

*Lamotrigine (Lamictal)*

*Levetiracetam (Keppra)*

*Oxcarbazepine (Trileptal)*

*Phenobarbital*

*Phenytoin*

*(Dilantin, Phenytek)*

*Pregabalin (Lyrica)*

*Primidone (Mysoline)*

*Tiagabine (Gabitril)*

*Topiramate (Topamax)*

*Valproate*

*(Depakote, Depakene)*

*Vigabatrin (Sabril)*

*Zonisimide (Zonegran)*

*Lorazepam (Ativan) and diazepam (Valium) may also be prescribed for epilepsy (including emergency treatment to halt an extended seizure). Rectal diazepam gel (Diastat) may be prescribed for emergency use by non-medical personnel to bring prolonged or cluster seizures to an end. Fosphenytoin (Cerebyx) is used in hospital settings to stop episodes of status epilepticus (non-stop seizures).*

Studies show that for most people epilepsy meds will prevent seizures or reduce how often they happen if they're taken every day, on time. Missing doses, or taking less than prescribed, make it more likely that a seizure will happen. Suddenly stopping anticonvulsant medication is a big mistake—it can cause severe rebound seizures that are difficult to stop.

Seizures that don't stop—for any reason—are a medical emergency. Convulsive seizures that continue for more than five minutes, or that start again after the first seizure has stopped, may become what's called status epilepticus. That's a medical term meaning a "state of epilepsy."

*Long lasting seizures put severe stress on your heart and other organs. Fortunately, they're rare but your family and those closest to you should know that if something like that happens to you, you need immediate treatment in the emergency room.*

### Choosing the right drug

Doctors consider several things when selecting one epilepsy medication over all the others. They look at the risk of side effects, especially cosmetic and reproductive side effects for women and girls. And they look at the drug's proven track record in controlling seizures.

### Search for control

It may take quite a while to find a medication that successfully prevents seizures without unacceptable side effects. Often, the first pick doesn't work. People respond differently to antiepilepsy drugs. What works for one woman may not be effective for another. Similarly, side effects may be much more of a problem for some than for others.

*It's not unusual for women (or men) to have to try several meds before finding one that works best for them. And although most doctors will try to control seizures with just one drug at a time, some people will need more than one to reduce or completely prevent seizures.*

### Seizure freedom: Is it possible?

Yes, but it may take a while to find the right drug or combination of drugs. The goal of treatment today is: No seizures. No side effects. And in many, many cases, people with epilepsy are able to go years without a seizure. However, that's not everybody. Studies show that

as many as one in five people with primary generalized epilepsy still have a few seizures despite treatment. As many as one in three people with partial epilepsy still have seizures.

### Sometimes, it's a trade off

When people continue to have seizures when on medication, the physician will often increase the dose. However, side effects, especially feelings of drowsiness and fatigue, are generally worse at higher doses. Sometimes women choose to risk an occasional seizure rather than take a drug at a level that affects quality of life.

### Can people ever go off the meds?

Maybe. When someone's been seizure free on epilepsy meds for two or three years, the doctor may suggest a slow reduction of medication. It's usually a kind of gradual weaning away from treatment. The idea is to see whether that person can stay free of seizures while gradually becoming free of medication.

Women faced with that kind of decision often find it difficult to make. Some people can remain seizure free off meds, but not everyone does. The seizures may return and it may be necessary to start taking the meds again. Deciding whether to try going off meds may depend on how the medication makes you feel and how much an unexpected seizure might affect your life.

### Epilepsy Medications: Side Effects

Unfortunately, all antiepileptic drugs, like all other drugs, have some side effects. That is, they may have unpleasant effects on how you feel and how you function in daily life. That's because, while these drugs are designed to affect your brain and the seizures that start there, they also can affect all the other systems in your body.

Side effects come in several forms. Some only affect women who are susceptible to them, like an allergic reaction. Other side effects only happen at high doses. A medicine that is fine at a low dose may suddenly produce unpleasant effects if the dose is raised. A third type of side effect, like feeling drowsy or dizzy, happens regardless of dose but may become less of a problem when your body gets used to the medication.

To check on side effects of individual antiepileptic drugs, go to the Epilepsy Foundation's website, check the Physician's Desk Reference at your local library, or check the website of the pharmaceutical company that makes the drug. It will have the FDA prescribing information that lists all the side effects that so far have been reported.

### Common side effects

Common side effects of epilepsy drugs include drowsiness, fatigue, nausea, changes in vision, clumsiness and rash. Doctors should be told promptly if you experience nausea, vision changes or rash. Some meds may affect your emotions and memory. Others may affect how quickly you can work at tasks that require attention and thinking.

*It's always a good idea to ask your doctor what to expect when a new epilepsy medication is prescribed, and what kind of effects should prompt you to get in touch with him or her, fast.*

### Long term effects

Side effects can be short term or long term. Most of the ones described above are short term. That means, they affect how you feel today but they may go away once the medicine or the dose of medicine is changed. However,

epilepsy meds may have effects on the rest of your body that won't show up for many years. Some short and long term effects on women have only been recognized in recent years. Some of them are of special concern.

### Weight gain and hormones

In recent years, researchers have discovered that women's hormones may affect epilepsy and that estrogen may increase seizures and progesterone may prevent them. Now we know that it also works the other way round: having epilepsy and taking certain epilepsy meds may affect women's hormones.

Hormone changes in women can produce a lot of unwanted effects. These effects include weight gain, higher insulin levels, irregular periods, ovarian cysts, infrequent ovulation, difficulty in getting pregnant, and even development of certain masculine features such as growth of facial and other body hair and thinning or loss of hair on the head. This collection of effects is called polycystic ovary syndrome (POS).

POS also occurs naturally in women who do not have epilepsy. However, studies suggest that some antiepilepsy drugs may increase a woman's chances of developing some of its symptoms.

So far, valproate (Depakene, Depakote) seems to be linked to weight gain and mild increases in male hormone levels, but not to be a cause of irregular periods, increased levels of fat in the blood, or insulin resistance. Gabapentin (Neurontin), carbamazepine (Tegretol, Tegretol XR and Carbatrol), and pregabalin (Lyrica) may also lead to weight gain. On the other hand, topiramate (Topamax) and zonisimide (Zonegran) may have weight loss among their side effects.

## Birth control and hormones

The same hormones that are affected by epilepsy (or the medications that control epilepsy) are also involved in birth control. The good news is that standard birth control pills, hormone implants and other hormone-based methods of birth control don't seem to make epilepsy meds less effective. The bad news is that some epilepsy meds make the birth control products less effective.

*Even at higher doses, birth control pills may still fail. Your doctor may suggest also using a barrier method, such as a condom or diaphragm, or an interuterine implant (IUD) to prevent an unwanted pregnancy.*

Drugs that affect hormone-based birth control methods are: carbamazepine (Tegretol, Tegretol XR), oxcarbazepine (Trileptal), phenytoin (Dilantin, Phenytek), phenobarbital, other barbiturates and primidone (Mysoline), and topiramate (Topamax).

Women with epilepsy who are being treated with these medications and want to prevent a pregnancy may have to use oral contraceptives containing a higher than usual hormone level. The current "low dose" pill or Norplant may not work, either. Standard injections of the DepoProvera hormone preparation may have to be given more often than the usual 12-week schedule in order to prevent pregnancy.

## Bone health

The effects of long term use of some antiepileptic drugs on women's bones is another recent discovery. Since most of these medicines have to be taken for many years, it is a major concern, especially for women

who've taken these medications since childhood and are approaching or have passed through menopause. Research shows that several drugs appear to reduce how quickly bones replace the minerals that give them strength, leading to thinner bones (osteopenia) and brittle bones (osteoporosis).

Phenytoin (Dilantin, Phenytek), phenobarbital, and primidone (Mysoline) seem to have the most effect on reducing bone density and increasing bone turnover. Carbamazepine (Tegretol, Tegretol XR, Carbatrol) and valproate (Depakene, Depakene XR and Depakote) have been linked to lower levels of serum calcium, a key factor in bone health.

*If you're taking certain epilepsy medicines to prevent seizures, ask your doctor about getting a bone scan to check on your bone health. Ask whether you should take extra calcium or other medicine to keep your bones as strong as possible.*

## Cognition and memory

Many women say it's one of the most upsetting side effects of epilepsy treatment: the feeling that their thoughts and speech have slowed down, that their grasp of challenging ideas isn't as quick as it used to be and that their memory is not as good as it once was. Paying attention and focusing on a task may be more difficult, and their reaction time may be slower. Unfortunately, both the condition itself (especially partial epilepsy that affects the temporal lobe) and the medications to prevent seizures may affect thinking and memory.

Phenobarbital, phenytoin (Dilantin, Phenytek), and valproate (Depakene, Depakote) have been shown to affect thinking processes, with phenobarbital having the greatest effect. Among the newer drugs, topiramate (Topamax) also appears to affect mental abilities, while gabapentin (Neurontin) and lamotrigine (Lamictal) seem to have less effects.

It's important to remember, however, that not all epilepsy drugs have been tested for these effects. What's known is the result of small studies on a limited number of drugs, usually the older drugs. Very little is known about the effects of the newer drugs. What's important is the effect that the medication you are taking has on you as a woman with epilepsy.

*If you feel that your memory or your mental abilities are being affected, check with your doctor. See if a different drug or some other change in your treatment might help.*

While treatment changes might make a difference, dealing with memory problems also means developing ways to compensate for them. If you don't remember appointments or plans for activities, keep a calendar and write everything down. If you forget to take meds, use a daily dose pill box from the drug store. If you forget the events of one day to the next, make it a habit to keep a journal. Fill it in each night to remind you of what you did that day, what you promised to do later, and what you plan to do tomorrow.

An unexpected benefit may be that in future years, if you keep your journals, you will have a unique record of your life and your children's lives, recorded day by day.

## Mood and emotions

Some women find that epilepsy meds affect their mood. If you start a new medicine and find that you are feeling unusually sad and unable to enjoy life, let your doctor know about it as soon as you can. Depression can be successfully treated, both with talk therapy and medication. It's not something you just have to put up with, whatever the cause.

*Epilepsy and depression can occur together, quite separately from the medications. Women are more at risk of this complication than men. If you find yourself feeling depressed, it's time to get help.*

## Drug interactions

When you're taking several medications at once, they can affect each other and affect you. Drug interactions, as they are called, may increase or decrease the effect each of them has. For example, as already discussed, some epilepsy meds can make hormone-based birth control methods less effective.

To avoid drug interactions, always tell all your doctors, dentists, pharmacists and any other health professional who is prescribing medication for you that you also take epilepsy meds. Even when you're buying over the counter drugs (or herbal supplements) for any reason, check with your pharmacist to be sure there's no possibility of interaction with your epilepsy meds.

Occasionally, an unexpected interaction with a common product can affect medication. Grapefruit, for example, interacts with carbamazepine (Tegretol, Tegretol XR, Carbatrol), increasing its concentration in the blood. Who would have thought something as ordinary as grapefruit juice could have such an effect? That's why it's worth telling

your health care team if something you eat or drink always seems suddenly to have an unusual effect on how you feel. It may just be that you've found a new kind of drug effect.

### Epilepsy Treatment: Surgery

If you have partial seizures (or partial seizures that spread to become major convulsions), and you've tried all the major epilepsy meds without success, your doctor may ask if you want to consider surgery. Most surgery for epilepsy means finding and removing a small part of your brain where partial seizures begin. The plan is: get rid of that small area, you'll get rid of the seizures that used to start there.

A lot of tests have to be done before epilepsy surgery. The doctors have to be sure that only one area of your brain is affected and that taking it out won't damage important things like speech or vision.

**How successful is surgery?** Lots of researchers have looked at this question. In general, they report positive results. One recent review, for example, showed that more than half (56 percent) of a group of people who had surgery for epilepsy had no more seizures afterwards. Another 26 percent were seizure free two years after surgery or five years after surgery. The remaining 18 percent continued to have seizures. Some studies report even higher rates of success. Success often depends on what part of your brain is affected. Generally, people whose seizures start in a small area of the right temporal lobe are more likely to be seizure free after surgery.

*Successful surgery doesn't necessarily mean that you can also give up the meds. While some people will be able to live seizure free and meds free, it takes time. People usually have to stay on medication for at least a year or two after surgery. Some people have to stay on meds longer than that if efforts to get off the meds leads to new seizures.*

**Surgery pros and cons.** The good news is that successful surgery boosts mood and, not surprisingly, improves quality of life. However, studies also show that between 25 and 40 per 100 people who've had the most common operation (to remove tissue in the temporal lobe) are left with memory problems. Memory problems may happen even if the operation stops the seizures. One day it may be possible to identify in advance those people who are at higher risk of memory difficulties after surgery.

Deciding whether or not to have epilepsy surgery is obviously a major step. The odds of success look pretty good, but there are less favorable consequences as well.

To find out more about surgery, its risks and benefits, methods and results, go to the Epilepsy Foundation's website and key in "surgery." And be sure to go over all the issues with your health care team before you make your decision.

### Epilepsy Treatment: Brain Stimulation

Researchers are working on new kinds of treatment to attack seizures where they happen—in the brain. They're doing it with small electrical charges designed to interrupt the surges of energy that cause seizures. Most of these efforts are still experimental, but one of them has been an approved treatment for several years.

**Vagus nerve stimulation (VNS)** is a treatment that may be tried when medicines alone don't stop seizures. It's also used to fight treatment-resistant depression.

VNS works like this: A small, thin, flat battery that looks like a pacemaker is implanted on the left side of the chest wall. In the same operation, thin wires (electrodes) are wrapped around a large nerve on the left side of the neck and threaded under the skin to link up with the battery implant. The nerve is called the vagus nerve and it leads into the brain.

The doctor then programs the battery to send out very small bursts of energy every few minutes. The energy travels along the electrodes, up the nerve and into the brain, where it works to interrupt any seizure activity that might be starting up. That's the theory, and for some people it works.

*Some people feel more positive about their lives after getting the VNS implant. They say it gives them a greater sense of being in control. That may be because, if they feel a seizure coming on, they can pass a special magnet over the battery. Doing this makes the battery send an extra electrical signal to the brain that they hope will prevent the seizure.*

### How successful is VNS?

VNS is unlikely to make people completely seizure free, but in many cases it seems to reduce how many seizures people have. It may also allow them to take a lower dose of medication. Common side effects of the VNS are hoarseness when the energy comes on, and an odd feeling in the throat.

To find out more about VNS, go to the Epilepsy Foundation's website, or call its Resource Center at 1-800-332-1000 for written materials, or go to the website of the manufacturer of VNS, [www.Cyberonics.com](http://www.Cyberonics.com).

### Epilepsy Treatment: Ketogenic Diet

It's a standard treatment for young children with very hard to control seizures. In children, it often works where other methods failed. However, it's a very rigid, very strict diet. As parents have discovered, just a few cookie crumbs or even use of sweetened toothpaste is enough to throw the diet off and cause a child to have a seizure. All food and liquid portions have to be weighed and measured to keep the diet in the right balance; that is, very high in fats, very low in carbohydrates, with little protein, few calories and no sugar.

If that combination sounds kind of familiar, it is. The popular Atkins diet also limits carbs and increases fat, but at much lower levels and without the strict limits on calories, protein and liquids.

*Would a ketogenic diet or even the Atkins diet work for adults with epilepsy? There have been one or two studies that suggest it might, but a lot more research has to be done before recommending that people try it for seizure control.*

To find out more, key in "ketogenic diet" or "Atkins" on the Epilepsy Foundation website. For information on the diet's use in children, also check [www.CharlieFoundation.org](http://www.CharlieFoundation.org) and [epilepsy.com](http://epilepsy.com).

### Complementary and Alternative Therapies

Many different ways of trying to prevent seizures have been proposed under the name of "complementary and alternative therapies." They include chiropractic manipulation, yoga, relaxation therapy, massage, art therapy, aromatherapy, music therapy, meditation, and even procedures derived from Indian and Chinese medicine. These and many more possible ways of keeping seizure free are described in a book published following a conference on these complementary and alternative therapies. The book is: *Complementary and Alternative Therapies for Epilepsy*, by Devinsky O, Schachter S, and Pacia. S (eds.) Demos, New York 2005.

Many of the proposed therapies appear to reduce stress, and since stress is, for some people, a seizure trigger, it makes sense to think that some of these therapies will help people. Most experts would say that if one or more seems to work for you, there's no reason not to continue with it, so long as you continue with the meds as well.

## Herbal supplements and vitamins

Can any of the hundreds of herbal supplements and vitamins help in the treatment of epilepsy? It's hard to say at this point, because there haven't been any large scale studies to test their effects on epilepsy. In very old lists of herbal preparations you'll find lots of claims that such products have a positive effect on epilepsy, but there's no research to support any of them.

What information there is so far comes from individual reports and those, unfortunately, are more likely to be about negative effects. The herb that people often use for depression (hypericum or St. John's Wort) may interact with some epilepsy meds and make them less effective. The affected drugs are: phenytoin (Dilantin, Phenytek), carbamazepine (Tegretol, Tegretol XR, Carbatrol) and phenobarbital.

There have also been reports that taking ginkgo and ginseng may increase the risk of seizures. Again, there have been no formal studies.

More is known about the effects of ephedra or ephedrine on epilepsy. These are adrenaline-like stimulant preparations derived from the Chinese herb Ma Huang. People with epilepsy are warned not to take products containing these stimulants, especially if they also contain caffeine. People who are taking the epilepsy meds Diamox, Topamax or Zonegran may be at higher risk of a reaction to ephedra.

*Taking a multi-vitamin, plus additional calcium and vitamin D for bone health, and folic acid if you are of child bearing age are all probably good ideas, but always check with your healthcare team before you start taking any preparations of this kind.*

For more information about alternative and complementary treatments, check out the Epilepsy Foundation website and [epilepsy.com](http://epilepsy.com).

## EPILEPSY AND SEXUAL FUNCTION



Some women with epilepsy—maybe as many as 25 to 49 of every 100—report some difficulties with sexual activity. It doesn't mean they can't have sex or gain pleasure from sex. What it does mean is that they have a variety of problems associated with it.

The most common ones seem to be lack of vaginal lubrication, painful vaginal spasms and pain during intercourse. Some women report difficulty in achieving sexual arousal and some say they have little sex drive. The reasons for these problems are not easy to pin down; however, discussing them with the doctor is a good idea. Treatments that may help are available.

Some women worry that they may have a seizure during intercourse. Although that risk is thought to be very low for the majority of women, being concerned about it may affect a woman's sex drive and level of arousal.

## PREGNANCY AND YOU

*“When I found out I was pregnant I was scared, even though my husband and I had started talking about having a baby about a year or two before we started trying. I ended up having a pretty good pregnancy. I had a couple of grand mal and some partials—besides that, it was uneventful. I had a grand mal when I was about 30 weeks. My doctor said as long as the baby’s still kicking, not to worry. The best advice I can give is: Take your vitamins and folic acid and enjoy being pregnant because there’s nothing like it. My son was born very healthy at 9 lb. 3 oz.”*



Many years ago, in some parts of the United States, men and women with epilepsy were not allowed to marry. That’s all in the past, of course, but even today, a woman with epilepsy may be told by well meaning but misguided people not to have children. Women with epilepsy also worry about the possible effects of pregnancy on their seizures, the effects of epilepsy and its treatment on the baby, and even their ability to care for a child. These concerns, plus other factors, may contribute to a slightly lower birth rate among women with epilepsy as a group.

Fortunately, research shows that the overwhelming majority of women with epilepsy who become pregnant have successful pregnancies and give birth to healthy children. The key to success is good pre-natal care, a well informed medical team, and lots of support from family and friends.

### First steps to a successful pregnancy

You and your spouse or partner have decided to start a family. You’ve talked with your doctor before you conceive to see if there should be any changes in your meds. If you haven’t had any seizures for some time, your doctor may suggest a reduction in dose, or even a trial period of weaning you off the meds before you get pregnant. Or, your doctor may suggest trying a different medication from the one you are taking during the pre-pregnancy period.

*Changes in treatment, whether they’re changes of dose or in the type of epilepsy meds you’re taking, should, if possible, take place before you become pregnant.*

## Second steps to a successful pregnancy

You've met with your health care team, and chances are you've already started taking your pre-natal vitamins, including folic acid to reduce the risk of spina bifida. Spina bifida is a birth defect in which the spine does not close. Valproate (Depakene, Depakote) and, to some extent, carbamazepine (Tegretol, Tegretol XR) appear to reduce naturally occurring levels of folic acid in the body. Low levels of this vitamin increase the risk of spina bifida. The spine is formed early in the child's development—before you even know you're pregnant. That's why doctors recommend taking extra folic acid (also called folate) throughout your childbearing years, no matter what other medication you're taking. Your doctor will tell you how much to take.

Some women with epilepsy have no difficulty getting pregnant. For others, it takes longer. If you have the cluster of conditions called polycystic ovary syndrome (POS), you may not ovulate regularly. You may need special help from a fertility specialist to improve your chances of conceiving.

### How pregnancy affects epilepsy

The good news is that most women (about two thirds according to the latest research) do not experience any changes in how many seizures they have while they're pregnant. Most will retain good seizure control.

Women who do have a change in how often they have seizures will be almost evenly split between those who have fewer seizures and those who have more.

Difficulty sleeping and missing doses of medication (sometimes because of worry about how the meds affect the baby) can make seizures more likely during pregnancy. Fortunately, seizures during delivery are rare (about three in a hundred deliveries).

*C-section rates tend to be higher in women with epilepsy, for unknown reasons. One explanation may be that fear of complications during a vaginal delivery leads both the mom and her doctor to opt for a C-section. However, a C-section is a major operation. Vaginal delivery usually has a quicker recovery period.*

The best way to prevent seizures during pregnancy is to keep a high enough level of medication in your blood. Making sure the level is right may take frequent blood tests and adjustments to the meds during pregnancy. As your blood volume increases (a natural part of being pregnant), your dose of seizure meds may have to increase also. That's a good reason to keep taking your epilepsy meds on time, keep follow up appointments and check with your doctor whenever an unexpected seizure occurs.

### Epilepsy meds and the baby

This is the million dollar question for all women who have epilepsy and become pregnant, Will the meds hurt the baby? What's the safest anticonvulsant? Should I continue to take epilepsy meds? What's worse, the meds or the seizures?

First, the risks. All women who get pregnant run a 2 - 3 per 100 births risk of having a baby with a major birth defect. Major birth defects include deformities of bone or major organs. Among women with epilepsy who are taking just one antiepileptic medication, the average risk is about 4 - 8 per 100 births.

*Cleft lip/cleft palate, heart abnormalities and spina bifida are the most common birth defects linked to use of epilepsy meds. The risk may be higher if a woman has to take more than one epilepsy drug or a higher than average dose to prevent seizures.*

Scientists are still trying to figure out whether it's the epilepsy or the meds that are linked to a higher rate of birth defects. In one study the rate for women with epilepsy who didn't take any epilepsy meds at all was about the same as for women who took just one (3.7 per 100 births vs. 3.5 per 100 births). However, most current information points to some increased risk with all the epilepsy meds that have been studied so far.

Still, seizures during pregnancy have risks, too. Generalized convulsions can interrupt breathing and the flow of oxygen to the baby. You don't want that. Generalized seizures can make a woman fall, and that's clearly a potential hazard. Partial seizures that cause blackouts and lost awareness of dangers in the environment have their own risks.

*Most women have to keep taking whatever medication best controls their seizures—during pregnancy and at other times. While the risks remain worrying, between 92 and 96 of every 100 women with epilepsy who become pregnant deliver healthy babies.*

## Searching for more answers

Why is it so hard to tell which meds are safest and which are most risky when taken during pregnancy? One reason is that it's hard to do research in this area.

To get new answers, the researchers have to recruit a lot of pregnant women with epilepsy who are taking different drugs, at different dosages, to make a comparison between them. Since most women with epilepsy have healthy babies, the researchers need a very, very large number of women to find any drug effect. All of this is difficult to set up, but new efforts are being made to tease out the answers.

## Pregnancy registries

A few years ago, concerns in the U.S. and overseas that very little was known about which epilepsy meds were safest for women and their babies led to the establishment of pregnancy registries.

Pregnancy registries invite women who have epilepsy to sign up once they know they are pregnant. They're asked to provide information about the medicines they're taking and, once the baby is born, to provide information about the health of their newborns.

In this way, a database can be built up to show whether there are differences in how epilepsy meds affect babies before birth. Hopefully, this information will help doctors prescribe the safest drugs for women in the future.

*To find out more, or to register with the North American Pregnancy Registry at Massachusetts General Hospital in Boston, call 888-233-2334 or visit their website at [www.aedpregnancyregistry.org](http://www.aedpregnancyregistry.org).*

## Early results from the registries

Some of the registries worldwide are now reporting early results. So far, valproate (Depakene, Depakote) and phenobarbital have been found to increase the risk of major birth defects. Valproate risks appear to be around 6.1 per 100 births, rising to as high as 16.7 per 100 births in one report. The rate for phenobarb is around 6.5 per 100 births. One study has linked lamotrigine (Lamictal), one of the newer drugs, to a slightly increased risk of cleft lip/cleft palate at higher doses. In one report, carbamazepine (Tegretol, Tegretol XR and Carbatrol) appeared to have the lowest risk among the small number of drugs studied. There may also be a link between use

of valproate during pregnancy and some IQ and developmental delay in infants.

However, differences in how these studies were set up still makes it very difficult to make comparisons between them. Newer results may be different. The fact is, until more women sign up with pregnancy registries worldwide, doctors will not know for sure which drugs are safest and which are most risky during pregnancy. The best anyone can say now is that the risk is generally low and that having seizures when pregnant also has risks for the baby. Keeping healthy and keeping all doctor appointments during pregnancy is currently the best advice for women with epilepsy. And remember, the odds of having a successful pregnancy and a healthy baby are overwhelmingly in your favor.

### **Will the baby have epilepsy?**

Epilepsy has many known causes, including developmental problems before birth, severe infections affecting the brain during childhood, a major head injury, lack of oxygen to the brain sufficient to cause damage, and inherited genes or changes in genes that produce seizures.

While it's hard to predict genetic risks, statistics offer some answers. The risk of developing epilepsy in the general population is about 1 per 100 babies. The risk of a child developing epilepsy if the mother has it is about three times that risk, at 3 per 100 babies. That means the baby has a 97 percent statistic in its favor. If both parents have epilepsy, or if there's a strong family history, the risk goes up substantially. But even then, it's still much more likely that the child will not develop epilepsy.

*If you have a family history of epilepsy—that is, if several members of your immediate or extended family have had seizures at some time or another—check with a genetic counselor to get a better idea of what the risks may be in your case.*

## **MENOPAUSE: WHEN TOMORROW COMES**



It's years in the future, right? Why worry about it now? Well, that may be fine if you're in your twenties or thirties, but if you're in your forties, you may want to give it some thought.

The fact is, menopause may come earlier for women with epilepsy. Nobody knows why, but statistics show that women who have epilepsy stop ovulating and having periods some years before other women do. It's a gradual process. Monthly periods slow down and stop while the level of female hormones, especially estrogen, drops.

Menopause is a time of change for all women—it used to be called the change of life. For women with epilepsy the name has extra meaning. Some women have more seizures than usual around the time of the menopause, only to find that their seizures decrease in later years. Other women experience no change.

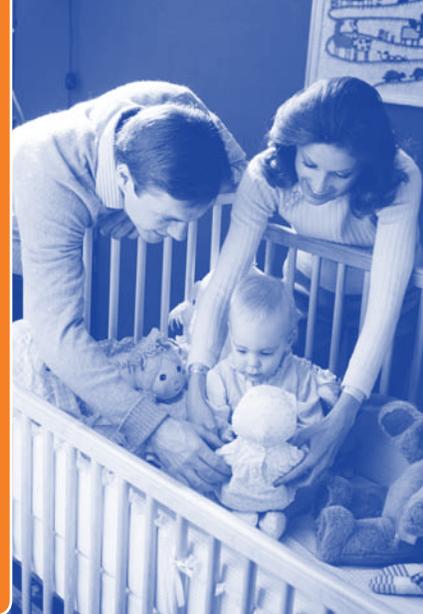
*Use of hormone replacement therapy to reduce some of the uncomfortable symptoms of menopause (hot flashes, for example) seems to have the unfortunate effect of increasing seizures. This may be because hormone replacement therapy replaces estrogen, and estrogen is known to increase the risk of seizures.*

The key to getting through this period in your life successfully is: keep track of changes in your body and your seizures, and check with your doctor about what is going on.



## SAFETY AND YOU

*"I had a seizure when my daughter was six months old. I woke up on the floor. She was on the bed. After that I set up a protocol. If my husband is at work late, my parents come over. When I'm cooking, I make sure she is in another room and my husband is there."*



Everyone lives with risk. But being a woman, being a mom and having epilepsy can increase the risks of an accident or injury if you have a seizure. And when you have young children, their safety may be affected, too. The following tips to reduce the chances of injury will probably be most helpful to women and moms who continue to have some seizures.

### Safer kitchens

- The average kitchen is full of little hazards that can add up to big trouble if you suddenly fall or lose awareness of where you are or what you're doing. Here are some suggestions to try: Slide containers of hot food along the counter instead of picking them up and carrying them. Even better, use a serving cart when taking hot foods or liquids from one room to another.
- Use plastic dishes and cups with lids (like commuter cups) to prevent cuts or burns from spills of hot liquid.

- Whenever possible, use a microwave oven for cooking.
- Use the back burners when you have to use the stove.
- Take the burner controls off gas or electric stoves when they're not in use.
- Wear long heavy duty oven mitts or holders when reaching into a hot oven.
- Wear rubber gloves when handling knives or washing china dishes and glassware in the sink. Use plastic rather than glass as much as possible.

### Safer bathrooms

Just as kitchens have hidden dangers if you suddenly lose consciousness, so do bathrooms. Here are a few ways to make them safer:

- Hang bathroom doors so they open outwards. Then, if someone in the bathroom falls against the door, it can still be opened.
- Put extra padding under carpeting in the bathroom. Those tile floors are hard to fall on.
- Hang an "occupied" sign on the outside handle of the bathroom door instead of locking it.
- Always check that the bathroom drain in the shower or tub is working properly before taking a shower or bath.
- If you fall during seizures, consider using a shower or tub seat with a safety strap.
- Keep water levels in the tub low.
- Consider using a hand held shower nozzle while seated in the tub or shower instead of standing.

- Set the hot water temperature low so that you won't be scalded if you should lose consciousness while hot water is running.
- Avoid using electrical appliances such as hair dryers or electric razors near water in the bathroom.

### Safer living areas

Even your living room can be risky if you suddenly lose consciousness. If this describes you, consider the following:

- Carpet the floors in your house or apartment with heavy pile and thick under padding.
- Pad sharp corners of tables and other furniture; look for furniture with rounded corners when you shop.
- Put guards around the fireplace and close fireplace screens when a fire is burning.
- Don't smoke or light fires when there is no other adult in the house.
- Don't carry hot fireplace ashes or lighted candles through the house.
- Avoid space heaters that can tip over.
- Use only curling irons or clothing irons that have automatic shut off switches.
- Use chairs with arms to prevent falling.
- Make sure motor-driven equipment, such as a lawnmower, has a "dead man's" handle that will stop the machine if your hand releases normal pressure.

## Safer recreation

Exercising is good for your health and mood. Remembering just a few safety tips will make it even better.

- Take frequent breaks, stay cool, and save your greatest exertion for the coolest part of the day.
- Exercise on soft surfaces if possible—surfaces such as grass, mats, or wood chips.
- Think about the risks before taking up sports which could put you in danger if you were suddenly to black out or be unaware of what you were doing.
- Wearing a life vest is always a good idea when you are on or close to water.
- Swimming can be safe and fun for everyone, but if you have seizures, don't swim alone. (Of course, no-one should swim alone!)
- Tell lifeguards and friends you swim with what kind of seizures you have, how to recognize them, and what to do if you have one. Make sure they swim well enough to help you if you need it.
- Wear head protection when biking or whenever there's risk of head injuries from falls.
- If you ski or hike, go with a buddy. You may need someone to get help if you have a seizure in a remote area.
- Always fasten the safety strap and hook when riding the ski lift.

## EMPLOYMENT AND YOU

*"I've been seizure free for four years and able to hold down a job. Last time I had a seizure in the office I was forced from the job. Now I've had a job for two years. I coordinate it with child care."*

*"I work for an obnoxious institution. It has a lot of prejudiced people in it though they're not supposed to show it."*

*"I wait until I feel comfortable with people. I hold back as long as I can."*

*"I was never honest about it. I'm not working now. When I go back I won't tell anyone until it becomes an issue."*



Women with epilepsy whose seizures are under reliable control can work at just about any job. If seizures continue, they can work successfully in positions where having seizures will not interfere with the basic responsibilities of the job. That's the yardstick set up by the Americans with Disabilities Act. The Act also forbids employers from asking about disabilities or health conditions before the position is offered.

Being successful in a job depends on a lot of things. One is qualifications. Another is how you feel about the work you're doing. And a third, for women with epilepsy, is how comfortable you feel talking about epilepsy and seizures, and whether you can help other people understand.

Sometimes, if you have excellent seizure control, you may decide that you don't need to discuss it at all. And that's your decision.

Women who do decide to talk about it say that describing epilepsy in a direct, friendly way that minimizes any possible disruption at work is the way to go. For example, a woman might say: "You know, I hardly ever have seizures, and if I do, they only last a minute or two. I recover very quickly. Here's what you can do—but I really don't think you'll have to."

If disclosure is your plan, explain how long you've had epilepsy and how well it's controlled. If you drive, mention that, too. Point out that research shows the longer a person is free of seizures the more likely it is that they'll stay that way. Your confident attitude about seizures and epilepsy will make people feel comfortable. It will encourage them to ask you questions and should help put any fears they might have to rest.

*If you don't have convulsive seizures, say so. People tend to think that having epilepsy means having convulsions all the time and they'll be relieved to hear that's not likely to happen in your case. Emphasize that even if you do have a seizure, of any kind, it's not going to affect your ability to do the job.*

Talking about epilepsy, either at the beginning of your employment (after the job offer) or once you've been at your job for a while and you're accepted within the workplace, may help protect you legally if later on there should be an effort to fire you because of having epilepsy. For more information about employment, epilepsy and the legal issues that may be involved, go to the Epilepsy Foundation's website and key in "employment" or "job discrimination."

## DRIVING AND YOU

*"Driving is always an issue for everyone. It's hard not being able to drive when you have to transport kids."*



One of the most challenging aspects of having epilepsy and still having seizures is not being able to drive. Fortunately, many women have good seizure control and can qualify to drive. How long you have to be seizure-free varies among the states, but is usually between six months and a year.

In some states there are no set limits. What you usually have to do then is get a statement from your doctor saying your seizure control is reliable and that you are safe to drive. Other driving rules may mean you have to renew your license more often, or get new letters from the doctor from time to time.

In some states, your doctor is required to inform Motor Vehicles if you've had a seizure. This usually leads to suspension of your license until you can show you have been seizure free for a required period of time. Most states, however, operate on the honor system. That means that if

you have a seizure, you're expected to notify the Department of Motor Vehicles and voluntarily give up your license. And most people do.

*A few states consider different types of seizures when deciding whether or not someone with epilepsy can drive. If you have partial seizures that don't affect your movement or awareness, you may be able to get a license. That's not the case nationwide, however.*

Sometimes, people are tempted to drive even though they've been having seizures. This is a big mistake. Not only does it risk the driver's life, but it puts others at risk as well. If you can't drive because of epilepsy, try to put together a community of support in which you or your children (or both) get rides in return for your paying for gas or providing some other valued neighborhood service. Or check out whether your community provides transportation for people with disabilities.

## RESEARCHING YOUR ISSUES

*"I use Google for information. It makes me more confident in dealing with doctors. I once met the founder of Google. It's meant so much to me I cried when I thanked him."*



We live in a world of information, including information about epilepsy and women's experience of epilepsy. The trick is to find it.

Your health care team is the first stop for information about your epilepsy. Another is using Google or Yahoo, the Internet's primary search engines (just key in "epilepsy.") Another important source of info should be the Epilepsy Foundation—either the local Foundation in your community or the national office.

The national office provides physician-reviewed information through printed materials (call 1-800-332-1000) and, increasingly, through its website ([www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)).

Your local Foundation can give you referrals for care, printed and video materials, offer discussion groups, and provide information about special meetings and conferences in your community.

The Epilepsy Foundation's website offers in-depth discussion of just about every issue covered in this publication. Just key in the topic you want to research, and the search engine will point you in the right direction.

The Foundation's website also offers women with epilepsy a way to connect with other women. Its unique set of online communities on parenting, childbearing, relationships and other aspects of living with epilepsy can be found in the e-communities section of the site.

*Epilepsy USA* and *BetweenUs* are Epilepsy Foundation print and online publications that provide a mix of features and hard news. *BetweenUs* focuses exclusively on the experience of women with epilepsy and relevant research. The website also offers a special section entitled Women & Epilepsy Initiative.

Other websites with information about epilepsy include [www.epilepsy.com](http://www.epilepsy.com), (which, like the Foundation's site, covers many issues related to living with epilepsy as well as research developments), and the website of the American Epilepsy Society ([www.aesnet.org](http://www.aesnet.org)).

The American Epilepsy Society is a professional society of scientists, neurologists, and other medical professionals who specialize in epilepsy treatment and conduct epilepsy research. Its major publication is *Epilepsia*, a peer-reviewed medical journal which carries reports of scientific research from around the world.

Society publications available online include its newsletter and *Epilepsy Currents*. While the newsletter reports mostly on Society activities, there are also articles on various aspects of epilepsy. *Epilepsy Currents* contains summaries of important research and commentary by

experts on what the research may mean for future research and treatment.

Other websites with information about epilepsy and treatment include those of pharmaceutical firms that produce epilepsy meds. These sites include the FDA-approved prescribing information on the firms' products, including information on side effects.

PubMed is a website sponsored by the National Library of Medicine and the National Institutes of Health ([www.pubmed.gov](http://www.pubmed.gov)) PubMed provides a way to search medical journals. PubMed articles on epilepsy from a variety of journals may also be found on the [epilepsy.com](http://epilepsy.com) site.

The National Institute of Neurological Disorders and Stroke (NINDS) is responsible for most federally-funded epilepsy research. Its website ([www.ninds.nih.gov](http://www.ninds.nih.gov)) contains news of research, and summaries of workshops and conferences.

The journal *Neurology* ([www.neurology.com](http://www.neurology.com)) offers abstracts of current and past articles on many aspects of neurological disorders, including epilepsy.

*Epilepsy & Behavior* is similarly a professional journal. It focuses on the psychological and social effects of epilepsy and how those issues are being treated. Its articles can be found online at [www.sciencedirect.com](http://www.sciencedirect.com) and on [epilepsy.com](http://epilepsy.com).

