

# Talking to Your Doctor

Information for Patients and Families

# EPILEPSY



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**EPILEPSY  
FOUNDATION**®



**epilepsy**  
therapy project

Stronger Together

This pamphlet is intended to provide basic information about epilepsy to the general public. It is not intended to be, nor is it, medical advice. Readers are warned against changing medical schedules or life activities based on this information without first consulting a physician.

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# TALKING TO YOUR DOCTOR

## Talking about partnership

Good medical care for epilepsy happens when the patient, the family, and everyone on the health care team work together as partners.

Being a health care partner means asking questions and finding out as much as you can about epilepsy as it affects you (or your child), and about the treatment your doctor has ordered for you.

Sometimes it's hard to ask the right questions and make your feelings known. That's what this pamphlet is all about.



## Talking about epilepsy

When you have questions about epilepsy, its treatment, and its other effects, write them down on a list.

Pick out two or three that are most important to you and take them with you next time you see your doctor.

And whenever your doctor or someone else on your health care team uses a word you don't know, stop and ask him or her to tell you what the word means.

If there are several things you want to talk about and there just isn't time at your regular appointment, tell the doctor you'd like to make another appointment so you can go over them in detail.

Or, when you are setting up the appointment, ask the nurse to set up a longer one for you.

## Talking about your health care

If you are going to be treated at a clinic, or through a group practice or a pre-paid health plan (such as an HMO) where several doctors provide care, the following questions should help you get a clearer idea of what to expect:

- Who do I see for general medical problems?
- Will I be seeing the same doctor every time?
- Is my doctor a neurologist? If I wish, can care for my epilepsy be in the hands of a neurologist?
- Are there any limits on how many tests (EEG's, scans, blood tests, etc.) that this plan will pay for?



- If I see different doctors or other specialists, who is the person overseeing and coordinating my total care? Who is the person I go to with my questions?
- How do the doctors share information about my medical history and treatment?
- Who do I call if I have a seizure?
- What happens if I have a seizure in public and someone calls an ambulance and I end up in the emergency room? Does this plan cover that?
- Who do I call to get my medicine renewed?

## Talking about treatment

If you (or your child) have epilepsy, your doctor will prescribe regular use of medicine to prevent seizures.

Here are some questions you may want to ask:

- What do I do if I forget to take my medicine?
- What side effects does this drug have? What should I watch out for?
- Why did you choose this drug? Are there other ones that I could take?
- How often will I need blood or other tests?
- Is it all right for the pharmacist to give me a generic drug, or should I have a brand-name drug?
- Are there any foods, drinks, or activities that I should stay away from while I'm taking this medicine?

If you decide you want to find out more about epilepsy or the medications you've been given, check out the Epilepsy Foundation's National Epilepsy Resource Center on its web site ([www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)) or ask your doctor for suggestions about reading materials.

If you are unsure about whether what you find out applies to your type of epilepsy, check with your doctor.

## Talking about seizures

If you've had seizures or side effects since your last visit, or if other things have happened that seem unusual, tell the doctor about them.

Sometimes people don't want to say they're not feeling well, or that they've been having seizures. They don't want to disappoint the doctor. Perhaps they're even afraid he or she'll be upset or angry because the treatment isn't working.

But unless the doctor knows about the seizures or side effects, he or she can't make the changes in treatment that might prevent them.

Sometimes people tell their doctors that they've been seizure free, thinking that only big seizures matter.

They forget to mention that they've been having little blackouts or odd feelings. But it's just as important for your health care team to know about the black-outs, auras, or little seizures.

It may also make a difference in the kind of medicine you take.

## Talking about your options

When seizures or unpleasant side effects from the medicine are affecting your life, find out if there are other things that you might try.

You can explore them with your health care team by asking:

- Would I do better on a higher dose of just one medicine? Is there a different medicine I could try?
- Are there any new drugs for epilepsy that might work for me?
- Should I have a blood level test to see if the dose I am taking is at the right level in my blood?
- Should I see a neurologist or go to a special center for more testing?
- Would the ketogenic diet work for my child? Is there a dietitian who has experience with the ketogenic diet associated with this plan?

- Do I have the kind of epilepsy that might be treated by surgery?
- What are the risks and the benefits of surgery?
- Would the VNS (vagus nerve stimulation) device help me (or my child)?

## Talking about other treatments

Many people today take multi-vitamins, herbal remedies, diet supplements and other kinds of products. People with epilepsy often wonder whether any of these would be helpful in treating seizures.

In thinking about this, remember that just because something is “natural” does not mean it is safe. Plants can be poisonous and so can large amounts of some vitamins.

Some herbal products may affect your epilepsy medicines, as well.

So it's always a good idea to tell your health care team (and pharmacist) about any herbal products or vitamins or any other health food treatment that you are taking or planning to take.

Questions include:

- Will this product have any effect on the epilepsy medicine I'm taking?
- Will vitamins help control my seizures?
- Is this treatment safe for someone with epilepsy?



## Talking about ending treatment

When seizures have been completely controlled for a long time, there will be different questions:

- What are the risks and benefits of a child coming off medication? What about adults?
- Have I (or has my child) been seizure free long enough for my doctor to start slowly stopping the medication?
- How long will it take to reduce the dose completely?
- What are the chances of staying seizure free off the medicine?
- What happens if the seizures begin again?
- Will they be different from before? Will the medicine work the same if I have to go back on it?



**Important:** Do not try to stop or reduce your medicine on your own. Stopping medicine suddenly or reducing the dose too quickly can cause seizures that are hard to stop. Your health care team will help you plan the safest way of making this important change in treatment.

## Talking about seizure management

Ask your doctor what should be done when your child has a seizure. Ask what you should tell members of your family to do if you have a seizure:

- What's the best first aid for my kind of seizure?
- Should the paramedics or an ambulance be called every time?
- What would be an emergency for me or my child?
- How long should I wait before calling an ambulance if the seizure goes on longer than usual?
- Are there any in-home treatments for clusters of seizures, or seizures that last longer than usual, that I should know about?
- Should I let my doctor or nurse know whenever I have a seizure, or just at check ups?

For people with a vagus nerve stimulation (VNS) implant:

- What should I do if I feel a seizure coming on?
- What should my family do if I have a seizure?

## Talking about how you feel

Many people with epilepsy have memory problems, depression, or anxiety. These experiences may be related to the epilepsy or the type of medicine that is being taken.

Learning disabilities and problems with attention, thinking or behavior may also be caused by the same brain condition that is producing seizures, or the medicines that control them.

So if you or your child are having any of these problems, tell your doctor or nurse.

You might ask:

- Could the fact that my child is not doing well at school be caused by the medicine he or she is taking? Or is it more likely due to the seizures or a learning disability?
- If it might be the medicine, is there another medicine that we could try?
- Could the medicine be making my child act up? Or is this all part of what's causing the seizures?
- Should I have my child tested for learning or attention problems, and can you tell me where I could get this done?

## Talking about what others think

Some types of seizures produce behavior that other people think is deliberate acting up.

A complex partial seizure might make a child or an adult wander around as if in a daze, or be unable to answer when spoken to, or do other things that don't make sense to other people.

If something like that happens at school or at work, a letter from your doctor explaining that what happened was caused by a seizure and not done on purpose might be helpful.

## Talking about pregnancy

If you are a woman who is taking medication to prevent seizures, and you want to start a family, make an appointment to tell your doctor about your plans before you become pregnant.

Questions to ask include:

- Should I continue to take my current medication while I am pregnant?
- Are there any changes in my treatment that should be made?
- Would having seizures hurt the baby?
- Are there any risks to the baby from the medicine I'm taking now?



- Is there anything I should be doing to reduce any risk? Should I be taking folic acid?
- Will you be checking with the doctor that I'll be seeing during my pregnancy?
- How often do you want to see me while I am pregnant?
- Will I be able to nurse the baby if I am taking medicine for epilepsy?

## Talking about a second opinion

Seizure disorders may be treated successfully by family doctors, pediatricians, and internists.

But if seizures keep happening, even with treatment, or if you're having a lot of unpleasant side effects, it is a good idea to see a neurologist.

A neurologist is a doctor with special training in how to treat epilepsy and other kinds of brain disorders.

In looking for another doctor, whether through referral from your own physician or from some other source, you will want to know:

- Is he or she a board-certified neurologist?
- Is he or she a neurologist with a special interest in epilepsy? In children with epilepsy?



## Talking about an epilepsy center

When seizures are very hard to control, you may want to ask your doctor about going to a special center that specializes in epilepsy, or you may decide to look for one on your own.

Epilepsy centers offer different kinds of services and staffing. Before making a decision, you may want to ask:

- What services or tests do I need, and does this center offer them?
- Does the staffing include the kind of medical specialists I need? Are there others (for example, psychologists or social workers) to help with special problems?
- Does this center help people with referrals to services offered in other places, such as helping people who want to find jobs?
- Does the center provide patient education? How does it help patients and families with problems related to epilepsy?
- How much does it cost? Are fees fixed or is a sliding scale used?
- What does the center do to help patients pay for the services?

When you have found (or been referred to) a new doctor or treatment center, you will want to ask your doctor to send copies of your records to the new doctor who will be treating you.

Treatment of epilepsy is getting better all the time, but there are still no guarantees except one — that people living with epilepsy have the most to gain from learning as much as they can about it. In that way, you become a full partner in your own treatment or your child's treatment.

## About the Epilepsy Foundation

The Epilepsy Foundation, a national non-profit with 47 affiliated organizations throughout the United States, has led the fight against seizures since 1968. The Foundation is an unwavering ally for individuals and families impacted by epilepsy and seizures. The mission of the Epilepsy Foundation is to stop seizures and sudden unexpected death in epilepsy (SUDEP), find a cure and overcome the challenges created by epilepsy through efforts including education, advocacy and research to accelerate ideas into therapies. The Foundation works to ensure that people with seizures have the opportunity to live their lives to their fullest potential. For additional information, please visit [www.epilepsy.com](http://www.epilepsy.com).

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# Notes

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