



Talking With Your Doctor

Information for Patients and Families



TALKING WITH YOUR DOCTOR

Talking about partnership

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

Being a health care partner means asking questions, finding out how epilepsy affects you, and understanding the treatment your doctor recommends.

This booklet is designed to help you ask the right questions, make your feelings known, and get the best care possible.



TALKING ABOUT EPILEPSY

It's important to keep track of questions you may have regarding the treatment of epilepsy and how it can change one's life.

Choose two or three questions that are important to you and take them with you the next time you see your doctor.

Make sure you fully understand your doctor's recommendations. Whenever they or someone else on your health care team uses a word you don't know, stop and ask them to explain it further.

If there are several things you want to talk about and there 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 schedule a longer one for you.

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 will 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 not, can a neurologist be my primary physician when it comes to my epilepsy?
- Are there any limits on how many tests (EEG's, scans, blood tests, etc.) this plan will pay for?

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

- 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 medication renewed?

TALKING ABOUT TREATMENT

Regular use of medication is a common way to prevent seizures.

Here are some questions to ask when starting a new medication:

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

To learn more about epilepsy and the medications you've been given, visit efmn.org or ask your doctor for suggestions about reading materials.

If you have questions or concerns about something you read make sure to discuss it with your doctor at your next visit.

TALKING ABOUT SEIZURES

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

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 will be upset or angry because the treatment isn't working.

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

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

They forget to mention that they've been having little blackouts or odd feelings. 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 medication you take.

TALKING ABOUT YOUR OPTIONS

When seizures or unpleasant side effects from medication are affecting your life, ask about other treatment options.

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

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

- Can my epilepsy be treated with surgery?
- What are the risks and benefits of surgery?
- Would I benefit from a neurostimulation device like the Vagus Nerve Stimulator (VNS) or Responsive Neurostimulation (RNS)?

It's important you let your doctor know about all vitamins, herbal remedies, diet supplements, and other health-related products you take as they may have an effect on your seizure medication.

TALKING ABOUT ENDING TREATMENT

Questions to ask when you've been seizure-free for an extended period of time:

- What are the risks and benefits of coming off medication?
- Have I been seizure-free long enough to begin reducing my dosage?
- How long will it take to get off medication completely?
- What are the chances of staying seizure-free without any medication?
- What happens if my seizures begin again?
- Will my seizures be different than before? Will the medication work the same if I have to go back on it?

Do not stop or reduce your dosage on your own. Stopping medication suddenly or reducing the dose too quickly can have negative health effects. Your health care team will help you plan the safest way of making this important change in treatment.

TALKING ABOUT HOW YOU FEEL

Many people with epilepsy have memory problems, depression, or anxiety. This can be attributed to the person's epilepsy or the type of medication they're taking.

Learning disabilities and problems with attention, thinking, or behavior may also be caused by the same brain condition that is producing seizures, or the medication that controls them. It's especially important to be aware of these potential problems in children with epilepsy.

If you think you or your child are experiencing any of these problems, some questions to ask your doctor are:

- Can medication be the reason for poor school performance or learning issues? Or is it more likely due to the seizures or a learning disability?
- If it might be the medication, is there another we could try?
- Can behavior problems or mood swings be attributed to medication? Or is this all part of what's causing the seizures?
- What tests are available to determine learning and attention problems?

TALKING ABOUT WHAT OTHERS THINK

Some types of seizures produce uncontrollable behavior that others may think is deliberate.

A focal impaired awareness seizure can make a child or adult wander around as if in a daze, or be unable to answer when spoken to.

If something like this happens at school or work, a letter from your doctor explaining the reason for it may be helpful.

TALKING ABOUT SEIZURE MANAGEMENT

Make sure to talk with your doctor about the steps that should be taken after a seizure occurs.

- What's the best first aid for my kind of seizure?
- Should the paramedics or an ambulance be called every time?
- What would be considered an emergency?
- How long should I wait before calling an ambulance if the seizure lasts longer than usual?
- Are there any in-home treatments for cluster seizures or seizures that last longer than normal?
- Should I call and let my doctor know every time I have a seizure, or just at check-ups?

For people with a neurostimulation devices (VNS or RNS) implant:

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



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 with your doctor before becoming pregnant.

Questions to ask include:

- Should I continue to take my current medication while 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 medication I'm taking?
- If so, is there anything I should be doing to reduce these risks? Should I be taking folic acid?
- What information should I be sharing with my pregnancy care team?
- How often should I come in for appointments while pregnant?
- Will I be able to nurse the baby if taking medication for epilepsy?



CONSIDERING A SECOND OPINION

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

However, you should consider visiting a neurologist if your seizures continue or you're experiencing unpleasant side effects from medication.

When looking for another doctor, whether through a 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?

CONSIDERING AN EPILEPSY CENTER

Epilepsy centers provide a team approach to epilepsy care and offer a greater range of tests and treatment options.

If you're having trouble maintaining seizure control ask your doctor about epilepsy centers near you.

Each epilepsy center offers different services and specialists, so before deciding make sure to ask:

- What services or tests do I need? Does this center offer them?
- Does the staffing include the kind of medical specialists I need? Are there specialists (for example, psychologists or social workers) to help with additional problems?
- Does this center help people with referrals to additional services?
- 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?

If you decide to switch to an epilepsy center for treatment, make sure to have your doctor send copies of all your medical records.

ADDITIONAL RESOURCES

For information on seizure first aid, seizure types, treatment options, driving, SUDEP, safety tips, additional resources, and more, please visit the following:

- efmn.org
- epilepsy.com

24/7 SUPPORT

Call 800.779.0777 or info@efmn.org during business hours or 800.332.1000 (en Español: 866.748.8008) after hours with any questions or concerns.

This booklet 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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