

You and Your Health Care Team



Getting good medical care for epilepsy and seizures is a team effort, and you are the most important member of the team. You want answers, and your doctor needs information from you, too! What you tell your doctors and other health care providers is critical – it helps them sort out if you have seizures and what type of epilepsy you have. It also helps them choose which medicine may be best for you.

Do your part by telling the doctor or other health care provider:

- Your history – when and what happened and when you first noticed seizure symptoms
- About your seizures or events
- What medicines you take and any allergies
- About any side effects or other health problems
- How epilepsy affects you and your family
- Your priorities and questions - what's bothering you most



Take an active role in your health care

The traditional approach to medical care is that the doctor asks questions, the patient answers them, and the doctor recommends the treatment. But there's another approach, called patient-centered health care, where the patient and family play a more active role on the health care team.

Making sure you get patient-centered care is especially important when you are coping with a chronic health problem like epilepsy. That's what managing your epilepsy is all about.

Be prepared - Share important information

Epilepsy is often “invisible” to doctors, since seizures don't usually happen during an office visit. That means your doctor is relying on you to say what your seizures are like, how often they happen, and how they affect your life.

Keep a seizure diary to track any seizures or other symptoms you have. Take it to your appointment. When you track your seizures and how you are feeling, you're bringing in critical data that your team will need.

Make a list of all the medicines you take – including any vitamins or herbal remedies – and the amount you take.

Be ready to talk about anything that has changed since your last visit, like a new job, school problems, or changes in how you feel. Tell them if you feel nervous, sad, depressed, or are having changes in sleep, appetite, or sex drive. This may make you uncomfortable, but your health care team is there to help. They want to know how you're doing.



Remember, your doctor can only help if you share all of the relevant information, including if you:

- Don't always take your medicine
- Are having side effects or aren't feeling well
- Don't like your treatment plan
- Are still having seizures
- Want a second opinion from a different doctor

Learn what to do

For your treatment to work, you'll need to learn new skills — like how to take your medicines, make lifestyle changes, teach others seizure first aid, and prevent injuries. If seizures are not responding to medicines, your health care team may want you to try a special diet or consider testing for surgery or a device.

All this can be overwhelming at times. If you are new to seizures and epilepsy, start with the basics.

- Think about what you need now to get diagnosed properly, stay safe, and follow your treatment plan. Remember, treatment will only work if you can follow the plans.
- Next think about how epilepsy is affecting you and your family. Ask for help. You may need to learn new skills here too — how to talk about epilepsy or cope with the impact it may have on relationships, work, family, and social life.



Ask questions

People work together best when they know what to expect from each other. Talk to your doctors and health care providers about your role, their role, and what to expect from each other.

Also talk to your doctors about new ideas or treatments, other people who should be part of your team, and any other concerns you may have. If you're still having seizures after trying at least two seizure medicines, ask to see an epilepsy specialist.

Discussions take time. You may need to set up special appointments to talk to different people about your questions, concerns, and next steps in your care.

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Stay in touch

Be sure to keep all follow-up appointments. Write them in your calendar, put a note on your fridge, or set a reminder on your phone – whatever will help you remember.

If you don't have time to talk about everything that's on your mind, make another appointment. It's also a good idea to ask what to do if you have questions after you get home. Find out who you can call and when.

You may want to contact your provider in situations like these:

- If you start having more seizures, or you have seizures that are different from your usual pattern
- If you have unexpected side effects, or bad side effects
- If you have an unexpected problem that develops after surgery
- When you're sick with another illness
- When you're taking a new medicine
- Before surgery or procedures for a different health problem



Getting urgent help

There may be times when you should not wait for a routine call back. Ask your doctor who to call in an emergency, and how to reach them.

- If the problem is urgent and you can't reach your own doctor, you may need to talk to a different doctor or go to an emergency room or urgent care clinic.
- If you have seizures that last too long or happen too close together, someone should call 911 for emergency medical help.

Once your health care team gets to know you, ask for help developing a seizure response plan. This will help you and others have the right information at home – what to do for seizures, when seizures could be an emergency and if anything can be done at home to prevent an emergency. Sometimes a rescue therapy (medicine or device) may be recommended for people who may have long or cluster seizures)

Visit epilepsy.com/managing to learn more about seizure emergency and seizure response plans.