

✓ Quick Read Series



Treatment & You



Information
for people
with seizure
disorders



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This pamphlet is designed to provide general information about epilepsy to the public. It does not include medical advice. People with epilepsy should not make changes in treatment or activities based on this information without first consulting a physician.

SEIZURES AND EPILEPSY

A seizure is a sudden change in awareness, actions, or feelings that you can't control.

Having a seizure is a sign that something has affected the electrical system that makes your brain work.

For a minute or two, it has changed the way your brain controls the rest of your body.

- It could be because of an old head injury.
- It could be because of something that happened before you were born.
- It could be because of a bad infection or a substance that affected your brain.
- It could be for no reason that anyone is able to discover.

The medical name for seizures caused by electrical changes in the brain is epilepsy. Some people call epilepsy a seizure disorder.

TYPES OF SEIZURES

One kind of seizure makes you fall and shake. That's the kind of seizure most people think of when they hear the word "epilepsy."

There are other kinds, too. One can make you black out for a minute or two. To other people it would look like sleep walking or being in a kind of trance.

Another kind of seizure can make you stop and stare for a few moments.

Seizures can make you feel strange and unable to speak. Seizures can make the things around you feel or sound strange, just for a short time.

Some people with epilepsy have just one kind of seizure. Other people have more than one kind.

TREATMENT TIP

- Don't let yourself run out of medicine. Renew your prescription when you have about one week's supply left.

PREVENTING SEIZURES

Epilepsy is treated with medicine to prevent any more seizures.

Doctors call these medicines anticonvulsants or antiepileptic drugs (AEDs).

Most people who take the medicines will have fewer seizures. Many will have none at all.

Epilepsy medicine doesn't cure epilepsy, unfortunately. It works only when it's taken regularly, every day.

TREATMENT TIP

- Don't ever stop taking your pills suddenly, on your own. You could have non-stop seizures, a serious problem.

FINDING THE RIGHT MEDICINE

Many different kinds of medicine are used to prevent seizures.

Your doctor will choose one that's most likely to work for the kind of seizures you have.

Sometimes medicines that worked well at first lose their effect after a while. Staying in touch with your doctor helps track how well you – and your medicines – are doing.

People respond differently to the medicines, too. The medicine that prevents one person's seizures may not work for someone else.

It may take some time to find exactly the right dose of the right drug for you.

TREATMENT TIP

- Ask your doctor ahead of time what to do if you forget a pill.

Doctors try to treat seizures with just one drug.

If that doesn't work, the doctor may try another one. Sometimes the doctor will add a second epilepsy drug to see if two will work better than one.

Your medicine will work best if you take it on time every day.

It's not a good idea to miss doses or take fewer pills than your doctor said.

Not taking enough medicine may make the drug level in your body too low to prevent seizures.

If that happens, the seizures are likely to come back.

ABOUT SIDE EFFECTS

Many people take epilepsy medicines without having any side effects.

But some people do have them.

Side effects are uncomfortable changes in how you feel that are caused by a medicine.

Feeling very tired is a common side effect of these drugs. Feeling sick to your stomach is another one.

Both of these side effects are more likely to happen when a drug is first started. They may go away later on, as your body gets used to the medicine.

TREATMENT TIP

- Tell your doctor if you notice any changes in how you feel when you take epilepsy medicine.

TREATMENT TIP

- When doctors are treating you for other illnesses, tell them you're taking medicine for epilepsy.

Other side effects may happen because one drug you are taking is affecting another one.

Or perhaps too much medicine is staying in your body. Doctors call this being "toxic." What are the signs? Feeling very tired, staggering, or slurring your words.

If this happens to you, your doctor may change how much of the medicine you are taking. Chances are this type of side effect will then go away.

If your doctor changes your medicine, don't drive until you know how it makes you feel.

Some people have bad reactions to a drug, like developing a rash. When this happens, a different drug may have to be used instead.

It's a good idea to ask your doctor what to watch out for and what to do if you have problems.

Always check with your doctor if you feel ill or uncomfortable soon after starting an epilepsy drug.

TREATMENT TIP

- Ask your doctor if there are any cold pills, fever medicines or other products that you should not use because you take epilepsy medicine.

OTHER TREATMENTS

Sometimes seizures keep happening even though you've tried a lot of medicines. Or perhaps you've had bad reactions to them.

When this happens, ask your doctor about new medicines. Have you had a chance to try them yet? Is there anything new that might help?

If you've tried all the medicines that your doctor says are likely to help you, ask about other kinds of treatment.

Surgery, a special diet, and a vagus nerve stimulation (VNS) device are three other kinds of treatment for epilepsy. Most are used with epilepsy medicines.

SURGERY

Surgery for epilepsy is usually done to remove a small part of the brain where seizures begin.

Your doctors may suggest surgery if you have seizures that:

- Always start in just one part of your brain.
- Are in part of your brain that can be removed safely without damaging speech, memory, or eyesight.

TREATMENT TIP

- **Tell your doctor if you are using – or planning to use – any herbal medicines, supplements or other kinds of treatment.**

Before surgery, you would have tests to find out exactly where your seizures were coming from.

You would probably go to a special medical center for the tests and the operation. Doctors who do surgery for epilepsy must have special skills and experience.

If you had surgery for epilepsy you would probably need to take epilepsy

medicine afterwards, at least for a while.

Many people who have surgery do well and don't have any more seizures. Others still have some seizures. And for a few, the operation does not help.

TREATMENT TIP

- If you use alcohol, ask your doctor about how it may affect your medicine or your seizures.

KETOGENIC DIET

The ketogenic diet is mostly used to treat children who are having a lot of seizures. For some reason, the medicines are not working for them.

Some adults who have lots of seizures have used the diet, too.

Children and adults on the diet are quite limited in what they can eat, and how much.

The diet is very high in fats, with no sugar at all. It has to be followed strictly in order to work.

A diet expert has to be part of the health team. She helps the family keep the child on the diet. She shows

them how to weigh all the food on a special scale.

Like all medicines, the ketogenic diet has some side effects.

From time to time, the health team does tests to see whether side effects are happening.

In children, the diet is usually tried for a couple of years if it seems to be working.

Children on the diet often take epilepsy medicine as well, but may not have to take as much.

After two years, the doctor is likely to suggest a slow return to regular food. If seizures come back, the diet can be started up again.

TREATMENT TIP

- Keep follow-up appointments.

VAGUS NERVE STIMULATION (VNS)

Vagus nerve stimulation (VNS) is a new kind of treatment that may be tried when medicine alone doesn't stop seizures.

The VNS sends regular bursts of electrical energy to the brain from a small, flat battery that's implanted like a pacemaker.

The doctor puts the battery under the person's skin on the chest wall. It's connected to a large nerve in the neck. This is done during same day surgery.

The little bursts of energy are intended to prevent seizures or to stop them if they start.

If you have the system and feel a seizure coming on, you can pass a small magnet over the battery.

Doing this turns the energy on. Sometimes that stops the seizure.

Some side effects of VNS treatment are a hoarse voice and a funny feeling in the throat.

Usually, the VNS doesn't stop all seizures. But most people who have it say they don't have as many as they had before.

Most people with VNS also take some type of epilepsy medicine to prevent seizures.

Make sure to tell doctors treating you for other conditions that you have a VNS system. Make sure to tell them if you or your child are being treated with the diet, too.

TREATMENT TIP

- Write down your questions for your doctor so you don't forget.

LOOKING AHEAD

If you or someone in your family are just starting treatment for seizures, it may be helpful to talk to other people who are living with this condition.

The Epilepsy Foundation in your community – or your doctor – may be able to put you in touch with others.

To find the Epilepsy Foundation nearest you, or to find out more about epilepsy and how it's treated, visit www.epilepsyfoundation.org or call 1-800-332-1000.

MEDICATION RECORD

Epilepsy
Meds

Dose

Date
Started

Date
Stopped

Other Meds

Reason for Use

Herbs, Vitamins, Other

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