

Seizures

Seizures are common symptoms of a brain tumor. For some people, a seizure may be the first clue that something unusual is happening in their brain.

Seizures might be caused by a brain tumor or the surgery to remove it. Seizures can also be totally unrelated to a brain tumor. For example, an injury to the head, a stroke, alcohol or drug withdrawal, and fever can all cause seizures. Or, the cause may be unknown.

About 60% of all brain tumor patients will experience a seizure at least once during their illness. Seizures are particularly common with slow growing gliomas, meningiomas located in the convexity of the brain, and with metastatic brain tumors. Sometimes, seizures help alert the doctor to the presence of a tumor.

Most seizures can be controlled with medications called antiepileptic drugs (AED's).

Understanding Your Disease

For many people, understanding is the foundation for coping. Arming yourself with information, understanding as much as you can about the options open to you, and making an informed decision can greatly increase your comfort level.

Begin by listening carefully to your doctors and nurses when they explain your illness and treatment options. They are the best source of information about *your* brain tumor. Don't be afraid to ask questions. Most healthcare professionals want patients to be knowledgeable so they can be active members of their treatment team.

You probably have lots of questions. List them in a notebook, placing the most important questions at the top of the list. Bring your questions to your doctor and jot down the answers. It can be helpful to have someone with you. A relative or friend can provide moral support and also help you remember what was said. If it's okay with your doctor, bring a tape recorder with you. You will then be able to listen to the doctor again in the comfort of your own home.

During your doctors' visits, ask for written information about your brain tumor, your symptoms, suggested treatments, and your medications. Before you leave the doctor's office, make sure you understand any instructions you were given. For example, do you have another appointment? If so, when is it? If you are scheduled to have additional tests, do you know when and where to go? Ask the nurse to write important dates and instructions in your notebook.

Telling Family and Friends

Many people find that it helps to share their news with others.

Telling your family and friends you have a brain tumor isn't easy. If you are uncomfortable telling them, consider having a care conference with your doctor and invite the primary members of your family. When you speak

with your family, remember that written information about brain tumors is available and can help explain your situation more easily. Like you, your family needs time to understand the diagnosis. A family that understands your illness and the options available to you has the opportunity to be supportive and helpful unlike an uninformed, or misinformed, family.

Social workers can help you find ways to share your feelings with your family, and help you and your family cope. Most hospitals have social work departments. You can also find social workers at community centers, government health agencies and schools.

If you are a parent with young children and you have a brain tumor, try to anticipate your children's concerns. Children use their imaginations to fill in the gaps; their fantasies can cause undue fears and anxieties. Give children information in words they understand. Use their questions as a guide to the amount of information they want. Be prepared for questions that aren't easily answered; reply honestly and simply. Young people often have remarkable insight and can be a source of great comfort.

TALKING WITH CHILDREN

These sample explanations can be adapted for conversations with your children. Change the phrases to match your situation.

"The doctor wants to do some tests to find out why you are getting sick to your stomach and having headaches..."

"An MRI scan takes picture of your brain, but it cannot see what you are thinking."

"A brain tumor is a lump in the brain that doesn't belong there. The doctor is going to operate and take it out."

"No one knows for sure what causes a brain tumor. They just happen. But we do know that nothing you did, or thought, or said caused the tumor. We also know that you don't 'catch' brain tumors from other people."

"Would you like to talk about this? Is there anything you would like to ask?"

Above all, reassure your children they are loved and will be taken care of.

For additional suggestions and explanations children can understand, please visit our children's web site — ABTA Kids — at www.abta.org/kids/home.htm.

HOW TO HELP SOMEONE DURING A SEIZURE

Once started, a seizure cannot be stopped abruptly. Most will end naturally. If you have never seen someone have a seizure, it can be an alarming experience. If you understand what is happening, however, you'll be knowledgeable about what to do.

First, make sure the person is breathing. Loosen clothes around the neck. If the person is having trouble breathing, immediately call for emergency help. Most of the time, a person having a seizure requires no assistance other than caring observation.

If the person appears to be breathing well on his own, take a moment to clear the area of sharp objects or anything else that could be dangerous. If possible, help the person lie on his side. This helps keep their airway open. Protect the patient's head from being bumped if he is having a generalized seizure. Do not put anything in the person's mouth. Do not attempt to restrain a person's limbs during a seizure as this may result in an injury such as a dislocation.

Most seizures last several minutes. After the seizure ends, allow time for the person to recover. He may be confused for a few moments — this is normal. Help re-orient him. Tell him who you are, where he is, and what happened. Help him find a place to rest until he feels like himself again.

Call for emergency assistance if:

- he is having difficulty breathing
- the person injures himself
- the seizure lasts more than 5 minutes
- a second seizure immediately follows

Myoclonic seizures

Myoclonic seizures cause single or multiple muscle twitches, jerks or spasms.

Tonic-clonic (grand mal) seizures

Tonic-clonic (grand mal) seizures are common in people with low grade gliomas but can occur with all gliomas. The seizure begins with a sudden outburst and then a loss of consciousness. This is followed by tonic (twitching) and clonic (relaxing) muscle contractions. During this time the person might bite his tongue, lose control of body functions, and take very shallow breaths. This usually lasts for two or three minutes and is followed by limpness. When the person regains consciousness he or she may be sleepy, have a headache, be confused, and/or have sore muscles. Most people are able to return to their normal activities after resting. If the seizure begins again, call for emergency assistance.

Treatment

Seizures may be controlled in three ways. The most common is with drugs. The second method is surgery. The third method is a special diet, called a ketogenic diet. Sometimes, a combination of methods is used.

MEDICATIONS

Medications are the most widely used method of controlling seizures. The medications are prescribed to prevent seizures or decrease their frequency. They are called antiepileptic medications, and many choices are available. The type your doctor prescribes for you depends on your seizure history as well as the type of seizures you experience.

SURGERY

Surgery to remove the tumor may also stop your seizures. If that occurs, the factor that was irritating the brain's electrical system was removed. Or, using sophisticated brain mapping techniques, the neurosurgeon may be able to define the exact area of the brain causing the seizures and surgically remove it.

KETOGENIC DIET

The ketogenic diet is used to treat epilepsy (recurrent seizures) in children, especially if seizure medications are not effective. The diet is based on a very high intake of fat which causes a chemical imbalance in the body

called “ketosis.” Because of the potential side-effects of ketosis, this diet must be prescribed and carefully monitored by a doctor, just as antiepileptic drugs are prescribed and carefully monitored.

About Antiepileptic Drug Therapy

The goal of drug therapy is always to prevent seizures with the lowest effective doses of antiepileptic medication and the least side effects. There are several important points to remember while you are taking antiepileptic medications.

Antiepileptic medications work best when there is a steady level of the drug in your body. The drug needs to reach and remain at the ideal level to be effective. With some medications, frequent blood tests are required to check the drug levels. Ask your doctor if the medication you are using needs to be monitored in this way — if yes, he or she will tell you where and when to have those blood tests done. Your medications might be adjusted based on the results. Remember to take your medication regularly as prescribed. If you miss a dose, don’t double up. Resume your regular schedule and notify your doctor. If you stop taking your medicine abruptly, seizure activity will increase. If you miss more than one dose, or if you notice an increase in your seizures or if you develop a rash, call your doctor for instructions.

There are many medications — both prescription and over-the-counter — that can influence the effectiveness of antiepileptic medications. Be sure your doctor is aware of all the medications you take. Don’t forget to mention vitamin and nutritional supplements, or herbal medications you may be using.

Ask your doctor about operating heavy equipment or having alcoholic drinks.

In the interest of protecting both the public and the driver, all states issue driving guidelines for people who have seizures. To protect yourself, ask your doctor about driving before you get behind the wheel, and follow the guidelines.

Do not change the dosage or stop taking your medicine without the approval of your doctor.

If one medication doesn’t control your seizures, another drug or a combination of drugs may be prescribed.

Depending on the risk of seizure recurrence, you may need to continue taking antiepileptic medications for several months or years following your last seizure. This risk is determined on an individual basis by your neurologist. The decision is based on many factors including MRI scans, EEG (electroencephalogram) results, and the outcome of tumor treatments. The decision to taper off antiepileptic medication should be carefully planned by your doctor and you, and all appropriate precautions taken.

Sometimes antiepileptic drugs are prescribed as a precaution following brain surgery. Your doctor can tell you how long s/he expects you to use the medication “prophylactically.”

Some of the medications for controlling seizures caused by brain tumors are:

- carbamazepine (Tegretol)
- divalproex sodium (Depakote)
- felbamate (Felbatol)
- gabapentin (Neurontin)
- lamotrigine (Lamictal)
- levetiracetam (Keppra)
- oxcarbazepine (Trileptal)
- phenobarbital (Luminal)
- phenytoin (Dilantin)
- tiagabine (Gabitril)
- topiramate (Topiramate)
- zonisamide (Zonegran)

Side-Effects of Drug Therapy

You will be given specific instructions for taking your medication. Your doctor or nurse will tell you the drug’s common side-effects, which side-effects you should call the doctor about, and which side-effects should lessen with time.

Because most of the antiepileptic drugs can cause blood or organ disorders, your doctor will perform frequent physical exams and blood tests to avoid these potential effects.

Listed below are the most frequent side effects of the commonly used antiepileptic drugs. This

is not a complete listing, however. Information about your drug and the circumstances in which to call your doctor should be provided by your healthcare team. Most of the side effects below may be avoided through careful dose adjustments and by slowly increasing medications up to their target dose. Some people simply do not tolerate certain medications and need to be placed on other medications. Also, a “side” effect for one person may be a “welcome” effect for another — for example, Lamotrigene may cause insomnia in one person but cause increased alertness in another.

CARBAMAZEPINE (TEGRETOL)

Double or blurred vision, dizziness, drowsiness, nausea, headache, skin rash. This drug may decrease the effectiveness of oral contraceptives. Other drugs can cause the blood levels of Tegretol to increase or decrease.

DIVALPROEX SODIUM (DEPAKOTE) OR VALPROIC ACID (DEPAKENE)

Nausea, vomiting, indigestion, diarrhea, abdominal cramps which may lessen with continued use, drowsiness, anorexia or increased appetite with weight gain, temporary hair loss, photosensitivity. Do not break or crush the pills as they will irritate the mouth and throat. When used with Dilantin, Depakote may cause Dilantin levels to change.

FELBAMATE (FELBATOL)

Insomnia, weight loss, headache, nausea, sedation, dizziness. Use has been restricted by small but significant incidence of bone marrow suppression and liver toxicity. Because it is a highly effective agent which is usually non-sedating it is still used in difficult cases, but with careful blood monitoring.

GABAPENTIN (NEURONTIN)

Dizziness, drowsiness, fatigue, ataxia, sleepiness, nausea, vomiting, slurred speech, skin rash. Should not be taken within two hours of antacids.

LAMOTRIGENE (LAMICTAL)

Headache, nausea, insomnia, vomiting, dizziness, double vision, and tremor. Rash may occur in 5% or more of patients usually within the first three months of starting the medication. The risk of rash is reduced by slowly increasing the lamotrigene dose.

Lamotrigene blood levels will be reduced by phenytoin and carbamazepine and increased by valproic acid.

LEVETIRACETAM (KEPPRA)

Sedation, dizziness, headache, decreased appetite, nervousness. This medication is being used with increasing frequency in patients with brain tumors because of its lack of interaction with other medications and relatively good tolerability.

OXCARBAZEPINE (TRILEPTAL)

Double vision, impaired balance and coordination, dizziness, tremor, drowsiness, headache, and nausea. Chemically related to carbamazepine with probable similar efficacy. May cause reduction in blood sodium concentration.

PHENOBARBITAL (LUMINAL)

Lack of concentration, sleepiness, hyperactivity, depression, “hangover-like” headache, skin flushing, nausea, vomiting, skin rash. Commonly used for seizures in children. In adults, it may be used with Dilantin, or when other antiepileptic drugs are not effective. Several drugs can increase the effect of phenobarbital.

PHENYTOIN (DILANTIN)

Drowsiness, dizziness, low blood pressure, rapid jerky eye movements, clumsy walk, swollen gums, skin rash. Many drugs, prescription (including chemotherapy drugs) and over-the-counter (including aspirin and antacids), can increase or decrease the effectiveness of this drug.

TIAGABINE (GABITRIL)

Dizziness, fatigue, nervousness, tremor, impaired concentration, general weakness, depression.

TOPIRAMATE (TOPAMAX)

Impaired concentration, irritability, poor coordination, weight loss, fatigue, dizziness, word finding difficulty, increased risk of kidney stones. May change phenytoin levels.

ZONISAMIDE (ZONEGRAN)

Decreased appetite and weight loss, dizziness, impaired coordination, sedation, fatigue, confusion and impaired concentration, and slightly increased risk of kidney stones.

NOTIFY YOUR DOCTOR IMMEDIATELY IF YOU:

- have any difficulty breathing
- run a temperature
- notice the whites of your eyes appear yellow
- have tiny purple spots on your skin
- become unusually confused
- have difficulty urinating
- bruise easily

Chest pain or inability to arouse someone taking antiepileptic drugs is always a medical emergency.

Managing Common Side Effects

The following hints may help you manage some common side effects of antiepileptic drugs.

DROWSINESS OR DIZZINESS

Do not operate equipment or machinery and don't drink alcoholic beverages. Use caution on stairways. Install grab bars in the shower and next to the toilet (these can be rented from a medical supply store). If the drowsiness persists, contact your doctor.

GUM SWELLING

This side effects occurs only with phenytoin (Dilantin). Good oral hygiene is a vital part of managing this side effect. If your gums are swollen, try using a mouth care "sponge" — they are available at most drug stores. A soft toothbrush is another option. Avoid mouthwashes containing alcohol as they will further burn and irritate your gums. Look for baking soda-based mouth rinses, or ask your dentist to suggest one. Be sure to tell your dentist about your medication — frequent professional cleanings may help limit gum swelling.

RASH

First, notify your doctor. A rash can indicate an allergic reaction to the drug, or may be due to an increased drug level. If itching accompanies the rash, a cool shower may help — it constricts the blood vessels in the outer layer of your skin. Pat skin dry instead of rubbing. Don't use lotions on the rash unless

your doctor or nurse suggests it. Do not take additional doses of the medication that may be causing the rash until you have spoken with your doctor.

NAUSEA AND VOMITING

Be sure to take your medication with meals to decrease stomach irritation. If stomach upset continues, ask your doctor about antiemetic medication. Antiemetics block the messages to the vomiting center of the brain. Don't use over-the-counter antacids or aspirin-containing preparations for upset stomachs without first checking with your doctor. They may interfere with some antiepileptic drugs.

CONTINUED SEIZURES AND IDEAL DRUG LEVELS

Some seizures simply do not respond to a given drug. You may have to try another medication. Be sure to let your doctor know how often you have seizures, and if the side-effects of a particular drug interfere with your quality of life. Be aware that flu vaccines, as well as some prescription and non-prescription drugs, can increase seizure activity.

CONTINUED SEIZURES AND IRREGULAR DRUG LEVELS

Antiepileptics are frequently affected by other medications. If you are experiencing this problem, make a list of all your medications (over-the-counter as well as prescription drugs) and take it to your doctor or pharmacist.

Be sure to keep a record of your seizures, particularly the frequency and type. Discuss this with your doctor, and ask about other options for controlling your seizures.

For Additional Information

For more information about seizures and seizure medications, contact:

The Epilepsy Foundation
4351 Garden City Drive
Landover, Maryland 20785

Phone: 800-332-1000
Website: www.epilepsyfoundation.org

There is a small charge for some of their publications.