

## TREATMENTS FOR PATIENTS WITH REFRACTORY EPILEPSY

If you or a loved one has epilepsy, this fact sheet will help you and your doctor discuss several treatment options for refractory epilepsy. People with **refractory epilepsy** continue to have seizures, even after trying several medications.

Neurologists from the American Academy of Neurology (AAN) who specialize in diseases of the brain and central nervous system, including epilepsy, and experts in epilepsy from the American Epilepsy Society (AES), believe you should know about the options for treating and managing your epilepsy.

The following information is based on a careful and complete look at the current data for the newest treatments. It is not intended to exclude any alternate reasonable treatment. The experts did not look at all of the available medications and treatments.

In the past several years groups of experts in neurology and epilepsy carefully reviewed data on new antiepileptic medications, epilepsy surgery, and a medical device that can help manage, or possibly end, seizures. The experts wanted to find out how effective and safe these various treatments are and the best way to use them for managing epilepsy.

### Antiepileptic Drugs (AEDs)

Seizures happen if there are changes in the way normal brain cells act or if brain cells send abnormal signals. During a seizure, too much electrical activity occurs in part of the brain and spreads to other areas. Consciousness, movement, sensation, speech, mood, memory, and emotions can all be affected during the one or two minutes that the seizure lasts.

Antiepileptic drugs are chemical compounds that affect the brain. There are more than 20 drugs used in the treatment of epilepsy. They do not cure the condition but will often control seizures completely if taken regularly.

If you have epilepsy, your physician will choose an AED based upon your seizure type, your age, and potential side effects. There is often a trial and error period to determine the therapy for each individual patient. Thankfully, there are many choices for physicians and people with epilepsy.

These drugs often enhance the quality of life for people with epilepsy. Antiepileptic drugs can make seizures less frequent or they can help people with epilepsy lead a completely seizure-free life.

The newer AEDs give people with epilepsy the option to possibly experience fewer side effects. While all medications have some side effects, the choice of which drug and which

side effects can be tolerated depends on the individual person. Your doctor should discuss serious side effects, if any, when starting any of the new antiepileptic drugs. It is important to discuss potential side effects with your doctor and how willing you are to tolerate these side effects.

Some of the side effects are short term, others continue as long as the medication is taken. Some side effects are linked to dosage—the higher the dose needed to control seizures, the greater the risk of side effects.

Long-term use of certain AEDs can affect bone health. Your doctor may discuss keeping an eye on your bone density. If necessary, he or she may recommend a bone density test, additional drugs, and calcium supplements to prevent loss of bone tissue and bone density. People on AEDs may want to consider an exercise program that includes weight-bearing exercise such as walking or weight lifting.

AEDs may affect women with epilepsy in their reproductive years. Some of the seizure medications available can decrease the effectiveness of hormone contraception and some seizure medications can increase the risk of birth defects. If you are a woman with epilepsy of childbearing age, ask your doctor *before you become pregnant* about any safety measures you should consider to minimize risks to the baby.

## Epilepsy Surgery

When medications cannot control seizures, brain surgery may be an option. The type of seizure a person has and the part of the brain in which the seizure occurs can help determine whether someone is a candidate for surgery. If the seizure activity occurs in just one part of the brain, the seizure is called a partial seizure. Partial seizures are the most likely to yield to a surgical treatment. When a seizure occurs throughout most or all of the brain, the seizure is called a generalized seizure. Surgery is rarely an option if you have seizures that are generalized, or if you have seizures in areas of the brain that contain crucial brain functions.

To determine whether a patient can have surgery, doctors will do an extensive medical evaluation in order to have as much information as possible. The evaluation includes a neurological examination, blood tests, standard and focused EEGs, an MRI of the brain, and possibly other tests. Your doctor may decrease or stop any AEDs you are taking during some of these tests.

Surgery for epilepsy can take several hours. During surgery, a neurosurgeon removes the area of the brain that tests have shown to be the site of the seizures—called the seizure focus. While there are no guarantees, these operations have a positive track record. In one group of patients who had surgery, 64% were free of seizures after one year. In the same group of patients, 10% to 15% did not improve.

Most patients continue to take AEDs following surgery—some can later be tapered off. All surgery has risks. Discuss your options, and the risks and benefits of the procedure, with your neurologist.

## Vagus Nerve Stimulator

For some people with refractory epilepsy who cannot benefit from surgery, an implanted medical device—called a *vagus nerve stimulator* or *VNS*—may be another treatment option.

The vagus nerve connects the lower part of your brain to your heart, lungs, and intestines. In some people with epilepsy, stimulating the vagus nerve with small pulses of electrical energy every few minutes can prevent seizures, reduce their strength and number, and in some cases stop them in progress.

The VNS device—which is about the size of a silver dollar—is surgically placed in the chest wall beneath the collarbone. The wires from the device connect to the vagus nerve in your neck. Once it is activated and depending how it is adjusted, the device turns on and off, stimulating your brain. The major side effect is having a hoarse voice during the brief periods that the stimulator turns on. Seizures are unlikely to be completely controlled with this device, but many people have benefited from the treatment. Most will continue to take AEDs as well.

## Talk to your neurologist

If you have questions about whether you—or someone you care for—could benefit from any of these treatment options, ask a neurologist. Together you and your doctor can determine which of these three recommended epilepsy treatment options will be the safest, most tolerable, and most likely to positively affect your quality of life.

For further information about epilepsy and its treatment, call 1-800-332-1000 or visit [www.epilepsyfoundation.org](http://www.epilepsyfoundation.org).

This is an evidence-based educational service of the American Academy of Neurology. It is designed to provide members with evidence-based guideline recommendations to assist with decision-making in patient care. It is based on an assessment of current scientific and clinical information, and is not intended to exclude any reasonable alternative methodologies. The AAN recognizes that specific patient care decisions are the prerogative of the patient and the physician caring for the patient, based on the circumstances involved. Physicians are encouraged to carefully review the full AAN guidelines so they understand all recommendations associated with care of these patients.



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