

AAN Patient and Provider Shared Decision-making Tool

AMERICAN ACADEMY OF NEUROLOGY

EPILEPSY SURGERY

FIVE QUESTIONS FOR... EPILEPSY SURGERY

Shared decision-making helps you and your health care providers discuss options and make decisions together. Health care decisions should consider the best evidence and the patient's health care goals. This guide will help you and your neurology provider talk about:

- When epilepsy surgery is considered
- Basic risks of epilepsy surgery
- Brief description of the types of epilepsy surgery available

1. WHAT IS TREATMENT-RESISTANT EPILEPSY?

Epilepsy is a condition where people have seizures. A seizure occurs when some or all brain cells are overactive. A person who has had two or more unprovoked seizures is often diagnosed with epilepsy. Anti-seizure medications can help people with epilepsy, but some people have seizures despite taking medications as prescribed. When someone continues to have seizures after trying two different anti-seizure medications, it is called having treatment-resistant epilepsy.

2. WHY SHOULD I THINK ABOUT EPILEPSY SURGERY AS A TREATMENT OPTION?

Seventy percent of people with treatment-resistant epilepsy who have had surgery stop having seizures or have less frequent seizures. For patients who try a third medication rather than surgery, only one to three percent will become seizure free. This means surgery is more effective than trying another medication for controlling seizures. People who have surgery report their quality of life improves because seizures are less frequent or have stopped. They are able to do more after they have recovered from surgery.

Unfortunately, many people or their health care providers do not realize that a patient may be able to have epilepsy surgery and do well. It is often hard to know who may do well with epilepsy surgery. Reports suggest that a delay up to 20 years can occur before someone is referred for epilepsy surgery. This is why it is very important for you to ask if you may benefit from epilepsy surgery if you have treatment-resistant epilepsy.

3. WHAT ARE MY OPTIONS FOR SURGERY?

Your surgery options will depend on the type of epilepsy you have. All surgeries may require you to stay in the hospital to recover and to monitor any new seizure activity. There are five main surgery options. They are called: resective surgery, invasive monitoring, corpus callosotomy, responsive neurostimulation, and vagal nerve stimulation. Please see the table for more information on each type, the risks, and benefits. If you are referred for epilepsy surgery, ask for more details for the type of surgery that is recommended for you. Surgery options depend on the type of epilepsy you have.

4. WHAT HAPPENS IF I THINK SURGERY MAY BE A TREATMENT OPTION FOR ME?

Before any surgery, you will need to have several tests to determine if surgery is right for you. Your doctor most likely will recommend one or more of the following:

- You see a specialist at an epilepsy center. Epilepsy centers focus on providing care only for patients with epilepsy and may have more resources and treatment options available than primary care providers or general neurologists. An epilepsy center is usually a part of a hospital system.
- An MRI, or magnetic resonance imaging scan, may be required to create very detailed pictures of the brain. You have to lie still in a narrow tunnel for the test. If a tight space might be difficult for you, tell your doctor. People with pacemakers, metal heart valves, or certain brain clips cannot have an MRI. Let everyone know if you have one of these devices. You may have had a brain MRI before, but it is not unusual that a more detailed repeat MRI is needed.

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- A long-term video EEG, or electroencephalograph, may be needed. This requires leads attached to your scalp and monitoring with a video camera for at least 24 hours, but usually for many consecutive days while staying in a hospital in a specialized unit. Not all hospitals are able to do this type of testing. The video camera is needed to see what happens while a seizure occurs. You can have breaks and privacy to change or go to the bathroom during the monitoring. Your neurology provider may ask you to stop taking medications and stay awake for a long period before starting this process. You will want to ask your neurology provider how to prepare for the test. Please don't stop your medications on your own as that can be dangerous.
- Other tests may be needed depending on what the epilepsy specialists feel would help get the best information about your seizures.

5. HOW CAN I TALK WITH MY DOCTOR ABOUT REACHING A TREATMENT DECISION?

- Talk with your neurology provider about getting a referral to a comprehensive epilepsy center if you have treatment-resistant epilepsy. Make sure you are comfortable with the place you may have your surgery.
- Discuss any concerns about surgery with your family, friends, and health care team including any after surgery follow-up care and what recovery to expect.
- Decide if you need more information to make the decision. You may also request to be referred to another epilepsy center for a second opinion.
- The testing and surgery are costly, so make sure that you understand your financial responsibility for the tests, surgery, and follow-up care.

Surgery name	What happens during the surgery?	When is this surgery used?	What are the risks?
Resective Surgery	The area of your brain producing seizures will be removed. During this operation, a neurosurgeon will remove the part of your brain tissue where the seizures start.	This surgery has the greatest chance of stopping seizure activity. It is recommended when evaluations clearly show the area in your brain where seizures start.	This surgery can have the most risks. Muscle weakness may happen after surgery that may not get better. Infection and bleeding in the brain can happen during or right after the surgery.
Invasive Monitoring	Leads, which record data from your brain, are inserted in your brain to locate the area of the brain where the seizures start.	It can be very hard to find the cause of seizures, and this procedure is helpful to find the cause of seizures. If the area of the brain where the seizures start is identified, you may return for a separate resective surgery (see above).	Infection and bleeding in the brain can happen during or right after the surgery.
Corpus Callosotomy	The pathways where the seizure spreads in the brain are disconnected.	This will stop the brain from spreading seizure signals. This surgery often is performed for people who have seizures causing them to fall or injure themselves frequently.	This surgery can provide decreased seizures, but it likely does not stop all seizures. Muscle weakness and confusion after surgery may happen that may not get better. Infection and bleeding in the brain can happen during or right after the surgery.
Responsive Neurostimulation	A doctor will implant a device in your brain that will recognize and stop seizure activity. During this surgery, leads are placed on the surface or into the brain area where your seizures start. The leads are connected to a device implanted in the skull, like a small battery. The device recognizes abnormalities between seizures and sends stimulations to treat the abnormalities.	This is recommended when doctors can identify two or three small areas in the brain where the seizures start or if you are not able to have the surgery to remove a part of the brain.	This surgery can provide decreased seizures, but it likely does not stop all seizures. Infection and bleeding in the brain can happen during or right after the surgery.
Vagal Nerve Stimulator	This is not surgery in the brain. Instead, doctors will put a wire around a nerve in your neck and a battery device in your chest. The battery will send signals along the nerve in your neck.	This is recommended when you have treatment-resistant epilepsy and are not able to have resective or corpus callosotomy surgery.	This surgery can provide decreased seizures, but it likely does not stop all seizures; it is designed to work with anti-seizure medication. Tingling sensations in the neck, cough, and some hoarseness when speaking during stimulation can happen. These usually go away with time.

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