

NEUROSCIENCES

What You Need to Know about Epilepsy Surgery



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Your journey to epilepsy surgery

1

Epilepsy Monitoring Unit (EMU). The first step is understanding your seizures and where they start in the brain. You will stay in the hospital's EMU. This is where we record your seizures with video EEG.

2

Magnetic resonance imaging (MRI). Get an MRI of the brain to look for sources of your seizures.

3

Neuropsychological testing. Do brain puzzles and tests to learn how the parts of your brain work. This helps us understand how surgery could affect memory, thinking and emotions.



A nurse will help arrange all the testing you have at OHSU

4

Epilepsy team conference. Your OHSU neurologist meets with a team of epilepsy specialists, a surgeon and a radiologist to go over your test results and talk about your options for surgery.

5

More tests (if needed) to plan surgery. Specialized brain images called PET, SPECT, or MEG.

6

Talk to your OHSU neurologist. They call you or talk with you at a visit about your surgery options.

7

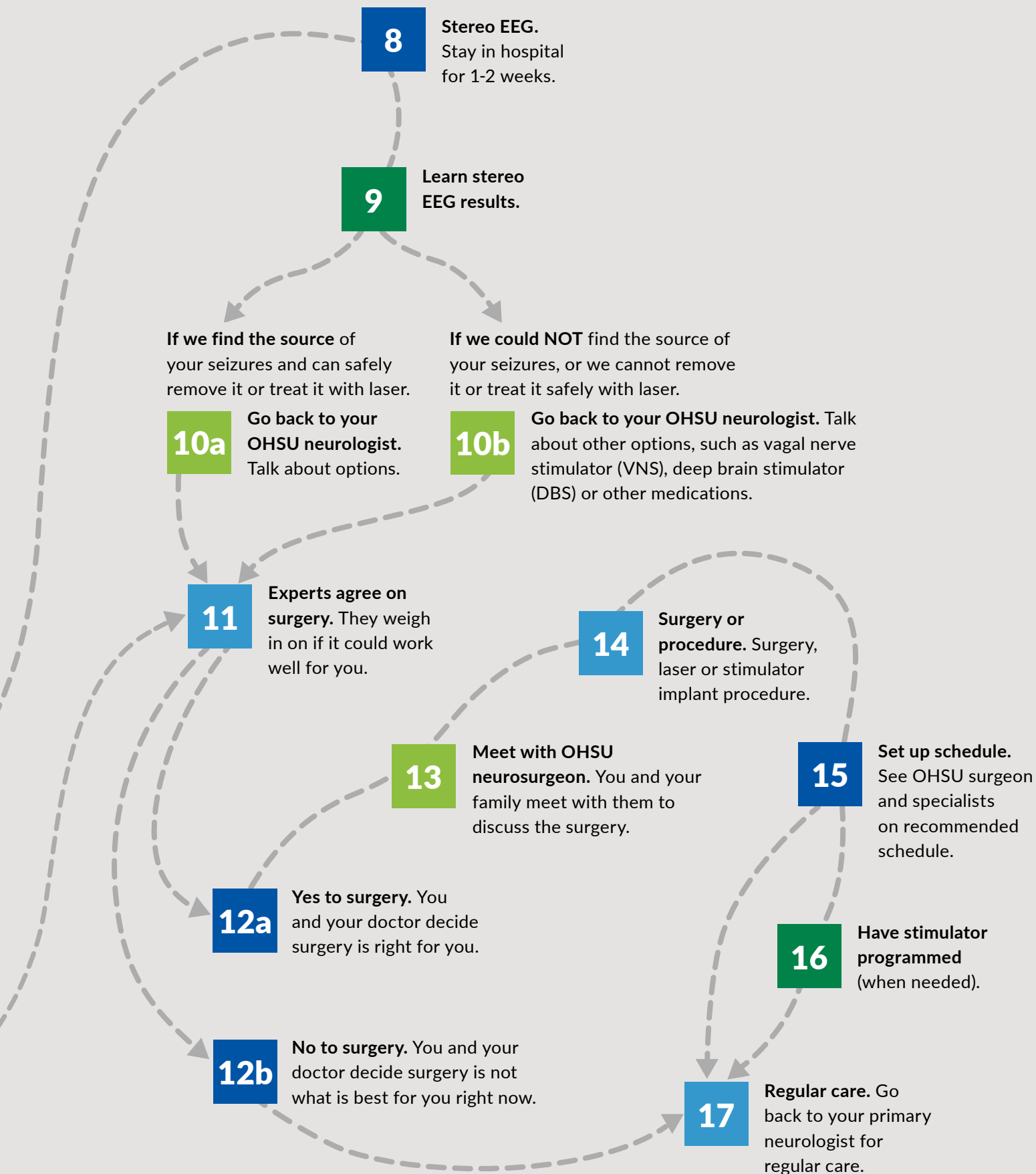
Learn and decide about stereo EEG.

If you are considering surgery, you may have already tried many treatments. You may also be eager to have surgery right away.

But, we want to make sure that surgery is your best option. This means taking enough time – from weeks to months – to understand your epilepsy.

Welcome to the journey

The information on this page is like a map. It shows all the ways you can go and where you will stop on the way to surgery.





About your epilepsy surgery

Surgery is a treatment option for severe epilepsy or epilepsy that has not responded to two or more medications.

You may have epilepsy surgery to:

- Stop seizures if medication has not worked.
- Make your seizures shorter and less intense.
- Lower the risk of a life-threatening seizure.
- Reduce your medication dose.
- Reduce side effects from medication.

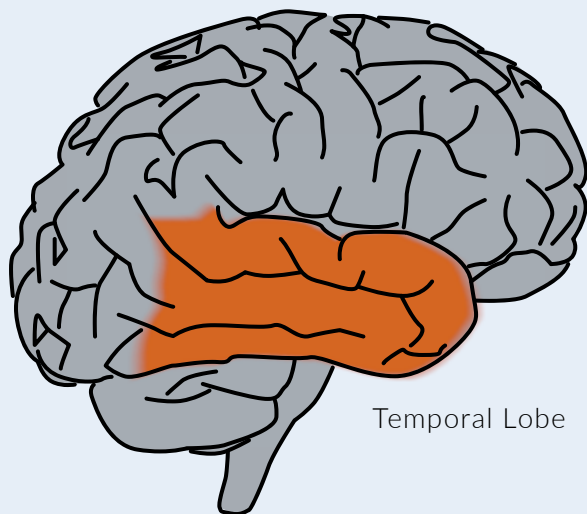
About our surgery technology

Almost all epilepsy surgery involves the brain. At OHSU, we use the most precise technology available to make your surgery as effective and safe as possible. The technology we use includes:

- **Stereo EEG.** This is an important tool we use to discover exactly where your seizures are coming from.
- **Intraoperative MRI, or iMRI.** This is MRI used during surgery with a machine that moves back and forth in the operating room. It is incredibly precise, and your surgeon can position it exactly where they need it for the clearest images of your brain. For some epilepsy surgeries — for children and adults — we use the iMRI suite at OHSU Doernbecher Children's Hospital.
- **ROSA, a surgical robot.** ROSA assists the surgeon during brain surgeries, using GPS-like navigation software to guide the surgeon to exactly the right spot in your brain.

“Almost all epilepsy surgery involves the brain. At OHSU, we use the most precise technology available to make your surgery as effective and safe as possible.”

Different types of epilepsy surgery



Laser treatment (laser ablation)

This surgery uses a laser probe placed through a small opening in the skull. Your surgeon uses MRI technology to place the probe in the part of your brain where seizures start. Then they aim the laser at that area to treat the cells that are causing seizures. The medical term for this surgery is laser interstitial thermal therapy, or LITT.

Because the procedure requires only a small incision, you will probably recover more quickly and go home sooner than with other procedures. LITT may also have fewer effects on your thinking.

Temporal lobe surgery

The most common part of the brain for seizures to start is called the temporal lobe. Most epilepsy surgeries involve the temporal lobe. This area is on the side of your head, above and behind your ear. You have a temporal lobe on each side of your head.

Temporal lobectomy is the medical term for removing part of the temporal lobe. More than 8 in 10 people who have this surgery have fewer and less severe seizures or no seizures at all after surgery.

Multiple factors influence your chances of having no seizures at all. Your doctors will give you an estimate of your personal chances of seizure improvement from this surgery.

Types of temporal lobe surgery include:

Anterior temporal lobectomy. This is the most common epilepsy surgery when medication does not work. The surgeon removes a small area of tissue from the front of a temporal lobe. Risks include losing some memory, vocabulary or peripheral vision (side vision). Some people also have mood problems after surgery. However, these effects may be temporary.

Selective amygdalohippocampectomy, or SAH.

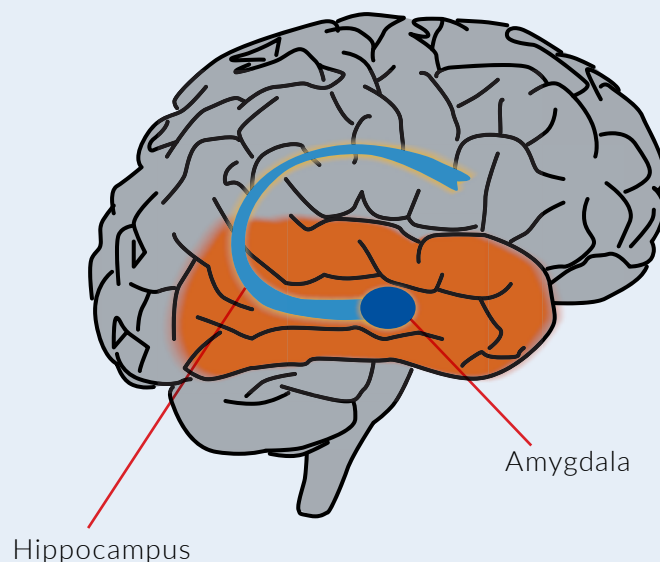
In SAH, your surgeon removes small areas of tissue from parts of the temporal lobe called the hippocampus and amygdala. This surgery may affect your memory and other brain functions less than an anterior temporal lobectomy.

Lesionectomy

During a lesionectomy, your surgeon will remove an area of damaged or diseased brain tissue, called a lesion, that is causing seizures.

A variety of brain lesions cause epilepsy:

- Tumors
- Dysplasia – Clumps of abnormal cells that develop before birth when the brain is formed.
- Traumatic brain injury
- Scar tissue from brain infection or inflammation
- Abnormal blood vessel formations



Planning your epilepsy surgery or procedure

Testing and planning before surgery

Before epilepsy surgery, you meet with one of our epilepsy specialists and are scheduled for specialized tests. We need the results to learn if the source of your seizures can be safely removed. If not, you may benefit from a stimulator or other treatment option.

Once we have the results of your tests, we will talk with you about our recommendations and options. Our goal is for you to live with the fewest seizures and side effects possible. Some people may be completely seizure free after epilepsy surgery. We will work with you to find the best approach, even if it takes several months.

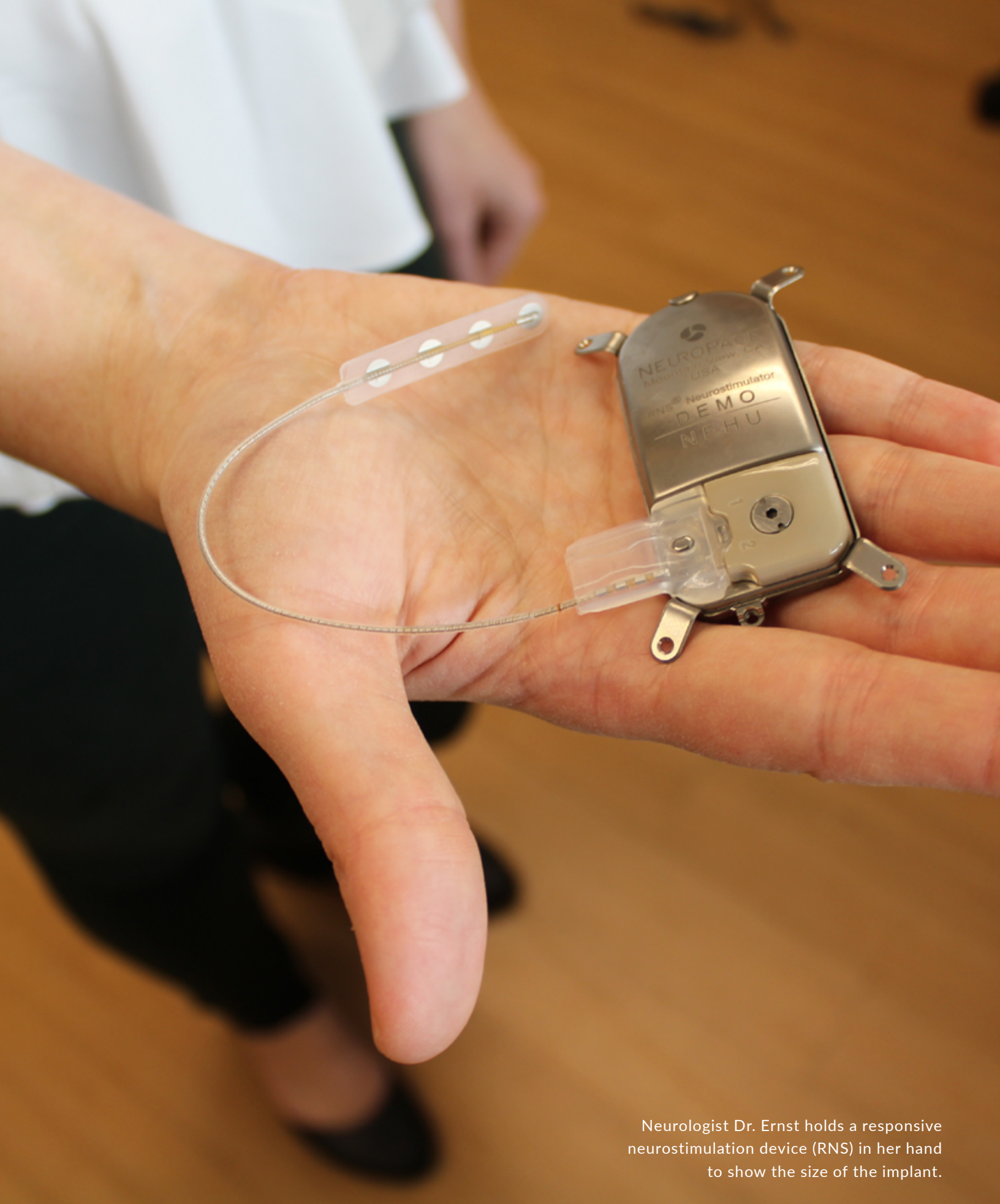
Please see the graphic **Your Journey to Epilepsy Surgery** in the front of this booklet to learn more about the testing and planning process.

Stimulator options

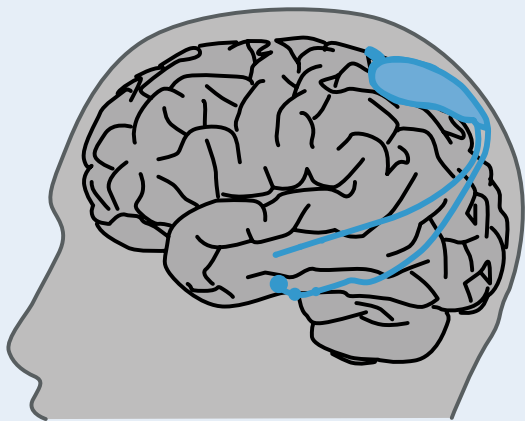
Sometimes we decide that removing the abnormal brain tissue causing your seizures is not possible or safe. In this case, we may recommend an implanted stimulator to treat seizures.

With stimulators, the goal is to reduce the number of seizures you have over time and for your seizures to become less severe over time.

The information below describes the different stimulators available. There are pros and cons to each stimulator type. Your neurologist can talk about these with you.



Neurologist Dr. Ernst holds a responsive neurostimulation device (RNS) in her hand to show the size of the implant.



The RNS system is a device that is implanted in the skull, with two wires connected to electrodes that detect seizures in the brain and treat them with electrical stimulation.

Responsive neurostimulation (RNS)

OHSU epilepsy specialists were involved in developing the implanted RNS system and doing the research that led to FDA approval in 2013.

Could RNS work for me?

RNS may be for you if you have tried several medications and cannot have surgery because your seizures:

- Start in more than one area in the brain.
- Happen in areas of the brain where surgery would affect critical brain function.

How does RNS work?

RNS includes a small device called a neurostimulator and one or two electrodes connected to tiny wires. During the procedure, your surgeon:

1. Places the electrodes in the area of the brain where your seizures start.
2. Connects the electrodes to the neurostimulator device, which is placed in an opening in your skull. The device is placed under your scalp, flush with your skull, so it does not come in contact with your brain.
3. Programs the RNS system to monitor your brain for seizures.

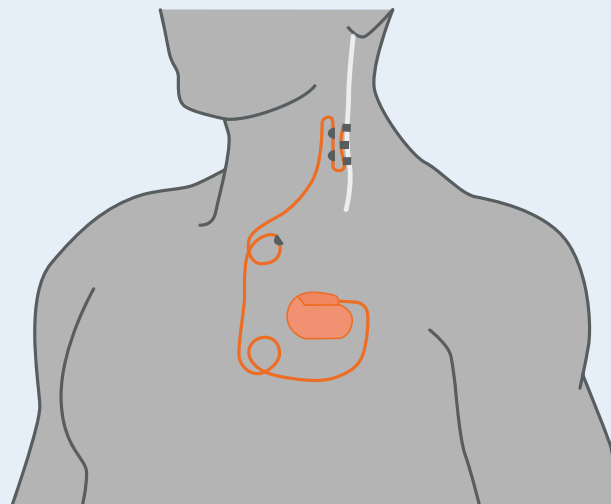
Later, usually about 1 month after surgery, your neurologist will program the RNS system to stimulate your brain when it detects seizure activity. It uses a small electrical pulse to do this.

Over time, the RNS learns to disrupt or prevent seizures. Your care team monitors your brain's electrical activity over time and adjusts your stimulator to make it work better.

Vagus nerve stimulation (VNS)

Vagus nerve stimulation, or VNS, uses a device and wires placed under the skin of your chest to help control seizures.

Picture showing one of the newer VNS devices and where it is placed in the chest, with wire attached to the vagus nerve in the neck (Courtesy of Livanova)



How does VNS work?

Your surgeon implants the device under the skin of your chest like a pacemaker. Then they connect the wires to a nerve in your neck called the vagus nerve.

The stimulator does not detect or monitor seizure activity. Instead, your neurologist programs it to send electrical pulses in specific patterns that disrupt or prevent seizures.

We give you a handheld magnet to turn the stimulator on when you sense a seizure is coming. Some of the newer VNS models also have a feature that monitors your heart rate and gives you extra pulses of electricity when your heart is racing. This can help because people often have a racing heart when they have seizures.

Could VNS work for me?

VNS could be for you if you have tried several medications and you cannot have surgery to remove the abnormal brain tissue that is causing seizures. VNS is the only epilepsy surgery option that does not involve the brain.

Deep brain stimulation (DBS)

Deep brain stimulation, or DBS, uses 2 electrodes placed in the brain. The electrodes are connected to wires and to a device placed under the skin of your chest to help control seizures.

Could DBS work for me?

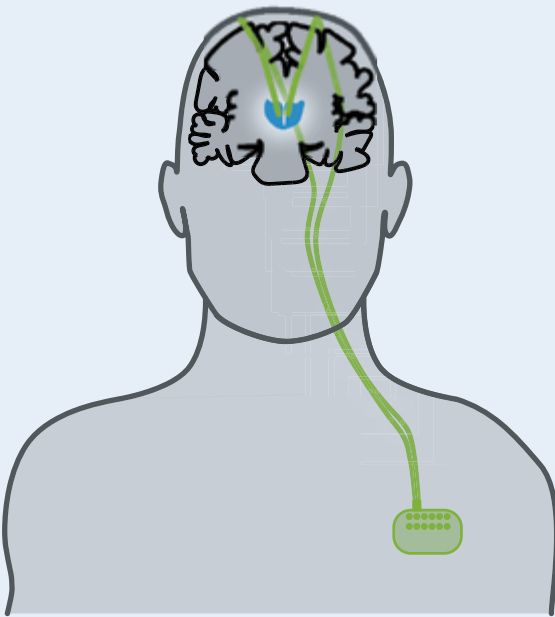
DBS may be for you if you have tried several medications and you cannot have surgery because your seizures:

- Start in more than one area in the brain.
- Are difficult to locate.
- Happen in areas of the brain where surgery would affect critical brain function.

How does DBS work?

Your surgeon implants the device under the skin of your chest like a pacemaker. Then they insert 2 electrodes through the top of your head into your brain. The electrodes go into a part of the brain called the thalamus. Finally, the surgeon connects the wires from the electrodes in your brain to the device in your chest, where the battery is.

The DBS stimulator does not detect or monitor seizure activity. Instead, your doctor programs it to send electrical pulses in specific patterns that disrupt or prevent seizures.



Location of DBS stimulator placed in the chest. The wires connect to an electrode that stimulates a part of the brain called the thalamus.

Before your epilepsy surgery

Tests all patients get before epilepsy surgery

The standard tests before epilepsy surgery are usually done in the order below.

1. Epilepsy monitoring.

We will record your seizures with video EEG to confirm where they start in the brain.

2. Magnetic resonance imaging (MRI). We capture high-quality images of the brain to look for any possible sources for your seizures.

3. Neuropsychological testing. You do a series of brain puzzles and tests that help us understand the way different parts of your brain are working and how epilepsy affects your brain.

What happens at your epilepsy surgery clinic appointment

You will meet with your OHSU neurologist and neurosurgeon, who will explain the surgery and answer any questions you have. Your family and caregivers can come to this appointment with you. It may help to write your questions down before the appointment and have someone help you take notes.

During your epilepsy surgery journey, an epilepsy nurse will communicate with you to help coordinate tests and appointments.

Risks and benefits of epilepsy surgery

Every type of epilepsy surgery has its own specific risks and benefits. Your neurologist and neurosurgeon will review the risks and benefits of the surgery type that our team is recommending for you. In some cases, you may have the chance to choose between 2 or more surgery options.

Tests you might need before having epilepsy surgery

Before you have epilepsy surgery, you might need some of the additional tests below.

Positron emission tomography (PET). This imaging test uses a safe radioactive substance called a tracer to create a map of how your brain uses energy. The “tracer” substance has low levels of radiation in it as well as a type of glucose, or sugar. The map made by this test can show abnormal parts of the brain that are causing your seizures.

Single-photo emission computerized tomography (SPECT). This imaging test uses a safe radioactive substance called a tracer to create a 3D map of the blood flow in your brain. The goal is to create an image while you are having a seizure. We will also create an image when you are not having a seizure. Then we can compare the differences in blood flow. The two images together show us an accurate map of where blood rushes into the brain during seizures, and can show us where the seizure starts.

Magnetoencephalography (MEG). This imaging technique uses magnetic sensors to detect abnormal activity in the brain. It can give us information about where your seizures start. We sometimes use this test when other tests are unable to detect this. Just a few centers in the United States have the equipment for this test. Currently, there is no MEG in the Pacific Northwest and you may need to travel to an out of state center for this test.

Wada test. During this test, your neurologist will evaluate your memory and language on each side of the brain. They do this by giving you a medication that temporarily puts half of your brain to sleep. We use this test when we want to learn about your personal risk for memory problems after surgery.



Functional MRI (fMRI) This is a special interactive MRI. It measures blood flow changes in your brain when you do different activities. We might ask you to talk, listen or move parts of your body during the test so that radiologists can see where those activities are controlled in your brain.

Visual field testing This is a test of your peripheral vision (side vision). It helps us understand your risk for peripheral vision problems after some surgeries.

Other special MRI or CT scans to prepare for surgery. Your neurosurgeon may request a special MRI or CT scan to use during surgery for GPS navigation of your brain.

You may have other tests. If so, your OHSU neurologist will talk with you about why you need them. The nurse will call you to arrange the test.

About stereotactic (stereo) EEG

You may need an important test called stereo EEG to learn if surgery is a good option for you. We use a surgical robot called ROSA to place very fine wires called electrodes into specific areas of your brain. The wires have sensors at the tip that pick up electrical activity from seizures, showing us where your seizures are starting.

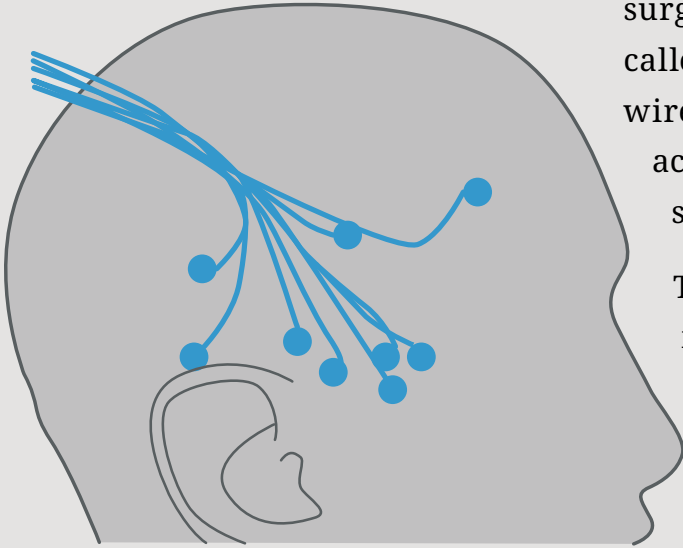
The stereo EEG process is very precise. It involves multiple tiny openings instead of one large opening. Although you will not need to have your entire head shaved, you may need to have small patches of hair shaved where each electrode goes.

After we place your electrodes, you spend about a week (up to 2 weeks maximum) in OHSU's epilepsy monitoring unit, or EMU. Your room will have a bed where an adult guest can stay overnight with you. It also has 24/7 video monitoring, so the nurses can make sure you stay safe and comfortable.

How is stereo EEG done?

You will have general anesthesia when the wires are placed, so you are not awake during the procedure. Your surgeon will create several very small holes in your skull and put the wires through them. Each hole is about 2 millimeters wide, about as large as the lead in a mechanical pencil. The wires are held in place on your head with round screw-like "bolts."

Once the wires are in place, you will have a CT scan. Then, after waking up from anesthesia in the recovery room, you will go to your room in the EMU. We will



carefully lower your anti-seizure medications over the time you are in the EMU so that we can record seizures. A GPS-like monitor will pick up the electrical signals from the sensors in your brain, helping us pinpoint where the seizures are starting.

When we are finished recording seizures, we will restart your normal doses of anti-seizure medications and prepare you to have your electrode wires removed. Most of the time, they can be safely removed in your hospital room while you are awake. However, you may need to have them taken out in the operating room.

If we take the wires out in your hospital room, we will give you pain medication in your IV. This is a thin tube that goes into a vein in your hand or arm. It lets your health care team give you medicine and fluids during procedures. We will also inject a numbing medication into your scalp. If you are feeling anxious, you may receive medication for anxiety.

The surgeons will clean your head, then unscrew the plastic bolts that hold the wires in place and pull out the wires. You may feel the bolts as they are unscrewed, but you will not feel anything when the wires are pulled out. The surgeons will use absorbable sutures (dissolvable stitches) to close the skin where the bolts were removed.

After the wires are removed, you will get a CT scan to make sure that there is no bleeding from the wire removal. If everything looks OK, you can go home that day. We will give you instructions for care after going home.

What happens after stereo EEG?

Your neurologist and neurosurgeon will discuss the results of your stereo EEG with other epilepsy experts. We will talk with you about the results when they are ready. This includes whether surgery is a good option to treat your epilepsy.

If you have questions about stereo EEG or any other tests, ask your doctor or someone else on your health care team. We are happy to answer your questions.

Who will do my epilepsy surgery?

One of our experienced neurosurgeons will do your stereo EEG and your epilepsy surgery or other procedure. You will have appointments with this



doctor before you have stereo EEG, to talk about the results afterward, and before any surgery to treat your epilepsy.

Your epilepsy team will also include other doctors, nurse practitioners, physician assistants, an anesthesia specialist, nurses and other team members. All surgery decisions are made as a group.

Agreeing to have epilepsy surgery

It is very important to understand your epilepsy surgery and have your questions answered. You, your family and other caregivers should feel free to ask any questions you have during your appointment. Your health care team can also give you contact information in case you have other questions before surgery.

After your doctor answers your questions, you will get a permission form to sign. This form says you understand the surgery, risks, and benefits and agree to have surgery.

Once you are scheduled for epilepsy surgery, you will have a physical examination in the OHSU Preoperative Medicine Clinic (PMC Clinic). We ask you to do this to make sure you are healthy enough for surgery.

Getting ready for your surgery

Your health care team will give you a folder with information before your surgery. It includes a guide called “Preparing for Your Surgery.” This guide tells you what to bring to the hospital, where to check in for surgery, and other important information. Please read it carefully and let your health care team know if you have questions.

What to expect during your epilepsy surgery

When you come to the hospital, the staff will send you to the pre-surgery area on the 6th floor of the main hospital. You will change into a hospital gown, and a nurse will put a thin tube into a vein on your hand or arm. This is called an “IV.” It lets your health care team give you medicine and fluids during surgery.

The nurse will ask you some questions, and you will meet the anesthesia team and neurosurgery team. You can ask any last questions that you have. The anesthesia team may give you some medications for anxiety if you are feeling anxious. You will be taken to the operating room on a hospital gurney.

The procedure

When you are ready, your team will take you to the operating room. Most epilepsy surgeries take place on the 6th floor of the main hospital. For some epilepsy surgeries — for children and adults — we use the iMRI suite at OHSU Doernbecher Children’s Hospital. The intraoperative MRI allows our surgeons to see fine details in the brain during surgery. We also use it during laser treatments for epilepsy.

In the operating room

Once you arrive in the operating room, we will move you from the hospital gurney to the operating bed. The anesthesia team will give you medications that will make you go to sleep. These medications also protect against having seizures during the surgery.

Once you are asleep, the anesthesia team will put a tube in your throat to allow you to breathe during the surgery. They will connect this to a ventilator (breathing machine). For most surgeries, you will have

a plastic tube inserted into your bladder to collect urine (pee) in a bag. This is called a urinary catheter or sometimes a Foley catheter.

About your hair

Next, the surgery team will start cleaning your head. We may shave some of your hair depending on the type of surgery you will have. Your surgeon will talk with you about how much hair will need to be shaved at an appointment before your surgery.

Keeping your head secure

We will place your head in a holder called a frame for the surgery. This keeps your head in a stable position. In many epilepsy surgeries, your surgeons will use an operating robot that connects to your head holder.



Mapping your brain

Your surgery team will inject a numbing medication into your scalp. For certain epilepsy surgeries, they will place small metal markers called “fiducials.” These markers are like landmarks to help the surgery team map out your brain. They go through your scalp into your skull, but they are temporary and removable.

If you have these markers, you will have a CT scan in the operating room that shows them. This creates the map of your brain that the surgeons will use during surgery.

Completing your surgery

The surgeons will complete your surgery with different steps depending on the procedure you are having. When it is done, your surgeons will close the incisions, usually with absorbable sutures. These are stitches that dissolve on their own without needing to be removed.

Occasionally, the surgeon will need to use non-absorbable stitches or staples. If so, we will take these out about 2 weeks after surgery.

Your surgery team will clean your head again. They will take out the metal place markers (fiducials) and remove your head holder. After your incisions are closed, we will wrap your head in protective gauze that contains antibiotic ointment. You will also receive antibiotics in your IV during the surgery to prevent infection.

The recovery room and where you will stay

Directly after surgery, we will take you to the recovery room and remove your breathing tube. Your catheter will likely be removed in the operating room or in the recovery area immediately after surgery.

Once you wake up, we will take you to your hospital room. This is usually on the 10th floor of OHSU Hospital, which is for neurology and neurosurgery. You may go to the neuroscience ICU on the 7th floor for a night or two before moving to the 10th floor.



After your epilepsy surgery

When can I go home?

Some of the things your health care team wants to see before they let you go home are:

- Your pain level is stable – This means your pain medicine is controlling your pain and you are fairly comfortable.
- You can eat and digest food – Including having a bowel movement and urinating (peeing).
- You can move safely around your hospital room without falling or being too weak.

What to expect in the hospital

Once you arrive in your hospital room, nurses will check your blood pressure and pain level. They will give you pain medication to keep you as comfortable as possible. If you are feeling nauseated, we will give you medication for nausea.

After surgery, the focus will be on recovery. Over the next few days, you will gradually move around more, starting with sitting up at the side of the bed, sitting in a chair, and walking around the room when you are able. You may start drinking fluids and eating simple foods immediately, gradually working up to eating regular full meals.

Your nurses will check your blood pressure, pulse, temperature and breathing while you are in the hospital. They will also check your pain level and give you pain medication, along with any other medications you take.

How long will I stay in the hospital?

You will stay in the hospital for approximately 1 to 5 days after epilepsy surgery. If you have stereo EEG, you might stay 1 to 2 weeks.

How long you stay depends on your pain levels and how long it takes for you to recover to the point where you can walk, eat, and go to the bathroom. Your neurology and neurosurgery teams will help you get ready to go home.



What to expect at home

An adult family member or friend must drive you home from the hospital. You cannot take public transportation home after surgery.

Most people will need help from friends or family for at least the first week after surgery. The main symptoms you may have after epilepsy surgery include head pain and fatigue (feeling very tired).

Other symptoms, all of which go away with time, may include:

- Nausea
- Pain in the jaw
- A feeling of fullness in the ears
- Balance problems

How long does recovery take?

Your recovery time depends on the type of surgery you had. After minimally invasive surgery, it may be 1 to 2 weeks before you go back to work or other normal activities. This includes stereo EEG, laser ablation, deep brain stimulation and vagal nerve stimulation.

It may be 4 to 6 weeks before you go back to work and normal activities if your surgery required a larger opening in the head. This includes temporal lobe surgeries, lesionectomies and responsive neurostimulation (RNS).

About your stitches and incision

The sutures (stitches) will eventually come out on their own, but this can take several weeks. If you have non-absorbable sutures or staples, we will remove these in the clinic in approximately 2 weeks.

You may experience some numbness or strange sensations in your scalp around the area where the surgeon made a cut in your scalp. This is normal as the tiny nerves in your scalp heal.

Your activity level

After epilepsy surgery, you should not lift anything over 10 pounds for a month. Avoid driving until:

- You have had your post-surgery checkup with your doctor.
- You are not taking pain medication any longer.
- Your neurologist says you may drive.

You can do regular activities if you feel OK when you do them. Walk 10 to 30 minutes each day, if possible.

Your incisions (cuts)

Avoid getting your head wet for 72 hours. You can wash the rest of your body in the shower when you go home. After 72 hours, you can take showers and let your head get wet. Avoid soaking in a bathtub, swimming pool, hot tub or other water.

There is no need to put any ointment or cream on the incisions. Check your incisions 1 or 2 times a day for signs of infection. These signs include:

- Redness
- Swelling
- Large hard areas under the incision site
- Yellow or cloudy pus around the area
- Feeling that the area is warm or hot

If you see any liquid or pus draining from the incisions, take a picture. Call your neurosurgeon's office if you have questions or think you have an infection.

When to call the clinic

To schedule an appointment in the epilepsy clinic, call **503-494-7772**.

Questions about your incision, pain after surgery, or healing

Please call the neurosurgery clinic at 503-494-4314 during regular business hours or send a MyChart message to your neurosurgery team.

Questions about treatment or medication

Call the epilepsy nurse advice line at 503-494-7237. You can also send a MyChart message to your epilepsy team.

Call immediately for these signs

Call us immediately if you have

- A lot of blood or fluid coming from your incisions
- Fever, chills, or sweating
- Nausea or vomiting that does not go away
- Confusion

Call the neurosurgery clinic at 503-494-4314 Monday-Friday, 8 a.m. – 4 p.m. All other times, call the OHSU operator at 503-494-9000 and ask to speak with the neurosurgery doctor on call.

Call 911 for

- Seizures that do not stop on their own
- Shortness of breath or other breathing problems
- Confusion that does not get better

These are emergencies. Call 911 right away.

Your checkups after epilepsy surgery

Your health care team will make the following appointments for you after epilepsy surgery.

- Appointment with the neurosurgery clinic – 2-4 weeks after your epilepsy surgery. This is called your “post-op” appointment.
- Appointments with your neurologist, usually starting about 1 month after surgery.

Talk with your health care team before surgery about where to have these appointments. Coming to the OHSU clinic is best. In some cases, you may be able to have virtual appointments or see a local doctor if you live far away.

Contact your OHSU epilepsy surgery team

My OHSU epilepsy specialist is:

My OHSU neurosurgeon is:

In an emergency, call:

After business hours and on weekends, call **503-494-8311** and ask to speak to the neurologist or neurosurgeon on call. Call 911 if:

My next appointment is:

[illegible]

[illegible]



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