

Deep Brain Stimulation (DBS) Surgery

A Handbook

Introduction

Welcome to the M Health Fairview Deep Brain Stimulation (DBS) program. Thank you for trusting us with your care.

M Health Fairview is a major center for DBS surgery in the United States. Our doctors were part of the first DBS studies in the country. We have been doing DBS for more than 25 years. We are one of the leading clinical and research DBS centers in the world.

In addition to these doctors, the DBS care team also includes skilled and caring neurosurgeons, award-winning nurses, and a highly supportive group of coordinators. We have a world-class imaging center that uses 7T MRI technology. We are also one of the few Centers of Excellence for Parkinson's disease research in the United States. Our team will walk with you through every step of the DBS process.

Consider this booklet a passport and first step in your care journey. We look forward to getting to know you and working with you. Please feel free to give us feedback along the way if you have questions or tips on how we can improve your care.

Best wishes,

The DBS Team

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What Is Deep Brain Stimulation (DBS)?

What is DBS surgery?

DBS is brain surgery to treat muscle movement problems from conditions like Parkinson's disease, essential tremor, and dystonia. It's not a cure and won't stop these from getting worse. For many people, it can improve symptoms like stiffness, slowness, tremors, and other abnormal, involuntary movements.

What are the benefits?

DBS may be able to:

- Help you move more easily
- Reduce medicine doses
- Improve tremor, slowness, and stiffness
- Reduce motor fluctuations (changes) and motor dyskinesias (involuntary fidgeting or writhing movements) in Parkinson's disease
- Reduce tremor in essential tremor
- Reduce sustained muscle contractions in dystonia.

It won't help problems with thinking, mood, balance, or speaking. Brain surgery can make thinking and mood problems worse. Because of this, DBS patients must be in stable physical and mental health.

How does it work?

DBS has been around for decades. We're still studying and trying to understand it. DBS experts think that it blocks abnormal signals in the brain.

Words to know

- Involuntary:** Something that you can't control.
Stimulation: Raising the level of feeling or action.

DBS is usually done in 2 surgeries.

- **1st surgery:** ("Phase 1") The surgeon puts a small, thin wire called a "lead" deep into the part of the brain that controls movement. You may plan to have a lead placed in both sides of the brain if you have movement problems on both sides of the body. Placing 2 requires 2 brain surgeries.
- **2nd surgery:** ("Phase 2") The surgeon puts a device like a pacemaker called an *implantable pulse generator* (IPG) in the chest area. The IPG connects to the lead with a wire. The entire system is under the skin.

We can adjust the IPG to give different strengths and patterns of stimulation. This is a key part of your care after surgery — adjusting and finding the stimulation that works best for you.

The battery inside the IPG lasts from 3 to 5 years. It lasts up to 15 years if it's a rechargeable battery. When the battery wears out, you'll need minor surgery to replace it. Your team can help you decide which type is best for you.

Who does DBS surgery work best for?

For patients with Parkinson's disease if:

- You've had Parkinson's for about 4 years or more
- Your symptoms aren't well controlled with medicine, or your medicine gives you uncontrolled movements

- You **don't** have another condition similar to Parkinson's disease (Progressive Supranuclear Palsy PSP or Multiple System Atrophy MSA).

For patients with tremor if:

- The cause of the tremor is essential tremor (also called *familial tremor*)
- The tremor is in the hands, arms, or legs (rather than head or voice).

For all patients if:

- You **don't** have dementia or severe memory problems
- You **don't** have major medical problems that would increase the risk of surgical problems.

What are the risks?

For DBS surgery, there is a small risk of:

- Bleeding in the brain (stroke)
- Infection
- Seizure
- Death (although extremely rare, death has been reported in DBS surgery).

Further risks of DBS include:

- Worsening of thinking, mood, balance, or speech problems
- Problems with the DBS system's parts (the lead, extension wire, and IPG)
- Symptoms not helped as much as patients expect
- The lead may not go in the right place. If needed, we can re-do the surgery to change where the lead is. This rarely needs to happen.

Side effects of stimulation:

- Speech changes
- Muscle tightness of the face or arm
- Numbness or tingling
- Visual changes

These usually stop after stimulation stops or gets adjusted.

This isn't a complete list of surgical risks and side effects. Please speak to your neurosurgeon and neurology care team about your own risks for having DBS surgery.

What do patients need to do?

- Have realistic hopes. If you expect a sudden miracle, you may be disappointed. Talk with your care team about what to expect from DBS.
- You must be able to handle being awake for phase 1 surgery.
- You must be able to describe what you feel and take part in your surgery, as well as the programming afterwards.
- Commit to long-term follow-up care.
- You or your family members must learn how to work your patient programmer.

Safety

You must always tell other healthcare teams and technicians about your DBS system and give them the maker's phone number. They must call the maker for safety steps before certain procedures or therapies. (See "Programming" in the "After DBS Surgery" section for more information.)

A Roadmap to DBS Surgery

Deciding if you're a candidate

- Meet with your M Health Fairview Movement Disorder provider.** They will help you decide if DBS surgery is right for you.
- Get an evaluation by our team.** This process is sometimes called a “workup.” You’ll meet with:
 - Neurosurgery
 - Neurology
 - Neuropsychology
 - MRI (Magnetic Resonance Imaging)

Neurosurgery appointment:

- We’ll review your symptoms and take a detailed medical history.
- The surgeon will describe DBS surgery so you know what to expect, as well as the risks.
- You’ll be able to talk about your goals and expectations. You’ll also be able to ask questions about the 2 surgeries, surgical risks, preparing for surgery, what to expect after surgery, and any other concerns you may have. Please bring a list of questions.

Neurology meeting:

For patients with Parkinson’s disease (PD):

- **On and off motor testing:** Come to the appointment off of your Parkinson’s medicines. We’ll tell you when to stop these medicines. You’ll do a series of tasks while off your medicines.

Midway into the appointment, you’ll take your PD medicines. After they start to work, you’ll do the same tasks. This will show how well the medicines manage your Parkinson’s symptoms.

We’ll record video for parts of this meeting.

For patients with essential tremor and dystonia:

- We’ll review your tremor or dystonia using a rating scale. We may ask you to come to the meeting off of your tremor medicines. We’ll ask you to do a series of tasks, such as writing and pouring water from a cup. We’ll record video for parts of this meeting.

Neuropsychological evaluation:

- The evaluation lasts about 4 hours.
- Please be rested, take medicines as usual (including during the exam), and bring a snack.
- Bring your hearing aids and eyeglasses.
- We’ll ask you questions during the first half of the evaluation. A family member may be with you while we ask you questions.
- The doctor will take a detailed health history and talk with you about DBS surgery.
- You’ll do tasks and surveys to review your memory, thinking, and mood.
- This evaluation can be tiring. Take breaks whenever you need to.

MRI (Magnetic Resonance Imaging):

- An MRI uses a strong magnet and radio waves to look inside the body. MRI captures very detailed images that help us check the structures and vessels of your brain.
- We will inject contrast dye through an IV in your arm for the MRI. Please let us know if you have an allergy to contrast.
- If you have claustrophobia (fear of enclosed spaces), ask your care team for medicine to help you relax.

- If you have another implanted device, you will need to provide the team with the make and model of that device.
- Arrive 30 minutes before your appointment.

For questions about the cost of workup appointments, please call our financial counselors at 763-782-6639. Ask to speak with a neurology or neurosurgery financial counselor. They can answer questions about coverage for DBS.

Watch the DBS video. We advise patients thinking about DBS surgery to watch the DBS video. The DBS team walks patients through the process before, during, and after DBS surgery. Please share the video with your family and friends so they can learn about DBS.

Your care team reviews your case and lets you know if DBS is right for you. If they don't think DBS is right for you, there may be different treatments.

Sometimes before making a decision about surgery, the team needs more details about:

- Depression, anxiety, other mental disorders
- High blood sugar
- High blood pressure
- Heart disease
- Support system needs.

If you get approved for DBS surgery, you can find out about being part of research studies. This may help lead to new treatments. This is your choice. You aren't required to be a part of research.

Schedule DBS surgery. If DBS is right for you, you must decide whether to move forward. Your workup tests are good for 1 year.

Complete prior authorization for surgery. Our neurosurgery team will send the required forms to your insurance company. This happens after we schedule your surgeries.

For questions about the cost of surgery, please call our financial counselors at 763-782-6639. Ask to speak with a neurology or neurosurgery financial counselor.

Complete any paperwork that your employer needs. Our neurosurgery team can help you with this after we schedule your surgeries.

30 to 14 days before surgery

- Preoperative Assessment Center (PAC) appointment: Our PAC team will help you prepare for surgery. The meeting includes:
- Review of your medical history and current health status
 - A history and physical (H&P) exam
 - Patient education, including details about eating and drinking before surgery, medicine and stopping smoking
 - Review of any specialist doctors who you see.

14 days before surgery

Review your preparing for surgery documents.

DBS surgery

Phase 1: Placing the lead

- Surgery lasts from 4 to 6 hours.
- You're asleep for the first part of the surgery.
- In the middle of the surgery, you're awake. This is because we want your brain cells to be awake. As the surgeon places a test electrode in your brain, the surgery team listens to your brain to find the best place to put the lead. This can last 1 to 2 hours. You will not feel this.
- The team will ask you to move your tongue, hands, and arms; speak; and write.
- You may feel numbness or tingling during this time. This is normal and will go away.
- After the surgeon finds the best place, they'll put the lead there.
- After surgery, you'll go to the post-surgery recovery area, then to a hospital room to be monitored closely overnight. If there are no problems, we will discharge you the next day.

What to expect after Phase 1:

You'll have 2 incisions (cuts) after Phase 1 surgery:

- A 5 cm (2 inch) incision on the top of the head
- A 2.5 cm (1 inch) incision behind the ear

You may notice a small bump on the side of your head behind your ear. This is the tail end of the lead. We'll connect this to the battery using an extension wire during Phase 2 surgery. The cap that keeps the DBS electrode in place creates a small bump on the top of your head. Please keep from touching this.

You may experience:

- Mild tenderness at the incision sites
- Mild headache
- Feeling tired and needing rest
- Puffiness and swelling around the eyes.

You may have what we call a "microlesion effect" after surgery, where your symptoms improve for a few days or weeks. This usually goes away, and your symptoms return to what they were before surgery.

Many patients remain off work between the Phase 1 and Phase 2 surgeries.

Phase 2: Placing the implanted pulse generator (IPG) or battery

- The surgeon places a battery beneath your collarbone, on top of the muscle under your skin. They connect this to the lead in your brain with a wire that runs down the side of your neck.
- This surgery happens about 1 week after lead placement surgery (Phase 1).
- You'll be asleep for this surgery.
- The surgery takes about 90 minutes.
- You'll go home the same day.
- Take your Parkinson's disease, tremor, or dystonia medicines the morning of surgery.

What to expect after Phase 2:

After Phase 2 surgery, you'll have a 6 cm (2.5 inch) incision in the chest just under the collarbone.

The thickness of the IPG (battery) will be visible.

You may experience:

- Mild tenderness at the incision sites
- Soreness along the side of the neck
- Feeling the extension wire in the neck when the head is turned to the other side
- Feeling tired and needing rest.

Most patients deal with more soreness and discomfort after Phase 2 than after Phase 1.

Your DBS system won't be turned on until your first programming appointment.

After DBS Surgery

Activity restrictions

- Don't lift, push, or pull anything heavier than 8 to 10 pounds.
 - Don't drive until you're able to move your neck fully; you're not taking medicines that can make you tired; and your surgeon says it's okay to drive.
 - **Medicine:** Return to taking your Parkinson's, tremor, or dystonia medicines after both surgeries. Take pain medicine as needed.
 - **Return to work:** Talk with your surgery care team about the best time for you.
- Incisions that are opening or warm to the touch
 - Incisions that become more painful over time
 - A temperature higher than 101.5 ° F (38.6° C).

Incision care

- Your incisions will be covered with surgical glue.
- You can get your incisions wet, but **don't** soak your incisions in a bath, pool, or hot tub for at least 1 month after surgery. Replace a wet dressing with a dry one.
- Don't scrub your incisions hard. Instead, let mild soap or shampoo run over them.
- Don't scratch your incisions. This may cause infection. Gently rub around itchy areas only.
- Return to the neurosurgery clinic 2 weeks after Phase 2. We'll make sure your incisions are healing well.

When to call us:

Call us right away if you have:

- Redness or swelling
- Drainage that is green or yellow or has a bad odor

Programming

About 4 to 6 weeks after DBS surgery, you'll have your first appointment for programming and a CT scan. Programming is where we set the level of stimulation. It will take around 2 hours.

- Stop Parkinson's disease or tremor medicines before the appointment, as your doctor tells you. We need to see all symptoms in order to program.
- Bring your Parkinson's or tremor medicines with you to the clinic.
- Have a driver to bring you to the clinic.
- Take other medicines as directed.
- Bring the patient programmer that you received after Phase 2 surgery. We'll teach you how to use it. If you have a rechargeable IPG, charge it before each programming session.
- Come ready with snacks, drinks, and any other medicines you may need. Bring something to do during the downtime.

After programming, it takes time for the brain to adjust. The settings may not be perfect right away. Some symptoms may be relieved, while others may take more time. Side effects may happen quickly or take a few days or weeks to appear. Contact your DBS neurology nurse with any questions or concerns. MyChart is an great way to do this.

Making too many changes too often can slow down getting the right settings. It will take a few visits to find the settings that relieve symptoms the best, with the least amount of side effects. This usually takes about 3 to 6 months. After we find the best settings for you, you'll only need to see your neurologist 1 or 2 times a year.

- Remember: Side effects from stimulation aren't an emergency. You can always turn off your system and keep taking your medicines until you're seen.

Things to do after programming

- Schedule a DBS system check every 6 to 12 months with your managing neurologist.
- Schedule a neuropsychological exam for 12 months after your DBS surgery to check for changes in your thinking or mood.
- The DBS battery needs to be replaced before it is drained. Ask your DBS care team when your battery will need to be replaced.
- You must inform other healthcare teams and technicians of your DBS system and give them the maker's phone number. They need to call the maker about any safety steps to take.

Safety details

- This isn't a full list. Refer to your device's manual and contact the maker directly for safety details for specific activities:
- Keep all electronic devices **at least 6 inches** away from the IPG (battery). This includes your smartphone, tablet, etc.
- Don't do any of the following:
 - Diathermy
 - Arc welding
 - Electroconvulsive therapy (ECT)
 - Transcranial magnetic stimulation (TMS).

- Avoid activities that could risk damage to the system (such as deep tissue massage of the neck).
- Avoid activities that could result in blows to the device (contact sports).
- Some MRIs may be allowed. Before you have an MRI, contact your neurology care team to see if you can have an MRI and to make sure your system is working correctly.
- Doctors should call the maker before electrocautery (used to stop bleeding in surgery), colonoscopies, and treatment for kidney stones (lithotripsy).
- Electrocardiograms (ECG/EKG): DBS systems will disrupt an ECG reading and must be turned off.
- Strong magnetic fields or theft detection devices may turn off your device.
- When traveling by air, the security scanners may turn your DBS system off or on. Always carry your patient programmer, so you can check to see that your stimulation is still on after you go through security.
- Manual dental cleanings only (no ultrasonic scaling), and avoid tools or cords being placed over your device. Before deep-root scaling, planing, or other invasive mouth surgery, call your care team for prophylactic antibiotics.
- Someone should be with you when swimming until you know you can move safely in the water with stimulation turned on.
- Always know where your patient programmer is and make sure a family member knows, too. Always take your programmer to doctor visits, procedures, or medical emergencies. You or your family member may need to be able to turn your DBS system off and back on again.

Important Dates to Remember

Appointment	Date	Time	Location
Neurosurgery consult			Clinics and Surgery Center 3rd Floor Neurosciences 909 Fulton St SE Minneapolis, MN 55455 612-626-6688
Neuropsychological exam			Clinics and Surgery Center 3rd Floor Neurosciences 909 Fulton St SE Minneapolis, MN 55455 612-626-6688
Movement exam and videotaping			Clinics and Surgery Center 3rd Floor Neurosciences 909 Fulton St SE Minneapolis, MN 55455 612-626-6688
3T Brain MRI			Center for Clinical Imaging Research (CCIR/CMRR) 2021 6th St SE Minneapolis, MN 55455 612-626-6900 (Or this may be at the CSC.)
7T Brain MRI (if you choose to take part in research)			Center for Clinical Imaging Research (CCIR/CMRR) 2021 6th St SE Minneapolis, MN 55455 612-626-6900
Pre-operative Assessment Center (PAC) appointment			Clinics and Surgery Center 4th Floor 909 Fulton St SE Minneapolis, MN 55455 612-626-6688

Appointment	Date	Time	Location
DBS surgery Phase 1: Electrode placement			East Bank Hospital University of Minnesota Medical Center 500 Harvard St SE Unit 3C Minneapolis, MN 55455 612-273-3000 option 4
DBS surgery Phase 2: IPG placement			East Bank Hospital University of Minnesota Medical Center 500 Harvard St SE Unit 3C Minneapolis, MN 55455 612-273-3000 option 4
Neurosurgery follow-up appointment			Clinics and Surgery Center 3rd Floor Neurosciences 909 Fulton St SE Minneapolis, MN 55455 612-626-6688
Initial programming and post-op CT scan			Clinics and Surgery Center 3rd Floor Neurosciences 909 Fulton St SE Minneapolis, MN 55455 612-626-6688

More appointments you may have

Appointment	Date	Time	Location
Side 2: Pre-operative Assessment Center (PAC) appointment			Clinics and Surgery Center 4th Floor 909 Fulton St SE Minneapolis, MN 55455 612-626-6688
Side 2: Phase 1 surgery			East Bank Hospital University of Minnesota Medical Center 500 Harvard St SE Unit 3C Minneapolis, MN 55455 612-273-3000 option 4
Side 2: Post-surgical follow-up			Clinics and Surgery Center 3rd Floor Neurosciences 909 Fulton St SE Minneapolis, MN 55455 612-626-6688
Side 2: Initial programming			Clinics and Surgery Center 3rd Floor Neurosciences 909 Fulton St SE Minneapolis, MN 55455 612-626-6688

Notes

