



Deep Brain Stimulation (DBS)

For patients with Parkinson's disease

► **Please read this handout before reading and signing the form "Special Consent for Procedural Treatment."**

This handout describes how to prepare for and what to expect from deep brain stimulation (DBS).

This material is in addition to the discussions you have with your doctors. It is important that you fully understand this information, so please read this information packet thoroughly.

Before Surgery

In the weeks before your deep brain stimulation (DBS) surgery, you will meet with care providers for:

- A consult about your surgery
- Tests to measure your memory, concentration, and other brain functions (*neuropsychological testing*)
- A videotape test to evaluate your Parkinson's disease when you are off and on your medicines (called Unified Parkinson's Disease Rating Scale, or UPDRS)
- A review of your health history
- A physical exam
- Lab work

Stage 1 Surgery: Deep Brain Lead Insertion

1 Week Before Surgery

- Stop taking any medicines for blood clotting, including aspirin, ibuprofen, Plavix, and Coumadin.
 - Ask for special instructions for clopidogrel (Plavix) and warfarin (Coumadin).

After Midnight the Night Before Surgery

- Stop taking your medicine for Parkinson's.
- Do not eat or drink anything.

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Day of Surgery

- Arrive at the UWMC Surgery Pavilion at 5:15 a.m.
- You will:
 - Have a metal frame attached to your head.
 - Have an MRI scan.
 - Be awake for your surgery.
 - Stay in the hospital overnight.
 - Be discharged the next day.

Care After Surgery

Wound Care

- You will have an incision on top of your head. The incision will be closed with skin staples or sutures (stitches).
- Keep your dressing on for 2 days.
- Keep the incision dry for 3 days (72 hours).
- After 3 days, you may get the incision wet, but do not soak or scrub the incision. Pat the incision dry after getting it wet.
- You may wear a loose-fitting, clean cap that is washable.
- A small amount of bleeding is normal when the dressing is first removed.

Suture Removal

- Suture or staple removal is usually done when you return for Stage 2 surgery.
- If you need your sutures removed at a different time, you will have an appointment in the Neurology Movement Disorders Clinic (206-598-7688) or Neurosurgery Clinic (206-598-5637).

Medicine

- Restart your Parkinson's medicines at your regular dose.
- Ask for special instructions for restarting aspirin, Plavix, or Coumadin.

Physical Restrictions

- Avoid strenuous activity and anything that makes you strain.
- For 2 weeks after surgery, **do not** lift anything that weighs more than 20 pounds.
- Walking and light exertion are OK.

Stage 2 Surgery: Pulse Generator Implantation

1 Week Before Surgery

- Stop taking any medicines for blood clotting, including aspirin, ibuprofen, Plavix, and Coumadin.

Ask for special instructions for clopidogrel (Plavix) and warfarin (Coumadin).

After Midnight the Night Before Surgery

- Do not eat or drink anything.
- You may continue to take your usual medicines for Parkinson's.

At the Hospital

- Your surgery time may be in the morning or the afternoon.
- You will be able to go home the same day.
- You will need someone to drive you home and stay overnight with you.

Care After Surgery

Wound Care

- You will have one incision behind your ear and one on your upper chest where the pulse generator is located.
- Keep your dressing on for 2 days.
- Leave the sticky tapes (Steri-Strips) on your incisions for 2 weeks.
- Keep the incisions dry for 3 days (72 hours).
- After 3 days, you may get the incisions wet, but do not soak or scrub them. Pat the incisions dry after getting them wet.
- You may wear a loose-fitting, clean cap that is washable.
- A small amount of bleeding is normal when the dressing is first removed.

Suture Removal

- Suture removal is usually not needed. Clear-colored sutures will dissolve within a few weeks.
- If you need suture removal, you will have an appointment in the Neurology Movement Disorders Clinic (206-598-7688) or the Neurosurgery Clinic (206-598-5637).

Parkinson's Medicine

- Restart your medicines at your regular dose.

Call the doctor if you have:

- **Fever greater than 101°F (38.5°C)**
- **Fluid draining from your incision**
- **Ongoing bleeding**
- **Increased redness and swelling of your incision**

For emergencies 24 hours a day, call 206-598-6190 and ask for the Neurosurgery resident on call to be paged.

Physical Restrictions

- Avoid strenuous activity such as heavy lifting or exertion for 2 weeks.

Hand-held “Access” Controller

- You will be given a controller for your DBS system.
- This controller will be activated at your first programming visit.

When to Call the Doctor

Call the doctor if you have:

- Fever greater than 101°F (38.5°C)
- Fluid draining from your incision
- Ongoing bleeding
- Increased redness and swelling of the incision

First Programming Visit

This visit is scheduled for about 1 month after your Stage 1 surgery.

- Stop taking your Parkinson's medicine **4 hours before** your appointment time for this, and all, programming visits.
- Bring your “Access” controller with you for programming.

Other programming visits may also be needed.

Follow-up Testing

About 6 months after your surgery, you will be scheduled for:

- Neuropsychological testing
- Videotaped tests to evaluate your Parkinson's disease (UPDRS) when you are off and on your medicines and during brain stimulation

Safety Warnings

Diathermy

Diathermy anywhere on your body may cause severe brain injury. Tell anyone treating you that you CANNOT have:

- Shortwave diathermy
- Microwave diathermy
- Therapeutic ultrasound diathermy (also known as deep heat treatment)

Magnetic Resonance Imaging (MRI)

MRI scanning of any body part on patients with DBS may cause severe injury. Permanent brain injury may result from improper use of MRI scanning.

MRIs should be performed only in centers that are familiar with DBS systems, and under very strict safety guidelines.

Risks, Discomfort, and Side Effects

Anesthesia and Sedation

There are always risks with anesthesia and sedation. This may include a reaction to the medicines you receive, heart attack, *apnea* (stop breathing), or even death. A tube will be placed in your mouth to help with your breathing while you receive general anesthesia. There also may be other unknown risks.

Risks of Surgery

Every effort will be made to minimize the risks of the surgery and of brain stimulation. However, complications may occur. Besides the general surgery risks your doctor has explained to you, these complications from the implantation of this device may occur:

- Paralysis, coma, or death
- Bleeding inside the brain (stroke)
- Leaking of fluid surrounding the brain
- Seizures
- Infection
- Allergic response to implanted materials
- Temporary or permanent neurological complications
- Brain lead placed in a location that was not the intended target
- Confusion or attention problems
- Pain at the surgery sites
- Headache

Discomfort

You will be awake during the placement of the head frame, the MRI scan, and for most of the surgery. During the MRI and surgery, you will not be able to move your head and neck. Although we will take care to make you as comfortable as possible, you may be uncomfortable or have pain during the surgery. You will be sedated for the parts of the surgery that are most unpleasant, but it is possible that you could remember these experiences.

Side Effects

Side effects of brain stimulation may include:

- Tingling sensation (*paresthesia*), shocking sensation, or numbness
- Temporary worsening of symptoms
- Speech problems like whispering (*dysarthria*), and trouble forming words (*dysphasia*)
- Vision problems (double vision) or difficulty opening your eyes
- Dizziness or lightheadedness (*disequilibrium*)
- Difficulty walking with increased risk of falling
- Facial and limb muscle weakness or partial paralysis (*paresis*)
- Abnormal, involuntary movements (*chorea, dystonia, dyskinesia*)
- Cognitive changes such as confusion or memory trouble
- Behavioral or mood changes such as depression or impulsive behavior
- Weight gain

Many side effects can be reduced with reprogramming or turning off the neurostimulator. You will be given a controller to take home, so that you may turn your stimulator on or off. Other side effects or complications may occur that are more unusual or are not yet known and cannot be predicted at this time. The lead will remain implanted unless a problem occurs and it needs to be removed. The length of time your neurostimulator battery lasts depends on your programmed settings.

Possible Complications

Possible complications from the device include:

- Pain, lack of healing, scarring, or infection where the system parts are implanted.
- Movement of the lead or extension connector may occur, possibly requiring additional surgery.
- DBS therapy could stop due to mechanical or electrical problems. Either of these would require surgery. The neurostimulator battery needs to be changed before the end of battery life.
- You may have an allergic reaction to the system, which your body may reject since it is a foreign object.
- Rarely, tissue damage can be caused by the programming parameters or a malfunction of one of the parts.

Interference with Other Devices

The neurostimulator may interfere with other implanted devices, such as an implanted defibrillator or pacemaker. External defibrillators, electrocautery devices, radiation therapy, and ultrasonic devices may interfere with the neurostimulator and may even damage it.

Also, the electrical signal from the neurostimulator may interfere with the function of an external defibrillator. The safety of external defibrillators on patients with this implanted system is not known.

Electromagnetic Interference (EMI)

Electromagnetic interference (EMI) is a field (electrical, magnetic or a combination of both) that is generated by various equipment found in medical, work, and home environments. This equipment can create enough interference to:

- Turn your neurostimulator off or on.
- Cause stimulation that can result in an uncomfortable sensation.
- Reset your neurostimulator to factory settings, requiring reprogramming by your doctor.

Your neurostimulator is designed to protect against most EMI. However, strong electromagnetic fields and permanent magnets can interfere with your system. Even when the therapy is turned off, interference can affect the lead(s).

If you suspect EMI:

- Move away from the source of the EMI.
- If possible, turn off the suspected source of EMI.
- Then use your control magnet to turn your therapy on or off.

Theft Detectors and Screening Devices

It is possible that patients sensitive to stimulation, or those with a low stimulation threshold, may experience a brief increase in the stimulation or additional stimulation as they walk through theft detectors and screening devices. They could also turn your stimulator on or off. Higher levels have been described as uncomfortable, “jolting,” or “shocking” by some people as they pass through theft detectors and screening devices.

Questions?

Call the Neurology
Movement Disorders
Clinic: 206-598-7688

Your questions are
important. Call your
doctor or health care
provider if you have
questions or concerns.
UWMC clinic staff are
also available to help.

Neurology Movement
Disorder Clinic:
206-598-7688

Neurosurgery Clinic:
206-598-5637

Other Equipment Exposure

Other equipment may also cause a brief increase in perceived stimulation. You may want to avoid this equipment if you experience an increase in stimulation:

- Electrical arc welding equipment
- Electric induction heaters used in industry to bend plastic
- Electric steel furnaces
- Power lines and electrical substations
- Power generators

Pregnancy

Safety and effectiveness of an implanted DBS system in pregnant women is not known.

More Information About the Neurostimulator

Your doctor will decide when to program your neurostimulator. Programming sessions set the stimulation to best control your symptoms and may take several hours. You may have to return to the clinic a few times to have the stimulation adjusted to achieve the best symptom control for you, especially during the first months after implant. There may be changes in the level of suppression of your symptoms over time. These changes may include less relief, no relief, or loss of effective stimulation.

In many cases, your doctor can correct these changes by programming the brain stimulation system again. However, surgery may be required to reposition or replace the lead, replace the system, or remove the system. Because your disease changes with time, your condition may improve, worsen, or remain unchanged with stimulation. If the neurostimulator is ruptured or pierced after implant due to outside forces, severe burns could result from exposure to battery chemicals.

There may be other risks from this therapy that are still unknown. If you have questions, please ask your doctor.

Clinic Locations and Hours

Neurology Clinic/Neurology Movement Disorders Clinic

The Neurology Clinic/Neurology Movement Disorders Clinic is in the medical center on 8-South in the Pacific Tower. Hours are weekdays, 8 a.m. to 5 p.m.

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