

Deep Brain Stimulation (DBS) Therapy

INSTRUCTIONS and INFORMATION for Patients and Caregivers



University of Pittsburgh Medical Center

UPMC Neurology Movement Disorders DBS Clinic

3471 Fifth Avenue, Suite 810
Pittsburgh, PA 15213
Phone: 412-692-4670
Fax: 412-692-4601

UPMC Presbyterian Hospital Neurosurgery Clinic

200 Lothrop Street, Suite A402
Pittsburgh, PA 15213
Phone: 412-864-3421
Fax: 412-647-4775

INTRODUCTION

Thank you for choosing UPMC Movement Disorders Clinic as your DBS center. The information in this packet is intended to educate patients about DBS as an option for therapy as well as to guide patients through the DBS process from initial pre-surgical evaluation to optimization of DBS therapy with stimulation programming.

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DEEP BRAIN STIMULATION THERAPY

Deep Brain Stimulation (DBS) surgery/programming is a therapy that can improve quality of life when medication management cannot be further optimized.

DBS surgery/programming is not a cure for Parkinson's disease, Essential tremor, or Dystonia. DBS can provide symptomatic benefit, similar to maximal benefit achieved with medications, but with reduced motor fluctuations. In some cases, DBS may provide benefit beyond that achieved with medications alone.



For patients with *Parkinson's disease*:

DBS therapy can benefit motor symptoms of Parkinson's disease including tremor (shakiness), rigidity (stiffness), and bradykinesia (slowness).

DBS can provide the best "on" time that you experience with your medications for PD, and a smoother therapy over time that reduces motor fluctuations between "off" and "on" periods throughout the day.

DBS therapy can also benefit patients with medication-induced dyskinesia (involuntary movement), as well as medication-refractory tremor, rigidity, and slowness of movements. Many patients who are not able to tolerate higher doses of medications due to side effects may benefit from DBS. Most people will continue taking medications for PD after DBS Surgery; however, with DBS programming the amount of medication is often reduced.

Non-motor symptoms of Parkinson's disease are typically not improved with DBS therapy. Symptoms such as constipation, urinary symptoms, and mood, memory, or sleep difficulties are not predicted to improve.

DBS may not be helpful in patients who do not experience any benefit from their medications; however, these patients should be evaluated by a Movement Disorder Neurologist to determine if they receive the correct medications at sufficient doses. Some patients who may benefit from higher doses of medications, but are unable to tolerate higher doses due to side effects (such as sedation, lightheadedness, etc) may benefit from DBS.

For patients with *Essential tremor*:

DBS therapy can significantly improve symptoms of Essential Tremor, usually superior to the best medical therapy. Patients with Essential Tremor may have tremors of the hands, head, and/or voice. Typically DBS improves hand tremors more than head or voice tremors.



For patients with *Dystonia*:

DBS can be effective therapy in dystonia, especially in patients with generalized and primary forms of dystonia. DBS may help patients with other forms of dystonia if medical therapy fails, but the rate of responders may be lower.

The DBS initial programming period could take 6 months to one year before symptoms of dystonia improve.



FREQUENTLY ASKED QUESTIONS

1. How do I know if I am a candidate for DBS?

Your movement disorder Neurologist and their team will determine whether or not you are a candidate for this procedure.

2. How do I know if the timing is right for me to get DBS?

Once the movement disorder Neurologist has indicated that you are a candidate for DBS surgery, then the decision is up to you. If you meet surgical criteria, the expectation is that your overall quality of life will improve with DBS.

3. How long will the DBS provide benefit?

Although your disease will progress, and may outpace the ability of the DBS to adequately control symptoms, the device will always provide some measure of therapeutic benefit.

4. Can I lead an active life with DBS implants?

Yes. We have patients who cautiously have returned to exercise, golf, tennis, and various hobbies requiring fine motor skills following DBS.

5. Can I speak with other patients of yours who have had DBS?

Yes. We have a list of many patients who are happy to speak with you on the phone about their experiences.

THE DBS PROCESS

The road to DBS surgery and beyond involves a multi-disciplinary team of health care providers including those from Neurology, Neurosurgery, and Neuropsychology. Once you have decided to pursue DBS, the following steps are involved in the process:

1. **Evaluation to see whether you are an appropriate candidate:**
 - Meetings with Neurology, Neurosurgery, and Neuropsychology
 - Evaluations by a Physical Therapist and a Speech specialist
2. **Pre-operative testing:**
 - For surgical clearance: blood work, EKG, chest x-ray, etc
 - For surgical planning: brain MRI
3. **DBS surgery:** in 2 stages
4. **DBS initial programming:** 3-4 weeks after surgery
5. **DBS maintenance programming:** typically every month initially, then spaced out to every few months
6. **DBS battery replacement:** typically every 3-4 years, unless you get the rechargeable batteries (about every 9 years). Battery replacement is typically an outpatient surgery.

THE DBS CANDIDACY EVALUATION

As part of the DBS evaluation to establish candidacy, you are asked to complete evaluations by a Neurologist, Neurosurgeon, Neuropsychologist, Speech specialist, and Physical Therapist. These evaluations help us to determine the best management plan for your care.

1) Evaluation by a Movement Disorder Neurologist

The movement disorders neurologists who specialize in DBS at our clinic are Dr. Sarah Berman, Dr. Houman Homayoun, Dr. Valerie Suski, and Dr. Amber Van Laar. A movement disorder neurologist, or their physician assistant, may videotape your examination during this evaluation.

For patients with diagnosis of **Parkinson's disease** you will undergo an "ON-OFF evaluation." You will come to the appointment "off" medications. You are asked to hold the medications that you take for Parkinson's disease 12 hours prior to the evaluation. You are to bring your medications for Parkinson's disease to this visit. You will first be examined using a clinical rating scale during an "off" medication state. You will then be asked to take your medications. The examination will be repeated during your "on" medication state. The total evaluation often lasts 1-2 hours. Please keep in mind that if you have difficulty walking during your "off" medication state, then you should bring a wheelchair or walker to the appointment.

For patients with **Essential Tremor or Dystonia**, an "off"/"on" medication evaluation may not be completed. However, your examination may be videotaped.

2) Consultation with Dr. Mark Richardson, Neurosurgeon

During the initial meeting, Dr. Richardson and his physician assistants, Danielle Wagner or Alicia Olson, will explain the surgical procedure, review potential risks of surgery and benefits, and evaluate your candidacy for surgery. Please note that a consultation with Dr. Richardson does not require you to be committed to DBS surgery. The purpose of the initial consultation is so that you may have your questions answered by the surgeon and get to know the team.

3) Neuropsychological evaluation with Dr. Luke Henry

This evaluation includes extensive testing of memory, language, and attention. This test may take up to 4 hours. Please take your medications as normally scheduled. You may bring your medications to this visit.

4) Brain MRI

Imaging of your brain will be ordered and reviewed by your Neurosurgeon and Neurologist.

5) Physical Therapy Evaluation, if needed

You may meet with a physical therapist who specializes in management of gait difficulties associated with neurologic conditions. She or he will evaluate your gait and motor function prior to DBS surgery and 6 months following DBS surgery/programming.

6) Speech Evaluation, if needed

You may meet with a Speech specialist for an evaluation of speech and swallowing prior to DBS surgery and following DBS surgery/programming.



Once these evaluations are completed, we will discuss your case at our **Multidisciplinary Movement Disorders Team Meeting**. This information will allow the team to determine the best treatment plan for you. After the meeting, we will discuss the plan with you either by phone or in a follow-up clinic visit.

DBS SURGICAL PROCEDURES AT UPMC

UPMC offers two types of DBS surgical procedures performed by Dr. Mark Richardson:

1) **Microelectrode Recording (MER)-Guided or “Awake” DBS:**

The surgeon uses preoperative MRI images to plan the procedure. The patient is under light anesthesia and awake for a portion of the surgery, but experiences minimal to no pain. In order to verify that the electrode is in the intended location, microelectrode recordings are used to map the target brain region. Once the desired trajectory is verified, the actual DBS electrode is inserted and turned on temporarily to test for symptom improvement and side effects.

2) **Interventional MRI (iMRI)-Guided or “Asleep” DBS:**

The surgeon uses MRI to guide DBS electrode placement in real-time, while the patient is under general anesthesia. Testing the electrode is not necessary as its location is determined at the time of implantation.

Please discuss with your Neurologist and Neurosurgeon which is the surgical procedure best suited for you.

The awake, MER-guided procedure is best suited for patients who would like to communicate with the team during the procedure, and possibly participate in neurophysiology research. The asleep, MRI-guided procedure is typically reserved for those patients who are symptomatic, or too anxious, to undergo awake surgery.



Stages of surgery: Implantation of the DBS system occurs in two stages.

- The first stage is placement of the electrodes, as described above. If indicated, both sides of the brain are usually implanted in the same procedure.
- The second stage is placement of a lead extender and internal pulse generator (we commonly refer to this as the “battery”) on each side of the body.

DBS SURGERY PLANNING

If the team determines that you are a candidate for DBS surgery, and you wish to proceed with surgery, then the following will be arranged by the Neurosurgery team:

- 1) **Surgery scheduling.**
- 2) **A brain MRI for surgical planning.**
- 3) **Pre-operative physical examination and testing.**
 - Includes a general physical examination, which may be completed by your PCP.
 - Pre-operative testing includes blood-drawn labs, EKG, and Chest x-ray.
 - If you have ongoing medical conditions such as heart disease or diabetes, or if you are taking blood-thinners, please discuss this information during your visit with the Neurosurgery team.

Continue your medications for Parkinson's disease during this time. You will continue these medications after surgery. Medications may be adjusted at the first initial programming visit after surgery.



Surgical Risks:

Potential risks of surgery include complications of bleeding or infection. It is also important to note that it is possible that an individual patient will not benefit from DBS surgery or programming.

PREPARING FOR DBS SURGERY

DBS PRE-OPERATIVE INSTRUCTIONS

DIAGNOSIS: _____

SURGERY: _____

DATE: _____

You are required to complete basic pre-operative testing before your upcoming surgery. Please complete your testing no later than 7 days prior to your surgery date. The history and physical and blood work expire 30 days after completed. The chest X-ray and EKG expire 90 days after completed. If you need medical clearance by a specialist, such as a cardiologist, arrange for your appointment as soon as possible as they often require special testing to be done prior to giving clearance for surgery.

The day before your surgery, you can expect a call from one of the pre-op nurses with information regarding your arrival time, scheduled surgery start time, and instructions about the surgical process and where to report for surgery. We are unable to confirm your scheduled arrival time until the day before. Unless otherwise directed, the morning of your surgery you may take any regularly scheduled medications with a small sip of water. You may not eat or drink for 8 hours before your surgery.

Remember to discontinue use of any medication that increases bleeding risk for 14 days prior to surgery (see attached list of medications to avoid before surgery). If you do take any blood-thinning medication within 2 weeks of your surgery, the surgery will be cancelled and rescheduled for a later date. If you experience any mild pain or headache within one week of surgery, the only approved over-the-counter pain medicine to take is Tylenol or its generic equivalent acetaminophen.

YOUR PRE-OP CHECKLIST: The following must be completed no sooner than 30 days and no later than 7 days before your surgery

DUE BY: _____

** It is YOUR responsibility to complete this testing and to be sure it is faxed to us by the above due date. Failure to do so will result in rescheduling your surgery for a later date.

- | | |
|---|--|
| <input type="checkbox"/> Visit with PCP | <input type="checkbox"/> Chest x-ray (90 days) |
| <input type="checkbox"/> History and Physical (PCP's clearance) | <input type="checkbox"/> EKG (90 days) |
| <input type="checkbox"/> Blood work (CBC, BMP, PT/PTT) | <input type="checkbox"/> Specialist clearance |

This testing can be performed at any medical facility as long as the results are sent to us. It may be easier to have your pre-op testing completed at our **Pre-operative Evaluation Center (PEC)** located on the 5th floor of Montefiore Hospital in Oakland (right next to Presbyterian). They can perform all your testing quickly within this outpatient clinic and you would NOT need to see your PCP.

- If you wish to schedule an appointment for the PEC, please call 412-692-4663.
- Otherwise, have all results sent to us at the fax below:

Danielle Wagner, PA-C, Physician Assistant to Dr. Mark Richardson
Phone: 412-864-3421
Fax: 412-647-4775

Medications to Avoid Prior to Surgery:

warfarin (Coumadin)- Must be discontinued 3-5 days before surgery under the guidance of your cardiologist or primary care physician. Please contact their office for instructions about stopping this medication and to make sure it is safe to do so. Your PT/INR (blood work) must be completely normal the morning of surgery.

clopidogrel (Plavix)- Must be discontinued 7 days before surgery under the guidance of your cardiologist or primary care physician. Please contact their office to make sure it is safe to stop this medication.

aspirin (Bayer, Bufferin, Ecotrin, St. Joseph, and ALL other brands)- Must be discontinued 14 days before surgery under the guidance of your cardiologist or primary care physician. Please contact their office to make sure it is safe to stop this medication.

NSAIDs (non-steroidal anti-inflammatory drugs)- Must be discontinued 14 days before surgery. Many NSAIDs are available over the counter and some by prescription only. They are commonly used to treat pain, inflammation, and fever. This category of medicines includes:

- ibuprofen (Advil, Motrin, and others)
- naproxen (Aleve, Naprosyn, and others)
- celecoxib (Celebrex)
- indomethacin (Indocin), etodolac (Lodine), ketorolac (Toradol), diclofenac (Voltaren, Cataflam), meloxicam (Mobic), and some others that are less common
- Some of these medications are used in topical forms (gels, pastes, etc) and these must also be discontinued before surgery
- Please remember the only over the counter pain medicine that is safe to use within 2 weeks of surgery is acetaminophen (Tylenol)

Miscellaneous medications:

The following medications must be discontinued 14 days before surgery:

- Alka-Seltzer, Midol, Pepto-Bismol

The following medications must be discontinued 48 hours before surgery:

- sildenafil (Viagra), tadalafil (Cialis), vardenafil (Levitra)

Vitamins- The following must be discontinued 14 days before surgery:

- Vitamin E (including any multivitamin that contains Vitamin E)

Supplements- The following must be discontinued 14 days before surgery:

- Fish oil or Omega 3 (This includes the prescription drug Lovaza)
- Coenzyme Q10

If you have any questions about medications to avoid prior to surgery, please contact Danielle Wagner at 412-864-3421.

INFECTION PREVENTION

Please read thoroughly.

Infection is a risk of any surgery, but an infection can be more serious in surgeries where a foreign device is placed in the body. We take every precaution to prevent this from happening, and now there is something you can do to help.

Hibiclens (chlorhexidine gluconate 4% solution)

Hibiclens is a medicated soap that kills germs that normally live on your skin. Its use has been shown to reduce the risk of surgical infection.

- Instructions for use:
 - Beginning 4 days before your surgery on _____, *as well as the morning of your surgery*, Hibiclens should be used in place of your regular soap or body wash. Apply Hibiclens to a wet washcloth and clean from your neck to your toes, including your arms and legs, front and back. To clean thoroughly, this should take about 3 minutes. Rinse with warm water. Pat yourself dry with a clean towel.
 - Do not use regular soap, powders, lotions, or creams on areas where Hibiclens was applied.
 - Do not use Hibiclens on your face or genital area.
- How to get Hibiclens:
 - You will receive a bottle in our office during your clinic visit scheduled _____.
 - A prescription has been sent electronically to your pharmacy.
 - It can be bought over-the-counter at most pharmacies. You do not have to buy this particular brand. You can buy any generic equivalent. A bottle should be \$10 or less.

Nasal swab for MRSA

MRSA is a “super-bug” that is resistant to many antibiotics. Many people have this bacteria living on their skin, and it does not cause an infection. However, when the skin is cut, like in surgery, the bacteria can infect the wound. We want to identify the patients who are carriers of MRSA and treat them before surgery to decrease the risk of this particular infection. We can do this by simply taking a culture from your nose with a cotton swab.

- You will be tested during your clinic visit scheduled _____.
- You will not be tested because you do not have a clinic visit scheduled.

Please call if you wish to come in to be tested.

If your culture is positive for MRSA, you will be notified and a prescription will be sent to your pharmacy for mupirocin ointment. You should apply the ointment inside both nostrils twice daily for 5 days before surgery.

DBS POST-OPERATIVE INSTRUCTIONS

Expectations

- There are two stages to DBS surgery. After the first stage you may be required to spend 1-3 days in the hospital. A majority of patients are discharged home after the first day, but some are required a longer hospital stay or require further rehabilitation at a rehab facility after surgery. The second stage of the surgery is typically an outpatient procedure.
- Although your DBS is not turned on, you might feel like your symptoms are improved for a few days after surgery. This effect should wear off before your initial programming.
- You will likely experience some facial swelling after surgery. Sometimes this swelling occurs immediately, but sometimes it shows up a few days after surgery. Occasionally, it can be very severe and also cause the skin under your eyes to look bruised. This is **NORMAL**. It will resolve on its own within a few days, but sometimes can take a week or more. It will continue to get better every day. Some things you can do to help it along:
 - Spend more time sitting/standing upright than lying flat
 - Apply an ice pack
 - Take Tylenol if it becomes painful

Wound Care

- You may remove any bandages from your head after 2 days.
- On day 3, please begin washing your hair once daily, using baby shampoo. It is ok to get your incisions wet and soapy. Gently rub some shampoo onto the incision with the pads of your fingers. Do not scratch or scrub with your nails. Washing the incisions daily helps keep the area clean and prevent infection.
- You may remove bandages from your chest after 5 days.
 - It is ok to shower before day 5. These dressings should be water-proof. If you suspect water has gotten inside the bandage, I would prefer you remove the dressing sooner than 5 days than have a soggy bandage over your incision. Moist environments breed bacteria.
 - Once these bandages are removed, it is ok to get these incisions wet and soapy just as above.

- You will probably notice white flakes around the chest incisions. This is skin glue that peels off in flakes. Don't pick at it! It will come off on its own with multiple showers.

Restrictions

- Once you get home, you may resume your normal activities as tolerated, except as below:
 - No lifting greater than 10-15 pounds for 30 days from your first surgery.
 - No vigorous exercise for 30 days from your first surgery. This includes anything that really increases your heart rate, such as running.
 - No driving for 2-4 weeks after your first surgery. The exact timing will be discussed at your follow up visit.

Follow up

- Your second surgery is scheduled for _____
- Your post-op visit/staple removal is scheduled for _____
- Your initial programming visit ("off" medications for 12 hours) is scheduled for _____

Reasons to call (Neurosurgery):

- Any questions about the above instructions
- If you develop a fever or notice any discharge from your incision
- If you develop any new symptom that you are concerned about

EXPECTATIONS FOR DBS PROGRAMMING

- DBS initial programming will take place in the Neurology Clinic 3-4 weeks after surgery (first stage).
- **Please come to the initial programming visit off medications for 12 hours.**

The first (initial) programming visit may take 1.5 to 2 hours. During the visit the clinician will turn the DBS device therapy “on”. Each electrode has four contacts. Each contact will be activated individually and the voltage slowly increased. As the voltage is increased you may experience benefit to symptoms or side effects. The side effects may be quickly reduced when the voltage is decreased. This process provides the clinician with information regarding the placement of the electrode and the settings that will provide the best benefit for your symptoms. The goals of the DBS programming include improving symptoms while avoiding side effects. Most side effects of DBS programming are experienced at the initial programming visit; however, in some instances side effects can be delayed. Please call our office if you experienced delayed side effects.

During the initial programming visit you may experience side effects of stimulation such as numbness, tingling, slurred speech, balance difficulty, facial pulling, or vision change. These symptoms may be temporary, but you must let your DBS programmer know, so that he/she may change the settings to reduce these symptoms.

Optimizing DBS programming may take up to 6 months. During this period we are also adjusting medications. Medications may be reduced once DBS programming is initiated.



DBS APPOINTMENT CHECKLIST

Please note, not ALL steps are required for all patients. Follow the instructions from your physicians.

- Consultation with a Movement Disorder Neurologist** 412-692-4670
Drs. Sarah Berman, Houman Homayoun, Valerie Suski or Amber Van Laar
Date: _____ Time: _____
- ON-OFF Examination by Neurology** (for PD patients) 412-692-4670
Please come to the clinic "off" medications for 12 hours, or as instructed
Date: _____ Time: _____
- Consultation with Dr. Mark Richardson, Neurosurgery** 1-877-986-9862
Take your medications as usual
Date: _____ Time: _____
- Neuropsychological Testing with Dr. Luke Henry** 412-647-6778
Take your medications as usual
Date: _____ Time: _____
- Brain MRI** *UPMC Imaging Services, 412-647-9729*
Take your medications as usual
Date: _____ Time: _____
- Physical Therapy Evaluation** *Centers for Rehab Services, 1-888-723-4277*
Take your medications as usual
Pre-op Date: _____ Time: _____
6 month Date: _____ Time: _____
- Speech Specialist Evaluation** *Voice Center, UPMC Mercy 412-232-7464*
Take your medications as usual
Date: _____ Time: _____
- Preoperative testing: labs/EKG/Chest x-ray**
Take your medications as usual
Date: _____ Time: _____
- Discussion of Pre-op/Post-op Instructions with Neurosurgery**
Take your medications as usual
Date: _____ Time: _____

SURGERY DATES: Stage 1 _____ Stage 2 _____

Additional resources:

For information about the UPMC Neurosurgery Program:

<http://www.neurosurgery.pitt.edu/centers-excellence/epilepsy-and-movement-disorders-program>

For helpful information from Medtronic, the manufacturer of DBS:

For patients with Parkinson's disease:

<http://www.medtronic.com/patients/parkinsons-disease/living-with/>

For patients with Essential Tremor:

<http://www.medtronic.com/patients/essential-tremor/living-with/>

For patients with Dystonia:

<http://www.medtronic.com/patients/dystonia/living-with/>