A Guide to Deep Brain Stimulation for Patients with Parkinson's Disease

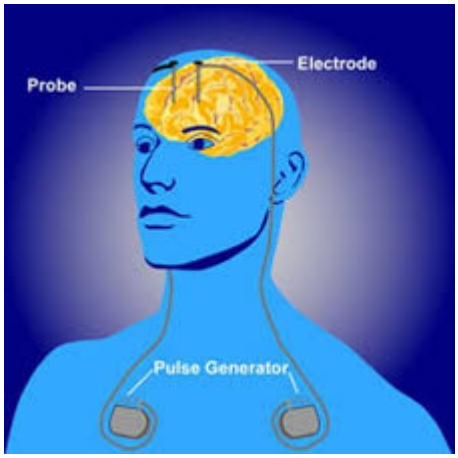
Thank you for your interest in Deep Brain Stimulation (DBS) at Boston Medical Center (BMC). Below, we have provided a general overview of DBS as well as information about our program. Please know that you will receive additional information that will be tailored to your specific needs. If at any time you have questions, you may always contact a member of our DBS team. Boston Medical Center has a long history of treating patients with Parkinson's disease.

Since 1978, the Parkinson's Disease and Movement Disorders Center has been providing patients with comprehensive care including the most current medical and surgical therapies. DBS has been performed at BMC since 2002. It is a proven surgical option for the treatment of Parkinson's disease, essential tremor, and dystonia. At BMC, an interdisciplinary team approach is used in DBS evaluation, surgery, and follow-up care. Our team includes experts from neurology, neurosurgery, neuropsychiatry, behavioral medicine, anesthesiology, and nursing. Our comprehensive care team provides support before, during, and after surgery. We are pleased to be able to offer this established and approved treatment to our patients.

What is DBS?

The Food and Drug administration approved DBS for Parkinson's disease in 2002. DBS can reduce symptoms such as tremor, slowness of movement, stiffness, and dyskinesia (involuntary, dance-like movements). By reducing these symptoms, it can improve quality of life. DBS is essentially a pacemaker for the brain.

The DBS system is composed of three parts that are surgically placed: the lead, the extension wire, and the pulse generator. The lead is connected to an extension wire that goes underneath the skin from the head to the neurostimulator, which is located in the chest below the collarbone. The neurostimulator delivers intermittent electrical pulses to targeted areas of the brain that control movement. The neurostimulator is programmed during office visits by your neurologist so that it gives you the best possible improvement in your symptoms. It can be adjusted over time, which provides flexibility in treating symptoms. There is also a small hand-held patient programmer that allows you to adjust certain settings at home if needed.



Credit: nimh.nih.gov

What are the Benefits of DBS for Parkinson's Disease?
Many symptoms can improve with DBS including:

- Dyskinesia or dystonia
- Tremor
- Levodopa-responsive walking abnormalities (such as shuffling)
- Muscle stiffness
- Slowness of movement

It is important to understand that some symptoms that will NOT improve with DBS, including:

- Non-levodopa responsive symptoms such as urinary dysfunction, constipation, difficulty with swallowing, memory, or mood
- Balance abnormalities
- Walking abnormalities that DO NOT respond to levodopa

Who Benefits from DBS?
Deep Brain Stimulation should be considered by patients with Parkinson's disease who respond to levodopa therapy but have medication side effects or motor fluctuations throughout the day despite being on optimal medical treatment. DBS can improve function and quality of life by reducing dyskinesia, increasing "on" time, reducing severity of "off" symptoms, and allowing medications to be reduced.

Patients who typically benefit overall from DBS are those at low risk for surgical complications. Through discussions with your doctor and the extensive screening process, it will be determined if you would benefit from DBS treatment.

If you are a DBS candidate, your primary neurologic condition must be idiopathic (or common form) of Parkinson's disease. You should have significant motor fluctuations requiring frequent doses, medication side effects, or a tremor that does not respond to medication.

Who is NOT a candidate for DBS?
Implanting a DBS device involves brain surgery and therefore patients who have significant surgical risks are not candidates for DBS. This includes medical conditions that make surgery impossible such as a problem with blood clotting. Your doctor will help determine if brain surgery is too risky for you based on your medical history. DBS is not appropriate for patients with the following conditions:

- Atypical Parkinsonism (such as multiple systems atrophy and progressive supranuclear palsy,
- Dementia or severe cognitive impairment
- MRI showing extensive loss of brain tissue or white matter disease
- Uncontrolled psychiatric illnesses such as anxiety or mood disorders
- Brain abnormalities that limit placement of the DBS lead

What are the risks of DBS surgery?
DBS surgery is an elective surgery that involves making a small hole in the skull through which the lead is placed into a target in the brain. Like most surgeries, complications may include infection (approximately 5%) or bleeding (less than 2% risk overall, 1-1.5% risk of severe hemorrhage). A full discussion of risks and benefits associated with the surgery will be discussed by the neurosurgeon.

Is DBS covered by insurance?
Most health insurances do cover DBS surgery for eligible patients. This includes Medicare when certain standard criteria are met. Private insurance plans will cover the cost of DBS surgery but may ask for a prior authorization or documentation detailing the need for surgery. Please check with your private insurance plan what copays or coinsurance you may be responsible for.

What is the process for undergoing DBS?
The steps for DBS at BMC are as follows:

Screening Process
You will initially undergo a full screening process prior to scheduling surgery. This includes:

- An MRI scan- Magnetic Resonance Imaging is a diagnostic technique that uses magnetic fields and radio waves to make detailed images of your brain.
- Neuropsychological testing – a series of standardized tests (questionnaires and interview) that measure thinking skills including attention, memory, planning, organization, motivation, and mood. The tests are administered and reviewed by a neuropsychologist. Generally the testing takes about two hours to complete.
- Evaluation by DBS neurologist – All DBS candidates will meet one of our DBS neurologists who will provide a thorough evaluation and discuss pre and post-operative procedures with you.
- On/Off testing –On/Off testing is an important part of the screening process to evaluate your response to levodopa. You will be asked to come into the outpatient office having

not taken your Parkinson's medications for about 12 hours. You will usually arrive in an "off" state meaning you may be slower or have difficulty moving. It is always important to have a family member or friend accompany you to this session. A series of tests are done which measure movement. You will then receive your usual dose of Parkinson's medication. Then, the same tests are repeated in the "on" state. On/Off testing is conducted in the morning so that you will experience the least amount of discomfort. On/Off testing is videotaped so that the team can see your motor state both ways. We will ask you to consent to videotaping. This will only be used for review by the healthcare team. On/Off testing generally takes about three hours.

- A psychological interview is performed by a psychologist as needed, to screen for mood and behavior.

These steps help to determine if you are a good DBS candidate. Once these are completed, you will meet with the neurosurgeon to discuss the procedure more fully including the risks and benefits. At the end of this meeting, your surgery date will be scheduled and insurance approval requested.

Surgery

If you have scheduled DBS surgery, you may have the option to be admitted to Boston Medical Center the night prior to surgery. Your Parkinson's medications will be discontinued before going to bed and will not be resumed until after surgery. Surgery requires that you are awake and interacting with the DBS neurologist during the procedure. A metal frame will be placed on your head and a CT scan will be obtained. This allows the neurosurgeon to accurately locate the part of your brain where the lead goes. You are then brought into the operating room and a small hole is drilled into your skull through which the lead is placed. During the procedure, you will be asked to perform certain tasks in order for the neurologist and neurosurgeon to confirm that the lead is in the correct location.

Post-Operative Care

Following surgery, you will resume your regular medication schedule and stay overnight. Once a CT scan is completed, you will be discharged home. The wound dressing can be removed 3 days after surgery. An appointment with your neurosurgeon will be scheduled to check that the wound is healing well.

Battery Placement

Battery placement is scheduled within weeks after the lead is placed. This is an outpatient procedure performed while you are under general anesthesia (fully sedated). During this surgery, a small incision is made in your chest wall and the neurostimulator is placed. It is then connected to the lead in the brain.

Initial Programming

Approximately 4-5 weeks after lead placement, you will have your initial programming which is a prolonged visit with the DBS neurologist. During this visit, the DBS is turned on and multiple settings are tried to see which configuration provides the most benefit. Some symptoms will

respond immediately to the stimulation while others will take weeks for benefit to be seen. Optimal programming may take weeks to months and is individualized for each patient. During these sessions, you will be educated on how to use your patient programmer. During this visit, your Parkinson's medications may be decreased or adjusted.

Physical Therapy

After successful DBS adjustments, you may consult with a physical therapist to help you adjust to your new, improved symptoms. Your movements will improve with DBS and this will need some getting used to. The physical therapist will evaluate your walking and balance and provide a proper exercise program for you.

Neurostimulator Replacement

The neurostimulator will need to be replaced approximately every 3-5 years depending on the settings of the stimulator and the type of battery used. Surgery will be scheduled when the battery is at a certain threshold. This ensures the battery does not become critically low or run out. This procedure is similar to the initial battery placement and will be done under general anesthesia. It takes less than an hour to remove the old battery and place a new one, and you will go home on the same day.

Long Term Management

Over time, DBS may need to be adjusted for symptom control. You will have regular follow-up appointments with your DBS neurologist. Battery life will be checked at these appointments and any required adjustments will be made. DBS will not change your need for general Parkinson's care. You will be referred to physical therapy and community resources as needed. We are here to support you along the way.

What are side effects of DBS?

Potential side effects from stimulation may include changes in your voice, balance, muscle stiffness, or gait. These are often reduced with adjustments in programming the DBS. There is also the possibility of infection. You will receive information on signs and symptoms of infection and should report any symptoms to your physician or DBS doctor.

Other safety precautions:

MRI: Neurostimulators are MRI compatible with strict radiology scanning guidelines and certain stimulation settings. When you are planning to have an MRI, the manufacturer of your device can help facilitate a safe scan by instructing you and the radiologist on what criteria are needed for the scan to be completed. We will provide you the appropriate information specific to your device.

Other scans (CT, X-rays): These scans are safe with DBS. Let the provider know that you have an implanted device.

EKG, EEG, and EMG: These tests are all safe with DBS but you may need to turn the stimulator off to keep it from interfering with the test readings.

Other safety precautions include:

- Wearing a seatbelt when in cars
- Wearing a helmet when skiing, biking, riding a motorcycle, or horseback riding
- Avoiding rollercoasters or other rides with fast acceleration
- Avoid bungee jumping, sky diving, or other extreme sports.

Hospitalization/Surgery

If there is a change in your health status, requiring hospital admission or surgery - be sure to inform your DBS doctor.

Frequently Asked Questions:

- ***Can surgery be performed on both sides of the brain?***
  Yes. Both sides are typically done during the same surgery. Each side can be done on different days if needed or preferred.

- ***How active can I be after I get DBS?***
  Until wounds are healed, heavy lifting (more than 10 lbs.), far reaching/stretching, strenuous activity or swimming should be avoided until about 3 weeks post-operative. Once you have healed, you can resume most of your daily activities but there are some restrictions once you have a DBS system implanted.

- ***Can I turn the DBS off?***
  Yes. During your neurology visits you will be taught how do this using your patient programmer.

- ***What are long- term results?***
  Long-term studies show that the benefits from DBS are still present at ten-year follow up, but DBS does not appear to prevent disease progression.

- ***What if I fall on my DBS?***
  If you fall on the stimulator or get into an accident where your head moves suddenly (such as a whiplash injury), and if you notice symptoms return, we may be able to help you check your device on your own to ensure that it is working properly. For further evaluation, you may need to come to the clinic to have the DBS checked by your neurologist.

- ***What happens if my battery runs out or the DBS stops working?***
  Typically, patients will notice a significant worsening in their symptoms such as difficulty walking, worsening tremor, and stiffness. You should contact your neurologist who will evaluate the functioning of the DBS system. During this time, your medication may be adjusted and battery replacement may need to be scheduled.

- ***Will my DBS system or scars be noticeable?***
  The DBS system is fully implanted under the skin. You may be able to feel the pulse generators under the skin on your chest similar to a cardiac pacemaker. Some people can feel or see the extension wire under the skin of their neck. You will be able to feel the site on your head where the wire is located. The surgical scars will be noticeable initially but will fade over time.

- ***How can I prevent damage to the system?***
  Use precaution when walking. Avoid contact sports or other activities where you can receive blows to the head or neck. Avoid cervical "neck" manipulation.

- ***Should I tell my other medical doctors and dentist about my DBS surgery?***
  Yes, all providers should be aware that you have a Deep Brain Stimulator, as certain procedures (such as EKG or surgery) must be done with the stimulator turned off.

- ***What must I avoid?***
  Diathermy (also known as therapeutic ultrasound) must be avoided once you have a DBS. Use caution with hot tubs, tanning beds, and electric blankets so that they do not heat the system and damage it.

For additional Information:

Boston University Medical Center Parkinson Program:
http://www.bumc.bu.edu/parkinsonsdisease/

Boston Medical Center Department of Neurology:
https://www.bmc.org/parkinsons-disease-movement-disorders-center

Boston Medical Center Department of Neurosurgery:
https://www.bmc.org/neurosurgery

Medtronic website:
https://www.medtronic.com/us-en/patients/treatments-therapies/deep-brain-stimulation-parkinsons-disease.html

Abbott website:
https://www.abbott.com/life-changing-tech/parkinsons-tremor-and-dbs.html

Boston Scientific website:
https://dbsandme.com/

Spotlight on DBS - APDA Webinar
https://www.apdaparkinson.org/webinar/the-abcs-of-dbs/

American Parkinson Disease Association Deep Brain Stimulation Support Group at Boston Medical Center:
For information, contact the APDA Information and Referral Center at 1-800-651-8466

To contact us Call 617-638-8456 and request to speak with a member of the DBS team

DBS Team

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