

Your Guide to DBS

*For patients, family, and friends interested
in learning more about Deep Brain Stimulation (DBS)*

What is Deep Brain Stimulation or DBS?

DBS is an invaluable tool to improve the symptoms of Parkinson's disease, essential tremor, or dystonia, that works like a pacemaker for the brain. Implanted by our highly specialized neurosurgeons and programmed by our movement disorders specialists, this revolutionary technology targets the source of these conditions to deliver a carefully controlled electrical stimulation to targeted areas, interrupting the brain's faulty signals. DBS has been FDA approved since the mid-1990s and has been widely used since that time. Its value has been proven in a large number of international studies that show both immediate and long-term benefit.

What symptoms can DBS relieve?

- Parkinson's Disease – improvement in or resolution of tremor, rigidity, bradykinesia, akinesia, and dyskinesia. Possible improvements in balance and gait, and some non-motor symptoms such as anxiety. In general, symptoms that respond to medication can be expected to improve with DBS, and symptoms that are a product of the fluctuations of medication can also improve as well.
- Essential Tremor – tremor improvement or resolution.
- Dystonia – dystonia improvement or resolution.

For Parkinson's Disease

Reduction in medications by 60-80% leads to a decrease in:

- Cost of medications and co-pays.
- Side effects (nausea, low blood pressure upon standing, cognitive change, and future dyskinesia risk).
- Polypharmacy (multiple prescription medications).

Many patients with DBS still take oral medication, but the DBS becomes the main driver of therapy, supplemented with less medication than before. Over time, we adjust the DBS and medications to optimize care.

For Essential Tremor and Dystonia

Reduction or elimination of medication leads to a decrease or removal of the following:

- Medications, including the possibility of not needing medication.
- Cost of medications and co-pays.
- Side effects (cognitive change, fatigue, lethargy, etc.).

Success Rates for DBS Treatment

With proper screening and programming, DBS leads to the following benefits:

Parkinson's Disease	Essential Tremor
<ul style="list-style-type: none">• 80% to 90% improvement from baseline in subjective patient quality of life scores• 60% reduction in medications• 60% reduction in dyskinesias• 80% improvement in "off" periods• 10% improvement in "on" periods	<ul style="list-style-type: none">• 80% improvement in tremor• 70% improvement in handwriting• Significant reduction in medications• Improvements in periods of good mobility from 26% to 74% of the day

Am I a Candidate For DBS?

A consultation with our movement disorders specialists can help you understand the risks and benefits and determine whether DBS may be right for you.

In the past, people were told to consider DBS as a last resort, but now earlier surgery is considered more helpful so that people can enjoy their optimal quality of life for longer. If the result is smooth, consistent symptom control with 60-70% less medication (or no medication with ET), then we need to consider DBS earlier.

If you meet the following criteria, DBS may be the right treatment option for you:

Parkinson's Disease	Essential Tremor or Dystonia
<ul style="list-style-type: none"> • Symptoms for at least 4 years • Documented response to medications • Fluctuations in symptoms during the day or side effects to medication 	<ul style="list-style-type: none"> • Moderate to severe symptoms or symptoms not adequately controlled with medication • Symptoms affecting daily activities such as eating, drinking, dressing, etc.

- Cognitively intact (no sign of dementia); age related cognitive change is allowed. Overall healthy, good surgical candidate.

Adaptable to Meet Changing Needs

As your disease changes over time, the DBS device will be adjusted to better address new or changing symptoms. It will become an integral tool in your treatment plan, working in conjunction with medication, rehabilitation, etc. to keep you living your best life.

Unique options through the Inova Movement Disorders Center



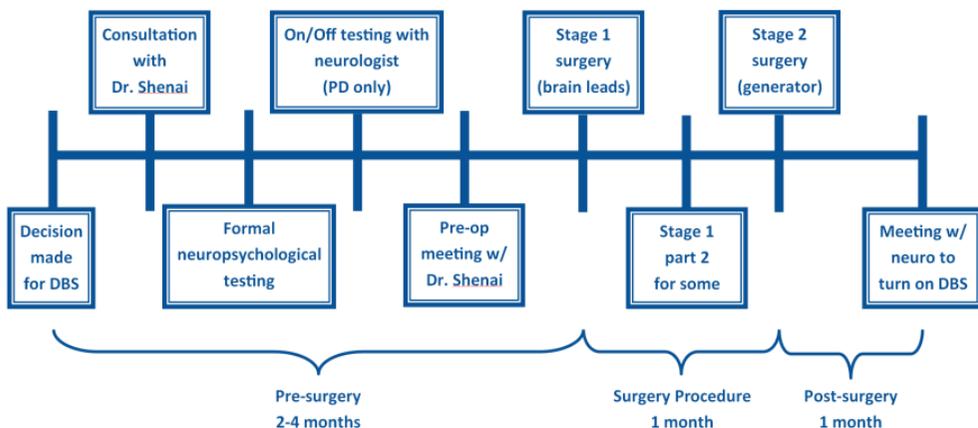
- State-of-the-art operating room designed for DBS.
- Ability to perform MRI-guided DBS where the procedure is performed **'asleep' under anesthesia.**
- Both Medtronic and Abbott Directional DBS devices available.
- Complete multidisciplinary team under one Center.
- Home to nationally recognized DBS programming specialists who train other physicians in DBS.

What are the risks?

DBS is quite safe and effective in carefully selected patients. However, as with any surgery, there are potential risks that must be considered. These include a 1-2% risk of stroke or brain bleeding causing new symptoms and a 3-4% risk of infection, which in extreme cases may require removal of the DBS for treatment. There is also a small risk of other events such as seizure, device malfunction, speech, motor and/or cognitive difficulties. All these risks are rare and, in most cases, do not cause permanent harm if they do occur. This will be discussed in detail during the neurosurgery consultation.

Side effects of stimulation are generally mild and reversible and may include tingling in the face or limbs, temporary pain/swelling at the site of implantation, speech or vision problems, jolting or shocking sensation, loss of balance, dizziness, reduced coordination, and concentration difficulties. **If there are any side effects to the DBS stimulation, the settings usually can be adjusted to minimize or eliminate these issues.**

Once you have made the decision to have DBS surgery what happens next?



First, you will be referred to our Neurosurgeon – Dr. Mahesh Shenai



Your movement disorders specialist will refer you to our neurosurgeon to explain the surgery process and discuss the options that are best for you. Your appointment will take about an hour and you will have the opportunity to ask questions.

Although our neurosurgeon has access to your medical records within the Inova system it would be helpful to:

- Advise of any other medical conditions and treatments you are undergoing that may impact surgery.
- Bring a current list of medications and questions.

You will leave with an Inova surgery packet, as well as instructions and referrals for pre-surgery testing. Please e-mail Sonia after this meeting with any questions or logistical issues (Sonia.Gow@inova.org).

Pre-surgery testing

Your neurologist will only recommend proceeding if he/she believes you are a good candidate for DBS. Referrals are transferable from one doctor to another if you are unable to make an appointment with the doctor named in the referral.

You will have requirements from the surgery team as well as requirements from the neurology team, outlined as follow.

Throughout this process, if you have any questions, please contact the neurosurgery nurse practitioner (Zahra.Mohseni@inova.org) or patient navigator (Sonia.Gow@inova.org).

Pre-surgery To Do List:

On/Off testing with your Movement Disorders Specialist (Parkinson's patients only)

This clinic meeting lasts around 2 hours. You will be advised to stop taking your Parkinson medications the night before and not to take them the morning of the appointment, but please **bring them with you.**

Your doctor will need to observe your symptoms off medication, and then how your symptoms react after you have taken your medication. This change is important to predict the effect of DBS and is important for insurance approval for the device. You might want to bring a book to read, some music to listen to, water, or a snack as you will be waiting for much of the time.

Schedule neuropsychological testing - *Important!*

This is an in-depth assessment of your neurocognitive functioning, which can take up to 4 hours. This is the first test you should schedule as it can take 4-6 weeks to produce the report. This testing serves to clear you cognitively for the surgery and give a baseline of cognitive functioning (great to have).

To make an appointment with one of our neuropsychologists, please contact Emily Gamez at 703-970-6610 to help ensure a timely appointment, and also email Sonia with the request (Sonia.Gow@inova.org) so that she can support your scheduling.

Pre-surgery To Do List (cont.):

Schedule your surgery

As soon as you have your neuropsychological testing scheduled, you may schedule your surgery. A scheduler with the neurosurgeon's office will do this for you.

You can email Zahra for help (Zahra.Mohseni@inova.org).

Schedule initial programming visit

This is a clinic visit with your neurologist/movement disorders specialist 4-6 weeks after your Stage 1 surgery (the first surgery). You can plan for this visit to take about 4 hours.

Once the surgery is scheduled, email Sonia to schedule the initial programming visit (Sonia.Gow@inova.org).

Schedule MRI of the brain

This is a special MRI that will assist the neurosurgeon with placement of the lead(s). If you are anxious, ask about medications you can take to remain calm during the scan. It is important to take your Parkinson's medications the day of the MRI to prevent movement during the scan.

There is only one place for this particular MRI:

Please call **Fairfax Radiology Center (703)-204-8333** to schedule your imaging at Fairfax MRI center, **Magnet 1**.

Location: Fairfax Radiology Center

8081 Innovation Park Drive, The Pavilion-3rd Floor

Fairfax VA 22031

Pre-surgery To Do List (cont.):

Visit to primary care physician

Please schedule an appointment with your primary care physician within 30 days prior to surgery to confirm that you are in good health for the surgery. This type of appointment is required for all surgeries and anesthesia. Your primary care physician will provide a letter stating your level of risk for surgery and anesthesia, as well as any instructions for post-operative management.

If your primary care physician has any questions, our neurosurgery nurse practitioner, Zahra, can assist via email (Zahra.Mohseni@inova.org).

Inova pre-surgery interview

This interview is done by the hospital for all planned surgeries. They will review your medications, history, etc. to confirm that records are up to date.

You can email Zahra if you need help scheduling (Zahra.Mohseni@inova.org).

The Surgery Process

1) Implantation of the Electrodes

The surgery will take place at Inova Fairfax Hospital in the Surgery Center, typically on a Thursday morning.

You will be advised what medications to stop or continue prior to your surgery, when to stop eating and drinking, what time to arrive, and when your surgery will begin. You will also be advised to not take your Parkinson's/essential tremor medications for 12 hours before the surgery. We need your symptoms to be present during the surgery to monitor response to therapy.

The standard approach to DBS is an "awake" surgery, as this allows your symptoms to be present during the procedure. Using test stimulation in the operating room, we can watch symptoms respond in real time to help confirm correct placement of the electrodes.

We also have the option of completing the surgery "asleep" (under anesthesia), where we use the real-time images of an MRI scan to place the leads in the correct location. This is used for patients who would not be able to complete the surgery "awake" for various reasons. "Awake" surgery is preferred, as you are able to participate in the surgery to confirm that the leads are in the correct spot by showing symptom improvement/resolution and no side effects to test stimulation during the procedure (described in more detail below).

A mild sedative can be given during the procedure if needed, though we try to avoid this as this could affect the placement of the electrodes by reducing symptoms and confusing the results. There will be additional staff with you to ensure your comfort through the procedure.

A catheter will be inserted to alleviate bathroom concerns. A special metal frame will be attached to your head with four screws. Local anesthesia will minimize discomfort though you will feel some pressure. When you are moved to the operating table the frame will be attached to the table, so your head does not move, while your arms and legs are free to move.

You will then have a CT scan, which will be merged with the pre-surgery MRI, and the team will then make the final plan for the approach and coordinates to target for the lead(s). A small area of hair is shaved for surgery; depending on your hair style and length, this can often be covered.

You may be lightly sedated, and topical anesthesia is applied before any incision is made. One (or two) holes about the size of a nickel will be drilled in your skull to allow placement of the leads. During this part of the procedure, you will not feel pain, but you will hear the drill and feel vibration from the drilling. This is very quick, lasting under a minute.

A recording electrode is then inserted into the brain and placed in the exact pre-determined position. The brain does not feel pain so you will not feel any discomfort. During this process, we (and you) will be able to listen to the firing patterns of your brain.

You will be asked questions and may be asked to perform tasks to ensure each electrode is placed in the correct position. The electrode will be turned on, and the team will look for symptom improvement or side effects to ensure it is in the correct place.

Next, the recording electrode will be removed and replaced with the permanent electrode and a similar process is repeated to again ensure that placement is correct.

When the team has determined that the electrode has been placed correctly, a cap will be placed over the hole to keep the electrode in place, and the incision will be closed.

For most patients, two leads need to be placed, one on each side of the brain. This is either done in one surgery (a bilateral implantation) or two separate surgeries (the dominant side first, then return for the second side at a later date). Your treatment team will determine the best approach for you.

Time in the operating room can be around 3-4 hours, though the actual time of the 'operation' is only 2 hours. The remainder of the time is preparation and planning to allow for success.

[Notes concerning Inova Fairfax Hospital and administering medications to Parkinson's patients](#)

You can expect to stay overnight in Fairfax Hospital's Neurology Intermediate Care Unit (IMCU), and a family member can stay with you.

PLEASE BRING YOUR HOME MEDICATION WITH YOU, AS SOME OF YOUR MEDICATIONS MAY NOT BE AVAILABLE IN THE HOSPITAL PHARMACY.

Following DBS surgery, patients are expected to continue taking their Parkinson's and other prescription medications. For safety reasons, all prescription medications taken in the hospital must be dispensed from the hospital pharmacy and administered by skilled nurses.

Patients and caregivers should plan to bring all prescription medications in their original bottles with the pharmacy's label clearly visible. This information will be used by the hospital pharmacy to verify the medications and ensure the correct doses and schedule.

How will you feel once you are home?

Recovery is expected to take 1-2 weeks from the first surgery. You will go home with bandages around your scalp and will visit with Dr. Shenai's team within 1-2 weeks. You will have some mild scalp pain as it heals.

What is your medication schedule between surgeries?

After each surgery, you will continue your prior medication regimen unchanged. The medications will begin to be adjusted by your movement disorders specialist once the device is turned on.

2) Implantation of the Neurostimulator

The surgery to implant the neurostimulator (battery) usually takes place 2-3 weeks after your initial surgery to place the electrodes. This is also done at Inova Fairfax Hospital in the Surgery Center and will take about 30-60 minutes under general anesthesia.

YOU DO **NOT** STOP YOUR PARKINSON'S MEDICATION FOR THIS SURGERY. FOR ESSENTIAL TREMOR, WHETHER TO STOP YOUR MEDICATION IS UP TO THE ANESTHESIOLOGIST.

A portion of the scalp incision will be reopened to access the electrode(s). Another incision is made under the collarbone and the neurostimulator is placed under the skin.

An extension wire is passed from the electrode under the scalp, behind the ear, and down the neck to attach to the neurostimulator. The device may be seen as a raised outline under the skin, but usually is not visible under clothing. Nothing is left 'outside' the body; the entire system is internal.

You will not be required to stay in the hospital overnight after this surgery. For 7-10 days, you will want to be careful raising your arm, moving your head, or stretching your neck while the incision heals. Recovery from the second surgery is usually quicker than the first but will include bruising on the upper chest and neck where the generator is placed and the connection is made.

3) Initial programming of the device

Programming your device will take place 4-6 weeks after the first surgery, to allow time for the brain to fully heal. This is performed by your movement disorders specialist in our outpatient clinic and needs to be scheduled through Sonia during the pre-op phase (Sonia.Gow@inova.org).

For the day of this programming, it is extremely important that you **do not** take your Parkinson's disease or essential tremor medications that day. We need your symptoms to be present for this visit. **Bring your medication with you.**

This visit will first involve turning on the device and running a diagnostic check. We then go through each 'contact' on each lead, increasing the power until a benefit is seen, then going higher until a side effect is found. This is an important step as it 'maps' the contacts to tell the programmer where the best place is to stimulate. Though it is important to find them, these side effects are temporary and will stop when the device is turned off. It is important to find side effect thresholds at this visit so we can avoid them moving forward.

You will also receive a tutorial from a representative of the company that produces your device with instructions on how to make adjustments, what to do if you should fall, navigating airport security, and more.

As with the pre-surgery on/off testing, you might want to bring a book to read or some music to listen to, as you will be waiting for much of the time. Some snacks and water might be handy, too. You will leave this appointment with your device ON.

Your doctor can help you determine when you can resume your normal daily activities and exercise. Usually by the time your device is turned on at 4-6 weeks from the initial surgery, there are no limitations to activities or work.

And then, life with DBS!

From this point onward, adjusting the DBS will be a part of your regular visits with our clinic. Many patients achieve immediate symptom improvement, but this starts an ongoing process of reducing/adjusting your medications and adjusting the DBS.

DBS batteries typically last 4-5 years, although this could vary based on your individual settings. Replacing the battery requires a quick outpatient surgery, with minimal risk and inconvenience.

DBS is not a cure, but it can “turn back the clock” and the benefits have been shown to last forever. Even 30 years into a disorder, the DBS continues to serve its purpose and imparts some degree of benefit. While it will not relieve all of your symptoms or stop them from progressing, it can improve the quality of your life, extend the time that your symptoms can be controlled, and serve as a key tool in partnership with medication and rehabilitation to allow you to live your best life.

Contact Information

Website: Inova.org/move
Main number: 703-845-1500.

Sonia Gow

Program and Community Care Manager
Email: sonia.gow@inova.org
Phone: 703.375.9987



Zahra Monseni, NP – best contact for neurosurgery

Dr. Shenai's Nurse Practitioner
Email: Zahra.Mohseni@inova.org
Phone: 571-472-4100

Neuropsychology

For an appointment, please contact Emily Gamez at (703) 970-6610 and email Sonia (Sonia.Gow@inova.org).

Pre-Surgery MRI – only available at this MRI facility

Please call **Fairfax Radiology Center (703)-204-8333** to schedule your imaging at Fairfax MRI center, **Magnet 1**.

Location:

Fairfax Radiology Center
8081 Innovation Park Drive, The Pavilion-3rd Floor
Fairfax VA 22031

If you'd like to hear about other patients' experiences and how DBS had a positive impact on their lives, please have a look at the videos on our website at www.inova/move.