

Parkinson's Disease
Deep Brain
Stimulation

A Practical Guide for
Patients and Families

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Chapter 1

Introduction to Surgical Therapies for Parkinson's Disease

Parkinson's disease (PD) affects an estimated one million Americans including men and women of all ages and races, though it is slightly more common in men. Parkinson's is caused by a combination of genetic and environmental factors, with age being the main risk factor. There is no cure, but there are many excellent symptomatic treatments. Medications, exercise, nutrition, holistic approaches, and surgical treatment all have the potential to reduce symptoms and to improve quality of life. Common symptoms of PD include shaking (tremor), slowness of movement (bradykinesia), muscle stiffness (rigidity), and difficulty with balance (postural instability). These are referred to as the "motor" symptoms of PD. There are also many non-motor symptoms, including – most prominently – depression, anxiety, apathy, fatigue, and sexual dysfunction.

During the initial stages of PD (i.e., the first several years after a diagnosis), medications typically control symptoms in the majority of patients. As the disease progresses, however, individuals may need to take more medications, increase the dosages, and, in many cases, take their medications more frequently. As disease duration increases, people with PD may notice that throughout a typical day they will experience periods of adequate symptom control ("on time"), periods where symptoms are much more noticeable ("off time"), and periods where peak medication levels (usually an hour after taking a medication dose) produce involuntary movements. These involuntary movements are referred to as dyskinesia. When individuals change from one of these three states to another, they are said to have motor fluctuations.

The aim of this book is to describe a type of surgical treatment that can be utilized to reduce PD symptoms in a subset of carefully selected individuals with a specific symptom or symptoms potentially responsive to this type of therapy. The treatment is known as deep brain stimulation (DBS). DBS is a proven and effective surgery that can be applied to treat some, but not all, of the disabling symptoms of PD. There are several other surgeries that have been utilized to treat the symptoms of PD, and these include thalamotomy, pallidotomy, and subthalamotomy. We will discuss each of these alternative techniques, all of which rely on making a lesion in the brain, in the pages that follow. When applied with the appropriate level of expertise, these therapies may also be options for individuals with PD.

Pallidotomy, thalamotomy, and subthalamotomy

Pallidotomy, thalamotomy, and subthalamotomy are types of surgical procedures in which a tiny heated probe is inserted into a precise region of the brain to destroy tissue. When the region known as the globus pallidus internus is lesioned, we refer to the procedure as a pallidotomy. Similarly, when the part of the brain called the thalamus is treated, we call it a thalamotomy. And when the subthalamic nucleus is lesioned, we refer to the procedure as a subthalamotomy. Of these three procedures, pallidotomy has been the most widely applied over the last several decades to help relieve symptoms of PD.

A pallidotomy lesion has the potential to improve tremor, rigidity, bradykinesia, motor fluctuations, and, in a few special cases, walking and balance. Pallidotomies are only effective against PD symptoms that respond to levodopa (Sinemet), with the exceptions of tremor and dyskinesia. Tremor and dyskinesia may potentially respond to pallidotomy even if medications are not effective. Pallidotomy has its advantages over DBS, including no implanted wires or batteries and no need for electronic programming sessions to fine-tune the parameters. Also, there are no hardware malfunctions to deal with, and once the initial surgical procedure is done, there is no risk of infection from an implanted device. For those who might have difficulty travelling for DBS programming (from another region or country), or in cases when DBS is too expensive or not available, pallidotomy may be a good choice. Pallidotomy can be as effective as DBS in treating the symptoms of PD, but the lesion must be placed in exactly the right spot. Recent studies have revealed that the benefits of pallidotomy can be long-lasting. Unlike DBS, pallidotomy should not be performed on both sides of the brain, and this is one major limitation of this surgery. Performing two pallidotomies can lead to permanent speech, swallowing, and cognitive problems. Patients with an existing pallidotomy who require a second surgery will usually have DBS on the opposite side of the brain.

Subthalamotomy has been gaining popularity because it can provide the same types of benefits as pallidotomy, and many medical groups have performed the surgery safely on both sides of the brain. Subthalamotomy is the PD procedure of choice in Cuba, and research suggests that it is very effective. A few subthalamotomy patients have developed a side effect called hemiballism (uncontrollable flinging of one arm and/or leg), but in most cases it is a transient adverse effect (goes away with time).

Thalamotomy is a procedure that is rarely performed in PD because it is usually only effective for tremor.

DBS

DBS involves the surgical placement of a thin wire, with four electrical contacts at its tip, into a very specific and carefully selected brain region. This wire is called the DBS lead (pronounced “leed”), and there are three main parts of the brain where it can be placed: the globus pallidus internus, the thalamus, and the subthalamic nucleus.

DBS differs from pallidotomy, thalamotomy, and subthalamotomy in that it does not permanently destroy brain tissue. The procedure is potentially reversible, usually with minimal damage to any brain tissue. For example, if you have a pallidotomy and develop slurred speech, there is nothing you can do to reverse it. With DBS, you can adjust the settings, and the majority of, if not all, slurred speech will improve. The DBS lead itself can have a lesioning effect, so adjusting settings does not always guarantee slurred speech (or other side effects) will improve, but the chance for improvement is much greater compared to permanent procedures such as pallidotomies.

The DBS lead is connected to a pacemaker-like device that is implanted in the chest region below the collarbone. This device, called the neurostimulator or implantable pulse generator (IPG), contains the battery and computer source that generates the electrical pulses that will be delivered via the lead to the brain. The system can be turned on or off by the patient or the clinician. In addition, the clinician can select which one or more of the four electrodes on each brain lead are to be activated to provide electrical stimulation. This process allows electrical stimulation to be delivered to a very precise part of the brain.

The DBS programmer (a doctor, nurse practitioner, physician assistant, or other qualified staff member) can adjust a variety of electrical parameters or settings to control the amount of stimulation provided. These adjustments are referred to as “programming” the DBS system. The adjustments allow the clinician to maximize the benefits and minimize the side effects. This adjustability is a benefit of DBS that is not available with pallidotomy, thalamotomy, or subthalamotomy. The reasons many patients cite for choosing DBS over a lesioning procedure include: the device can be programmed and reprogrammed for symptoms and symptom changes; the procedure can be performed safely on both sides of the brain; and the procedure is reversible.

This book was designed as a practical guide to explain the complete process required for patients and families considering DBS therapy. The content describes everything from the decision to have surgery and the day of surgery to surgical recovery and DBS programming. While the information contained in this book is intended to facilitate a discussion of DBS with family, friends, and health care team members, it is not meant to replace the advice of expert health care professionals involved in your care.



If you are considering DBS

- Consult with a movement disorders specialist. A movement disorders specialist is a neurologist who has completed specialized training in PD and movement disorders, usually through a one- or two-year fellowship (make sure you ask for credentials). There are also neurologists in practice who have become experts in this area through their experience caring for many patients and by taking continuing medical education courses.
- Do your homework: Learn all you can about DBS. Call the centers you are considering, and ask questions about the care they provide. Make sure that you choose a DBS center with an interdisciplinary team of health care professionals. These professionals should have the training, technology, and expertise required to provide specialized and expert DBS therapy. Make sure the interdisciplinary team has a team meeting where your case will be discussed by everyone who evaluated you (prior to any surgery). This type of collaboration is considered an essential element to the success of this procedure.
- Be prepared to invest a significant amount of time, energy, and travel for both pre-and post-operative appointments. A published survey conducted by the DBS Society (*Stereotactic and Functional Neurosurgery*, 2005) revealed the need for a significant number of post-operative visits for both DBS programming and medication adjustments. These visits are most frequent during the first 6 months following implantation, and many experienced centers require monthly visits for the first six months. Undergoing DBS therapy requires a large emotional, physical, and possibly financial commitment, depending on your insurance status. These are all important factors to consider before an operation.
- Make sure to ask who will be programming the deep brain stimulator, and what kind of follow-up you can expect.

Chapter 2

An Overview of Deep Brain Stimulation (DBS) Therapy

“The last 5 years before Sam had his brain surgery were very hard. I had to help Sam with everything, including getting dressed, getting out of bed, taking a bath. It was emotionally draining. The joy was taken out of our lives. I felt more like a nurse than a wife. We almost never socialized as it was just too difficult. He is like a new man since having the surgery. He can do almost everything for himself now. He doesn’t need his walker anymore, and I only need to help him get dressed in the morning before his medication starts working. We aren’t afraid to go out to dinner or shopping because he doesn’t shake as badly and he doesn’t get stuck or frozen. The surgery gave us both back our independence and our marriage; life is good again. We are truly blessed and grateful.”

- Barbara

Deep brain stimulation (DBS) is a surgical therapy used for the treatment of Parkinson’s disease (PD). During DBS surgery, a special wire, called a lead, is inserted into a specific area of the brain. The lead, which has four electrodes, delivers electrical currents to precise brain locations responsible for movement, regulating the abnormal brain cell activity that causes symptoms such as tremor and gait problems. It is important to keep in mind that DBS can only help relieve the symptoms of Parkinson’s, not cure or stop its progression.

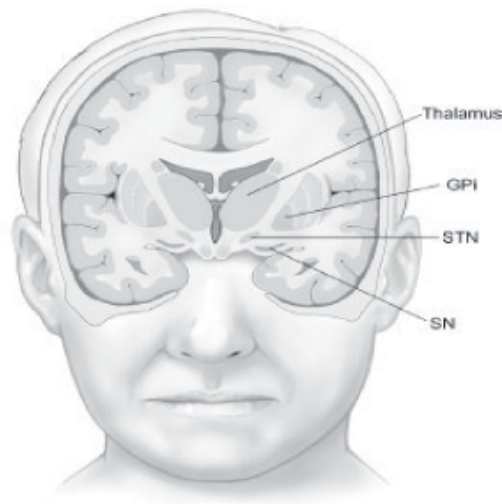
Modern DBS was developed in France in 1987 by professor and neurosurgeon Dr. Alim-Louis Benabid. His procedure was the culmination of many decades of research from many talented researchers who studied the electric brain. With advances in technology and surgical practices, the therapy has continued to improve. DBS was first approved by the Food and Drug Administration in the United States in 1997, and it is now considered a safe and effective treatment for carefully selected patients with PD. However, DBS is not for everyone. Though patients like Sam have greatly benefited, the current technology has fallen short in helping most patients to regain walking, talking, and thinking functions.

How DBS works

Though we do not currently fully grasp the mechanisms underpinning DBS, we have over the last two decades uncovered many important clues. Understanding DBS and how it may work to suppress symptoms requires a basic understanding of brain function. The brain is a complex organ with billions of cells and cell connections called synapses. These cells are connected to each other by axons, or “pipes,” that send messages back and forth. Communication is facilitated through a series of circuits that are organized to sort and process information. The connections in the brain circuits are similar to the electrical wiring in your house or car. If one circuit malfunctions, it can disrupt the entire system. Research has shown that in PD there are faulty signals in several brain circuits.

These faulty or disruptive signals seem to underpin many of the symptoms of PD (e.g., slowed movement, tremor, and stiffness). When electricity is introduced into the circuit it “disrupts the disruption,” restoring order and improving disabling symptoms. The electric current is thought to inhibit cell firing, excite the axons (the pipes), and release calcium from brain cells called astrocytes. Calcium seems to trigger a series of reactions that leads to the release of chemicals called neurotransmitters and the stimulation of blood flow. This symphony of changes elicited by electrical stimulation in some unknown way acts to combat the symptoms of PD.

In PD, there is an area of the brain called the substantia nigra pars compacta (SNc) where electrical signals are not processed normally. In this region, there are over 400,000 dopamine-producing brain cells. Over time, these brain cells can become injured and slowly die. This process reduces the natural production of dopamine, and this loss of dopamine heavily influences the appearance of PD symptoms. The SNc has connections to important areas of the brain that control both motor and non-motor functions. Two important interconnections are with the globus pallidus internus (GPi), and the subthalamic nucleus (STN). These are critical brain areas that send signals affecting the movement of your arms, legs, and neck, as well as other functions (e.g., thinking and mood). By placing DBS leads in either the GPi or the STN, the transmission of electrical signals through these areas can be altered, and, in most cases, this results in smoother and more fluid movement. Small areas within the GPi and STN have been shown to be powerful DBS targets, especially to address the symptoms of tremor, rigidity, bradykinesia, motor fluctuations, and dyskinesia.



Location of DBS target areas and substantia nigra (SN)

DBS may be placed in many other brain locations and has been used in many other neurological disorders. Occasionally, the ventralis intermediate nucleus of the thalamus (Vim) is also targeted for treatment. A DBS lead in this area can result in an impressive reduction in arm tremor. In most cases, however, it does not improve lower extremity tremor, rigidity, bradykinesia, or dyskinesia. Vim is, therefore, the preferred site for another condition known as essential tremor.

The following table summarizes the three different sites for DBS therapy.

DBS site	Effect of therapy
Thalamus (Vim)	Reduces tremor but not the other symptoms of PD
Globus pallidus (GPi)	Reduces tremor, rigidity, bradykinesia, gait problems, dyskinesia
Subthalamic nucleus (STN)	Reduces tremor, rigidity, bradykinesia, gait problems, dyskinesia

DBS surgery



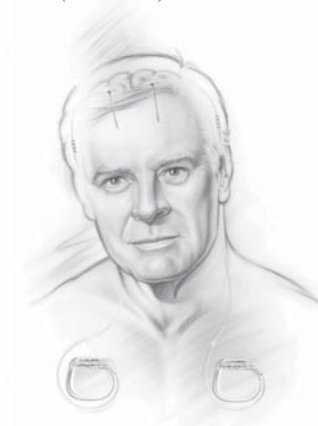
See Chapter 6 for details about what happens during DBS surgery

In DBS surgery, leads (wires with tiny electrodes) are implanted within a small and specific target area in the brain. Depending on the case, the target will be the STN, GPi, or Vim. STN or GPi are the preferred targets for improving most PD symptoms. Leads may be placed on one side of the brain (unilaterally) or on both sides (bilaterally). Once the lead is placed, it is attached to a wire that runs under the scalp and just beneath the skin of the neck. It is then connected to a pulse generator, or neurostimulator. The neurostimulator is located just below the collarbone and under the skin of the chest. Similar to a pacemaker, the pulse generator delivers electricity to the lead that is implanted in the brain. The pulse generator can be either single-chamber (connects only one lead) or dual-chamber (connects two leads). The pulse generator is turned on and off by a remote control similar to the ones used for televisions. The DBS programmer can adjust the DBS settings to one of thousands of combinations to achieve optimal symptomatic improvement.

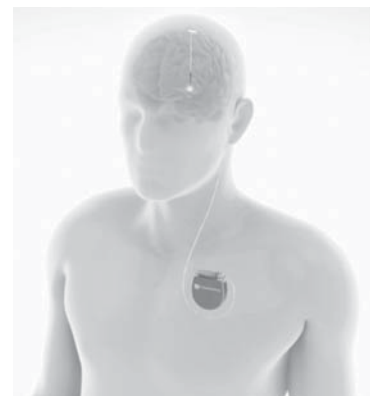
Dual chamber battery with bilateral DBS leads (Activa PC or Activa RC)



Bilateral single chamber batteries with bilateral DBS leads (Activa SC)



Neurostimulator with directional lead (St. Jude Medical Infinity DBS System from Abbott)



(Images courtesy of Medtronic, Inc.)

(Image courtesy of Abbott)

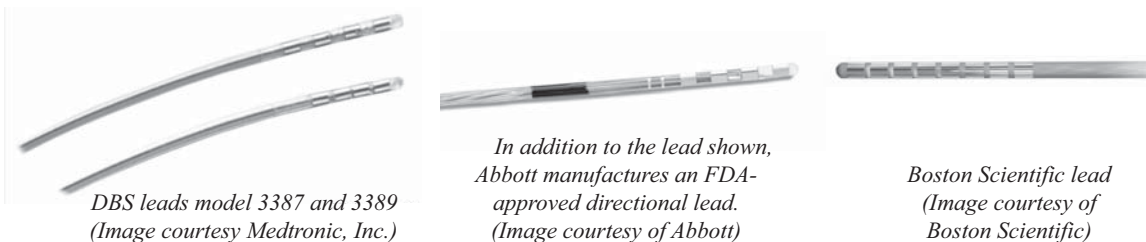
Following DBS activation, the lead and the electricity it emits will work to normalize the brain signals in the affected circuits. Most people with DBS report experiencing a smoother response to medication, more “on” time, and improvements in dyskinesia, tremor, and rigidity. When the DBS electrode is activated some side effects can occur. Depending on the type of DBS electrode that is implanted, different strategies can be used by the DBS programmer to try to avoid these side effects. This is discussed in more detail in Chapter 8: Adjustment of Stimulation.

Following DBS therapy some patients will require less help from their family and friends, and they will achieve more independence in their daily lives. **However, it is important to keep in mind that DBS does not replace the caregiver, does not return most patients to work, and will not, in most cases, allow patients to return to complex activities such as golfing.**

DBS devices

Several components make up the DBS system. Three companies currently have FDA-approved devices: Medtronic manufactures Activa® Parkinson’s Control Therapy; Abbott manufactures the St. Jude Medical Infinity DBS System™; and Boston Scientific manufactures the Vercise™ DBS System.











First, the **DBS lead (thin wire)** is implanted in, or as close as possible to, the intended brain target area. The wire is just over a millimeter in diameter – about the size of a thin wire used for hanging pictures. The Medtronic lead has four electrodes and can target the STN or GPi. The Abbott and Boston Scientific devices have eight electrodes and target the STN.



Next, the **connecting wire** is attached to the brain electrode and then to the pulse generator, which is also called an **implantable pulse generator (IPG) or neurostimulator**.



The IPG supplies electricity through the connecting wire to the 4-8 electrode contacts on the DBS lead. The IPG is typically placed in the chest, but can in rare circumstances be placed in the abdomen. The currently available IPGs are below:

Device Name and Description	IPG	Patient Programmer
1. Aactiva SC – controls one brain lead for unilateral stimulation. Patient programmer is digital and allows for up to 4 group settings that patient can change between (see Chapter 8 for explanation of group settings and adjustment of stimulation). Can also allow for some patient self-adjustment within certain parameters provided by the DBS programmer.	 <p>Image courtesy of Medtronic, Inc.</p>	 <p>Image courtesy of Medtronic, Inc.</p>
2. Aactiva PC – controls two brain leads for bilateral stimulation. Patient programmer is digital and allows for up to 4 group settings (see Chapter 8) that patient can change between. Can also allow for some patient self-adjustment within certain parameters provided by the DBS programmer.	 <p>Image courtesy of Medtronic, Inc.</p>	 <p>Image courtesy of Medtronic, Inc.</p>
3. Aactiva RC – controls two brain leads for bilateral stimulation. Patient programmer is digital and allows for up to 4 group settings that patient can change between. Can also allow for some patient self-adjustment within certain parameters provided by the DBS programmer. This device is rechargeable and can last up to six to nine years.	 <p>Image courtesy of Medtronic, Inc.</p>	 <p>Image courtesy of Medtronic, Inc.</p>
4. Infinity – comes in two sizes and has a non-rechargeable, maintenance-free battery. The system features Bluetooth wireless connectivity. Patients are provided with an Apple iPod Touch controller to allow them to turn the device on and off and change modes.	 <p>Image courtesy of Abbott</p>	 <p>Image courtesy of Abbott</p>
5. Vercise – Rechargeable battery with multiple independent current control (MICC) technology capable of bilateral stimulation and an FDA approved battery longevity of 15 years.* Patients receive a Patient Remote Control with wireless connection and the ability to switch between four program settings, check the battery level and turn the device on and off.	 <p>Image courtesy of Boston Scientific</p>	 <p>Image courtesy of Boston Scientific</p>

*Battery life is dependent on the stimulation settings and conditions.

The Medtronic IPGs are adjusted with the N’vision **programmer**, a device that communicates through the use of radio waves, which can regulate the electricity delivered to the electrodes. Programming is performed by holding the programmer over the IPG (i.e., over the chest or abdomen). The Abbott device leads



(Images courtesy of Medtronic, Abbott, and Boston Scientific)

are programmed by providers with an iPad Mini during office visits. Clinicians can do their motor skills assessments wirelessly. The Boston Scientific device is programmed by physicians using a Surface Pro 3 and the Patient Remote Control. Programming is performed by placing the remote control over the IPG.

Finally, the last part of the system is one that is not implanted into the body. It is the patient controller. The Activa SC/PC/RC all use the same remote. The Infinity device uses an Apple iPod Touch as the patient controller; it has Bluetooth wireless connectivity. The Boston Scientific Patient Remote also connects wirelessly to the IPG. All three controllers allow the patient to turn the IPG on and off and to check the battery status. They also allow the patient to self-adjust within parameters provided by the DBS programmer.



DBS: Questions and answers

Q: Is DBS a cure for Parkinson's disease?

A: No, DBS is not a cure for PD. It is a treatment that helps relieve the motor symptoms of PD, as well as some of the non-motor symptoms. It is called a symptomatic therapy; it does not change disease progression.

Q: What symptoms does DBS help?

A: DBS can help improve the motor symptoms of PD. Typically, these are:

- Tremor**, or shaking (in 80% of sufferers). Complete or partial tremor suppression
- Rigidity**, or stiffness
- Bradykinesia**, or slowness of movement

DBS is a powerful therapy for addressing the motor complications of PD, which are often related to medication (e.g., Sinemet and agonists):

- Dyskinesia** – involuntary, irregular, writhing movement – can range from mild to violent and can sometimes be unpredictable. Dyskinesia can be particularly severe when medications are at peak levels.
- Dystonia** – sustained, involuntary contraction of muscles – can lead to painful cramping of the feet or hands, curling toes, or turning and twisting of the neck. Dystonia can also in select cases be a side-effect of medications.
- “On/off” fluctuations** are when a person cycles between “on” time, when the medication is working to control symptoms, and “off” time, when medication has worn off and PD symptoms return. DBS is helpful in addressing symptoms that respond to dopaminergic medication (e.g., Sinemet, Madopar, agonists). DBS will usually temper the degree of fluctuations experienced during “on” and “off” periods. **DBS will not address dopaminergic unresponsive symptoms, such as walking, talking and thinking issues. DBS will, however, address medication-unresponsive tremor.**

DBS can also improve some non-motor symptoms, including the following:

- Mood
- Energy level
- General sense of well-being

As a general rule, symptoms that are helped by medication will be improved by DBS.

Q: Is it better to have DBS on one side of the brain or both sides?

A: DBS on one side of the brain mainly helps symptoms on the opposite side of the body. Placing two leads can, in some cases, provide incremental improvement in motor function, especially if patients have significant symptoms on both sides of the body. Two leads will also improve walking in select patients, although walking often becomes resistant to medications and to DBS over time. For patients whose symptoms are mainly affecting one side of the body, DBS surgery on the opposite side of the brain may be sufficient. New research has suggested that one third or more of patients with PD may actually do well long-term with a single-sided DBS lead (*Journal of Neurosurgery*, 2009). Many expert centers will implant a single DBS lead, optimize DBS settings and medications, and in a follow-up visit re-evaluate the need for a second DBS. A single DBS lead carries half the surgical and post-surgical risk for complications.

Q: How long do the benefits of DBS last?

A: The duration of DBS benefits varies from patient to patient, but in the majority of cases it lasts many years. Patients have now been followed for 10 or more years with DBS, and the general rule has been that if the symptoms still respond to dopaminergic medications, then DBS will continue to work. DBS also will continue to work long-term against tremor and dyskinesia.

DBS settings are rarely changed much after the first year of therapy, and patients should be educated that once settings are optimized, most of the changes will be made to the medication regimen.

Q: Will I be able to stop taking my PD medications after I have DBS?

A: DBS is not a substitute for medication therapy. After the DBS system has been optimized through programming, the neurologist or nurse may attempt to gradually lower medication doses. Although most patients will need to remain on medications after DBS surgery, many will be able lower their total daily dose by 30 to 50%. Many will also be able to spread out the intervals at which they take medications. Rarely will a patient be able to stop medications completely. Those who are able to stop taking medications will probably need to restart them later in their disease, as more symptoms emerge over time. There is, in general, more medication reduction with STN DBS when compared to GPi DBS. There is also more medication reduction with two implanted leads when compared to one. It is important that patients understand that medication reduction following DBS is not a guarantee and should not be a goal of surgery; rather, you should consider the right marriage between medication usage and DBS therapy.

Q: How do I know if I am a good candidate for DBS?

A: Movement disorders neurologists are experts in PD and its treatments. You should consult a movement disorders neurologist to help you determine if DBS is the right choice for you. Keep in mind that an expert neurologist may be able to improve PD symptoms so that DBS is not necessary, or could be delayed for several years. DBS is, in general, not helpful and could be harmful when applied to other conditions that can mimic PD, such as Lewy body disease, progressive supranuclear palsy, multiple system atrophy, and corticobasal degeneration. A movement disorders specialist is the best resource for confirming that you have PD before you have surgery.

The best candidates for DBS therapy will meet most of the following criteria:

- You have had PD symptoms for at least five years.
- You have “on/off” fluctuations, with or without dyskinesia.
- You continue to have a good response to PD medications, especially carbidopa/levodopa (though the duration of response may be insufficient).
- You have tried different combinations of carbidopa/levodopa and dopamine agonists under the supervision of a movement disorder neurologist or specialist.
- You have tried other PD medications – such as entacapone, tolcapone, selegiline, apomorphine or amantadine – without beneficial results.
- You have PD symptoms that interfere with daily activities.

Not all patients are good candidates for DBS therapy. DBS is generally not appropriate for people who:

- Have as the main disabling symptom trouble with balance, walking, or freezing that is not helped by PD medication.
- Have as the primary disabling symptom trouble with speech that is not helped with PD medications.
- Have confusion, disorientation, and/or difficulties with memory and thinking on a daily basis.
- Have depression, anxiety, or another psychiatric illness that has not improved or been stabilized with proper therapy such as medication and counseling.
- Have a questionable PD diagnosis.
- Have another serious health condition, such as severe heart or lung disease.

Q: What if DBS doesn't work?

A: It is possible that DBS therapy will not help; this condition has been referred to as DBS failure(s). There are many reasons for DBS failures, and most are preventable. These reasons include improper patient selection, problems with the surgery (suboptimal lead placement or hardware dysfunction), problems with programming, problems with medication management, or disease progression. If you have not improved 6 months following your DBS surgery, you should discuss with your doctor the possibility of a complete workup to search for a correctable cause of the DBS failure. For the best possible results, it is extremely important to choose a center with a neurosurgeon, movement disorders neurologist, and health care team that are trained and experienced in DBS therapy. Make sure you go to an experienced movement disorders neurologist to assess whether or not you are a good candidate prior to surgery.

Q: Are there activities that I need to avoid following DBS therapy?

A: Generally, you can return to normal daily functioning within a few months of the DBS surgery. Always check with your neurologist for specific instructions. It is best to avoid neck manipulation, massage, or other direct physical contact with the implanted devices. Also avoid climbing, reaching for objects above head level, and working on the roofs of houses and buildings. Swimming and sporting events are generally okay, as long as there is no contact with the device.

Q: Can I exercise after having DBS?

A: Yes, most PD patients return to low-impact exercise within 4 to 6 weeks following DBS surgery. Contact sports or exercise that poses a risk of physically striking the neurostimulator or the connecting wire should be avoided. Exercise is like medication in that it should be considered an integral part of treatment for PD. We encourage all people with Parkinson's, pre- and post-DBS, to exercise daily.

Q: Are there some electrical devices I should avoid?

A: Most basic household and garden electrical devices are safe to use and contact; this includes microwaves, radios, and computers. Certain medical devices and possibly some high-power industrial machinery can be dangerous. Diathermy, a deep heat treatment administered by some health care providers, is dangerous and should never be performed in patients with existing DBS. Total body coil MRI (magnetic resonance imaging that is used to image the body) can be dangerous to the patient with DBS; note that MRI scanning of the brain can be performed, as long as proper safety precautions have been followed. Before having any medical procedure that may interfere with the DBS device, check with your medical team or the manufacturer of your DBS equipment. See Chapter 9 for more information about electrical devices and DBS therapy.

Q: How long will the battery last? What should I do when it stops working?

A: The battery usually lasts between 2 and 5 years. The battery life varies depending on the settings needed to control your symptoms. The Activa RC is a rechargeable IPG and will last up to 9 years. Your DBS programmer should periodically check the battery life and inform you as to when the neurostimulator needs to be replaced. Devices such as the Access Review can also be used to check your battery. When the battery life is approximately 10% or less, it is recommended that the battery be replaced. We generally recommend preemptive replacement of batteries before they fail. This replacement can be done as an outpatient procedure. Once battery power is depleted, your symptoms will likely worsen and more medication than usual may be needed until the neurostimulator is replaced. A good rule of thumb is to have the battery life checked at every visit and to have a proactive plan for replacement.

Q: Can the DBS stop working suddenly, after working for several months or years?

A: Yes, malfunctions can occur, and they usually happen as a result of one of two reasons: either the battery power has been depleted, or the hardware in the device is malfunctioning. For example, there could be a break in the connecting wire in the neck or scalp. Do not push on the device in your chest or twist it, as this can lead to fractures of the wires. If your PD symptoms suddenly worsen, contact your treating neurologist or neurosurgeon immediately, as there may be a problem with the DBS system.

Q: If a cure or new treatment for PD is found, can I have the DBS system removed?

A: Yes. DBS is removable and reversible. You can have the leads and neurostimulator taken out. You can try any new FDA-approved symptomatic treatment or cure if it becomes available. Rarely over the last decade have we encountered patients wishing to have their hardware removed.

Q: How expensive is DBS? Will my insurance cover the costs?

A: Each DBS surgery can cost between \$35,000 and \$50,000, and upwards of \$70,000 to \$100,000 for bilateral procedures. These estimates include the cost of the surgery, devices, anesthesia, hospital fees, and physician fees. The type and amount of health insurance you have will affect the overall cost. Since DBS is approved by the Food and Drug Administration for the treatment of PD, Medicare and most private insurance carriers will cover most, if not all, of the costs of the operation. Your personal insurance policy will specify DBS coverage. If you are worried about cost, ask the neurosurgeon to meet with his or her financial counselor so that you and your family will know what to expect.



Key points about DBS

- ✓ DBS has been proven to be a safe, effective therapy for a group of well-selected people with PD.
- ✓ DBS therapy is not a cure for PD, but it is a powerful symptomatic treatment.
- ✓ DBS is not a substitute for medications, and most patients will not stop medications after the procedure.
- ✓ DBS can improve the motor symptoms of PD, including tremor, rigidity, and bradykinesia; it can also help improve dyskinesia, dystonia, and motor fluctuations.
- ✓ As a rule, DBS will be effective against symptoms that improve with medication.
- ✓ Unilateral or bilateral leads may be placed in one of three brain regions:
 - **Globus pallidus internus (GPI):** Effective for tremor, rigidity, bradykinesia, motor fluctuations, and/or dyskinesia and dystonia.
 - **Subthalamic nucleus (STN):** Effective for tremor, rigidity, bradykinesia, motor fluctuations, and/or dyskinesia and dystonia.
 - **Ventral intermediate nucleus of the thalamus (Vim):** Only effective for upper extremity tremor; inconsistent for lower extremity tremor.
- ✓ The DBS system consists of the lead, connecting wire, implantable pulse generator (IPG), programmer, patient controller, and/or magnet.

Chapter 3

Risks and Complications of DBS

“I didn’t have a very good experience with DBS. I read about it and passed all my evaluations, so the Parkinson’s doctor said I could have it done. I expected it to make my Parkinson’s go away or at least make it so I didn’t feel like I had PD anymore. That isn’t what happened. I had a seizure the day after the surgery. Luckily, my brother was with me when it happened and called 911. I don’t remember anything except feeling funny and then waking up in the ambulance and feeling tired. I didn’t have any more seizures. Then, about a month after the surgery, I had the system programmed, and I had less tremors and slowness. But then they came back just like before, so I had 6 more programming sessions over the next 5 months without much of a difference. I could move a little faster and my muscles weren’t as stiff, but it wasn’t a very big improvement. I’m now thinking about having the system taken out. The doctors explained that sometimes it just doesn’t seem to work and they have to remove the electrodes and put them in a different spot. The doctors think that the electrode might have moved because of my seizure and that it is not in the spot they wanted it to be in. I haven’t decided whether I want to have the surgery done again or not.”

– Jean

Like any surgery, deep brain stimulation (DBS) carries with it a risk of complications. Problems that may occur as a result of the procedure can be serious and permanent, or alternatively temporary and reversible. In addition, malfunctioning DBS devices can result in post-operative problems.

Serious or permanent complications

The risk of serious or permanent complications from DBS therapy is very low. The risk of **death** is less than 1%. There is a small risk of **stroke** from bleeding in the brain during surgery, about 2 to 3%. While most complications will have no after-effects, some people may experience lasting, stroke-like symptoms, such as weakness, numbness, problems with vision, or slurred speech. People with a history of bleeding problems will have a higher risk for a stroke during DBS surgery. Hydrocephalus is a rare but possible complication of DBS, usually caused by a buildup of fluid in the brain, which leads to increased pressure. If hydrocephalus develops, a neurosurgeon may need to insert a shunt to redirect the fluid and relieve the pressure.

Temporary or reversible complications

Temporary or reversible complications may result as a side effect of the surgery or electrical stimulation. These potential complications include the following:

- ❑ **Changes in mood, memory, and thinking** – DBS can worsen memory and thinking. Other changes could include anxiety, depression, confusion, hallucinations, or developing an overly excited mood. These so-called psychiatric symptoms usually lessen within days or weeks of the surgery and typically disappear completely. If these symptoms persist, medication or stimulation adjustments can remedy them. People with known cognitive or psychiatric problems, such as dementia or severe depression, are at a much greater risk for these complications, and they typically do not qualify for DBS therapy. Suicidal thoughts and suicide have been reported with DBS therapy as well.
- ❑ **Seizures** – A few people who undergo DBS will have a seizure. If a seizure does occur, it will usually occur during the surgery or within the first week after surgery. Seizures related to surgery will usually resolve. If seizures continue, they are more likely related to a stroke, brain infection, or irritation of the brain by the DBS lead. In these cases, seizure medications may be prescribed.
- ❑ **Infection** – There is a risk of infection at the surgery sites in the brain, scalp, or chest—about a 5 to 20% chance. To prevent infection, antibiotics are administered during surgery. If a serious infection develops, the electrode, connecting wire, and/or neurostimulator may have to be removed.
- ❑ **Problems with movement and speech** – Dyskinesia, temporary worsening of movement, balance problems, and slurred speech are all possible following DBS. Sometimes these symptoms can be improved with expert programming of the DBS. In other cases these symptoms are permanent.
- ❑ **Headache, dizziness, tingling of the face or limbs, and an electrical jolting sensation** – These problems, along with worsening dyskinesia, may be improved by adjusting the stimulator settings. These unpleasant effects can be, in many cases, almost immediately improved by turning off the stimulator with the hand-held magnet or the patient controller. An adjustment of the stimulation settings will most often take care of these side effects.

Other risks of surgery

- ❑ Pain, inflammation, or swelling at the surgery sites.
- ❑ A very small risk of swelling or an allergic response to implanted materials.

Malfunctioning DBS devices

Finally, there are some technical problems that can be associated with the DBS lead, connecting wire, and neurostimulator. These types of difficulties include the following:

- Lead migration, when the electrode has moved away from the optimal target site.
- Fracture, disconnection, or damage of the connecting wire.
- Malfunction or injury to the neurostimulator.
- Misplacement of the brain electrode.

Many of these problems cannot be predicted or prevented. Anything that puts direct pressure over the implanted devices should be avoided. Even with the best equipment, skills, and technique, there is always the possibility that the lead may not be placed in the optimal brain location. Even highly trained experts working at DBS centers will misplace electrodes at times. In some instances, a repeat surgery may be needed to adjust placement or correct a faulty device.

Avoid twisting or pushing the implanted parts of your DBS system, such as the neurostimulator (battery). Manipulations can damage the system or cause skin erosion, and doing so may require surgery.



Key points about risks and complications of DBS

It is important to understand the risks of DBS surgery. The benefits and risks will vary with each individual case. Only you and your neurologist will be able to make the final decision for or against DBS therapy.

Possible complications to be discussed with your neurologist include the following:

- ✓ Death
- ✓ Stroke
- ✓ Stroke-like symptoms, such as weakness, numbness, and slurred speech
- ✓ Problems with mood, memory, and thinking, such as confusion and/or hallucinations, depression, or being overly excited (i.e., manic)
- ✓ Seizures
- ✓ Infection
- ✓ Worsening dyskinesia
- ✓ Headache, dizziness, tingling face or limbs, or a jolting sensation
- ✓ The connecting wire may become fractured, damaged, or disconnected
- ✓ Problems with the neurostimulator
- ✓ Misplacement or migration of the lead

Chapter 4

Is DBS Right for You?

“I was too young to have Parkinson’s disease at age 36. It was devastating to me. I was angry and in denial for the first 3 years. Once I accepted it and was better about taking my medication, life got better because I could move okay and take care of myself. I thought, ‘I can live with this.’ But after only 6 years with PD, at age 42, I had a lot of problems with dyskinesia and wearing off of my medication. After carefully researching DBS therapy, my doctor and I decided it was the best thing for me to do. First, I had an electrode placed into the left brain; 4 months later I had the second electrode placed into the right side. The dyskinesia went away completely, my muscles were less stiff, and I could move better. My medications seemed to last longer, too. It was as if I had gone backward in time 4 years. It was the best decision I ever made, and I have no regrets. I am not perfect and I still have to take medication 4 times a day, but I didn’t expect a cure. I just wanted to have less dyskinesia and less slow time and for my medicine to work better. I got more benefit than I expected, so I am glad I had DBS surgery.”

– John

Deep brain stimulation (DBS) is one of several elective therapies that a patient may choose as a treatment for Parkinson’s disease (PD). The decision to undergo DBS surgery should always be accompanied by several important considerations. Once your condition has been evaluated by a movement disorders neurologist, and it has been determined that you are a candidate, you will need to work closely with your doctors to evaluate the risks outlined in Chapter 3. You and your family will need to understand that a substantial commitment of time, energy, travel, and expense – both before and after the surgery – will be required. What is most important, however, is that you have **realistic expectations** about the surgery. Some patients anticipate dramatic improvement to a near-perfect state of health following DBS. Unfortunately, this is not likely to happen, though in well-selected candidates there can be meaningful benefits.

Movement disorders neurologists at the University of Florida developed a tool to help you understand what you can and cannot expect from surgery. Before you make the final decision, review the mnemonic below with your family members, caregivers, and neurologists.

University of Florida mnemonic: DBS in PD

Does not cure.

Bilateral DBS is often required to improve gait, although sometimes unilateral DBS has a marked effect on walking.

Smooths out on/off fluctuations.

Improves tremor, stiffness (rigidity), bradykinesia, and dyskinesia in most cases, but may not completely eliminate them.

Never improves symptoms that are unresponsive to your best “on.” For example, if gait or balance do not improve with best medication response, they are very unlikely to improve with surgery.

Programming visits are likely to occur many times during the first 6 months, and then follow-up visits as frequently as every 6 months. There will be multiple adjustments in the stimulator and in the medications.

Decreases medications in many, but not all, patients.

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Chapter 5

Preparing for Surgery

“Parkinson’s disease is something I have come to live with, but DBS surgery has made it so much easier. I was very scared to have it done. My doctor recommended it to me for 2 years before I decided to go to a DBS center for an evaluation. What I would tell someone with PD who thinks they might need DBS is to go to a good center and get a lot of information about it. The thing that really convinced me to have the DBS was talking to another patient who had it done. Only someone who has had it can really explain it and let you know just how scary, but also how helpful, it can be.”

– Jose

If you decide to pursue deep brain stimulation (DBS) therapy, the next step will be to plan and prepare for your surgery and recovery. Understand that it is important to select a center that has a staff of experts who specialize in DBS therapy for the treatment of Parkinson’s disease (PD).

Once you have been referred to a DBS center, plan to bring a family member or friend with you to your appointments. Make sure that you meet with the movement disorders neurologist, neurosurgeon, neuropsychologist, psychiatrist and nurses who will be involved in your care. In many cases a physical therapist, occupational therapist, and speech therapist will be necessary members of the team. Be prepared to ask questions about DBS, and make sure that they are answered to your satisfaction before the procedure takes place. Ask the staff if there are other patients who have had the surgery performed, and if you can speak to them about their positive and negative experiences.

The following are suggested questions for the neurologist, neurosurgeon, or nurse during your visit to the DBS center:

- ❑ **How many DBS surgeries have been performed at this center? How many are performed each month?** Most centers will do one or more surgeries per week. Larger centers may do one to five procedures per week.
- ❑ **Does this center use microelectrode recording?** Microelectrode recording involves using a special, thin electrode that allows the surgeon and neurologist to precisely locate the target site. Some neurologists and surgeons will use this technique, while others will not. If the center uses microelectrode recording, ask about the experience of the neurologist/physiologist who will be doing this specialized procedure. If the center is not adequately experienced in microelectrode recording, it may not be in your best interest to have the surgery at that center.

- ❑ **Will both sides of the brain be operated on during the same surgery, or is a separate surgery done for each side?** Depending on your individual situation, both leads may be implanted in one surgery, or each side may be performed as a separate surgery. It is safer in some cases to have the leads implanted in different procedures. Additionally, in one third or more of cases, a second DBS lead may not be needed.
- ❑ **Will I have the IPG placed in my chest when the lead is implanted, or will that be done later?** Some centers require that the patient return several weeks after the lead is placed to have the IPG implanted under the chest wall, while other teams will place the IPG on the same day as the brain lead(s).
- ❑ **Who will program my DBS system and adjust my PD medications after the surgery?** Some centers perform the surgery then have you return to your regular neurologist for adjustment of DBS settings and medications. Other centers will have you return 4 to 6 weeks after the surgery for adjustments at their facility. For the first several months, it is best to return to the center where the surgery was done for programming and adjustments. When the programming is working and frequent adjustments aren't needed, you can, in many cases, return to your regular neurologist for care. Centers that perform the surgery should offer full post-surgery services. In many cases monthly visits are necessary to not only change stimulation settings, but also to adjust medications and monitor for mood and thinking changes.
- ❑ **After surgery, how long will it be before I am able to go home?** Most patients are hospitalized for one night following implantation of the brain leads. Confusion or other neurological manifestations could delay your discharge.

DBS centers will differ in how they evaluate and care for the patient, as well as in the surgical technique and after-surgery care. Despite these differences, there are several important evaluations that all centers should perform prior to surgery. Some of the evaluations are specific to DBS, while others are standard tests that patients typically will undergo prior to any type of surgery.

Pre-surgery tests and evaluations

Several visits to the DBS center may be required. The movement disorders neurologist should perform a baseline Unified Parkinson's Disease Rating Scale (UPDRS). This scale will help the neurologist evaluate the status of your PD. The neurologist will likely perform the UPDRS when you are on medications and again when you are off. The UPDRS will help your neurologist gauge which symptoms DBS has the best chance of improving (i.e., symptoms that respond to medications typically improve with DBS).

You will also undergo a series of memory and thinking tests, called a neuropsychological battery. These tests are performed to make sure that you do not have confusion, memory issues, untreated mood problems, or depression. These tests should be performed by a neuropsychologist who has experience working with patients with PD. You may also be required to see a psychiatrist for treatment of depression, anxiety, or other psychiatric conditions prior to DBS placement. A social worker may perform an assessment of your

network of family and friends to make sure that there is someone to help you before and after surgery. It is very important that you have a spouse or full-time caregiver if you undergo DBS.

Other standard, pre-operative tests may be performed by your local physician or the DBS staff. The specific tests will depend on your age and other health conditions. You may have one or more of the following:

- Magnetic resonance imaging (MRI) of the brain to make sure there are no other important issues such as brain shrinkage, strokes, or tumors
- Chest X-ray
- EKG, which measures heart rhythm
- Blood tests for blood counts, bleeding times, kidney function, and liver function
- Blood pregnancy test if female and of childbearing age
- Possible type and cross-match of blood, or donation of patient's own blood

Preparing for the surgery

As the day of surgery approaches, it is normal to experience nervousness or anxiety. At first, patients are often excited about the prospect of having DBS therapy. But after the evaluation and approval process, some find themselves apprehensive about the actual event. Being nervous, scared, or worried is normal and expected behavior. Talking to other people who have had the surgery may help to ease your concerns. Being organized, planning ahead, and knowing what to expect will help prepare you for the surgery. Having a friend or family member plan to be with you before, during, and after the surgery can be reassuring. Here is a checklist that can help you stay organized as you prepare for DBS.

A few weeks before surgery

- Make sure you know where to go the day of surgery. This may be a different location from where you were evaluated. Write down the address, phone numbers, and parking instructions of the center. You may wish to practice in a rehearsal trip.
- If traveling from out of town, make arrangements to arrive a day early. Be sure to stay near the hospital. Check with the DBS center for recommended lodging and potential discounts.
- Get instructions from the DBS staff about when to take your PD medication the night prior to and the day of surgery. Most doctors will instruct you to not take PD medication the day of surgery. Therefore, your last dose will likely have to be taken the night before.

You will most likely be awake during surgery, so learning some relaxation techniques can help create a calm experience. Meditation, mindful breathing, or listening to music may help. Some centers will allow patients to go to sleep during the surgery with a light anesthetic. This is usually not preferred as it could change the firing patterns of the cells in your brain and make the brain mapping more difficult.

Packing list for the hospital stay

Make sure that you bring the following items:

- All your medicines, along with a list of the exact medication names, dosages, and times taken. Pack at least a week's worth of medication in the original, labeled bottles.
- A list of names and phone numbers that you would want contacted in case of emergency.

You may also want to include personal items, such as photos or reading materials.

The night before surgery

Get a good night's sleep, and follow the instructions you received from the DBS staff for the night before surgery. These will include not eating or drinking after midnight.

Chapter 6 The Surgery

On the day of the surgery, plan to arrive at the center an hour before your operative time. From the admitting area, you will be taken to a preoperative room where you will change clothes for surgery and have your blood pressure, pulse, and breathing checked. You will be given the opportunity to take care of any bathroom needs. An intravenous line (IV) may be placed at this time.

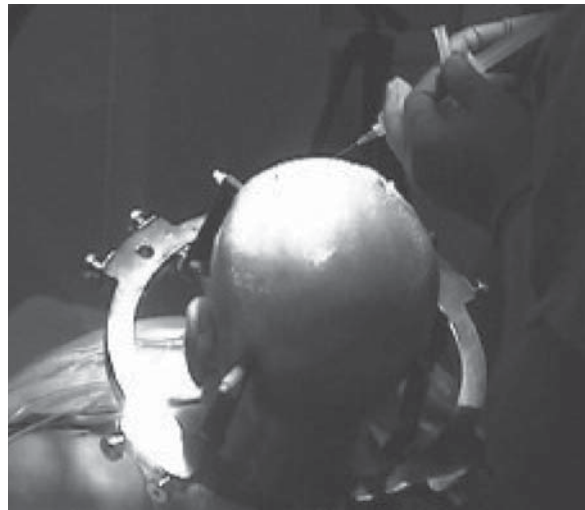
In the operating room, the neurosurgeon will place the head frame onto your skull. The box-like frame is necessary to precisely guide the neurosurgeon to the target. Because application of the head frame can be uncomfortable, local anesthesia is injected, which will numb the areas where the screws will attach to the skull to hold the head frame in place. Mild pain medication may also be offered. The head frame will remain in place for the entire surgery. After the head frame is attached, a CAT scan (computed axial tomography) or MRI will be done. This scan helps the neurosurgeon locate the exact site in the brain where the lead will be placed. The area where the skull will be opened will be shaved or cleaned with a special shampoo. In many operating rooms it is no longer necessary to completely shave the head.



Pre-operative head frame placement

Some surgical practices will utilize a “frameless DBS system.” With this procedure, you will visit the neurosurgeon a day or more before the operation. He or she will place several screws and plates in your skull in order to hold the frameless system. When you arrive in the operating room, he or she will attach the recording equipment to the plates and perform the surgery, essentially in an identical fashion to the frame-based system. Individual neurosurgeons will choose one method over the other based on experience and individual preference. The most important thing is that your surgeon is comfortable with the procedure, whether or not a frame is used.

After the brain scan, you will be taken to the operating room. Besides the neurosurgeon, there will be nurses and a movement disorders neurologist or neurophysiologist who will record the brain activity. The neurosurgeon will inject more anesthesia into your scalp and then use a drill to create a dime-sized hole in the skull, where a microelectrode will be inserted.



Numbing of surgical site

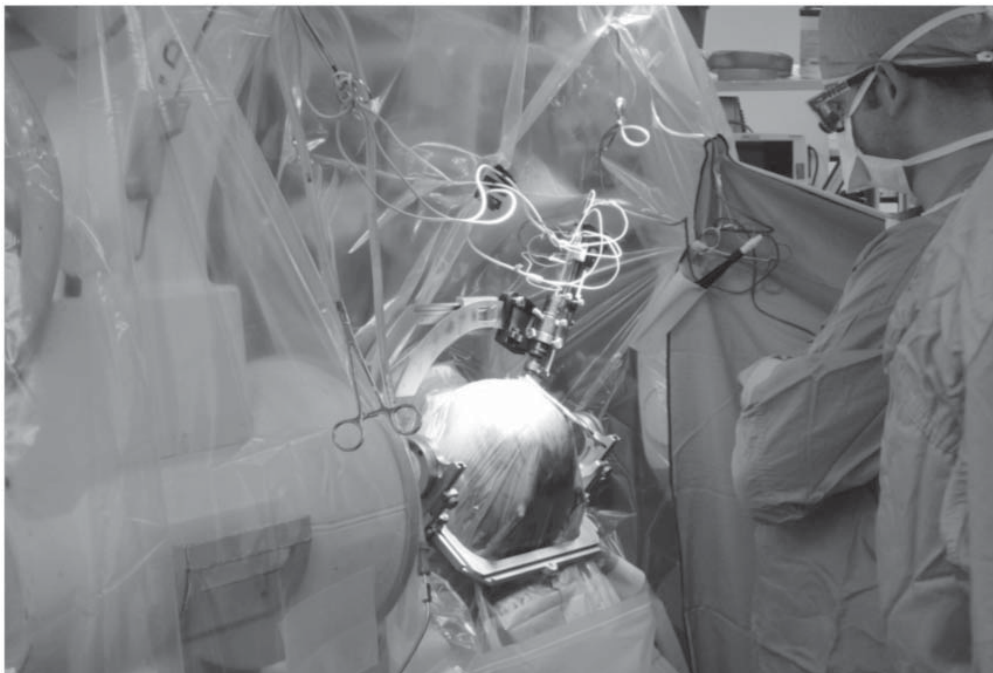


Drilling burr hole



Microelectrode recording computer

The microelectrode recording is a critical part of the surgery. This specialized procedure will guide the neurosurgeon in placing the lead in the exact area of the brain that will offer the best possible results. This part of the surgery can take a number of hours, depending upon the number of microelectrode passes required to pinpoint the target site, and also whether or not both sides of the brain are being operated on in one session.



Microelectrode recording apparatus that is attached to the head frame during DBS surgery

During the microelectrode recording, you may be asked to move your face, arm, or leg, or the examiner may move them. You may feel twitches, pulling, or tingling as electrical current is passed through the microelectrode. These are all normal and expected sensations. The neurologist will ask you to be quiet during the recording, and he or she will move your face, arm, or leg in order to pinpoint the brain activity that is responsive to movement or touch. Your patience, silence, and cooperation will be necessary to ensure the best results. After the microelectrode recording locates the precise target, the neurosurgeon and neurologist will determine the best placement and put the permanent DBS lead in place.



Neurologist examining the patient during a DBS procedure

After the lead is placed, the neurologist or neurosurgeon will connect it to an external generator and administer brief electrical stimulation to observe if it improves your PD symptoms; however, the extent of improvement observed in the operating room does not always reflect the amount that will ultimately be achieved. The neurologist and neurosurgeon will purposely induce side effects, such as having you see spots or feel tingling or pulling sensations. Inducing side effects helps to gauge the position of the DBS lead. When it is confirmed that the lead is in the correct target region, the neurosurgeon will fasten the permanent lead into place (with a capping device) and run the connecting wire outside the brain and under the skin of the scalp. The hole in the skull is sealed with a plastic cap and stitches. At some centers, you will then be put to sleep under general anesthesia for the placement of the pulse generator, which is typically put in the chest area below the collarbone. In other centers this second procedure will be performed on a separate day.

After the surgery, you will be taken to a post-operative area and closely monitored for an hour or more. Then you will be taken to a hospital room. During the first 24 hours after the surgery, it is important to watch for any complications, such as a seizure or confusion. In some cases you may be admitted to a special unit for close monitoring. Most patients are discharged from the hospital the next day. However, you may stay longer if you feel weak or confused, develop signs of an infection, or have an unexpected complication, such as stroke-like symptoms. Approximately 10 to 20% of patients will spend more than one post-operative night in the hospital.

The implantable pulse generator (IPG) is often placed several weeks later and is performed as a separate surgery, but it may also be placed on the same day as the brain lead implantation. At that time, the connecting wire will be attached to the brain lead and the IPG. This procedure takes about 40 minutes and requires general anesthesia. Most surgeons will place the IPG and discharge the patient the same day, while others may require an overnight stay. Be sure to ask your DBS staff if you will have the IPG placed at the same time as the brain leads, or if this will be placed later. PD medication should be continued just as before the surgery, or as directed by your neurologist. Typically, medications are adjusted after the DBS system has been programmed.

Chapter 7

After Surgery Care

At the end of your hospital stay, the deep brain stimulation (DBS) staff will provide you with discharge instructions to help you care for yourself at home. These instructions provide detailed information about how to care for your incisions (surgical cuts), the dates of follow-up appointments, and dosing information for your Parkinson's disease (PD) medications. These instructions should also include phone numbers to call in case of emergency.

You may be issued your own hand-held magnet or patient controller device that will allow you to turn the DBS system on and off and check the battery power in your device. Sometimes these items are provided upon discharge from the hospital, but they may also be provided at follow-up clinic visits, especially if the DBS system is not activated immediately. Once you receive these items, be sure that you know how to properly use the remote devices. You will also receive a wallet-size card in the mail that includes information about the DBS device, as well as your physician's name and phone number. You should always carry the magnet or patient controller and the information card with you.

Be sure to schedule appointments for the following:

- Removal of sutures or staples
- Placement of the neurostimulator, if it has not been implanted at the time of the brain surgery
- Your first stimulator programming session

Complications can develop during the first few weeks or even months after surgery. You should know the signs and symptoms of infection, and you should be on the look-out for changes in mood, stroke-like symptoms and seizures.

Infection

Around the time of surgery, your doctor may prescribe antibiotics to reduce the chances of an infection at the incision sites. Other precautions that you can take to prevent an infection include the following:

- Carefully follow any instructions that were given by the DBS staff about caring for your incision.
- Wash hands frequently.
- Keep the stitches clean and dry. Clean stitches with a small amount of antibacterial soap and water, then pat dry with a clean towel or gauze. Keep stitches covered with a dry bandage or piece of gauze, especially while bathing.

- Do not go swimming or bathe in a hot tub while you have stitches.
- Never scratch, touch, or put any pressure on the incision.
- Be sure pillows, sheets, and bedding are clean.
- Make sure that hats and wigs are clean.
- Wash hands after handling pets.
- Return to have sutures and/or staples removed at the scheduled time. Most centers will remove sutures 7 to 10 days after surgery. Some surgeons may use stitches that dissolve on their own.

Look for the signs of infection:

- Redness, swelling, or warmth at the incision or around the stitches
- A fever of 100 degrees or higher
- Pain or tenderness at the incision
- Puss, blood, or oozing at the incision

Any signs of infection should be immediately reported to your physician, who will likely prescribe antibiotics. While an infection may mean that some or all components of the system must be removed, early detection and treatment with antibiotics can sometimes prevent this from happening.

Mood changes

Mood changes, especially depression and anxiety, should be reported to your neurologist. There are reports of DBS patients who have become severely depressed and even suicidal. If you feel depressed, tell your doctor immediately. If you have thoughts of suicide, tell a friend or family member. Have someone take you to the nearest emergency room, or call 911. The depression may be related to DBS and is reversible with appropriate treatment. Here are some of the signs of depression:

- Saddened mood
- Excessive tearfulness or crying episodes
- Not feeling like doing your normal daily activities
- Wanting to be alone
- A sudden change in your sleeping habits—either sleeping too much or not enough
- Change in appetite, along with weight gain or loss
- Loss of libido, or sex drive
- Feeling irritable, anxious, or having feelings of panic
- Thinking and talking negatively
- Extreme loss of energy, tiredness, or fatigue



Feelings of depression or thoughts of suicide should be immediately reported to your physician.

Recently, it has been recognized that DBS can exacerbate impulse control disorders (e.g., inappropriate shopping, gambling, eating, and/or sexual behaviors) and dopamine dysregulation syndrome (where a patient craves dopamine). Additionally, there are several reported cases where these types of behavioral side effects can occur following DBS surgery. If you experience any of these behaviors, contact your doctors immediately for treatment.

Stroke-like symptoms

Signs and symptoms of a stroke or brain bleed include the following:

- Sudden severe headache, nausea, and vomiting
- Suddenly becoming confused
- Numbness and weakness on one side of the body
- Difficulty talking
- Worsening of balance, or falling to one side
- Thinking and memory problems
- Loss of vision

If you experience these symptoms, seek medical attention immediately. A brain scan can determine if there is bleeding or a stroke. The brain scan can also be used to check DBS lead placement.

Seizure

Seizures can occur when brain cells become irritated by head trauma, infection, blood, or, in the case of DBS, from the electrode placement itself. Seizures from DBS therapy are rare and usually occur during surgery or within the first 24 hours following surgery. Seizures most often present with uncontrolled jerking of the face, arms, and legs, along with loss of consciousness. They can also result in sudden confusion or abrupt numbness. If you suspect that you have had a seizure, you should call your doctor and seek immediate medical care. Anti-seizure medications may be prescribed and will likely control your symptoms. Most patients who experience a seizure during surgery or shortly after will not need medications for more than 6 months, and the seizures usually will not recur.



Key points about after surgery care

After going home from the hospital, you should call your doctor if you experience any of the following:

- ✓ An electric shock-like or burning sensation near the battery device, connecting wire, or implant site
- ✓ Signs of infection
- ✓ Signs of stroke
- ✓ Sudden severe change in thinking, such as confusion, hallucinations, or memory loss.
- ✓ Sudden change in mood, especially depression or any strange behavior
- ✓ Thoughts of suicide
- ✓ A seizure
- ✓ Any sudden, unexpected change in your health

When in doubt, call your doctor and seek medical care.

Chapter 8

Adjustment of Stimulation

“I was diagnosed with PD 10 years ago, and I had DBS surgery after 8 years. I only had one electrode put into the left side of my brain because my Parkinson’s was much worse on my right side. It definitely helped. I can still move my right side much better than before the surgery, and I am taking less medicine now. I did have some trouble with tingling on the right side of my face, and my speech got slurry so they had to change the electrode settings a couple of times to make me better, but after a few programming sessions the numbness and speech were better.”

– Mike

Programming of the stimulator system is usually performed on an outpatient basis, although in some deep brain stimulation (DBS) centers the system may be activated before discharge from the hospital. Activation may also occur in a rehabilitation center, where other types of therapies are provided. Programming usually starts within a few weeks of the DBS surgery. Most centers prefer to wait 2 to 4 weeks after surgery for brain swelling to resolve around the DBS lead.

During the programming process, the DBS programmer will use a small device to adjust the settings of the DBS system. He or she will hold a small wand over the neurostimulator, checking the effects of various electrode and stimulation settings. During this process, you will be examined and questioned about how you are feeling. The programmer will be looking for improvements in your tremor, rigidity, bradykinesia, and dyskinesia/dystonia, as well as side effects such as numbness, tingling, muscle cramping or pulling, electrical shock-like sensations, and possibly a worsening of Parkinson’s disease (PD) symptoms.

Often there is an immediate improvement in some PD symptoms, and this may be followed by their return in a matter of hours or days. Some programmers will ask you to stay near the clinic for several hours after a programming session, or ask that you return periodically for the first 6 months. You may also be admitted to a rehabilitation facility, which allows for close evaluation of your response to DBS programming and medication adjustments.

Most people with PD undergoing DBS therapy will require several programming sessions to achieve optimal symptom control. During the first 6 months, the average number of programming sessions reported in DBS centers throughout the United States is usually around six. Some people may be able to lower dosages of PD medication in the first few months following DBS surgery. Once the best settings and medication adjustments have been determined, you will be asked to return for routine follow-up appointments. The exact schedule will vary according to your condition, and your neurologist’s recommendations.

We recommend that you ask if you should take your usual medication before the appointment. **Programming is typically more successful when your last medication dose before the programming session is the night prior**, so your symptoms are more obvious and they are not confused with medication effects. Additional programming may be performed later that day, or after you have taken your PD medications. Always bring your medications to a programming session, in case you are asked to take them during or after programming.

Finding the optimal setting for a patient takes time due to the multiple combinations of settings, and also because many DBS leads may be activated. Each DBS electrode has four leads within it. All four electrodes are not activated. Depending on response, usually one or two electrodes are activated. Rarely, three electrodes are activated. In addition, how these electrodes are activated determines the shape of the stimulation field. Additional settings that are adjusted include the voltage and pulse width and frequency. Newer neurostimulators such as the Aactiva SC allow for even more advanced programming options with interleaving. Often patients will ask for “higher” settings, but higher is not necessarily better. Sometimes a side effect from stimulation, such as slurred speech, is due to a setting being too high. It takes time to find the right combination of settings for each individual. Just like a combination lock can have low or high numbers to open the lock, the DBS device will require the right combination of settings to obtain optimal benefit for the patient.

When the DBS electrode is activated, the goal is to adjust the settings to affect the intended target in the brain (STN or GPi). As the settings are increased, the stimulation field can spread to other regions in the brain around the target and cause side effects, such as slurring of speech, tingling, pulling sensations, nausea, etc. With traditional DBS electrodes, the leads can be activated to try to avoid these side effects. However, as side effects are reduced, the level of benefit from the stimulation may also decrease.

The benefits or side effects from a particular DBS setting may not be immediately apparent in the clinic setting. It may take several days to a couple of weeks for a patient to weigh and appreciate a side effect such as tingling or slurred speech versus the benefit of DBS. This is another reason why it can take several DBS programming visits before an optimal setting is determined.

Patients with the Medtronic neurostimulators Aactiva SC, PC, and RC have “group” setting options. This is at the discretion of the DBS programmer. Patients can have up to 4 groups that are lettered: Group A, Group B, Group C, and Group D. Patients can be provided a different combination of settings in each group and can switch to a different group with their patient controller. This allows the patient to try alternative settings between programming visits.

Another way to use the group settings can occur when patients require higher voltage settings to control their tremor, but the high-voltage setting causes slurring of speech. You could use one group with finer tremor control but slurring of speech. Then, when you want to have a conversation without slurring, you could switch to a different group that may have only partial tremor control but minimal slurring of speech. Other types of advanced programming can also be attempted by the DBS programmer. Another option with the newer neurostimulators is to allow the patient the ability to adjust either the voltage or pulse width or frequency within certain parameters.

Once the optimal settings have been chosen, you will be advised to NOT turn off your DBS system. If the device is turned off for some reason, you can use your hand-held magnet or patient controller device to turn it back on.

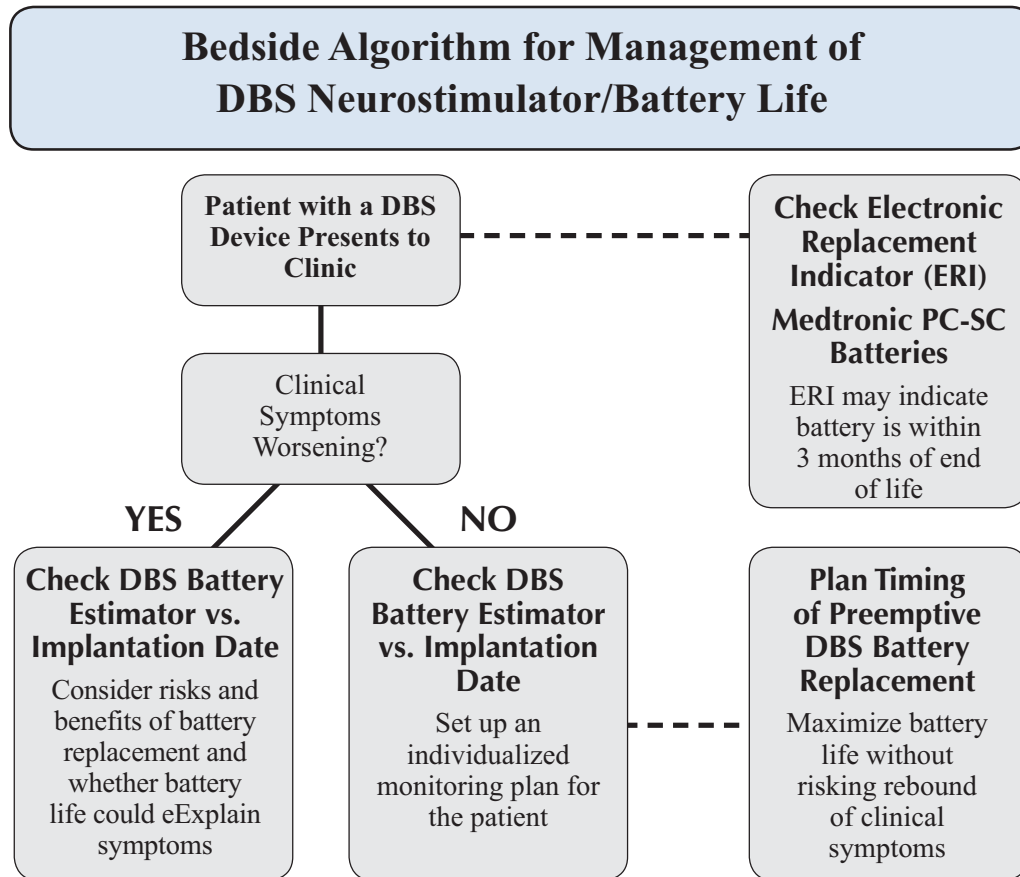
Depending on the settings, the battery life of the neurostimulator should last from 2 to 5 years. Your PD motor symptoms may worsen when the battery is running low. As the battery life of the neurostimulator nears its end, your neurologist or neurosurgeon will want to schedule you to have the old neurostimulator replaced. This is a simple outpatient procedure in which an incision is made to open the area in which the neurostimulator is implanted, the DBS extensions are unplugged, and a new neurostimulator is implanted and connected. The new neurostimulator can be turned on immediately after it is implanted.

It is very important that at each programming session, the programmer checks the battery life and has a plan for replacement. Sometimes the indicators of battery life can be misleading, and a battery replacement may be needed. There are web-based DBS estimators that can be used by your DBS programmer at <http://mdc.mbi.ufl.edu>. Also see the algorithm on the next page, which takes into account your clinical symptoms (Montuno, Kohner, and Okun, 2012). Estimators will provide an approximate length of time that the DBS battery is expected to last. The DBS battery may need to be replaced prior to the estimated timeframe, or it may last several months beyond the estimated timeframe. For this reason, it is important that a DBS programmer check the device regularly to help determine when the DBS battery needs to be replaced in order to avoid battery failure and loss of therapy efficacy.

A note about magnetic fields and household appliances

The neurostimulator can be turned off accidentally by any type of electromagnetic or magnetic field, including theft detection devices in department stores and security devices at airports and public buildings. Common magnets such as those placed on refrigerators, those used to close cabinet doors, and those found in radios and wireless phones can also affect the neurostimulator. Though not dangerous, symptom control will be reduced if the device is accidentally turned off. The neurostimulator can be turned back on with the hand-held magnet or patient controller.

The Soletra[®] and Kinetra[®] neurostimulators are more sensitive to magnetic fields and accidental device deactivations. The newer generation Activa SC/PC/RC neurostimulators as well as the Infinity neurostimulators are less sensitive to magnetic fields and are less likely to have accidental device deactivations.



Additional DBS information

After your surgery, your implanting institution should provide you with a patient remote (Medtronic) or iPod Touch (Abbott). All companies that have DBS products provide informational booklets about their devices for your review.

- ❑ Medtronic provides the *DBS Patient Therapy Guide*, which contains information about all DBS therapies, and the *DBS Therapy-Specific Patient Booklet*, which contains DBS therapy information specific to your medical condition.
- ❑ Abbott provides the *St. Jude Medical Infinity Deep Brain Stimulation (DBS) Brochure for Parkinson’s Disease* and the *St. Jude Medical Patient Controller Quick Reference Guide*.
- ❑ Boston Scientific provides *How It Feels to Be You Again: DBS and Parkinson’s Disease - An Educational Guide for Patients*, which can be downloaded at DBSandMe.com; *Your DBS. Your Discussion*, a self-assessment for people with Parkinson’s to work through symptoms and discuss best treatment options with a movement disorders specialist; and the *Vercise Charging System Quick Start Guide* and *Vercise Remote Control Quick Start Guide*, two short brochures for patients to learn how to use their IPG charging system and remote control, respectively.

The DBS Battery Est is an iPhone and Android app that can be used to monitor your DBS battery life.



Key points about programming

- ✓ Programming sessions usually start within a few weeks of surgery, although the system may be activated before discharge from the hospital.
- ✓ Several programming sessions will be needed to find the optimum stimulation settings and medication doses.
- ✓ Signs of a low battery include worsening of PD symptoms.
- ✓ Magnetic fields from theft detection devices and common household appliances are not harmful but can turn the neurostimulator off, reducing symptom control.
- ✓ Ask if you should take your usual medication before a programming appointment. Typically, most expert programmers prefer you come to appointments “off” medications.

Chapter 9

Special Information and Warnings

Once these electrical wires (leads) have been placed in the brain, there are some strict rules you will need to follow regarding other electrical devices. Magnetic and electrical currents in the environment can cause the deep brain stimulation (DBS) system to malfunction and can be dangerous.

MRI and X-rays

MRI scanning uses magnetic fields and radio waves to view images of organs and other structures, including the brain. While you can have an MRI after you have DBS, it should only be done under close supervision by physicians who are familiar with procedures for DBS patients. For example, a brain MRI should only be performed with a head coil MRI, with a strength of 1.5 Tesla or less. No complications or injuries have been reported using this type of head MRI, and it is considered safe for those with DBS. The magnetic field of the head coil MRI can turn some DBS systems on and off. The Soletra and Kinetra systems require for the voltage to be turned to zero volts and the device to be turned off. The Activa SC/PC/RC only need to be turned off. The Activa SC 37602 is only safe for head MRI, whereas the Activa SC 37603 is safe for full-body MRI with certain precautions. (If the DBS batteries are placed in the abdomen, then full-body MRI is not safe.) There are other criteria that determine the type of MRI that is safe for each individual. Prior to any MRI, you should always check with your DBS center staff to ensure the type of MRI is safe with your particular DBS system.



A person with DBS leads should never have a total-body or full-body radio frequency coil MRI, or a head transmit coil MRI that extends over the chest. MRI should only be performed on the head region, not the neck or body. Some DBS systems are full-body MRI-compatible, while other systems are not. Always check with your implanting institution for the type of MRIs that are safe with your DBS system.

CAT scans, DAT/SPECT scans, common X-rays, fluoroscopy, and PET (positron emission tomography) scans are safe for people with DBS. However, scans of the brain or head will have some distortion of the picture from the DBS leads, so the quality of the image may be compromised.

Diathermy

Diathermy is a deep heat treatment that is sometimes used by dentists and physical therapists for the treatment of pain. **Diathermy should never be used in a person who has DBS leads, as it can quickly heat up the leads, resulting in stroke or even death. It can also damage the neurostimulator system.**



A person with DBS leads should never have diathermy.

Electrocautery

Most surgeons use electrocautery, a form of electrical heat, to stop minor bleeding during surgery. Electrocautery can be used on people with DBS, but only with the following safeguards to minimize any flow of the electrical current toward the DBS device:

- ❑ Inform the surgeon that you have DBS therapy well before the surgery; contact your neurologist to let him or her know that you are having surgery.
- ❑ Just before surgery, the leads should be turned off, and the amplitude settings turned to zero.
- ❑ Bipolar electrocautery should be used to lessen transfer of electricity. **Do not use a unipolar device.**
- ❑ A ground lead should be placed on one of your legs. Any electrical charges that might transmit from the electrocautery device will be directed to the ground lead on your leg instead of the neurostimulator system.

Ultrasound

Ultrasound procedures, such as carotid doppler or abdominal ultrasound, can be performed safely. Again, the amplitude/voltage of the DBS system should be turned to zero and the device turned off prior to procedures. Also, the ultrasound microphone should be placed at a distance of 6 inches or more from the neurostimulator on the chest wall. If a person has a neurostimulator placed in the left chest, they should not have an echocardiogram, or ultrasound of the heart, unless the microphone is greater than 6 inches from the DBS neurostimulator. After any ultrasound procedure, it is a good idea to visit your DBS center to check your device for proper function. The main problem with having ultrasound procedures is that the neurostimulator may affect the ultrasound quality, so the test may not be accurate. Otherwise, there is no serious risk involved in having these procedures performed.

Cardiac pacemakers

Cardiac pacemakers can usually be placed in persons who have had DBS therapy as long as the neurostimulator and cardiac pacemaker are 10 inches apart.

Miscellaneous procedures

- ❑ Any type of medical procedure that will be performed directly over the neurostimulator device or connecting wire is not recommended. It could damage the device. Most X-rays can be performed safely.
- ❑ Do not allow your dentist to place electric drills or cleaning tools near the neurostimulator, connecting wire, or implant site on the scalp. Dental X-rays are okay.
- ❑ If you have a mammogram, be sure that the pressure of the machine on the breast does not directly compress the neurostimulator or connecting wires.
- ❑ Radiation therapy for the treatment of cancer can be performed as long as it is not performed too close to the neurostimulator and a protective shield is placed over it.
- ❑ Lithotripsy, a procedure to break up kidney stones, is not recommended unless it is the only medical option, as the treatment can damage the neurostimulator. If it is the only medical option, then protective shielding should be placed over the neurostimulator, which should be turned off and amplitude/voltage set to zero.



Frequently asked questions about electricity and DBS

Q: Will my neurostimulator device activate the metal detector at the airport?

A: Yes, it will set off the alarm, and the security equipment may turn the neurostimulator off. Most airports will make special accommodations for people with medical devices and will allow them to bypass the metal detector. Show the security personnel your medical card explaining the neurostimulator and how it may be affected by the detector.

Q: Will I feel the electricity when the stimulator is turned on?

A: Most people with DBS report feeling a brief tingling sensation for a few seconds after the device is turned on. You may temporarily feel a more intense electric sensation during stimulator programming or if you are near a strong magnetic field, such as a security device.

Q: If I have a heart pacemaker can I have DBS? If I have DBS and later need a heart pacemaker, does my DBS system need to be removed?

A: A person can have both a brain stimulating system and a cardiac pacemaker.

In order for both systems to work and not interfere with each other, they should be placed at least 10 inches apart. This might require placing the neurostimulator for the brain stimulation system under the skin of the abdomen instead of the chest wall.

Q: What if a person needs emergency resuscitation for a heart problem, such as a cardiac arrhythmia, a change in the heart rhythm, or a heart attack? Can they safely have electrical shock procedures such as cardioversion or defibrillation?

A: The general consensus is that if emergency cardioversion or defibrillation is needed, then it should be performed. The most likely complication is that the neurostimulator will become defective and will need to be replaced. Elective, non-emergent cardioversion for less serious arrhythmias, such as atrial fibrillation, can be performed if necessary, but the DBS system(s) should be turned off and the amplitudes/voltages set to zero before and during the cardioversion. In addition, protective shields should be placed over the neurostimulator(s) prior to elective cardioversion.

Q: Can I use household electrical appliances if I have DBS?

A: Yes, you can use simple everyday electrical devices such as vacuum cleaners, radios, computers, microwaves, and kitchen appliances. Electrical appliances or other items that produce a large enough magnetic field, such as large stereo speakers, could turn your neurostimulator off as discussed above.

Q: Can I use machinery and electric tools?

A: Some machinery and tools that produce a strong magnetic field can turn the neurostimulator off and on. Most small power tools (e.g., drills and saws) and yard tools (e.g., lawnmowers or tillers) can be used without any problems. To decrease interference with the DBS system, try to avoid any direct or close contact with the tool and the neurostimulator. Never use or be near large power machinery, power lines, arc welding equipment, electric steel furnaces, induction heaters, or MRI machines.

Q: Should I turn my stimulator off at any time, like before I go to bed?

A: The system should remain on at all times, even while sleeping or during times of rest. Continuous stimulation has been shown to offer the best control of PD motor symptoms. However, in the case of Vim DBS lead placement for tremor only, most patients can turn off the neurostimulator at night to save battery life. In special circumstances your doctor may recommend turning the device off at night.



Key points: Special information and warnings

Things to do to avoid potential problems with electricity and magnetic fields:

- ✓ **Never have an MRI until you have checked with your DBS provider about which type of MRI is safe for your particular DBS system. Some patients can safely have MRIs and some cannot.**
- ✓ **Never have diathermy**
- ✓ Surgery should be performed with bipolar electrocautery and a leg ground attached.
- ✓ When entering stores with theft detection devices, walk in the middle of the door opening to minimize the likelihood of the DBS system being turned off.
- ✓ Remove any unnecessary magnets in your home.
- ✓ Stand away from the microwave when in use.
- ✓ Avoid walking through metal detection devices if possible; ask security personnel to perform a manual body check at airports.
- ✓ Carry a wallet-size medical card that describes the DBS system and medical warnings – these can be shown to security and store personnel.
- ✓ Get a medical-alert bracelet that states you have a DBS system and that you have a wallet card with special warnings and emergency contact phone numbers.
- ✓ Avoid having elective lithotripsy, an ultrasound procedure used to break up kidney stones. If it is critical that you have lithotripsy, be sure to have a protective shield placed over your neurostimulators, and have your device turned off and the amplitude/voltage turned to zero.
- ✓ Do not allow any electrical or magnetic device to be placed near your neurostimulator, connecting wire, or implant site on your scalp.
- ✓ Carry your magnet or patient controller with you whenever possible.
- ✓ If you or your physicians are in doubt about a particular test that involves the use of electricity, magnetic fields, or ultrasound, do not have the procedure unless you are fully assured that it is safe. Check with your DBS center. You can also call Medtronic at 1-800-510-6735; Abbott at 1-800-727-7846; or Boston Scientific at 1-833-327-4636.
- ✓ Avoid hobbies or occupations that involve routine exposure to high voltage electrical and/or magnetic fields; in particular avoid arc welding.

Chapter 10: Emerging Changes and Future Directions in Deep Brain Stimulation for Parkinson's Disease

Deep brain stimulation (DBS) is a powerful tool that can help make life easier for some people living with Parkinson's disease (PD). Scientists are continuously studying DBS to figure out ways to make it better and safer for people to manage their disease. Recent research has yielded insights that will allow scientists to think about new ways to make the surgery even better. In fact, the main reason that scientists continue to study DBS is because of the original life-changing, ground-breaking success of DBS surgery, which is now considered the gold standard. While various advances—such as better batteries, better programming/targeting that allows DBS devices to last longer on the same batteries, and electrodes that deliver the best possible stimulation—have been very beneficial, the work of scientists is far from complete.

Following are some innovations that will put you in the driver's seat, letting you make more choices about your Parkinson's therapy.

A new DBS approach to surgery

You have a choice between awake and asleep surgery for deep brain stimulation. DBS was originally done with patients awake because this enabled neurologists and surgeons to get feedback from patients during the surgery. Many teams continue to perform surgery this way because it is associated with good treatment outcomes. For example, patients who are awake can participate in the procedure, assisting the neurologist and the neurosurgeon in “mapping” the brain and in locating cells associated with movement or vision. Additionally, when DBS is done with patients awake and off their Parkinson's medications for 12 hours or more, expert neurologists can identify the signals in the brain that indicate PD. This helps pinpoint the optimal location for the DBS electrode. Some groups have started using a new procedure where they use partial or full anesthesia to put patients to sleep. Many people are anxious about the surgery and feel more comfortable knowing they will be asleep. However, it is harder for the surgeon to pinpoint exactly where the electrode should go if the patient is asleep. Most of the time, the surgeon's experience will help him or her to put the electrode in exactly the right place, but being able to verify this by having a team member listen to signals from the brain—called microelectrode recording—can help you feel more assured that the location is just right. When you are asleep, the doctor cannot do microelectrode recording as effectively. Some doctors think that the benefits of microelectrode recording to verify proper electrode placement outweigh the challenges of managing patients' anxiety, and others do not.

As with any surgery, it is important to see a surgeon who is experienced in the specific surgery you need. Going to a Parkinson's Foundation Center of Excellence is a good way to ensure that you find a skilled surgeon. Visit our website, Parkinson.org/search, or call the Helpline at 1-800-4PD-INFO (473-4636) to find a Center of Excellence near you.

MRI- or CT-guided DBS versus traditional microelectrode recording

There are two approaches your neurosurgeon can use to place your DBS electrode:

1. Microelectrode recording (**MER-guided**): In this “gold standard” method, the surgeon plans the surgery using MRI or CT scans but then verifies that the electrode is in the right place by listening to signals from your brain cells using microelectrode recording.
2. MRI or CT scans in the operating room (**imaging-guided**): In this new technique, the surgeon still plans the surgery using MRI or CT scans but then uses a scanner during the surgery to watch the progress of the placement of the electrode into the brain, making sure that the electrode is correctly placed within the original target region. This method can be done with the patient asleep (under anesthesia).

The benefit of imaging-guided surgery is that the neurosurgeon can visualize the target region while he or she operates, then quickly adjust to any shifts or movement of the brain. However, MER is better at identifying the brain cells that will help determine a precisely located electrode. Cells don't show up on a scan. If the electrode is not in the right place, it is much harder for the neurologist to program it adequately to treat your Parkinson's disease. In rare cases, patients have had to go through surgery a second time to fix the placement. There is ongoing research to examine and improve the outcomes of this approach, as many patients are interested in a faster DBS procedure in which they can remain asleep. Ultimately, the most important factor in treating Parkinson's is correct electrode placement, no matter what tools your surgeon uses.

Getting DBS therapy sooner rather than later

If you are going to get DBS eventually, would it be better to go ahead and have the surgery done earlier rather than later? While the benefits of early DBS therapy are promising, most experts favor a more cautious approach when considering this important decision. A 2013 study of early DBS, called the EARLY-STIM trial, got the attention of doctors worldwide when it was featured in *The New England Journal of Medicine*. In the study, patients who were younger and in earlier stages of the disease underwent DBS. Typical PD patients, in their mid-sixties and older, were not included in the study, and we do not know yet how this large group will perform with earlier intervention. What we do know is that younger PD patients with motor fluctuations for approximately two years or less do seem to perform well with DBS. Most practitioners should carefully consider the merits of earlier intervention in this select group of patients. We do not have information on DBS for those who have not yet developed motor fluctuations.

On the horizon

Although we have made some big leaps forward with DBS therapy, there are many important issues that will need to be explored, and there is still much that can be improved upon. Parkinson's affects the brain in very complex ways and we have only so far scratched the surface on the best techniques and approaches for using stimulation to treat this disease. With DBS, we stimulate a "target"—a part of the brain that has been affected by Parkinson's. But there are many new targets to consider: the centromedian thalamus, the zona incerta, the motor cortex, and the pedunculopontine nucleus. And it is possible that stimulating one of these will treat symptoms that do not currently respond well to standard DBS targets (e.g., walking, balance, talking, thinking).

Today, DBS devices pulse regularly like a clock. What if they could pulse only when your brain needed the stimulation? What if a computer could listen for signs of trouble and then respond by pulsing to bring it back to normal, like a heart pacemaker? These "adaptive DBS" devices are close to being a reality. Electrodes that can be aimed—not just put in the right place but aimed to stimulate exactly the right cells and not the wrong ones—could enable your doctor to avoid side effects and enhance your benefits. In the near future, we may be able to employ multiple leads implanted into multiple brain regions to monitor brain signals from PD and even remotely program them. We will be able to treat specific symptoms in real-time with smarter DBS devices, so you can fight back against Parkinson's where and when you need to.

Talk it over

If you have read this book and think that DBS may benefit you, be careful not to wait too long for a potential breakthrough therapy. DBS may be that breakthrough for you. Take the time to talk to your neurologist about DBS therapy, so you can decide if it is right for you.

Appendix A

Glossary of Terms

Bradykinesia Slowed movement, such as slow walking, reduced arm swing, or less facial expression. One of the common motor symptoms of Parkinson's disease (PD).

Bilateral Occurring on both sides, as in the case of deep brain stimulation (DBS) lead placement into both the right and left sides of the brain.

Computed axial tomography (CAT) scan A special X-ray that takes detailed pictures of the brain and other body regions. Used with DBS to help locate the target site for the brain leads.

Connecting wire A wire that connects the brain electrode to the neurostimulator or battery source. The connecting wire is surgically placed under the scalp and the skin and soft tissue of the neck and threaded to the neurostimulator under the skin of the upper chest.

Corticobasal degeneration A neurological disease in which several areas of the brain degenerate.

Deep brain stimulation (DBS) A type of surgical therapy for the treatment of PD and essential tremor. The therapy involves placing a metal wire (brain lead) into a specific site in the brain, and then stimulating the site with continuous electrical pulses.

Dyskinesia Involuntary, irregular, rapid, dance-like movements of the body that may involve the head, face, neck, trunk, and limbs. This can occur as a side effect from long-term use of PD medications and with a number of other neurological conditions.

Dystonia Involuntary, irregular, slow, sustained contraction of muscles that results in painful twisting or positioning of the body, such as turning of the head or neck, cramping and flexion or extension of the toes, fingers, feet, arms, or facial muscles. This can occur as part of PD or as a side effect from medications used to treat it.

Diathermy A type of ultrasound therapy that involves applying a heat coil to the skin or body. Most often used by dentists, pain specialists, and physical therapists to help reduce pain. Diathermy should never be used on someone who has DBS therapy as it can heat the brain electrodes, causing serious brain damage and even death.

Electrocautery A surgical technique that involves the use of heat to cut through body tissues and stop small blood vessels from bleeding during surgery. There are some special guidelines outlined in chapter 13 for use in patients who have had DBS therapy. There is a small risk of the heat being transmitted to the implanted neurostimulator, connecting wires, or even the brain lead.

Essential tremor Also known as familial tremor, usually affects both hands, and often involves a head tremor and tremulous quality of voice. Essential tremor is relatively easy to distinguish from PD.

Frame A metal box-like device that is placed over the head and attached to the scalp of the person having DBS therapy. By immobilizing the patient's head, it allows the surgeon to precisely locate the target for the brain lead and to place the lead safely.

Globus pallidus internus (GPI) A specific region of the brain that is involved in motor pathways. It is one target site for DBS therapy.

Implantable pulse generator (IPG) Also called the neurostimulator, the IPG is the battery-powered device that is used to deliver electricity to the brain lead. A similar generator is also used for heart pacemakers. It is most often surgically implanted under the skin of the upper chest just below the collarbone.

Lead A thin, metal wire that allows for transmission of electricity. In DBS therapy the lead is surgically implanted into the brain. There are four different electrodes along the tip that deliver electrical pulses to exact locations of the brain.

Lewy body disease A neurological disease in which abnormal protein deposits called Lewy bodies are found in certain areas of the brain. Symptoms can be similar to PD and Alzheimer's disease.

Magnetic resonance imaging (MRI) A special scan that allows for detailed pictures of the brain and other body regions. It is used to help locate the brain target for DBS therapy and sometimes used after surgery to check for proper lead placement. MRI should only be done under close supervision by staff at the DBS center. See Chapter 11 for specific guidelines on the use of MRI after DBS therapy.

Motor symptoms Symptoms of PD that affect movement, such as tremor, rigidity, and bradykinesia.

Movement disorders neurologist A neurologist who has specialized training in PD and other movement disorders such as dystonia and essential tremor.

Multiple system atrophy A progressive neurological disease involving more than one system. Symptoms affect movement, blood pressure, and other body functions.

Neuropsychologist A psychologist who specializes in relating the nervous system to how we think and behave.

Neuropsychological tests A series of tests that measure various aspects of memory and thinking.

Neurosurgeon A physician who specializes in surgery of the nervous system.

Neurophysiologist A scientist who specializes in understanding brain cell firing patterns. A neurophysiologist or neurologist may use these patterns to map your brain function during a DBS operation.

Non-motor symptoms Symptoms of PD that do not relate to movement, such as mood changes, sweating, drooling, and constipation.

“Off” time The time during which a person with PD feels as though the motor symptoms (tremor, bradykinesia, rigidity) are worse; often when the medication is not working properly, upon waking before taking medication, or just before taking the next dose of medication.

“On” time The time during which a person with PD feels as though the medication is working well, or that they are functioning well and the motor symptoms of PD (tremor, bradykinesia, rigidity) are minimal or absent.

Progressive supranuclear palsy An atypical parkinsonian syndrome that involves limitations in eye movements, severe balance problems, and difficulty swallowing.

Rigidity Muscle stiffness or an increase in muscle tone; one of the motor symptoms of PD. It is sometimes associated with achy pain or cramping sensations.

Subthalamic nucleus (STN) A specific part of the brain that is involved in the motor pathways. It is one of the target sites for DBS therapy.

Tremor A rhythmic shaking, involuntary movement of a body part such as the arm, leg, head or chin. One of the motor symptoms of PD.

Unified Parkinson’s Disease Rating Scale (UPDRS) A specific tool used by Parkinson’s specialists to score the presence and degree of Parkinson’s motor symptoms. Often used in research studies and with patients before and after having DBS therapy.

Unilateral Occurring on one side. In the case of DBS therapy, placing a DBS lead on only one side of the brain.

Appendix B Resource List

If you are considering deep brain stimulation (DBS) therapy, or if you have already had it done, the following sources will provide you with additional information and patient assistance programs. In addition, consider contacting the nearest university or private hospital to ask if there are any neurologists who have extra training in movement disorders or Parkinson's disease (PD).

If you have limited computer access, bring this page to your local library and ask someone to help you find these Internet sites. Also request printed copies of the material that interests and is relevant to you.

The Parkinson's Foundation website, www.parkinson.org, has comprehensive information about Parkinson's disease, from symptoms to treatments to research to living well today. Find expert PD centers and community organizations near you at www.parkinson.org/search.

Contact the Parkinson's Foundation Helpline for up-to-date information about PD, referrals to health care providers and local resources, and more. You can reach a PD Information Specialist at **1-800-4PD-INFO (473-4636)** or helpline@parkinson.org.

For information about DBS centers, the Medtronic website is an excellent resource: www.medtronic.com. This website lists physicians and centers throughout the United States that perform DBS surgery. Note that Medtronic does not endorse or guarantee any listed physician's or center's services. Deciding on a DBS center with the highest quality of care and skill will take some research (see Chapter 5, "Preparing for Surgery"). You can also call the toll free number, **1-800-664-5111, extension 1050**, to speak with a Medtronic representative.

Abbott has a website for patients at www.sjm.com/dbs. You can find information on DBS for Parkinson's, including a video on how DBS works. There is a Contact Us form, which you can fill out to receive more information and/or have an Abbott representative contact you.

DBSandMe.com is Boston Scientific's website for patient education and information on Parkinson's disease and DBS.

Six regional Veterans Administration hospitals are designated Parkinson's Disease Research, Education, and Clinical Centers (PADRECCs). These are DBS centers with considerable experience and are involved in clinical studies. For contact information on the nearest regional center, visit: www.parkinsons.va.gov.

Patients and physicians who want information about billing and reimbursement for DBS therapy can call **1-800-972-9298** or visit www.prsnetwork.com.

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Michael S. Okun, MD, received his BA in History from Florida State University and his MD from the University of Florida (UF), where he graduated with Honors. Dr. Okun completed an internship and neurology residency at UF. Following residency he was trained at Emory University in basal ganglia disorders and in the physiology and surgical approaches to these diseases. He has, with Dr. Kelly Foote, placed over 900 deep brain stimulation (DBS) leads. He is Co-Director of the UF Center for Movement Disorders and Neurorestoration, the busiest clinic in the world specializing in DBS failures. Dr. Okun was one of the driving forces behind the creation of the Center for Movement Disorders and Neurorestoration and its patient-centric approach to care. The Center combines all specialties, clinical care, and research under one roof. Dr. Okun has dedicated much of his career to the development of care centers for people suffering with movement disorders, but he has also enjoyed a prolific research career exploring non-motor basal ganglia brain features. He has participated in pioneering studies exploring the cognitive, behavioral, and mood effects of DBS. Dr. Okun is Chair of the UF Department of Neurology and holds the Adelaide Lackner Professorship in Neurology. He has published over 300 peer-reviewed articles, is a published poet (*Lessons From the Bedside*, 1995), and has served as a reviewer for more than 25 major medical journals including *The Journal of the American Medical Association (JAMA)* and the *New England Journal of Medicine*. He has been invited to speak about Parkinson's disease, DBS, and movement disorders all over the world. Dr. Okun is an associate editor for *New England Journal of Medicine*, *Neurology Journal Watch*. Dr. Okun is also the author of the Amazon bestselling book *Parkinson's Treatment: 10 Secrets to a Happier Life*, which has been translated into over 20 languages, and 2015's *10 Breakthrough Therapies for Parkinson's Disease*. He is the Parkinson's Foundation Medical Director.

Pamela Rose Zeilman, MSN, ANP-BC, received her Bachelor of Science in Nursing from the University of Florida in 1995. From 1995 to 1998, she worked on a Medical-Surgical floor with intermediate care patients, and then worked in a Medical Intensive Care Unit from 1998 to 2006. In 2006, she received her Master of Science in Nursing (MSN) from the University of Florida. She is board certified as an adult nurse practitioner (ANP-BC) through the American Nurses Credentialing Center. Since 2006 she has been an integral member at the University of Florida Center for Movement Disorders and Neurorestoration. Mrs. Zeilman performs deep brain stimulation (DBS) programming, and manages the care and treatment of over 1000 deep brain stimulator patients. Recognized as an expert care provider for Parkinson's disease, she has participated in several roundtable discussions with subsequent publications regarding the care of Parkinson's disease patients. Mrs. Zeilman is considered an expert DBS programmer and has assisted in training neurology residents and fellows in programming and managing DBS devices. Many of these fellows now practice nationally and internationally. She has written over 20 peer-reviewed publications, mostly focusing on DBS. She has contributed to two chapters in the book *The Dystonia Patient: A Guide to Practical Management*, 2009.