

Deep Brain Stimulation

# Patient Resource Guide





**SWEDISH**  
NEUROSCIENCE  
INSTITUTE

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# Welcome to Swedish

Welcome to the Swedish Neuroscience Institute at Swedish Medical Center. We understand that undergoing Deep Brain Stimulation (DBS) surgery is a significant decision for you and your family. We realize you may have many questions and concerns.

We'd like to assure you that nothing is more important to us than your health and well-being. Our staff is expertly trained to offer you the best possible care, and we will make every effort to keep you as comfortable as possible during every step of process.

We hope this Patient Resource Guide answers many of your questions about your surgery and rehabilitation. You may have other questions not addressed in this guide. Please feel free to call us at any time if you'd like more information.

We thank you for choosing Swedish for your Deep Brain Stimulation surgery. We look forward to providing you with excellent care and ongoing support as you go through this process.



**DEEP BRAIN STIMULATION**

550 17th Ave., Suite 540  
Seattle, WA 98122

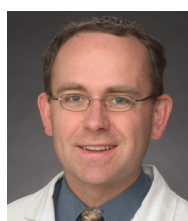
[www.swedish.org](http://www.swedish.org)

# Swedish DBS Program

## Meet the Deep Brain Stimulation Team



**Peter C. Nora, M.D.**, is a board-certified neurosurgeon at the Swedish Neuroscience Institute. He specializes in the surgical treatment of movement disorders, such as Parkinson's disease, using Deep Brain Stimulation. He has one of the busiest DBS practices in the region. He received his medical degree from Tulane University in New Orleans and completed his residency in neurological surgery at George Washington University in Washington, D.C.



**Ryder P. Gwinn, M.D.**, is a neurosurgeon who has extensive experience using neurostimulation to treat patients with movement disorders, chronic pain and epilepsy. Dr. Gwinn received his medical degree from the University of California, Los Angeles and completed a residency in neurosurgery at Georgetown University in Washington, D.C. He completed a fellowship in epilepsy surgery at Yale.



**Jennifer L. Witt, M.D.**, is board-certified in neurology and psychiatry and serves as medical director of the Movement Disorders Program at Swedish. She works closely with the Deep Brain Stimulation Program to screen patients for this treatment. She received her medical degree from Wake Forest University and completed a residency in neurology at the University of California, Davis. She completed fellowships in neurology and movement disorders at the University of California, San Francisco.



**Susie I. Ro, M.D.**, is board-certified in neurology and clinical neurophysiology and works closely with the Deep Brain Stimulation Program to screen patients for this treatment. She received her medical degree from McGill University in Montreal and completed a residency in neurology at Yale-New Haven Hospital. She completed fellowships in clinical neurophysiology (EMG) and movement disorders at Beth Israel Deaconess Medical Center in Boston.

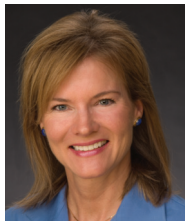


**David R. Clawson, M.D.**, is a physiatrist who specializes in brain injury and stroke. He evaluates patients to determine if they are candidates for post-DBS rehabilitation treatment. Dr. Clawson received his medical degree from the University of Kentucky and completed his residency at the University of Washington. He is board-certified in physical medicine and rehabilitation.

## Swedish DBS Program



**William A. Burkhart, Ph.D.**, is a neuropsychologist who specializes in the neurocognitive and neurobehavioral aspects of Parkinson's disease and other neurological illnesses and injuries. Dr. Burkhart completed post-doctoral work in medical psychology and behavioral medicine at Wilford Hall USAF Medical Center in San Antonio, and in traumatic brain injury and chronic pain at the University of Washington. He is board-certified by the American Board of Professional Neuropsychology.



**Peggy O'Neil Shortt, MN, ARNP**, is the manager of the Deep Brain Stimulation Program at Swedish. She oversees all DBS surgical outcomes, communicates with referring doctors, and coordinates pre- and post-operative clinical procedures and follow-up care. She has a bachelor's degree in nursing from Pacific Lutheran University and a master's degree in nursing from the University of Washington.



**Diana Herring, MN, ARNP** is a nurse practitioner experienced in the management of patients with neurological conditions. She has expertise in the treatment of movement disorder patients with deep brain stimulation systems, and is currently responsible for clinical support for the DBS and Spasticity Programs at Swedish on the Cherry Hill Campus. Diana practices patient-centered care, always putting patient and family needs first.



**Alexa Martin, PA-C**, is physician assistant who is nationally certified to practice medicine as an advance practice clinician and is part of the Swedish DBS Neuroscience team. Alexa began her career as a PAC in 1995 after graduating from the University of Washington School of Medicine's Medex NW Physician Assistant program. Before joining the team here, she worked in family practice, emergency medicine, oncology pain service, neurological surgery and most recently was a faculty member at the UW School of Medicine.



**Michelle Bauer** is the program operations supervisor for the DBS program. She oversees and coordinates clinic operations, tracks surgical outcomes, and organizes patient educational events. She has her Bachelor of Science degree in Biology from the University of Puget Sound and worked in cancer research for 8 years before coming to Swedish. To contact Michelle, call 206-320-2883 or e-mail her at [michelle.bauer@swedish.org](mailto:michelle.bauer@swedish.org).



**Morgana Rauls** is the clinical coordinator for the DBS program. She schedules surgery and oversees patients' schedules, transportation, lodging and other needs. She has worked in health care for more than 20 years and received her degree in medical assisting from North Seattle College. To contact Morgana, call 206-320-2847 or e-mail her at [morgana.rauls@swedish.org](mailto:morgana.rauls@swedish.org).



### **Other health-care professionals**

Additional professionals who may be involved in your care include physical, occupational, speech and respiratory therapists; intravenous nurses; laboratory technicians; diagnostic imaging staff; dietitians; pharmacists; social workers and chaplains. All are highly trained professionals whose primary interest is giving you the best possible care and support.

Our nurses are specially trained and experienced in attending to the specific care and needs of movement-disorder patients. While you are hospitalized, your nurse will develop a specific plan of care for you that will serve as a guide for everyone on your treatment team. It is important that you be aware of who your assigned nurse is at all times. If a shift has changed or you are simply not sure who your nurse is, ask any staff

member and they will help identify your nurse. Look at the name badges of your caregivers to help you remember their names.

An internal medicine physician — or “hospitalist” — may also participate in your care. Hospitalists are physicians who attend to patients in a hospital 24 hours a day, seven days a week. They closely monitor patients for other medical problems, such as hypertension, diabetes, and heart and pulmonary issues. When your physician is not at the hospital, a hospitalist who is familiar with you and your needs will be available. This physician will work closely with your own doctor and nurse.

Certified nursing assistants may also participate in your care.

## **DBS clinic Location and Contact Information**

The Deep Brain Stimulation Program of the Swedish Neuroscience Institute is located at the Cherry Hill campus of Swedish Medical Center. Please see the Appendix for a map and driving directions to Swedish/Cherry Hill.

### **Deep Brain Stimulation Program**

Swedish Neuroscience Institute

James Tower

550 17th Ave., Suite 540

Seattle, WA 98122

Phone: **206-320-2847**

Fax: **206-320-2226**

Emergency after hours: Call **206-320-2800** and ask for the neurosurgeon on call.



## DBS Overview

Millions of Americans suffer from Parkinson's disease, essential tremor, dystonia and other incurable neurological disorders. These disorders are characterized by involuntary movement, such as trembling and uncontrollable muscle contractions, that make even simple daily activities — like buttoning a coat, signing a check and holding a cup of coffee — a major challenge.

These tremors are not only embarrassing and frustrating, they can be debilitating. In particular, patients with Parkinson's disease often have difficulty controlling their symptoms with medication, or they suffer intolerable side effects from their medication. As a result, Parkinson's patients can experience significant impairment in function and decreased quality of life.

The good news is there is hope for these patients. An innovative surgical treatment, known as Deep Brain Stimulation (DBS), has proven very effective in helping people who suffer from these neurological disorders gain control of their symptoms and improve their quality of life. Thousands of movement-disorder patients have already been helped by DBS treatment in the United States.

### What is Deep Brain Stimulation?

Deep Brain Stimulation can be thought of as a “brain pacemaker.” One or two tiny wires or electrodes are surgically implanted into the part of the brain involved in movement-related communication between brain cells. The electrodes are connected to a pulse generator — similar to a

cardiac pacemaker — under the skin and below the collarbone on the chest wall. The electrodes deliver mild electrical pulses to the brain, blocking the brain signals that cause abnormal movement, such as muscle tremor, stiffness, slowness and muscle contractions. The stimulator is fully programmable, and patients can use a simple hand-held remote control device to turn it on or off. There are no external wires to the devices; the entire system is fully implanted under the skin.

### What Does Deep Brain Stimulation Involve?

Deep Brain Stimulation surgery is completed in a series of steps (outlined in greater detail later in this guide) that typically span about 10 to 16 weeks. Patients report full benefits from the surgery at about four to six months.

#### Step 1 – Lead implantation surgery

The first step involves implanting the leads in the brain. During this procedure, you will be mildly sedated and given local anesthetic to numb your skin. It is important that you are physically and mentally able to follow instructions and answer questions during this surgery; we typically determine the benefits of stimulation while you are

awake. Recovery after the initial surgery is fairly quick. You will be closely monitored in our intensive care unit (ICU) for 24 hours. Some patients may require an additional stay on the neurological nursing unit, but most are discharged after their 24-hour ICU stay.

## **Step 2 – Battery implant surgery**

The next step involves implanting the battery, also known as a pulse generator or neurostimulator. It is similar to a cardiac pacemaker. This procedure usually occurs seven to 10 days after the leads are implanted in the brain and is performed while you are under general anesthesia. Most patients are able to go home the same day of their surgery. During the procedure, the leads in the brain are connected to the pulse generator, which is implanted under your skin in the upper chest wall. The system is completely internalized beneath a layer of fatty tissue and skin.

## **Step 3 – Programming the neurostimulator**

About three weeks after the battery implantation, the neurostimulator is activated at an office follow-up visit. The newly implanted system will deliver mild electrical pulses to your brain, blocking the signals that cause abnormal movements (e.g., tremor, stiffness, slowness, muscle contractions). The stimulator is fully programmable, and you will use a simple hand-held remote control device to turn the stimulator on or off.

Please keep in mind that Deep Brain Stimulation is a process, and it may require weeks of follow-up medication and adjustments to your stimulator to achieve the maximum benefit. We encourage you to discuss your personal goals and expectations of the surgery with your doctor.

Be assured that, with your physician's initial referral, you will undergo extensive, independent evaluations by the multidisciplinary DBS team to determine whether you are a good candidate for this surgery.

# The Deep Brain Stimulation (Activa<sup>®</sup>) System

**Activa Parkinson's Control Therapy** — under the brand name Activa System — comprise the Deep Brain Stimulation implantable components made by Medtronic, Inc. Since 2002, Activa Parkinson's Control Therapy has been approved and widely used in the United States. The Activa System has also been approved for use in Canada, Europe and Australia since 1998.

The therapy is completely FDA-approved and non-experimental. Thousands of patients in the United States alone have successfully undergone DBS implantation for movement disorders.

## **Activa Parkinson's Control Therapy is used for:**

- Patients who suffer from advanced Parkinson's disease. Patients should be carefully screened for other movement disorders that may not respond to Activa Therapy.
- Patients who have shown benefit from levodopa therapy. Activa Therapy has not been shown to improve symptoms that do not also respond to levodopa.
- Patients whose symptoms are not adequately controlled by medications.

## **To be eligible for Activa Parkinson's Control Therapy:**

- Patients must be physically able to endure the surgery and answer questions and follow directions during the surgery.
- Patients must understand the nature of the therapy and be able to operate a hand-held control device.
- Patients must be available for periodic follow-up visits.
- Patients with significant cognitive decline or dementia may not be considered for Activa implant surgery.

## **The safety and effectiveness of this therapy has not been established for use in:**

- Patients with neurological disease origins other than idiopathic Parkinson's disease
- Patients who are pregnant
- Patients with dementia
- Patients with coagulopathies (bleeding disorders)
- Patients with moderate to severe depression or anxiety
- Patients under the age of 18
- Patients over the age of 75 are considered for surgery on a case-by-case basis

## Surgical risks

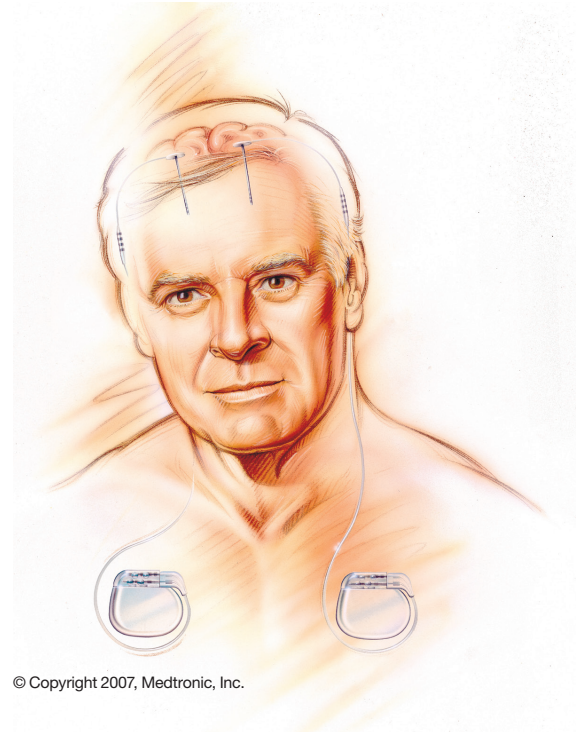
- There is a slight risk of infection due to the presence of implanted hardware.
- Medtronic clinical studies have reported minimal risks of adverse events that include intracranial hemorrhage, stroke, worsening of motor impairment or Parkinson's symptoms, pain, dysarthria, hypophonia, speech disorder, electromagnetic interference, lead breakage and skin erosion.

## Microlesion effect

After surgery, many patients experience an immediate reduction in their symptoms. This is called a microlesion or “honeymoon” effect. It can last several days, although the peak effect is usually in the first five days, then it gradually dissipates. Your DBS team will carefully monitor your symptoms. Do not reduce or discontinue your medications without the advice of your neurologist or DBS medical team.

## DBS (Activa System) Components

The Activa System consists of the following implantable components:



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**Lead** – The lead is an insulated platinum iridium wire, about the size of a thin coffee stirrer, with four tiny electrodes at the tip. The target for implantation of the wire corresponds to a specific location in the brain for each movement disorder. For Parkinson's disease, the final tip is implanted in the subthalamic nucleus (STN); for essential tremor, the tip is implanted in the ventral intermediate nucleus of the thalamus (VIN); and for dystonia, the tip of the electrode is implanted in either the STN or the globus pallidus interna (GPi).

**Extension** – The lead is connected to an insulated coiled wire, called an extension. This is tunneled under your scalp through a small, flexible metal tube, similar to a straw. This tunnel runs behind your ear, along the side of your neck and over your collarbone, where it will be attached to a battery implanted under the skin on your chest wall. In some cases, a longer extension may be used, with the battery implanted in the abdominal wall.

**Battery (neurostimulator)** – The extension is connected to a pacemaker-like device that powers the entire system. At two inches wide and one-half inch thick, the lithium-powered battery has a computer chip programmed to send electrical pulses through the lead to control movement-disorder symptoms. The battery generally has a three- to five-year life expectancy, depending on how high the parameters are programmed to control your symptoms.

The battery and extension are usually implanted in a separate surgical procedure, under general anesthesia, at least one week following your brain lead implantation. There are several types of batteries. Your surgeon will decide with you which one is most appropriate.

**Easy patient programmer** – During your first (or second) follow-up visit to the DBS clinic after your surgery, you will receive a hand-held remote control device. This allows you to turn your stimulators on or off, determine whether they are on or off, and check your battery life. For essential tremor patients, batteries are typically turned off at night while sleeping. For Parkinson's and dystonia patients, batteries are left on all the time.

# Lead Implant Surgery

## So You've Decided to Have DBS Surgery

After you have been selected as an appropriate candidate for Deep Brain Stimulation surgery, your referring physician will receive the DBS screening reports from our movement-disorder neurologist, neuropsychologist and neurosurgeon.

The DBS scheduling coordinator will contact you by phone to discuss possible dates for your surgery, as well as the multiple screening assessments that will be performed during the few weeks prior to your surgery. This requires coordination among many departments and may take several phone calls to confirm all the arrangements.

### Selecting a date for surgery

When choosing a date for your surgery, please consider the schedules of family members who may need to fly in from other parts of the country. Also, you may need to make arrangements for extra support at home, transportation to and from Swedish, and lodging if you are from out of the area. If you are employed, you may need to make special arrangements for leave prior to committing to a surgery date.

Keep in mind that, for at least two months after your surgery, you should not plan to travel any distance for any length of time. You will need this time at home for healing, stimulation and medication adjustments, and initial rehabilitation.

Due to the nature of neurosurgery, there's always a chance your surgeon could be called to attend

to a last-minute emergency. In this event, your surgery date may be cancelled or postponed. This does not occur often, but you should be prepared for this possibility. Because of this, you may not know the exact start time of your surgery until the day that your surgery takes place.

**Three to four weeks before your surgery, you will receive a schedule in the mail outlining the specifics of your presurgical and surgical agenda. If you see any conflicts or have any questions, please call the DBS clinic at 206-320-2847 right away.**

## Lead Implantation Surgery – Pre-operative Phase

### One month prior to your surgery

To make certain your DBS surgery is as successful as possible, we need a thorough understanding of your physical, psychological and emotional health. To help us with this evaluation, you will have several appointments at the Swedish/Cherry Hill campus before your surgery. Out-of-town patients may prefer to accomplish these visits over three days while staying at a local hotel. Patients living nearby may wish to space these visits out over a few weeks.

The appointments described below are required before your surgery. All of these visits will be scheduled through the DBS clinic and take place at Swedish/Cherry Hill in Suite 540 of the James Tower, unless otherwise specified. Please remember to bring the medications you will need to take during the course of these visits.

You will receive a printed schedule, which we usually mail, listing the dates and times of your appointments and further directions. You will also receive a packet with questionnaires and other requests for information. **Please bring this completed packet with you to your history and physical visit.**

It is imperative that a spouse, caregiver, family member or close friend attend all visits with you — preferably the same person each time. Ideally, this same person will be with you after your surgery.

1. **Neuropsychological evaluation** (2 hours)  
– If you have not had a neurological psychological evaluation within the past 12 months, we will perform one before your surgery. On the day of this evaluation, you should be rested and on your best *on-state* medication.
2. **Pre-operative history and physical** (1½-2 hours) – During this visit, we will give you a full physical, take your medical history, and videotape you. Please come to the visit *off-state*. This will be an educational visit as well, and you will have an opportunity to ask any questions you may have.
3. **Neurosurgical consultation** (45 minutes)  
– During this visit, you'll meet with your neurosurgeon. This is your opportunity to

get to know your neurosurgeon, as well as your surgeon's opportunity to get to know you. The risks and benefits of the surgery will be discussed in detail, and you will be able to share your personal goals and expectations of the surgery.

4. **Pre-operative MRI scan** (4 hours) – If you have a history of spine problems requiring surgery or carry a diagnosis of chronic back pain, we will take images of your spine as well. We do this because, once you have Deep Brain Stimulation surgery, you will no longer be able to have body MRI scans. You may need mild intravenous sedation to help you remain still during the exam. If so, you will be scheduled for a three- to four-hour outpatient hospital admission through our Same Day Surgery unit.

*Note:* After reviewing your MRI scan and looking at the specific architecture of your brain, your surgeon may decide it is best to perform your Deep Brain Stimulation surgery in stages. If this is the case, surgery would be completed on one side of your brain first and then on the other side six to eight weeks later. If the procedures are staged like this, the battery is usually implanted immediately following electrode implantation.

5. **Rehabilitation assessment visit** (3 hours)  
– During this visit, you will receive physical therapy, occupational therapy and speech therapy evaluations. You will be seen in the medications *on-state*. Some patients will also see Dr. David Clawson for a medical rehabilitation evaluation. His office is located at Swedish/Cherry Hill in Suite 600 on the 6th floor of the Jefferson Tower.



## **Two weeks prior to your surgery**

If you have a dry, itching, scaling scalp, begin using a dandruff shampoo, such as Tegrin or Selsun Blue, two weeks before your surgery. This is not necessary if your hair and scalp are healthy.

For two weeks prior to your surgery, please do not take any products containing aspirin; aspirin can prolong bleeding time and interfere with clotting. A list of medications commonly containing aspirin is located in the Appendix of this guide. If you are unsure of whether or not a product contains aspirin, please ask one of the DBS clinic providers.

Also, please do not take any non-steroidal anti-inflammatories such as Motrin or Advil in the two weeks prior to surgery. Discontinue taking fish oil and vitamin E supplements, as these can also cause problems with bleeding. Do not take any herbal dietary supplements; their reactions with anesthetic are unclear. You may continue to take a multivitamin. You may use Tylenol for pain.

## **The weekend prior to your surgery**

We ask that you cut your hair to a “buzz” cut or a very short scissor clip down to less than a half-inch from your scalp. Please be careful not to nick or scrape your scalp.

Have fresh pillowcases and towels ready at your home. From this point on, we ask that you use fresh towels and pillowcases every day until your incisions have healed.

You should not have close contact with pets or any livestock until your incisions have healed. This means you should not share furniture with your pets, change litter boxes or clean up after animals. You may need to arrange for pet care, board animals, or arrange for additional household help. These extra precautions are necessary to promote wound healing and prevent infection.

## **The night before surgery**

**Take a shower using Hibiclens.** At your presurgical visit, you will be given a four-ounce bottle of Hibiclens, an anti-bacterial soap. (*Note:* Please save about half the bottle to use before your second surgery.) Wash gently and avoid getting the cleanser in your eyes or mucous membranes. Use clean towels to dry off and sleep in clean sheets and pillowcases. Set aside freshly laundered clothing to wear on the morning of your surgery. Repeat the Hibiclens shower in the morning. You should wear a shirt that opens in the front, to avoid the need to pull clothing over your head.

**After midnight, do not eat or drink anything.** An empty stomach on the day of surgery decreases the risk of complications during surgery.

**Remember, do not take your medications that have been prescribed for Parkinson's, tremor or dystonia after midnight, prior to your surgery.**

## Other medications

The use of other medications prior to surgery, such as those prescribed for high blood pressure, heart disease, diabetes or hormonal therapy, should be discussed with your DBS medical team.

## Packing for the hospital

For a comfortable stay at Swedish, please bring all of the following:

- Robe
- Slippers
- Comfortable clothes and shoes (shirt should open up in the front)
- Books or magazines
- Hairbrush, comb, shampoo, toothbrush and toothpaste
- Personal items such as contact lenses, eyeglasses, hearing aids, dentures and prostheses
- Your cane, walker, or other personal assistive devices you normally use
- Paperwork and questionnaires and an updated medications list

## A note about medications

Please note that prescription drugs should not be brought to the hospital for your first surgery. The hospital will provide all the medications you need during your stay. During your second outpatient procedure, you may bring your own medications. It is important that you communicate your medication needs to your nurses before you take any of your own medications.

## Smoke-free environment

Swedish is a smoke-free campus — inside and out — at all locations. Smoking is not allowed at any time on Swedish property, owned or leased, including parking garages and lots. While you are a patient at Swedish, you will not be allowed to smoke.

## Day of Surgery

### Arriving for surgery

Your lead implant surgery will likely be scheduled in the morning. If your surgery is scheduled at 7:40 a.m., you will need to arrive two hours in advance for surgical preparation. If your case is scheduled following one or more other surgeries, please check in at the time designated by the DBS clinic on your agenda.

If you live a significant distance from Swedish, it might be wise to stay in a hotel close to the medical center the night before. A list of nearby hotels and transportation services can be found in the Appendix of this guide.

## Where to go

Because you will be off your medications when you arrive for surgery, you may be uncomfortable walking and need extra assistance. Your driver can drop you off at the main entrance at 17th and Jefferson. (See Swedish/Cherry Hill map in the Appendix.) A wheelchair will be available if you need it.

Your driver may park below the main entrance, or in the 16th Avenue parking garage across the street from the west entrance. (See the Appendix for a map and parking information.) You will also find a few parking spaces for disabled individuals. If your car is so designated, you may park there.

Register at the main lobby hospital admissions desk and you will be instructed to proceed to the Surgical and Procedures Admissions Unit.

## Patient Registration

Please bring the following with you to Patient Registration:

- Social Security number
- Medicare card
- Insurance card(s), including prescription card
- Military ID card, if applicable
- Medicaid coupon, Healthy Options card, award letter or verification of application, if applicable
- Co-pay or deductible, if appropriate
- Advanced directive/power of attorney

- Current list of medications and dosages
- Personalized agenda of appointments

For your convenience, you may want to put all of this information in a folder ahead of time and bring it to all of your hospital visits (e.g., surgery, MRI, rehabilitation).

If you have any questions about your admissions paperwork, please call the Swedish Pre-Admission Center at **206-386-2997**.

## Preparing for surgery

After you are checked in, you will change into a hospital gown and be made comfortable on a gurney. We want you to be as comfortable as possible, so please do not hesitate to ask for extra blankets and pillows.

Additional blood draws or an electrocardiogram (EKG) may be required at this time.

Your family may stay with you until a member of the transport team takes you downstairs for surgery. Your family will be asked to wait in the surgery waiting area. A volunteer in this area will assist with communication between your family and your surgical team during and after your surgery.

## The Procedure

Electrodes for each side of the brain are usually not implanted at the same surgery. However, occasionally, lead wires for both the left and right brain are implanted during this first surgery. Your physician may decide to implant one lead wire now and the second one in one to two months. This will depend on your unique needs and diagnosis, and your physician will discuss this decision with you.

## **Arriving at the surgery suite**

You will be in a pre-surgery waiting area for about 30 minutes before you are transferred to the operating room where your surgery will take place. During this time, you will meet your anesthesiologist who will review your medical history and start an intravenous (IV) line through which medications will be administered. You will also meet the rest of the team (e.g., nurse, assistant, technician) who will attend to you during the procedure.

If you are Dr Young's patient you will be transferred directly to the MRI suite from the SPAU to meet with the anesthesiologist in preparation for application of the stereotactic frame as described below. You will then go immediately to the MRI scanner as opposed to having a CT scan prior to surgery. Following the MRI scan, you will be transferred directly to the operating room where the surgical procedure will take place. The MRI scan and the surgery both take place on the B level of the hospital.

## **Stereotactic head frame**

Next, we will escort you to the operating room. You will be positioned on the gurney to an upright, semi-sitting position and asked to look straight ahead. Your surgeon will then size a head frame to fit your skull. The frame will support your head and keep it in position during the procedure. After IV medication makes you feel relaxed and sleepy, you will receive four injections of local anesthetic — one above each eyebrow and one at the back of your head on each side. The surgeon will place a ring around

your head and secure four pins into your skull at these sites. You will not feel the pins penetrating your skin, but you will feel a pressure sensation — lasting up to two minutes — while the pins are tightened and the frame is fixed into position.

This procedure is well-tolerated by patients. We will provide sedating medication to make you as comfortable as necessary. Your head will feel heavy due to the hardware weight of about 1½ pounds. It is important to remember to relax the muscles of your head, neck and shoulders, knowing that your head is well-supported.

Relaxing these muscles as much as possible will help prevent uncomfortable neck and shoulder muscle spasms and cramps during the surgery.

## **CT imaging**

After the head frame has been placed, you will be taken on a gurney down the corridor to the nearby CT scanner, where you will undergo CT imaging. This test lasts approximately five minutes. You will then return to the same operating room where your head frame was placed. The new CT images will be merged with the MRI scan that was taken in the weeks prior to your surgery. Your neurosurgeon will then use a sophisticated computer software program to precisely identify the intended brain target.

## **Surgery**

Your surgery will proceed as follows:

- A nurse will gently insert a catheter through your urethra into your bladder.

- We will transfer you to the operating table and make you comfortable in a reclining “beach chair” position. The head ring holding your head will be secured to the operating table. You will be able to move your arms at your sides and your lower legs. Once you are comfortable, we’ll further shave, prep and mark your head.
- Additional hardware will be attached to the ring around your head. This is not painful, but you will hear metallic sounds off and on as we make the necessary adaptations to the hardware. A large plastic drape will adhere to your scalp and tuck behind the ring. You will be unable to turn your head, but you will be able to see forward and sideways, as though you are looking out from a tent. The anesthesiologist will be positioned at your feet. One of the DBS practitioners will be at your immediate left.
- The surgeon will inject local anesthetic into the frontal area of your scalp, then make an incision. Please report any painful or sharp sensations, so that we can provide additional IV medications and local anesthetics to make you more comfortable.
- Next, the surgeon will make a pocket below the incision, above and behind the ear. This is where the excess wire will be tucked after the lead is placed. You may feel brief, mild pressure or burning. After the incision is made, you may hear clicking, scraping and buzzing in preparation for drilling the dime-sized burr hole. You may also feel the sensation of cool water dripping as the wound is frequently irrigated (bathed) during the procedure.
- Just prior to the drilling, the anesthesiologist will give you medication. Patients are often very sleepy during this part of the procedure. The drilling lasts about a minute and a half. Even though sleepy, you may notice fine vibrations throughout your head, neck and body, as well as a loud whirring sound. During the last few seconds of drilling, the noise may become louder and the vibrations more coarse, as the drill clutch engages to stop the drill. This occurs when the bone becomes thin and the opening is completed. Keeping your mouth open during drilling helps reduce the intensity of vibration and sound.
- A tiny wire will be slowly advanced through the newly drilled hole to the predetermined target in your brain. This wire — a recording microelectrode — enables the surgeon to hear the sound created by the neurons of the subthalamic nucleus (STN) when it is encountered. This process is called microelectrode recording. The amplified sounds range from an occasional popping to the sound of rain falling on a tin roof. The pattern of neuron activity can also be seen on a screen and leaves a very specific signature of these cells, further indicating when the STN is encountered. In cases of essential tremor and dystonia, brain cell recording is not typically performed.
- After the surgeon is satisfied with the response obtained with microelectrode recording, the tiny wire (i.e., recording microelectrode) is removed, and the permanent DBS electrode is implanted in this exact location. You will be awake and alert during this part of the procedure. You will not feel the probe when it is in

place; the brain does not have the capacity to feel sensation or pain. The permanent electrode is then attached by a cable to a small hand-held transmitter, and gradually, a small amount of gentle current flow begins the process of trial stimulation.

- During trial stimulation, we will ask you to perform some simple verbal and motor tasks, such as opening and closing your hands and counting. We will test your movement on the opposite side of your body (your right brain corresponds to the left side of your body and vice versa) to determine how the stimulation affects your symptoms (e.g., tremor, rigidity, stiffness). You may experience some mild reversible side effects, including tingling of your extremities, double vision, change in speech, or muscle twitching or contraction. When we are satisfied with the improvement in your movement without these side effects, the electrode will be secured into position using a dime-sized plastic cap which covers the opening of the burr hole. Your incision is then closed with sutures.
- In rare cases, patients may be selected as candidates for bilateral electrode implantation. This means you would have your second side surgery done immediately following completion of the first side. The surgeon and team, in consultation with you, will determine if you are ready to proceed with implantation on the other side of the brain. Upon completion of the second side, we remove the ring apparatus from your head. You will then be transferred to a bed and taken directly to the intermediate care unit (IMCU) for the typical 24-hour stay.

*Note:* Occasionally, under special circumstances, the battery is implanted at the same time, under a general anesthetic. With these exceptions, patients go to the recovery room for about an hour immediately following surgery, before being transferred to the ICU.

### **Recovering in the intermediate care unit (IMCU)**

Your family or support people will be able to join you within 15 minutes of your arrival in the IMCU. You will be able to eat and drink within a few hours, **after** the routine post-operative MRI is complete. The scan will show the exact final position of the electrode, and will confirm that the post-operative appearance of the operated areas is satisfactory.

You will spend the night in the IMCU so the nursing staff can observe and monitor your general condition. It's best to simply rest and relax in bed on this night, as it has been an eventful day for you. Your family may visit you, and a loved one can actually stay in your room if special arrangements are made with the nursing staff.

Your blood pressure will be closely monitored, and you may be given medication to keep it within normal limits. You will be restarted on all of your usual medications. You may experience a mild to more-severe headache, in which case we will provide you with pain medication. You may hear bubbling or swooshing sounds when you move your head; this is due to small bubbles trapped between your brain and skull. You may also hear a pulse sensation in the rhythm of your heartbeat. This is normal and expected, and will subside within a few days. Some patients

feel nauseated for several hours, so it is recommended to take a liquid diet to start with clear liquids in the first several hours after surgery and progress your diet as tolerated, avoiding rich foods and large meals while in the hospital. The rounding physician who attends the ICU patients will likely visit you, in addition to your DBS team.

The bladder catheter will be removed the following morning. If appropriate, a physical therapist will help you out of bed and walk with you to assess your readiness to go home. Occasionally patients will require an additional 24-hour stay in the hospital, either in the ICU or in the neurological nursing unit.

When you are discharged from the IMCU, you will be given verbal and printed instructions. It is important that your caregiver be present at this time. If you have traveled from outside of the area, we recommend that you stay in the Seattle area for 24 hours before you return home.

After you return home, it is important to follow the post-operative DBS lead-implantation discharge instructions.

- If you have any questions, concerns or problems, please call the DBS clinic during office hours at **206-320-2847**.
- After hours and on weekends, please contact the neurosurgeon on-call at **206-320-2800** regarding any problems related to your surgery (e.g., incisions, pain, bleeding, new neurological symptoms, loss of strength or sensation, severe headache).

- If you have questions or concerns about medicines prescribed for your movement disorder, contact the neurologist on-call at **206-386-3880**.

## Post-operative DBS Lead Implantation Discharge Instructions

### Important phone numbers

DBS clinic: **206-320-2847**

**Emergency after hours: 206-320-2800** and ask for the neurosurgeon on call

### Care of your incisions

You may remove the dressing four days after you return home. At that time, you may also gently wash your head with mild shampoo. Do not soak your head under water or allow water to beat down heavily on the top of your head. Even if your incision was not covered with a dressing after surgery, wait four days after you return home to wash your head. Do not touch, scrub, scratch or pick at your incisions. If there is dried blood or a scab, do not remove it, as further healing needs to occur. Over time, as you gently cleanse the area and it begins to heal, the scab will come off by itself. *Please do not remove it.*

Do not apply any topical products, including ointments, salves, alcohol or hydrogen peroxide to your incisions.

Wash or gel your hands frequently, and change your pillowcases and towels daily during the first



week after surgery. You may wear a cap if it is freshly laundered and loose fitting.

After your surgery, you may notice slight pink drainage for a few days. If your dressings become soiled, please change them using sterile gauze and avoid directly touching the area. If drainage is excessive or appears yellowish or white, this can indicate infection. If this occurs, please contact a member of the DBS team immediately.

### Head frame pin sites

The four small skin punctures above your eyebrows and at the back of your scalp should heal without any special attention. You may clean them with mild soap and water. If there is a small amount of drainage, you may cover them with a bandage. If they become red, swollen or tender, or if the drainage increases, this could indicate infection, and you should be seen in the office *immediately*.

### Activities

Remember, you have been in bed for long periods of time, and you may experience fatigue or dizziness when you start getting up and on your feet again. It is fine to be out of bed, but you will most likely feel tired and need more rest than usual. Keeping your head elevated on a few pillows will help prevent swelling and keep you more comfortable. Do not engage in any strenuous activities, including swimming, jogging or sexual activity, for a minimum of three to four weeks. During this time, do not lift anything heavier than 10 pounds, and avoid stooping or straining. Move cautiously to prevent falls. Do not resume driving until you have checked with a member of your medical team.

### Pain medication

Your incisions should start feeling better every day. Use pain medication as directed, but you should not need it for more than 48 hours. After that, you may take 650 mg of plain Tylenol (acetaminophen) every four hours as needed. (You will need the remainder of your prescription pain medicine following the battery implant surgery.) You may also use the ice packs that you brought home from the hospital to provide relief. If your pain or headache increases after the second day, please notify the DBS clinic. Do not use aspirin or NSAIDS (like ibuprofen) until authorized — no sooner than one week following your battery implant surgery. *If you have a severe headache during the week following surgery, you should report this immediately to the DBS clinic so that you can be evaluated.*

### Other medications

You may feel immediate improvement following your DBS surgery. If you have Parkinson's disease, this may include decreased tremor, rigidity and slowness. For a few days, you may feel like your medications "on-time" is increased, and dyskinesias may even be a little worse. This is called the DBS "honeymoon effect," and it may last for a few days. Do not change your medication regimen without talking to a member of your DBS medical team. Abruptly discontinuing certain medications can cause serious side effects; you should gradually taper off these agents, and only with medical supervision.

## Bladder function

If you had a catheter in your bladder during and after surgery, you may experience some mild burning during urination for a day or two. If this persists or gets worse, call the DBS clinic, as this can indicate a urinary tract infection. If you have bladder control issues, this may become slightly worse for a few days following surgery. Again, always report any persisting symptoms.

## Bowel function

Inactivity coupled with pain medication can significantly reduce your bowel function. It is important that you avoid becoming constipated, because this can cause you to strain and increase the risk of headache and bleeding. Take plenty of fluids and fiber, and if necessary, a stool softener or mild laxative.

## Contact the DBS Clinic immediately:

- If you experience any new or unusual symptoms such as increased pain, fever, lethargy, weakness, numbness or confusion
- If you experience problems with your incisions such as increased tenderness, redness, swelling or drainage
- If you experience persistent headache or a fever greater than 101 degrees

## Daytime contacts

Call **206-320-2847** and you will be put in touch with your clinician.

## After-hours or weekends

Contact the neurosurgeon on call at **206-320-2800**.

## When to call 911

If you experience sudden onset of weakness, numbness, difficulty speaking, loss or change in vision, or a significant change in your level of alertness, **call 911 immediately**.

## Battery Implant Surgery

This procedure is done under general anesthesia; you will be asleep until you wake up in the recovery room. The batteries are implanted one to two weeks following brain electrode implantation during an outpatient surgery.

During the procedure, the surgeon will implant an extension wire that connects your brain lead to the battery. This is accomplished by making a small incision in your scalp and behind your ear, and one below your collarbone. The connecting wire is tunneled just below the skin of your neck. All the hardware is completely buried underneath your skin; none will be visible externally. The battery itself is placed in a small pocket on your chest wall, a few inches below the collarbone. Your surgeon will determine ahead of time whether you will need one or two batteries. The incisions are closed with sutures; light dressings may be applied.

### Pre-operative Phase for Outpatient Surgery

As you did prior to your lead implant surgery, have fresh pillowcases and towels ready at your home. We ask that you use fresh towels and pillowcases every day until your incisions have healed.

You should not have close contact with pets or any livestock until your incisions have healed. This means you should not share furniture with your pets, change litter boxes or clean up after animals. You may need to arrange for pet care, board animals, or arrange for additional household help. These extra precautions are necessary to promote wound healing and prevent infection.

*For two weeks prior to your surgery, please do not take any products containing aspirin; aspirin can prolong bleeding time and interfere with clotting. A list of medications commonly containing aspirin is located in the Appendix of this guide. If you are unsure of whether or not a product contains aspirin, please ask one of the DBS clinic providers.*

Also, please do not take any non-steroidal anti-inflammatories such as Motrin or Advil in the two weeks prior to surgery. Discontinue taking fish oil and vitamin E supplements, as these can also cause problems with bleeding. Do not take any herbal dietary supplements; their reactions with anesthetic are unclear. You may continue to take a multivitamin. You may use Tylenol for pain.

### The night before surgery

**Take a shower using Hibiclens.** You will be given a second bottle of Hibiclens anti-bacterial soap prior to the battery implant. Wash gently and avoid getting the cleanser in your eyes or mucous membranes. Use clean towels to dry off and sleep in clean sheets and pillowcases. Repeat the Hibiclens shower in the morning. Set aside freshly laundered clothing to wear on the morning of your surgery. You should wear a shirt that opens in the front, to avoid the need to pull clothing over your head.

**After midnight, do not eat or drink anything.** An empty stomach on the day of surgery decreases the risk of complications during surgery.

Unlike your first (lead implant) surgery, **please do take your usual medications** that have been prescribed for Parkinson's, tremor or dystonia, with a tiny sip of water prior to your surgery.

### Other medications

The use of other medications prior to surgery, such as those prescribed for high blood pressure, heart disease, diabetes or hormonal therapy, should be discussed with your DBS medical team. They are often continued prior to your anesthetic.

### Packing for the hospital

To make certain your stay is as comfortable as possible, please bring the following:

- Slippers
- Slip-on shoes
- Comfortable clothes that open in the front
- Medications (you may be asked to use your own medications; if so, it is important to check with your nurse before taking them)
- Personal items such as contact lenses, eye-glasses, hearing aids, dentures and prostheses
- Your cane, walker or other personal assistive devices you normally use
- Any needed paperwork, including an updated medications list

## Day of Outpatient Surgery

### When to arrive

You will be notified of the time you should arrive at the hospital well in advance of your surgery. Your arrival time will be approximately two hours prior to your scheduled surgery.

### Where to go

For this surgery, you will register at the same place you did for your lead implant — Hospital Admissions — at Swedish's Cherry Hill campus main lobby. Your driver can drop you off at the south entrance on 17th Avenue. A wheelchair will be available if you need it.

Your driver may park below the main entrance, or in the 16th Avenue parking garage across the street from the west entrance. (See the Appendix for parking information). You will also find a few parking spaces for disabled individuals. If your car is so designated, you may park there.

If you have any questions, please call the Swedish Pre-Admission Center at **206-386-2997** or the DBS clinic at **206-320-2847**.

### Preparing for surgery

After you are checked in, you will go to the Surgery Admission Unit, where you will change into a hospital gown and be made comfortable on a gurney. Please do not hesitate to ask for extra blankets and pillows.

You may undergo additional blood draws at this time.

Your family may stay with you until a member of the transport team takes you downstairs for surgery.

## Arriving at the surgery suite

After a transporter takes you to Surgical Services, you will be in a pre-surgery waiting area for about 30 minutes before you're transferred to the operating room where your surgery will take place. During this time, you will meet your anesthesiologist who will review your medical history and start an intravenous (IV) line through which medications will be administered. You may be given an IV sedative to help you relax, and IV antibiotics to help prevent infection. You will also meet the rest of the team (e.g., nurse, assistant, technician) who will attend to you during the procedure.

## The Procedure

Your battery implantation surgery will proceed as follows:

- You will be given a general anesthetic — and will be fully asleep — before your surgery begins.
- The surgeon will connect the lead in your brain to an extension that is tunneled under the skin of the neck and connected to the battery that will be implanted under the skin on your upper chest, in the pectoral area (as described earlier in this section).

## Recovery

After your surgery, you will be transferred to the recovery room, where the nursing staff will monitor your progress as you awaken. This will take about an hour. Your surgeon will meet with your family members or support persons in the surgery waiting area. To respect the privacy of all patients, visitors are not allowed in the recovery

room. Your family will be notified when you leave the recovery room and will be able to see you when you return to the Same Day Surgery Unit.

If you are going home the same day of your surgery, discharge usually occurs about four hours after returning to the Same Day Surgery unit. It is important that a friend or family member accompany you so that they can drive you home. You will not be able to drive on your own. If you are from out of town, we strongly suggest that you stay at a nearby hotel for 24 hours before returning home. You will find a list of nearby hotels in the Appendix of this guide. It is important that a caregiver or family member stay with you for 24 hours following your surgery. Infrequently, patients will require an overnight stay on the Neurological Nursing Unit.

You will be given verbal and printed discharge instructions when you leave the hospital and return home.

## Follow-up

Prior to your surgery, we will give you your first three DBS clinic follow-up appointment times. Your sutures will be removed at the first follow-up visit in the DBS clinic. Your DBS systems will be activated approximately three weeks after surgery in the DBS clinic.

After you return home, it is important to follow the Post-operative DBS Battery Implantation Discharge Instructions.

- If you have any questions, concerns or problems, please contact the DBS clinic during office hours at **206-320-2847**.

- After hours and on weekends, contact the neurologist on call at **206-320-2880** regarding any issues related to changes in your routine medications.

**Please do not discontinue any of your medications unless directed by your neurologist or nurse practitioner.**

## Post-operative DBS Battery Implantation Discharge Instructions

### Important phone numbers

DBS clinic: **206-320-2847**

*Emergency after hours: **206-320-2800** and ask for the neurosurgeon on call*

### Care of your incisions

You may remove the dressing four days after you return home. At that time, you may also gently wash your head with mild shampoo. Do not soak your head under water or allow water to beat down heavily on the top of your head. Even if your incision was not covered with a dressing after surgery, wait four days after you return home to wash your head. Do not touch, scrub, scratch or pick at your incisions. If there is dried blood or a scab, do not remove it, as further healing needs to occur. Over time, as you gently cleanse the area and it begins to heal, the scab will come off by itself. *Please do not remove it.*

Do not apply any topical products, including ointments, salves, alcohol or hydrogen peroxide to your incisions.

Wash your hands frequently, and change your pillowcases and towels daily during the first week. You may wear a cap if it is freshly laundered and loose fitting.

After your surgery, you may notice slight pink drainage for a few days. If your dressings become soiled, please change them using sterile gauze and avoid directly touching the area. If drainage is excessive or appears yellowish or white, this can indicate infection. If this occurs, please contact a member of the DBS team *immediately*.

### Activities

Following an anesthetic, you may experience fatigue or dizziness when you start getting up and on your feet again. It is fine to be out of bed, but you will most likely feel tired and need more rest than usual. A general anesthetic can make you feel weak and lethargic for a day or two, so give yourself plenty of time to rest. Keeping your head elevated on a few pillows will help prevent swelling and keep you more comfortable. Do not engage in any strenuous activities, including swimming, jogging or sexual activity, for a minimum of three weeks. Do not resume driving until you have checked with a member of the medical team. During this time, do not lift anything heavier than 10 pounds, and avoid stooping or straining. Move cautiously to prevent falls.

### Pain medication

Your incisions should start feeling better every day. Use pain medication as directed, but you should not need it for more than 48 hours. After that, you may take 650 mg of plain Tylenol

(acetaminophen) every four hours as needed.

You may also use the ice packs that you brought home from the hospital to provide relief. Do not use aspirin or NSAIDS (like ibuprofen) until authorized — no sooner than one week following your battery implant surgery.

Your incisions should be less tender after the third day. If pain increases after day three, please notify the DBS clinic. *If you experience a severe headache during the week following surgery, contact the DBS clinic immediately.*

### Other medications

Temporary improvement in movement will most likely be gone at this point, so you may need to adjust your medications. Do not, however, change your medication regimen without first talking to a member of your DBS medical team. Abruptly discontinuing certain medications can cause serious side effects; you should gradually taper off these agents, and only with medical supervision.

### Bladder function

If you had a catheter in your bladder during and after brain electrode implant surgery, you may experience some mild burning during urination for a day or two. If this persists or gets worse, call the DBS clinic, as this can indicate a urinary tract infection. If you have bladder control issues, this may become slightly worse for a few days following surgery. Again, always report any persisting symptoms.

### Bowel function

Inactivity, pain medication and general anesthesia can all combine to significantly reduce your bowel function. It is important that you avoid becoming constipated, because this can cause you to strain and increase the risk of headache and bleeding. Take plenty of fluids and fiber, and if necessary, a stool softener or mild laxative.

### Contact the DBS clinic immediately:

- If you experience any new or unusual symptoms such as increased pain, fever, lethargy, weakness, numbness or confusion
- If you experience problems with your incisions such as increased tenderness, redness, swelling or drainage
- If you experience persistent headache or a fever greater than 101 degrees

### Daytime contacts

Call the DBS clinic at **206-320-2847** and you will be put in touch with your clinician.

### After hours or weekends

Contact the neurosurgeon on call at **206-320-2800**.

### When to call 911

If you experience sudden onset of weakness, numbness, difficulty speaking, loss or change in vision, or a significant change in your level of alertness, *call 911 immediately.*



# Programming Your Deep Brain Stimulation System

Approximately three weeks after your battery implant surgery, your Deep Brain Stimulation system will be programmed. This often takes place during your second post-operative office visit.

## **Stimulation side effects**

When the stimulation is first started, you may notice a variety of reversible side effects. In Parkinson's patients one of these is dyskinesia, or abnormal and involuntary twisting and rolling motions. Do not be alarmed by this. If it becomes severe, you should turn off your device and call the DBS clinic during regular office hours. This is not an emergency, but you should report it. This should resolve in time, with slower increases in stimulator programming and gradual medication withdrawal. In essential tremor patients, a common side effect is tingling in the upper extremity and cheek when the system is first turned on. Other stimulation side effects, such as dizziness, speech impairment, vision changes, muscle twitching or tension, are apparent during your programming session and are usually easy to correct with reprogramming.

## **Safety and medical procedures**

You will be given special instructions regarding DBS safety measures. It is important that you order the Medic Alert bracelet, using the form in the Appendix at the back of this guide. Remember, you will not be able to have MRI scans of your body, spine or limbs in the future. If

an MRI of your brain is needed, the DBS system will need to be turned off and reset to zero volts prior to the scan. If you undergo surgery below the waist in the future, you should also turn off your own DBS system for the procedure. CT scans, regular X-rays and ultrasound for diagnosis are fine without restrictions. Diathermy (high-intensity focused ultrasound, deep-heat treatment) could be dangerous and should be avoided.

If a physician recommends that you have a surgical procedure, please ask the surgeon to contact Medtronic at **1-800-707-0933** for appropriate safety guidelines. A brain MRI can be done safely with your device turned off and zero volted. If the MRI is scheduled at Swedish, please call the DBS clinic and a clinician will arrange to meet you before and after the MRI to deactivate and reactivate your devices as necessary for your safety.

## **Medications**

After your initial programming session, any changes in your medication regimen should be reviewed with the DBS staff or your neurologist.

Your symptoms may seem much improved, and you may be tempted to reduce or discontinue your medications. *Please do not do this*, as rapid withdrawal from certain agents can cause serious side effects. You should slowly taper off these medications, and only under the supervision of your medical team.

### **Patient programmer**

During your initial programming session, you will receive a hand-held programmer that is compatible with your implant. It will allow you to turn your device on or off, check to see if it is on or off, and check the status of the battery life. In time, you

may even be given additional parameters that you can adjust on your own. We will give you verbal and written instructions on how to use this device. Keep the instructions with you at all times during the first several weeks, in case something in your environment has a strong electromagnetic field that could turn off your stimulators. If you experience an increase in symptoms, always check to make sure the stimulators are still on.

**Your neurologist and primary-care physician will be updated on your progress during and after your surgery, particularly as medication adjustments may be required.**

# After Your Surgery

## Your Rehabilitation

It is important that all patients receive rehabilitation following Deep Brain Stimulation — whether inpatient or outpatient.

### Inpatient Rehabilitation

Following your Deep Brain Stimulation surgery, you may be a candidate for a five- to ten-day inpatient stay on Swedish's Rehabilitation Unit. The purpose of the stay is to work on your mobility, speech and specific motor skills to help you gain optimal function. Your medications and stimulation levels may be fine-tuned during this hospital stay.

The Swedish Rehabilitation Team will give you the assistance and support you need to become more independent. The multi-disciplinary team consists of:

- You and your family
- Physiatrist (a physician specializing in rehabilitative medicine)
- DBS nurse practitioner (who will see you daily)
- Movement disorders neurologist (as consult needed)
- Rehabilitation nurse
- Physical therapist
- Occupational therapist
- Recreation therapist

- Speech and language pathologist
- Social worker/program coordinator
- Rehabilitation psychologist
- Rehabilitation case coordinator

We encourage you and your family to ask questions and actively participate in the program and discharge planning. You will be asked what goals you would like to achieve during your stay on the Rehabilitation Unit, so that we can create a customized program that best meets your needs.

During your rehabilitation stay, you can expect to be involved in therapy at least three hours a day, eat your meals in the dining room, and dress in your regular clothes. Therapy will focus on increasing your strength, endurance and flexibility. The emphasis will be on preparing you for improved function when you return home and setting you up for ongoing success and a better quality of life. You will have the opportunity to practice new skills, both in the unit and during community outings, with staff assistance.

## Please bring the following for your stay on the Rehabilitation Unit:

Clothing	Equipment (as applicable)	Personal items
3 sets of underwear	Wheelchair	Electric shaver
3 sets of socks	Wheelchair cushion	Deodorant
3 pairs of loose sweat pants	Walker	Brush and comb
1 pair of good support shoes	Crutches	Toothbrush
Loose-fitting shirts/blouses	Cane	Glucometer (if you have diabetes)
Coat or jacket	DBS remote device	Any hobby, leisure or special-interest projects that can be incorporated into your therapy

## Outpatient Rehabilitation

If you are not admitted to the inpatient rehabilitation unit, you will still receive outpatient rehabilitation about a month after your last surgery. You will also have a repeat evaluation and six months post surgery with the rehab team. The results of this evaluation will be compared to your pre-operative assessments to help determine your overall improvement after DBS. This will include occupational, physical and speech therapy to help you achieve optimal functioning.

If you have any questions about the DBS rehabilitation program, please call **206-320-2404**. For questions about scheduling and planning, please call the DBS clinic at **206-320-2847**.

## Frequently Asked Questions About DBS

### What is Deep Brain Stimulation?

Deep Brain Stimulation can be thought of as a “brain pacemaker.” One or two thin wires or electrodes are surgically implanted into the part of the brain involved in movement-related communication between brain cells. The electrodes are connected to a pulse generator (similar to a

cardiac pacemaker) under the skin and below the collarbone on the chest wall. The electrodes deliver mild electrical pulses to the brain, blocking the brain signals that cause abnormal movement, such as muscle tremor, stiffness, slowness and muscle contractions.

### How does the stimulator work?

The exact mechanism of stimulation is unknown. The electrical impulses quiet the overactive part of the brain that causes abnormal movement. Electrical and chemical changes take place in the areas where one brain cell communicates with another.

### Who benefits from Deep Brain Stimulation?

Candidates for DBS include people with uncontrollable motor symptoms of idiopathic (no known cause) Parkinson’s disease, essential tremor and dystonia, whose symptoms are no longer well-controlled with medication. DBS can also be effective in treating tremors from brain injury and Multiple Sclerosis.

## **Does Deep Brain Stimulation really work?**

Studies show that people who have been implanted with the DBS system for essential tremor experience approximately a 90 percent reduction in tremor. Parkinson's patients liken symptom improvement from DBS to their best "on medications" time, with a significant reduction in motor fluctuation and medication side effects.

## **Can I turn off the stimulator?**

The stimulator is fully programmable, and patients can use a simple hand-held remote control device to turn the stimulator on or off.

## **What are the long-term results of Deep Brain Stimulation?**

Five-year follow-up studies have shown continued excellent improvement in symptoms over time. Only in rare cases has DBS not been effective.

## **Are there other ways to treat tremor?**

While there are other options for treating tremor, including medications or Gamma Knife thalamotomy (a surgery that destroys, rather than stimulates, a small area of the thalamus), Deep Brain Stimulation has been shown to be the most effective means of tremor control and has widely replaced other forms of treatment.

## **What are the advantages of Deep Brain Stimulation over other therapies?**

DBS offers patients a number of unique benefits, the most notable being:

- *Adjustability* – The level of stimulation can be controlled and adjusted as needed to provide the highest degree of symptom relief, while minimizing possible side effects.
- *Reversibility* – Because this procedure does not destroy brain tissue, the risk is minimal and complications are rare. If needed, the system components could be removed should better therapies or cures become available in the future.
- *Medication reduction* – Following DBS surgery, patients with Parkinson's disease are able to reduce medications on average up to 50 percent, diminishing the side effects and associated costs of medications.

## **Will I be put under anesthesia during surgery?**

During the first procedure, patients are given local anesthetic and mild sedation. The recovery period is quick. After a 24-hour hospital stay, most patients go home and resume normal activities. The battery is implanted five to 10 days later, under general anesthesia, and patients typically go home the same day of surgery.

## **Are there any complications or side effects of DBS surgery?**

Although rare, bleeding and infection can occur. Side effects of Deep Brain Stimulation are usually reversible and can include a slight tingling sensation, dizziness, balance difficulties, limb weakness or slurred speech. For the most part, however, side effects are very mild and can be minimized by adjusting the stimulation.

### **How active can I be after surgery?**

Do not reach over your head, lift more than 10 pounds, or do any far-reaching or stretching during the first three weeks after your surgery. You should not participate in any strenuous activity, swim or soak in a bathtub for four weeks, until your incisions and implanted hardware pockets are completely healed.

### **How often do I need to come back after surgery?**

During the first few weeks after surgery, weekly appointments are typical. After that, appointments are scheduled as needed. Plan a routine follow-up visit about every six months. Please keep in mind that it can take up to six months to fine-tune your DBS programming and medications. Further adjustments may be needed periodically to vary the level of stimulation.

### **Will my DBS surgery scars and equipment be noticeable?**

Scarring is usually minimal and improves with time. If your hairline is receding, the scalp incision scars and two small bumps — about the diameter of a quarter — may be slightly noticeable. The extension wire is tunneled from a scalp incision to the incision below the collarbone, just under the skin. There are no external wires to the devices; the entire system is fully implanted under your skin. There may also be a tiny, half-inch incision on the side of your neck.

### **How can I prevent damage to my DBS System?**

Damage to an Activa System can occur if a patient repeatedly overextends his or her neck. A blow to the head can cause the electrode to move off the target or the lead to break, resulting in a loss of some or all stimulation. To lower the risk of damage or complications:

- Do not allow health-care and wellness providers to treat your head or neck without first consulting with your DBS health team
- Read and be familiar with the Activa Therapy Patient Manual
- Do not hold electrical or magnetic devices near your chest
- Do not use your chest to prop up or hold things, not even to free a hand for a moment

### **Should I tell my health-care provider and dentist about my DBS surgery?**

Yes. Always tell your dental and health-care providers that you have an implanted neuro-stimulation system and show them your identification (ID) card. Avoid dental ultrasonic cleaners. Antibiotics should be prescribed prior to any invasive dental procedures, such as root canals, extractions or implants.

### **Will my primary-care physician be kept informed?**

Yes, your neurologist and primary-care physician will receive copies of the DBS clinic reports.

### **Can I have special diagnostic tests and exams?**

You will not be able to have MRI scans of your body, spine or limbs in the future. If an MRI of your brain is needed, the DBS system will need to be turned off and reset to zero volts prior to the scan. If you undergo surgery in the future, you should also turn off your DBS system for the procedure. Dental drills and ultrasonic probes should not be used over the implant site. Electrolysis, radiation therapy and electrocautery should not be used over the implant site. CT scans can be done, however you will need to turn your device off prior to the scan and back on with your patient programmer after the scan. Regular X-rays and ultrasound for diagnosis are safe without restrictions. The electrical discharges from defibrillators may damage the neurostimulator electronics.

### **Can I have deep-heat treatments?**

Deep-heat treatments, known as diathermy, deliver energy to treat specific areas of the body. Activa therapy patients should not receive any diathermy as it could result in severe injury or death.

### **Can I have a pacemaker or a cardioverter defibrillator (ICD) implanted?**

For many patients, these devices are possible, but care must be taken with their placement and programming so as not to interfere with your Activa System.

### **Can I use a transcutaneous electrical nerve stimulation (TENS) unit?**

Yes. This unit should not interfere with your neurostimulator. However, use it with caution and notify your physician if you feel the TENS unit is interfering with your Activa device.

### **Can I use magnet therapy products such as wrist and elbow wraps?**

These are not recommended as they may interfere with your neurostimulator.

### **Can I use bone growth stimulators?**

Medtronic, the maker of the Activa System, has no experience with and is not aware of potential risks from bone growth stimulators.

### **If I get cancer, can I have radiation therapy?**

Yes, although you must be careful and protect your Activa System. Be sure to tell your radiation therapist about your device.

### **Can I have lithotripsy?**

Nonessential lithotripsy, which is used to treat stones in the kidney, liver or gallbladder, is not recommended. If lithotripsy is essential, physicians should not direct or focus lithotripsy within six inches of the battery. Lithotripsy may damage the battery, and surgery may be required to replace it.



### **What sun exposure precautions, if any, should I take?**

For at least six months after surgery, avoid direct sun exposure to your incision areas. Sunburn can increase the risk of infection, and too much exposure to the sun can cause increased pigmentation of scar tissue.

### **Can I drive an automobile while the neurostimulator is on?**

The decision about driving is a complex one. Talk with your health-care team and your family. In some cases, repeated drivers' education courses and testing may be advised.

### **Can I fly?**

Yes, you can fly if you do not have other conditions that make air travel inadvisable. Your Activa System should not be affected by airplane flights of long duration. However, you must avoid airport screening that exposes your DBS system to high electromagnetic fields. You will receive a letter to present to airport security personnel explaining your DBS system and the importance of avoiding screening devices. Carry your plastic Medtronic ID card with you at all times; you will receive this card by mail three to four weeks after your surgery.

### **Will other security systems interfere with my DBS system?**

Yes, if you have an older neurostimulator model implanted. In addition to airport security checkpoints, you must avoid theft detectors in department stores, libraries and pharmacies. Always show your neurostimulator ID card or form and ask for assistance in going through security.

### **Why are electromagnetic fields a problem?**

With the older neurostimulator models, the DBS system may turn itself on or off if the interference is too high, your neurostimulator could reset itself to factory settings. If this occurs, the device will not deliver any stimulation — even when turned on — because the amplitude has reset to zero, so your device will need to be reprogrammed by your health-care team.

### **Can I be near electric substations or power lines?**

Yes. Just stay outside of the protective fencing around these installations.

### **Can I use hot tubs or tanning beds?**

Hot tubs and tanning beds may expose your Activa System to higher than normal levels of heat. Limited exposure (10 to 15 minutes) to heat equal to or less than 100°F should not pose any difficulties, but hot tubs and tanning beds are often above this range. Tanning beds should be avoided. Discuss hot tub use with your provider.

### **Can I use everyday household appliances?**

Yes. Most electrical appliances will not harm your DBS system. But permanent magnets such as those found in stereo speakers, radios, telephones and refrigerator magnets could turn the neurostimulator on or off if they're brought within inches of the neurostimulator.

### **Can I arc weld?**

No.

### **Can I work on an automobile?**

Yes, but you may experience discomfort if you engage in excessive bending or twisting, which may dislodge or fracture your neurostimulator. Avoid leaning directly on your battery implant(s).

### **Can I be around industrial equipment?**

Yes, but be aware that your system may turn on or off if exposed to high levels of electromagnetic interference found in industrial equipment. Always check to make sure that your neurostimulator is on when you are finished with the equipment.

### **Can I use power tools?**

Yes, but keep them away from your neurostimulator and make sure it is functioning properly after you have finished.

### **Are pets okay?**

It is important that your environment be kept sanitary at all times. This includes avoiding contact with any pets or livestock while your incisions are healing. Pets should not sit or sleep with you, and you should wash your hands after any contact with the animals or their bedding, dishes, etc., until your incisions have completely healed.

### **Can I scuba dive?**

Call your DBS team before scuba diving. Your neurostimulator will operate normally down to 33 feet of seawater.

### **Can I skydive?**

Skydiving is not recommended. While high altitudes should not affect the neurostimulator, skydiving involves movement and impact that could easily damage your Activa System.

### **Can I take part in other high-altitude activities, such as skiing or hiking?**

High altitudes are unlikely to affect the neurostimulator, but falls and sudden jerks, twists or stretches could damage your Activa System. Please talk to your health-care team before you try these activities.

### **Where can I learn more about Deep Brain Stimulation?**

If you still have questions about Deep Brain Stimulation, talk to your DBS team at the Swedish Neuroscience Institute at **206-320-2847**. Medtronic, the medical technology company that manufactures the stimulator used in DBS, has information available at **[www.medtronic.com](http://www.medtronic.com)**. You can also find information on the Swedish Web site at **[www.swedish.org](http://www.swedish.org)**.

## Miscellaneous

### Insurance and Billing

You will receive bills from two different parts of the Swedish health system:

- Swedish Medical Center will bill you for your surgery and use of hospital facilities, including (but not limited to) your anesthesiologist, rehabilitation and ICU stay. If you have questions about these bills, contact Swedish Medical Center Financial Services at **206-320-5300** or **1-877-406-0438**
- You will receive separate bills from the Swedish Medical Group for your surgeon, DBS care team and any outpatient visits. If you have questions regarding these bills, contact Swedish Medical Group Billing Services at **206-320-4476** or **1-888-294-9333**.

### Insurance billing for hospitalization

Deep Brain Stimulation is an elective surgery, which is usually covered by insurance and Medicare. Although the medical center and provider bills are your responsibility, we will bill your insurance plan(s) and provide you with monthly statements on the status of your account. On occasion, insurance providers may ask for additional information, which we will request from you. For questions about benefits received from your insurance company, please contact your insurance company first. If you still have questions, please call DBS program operations coordinator Michelle Bauer at **206-320-2883**.

### Insurance plans

Swedish Medical Center is included in a wide variety of health insurance plans. Please keep in mind that insurance plans are often updated, so it is always a good idea to check with your insurance company or physician for specific information about your health plan, the coverage it provides, and your choice of hospitals.

Your surgery will be pre-authorized, if necessary, through the DBS clinic. Your enrollment, benefits and authorization will be confirmed through the DBS clinic. It is your responsibility to know what percentage of the surgery and hospitalization is covered by insurance, and what percentage is your personal financial responsibility.

### Medical and Support Services

#### Interpreter services

Interpreter services are available to all Swedish patients (inpatient and outpatient) free of charge. We provide services in a variety of languages, as well as for patients with hearing or sight impairments. Swedish discourages family members from serving as interpreters, as it may be difficult to translate complex medical terminology and ideas. Our interpreters are specially trained in the medical field. If you would like more information about interpreter services at Swedish, please talk to your doctor or nurse. If you need an interpreter, please call DBS clinical coordinator Morgana Rauls at **206-320-2847**, and she will coordinate this with you.

## **Discharge information**

While you are still in the hospital, your practitioners will write your discharge orders. Your nurse will give you written instructions for your care at home and for taking any prescribed medications. A one-week supply can be filled at the hospital pharmacy. Check-out time is 11 a.m. If you check out after 11 a.m. and before 6 p.m., you will be charged for a partial day's occupancy. After 6 p.m., patients are charged for an extra day's stay. When you are ready to leave the hospital, a staff member or volunteer will escort you to the front entrance and help you into your car.

## **Visiting hours**

Visiting hours are flexible to accommodate you, your family members and friends. We encourage visitors to talk with a nurse about the best time to visit. If at any time you do not want visitors, your nurse will be glad to convey that message.

## **Privacy notice**

Swedish Medical Center protects its patients' privacy by not sharing their personal health information unless required for treatment. All patients receive a Notice of Health Information Practices at the time of admission or registration, or they may request a copy from their provider or the Swedish Medical Center Patient Registration office.

## **Notice of Health Information Practices**

Swedish Medical Center is required by law to maintain the privacy of your health information, to provide you with a notice of its legal duties and privacy practices, and to follow the information practices that are described in this notice. This notice explains how your health information may be used and/or disclosed, and you have a right to request and receive a paper copy of this notice. Swedish will not use or disclose your health information except as disclosed in this notice.

# Appendix

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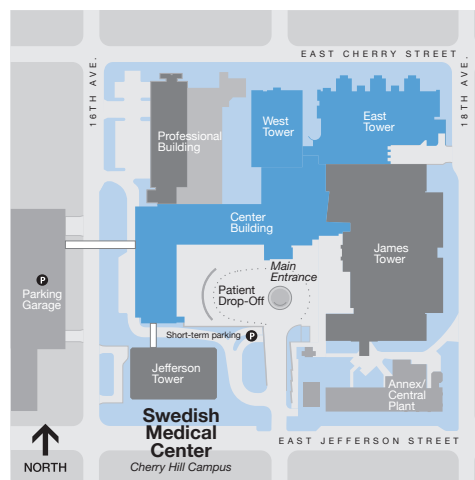
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## Swedish/Cherry Hill Map and Driving Directions

Swedish Medical Center/Cherry Hill Campus  
500 17th Ave.  
Seattle, WA 98122-5711

**From the South**, take I-5 northbound to the James Street exit (164A). Turn right (east) onto James Street. James will become East Cherry Street. Turn right onto 16th Avenue. Parking is on the right.

**From the North**, take I-5 southbound to the James Street exit (165A). Turn left (east) onto James Street. James will become East Cherry Street. Turn right onto 16th Avenue. Parking is on the right.



## Parking at Swedish/Cherry Hill

For the most current parking rates and other related information, contact Swedish Parking and Commuting Services at **206-386-2235** or visit the Swedish Web site at [www.swedish.org](http://www.swedish.org). Valet parking and patient drop-off is located at the main hospital entrance on 17th Avenue and Jefferson Street.

### Extended stay patients

Patients who are admitted to Swedish as an inpatient for an extended period may qualify for special parking discounts. Prices and policies vary between medical center campuses. For more information, please call **206-860-3868**.

### Disabled parking permits

Application forms for disabled parking permits are available through your physician's office or at the King County Administration Building, Fifth and James Street, Room 401, Seattle, WA 98104. A physician's signature on the completed application form is required. You can also get a copy of this form by calling any vehicle licensing agent or subagent office; by calling **360-902-3770**; or by visiting the Department of Licensing Web site at [www.wa.gov/dol](http://www.wa.gov/dol).

<b>Cherry Hill Parking Rates</b> <table><tr><td>0-1 hour</td><td>\$4</td></tr><tr><td>1-2 hours</td><td>\$6</td></tr><tr><td>2-3 hours</td><td>\$8</td></tr><tr><td>3-4 hours</td><td>\$10</td></tr><tr><td>4-6 hours</td><td>\$12</td></tr><tr><td>6-7 hours</td><td>\$14</td></tr><tr><td>7-8 hours</td><td>\$16</td></tr><tr><td>Special patient rate*</td><td>\$10</td></tr></table> <p><i>* Customer must tell the cashier they are a patient to receive discount</i></p> <p><b>Cherry Hill Garage</b> 511 16th Avenue Monday-Friday, 7 a.m.-11 p.m. Saturday, 9 a.m.-5 p.m. Unattended Sundays \$8 unattended exit and holidays 6'6" clearance</p>	0-1 hour	\$4	1-2 hours	\$6	2-3 hours	\$8	3-4 hours	\$10	4-6 hours	\$12	6-7 hours	\$14	7-8 hours	\$16	Special patient rate*	\$10	<b>Cherry Hill and First Hill Valet Parking Rates</b> <table><tr><td>0-1 hour</td><td>\$6</td></tr><tr><td>1-2 hours</td><td>\$9</td></tr><tr><td>2-3 hours</td><td>\$10</td></tr><tr><td>3-6 hours</td><td>\$14</td></tr><tr><td>6-24 hours</td><td>\$22</td></tr></table> <p><b>Cherry Hill Main Lobby Valet</b> 500 17th Avenue Monday-Friday, 7:30 a.m.-5 p.m. Unattended weekends and holidays</p> <p><i>Rates subject to change without notice.</i></p>	0-1 hour	\$6	1-2 hours	\$9	2-3 hours	\$10	3-6 hours	\$14	6-24 hours	\$22
0-1 hour	\$4																										
1-2 hours	\$6																										
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0-1 hour	\$6																										
1-2 hours	\$9																										
2-3 hours	\$10																										
3-6 hours	\$14																										
6-24 hours	\$22																										



## Hotels/Accommodations

### Swedish/Cherry Hill Area

#### **The Inn at Cherry Hill**

500 17th Ave.  
Seattle, WA 98122  
206-320-2164  
[www.swedish.org/theinn](http://www.swedish.org/theinn)

#### **Baroness Apartment Hotel**

1005 Spring St.  
Seattle, WA 98104  
206-624-0787  
[www.baronesshotel.com](http://www.baronesshotel.com)

#### **Silver Cloud Inn**

1100 Broadway  
Seattle, WA 98122  
206-325-1400 or 1-800-590-1891  
[www.silvercloud.com](http://www.silvercloud.com)

#### **Residence Inn by Marriott/Lake Union**

800 Fairview Ave. N.  
Seattle, WA 98109  
206-624-6000 or 1-800-331-3131  
[www.residenceinn.com/sealu](http://www.residenceinn.com/sealu)

#### **Courtyard by Marriott/Lake Union**

925 Westlake Ave. N.  
Seattle, WA 98109  
206-213-0100 or 1-888-236-2427  
[www.courtyardlakeunion.com](http://www.courtyardlakeunion.com)

#### **Inn at Virginia Mason**

1006 Spring St.  
Seattle, WA 98104  
206-583-6453  
[www.innatvirginiamason.com](http://www.innatvirginiamason.com)

## Transportation

### Airport Shuttle

206-622-3400

### Airport Transportation

206-261-1234 or 1-866-861-8900

### Bellevue Limousine, Inc.

206-271-5200

### Destination Northwest

206-786-4000 or 1-800-260-1114

### Emerald City Taxi

206-246-6666

### Farwest Taxi

206-622-1717

### Mercy Transportation

425-347-4700 or 1-877-91-MERCY

### Seattle Express Town Car Service

206-325-2255

### Sound Transit

Rider Information Line: 1-888-889-6368

TTY/TDD General Info: 206-398-5410

## Cabulance

### Bluebird Cabulance

206-365-2700

### Cascade Cabulance

206-767-1717

## ParaTransit Trips

Transit System	Provider	Reservation Number
Community Transit	Dial-A-Ride Transportation (DART)	425-347-5912 425-347-7997 TTY Toll-free: 1-800-562-1381
Everett Transit	ParaTransit	425-257-8801 425-778-2188 TTY
King County Metro	Access Transportation	206-205-5000 206-749-4286 TTY Toll-free: 1-866-205-5001 Toll-free: 1-877-749-4286 TTY
Pierce Transit	Shuttle	253-581-8100

## Washington State Ferries

The medical preference form may be available in your physician's office. For additional information, contact the Washington State Ferries at 206-464-6400 or 1-888-808-7977.

## Common Medications Containing Aspirin or Aspirin Compounds

**Note:** This is not a complete list. Other products may also contain aspirin and/or aspirin-like ingredients. If you are not sure whether a product you use contains aspirin, please call the DBS clinic at **206-320-2847**.

### A

Acuprin 81 adult low dose  
Advil  
Aleve  
Alka-Seltzer (check label)  
Alpha-Phed  
Aluprin  
Anacin (check label)  
Anaprox  
Ansaid  
Anexia with Codeine  
Anodynos  
Apac Improved  
Argesic  
Arthritis Pain Formula  
Arthropan Liquid  
A.S.A. Tablets/Enseals  
Asacol  
Ascriptin  
Asperbuf  
Aspergum  
Aspirin (any form)  
Azotal  
Azdone

### B

B-A-C  
Bayer's (check label)  
BC (powder or tablets)  
Bexophene

Buff-A-Compound  
Buffered aspirin  
Bufferin (any form)  
Buffits II  
Buffex  
Buffinol  
Buff-Tabs  
Butazolidan

### C

Cama Arthritis Strength  
Carisoprodol Compound  
Celebrex  
Celecoxib  
Clinioril  
Codoxl  
Co-gestic  
Comtrex  
Congesprin  
Cope  
Cosprin  
CP-2 Cramp End Tablets

### D

Damason-P  
Darvon (any form)  
Dasin

### E

Encaprin  
Equagesic

Equazine-M  
Exgic  
Excedrin

### F

Fiorgesic  
Feldene  
Fioricet  
Fiorigen (any form)  
Fiorinal (any form)  
4-Way Cold Tablets

### G

Gaysal-S  
Gelprin  
Gemnisyn  
Goody's Powder

### H

Halfprin  
Haltran

### I

Ibutablets  
Ibuprofen  
Ibuprohm  
Indocin  
Indomethicin  
Isolly Improved

## L

Lanorinal  
Lodine  
Lopruin

## M

Magan  
Magnaprin  
Magsal  
Maprin (any form)  
Marnal  
Measurin  
Meclomen  
Medipren  
Meprogesic Q  
Methcarbamol with ASA  
Macranin  
Midol  
Midol IB Cramp Relief  
Midrin  
Mobidin  
Mobigesic  
Momentum  
Mono-gesic  
Motrin

## N

Nalfon  
Naprosyn  
Neocylate  
Norgesic  
Norgesic Forte  
Norwich Aspirin  
Nubain  
Nuprin

## O

Orudis

## P

P-A-C  
Pabalate  
Pain Reliever  
Pamprin, Maximum Pain Relief  
Panadol  
Parfon  
PC-CAP Propoxyphene  
Pedia-Profen-Suspension  
Pepto Bismol  
Percodan (any form)  
Persantine  
Phenaphen  
Phenetron Compound  
Piroxican Caps  
Ponstel  
Presalin  
Propoxyphene HCL

## Q

Quiet World

## R

Relafen  
Rhinocaps  
Rid-a-Pain with Codeine  
Robaxisal  
Rofecoxib  
Roxiprin  
Rufen

## S

S-A-C Tabs  
St. Joseph's Children's  
St. Joseph's Cold Tablets  
Salatin  
Saleto  
Salflex

Salocol  
Sine-Aid  
Sine-Off  
Sinubid  
SK-65 Compound  
So-Cal-Gesic  
Soma Compound (any form)  
Stadol  
Supac  
Synalogs

## T

Talwin Compound  
Tenol-Plus  
Tolectin  
Toradol  
Trigesic  
Trilisate  
Triminicin  
Tri-Pain

## U

Uracel  
Ursinus Inlay

## V

Vanquish  
Verin  
Vioxx  
Voltaren

## W

Westprin Buffered  
Wygesic

## Z

Zorprin

# Glossary

**Ablation** – Surgically removing a part of body tissue.

**Access review device** – A hand-held programmer that allows you to turn your “brain pacemaker” device on or off, check to see if it is on or off, and determine if the battery life is ending.

**Advanced Registered Nurse Practitioner (ARNP)** – A registered nurse who has advanced education and clinical training in a health-care specialty, such as neurology or neurosurgery. Working along with the doctor, an advanced registered nurse practitioner diagnoses and treats patients for health problems and provides patient education and counseling. Also referred to as an ARNP.

**Akathisia** – Restlessness and a desire to move to relieve uncomfortable sensations, which may include a feeling of crawling, itching, stretching or creeping, usually in the legs.

**Amplitude** – Measurement of the width, breadth, range or extent of a wave, such as in microelectrode recording.

**Anesthesia** – The absence of all feeling and sensation of pain, as induced by an anesthetic substance. An anesthetic can be local, regional or general.

**Anesthesiologist** – A physician who completes an accredited residency in anesthesia.

**Antiemetic** – A medicine that prevents or controls vomiting.

**Asthenia** – A feeling of weakness without actual loss of strength.

**Athetosis** – A continuous stream of slow, writhing, uncontrollable movement of the arms and legs.

**Axon** – A nerve fiber that is a long, slender projection of a nerve cell that sends electrical impulses away from the cell body.

**Ballism** – A movement disorder characterized by wild, large, flinging movements of the arms and legs. This condition, also called ballismus, can occur on both sides of the body or on one side only (hemiballismus).

**Basal ganglia** – The islands of gray matter, largely composed of cell bodies, within each cerebral hemisphere.

**Battery** – A device of two or more electrolytic cells connected to form a single source providing direct current or voltage.

**Blepharospasm** – The involuntary contraction of eyelid muscles.

**Botox** – Botulinum toxin.

**Bradykinesia and Akinesia** – Slow movement or the inability to start moving.

**Brain** – The brain is the portion of the central nervous system located within the skull. It functions as a primary receiver, organizer and distributor of information for the body. It has two halves — right and left — that are called hemispheres.

**Brain scan** – The use of radioisotope imaging to localize and identify intracranial masses, lesions and tumors.

**Brain stem** – The stem-like part of the brain that is connected to the spinal cord.

**Brain wave** – Any of a number of patterns of rhythmic electric impulses produced in different parts of the brain. Brain waves help in the diagnosis of certain neurological disorders.

**Catheter** – A flexible tube used to deliver fluids into or withdraw fluids from the body.

**Central nervous system (CNS)** – The brain and spinal cord.

**Central venous catheter** – A special thin, flexible tube placed in a large vein, where it remains as long as it is needed to deliver fluids or draw blood. Also called a “central line,” types include Portacath, Hickman and PICC line.

**Cerebrospinal fluid (CSF)** – The fluid flowing around the brain and spinal cord.

**Chorea** – Rapid, non-rhythmic, jerky movements found most often in the arms and legs.

**Coagulopathy** – A pathological condition that affects the ability of the blood to coagulate.

**Contraindications** – Meaning that a procedure, device or drug should always be avoided because of the health risks.

**Computed tomography (CT) scan** – A radiographic technique that produces an image of a detailed cross-section of tissue. The procedure is painless and noninvasive and requires no special preparation.

**Deep Brain Stimulation** – Patient-controlled, continuous, high-frequency electrical stimulation of a specific area of the brain by means of an implanted electrode, which is controlled by a battery implanted just below the collarbone. The electrical impulses block the signals from the brain that cause tremors and other movement disorders.

**Dementia** – A progressive organic mental disorder characterized by chronic personality disintegration, confusion, disorientation and deterioration of intellectual capacity.

**Dendrite** – A slender branching projection, which extends from the cell body of a neuron that is capable of being stimulated by a neurotransmitter.

**Diathermy** – Deep-heat treatment that delivers heat to treat specific areas of the body. Active therapy patients should not receive any diathermy, as it could result in severe injury or death.

**Diuretics** – Drugs that help rid the body of excess water and salt.

**Dopamine** – A naturally occurring sympathetic nervous system neurotransmitter. A depletion of dopamine produces the symptoms of rigidity and tremors, which are characteristic of Parkinson’s disease.

**Dysarthria** – Difficult, poorly articulated speech, which results from interference in the control and execution of the muscles of speech; it is usually caused by damage to a central or peripheral motor nerve.

**Dyskinesia** – An impairment of the ability to execute voluntary movements.

**Dystonia** – A movement disorder characterized by sustained muscle contractions, usually producing twisting and repetitive movements or abnormal postures or positions.

**Electrode** – A medium for conducting an electrical current from the body to physiologic monitoring equipment. A microelectrode is thinner than a human hair.

**Electromagnetic field** – A field of force associated with an electromagnetic charge in motion. Electromagnetic energy has both electric and magnetic components.

**Electromagnetic interference (EMI)** – Electrical or magnetic energy that is strong enough to interfere with or disrupt medical therapy.

**Epilepsy** – A group of neurological disorders characterized by recurrent episodes of convulsive seizures, sensory disturbances, abnormal behavior, loss of consciousness or all of these.

**Essential tremor** – A disorder marked by violent shaking, usually of the upper extremities. Approximately two million Americans have been diagnosed with essential tremor.

**Eye movement disorders** – Repetitive and involuntary eye movements, including back-and-forth eye movements, Nystagmus, rapid-eye movements from side to side, and eye movements that are uncontrollable.

**Fluoroscopy** – An X-ray procedure that makes it possible to see internal organs in motion.

**Freezing** – The inability to begin a movement or the involuntary stopping of a movement before it is completed.

**Gamma Knife** – An apparatus for producing intracranial lesions by precisely aimed intersecting beams of gamma rays; used in stereotactic radiosurgery.

**Globus pallidus (interna)** – A key structure in the basal ganglia that is overactive in Parkinson's disease; one of two surgical targets for Deep Brain Stimulation surgery in treating Parkinson's disease.

**Hemifacial spasm** – Involuntary twitching of one side of the face. It usually starts around the eye and slowly progresses to involve the lower face. In some patients, it starts around the musculature of the mouth and progresses up the face towards the eye. The muscles in the forehead and neck are usually the last to be affected.

**Hemiparesis** – Muscular weakness of one half of the body.

**Hemiplegia** – Paralysis of one side of the body.

**Hospitalist** – A physician who provides care for patients who are in the hospital.

**Hypophonia** – A weak or whispered voice.

**Idiopathic** – No known cause.

**Imaging** – Tests that produce pictures of areas inside the body.

**Intensive care unit (ICU)** – A hospital unit for patients who require close monitoring and intensive care.



**Intracranial hemorrhage** – A hemorrhage within the cranium.

**Levodopa** – The generic name for the main medication used for the treatment of Parkinson's disease.

**Lithotripsy** – A medical device used in non-invasive treatment of kidney stones or stones in the gallbladder or liver.

**Magnetic resonance imaging (MRI)** – A procedure in which a magnet linked to a computer is used to create detailed pictures of areas inside the body.

**Microlesion effect** – A temporary improvement in Parkinsonian motor symptoms due to micro-electrode recording or Deep Brain Stimulation lead insertion.

**Movement disorder** – Any of numerous neurological disorders characterized by disturbances of muscular movement.

**Myoclonus** – A spasm of a muscle or a group of muscles; a sudden, shock-like muscle contraction. Myoclonic jerks may occur singly or repetitively.

**Neurological assessment** – An evaluation of the patient's neurological status and symptoms.

**Neurological examination** – A systematic examination of the nervous system, including an assessment of mental status, the function of each of the cranial nerves, sensory and neuromuscular function, and other cerebellar functions.

**Neurological monitoring** – A nursing intervention to collect and analyze patient data to prevent or minimize neurological complications.

**Neurologist** – A physician who specializes in the nervous system and its disorders.

**Neurology** – The field of medicine that deals with the nervous system and its disorders.

**Neuron cell** – A nerve cell that sends and receives electrical signals over long distances within the body.

**Neurosurgeon** – A doctor who specializes in surgery of the brain, spine and other parts of the nervous system.

**Neurosurgery** – Any surgery involving the brain, spinal cord or peripheral nerves.

**“Off” time** – The period when a patient does not receive relief from Parkinson's disease symptoms despite having taken medication.

**“On” time** – The period when a patient does receive relief from Parkinson's disease symptoms after taking medication.

**“On” time with dyskinesia** – The period when a patient is receiving relief from symptoms, but has uncontrolled movements caused by medications.

**Paresis** – Motor weakness or partial paralysis.

**Parkinson's disease** – A neurological condition characterized by trembling. As many as 1.5 million Americans have Parkinson's disease.

**Per Os (PO)** – By mouth; orally.

**Physiatrist** – A physician specializing in rehabilitative medicine.

**Physician assistant (P.A.)** – A health-care professional who is licensed to provide patient education, evaluation and health-care services. A physician assistant works along with the doctor to provide medical care to a group of patients. Also referred to as a P.A.

**Physician programmer** – A computer used to program the Activa System. Your health-care team can change the therapy settings using this programmer.

**Platelets** – Blood cells that help stop bleeding.

**Port** – A small plastic or metal container that is surgically placed under the skin and attached to a central venous catheter inside the body. Blood and fluids can enter or leave the body through the port using a special needle.

**Postural instability** – Problems with balance or coordination.

**Prognosis** – The likely outcome or course of a disease; the chance of recovery.

**Pulse generator** – The power source for a pacemaker system, usually fueled by lithium, supplying impulses to the implanted electrodes either at a fixed rate or programmed pattern.

**Rigidity** – Muscle stiffness.

**Risk factor** – Anything that increases the chance of developing a disease.

**Screening** – Checking for disease when there are no symptoms.

**Sensory nerves** – A nerve consisting of fibers that conduct sensory impulses from the periphery of the body to the brain or spinal cord via the dorsal spinal roots.

**Side effects** – Problems that occur when treatment affects healthy cells. Common side effects of Deep Brain Stimulation are usually reversible and can include a slight tingling sensation, dizziness, balance difficulties, limb weakness or slurred speech. However, for the most part, side effects are very mild and can be minimized by adjusting the stimulation.

**Spasticity** – A form of muscular hypertonicity with increased resistance to stretch. Movements that require great effort and lack of normal coordination characterize moderate spasticity.

**Stereotactic head frame** – A titanium ring that fits around the head and attaches at four points to the skull.

**Steroid** – A potent anti-inflammatory agent that helps prevent drug reactions.

**Stimulation** – The delivery of electrical signals to the brain cells. The electrical signals may block some of the incorrect messages processed by the brain in the areas that control movement.

**Subcutaneous (SQ or SC)** – Under the skin.

**Subthalamic nucleus** – A key structure in the basal ganglia that is overactive in Parkinson's disease; one of two surgical targets for Deep Brain Stimulation for Parkinson's disease.

**Surgery** – A procedure to remove or repair a part of the body or to determine if disease is present.

**Test stimulation** – The period during the Alevia System implant procedure where brain stimulation is evaluated to determine how well it controls a patient's symptoms.

**Thalamus** – The message relay center located deep within the brain; the surgical target for Deep Brain Stimulation surgery to treat essential tremor.

**Tomography** – A series of detailed pictures of areas inside the body; the pictures are created by a computer linked to an X-ray machine. Also called computed tomography (CT) scan or computed axial tomography (CAT) scan.

**Tourette's syndrome** – A treatable neurological disorder characterized by involuntary body movements called tics and uncontrollable speech. The inherited neurological disorder typically appears in childhood and can be associated with behavioral and developmental problems.

**Tremor** – Uncontrollable, involuntary shaking of a body part. Tremor may occur only when muscles are relaxed, or it may occur only during an action or while holding an active posture.

**Ultrasound** – The use of high-frequency sound waves for diagnostic or therapeutic purposes.

**Ventral intermediate nucleus** – The composite middle third of the ventral nucleus of the brain.

**Volt** – In an electric current, a volt is the force required to send one ampere of current through one ohm of resistance.

**X-ray** – High-energy radiation used in low doses to diagnose diseases.

## National Movement Disorder Organizations and Support Groups

Many national and local community organizations offer help and support to movement disorder patients and their families.

### General

#### **National Institute of Neurological Disorders and Stroke**

NIH Neurological Institute

P.O. Box 5801

Bethesda, MD 20824

Phone: 301-496-5751 or 1-800-352-9424

TTY (for people using adaptive equipment):

301-468-5981

[ninds.nih.gov/disorders/parkinsons\\_disease](http://ninds.nih.gov/disorders/parkinsons_disease)

#### **Worldwide Education and Awareness for Movement Disorders**

WE MOVE

204 West 84th Street

New York, NY 10024

E-mail: [wemove@wemove.org](mailto:wemove@wemove.org)

[www.wemove.org](http://www.wemove.org)

#### **The Movement Disorder Society**

555 East Wells Street, Suite 1100

Milwaukee, WI 53202-3823

Phone: 414-276-2145

Fax: 414-276-3349

E-mail: [info@movementdisorders.org](mailto:info@movementdisorders.org)

[www.movementdisorders.org](http://www.movementdisorders.org)

### Neurology Channel

[www.neurologychannel.com](http://www.neurologychannel.com)

### Deep Brain Stimulation

#### **Re-Wired for Life**

E-mail: [info@rewiredforlife.org](mailto:info@rewiredforlife.org)

[www.rewiredforlife.org](http://www.rewiredforlife.org)

#### **Activa University**

[www.medtroniceducation.com/kma/www/](http://www.medtroniceducation.com/kma/www/activa_education/index.html)

[activa\\_education/index.html](http://activa_education/index.html)

#### **New Hope for Parkinson's**

[www.newhopeforparkinsons.com](http://www.newhopeforparkinsons.com)

#### **DBS-STN.org**

[www.dbs-stn.org](http://www.dbs-stn.org)

#### **Deep Brain Stimulation Programmer Database**

[www.dbsprogrammer.com](http://www.dbsprogrammer.com)

### Parkinson's Disease

#### **National Parkinson Foundation, Inc.**

1501 N.W. 9th Ave./Bob Hope Road

Miami, FL 33136-1494

Phone: 305-243-6666 or 1-800-327-4545

Fax: 305-243-5595

[www.parkinson.org](http://www.parkinson.org)

**American Parkinson Disease Association, Inc.**

**(National Office)**

135 Parkinson Ave.  
Staten Island, NY 10305  
Phone: 718-981-8001 or 1-800-223-2732  
Fax: 718-981-4399  
E-mail: [apda@apdaparkinson.org](mailto:apda@apdaparkinson.org)  
[www.apdaparkinson.org](http://www.apdaparkinson.org)

**(West Coast Office)**

10850 Wilshire Blvd., Suite 730  
Los Angeles, CA 90024-4319  
Phone: 310-474-5391 or 1-800-908-2732  
Fax: 310-474-0292  
E-mail: [apdawc@earthlink.net](mailto:apdawc@earthlink.net)  
[www.parkinsonsapda.org](http://www.parkinsonsapda.org)

**The Michael J. Fox Foundation for Parkinson's Research**

Grand Central Station  
P.O. Box 4777  
New York, NY 10163  
Phone: 1-800-708-7644  
[www.michaeljfox.org](http://www.michaeljfox.org)

**Parkinson's Action Network**

300 North Lee Street, Suite 540  
Alexandria, VA 22314  
Phone: 703-518-0673 or 1-800-850-4726  
Fax: 703-518-0673  
E-mail: [info@parkinsonsaction.org](mailto:info@parkinsonsaction.org)  
[www.parkinsonsaction.org](http://www.parkinsonsaction.org)

**Parkinson's Disease Foundation**

William Black Medical Building  
Columbia-Presbyterian Medical Center  
710 West 168th Street  
New York, NY 10032-9982  
Phone: 212-923-4700 or 1-800-457-6676  
Fax: 212-923-4778  
E-mail: [info@pdf.org](mailto:info@pdf.org)  
[www.pdf.org](http://www.pdf.org)

**The Parkinson Alliance**

1250 24th St. N.W., Suite 200  
Washington, DC 20037  
Phone: 1-888-331-4673  
Fax: 202-466-0585  
[www.parkinsonalliance.org](http://www.parkinsonalliance.org)

**American Parkinson's Disease Association, Washington Chapter**

[www.waparkinsons.org](http://www.waparkinsons.org)

**My Parkinson's Info**

Prefab Markets, Inc.  
45 West 9000 S., Unit 2  
Sandy, UT 84070  
Contact: Brian Ranck  
Phone: 801-809-8833  
E-mail: [branck@prefabmarkets.com](mailto:branck@prefabmarkets.com)  
[www.myparkinsonsinfo.com](http://www.myparkinsonsinfo.com)

**Northwest Parkinson's Foundation**

400 Mercer St., Suite 401  
Seattle, WA 98109  
Phone: 1-877-980-7500  
E-mail: [nwpcf@nwpcf.org](mailto:nwpcf@nwpcf.org)  
[www.nwpcf.org](http://www.nwpcf.org)

**Pyramid of Health**

[www.pyramidofhealth.org](http://www.pyramidofhealth.org)

**The Arlette Johnson Young  
Parkinson's Information and  
Referral Center**

Glenbrook Hospital

2100 Pfingsten Road

Glenview, IL 60026

Phone: 847-657-5787 or 1-800-223-9776

E-mail: [info@youngparkinsons.org](mailto:info@youngparkinsons.org)

[www.youngparkinsons.org](http://www.youngparkinsons.org)

**Parkinson's Hope**

[www.parkinsonshope.com](http://www.parkinsonshope.com)

**WebMD Parkinson's Disease  
Condition Center**

[www.webmd.com](http://www.webmd.com)

**Parkinson's Control**

[www.parkinsonscontrol.com](http://www.parkinsonscontrol.com)

**The Parkinson's Training  
for Caregivers**

[www.parkinsonseducator.org](http://www.parkinsonseducator.org)

**Essential Tremor  
International Essential  
Tremor Foundation**

7046 West 105th St.

Overland Park, KS 66212

Phone: 913-341-3880

Fax: 913-341-1296

[www.essentialtremor.org](http://www.essentialtremor.org)

**Western Essential Tremor Network**

15 Altarinda Road, Suite 105

Orinda, CA 94563

Phone: 925-253-3500

Fax: 925-253-7635

[www.west-net.org](http://www.west-net.org)

**Dystonia**

**Dystonia Medical Research  
Foundation**

One East Wacker Drive, Suite 2430

Chicago, IL 60601-1905

Phone: 312-755-0198

In Canada: 1-800-361-8061

Fax: 312-803-0138

E-mail: [dystonia@dystonia-foundation.org](mailto:dystonia@dystonia-foundation.org)

[www.dystonia-foundation.org](http://www.dystonia-foundation.org)

**Benign Essential Blepharospasm  
Research Foundation, Inc.**

P.O. Box 12468

Beaumont, TX 77726-2468

Phone: 409-832-0788

[www.blepharospasm.org](http://www.blepharospasm.org)

**National Spasmodic  
Torticollis Association**

9920 Talbert Ave., Suite 233

Fountain Valley, CA 92708

Phone: 714-378-7837 or 1-800-487-8385

[www.torticollis.org](http://www.torticollis.org)

**Exploring Spasticity**

[www.exploringspasticity.com](http://www.exploringspasticity.com)

## **Other Web Sites for Support**

### **CaringBridge**

1995 Rahn Cliff Court, Suite 200

Eagan, MN 55122

Phone: 651-452-7940

[www.caringbridge.org](http://www.caringbridge.org)

### **National Family Caregivers Association**

10400 Connecticut Ave., Suite 540

Kensington, MD 20895-3944

Phone: 1-800-896-3650

Fax: 301-942-2302

E-mail: [info@nfcacares.org](mailto:info@nfcacares.org)

[www.nfcacares.org](http://www.nfcacares.org)

### **Well Spouse Foundation**

Phone: 1-800-838-0879

[www.wellspouse.org](http://www.wellspouse.org)

### **Senior Information and Assistance Program**

Phone: 206-448-3110 or 1-800-972-9990

[www.seniorservices.org](http://www.seniorservices.org)

### **Senior Services of Seattle/King County**

Phone: 206-448-5757

[www.seniorservices.org](http://www.seniorservices.org)

### **Social Security Administration**

Phone: 1-800-772-1213

[www.ssa.gov](http://www.ssa.gov)

### **Caregiver.com**

Phone: 1-800-829-2734

[www.caregiver.com](http://www.caregiver.com)

### **American Speech-Language-Hearing Association**

10801 Rockville Pike

Rockville, MD 20852-3279

Phone: 301-897-5700 or 1-800-638-8255

[www.asha.org](http://www.asha.org)



## Washington State Parkinson's Disease (PD) Support Groups

The Washington Chapter of the American Parkinson Disease Association maintains a list of PD support groups on its Web site at [\*www.waparkinsons.org/support\\_groups\*](http://www.waparkinsons.org/support_groups).

Please check the Web site for the most current information on support groups.

Another resource is the Information and Referral Center on the American Parkinson Disease Association Web site at [\*www.apdaparkinson.org\*](http://www.apdaparkinson.org).

## Reading Resources

*Carolyn's Journey: From Parkinson's Disease to a Nearly Normal Life After Deep Brain Stimulation*, Victor Anderson, 2006

*Cook Well, Stay Well with Parkinson's Disease: Super Foods for Super People with Parkinson's*, Kathrynne Holden, M.S., R.D., and Abraham Lieberman, M.D., 2003

*Hope: Four Keys to a Better Quality of Life for Parkinson's People*, Hal Newsom, Northwest Parkinson's Foundation, 2002

*Living Well, Running Hard: Lessons Learned from Living with Parkinson's Disease*, John Ball, 2005

*My Second Life: Living with Parkinson's Disease*, Bill Hardshaw, Dundurn Press, Toronto, Canada, 2001

*Parkinson's Disease: A Complete Guide for Patients and Families*, William J. Weiner, Lisa M. Shulman and Anthony E. Lang, Johns Hopkins Press Health, 2006

*Parkinson's Disease and the Family: A New Guide*, Dr. Sharma Nutan and Dr. Elaine Richman, The Harvard University Press Family Health Guides, 2005

*Parkinson's Disease for Dummies*, Michele Tagliati and Dr. Gary Guten, For Dummies, 2007

*Parkinson's Disease: Questions and Answers, 5th Edition*, Theresa A. Zesiewicz, Kelly E. Lyons, Wolfgang H. Oertel and Rajesh Pahwa, 2006

*Parkinson's Disease: 300 Tips for Making Life Easier*, Shelley Peterman Schwarz, Demos Medical Publishing, New York, 2002

*The Parkinson's Disease Treatment Book: Partnering with Your Doctor to Get the Most from Your Medications*, J. Eric Ahlskog, 2005

*Parkinson's Post* newsletter, [www.nwpf.org](http://www.nwpf.org), 1-877-980-7500

*Peas, Pills, and Parkinson's*, Alice Crooker, 2006

*Pills, Bills & Parkinson's Disease: Coping with the On-Off Syndrome*, Paul A. Luscombe, 2006

*Prepare for Surgery, Heal Faster: A Guide of Mind-Body Techniques*, Peggy Huddleston

*Shaking Up Parkinson's Disease: Fighting Like a Tiger, Thinking Like a Fox*, Abraham Lieberman, M.D., Jones and Bartlett, Sundbury, MA, 2002

*A Shock to the System*, *Wired Magazine*, [www.wired.com/wired/archive/15.03/brainsurgery.html](http://www.wired.com/wired/archive/15.03/brainsurgery.html)