Living With Deep Brain Stimulation Therapy

A POST-SURGICAL GUIDE

ST. JUDE MEDICAL™

This guide is being provided to help answer your questions and to give you the information you need for living with your St. Jude Medical DBS system.

You are unique. Each person with Parkinson's is unique. And every person's response to DBS is different. You have taken a bold step in your journey with PD by choosing to make DBS part of your Parkinson's treatment plan.

Be sure to discuss your expectations about DBS with your doctor. Your doctor will help you set realistic expectations about living with a DBS system.

This information is not intended to be a substitute for professional medical advice from your doctor or other health care provider. You should always talk with your doctor about your treatment and any symptoms you are experiencing.

You should also read your DBS system User's Guide for complete information about your St. Jude Medical DBS system.

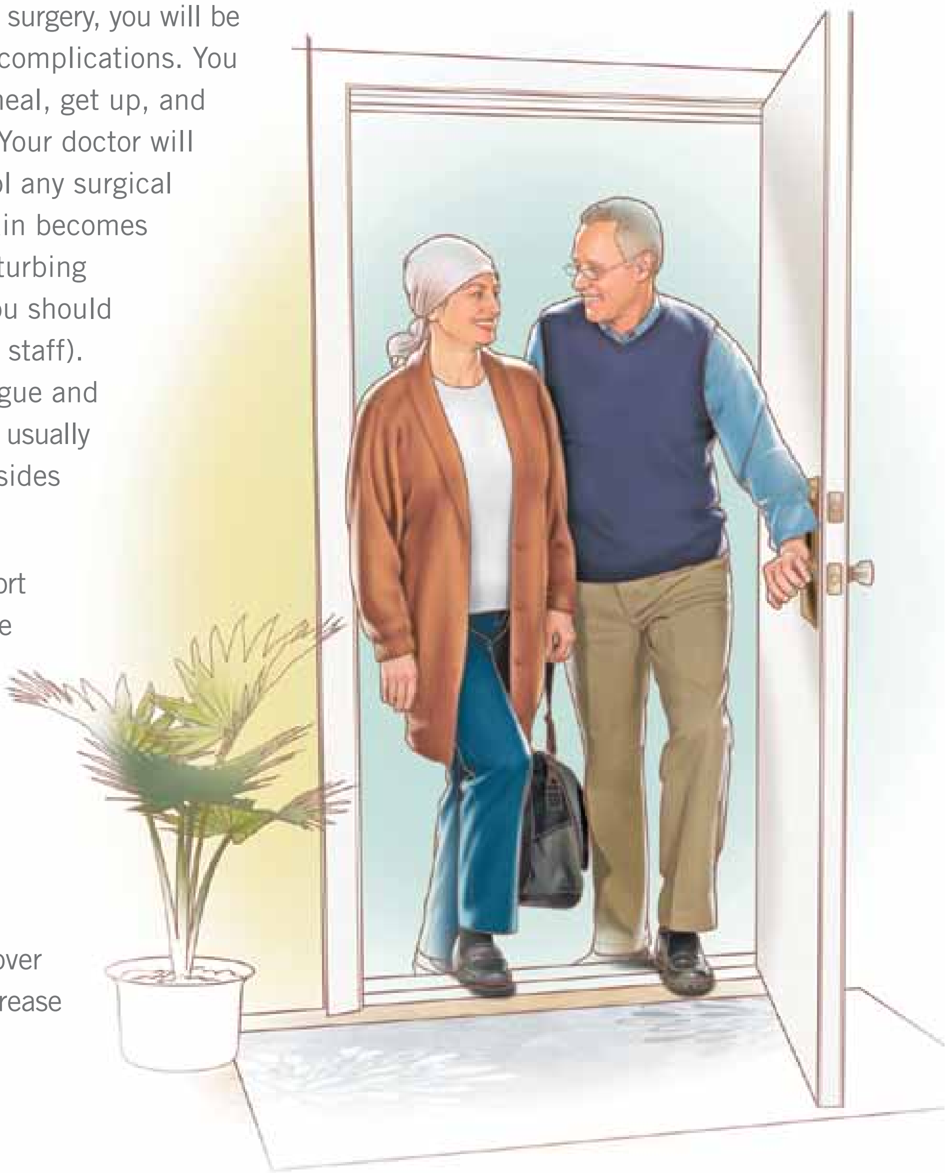
What to Expect After Your Procedure

The months following your DBS surgery can be an exciting time as you become familiar with your DBS system. You may begin to return to some of the activities you enjoy. But the first few weeks after your procedure should be dedicated to healing and recovery. Your individual recovery time will vary depending on your body and your exact surgical procedure. Talk with your doctor about what to expect during your recovery.

Post-Surgical Care

During the first 24 hours after your surgery, you will be closely monitored for any sign of complications. You will most likely be able to eat a meal, get up, and move around your hospital ward. Your doctor will provide medication to help control any surgical pain or headache. If headache pain becomes too severe or you notice other disturbing effects, such as blurred vision, you should notify your doctor (or the hospital staff). Some people may experience fatigue and mild confusion after surgery. This is usually only temporary and generally subsides within 24 to 48 hours.

You may experience some discomfort around the incision areas or where the leads and extensions were placed. Follow your doctor's instructions regarding the use of pain medications. Your doctor may also recommend ice packs (with a dry cover) to help relieve some pain. The pain from your surgery will continue to decrease over time, and your energy level will increase as you heal.



Preventing Infection

During your stay in the hospital and for the first several weeks after surgery, the key goal is to prevent infection.

The following are general guidelines your doctor may recommend for reducing the risk of infection and irritation:

- Keep the incision areas clean and dry.
- Wash your hands before touching an incision area.
- If you wear a hat or head covering, make sure that it is very clean.
- Avoid using lotions or creams around incision areas unless your doctor tells you to.
- Avoid bumping or putting pressure on the incision areas. When riding in an a car, consider placing a folded piece of soft cloth or a hand towel between the chest and the shoulder harness to help reduce pain and irritation.
- Do not pick or pull at the skin as it heals. This is especially important and sometimes can be difficult because your skin may itch as it heals.

Call your doctor or PD nurse immediately if you notice signs of infection, such as the following:

- A fever of 37.8°C or higher
- Redness or swelling at the incision or around your stitches
- Excessive pain around the incision site
- Any type of yellow or bloody drainage from the incision

Activity Restrictions

Upon discharge, your doctor will provide you with instructions about activities that you should and should not do. Follow these instructions carefully. They are intended to allow your body the time it needs to heal. And be sure to take all of your medications as instructed, including any new antibiotics.

Your doctor's instructions

Use the space below to write or attach the post-surgical care instructions you receive from your doctor.

Frequently Asked Questions

This section will help address some commonly asked questions and concerns you may have after your procedure.

When will my stimulation be turned on?

Recovery from DBS surgery is a process that involves your entire body. Although medical opinions differ about how soon after surgery the stimulation should be turned on, most centres wait several weeks. Your doctor will decide when to turn your stimulator on based upon what is right for you and your recovery.

When will my symptoms improve?

Some people may notice an immediate improvement in their symptoms even though the neurostimulator has not yet been turned on. Although this can be very exciting, it is only a temporary improvement. Keep in mind that pre-surgery symptoms will return until the stimulator is turned on and programmed.

In addition, you should not worry if you do not experience an immediate improvement in your symptoms after surgery. This does not mean your procedure was unsuccessful, nor does it indicate how well your stimulation will work later. Just as every person's PD is different, so is every person's response to the surgery.

If your doctor chooses to turn on stimulation before discharging you from the hospital, you should be aware that your stimulation setting will likely not be ideal yet. At this point, it is best to go slowly and allow your body to adjust to the stimulation. Over the next few months, you will work with your doctor to achieve your best possible results.

When will I be able to reduce my medications?

You and your doctor may have discussed your goals with DBS. Remember the primary goal of DBS is to improve the amount and quality of your daily on-time. You may have also had a goal to reduce the amount of your anti-Parkinson medications to help reduce medication side effects. This is a goal to be completed over time and may occur only minimally in the first 30 to 90 days. Most people continue with the same medication schedule until their doctor determines how their body is responding to the surgery and the effects of stimulation.

What will I be able to do when I get home?

You should always follow your doctor's instructions regarding restrictions. You should be able to resume many of your normal daily activities when you return home. Take things slowly to prevent falls and injuries. Remember, you have been living with the physical symptoms of PD for a while. During that time, your body has adjusted to your symptoms. Your muscles may not be prepared to perform certain activities. It is important to be aware of what you are capable of doing and slowly engage in more physically demanding activities, if appropriate, to prevent an accident from occurring.

How will I "retrain" my muscles?

As your stimulation works to help decrease the stiffness (rigidity) and slowness (bradykinesia) associated with your PD, your muscles may need to be retrained on some of the basics of everyday living, such as walking or getting in and out of a chair. This is not a concern, simply something to be prepared for. To help with the relearning process, your doctor may refer you to physiotherapy after your surgery. Discuss with your doctor any difficulties you might be having after your DBS surgery.

My questions

After Your Procedure: Recovery Expectations

Every person with Parkinson's is different and so is the recovery process for everyone who undergoes DBS surgery. Discuss with your doctor what your recovery process may be like.

Some questions to ask your doctor might include

- How long will it take for me to heal after my operation?
- What can I do to help the healing process?
- What activities must I limit and for how long?
- When can I resume my normal daily activities?
- When will my stimulation be turned on?

Focus on making small improvements each day, and set goals for what you would like to accomplish in the future.

The space below is for you to record information about your recovery and DBS therapy expectations you and your doctor have set together. You should also share this information with your carer.

My recovery process

DBS therapy expectations

What are realistic expectations for me to have about my DBS therapy?

How long after my surgery will it be before I see improvements?

How often will I need to return to the clinic for visits?

My questions

Living With Your DBS System

The weeks following the implantation of your DBS system can be an exciting time but also a period of adjustment. As your body heals and you adjust to the effects of stimulation, you should be able to do more of the things you want to do.

What will life be like with DBS therapy?

The experience of life with DBS has been well expressed by Jackie Hunt Christensen in her book *Life with a Battery Operated Brain*. She said, "If I have learned anything at all about DBS since I had the surgery, it's that DBS is a process, and not an event." As mentioned previously, it is important to remember that DBS does not work simply by turning on the system. Turning the system on is just the start. Over the course of the next several months, you should gain more control over your PD symptoms. Although results vary from person to person, this control should help you to return to doing some of the activities that are meaningful to you and that your PD symptoms may have prevented you from doing.

Programming

Over the next several months, you and the doctor or nurse programming your DBS system will work together to develop the right customized combination of stimulation and medication for you. Don't be discouraged if you do not see immediate results. This does not mean that your surgery was not successful. While you are working together, continue to discuss your expectations, as well as any questions or concerns, with your doctor.

How long will programming take?

The first sessions to program your device may take a considerable amount of time. Be sure to discuss with your doctor or nurse how long your programming session will take and what to expect. After a while, your programming sessions will be shorter and less frequent.

What is a programming session like?

Programming itself is generally painless and will be done using a device that can "speak" with your stimulator without the use of wires. During the programming session, the clinician will explore a range of stimulation variables to determine the optimal setting for you.

While your clinician is determining your settings, you may experience some temporary sensations, such as

- Numbness or tingling, often in the face or hands
- Dizziness or balance impairment
- Twisting movements that resemble dyskinesias
- Muscle spasms, usually in the face or hands
- Slurred speech
- Double vision

These temporary sensations should stop when the DBS settings are changed or adjusted. They should not be present at the end of your session or after you get home. If any of these sensations appear when you are at home, notify your doctor.

Should I take my medications before my programming session?

During your first programming sessions, your doctor or PD nurse may ask you to stop taking your medication the night before your appointment so that the clinician who is programming your DBS system can determine the actual effects of the stimulation.

Then during the session, the clinician will ask you to take your medication. Most centres will usually ask you to stay for a short period to observe how you respond to medication and stimulation together.

Finding the optimal stimulation settings

You and your clinician will work together to find the settings and medication levels that provide the best results for you. You can help by providing your clinician with accurate information about the effects of the stimulation on your PD symptoms. Don't try to control your tremor or other body motions. Your clinician must see these effects to determine the appropriate settings for you. Remember, your best day or period on stimulation will be similar to your best period on levodopa, but your on-time should last longer.

To help keep track of symptoms as you and your clinician work together, you may find it helpful to keep a diary or journal, which may be similar to one you kept prior to your surgery. The following pages are provided to help you record your symptoms and medications.

Date ________________

SYMPTOM CONTROL

Place an “X” in the box under the time of day in which the statement applies

	Asleep	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23
ON Good Symptom Control																			
ON With Dyskinesias																			
OFF																			

MEDICATION SCHEDULE

List the medications you are currently taking and place an “X” in the box when you take a dose of medication

MEDICATION NAME	Asleep	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23

Date ________________

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Living With Your DBS System: Additional Precautions

Travel Precautions

Listed below are a few reminders that may help you when you are travelling.

Things to take with you

- Phone numbers for your neurologist and PD nurse
- Patient controller and extra batteries

Travelling with your system

Inform security personnel that you have an implanted device before you approach a theft detector or metal screening device at a security checkpoint. You should request assistance to bypass the device.

If you must pass through an anti-theft or screening device, move quickly through the device. Afterward, use your patient controller to check the status of your neurostimulator and ensure that it is still turned on.

Medical Test Precautions

Always inform any medical personnel that you have an implanted DBS system, especially your general practitioner (GP) and dentist.

Can I have an MRI?

People with DBS systems should not have a total body MRI, a full-body radiofrequency (RF) coil MRI, or a head transmit coil MRI that extends over the chest.

People with DBS systems can have common X-rays.

Can I have diathermy?

No. People with DBS should never undergo any form of diathermy (the use of high-frequency electric current for deep heating of tissue), which is sometimes used by dentists and physical therapists for the treatment of pain. Injury can occur during diathermy whether the DBS system is turned on or off.

Is it safe to have an ultrasound?

Certain care and precautions should be taken when ultrasound is done on a person with a DBS device. Consult your User's Guide for additional information.

Frequently Asked Questions

Can I take a bath or go swimming with a DBS system?

Most people with a DBS system can shower and swim once their incisions are completely healed. However, you should check with your doctor before doing either activity. Remember, your programmer is not waterproof. Keep it dry to avoid damage.

Do I keep my DBS system on 24 hours a day?

Most people do keep their DBS systems on 24 hours a day to continue to receive the best possible benefit from the therapy.

Can I use household appliances or mobile phones with my DBS system?

You can use computers and standard household appliances, including microwave ovens with your DBS system. Household appliances that contain magnets may unintentionally cause the DBS system to turn on or turn off. You can also use a mobile phone, but the effects of mobile phones on DBS systems are unknown. Avoid placing mobile phones (on or off) directly over the neurostimulator.

Can I drive with the DBS system turned on?

Talk with your doctor before and after the procedure. You should not operate potentially dangerous machinery, power tools, or vehicles or engage in any activity that would be potentially unsafe if your symptoms were to return unexpectedly.

How often will I need to have my settings adjusted?

In the first six months following surgery, the need to adjust your stimulation will be the greatest and may require a significant number of visits back to the DBS centre. As you and your doctor or nurse work together to find the best combination of stimulation and medication, the need for follow-up visits will decrease and may be reduced to only once every six months.

How long will my neurostimulator's battery last?

It is difficult to predict exactly how long your battery will last. A neurostimulator's battery life depends on the settings programmed into your device. Your doctor will work to find the settings that help conserve battery life without limiting the effects on your symptoms.

The volume of my voice seems to be affected. Is this a side effect of DBS?

Studies show that speech difficulties are a common issue with Parkinson's disease. In some people, DBS can cause these speech issues to worsen.[1] You should discuss this with your doctor to determine if programming might help improve this situation. In addition, discuss with your doctor what other resources might be available to assist you with improving the quality of your speech.

I've heard people talk about gaining weight after surgery. Is this true and how much weight will I gain?

Some people do experience weight gain after DBS surgery. The exact reason for this is unknown, but it is thought to be the result of the decrease in motor fluctuations and energy use experienced after DBS.[2] It is important to discuss with your doctor what you might expect. The best way to reduce the chance of gaining weight is to discuss with your doctor a plan for proper eating and physical activity after surgery.

Your DBS Neurostimulator and Controller

During your initial programming session your physician should provide you with a hand-held controller for your device and a User's Guide. Make sure to keep the controller User's Guide in a place where you can easily find it. Refer to your controller User's Guide for complete instructions on how to use and care for your controller.

When and how to check your battery status

Your controller allows you to check whether or not your stimulator is on and if the battery is getting low. However, you will not need to do this on a daily basis. Discuss with your doctor how frequently to check the status of your battery.

You should schedule regular follow-up visits with your DBS centre to determine if your system is functioning properly and to estimate the life of your neurostimulator battery.

Signs and symptoms that you may not be getting optimal stimulation

Under certain circumstances, your DBS neurostimulator could be switched off by accident, such as when you are walking through an anti-theft device in a department store. Events like these are not harmful to you or your device. However, you may experience a return of your PD symptoms when this happens. You can easily check the status of your neurostimulator and, if necessary, turn it back on by using your hand-held controller.

In addition, if you experience an unexplained and immediate return of your PD symptoms, it is always a good idea to check the status of your device. If you do experience an unexplained return of symptoms, make sure to contact your doctor or PD nurse as soon as possible.

Notes

Important Contact Information

Please fill in the information below, so you have easy access to contact information for your care team.

Parkinson’s Doctor **Telephone Number**

Parkinson’s Nurse **Telephone Number**

DBS Programmer **Telephone Number**

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1 Hanson, WR, Svensson, Effect of bilateral stimulation of the subthalamic nucleus on parkinsonian dysarthria. *Brain & Language*. 1994, 85(2), 190-196.

2 Montarurier C., Moria, B, et al, Mechanisms of body weight gain in patients with Parkinson's disease after subthalamic stimulation. *Brain*. 2007;130(7):1808-1818.

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St. Jude Medical Neuromodulation Division deep brain stimulation (DBS) systems are indicated for use in unilateral or bilateral stimulation of the thalamus, internal globus pallidus (GPi), or subthalamic nucleus (STN) in patients with levodopa-responsive Parkinson's disease.