

Deep Brain Stimulation to Treat Dystonia

Reading this booklet can help you learn how Deep Brain Stimulation is used to help relieve symptoms of Dystonia.

Your health care team will talk with you about DBS and its risks and benefits. Together, you can decide if this treatment is right for you.

Inside this booklet

Learning about Deep Brain Stimulation.....	Page 3
Deciding if DBS is right for you	Page 8
Preparing for DBS surgery.....	Page 13
Your hospital stay and DBS surgery	Page 14
Recovering at home.....	Page 18
What to watch for	Page 20
Programming your DBS	Page 21
Living with your DBS system.....	Page 22
Frequently asked questions.....	Page 26
Where to get more information.....	Page 27



Learning about Deep Brain Stimulation

What is Deep Brain Stimulation (DBS)?

DBS is a treatment for dystonia that can help certain patients when medications do not work well enough for a good quality of life.

In this treatment, a mild electrical current is used to stimulate an area deep in the brain that controls movement. The stimulation changes the activity of the brain cells in a way that helps relieve the symptoms of dystonia.

The electrical stimulation comes from a DBS system, which is implanted in the body during surgery.

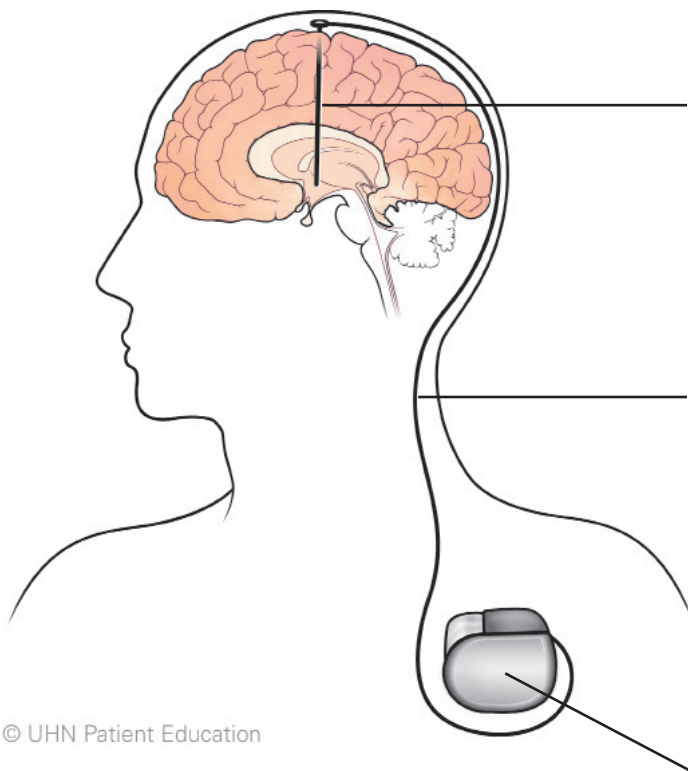
DBS has been proven to be effective and safe for the treatment of dystonia.

DBS cannot cure dystonia or change the progression of the disease, but it can help relieve symptoms and improve quality of life.

How does DBS work?

1. You will have surgery to put 3 parts of the DBS system inside your body. This is done by a Neurosurgeon.

The parts of the DBS system



© UHN Patient Education

Electrodes

- Very thin wires placed deep inside your brain.
- The tip of each electrode is positioned in a specific part of your brain that is affected by dystonia.

Extension wires

- Thin wires placed under the skin of your scalp, neck and chest.
- These wires connect the electrodes to the Internal Pulse Generator.

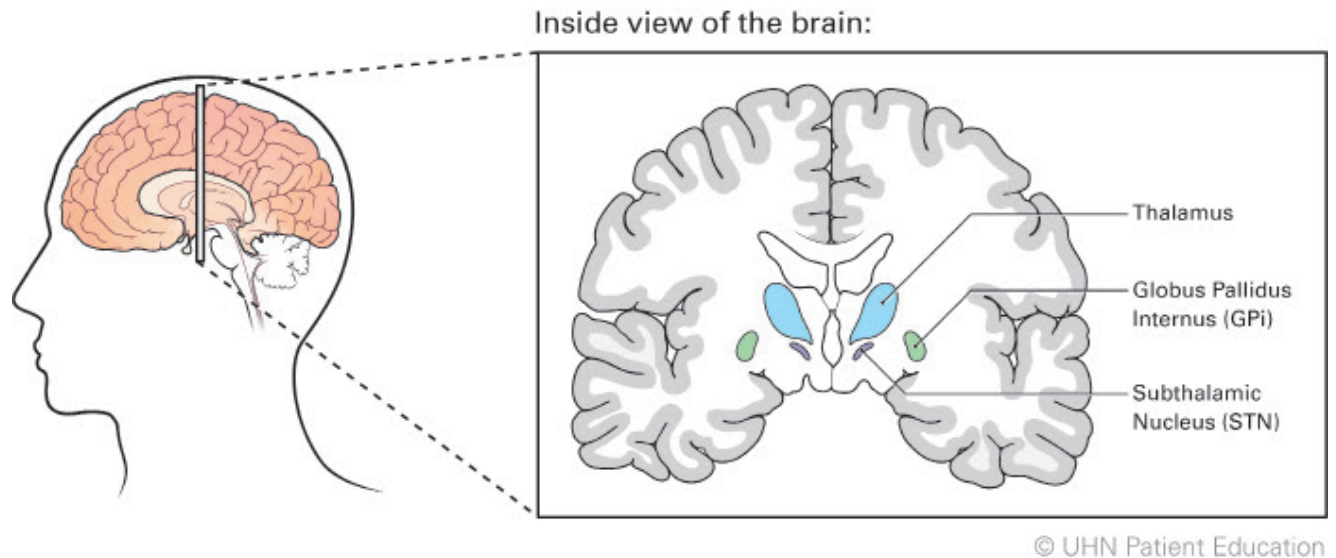
Internal Pulse Generator (IPG or neurostimulator)

A battery like device placed under the skin (implanted) in your chest, near your collarbone.

2. Several weeks after surgery, your IPG is turned on.
 - The IPG creates electrical impulses and sends them up along the extension wires to the electrodes.
 - The tip of the electrodes deliver the electrical impulses to the target area in your brain. This stimulates the target area without damaging the brain.
3. Your IPG is programmed to give you the best results.
 - This means adjusting the electrical impulses to the setting that best relieves your symptoms with as few side effects as possible.

What is the main target area for DBS to treat dystonia?

The target area for DBS for dystonia is a small part of the brain involved in making and controlling movements called the Globus Pallidus Internus (GPI). In rarer cases Thalamus is targeted (to exclusively treat tremor) or both targets are used to maximize the chances of improvement.



Benefits

- DBS treatment can relieve specific symptoms of dystonia.
- With fewer symptoms you can move better, do daily activities more easily, gain independence and enjoy a better quality of life.

Side effects

- Many side effects can be avoided or reduced by adjusting the settings of your DBS system (see next page).

Globus Pallidus Internus (GPi)

The GPi is a small part of the brain that helps control movements.

Benefits of GPi stimulation	Possible side effects of stimulation
<p>Stimulating this area may improve these symptoms of dystonia:</p> <ul style="list-style-type: none">• Abnormal pulling of muscles• Abnormal posture/ contractures• Abnormal involuntary movements• Pain associated with pulling of the muscles <p>DBS may also help reduce medications for the abnormal posture as well as pain medications</p>	<ul style="list-style-type: none">• Tingling• Seeing flashes• Slurred speech• Muscle contractions• Slowness

Is DBS surgery done on one or both sides of the brain?

DBS surgery may be done on one side of the brain (unilateral surgery) or on both sides (bilateral surgery).

Most patients have bilateral surgery because dystonia affects both sides of the body

- Electrodes are placed on both sides of the brain to help symptoms on both sides of the body.
- Usually, one dual-channel IPG is used to deliver stimulation through both electrodes. It is placed on the right side of the chest.
- A few patients receive two single-channel IPGs. One is placed on each side of the chest. Each IPG delivers stimulation through one electrode to one side of the brain.

Some patients have unilateral surgery

- An electrode is placed on one side of the brain to help symptoms on the opposite side of the body.
- A single-channel IPG is used to deliver stimulation through one electrode to one side of the brain. The IPG is placed in the chest on the same side as the stimulation. For example: if the target area is in the left brain, the IPG is implanted on the left side of the chest, to control symptoms on the right side of the body.

Unilateral surgery is done:

- When a patient has symptoms only on one side of the body.
- When surgery on both sides is not possible due to the patient's health.

What are the steps in DBS surgery?

Step 1

- The electrodes are placed in the target areas of your brain.
- This is usually done under local anesthesia. This means that you will be awake and able to answer questions that help the Neurosurgeon confirm the exact position for the electrodes.

Step 2

- The extension wires and IPG are put under the skin. The parts of the DBS system are connected, but not turned on.
- This is done under general anesthesia, which means you will be asleep.

Step 1 and Step 2 are done separately, two or three days apart.

OR

Both steps may be done during one surgery

What are the possible risks of DBS surgery?

DBS surgery has similar risks to other types of brain surgery. The risks may include (from most common to least common):

- Pain at the surgery sites, which usually goes away
- Confusion or attention problems, which usually go away
- Infection: 3 to 5% of patients having DBS surgery at Toronto Western Hospital develop infection.
- Seizures
- Headaches
- Bleeding in the brain: 1 to 2% of patients having DBS surgery at Toronto Western Hospital have bleeding in the brain that can result in temporary or permanent neurological problems such as paralysis.
- Problems with the DBS system: In less than 1% of patients, the electrodes move out of place or break.
- Coma
- Death

Deciding if DBS is right for you

Each person with dystonia is unique and DBS cannot help all of them. Your health care team will help you decide if DBS is a good option for you.

To gather the information needed to make this decision, you will have tests and appointments with members of the health care team. These are called screening assessments.

Planning for your screening appointments

The screening assessments you have will depend on the reason for your DBS surgery.

Please bring a family member or support person to all your appointments.

Please make sure that the images (usually a CD-ROM) of your brain MRI has been sent to the clinic beforehand (or that you have a CD-ROM yourself), unless you had the MRI done in one of the hospitals affiliated to UHN (University Hospital Network).

We welcome your questions. We encourage you, your caregiver and family to write down any questions you have and bring them to your appointments.

Who is part of your health care team?

Neurology team (Includes Staff Neurologists, Nurse Practitioner, Nurse Coordinators and Fellow Doctors)

- Evaluates you before and after the surgery.
- Monitors and adjusts your stimulation and medications after you have surgery.

Neuropsychiatrist

- If indicated, the neuropsychiatrist will see you to evaluate you before the surgery and after surgery as needed.

Neurosurgeons

- Evaluate you before the surgery and perform the surgery.
- You will then see your neurosurgeon once after surgery and when your IPG needs to be changed.

Usually, a Fellow Doctor, a Nurse Practitioner or a Nurse Coordinator will be the first to examine you during your appointments. At the end of the visit you will see your main Neurologist, Neuropsychiatrist or Neurosurgeon.

What screening assessments are needed?

Magnetic Resonance Image (MRI) of the brain

- MRI uses a strong magnetic field to create detailed images of your brain. These images help the health care team make decisions about the best treatment and plan the placement of electrodes.
- A recent MRI of your brain is most helpful. This does not have to be done at Toronto Western Hospital. We may accept results from an MRI done in the last 5 to 10 years, depending on your age.

Neurological Assessment

During this visit, the doctors or nurses will:

- Assess your dystonia to see how much your body and movements are affected.
- Discuss the factors that help determine whether surgery is the right treatment for you. This includes your health history and whether you have help and support from family and friends.
- This assessment takes about 1.5 to 2 hours.

Neuropsychiatric Assessment (if needed)

- During this visit, the Psychiatrist will assess your mental health and the risk of developing problems such as depression or anxiety after DBS surgery.
- The Psychiatrist will tell you if you are at risk and may give you recommendations.
- This assessment takes about 1 hour.

Video Assessment

- During one of your visits before the surgery, the doctors or nurses will assess and videotape your symptoms.
- Sometime after surgery your symptoms will be videotaped again. This will be kept in an internal database and will help to monitor your progression and response to the treatment.

Who decides if DBS is a good choice for me?

After your screening assessments are done, your neurology team will:

- Review the results of your assessments
- Discuss whether your condition and needs can be helped with DBS surgery
- Discuss what type of surgery would suit you best
- Refer you to one of the neurosurgeons

Neurosurgery Evaluation

A few months after you are referred to your neurosurgeon, you will meet him or her to:

- Review the results of your assessments
- Discuss the risks and benefits of having DBS surgery
- Explain the details about the surgery and answer any questions you may have

Once you have met the neurosurgeon, all the health care practitioners that have assessed you will meet to discuss your case and decide together whether you should have surgery.

A member of the neurology team will call you to explain the decision.

If you agree to have DBS surgery, the Neurosurgeon's office will schedule:

- a visit for you to sign a consent form
- a Pre-Admission Clinic visit to help you prepare for surgery
- your DBS surgery



If you have a fear of closed spaces (claustrophobia) or cannot hold still because of your health problems, tell your Neurosurgeon before the date of your surgery.

Preparing for DBS surgery

What happens at my Pre-admission Visit?

You will have a pre-admission visit a few days or weeks before your surgery. Come to the Pre-Admission Clinic, Main Pavilion, 1st Floor (Room 406). This visit takes about 3 to 4 hours.

Please bring:

- Your Ontario Health Card (OHIP)
- All the medicines you take in their original containers

During this visit:

- You will meet an admitting department clerk, a Nurse, a Pharmacist and an Anesthetist (a doctor who gives patients anesthesia)
- You will be asked specific questions about your health and medical history
- You may have tests, such as blood tests, an electrocardiogram (ECG) and a chest x-ray

Part of planning for your surgery is making arrangements for someone to:

- Drive you home from the hospital after surgery
- Stay in your home to care for you the first week after surgery

Your hospital stay and DBS surgery

Do not have ANYTHING to eat or drink after midnight, the night before surgery.

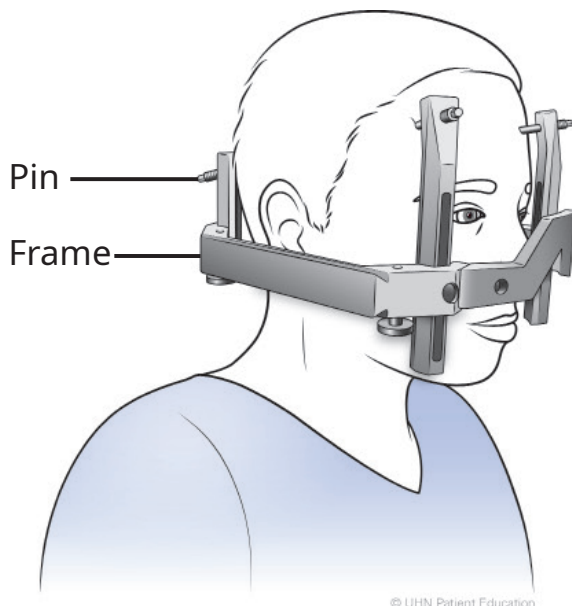
What happens on the day of the surgery?

Come to the Pre-Operative Care Unit (POCU) in the Fell Pavilion (2nd floor) at 6:00 am to check in. Please bring:

- Your Ontario Health Card (OHIP)
- All the medications you take regularly in their original containers
- You may also want to bring personal items, such as photos or reading materials

Before surgery

After you check in, the Nurses admit you and help you get ready for surgery. They check your blood pressure, pulse, temperature and breathing. They will also put an intravenous needle (IV) in a vein in your arm. You will change into a hospital gown.



We put a special frame on your head.

This frame has 2 pins at the front and 2 at the back to keep your head still during surgery. We give you a medication (local anesthetic) with a small needle to numb the areas where the pins are put in.

You will have pictures taken of your brain. You will have a brain MRI (Magnetic Resonance Imaging) or CT (Computed Tomography) scan. These tests create detailed images of your brain that help your Neurosurgeon position the DBS electrodes. Please try to stay as still as possible. This helps the technician get the clearest pictures of your brain.

- If you have an MRI, a box and coil are attached to the frame. This may feel heavy. After the MRI, we remove the box and coil. Only the frame will remain on for the surgery. The MRI takes about 45 minutes.
- If you have a CT scan, it will take 15 minutes.

You are taken to the holding area. A Nurse will check that everything is ready for your surgery. You will see the Anesthetist, who will give your anesthetic and monitor you during your surgery.

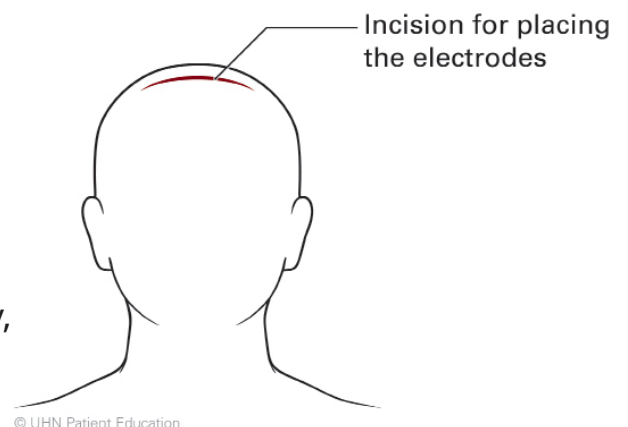
During surgery

When everything is ready, you go to the operating room. The surgical team helps you move onto the operating table and get comfortable. The table is angled so your back is raised, but not all the way. Your head frame is attached to the table to keep your head still.

Step 1: Placing the Electrodes

You may be given a sedative to make you relaxed but be awake enough to answer questions about how and what you feel when the electrodes are stimulated. Being awake is important because your answers help the Neurosurgeon confirm the right placement of the electrodes. The Neurosurgeon will:

- Shave and wash your head with a special soap that kills germs.
- Numb parts of your scalp so you will not feel pain.
- Make an incision (cut) on the top of your head and a small round opening in your skull (about the size of a nickel). If you are having surgery for both sides of your body, you will have two openings in your skull.



© UHN Patient Education

- Put in each electrode so the tip is in the proper area of your brain.
- Stimulate the electrodes and measure how your brain cells react.
- Ask you what or how you feel and whether you feel things like tingling or numbness.
- Use plastic caps to close the holes and make sure the electrodes stay in place, and close the incision with staples.
- Remove the frame from your head.

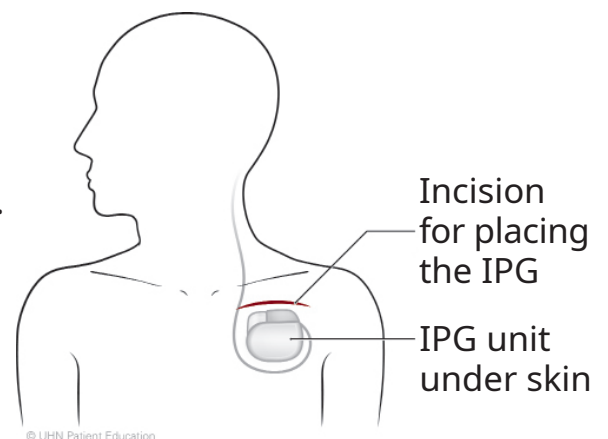
Step 1 takes 4 to 6 hours, depending on the number of electrodes needed and complexity of the surgery.

Step 2: Placing the Extension Wires and IPG

The Anesthetist will give you medication (general anesthetic) so you will be asleep during this part of the surgery.

The Surgeon will:

- Connect the extension wires to the electrodes.
- Place the extension wires under your skin, from the top of your head, behind your ear, down your neck to your chest.
- Connect the extension wire to the IPG unit.
- Place the IPG under the skin below your collarbone. It will remain off.
- Close the incision in your chest with staples.



Step 2 takes about 45 minutes.

After surgery

When the surgery is finished, you will go to the **Post Anesthetic Care Unit (PACU)** for 1 to 3 hours to recover.

- The Nurses in PACU check your blood pressure, pulse, temperature and breathing often, as you wake up. If you have pain or nausea, they will give you medication that will help.
- You may have an oxygen mask over your mouth and/or nose.
- There will be a bandage covering the incision on your head and chest.

When you are ready, you will go to your room on the **Neurosurgery Unit (5A or 5B)**.

- In the Neurosurgery Unit, your health care team continues to check your condition and progress.
- You may have a headache, feel pain at your incisions or feel sick (nausea).
- This will gradually get better. The Nurses can give you medication to help, if needed.
- In the afternoon or evening you can start to drink and eat.
- Later in the day or the next day, the Nurses will help you get out of bed and walk. You may feel dizzy, so it is important that someone is with you the first few times you get out of bed.
- You will have another MRI or CT scan to check the position of the electrodes.

Taking part in research

The day after your surgery, we may invite you to take part in research studies to help us learn more about how the brain works. You can decide whether or not you wish to take part. Your decision will not affect your care in any way.

Leaving the hospital

You can expect to leave the hospital 1 or 2 days after the IPG is placed in your chest.

Before you leave the hospital, we will:

- Teach you how to take care of yourself and your incisions
- Tell you when your DBS system will be turned on
- Tell you about your follow-up appointments

On the day you go home or your next place of residence, please arrange to be picked up before 11 am.

Recovering at home

At home, your medications will remain the same until your DBS is turned on.

In the weeks following surgery, you may feel a temporary improvement in your symptoms, even though your DBS system is not yet turned on. This is due to swelling caused by the electrodes. As the swelling goes away, your symptoms will likely return.

Please allow 4 to 6 weeks to recover from the surgery. Then you may return to your usual activities. Please talk with us if you have any questions or concerns about returning to work.

Taking care at home after your DBS surgery

Incision (cuts)

- Your incisions will have staples and will be covered with bandages.
- You will need to remove the bandages 4 days after your IPG is inserted in your chest. The sites can be left without a dressing.
- Keep your incision sites dry. Do not put on creams, lotions or ointments to the area.
- Keep your head covered by wearing a scarf or a loose fitting hat when you go outside.
- Never touch, scratch or apply any pressure on the incision sites.

Hygiene (such as bathing and showering)

- You can take a shower and wash your hair with mild soap or shampoo 4 days after your last surgery.
- Do not soak your incisions in water for the first 4 weeks after your surgery. This means you cannot soak in a bathtub or go swimming.
- Make sure your hats, bed linen, pillows and wigs are clean.
- Stop pets from going close to your incisions and wash your hands well after touching them.
- Wash hands frequently.
- Do not dye your hair or use a hair dryer until after you see your neurosurgeon after the surgery.

Physical activity

- Do not lift anything heavier than 5 pounds (or 2.5 kilograms) with your left arm, right arm or both arms for 3 weeks. This depends on where your stimulator was placed.
- Don't play sports or do tiring activities for 3 weeks.
- After 3 weeks, you can start to increase your activity level as much as you can handle.



Don't ever do any activity that could overheat your stimulator (such as using tanning beds, hot tubs, saunas and steam rooms) until your incision sites are completely healed.

Watch for these signs of infection

Look at your incisions every day and watch for these signs of infection:

Signs of infection	What to do
<ul style="list-style-type: none">• Redness or swelling at your incision site that is getting worse• Leaking (for example with yellow or green-like pus) from your incision• Bleeding from your incision• Pain at your incision site that does not go away• Fever, a temperature over 38°Celsius (or 101°Fahrenheit)	<p>If you notice any of these signs or symptoms please tell your neurosurgeon, nurse coordinator or nurse practitioner as soon as possible.</p>

It is important to check mood and behaviour after surgery and after DBS programming sessions. **You or your family members need to report any changes to your health care providers.**

When to go to the Emergency Department after surgery

- Any sudden, unexpected change in your health
- A seizure
- Signs of infection
- Signs of stroke
- Sudden severe change in thinking, such as confusion, hallucinations, or memory loss
- Sudden change in mood, especially depression or any strange behaviour
- Thoughts of suicide

Programming your DBS

Your DBS system will be off for several weeks. Once it is turned on, it will deliver continuous stimulation to the target area of your brain. This helps relieve dystonia symptoms all day and night.

How to program your DBS

Programming means adjusting the electrical impulses from your IPG. This can begin when your brain has recovered completely, which is usually within 8 weeks after surgery.

Programming is done in a series of clinic visits over several months.

- Your first programming appointment will take 2 to 3 hours. During this visit, we will test your response to stimulation and record what levels of stimulation cause side effects.
- You will need about 4 to 6 more visits to program your stimulator to the best setting. Getting to the best setting can take as long as 6 to 12 months.
- We will give you a remote control to check that your stimulator is on. The team will teach you how and when to use it during your programming appointments.

Adjusting your medications

As your symptoms improve, your neurology team may begin to reduce your medications. Your medications must not be stopped suddenly, so carefully follow any instructions to slowly reduce your medications.

Programming your DBS takes time. The result will be the best relief of dystonia symptoms with the least side effects.

Living with your DBS system

What follow-up care will I need?

Family doctor	Make an appointment with your family doctor to have your staples removed 10 to 14 days after surgery.
Neurosurgeon	You will see your neurosurgeon 6 to 8 weeks after your surgery. They will check your condition and incisions.
Neurology team	After your IPG is programmed to the best setting, you will have follow-up visits with the neurology team every 4 to 6 months.
Video Assessments	You may have video-taped assessments of your symptoms at 1, 3, 5 and 10 years after surgery to monitor your dystonia symptoms and response to brain stimulation over time.
Neuropsychiatrist	You may have follow-up visits to make sure there are no concerns about your mental health after surgery.
Brain MRI	You may have more brain imaging during your recovery and follow-up care.
Your Neurology team will compare the results of follow-up tests with the ones you had before surgery to see how well your DBS treatment is working.	

How long does the IPG battery last? How it is replaced?

Checking the battery

- The battery lasts about 2 to 4 years, depending on the amount of energy used.
- Each time you visit the DBS clinic, they will check the battery. You will learn how to check it with your own remote control.



Examples of IPG and remote control (Boston Scientific Inc.)



Examples of IPG and remote control (Medtronic Inc.)

When the battery is getting low

- The DBS team will refer you to the Neurosurgeon to replace the battery. This will be done in Day Surgery.
- Your Neurosurgeon's office will send you some forms to be filled by your family doctor. They will arrange for blood tests, an electrocardiogram (ECG) and chest x-ray to be done at the hospital.
- If you do not live near the hospital, they will send you requisitions to have these tests done in your community.
- You may need to see your Neurosurgeon to sign a consent form for surgery.

Changing the battery

- The Neurosurgeon replaces the battery during surgery. After surgery, you will go to the Day Surgery Unit.
- A member of the DBS team will program your IPG with the stimulation settings you had before the battery was changed.
- You will go home the same day, usually within 4 hours.

Some batteries are rechargeable and can last 15 years or longer.

If you have this type of battery, you must recharge it regularly (every day for close to 1 hour or every week for many hours).

What do I need to do to stay safe with a DBS system?

You must follow these rules for your health and safety

Always carry your DBS Registration Card

- Before you leave the hospital, you will get a temporary registration card for your DBS system from the company that makes it. A permanent card will be mailed to you. Carry this card with you at all times.

Tell all your health care providers that you have a DBS system

- All your health care providers need to know that you have a DBS system implanted in your body so they can take steps to keep you safe.
- Consider getting a Medic Alert bracelet. In an emergency, the bracelet tells medical staff that you have a DBS system.

NEVER apply heat to your DBS system

- Do not put heat on any part of your DBS system as this could damage it and harm you.
- Do not have diathermy treatments (heat therapy), which deliver energy to heat and heal tissues in your body.

Check with your doctors before having an MRI

- The safety of having MRI of your brain or body depends on the type of DBS system you have and the MRI services. This chart is a general guide.

DBS Manufacturer	Head MRI	Rest of the body MRI
Medtronic – Old systems	Only allowed at Toronto Western Hospital	Not allowed
Medtronic – New systems	Allowed in any radiologic service but with restrictions	Allowed in any radiologic service but with restrictions
Boston Scientific	Not allowed	Not allowed
St. Jude Medical	Not allowed	Not allowed

Check with your doctor or the manufacturer of your device before having other medical procedures

- Most medical procedures are safe (such as a CT scan or x-rays), but some need extra precautions, and others are not possible because they could cause serious harm or death.



Frequently asked questions by patients about their DBS

Can I use household electrical appliances if I have DBS?

Yes. Using everyday electrical and electronic devices does not affect how your IPG works.

Will I feel the electricity in my body when the IPG is working?

Some people might have a tingling feeling for a few seconds after the device is turned on, but this goes away within seconds.

Will my IPG activate metal detectors at the airport?

Yes, it will set off the alarm and the security equipment may turn the neurostimulator off. Most airport security personnel will let you bypass the metal detector. You can show your medical card to them.

What if I need electrical shock for resuscitation?

If you need heart resuscitation, it should be done. The most common result is that the IPG might break and will need to be replaced.

What happens if I need a heart pacemaker?

You can have both a DBS system and a heart pacemaker. Both devices can work without interfering with each other. Tell any surgeon that you carry a DBS system.

Where to get more information

If you have any questions, please ask a member of your health care team during your appointments or give us a call.

Neurologists	Dr. Fasano Dr. Munhoz	416 603 5800 Ext. 5729
Neurosurgeons	Dr. Lozano Dr. Hodaie Dr. Kalia	416 603 6200 416 603 6441 416 603 5866
DBS Nursing Team	Alex Valencia, Nurse Practitioner	416 603 5800 Ext. 2356
DBS Administrative Staff	Cecilia Miraldo	416 603 5800 Ext. 5729
DBS Front Desk	Anna Robitaille	416 603 5800 Ext. 5729

For technical questions about your DBS or about medical procedures, you or your doctors can also call the customer service of the manufacturer of your device.

Important: This is not a full list of vendors. The University Health Network does not recommend one company or person over another and is not responsible for the care and services provided. Please contact the vendors directly to make sure the information is correct or to find out more about their products.

Reviewed by UHN Patient Education & Engagement



Have feedback about this document?

Please fill out our survey. Use this link: surveymonkey.com/r/uhn-pe

Visit www.uhnpatienteducation.ca for more health information. Contact pfep@uhn.ca to request this brochure in a different format, such as large print or electronic formats.

© 2021 University Health Network. All rights reserved. Use this material for your information only. It does not replace advice from your doctor or other health care professional. Do not use this information for diagnosis or treatment. Ask your health care provider for advice about a specific medical condition. You may print 1 copy of this brochure for non-commercial and personal use only.