Using Surgery to Treat Tremor

Reading this guide can help you learn about the various ways to treat tremor.

Your health care team will talk with you about the risks and benefits of all the treatments and decide with you which treatment is right for you.

Inside this guide

Learning About Neurosurgery for Tremor .............................................. 3
Deciding if Tremor Surgery is Right for You ............................................ 13
Preparing for Surgery ........................................................................ 17
Your Hospital Stay and Tremor Surgery................................................. 18
What to Watch For .............................................................................. 26
Programming Your DBS ..................................................................... 27
Living with Your DBS System.............................................................. 28
Frequently Asked Questions About DBS.............................................. 32
Where to Get More Information........................................................... 33
Learning About Neurosurgery for Tremor

Which conditions are treated with neurosurgery?
Essential tremor is a common movement disorder. It’s a condition that usually affects the arms and hands by causing involuntary shaking. It can also affect the head, jaw, tongue and legs. Essential Tremor is commonly treated with neurosurgery, although other types of tremor can also benefit from surgery depending on how serious the tremor is and what has caused it.

This guide will focus on Essential Tremor or “ET”.

When should surgery be used to treat tremor?
Neurosurgery may be an option when the tremor is serious enough that you have trouble doing your everyday activities such as eating and dressing, and when medications are not working effectively.

At this time there are few surgical options to treat tremor. We will explain them in this guide.

What are the main surgical brain target areas for tremor?
The target area for all tremor surgeries is a small brain structure involved in making the tremor called ventral intermediate nucleus or VIM for short. VIM is part of a larger brain structure called the thalamus.
Your health care team will:

• Discuss with you the various surgical options, and
• Decide with you which approach is the best for your condition

There are 2 options for surgery: non-invasive and invasive.

1. **Non-invasive surgery**

This is surgery done without cutting your skin (or skull).

There are 2 types of non-invasive surgeries:

• Gamma Knife Radiofrequency (GKRS) Thalamotomy, or
• MR-Guided Focused Ultrasound (MRgFUS) Thalamotomy

With these surgeries, the surgeon uses radiation (GKRS) or ultrasound waves (MRg-FUS) to burn and destroy the cells causing tremor.
2. Invasive surgery

This option involves cutting the skin, drilling a hole in the skull and passing electrodes through the brain.

There are 2 types of invasive surgery that can be done to treat tremor:
- Radio-frequency Thalamotomy, or
- Deep Brain Stimulation

- Gamma Knife Radiofrequency (GKRS) Thalamotomy

<table>
<thead>
<tr>
<th>Gamma Knife Radiofrequency Thalamotomy</th>
<th>Possible side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>GKRS sends focused radiation through the skull to make a permanent lesion in a brain part known to contribute to tremor.</td>
<td>• Tremor may come back over time</td>
</tr>
<tr>
<td>Features of GKRS:</td>
<td>• Tingling feeling in parts of the body</td>
</tr>
<tr>
<td>• Non-invasive (no cut or hole is made in the skull)</td>
<td>• Speech problems (trouble saying words)</td>
</tr>
<tr>
<td>• Uses radiation</td>
<td>• Dizziness, unsteadiness, lightheadedness</td>
</tr>
<tr>
<td>• No general anesthesia needed</td>
<td>• Change in how food tastes</td>
</tr>
<tr>
<td>• Irreversible (there is a permanent lesion)</td>
<td>• Weakness in the muscles of the face and limbs or partial paralysis</td>
</tr>
<tr>
<td>• Only one side can be treated</td>
<td>• Less coordinated</td>
</tr>
<tr>
<td>• You do not carry any device in your body</td>
<td>Some of these side effects can be permanent and even get worse over time.</td>
</tr>
<tr>
<td>• You may notice tremor improvement only weeks or months after the procedure</td>
<td></td>
</tr>
<tr>
<td>• Rarely done expect for certain patients (such as patients who cannot stop taking a blood thinner)</td>
<td></td>
</tr>
</tbody>
</table>
MR-Guided Focused Ultrasound (MRgFUS) Thalamotomy

<table>
<thead>
<tr>
<th>MR-Guided Focused Ultrasound thalamotomy</th>
<th>Possible side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>MRgFUS Thalamotomy sends ultrasound waves through the skull to make a permanent lesion a brain part known to contribute to tremor.</td>
<td>• Pain such as a transient (passing) burning sensation over the scalp</td>
</tr>
<tr>
<td>Features of MRgFUS:</td>
<td>• Tremor may come back over time</td>
</tr>
<tr>
<td>• Non-invasive (no cut or hole is made in the skull)</td>
<td>• Tingling feeling</td>
</tr>
<tr>
<td>• No radiation</td>
<td>• Speech problems (trouble saying words)</td>
</tr>
<tr>
<td>• No general anesthesia needed</td>
<td>• Dizziness, unsteadiness, lightheadedness</td>
</tr>
<tr>
<td>• Real-time MRI image guidance</td>
<td>• Change in how food tastes</td>
</tr>
<tr>
<td>• Irreversible (lesion is permanent)</td>
<td>• Weakness in the muscles of the face and limbs or partial paralysis</td>
</tr>
<tr>
<td>• Only one side can be treated</td>
<td>• Less coordinated</td>
</tr>
<tr>
<td>• Not possible in patients who cannot have an MRI</td>
<td>Often these side effects go away over time. Some can be permanent with or without some improvement over time.</td>
</tr>
<tr>
<td>• Not possible for patients with a certain thickness of skull</td>
<td></td>
</tr>
<tr>
<td>• Not a procedure that is done often worldwide</td>
<td></td>
</tr>
</tbody>
</table>

We do not know how long the tremor control lasts.
### Radiofrequency Thalamotomy (RF)

<table>
<thead>
<tr>
<th>Radiofrequency Thalamotomy</th>
<th>Possible side effects</th>
</tr>
</thead>
</table>
| The surgeon inserts a probe into the VIM brain region of the thalamus. The heat at the tip of the probe damages the cells hence stopping tremor. Features of RF:  
- Requires passage of a probe through the brain tissue (skin incision, drilling)  
- No general anesthesia needed  
- Irreversible (there is a permanent lesion)  
- Only one side can be treated  
- Patients do not carry any device in their body  
- RF is a well known treatment that has been done worldwide since the 1950s.  
| Tremor may come back over time  
- Tingling feeling in parts of the body  
- Speech problems (trouble saying words)  
- Dizziness, unsteadiness lightheadedness  
- Change in how food tastes  
- Weak muscles in the face and limbs or partial paralysis  
- Less coordinated  
- Stroke/bleeding  
- Infection  

The effect on the symptoms is due to the permanent lesion made.
## Deep Brain Stimulation (DBS)

<table>
<thead>
<tr>
<th>Deep Brain Stimulation</th>
<th>Possible side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>DBS uses mild electrical impulses to stimulate an area deep in the brain that controls tremor. The stimulation changes the activity of the brain cells in a way that helps relieve the tremor.</td>
<td>• Tingling sensation</td>
</tr>
<tr>
<td>The electrical stimulation comes from a DBS system, which is implanted in the body during surgery. Features of DBS:</td>
<td>• Speech problems (trouble saying words)</td>
</tr>
<tr>
<td>• Highly effective at controlling tremor</td>
<td>• Dizziness, unsteadiness, lightheadedness</td>
</tr>
<tr>
<td>• The most common procedure for tremor worldwide</td>
<td>• Change in how food tastes</td>
</tr>
<tr>
<td>• Stimulation levels can be externally programmed and adjusted to minimize side effects and reduce tremor</td>
<td>• Weakness or partial paralysis in the face or limb muscles</td>
</tr>
<tr>
<td>• Invasive (an incision is made on head and chest)</td>
<td>• Less coordinated</td>
</tr>
<tr>
<td>• Invasive (an incision is made on head and chest)</td>
<td>• Some of these side effects can be stimulation-induced (can be controlled or managed by adjusting the stimulation settings) or they can be a result of the surgical intervention</td>
</tr>
<tr>
<td>• Hardware is implanted inside the body</td>
<td>• Infection</td>
</tr>
<tr>
<td>• General anesthesia is needed to insert the battery in the chest</td>
<td>• Stroke</td>
</tr>
<tr>
<td>• Battery needs to be replaced (every 4 to 7 years)</td>
<td>• Tremor may return over time, but can be controlled or managed by adjusting the stimulation settings. However, in some cases these adjustments are not enough to guarantee a satisfactory tremor control.</td>
</tr>
<tr>
<td>• Only one side at the time is usually treated but bilateral procedures (often staged) are possible</td>
<td>• Long term benefit: DBS has been proven to be effective and safe for the treatment of tremor</td>
</tr>
</tbody>
</table>
### Comparing surgeries

<table>
<thead>
<tr>
<th></th>
<th>Thalamotomy</th>
<th>DBS</th>
<th>Gamma Knife</th>
<th>Focus Ultrasound</th>
</tr>
</thead>
<tbody>
<tr>
<td>How long have surgeons been doing this procedure worldwide?</td>
<td>Over 70 years</td>
<td>Over 30 years</td>
<td>Over 15 years</td>
<td>7 years</td>
</tr>
<tr>
<td>Is a bilateral procedure possible?</td>
<td>✗ No</td>
<td>✓ Yes</td>
<td>✗ No</td>
<td>✗ No</td>
</tr>
<tr>
<td>Uses general anesthesia?</td>
<td>✗ No</td>
<td>✓ Yes</td>
<td>✗ No</td>
<td>✗ No</td>
</tr>
<tr>
<td>When will I see tremor improve?</td>
<td>Immediately</td>
<td>Delayed until the device is programmed</td>
<td>Delayed – up to 1 year</td>
<td>Immediately</td>
</tr>
<tr>
<td>Is there a permanent lesion?</td>
<td>Yes</td>
<td>✗ No</td>
<td>✓ Yes</td>
<td>✓ Yes</td>
</tr>
<tr>
<td>Do I need for multiple visits?</td>
<td>✗ No</td>
<td>✓ Yes</td>
<td>✗ No</td>
<td>✗ No</td>
</tr>
<tr>
<td>Reversible, or changes are possible over time?</td>
<td>✗ No</td>
<td>✓ Yes</td>
<td>✗ No</td>
<td>✗ No</td>
</tr>
</tbody>
</table>

These treatments do not change the progression of the disease, but they can help relieve tremor and improve your quality of life.
How does DBS work?

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

The parts of the DBS system

**Electrodes**
- Very thin wires placed deep inside your brain.
- The tip of each electrode is positioned in a specific part of your brain (VIM or Thalamus) that is affected by tremor.
- More rarely, other brain structures are targeted to improve certain tremors or certain features of tremor.

**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 put 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 delivers 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.

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 to treat the side of the body that is most affected

• An electrode is placed on one side of the brain to help tremor on the opposite side of the body. For example: The electrode will be placed into the left hemisphere to treat right hand tremor.

• 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.

• The patient may have the second side operated at least 6 months (usually 12 months) after the first surgery.

• Bilateral surgery is needed to improve tremor affecting both sides of the body and mid-line tremors (tremors of the head, face and voice)

Having one side of the brain operated on at a time lowers the chances of having problems after surgery such as speech and balance problems.
What are the steps in DBS surgery?

Step 1

• The electrode is 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 Tremor Surgery is Right for You

Each person with tremor is unique and surgery cannot help all of them. Your health care team will help you decide if surgery 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.

The screening assessments you have will depend on the reason for your 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 with 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 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 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 tremor 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 surgery 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 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 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 surgery

If you have a fear of closed spaces (claustrophobia) or cannot hold still because of your health problems (such as a head tremor), tell your neurosurgeon before the date of your surgery.
Preparing for 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 Tremor Surgery

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

What happens on the day of the surgery?
Do not take any tremor medications.

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. If you are having a Focused Ultrasound Thalamotomy,

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 or CT scan. These tests create detailed images of your brain that help your neurosurgeon identify the area of the brain that needs to be operated and 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 the treatment

If you are having Focus Ultrasound Thalamotomy:

- When everything is ready, you lie down in the MRI machine and a frame is attached to a helmet-like device. This contains the MRgFUS machine.

- As you are having the treatment, the neurosurgeon watches and communicates with you from the next room and communicating.

- You will have several MRI scans to confirm the location of the targeted radiation and the ultrasound lesion.

- The procedure lasts about 4 hours. You will not be able to leave the MRI machine or get up during that time.

- When the procedure is done, the frame is removed, and you are transferred to the neurosurgical unit where you will be watched closely overnight.

If you are having Gamma Knife Radiofrequency (GKRS) Thalamotomy:

When everything is ready, you will lie down on your back on the treatment bed. Your head frame is attached to the table to keep your head still. The radiation therapists will leave the treatment room during your treatment. They can see you on the video cameras and talk to you if they need to.
During treatment, you will not feel the radiation. There is also no noise from the treatment unit. The treatment can take several hours to finish. You may move in and out of the treatment unit several times during your treatment. You will need to stay still during your treatment.

When the procedure is done, the frame is removed and you will be observed for one hour before you can go home.

**If you are having Thalamotomy or DBS 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 Electrode**

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. Your answers help the neurosurgeon confirm the right placement of the electrode. 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).
- Put in the electrode so the tip is in the proper area of your brain.
- Stimulate the electrode and measure how your brain cells react.
- Ask you what or how you feel and whether you feel things like tingling or numbness.
- Check your tremor to make sure the proper areas of your brain are stimulated.
If you are having a Thalamotomy:

- The neurosurgeon will deliver current to burn the area of the brain causing tremor and the electrode will be removed. Then the opening to your skull will be closed and secured with staples.

If you are having DBS:

- The neurosurgeon will use plastic caps to close the holes and make sure the electrode stays in place, and then close the incision with staples.
- The neurosurgeon then removes the frame from your head.

**Step 1 takes 4 to 6 hours depending on the complexity of the surgery.**

Please note!

Some patients have step 1 and 2 done together.
Other patients have Step 1 and 2 done separately, two or three days apart. If you are having Step 2 done later, the end of your electrodes will be left outside of your head and covered by a bandage.

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 neurosurgeon 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 Thalamotomy or DBS 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 electrode.

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.
**Going home after tremor surgery**

You can expect to go home 1 or 2 days after your surgery is completed, except patients having GKRS who can go home the same day.

Before you leave the hospital, we will:

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

**On the day you go home, please arrange to be picked up before 11 am.**

**Recovering at Home**

At home, your medications will remain the same until you see your neurologist.

If you had Focus Ultrasound or Thalamothomy, you will probably see lasting improvements in your tremor. However, if you have DBS surgery, your tremor may improve but the changes may not last. It’s normal for your tremor to improve once the stimulation starts a few weeks after surgery.

If you had GKRS, you might not notice tremor improvement for weeks or months after the procedure.

**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 last surgery. 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

• If you had DBS surgery and a device implanted in your chest, 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 DBS 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:

<table>
<thead>
<tr>
<th>Signs of infection</th>
<th>What to do</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Redness or swelling at your incision site that is getting worse</td>
<td>If you notice <strong>any</strong> of these signs or symptoms please tell your neurosurgeon, nurse coordinator or nurse practitioner as soon as possible.</td>
</tr>
<tr>
<td>• Leaking (for example with yellow or green-like pus) from your incision</td>
<td></td>
</tr>
<tr>
<td>• Bleeding from your incision</td>
<td></td>
</tr>
<tr>
<td>• Pain at your incision site that does not go away</td>
<td></td>
</tr>
<tr>
<td>• Fever, a temperature over 38 °Celsius (or 101 °Fahrenheit)</td>
<td></td>
</tr>
</tbody>
</table>

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 tremor all day.

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 1 to 3 more visits to program your stimulator to the best setting.

• 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.

Keep taking your tremor medications without discontinuing them before you see your neurologist, unless you are given other instructions.
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 and adjusting your medications takes time. The result will be the best relief of tremor with the least side effects.

Living with Your DBS System

What follow-up care will I need?

<table>
<thead>
<tr>
<th>Family doctor</th>
<th>Make an appointment with your family doctor to have your staples removed 10 to 14 days after surgery.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurosurgeon</td>
<td>You will see your neurosurgeon 6 to 8 weeks after your surgery. They will check your condition and incisions.</td>
</tr>
<tr>
<td>Neurology team</td>
<td>After your IPG is programmed to the best setting, you will have follow-up visits with the neurology team every 6 to 12 months.</td>
</tr>
<tr>
<td>Video Assessments</td>
<td>You may have video-taped assessments of your symptoms at 1, 3, 5 and 10 years after surgery to monitor your tremor and response to brain stimulation over time.</td>
</tr>
<tr>
<td>Neuropsychiatrist</td>
<td>You may have follow-up visits to make sure there are no concerns about your mental health after surgery.</td>
</tr>
<tr>
<td>Brain MRI</td>
<td>You may have more brain imaging during your recovery and follow-up care.</td>
</tr>
</tbody>
</table>

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 4 to 7 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.
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.

<table>
<thead>
<tr>
<th>DBS Manufacturer</th>
<th>Head MRI</th>
<th>Rest of the body MRI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medtronic – Old systems</td>
<td>Only allowed at Toronto Western Hospital</td>
<td>Not allowed</td>
</tr>
<tr>
<td>Medtronic – New systems</td>
<td>Allowed in any radiologic service but with restrictions</td>
<td>Allowed in any radiologic service but with restrictions</td>
</tr>
<tr>
<td>Boston Scientific – non rechargeable battery</td>
<td>Only allowed at Toronto Western Hospital</td>
<td>Not allowed</td>
</tr>
<tr>
<td>Boston Scientific – non rechargeable battery</td>
<td>Allowed in any radiologic service but with restrictions</td>
<td>Allowed in any radiologic service but with restrictions</td>
</tr>
<tr>
<td>St. Jude Medical-Abbott</td>
<td>Not allowed</td>
<td>Not allowed</td>
</tr>
</tbody>
</table>
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.

<table>
<thead>
<tr>
<th>Neurologists</th>
<th>Dr. Fasano</th>
<th>416 603 5800 Ext. 5729</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Dr. Munhoz</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Neurosurgeons</th>
<th>Dr. Lozano</th>
<th>416 603 6200</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Dr. Hodaie</td>
<td>416 603 6441</td>
</tr>
<tr>
<td></td>
<td>Dr. Kalia</td>
<td>416 603 5866</td>
</tr>
</tbody>
</table>

| DBS Nursing Team | Alex Valencia, Nurse Practitioner | 416 603 5800 Ext. 2356 |
|                 | Melanie Fallis, Nurse Coordinator |                        |
|                 | James Holder, Nurse Coordinator   |                        |

| DBS Administrative Staff | Cecilia Miraldo | 416 603 5800 Ext. 5729 |
|                         | Anna Robitaille |                        |
|                         | Prasha Sasitharakumar |                    |

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 resource does not include a full list of vendors. The University Health Network does not recommend one company or person over another and is not responsible for the products, 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

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.

© 2022 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.