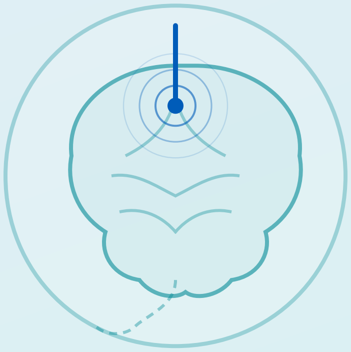


Deep Brain Stimulation (DBS) in Movement Disorders

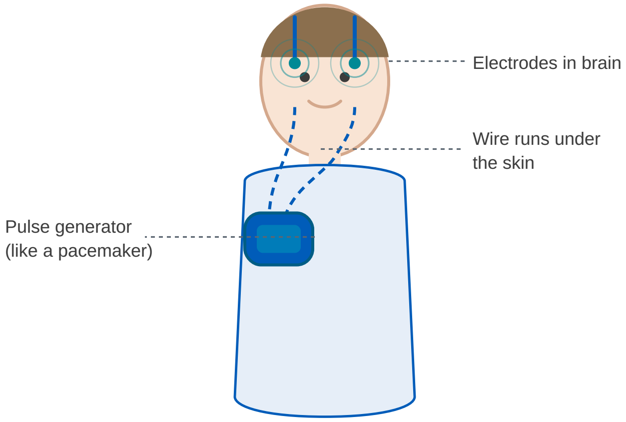
Patient Information Brochure

Movement Disorders Program
University of Calgary, Calgary, Alberta, Canada

? What Is Deep Brain Stimulation?

Deep brain stimulation (DBS) is an advanced treatment for certain movement disorders and other brain conditions. It is used when symptoms are not well controlled by medications alone.

During DBS, doctors place thin wires called **electrodes** into specific areas of the brain. These electrodes send small electrical signals that change how the brain works in those areas, helping to control symptoms.



How the DBS system works inside the body

The electrical signals come from a small device called a **pulse generator**, which is similar to a heart pacemaker. It is placed under the skin near the collarbone in the upper chest and contains the battery that powers the system. A wire runs under the skin from the pulse generator up to the electrodes in the brain.

Conditions Treated with DBS

Most commonly used for:

- **Parkinson's disease**
- **Dystonia** — involuntary muscle contractions
- **Essential tremor** — uncontrollable shaking

Also used for:

- Tourette syndrome
- Obsessive-compulsive disorder (OCD)
- Epilepsy

> **Research is ongoing:** Scientists are studying whether DBS could also help treat Huntington's disease, chronic pain, cluster headaches, depression, and other conditions.

DBS for Parkinson's Disease

In the early years of Parkinson's disease (PD), medications usually work well throughout the day. However, as the disease progresses, patients may develop what doctors call **"motor complications."**

> **Understanding ON and OFF periods:** When medication is working, you are in an **"ON" period**. When it stops working before the next dose, symptoms like tremor, slowness, and difficulty walking may return — this is an **"OFF" period**, also called **"wearing off."**

Patients may also develop involuntary movements called **dyskinesias** — twisting and turning motions that can be uncomfortable and hard to control. Your doctor can adjust medication doses and timing, but when those adjustments are no longer enough, DBS may be an option.

Are You a Good Candidate?

DBS may be right for you if:

- You still get good benefit from medication during ON periods
- You have troublesome OFF periods and/or dyskinesias not controlled by medication changes
- You have good support from family or caregivers
- You have had PD for at least four years

DBS may not be recommended if you have:

- Significant problems with memory or thinking
- Serious psychiatric conditions
- Major balance problems when walking, even when medications are working

What Results Can You Expect?

DBS does not cure Parkinson's disease, but it can significantly reduce symptoms. Many patients notice clear improvement, though symptoms usually do not go away completely. You will likely still need some medications.

Symptoms that often improve:

- Less time in OFF periods
- Reduced dyskinesias
- Medication doses may be adjusted — but changes should only be made with your doctor's guidance
- Pain and sleep problems
- Better quality of life
- Overall, many patients experience a meaningful improvement in motor symptoms and daily function

Symptoms that typically do not improve:

- Walking problems not helped by levodopa
- Balance difficulties
- Speech or swallowing problems
- Memory or thinking changes
- Mood, bladder, bowel, or sexual issues

Is There an Age Limit?

There is no strict age cut-off. However, special consideration is given to patients aged 70 or older, as they may not respond as favourably. Your symptoms, levodopa response, mood, thinking abilities, and other health conditions are generally more important than age alone.

What Are the Possible Risks?

DBS is generally considered a low-risk procedure. However, like any surgery, complications can occur. These can be related to the surgery itself, the device, or the electrical stimulation.

Surgical and Device Risks

Bleeding in the brain — while this is the most worrisome complication, it is very rare. Large bleeds causing significant stroke, cognitive changes, or death are exceedingly rare.

Infection — infection is a risk of any operation but is generally uncommon in DBS due to the use of sterile surgical techniques and antibiotics given around the time of surgery. If it does occur, it tends to happen at the pulse generator in the chest, usually weeks or months after surgery. Infection is treated with antibiotics and may sometimes require removal of the device. Not all patients are able to have a replacement device placed. It is exceedingly rare for infection to occur in the brain itself.

Hardware and lead issues — like any implanted medical device, DBS components may require surgical repair if there is breakage or other hardware-related issues. There is also a small risk of lead malposition resulting in sub-optimal performance. Overall, the chance of revision surgery is very low.

Anesthetic risks — all surgeries carry risk of medical complications, such as problems with the heart, lungs, or other body systems. Overall, these risks are very low for most people.

Possible Side Effects from Stimulation

Some patients may experience side effects from the electrical stimulation itself. These can often be improved by adjusting settings:

- Numbness or tingling
- Muscle tightness in face or arm
- Speech difficulties
- Balance problems
- Light-headedness or dizziness
- Vision changes (e.g., double vision)
- Mood changes (irritability, elevated mood, or low mood)

How Are Patients Evaluated?

Because DBS is a major procedure, the risks and potential benefits are carefully discussed with your DBS team. Before surgery, you will need medical tests and up-to-date brain imaging (such as an MRI) to plan the procedure.

You will be evaluated by a team of specialists. This typically includes:

- Assessment by a **neurologist** specializing in movement disorders
- Detailed evaluation of **memory and thinking** by a neuropsychologist
- Assessment with **neuropsychiatry** to evaluate mood and mental health status might be recommended
- Assessment by a **DBS specialist nurse**, both while OFF and ON medications — this is important because the best predictor of response to DBS is how well you respond to levodopa
- A **brain scan** (MRI or CT) to check for any changes that might prevent surgery
- Consultation with the **neurosurgeon** who performs the surgery

What Happens During the Procedure?

Part 1: Brain Surgery

Local anesthetic and sometimes sedative medications are used throughout the surgery so that you are comfortable and do not feel pain.

First, the surgical team places a metal frame on your head. This frame is shaped like a ring and keeps your head perfectly still during the procedure. A brain CT or MRI scan is then done to create a detailed map of your brain so the surgeon can locate the exact area where the electrodes should go.

Small openings are then made in the skin and skull so that the wires ("leads") can be placed into the brain. Electrical recordings are sometimes taken from the brain to help position the leads. Once the leads are in place, they will be tested by your DBS nurse. Once stimulation is deemed adequate, the second stage of the surgery can begin.

Part 2: Chest Surgery

This second stage can be done immediately following the first stage, or on a separate day. It is done under general anesthesia (you will be fully asleep). The surgeon will thread the wires from the brain under the skin in the neck to a generator placed on the chest just below the collarbone.

After the Procedure

Some patients may notice an initial improvement in symptoms shortly after the electrodes are placed, even before the stimulator is turned on. This is sometimes called a "microlesion effect" and is usually temporary.

A few weeks after surgery, the pulse generator is turned on at your doctor's office. The stimulation is adjusted to suit your needs — it may take **4 to 6 months** to find the best settings. You will receive a remote control to turn stimulation on and off at home. The battery will eventually need replacing in a short outpatient procedure.

DBS for Dystonia

DBS is a well-established treatment for several forms of **dystonia** — a condition in which muscles contract involuntarily, causing abnormal postures or repetitive movements. The surgical procedure and device are the same as described earlier, but there are important differences in patient selection, expectations, and timing of improvement.

> **Key difference from Parkinson's:** The response to DBS in dystonia is usually **gradual**. It can take months to see the full benefit. Careful patient selection and realistic expectations are especially important.

When Is DBS Considered for Dystonia?

DBS may be an option when dystonia remains disabling despite trying medications, botulinum toxin injections (when appropriate), and other supportive treatments. Types that may benefit include:

- **Cervical dystonia** — severe abnormal head posture or significant neck pain
- **Generalized dystonia** — affecting many parts of the body, particularly primary (genetic) forms
- **Segmental dystonia** — affecting two or more neighbouring body regions
- **Tardive dystonia** — caused by previous use of certain psychiatric medications

How Much Improvement Can You Expect?

The degree of improvement depends on the type of dystonia and individual factors. But in general, aiming for a **50% improvement** in motor symptoms is a reasonable goal in most cases.

When pain is present, it often improves earlier and more consistently than the abnormal movements or postures.

Patients with primary or genetic dystonia tend to respond better than those whose dystonia was caused by brain injury. However, tardive dystonia is a notable exception — it often responds well.

Timeline for Improvement

- **First few weeks** — Initial changes may be subtle
- **1 – 3 months** — Meaningful improvement usually begins
- **6 – 12+ months** — Maximum benefit (ongoing programming adjustments are critical)

> **Be patient:** A lack of immediate improvement does *not* mean the treatment has failed. DBS for dystonia requires patience and close follow-up with your care team.

DBS for Essential Tremor

DBS is a highly effective treatment for **essential tremor** — a condition that causes uncontrollable shaking, most often in the hands, that worsens during movement. The surgical procedure is the same, but there are important differences in candidacy, brain target, and speed of improvement.

When Is DBS Considered?

DBS may be an option if:

- Your tremor causes significant difficulty with daily activities such as writing, eating, or drinking
- Medications such as propranolol, primidone, or topiramate have not worked well enough or cause side effects you cannot tolerate

DBS is most effective for **postural tremor** (shaking while holding a position) and **action tremor** (shaking during movement) in the hands. It is less effective for tremor in the face, head/neck, and lower limbs.

> **Other treatment options:** For some patients with essential tremor, focused ultrasound thalamotomy may be an alternative to DBS. Your neurologist can discuss whether DBS or focused ultrasound is more appropriate for your situation.

One Side or Both?

In most cases, patients are satisfied with DBS on only one side of the brain, as this is enough to control tremor in the dominant hand. DBS on both sides may be considered for patients with severe tremor in both hands, though it carries a higher risk of side effects such as speech or balance difficulties.

How Much Improvement Can You Expect?

70–90%	Significant
Tremor reduction in the treated hand	Improvement in handwriting, eating & daily tasks

Benefits typically last for many years, although the disease may progress in untreated areas. Head and voice tremor may also improve, but results are more variable.

Timeline for Improvement

> **Unlike dystonia, the response is fast:** Improvement is often noticeable **right away** once stimulation is turned on. Programming adjustments over the following weeks and months help optimize results. Improvements in daily activities are usually seen early after the device is activated.

At a Glance: How DBS Differs by Condition

Feature	Parkinson's	Dystonia	Essential Tremor
Brain target	STN or GPi	GPi	VIM
Speed of response	Days to weeks	Months (6–12+)	Immediate
Typical improvement	Reduced OFF time & dyskinesias	Marked improvement of shakes and muscle pulling	Marked tremor reduction
Bilateral DBS	Usually yes	Usually yes	Often one side

Living with DBS

Once fully recovered, you can return to most regular activities. Many people feel more active because their symptoms are better controlled. Always speak with your care team if you have questions.

Daily Activities

Cell phones, computers, microwaves, and other electronics should not interfere with DBS. Metal detectors may alarm but rarely turn off your device. If symptoms suddenly return, check your device and turn it back on.

Exercise

Once your neurosurgeon gives the go-ahead, regular exercise is strongly encouraged. Avoid sudden, forceful, or repeated bending, twisting, or stretching that could damage the device.

Travel

Avoid walking through airport security scanners. Ask for manual screening instead. Always carry your device information card and programmer.

Medical & Dental Procedures

You can have most imaging including MRI (with specific settings and DBS in MRI mode). Turn DBS off before EEG or EKG tests.

Avoid:

- Diathermy (heat therapy to muscles)
- Transcranial magnetic stimulation
- Forceful head turning or neck twisting (massage/chiropractic)
- Hyperbaric chambers

Most dental care is fine, but your dentist may need to make slight adjustments. Always tell all healthcare providers about your DBS before any medical or dental procedure, and before trying any alternative or complementary therapy.

Other Activities

Scuba diving is not recommended for patients with DBS. Talk to your care team before starting any new activity you are unsure about.

Meet the DBS Team in Calgary

Our multidisciplinary DBS team at the University of Calgary is here to support you through every stage of your DBS journey.

All movement disorder neurologists from the University of Calgary team are active members of the DBS program and actively participate in the decision process for DBS candidacy. Your primary neurologist will continue to care for you after implantation and throughout your DBS programming.

Neurologist

Dr. Camila Aquino

Neuropsychiatrist

Dr. Angela Haffenden

Neuropsychologists

Dr. Brienne McLane
Dr. Kimberly Williams

DBS Nurses

Pia Lawrence
Wonny Suk

Functional Neurosurgeons

Dr. Fady Girgis
Dr. Zelma Kiss

Administrative Staff

Alyssa Steward

Key Points to Remember

- **DBS treats symptoms — it is not a cure.** The underlying condition will still be present.
- **Results depend on your diagnosis,** individual disease characteristics, and careful programming of the device.
- **Ongoing follow-up** and device management are essential for the best possible outcome.
- **Realistic expectations** and being part of the decision-making process are important for your satisfaction.
- **Your care team is here to support you** at every stage — from evaluation through surgery and long-term follow-up.

Disclosure: This information is educational only and does not replace any information given by your care team. Treatment benefits and adverse events may be variable. This document does not exhaust all the information on benefits and risks of DBS and should not be used as the main decision-making tool.

Questions? Talk to your DBS care team.

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