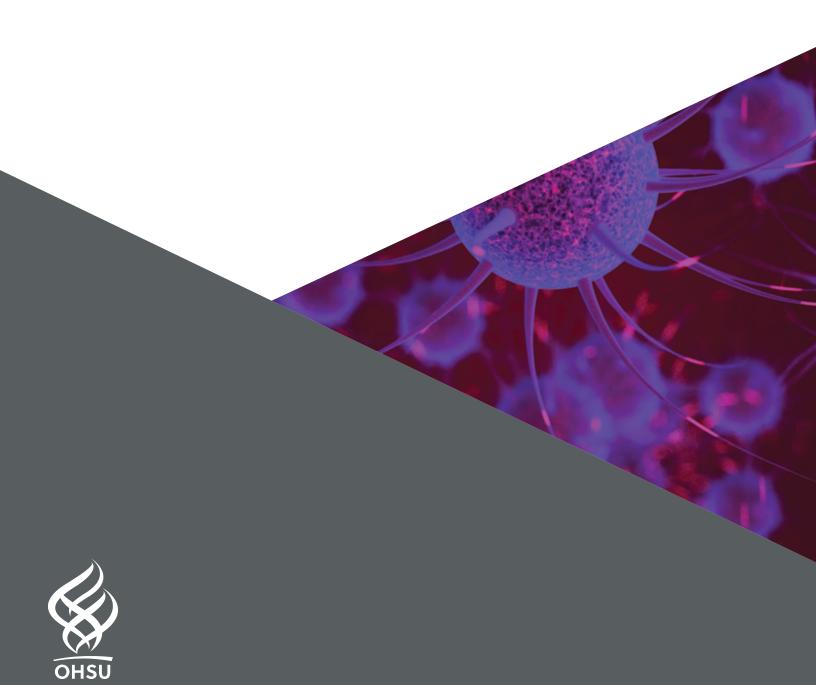
Deep Brain Stimulation for Parkinson's Disease





Introduction

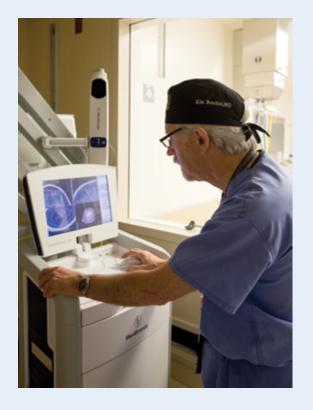
Welcome to OHSU's guide to deep brain stimulation surgery for patients with Parkinson's disease. For some patients with Parkinson's disease, DBS surgery offers life-changing relief.

DBS isn't for everyone, though. This guide explains the benefits and risks. It will also tell you how we learn if you are a good candidate.

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What is DBS?



DBS stands for deep brain stimulation. It comes from a small device that works like a pacemaker for the brain. Tiny leads, or electrodes, are placed in parts of your brain that control movement. The leads are connected by thin wires to a small device in the chest called an implanted pulse generator. The pulse generator sends steady, low-voltage electrical pulses to the leads. This stimulates those areas in your brain.

Researchers believe these pulses change the abnormal network of nerve signals in Parkinson's disease. Or the pulses may change the brain chemicals that cause tremors and other symptoms.

DBS involves two surgeries. In the first surgery, your doctor puts in:

• The leads: Your doctor places the tiny leads, or electrodes, in parts of the brain that control movement.

In the second surgery, your doctor puts in:

- The extensions: Your doctor puts thin wires called extensions under the skin of the shoulder, neck and head.
- The implanted pulse generator: Doctors also call this an IPG or stimulator. Your doctor places it under the skin, usually below your collarbone, then connects it to the extension wires.

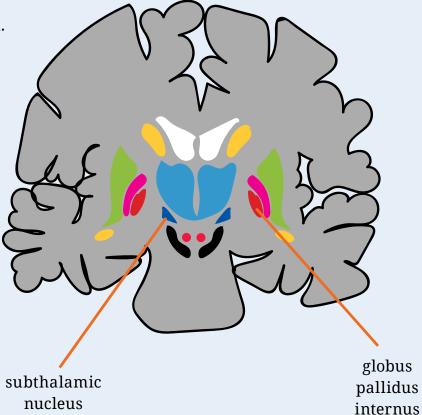
After surgery, your DBS team will adjust the stimulator settings. This is called programming. You may need several programming sessions to get the most relief. After that, you or your provider can use a programming device to adjust your stimulator or check the battery.

Most patients have leads on both sides of the brain, but sometimes they go on just one side. Your DBS team will decide on the best place based on your presurgery evaluation.

The leads go in one of two parts of the brain:

• The subthalamic nucleus, or STN.

• The globus pallidus internus, or GPi.





Meet our clinical leaders

OHSU's DBS team is one of the most experienced in the nation and has received international recognition for its pioneering research and treatment.



Kim J. Burchiel. M.D., FACS

Dr. Burchiel is one of the most experienced DBS surgeons in the United States. In 1991, he was the first doctor in the U.S. to successfully treat a Parkinson's patient with DBS surgery. In 2011, he introduced asleep DBS, making the surgery faster, safer and more precise.



Delaram Safarpour, M.D.

Dr. Safarpour is a movement disorders specialist and the medical director of the DBS program at OHSU, with a focus on improving patient care and satisfaction. She brings her experience in DBS candidate evaluations and programming from her training at University of Pennsylvania and Yale University.

Team approach

You will receive coordinated care from a team of specialists. These include experts in neurological surgery, neurology, physical therapy, speech therapy, neuropsychology and other areas. The team works together to give you the best treatment at every stage, from your first appointment to your care after surgery. Our specialists are experts in balance, gait, caring for older adults and other issues that are important for essential tremor. To learn more about our team members, visit www.ohsu.edu/dbs.

Research

OHSU doctors and researchers are continually improving treatment for movement disorders. We have published dozens of studies on DBS and hundreds on Parkinson's disease.

Screening

Our careful evaluation process makes sure you have DBS only if it is very likely to make a real difference. We offer other treatment options if DBS is not a good option for you.

Partnerships

Our nationally recognized OHSU Parkinson's Disease and Movement Disorders Program helps medical team members and scientists turn laboratory discoveries into treatments as quickly as possible.

- "All I can say to anyone thinking about DBS is this: It's not a cure, but it's the next best thing. Everyone may not have equal results, but for me, the results have been nothing short of miraculous. I love it. I wear my DBS with pride."
 - Thom, who had DBS surgery at OHSU

Our team

Neurological surgery



Kim J. Burchiel, M.D., FACS



Antonia Gragg, M.S., P.A.-C.



Ahmed M.T. Raslan, M.D.

Meet the entire DBS team, including our care coordinator, neurologic rehabilitation specialists and neuropsychologists at www.ohsu.edu/dbs.

Neurology



Shannon Anderson, M.P.A.S., P.A.-C.



Matthew A. Brodsky, M.D.



Kathryn A. Chung, M.D.



Amie Hiller, M.D.



Jeff A. Kraakevik, M.D.



Delaram Safarpour, M.D.

You don't have to be awake for DBS

Asleep DBS

OHSU only performs asleep DBS. In asleep DBS, you have surgery under general anesthesia. You are not aware of any part of the procedure. During your surgery, the doctor uses high-resolution scans to precisely place the tiny electrodes in the brain.

Asleep DBS is faster and safer and you can also take your Parkinson's disease medication on the day of surgery.

"My dad saw me
after surgery, and he
started crying and said
I moved and sounded
like I used to."

Colin Halstead, DBS patient at OHSU

Awake DBS

In awake DBS, you stay awake during surgery. You have medication to keep you comfortable, but you are aware of the procedure. This is because you must respond to questions and move to help the doctor place the DBS electrodes in the right part of your brain.

Many patients are anxious about being awake during brain surgery. You also can't take your Parkinson's disease medication on the day of surgery.



Why choose OHSU?

Dr. Kim Burchiel of OHSU was the first doctor in the United States to perform DBS to treat Parkinson's disease. No other medical center has OHSU's experience with this procedure. Our team has excellent results and uses the most advanced technology available.

- Experience: OHSU is a leading center for DBS surgery. Since 1991, our team has done more than 2,000 procedures.

 Recently, a study ranked OHSU in the top four DBS providers for all teaching hospitals in the United States.
- Excellence: The Journal of Neurosurgery published a study of 60 OHSU patients who had asleep DBS. The study found this procedure was more precise than awake DBS and had very low risk. OHSU patients also have few complications from surgery. A recent study showed that fewer than four of every 100 DBS patients needed to return to the hospital within 30 days of having DBS. That puts OHSU among the nation's best.
- Collaboration: Your regular doctor remains part of your health care team. We help your doctor track your care online.
 We also make sure your doctor can contact your OHSU specialists at any time.
- Convenience for patients outside Portland: We treat patients from all over the world. We go out of our way to make appointments and testing as convenient as possible.
- Nationally recognized program: OHSU's Parkinson's Disease and Movement Disorders Program has been named a Center of Excellence by the National Parkinson's Foundation. The center demonstrates OHSU's commitment to the most advanced patient care, research and education.



When should I consider DBS?

been able to reduce my medication eightfold. I feel like I have a new lease on life. I'm 53, with a lot of hope for the future. No more living in the recliner! I can get on the floor and play with my grandkids. That's made it all worth it."

- Bruce, DBS patient at OHSU

You can start to consider DBS any time after learning you have Parkinson's. Even if you are not ready now, you might want to have DBS in the future. Here are some guidelines for when DBS might be right for you:

- Your Parkinson's disease initially got better with levodopa.
- Your medication does not last as long as it once did, you need to take medication more often, your medications fail to kick in or wear off unexpectedly, or you need higher doses.
- You have side effects from your Parkinson's disease medications.
- You need several medications to control your Parkinson's disease symptoms.
- Your tremor has become disabling and unresponsive to medications.
- You know you have idiopathic, or classic, Parkinson's disease.

You are not a good candidate if:

- You do not have a clear diagnosis of Parkinson's disease.
- You have Parkinson's-plus symptoms, such as multiple system atrophy, progressive supranuclear palsy or vascular parkinsonism.
- You have certain brain conditions. These include ischemic brain disease, demyelinating brain disease or brain tumors.
- You have significant cognitive problems or dementia.
- You are not healthy enough for surgery.
- You are not doing well, even with medication.

"Ever since my DBS surgery, I'm not shaking anymore. I still take some medication, but a whole lot less. Also, the medications I do take are more effective — I can go much longer between doses."

Thom, DBS patient at OHSU

Benefits and risks of DBS

Benefits

- DBS can improve your quality of life by improving your motor function. You can regain the ability to do daily activities, such as getting dressed.
- DBS works 24 hours a day, so you can depend less on medication to control your symptoms. This can also ease the side effects from medication.
- Because DBS works all the time, you notice less when your medication takes effect or wears off.
- DBS is reversible. Your DBS team can turn off your stimulator. The system can be left in place or removed.
- DBS is adjustable. Your team can change the settings to make it more effective or to reduce side effects.
- Patients continue to receive benefit 15 or more years after implantation.

Symptoms DBS helps

DBS helps with the motor (movement) symptoms that levodopa helps, including:

- Uncontrolled movements called dyskinesias.
- Tremor.
- Slow movement, also called bradykinesia.
- Rigid muscles.

Symptoms DBS does not help

Non-motor symptoms of Parkinson's disease. These include:

- Constipation.
- Memory or thinking problems.
- Depression or anxiety.
- Swallowing problems.
- Balance problems.
- Sleep problems such as restless leg, sleep fragmentation, etc.

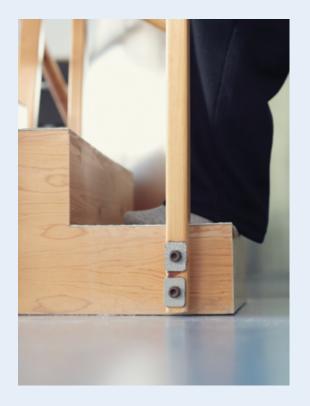
Surgical risks

DBS is safe and effective. But, like all surgeries, it has risks and possible side effects. Your DBS team will talk with you about the risks in detail. Some risks include:

- Infection.
- Bleeding in the brain.
- Stroke.
- Part of the DBS system breaking.
- The stimulator not working.

DBS is renewable. The battery lasts one to four years, and your DBS team can replace it with a minor, low-risk, outpatient surgery.

Your steps to DBS at OHSU



Your DBS journey for Parkinson's disease has five steps at OHSU. If you live outside Portland, Oregon, we go out of our way to schedule these appointments as conveniently as possible. Please bring a family member or caregiver to all your appointments.

Step 1 — Meet with a neurologist and neurological surgeon

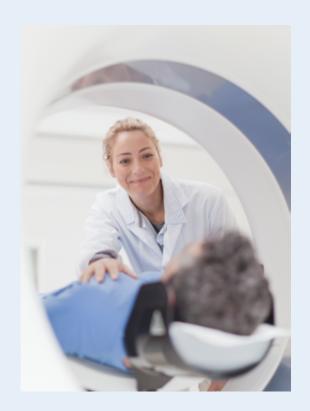
You'll meet with an OHSU movement-disorder-trained neurologist about candidacy and then a neurological surgeon. An interdisciplinary panel will then review your records. If you are not a good candidate for DBS, you will get recommendations for other treatments.

Step 2 — Meet with the rest of our DBS team

- Physical therapy: You will have two days of testing for your gait (movement when you walk), balance and response to levodopa. On the first day, you will not take your Parkinson's disease medications. On the second day, you will be taking your medications.
- Neuropsychology: We will check your memory and thinking. Please bring a caregiver to this appointment.
- Speech therapy: We will check how you speak. We will also talk with you about possible DBS side effects on speech and swallowing.

Step 3 - Presurgery appointments

- MRI: You will have a precise scan with OHSU's
 powerful 3-Tesla MRI unit. The images will allow
 your neurological surgeon to begin planning where
 to place the leads during surgery.
 - -This MRI is typically done without sedation. But please do not eat or drink before your appointment, in case you do need sedation or anesthesia. We will tell you how long to stop eating or drinking for, before the MRI.
 - If you do need sedation, you might need an extra day for this appointment.
 - Please bring a caregiver with you.
 - If you're in the Portland area, your MRI will be about two weeks before surgery. If you travel to Portland, it will be the day before surgery.
- Neurological surgery: You will sign surgical consent forms and can ask any questions. You and your family will also receive instructions for coming to the hospital on the day of surgery and for postsurgery care.
- **Presurgery physical examination:** This can often be done the day before surgery. We want to make sure you are healthy enough for surgery and anesthesia.



It is best to have a caregiver with you at home as you heal from surgery.

Step 4 - Surgery

Stage 1

- Arrival and anesthesia: You'll come to OHSU
 Hospital on the day of your surgery. The procedure
 will take two to three hours. In the operating suite,
 you'll be placed under general anesthesia. You will
 not be aware of anything during the procedure.
- CT scan: Your DBS team will position your head in a secure frame connected to a high-resolution CT scanner. The team will take a scan to match up with your high-resolution MRI images from before surgery. This will give your neurological surgeon the most accurate information possible for placing the leads.
- Placing the leads: Your neurological surgeon will
 make two small incisions. He or she will place the
 leads, then take another CT scan to make sure they're
 in the right place. You will spend the night in the
 OHSU Hospital and will most likely leave the next day.

Stage 2

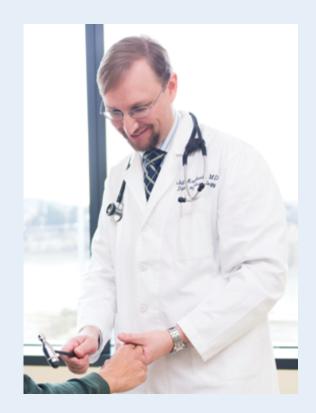
• Placing your stimulator: Through a small incision above your ear, your neurological surgeon and the team will connect extension leads under the skin from the ends of the DBS leads to the implanted pulse generator, placed under the skin below your collarbone. This is done in a second surgery two to 10 days



after the first surgery. This surgery takes about one hour. Your stimulator will not be programmed. You will leave OHSU the same day.

Step 5 — Programming and follow-up care

- Programming your stimulator: After your second surgery, a physician assistant, neurologist or both will program your stimulator. They will adjust the DBS settings with a small device called a programmer. You may need several programming sessions before you get the best symptom control. You will also receive a handheld programmer so you can check your stimulator's status and battery.
- Follow-up appointments: Patients are seen monthly until programming settings have been optimized. After optimization you will return to seeing your doctor every six months for continued Parkinson's disease care. You should have your stimulator battery checked once every six months by a DBS provider. Your settings may be adjusted as your disease progresses or as needed.





Safe surgery

Make sure to tell your DBS team about all your medications and health conditions. You must stop taking some medications one to two weeks before surgery. Talk to your main doctor or cardiologist before stopping. Medications you need to stop before DBS surgery include:

- Warfarin (brand name: Coumadin)
- Plavix
- Apixaban (Eliquis)
- Dabigatran (Pradaxa)
- Rivaroxaban (Xarelto)
- Cilostazol (Pletal)
- Ibuprofen (one brand name is Motrin)

- Indomethacin (Indocin)
- Naproxen (brand names include Naprosyn and Aleve)
- Ketoprofen (Orudis)
- Celecoxib (Celebrex)
- Aspirin or medications that contain aspirin
- Mesalamine (Canasa, Apriso)

What to expect after DBS

Maximum symptom control: It usually takes a few months and several adjustments to your stimulator to see the full benefit of DBS.

The honeymoon phase: Occasionally symptoms can improve temporarily after surgery. Doctors call this the microlesion or honeymoon effect. It can last days or weeks. Do not lower your medication doses without talking to your neurologist. Not everyone experiences a honeymoon phase. Many patients report no change in symptoms and some report a temporary worsening of symptoms. Stay in touch with your neurologist to ensure your experience meets your expectations.

Cost and insurance

The cost of DBS is different for each person. It depends on your insurance and other factors. The DBS team will help you learn the details.

Does Medicare cover DBS? Read the Medicare standards for DBS or call the number on your Medicare card to learn more. You must still pay deductibles, coinsurance and copayments.

What about other health insurance? Non-Medicare health insurance often covers DBS if you get approval before surgery. Your doctor's office usually has to get authorization from your insurance company prior to surgery. This often means your doctor writes a letter saying why you are a good candidate.



Visiting Portland

Portland offers many lodging options, excellent restaurants, superior mass transit and a generally mild climate. OHSU's DBS sites are centrally located and accessible by car, bus, light rail and the Portland Aerial Tram. Some helpful websites:

- Lodging and dining: Travel Portland at www.travelportland.com.
- Transit: TriMet (bus and light rail) at www.trimet.org.
- Tram: The Portland Aerial Tram at www.gobytram.com offers easy access between our sites at the South Waterfront and Marquam Hill. Free courtesy tickets are available for patients and their loved ones.

Visiting OHSU

Getting here and parking

We provide DBS services at two locations, depending on the appointment. These are OHSU Hospital on Marquam Hill and the Center for Health & Healing at the nearby South Waterfront campus. For directions and parking information, please visit www.ohsu.edu/parking.

Questions and answers about DBS

Is DBS a cure? No. DBS can make your quality of life much better. But it does not cure Parkinson's disease or keep it from getting worse over time.

Is DBS experimental? No. OHSU has been performing DBS since 1991. The procedure is FDA approved for treating patients with Parkinson's disease.

Will DBS make my Parkinson's disease symptoms go away? If you're a good candidate for DBS, you can expect it to significantly improve your symptoms. But it will not make them go away.

Will DBS keep me from doing certain activities? Talk to your neurologist about specific activities. After you recover from surgery, DBS should not keep you from regular activities such as swimming, bathing, sexual activity or sports.

Can I stop taking medication after DBS? No. Some patients can decrease the amount of medication they take under the guidance of their neurologists.

How long will the benefits of DBS last? This is different for everyone. For most patients, benefits last many years. A study published in JAMA Neurology in 2011 found that patients still had significant improvement 10 years after DBS.

I don't live near Portland, Oregon. Can I still consider OHSU? Absolutely. Our DBS team can work with patients from any area. We do everything we can to schedule multiple appointments on the same day to make it as convenient as possible.

Can I still see my regular neurologist? Yes. OHSU makes your regular health care provider a partner in your care through the entire DBS process.

Will I feel the electric pulses from my DBS? No. You will feel changes during programming appointments.

Should I turn off my stimulator at night? No. Parkinson's disease patients should keep their stimulator on all the time.

Can I control my DBS programming? Talk to your neurologist. Some patients have a controller that lets them adjust their DBS stimulator. The controller also lets them turn the stimulator on or off, or check the battery.

Will surgeons shave my head? Yes, shaving your entire head reduces the chance for infection, which is one of the most common complications of surgery. Our rate of DBS infection is among the lowest in the world.

Can I have DBS and a heart pacemaker? Yes. The devices need to be at least 10 inches apart. This might mean your DBS stimulator is placed in your right chest area instead of your left chest.

Where to learn more

At OHSU

To learn more about DBS at OHSU, visit www.ohsu.edu/dbs.

National

Find more at each site by entering DBS in the search field.

Parkinson's Disease Foundation:

www.pdf.org.

National Parkinson's Foundation:

www.parkinson.org.

National Institute of

Neurological Disorders and Stroke:

www.ninds.nih.gov.

The Parkinson Alliance:

www.parkinsonalliance.org.

Abbott:

www.abbott.com.

Boston Scientific:

www.bostonscientific.com.

Medtronic:

www.medtronic.com.

Find a support group: Call the Parkinson's Disease Foundation at 800-457-6676 or email info@pdf.org.



Parkinson's disease patient DBS surgery journey map

Each Parkinson's disease patient is unique, as is their treatment plan. The guide below provides a general idea of the journey a typical DBS patient might experience.



Diagnosed with idiopathic Parkinson's disease



Significant quality-of-life impact
Symptoms are no longer controlled adequately with medication



Consider deep brain stimulation (DBS) surgery as an option and discuss with your neurologist



DBS candidacy evaluation* (typically requires one to two days)

- ✓ Confirm idiopathic PD diagnosis
- ✓ Cognitive function testing
- ✓ Physical therapy: motor testing while on medication (ex., Sinemet, L-dopa) and off medication
- ✓ Speech and/or swallowing evaluation
- ✓ Additional factors considered: comorbidities, age, degree of disability

^{*}Some or all of these appointments may need to occur at OHSU with a movement disorders neurologist or neurological surgeon, if unable to be provided by your referring provider.



DBS surgery at OHSU

Before surgery

Preoperative visits with neurological surgery Receive medical clearance for procedure Brain imaging (under anesthesia if needed)

Stage 1 DBS surgery

Inpatient surgery
Discharged the following day

Stage 2 IPG implant surgery

Takes place within 10 days of Stage 1 surgery Outpatient surgery Discharged the same day

After surgery

Within 1 month of Stage 2 surgery: Programming with OHSU or local neurologist



Follow-up appointments*

- ✓ Post surgery: neurology visit, ongoing programming adjustments/optimization
- ✓ Post surgery: neurology visit, ongoing programming adjustments/optimization
- ✓ Post surgery: neurology visit, ongoing programming adjustments/optimization
- ✓ Six-month intervals: follow-up care visits

^{*}Some or all of these appointments may need to occur at OHSU with a movement disorders neurologist or neurological surgeon, if unable to be provided by your referring provider.



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www.ohsu.edu/dbs

OHSU accepts most major health plans.

OHSU is an equal opportunity, affirmative action institution.

OHSU protects the privacy of its patients' and research participants' personal health information. If you would like a copy of the OHSU Notice of Privacy Practices, please call 503-494-8849.

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