

Deep Brain Stimulation and Parkinson's

From Decision-making to Daily
Life with the Device



ON THE COVER:

Richie Rothenberg, MJFF Patient Council Member, who had DBS for Parkinson's at age 43 | Los Angeles, California. Read Richie's story on **page 11**.

People and families with Parkinson's think about deep brain stimulation (DBS) for different reasons and at different times in their journey.

Early on, some look for general information. Others seek more detailed guidance a few years or more into living with disease. No matter when or why you're wondering about DBS, there are many common questions: What symptoms does it help? Can it slow disease progression? How long does it work?

Deep brain stimulation is the most common surgical treatment for Parkinson's disease (PD). To date, more than 160,000 DBS devices have been implanted worldwide. In Parkinson's, DBS can decrease motor symptoms, such as tremor, slowness and stiffness; lessen medication complications, such as involuntary movement (dyskinesia) or wearing off; and reduce medication needs. But like all currently available PD treatments, it has not yet been proven to slow or stop disease progression. It's not a cure, and it's not for everyone.

People report a wide range of emotions when thinking about DBS: hope and optimism for how the treatment may

help, sadness about disease progression, and an understandable hesitation at the idea of brain surgery.

As you consider DBS, give yourself every opportunity to learn and ask questions. Speak with your Parkinson's doctor and get a second opinion if needed. Talk with your spouse or care partner, family and loved ones. And draw on the experiences of others with PD who've had DBS. You can attend a support group or educational seminar or connect one-on-one with a community member who's living with DBS.

This guide provides information and tips for thinking about, undergoing, and living with DBS. It also answers common questions and discusses the latest research. And it shares the personal stories of people with Parkinson's and their loved ones. Use it to begin learning about DBS, round out what you've read or heard from others, or start or continue a conversation with your doctor or loved ones.



Is DBS for Me or My Loved One?

DBS isn't for everyone. Because, like all treatments, it doesn't work for everyone. And because it involves brain surgery, doctors are careful to recommend DBS only in people who are more likely to benefit and less likely to experience certain complications.

Deep brain stimulation typically works best in people who:



HAVE HAD PARKINSON'S FOR AT LEAST FOUR YEARS

Currently, the procedure is U.S. Food and Drug Administration (FDA) approved for people who have had a diagnosis of PD for at least four years.

Outside of this — because every person's course and symptoms are unique — there are no hard and fast rules around when to have DBS. But there are indicators that may point to the right “window.” A person is a good candidate when they have a good response to levodopa and are still physically active but are having trouble with how long their medications work or with involuntary movement (dyskinesia). Many experts consider DBS to be “too early” if motor symptoms, such as tremor, slowness and stiffness, are adequately controlled throughout the entire day and medications don't cause unacceptable side effects. “Too late” is if, as disease progresses, symptoms such as balance problems or significant cognitive changes develop. These do not respond to DBS and could offset any benefits from surgery.

DBS also does not work for people with atypical forms of parkinsonism, or “Parkinson's plus” syndromes, which can mimic PD early on. These include Multiple System Atrophy (MSA), Progressive Supranuclear Palsy (PSP) and others. (Learn more about atypical parkinsonism at michaelfox.org/atypical-parkinsonism.)



BENEFIT FROM LEVODOPA

DBS treats symptoms that go away or get much better after taking levodopa. One exception is tremor that does not respond to medication. DBS *can* work for this symptom.

In general, DBS works as well as your best “on” time (when medication is working) with levodopa. With DBS, medications last longer and “off” periods (when medication is not working) are reduced. Many patients are able to lower their total daily dose of PD meds after DBS.

The surgery works best for motor symptoms (slowness, stiffness and tremor). It also may help some walking problems — especially those caused by slowness, dystonia (abnormal muscle cramping), or dyskinesia (involuntary movement).

DBS does not work well for balance changes. And it often does not ease non-motor symptoms. But some, such as sleep problems caused by nighttime stiffness or tremor, for example, may improve because motor symptoms improve. DBS does not treat memory, mood or speech changes.





EXPERIENCE MEDICATION-RELATED COMPLICATIONS

These may include troublesome dyskinesia and/or significant “off” time (when Parkinson’s symptoms come back). In some people, “off” time alternates with “on” time (when symptoms are controlled) throughout the day. For example, a person feels “on” for a short while, then has dyskinesia, then is “off.” And this cycle repeats many times in one day. DBS can smooth this out, decreasing dyskinesia and “off” time, and increasing “on” time.



DO NOT HAVE SIGNIFICANT THINKING, MEMORY OR MOOD CHANGES

DBS could worsen thinking and memory (cognitive) or mood problems in people who already have significant problems in these areas, such as dementia or uncontrolled depression or anxiety. Those with mild thinking or memory changes and well-managed mood changes often are still eligible.



HAVE OVERALL HEALTH CONDUCIVE TO SURGERY

Certain heart diseases, blood clotting problems or other medical conditions might make surgery too risky. Doctors consider all your conditions and medications when evaluating for DBS.

To qualify for DBS, a person should fit all the criteria outlined in this section. This is to ensure the highest likelihood of success and lowest possibility of side effects with surgery. (If you aren’t a candidate or don’t want DBS, there may be other options. See **page 18** for more.)

IS THERE AN AGE LIMIT FOR DBS?

There is no absolute age cut-off for DBS. But some medical centers find that people who are 70 or older may not experience as robust a response as younger patients. Other factors — such as symptoms, levodopa responsiveness, mood and cognition, and other health conditions — probably are more important to consider than age alone.



What Symptoms Can DBS Help?

What Can't It Help?

Deep brain stimulation mainly helps motor symptoms that get better with levodopa. (Meaning the symptoms temporarily decrease or go away after taking medication.)

These may include:

- + Slowness
- + Stiffness
- + Shaking (DBS also can help tremor that does not respond to medication)
- + Mild walking problems, including freezing of gait, that improve with levodopa
- + Irregular symptom control throughout the day (motor fluctuations) — “on” time, when symptoms are controlled, alternating with “off” time, when they aren’t
- + Involuntary uncontrolled movement (dyskinesia)
- + Abnormal, often painful, muscle contractions (dystonia), such as the toes curling under or foot twisting inward

DBS usually does not help where levodopa doesn’t, such as with:

- + Walking problems, including freezing of gait, that do not improve with levodopa
- + Balance difficulties
- + Speech or swallowing problems
- + Thinking or memory changes
- + Mood problems, such as depression, anxiety or apathy (lack of motivation)
- + Bladder, bowel or sexual changes

→ *Not everyone is a candidate for DBS, but those who are may see a substantial benefit in terms of symptom and medication reduction following the procedure.*



What Happens in the Operating Room? And Beyond?

BEFORE DBS

If you decide to pursue DBS, a team of expert health care professionals will perform a thorough evaluation of you and your symptoms. This multidisciplinary team may include: a movement disorder clinician (Parkinson's doctor, nurse practitioner and/or physician assistant), brain surgeon (neurosurgeon), physical therapist, occupational therapist, speech therapist, social worker, dietitian, neuropsychologist (thinking/memory expert) and/or a psychiatrist. These clinicians assess your:

+ Medications and therapies

You'll describe what medications and other treatments you're currently taking and what you've tried as well as any benefits or side effects.

+ Brain imaging and other tests

These may include detailed memory and thinking exams, administered by a neuropsychologist.

+ Movement and motor symptoms

They'll examine you when you are both on and off medication to see if and how much symptoms improve with medication as well as if you have dyskinesia or dystonia.

+ Non-motor symptoms

Your clinicians will discuss and treat any mood, swallowing and speech, or thinking and memory changes. They'll also evaluate for impulse control disorders (such as excessive shopping, eating, cleaning or other activities), which can happen in some people with PD.

+ Other medical problems or concerns relevant to surgery

Your team will review any medical conditions or other factors that may impact surgery or recovery.

HOW DO I FIND A DBS DOCTOR?

Your Parkinson's doctor may be part of a medical center or team that evaluates people for DBS and performs surgeries. And they may be able to program your device. But some, who do not focus on deep brain stimulation, may not be as familiar with the different devices or programming. They may refer you to another clinician in their practice or to another location that specializes in DBS. (You also can search an online database at mds.movementdisorders.org/directory

for a movement disorder specialist in your area. Be sure to confirm they do DBS.) And ask other Parkinson's community members about their experiences.

While you can find high-quality DBS care in most locations around the world, some people want or need to travel significant distances for the procedure. Make sure to think ahead about logistics following surgery, such as if clinicians at that center will program the device and how often you'll need to visit. (Nearby family or friends may provide a place to stay, for example.) And always maintain a relationship with your local neurologist or Parkinson's specialist, who can help with ongoing care as well as urgent issues.



Together, the group then discusses findings. They talk about what symptoms DBS may help, may not help or may worsen, and potential risks. And they decide on best next steps.

Sometimes, they suggest further testing, treatment, conversation, or observation of specific symptoms, such as mood or cognitive changes. Other times, they recommend DBS and plan logistics, such as:

+ Which DBS device and battery to use

At the time of this writing, three DBS manufacturers offer several different FDA-approved devices. Some have special capabilities and/or rechargeable batteries. (For more on available DBS devices, see **page 17**.)

+ Where to place wires (also called electrodes or leads) in the brain

Which area of the brain; both sides of the brain or only one side

+ Where to put the battery in the body

In the chest or abdomen; right or left side. (Some people get two batteries, one on each side.)

+ How to do the procedure

With patient awake or asleep; with both electrodes at once or separately to allow for observation and recovery between surgeries

+ What other medical conditions require close monitoring before and during surgery

Anxiety, heart disease, or blood pressure changes, for example

+ What medications to adjust around surgery

You may need to stop aspirin, blood thinners or similar medications for a short period prior to surgery. Doctors also typically recommend you hold Parkinson's and tremor medications the morning of surgery.

As you meet with team members, talk not only about possible benefits and risks, but also about what you hope to gain with DBS. And describe what symptoms are most affecting or impacting your quality of life. Would you like less dyskinesia, tremor or dystonia? Better walking? Fewer pills each day? To play guitar again? Travel? The more specific, the better. This guides conversations around if and how DBS may help you meet your goals. (No one wants to have surgery only to be disappointed with the outcome.)



“DBS wasn’t the amazing ‘fix all’ that we thought it would be. After my dad, Ade, had DBS, we realized our expectations were too high and had to reevaluate them. If we could go back, we wouldn’t hesitate to have it done, but it has certainly been a journey that is still ongoing.”

— CHARLIE (LAST NAME WITHHELD),
DAUGHTER OF ADE, 56 | READING, UK



DURING SURGERY

DBS surgery involves two main procedures: placing wires in the brain and placing a battery/electrical stimulator (the neurostimulator) in the chest or abdomen.

+ Placing brain wires

Thin wires, called electrodes or leads, are placed into one or both sides of the brain in areas that control movement. Some people get one lead in each side of the brain in one procedure. Others wait a short period between the first and second wires. (To make sure certain symptoms don't worsen, for example, or because that's the center's protocol.) In rare cases, such as with significant tremor on one side, only one lead is placed in one side of the brain.

The morning of surgery, your doctors will ask that you not take Parkinson's or tremor medications. They want to see and evaluate your symptoms during the procedure so that they can get the brain wire to the right location. (Sometimes, such as with significant slowness or stiffness that makes it difficult to travel to the hospital, doctors will allow a small medication dose.)

At most centers, right before surgery, doctors will position a small, lightweight frame on your head and perform brain imaging. This helps them guide the wires to the right spot in the brain.

During the procedure, a person typically is awake for some of the time. This allows them to describe benefits or side effects and lets doctors monitor their symptoms and response with examination and brain recordings. Some centers now offer DBS while a person is asleep, using brain imaging (MRI) to correctly place the wires.

This may be a better option for someone with significant anxiety or other symptoms that make it difficult to temporarily hold medication or to be awake for part of the procedure. Awake and asleep surgery both have pros and cons but, in general, results seem similar.

Surgery usually lasts several hours. Many people feel an immediate, sometimes significant, lessening of symptoms. This is the result of minor, expected swelling around the end of the brain wire. As swelling fades, this response fades. But benefits return when the device is turned on and programmed several weeks later.

Most people spend one or two nights in the hospital for recovery and monitoring.

+ Placing the neurostimulator

One or two weeks after lead placement, the surgeon implants a battery-operated device, the neurostimulator, below the collarbone or in the abdomen. This is connected to the brain leads with an extension wire that runs underneath the skin. (Some people get two batteries, one on each side, to connect to each brain lead.) When programmed by your clinician several weeks later, the neurostimulator sends small, carefully controlled electrical pulses to the brain through the leads. This stimulation interrupts abnormal brain cell signaling to decrease symptoms.

For this procedure, you are put to sleep (under general anesthesia) and go home the same day.

The components of DBS and surgical processes to implant them are essentially the same no matter what device you get or where you have surgery. But details differ across devices (see **page 17** for more) and specific procedures



“My husband, Robert, had DBS in 2019, just after his 40th birthday. It’s made a huge difference in both of our lives. He still takes a lot of medication, but his quality of life has improved immensely.”

— LYN S A Y J A Q U E S , W I F E O F R O B E R T , 4 1 | N O T T I N G H A M S H I R E , U K



WHAT ARE THE POTENTIAL RISKS WITH DBS?

Complications with DBS typically are rare. The most serious potential risks of the surgery are bleeding in the brain and infection.

Bleeding happens in one to three percent of people. Most often it is minor. If it is more significant, it could cause a stroke, language problems or seizures, for example.

Infection occurs in about three to four percent of surgeries. Most commonly, infection happens near the neurostimulator (in the chest or abdomen), usually

weeks or months after the procedure. Treatment may include removal of the neurostimulator, intravenous antibiotics and re-implantation of a new device. If the infection hasn't spread, the brain leads can stay in place and no additional brain surgery is needed. Rarely, infection starts in the scalp or the brain, which may require removal and re-implantation of the electrodes.

Another possible, but only occasional, complication is placement of a brain lead outside of the ideal or intended location. In these situations, DBS may not be able to adequately control symptoms or may cause side effects. If this happens, doctors may consider surgery to reposition the lead or place a new one.

Rarely, over time, a lead may break, disconnect from the battery, or cause other problems. If this happens, surgery may be necessary to repair or reconnect the wire.

and timing can vary from medical center to medical center.

AFTER SURGERY

A few weeks after surgery, you'll see your movement disorder clinician in the office. At this visit:

- + Your clinician turns on the DBS and programs settings for your symptoms**

To find your settings, they test different combinations of electrical stimulation and observe how symptoms respond and if any side effects occur. So, it's often best to hold Parkinson's medications the morning of this office visit, if possible. Programming takes at least an hour or more.

- + Your doctor prescribes any medication adjustments**

Typically you'll begin to gradually decrease and sometimes discontinue certain medications. Most people can significantly decrease Parkinson's medications over time.

- + You learn how to use the patient programmer**

This allows you to turn the device on and off, check

the battery, and, if you wish, adjust settings at home within parameters set by your clinician.

From then on, you'll visit your clinician every few weeks or months for continued adjustment. Over time, you and your doctor will determine the best combination of DBS settings and medication to control your symptoms with no or few side effects. Finding this combination can take six months or more. After that, your clinician will, a few times per year, check the device battery and function and adjust settings as necessary.

Certain DBS devices allow you to meet with your clinician and get programming remotely, from your home or other location. (See **page 17** for more.) For some, this provides greater comfort and ease of living with DBS.

After a few years or even decades, the battery will need replacement. How long it lasts depends on your device and settings. Some rechargeable batteries, which require recharging every few days or weeks, can last 15 years or more. (Your clinician will check your battery each visit.) Battery replacement usually is an outpatient procedure under general anesthesia, in which you go home the same day.





“WHO KNOWS WHERE WE’D BE WITHOUT DBS”

BY MARISSA YOUNG, DAUGHTER OF
MICHAEL, 59 | STERLING, MASSACHUSETTS

My dad, Michael, had Parkinson’s since 2000. In 2019, at age 57, he got DBS. The previous summer, he experienced psychosis (hallucinations and delusions), which was brought on by Parkinson’s medication. This ultimately led us to DBS because his body couldn’t take any more medicine. (Meaning he couldn’t tolerate more medication for his Parkinson’s symptoms, because that would worsen psychosis.)

DBS really improved his fine motor skills. And his sleep has gotten much better. He still has some rough nights, but he can consistently get a few good hours of sleep. His medicine also has been decreased since DBS. Before, he was taking pills every two hours. Now, it’s every 2.5 hours and we haven’t had to change it over the past few years.

Unfortunately, his cognition (memory and thinking) are much worse. He gets confused easily and overwhelmed if too much information is thrown at him. He can no longer work with wood, numbers and measurements like he used to.

The surgery itself wasn’t too bad but neither my dad nor my family was prepared for the recovery process. That was hard on all of us. Many people say they have a “honeymoon” phase with little or no symptoms after surgery. My dad had to use a walker for a few months after surgery, even though he’d never used one before. (Now he’s back to no walker.)

For anyone considering DBS, I’d offer these tips:

- + **Talk to people who’ve had DBS.**
- + **Write everything down.** This includes all the information you get from doctors or others and any questions you have.
- + **Make sure you have a support system to help you during and after surgery.** For my dad, that was me, my mom and my sister. The day of surgery, my sister and I helped my mom (texting family members updates, for example). And have someone to drive you to doctor appointments after surgery. My mom and I always went so we both got the information directly from doctors and we could tell them about symptoms my dad may not have noticed.
- + **Prepare (or ask family and friends to make) food before surgery.** It’s nice to have meals ready when you get back home.
- + **If you live far from the hospital, stay in a nearby hotel the night before surgery.** For us, this made getting to the hospital at 6 a.m. much easier. (We live an hour from the hospital.)
- + **Don’t prepare for DBS to be a cure.** And do prepare for the recovery — it takes a long time for medications and DBS stimulation to be in sync! I think maybe we expected DBS to do more. But overall, it did help! Who knows where my dad would be today without it — he may have gotten worse.



LIFE WITH DBS

Once fully recovered, you can resume most of your regular activities. Some people say they are more active after DBS because their symptoms are better controlled. Always speak with your clinician before restarting activity and before any medical, dental or other procedure. Here are general guidelines for certain activities:



Exercise

Once your neurosurgeon gives you the okay, you can (and should!) exercise regularly. But avoid activities with sudden, excessive, or repeated bending, twisting, or stretching as they could damage the DBS device. These include rock climbing, which involves reaching overhead, contact sports such as football, and others. Swimming is typically okay, but a few people have reported difficulty after DBS. Be careful by going with a buddy and starting in the shallow end of a pool, for example.



Medical and dental procedures

You can have most imaging procedures, including MRI, but only with specific MRI settings and with your DBS set to MRI mode. And you'll want to turn DBS off before brain wave (EEG) or heart rhythm (EKG) studies to avoid interference with the test. People with DBS should not have diathermy, a treatment that delivers energy and heat to muscles and tissues; transcranial magnetic stimulation; or massage or chiropractic treatment that involve head turning or neck twisting.

Most dental care is fine, but your dentist may need to make slight adjustments in how procedures are done.

Always inform all providers about your DBS before any medical or dental procedures and before pursuing any alternative or complementary therapy. (This includes hyperbaric chambers as high pressure could damage the system.)



Daily and household activities

Your cell phone, computer, microwave and other electronics should not interfere with DBS. Metal detectors can alarm because they sense the metal in your DBS device. But it is rare for these to turn off your device. If you feel symptoms return suddenly, check your device and turn it back on, if necessary.



Travel

Avoid walk-through airport scanners or metal detectors, which detect metal in the DBS device. Ask for a manual screening instead and always carry your device information card and programmer.



Other activities

Rollercoaster riding and sky diving are discouraged after DBS. Scuba diving below 10 meters is not allowed. Talk to your clinicians before any other specific activities.



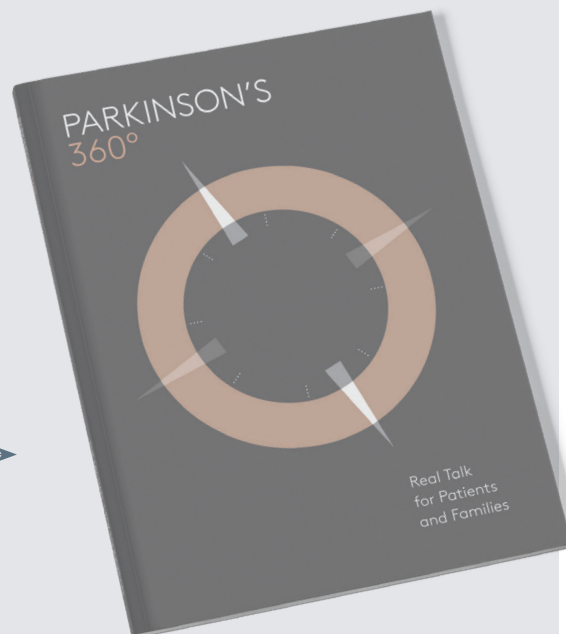


“I’M A RISK TAKER”

At 43, seven years after being diagnosed with Parkinson’s disease, The Michael J. Fox Foundation’s Patient Council Member Richie Rothenberg felt encumbered by his body. He often found himself freezing without warning while powerful dyskinesias took over his body. “It was a very difficult time,” he remembers. While deep brain stimulation isn’t right for everyone, Richie’s intense response to levodopa meant he was an excellent candidate. On his doctor’s recommendation, Richie decided to undergo the procedure in December 2010. Unfortunately, after surgery he came down with a staph infection — a complication experienced by a small percentage of people who undergo any surgery — and spent New Year’s Eve getting the whole apparatus taken out. “I had to wait another six weeks before I could be ready to do it again,” he recounts. The good news? He had done so well in the first surgery that doctors were able to redo the operation and implant the battery in one procedure the second time. “My endurance was proven that I could stand a six- to eight-hour procedure. It’s a long procedure,” he says. The results

were dramatic. Like many people, Richie experienced an immediate, but temporary, benefit, even before doctors had programmed his device. (This happens because of the surgery itself.) It took a couple of years to get back to that instant moment. “The body settles down, the brain, the excitement settles down,” he explains. “It took about two years of going in every month or so for a different tweaking of the DBS settings.” He now sees his doctor for regular visits to maintain the pacemaker-like DBS device. A year and a half after his operation, he married his high school sweetheart. He balances his professional life with his personal life, parenting their twin daughters and two children from a previous marriage. “Parkinson’s is the best thing that ever happened to me,” he says. “It changed my life in a profound way that made it much more meaningful and much more appreciative and filled with love.”

Watch more of Richie’s story at
michaeljfox.org/PD360.





What Questions Should I Ask about DBS?

Susan Gilbert Cohen, whose husband Stephen had DBS for Parkinson's, offers a list of questions to consider discussing with your care team.

BEFORE DBS SURGERY

Potential benefits

Am I a candidate for DBS?
If not now, when should I consider it?
For which of my symptoms is DBS most effective?
How long does treatment last?

Possible risks

What are the possible side effects?
How might DBS affect speech, balance, thinking or memory, or mood?

Pre-op testing

What's required?

Wire (electrode/lead) placement

Which part of the brain?
One wire in each side of the brain or only one side?

Doctor experience

How many Parkinson's DBS surgeries have you and your center done?
How many do you do per month?
How often do you see complications? What kind?

DBS device

Which devices are currently available?
Specific capabilities, such as remote clinician programming or brain signal sensing? Pros and cons of each?
Which do you recommend? Why?
What is neurosurgeon and movement disorder clinician experience with each?



BEFORE DBS SURGERY (CONTINUED)

Research	Any ongoing DBS trials (of new devices or surgery methods) that I may want to consider joining?
-----------------	---

Battery

Type	One or two batteries? Rechargeable or non-rechargeable? Pros/cons of each?
-------------	--

Placement	Under collarbone in chest or in abdomen? Right or left side? Or both (if two batteries)?
------------------	---

Duration	How often does the battery need to be replaced?
-----------------	---

If rechargeable	Equipment needed to recharge battery? How often does battery need to be recharged and how long does it take? How to know when battery needs recharging?
------------------------	---

Medications	Need to stop medications prior to surgery? Which ones? When?
--------------------	---

Cost	Is DBS covered by insurance? Does coverage vary for different devices? What is my out-of-pocket cost?
-------------	---



DBS SURGERY

Potential risks

What are the possible risks with surgery? (Bleeding, infection, stroke, seizure, other.)
How likely are these?
What are potential complications related to the device? (Lead disconnecting or breaking, for example.)

Process

Do you shave my hair? How much?
Will I be awake or asleep during the procedure?
Will leads be placed in each side of the brain?
Will both leads be placed at the same time or is there an observation and recovery period between? Why?

Hospital stays

Required?
After which procedure?
For how long?



“My wife, Kathy, was diagnosed with Parkinson’s at 33 years old in 1997. She had DBS surgery in 2012. It gave her a few more good years working, which she enjoyed.”

— JEFF WILK, HUSBAND OF KATHY, 56 | PLAINFIELD, ILLINOIS

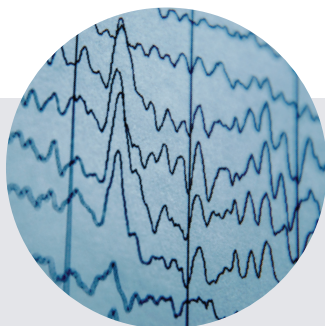


AFTER DBS SURGERY

Medications	If stopped prior to surgery, when to resume? What dose?
Post-op follow-up	What to expect in terms of pain, soreness, swelling? Activities to do or not do? Are there staples or stitches to remove?
Return to work	How soon after? Any restrictions?
Driving	How soon after? Any restrictions?
Other limitations	Ok to drink alcohol? Are there restrictions on exercise, such as weightlifting, swimming, or other activities? What type and for how long? What about travel? Flying?
Programming	Who programs the device? When does this start? How often are visits for adjustments? Any option for remote programming (through telemedicine)? How long to get to “normal”? Can I control the device? How?
Other considerations	Any limitations on MRIs, X-rays, or other medical or dental procedures? What about future research participation?



HOW DOES DBS WORK?



Exactly how DBS works is unknown, but experts believe it regulates abnormal electrical patterns in the brain. To control normal movement, brain cells communicate with each other through electrical signals. In Parkinson's disease, these signals become irregular and uncoordinated, which leads to motor symptoms. DBS may interrupt the irregular signaling so cells can communicate more smoothly, and symptoms lessen.

HOW LONG WILL DBS WORK?



Some say DBS seems to “turn back the clock” on their disease. And for most, the main effects of DBS last many years. But like all current Parkinson's therapies, DBS is not a cure and has not been proven to slow disease progression. Over time, new or increasing symptoms, such as balance problems or non-motor changes, may not fully respond to DBS and may require medication adjustments or additional therapies.



What Are the Different DBS Devices?

At the current time, the FDA has approved several different DBS devices from three separate manufacturers. While all DBS systems have the same basic components and work the same way, each device is unique. The differences are not drastic, but they represent innovation and improvement in care and care delivery. Variations, such as rechargeable batteries or electrodes that can deliver stimulation in novel ways or sense and record your brain signals, may lead you and your doctor to pick one over another. When deciding on a DBS device, think about how much you wish to interact with the device (changing settings at home, recharging the device) and which system, if any, your movement disorder clinician and neurosurgeon prefer. Available DBS devices for Parkinson's include:

ABBOTT

Infinity

Abbott's Infinity DBS was FDA-approved for Parkinson's in 2016. Infinity's brain leads allow "directional stimulation," which is a potentially increased ability for the clinician to guide electrical stimulation toward areas associated with symptoms and away from side effects. This device operates with Apple iOS software and controllers. (For some, this may be a more familiar interface and offer an easier programming experience.) It also uses a non-rechargeable battery. In 2021, Abbott developed a new technology (the first and only of its kind in the U.S.) that enables people with these devices to communicate with their clinician and receive DBS adjustments remotely, from their home or other location through WiFi, using the patient controller device.

For some, knowing they can connect with their doctor and get adjustments anytime and anywhere makes life with DBS a little easier. (And while Abbott is the first to offer remote programming, this capability is likely to become more broadly available in the future.)

Support from Abbott Laboratories made this educational resource possible.

BOSTON SCIENTIFIC

Vercise

Boston Scientific's Vercise became available for PD in Europe in 2012 and first gained FDA approval in 2017. Vercise's brain leads also allow "directional stimulation." (But they use a different technique than Abbott's Infinity to focus stimulation.) There are three different Vercise models. Some have rechargeable batteries. And some let the clinician visualize models of where leads are in your brain while finding or adjusting settings, which could enable more efficient programming.

MEDTRONIC

+ Activa

Medtronic's DBS was the first to be FDA-approved for Parkinson's, in 1997. There are two different Activa batteries that can be used — one rechargeable, the other non-rechargeable. Clinicians program using an Android tablet.

+ Percept

Medtronic Percept gained FDA approval in 2020. This first-of-its-kind device can sense and record an individual's unique brain signals. With this data, doctors may be able to correlate symptoms with brain signals, which might eventually lead to more precise DBS adjustments. Patients also can track their medications and symptoms in an electronic diary on their patient controller (a Samsung handheld device), so that their doctor can look for patterns between symptoms and brain signal changes.

Across all DBS devices, rechargeable batteries may last up to 15 years (or more in some people) and non-rechargeable last, on average, about three to five years. The length of battery life depends on your individual settings. All current DBS devices also are safe for MRI, as long as certain safety conditions are met.



Are There Alternatives to DBS?

Sometimes, someone does not match the criteria for DBS, which aim to maximize safety and benefit. Other times, a person does not want to undergo surgery to implant the device or have periodic programming visits.

DBS is an optional (elective) procedure. Although it may be strongly recommended for some, it's not mandatory for anyone at any point in Parkinson's. There may be other options in progressing PD:

+ Duopa (levodopa/carbidopa)

This levodopa/carbidopa gel is infused continuously through a pump directly into the small intestine, where the medication is absorbed. (Pump placement requires a minor surgical procedure.) Like DBS, it may reduce “off” times (when medication isn't working) and dyskinesia. Unlike DBS, it does not require regular programming, but some may benefit from additional care partner support to maintain the device and administer medication.

+ Focused ultrasound

This is a non-invasive surgical procedure. It destroys defined areas of brain cells that cause motor symptoms, such as tremor or stiffness, or dyskinesia. (These are the same brain areas where DBS works.) To avoid certain possible side effects, it is typically performed only on one side of the brain. (Meaning it treats symptoms only on one side of the body.) It takes effect immediately and does not require programming, but it is not reversible. Learn more at michaeljfox.org/news/focused-ultrasound.

Treatment options may continue to expand as new therapies, such as under-the-skin, continuous infusions of levodopa/carbidopa or apomorphine (a drug that mimics dopamine, the brain chemical that decreases in Parkinson's) move through clinical trials and approval processes.



“My husband, Jewell, had DBS in 2016, as part of a clinical trial. It's been nothing short of life-changing for us, but I know of others who didn't get as much benefit from DBS.”

— MARY BETH MOHN, WIFE OF JEWELL, 61 | EDINA, MINNESOTA



Research on DBS and Parkinson's

DBS in Parkinson's is an extremely active area of research. To date, The Michael J. Fox Foundation has funded more than \$9 million in DBS and Parkinson's. Ongoing efforts focus on:

+ **Discovering new brain targets**

Researchers are working to better understand the complex brain circuitry involved in Parkinson's and how DBS impacts it. This may help identify new DBS targets that could address a wider range of PD symptoms.

+ **Improving programming methods**

Currently, clinicians program a person's settings using their examination and patient report of symptoms or side effects. (This can be a time-consuming process.) Researchers are using specialized brain imaging and machine learning to find more efficient and even automated programming methods.

+ **Improving approaches and delivery**

Scientists are investigating "smart" (or closed-loop) DBS, which can sense, record and monitor a person's unique brain signals and correlate them with symptoms, such as freezing of gait, dystonia or tremor. These devices aim to deliver stimulation on-demand, as needed for specific symptoms, rather than continuously as the current devices do. This may further ease symptoms while decreasing side effects and prolonging battery life.

Some studies are using smartwatches to monitor symptoms, such as tremor or dyskinesia, to measure response to DBS or even direct DBS adjustments.

Researchers also are studying whether DBS may be beneficial earlier in PD, even before complications arise. Small studies suggest that DBS may lessen symptoms and medication needs in people who've had Parkinson's for less than four years. Researchers now hope to conduct larger, controlled trials to fully evaluate potential benefits and safety.

+ **Treating more symptoms**

Researchers are examining how different brain targets and device settings could ease symptoms that DBS doesn't currently treat, such as swallowing problems and depression.

+ **Guiding care decisions**

Researchers also are gathering data on DBS through The Michael J. Fox Foundation's RAD-PD DBS Registry. This database includes critical information on people who undergo DBS, such as when, in the course of Parkinson's, a person has the procedure; for what symptoms; with which device and in what part of the brain; and other measures. Following individuals' responses over time will deepen understanding of the best DBS timing, placement and procedures and, ultimately, better guide clinicians and patients in pursuing this therapy.

Many people wonder whether having DBS excludes them from future research participation. Each trial has unique criteria for who is and isn't eligible. These standards are for participant safety and to allow researchers to obtain the clearest, most accurate results. Certain trials testing therapies to potentially slow or stop disease progression, for example, may need people who do not have DBS. (It otherwise may be difficult to tell which improvements are from DBS and which are from the investigational therapy.)

There are many ways to participate in research: filling out questionnaires about your symptoms and treatments, allowing doctors to observe your symptoms over time, giving blood samples or undergoing brain imaging. These studies aim to understand the experience and effects of disease and DBS for people with Parkinson's, their families and their care partners.

For the most up-to-date information on Parkinson's clinical trials, visit [foxtrialfinder.org](https://www.foxtrialfinder.org).





TURNING BACK THE CLOCK ON PARKINSON'S

Nearly 20 years after his Parkinson's diagnosis at age 31, Jim McNasby, JD, chief people officer and general counsel at The Michael J. Fox Foundation, reached a turning point. He was taking 15 prescription pills and 12 supplements a day to manage the tremors, stiffness and slowness of Parkinson's disease. He had trouble performing simple tasks — he couldn't button his shirt without help. At the time, Jim was working at an insurance brokerage firm with international travel demands. "I was traveling two weeks at a time and I'd need an extra bathroom kit just for my medication," He recalls.

It was Jim's husband, Donald Moss, who suggested deep brain stimulation (DBS). The couple had previously discussed the therapy but dismissed it because the idea of brain surgery seemed too scary. Donald says, "I was at a care partner focus group where other people were really surprised that Jim hadn't gotten DBS after hearing about his experiences."

That triggered Jim to call his doctors and ask about DBS. He says, "My symptoms were getting worse. Some were embarrassing. And I couldn't keep up with Donald when we'd walk at night." He goes on, "I took any negative energy I had about DBS, unplugged it, and plugged it into the courage socket in my brain."

Jim's response to Parkinson's medications and the daily ups and downs of his symptoms made him a DBS candidate. He decided to undergo the procedure in early 2019. Jim and Donald were, naturally, worried going into surgery. Jim had three different procedures: one for the first brain lead; another for second lead; and a third for the batteries implanted in

his chest. Jim laughs remembering his doctor saying he got a "free haircut with each surgery" when they shaved his head for the procedure. His procedures went smoothly, except for a minor complication: a small bleed in the brain around one lead. Luckily, this did not cause any symptoms and resolved on its own.

Shortly after the last surgery, Jim's device was activated and programmed. He recalls, "Right when the DBS was turned on, my posture improved, my tremor diminished, and I felt 70 percent better." He adds, "I was so excited. After five minutes, I was running up and down the hallway." To date, Jim has had five programming sessions with his doctor to tweak his settings. He reminds others it's a process and "You can't expect that you're going to start off perfectly programmed."

Two years post-DBS, Jim says he "rarely thinks" about his DBS and takes about one or two Parkinson's pills a day. Things aren't perfect: He occasionally has trouble with his gait and feels a bit unsteady at times. And he's more cautious these days. But he feels "a quiet calmness" inside. He has also regained his sense of independence. He can put on his own tie and walk six miles with Donald every night without a problem.

Donald describes, "DBS wasn't a cure, but it turned back the clock to a time when Jim was far less symptomatic and had a better quality of life." He adds, "In hindsight, we should have done it sooner. It was such a radical transformation — so much bigger than either of us could have anticipated. Both of our lives have changed."



Dystonia and DBS

Dystonia is an abnormal, often painful, muscle contraction, such as the wrist or fingers pulling inward, the foot turning out, or the neck twisting to one side. Dystonia can be part of Parkinson's, but it also can be a condition on its own. (Dystonia is the third most common movement disorder.) It can involve one body part, one side of the body, or the entire body. Sometimes a genetic mutation causes dystonia; other times there is no known cause.

In Parkinson's, not everyone has dystonia. This symptom is more likely in people with early-onset PD, diagnosed at age 50 or younger, and those who have a genetic mutation, parkin (PRKN), which is linked to Parkinson's. Dystonia often happens during exercise or "off" time, when symptoms return because medication isn't working. Like all PD symptoms, dystonia varies from person to person.

Researchers aren't yet certain why dystonia happens, but it likely involves a miscommunication between cells in the same brain regions involved in Parkinson's. Ongoing research is looking at how environmental and genetic

factors connect to dystonia and how brain circuitry changes in dystonia to deepen understanding and develop better treatments. In partnership with the Bachmann Strauss Dystonia and Parkinson Foundation, MJFF has annually awarded **The Bachmann-Strauss Prize for Excellence in Dystonia Research**. This award recognizes profound contributions to dystonia research and supports further research in the area. Because of overlaps between dystonia and Parkinson's, research in dystonia can inform understanding in PD (and vice versa).

There are many options for treating dystonia. These include Parkinson's and other medications, such as muscle relaxants; botulinum toxin injections; physical or occupational therapy; exercise and others. If these cannot control dystonia, deep brain stimulation may be an option. The DBS evaluation, procedure and programming are similar for both dystonia and for Parkinson's (with or without dystonia). Learn more about dystonia at michaeljfox.org/news/dystonia.



Parkinson's Progression Markers Initiative

Through MJFF's Parkinson's Progression Markers Initiative (PPMI) study, researchers are learning about the Parkinson's experience to develop better tests and treatments.

PPMI gathers data and samples over time from volunteers around the world — both with and without Parkinson's — to increase understanding of symptoms and progression; find measurements in the earliest stages (even before motor symptoms); and advance treatments to slow, stop or prevent disease.

Whether you have Parkinson's or care about someone who does, you can help.

Find out how and join PPMI, the study that could change everything, at michaeljfox.org/ppmi.



This Guide Was Written by:

Rachel Dolhun, MD

Movement Disorder Specialist and
Senior Vice President of Medication Communications at
The Michael J. Fox Foundation for Parkinson's
Research | New York, New York

Medical Review by:

Joohi Jimenez-Shahed, MD

Medical Director, Movement Disorders Neuromodulation &
Brain Circuit Therapeutics, Icahn School of Medicine at
Mount Sinai | New York, New York

Joan Miravite, DNP, RN, FNP-BC

Assistant Professor of Neurology at Icahn School of
Medicine at Mount Sinai and Director of Interdisciplinary
Clinical Care for Movement Disorders at Mount Sinai Beth
Israel Strauss Movement Disorders Center at Mount Sinai
Beth Israel | New York, New York

Thank You to Our Community Members and the Families Who Shared Their Experiences and Expertise:

Susan Gilbert Cohen

Managing Partner, Diversity Marketing and
Communications, LLC, and spouse of Stephen Cohen, who
lives with Parkinson's and DBS | Maplewood, New Jersey

William Marks, MD, MS-HCM

Adjunct Clinical Professor of Neurology and Neurological
Sciences at Stanford University | Stanford, California

Jim McNasby, JD

Chief People Officer and Patient Council Member,
The Michael J. Fox Foundation for Parkinson's
Research | New York, New York

Donald Moss

Animal Rights Advocate and spouse of Jim McNasby, who
lives with Parkinson's and DBS | New York, New York

Richie Rothenberg

Patient Council Member, The Michael J. Fox Foundation for
Parkinson's Research | Los Angeles, California

The information in this guide was accurate at the time of publication in June 2021. For the latest on deep brain stimulation and Parkinson's, visit michaelfox.org.

The medical information contained in this article is for general information purposes only. The Michael J. Fox Foundation has a policy of refraining from advocating, endorsing or promoting any drug therapy, course of treatment, or specific company or institution. It is crucial that care and treatment decisions related to Parkinson's disease and any other medical condition be made in consultation with a physician or other qualified medical professional.



This publication was made possible by Abbott Laboratories. Partner support allows us to furnish high-quality educational content to the Parkinson's community while maintaining our commitment to allocate donor dollars to high-impact research. The Michael J. Fox Foundation is solely responsible for the content in this guide.





**He doesn't
have Parkinson's.
But he can help
end it.**

Join the study
that could change
everything.



Parkinson's
Progression
Markers
Initiative

Through MJFF's Parkinson's Progression Markers Initiative (PPMI) study, researchers are learning about the Parkinson's experience to develop better tests and treatments. Whether you have Parkinson's or care about someone who does, you can help.

Participate today at michaeljfox.org/ppmi.