

A Decision Aid For

## Deep Brain Stimulation (DBS) Surgery

An advanced therapy option for people with Parkinson's Disease



You are considering DBS surgery for Parkinson's disease. Others in your position have told us the thought of brain surgery is scary. We hope this booklet will help you understand what DBS is and help you and your family think about whether this surgery is right for you.

### Along the way, we want you to think about:

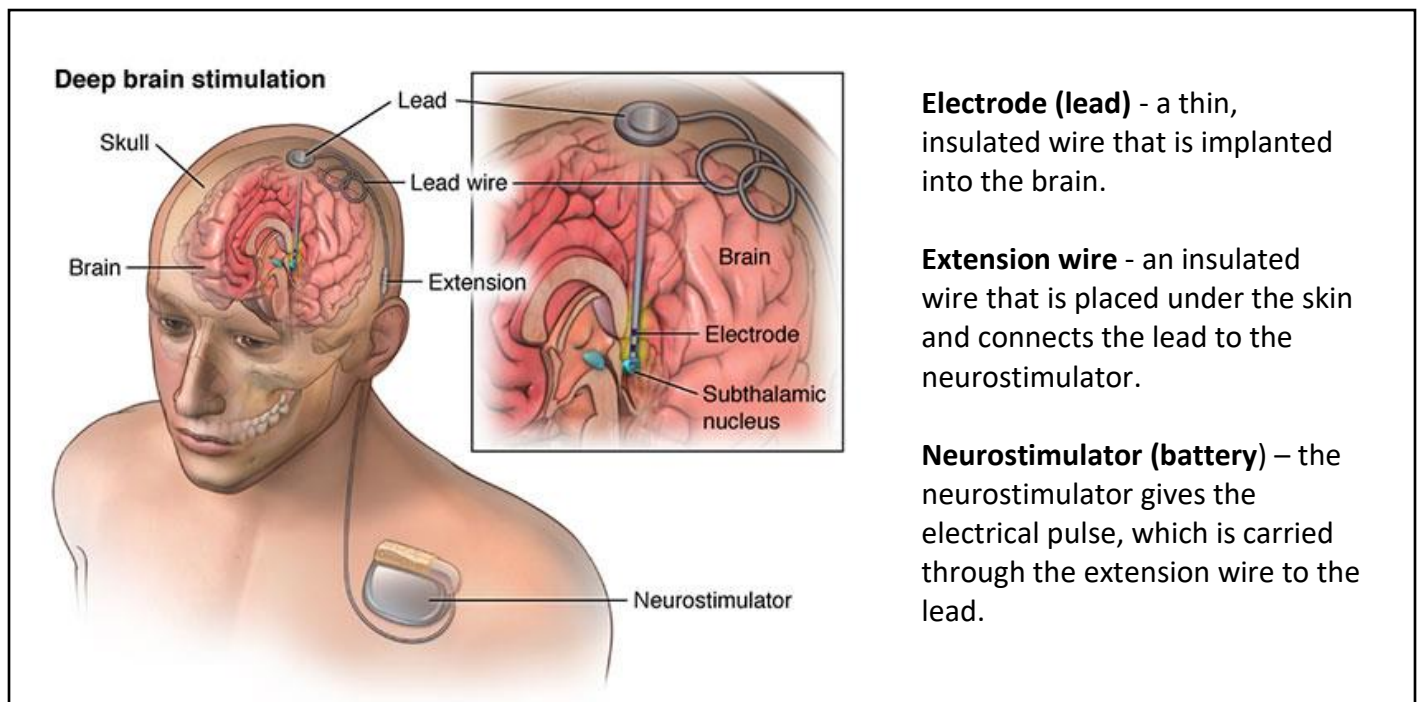
- ❖ What are your goals and expectations for DBS surgery?
- ❖ What symptoms do you hope will improve?
- ❖ What concerns do you have about DBS?
- ❖ What additional questions do you have for your doctor?

## What is Deep Brain Stimulation (DBS)?

Deep Brain Stimulation surgery is an FDA approved surgical option for people with Parkinson's disease (PD) that can improve many symptoms of PD, including tremor, slowness, stiffness, dyskinesia (involuntary movements), and some non-motor symptoms. In many cases, people are able to decrease their PD medications after surgery, decrease OFF time (when medications are not working well), and improve their quality of life. Some non-motor symptoms, such as sleep, may improve, but more studies are needed to figure out which non-motor symptoms may improve and by how much.

*DBS is not a cure for Parkinson's disease, and it does not slow progression.*

The response from DBS is usually as good as your best ON time (when your medication is working well). It can also work for tremor that does not improve enough with medication. DBS can increase ON time and decrease OFF time.



The DBS system consists of one lead implanted deep in each hemisphere (side) of the brain. The lead is connected to an extension wire that runs down one side of the neck, under the skin, and connects to a single neurostimulator. **All components are under the skin.** The leads may be implanted one side at a time in different surgeries or both at the same time in one surgery. Some people may only have one lead implanted on one side, while most people will have a lead implanted on both sides. Talk with your team about whether one side or both sides is right for you.

## DBS treats many symptoms, but it does not treat everything.

### What Symptoms Does DBS Treat?

- ❖ Slowness of movement (*bradykinesia*)
- ❖ Stiffness (*rigidity*)
- ❖ Shaking (*tremor*)
- ❖ Times when medications are not working well (*OFF time*)
- ❖ Involuntary movements from levodopa (*dyskinesia*)
- ❖ Freezing of gait that improves with levodopa.
- ❖ Toe curling, foot turning inward (*dystonia*)

*Because people are usually able to take less Parkinson's medication after DBS, the side effects from medication often decrease or go away.*

### What Symptoms Does DBS Not Treat?

- ❖ Balance Trouble
- ❖ Thinking/memory problems
- ❖ Depression, anxiety and apathy (*lack of motivation*)
- ❖ Constipation, bladder issues
- ❖ Speech or swallowing problems
- ❖ Freezing of gait that does not improve with levodopa

*Thinking or memory problems do not improve with DBS, and if they are severe, they can worsen after DBS. Change in anxiety and depression after DBS is variable, but some people do report improvement.*

## Who Gets DBS Surgery?

- ✓ People who have motor fluctuations, including '**OFF time**' when medication effects wear off and/or '**dyskinesia**' (involuntary movement due to levodopa).
- ✓ People who have tremor that does not improve enough with medication.
- ✓ People who have bothersome and unmanageable side effects from Parkinson's medication, such as nausea and vomiting, that limits how much medication they can take.

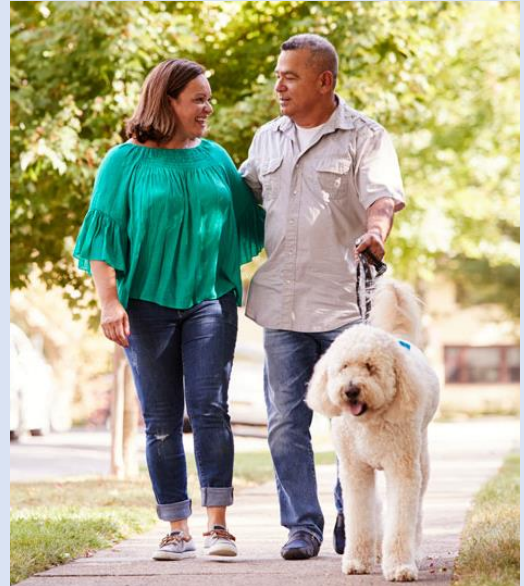
### You might be a good candidate for DBS if:

- 1) You have a clear diagnosis of Parkinson's disease
- 2) Your motor symptoms get better with carbidopa/levodopa (except tremor)
- 3) You have not had big changes in thinking or memory. People who have mild changes in thinking or memory are often still candidates for surgery.

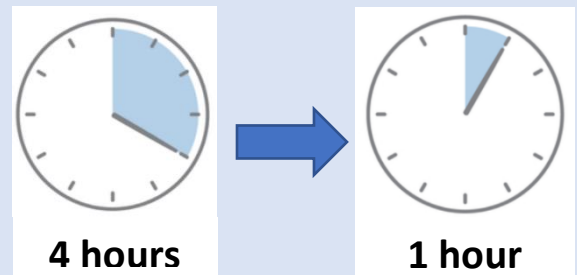
## What are the benefits of getting DBS?

*On average, people who get DBS will experience the following benefits. Because these are averages, the exact benefits will be different for each person.*

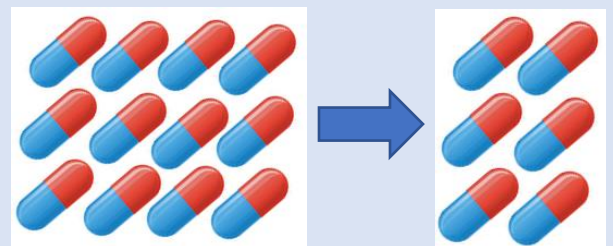
- **Motor Symptoms:** up to **70%** improvement in motor symptoms, which may include less stiffness, faster movements, less time with tremor (and less severe tremor when it occurs), and less shuffling when walking. There is often a smoothing out of motor fluctuations between OFF and ON.
- **Dyskinesia:** **65%** reduction in dyskinesia. People may experience this improvement as less time with dyskinesia and/or less bothersome dyskinesia if it does occur.



- **OFF Time:** **70%** reduction in OFF time (when medications are not working). For example, if you have a total of **4 hours** of OFF time per day before DBS, you would have just over **1 hour** of OFF time per day after DBS.



- **Medications:** The number of Parkinson's pills may decrease by **half or more**, which may also decrease side effects from medications. For example, if you take **12 pills per day** for Parkinson's disease before DBS, you would take **6 pills or less per day** after DBS.




*This decrease in medication does not apply to people who get DBS in the globus pallidus (Gpi).*


- **Quality of Life and Daily Activities:** People may experience improvement in the ability to cook, look after their home, get around in public, get dressed, exercise and participate in leisure and social activities. Some people may also feel less embarrassed and more confident going out in public.





## What are the risks of DBS surgery?

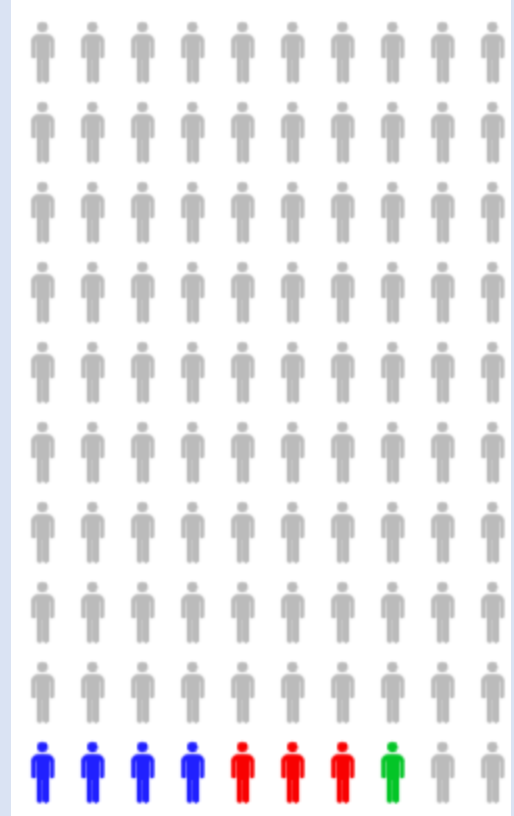
All surgeries are associated with risks. The complications of DBS surgery are usually quite rare. The following are based on ***national and international studies***. **Outcomes will vary by center**. Ask your surgeon about what they think these numbers mean for you.

 **2-4** out of every **100** patients will develop a device related infection, usually within weeks to months after surgery.

 **3** out of every **100** patients will have a brain bleed or stroke during surgery.

 **Less than 1** out of every **100** will experience a seizure after DBS, usually within 24-48 hours after surgery.

 **Approximately 92** out of every **100** will not be affected by these complications.



## What happens if I experience one of these events?

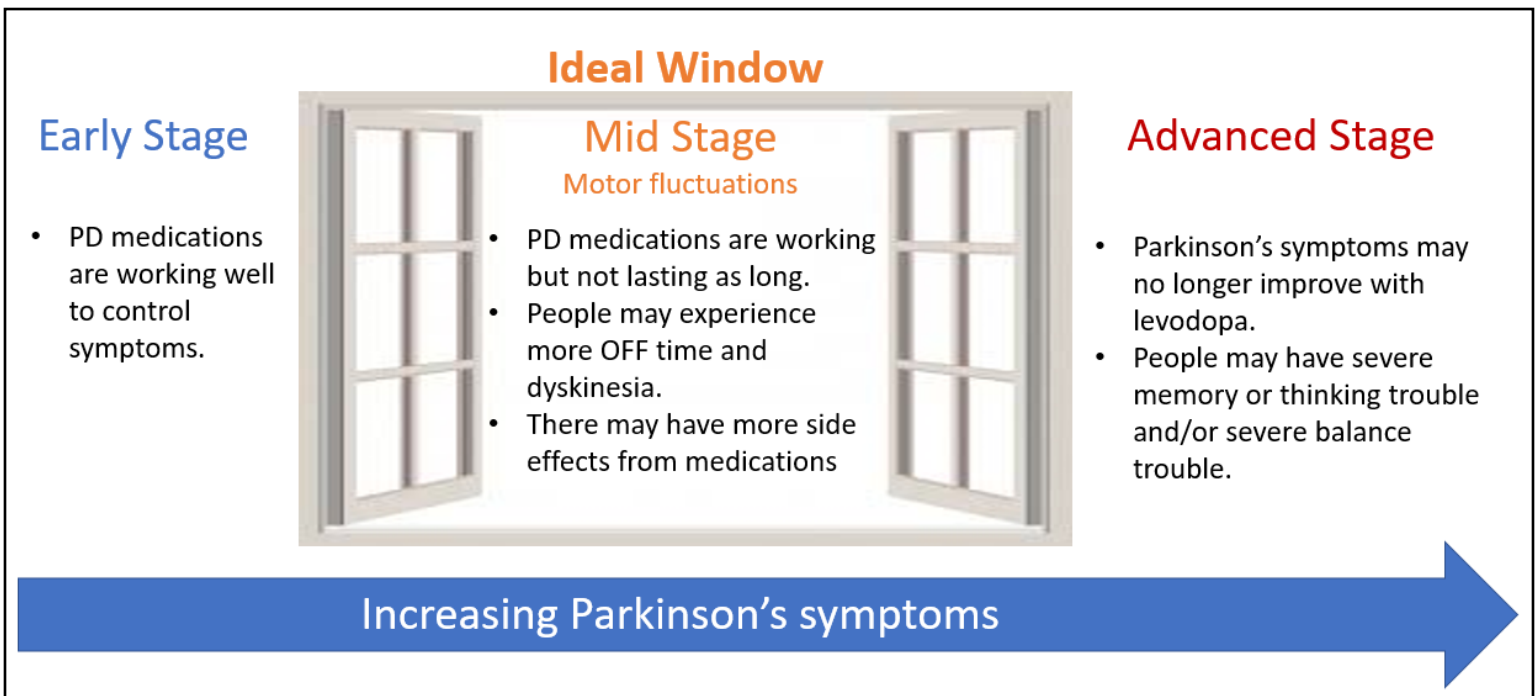
**Infections.** The most common type of infection happens near the neurostimulator within the first few weeks to months after surgery. These infections are often treated with antibiotics and the neurostimulator will be taken out. When the infection is cleared, the neurostimulator can be replaced. Less often, the infection can occur near or around the brain leads. The infection is treated with antibiotics and requires the brain leads to be removed. Once the infection is cleared, the leads can be re-implanted.

**Brain Bleed or stroke.** A small brain bleed or stroke may be seen on CT scan after surgery and may not have any symptoms. Larger bleeds or stroke are rare, but may cause weakness or problems with talking. More scans may be done to monitor the bleed or stroke.

**Seizure.** If seizures occur, they are treated with seizure medication. Seizures usually resolve within 24 hours and do not typically lead to a long-term seizure disorder.

## What is the “ideal window” for DBS?

DBS is a good option for mid-stage Parkinson’s disease and is not a therapy of last resort. The best time to get DBS is generally thought to be when your Parkinson’s medications are still working but may not last as long and before Parkinson’s symptoms no longer improve with levodopa. Your neurologist and the evaluation process help determine if you are in the ideal window. It can look different for each person.



DBS is FDA approved for patients with Parkinson’s disease who have had symptoms for at least **4 years**. Medications may still be working but not lasting as long. There is no age cut-off for DBS, but your overall health and other medical conditions will be considered in determining if you are a candidate for surgery.

Notes and Questions: \_\_\_\_\_

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## What if I decide not to get DBS?

*Some people may choose to undergo Duopa or Focused Ultrasound because they do not want to pursue DBS. Others may choose one of these options because they are not a candidate for DBS.*

**Talk to your doctor about which treatment option is right for you.**

### **Duopa**

Duopa is a gel form of carbidopa/levodopa that is infused directly into the small intestine where the medication is absorbed. It can reduce OFF time, dyskinesia and carbidopa/levodopa pills. It requires the insertion of a PEG tube, which is hooked to a pump up to 16 hours per day.



### **Focused Ultrasound**

Focused ultrasound is a *one-time, irreversible* procedure in which beams of ultrasonic energy are focused on a specific area deep in the brain to reduce tremor. It is currently only done on one side of the brain, meaning it only treats one side of the body. No programming is required.



### **Clinical Trials**

New therapies may be available as part of a clinical trial.

### **Medications**

Continue your Parkinson's medications with or without changes.

**You can learn more about these options at the following websites:**

<https://www.duopa.com>

<https://www.fusfoundation.org/diseases-and-conditions/neurological/parkinsons-disease>

<https://www.michaeljfox.org/news/focused-ultrasound>

<https://www.parkinson.org/Understanding-Parkinsons/Treatment/Surgical-Treatment-Options/Duopa>

<https://clinicaltrials.gov>

## What is the evaluation process for DBS?

If you are interested in undergoing DBS surgery, you will first undergo an evaluation to determine if you are a good candidate for surgery. The testing and appointments generally occur on multiple days over several weeks. Afterwards, your DBS team will meet to review your case. The team usually includes a Movement Disorder Neurologist, Neurosurgeons, a Neuroradiologist and a Neuropsychologist. *Evaluations will likely include the following:*



**OFF/ON Testing:** This test shows how much your symptoms improve with levodopa. You arrive in clinic having not taken your PD medications for 12-24 hours. Your symptoms are measured off PD medication and then again after you take your medication. This appointment may take several hours. Some people find it uncomfortable to be off medication and may need help getting to the visit.



**Neuropsychological testing:** You have an interview and are given multiple tests to determine if there are problems with thinking and memory. The interview and tests may be scheduled on separate days and can take several hours (with breaks) to complete. It is normal to feel frustrated with some of the questions and tests.



**MRI Brain:** An MRI of the brain is done to help plan for surgery and to make sure there are no problems that would increase your risk for surgery. The MRI usually takes between 30-60 minutes to complete. If you are claustrophobic, talk with your doctor about a medication to help during the MRI.



**Neurosurgery Consultation:** You meet with the neurosurgeon to discuss DBS surgery, including risks and benefits. They give you details of the recovery process, including activity restriction after surgery.

Some centers may have you meet with additional team members:

- ❖ Neuropalliative care
- ❖ Social work
- ❖ Physical, occupational or speech therapy
- ❖ Psychiatry

Within a few weeks, your DBS team will let you know if DBS surgery is recommended based on your evaluation. Some reasons you may not be a good candidate for DBS include:

- 1) Your motor symptoms did not improve with levodopa
- 2) Your neuropsychological testing showed significant cognitive impairment
- 3) You have medical problems that increase your risk for surgery and/or anesthesia

***Even if you are a good candidate, you can choose not to have DBS surgery.  
If you delay your decision, evaluations are usually good for a year.***



# Surgery Timeline

The figure shows a typical timeline for surgeries and programming. The exact timing of surgeries may differ by center. Talk with your team to find out what your exact timeline will look like.

Depending on your center, the Week 1-3 surgeries may be done at one time.

## Timeline

**Week 1: First Lead Inserted**



### Electrode/Lead Implantation

A thin wire or lead is placed on one side of the brain. You are off Parkinson's medication the day of surgery so the surgical team can see the change in your symptoms while placing the lead. A frame is placed on your head unless you already had fiducials placed (frameless) for both surgeries to help guide the leads. Part of your hair will be shaved for lead insertion. About a week later, the second lead is placed. For both surgeries, patients usually stay in the hospital overnight.

**Week 2: Second Lead inserted**



### Neurostimulator

After the leads are placed, you return a week or so later to have the neurostimulator placed. It is often placed in the chest below the collarbone. You usually do not stay in the hospital after this surgery.

**Week 3: Neurostimulator Placed**



**~Week 5-7: Initial Programming**



### Programming

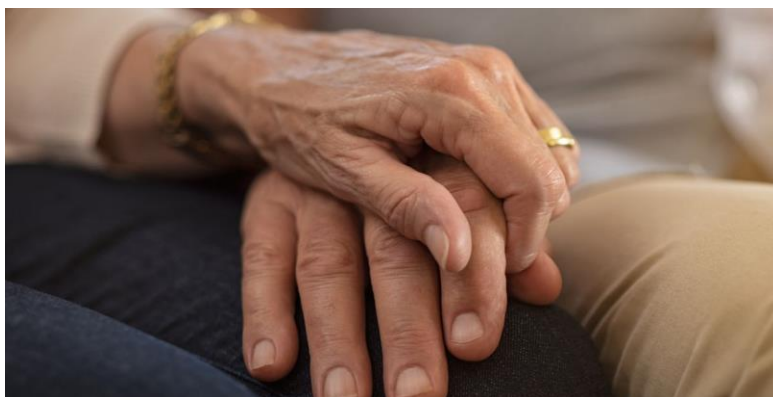
Several weeks after your last surgery, your doctor will turn on your DBS and try different ways to program your device. You come to this session off medication. Every few weeks to months, you will return for adjustments to your DBS and medications to try to further reduce your symptoms. It can take up to 6 months or longer to find the optimal combination of DBS settings and medication. Your medications are usually slowly decreased after programming starts. Your own patient programmer device will allow you to turn the stimulator off and on and to possibly increase and decrease stimulation if your doctor enables it. Programming can take up to an hour or more per session.

**Week 8 and beyond: Follow-up programming**



**Awake and Asleep.** During the part of the surgery when leads are inserted, the person is often awake. You receive conscious sedation, so you are not fully awake and you will be asleep for other parts of the surgery and for neurostimulator placement. Some centers only perform asleep surgery in which the person receives general anesthesia and is asleep for the entire surgery. An MRI or CT scan is used to help place the lead. Talk with your team about which surgeries are offered at your center and which may be better for you.

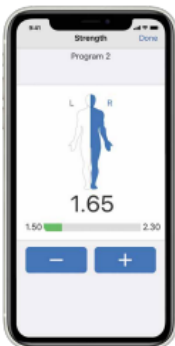


**What help or support might I need before, during and after DBS surgery?**



Activity	Support Needed
DBS evaluation appointments	<ul style="list-style-type: none"> <li>• It is helpful to have someone accompany you to the evaluation appointments to help take notes and ask questions. These appointments can be long and tiring.</li> <li>• You will likely need someone to drive you to your OFF-medication evaluation. You may need other help, such as getting in and out of the car.</li> </ul>
Deciding whether to get DBS	<ul style="list-style-type: none"> <li>• It can be very helpful to talk with others who have undergone DBS surgery. Ask your DBS team if they can help connect you with someone who has had surgery.</li> <li>• You may also meet others who have had surgery at support groups and other local Parkinson association events.</li> </ul>
Surgery	<ul style="list-style-type: none"> <li>• If you live far away from the center where surgery is being performed, you may want to consider staying in a hotel the night before.</li> <li>• Because you are OFF your Parkinson’s medication, you will likely need help getting to the hospital. You will usually stay in the hospital overnight and will need someone to drive you home from the hospital.</li> <li>• Some prefer to stay in the hotel the night after discharge to rest before the long drive home.</li> </ul>
Days after surgery	<ul style="list-style-type: none"> <li>• You will likely be very tired and need help with many of your daily activities. Rest when you are feeling tired.</li> <li>• If you do not have a caregiver who can stay with you after surgery, talk with your team about your options for help, including home health and local Parkinson association volunteers.</li> <li>• Many people have told us it is helpful to make and freeze meals before surgery, so they are ready when you get home. Ordering meals can be helpful as well.</li> </ul>
Weeks after surgery	<ul style="list-style-type: none"> <li>• Your neurosurgeon will give you post-op instructions and limitations at discharge. These will include restrictions on driving and lifting, which are generally around 2 weeks. Strenuous activities, such as running, will be restricted longer.</li> <li>• There will be many appointments after DBS surgery, including post-op appointments with the neurosurgeon and programming appointments with your neurologist. While under driving restrictions, you will need someone to bring you to the appointments. It can also be helpful to have someone with you to take notes.</li> </ul>
After recovery	<ul style="list-style-type: none"> <li>• Many people can return to work or their regular activities after 4-6 weeks. Talk with your DBS team to make sure you are ready to return.</li> </ul>

# Choosing a Device

There are three companies that make DBS devices - Abbott, Boston Scientific, and Medtronic. All three devices offer directional programming, which allows your neurologist to direct the stimulation to areas of the brain that improve Parkinson's symptoms and away from areas that cause side effects. All are considered MRI conditional, meaning patients with these devices can have an MRI done as long as certain conditions are met. The table below shows some of the unique features of each device.

	Abbott	Boston Scientific	Medtronic
<b>Unique Features</b>	<p><b>Virtual Clinic</b> Programming can be done without you having to come to the clinic. Keep in mind that the virtual clinic feature works as well as your internet connection. Also, if you live out of state, your neurologist will have to have a license in your state in order to do virtual programming with you in your home.</p>	<p><b>Precision Therapy</b> They are known for their multiple independent current control (MICC) which, along with a directional lead, allows precise and sensitive control of therapy.</p> <p><b>Image Guided Programming</b> Allows programmers to see where leads are located, which may decrease the time needed for programming.</p>	<p><b>Brain Sense Technology</b> Brain sensing technology can capture and store brain signals, which may be used by your neurologist to adjust your settings.</p> <p><b>Digital Diary</b> The patient programmer contains a digital diary that enables patients to track events, such as taking medication.</p>
<b>Patient Controller</b>	<p><b>Apple device</b> Can also download app to your own iPhone.</p> 	<p><b>Standard controller</b> Can be good for those who prefer to avoid smartphones</p> 	<p><b>Samsung device</b></p> 
<b>Batteries</b>	Non-rechargeable & Rechargeable	Non-rechargeable & Rechargeable	Non-rechargeable & Rechargeable



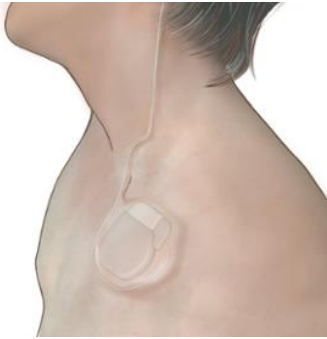
## Websites

Abbott: <https://www.neuromodulation.abbott/us/en/parkinsons.html>

Boston Scientific: <https://www.dbsandme.com/en.html>

Medtronic: <https://www.medtronic.com/us-en/patients/treatments-therapies/deep-brain-stimulation-parkinsons-disease.html/>

# Choosing a Battery

	Non-Rechargeable	Rechargeable
<b>Longevity</b>	On average, these batteries last three to five years.	These batteries may last up to 15 years.
<b>Size</b>	These batteries are larger. 	These batteries are smaller. 
<b>Considerations</b>		
<b>Number of surgeries</b>	More frequent surgeries to replace these batteries since they last 3-5 years.	Less frequent surgeries to replace these batteries since they last up to 15 years.
<b>Charging</b>	Does not require charging.	Requires a commitment to charge the battery at regular intervals to maintain therapy.*
<b>Placement</b>	 <p>The battery is placed in the chest just below the collar bone. Some batteries are best positioned on the right side, while others can be placed on either side. Some considerations include your handedness and if you have hobbies, such as rifle shooting, that would affect the ideal location of the battery.</p>	

\*The amount of time required to recharge the battery depends on the specific settings and brand of battery.

Take some time to **CONSIDER** what you have learned about DBS and think about what is most important to you. Do your expectations and hopes for DBS match what DBS can do?

**Which Parkinson’s symptoms bother you the most?**

<i>Symptoms that can improve with DBS</i>	<i>Symptoms that may not improve with DBS</i>
<ul style="list-style-type: none"> <li><input type="checkbox"/> Slowness</li> <li><input type="checkbox"/> Stiffness</li> <li><input type="checkbox"/> Shaking (tremor)</li> <li><input type="checkbox"/> Times when medications are not working well (OFF time)</li> <li><input type="checkbox"/> Involuntary movements from levodopa (dyskinesia)</li> <li><input type="checkbox"/> Freezing of gait (feet sticking to floor)</li> <li><input type="checkbox"/> Toe curling, foot turning inward</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Balance trouble</li> <li><input type="checkbox"/> Thinking/memory problems</li> <li><input type="checkbox"/> Depression, anxiety</li> <li><input type="checkbox"/> Lack of motivation (apathy)</li> <li><input type="checkbox"/> Constipation</li> <li><input type="checkbox"/> Bladder issues</li> <li><input type="checkbox"/> Changes in voice or speech</li> <li><input type="checkbox"/> Acting out dreams</li> <li><input type="checkbox"/> Other _____</li> </ul>

What symptoms ***must*** get better for you to consider DBS successful for you?

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What risks really concern you? \_\_\_\_\_

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**What are your biggest questions...**

...for your doctor or surgeon? \_\_\_\_\_

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...for your caregiver or family? \_\_\_\_\_

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...for patients with DBS? \_\_\_\_\_

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## **Definitions**

**Tremor** – An involuntary, rhythmic shaking of part of the body. It often affects the hands, but can also affect the legs, chin, lips or face.

**Bradykinesia** – Slowness of movement. Daily activities may take longer.

**Rigidity** – Muscle stiffness that can occur in any part of the body. It can limit range of motion.

**Dyskinesia** – involuntary movement that can look like fidgeting, wriggling or body swaying due to long-term levodopa use.

**Dystonia** – When muscles contract, causing part of the body to curl or twist. Examples include curling of the toes or in turning of the foot.

**Postural instability** – Trouble with balance making someone unsteady when standing. It increases the risk of falls, especially backwards

**Freezing of gait** – Sudden inability to move when walking or feeling like your feet are stuck to the floor.

**Motor symptoms** – The three main motor symptoms of Parkinson's disease are tremor, bradykinesia and rigidity.

**Non-motor symptoms** – These are symptoms that are related to Parkinson's disease but do not cause movement trouble. Some examples include anxiety, depression, memory and thinking changes, constipation, fatigue and urinary frequency and/or urgency.

**ON Time** – The periods of time when Parkinson's medications are working well and controlling Parkinson's symptoms.

**OFF Time** – The periods of time when Parkinson's medications have worn off or are not working well and Parkinson's symptoms return. This can include motor and non-motor symptoms.

**Motor fluctuations** – Variations throughout the day in motor function. People may have periods of ON time, when medications are working well, alternating with OFF time, when medications are not working well.

# Questions to Ask your DBS Ambassador\*

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## Timing of DBS

- How did you decide it was the right time for DBS?
  - Do you wish you had done it sooner? Waited longer?
  - What benefits of DBS stood out to you and helped you make your decision?
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## DBS Evaluation

- What was the evaluation process like?
  - How hard was it for you to be off medications for the OFF/ON testing?
  - Did you find the neuropsychiatric testing difficult or frustrating?
- 

## Decision Making

- What were your goals for DBS?
  - What hesitations or concerns did you have about DBS?
  - Did you consider any other options?
  - What information resources did you find helpful to learn more about DBS and make your decision?
  - How did you decide which device/system to get?
  - Would you do it all again? Are you satisfied with the outcome?
- 

## Surgery Experience

- What was the surgery like? What was it like to be awake during it?
  - How much of your hair did they have to shave? Did it grow back well?
  - What was it like to wear the halo (frame) or have the frameless system?
  - Is there anything you wish you had known before having surgery?
  - Anything you wish you had brought with you to the hospital?
- 

## Recovery

- How much help did you need after each surgery?
  - When were you able to return to your normal activities?
  - When were you able to return to work?
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## Life with DBS

- What does DBS feel like when stimulation is on?
  - How did you decide where to have your battery placed?
  - How much were you able to decrease your Parkinson's medications?
  - How have your symptoms improved or changed after DBS?
  - How has your quality of life changed? Are you more independent in your activities now?
  - Is there anything that DBS did not help with that you had hoped or expected it would? Anything you wish you had known?
  - If you could do it again, would you?
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*\*your experience may be different from that of your Ambassador. Some people like to talk with more than one person who has had DBS to hear about the differences in experience.*

# Questions to Ask your Doctor or Surgeon

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## Timing of DBS

- Am I a good candidate for DBS?
  - Is now a good time to consider DBS for me?
  - How long do the effects of DBS last?
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## DBS Evaluation

- What tests will I have before DBS?
  - What were the results of my tests?
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## Decision Making

- Which of my symptoms should improve with DBS?
  - What are the possible side effects of DBS? Am I at increased risk for any of them?
  - Is there a specific device/system that you would recommend for me?
  - How many surgeries do you do per month?
  - What kind of complications do you see? How often do they occur?
  - If I choose not to have DBS, what are my other options?
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## Surgery Experience

- Do I need to stop my Parkinson's medications before surgery? When?
  - How many surgeries will I have?
  - How long will I stay in the hospital after each one?
  - How much of my head will be shaved?
  - Will I be awake during surgery?
  - Which part of the brain will the lead be placed in? Do you recommend one side or both sides?
  - Where will the neurostimulator (battery) be placed?
- 

## Recovery

- What restrictions will I have after surgery?
  - When will I be able to return to normal activities? When will I be able to drive?
  - When will I be able to return to work?
  - When will I be able to travel or fly after DBS? Go through metal detectors?
- 

## Life with DBS

- How often will I come in for programming? Who does the programming?
  - Will I be able to decrease my Parkinson's medications? When and by how much?
  - How often will the battery need to be replaced? If rechargeable, how often and for how long will I need to recharge?
  - Will I be able to make any adjustments to my stimulator in between appointments?
  - How does having DBS affect my ability to get MRIs? Mammograms?
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## **Development of This Tool**

### **Authors**

The authors of this decision aid are a team of researchers and clinicians with expertise in movement disorders, shared decision-making and decision aid development, and qualitative and mixed methods. The steering group who critically reviewed this decision aid was made up of movement disorder neurologists, functional neurosurgeons, neurophysiologist and DBS nurses and navigators.

- 1) Michelle Fullard, MD, MS is an Assistant Professor of Neurology in the Division of Movement Disorders at the University of Colorado and Director of Clinical Research for the division.
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### **References**

To develop this decision aid, we reviewed studies, meta-analyses and systematic reviews on DBS outcomes. The majority of these studies were randomized clinical trials, which is the highest level of clinical evidence available. We conducted interviews with people with Parkinson's disease who had either undergone DBS or had considered DBS but decided not to undergo surgery. In these interviews, we asked people how they made their decision about undergoing DBS and about their experience with DBS. We combined the findings from the literature and interviews to develop a DBS decision aid prototype. We showed this prototype to people with Parkinson's disease who had

undergone DBS or were considering DBS to get their feedback on the tool. After each round of interviews, we made changes to the decision aid and then presented it to another group. This process continued until no new feedback was obtained. The tool was then presented to the Colorado Program for Patient Centered Decisions Patient and Family Research Advisory Panel for additional feedback. Lastly, the tool was presented to the Steering Group and final changes were made.

Members of the research team will continue to review the clinical evidence yearly and revise the content of the decision aid to ensure it is up to date.

1. Mahlknecht P, Foltynie T, Limousin P, Poewe W. How Does Deep Brain Stimulation Change the Course of Parkinson's Disease? *Mov Disord* 2022;37:1581–92.
2. Deuschl G, Schade-Brittinger C, Krack P, Volkmann J, Schäfer H, Bötzel K, et al. A Randomized Trial of Deep-Brain Stimulation for Parkinson's Disease. *N Engl J Med* 2006;355:896–908.
3. Williams A, Gill S, Varma T, Jenkinson C, Quinn N, Mitchell R, et al. Deep brain stimulation plus best medical therapy versus best medical therapy alone for advanced Parkinson's disease (PD SURG trial): a randomised, open-label trial. *Lancet Neurol* 2010;9:581–91.
4. Okun MS, Gallo B V., Mandybur G, Jagid J, Foote KD, Revilla FJ, et al. Subthalamic deep brain stimulation with a constant-current device in Parkinson's disease: an open-label randomised controlled trial. *Lancet Neurol* 2012;11:140–9.
5. Weaver FM, Follett K, Stern M, Hur K, Harris C, Marks WJ, et al. Bilateral deep brain stimulation vs best medical therapy for patients with advanced parkinson disease: A randomized controlled trial. *JAMA - J Am Med Assoc* 2009;301:63–73.
6. Vitek JL, Jain R, Chen L, Tröster AI, Schrock LE, House PA, et al. Subthalamic nucleus deep brain stimulation with a multiple independent constant current-controlled device in Parkinson's disease (INTREPID): a multicentre, double-blind, randomised, sham-controlled study. *Lancet Neurol* 2020;19:491–501.
7. Schuepbach WMM, Rau J, Knudsen K, Volkmann J, Krack P, Timmermann L, et al. Neurostimulation for Parkinson's disease with early motor complications. *N Engl J Med* 2013;368:610–22.
8. Daniels C, Krack P, Volkmann J, Raethjen J, Pinski MO, Kloss M, et al. Is improvement in the quality of life after subthalamic nucleus stimulation in Parkinson's disease predictable? *Mov Disord* 2011;26:2516–21.
9. Lachenmayer ML, Mürset M, Antih N, Debove I, Muellner J, Bompert M, et al. Subthalamic and pallidal deep brain stimulation for Parkinson's disease-meta-analysis of outcomes. *NPJ Park Dis* 2021;7: 77.
10. Perestelo-Pérez L, Rivero-Santana A, Pérez-Ramos J, Serrano-Pérez P, Panetta J, Hilarion P. Deep brain stimulation in Parkinson's disease: meta-analysis of randomized controlled trials. *J Neurol* 2014;261:2051–60.
11. Mansouri A, Taslimi S, Badhiwala JH, Witiw CD, Nassiri F, Odekerken VJJ, et al. Deep brain stimulation for Parkinson's disease: meta-analysis of results of randomized trials at varying lengths of follow-up. *J Neurosurg* 2018;128:1199–213.









