Surgery for Parkinson's Disease - Patient Information

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Introduction

<u>Parkinson's Disease</u> (PD) is a neurologic disorder that results from a gradual loss of nerve cells in the brain that produce a chemical called dopamine. We do not know what causes these nerve cells to disappear, but the loss of dopamine within the brain causes a variety of symptoms related to movement, including tremor, stiffness, slowness, and trouble with gait and balance. Patients with Parkinson's often also have other symptoms that are not related to movement: loss of sense of smell, trouble with sleep, constipation, dizziness, and others. Symptoms are progressive, meaning that they worsen gradually over time.

Treatment for Parkinson's often begins with replacing dopamine using medications - the most common being Sinemet (carbidopa/levodopa). For patients who develop problems with medications or whose symptoms stop responding to medications, surgery should be considered.

What is the surgery for Parkinson's?

For the past 20 years, the most common and effective surgery for PD in the United States has been <u>deep brain stimulation (DBS)</u>. DBS involves inserting a tiny wire into the brain. The wire delivers targeted, painless pulses of electricity that disrupt the abnormal brain rhythms that contribute to the movement symptoms of PD. The wire runs under the skin and is connected to a small battery that is implanted under the collarbone, similar to a heart pacemaker. DBS has a number of benefits for patients with PD, described in more detail below.

Recently, another procedure called <u>MRI-guided focused ultrasound</u> was approved by the US Food and Drug Administration for treating PD. The procedure does not require a brain implant or hospital stay, but it is limited in that it only treats tremor. When used for Parkinson's, **it is also not covered by any insurance companies**.

I perform both DBS and focused ultrasound. Additional information on the benefits of DBS vs focused ultrasound is provided below.

Who should consider surgery for Parkinson's?

You should consider surgery for PD if all of the following are true:

- 1. A neurologist has diagnosed you with PD.
- 2. You have problems such as needing to dose your medications frequently during the day, dyskinesias (uncontrolled writhing or spasms), or bothersome tremor or dystonia despite medications.
- 3. Your movement symptoms interfere with your daily activities and enjoyment of life.
- 4. You do not have signs of dementia.

What are the benefits of DBS for PD?

DBS has been studied in a number of randomized, controlled trials - the gold standard in medicine. These trials have established the following benefits:

- Improvement in tremor, stiffness, slowness, and other movement symptoms.
- More time per day at your best level of movement function (4-5 extra hours).
- Reduction in your medication doses.
- Improvement in your ability to perform everyday tasks.
- Improvement in your quality of life.

Which of my PD symptoms can I expect to improve with DBS?

DBS is effective for improving the *movement* symptoms of PD (tremor, stiffness, etc.). It is not effective for non-movement symptoms like sleep problems, constipation, dizziness, etc.

A good rule of thumb is that the PD symptoms that improve with Sinemet (carbidopa/levodopa) will likely also improve with DBS. An exception to this rule is tremor, which almost always improves with DBS - even if it is no longer helped by medications.

What are the benefits of focused ultrasound for PD?

Focused ultrasound was developed first as a treatment for patients with a disorder called <u>Essential Tremor (ET)</u>. The tremor of ET looks different than the tremor of PD, but focused ultrasound is effective for both.

Unlike DBS, focused ultrasound *only helps the tremor in PD; it does not help other PD symptoms*. Importantly, it is not an option yet for most patients because it is not yet covered by insurance.

Which procedure is better for me - DBS or focused ultrasound?

Deciding between DBS and focused ultrasound involves a thoughtful discussion between you, me, and your neurologist regarding your symptoms, goals, and medical history.

With that in mind, <u>most patients with PD will have a better outcome with DBS than with</u> <u>focused ultrasound</u>. DBS helps with many movement symptoms, while focused ultrasound helps only with tremor.

Exceptions to this statement include older patients or those who are not healthy enough to have DBS as well as patients whose only significant symptom is tremor.

Once again, please keep in mind that focused ultrasound is currently not covered by insurance (including Medicare) for Parkinson's, so it is only an option if a patient is willing to consider a cash-pay option.

Do I need testing to confirm I am a candidate for surgery?

Testing before DBS includes a neuropsychological exam and, in some cases, a levodopa sensitivity challenge.

The neuropsychological exam involves a meeting with a specialized doctor who will perform a detailed cognitive and emotional assessment. The purpose of this exam is to screen for signs of dementia related to PD as well as for untreated psychiatric disorders. If you have not had this exam, I will arrange for one.

In some cases, I will request a levodopa sensitivity test (also known as an ON-OFF test) before DBS. This involves a brief exam with a neurologist or physical therapist when you have not taken your PD medications and again after you have taken them. The purpose is to confirm that the medications indeed help your movement symptoms. As a reminder, the best predictor of a good response to DBS is a good response to medications like Sinemet.

Before focused ultrasound, a special CT scan of your brain is required. The CT scan evaluates the density of your skull to confirm that the ultrasound waves will penetrate it and reach the target in the brain. Most patients have suitable skull densities, but around 15% of patients have skull densities that are too low; these patients are not candidates for focused ultrasound.

Is there an age limit for surgery?

No. Your overall physical health and your performance on the neuropsychological exam matter much more than your age.

What are possible side effects of these procedures?

Significant side effects are possible but not common after DBS. The main side effect I highlight to patients is a possible temporary period of confusion immediately after surgery. This may take a few days to a week or two to resolve. Studies have also documented subtle, long-term changes in cognitive measures including verbal fluency, but in my experience this is rarely noticeable to patients (provided they are chosen carefully).

Side effects are common in the first few weeks after focused ultrasound, especially trouble with gait or balance. Most of these side effects improve time, but a small percentage of patients may have permanent side effects. Common side effects include trouble with balance or coordination, slurring of speech, and tingling or numbness - usually in the hand.

Will the procedure be covered by my insurance?

DBS is (almost) always covered - regardless of your carrier or policy. My office will obtain a *pre-authorization* from your insurance company to confirm that it will be covered before we schedule your surgery. The actual cost to you depends on the particulars of your insurance plan (i.e. your policy's out-of-pocket or deductible).

Focused ultrasound is not yet covered by insurance - including Medicare - when used for Parkinson's Disease - even though it is approved by the FDA. A cash pay option is available, but the cost is not affordable for most patients, unfortunately (approximately \$30,000).

Where can I read more about the procedures themselves and what to expect?

Posted on my website are both a <u>DBS patient guide</u> and a <u>focused ultrasound patient</u> <u>guide</u>. These guides review how to prepare for surgery, what to expect after, etc.

Where can I learn more?

My <u>website</u> is an excellent resource for patients wanting to learn more about PD and the procedures I perform. Here is a list of relevant links from the site:

- Parkinson's Disease
- Deep Brain Stimulation
- Deep Brain Stimulation Guide for Patients
- Focused Ultrasound
- Focused Ultrasound Guide for Patients