FAQ for Patients: Deep Brain Stimulation for Essential Tremor (ET)

When should one consider surgical therapy?

For patients with essential tremor, primidone and other anti-tremor medications are frequently effective for maintaining a good quality of life. As the disorder progresses, however, medications can become less effective, and/or be associated with side effects (e.g.-depression) at the high doses that are needed to control the tremor. When patients no longer have an acceptable quality of life due to these shortcomings of medical therapy, surgical treatment should be considered.

What are the different types of surgery for essential tremor?

There are several different types of surgery for essential tremor. The first surgical procedures developed were the ablative, or brain lesioning, procedures. An example of lesioning surgery includes thalamotomy. Lesioning surgery involves the precisely controlled destruction, using a heat probe, ultrasound, or radiation (Gamma Knife Surgery), of a small region of brain tissue that is abnormally active. It produces a permanent effect on the brain. In general, it is not safe to perform lesioning on both sides of the brain.

We continue to perform some lesioning surgeries for patients who desire it, although in our practice lesioning has been largely replaced by deep brain stimulation (DBS). DBS surgery involves placing a thin metal electrode (about the diameter of a piece of spaghetti) into an appropriate brain target and attaching it to a computerized pulse generator, which is implanted under the skin in the chest (much like a heart pacemaker). All parts of the stimulator system are internal; there are no wires coming out through the skin. To achieve maximal relief of symptoms, the stimulation can be adjusted during a routine office visit by a physician or nurse using a programming computer held next to the skin over the pulse generator. Unlike lesioning, DBS does not destroy brain tissue. Instead, it reversibly alters the abnormal function of the brain tissue in the region of the stimulating electrode. DBS is the procedure most often recommended in many Movement Disorders Surgery Programs. Although deep brain stimulation is a major new advance, it is a relatively complicated therapy that may demand considerable time and patience before its effects are optimized.
What are the possible brain targets for DBS?

There is one major target site in the brain that is selected for placement of stimulating electrodes for essential tremor: a subdivision of the thalamus referred to as Vim (ventro-intermediate nucleus). This structure is a small cluster of nerve cells that play a critical role in the control of movement. Thalamic (Vim) stimulation is highly effective for the treatment of tremor in the arms and legs, and occasionally in the head and neck. This target was approved by the U.S. Food and Drug Administration (FDA), which oversees medical devices, in 1997.

How does DBS work?

First you need to understand the source of your symptoms. When you experience symptoms of tremor or abnormal movements, the source of these problems is not in the muscles themselves but in the brain! Science has shown that bad, or abnormal, electrical brain activity is one reason why you experience Parkinson’s disease, essential tremor, or dystonia. This irregular, or abnormal, brain activity can be fixed by very small, safe amounts of electricity delivered directly into the brain so that it discharges, or fires, more normally. This is why deep brain stimulation (DBS) is sometimes referred to as a “brain pacemaker.” Like the heart, the brain will start working better when it receives small, regular pulses of electricity through the DBS system.

How is the surgery performed?

In the most common method, implantation of the brain electrode is performed with the patient awake, using only local anesthetic and occasional sedation. The basic surgical method is called stereotaxis, a method useful for approaching deep brain targets though a small skull opening. For stereotactic surgery, a rigid frame is attached to the patient's head just before surgery, after the skin is anesthetized with local anesthetic. A brain imaging study (MRI or CT) is obtained with the frame in place. The images of the brain and frame are used to calculate the position of the desired brain target and guide instruments to that target with minimal trauma to the brain. After frame placement, MRI/CT, and calculation of the target coordinates on a computer, the patient is taken to the operating room. At that point an intravenous sedative is given, a Foley catheter is placed in the bladder, the stereotactic frame is rigidly fixed to the operating table, a patch of hair on top of the head is shaved, and the scalp is washed. After giving local anesthetic to the scalp to make it completely numb, an incision is made on top of the head behind the hairline and a small opening (1.5 centimeters, about the size of a nickel) is made in
the skull. At this point, all intravenous sedatives are turned off so that the patient becomes fully awake.

To maximize the precision of the surgery, we employ a "brain mapping" procedure in which fine microelectrodes are used to record brain cell activity in the region of the intended target to confirm that it is correct, or to make very fine adjustments of 1 or 2 millimeters in the intended brain target if the initial target is not exactly correct. The brain mapping produces no sensation for the patients, but the patient must be calm, cooperative, and silent during the mapping or else the procedure must be stopped. The brain's electrical signals are played on a stereo speaker so that the surgical team can hear the signals and assess their pattern. The electronic equipment is fairly noisy, and the members of the surgical team often discuss the signals being obtained so as to be sure to interpret them correctly. Since each person's brain is different, the time it takes for the mapping varies from about 30 minutes to up to 2 hours for each side of the brain. The neurological status of the patient (such as strength, vision, and improvement of motor function) is monitored frequently during the operation, by the surgeon or by the neurologist.

When the correct target site is confirmed with the microelectrode, the permanent DBS electrode is inserted and tested for about 20 minutes. The testing focuses on relief of tremor and on unwanted stimulation-induced side effects. For the testing, we deliberately turn the device up to a higher intensity than is normally used, in order to deliberately produce unwanted stimulation-induced side effects (such as tingling in the arm or leg, difficulty speaking, a pulling sensation in the tongue or face, or flashing lights). The sensations produced at high intensities of stimulation during this testing are experienced as strange but not painful. We thus confirm a good “therapeutic window,” or demonstrate that the stimulation intensity (e.g.-power) needed to produce side effects is much higher than the intensity needed to help stop the patient’s symptoms.

Once the permanent DBS electrode is inserted and tested, intravenous sedation is resumed to make the patient sleepy, the electrode is anchored to the skull with a plastic cap, and the scalp is closed with sutures. The stereotactic headframe is removed and the patient is taken to the recover room.

**What are the cosmetic considerations with DBS surgery?**

Complete shaving of the head is not necessary for surgery. However, patches of hair on top of the head and behind the ear are shaved immediately before surgery when the patient is sedated. Many patients elect to get a short haircut after surgery (must be at least
2 weeks afterwards) so that the hair grows in evenly.

There are generally 3 incisions made on each side for DBS: a 5 cm (2 inch) incision on top of the head, a 2.5 cm (1 inch) incision behind the ear, and a 6 cm (2.5 inches) incision in the chest just under the clavicle. For patients with receding hairlines, a slight scar from an incision will be visible on top of the head, but is not especially prominent. The cap used to anchor the DBS electrode (under the scalp) forms a slight bump, which again may be visible in the case of a receding hairline.

There is often puffiness around the eyes for a few days after surgery, but this goes away rapidly.

All parts of the device are internal (under the skin), so there are no wires sticking out. In a thin person, the connecting wire running down the neck may be visible as a slight bulge when the head is turned all the way to the opposite side. The incision for the pulse generator in the chest is closed with particular attention to minimize scar formation; this incision would be visible with the shirt off, or in a swimsuit, or in a low-cut evening gown. In thin persons, the pulse generator itself forms a bulge under the skin in the pectoral area that may be apparent if the area is uncovered, but is not visible through clothing.

**Would both sides of the brain be done at once, or only one side?**

DBS on one side of the brain mainly affects symptoms on the opposite side of the body. Most patients have symptoms on both sides of the body and thus require both sides of the brain to be implanted for maximal benefit. Depending on the particular case, we may offer "simultaneous bilateral" procedures, or implantation of both leads in a single surgery, to many patients. The brain side opposite the most affected body side is implanted first. Then, if the patient and anesthesiologist agree to proceed, the second side is then implanted. For elderly patients, or patients concerned about a longer operation, it may be best to stage the procedures several months apart.

**What are the benefits of DBS surgery?**

The major benefit of DBS surgery for ET is that it can control tremor in the arms and legs, as well as in the head and neck. Thus, the procedure is most beneficial for patients who are experiencing significant disability from tremors in one or more of these areas. Although we expect a dramatic reduction in tremor after deep brain stimulation,
frequently patients can still experience a small degree of tremor, particularly in stressful situations, even after surgery.

**What are the risks of DBS surgery?**

The most serious potential risk of the surgical procedures is bleeding in the brain, producing a stroke. This risk varies from patient to patient, depending on the overall medical condition, but the average risk is about 2%. If stroke occurs, it usually occurs during, or within a few hours of, surgery. The effects of stroke can range from mild weakness that recovers in a few weeks or months to severe, permanent weakness, intellectual impairment, or death. The second most serious risk is infection, which occurs in about 4-5% of patients. If an infection occurs, it is usually not life threatening, but it may require removal of the entire DBS system. In most cases, a new DBS system can be re-implanted when the infection is eradicated. Finally, hardware may break or erode through the skin with normal usage, requiring it to be replaced.

In the first few days after surgery, it is normal to have some temporary swelling of the brain tissue around the electrode. This may produce no symptoms, but it can produce mild disorientation, sleepiness, or personality change that lasts for up to 1-2 weeks.

**What makes a patient a good candidate for DBS for essential tremor?**

In determining whether a patient is a good candidate for surgery, we look for the following:

**Intact intellectual function and memory.** Dementia (significantly impaired memory or thinking) is a major contraindication to surgery, since such patients have great difficulty tolerating the surgery, may have further loss of intellectual function due to the surgery, deal poorly with the complexity of DBS therapy, and realize little overall functional benefit.

**Certainty of diagnosis.** A number of illnesses can look like essential tremor, including dystonic tremor and tremor associated with multiple sclerosis. Other types of tremor may not respond to DBS as well as true essential tremor.

**Lack of other untreated or inadequately treated illnesses.** Serious cardiac disease, uncontrolled hypertension, or any major other chronic systemic illness increases the risk and decreases the benefit of surgery.

**Realistic expectations.** People who expect a sudden miracle are disappointed with the results, and they may have difficulty with the complexity of the therapy.

**Patient age.** The benefits of DBS for PD decline with advancing age, and the risks go
up. We rarely offer surgery to a person over 85 and would only consider it if they are in otherwise excellent health, are cognitively intact, and have good function. For patients over 80, the benefits can be modest.

**MRI of the brain should be free of severe vascular disease, extensive atrophy, or other abnormalities.**

**What tests are needed prior to surgery?**

Patients should have a brain imaging study (MRI or CT) to determine if there are problems in the brain that would pose excessive risk for surgery, unless one has been done within 2-3 years. Patients will have a formal neurological exam and rating scale evaluation by one of our neurologists. Patients may or may not be recommended for formal neurropsychological testing, which is done by our neuropsychologist. All patients with a history of significant depression or anxiety are sent to neurropsychological testing prior to DBS to make sure he/she will be able to tolerate brain surgery successfully. All patients must have a blood test (mainly for blood clotting ability) and visit with the anesthesiologists in the week prior to surgery.

**How should the patient prepare for surgery?**

For 10 days prior to surgery, patients must not take aspirin, any aspirin containing drugs, related drugs such as ibuprofen (Advil, Motrin) or naproxen (Naprosyn), or Vitamin E. These drugs can increase the risk of bleeding. The evening before surgery, patients should wash their head, neck, and chest with hibiclens (or other soap containing chlorhexidine) in the shower. The morning of surgery, the patient should take any medications they normally take for other problems, such as high blood pressure, as instructed by the anesthesia clinic at the preoperative visit. Patients should inform the surgeon if they develop a cold, cough, or any type of infection in the days prior to the surgery. Patients should hydrate (drink a lot of non-alcoholic, non-caffeinated drinks) prior to surgery.

**What type of follow-up is needed after surgery? Who will program the DBS unit?**

Patients normally leave the hospital two to three days after DBS brain surgery. Patients will return to our hospital approximately 1 week later for suture removal of the head incision and placement of the extension wire and the battery in the chest area under general anesthesia. This is an outpatient procedure that takes 1 to 2 hours. You will be able to go home the same day. You will then follow-up with us in 2 weeks for a check of the incisions by our DBS nursing specialist, and a programming session with our
neurologist in the Surgical Movement Disorders Clinic. Some patients have temporary disorientation or sleepiness for a few days after surgery due to temporary brain swelling, and if this occurs programming is deferred until the mental state completely returns to baseline. For subsequent programming needs after the initial stimulator activation, the patient is welcome to continue in our Surgical Movement Disorders Clinic. For patients who have neurologists outside of LSU who are comfortable with programming, it is often most convenient to return to their regular neurologist. We are happy to advise referring neurologists regarding programming strategies.

In the first month following DBS implantation, some patients may develop an infection of the device or of the skin over the device. This would present as drainage, increasing redness, increasing swelling, or increasing pain starting a few days to a few weeks post-surgery. It is very important to let our office know IMMEDIATELY if such signs are noted, since early wound care may be effective at salvaging the device. If such symptoms are ignored for even a few days, however, the patient will usually have to have all of the hardware removed.

Patients will typically require replacement of the battery, or pulse generator, after 3-5 years, depending on the exact settings of the device. This is an outpatient procedure that takes about 1 hour.

**How long does it take before the full benefit of DBS is apparent?**

The DBS effect on tremor is usually immediate after the device is turned on at the first programming visit.

**What types of batteries or pulse generators (implanted DBS control unit) are available?**

As of 2014, there are 3 types of pulse generators in PD patients, all made by Medtronic, Inc.: Activa SC, Activa PC, and Activa RC. The choice of pulse generator for an individual patient is based on considerations of size of the device, desire for patient control over the stimulation level (see below), and need for recharging.

The Medtronic Activa RC is a re-chargeable pulse generator. It has the advantage of a very long interval (estimated at 9 years) prior to the need for surgical replacement. It has the disadvantage that the patient must charge it with a device strapped over the pulse generator, for a few minutes every day or for a few hours each week. At this time, we are recommending the Activa RC only for patients with existing DBS systems who have
used up their non-rechargeable system less than 2 years from implantation. Patients must have a teaching session preoperatively about the recharging requirements, to make sure they are willing to do this.

**Can patients control the DBS device themselves?**

Following surgery, the patient is given the Medtronic Access Review unit, a hand-held battery-operated programmer that can be used to determine if the device is on or off, to turn it on or off, to check battery life, and to change settings such as voltage. All devices can be turned on or off by the patient.

**Are there any restrictions on a person's activity after a DBS system is implanted?**

For at least 4 days after surgery, the patient should refrain from flying in commercial aircraft. For one week after surgery, the incisions should be kept dry, so for showering in the first week incisions must be covered with an occlusive dressing. Tight clothing or tightly fitting hats should be avoided in the two weeks after surgery. After the incisions are completely healed (4 weeks), the patient may return to all normal activities, including exercise. Normal physical activities will not harm the device. Security devices (such as those in airports or stores) will not harm the device or the patient, although in rare cases they may activate the on-off switch, thus turning off a DBS system that had been on. The loss of benefit to the patient may take minutes or hours to be apparent. When traveling extensively away from home, patients should carry their Medtronic Access Review programmer so that they can easily re-activate the DBS system if it is de-activated by a security device.

**Can I have an MRI scan after DBS?**

After DBS implantation, patients should avoid most types of MRI exams, as the exam may produce heating of the brain electrode. At LSU and WKHS, we have developed a specialized, low energy protocol for brain MRI, allowing us to perform postoperative brain MRI safely. However, we do not recommend any other forms of MRI (such as spine or chest MRI), because safe conditions for performing these have not been worked out.

**Is DBS surgery covered by health insurance?**
Medicare and almost all private insurers now cover DBS for essential tremor. Insurance approval is typically sought prior to hospital admission.

**Summary**

There are more medical and surgical treatment options for patients with essential tremor than ever before. Deep brain stimulation surgery offers important symptomatic relief in patients with moderate disability from essential tremor and who are cognitively intact. The major risk is a 2% risk of stroke, due to bleeding in the brain. DBS is a relatively complex therapy requiring regular neurological follow-up and battery changes every 3-5 years. It reduces, but does not eliminate, the symptom of tremor. The time to consider DBS surgery is when quality of life is no longer acceptable on optimal medical therapy as administered by a neurologist.

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