

Is DBS Right for Me?

DBS is not an appropriate treatment for everyone with dystonia. DBS may be considered if medications and other treatments are not providing adequate relief, and if the symptoms negatively affect quality of life to the extent that the surgical risks are justified.

Based on the research to date, individuals who have isolated (primary) dystonia, which means dystonia is the only present neurological disorder, are likely—but not guaranteed—to have the best outcomes from DBS. Patients who are younger and test positive for the DYT1 dystonia gene mutation may also be more likely to have a good response to treatment. Individuals with cervical dystonia or dystonia acquired by drug exposure (tardive dystonia) may be good candidates for DBS. Individuals with other forms of acquired (secondary) dystonia are evaluated on a case by case basis. There are promising data on the use of DBS to treat myoclonus-dystonia and focal dystonias including cranial dystonias such as blepharospasm and oromandibular dystonia.

What is DBS?

Deep brain stimulation (DBS) is a surgical procedure that uses an implanted medical device to treat neurological disorders. A battery-powered stimulator is implanted in the body and delivers electrical stimulation to the brain. The stimulator is implanted through an incision in the chest and placed under the skin. Extension wires run along the inside of the neck to connect the stimulator in the chest to leads (electrodes) deep in the brain. The leads are inserted through tiny holes made through the skull. The stimulation to the brain is adjusted by remote control to achieve the appropriate settings for each individual patient.

DBS is completed in several phases:

- Pre-surgical assessment & work-up
- Implanting the leads in the brain
- Implanting the stimulator and extension wires
- Turning on the stimulator
- Adjusting the stimulation settings

Once the leads and stimulator are implanted, the stimulator must be turned on. The stimulation settings are adjusted over a series of appointments with a DBS programmer. It can take weeks or months for individuals to experience the full benefit of DBS for dystonia.

How Can I Learn More About DBS?

The Dystonia Medical Research Foundation (DMRF) can provide information, identify movement disorder specialists, and connect you to individuals who have undergone DBS.

What is the DMRF?

The Dystonia Medical Research Foundation (DMRF) is a 501(c)3 non-profit organization that advances medical research toward a cure, promotes awareness and education, and supports the well being of affected individuals and families.

Contact us:

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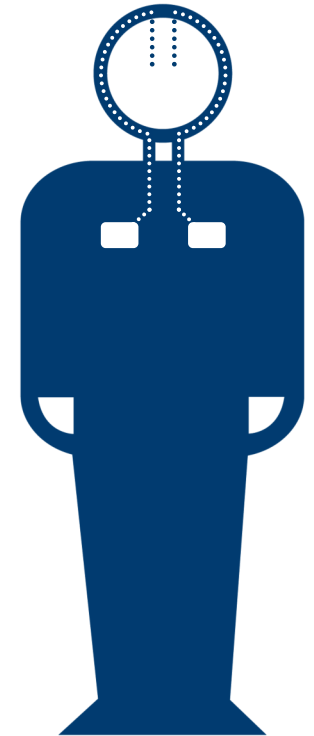
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Deep Brain Stimulation for Dystonia



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Is DBS Safe?

The movement disorders field now has more than two decades of experience regarding the long-term safety and efficacy of DBS. The main risk in DBS is bleeding in the brain during the surgery to implant the leads, resulting in stroke. This occurs in about 1% of patients. Infection occurs in approximately 5% of patients. Infection can be serious and require the removal of the DBS devices. Device failure is also a concern, for example wire disconnection or stimulator battery failure. Most complications that occur can be resolved without removing the DBS device.

Once the stimulator is turned on, side effects from stimulation to the brain may include lightheadedness, tingling sensations, speech problems, balance problems, muscle tightness or pain, and new involuntary movements or slowness of movement. Side effects from stimulation can often be lessened or eliminated by adjusting stimulation settings.

How Does DBS Treat Dystonia?

Although DBS is proven to be a safe and effective treatment for a variety of disorders, the exact mechanism of action is not fully understood. In dystonia, DBS interrupts the abnormal signals in the nervous system that cause the involuntary dystonic muscle movements and postures.

How Long is the Recovery?

DBS typically requires a one or two night stay in the hospital. It may take several weeks for incisions in the head and chest to fully heal. The stimulator is typically turned on two to four weeks following surgery, at which point the stimulation settings are adjusted by remote control. Several appointments with a DBS programming expert may be required to determine the ideal settings for the patient's specific needs. The effects of DBS for dystonia are not immediate. It can take months or a year to achieve full benefit from treatment.

What are the Benefits?

One of the challenges of treating dystonia with DBS is that it is difficult to predict which patients will benefit and to what degree.

From the research data available, improvements of 50-60% are generally observed overall, with some patients experiencing a 90% reduction in symptoms and disability. Depending on the individual patient, however, even an improvement rating of 30% can have a significant positive impact on a person's ability to function.

What Maintenance is Required?

Having DBS is a life-long commitment that requires ongoing management. Maintenance includes battery changes (which consist of outpatient surgery) and periodic adjustments to the stimulation settings. Device problems may occur. The most common device problem is lead breakage, which is reported in about

4% of cases, but occurs less frequently with newer devices.

Individuals with DBS must be aware of situations that can interfere with the functioning of the DBS devices. This includes certain medical MRI imaging (magnetic resonance imaging), diathermy therapies, and security metal detectors and wands.

Is DBS Covered by Insurance?

In the United States, DBS for dystonia received a special approval category by the Food & Drug Administration (FDA), called a Humanitarian Device Exemption. In most cases, health insurers cover the procedure. Some insurers may initially deny coverage but approve after an appeal. Health insurers may cover specific models or brands of the DBS device. DBS for dystonia is covered by Medicare and Medicaid.

How Do I Select a Medical Team for DBS?

DBS for dystonia is a highly specialized procedure that should be performed by a team of experts with extensive training and experience. Medical centers that offer DBS may vary in their procedures. For example, some centers will implant the leads and stimulators in one day, while others separate those steps by days or weeks. There are several models of stimulator batteries, for example non-rechargeable and rechargeable. The DMRF can help locate movement disorder centers in your region.

Questions for Your Doctor

If you are considering DBS or if DBS has been recommended to you by a movement disorder specialist, consider discussing the following questions with your doctors:

- Am I a good candidate for DBS?
- What are the steps of the DBS process?
- What is the make and model of DBS device recommended for me, and how does it work?
- What benefits can I expect?
- What are the risks?
- What is the experience of the surgical team with DBS for dystonia?
- What are the most common complications your DBS patients have and how are they resolved?
- What percent of your DBS patients develop infection?
- Who will program my DBS stimulator, and what is their experience with dystonia?
- How long is the recovery?
- Will DBS reduce my need for other therapies?
- Where can I get a second opinion?
- How much does DBS cost and who will pay for it?
- Is there anything about DBS I should know that we have not yet discussed?