

FAQ about Deep Brain Stimulation for Tourette Syndrome

Deep brain stimulation (DBS), is most often used to treat movement disorders and is approved for Obsessive-Compulsive Disorder (OCD) treatment under a Humanitarian Device Exemption. DBS is also a potential option for Tourette syndrome (TS) patients whose motor and/or vocal tics significantly impact their quality of life and are unresponsive to other treatment options.

What is Deep Brain Stimulation (DBS)?

DBS is a medical procedure that involves electrically stimulating the brain to change its activity and relieve symptoms of a neuropsychiatric disorder. The surgery involves placing a thin metal electrode (about the diameter of a piece of spaghetti) into a desired target in the brain and attaching it to a pacemaker implanted under the skin in the chest below the collarbone.

How Does DBS work?

DBS is not a cure for TS, but it can successfully treat symptoms by disrupting the abnormal patterns of brain activity that become prominent in this disease. DBS is often described as a brain “pacemaker” because constant pulses of electrical charge are delivered at settings that are thought to restore normal brain rhythms. The exact mechanisms of this neuromodulation are still unknown.

Who Should Consider DBS for Tourette syndrome?

DBS may be considered for a patient who...

- Has a diagnosis of TS with a documented duration of at least a year
- Has TS rated as a severe or extreme illness (YGTSS Total Tic Severity Scale ≥ 35)
- Has failed to improve following treatment with alpha agonists, neuroleptics, topiramate, and a VMAT inhibitor (tetrabenazine, deutetabenazine, valbenazine)
- Is unable to complete or fails a full Comprehensive Behavioral Intervention for Tics (CBIT) treatment course
- Is 18-years-old or older

DBS is not appropriate for a patient who...

- Has another severe psychiatric disorder (personality disorder, psychotic/bipolar disorder, etc) or substance abuse issues
- Is pregnant
- Has abnormal MRI imaging as assessed by the team
- Has a cognitive disorder or dementia
- Is at imminent risk of suicide

What is the process of evaluation for DBS for Tourette syndrome?

As part of the evaluation for DBS for TS, we require a letter of referral from the patient's current treating psychiatrist and therapist as well as a transfer of records. A 2 day evaluation is then performed by our team of psychiatrists. An independent evaluation may also be required from a second psychiatrist independent of the team to confirm the patient's candidacy. If necessary, additional imaging of the brain will be performed as well as neuropsychological and other testing. An independent evaluation is also done by the neurosurgery department, who will also determine whether someone is a candidate for DBS.

How is the surgery performed?

DBS electrode placement in the awake patient using a stereotactic frame has been the gold-standard for more than a decade. Under anesthesia, a small incision (less than the size of a quarter) is made in the skull to allow for the placement of an electrode wire (about the width of a spaghetti noodle). Brain

mapping may be performed to record the activity of the brain, and brief electrical stimulation may be delivered, which may elicit changes in your emotional response, to confirm that the wire has been correctly placed. When the correct target site is confirmed, the permanent DBS electrode is inserted and tested. After the surgery, all parts of the stimulator system are internal. There are no wires coming out through the skin. Your neurosurgeon will discuss the surgical procedure as well as the associated risks and benefits in more detail prior to consenting you for the procedure.

What happens after surgery?

You will return to the office a few weeks after surgery to turn on the DBS and make initial programming adjustments. This first visit may take between 1-3 hours. During these visits, a programming computer held next to the skin over the pulse generator is used to adjust the settings of the pacemaker during routine office visits. The effects of DBS are typically not immediate. It may take several months or even a year to achieve optimal results. Optimization of DBS requires multiple office visits which may be as frequent as every 2-4 weeks initially. If you are considering DBS, keep in mind that the entire DBS process is a serious time commitment before proceeding with surgery.

What are the outcomes for DBS in TS?

Based upon existing studies, patients on average experience a **40-50% reduction** in their *tic* symptoms with DBS². Better response was associated with *longer time on treatment*. It may take several months or years for the full effect of the DBS treatment to be realized. DBS is often also associated with an improvement in OCD symptoms².

What are the adverse side effects associated with DBS in TS?

Adverse events associated with DBS can be related to the surgery, device complications, or effects of the stimulation. The rate of surgical complications with DBS for both mental health and neurological conditions is on average 2-3%⁵. These risks will be discussed in greater detail during your appointment with the neurosurgery team. The most common problems that arise with stimulation treatment are a rebound in depression and anxiety if the stimulation is turned off without recognition of the team. This may occur if the neurostimulator battery require replacement or reaches the end of its batter life, which is every 6-16 months. The replacement will require a simple outpatient surgical procedure under general anesthesia or heavy sedation and local anesthesia to remove the battery implanted under the skin and replace it with a new battery. The replacement procedure will take less than an hour.

Because DBS can be turned ON and OFF, most adverse side effects associated with the treatment are transient and reversible. There is a risk of transient mood elevation and impulsivity that can occur as stimulation settings are being changed. In some cases, the treatment may transiently worsen depression, anxiety, or suicidal ideations. These changes in mood and behavior can be reversed by changing the stimulation settings. If you or a family member notices a change in your behavior while receiving treatment, please contact the treatment team immediately.

Who can answer additional questions that I have?

If you have additional questions, please talk with your treating psychiatrist. If you have additional questions regarding your treatment or your patient rights as it relates to DBS treatment, please call the Office of the Committee on Human Research at 415-476-1814.

References:

1. Martino D, Deeb W, Jimenez-Shahed J, Malaty I, Pringsheim TM, Fasano A, Ganos C, Wu W, Okun MS. The 5 Pillars in Tourette Syndrome Deep Brain Stimulation Patient Selection: Present and Future. *Neurology*. 2021 Apr 6;96(14):664-676. doi: 10.1212/WNL.00000000000011704. Epub 2021 Feb 16. PMID: 33593864; PMCID: PMC8105965.
2. Johnson KA, Fletcher PT, Servello D, Bona A, Porta M, Ostrem JL, Bardinet E, Welter ML, Lozano AM, Baldermann JC, Kuhn J, Huys D, Foltyne T, Hariz M, Joyce EM, Zrinzo L, Kefalopoulou Z, Zhang JG, Meng FG, Zhang C, Ling Z, Xu X, Yu X, Smeets AY, Ackermans L, Visser-Vandewalle V, Mogilner AY, Pourfar MH, Almeida L, Gunduz A, Hu W, Foote KD, Okun MS, Butson CR. Imagebased analysis and long-term clinical outcomes of deep brain stimulation for Tourette syndrome: a multisite study. *J Neurol Neurosurg Psychiatry*. 2019 Oct;90(10):1078-1090. doi: 10.1136/jnnp-2019-320379. Epub 2019 May 25. PMID: 31129620; PMCID: PMC6744301.