

Deep Brain Stimulation for treating Tourette Syndrome ?

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In recent months, there has been substantial publicity about the possibility of treating tics in Tourette Syndrome (TS) with deep brain stimulation (DBS). This publicity has resulted in increased interest among individuals TS and their families. Very little is known about the use of DBS for treating other movement disorders such as Parkinson disease, essential tremor, and dystonia. Below are some common questions and answers about DBS and its potential use in treating TS.

What is DBS ?

DBS involves surgical implantation of electrodes into a deep part of the brain. This is done with careful planning to locate the target with MRI scans and with recording of brain activity patterns with a microelectrode. The surgery is usually done with the patient awake to help the neurosurgeon locate the proper part of the brain. After the electrodes are inserted, they are attached to the skull to prevent them from moving and one end of each electrode is tunneled under the skin and attached to pacemaker – like stimulators that are implanted under the skin just below the collar bone. The surgery is often done in two stages with the electrode implanted one day and the pacemakers implanted a few weeks later. Once the stimulators are implanted, they are turned on to deliver high frequency stimulation to the targeted parts of the brain. The stimulators are programmed with a computer and can be turned on and off by the patient.

How does DBS work ?

This is an area of active research. We don't know for sure why it works, but we do know that it changes the activity of nerve cells in the area that is stimulated. It is thought that it either disrupts abnormal signals, or changes those signals so that they no longer cause the symptoms.

Does DBS work for TS ?

In the medical journals, there are reports of three patients with TS who have been treated with DBS. All three have good reduction of tics to different degrees. Other patients have had the procedure, but these have not been reported in the medical journals, so it is difficult to know how many people have had DBS for TS and, more importantly, in how many it has been effective. Having said that, DBS has been proven to be effective for treating Parkinson disease and essential tremor. There is increasing evidence that it is effective for many types of dystonia. However, for TS, DBS must be viewed as highly experimental.

Are there risks ?

There are risks associated with any medical procedure. For implantation of DBS electrodes, the risks include bleeding in the brain, infection and stroke. The risk of complications is about 2%. There are also risks of side effects from the stimulation. These can include mood changes, changes in motor function, changes in sensation, and changes in thinking ability. Since so few individuals with TS have had this surgery, it is difficult to say at this time which side effects of stimulation are most likely to occur when DBS is used to treat TS. The other risk is that it won't work.

Is DBS a cure for TS ?

Several newspapers and TV programs have reported on a recent case of TS treated with DBS with headlines such as "Brain Surgery May Cure Tourette." Based on what we know about how DBS works in other disorders, it is unlikely that DBS will be a "cure". Instead, it appears that in this recent case, so far DBS reduces tic symptoms, but when the stimulation is stopped the tics return.

What is the cost of DBS ?

The cost of DBS varies from place to place, but on average the cost of putting electrodes in both sides of the brain and implanting the pacemakers is \$50,000 - 60,000, including the costs of the hospital stay. Moreover, the pacemaker has a limited battery life and has to be replaced every few years at a cost of \$10,000 - \$20,000. Because DBS for TS is still considered to be investigational, most insurance companies are unlikely to pay for it at this time.

Can DBS be done in children with TS ?

There is limited experience using DBS to treat movement disorders in children, but it has been done with other disorders. There have been no reports of children having DBS for treating TS at this time. Since the symptoms of TS often improve as children become adults, DBS is probably not appropriate for children with TS.

Can DBS improve ADHD and OCD symptoms in people with TS ?

We don't know. There have been a few reports of people with OCD (without TS) undergoing DBS with promising results, but it is still an experimental treatment for OCD.

Is the TSA doing anything to learn more about DBS for TS ?

The TSA Scientific Advisory Board has recommended that a panel of experts from around the world be convened to provide a comprehensive review of DBS, and advise the TSA on the safety, current research, and efficacy of this procedure. TSA is moving forward with the organization of such a study panel that will meet at the upcoming 4th International TS Symposium in June, 2004.

Deep Brain Stimulation and Tourette Syndrome

Official Statement of TSA USA

On Thursday, April 1, 2004, "Good Morning America" aired a segment on a medical procedure on one patient with Tourette Syndrome. Following is a statement from TSA Medical and Scientific Advisors.

The Tourette Syndrome Association (TSA) is keenly interested in the neurosurgical procedure performed one month ago on a severely affected adult male patient with Tourette Syndrome (TS) at the University Hospitals of Cleveland.

Highly experimental, the procedure used -- Deep Brain Stimulation (DBS) -- involves the implantation of electrodes in the brain that are stimulated by a surgically implanted pulse generator in the upper chest. Some published reports indicate that this surgical intervention may aid in the amelioration of involuntary movements in patients with several movement disorders, among them Dystonia and Parkinson's Disease.

However, it should be noted that this is a single case report involving one patient with TS. While it is encouraging that at the present time the patient is experiencing a reduction in symptoms, insufficient time has elapsed since the operation to conclude that this symptom abatement will persist. Moreover, it should be understood that when undergoing this procedure, there are serious risks involved that could include cerebral bleeding and infection. In many cases, currently available medications and behavioral therapies do bring substantial relief to many by reducing the tics, obsessions, compulsions and attentional problems that often co-occur in people with TS.

Unfortunately, in the past we have witnessed a variety of therapies heralded as breakthroughs in TS treatment that have proved ineffective in the long run. Only rigorous, methodologically sound scientific study of DBS will provide the answers we seek.

Toward that end, in February, 2004 the TSA Scientific Advisory Board recommended that TSA convene a panel of experts from around the world to provide a comprehensive review of DBS, and advise us on the safety and efficacy of this procedure. TSA is moving forward with the organization of such a study panel.

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