

Information on DBS for movement disorder patients



DBS SELECT

DEEP BRAIN STIMULATION

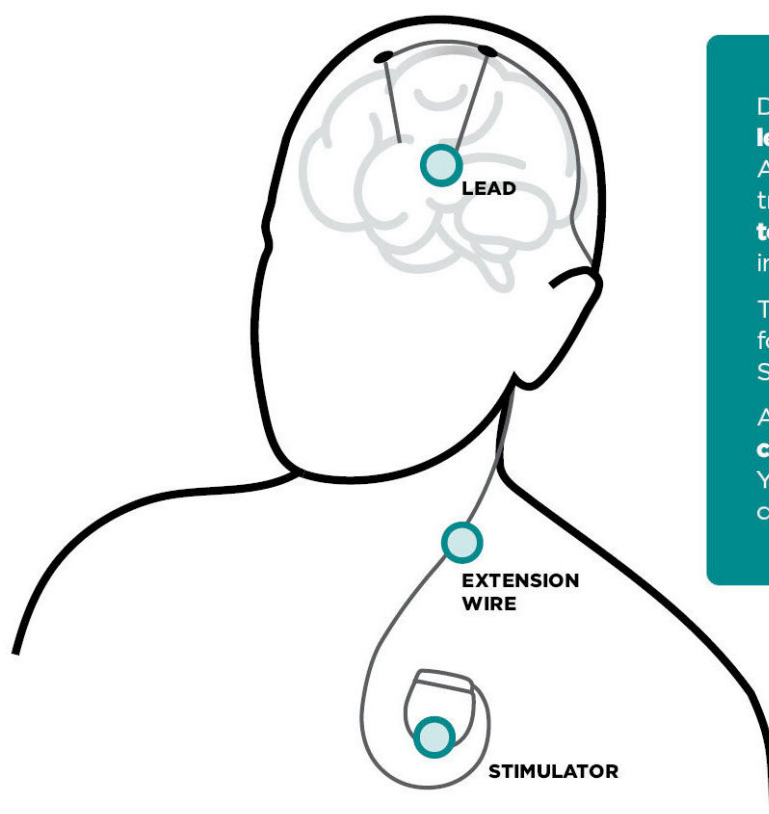
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1. What is deep brain stimulation (DBS)?

DBS stands for Deep Brain Stimulation. An electrode is implanted in each hemisphere of the brain at the level of the diseased nucleus. This electrode is connected to the neurostimulator, which is located in the chest or the abdomen. The neurostimulator sends out electrical pulses that can restore the activity of the diseased brain nucleus. DBS treats symptoms of a disease and is not a cure.

2. What are the components of a DBS system?



DBS system consists of an **electrode lead** which is implanted in the brain. An **extension lead** connects the electrodes to an **implantable pulse generator (IPG)** which is placed under the skin in the chest or abdomen.

There are **three main manufacturers** for DBS systems: Medtronic, Boston Scientific and Abbott.

All DBS systems have the **same basic components** and work in a similar way. Your surgeon will help you choose the device most optimal for you.

IPG

The **IPG (implantable pulse generator) or neurostimulator** is the third component and is connected to the extension wires. The IPG is usually implanted under the skin near the collarbone or in the abdomen (depending on the amount of body fat you have). The IPG contains a battery and electrical circuits that generate the electrical stimulation pulses.

EXTENSION WIRE

The **extension wire** is a wire that is connected to the lead, just outside the skull, and then goes under the scalp, under the skin of the neck and shoulder, to the chest, where it connects to the IPG.

LEAD

The **lead (also called the electrode)** is a thin wire that is inserted through a small opening in the skull and implanted in one of the deep structures of the brain.

3. Am I eligible for a DBS system?

Parkinson's Disease (PD)

- You have idiopathic Parkinson's disease.
- You respond well to levodopa (with the exception of levodopa resistant tremor), but you suffer from fluctuations. Good periods (often with overactivity/dyskinesias) are followed by worse periods (OFF periods with severe stiffness and slowness).
- You have experienced side effect of some drugs.
- You have no intellectual or memory deficit or active psychiatric disease.
- You suffer from another disease that impacts your quality of life and/or your life expectancy.
- You suffer from another brain disease, such as a stroke, multiple sclerosis or a brain tumor.

Effects of a DBS system with Parkinson's Disease (PD)

- If you have a DBS system, you will **experience less fluctuations in your symptoms** (more ON-time, less OFF-time). The OFF-periods will be less severe. The dyskinesias will typically improve or disappear, but can return when your disease progresses.
- You will experience the **biggest benefit** from DBS on motor function in **the first years after surgery**. Later on your mobility may deteriorate again and return to its preoperative level due to disease progression.
- Stiffness (rigidity) and shaking (tremor) respond better** compared to slowness of movement (bradykinesia) and gait problems.
- Gait and speech difficulties respond variably** to DBS. Sometimes these symptoms can even worsen due to DBS.
- On average **no major difference** has been found in the rate of **dementia or psychiatric** symptoms between patients with and without DBS. However, **individual patients can experience psychiatric symptoms after DBS** (e.g. a change in character)..
- Weight gain** is the most common side effect after DBS for PD.

Essential Tremor (ET)

- You have essential tremor.
- Drugs do not control your tremor enough or cause strong side effects.
- Your essential tremor is affecting your daily activities
- You have no intellectual or memory deficit or active psychiatric disease.
- You suffer from another disease that impacts your quality of life and/or your life expectancy
- You suffer from another brain disease, such as a stroke, multiple sclerosis or a brain tumor.

Effects of a DBS system with Essential Tremor (ET)

- You can expect a **significant decrease of your tremor** and a **significant rise in your quality of life**. Most probably, you will be able again to perform daily activities such as eating and drinking, combing your hair or shaving.
- The **effectiveness of stimulation can decrease** over a number of years. This is called habituation. Currently, we cannot predict which patients will develop habituation.
- Side effects** of DBS for ET may be **speech and balance problems**. These side effects can be addressed by optimizing the stimulation parameters, but may persist despite optimal programming.

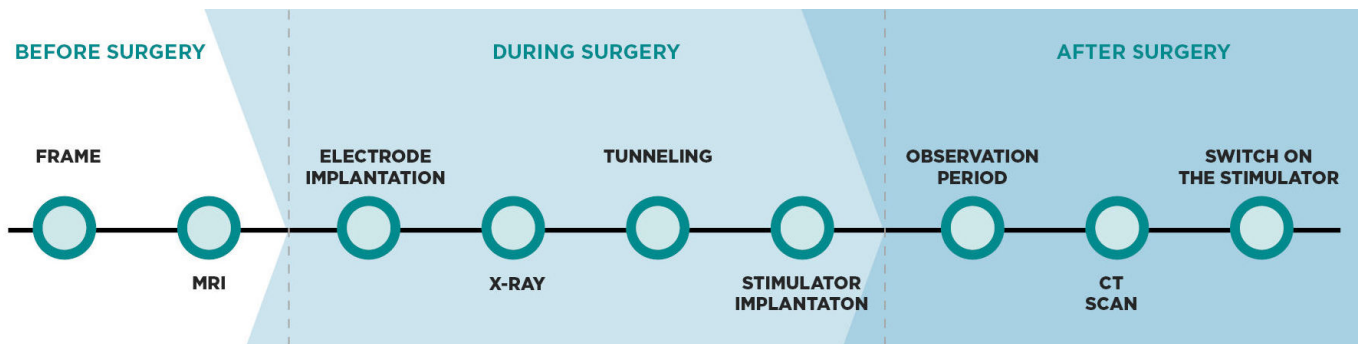
Dystonia

- You suffer from dystonia (focal, segmental or generalized)
- Medication no longer controls your symptoms enough, even at the highest recommended dose.
- You have tried combination of medications.
- You suffered from severe side effects of the prescribed drugs.
- You have no intellectual or memory deficit or active psychiatric disease.
- You suffer from another disease that impacts your quality of life and/or your life expectancy.
- You suffer from another brain disease, such as a stroke, multiple sclerosis or a brain tumor.

Effects of a DBS system with Dystonia

- There is evidence for **benefit of DBS on cervical, segmental and generalized dystonia**. The size of the effect however, is highly variable.
- Age at surgery, duration of dystonia and the genetic background may play a role in **the outcome**.
- Programming of DBS for dystonia takes longer** (compared to Parkinson's disease and essential tremor) as the effect of DBS is often only seen after a few weeks.

4. What about the surgery?



BEFORE SURGERY:

- **Frame:** On the morning of the operation, a lightweight frame will be mounted onto your head. This is done under light sedation and local anesthesia. This frame will assist the surgeon to place the DBS electrodes with the highest precision.
- **MRI:** Shortly before surgery, an MRI of your brain will be made. These images are used to determine the most optimal position of the DBS electrodes. In some centers the MRI is done up to one week pre-operatively. In that case the frame is mounted on the head on the morning of the surgery and an additional CT scan is made which is fused with the MRI from one week earlier.


DURING SURGERY:

- The surgery itself can be performed under general anesthesia or the anesthesiologist can wake you up during the procedure so that the neurologist can test you by for example making movements with your hands to evaluate the first effects of the DBS electrode stimulation. You will not experience any pain in this stage.
- **Electrode implantation:** The electrodes will be implanted through two small burr holes, one left one right. The operation can be done in 2 ways. Each surgeon has his/her own habit in this. (1) You are awake for most of the operation. Your cooperation is required during the implantation of the electrode. We observe tremor and repetitive movement of your hands. You will be asked to repeatedly sum up the days of the week in order to evaluate speech. (2) The procedure is done entirely under general anesthesia. The electrode is then implanted only based on a detailed scan.
- **X-ray:** After the placement of the electrodes, their position is checked in the operation room by an X-ray or CT. When the electrodes are in the right place, the holes are closed and the other end of the DBS leads are left under the skin.
- **Tunneling:** The extension cables are tunneled underneath the skin behind the ear, on the same side of the neck to the chest/abdomen wall. This is always performed under general anesthesia.
- **Stimulator implantation:** The other ends of the extension cables are connected to the neurostimulator which is implanted under the skin in the chest or abdomen. In some centers the IPG implantation is done a few days after the lead placement.

AFTER SURGERY:

- **Observation period:** After surgery, you will be transferred to the recovery room for a brief period of observation before being transferred to a neurosurgical or neurological ward.
- **CT-scan:** The same or the following day a CT scan will be used to confirm that the electrodes are implanted in the correct location and that no hemorrhage has occurred.
- **Switch on the stimulator:** The stimulator can be activated immediately after surgery or one can wait 2-4 weeks to do so. Both options are applied.

5. How does the programming go?



To find the **right stimulation settings**, you need to come into the hospital around **4-5 times**.

During these visits the stimulation will be adjusted to find the best settings for you. On average, it takes up to **6-8 months** to find the **perfect stimulation settings**.

In the years to come, you might need **some adjustments**, especially when your disease progresses.

Stun Effect

You may feel very well after the operation. It may even feel as if all your symptoms have disappeared. This is due to **swelling of the brain** around the electrode, which is a **temporary effect** of about a week.

Afterwards, this swelling subsides and the **'stun effect'** disappears. It is therefore possible that a few weeks after the operation you feel worse again. At that moment, the stimulator needs to be adjusted.

6. What are the benefits and risks of DBS?

BENEFITS

- ✓ **Safer than permanent lesioning** (thermocoagulation).
- ✓ Can nearly **double the number of 'on' hours** each day for patients with Parkinson's disease.
- ✓ Can **reduce dyskinesia** by reducing medication.
- ✓ Is also **effective for tremor not responding to levodopa**.
- ✓ Stimulator **can be adjusted** to the needs of every patient.
- ✓ **Reversible therapy**.

RISKS (Strongly dependent between centers worldwide)

- ✓ **Risk related to anesthesia:** Every surgery has this risk. Therefore, you may be asked to visit the anesthesiologist before surgery to make sure you are fit for surgery.
- ✓ **Cerebral bleeding (1-3%):** The brain is a highly vascularized organ. Your neurosurgeon minimizes this risk by planning the surgery with a planning software that avoids crossing blood vessels.
- ✓ **Risk of infection (3-10%):** Every surgery has a risk for infection. This risk is minimized by working in a sterile environment for implantation. Nevertheless, infection of the DBS system can occur. If infection occurs, the leads, wires and IPG need to be explanted and you'll have to take antibiotics. You will have to wait at least 4 months before you can be reimplanted.

SIDE EFFECTS

SIDE EFFECT DUE TO THE STIMULATION

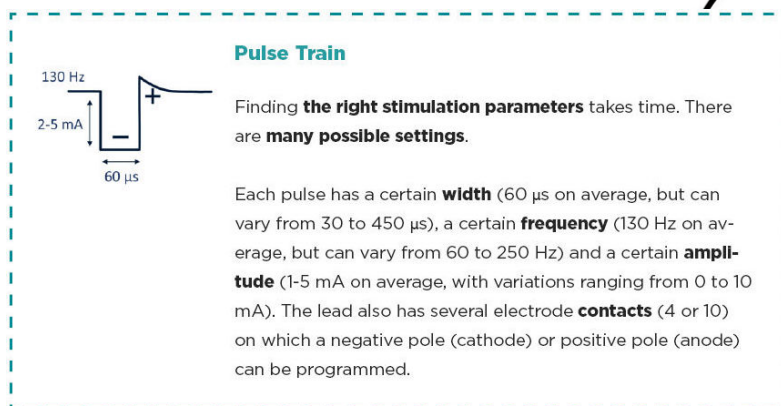
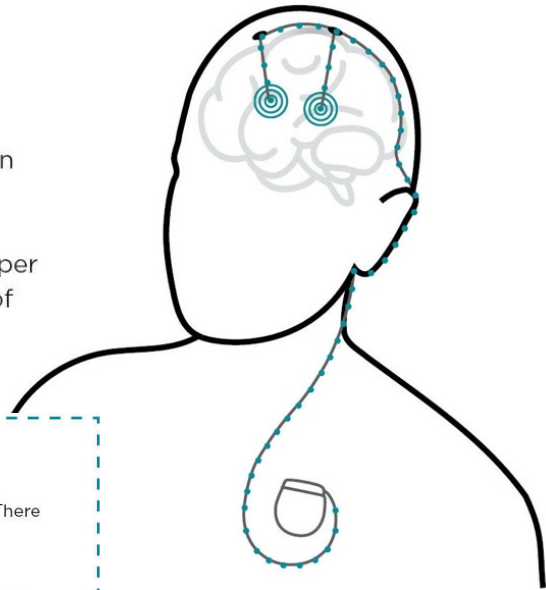
- **Transient tingling sensation, feeling of tightness in face/limbs, unintelligible speech, unsteady gait with falls.**
- **Change in character (e.g. more irritable). In case of Parkinson's disease psychiatric complications may occur.**
- **Some patients experience a limited effect of the stimulation on the symptoms. This happens most frequently in dystonia. In patients with essential tremor habituation (decrease of efficacy of the stimulation) may occur.**

7. How does DBS work?

Certain region of your brain has become **overactive**, which causes your symptoms.

The **DBS electrode** is implanted in that region and then connected to the **neurostimulator**.

This stimulator then starts sending **pulses** (130 times per second on average) to mimic the normal functioning of that brain region and **reduce your symptoms**.



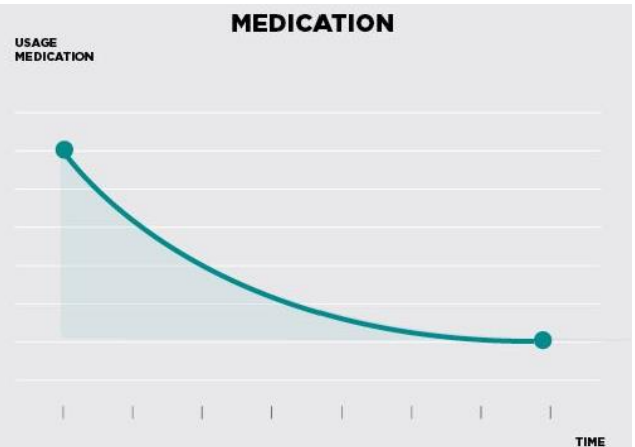
8. Can DBS cure my disease?

NO DBS **won't cure** your disease.

BUT It can **control your symptoms**. It may be the case that not all your symptoms completely disappear.

In Parkinson's disease, you usually end up taking less than half of the medication after surgery.

In dystonia and essential tremor, medication can usually be stopped.



9. What can I expect on short- and long-term?

SHORT TERM

- ⦿ **After the implantation**, you will go to the hospital quite frequently to find the **best settings** for your DBS system. Tremor is a symptom that reacts quite fast once the DBS is turned on.
- ⦿ **Parkinson's disease patients** can also experience a quick improvement of their stiffness and slowness.
- ⦿ **Dystonia patients** will have to be a little more patient as it might take a few weeks to months before the dystonia improves.

LONG TERM

- ⦿ Once implanted, you will go to the hospital on a **regular basis to check the integrity of your DBS device** (at least once a year). If you experience a **decrease in treatment effect** or if side effects arise, the health professional can adjust your stimulation settings.

10. What about after surgery?

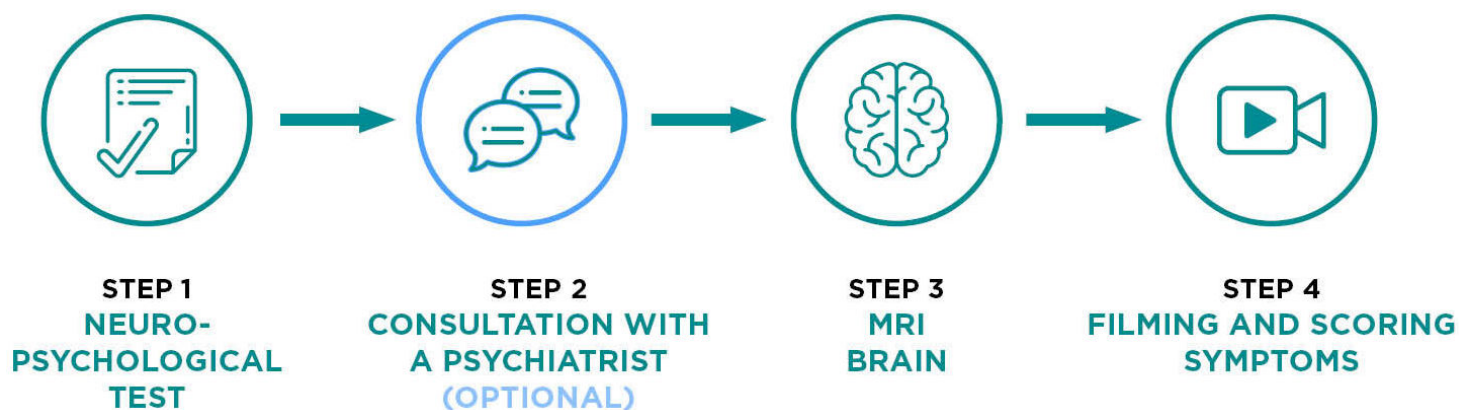


Walking through some theft detectors or security gates, **may increase the stimulation or turn of your stimulator**. Many detectors are safe, but the small amount of metal in the stimulator may set off the alarm of the detector. At the airport, show your **Device Identification Card** to security and request a hand search. If a security wand is used, ask the security personnel to avoid placing it over your neurostimulator.

The latest neurostimulators and electrodes can be used in the MRI scanner (1.5 Tesla). Strong MRI machines (3 Tesla) or long examinations are usually not possible or only under strict conditions. You should therefore always contact your neurologist or neurosurgeon in advance to discuss this. During the examination, the stimulator must be switched off.



11. What tests should I have carried out before the operation?



- **STEP 1: Neuropsychological test.** Your cognitive function will be examined using various tests. You must not show any signs of dementia on this examination.
- **STEP 2: Consultation with a psychiatrist.** Sometimes the advice of a psychiatrist is requested during the preparation process. The psychiatrist will check whether there are underlying mental issues that require extra support or follow-up.
- **STEP 3: MRI brain.** A high-quality brain scan is necessary to see if the target structure of the brain is intact and assure that there are no reasons to have an increased risk of bleeding.
- **STEP 4: Filming and scoring symptoms.** In all patients, the symptoms are also filmed and scored. For people with essential tremor or dystonia this is done during the consultation or during a short hospitalization. People with Parkinson's disease are hospitalized for 2-3 days. The mobility is scored and filmed in the best possible state (ON) and the worst possible state (OFF). The difference between these two scores should be more than 30%. This test indicates responsiveness to levodopa and is a good predictor of response to DBS.

12. Comparison non-rechargeable vs rechargeable IPG

	NON-RECHARGEABLE BATTERY	RECHARGEABLE BATTERY
RECHARGE	Never.	1 hour every week OR 3 hours every three weeks <small>Note: Over time and with repeated charging, the stimulator may require shorter intervals between charging.</small>
SERVICE LIFE	Every 3 to 5 years <small>depending on the stimulation settings</small>	15-25 years.
ADVANTAGES	You can go 3-5 years without having to be bothered by recharging.	The battery life is longer and therefore does not need to be replaced or at the most only once.
DISADVANTAGES	When replacing the stimulator, there is a risk of infection of the device. In this case, the material must be removed and you must take antibiotics before the new device can be implanted.	You should recharge the stimulator weekly or at least monthly.

13. Will DBS have an **impact** on my **independence** and my **personality**?



Once the DBS system is well programmed, the patient will be **more independent** than before the surgery. **The caring duties of the family and partner will be reduced**, meaning they may be able to spend more time doing different things.

The character of the patient may change. The patient can become **more or less joyful**, but also **more or less assertive**. The change in character can be due to the decrease of medication or the stimulation.

You should **discuss** these mood and character changes with your **physician**. Sometimes it is necessary to **adjust the medication** and/or stimulation to improve these changes.

14. Will DBS impact my relationship with my family and partner?



The goal of DBS is to **increase your independence**. You should be able to **take better care of yourself**. This means that your partner may need to help you less. For example, you may be able to wash and dress yourself.

This change of caretaking can impact your relationship and you may need some **time to adapt to the new situation**.

DBS can bring a change to activities in your spare time. You might be able to cycle again or go for a walk. **Sharing joyful activities** with your partner and family can have a **positive influence on your relationship**.

15. Future direction – International research



CLOSED-LOOP SYSTEM.

In this technique your DBS-system will fire the exact amount of pulses that your brain needs at a certain time. The pulses will be delivered 'on demand'.



MINIATURIZED IPG'S

Currently, research groups are making a smaller generator that can be implanted in your skull. In this case, it won't be necessary anymore to implant the generator in your chest or abdomen.



EFFICIENT RECHARGEABLE BATTERIES

Researchers are trying to make the new batteries more efficient. This way you have to recharge your battery less frequently and the overall battery life will be longer.

16. Useful links

<https://www.michaeljfox.org/deep-brain-stimulation?deep-brain-stimulation=>
<https://www.parkinsons.org.uk/information-and-support/deep-brain-stimulation>