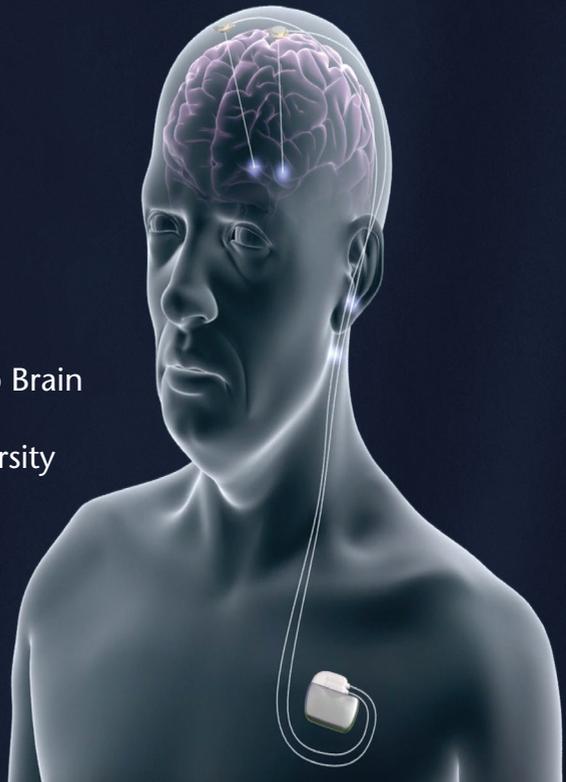


Information for patients

Tremor and Dystonia

Deep Brain Stimulation for Tremor and Dystonia at the
National Scottish Service in Glasgow

National Scottish Deep Brain
Stimulation Service
Queen Elizabeth University
Hospital Glasgow





Contact Details

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Website address: www.nhsggc.org.uk/your-health/health-services/deep-brain-stimulation/

On your first visit you will meet several of the following team members:

- **Tracy Murphy and Elaine Tyrrell**
Movement Disorder and Deep Brain Stimulation Nurses
- **Mr Michael Canty and Miss Patricia Littlechild**
Consultant Neurosurgeons
- **Dr Ed Newman and Dr Vicky Marshall**

Consultant Neurologists

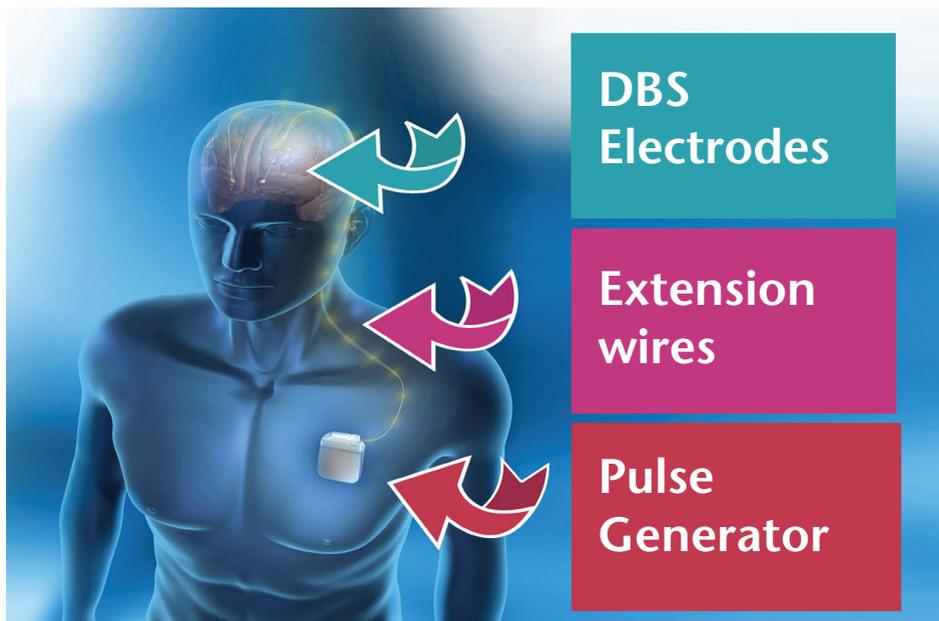
Introduction to Deep Brain Stimulation (DBS) for Tremor or Dystonia

You have been referred or are considering Deep Brain Stimulation (DBS) as a treatment for Tremor or Dystonia. This information leaflet has been written to give you further information on this. You can also get further information from the team (please see page 3).

In the following booklet we use the term “**tremor**” to include conditions such as Essential Tremor and Dystonic Tremor although we may also consider people with other types of tremor for DBS. We use the term “**dystonia**” to include various types of dystonia, which may be generalised or more limited to a particular group of muscles.

What is Deep Brain Stimulation?

We can use Deep Brain Stimulation as a treatment for some people with Tremor or Dystonia.



This involves very fine wires with electrodes at their tips being implanted into the brain. The electrodes send a continuous electrical pulse through them to change some of the electrical signals in the brain and reduce the symptoms of tremor or dystonia.

These wires are connected to extensions that are tunnelled under the skin behind the ear and down the neck. They are connected to a pulse generator (a device like a pacemaker) that is placed under the skin in the chest area or stomach area.

You will have a general anaesthetic, which means you will be asleep during parts of the process. You may be asleep for the whole operation if you have some types of dystonia.

The neurosurgeons in Glasgow's Queen Elizabeth University Hospital have been implanting stimulators since 2004.

Is this operation appropriate for me?

- You must have been assessed and diagnosed by a movement disorder specialist
- Your tremor or dystonia must be interfering significantly with your quality of life
- All suitable medication options (including botulinum toxin for dystonia if appropriate) should have been tried at highest tolerated doses and either be unhelpful or give unacceptable side effects
- You should have no evidence of dementia or significant memory disturbance.

What type of DBS is suitable for me?

Your DBS team will decide which type of operation is most suitable for you. There are a number of different areas in the brain that we can usefully target with the electrodes. Which area we target depends on your underlying diagnosis and your symptoms and signs. Generally,

- patients with significant tremor undergo DBS of the **Ventral Intermediate (VIM)** nucleus of the thalamus
- patients with dystonia undergo DBS of the **Globus Pallidus (GP)**

What could the benefits of DBS be for me?

- The aim for surgery for tremor is to reduce the tremor
- The aim for surgery for dystonia is to reduce the abnormal movements and postures caused by dystonia

What DBS cannot do

- DBS is not a cure for these underlying conditions, and is unlikely to completely take away symptoms of tremor or dystonia.

What are the complications of the operation?

- Haemorrhage which can cause stroke (the risk of stroke is 0.5% [1 in 200]) or death (the risk of death is low at 0.2% [1 in 500])
- Infection risk is 5% (1 in 20). If antibiotic treatment does not help we may need to remove the whole DBS system
- Seizures or Epilepsy- there is a small risk of the operation causing a seizure (fit) or recurrent seizures. The risk is less than 1% (less than 1 in 100)
- Complications from general anaesthesia
- It is possible that the electrode may not be in the most suitable location, or moves

Complications from the hardware

- Lead breakage (lead fracture) which would mean replacing some parts of the system

- Parts of the system eroding through the skin
- Battery failure (we monitor for this)

Potential side effects from Deep Brain Stimulation

(Many are temporary and we can treat them by either adjusting the stimulation or medication)

- Speech problems
- Abnormal, involuntary muscle contractions
- Dizziness
- Movement problems

What happens next if an operation is appropriate for me?

If we think that an operation may be the correct option for you then we discuss this with you at your outpatient appointment. You may not be certain yourself about whether you want to undergo an operation and there will be plenty of time to consider this, and no decision needs to be made on the initial day of assessment. We then organise further tests. You may need to have these as an inpatient or some may be done as an outpatient or day case. These tests need careful planning and this will be done via the DBS administrator (Please see page 3 for contact details).

What happens if DBS is not appropriate for me?

An operation will not be appropriate for all patients. This may be because there are reasons why it may be riskier to do the operation, or it may be apparent that an operation will not improve your symptoms and problems. If this is the case we will be able to discuss and explain why. You will not need further assessments with the DBS team and your care will continue with the team that referred you. They will consider what other treatments may be suitable for you.

Further assessments

If we think that an operation may be appropriate, we will organise further assessments. For these you may need to come into the ward for 2-3 days. Some patients can have the neuropsychology assessment as an outpatient.

- **MRI brain under general anaesthetic**

In order to get the best quality scan of your brain, you will have a brief general anaesthetic to put you to sleep for your MRI. You will need this MRI to help us plan your operation. It tells us if there are any changes in the brain that could make an operation more risky and this is used to target the area of the brain where the electrodes are placed.

- **Neuropsychology or Neuropsychiatry**

You will need a more detailed assessment of your thinking, memory and mood. DBS works best for patients with no or very mild memory or thinking problems. These tests need concentration and may be tiring. We may refer some patients to see a neuropsychiatrist.

- **Video recording**

We often do video assessments of patients before an operation, this helps us to document the severity of your condition. We would only do this with your consent, and it would be stored on your electronic file.

Once these assessments are completed we will review the results with the DBS team at the next multidisciplinary team meeting and make a final decision on whether we will offer you an operation. These meetings take place once per month. We will discuss this with you, usually in a clinic, or sometimes over the phone.

Getting the operation: admission

Day 1: admission

We will admit you to a neurosurgical ward and experienced staff will care for you. You will be able to eat, drink and take any other medications up until midnight before the day of the operation. The anaesthetist will usually visit you today.

Day 2: operation

On the day of the operation staff will help you into a hospital gown. The staff will then take you to the anaesthetic room where the anaesthetist will put you to sleep.

Once you are asleep, we will shave your head and attach a special frame to your head. Whilst still asleep, you will then have a CT scan with the frame on. We use this in combination with your previous MRI scan to identify the targets we are aiming for in your brain.

If you are getting DBS to the thalamus for tremor:

- The way that we perform DBS in Glasgow is that after this initial general anaesthetic, we wake you up in the middle of the operation. It is important to do this so that we can tell whether the electrodes are in the correct place, and improving your symptoms, without giving any significant side effects.
- Before we wake you, we will insert a recording electrode into the brain to make sure we are at the correct target. When you are awake we will make sure we are at the correct target from a combination of examination of you and recording from this electrode. Once we are certain we are in the correct place we will then insert the permanent electrode and fix it into place.
- **If you are having bilateral electrodes (on both sides of the**

brain) we will repeat this process on the other side.

- After this we will put you back to sleep and you will have another CT head scan. We will then remove the frame. Then an incision (cut) will be made into the skin of the chest wall and neck and the connecting wires and the stimulator (implantable pulse generator) will be placed into their positions.
- Many patients have only a vague memory of being woken during the operation.

If you are getting DBS to the Globus Pallidus for dystonia:

- You remain asleep throughout (unlike tremor patients)
- We will insert a recording electrode into the brain to make sure that we are at the correct target. Once we are happy that we are at the correct target then we will insert the permanent electrode and fix it into place. **If you are having bilateral electrodes (the majority of patients), we will repeat this process on the other side.** After this, you will have another CT head scan. We will then remove the frame. Then an incision (cut) will be made into the skin of the chest wall and neck and we will place the connecting wires and the stimulator (implantable pulse generator) into their positions.

Both types of operation are likely to last all day. At the end of the procedure we close the surgical incisions (cuts) with metal clips and place a bandage on your head.

Day 3-5: after your operation

Most patients recover quickly from the surgical procedure and are able to get up and around on the day after the operation and start taking their normal medications. We usually remove your head bandage on the second day after your operation.

When you are well enough after your operation you will be able to go home. At this time, we will not switch your stimulator on and you will need to come back to the hospital for this.

Surgical wound care - see photos on page 12

The clips in your wounds are normally left for 5-7 days after the operation and can be removed at your local GP surgery. If you notice increasing redness, pain, swelling or discharge from any of your wounds after your discharge from hospital, you should contact your own GP or the ward directly.

What happens after the operation?

Many patients feel their symptoms are better even before the stimulator is switched on, which is thought to be the result of swelling to the area of the brain after an operation. This is also known as implantation or impact effect. This initial effect will settle, and the amount of stimulation that you need will change as the brain recovers from the implantation, so it is usual to change the stimulator settings regularly during the months after your operation. You will need to attend regular outpatient appointments over this time, and it may take up to a year to understand properly how DBS is working for you.

The lifetime of the non-rechargeable DBS battery varies between patients, but usually lasts 3-5 years. We monitor the battery life in order that we can plan the battery replacements, which is a minor operation, which takes place under general anaesthetic. There is also a rechargeable battery available which may be beneficial for some patients.

1. Healing wounds at the top of head where the electrodes have been implanted



2. Healing wound just behind the ear over extension wires



3. Healing wound on the chest over pulse generator



Other advice and precautions after your operation

- **Driving**

After your operation we advise that you do not drive for at least 6 weeks. DVLA rules and regulations are frequently updated so we advise you to check this with the DVLA at www.gov.uk/driving-medical-conditions; (look under implanted electrodes or deep brain stimulation for movement disorder or pain).

- **Magnetic Resonance Imaging (MRI)**

After the operation you should not have a MRI without discussing this with the DBS team. It may not be possible to have a MRI scan because of the implanted device.

- **Other surgery or medical procedures including dentistry**

You may need a surgical procedure sometime in the future after your DBS operation (such as a joint replacement or spinal surgery). Your surgical team will need to know that you have a DBS device implanted before performing surgery, and may need to take some precautions (such as turning off the device).

We advise you to have prophylactic antibiotics if you need dental work or procedures involving either a general anaesthetic or urinary catheterisation. This is to try to avoid bacteria settling on the DBS hardware and causing infection.

- **Diathermy (also known as electrocautery)**

This is when an electric current is used to heat body tissues during surgery in order to seal blood vessels. If possible, only bipolar diathermy should be used in operations. However if only monopolar is available then the high voltage mode should be avoided. The power setting should be kept as low as possible and the ground plate should be kept as far away from the neurostimulator, extension and leads as possible.

You must avoid Shortwave Diathermy, Microwave Diathermy and Therapeutic Ultrasound Diathermy, physiotherapists tend to use these to relieve pain, stiffness and muscle spasms.

- **Other devices or equipment to avoid**

Avoid security screening devices such as those in airports. When approaching them hand over your patient identification card and request a search by hand.

- **Other tests or scans**

X-rays, CT scans and PET scans are not likely to affect the DBS system.

- **Devices that you can operate without any problem**

Computers, copiers, faxes, electric blankets, heating pads, washing machines, dryers, garage door openers, electric stoves, vacuum cleaners, hair dryers, shavers, remote controls, toasters, blenders, electric can openers, food processors, microwave ovens, televisions, radios, video recorders, CD players, mobile phone and tablets.

- **Physical Activity**

After the surgical scars are healed (usually at least 6 weeks) you can return to most physical activities except for those that result in repeated blows to the device such as boxing. You should always wear a helmet for sports such as cycling, skiing, snowboarding and horse riding. You should avoid parachute jumping and skydiving.

- **Flying**

You should not fly until 6 weeks after the operation.

Any questions

If you have any questions please ask the staff.

Notes...



Images Courtesy of Medtronic and Abbott.

National Scottish Deep Brain Stimulation Service
Queen Elizabeth University Hospital Glasgow.

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