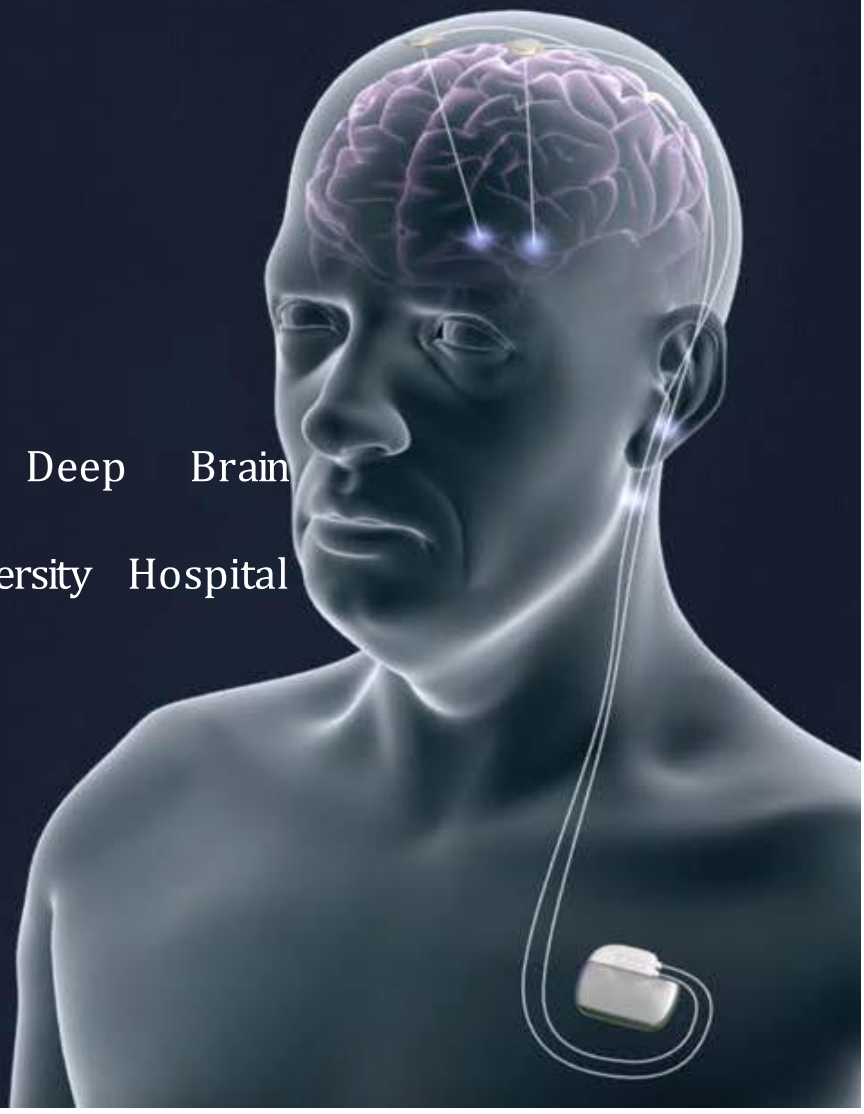
NHS SCOTLAND

NHS Greater Glasgow and Clyde

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

Margaret Reynolds and Maria Nicol

Deep Brain Stimulation Administrator
Institute of Neurological Sciences Queen Elizabeth University Hospital 1345 Govan Road
Glasgow G51 4TF

Tel: 0141 232 7512
Email: ggc.dbsadmin@ggc.scot.nhs.uk

Website address: https://rightdecisions.scot.nhs.uk/scottish-deep-brain-stimulation/

On your first visit (which often lasts a whole day), 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 Mr James Manfield**
  Consultant Neurosurgeons
- **Dr Ed Newman and Dr Vicky Marshall**
  Consultant Neurologists

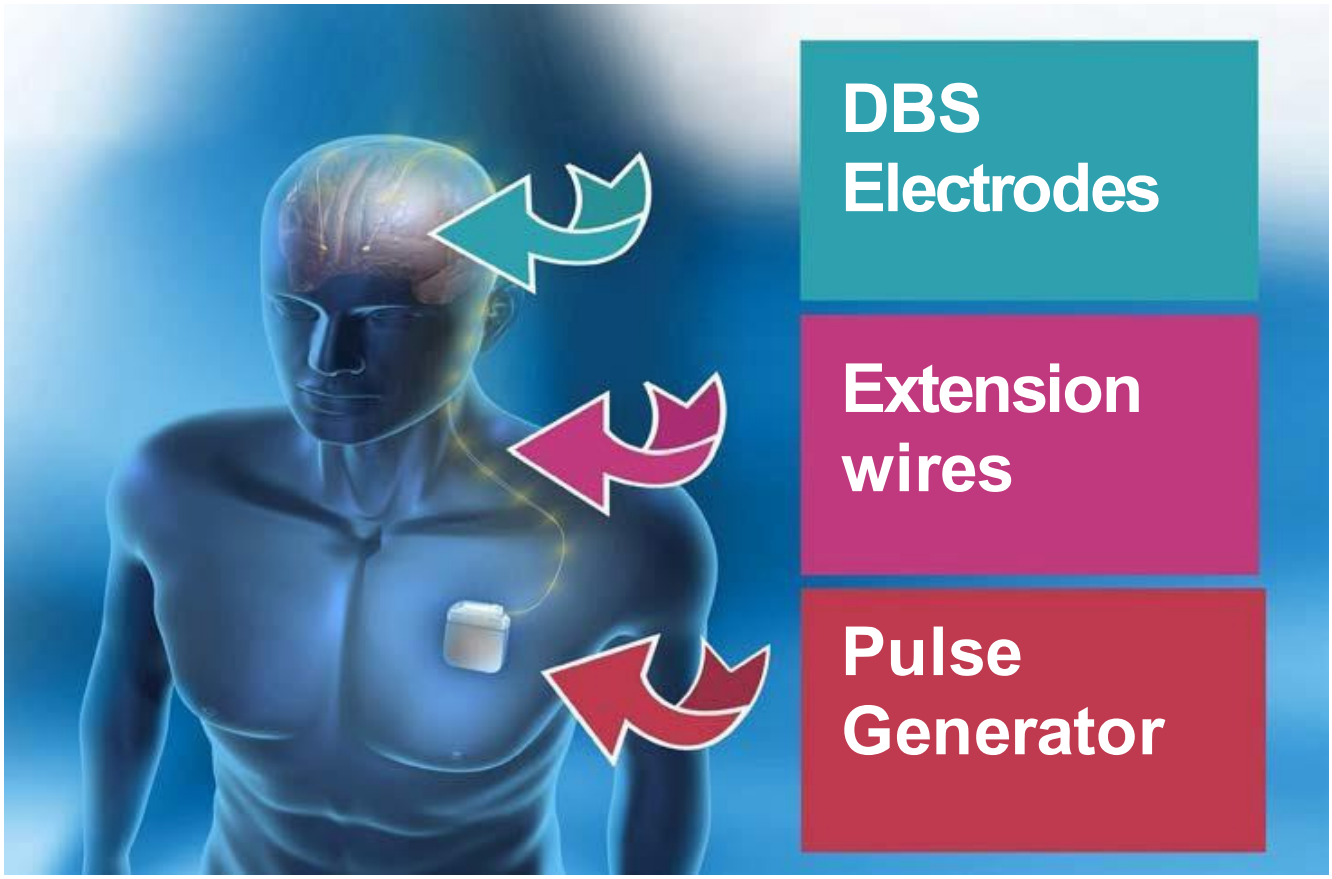
Introduction to Deep Brain Stimulation (DBS) for Tremor or Dystonia

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.
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 usually in the chest area.

Modern hardware is now much smaller than it was in the past and it is unusual for patients to be bothered by this. The team can show you examples of what the kit looks like.

You will either be asleep (general anaesthetic) for the whole process, or have sedation which means you will be awake but relaxed during part of it. Your consultants will discuss this with you and your preferences will be accommodated where possible.

The team in Glasgow's Queen Elizabeth University Hospital have been implanting stimulators since 2004, and run the national DBS service for the whole of Scotland.

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
- 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 thinking / memory disturbance.

What type of DBS is suitable for me?

Your DBS team will advise which type of operation is most suitable for you. There are several different areas in the brain that we can usefully

target. This 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 or the **Zona Incerta** region of the subthalamus.
- Patients with dystonia undergo DBS of the **Globus Pallidus internus (GPi)**

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 possible complications of the operation?

- Haemorrhage which can cause stroke or death. Both of these outcomes are rare; the risk of stroke is less than 0.5% (1 in 200) and the risk of death is 0.2% (1 in 500)
- Infection risk is less than 5% (1 in 20). If antibiotic treatment does not help we may need to remove part or the whole DBS system (which can be re-implanted later). The risk of needing the device removed is much less than 5%.
- 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 (such as chest infection).
- It is possible that the electrode may not be in the most suitable location, or moves, needing further surgery.

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 (rare and 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 or balance problems
- Mood disturbance

What happens if an operation is appropriate for me?

If we think that an operation may be a suitable 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 surgery and there will be plenty of time to consider this. 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/day case or outpatient. These tests need careful planning and this will be done via the DBS administrators (Please see page 3 for contact details).

What happens if DBS is not appropriate for me?

An operation will not be appropriate for everyone. This may be because there are factors making the operation either risky or unlikely to 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.

Some patients with tremor unsuitable for DBS may be suitable for an alternative lesioning procedure to treat one side only. The team will advise you if this is applicable.

Further assessments

If we think that an operation may be appropriate, we will organise further assessments. These can usually be done as an outpatient or day case. These include:

- **MRI brain under general anaesthetic**

This is usually done a few weeks or months before surgery. To get the best quality scan of your brain, you will usually 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.

- **Physiotherapy assessment**

  We formally assess your movement and balance. This is important as some patients' walking can worsen with stimulation. This helps identify patient at high risk of these issues.

- **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 can 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. This may be the day before (usual) or morning of surgery. You will be able to eat, drink and take any
other medications up until midnight before the day of the operation. The anaesthetist will visit you today or on the morning of surgery.

Day 2: operation

On the day of the operation, staff will help you into a hospital gown. The staff will take you to the anaesthetic room where the
anaesthetist will either give you a general anaesthetic or
sedation, this puts you into a comfortable, lightly sleeping

state. This will have been agreed with you prior to surgery. It is unusual for dystonia patients to have surgery awake.
We will trim a small amount of hair and apply a frame to your scalp either with you asleep or under local anaesthetic (with sedation). We will take you for a CT head scan.

We make two small incisions on the top of your head. In certain cases we insert a recording electrode into the brain and lighten your sedation to assess you awake. In other cases this is not required. This will be discussed with you before the surgery. If you are awake we will perform a combination of examination of your tremor and recording from the electrode to verify its position is as intended. We will also assess for side effects from stimulation. Once we are satisfied we are in the intended place and we will then insert the permanent electrode and secure it.

If you are having bilateral electrodes (most patients), this process will be repeated on the other side.

After this you will have another CT head check. If this is satisfactory, we will then remove the frame, and put you to sleep with a general anaesthetic (if you are not already asleep) 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 the time spent under sedation during the first part of the operation.

The operation often takes several hours. At the end of the procedure we close the surgical incisions (cuts) with stitches.

Day 3-5: after your operation

Most patients recover quickly from the surgical procedure and can get up and about the next day.

When you are well enough after your operation you can go home. This may be the next day after surgery. We will not switch your stimulator on at this point; you will need to come back for this (after around 6 weeks).

Surgical wound care – see photos on page 12

The sutures in your wounds are normally left for 7 days after the operation, unless they are dissolvable, and are usually removed by the team in Glasgow. If you live very far away they can be removed at your local GP surgery. If the some or all sutures are dissolvable your discharge letter will state this clearly. It is important to keep the wounds dry for the 7 days or until the stitches have been removed.

If you notice increasing redness, pain, swelling or discharge from any of your wounds after your discharge from hospital, you must contact us directly immediately, either via the ward or the DBS admin team. See photos on page 12.

What happens after the operation?

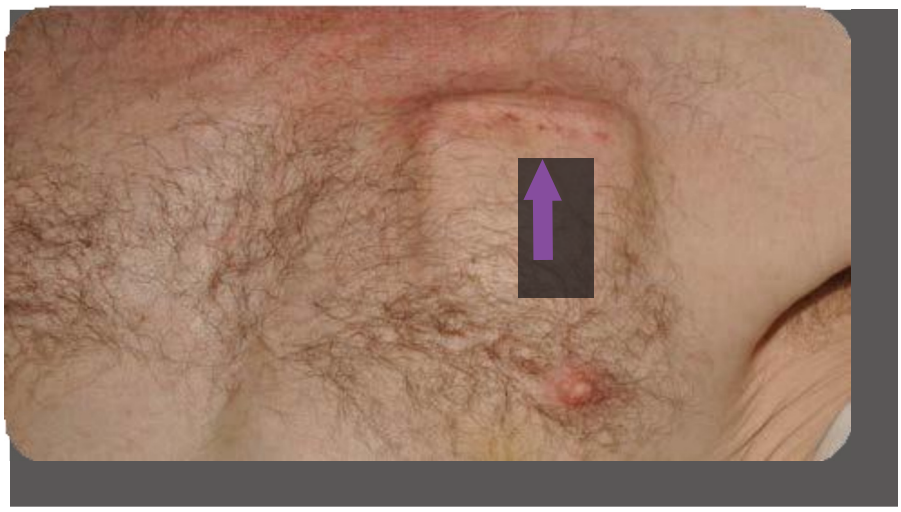
Many patients feel their symptoms are better even before the stimulator is switched on, which is thought to be the result of swelling to the area of the brain after an operation. This is known as implantation, 'stun' or impact effect. This initial effect will settle, and the amount of stimulation that you need will change as the brain recovers from the implantation, so it is not unusual 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.

DBS batteries (also known as IPGs) can be rechargeable or non-rechargeable and you can normally choose which you prefer. Rechargeables need to be charged for a varying time e.g. one hour per week. This is wireless and can be done during other activities like watching TV or reading. They are expected to last many years (over 15). The lifetime of the non-rechargeable DBS battery also varies - often around 3-5 years. We monitor the battery life so we can plan the battery replacements, which is a minor procedure that takes place under general anaesthetic or sedation.

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 scan without discussing this with the DBS team. It is usually possible to have a MRI scan with the implanted device but specific conditions must be met which needs specialist input.

  It may be you are advised by another hospital MRI scanning is not possible. Please check with us as it may in fact be possible here.

- **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 in order 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.

Monopolar diathermy poses risks of hardware damage and heating injury. Certain safer alternatives using radiofrequency (RF) energy are available.

You must also 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, electric cars, 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.

- **Special circumstances**

Some devices in everyday life contain magnets. If your IPG comes into very close proximity (*e.g.* within 30cm) with such a device, there is a small risk it can be switched off. This includes electric car chargers, induction hobs, and certain modern mobile phones which can charge by induction. In our experience such interference is actually very rare; in any case your IPG can be switched back on again immediately using your handheld programmer.

Saunas and hot tubs can raise the local temperature around your IPG significantly, and in general we recommend avoiding them.

- **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 …

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Images Courtesy of Medtronic and Abbott.

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