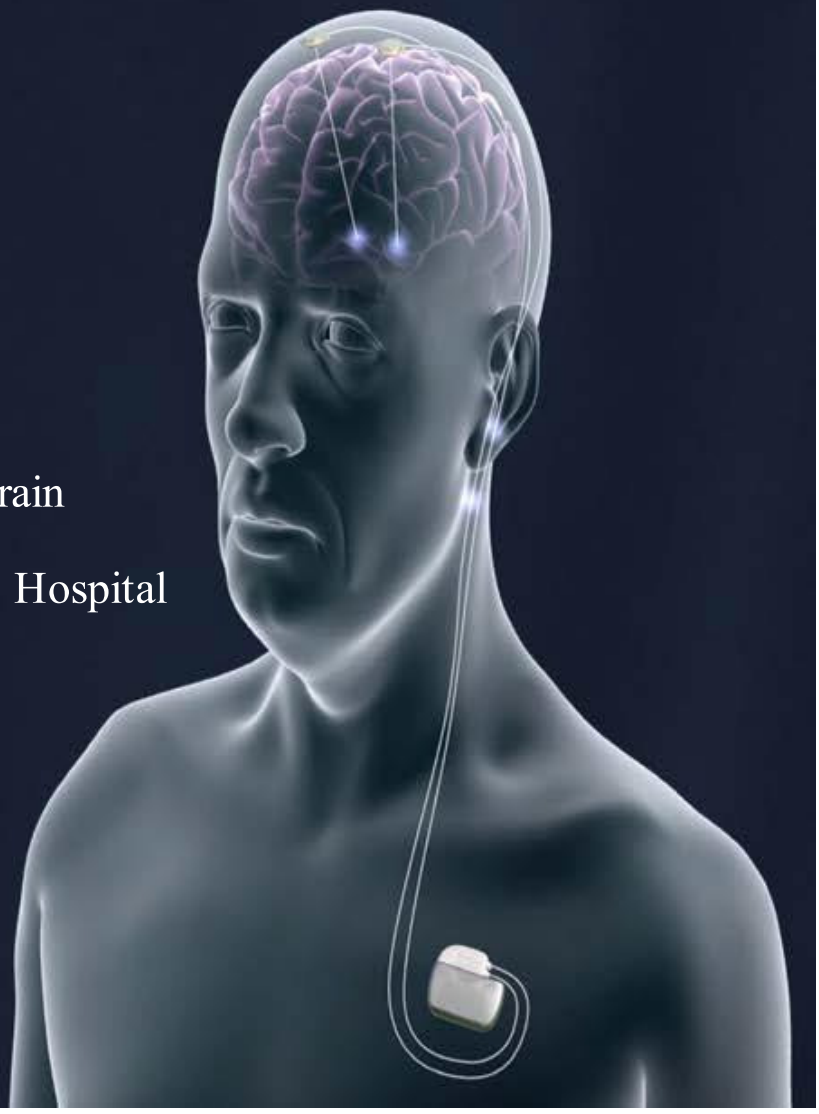
NHS SCOTLAND

NHS Greater Glasgow and Clyde

Information for patients

Parkinson's Disease

Deep Brain Stimulation of the Subthalamic Nucleus at the National Scottish Service in Glasgow



National Scottish Deep Brain Stimulation Service
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Contact Details

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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)

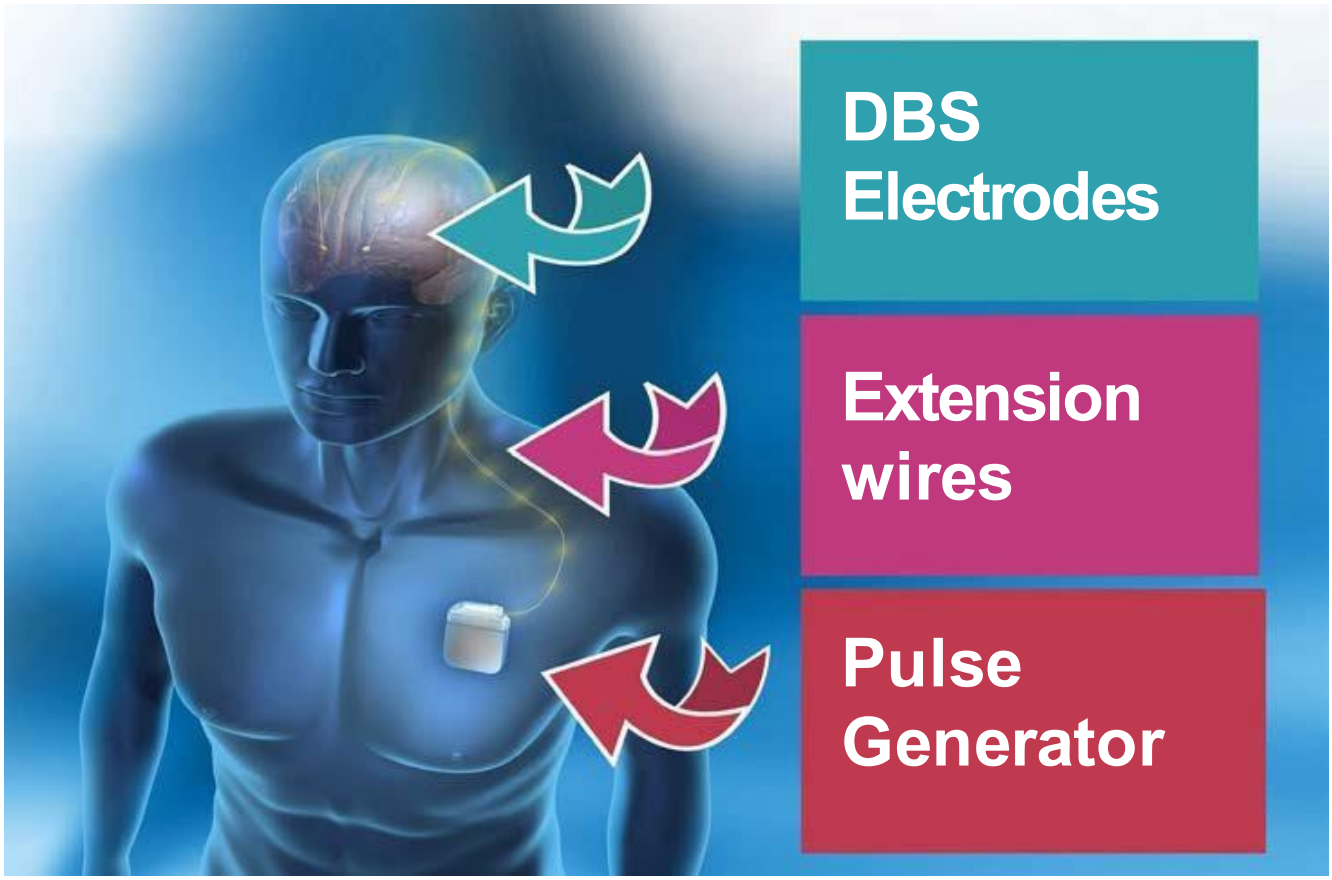
You have been referred or are considering DBS as a treatment for Parkinson's disease (PD). This information leaflet has been written to give you further information. You can also get further information from the team (please see page 3).

What is Deep Brain Stimulation?

We can use Deep Brain Stimulation as a treatment for some people with Parkinson's disease who have developed side effects from medication, or whose tremor is inadequately controlled. It is a well-established therapy in use worldwide.

This involves very fine wires with electrodes at their tips being implanted into the brain. The targets used are the Subthalamic Nuclues (STN – most common) and the Globus Pallidus Internus (GPi). The electrodes send a continuous electrical pulse through them to change some of the electrical signals in the brain and reduce the symptoms of PD.

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 small 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.


DBS Electrodes
Extension wires
Pulse Generator

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 will try to accommodate your preferences where possible.

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

Is this surgery appropriate for me?

- You must have had a good response from your levodopa (Sinemet or Madopar) but have side effects (such as variable control, on or off fluctuations or dyskinesias) limiting effectiveness.
- You may have a significant tremor which is unresponsive, or only partially responsive to medication.
- You should have no evidence of dementia or significant thinking or memory disturbance.

What could the benefits of DBS be for me?

- Improved quality of life
- Improvement in amount of "on" time
- Reduction in severity and amount of "off" time
- It is usually possible to reduce medication after DBS. This can reduce the amount and duration of abnormal involuntary movements that often occur as a side effect of medications in Parkinson's disease.
- The levodopa challenge test (below), which shows us the difference between your "off" and "on" state, will be able to give us an idea about the possible benefits for you.

What DBS cannot do?

- DBS cannot typically make you better than you are at your best "on", other than fewer unwanted movements and tremor.
- DBS is not a cure for Parkinson's disease, and the underlying disease process does continue, but it is a way of managing symptoms.

What are the complications of the surgery?

- 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% (1 in 20).
- Seizures or Epilepsy – there is a small risk of the surgery causing a seizure (fit) or recurrent seizures. The risk is less than 1% (less than 1 in 100). The DVLA forbids driving "until recovery" – we usually advise no driving until we have seen you at your first programming appointment six weeks after surgery.
- 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):

- Confusion
- Speech problems
- Abnormal, involuntary muscle contractions (dystonia)
- Dizziness
- Balance or walking difficulties
- Weight gain
- Mood disturbance

What happens next if surgery is appropriate for me?

If we think that surgery 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 the DBS administrators will arrange this. (Please see page 3 for contact details).

What happens if DBS is not appropriate for me?

Surgery will not be appropriate for everyone. This may be because there are factors making the surgery either risky or unlikely to improve your symptoms and problems. If this is the case, we will be able to discuss this with you 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 surgery may be appropriate, we will organise further assessments. For these you may need to come to the ward. Some assessments can take place as an outpatient. These include:

- **Levodopa challenge test**

  Please note this test takes place after your initial clinic appointment, at a separate visit. When attending your initial clinic appointment, you can take all your usual medications as normal; you **do not** need to attend in the "off" state.

  We need to see you in the "off" state (when your medications are not working, and you are usually slow and stiff, with more tremor), and compare it to your "on" state (when your medications are working, and your symptoms are controlled). To assess this, you do not take any medications on the morning of the test; we will assess you, and then give you a large dose of dopamine (levodopa), followed by a repeat assessment. We are looking for at least a 40% improvement from "off" to "on"; otherwise, DBS is unlikely to significantly improve your symptoms (with the exception of tremor).

- **MRI brain scan under general anaesthetic**

  This usually takes place a few weeks or months before your 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 surgery. It tells us if there are any changes in the brain that could make surgery more risky and we use this to target the area of the brain where we place the electrodes.

- **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 patients at high risk of such problems.

- **Video Recording**

  We often do video assessments of patients before surgery, 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 surgery. These meetings occur once a month. We will discuss this with you, usually in a clinic, or sometimes over the phone.

Getting the surgery: 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 your surgery. In some cases, you can continue all your regular Parkinson's medications as usual. Otherwise, there will be a plan in place to reduce your Parkinson's medications in the days before your admission. You will be able to eat, drink and take any other medications up until midnight before the day of your surgery. The anaesthetist will visit you today or on the morning of your surgery.

Day 2: surgery

On the day of your surgery, 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. We will have agreed this with you before the surgery. 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 (cuts) 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. We will discuss this with you before the surgery.

If you are awake, we will examine you and check the recording from the electrode to confirm it is in the correct position. Once we are satisfied that we are in the intended place we will then insert the permanent electrode and secure it.

Most patient will have bilateral electrodes (electrodes on both sides of the head)), and we will repeat this process on the other side.

After this you will have another CT head scan. 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 we will make an incision (cut) into the skin of the chest wall and neck and place the connecting wires and the stimulator (implantable pulse generator) into their positions.

Many patients have only a vague memory of the time spent under sedation during the first part of the surgery.

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

Day 3-5: after your surgery

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

When you are well enough after your surgery you can go home. This is likely be a couple of days after the surgery but may be less or more. We will not switch your stimulator on at this point; you will need to come back for this (usually 6 weeks later)).

Surgical wound care

The stitches in your wounds are normally left for 7 days after the surgery, unless they are dissolvable, and usually staff from the DBS team remove these . If you live very far away, your local GP surgery can remove these. If the some or all stitches 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. Please see the photographs page 14.

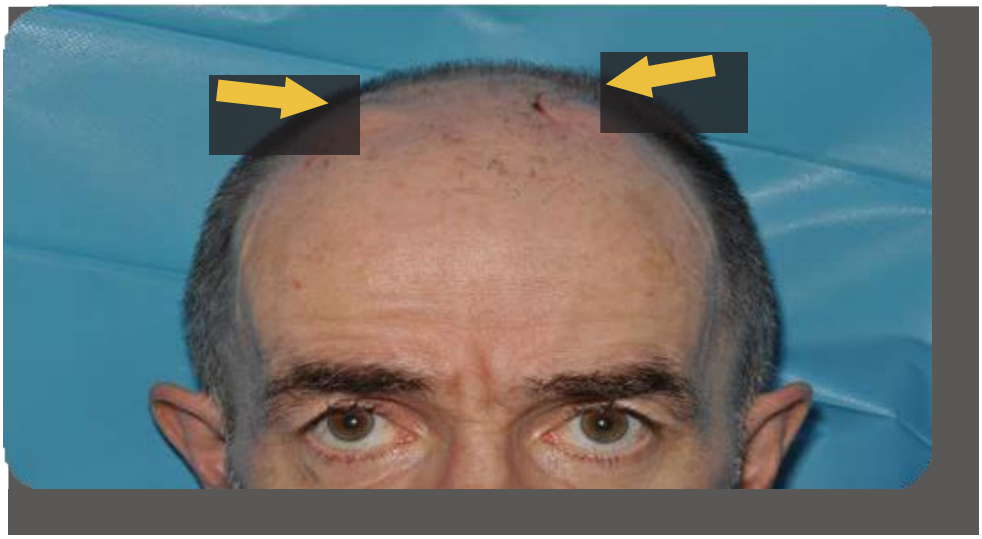
What happens after the surgery?

Many patients feel their Parkinson's 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 surgery. 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 surgery 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 you can do this during other activities like watching TV or reading. They are expected to last many years (over 15 years).
- 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.

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



Healing wound just behind the ear over extension wires

Healing wound on the chest over pulse generator

Other advice and precautions after your surgery

- **Driving**

  After your surgery 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). You should also check with your insurance company before driving.

- **Magnetic Resonance Imaging (MRI)**

  After the surgery **you should not have an MRI scan without discussing this with the DBS team.** It is usually possible to have an MRI scan with the implanted device but this need to be under specific conditions and needs specialist input.

  Other hospitals may advise that you cannot have an MRI scan. Please check with us as it may in fact be possible at the Queen Elizabet University Hospital.

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

  You may need a surgical procedure sometime in the future after your DBS surgery (such as a joint replacement or spinal surgery). Your surgical team will need to know that you have a DBS device implanted before your surgery and may need to take some precautions (such as turning off the device). If you are having dental work or a procedure involving a general anaesthetic or urinary catheter, we advise you to have prophylactic antibiotics to avoid bacteria settling on the DBS hardware and causing infection.
  (These are antibiotics that you take before the procedure to prevent infection).

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

This is when we use an electric current to heat body tissues during surgery in order to seal blood vessels. If possible, only bipolar diathermy should be used during surgery.
Monopolar diathermy poses risks of hardware damage and heating injury. There are other safer alternatives using radiofrequency (RF) energy.

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, , 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 DBS battery (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 surgery.

Any questions

If you have any questions, please ask the staff.

Notes...

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Images Courtesy of Medtronic and Abbott Inc.

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

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