Tremor and Dystonia

The Patients Journey Through Deep Brain Stimulation for Tremor and Dystonia at Queen Elizabeth Hospital Birmingham.
The Movement Disorder Team at the Queen Elizabeth Hospital Birmingham wishes to acknowledge the significant support of all patients and carers for their unique perspective on their experience of undergoing deep brain stimulation at this centre. The patients’ and carers’ views have provided us with an insight that we would not have had otherwise.

As a result of the valuable feedback from patients/carers we have placed greater emphasis on patient involvement and partnership working. Together we have re-designed and significantly improved patient information, to ensure accurate information is given at the appropriate time along the journey of deep brain stimulation surgery.

All patients referred to our centre for deep brain stimulation surgery will have access to:

- Patient-centred written information
- Opportunity to meet a patient that has already had the surgery
- An album of patient stories available to view on request

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Why do we offer deep brain stimulation?

Tremor and Dystonia are symptoms that arise from various neurological diseases such as Parkinson’s Disease, Essential Tremor, Multiple Sclerosis and Dystonia.

Tremor is an involuntary rhythmic repetitive movement, most frequently affecting the upper limbs. It can occur at rest or can be brought on, or exacerbated by, posture or intentional movement. Bilateral or unilateral deep brain stimulation (DBS) is currently the best surgical option we offer patients whose tremor leads to functional disability that interferes with daily living. The area of the brain that we target is the Ventral Intermediate (VIM) nucleus of the thalamus. The aim of this surgery is to reduce tremor that is resistant to the highest tolerated doses of medication.

Dystonia is the simultaneous uncoordinated contraction of opposing antagonistic muscles. It may be limited to a particular group of muscles or it may be generalised.

Bilateral deep brain stimulation is currently the best surgical option we offer to patients with this condition. The area of the brain we target is the globus pallidus (GP). The surgery does not cure dystonia: it can decrease the abnormal movements and postures of dystonia but usually does not totally eliminate them.

Neurosurgeons have used electrical stimulation since the 1960s as a way to locate and distinguish specific sites in the brain. In the process they discovered that stimulation of certain brain structures suppresses the symptoms of neurological disorders such as tremor and dystonia. The development of brain stimulation technology occurred in the 1980s.

In 1987, Professor Alim-Louis Benabid and Pierre Pollack of the University of Grenoble in France published the results of the first application of deep brain stimulation for the treatment of movement disorders.

The neurosurgeons at Queen Elizabeth Hospital Birmingham have been implanting deep brain stimulators in the thalamus and globus pallidus area of the brain since 1998.

It is our aim to make the procedure as minimally distressing for the
patient as possible so we have developed a technique whereby the whole procedure is done under general anaesthetic in one day, enabling the patient to be discharged 2-3 days after surgery.

DBS does not cure the underlying neurological disorder. It is reversible in that should new therapies or a cure be developed, the system can be turned off.

**Neurostimulator**
A pacemaker-like device that contains a battery and circuitry to generate electrical signals that are delivered by the leads to the targeted structures deep within the brain.

**DBS lead**
Thin, insulated wire, with four electrodes, that deliver stimulation to targeted areas.

**Extension**
An insulated wire that connects the lead to the neurostimulator.
What does the treatment involve?

The procedure involves the insertion of one or two leads – insulated wire terminating in four electrodes (contacts) – into the appropriate area of the brain.

The electrode lead is connected to an extension lead which is passed under the skin across the top of the scalp, down the side of the neck and shoulder and then connected to a pulse generator which is implanted under the skin, just under the collar bone. The pulse generator provides power and an electrical pulse for stimulation. It is a small sealed device similar to a cardiac pacemaker.

Am I suitable for surgery?

To be suitable for deep brain stimulation of the thalamus (VIM) procedure for tremor

- All suitable drug options should have been tried
- The tremor must be interfering with quality of life
- You should have no evidence of dementia or significant memory disturbance

To be suitable for deep brain stimulation of the Globus Pallidus (GP) procedure for dystonia

- You will have a history of being assessed and treated by a qualified movement disorder neurologist who has clearly diagnosed the type of dystonia and excluded other neurological problems
- The dystonia adversely affects your quality of life by interfering significantly with normal activities
- Your neurologist has tried all best medical therapy, including botulinum toxin injection
- You should have no evidence of dementia or significant memory disturbance
A – The risks of stimulation related to surgery
- Haemorrhage which can cause stroke or death
- Infection which could lead to the removal of the system
- Seizures
- Complications from general anaesthesia

B – The complications from hardware and its components
- Parts of the system eroding through skin
- Lead breakage
- Battery failure

C – The potential side-effects of deep brain stimulation
Many of these side effects are transient and can be treated by either adjusting stimulation or medication
- Speech problems
- Abnormal, involuntary muscle contractions
- Dizziness
- Movement problems or reduced coordination.

The number of reported complications and adverse events is very low. We continuously monitor and record all incidents. If you would like to know our up-to-date results please contact the movement disorder specialist on 07770971781.

After your first outpatient consultation
You will be asked to reflect on the consultation at home before making your decision to proceed with surgery.

Once you have decided to go ahead with surgery the movement disorder nurse specialist will arrange an appointment for you to see a clinical neuropsychologist and an application for funding for the operation will be submitted to your local primary care team.
Psychometric testing

As part of the pre-surgery assessment, every patient wishing to undergo surgery for deep brain stimulation will be required to undergo psychometric testing. This is to ensure that there is no evidence of significant cognitive decline or dementia. During this consultation the psychologist will ask you to do a number of tests that look at things such as memory, language, concentration, problem-solving and other brain functions. The testing is completed in a single appointment but can take a whole morning (with breaks).

Please bring with you all your current medication and a snack. You are welcome to bring a friend or member of your family with you.

The movement disorder nurse specialist will inform you of the results within four weeks and if you still wish to continue on the journey then she will arrange your next appointment with pre-admission clinic.

The pre-admission clinic

The aim of the pre-admission clinic is to gather some basic medical information and check that you are fit for general anaesthetic.

During your appointment you will be given a health screening questionnaire to complete. The pre-admission clinic nurse will then go through your completed form with you and ask about your relevant medical history.

In order to ensure your safety and the highest quality of care during the procedure, you will also undergo the following tests:

- Weight and height check
- Heart tracing (ECG)
- Blood tests
- Any other test that may be relevant such as a chest X-ray
- A medical examination by a doctor
- Urinalysis (test on a sample of urine)
- Anaesthetic review to identify any problems
- MRSA screening (the purpose of this is to reduce the risk of healthcare associated infections developing such as MRSA. The screening also helps reduce the rates of MRSA by cross-infection, that is, from patient to patient)

The treatment

Day 1

You will be admitted to a ward within the Neuroscience Department and cared for by ward staff who are experienced in looking after patients with movement disorders.

The movement disorder nurse specialist will ensure your medication is accurately prescribed on the hospital system so there is no disruption to your regular regime.

You may also be given the option to have a pre-surgery video made.

The ward staff will carry out routine observations.

You will be able to take all your medication, eat and drink, up to 03:00am of day two.

Day 2

On the day of your operation the anaesthetist who will be administering your anaesthetic will visit you on the ward. This pre-operative visit is your opportunity to ask questions or voice any concerns you may have about any aspects of the anaesthetic you are going to receive.

Between 07.30-08.00, you will be assisted to put on a theatre gown and, using a black marker pen, the site of the operation will be marked and you will be taken down to the MRI anaesthetic room.

In the anaesthetic room, you will be put to sleep and then the frame
will be fitted to your head.

The type of anaesthesia used is general anaesthetic which will render you completely unconscious. You will have no memory of the surgical procedure when you wake. The amount of anaesthetic received will be carefully monitored, controlled and adjusted for the duration of the procedure.

You will then be taken to the Imaging room for a magnetic resonance scan (MRI). The target area for deep brain stimulation is measured from the scan pictures.

In theatre, your hair will be washed with an antibacterial shampoo. The surgeon will then mark your scalp where the electrodes need to enter the skull and a small disc of bone will be removed on each side. A plastic ring is fixed to the bone to hold the electrodes in place.

A recording electrode is inserted into the brain to check the exact position of the target area and, when the doctor has a good electrophysiological recording, the test electrode is removed and the permanent electrode is inserted and fixed in place.

The frame is now removed and the skin of the chest wall and neck prepared for the battery and wires.

At the end of the procedure, you will have a chest wound for the battery, two head wounds for the electrodes and a small wound near the ear for the tunnelling of the wires.

The whole system is under the skin.
Day 3

The movement disorder nurse specialist will visit you on the ward in the morning and assess your symptoms. It is important that you get up and move around the ward as much as possible and rest at regular intervals throughout the day.

The majority of our patients experience significant improvement immediately after surgery, despite the neurostimulator not being switched on. This improvement is temporary and will wear off as brain swelling subsides. The neurostimulator is turned on when symptoms have returned.

Day 4-5

As long as there are no complications as a result of surgery, you will usually be discharged on day 4 or 5.
Surgical wound care

There are one or two wounds on the top of your head, one just behind the ear and one on the left/ right side of your chest.

You will need to arrange an appointment with your GP practice nurse or district nurse to remove the clips from your wound. Clips need to be removed seven days after your operation.
Frequently asked questions

Q Can one of my family members visit me on the morning of surgery?
A Yes, family members and carers are welcome to come in and see you before 08.00 on the day of surgery.

Q How long will I be in theatre for?
A You are normally taken down to theatre between 08.00 and 08.30. The operation is an all-day procedure.

Q Will any of my hair be shaved off?
A No, we do not shave any hair off. It will be shampooed with antibacterial wash before and after surgery.

Q Will I be able to feel the device in my body?
A Yes, you will notice very small bumps on either side of your head. The wires and battery box can be felt under the skin.

Q How long will the battery last before I have to have it replaced?
A Approximately between 3-5 years but possibly longer.

Q Are there any activities I can’t do once I have had this surgery?
A It is recommended that you do not do any strenuous physical activity for at least six weeks after surgery to allow the surgical wound to heal properly.

Parachute jumping and skydiving are not recommended as these types of activities can cause damage to the implanted device and cause the leads to dislodge.
How long do I have to wait before I can drive?

DVLA rules and regulations are frequently updated. It is advisable to check this with the DVLA or ask the movement disorder nurse specialist for the most up-to-date regulations on driving.

After DBS do I need to take special precautions before having certain medical procedures?

After DBS it would be advisable to have prophylactic antibiotics if you need dental work or procedures involving either general anaesthetic or urinary catheterisation in order to avoid bacteria settling on the hardware and causing infection.

Can I have laser procedures?

Laser procedures are unlikely to affect the DBS system as long as the laser is directed away from the neurostimulation system.

What devices and equipment should I avoid?

You should avoid security screening devices like those in airports. When approaching security gates you should show your patient identification card to security personnel, ask that you be allowed to bypass the security device and request a search by hand.

You can normally operate the following household items and office equipment without any problem:

- Microwave ovens
- Televisions, radio, video recorder, CD player, mobile phone
- Tabletop appliances such as Toasters, blenders, electric can openers and food processors
- Hand-held items such as hair dryers, shavers, and remote controls
- Appliances such as washers, dryers, garage door openers, electric stoves and vacuum cleaners
- Electric blankets and heating pads
- Personal computers, copiers and fax machines
Can I have X-ray and CT or PET scan after DBS?

Yes, X-ray, CT and PET scans are not likely to affect an implanted neurostimulator system.

Can I have MRI scan?

MRI of the head can be carried out in centres who perform surgery.

Can I have diathermy?

Diathermy in the UK means electrocautery as used in operating theatres. We would recommend that only bipolar diathermy should be used in operations if possible. However, if only monopolar is available then high voltage mode should be avoided. The power setting should be as low as possible and the ground plate should be kept as far away from the neurostimulator, extension and leads as possible.

Some confusion has arisen as the neurostimulators are made in America and the American guidance on diathermy is used to mean Shortwave Diathermy, Microwave Diathermy and Therapeutic Ultrasound Diathermy, which are used to relieve pain, stiffness and muscle spasms and are often used by physiotherapists. All three of these are dangerous for people who have had DBS and can lead to severe injury, so must be avoided.
Glossary

**CT Scan** – Computerised Tomography Scan

**DBS** – Deep Brain Stimulation

**DVLA** – Driver Vehicle Licencing Agency

**ECG** – (Electrocardiogram) A test that measures the electrical activity of the heart

**Electrocautery** – A surgical technique that uses high frequency current to seal blood vessels

**Globus Pallidus (GP)** – One of the components that make up the basal ganglia in the brain

**MRSA** – Methicillin Resistent Staphylococcus Aureus is a bacterium responsible for several difficult to treat infections in humans

**MRI** – Magnetic Resonance Imaging scan is a imaging test that uses powerful magnets and radio waves to create pictures of the body

**PET Scan** – Positron Emission Tomography

**Thalamus (VIM)** – Ventral Intermediate Nucleus of Thalamus
Images courtesy of Medtronic and St Jude.