

Department of Neurological Surgery
John Radcliffe Hospital

Deep Brain Stimulation (DBS)

Pre-operative information for
people with Dystonia



We have been able to help many people with dystonia using Deep Brain Stimulation (DBS) treatment. This information leaflet will give you more information about DBS and answer some of your questions. If there is anything else you would like to know, please do not hesitate to contact the Movement Disorder Team (see the end of the booklet for contact numbers).

Deep Brain Stimulation (DBS)

Dystonia is a disorder which causes abnormal contraction (tightening) of groups of muscles. This results in involuntary, sometimes painful movements of the affected parts of the body. The cause of dystonia is unclear, although some types are hereditary (inherited) and start to develop in childhood. Deep Brain Stimulation can be used to treat some people with the following types of dystonia:

- generalised (involving much of the body)
- segmental (involving just certain parts of the body)
- cervical (involving the neck and shoulders).

Dystonia can affect both adults and children.

Deep Brain Stimulation involves implanting fine wires into a place in the brain called the internal pallidum (also known as the Globus Pallidus interna or GPi). A constant electrical pulse is sent through the wire to the brain. This modifies the brain activity and reduces some of the symptoms of dystonia.

Assessment

You will be seen in clinic first of all by members of the Movement Disorder team. They will discuss your symptoms with you and any treatment that you have tried in the past. They will perform a physical examination to assess your dystonia.

If you normally have botulinum toxin (Botox) injections for your dystonia we may need you to stop having them for 3 months before your appointment. This is because these injections improve your symptoms and make it more difficult for us to assess how severe they normally are. As the reaction to botulinum toxin injections is very individual to each person, please phone one of the Movement Disorder Nurses before your appointment to discuss your treatment.

If the team recommends DBS surgery we will talk to you about what this involves. We will give you the opportunity to ask further questions about the operation and your care afterwards. There are some things that you will need to be aware of in terms of your lifestyle after DBS surgery and you will also be able to discuss what this will mean for you personally.

We will ask you whether you wish to go ahead with the DBS surgery, but you may want to go away and think about whether you feel it would be right for you. We will not put you under pressure to make a decision on the day of your appointment.

If we have recommended surgery and you decide to go ahead with this, we will arrange a date with you for you to be admitted to hospital for further assessment. This assessment is usually carried out as a day-case. This means you will need to come into hospital early but should be able to go home later on the same day. In certain circumstances, we may need to apply for funding for surgery from your local health authority. If this is needed, we will discuss this with you in clinic.

Your admission to hospital for further assessment

Assessment of dystonia includes taking video recordings of you during various activities. These help us to see your dystonic movements.

You will also need to have a Magnetic Resonance Imaging (MRI) brain scan. This scan helps the surgeon to see the area that will be targeted during the operation. To get the best picture this scan is usually done under a general anaesthetic (with you asleep). The MRI may be carried out during your main assessment, but it is more likely that we will need to arrange a separate admission for this to be done as a day case procedure. You will be told when the scan is likely to happen and when you will need to stop eating and drinking in preparation.

A neuropsychological assessment is also part of the assessments carried out before surgery. This looks at your memory, mood and the way you think.

The assessment is an opportunity for the team to have a look at your symptoms to see if DBS would help you. If, after the assessment, we feel that DBS would not be appropriate, the surgery will not be offered to you. If this is the case, you will have the opportunity to discuss this decision with the team by telephone or in person.

We may be able to give you the results of the assessments and the decision as to whether or not surgery is appropriate for you before you go home. If not, we will contact you when you are back at home. You will be able to discuss the results with one of the consultants if you wish; this may need to be at another clinic appointment.

Consent

Our aim is to make sure that you have enough information to help you make an informed decision about whether to go ahead with surgery or not. You should have the opportunity to talk with different members of the Movement Disorder Team about any concerns or queries that you may have.

If you decide to go ahead with surgery (having been told that you are suitable for DBS) a surgeon who understands all the possible risks and benefits will explain the operation to you. If you are happy with the explanation you will then be asked to sign a consent form before the operation takes place. The main risks and benefits are described later in this information sheet.

Precautions

It is important that you stop certain drugs before surgery, especially ones which thin your blood. It is very important that you contact the hospital at least two weeks before your admission if you are taking:

- aspirin
- warfarin
- clopidogrel
- any other drugs which thin the blood
- certain types of painkillers, such as ibuprofen and diclofenac (Voltarol).

If you are taking warfarin we may need to admit you earlier before your operation.

It is **very** important that you tell us about any new symptoms or medical diagnoses that develop whilst you are waiting for surgery, as these may mean we have to change the surgical plan.

As each person is different, it is important that you phone the hospital team so that we can discuss a plan for you.

Your admission for surgery

Whilst we make every effort to make sure your admission can go ahead as planned, the John Radcliffe Hospital is a regional centre for neurosurgery and takes emergency cases. This may mean your admission is postponed.

People are normally admitted to hospital on a Tuesday or Wednesday. Your main operation will be done on the Wednesday or Thursday and usually takes place first thing in the morning. You will be in hospital for up to 5-7 days.

The operation

Although DBS is sometimes carried out for certain conditions with the person awake, we usually do the surgery for dystonia under general anaesthetic (with you completely asleep). This is because we would not want your dystonic muscle spasms to cause you pain or harm during the operation. We also won't expect to see an improvement in your symptoms immediately after the electrodes have been placed. The improvement in dystonia often takes weeks or months to be seen, so there would be no benefit for you in being awake during the operation.

The nurse will tell you when to get ready for theatre. You will be asked to wear a theatre gown and special stockings to reduce the risk of a blood clot (deep vein thrombosis) developing in your leg.

You will also see the anaesthetist who will talk to you about the anaesthetic. When it's time, the nurse will take you down to the anaesthetic room where you will be prepared for your operation.

The operation is usually (but not always) carried out in two stages on the same day, with you under a general anaesthetic for the whole time.

Stage 1

On the day of surgery you will firstly be taken to the anaesthetic room and given a general anaesthetic to make you go to sleep.

Four pins will be used to temporarily fix the stereotactic (head) frame to your skull. The pins are designed to pierce the skin and screw a few millimetres into the bone.

You will then have a CT (Computerised Tomography) scan which will help us to work out where the electrodes will need to go in relation to the metal frame. The frame must stay on for the surgery. It is used to hold your head in one place during the operation and allow the surgeon to pass the wires accurately to the correct position in the brain. It will be removed as soon as the operation is over, before you wake up from the anaesthetic.

What happens during stage 1 surgery?

The surgeon will drill two small holes (each about 3mm wide) into your skull, one on each side of the top of your head. These allow him/her to put the electrodes into your brain at the calculated site. Another CT scan will be taken to confirm the position of the electrodes. If they are correctly placed, the permanent stimulation wire (electrode) will be fixed to your skull. This is done using a small metal plate and screws so that it can't move out of position. If the wires are seen to be incorrectly placed, their position can be adjusted.

The frame is then removed from your head and you will be woken up from the anaesthetic. When the pins are unscrewed the four holes may bleed or leak a little fluid, but should not normally need stitches. The whole procedure will take approximately two hours but this does vary from person to person.

Stage 2

If all goes well, we will carry out the full implantation on the same day, after you have had your CT scan to check the lead position. This operation is also performed under general anaesthetic (you will be asleep). The brain leads will be attached to an Implantable Pulse Generator (IPG) or 'battery' which is normally implanted under the skin just below your collarbone, or on your abdomen.

Sometimes we perform stage 1 and stage 2 over two weeks. We would bring the wires out through the side of your skull to allow them to be attached to an external stimulator. We can then test the effects of the stimulation for a week before we implant the battery. The decision about whether this will be done in your case will be discussed with you before your operation day.

After the operation

After each operation you will be taken to the recovery room for a short while. There may be a drip in the back of your hand to give you fluids or medication if needed. You will then be taken back to the ward where we will monitor your pulse, blood pressure and wounds regularly. We will offer you regular pain relief. It is important that you tell a nurse if you are feeling sick or if you have pain so we can help make you comfortable. It is also important that you change your position in bed at least once every 2-3 hours to prevent prolonged pressure on individual parts of your body; the nurses will help you if necessary.

When your condition is stable you will be allowed to get out of bed. Be careful not to do too much. The next few days should be seen as an important part of your recovery process.

Going home

You should be ready for discharge from hospital about 2 days after the second stage of your operation. The stimulator will usually, but not always, be switched on before you go home. If you have had stage 1 and stage 2 done on separate days, you may need to stay in hospital for about 7-10 days in total.

Before you go home we will give you a booklet written by the manufacturer about the stimulation system. This explains how the system works, as well as "Do's" and "Don'ts" regarding safety. You will also be given an ID card to carry with you giving details of the stimulator and contact details for the surgeon and your next of kin.

We advise you not to drive for 6 weeks following your DBS surgery. You will also need to take 4-6 weeks off work. Your stitches will be removed 10-14 days after the operation. This can be done by your GP or practice nurse.

You will also be given a leaflet written by the Movement Disorder Group which contains more information about your aftercare and other advice about going home. By the time you leave hospital we would expect you to be able to care for yourself as you did before the surgery but it may be sensible to make arrangements for help with shopping, housework, gardening and caring for small children.

Follow-up

You will remain on long-term follow-up with the Movement Disorder Team. It is usual to have to change the stimulator settings several times during the months after implantation of DBS. This means you will need further visits to hospital, sometimes with a stay overnight, for us to make the necessary adjustments.

The amount of stimulation needed will change as your brain recovers from the electrodes being implanted. It is also important to reassess the medication you take for your dystonia, as adjustments may be needed when the stimulation begins to take effect.

A non-rechargeable IPG (battery) will last between 3-5 years, depending on the stimulator settings. It will have to be replaced when it runs out. This involves a minor operation to take out the old battery and connect a new one. There is now a rechargeable IPG available which may be beneficial for some people. We will discuss this option with you before the operation is carried out.

Risks and complications

As with all types of surgery, DBS involves some degree of risk and the chance of complications:

- There is a chance that the surgery will not benefit you as much as you would like. It is not possible to be certain before the operation how much benefit you will get from the DBS.
- The most serious complication is a 0.5% (1 in 200) chance of stroke from this procedure. A stroke is a bleed into the brain. This can result in weakness down one side of the body, speech difficulties or impairment of vision. How much a stroke affects a person is related to the position of the bleed and how severe it is.
- There is a 5% (1 in 20) risk of infection in the wounds. If treatment with antibiotics does not stop the spread of infection, the whole system may have to be removed.
- It is possible that the electrode may not be in the ideal position or that it could move. If this occurs it may need to be replaced. This would mean repeating stage 1 of the procedure at a future point in time.
- There is the possibility of lead fracture (the wire breaking). This would usually mean repeating stage 1 of the procedure, but may also mean replacing additional parts of the DBS system.
- There is a small risk of the surgery inducing (causing) epilepsy. This risk is less than 1% (less than 1 in 100).
- The risk of death resulting from the operation is very small, at around 0.2% (1 in 500).
- Deep Brain Stimulation can cause side effects such as tingling in one side of your body, involuntary movements, or changes to your sight. We try to programme the DBS settings to control your dystonia without causing side effects, but sometimes this can be difficult to achieve.

Benefits

Surgery on the pallidum (Gpi) can significantly improve the quality of life for some people with dystonia. The aim of the stimulator is to help to reduce the severity of symptoms, including the muscle spasms, posture and pain. The stimulator does not provide a cure for your dystonia; it can only improve your symptoms. The amount of improvement people get varies from one person to another.

On average people have around a 60% improvement in their symptoms, although some people will experience more than this and some will experience less. It is not possible to predict accurately how much improvement you will get. The improvement is usually gradual, taking anything from a few weeks to several months to happen.

If you would like to speak to someone who has had this treatment, please let us know. We will be pleased to put you in contact.

If you have any questions that you would like to ask, please contact a member of The Oxford Movement Disorder Team – see the end of this booklet for contact numbers.

Contact numbers

Consultant's secretaries: 01865 234 605

01865 231 782

01865 572 466

Consultant Neuropsychologist: 01865 234 264

Movement Disorder

Team Nurses: 01865 231 873

01865 231 875

01865 231 876

Functional Neurosurgery

Service Administrator: 01865 572 466

Neuroscience inpatients ward reception:

01865 231 526

A member of the team is usually available between the hours of 8.30am and 4.30pm. As we are working with patients we may not be able to answer your call, but please leave an answer phone message and we will return your call at the earliest opportunity.

If you have a specific requirement, need an interpreter, a document in Easy Read, another language, large print, Braille or audio version, please call **01865 221 473** or email **PALSJR@ouh.nhs.uk**

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