

Department of Neurological Surgery
John Radcliffe Hospital

Deep Brain Stimulation (DBS)

Pre-operative information for
people with Parkinson's Disease



We have been able to help many people with Parkinson's disease (PD) 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)

Deep Brain Stimulation can be used to treat some people with Parkinson's disease.

Within a normal brain, the chemical dopamine acts like a brake on the pathways that control movement. In Parkinson's disease, because dopamine is in short supply, these circuits become overactive. This causes stiffness, slowness (bradykinesia), and tremor. You may experience uncontrolled movements (dyskinesias). These can be caused by some of the medications used to treat Parkinson's disease in the long term.

Deep Brain Stimulation involves implanting fine wires into one of the places in the brain that is affected by Parkinson's disease. Mainly, these are the thalamus, pallidum and subthalamic nucleus (STN). A new site, the pedunculopontine nucleus (PPN) is being used for some people whose main symptoms are poor balance and walking difficulties even when their medications are working well. A constant electrical pulse is sent through the wire to the brain. This changes the brain activity and reduces some of the symptoms of PD.

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 you have tried in the past. The surgeon and neurologist will discuss with you whether they think that DBS will be the best treatment for you.

If the team recommends DBS surgery then 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.

You will be asked whether you wish to go ahead with the surgical treatment, 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 DBS 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 assessments. You may need to stay in hospital for about three days, or sometimes the assessments are carried out as day case appointments. There are a number of investigations to fit in, so dates need careful planning. 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 Parkinson's disease includes video recordings of you during various activities. These help us to see any differences between when you are 'off' and 'on' your PD medication and your response to dopamine.

- An 'off' state is where your PD medication has worn off and your symptoms are at their worst, e.g. not being able to move around, stiffness, slowness and tremor.
- An 'on' state is where your PD medication is working and you are at your best, with your PD symptoms more controlled, e.g. moving around more easily, less stiff and slow, less or no tremor.

Because of this we will ask you not to take your normal Parkinson medication the on the morning of your assessment.

If you take a dopamine agonist such as pramipexole (Mirapexin), cabergoline (Cabaser) or ropinirole (Requip), you may need to stop taking it before coming into hospital for your assessment. Please phone the Movement Disorder Team before you come in, so that we can discuss this with you. These medications stay in the body for quite a long time and may make some of your symptoms less obvious. This means we may not get accurate results when we carry out the 'off' medication assessment of your disease.

We will be looking for an improvement of at least 40% between your 'off' and 'on' states with your ability to do activities (walking, dressing, etc.) and in your symptoms (stiffness, slowness etc.). If little or no improvement in your symptoms is seen when you take your PD medication then there is little chance of improving them with Deep Brain Stimulation.

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. 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. Usually we will contact you when you are back at home a few weeks after the assessment. 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.

If the Movement Disorder Team has decided you would benefit from DBS, we will also then decide which procedure will give you the best results.

Once the decision has been made to go ahead with surgery, you will need to have a Magnetic Resonance Imaging (MRI) brain scan. This scan helps the surgeon to see the area they will target during the operation.

If you suffer from tremor or dyskinesia (uncontrolled movements) as part of your PD symptoms, you may need to be given a sedative. This will help to make you feel relaxed so we can get the best picture during the scan. The MRI scan may be carried out during your main assessment, or you may need a separate appointment.

People often need a general anaesthetic for the scan. This will mean you are given anaesthetic to make you sleep. If you need to have general anaesthetic, we will need to arrange a separate admission for this to be done as a day case procedure. This means that you would need to be in the hospital early in the

morning and would be able to go home later on the same day. You will be told when the scan is likely to happen and when you will need to stop eating and drinking in preparation.

We will discuss with you whether you feel that you would be able to keep completely still for the scan without sedation or a general anaesthetic.

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 (Voltorol).

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, usually first thing in the morning. You will be in hospital for around 10-14 days.

On the evening before surgery, you will need to stop taking all

your Parkinson medications. The one exception is apomorphine, as this is a shorter acting medication and can be stopped nearer to the time of surgery.

Stopping medication will naturally cause you to go into an “off” state (when your PD symptoms are much more noticeable). This is necessary in order for us to be able to see the symptoms that the surgery is hoping to improve.

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. Stage 1 (see below) of DBS for Parkinson’s disease has to be done with you awake so that we can see what effect the stimulation is having on your symptoms. However, you will have anaesthetic to make your skin and surrounding area go numb, so you won’t feel any pain. 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 sometimes (but not always) carried out in two stages, a week apart.

Stage 1

On the day of surgery you will first be taken to the anaesthetic room in theatres. Local anaesthetic will be injected into your scalp at four sites. These will be where pins will temporarily fix the stereotactic (head) frame to your skull. This may occasionally be done on the ward before you are brought to theatres. People have described this as feeling like four “bee stings” until the skin goes numb.

When your skin is numb four pins will be inserted to fix the frame to your head. They are designed to pierce the skin and screw a few

millimetres into the bone. Wearing the frame has been likened to “wearing a hat several sizes too small”.

A sedative (to make you feel sleepy) can be given during this procedure to help with any discomfort.

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 still during the operation and allow the surgeon to pass the wires accurately to the correct position in your brain. It will be removed as soon as the procedure is over.

What happens during stage 1 surgery?

The surgeon will inject some more local anaesthetic into your scalp to numb the skin. You should not feel any pain in your head. If you do, you must let us know and we can inject more local anaesthetic if needed.

They will then drill a small hole (about 3mm wide) into your skull, on one side on the top of your head. This allows them to put the electrode into your brain at the calculated site. We need you to be awake while this is done so that you can talk to the team when the tiny electrical pulse is transmitted down the wire to the electrode.

We will work with you to find the best position for the electrode to be placed to help reduce your PD symptoms, whilst trying to avoid any side effects. We may ask you to speak, move your limbs and describe any unusual or unpleasant sensations.

If the point is found at which your symptoms of Parkinson’s disease are reduced or improved without causing any unwanted side effects, 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. We will repeat this procedure on the other side of your brain, if necessary.

If we are unable to improve your symptoms without causing side effects we may have to remove the electrode and stop the operation.

If all goes well, another CT scan will be done to confirm the position of the electrodes. If these are correct, the head frame will be removed. If the wires are seen to be incorrectly placed, their position can be adjusted before the frame is removed. When the pins are unscrewed, the four holes may leak a little fluid or blood, but should not usually need stitches. The whole procedure will take approximately two hours but this does vary from person to person.

After stage 1 of the DBS procedure

One or two wires will be coming out through your skin (depending on which areas of the brain have had electrodes attached). These wires are not the electrodes – they are connecting wires. If these wires are accidentally pulled, the risk of pulling out the electrodes is very small as they are secured to your skull and scalp.

We will attach these wires to a small external stimulator and test the stimulation for a week before the final decision is made to fully implant the system. We may also make recordings from the electrodes during this time, in order to give us additional information. This will help the Movement Disorder Team decide whether or not you will benefit from the full Deep Brain Stimulation system.

If there does not appear to be any change in your PD symptoms when the stimulator is working, the surgeon may decide that the full DBS system should not be implanted. In this case, they will discuss the findings with you. The wires will be removed, usually under a general anaesthetic (you will be asleep), and you should be able to go home the next day.

Stage 2

If all goes well, we will carry out the full implantation the following week. This time the operation is performed under general anaesthetic (you will be asleep). The external connecting wires are removed and the electrodes connected to internal connecting leads. These 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 on the same day. The decision about whether this will be done in your case will be discussed with you before your operation.

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 two days after the second stage of your operation. Just putting an electrode into your brain will often improve your symptoms for a short while. Therefore, we would not normally switch the stimulator on before you go home. Once your symptoms return, you will need to come back to hospital to have the stimulator battery switched on and programmed. Occasionally we may decide that we should switch the stimulator on before you go home. We will discuss this decision with you at the time.

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 stay 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 PD, as adjustments may be needed when stimulation starts or increases.

A non-rechargeable IPG (battery) will last between 3-5 years, depending on the stimulator settings. It has 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 and it is not possible to be certain before the operation how much benefit you will obtain
- The most serious complication is a 0.5% (1 in 200) chance of a 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 DBS system may have to be removed.

- There is a very small risk that you may feel confusion after the operation. This could last for a few days or weeks and may require treatment with medication for a period of time.
- It is possible that the electrode may not be in the ideal position, or that there could be movement of the electrode. 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 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 slurred speech, tingling feelings, difficulty walking, or poor balance. By programming the stimulation we aim to minimise these side effects whilst improving your Parkinson's disease symptoms, but sometimes this can be difficult to achieve.

Benefits

Surgery on the pallidum (GPi) and subthalamic nucleus (STN) can significantly improve the quality of life for people with Parkinson's disease. The aims of the stimulator are to extend your "on" time and help to reduce the severity of "off" symptoms. The DBS cannot make you better than you are at your best "on" state. Stimulation is a way of managing Parkinson's Disease symptoms, it is not a cure.

Surgery on the pedunculopontine nucleus (PPN) aims to improve balance and walking difficulties when you are in the "on" state, but will not improve your other PD symptoms.

On average people have around an 80-90% improvement in their tremor, although some people will experience less than this. It is never possible to predict with absolute certainty how much benefit you will get. The aim of the assessment carried out whilst you are "off" and "on" your PD medication can help to give us some idea about the likely benefits for you.

People who only have tremor may have surgery on their thalamus, rather than their GPi or STN. Some people may notice a change in how clear their speech is when the stimulation is set to provide best control of their PD symptoms. In this case, we can provide limits of stimulation so that you can adjust the settings to suit you in particular situations.

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. The address and contact numbers are at the back of this leaflet.

How to contact us

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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