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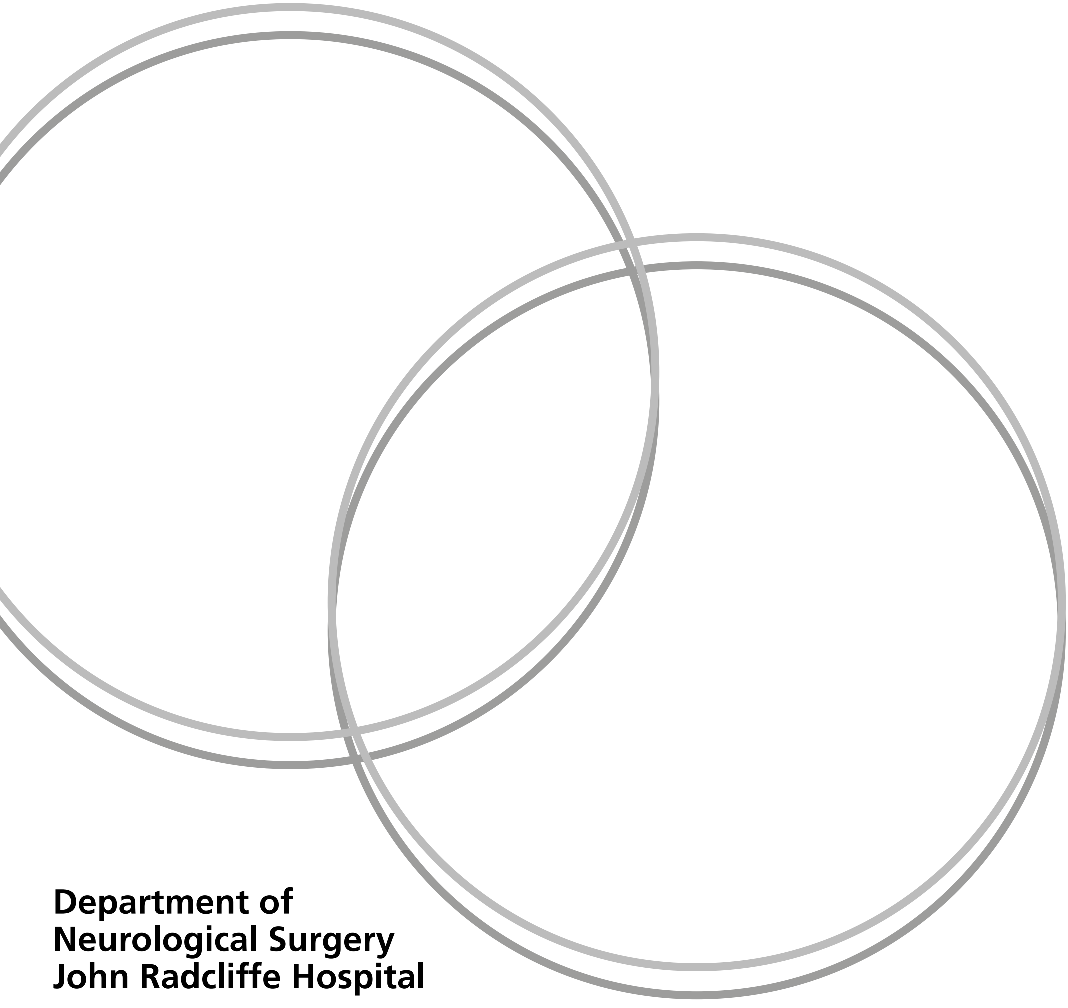
Deep Brain Stimulation (DBS) Pre-operative Information for People with Parkinson's Disease



Department of
Neurological Surgery
John Radcliffe Hospital

We have been able to help many people with Parkinson's disease (PD) using Deep Brain Stimulation (DBS). This information leaflet will give you more information about DBS and will 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 (please see the end of the booklet for contact details).

What is Deep Brain Stimulation? Stimulation (DBS)

Deep Brain Stimulation can be used to treat some people with Parkinson's disease (PD). Within a normal brain the chemical dopamine is important for the pathways that control movement. In Parkinson's disease, because dopamine is in short supply, these circuits do not work properly. This causes stiffness, slowness (bradykinesia), and tremor. You may also experience uncontrolled movements (dyskinesias) which are caused by some of the medications used to treat Parkinson's disease in the long-term.

Deep Brain Stimulation involves implanting fine wires ("electrodes") into some of the places in the brain that are affected by Parkinson's disease. Most commonly, wires are inserted into areas deep inside the brain known as the subthalamic nucleus (STN), pallidum (GPi), or thalamus (Vim). Often two brain electrodes are implanted, one on each side. A constant stream of electrical pulses is sent from a neurostimulator under the collar bone or in the abdomen, through an extension wire beneath the skin, to the brain electrodes. These electrical pulses change brain activity and reduce some of the symptoms of PD.

Benefits of DBS

Surgery can significantly improve the quality of life for people with PD. The aims of stimulation of the pallidum (GPi) and subthalamic nucleus (STN) are to extend “on” time, to help to reduce the severity of “off” symptoms, and to reduce dyskinesia (involuntary movements caused by some PD medications). DBS is usually no better than medication at improving stiffness, slowness or walking, but it has a more continuous effect. DBS may be better than medication for controlling tremor and dyskinesia.

Surgery on the thalamus (Vim) can be very effective at controlling tremor but has no effect on other Parkinson’s symptoms.

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

The assessment carried out whilst you are “off” and “on” your PD medication gives us some idea of the likely benefits of surgery, and helps us to select the best target for your symptoms.

Deep brain stimulation is a way of managing PD symptoms. It is not a cure and it will not stop the gradual progression of PD.

Is DBS right for you?

You will be seen in clinic first by one of our Consultant Neurosurgeons or Consultant Neurologists. They will discuss your symptoms with you and any treatment you have tried in the past. They will discuss with you whether DBS might be the best treatment for you.

If we think that DBS surgery may be a suitable treatment for you, 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 assessment, but you may want to go away and think about whether it would be right for you. You should not feel under pressure to make a decision on the day of your appointment.

If we recommend DBS surgery as a possible treatment and you decide to go ahead, we will arrange a date for you to come to hospital for further assessments. These are usually carried out as several 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 so, we will discuss this with you in clinic. Whilst you are on the waiting list for assessment, one of the Movement Disorder Team's Specialist Nurses or Consultants will contact you every six to nine months. This will usually be via telephone or video link but occasionally we may ask you to come for a face-to-face appointment. This is to check on your state of health and how PD is currently affecting you. We will also update you about when the assessments might occur and give you and your family the chance to ask questions.

Assessment of your 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 levodopa (which is part of many combination medications used to treat PD).

- **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, possibly with involuntary movements (dyskinesia)

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

If you take a dopamine agonist such as pramipexole (Mirapexin), ropinirole (Requip), rotigotine patches (Neupro) or cabergoline (Cabaser), you may need to stop taking it earlier and we will advise you what to do. 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 a 40% between your 'off' and 'on' states in your ability to do activities (walking, dressing etc.) and in your symptoms (stiffness, slowness etc.). We measure this using standardized rating scales based on physical examination. If little or no improvement is seen when you take your PD medication then there is little chance of improving them with Deep Brain Stimulation. The exception to this is tremor which can still sometimes be treated even if it does not respond to your PD medication.

A neuropsychological assessment is also an important part of the assessments carried out before surgery. This looks at your memory, mood and the way you think, which can sometimes be affected by PD. It is important for us to know if these are affected as it may increase your risk from surgery. This appointment is usually carried

out on a separate day from your main PD assessment. (For more information about the neuropsychological assessment visit:
www.ouh.nhs.uk/information
Adult Clinical Neuropsychology Information for patients

The assessment helps us make an objective assessment of your condition and the prospects for improvements with DBS. We will also ask you what you hope to achieve from surgery (your goals) and we will check that these are realistic. It is very important that patients undergoing DBS have sensible expectations of what DBS can – and cannot – do for them.

The decision about your suitability for surgery is made jointly by the whole DBS team. Usually, we will contact you within a month of the assessment date to let you know the outcome. If we feel that DBS would be unlikely to improve your quality of life, or would be too risky, then we would not offer you an operation. We do understand that you may be very disappointed if you cannot go forward to surgery. You will have the opportunity to discuss our decision with one of the consultants, by telephone or in person, should you wish.

Planning MRI scan

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 need to target during the operation. It is usually done at a separate appointment.

If you suffer from tremor, other involuntary movements or claustrophobia, you may need to take a sedative tablet one hour before the scan. This will help to make you feel relaxed so we can get the best images of the brain.

Occasionally, when the involuntary movements are very bad, people need a general anaesthetic for the scan. This will mean you are given an anaesthetic to make you sleep. If you need to have a general anaesthetic, we will 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. You cannot fly or drive for 48 hours after having a general anaesthetic.

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

Consent

Giving your consent

Our aim is to make sure that you have enough information to help you make an informed decision about whether or not to have surgery. You will have the opportunity to talk with different members of the Movement Disorder Team about any concerns or queries that you may have. One of our surgeons will explain the operation to you and will discuss the risks and benefits of surgery in detail. If you are happy with this explanation, you will then be asked to sign a consent form before the operation takes place. The main risks and benefits are listed later in this information sheet. Please be aware that the surgeon you meet in clinic, or when signing the consent form, may not be the surgeon who actually carries out your operation.

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 four weeks before your admission for surgery if you are taking:

- aspirin
- clopidogrel
- warfarin
- dabigatran, apixaban, rivaroxaban, or edoxaban
- any other drugs which thin the blood
- certain types of non-steroidal painkillers, such as ibuprofen, naproxen or diclofenac
- Hormone treatment such as the contraceptive pill or HRT
- Please also tell us if you take any herbal remedies or supplements such as cod liver oil

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

If you are taking Rasagiline, Selegiline or Safinamide as part of your Parkinson’s disease medications, they will need to be stopped two weeks prior to surgery.

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

It is very important that you tell us about any new symptoms, medical diagnoses, changes to your medication regime or other changes in your health that develop whilst you are waiting for surgery. Your safety is our top concern and this depends on us having up-to-date information.

Your admission for surgery

Usually, you will be admitted on the morning of surgery and will need to stay in hospital for one night after the operation. If you are very immobile off-medication, or for special reasons, we may admit you the night before surgery. We make every effort to make sure that your admission can go ahead as planned, but sometimes operations are cancelled at very short notice to make way for emergency cases. The John Radcliffe Hospital is the regional neurosurgery and trauma centre and therefore demand for operating theatre space is not always predictable.

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 meet the anaesthetist who will talk to you about the anaesthetic. Most people with PD are now able to have the whole procedure under a full general anaesthetic (asleep). However, if your main problem is tremor you may need to be awake for the first part of the surgery (stage 1). The DBS team will discuss whether you need to be awake or asleep for stage 1 during your pre-operative assessment. The whole procedure (stage 1 and 2) usually takes around 4 hours.

STAGE 1

On the day of surgery, a nurse will take you down to the anaesthetic room in the theatre suite. If you are having the procedure carried out asleep, the anaesthetist will give you a general anaesthetic and you will not know anything about the operation until you wake up in the recovery room a few hours later.

If you are having the surgery whilst awake, a sedative (to make you feel sleepy) can be given during the first part of the procedure. Local anaesthetic will be injected into your scalp at four sites where the pins which temporarily fix the stereotactic (head) frame to your skull are located. The frame is used to hold your head still during the operation and allows the surgeon to pass the wires accurately to the correct position in your brain. The experience of having the local anaesthetic is similar to a dental procedure. People describe the feeling as being 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 grip the bone. Having the frame on your head has been likened to “wearing a hat several sizes too small”.

After the frame is put on you will have a CT (Computerised Tomography) scan which will help us to work out where the electrodes need to go in relation to the metal frame. We use computer software to “fuse” the CT scan to the MRI scan which was done previously. A small area of hair is shaved from the scalp on each side where the electrodes will be inserted. If you are awake, the surgeon will then inject some more local anaesthetic into your scalp to numb the skin before making a cut in the scalp. You should not feel any pain in your head. If you do, you must let us know and we can inject more local anaesthetic.

The surgeon will then drill a small hole (about 3mm wide) into your skull on one side at the top of your head. This allows them to put the electrode into your brain at the calculated site. You might feel a very brief head pain as the probe goes through the lining of the brain (the meninges) but the brain itself does not feel pain. If you are awake for the surgery, 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, to move your limbs and to describe any unusual sensations. If you do experience side effects, we will switch the stimulation off and they will go away.

When the point is found at which your PD symptoms are most improved without causing any unwanted side effects, the 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 place. We will repeat this procedure on the other side of your brain, if planned. 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. Occasionally a wire may be slightly off-target as seen on the second CT scan. If we feel the position could be improved, we will immediately re-site the electrode. If you are awake for stage 1 this would involve drilling a second hole and re-testing as described above. When the surgeon judges that the position of the wires are good enough to be used for stimulation, we will move on to stage 2 of the procedure. However, in a few cases when the stimulator is actually turned on, the response is disappointing or side-effects occur. If we cannot fix this by adjusting the DBS settings, we may suggest further surgery to reposition the electrodes (a “lead revision”), usually within six months of the first operation. This is needed for around 1 in 35 electrodes that we insert.

Before proceeding to stage 2 the pins are unscrewed and the head frame is removed, the four holes for the pins may ooze a little fluid, but do not normally need stitches.

STAGE 2

If possible, we will carry out full implantation of the DBS system on the same day. This part of the operation is always performed under general anaesthetic (you will be asleep). The electrodes are connected to an Implantable Pulse Generator (IPG) or ‘battery’ that is normally implanted under the skin just below the collar bone, or in the abdomen.

Externalisation

Occasionally, the DBS team may decide that more time is needed to test the effect of stimulation on your symptoms. To do this we will “externalise” the system, meaning that one or two wires will be coming out through the side of your scalp. These wires are not the electrodes – they are extension 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 decision is made whether to implant the full system. We may also make recordings from the electrodes during this time, in order to give us additional information.

If there does not appear to be any change in your PD symptoms when the stimulator is switched on, the DBS team may decide that the full DBS system should not be implanted. In this case, we will discuss the findings with you. The wires will be removed, usually under a general anaesthetic and you should be able to go home the next day. On the other hand, if the team is happy with the effect of the DBS on your symptoms, the neurostimulator will be implanted under a general anaesthetic as described above.

After the operation

After the 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 as 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 the day after the second stage of your operation. Depending on the type of stimulator you have, before you go home you may be given a booklet, written by the manufacturer of the stimulation system. This explains how the system works as well as “dos 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 DBS team.

If you have stitches that need to be removed, this will be done 10-14 days after the operation by your GP or practice nurse. You may have dissolvable sutures which will not need to be taken out. We will discuss this with you before you go home. You will also be given a leaflet written by the Movement Disorder Team that contains more information about your aftercare and other advice about going home. By the time you leave the hospital we would expect you to be able to care for yourself as you were able to do so before surgery. It may be sensible to make arrangements for help with shopping, housework, gardening and caring for small children, partners and dependants.

You are not allowed to drive for 6 weeks following your DBS surgery. You will also need to take 4-6 weeks off work.

Switching on the DBS system

Just putting an electrode into your brain will often improve your symptoms for a short while (the so-called “stun effect”). This will gradually settle and your symptoms will return to their previous levels over a few days or weeks. We would normally switch the stimulator on and program it approximately six weeks after surgery, to give time for any stun effect to settle. You will need to come back to hospital as a day case to have the stimulator battery switched on and programmed.

Follow up appointments

It is common to have to adjust the stimulator settings one or more times during the months after implantation of DBS. This means you may need further visits to hospital for us to make the necessary adjustments. The amount of stimulation needed may change as your brain recovers. It is also important to reassess the medication you take for your PD, as adjustments may be needed when the stimulation begins to take effect. In most cases, when the electrodes have been implanted in the STN, we are able to reduce the medication by around 30-50%. Smaller reductions are sometimes possible with other targets. It is, however, very rare to be able to stop medication altogether.

A neurostimulator with a non-rechargeable battery will last between 3-5 years, depending on the stimulator settings. When it runs out a minor operation to take out the old battery and connect a new one will be carried out. When the battery is running down, we will ask you to check the voltage more regularly using the patient programmer which we will give you. If you have a rechargeable neurostimulator, this will last 15 – 25 years depending on the system in place. We will discuss the battery options with you before the operation is done.

You will stay under long-term follow-up with the DBS team (as well as your local neurologist and Parkinson’s nurse). The appointments will either be face to face, or carried out remotely in telephone or secure video clinics. This means you will not always have to travel to the hospital to be seen. After five years, we will see you less frequently, usually only when requested or for a battery change. At this point the management of your condition will mostly be determined by your local neurologist and Parkinson’s nurse specialist.

Deep Brain Stimulation is not a cure, but helps to manage the symptoms of Parkinson’s disease for several years. However, as the condition progresses over time, there will be a point when making changes to the DBS settings will not provide further benefit. When we feel adjusting the system will not help, we will discuss this and any other available treatment options with you. Your local Parkinson’s team remain important for your long-term care even when DBS has been very successful.

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. However, at the one year, mark, 8 out of 10 patients report that their condition is “much improved” or “very much improved”.
- The most serious complication of surgery is a stroke due to a bleed into the brain or another cause. This can result in weakness on one side of the body, speech difficulties or loss of balance. This occurs in around 1 in 100 operations. About half the people who experience a stroke will make a full recovery by 3 months. Therefore, the chance of a longer-lasting problem is around 1 in 200 operations.
- The risk of death resulting from the operation is very small, at around 1 in 500 operations.
- There is a very small risk of the surgery causing epileptic seizures.
- There is a 3% (1 in 33) risk of infection in the wounds leading to removal of all or part of the DBS system within the first year. Infection usually occurs around the neurostimulator and/or extension leads and may lead to the wounds re-opening. If this happens, we may be able to implant new components after a few months.
- There is a very small risk that you may experience confusion or have a change in behaviour after the operation. This could last a few days or weeks and may require treatment with psychiatric medication for a period of time. The risk of this is around 1 in 250 operations.
- In the longer term, with wear and tear, there is the possibility of lead fracture (a wire breaking). This would mean repeating stage 1 of the procedure, but may also mean replacing additional parts of the DBS system

- When the stimulator is turned on patients can experience reversible side effects such as slurred speech, tingling feelings, involuntary movements, changes in vision, difficulty walking, poor balance or falls. By programming the stimulator, we aim to minimise these side effects whilst improving your symptoms. If this cannot be achieved then we will consider whether repositioning one or both brain electrodes would help.
- Very rarely, patients who have had DBS notice changes in speech, balance, cognition, mood, thinking or behaviour that does not improve if the DBS is turned off, and cannot be reversed by removing the system.
- People who have had surgery on the thalamus sometimes find that in their speech is less clear when the stimulator is running at levels which stop their tremor. If so, we can allow you to adjust the stimulator yourself to suit your needs in particular situations. For example, you can choose between two settings, one of which is better for tremor control and the other which is better for speaking clearly.
- Patients who have had electrodes in the STN can sometimes experience an increase in dyskinesia (or dyskinesia for the first time). This usually indicates that the electrodes are exactly on-target. If so, it may only be possible to increase the stimulation settings very slowly whilst reducing the amount of medication very gradually.

Research

The John Radcliffe Hospital is closely associated with the University of Oxford and you may be asked if you would like to participate in one or more research studies. You are under absolutely no obligation to do so and if you choose not to it will not affect your care in any way. If you are invited to take part in a research study, a member of the research team will discuss in depth with you the purpose of the study and what it would involve.

Further information

If you have any questions that you would like to ask, please do not hesitate to contact a member of The Oxford Movement Disorder Team.

Contacts

Movement Disorder Team Nurses:

Tel: **01865 231 876**

Email: **neuromodulation@ouh.nhs.uk**

(A member of the team is usually available between the hours of 8.30am and 4.30pm Monday to Friday. As we may be 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.)

How to contact us

Consultant's secretaries:

Tel: **01865 234 838**

Consultant Neuropsychologist

Tel: **01865 234 264**

Functional Neurosurgery Service Administrator:

Tel: **01865 234 838**

Neuroscience inpatients ward reception:

Tel: **01865 231 526**

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

Author: Surgical Movement Disorder team
November 2022
Review: November 2025
Oxford University Hospitals NHS Foundation Trust
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