

Department of Neurological Surgery
John Radcliffe Hospital

Deep Brain Stimulation (DBS)

Pre-operative information for
people with Tremor



We have been able to help many people with tremor 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 contact the Movement Disorder Team (see the end of the booklet for contact numbers).

Deep Brain Stimulation (DBS)

Tremor can be a symptom of a number of different disorders, some of which are hereditary (inherited). Sometimes tremor can occur as a result of a head injury, stroke or multiple sclerosis, but sometimes the cause is not known. Tremor may also be one of the symptoms of Parkinson's disease (PD) but Deep Brain Stimulation for Parkinson's disease will not be discussed in this leaflet. We have a separate information sheet for people with Parkinson's disease.

Deep Brain Stimulation involves implanting fine wires into a site in the brain called the thalamus. An electrical pulse is then sent through the wire to the thalamus. This inhibits (slows down) the brain activity and can reduce tremor.

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 also perform a physical examination with you to assess your tremor. The surgeon and neurologist will discuss with you whether they think that DBS will be the best treatment for you. Usually you will need to have tried certain medications before surgery can be offered.

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 surgery 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, we will arrange a date with you for you to come in for further assessments. These are usually carried out as a day case, which means you shouldn't have to stay in hospital overnight. 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 tremor includes taking video recordings of you during various activities. These help us to see your tremor in different situations. We will also record the activity of your arm muscles while you are doing specific tasks. If you have tremor that is not due to Parkinson's disease, we will measure your tremor using a special recording device on your wrist (like a wrist-watch).

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 may need to be done using a sedative to help you relax and also help control your tremor. We will discuss with you whether you feel that you would be able to keep completely still for the scan without sedation. This MRI may be carried out during your main assessment or it may require a separate appointment.

Some people may need a general anaesthetic (where you are asleep) when they have the scan. If this is the case for you we will need to arrange a separate appointment 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 but would be able to go home later on the same day. You will be told the approximate

time of the scan 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. If this is the outcome for you, you will have an 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 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 that 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 ensure admission can go ahead as planned, the John Radcliffe 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. We will tell you approximately what time your operation will be and when to stop eating and drinking. 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 around 10-14 days.

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. DBS for tremor has to be done with you awake so that we can see what effect the stimulation is having on the tremor. However, you will have anaesthetic to make your skin and the 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

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 the four pins will be inserted. They are designed to pierce the skin and screw a few millimetres into the bone. You will then have the stereotactic frame fitted to the pins.

Wearing the frame has been likened to "wearing a hat several sizes too small". A mild sedative (to make you feel sleepy) can be given to you during this procedure to help with any discomfort.

You will then have a CT (Computerised Tomography) scan that 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 will allow the surgeon to pass the wires accurately to the correct position in your brain. It will be removed as soon as the operation is over.

What happens during stage 1 surgery?

The surgeon will inject some more local anaesthetic into your scalp to numb the skin further. 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.

The surgeon will then drill a small hole (about 3mm wide) into your skull, on one side of the top of your head. This allows him/her 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 then test the stimulation to see if we can control your tremor without causing you to have any side effects such as slurred speech or pins and needles in your hand or arm. If we manage to do this successfully, the surgeon will fix the permanent wire to your skull so that it can't move out of position. This is done using a small metal plate and screws. If you have tremor on both sides we will repeat this procedure for your other arm using another hole made on the other side of your head. If we are unable to control your tremor 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 and the head frame is then 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 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

Two wires will be coming out through your skin. 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.

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 take recordings from the electrodes and assess your tremor again with the recording device (the same device used during your assessment) 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 tremor when the stimulator is working, the surgeon 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 (you will be asleep). You will probably feel well enough to go home the same 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 will be discussed with you before your operation.

After the operations

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 so that you can be given fluids or medications. You will then be taken back to the ward where we will monitor your pulse, blood pressure and wounds. 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 be switched on before you go home. If you have had stage 1 and stage 2 done on the same day, you may need to stay in hospital for about 5-7 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 after your 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.

Some people with tremor will keep the stimulator switched on all the time, but for other people it is better to only use the stimulation when it is needed; for example when you are trying to do a task and your tremor is interfering. If we suggest that you should switch the stimulator on and off, you will be given a patient programmer and shown how to use it to control your tremor.

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.

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 obtain.
- 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 changes to 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 would have to be removed.
- 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 some point in the future.
- 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 slurred speech, tingling feelings, or poor balance. By programming the stimulation we aim to minimise these side effects whilst improving your tremor, but sometimes this can be difficult to achieve.

Benefits

DBS to the thalamus can significantly improve the quality of life for people with tremor. The aim of the stimulator is only to help to reduce the severity of your tremor. It will not provide a cure for any underlying cause. The degree of improvement people get varies from one person to another. The DBS will not improve any ataxia (uncoordinated movements) you have in addition to the tremor. It may be the case that we can improve your tremor so that the violence of the movement doesn't interfere with activities, but your control of fine movement may not improve.

On average people have around an 80-90% improvement in their tremor, although some people will experience less than this. The tremor recording that we did before the operation can help us to predict how much improvement you will get, but it is never possible to be absolutely certain of this before the operation. It is for this reason that we often perform the DBS surgery in two stages, so that we can see how well your tremor responds to the stimulation before we implant the whole DBS system.

Some people may notice a change in how clear their speech is when the stimulation is set to provide best control of their tremor. 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 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 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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