Parkinson's Disease

Deep Brain Stimulation

Information for Patients Being Considered for Deep Brain Stimulation
Introduction To DBS for Parkinsons

At the Walton Centre for Neurology and Neurosurgery Foundation NHS Trust, we have been using DBS treatment for a number of years to help patients with Parkinsons disease and other movement disorders. We are one of the largest implanting centres in the UK. This information leaflet will give you more information about Deep Brain Stimulation (DBS) treatment in general and answer some of your questions. It is a guide for patients who have been assessed as suitable for the DBS surgery.

DBS for Parkinsons

Deep Brain Stimulation can be used for approximately 10% of patients with Parkinson's disease. Parkinson’s disease involves certain brain cells which produce the chemical dopamine. Parkinson’s disease symptoms, such as bradykinesia (slowness in movement), rigidity and tremor are linked to the reduced level of these cells and of dopamine in the brain.

After several years, Parkinson’s Disease can also cause involuntary movements (known as dyskinesia) often after medication is taken. Parkinson’s Disease is a chronic condition and is usually controlled with medication. Surgery may be considered for some features of the disease; worsening tremor and muscle rigidity, as well as unstable response to medication (on-off effect) and dyskinesia.

Deep Brain Stimulation works by implanting fine, electrodes into particular parts of the brain that control movements. With a constant electric pulse, we aim to modify the brain activity.

Target areas

Areas of the brain that we target for Parkinson’s Disease are the Thalamus (Vim), Sub Thalamic Nucleus (STN), Globus pallidus (GPI).

Assessment

You will meet the DBS team for thorough assessment of suitability for DBS surgery. The team contains a consultant neurologist, a consultant neurosurgeon, a clinical psychologist and advanced nursing team. Usually, you will meet each consultant on different dates and times. This is to allow for thorough assessment and consultation between clinicians.

DBS team

Your DBS team is a multidisciplinary team consisting of your neurosurgeon, neurologist, neuropsychologist or neuropsychiatrist, theatre advanced nurse practitioner and specialist nursing and physio team.
What to expect at each meeting

Each clinician will assess your suitability for DBS surgery and the neurologist and surgeon will discuss the DBS surgery benefits, risks and the improvements you can realistically expect, for you as an individual. At all these appointments you will be able to ask questions you may have regarding DBS.

If the DBS team recommend DBS surgery for you as an option, you are encouraged to ask questions and discuss the impact on your lifestyle and condition. We are anxious that you feel able to make an informed choice.

The clinical neuropsychologist will assess your memory, mood and mental (cognitive) function— to check that DBS is a suitable treatment for you.

Which patients benefit from DBS?

This depends on the nature of the Parkinson’s Disease symptoms and other medical considerations. Only approximately 10% of Parkinson’s Disease patients are helped by DBS.

Criteria includes

- A diagnosis of Parkinson’s Disease
- How advanced your Parkinson’s Disease is
- Levodopa medication response
- Severe motor fluctuations including Dyskinesia (involuntary movements)
- No evidence of significant cognitive decline, hallucinations, dementia, or severe depression.
- Well enough to undergo surgery.

Can I think about it? Yes!

No pressure will be put on you to make a decision on the day of your appointments. After discussion with your consultants it is very important to think about the DBS surgery and whether it is right for you.

What happens next?

If we recommend DBS surgery and you accept, you will be seen by a psychologist and the specialist nurses for outcome measurements.

Specialist DBS nurses

The specialist nurses will contact you to discuss the surgery and assessments. At these appointments, please take the opportunity to discuss any questions you have. During these appointments we will discuss the DBS surgery, follow up care and conduct a pre-operative assessment, including a video recording of your movement disorder. These assessments are kept safe, and access is only allowed by the DBS team for audit of our results. Your details will remain anonymous and access to the videos is limited to the DBS team.
Why do we do assessments?

These assessments, including a video are important to carefully record the pre-operative severity of your Parkinson's disease. They will be carried out post operatively at 6 months, 12 months and annually. They include assessment on and off levodopa medication, of your ability to do activities such as walking, daily activities and symptom control, such as slowness, tremor, dyskinesia and stiffness. The specialist nurses will contact you before the appointment to discuss with you particulars about the assessment and preparation.

Date for surgery

You will be kept informed about the date from the surgeon's secretary. You will be asked to come in to see the specialist nurses for a pre-operative assessment for surgery. Here we will discuss, again, the procedure, realistic goals and follow up care and review your medical condition and home situation. Pre-operative screen, heart recording and blood tests will be taken at this appointment too.

Things to remember on your Pre-operative assessment appointment

- Please bring with you an up-to-date list of your medications.
- It may be helpful to write down any questions you have, and we will go through them in this appointment.
- It is important to be honest about your medical and social history and medication as we can prepare for your admission, theatre and discharge accordingly.
- If you are on any blood thinning drugs such as aspirin, warfarin and Clopidogrel then we may need to admit you a few days earlier.
- Let the specialist nurse know if you need transport to and from hospital or any admission concerns you have.
- Let the specialist nurse know if you are a carer for any dependents.
- Let the specialist nurse know if you have any sores/ulcers that were or are being dressed by a local service/GP/district nurses.
The operation

This procedure is done under local anaesthetic and with your full cooperation. You should feel ‘pulling’-such as you may feel at the dentist, when you have this procedure, but no pain. The nurse specialist and the anaesthetist will be on hand talking you through the procedure and distracting you while this procedure takes place. You need to be awake during this procedure, and be off medication. This is because when the electrode is in place we will speak to you, move your limbs and ask specific tasks. During this phase, we are establishing the best results in reducing the PD symptoms. The neurophysiology team will also monitor the electrode placement and during this phase you may hear some crackling noises from the equipment.

When the surgeon is satisfied with the electrode placement, the surgeon will secure the electrode in place and he will repeat the same procedure on the other side.

After the procedure, a dressing then a bandage will be secured around your head, and you will be moved to the trolley and have a check CT scan, to check positions of the electrodes, as a base line.

You will be monitored for one hour on the recovery unit, and will be given your PD medication, and from then onwards as per your usual regime. If you are in a severe OFF state, you may be given a rescue injection of Apo morphine to make you comfortable and speed up coming on. You will then be taken to the ward, where the nurses will closely monitor you, and in the evening encourage you to move and walk to the toilet/bathroom, with minimal assistance. The next morning you will be encouraged to move and sit out. Depending how you are clinically, you will go home later that day, or the next day. Usually you will recover at home and have the next date for ‘stage 2’ 7-14 days post discharge. This is to allow you to recover and reduces the risk of infection. You will be advised of post op care of your wounds upon discharge.

Impact effect of DBS

As a result of the DBS electrodes being placed, the target area of the brain may be stunned (impact effect). This can result in a temporary relief of symptoms. Please be aware that this is a temporary phenomenon and will wear off, typically, ranging between a few days to weeks.
Implantation of electrodes

The scans to plan targeting and actual insertion of the electrodes is called ‘Stage 1’

Monday
Please ring the Bed managers around 10.30am, who will let you know the time to come in, and what ward. When you arrive you will be admitted, by nursing and medical staff, and shown the ward.
You will be measured for stockings that prevent blood clots forming in your legs. You will be advised to wear these along with a theatre gown on Tuesday and Wednesday. The stockings are advised to be worn during admission and thereafter for 2 weeks. Each day, please remove them for leg washing, and replace when legs are dry.
The anaesthetist will see you either in the Monday evening or the Tuesday morning.
You will be seen by the advanced nurse practitioner throughout the stage 1 admission.

Tuesday
All PD medication is taken as usual.
CT and/or MRI to plan exact target, and position of adjacent structures. Typically, your hair is shaved off and small superficial screws/pins will be put around your head. These are removed on the next day, but are very important for the electrode placement as they aid with exact targeting of the DBS electrodes. You will be asleep, and this usually takes place in the morning. You will return to the ward around lunch time.
Relatives are welcomed at visiting hours. Out of hours–Please obtain permission from the nurse in charge.
Into the afternoon, we expect you to be up and moving around to the bathroom and sitting out at tea time. If you have any sickness or soreness, this will be well managed on the ward.

Wednesday
Morning list:
Fast from midnight and nil Parkinson’s Disease medication or food upon waking.
Down to theatre at 8.30am where a theatre check list will be verified.

Afternoon list:
6am-7am Light early breakfast and ONLY Levodopa PD medication. Your nurse will advise you of what other routine medication may be taken and when. Water taken till 10am. At 12:30 you will be taken down to theatre reception, where a theatre check list will be verified.
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<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Event</th>
<th>Comments</th>
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<tbody>
<tr>
<td>Monday</td>
<td></td>
<td>Medical clerking in.</td>
<td>Familiarise with Ward. Fast from midnight</td>
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<tr>
<td>Tuesday</td>
<td>09.00</td>
<td>MRI/ CT Scan under GA.</td>
<td>Take Parkinson’s medication at 7am, NBM from then</td>
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<td></td>
<td></td>
<td>Afternoon</td>
<td>Restart Parkinson’s medications and continue as per time on chart Fast from midnight Nighttime/evening dose. Do not take ropinerole or pramipexole or any Controlled Release dopamine)</td>
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<tr>
<td>THEATRE MORNING LIST Wednesday</td>
<td>06.00</td>
<td>Ward staff preparing patient for operation.</td>
<td>Do not give Parkinson’s Medication (L-Dopa ropinerole or pramipexole or any Controlled Release dopamine) Thereafter, omit all oral anti-parkinsonian medication until after the surgery is completed. NBM. If there is a problem, or patient is concerned, please bleep the DBS team- 5336</td>
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<tr>
<td></td>
<td>09.00</td>
<td>DBS surgery</td>
<td>NBM Post op CT scan</td>
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<td></td>
<td>12.00</td>
<td>Recovery unit</td>
<td>Restart Parkinson’s medications and continue as per time on chart.</td>
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<td></td>
<td>14.00</td>
<td>Return to ward</td>
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<tr>
<td>Time</td>
<td>Activity</td>
<td>Notes</td>
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<tr>
<td>AM</td>
<td>Ward staff preparing patient for operation.</td>
<td>Give Parkinson’s Medication (L-Dopa only. NOT ropinerole or pramipexole or any Controlled Release dopamine) at 7 am latest, with a light early breakfast. Thereafter, omit all oral anti-parkinsonian medication until after the surgery is completed. NBM.</td>
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<tr>
<td>12.30pm</td>
<td>DBS surgery</td>
<td>NBM</td>
<td></td>
</tr>
<tr>
<td>17.00</td>
<td>Recovery unit</td>
<td><strong>Restart Parkinson’s medications and continue as per time on chart.</strong></td>
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<tr>
<td>18.00</td>
<td>Return to ward</td>
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<td>PM</td>
<td>Discharge if surgically fit &amp; has been reviewed by the surgeons.</td>
<td>DBS Specialist nurse (Bleep 5336) to give Patient discharge information/contact details, before discharge. Follow up to be arranged. Ward staff to arrange clip removal in 7-10 days by District Nurse.</td>
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Implantation of battery (Internal Pulse Generator)

The connecting of the electrodes and battery is called ‘internalisation’ and known as ‘stage 2’
You will be given a date for this surgery from the secretary.

Day 1
Typically you are fasted from midnight, but the nursing staff on the ward will direct you regarding this and when to get ready, Inc. shower

Day 2
You will be taken down to theatre on a trolley and the anaesthetist will put you to sleep, with a general anaesthetic.
The surgeon will make 2 small cuts. One on your head, behind your ear and one on your chest below your collar bone.
The wires and battery all stay under your skin and fat layer. The battery is placed where the cut has been made in your chest.
You will be closely monitored by nursing staff on the ward post operatively. You will be expected to be sitting out, and walking with assistance to the toilet/bathroom by the evening.

Day 3
You will be visited by the specialist nurse and your system will be activated and checked. Full switch on and programming will take place a month later to allow for the post op swelling to reduce.
Discharge Information

On day of discharge someone will need to take you home. Before you are discharged home, we will check that you are at the same preoperative level of everyday activity; Such as dressing, washing and walking. You may feel tired, and should take the time to recover. This can take up to 3 months.

Removal of sutures/clips will be done by the district nurses or your GP centre, in 10-14 days. This is arranged by the ward staff. You must not have a full shower/bath until they are removed, due to risk of infection. All wounds must be kept dry.

Appointments

Please come to all appointments OFF medication but bring it with you to take after your appointment.

Following discharge, you will be reviewed depending on your clinical and programming requirements. If more support is required such as extra appointments, we can arrange this.

4 weeks post operation. Review by DBS nurse. This appointment can take up to 2 hours.
3 months. Review by your Neurologist.
2-3months. Review by your Neurosurgeon, depending on their protocol.
6 month assessment of Parkinson's Disease performed on video
12 month assessment of Parkinson's Disease performed on video

The DBS nurses offer support over the phone and ‘open’ appointments for review/programming, regardless of next appointment date.
Frequently asked questions

How long does the procedure last?

Stage 1. Scans – 2 hours,
Stage 1. Electrode position – 4 hours, 1 hour in recovery
Stage 2. IPG positioning – 2 hours, 1 hour in recovery

How many scars?

3

Does it hurt?

The majority of patient report NO pain, but do report some discomfort. The local anaesthetic can sting on injection on your scalp, but there are no pain receptors in your brain. You may feel ‘pulling’ such as you may have experienced at the dentist. The majority of patients experience a headache, the day after stage 1, and soreness to the neck and chest, where the battery is implanted, from stage 2. There will be bruising here, and it takes weeks to reduce.

When can I drive?

We recommend ceasing driving for up to 3 months after the operation. This is to allow for you to recover fully. Please check the DVLA website for more information regarding guidelines as they are frequently updated.

How long is the admission each time?

Stage 1. 5-6 days
Stage 2. 3-4 days.
If you are on any blood thinning medication, then admission is prolonged, adding up to 5-10 days more.

What are the side effects of stimulation?

Usual side effects are all reversible by changing the settings on the stimulator. These include tingling in the fingers and face, altered, slurred speech, light headedness
Frequently asked questions cont.

What are the risks?

Please discuss latest infection rates with your surgeon
Small risk of bleeding
Small risk of hardware failure. (Electrode or battery don’t work properly)
Balance impairment
Changes to speech
Some patients don’t respond to stimulation for a number of individual reasons please ask your surgeon about success rates.

How will I improve?

This is very individual, and specific goals are selected by your neurologist. It can take up to 12 months to reach therapeutic levels.

Is it guaranteed to work?

You have been carefully selected for this treatment by your neurologist and DBS team as they feel you have a reasonable chance of improvement. Unfortunately no treatments are guaranteed to work.

What Parkinson’s symptoms should I expect to not improve?

Unfortunately it doesn’t improve your gait/balance, walking, falling, and ‘freezing’ on walking. It is a treatment for PD symptoms, and so the progression of the disease will continue. Speech is not helped by DBS.

Could it make the PD worse?

DBS does not affect disease progression. In some cases there can be progression of dementia if it is there before surgery.

Can I talk to someone else who has had it done?

Please let the specialist nurses know, and they will arrange this.

What are visiting times?

14:30-16:00 and 18:30-20:00
Relatives are welcomed at visiting hours. Out of these hours—Please obtain permission from the nurse in charge.
Contact us

If there is anything else you would like to know that this booklet does not answer, please do not hesitate to contact the Functional Surgery, DBS, movement disorder team.

DBS team.

**Neurologists**
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