Dystonia

Deep Brain Stimulation
Introduction To DBS for Dystonia

At the Walton Centre for Neurology and Neurosurgery Foundation NHS Trust, we have been using DBS treatment to help many patients with Dystonia Disease.

Particulars and stats are not discussed in this booklet. The Consultants, Neurologist and Neurosurgeon will have discussed your realistic improvements and goals.

This information leaflet will give you more information about Deep Brain Stimulation (DBS) treatment and answer some of your questions. It is a guide for patient's who have been assessed as suitable for the DBS surgery and those who have been offered and/or are considering the DBS treatment for dystonia. 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, movement disorder team.

Deep Brain Stimulation for dystonia.

Deep Brain Stimulation is a treatment that can be used for some people with dystonia. Dystonia is a disorder with sustained abnormal muscle contractions and/or spasms that are consistently present. The movements are forcing the affected body part into an abnormal position, and thus painful movements are associated with the condition.

Emotional upset, fatigue and stress can cause an increase in dystonic symptoms, and periods of rest can cause a decrease in symptoms.

Dystonia can affect adults and children. The cause is unclear, although there are some hereditary types.
Dystonia can affect most of the body, generalised; aim 50% improvements.
Dystonia can affect parts of the body, including shoulder and neck, Segmental and torticollis; aim 50-70% improvement inc. pain.

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 dystonia are Internal Pallidum (GPI)

Assessment

You will meet the DBS team for thorough assessment of suitability for DBS surgery. One Consultant Neurologist, One Consultant Neurosurgeon and Clinical Psychologist
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, theatre advanced nurse practitioner and specialist nursing and therapist 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 and realistic improvements for you as an individual. At all these appointments you will be able to discuss questions you may have regarding the DBS and surgery.

If the DBS team recommend DBS surgery for you, you will have the opportunity to ask questions and discuss the impact on your lifestyle and plan for realistic attainable goals.

The clinical neuro psychologist will assess your cognitive function, memory, mood and how you think.

**Which patients benefit from DBS?**

This depends on the nature of your dystonia symptoms and other medical considerations.

**Criteria includes**

1. The diagnosis is that of a primary dystonia or secondary dystonia.
2. Dystonia is considered disabling (by patient and clinician) or likely to worsen with time.
3. A trial of L-Dopa has taken place to exclude (Dopamine Responsive Dystonia; DRD).
4. Refractory to available medical therapy (Trihexphenadyl, baclofen).
5. There are no significant contraindications to neurosurgery, and you are fit enough for 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 assessment.

**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. These assessments are kept safe, and access is only allowed by the DBS team for audit of our results. Your details will remain anonymous.
Why do we do assessments?

These assessments, including video are important to note the pre operative level of your Dystonia disease and symptom control. They will be carried out post operatively at 6 months, 12 months and annually. The specialist nurses will contact you before the appointment to discuss with you particulars about the assessment and preparation. The data is also very important for quality control and recording device data.

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.
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**

CT and/or MRI to plan exact target, and position of adjacent structures. Typically, your hair is shaved off. 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**

6am-7am Light early breakfast. Water taken till 10am. At 12pm you will be taken down to theatre reception to be checked in for your procedure with theatre staff.
**The operation**

This procedure is done under general anaesthetic, so you will be asleep, and you will NOT be aware of what is taking place. During the operation you will neurophysiology monitoring, this is used to assist the surgeon with the electrode placement.

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 regular medication, and from then onwards as per your usual regime. You are then 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 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 (Micro lesion effect)**

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.
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<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Event</th>
<th>Comments</th>
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</thead>
<tbody>
<tr>
<td>Monday</td>
<td></td>
<td>Medical clerking in.</td>
<td>Familiarise with Ward.</td>
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<td>NBM from midnight</td>
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<tr>
<td>Tuesday</td>
<td>09.00</td>
<td>MRI/ CT Scan under GA.</td>
<td>NBM</td>
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<td>PM</td>
<td>Recovery unit.</td>
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<td></td>
<td>Transfer patient back to ward.</td>
<td>Nursing staff, continue close observation.</td>
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<td>THEATRE MORNING LIST Wednesday</td>
<td>06.00</td>
<td>Ward staff preparing patient for operation.</td>
<td>Pt is FFM.</td>
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<td>Give normal medication as per pre op protocol.</td>
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<td>NBM.</td>
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<td>If there is a problem, or patient is concerned, please bleep the DBS team</td>
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<tr>
<td></td>
<td>09.00</td>
<td>DBS surgery</td>
<td>NBM</td>
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<td></td>
<td>Post op CT scan</td>
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<td>12.00</td>
<td>Recovery unit</td>
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<td>14.00</td>
<td>Return to ward</td>
<td>Restart medications and continue as per time on chart.</td>
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<tr>
<td>AM</td>
<td>Ward staff preparing patient for operation.</td>
<td>6am light early breakfast with normal medication as per pre op protocol. Water till 7am. NBM.</td>
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<td>12.30</td>
<td>DBS surgery</td>
<td>NBM</td>
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<tr>
<td>17.00</td>
<td>Recovery unit</td>
<td>Continue all medications as per time on chart.</td>
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<tr>
<td>18.00</td>
<td>Return to ward</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. This allows for the post op swelling to reduce.
**Discharge Information**

On day of discharge you will need someone 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**

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.
- 2-3 months. Review by your Neurosurgeon, depending on their protocol.
- 6 month assessment of dystonia performed on video
- 12 month assessment of dystonia 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 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 my dystonic symptoms improve?

This is very individual, and specific goals are selected by your neurologist. On average improvements are 60%, with some gaining more, some a lot less improvements.
Typically, first, you may notice an improvement of the pain associated with the dystonic movements, and an easing of your muscles. Depending on your type of dystonia you should feel 'straighter'. Friends and family may notice this before you do.

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 dystonic symptoms should I expect not to improve?

If you suffer from a head tremor, this may not be improved.

Could it make the dystonia worse?

No

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**
Dr Alusi, Dr Panicker, Dr Damadoran  
Dr Bonello, Dr Macerello

**Neurosurgeons**
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