Deep brain stimulation (DBS) is a surgical procedure in which two electrodes are inserted into the brain to deliver targeted electrical pulses to block the signals that cause the disabling motor symptoms of dystonia. As a result, many patients achieve greater control over their body movements.

The therapy also requires a surgically implanted pulse generator/battery device, similar to a cardiac pacemaker, to deliver continuous electrical stimulation through electrodes. The pulse generator/battery unit is implanted underneath the skin usually on the chest wall or occasionally in the lower abdominal wall so is barely visible.

**How does it work?**

The carefully controlled minute electrical currents delivered through the electrodes on both sides of the brain have a beneficial effect on the major disabling symptoms of dystonia such as the involuntary muscle contractions causing abnormal contorted and sometimes painful movements and postures. The electrodes are implanted into an area known as the *Globus Pallidus Interna (GPi)*. Stimulation of this area is also known as pallidal stimulation.

**What does the operation involve?**

It is usual for the patient to undergo a rigorous assessment process by the multidisciplinary team to ensure that other less invasive treatment options have been exhausted. A comprehensive medical history is taken, often the patient undertakes neuropsychological assessments and it is usual for the patient to be videoed prior to surgery so a comparison can be made subsequent to the implant. Once the procedure and process is fully discussed with the patient and all the implications are fully understood, the patient is consented for treatment.

The patient next undergoes a series of scans of the brain usually both MRI and CT which allows the implanting team to accurately pinpoint the exact areas for placement of the electrodes within the GPi. The CT scan requires the fixation of a lightweight frame. The implant procedure is performed under a general anaesthetic, unlike the procedure in Parkinson’s disease or essential tremor where the patient may be implanted awake under sedation according to the technical preference of the implanting centre.

**How long will I be in hospital?**

The length of hospital stay varies from one implanting centre’s practice to another. It is usual to be admitted one to three days prior to the implant procedure for further tests. The operation, again dependent on technique, often lasts from 3 hours to 6 hours start to finish.

Assuming accurate placement of electrodes during the initial surgery and no complications, the post-implant recovery period can extend from 3 days to 5 days when the patient will be discharged with clear and precise instructions on what levels of activity to adhere to and a structured outpatient appointment schedule.

**How long will it take to work?**

Unlike the clinical effects on the movement disorder symptoms of patients with Parkinson’s disease and essential tremor where they are often immediate or within a few hours, the clinical benefits of GPi stimulation in dystonia often take several months to reach its maximal effect.
Patience is the key word. As each patient is an individual then each patient’s response to stimulation is individual. That said, immediately after implant many dystonia patients report losing the chronic pain associated with their muscle contractions and contorted postures. This is normally a good prognostic indicator that benefit will also be realised on the involuntary muscle contractions and abnormal postures. Dystonic tremor (if present) may also improve rapidly.

What are the risks?

The risks can be divided into the risks inherent with brain neurosurgery and device related risks associated with the presence of a foreign body and the stimulation itself.

All surgical procedures carry a measured degree of risk from the surgery itself and the introduction of anaesthesia. Risks of the implantation procedure include (but not exclusive to) the risk of stroke, which is reported to be between 1-3% in the clinical literature; intracranial haemorrhage; hemiplegia, infection, headaches and seizures. The significant advances in MRI technology have aided in the DBS electrode targeting procedure allowing the neurosurgical team to plan trajectories to avoid unwanted brain structures including major blood vessels.

What if it does not work?

The rigorous patient assessment, selection and de-selection process, the accuracy of targeting and expertise in post-implant management significantly increase the likelihood of a successful outcome. Prior to the implant, realistic expectations and goal setting are discussed fully between the physician, patient and their family on what clinical improvements should be expected on chosen targeted symptoms. Each individual patient will experience an individual response but the published data show an improvement in the mean dystonia movement scores of 51% with many patients showing more than a 75% improvement.

If it is decided that a satisfactory clinical result is not achieved and because the implantation of the electrodes does not destroy brain tissue, the DBS system can simply be turned off or removed (explanted). Removal requires an additional operation under general anaesthetic.

How do I go about being considered for DBS?

Consideration and assessment for DBS can only be achieved by seeking a GP referral to a specialist neurologist or directly to the specialist implanting neurosurgeon who has an interest and expertise in this field. Locating a specialist neurologist can often be difficult and may require a referral outside the immediate area where the patient lives.

Once referred the patient will undertake the rigorous patient selection and deselection process. If deemed a suitable patient, the contracts and purchasing department of the implanting centre will then seek funding approval and authorization from the patient’s GP and local PCT. This process may be lengthy and not guaranteed. If approved the patient is placed on a DBS neurosurgical waiting list.

Where can I get the operation?

There are many neurosurgical centres in the UK that are prepared to accept patient referrals for consideration of DBS therapy. The Dystonia Society has a complete listing of the centres and specialist functional neurosurgeons. It may be likely that the patient will need to travel to a neighbouring county since not all counties have a neurosurgical centre with this expertise. The implanting centres will also implant patients with other movement disorders such as parkinson’s disease and essential tremor. The patient may wish to take this listing of centres to their GP when seeking a referral.
How long does the recuperation take?

Assuming no complications arising from the surgery, patient stay in hospital after the implantation surgery will be approximately 3 to 5 days dependent on the preferences and clinical practices of the centre. Exceptions to this will be those centres involved in clinical research programmes; these centres may ask the patient to voluntarily participate in their studies, this may involve a slightly longer hospital stay.

What types of dystonia can be treated?

The forms of dystonia that can respond well to DBS and are considered to be primary indications include the following:

- Primary generalised dystonia
- DYT1 positive or negative dystonia
- Hemidystonia
- Regional dystonias such as torticollis, anterocollis or retrocollis

In addition there are case reports in the clinical literature for less frequently reported dystonias such as craniofacial dystonia, choreoathetoid dystonia and dystonic movements in cerebral palsy.

Upper age is not a limiting factor as long as the patient does not suffer from other concomitant illnesses, which may prove a contraindication to implantation. This will be discussed during the patient assessment.

Unless in very special circumstances, children are not considered for DBS implant until they are 7 years old although assessments may be made earlier in preparation for the child’s seventh birthday.

What follow-up treatment is needed?

Adhering to the follow-up schedule provided by the implanting team is crucial to maximising the clinical efficacy of the stimulation and any adjustments of medications that may be required. In addition the patient may be considered for additional therapies such as botulinum toxin injections for added clinical benefits.

It is important during the post-implantation period that the patient reports back to the implanting team any signs of redness or soreness over any incision site, or any pain (other than what would be anticipated after surgery) or any other unusual symptoms.

During the initial months immediately after the implantation it will be necessary to attend an outpatients clinic to assess the clinical efficacy of the stimulation and make any necessary adjustments to the stimulation parameters. The adjustments are performed using a physician programmer using radio waves to ‘talk’ to the stimulator; this is a painless procedure. The number of outpatient visits varies from one patient to another; eventually the stimulator parameters plateau to provide maximal clinical effect on the targeted symptoms, the stimulator then requiring very minimal further adjustments on a needs-be basis.

The stimulator is powered by a battery, which has a finite life span that varies according to the level of the stimulation parameters that are necessary to provide clinical benefit. Once the battery is reaching its ‘end-of-life’ an elective battery replacement procedure is scheduled. This is a surgical procedure requiring the stimulator to be removed and replaced with a new stimulator unit.

N.B. For cosmetic reasons the stimulator may be placed on the lower abdominal wall in children and female patients.
What questions should I ask my specialist?

The patient may wish to include the following questions during any discussions with the expert multidisciplinary team when discussing DBS and the DBS procedure:

- Am I a candidate for this therapy? Why? Why not?
- What are the potential risks and benefits of the therapy?
- What are the potential risks and benefits of the surgery?
- What are the side effects of the therapy?
- Can the side effects be controlled?
- What activities may I be able to resume as a result of the therapy? How likely is it that I will be able to walk, feed myself, write, work, drive and sleep through the night?
- How should I prepare for surgery?
- What kinds of tests will be conducted before the surgery?
- What can I expect the day of surgery? How long does the surgery last? Is it painful? How long will I need to be hospitalised?
- Will my condition improve immediately after surgery, or will it take more time? What precautions will I need to take after surgery?
- How often will I need to return for follow-up visits?
- How many programming sessions to adjust the stimulation can I expect? Will I still need to take medication after having the system implanted?