

# Deep brain stimulation (DBS) for patients with dystonia

**This leaflet gives more information about DBS in children, including how it works, risks, possible benefits and what you can expect when your child comes to hospital. If you have any questions please speak to a doctor or nurse caring for your child.**

## What is dystonia?

Dystonia is the involuntary or unwanted muscle contractions (spasms) that lead to abnormal movements and postures. Sometimes these can cause pain and interfere with many aspects of daily life. Usually, a child with dystonia will feel floppy when asleep and more relaxed when calm, but display involuntary movements when excited, upset or trying to do something actively. Dystonia typically disappears during sleep and is not as prominent when the person is relaxed.

## What is DBS and how does it work?

Your child's surgery will all be carried out under general anaesthetic. DBS involves an operation where a brain 'pacemaker' is implanted into the body. Very fine wires (electrodes) are placed into carefully targeted areas of the brain, and a battery device (neurostimulator, implanted pulse generator (IPG)) is put under the skin in the abdomen (tummy). Extension wires connecting the wires and the battery device are passed down one side of the neck. The battery device sends continuous electrical impulses through the electrode wires to change the way electrical signals are processed in the brain. The areas of the brain usually targeted are those that control coordination of body movements and postures.

## What does DBS surgery for dystonia involve?

It is necessary for your child's hair to be shaved where the incisions will be made (two small areas on top of head and usually behind the ear.) Most of our young people do not like the idea of this, so it is important to prepare your child. It is important to remember that your child's hair will grow back, often very quickly.

## Deciding on DBS

We understand that deciding for your child to have this surgery is a big decision for families to make. This is why we make every effort to thoroughly assess your child so we can be as clear as possible about what DBS might offer your child. It is important to note that DBS is not a cure, but it may be helpful to control some symptoms. It is also important to know that DBS is not a quick fix, and patients usually take months or years to achieve the best possible response.

In general terms, improving dystonia and other involuntary movements may help to:

- reduce pain and discomfort
- improve sleep and day-time tiredness
- ease handling, positioning and transfer difficulties
- make it easier to carry out daily care activities
- improve voluntary control of movement
- reduce medications and their side effects

This may help to:

- improve your child's general well being
- improve concentration and optimise learning potential
- reduce the overall burden of daily care
- improve your child's independence in daily life.

## Setting goals

Each child is very different and has their own set of abilities and difficulties. Each child will have their own set of specific aims for the surgery and these will be discussed in detail with you and your child during the assessment period and during a meeting with our multidisciplinary team and the neurosurgeon.

These goals help us to reach shared agreement about what might be realistically expected after the surgery. As your child's situation changes, new goals can be set so that your child's progress can be monitored.

## How much will your child improve?

This depends on how bad the dystonia is and what is causing it. DBS works best for genetic dystonia (where it is inherited from a parent). In these cases the brain scans show no injury or scarring. DBS can also be effective in acquired dystonia, where there is a known cause for the movement difficulties (for example, premature birth, cerebral palsy, or stroke). This is why setting goals before the surgery is essential. It helps to identify what is important for you and your child, and helps you decide if your child should have DBS surgery. It also can measure your child's progress after the surgery.

## When will the DBS surgery take place?

We try to do the DBS surgery as soon as possible, once the decision has been made. This is because your child's dystonia is always changing, and to make sure that our assessments are a true reflection of the impact of the dystonia on your child at the time of surgery. As with all procedures, surgery may have to be delayed because of your child's ill-health. We will try to find another date for the surgery for as soon as possible.

## How long will the surgery take?

The operation takes 4-6 hours. A lot of this time is spent taking brain scans and planning the surgery, so we can make sure that the electrodes are in exactly the right place.

## Who will perform the surgery?

DBS is only performed by senior neurosurgeons experienced in the technique of DBS. They are supported by a team of specialists (anaesthetists, nurses) who all play an important role in your child's surgery. Our team's neurologist tries to be at the surgery so there is often a familiar person present.

## Where will the surgery take place?

The surgery will be performed at Evelina London. Arrangements will be made for your child to be admitted to Savannah Ward the day before their surgery.

## **What stimulator model will my child receive?**

Activa™ RC has become available and is particularly suitable for small children who are likely to require long-term DBS. You will be able to physically handle the stimulators and stimulating wires before the surgery. You will also be able to discuss how DBS will affect your child's daily routine, and be shown how to recharge the Activa™ RC stimulator if this is used.

## **Who will switch the stimulator on?**

This is done by the neurologist from the Evelina London Complex Motor Disorders Service, who knows your child, and is usually present during the surgery when it will be switched on.

## **Are there any complications to DBS surgery?**

The neurosurgeon will go over the surgery and its risks with you in detail.

Infection of the implanted devices is the most common complication. This happens in up to 1 in 10 operations in the three months after surgery. Although this is frustrating and disappointing we can usually manage this with courses of antibiotics. Sometimes we have to remove all or part of the device, treat with antibiotics and re-implant the stimulator about six months later.

There is a less than 1% risk of a significant bleed (intracranial haemorrhage) into the brain at the site of electrode implant. A bleed may have no obvious clinical effect on your child, but if it is serious, it could cause a stroke leading to weakness on the opposite side of the body.

Death is extremely rare in DBS surgery and, as far as we know, has only happened in the frail and elderly receiving DBS for Parkinson's disease. Please, also remember that dystonia in childhood can be life-threatening during crises (status dystonicus).

## **Equipment failure**

Like any electrical device, there may be problems with the device. Sometimes wires become disconnected or break and they need to be replaced (but this is not very common). If the electrical equipment fails (it is accidentally turned off or runs out of battery), your child's dystonia may become more severe. This may be resolved by reprogramming the stimulator or replacing all or part of the old stimulator. A battery replacement is a minor operation done under general anaesthetic, and normally only needs an overnight stay.

## **Failure to maintain DBS battery charge**

It is essential that families understand the importance of regularly recharging the DBS battery. This is because the rechargeable DBS systems may not work properly if they are allowed to go completely flat. If this happens, your child will not receive their DBS therapy, and it means they will need another operation to replace the battery component.

## **After your child's DBS surgery**

Your child will stay on Savannah Ward for 5-7 days after surgery. This is to allow the DBS system to settle in. Intravenous (via a thin tube into a vein) antibiotics are given for five days to prevent stimulator infections. Dressings will be checked on day 5.

Pain relieving medicines are prescribed immediately after surgery and are not normally needed after 2-3 days. Do not give ibuprofen or other non-steroidal anti-inflammatory drugs (NSAIDs) for one week after the DBS surgery (new or replacement surgery). Often children will complain of some neck discomfort and there may be some bruising. Extra pain relief can be offered to keep your child comfortable, so try not worry about this.

Before you leave hospital, we will give you a DBS passport (see below) and discharge report detailing your child's recovery and post-operative recommendations.

### Your child's DBS passport

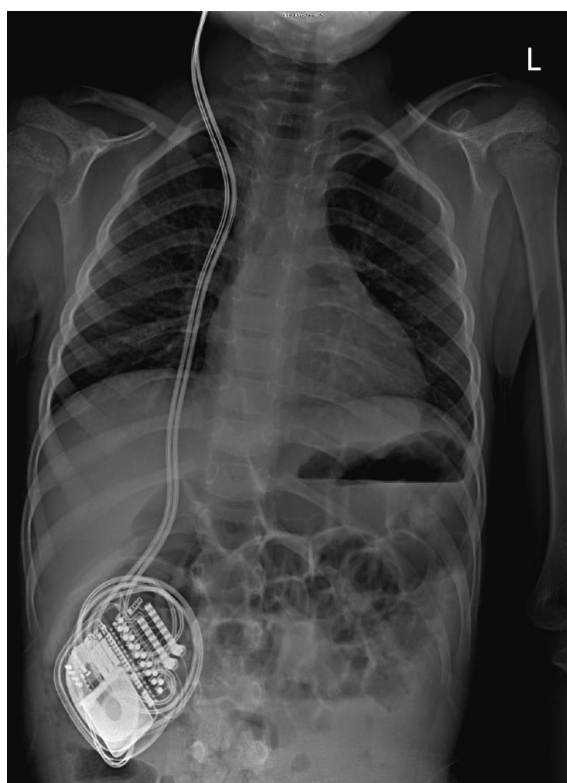
An X-ray of the DBS system is taken and a DBS passport is created for you to keep. This shows where the equipment has been placed, the stimulator model and serial numbers, and who to call in an emergency.

It also includes the names of your DBS nurse coordinator, neurologist and functional neurosurgeon, important telephone numbers and the Complex Motor Disorders Service email address. You or your team may contact us for advice.

There is always a member of the neurology service available, 24 hours a day, to help you with urgent advice.

Remember: your ambulance service will take your child to the nearest hospital in the event of sudden emergencies. Your child can then be transferred to the neurology service at Evelina London.

The DBS passport also has some important information for other health professionals. Due to the presence of wires in the brain, your child can never have an MRI scan unless they are in a specialist DBS centre. In the event of any future surgery, specific guidance needs to be followed, so you will need to make the surgeon aware your child has a DBS implant and show them the passport.



## Follow-up after DBS surgery

The Complex Motor Disorders Service will monitor your child's response to DBS at 1, 2, 3, 6, 9 and 12 months after implant. In the second year, visits are every six months. These are used to answer your questions, check and update the deep brain stimulators, review your child's progress, and set new goals. Detailed reports are sent to your local team, your GP and any other teams involved in your child's care.

## Recovery and recommendations after DBS

Although DBS is brain surgery, it is very well tolerated by most children. The surgery is not particularly painful and recovery is fairly quick. We understand that many of our patients have additional complex health needs and so recovery is a personal journey. The instructions below are a guideline for you to follow, unless a different timeframe is given by your doctor.

- For two months, don't let your child sit in a bath with their wounds under water for two months after surgery (until you have been reviewed by the medical team). Hair can be washed gently (no rubbing of the wounds, gentle pat dry with a clean towel) from 14 days after surgery. Octenisan<sup>®</sup> wash can be used for the first month. Showering from the neck and below is ok 10 days after surgery. This is to reduce the risk of wound infection and allow wounds to heal.
- We encourage active neck movements each day until your child can move their neck freely.
- Hydrotherapy and swimming should be avoided for three months, or until your doctor has said it is okay.
- Do not give NSAIDS (including ibuprofen) for a week after DBS surgery. Paracetamol can be used.
- If possible, avoid going through security scanners in airports and shops, as the magnetic fields can interfere with the stimulator settings (switching it off). Your child's DBS passport, can be shown to security staff, to explain why they should bypass security scanners.
- Your child can return to normal activities as soon as they feel ready. Most children return to school within two weeks of surgery. Some may need a slower return due to fatigue (tiredness).
- Equipment should be checked to make sure no straps or clothing are rubbing over the battery site or wound. Standing or lying may be uncomfortable over the wounds but can be reintroduced as pain allows, perhaps with a small cushion to protect the wound.
- Activities where a helmet is to be worn (such as cycling, horse-riding) should be checked with your DBS doctor before being done, but three months after surgery is usually fine.
- Other activities can be started as and when your child feels ready.
- Your child **must not do** any activity that is going to move their neck about vigorously, or in an unpredictable manner. This is because of the risk of damage to the wires connecting the electrodes and the pacemaker. This includes rebound therapy, trampolining, and bungee jumping.
- For other activities (such as skiing, most contact sports and some fairground rides), avoid if possible, but speak to your doctor for advice.

## Contact us

If you have any questions, would like more information, or to check anything about the DBS surgery programme, **t:** 020 7188 8533, **e:** [complexmotordisorders@gstt.nhs.uk](mailto:complexmotordisorders@gstt.nhs.uk)

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit **w:** [www.evelinalondon.nhs.uk/leaflets](http://www.evelinalondon.nhs.uk/leaflets)

## Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline.

**t:** 020 7188 3003, Monday to Friday, 10am-5pm **e:** [letstalkmedicines@gstt.nhs.uk](mailto:letstalkmedicines@gstt.nhs.uk)

## Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

**t:** 020 7188 8801 (PALS) **e:** [pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk)

**t:** 020 7188 3514 (complaints) **e:** [complaints2@gstt.nhs.uk](mailto:complaints2@gstt.nhs.uk)

## Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch.

**t:** 020 7188 8815 **e:** [languagesupport@gstt.nhs.uk](mailto:languagesupport@gstt.nhs.uk)

## NHS 111

This service offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

**t:** 111 **w:** [www.111.nhs.uk](http://www.111.nhs.uk)

## NHS website

This website gives information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing.

**w:** [www.nhs.uk](http://www.nhs.uk)

## Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, please get in touch.

**t:** 0800 731 0319 **e:** [members@gstt.nhs.uk](mailto:members@gstt.nhs.uk) **w:** [www.guysandstthomas.nhs.uk/membership](http://www.guysandstthomas.nhs.uk/membership)

## Was this leaflet useful?

We want to make sure the information you receive is helpful to you. If you have any comments about this leaflet, we would be happy to hear from you, fill in our simple online form, **w:** [www.guysandstthomas.nhs.uk/leaflets](http://www.guysandstthomas.nhs.uk/leaflets), or **e:** [patientinformationteam@gstt.nhs.uk](mailto:patientinformationteam@gstt.nhs.uk)

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