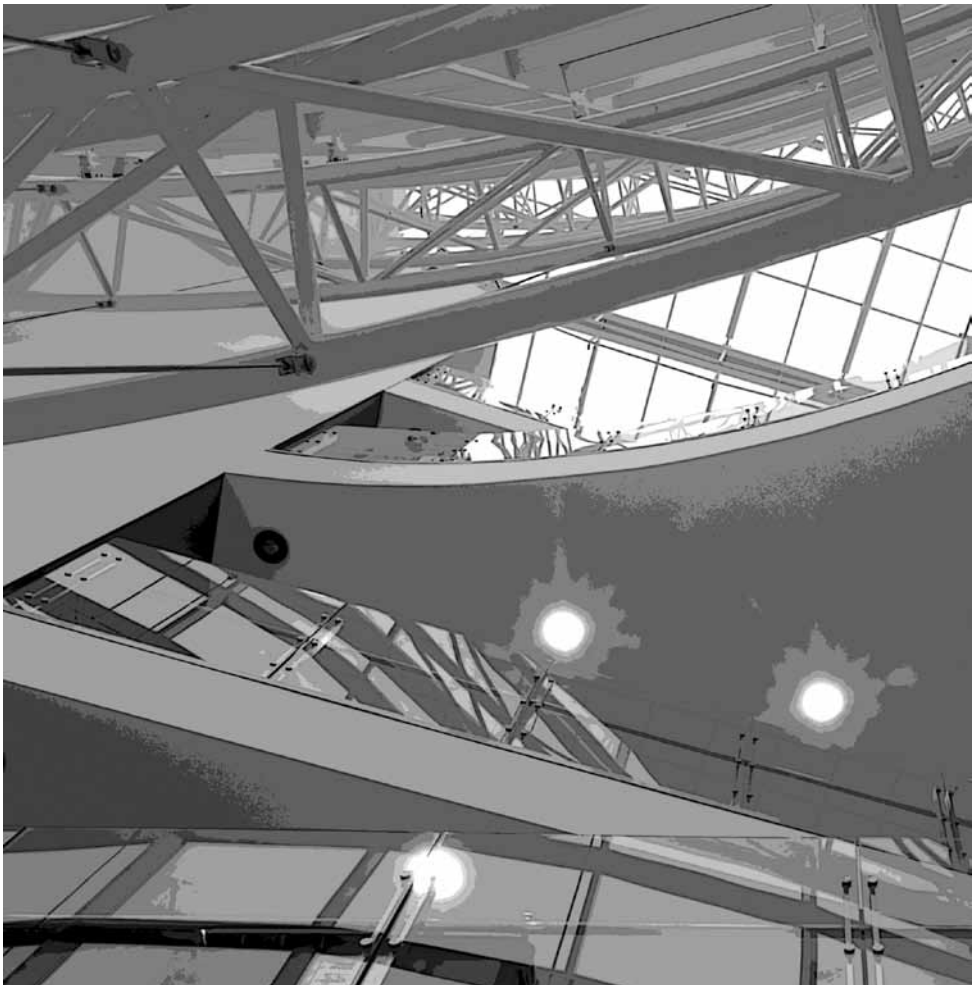


Department of Neurosciences

Deep Brain Stimulation for Cluster Headaches / Migraine

Pre-operative information for patients



We have seen you in clinic as you have long-term headaches which have not responded to medical management. We have been able to help patients with headache using Deep Brain Stimulation (DBS) treatment. This information sheet gives you more information about this procedure and answers some of the questions patients often ask. If there is anything else you would like to know, please call us on the numbers given at the end of the leaflet. You can also contact the team via email or fax.

Deep Brain Stimulation

You have probably tried a number of different treatments for your headaches which have not helped you. This surgical procedure works by targeting an area of the brain that is part of the pain pathway involved in headaches. We introduce a small amount of electrical current to the area, which helps to block the pain signals and hopefully reduce your level of pain.

The role of the Nurse Specialist

You will be assigned to a nurse specialist who will follow you from referral to the service, through to assessment and surgery, and then coordinate your long term follow up.

The nurse specialist will support you by telephone or e-mail pre-operatively, be with you for your surgery where possible and will coordinate your care post surgery.

Before your admission to hospital

We will send you questionnaires and charts to fill in so that we can assess all aspects of your pain and general health. These charts enable us to get an overall picture of your headaches.

We also require this information in order to submit a case for funding for the procedure to your local Primary Care Trust (PCT).

Funding

We will apply to your local PCT for funding for your operation. This can take a few months but it may take much longer. If funding for your operation has been approved we will try to arrange a date for admission that will be convenient to you. You may have to wait up to 3 months. If funding is declined, there may be an appeals process. Funding for this surgery is not routinely available and varies around the country. If funding is declined we will support you through an appeal process if this is offered.

Admission to hospital

Your treatment will involve two visits to hospital – an outpatient visit for assessment and then your admission for the procedure. First of all we will review you as an out-patient for a neuropsychological assessment. This will include assessment of your suitability for this operation, as well as discussion about your history and expectations of surgery.

You will also need an MRI scan before surgery. This is done on admission where possible. If there are no appointments available it will be done as an out-patient before admission.

Both of these assessments together enable us to make a final decision about your suitability for this procedure.

It is important that we stop certain drugs before surgery, especially ones that thin your blood. If you are taking aspirin, warfarin, clopidogrel or non-steroidal anti-inflammatories (e.g. ibuprofen or Voltarol) it is very important that you contact us two weeks before your admission and we can discuss stopping them with you. If you are taking warfarin we may need to admit you earlier, but each case varies, so it is important that you phone and we can discuss the plan for you.

The Operation

This is usually done in two separate stages. You will stay in hospital throughout – usually for about 12 days in total.

Stage one

We target an area in the brain, which we know can potentially help your headaches.

In order to target the small area of the brain accurately we have to use a type of surgery called 'stereotactic surgery'. On the day of your surgery you will be taken to the operating theatre. There will be many people in theatre to look after you including the neurosurgeons, nurse specialist, anaesthetist, and theatre and anaesthetic nurses.

In the anaesthetic room the anaesthetist will give you a sedative first and then areas of your skull will be numbed with local anaesthetic. With your skull numb a metal frame will be securely attached.

You will then be taken to the radiology department to have a CT scan that will help us to target the correct areas in relation to the metal frame. The frame must stay on for the surgery, but will be removed as soon as it is over. You will be awake for the surgery so that you can tell us if the area we are targeting is the correct area for your pain, and also to test for any side effects.

When you enter the operating theatre the doctor will inject a small area of your head with local anaesthetic to numb the scalp where the operation will be. You should not feel any pain in your head. If you do, you must let the doctor know so that you can be given more local anaesthetic if you need it.

The doctor will drill a small hole into your skull (3mm) which allows the electrode (wire) to be put into your brain. Once the wire has been passed the doctor or nurse will ask you what you feel. Once we are happy that the electrode is in the correct position, the doctor will implant the electrode. You will have

stitches over the site where the wires have been passed. The procedure will take approximately 2 hours but does vary from patient to patient.

After stage one

The electrode wire/s will be coming out through the skin in your head. We will attach these wires to a small external stimulator and test the stimulation for a week. This gives us time to find the best settings for you. You may need another scan after surgery for us to see the exact position of the electrodes for future reference. We may also ask you to allow us to record your brain waves with stimulation on and off, so that we can see the effect of it on your brain.

Throughout your admission you will frequently be asked to score and describe your pain/headaches. This will allow us to see if the treatment is working or not. It also gives time for you to decide whether or not you are happy with the amount of pain relief you are getting.

Stage 2

If you are happy with the amount of pain relief, we will carry out the full implantation the following week. This is performed under general anaesthetic (you will be asleep). The external wires are removed and the electrodes connected to a battery that is normally implanted under the skin just below the collarbone or in the tummy. There will be stitches over the battery site which will stay in for 2 weeks. Your battery will be programmed using an external programmer through the skin. You will be given a patient programmer to turn the stimulator on and off, up and down.

Discharge

You should be ready for discharge from hospital about 1-2 days after the second stage of your operation. We will advise you when to have your stitches removed at your GP's surgery. There are some restrictions on the types of scans you can have once the stimulator has been inserted but we will discuss all of these with you before your discharge.

If you hold a driving licence you will have to inform the DVLA of your brain operation. There are guidelines available from the DVLA about driving after surgery. At present there are no restrictions placed on you after this surgery, except that you wait until you have fully recovered from your operation. If there have been any complications after surgery then we will discuss driving with you.

You will be given a separate discharge advice information leaflet when you go home after your surgery.

Success rates

Our success rates should give you an idea to what extent we may be able to reduce your pain.

Deep brain stimulation helps about 80% of the patients we have treated to some degree. The rate of reduction in pain varies from patient to patient.

Complications

As with all types of surgery, there is a small chance of complications:

- It is reported that there is a 1-3% chance of stroke from this procedure.
- There is a risk of infection in the wounds – approximately 7%.

- It is possible that the electrode could move. If this happens it may need to be replaced. This would mean repeating stage one of the procedure.
- Failure of the stimulator, i.e. it does help your headaches.
- Mechanical failure of equipment – is rare but not unheard of.

Follow-up

We will keep in close contact with you after your discharge from hospital and will alter your stimulation if necessary to maintain pain relief.

The battery life will vary depending on your stimulation settings. (On average the battery will last between 2-4 years.) We do use rechargeable batteries in some cases. We will need to see you at least once a year to check the battery if it is non-rechargeable, and to make sure you have continued pain relief.

If you would like to speak to someone who has had this treatment, we will be pleased to put you in contact. Please let us know.

If you have any questions that you would like to ask, please do not hesitate to contact the team on the numbers below:

Contact Numbers

Liz Moir, *Clinical Nurse Specialist in Neuromodulation & Pain Management*

Tel: 01865 231874

e-mail: Liz.Moir@orh.nhs.uk

Professor Aziz, *Consultant Neurosurgeon*

Via PA Joanne Lavender

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Mr Alexander Green, *Consultant Neurosurgeon*

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Departmental Address:

Department of Functional Neurosurgery

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If you need an interpreter or need a document in another language, large print, Braille or audio version, please call

01865 221473 or email **PALSJR@orh.nhs.uk**

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Version 1, December 2010
Review, December 2013
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