University College London Hospitals NHS
NHS Foundation Trust

National Hospital for Neurology and Neurosurgery

Ablative Neurosurgery for Depressive Disorder:

Anterior Cingulotomy

Unit of Functional Neurosurgery

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Introduction

This booklet was prepared by the Functional Neurosurgery Team at the National Hospital for Neurology and Neurosurgery, in partnership with the Advanced Interventions Service at Ninewells Hospital, Dundee.

This booklet is intended for patients with severe depressive disorder that may benefit from ablative neurosurgery. It is not intended to replace discussion with your consultant.

This information is designed to help people understand this neurosurgical treatment. Some people want more detail of what is involved in the operation. Please ask us for as much information as you would like to help you understand the treatment.

We know that understanding and remembering information can be difficult when you are depressed. Our advice is:

- Take your time
- Only read small sections of the guide at any one time
- Ask other people to help you read it
- Highlight any areas of concern so that we can discuss these with you. We suggest that you write on this information sheet so that you can ask questions. We can provide you (or friends/ relatives) with another copy.

Why operate for depression?

For some people suffering from depression, treatment with antidepressant drugs, electroconvulsive therapy (ECT) and psychological treatments (for example, cognitive behavioural therapy, CBT) fails to relieve symptoms. They continue to suffer from depressed mood, a loss of interest in previously enjoyed activities and they can feel hopeless. Usually, they have negative and pessimistic views of themselves, others, the world around them, and their future. They usually have difficulties with sleeping, eating and concentrating. These persistent feelings and symptoms may lead to thoughts of suicide. When depression does not respond to standard treatments, people endure great suffering, have a very poor quality of life, and may be at risk of suicide. The consequences for the family and friends of the patient can be severe.

There are many different treatments for depression, but some sufferers do not respond to any of them. After all clinically proven treatments have been tried, individuals may be considered for a neurosurgical operation. This brain surgery is also known as Neurosurgery for Mental Disorder (NMD). Currently, about 3-4 people per year have operations in the UK.

What are the operations called?

Although there are several different operations performed around the world, the one that we use first is called an anterior cingulotomy (see figure 1, page 24). The other procedure commonly performed is called an anterior capsulotomy. Sometimes, after an anterior cingulotomy has been unsuccessful, or only partly successful, a patient will have an anterior capsulotomy in an attempt to improve symptoms.

Is this a lobotomy?

No. Brain operations to relieve the symptoms of mental disorders have been carried out since the late 1930s. In the past, such procedures were referred to as ‘psychosurgery’. When surgery was used to treat schizophrenia in the 1940’s and 50’s, the operation was crude, destroying large areas of brain tissue. The extensive damage to those parts of the brain called the frontal lobes led to problems with apathy, personality changes and a blunting of emotional responses and feelings. *The operations conducted today are very different.*

How are these operations different from a lobotomy?

First, surgery is only offered to people suffering from prolonged depression and only when all other reasonable treatments have been tried and failed. Second, the surgery involves the insertion of a 2mm-thin surgical probe into the brain causing a minimum of damage. The probe is guided into position very accurately using a frame that holds the probe and special imaging machines that produce detailed images of the brain; computerised tomography (CT) or magnetic resonance imaging (MRI) scanners. When placed in position by the surgeon, the end of the probe is heated to damage the tissue immediately around the tip. This heat-damaged tissue stops the function of that small part of the brain. This effect is very localised and is permanent.

Anterior cingulotomy affects two areas, one on either side and close to the middle and front of the brain, called the cingulate gyrus. Within the small areas that are affected by a cingulotomy operation there are thought to be a range of different functions. These functions include some aspects of the regulation of emotion and of automatic bodily responses to events in the world around us. The cingulate gyrus is also involved in some aspects of learning, particularly learning which events in the outside world are pleasant and which are unpleasant.

Asking for your consent

We want to involve you in all the decisions about your care and treatment. If you decide to go ahead with treatment, by law we must ask for your consent and will ask you to sign a consent form. This confirms that you agree to have the procedure and understand what it involves. Staff will explain all the risks, benefits and alternatives before they ask you to sign a consent form. If you are unsure about any aspect of your proposed treatment, please do not hesitate to speak with a senior member of staff again.

How should I prepare for this surgery?

You should continue taking your medications as normal unless your psychiatrist or neurosurgeon tells you otherwise. Medicines containing aspirin or aspirin-related drugs (non steroidal anti inflammatory drugs or NSAIDs) commonly used in cold remedies and off-the-shelf pain relief (for example diclofenac and ibuprofen) can thin the blood and increase the risk of a brain bleed. It is very important to avoid taking these medicines completely in the two weeks prior to the date of your surgery. The only off-the-shelf pain medicine that can be safely taken is paracetamol (with or

without codeine). If you are unsure whether you should take a new type of medicine please contact us before you do so.

You may also be seen in the Pre-operative Assessment Centre a few weeks prior to the planned surgical date. You may take this opportunity to clarify any concerns you have over medication usage.

What does the operation involve?

The operation takes about 3 hours, although much of this time is taken up by brain scans to locate the correct position for the probes. The surgery itself takes about one hour. The two incisions are usually placed on either side of the top of the patient's head, around 2 cm from the midline, behind the hairline to hide the scars (although this is not always possible). Most times, no shaving is required at all, but sometimes the scalp around the incisions is shaved. People do not have their whole head shaved. The scars will eventually fade to a pale line within three to six months and the hair will usually grow back normally if it has been shaved. The skin is closed by a variety of different methods using stitches or skin staples. Stiches or staples are normally removed after about 5-7 days depending on how well the wound has healed.

What should I expect after surgery?

The operation can be carried out either under local anaesthetic (with the patient awake, similar to a dental procedure) or under a general anaesthetic (with the patient asleep). A frame for the surgery is attached firmly to the patient's skull, using local anaesthetic to numb the skin and tissue. Unlike skin, bone and other parts of the body, the brain has no sensory nerve supply and cannot 'feel' pain.

If the surgery is performed under local anaesthetic, parts of the procedure can be uncomfortable, but it is *not* painful and your surgeon will guide you at every step.

Although many people feel their symptoms improve immediately, it is important to be aware that there may be NO EFFECT at this stage. This does not mean that the operation will not be successful over a longer time.

Although some people feel their symptoms start to improve soon after surgery, it is important to be aware that there may be NO EFFECT at this stage. This does not mean that the operation will not be successful over a longer time.

After surgery, most people usually complain of a headache. This tends to be around the areas where the frame has

been attached to the head and the incisions where the probes have been inserted through the skull. Simple painkillers, such as paracetamol, are given to make the patient more comfortable. Some people require slightly stronger painkillers such as codeine. This does not usually last longer than a couple of days.

The patient may experience some confusion and problems with their memory, for example – remembering which day it is. This usually settles quickly. Also, there can be problems controlling the bladder, although normal ability to hold urine will return.

There can be some bruising and swelling of the face around the eyes. However, this is rare, short lasting and requires no specific treatment.

How effective is this kind of operation?

Research over many decades in different countries suggests that this kind of operation helps the majority of all people who have it. Overall, around one fifth (20%) to one third (33%) of people do quite well, with a significant improvement in symptoms. Approximately one third (33%) may experience a more modest improvement in symptoms. The remaining people get little benefit.

Some people may notice a slight improvement in their symptoms in the weeks following surgery. However, for the majority of people, it may take 6-12 months before a sustained improvement is obvious. This improvement is often gradual, and may not be noticed by the patient initially.

Is it a cure?

Even if the operation is very successful and most symptoms are relieved, there are often continuing difficulties. When someone has suffered from depression for a very long time, there are usually many problems and difficulties in their lives. These can take time to resolve. The year following surgery can be a difficult one. It can be very frustrating to have to wait to see if the operation is going to help. If the operation brings improvement, it can be difficult to adjust to feeling well after such a long period of illness. Full support from family, friends and the local mental health services is very important. The individual's local mental health services are asked to be involved in a care plan for this period after the operation. People who have the operation will need to remain in contact with psychiatric services for a lengthy period afterwards. Continuing treatment with medications and psychological treatments is almost always necessary,

and we would certainly recommend that such treatments continue.

Sometimes, other treatments such as ECT are still required. Please note that some people find treatments (such as antidepressant drugs or ECT) that were previously unhelpful may become helpful after surgery.

What are the risks of the operation?

With all surgical operations and general anaesthetics, there are risks. When carrying out operations on the brain, the two main risks are of introducing infection and of bleeding into the brain. The risk of infection or bleeding is very low but these rare events can lead to serious problems; similar to having a stroke. This happens approximately one time in a hundred procedures. Effects can vary, but do not necessarily result in paralysis. Recent reviews of the outcome of a large number of brain operations reveal that the risk of death is about one in a 1000 (0.1%).

Occasionally people develop epileptic seizures in the period after the operation (around 1 in 50), although this can usually be controlled, if required, with drug treatment. Because of this risk of seizures, people are not permitted to drive motor vehicles for a period of at least **six months**

after surgery, (see address for DVLA at end of this document).

Other, more common, short term side effects of the procedure may include swelling of the face, tiredness, weight gain and problems with holding urine in the bladder, particularly while sleeping. In most cases, these problems resolve in the weeks after surgery. Sometimes, the person can have periods of confusion, with impairments of memory and attention, during the immediate post-operative period. For example, the patient may become confused about which day it is. This does not usually persist for more than a few days or, at worst, a couple of weeks for most people. There is no convincing evidence that the operation affects the intellectual functioning or personality characteristics of the patient in any negative way.

What will happen if I choose not to have this surgery?

The choice to have surgery is entirely yours. If you choose not to have surgery you will continue to receive the best possible care from your local mental health services.

If I decide to have the operation, what is involved?

To determine suitability for surgery, the clinical team from the Advanced Interventions Service (AIS) in Dundee assess people. This usually takes place over an extended period of time and usually involves several assessments. Such appointments can take place either at the AIS in Dundee, in the patient's local area, or at the National Hospital in London. Assessment involves an extensive series of interviews with the patient and usually also with their relatives. The doctors and nurses and other health professionals involved in their care are also involved in the assessment. The medical case records, including all aspects of psychiatric treatment, are examined in detail. If surgery appears to be an appropriate treatment for the patient, the clinical team from the Advanced Interventions Service will make a referral to the Care Quality Commission to ask for an assessment. The purpose of this assessment is to provide a 'second opinion' about the suitability of the proposed surgery and to assess how well the patient and their family understand the potential risks and benefits of surgery. This assessment is required by law.

At this stage, the clinical team from the Dundee Advanced Interventions Service and the London neurosurgical team from the National Hospital will arrange to meet together with the patient to explain in detail the proposed surgery and plans for post-operative treatment. This plan will have been drawn up jointly with input from the local mental health services and with the patient. Any decision whether or not to proceed with surgery is made jointly with the patient.

Surgery is **never** carried out unless the patient wishes to proceed. The patient is able to withdraw from surgery at any time. Test results and details of the procedure can be discussed at any stage with members of the Advanced Interventions Service and/or with the Functional Neurosurgery Team.

Where does the surgery take place?

Once a definite decision has been made regarding suitability for surgery, arrangements are made for admission to Hughlings Jackson ward at The National Hospital for Neurology and Neurosurgery, London for a period of around one week. Hughlings Jackson ward has 12 beds dedicated to the treatment of patients with neuropsychiatric problems. During this time, a number of assessments and tests are

conducted before surgery. These include clinical interviews, the completion of different questionnaires and rating scales, some computer-based psychological tests, tests of learning and memory, and a videotaped interview to record how the patient feels, speaks and behaves before surgery.

The Neurosurgical team will discuss the technique and explain the risks of the surgery again, will answer any of your questions and ask for your final consent to proceed with surgery. This is a new procedure to this hospital but the neurosurgical team has experience of performing such procedures in other institutions. The neuroanaesthetist and other members of the team will also see the patient. After surgery, people remain in the neurosurgical ward for 24-48 hours, depending on how quickly they recover from the operation.

Most people are able to return to Hughlings Jackson ward the day after surgery, and most people are up and about, walking and eating within 24 hours of surgery. The length of stay after surgery depends on the patient’s progress.

Before leaving Hughlings Jackson Ward, everyone has some of their tests repeated. The patient has a repeat MRI scan and a repeat of the some of the interviews.

What happens after I leave the hospital?

Most patients are ready for transfer back to their base hospital, or to return home, within three weeks. People return to the care of their local mental health services. The clinical team will discuss drug treatments with the patient's own psychiatrist and will usually recommend as few changes as possible. The post-operative plan for the patient is then put into action. It is very important that the local mental health services provide a programme of assistance that will maximise the chances of sustained improvement. This may involve psychological and/or behavioural treatments.

Everyone is followed up by the clinical team from the Advanced Interventions Service and will have repeated testing after 12, 24 months and five years to follow progress and to ensure that they can advise on further treatments as necessary. We will usually ask to you complete regular rating scales of your symptoms and we will remain in touch with the local psychiatric team.

Can I drive after surgery?

Because of the small risk of seizures following this type of procedure, the DVLA normally recommends a 6-month driving ban after this type of surgery. However, you will have

to inform the DVLA that you have undergone this procedure and you should wait for permission from the DVLA before returning to driving.

What if the operation doesn't work?

As explained above, around 1 in 3 people may not feel any benefit in the two years after surgery. Depending on the results of the clinical ratings, the neuropsychological testing, and the MRI scans, people may be offered an additional procedure to extend the cingulotomy. This means that the lesions from the previous operation are increased in size. Another alternative is to consider an anterior capsulotomy. The areas affected by an anterior capsulotomy are slightly deeper within the brain and are thought to be part of the same "brain circuit" that can be affected in people with severe depression.

If this is not considered likely to help, the team will review and discuss other non-surgical treatment options with you and your local mental health services.

Glossary

Anterior - Towards the front

Capsulotomy - To place a thermal lesion in the internal capsule of the brain

Care Quality Commission - An independent body who have the legal responsibility to protect the welfare and rights of people with mental disorders in England. They must formally authorise any neurosurgery for psychiatric disorders taking place in England and Wales.

Cingulate - Part of the brain known as the cingulate gyrus

Cingulotomy - To place a thermal lesion in the cingulate gyrus of the brain

Confusion - A mental state characterized by a lack of clear and orderly thought and behaviour (in this case temporary)

Gyrus - one of the ‘folds’ of the brain

Where can I get more information?

You may find these websites useful:

Driver and Vehicle Licensing Agency (information about driving after neurosurgery):

www.gov.uk/dvla-medical-enquiries

Dundee Advanced Interventions Service Website:

www.advancedinterventions.org.uk

Care Quality Commission:

http://www.cqc.org.uk/

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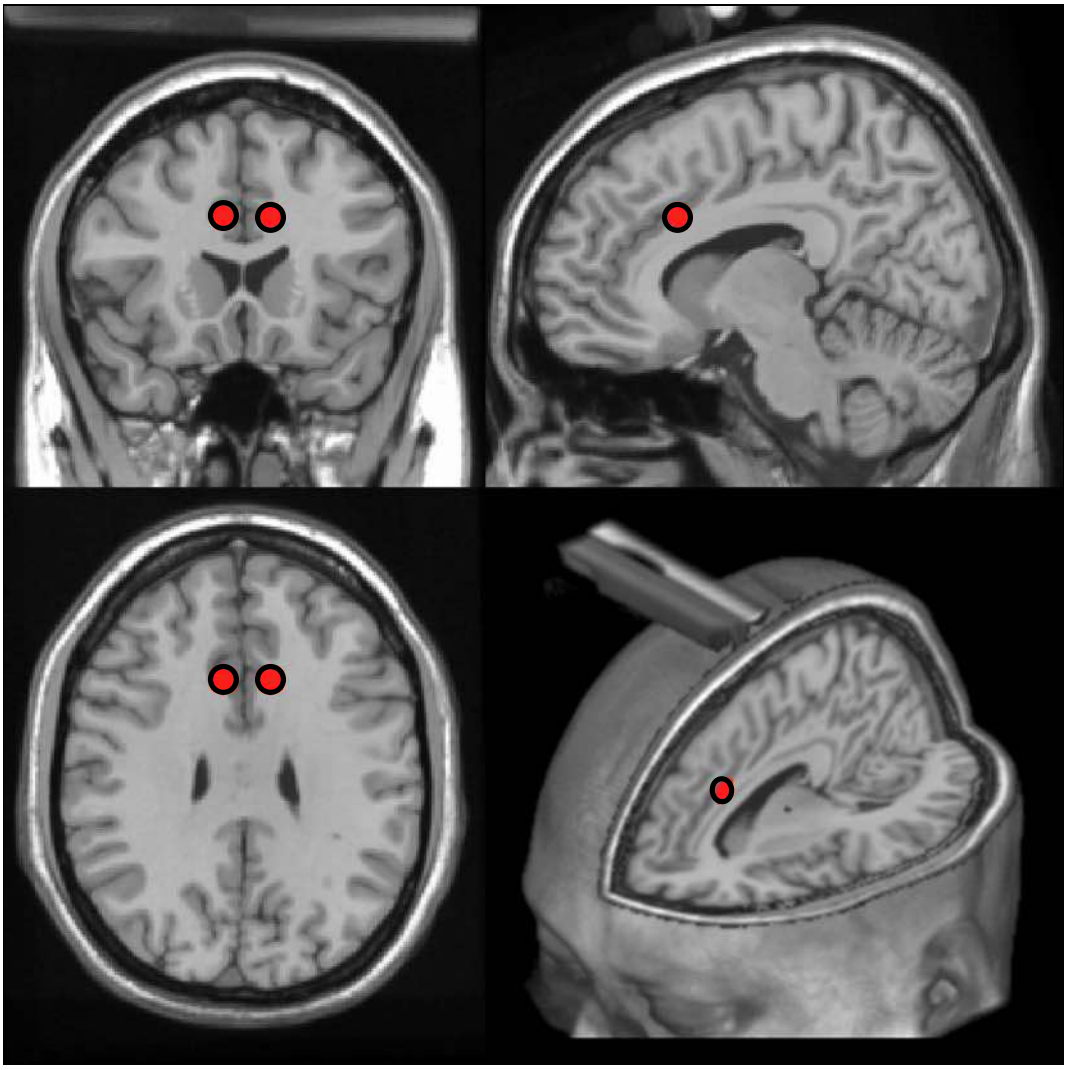

Figure 1. Illustration of the lesions in anterior cingulotomy (shown in red). Lesions are not to scale.

Contact details

Your Functional Neurosurgery team can be reached via:

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Direct line: 020 344 88722

Switchboard: 0845 155 5000 / 020 3456 7890

Website: www.uclh.nhs.uk /nhnn

The NHNN Neuropsychiatry Team can be reached via:

The Neuropsychiatry Department

8-11 Queen Square

London

WC1N 3BG

Direct Line: 0203 448 3524

The Advanced Interventions Service can be reached at:

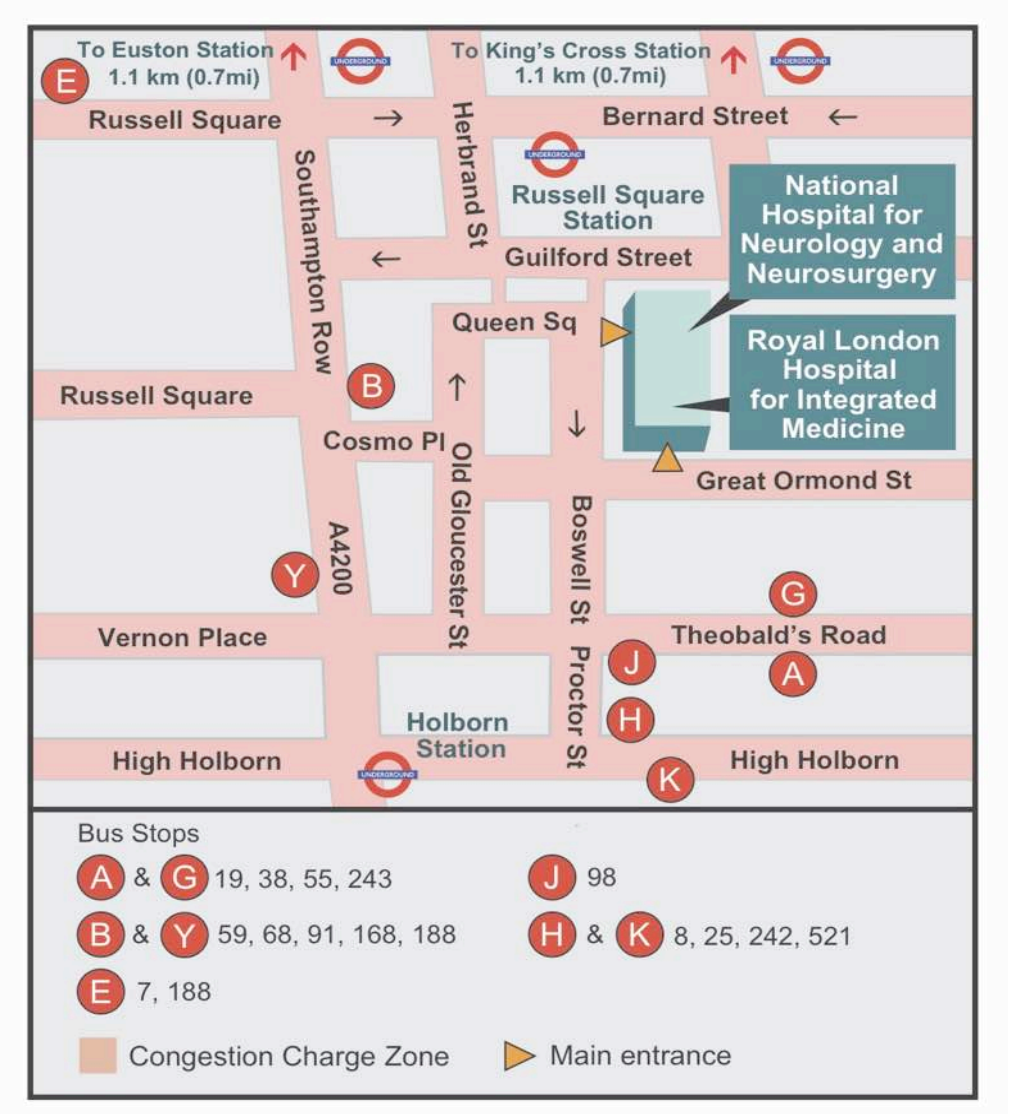
The Advanced Interventions Service
Area 7, Level 6 South Block
Ninewells Hospital and Medical School
Dundee DD1 9SY
Direct Line 01382 496233
Switchboard 01382 660111

enquiries@advancedinterventions.org.uk

http://www.advancedinterventions.org.uk/

Space for notes and questions

How to find us



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We are committed to delivering top-quality patient care, excellent education and world class research
Safety
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