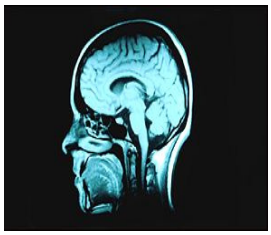

Advanced Interventions and Neurosurgery for Mental Disorder

CINGULOTOMY FOR OBSESSIVE COMPULSIVE DISORDER

Patient Information Sheet
Neurosurgery for Obsessive Compulsive Disorder
Anterior Cingulotomy

How to use this guide

This information is designed to help patients understand one of the modern neurosurgical treatments for obsessive compulsive disorder. Some patients want more detail of what is involved in the operation. We can include a section at the end of the guide with diagrams if you wish.

We know that making decisions and worry about uncertainty can be a problem for people with OCD. Our advice to you is:

take your time

only read small sections of the guide at any one time

highlight any areas of concern so that we can discuss these with you.

"Why operate?"

For some patients suffering from prolonged and disabling Obsessive Compulsive Disorder, treatment with drugs and, a special type of Cognitive Behavioural Therapy called Exposure and Response Prevention (ERP) fails to relieve symptoms. A small number of patients, because of the severity or nature of their Obsessive Compulsive Disorder, cannot, or are unable to, go through exposure and response prevention. They continue to suffer from unwelcome intrusive thoughts, repeatedly performing behaviours to make them feel safe or simply

"right". They can feel exhausted, trapped and quite hopeless. Usually they have a very restricted life-style designed to avoid the "triggers" of their obsessions. They may have difficulties with sleeping, eating and thinking about anything except their own troubling thoughts. When Obsessive Compulsive Disorder does not respond to standard treatments, patients endure great suffering, have a very poor quality of life and can feel very desperate. Depression often accompanies Obsessive Compulsive Disorder and can add to patient's feeling of despair. The consequences for the family and friends of the patient can also be severe.

The main treatments for Obsessive Compulsive Disorder are drugs and particular types of psychological therapy, but some sufferers do not respond to either of them. After all clinically proven treatments have been tried, patients may be considered for a neurosurgical operation. This brain surgery is also known as **neurosurgery for mental disorder**. Dundee is the only centre performing this type of surgery in Scotland. Currently, about three people per year have operations in Dundee.

"What are the operations called?"

Although there are several different operations performed around the world, the one that is used currently in Dundee is called an **Anterior Cingulotomy (see figure 1.)**. The other main procedure performed, is called an **Anterior Capsulotomy.** Sometimes, after a **Capsulotomy** has been unsuccessful, or only partly successful, a patient will have an **Anterior Cingulotomy** in an attempt to improve symptoms. The following information refers to the **Cingulotomy** operation. Please note that figures describing outcome and risks of other procedures may be different

“Is this a lobotomy?”

Brain operations to relieve the symptoms of mental disorders have been carried out for many years. In the past they were called 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 they different?”

First, surgery is only offered to patients suffering from **obsessive-compulsive disorder** or prolonged **depression,** where other treatments have been unhelpful. Second, the surgery involves the insertion of thin surgical probes into the brain causing a minimum of damage. The probes are guided into position very accurately using special machines that produce detailed images of the brain; Computerised Tomography (CT) or Magnetic Resonance Image (MRI) scanners. When placed in position by the neurosurgeon, the ends of the probes are heated to damage the tissue immediately around the tip. This heat-damaged tissue stops functioning. This effect is permanent.

There are two areas, one on either side and close to the middle and front of the brain, called the cingulate **(see figure 2.).** 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 is also involved in some aspects of learning, particularly learning which events in the outside world are pleasant and which are unpleasant.

"What will I feel?"

The operation is carried out under a general anaesthetic so patients are asleep during surgery. While the patient is unconscious the frame for the surgery is attached firmly to the patient's skull. Unlike skin, bone and other parts of the body, the brain has no sensory nerve supply and cannot 'feel' pain. However, the scalp and skull do have such nerves and it is normal to feel a headache where the frame has been attached and the probes have been passed through the top of the skull for a few days after surgery. Normally, simple painkillers, such as paracetamol, relieve this.

"How effective is this kind of operation?"

Research over many years in different countries suggests that this kind of operation helps around **a half** of all patients who have it. Around **one third** of patients seem to do well, with a significant improvement in symptoms. Another **one third** experience a small improvement in symptoms. The remaining **third** experience no benefit. **However, the effectiveness of a cingulotomy that is performed *after a capsulotomy has already failed* is much less well established**. **A beneficial response may be less likely in these circumstances**.
Most, but not all, patients notice some improvement in their symptoms almost immediately. However, this improvement in the days following surgery may not last. For many patients, it may take 6-12 months before a sustained improvement is obvious.

"Is it a cure?"

Even if the operation is very successful and most symptoms are relieved, there will be continuing difficulties. When someone has been troubled by obsessional

symptoms for a very long time, there are usually many problems and difficulties in their lives. These take time to try 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 rapid relief, 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 patient's local mental health services are asked to design a care plan with the patient, for this period after the operation. In Obsessive Compulsive Disorder this plan will involve a combination of drug treatment and psychological therapy, normally cognitive behavioural therapy that includes a programme of exposure and response prevention (ERP). Most patients who have the operation remain in contact with psychiatric services for a lengthy period afterwards. Continuing treatment with drugs and psychological treatments is almost always necessary. Please note, some patients find that treatments that were previously unhelpful, may become helpful after surgery. Sometimes the reduction in symptoms is enough to enable the patients to cooperate in psychological treatment which previously seemed too difficult.

"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 low but these rare events can lead to serious problems, rather like having a stroke. This happens approximately **one time in a hundred** procedures. Recent reviews of the outcome of a large number of brain operations reveal that the risk of death is about **one** in a **1000**.

However, there are more common complications that patients and relatives need to be aware of. Around **1** in **50** patients develop **epileptic seizures** in the period

after the operation, although this is usually controlled quite easily with drug treatment. Because of this risk of seizures, patients are not permitted to drive motor vehicles for a period of six months after surgery. Over a period of 10 years post-surgery, this risk of epilepsy persists. This may lead to **1** in **10** patients experiencing **at least one seizure**. However, when seizures do occur, they are usually controlled quite easily with medication.

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. The **bladder problems** tend to occur alongside 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, weeks for most patients. There is **no convincing evidence** that the operation affects the personality of the patient in any negative way.

"If I have the operation, what is involved?"

To determine suitability for surgery, **Professor Matthews** (University of Dundee, Department of Psychiatry) and his specialist team assess all patients either at their own hospital base or in DUNDEE. This involves an extensive interview 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, Professor Matthews will ask representatives from the **Mental Welfare Commission for Scotland** to visit the patient. The purpose of this visit is to

provide a second opinion about the suitability of surgery and to assess how well the patient and their family understand the potential risks and benefits of surgery.

Sometimes, Professor Matthews will recommend other treatment options to be tried before surgery, or he may ask other psychiatrists or psychologists for their opinions regarding additional psychological treatments.
The decision whether or not to proceed with surgery is made jointly with the patient.

Surgery is <u>never</u> 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 with **Prof. Matthews** and with the neurosurgeon, **Mr M.S. Eljamel**.

"Where do I stay?"

Once a definite decision has been made regarding suitability for surgery, arrangements are made for admission to the **Carseview Centre**, the psychiatric unit on the **Ninewells Hospital** site. Over a period of a week or so, a number of assessments and tests are conducted. 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.

On the day before surgery, the patient is transferred to the neurosurgical unit at **Ninewells Hospital** (**Ward 23b**). The patients will meet the neurosurgical team. At this point, the technique and the risks of the surgery will be discussed again, and a final consent will be obtained. The patient will also be seen by the neurosurgeon, the neuroanaesthetist and often by the neurotheatre nurse on the day of the operation.

"What is involved in the operation?"

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, behind the hairline to hide the scars although this is not always possible. The scalp around the incisions is shaved. The scar will eventually fade to a pale line within three to six months and the hair will usually grow back normally where it has been shaved. The skin is closed by a variety of different methods, but, currently staples or skin glue is used. Staples are normally removed in about 3-5 days depending on how well the wound has healed. After surgery, patients remain in the Neurosurgical Unit for 24-48 hours, depending on how quickly they recover from the anaesthetic.

"What will I feel after surgery?"

Although many patients 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.

On waking up from the anaesthetic, patients usually have a headache. This tends to be around the areas where the frame has been attached to the patients head and the incisions where the probes have been inserted through the skull. Simple painkillers are given to make the patient more comfortable. 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. This is short lasting and requires no specific treatment.

Most patients are able to return to the psychiatric ward the day after surgery. The length of stay after surgery depends on the patient's progress. Most are ready for transfer back to their base hospital or home within two to three weeks. Before leaving Dundee, all patients have some of their tests repeated. The patient has a repeat MRI scan, (see separate leaflet) and a repeat of the some of the interviews. All patients are brought back to Dundee for repeated testing (*for example, after 12 months*) to follow progress and to advise on further treatments as necessary.

"What happens after I leave Dundee?"

Patients return to the care of their local mental health services. Professor Matthews 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 treatments. Professor Matthews will review progress after surgery at 12 and 24 months. The first follow-up appointment may be at the patient's base hospital. The others will probably be in Dundee so that some of the specialised tests can be repeated.

"What if the operation doesn't work?"

As explained above, around **1** in **3** patients may not feel any benefit in the **two years** after surgery. If a previous surgical procedure, either a **Capsulotomy** or a **Cingulotomy,** has failed to help, the chances of not improving may be higher. If

this happens, **Professor Matthews** will review the situation and he may arrange to repeat brain scans to look at the effects of surgery. Depending on these scan results, patients may be offered an additional procedure. In the case of patients who have had a **Capsulotomy**, to have the different procedure a **Cingulotomy**. In the case of patients who have had little effect from a **Cingulotomy** they maybe offered a further procedure to extend the **Cingulotomy**. This means that the lesions from the previous operation are increased in size. If this is not considered likely to help, Professor Matthews and his team will review and discuss other non-surgical treatment options with the local mental health services.

Glossary

anterior	towards the front, front
capsulotomy	to divide, cut or place a lesion in the internal capsule of the brain
cingulate	part of the brain known as the cingulate gyrus
cingulotomy	to divide, cut or place a 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	a convoluted elevation or ridge
mental welfare commission	an independent body who have the legal power to protect the welfare and rights of people with mental disorders

Driver and Vehicle Licensing Agency
Swansea SA6 7JL
Web: http://www.dvla.gov.uk/at_a_glance/content.htm *(last updated April 2005)*

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In these diagrams the brain is viewed as if it is sliced vertically dividing it into equal left and right sides.

Figure 1. The size and location of a cingulotomy (yellow dot).

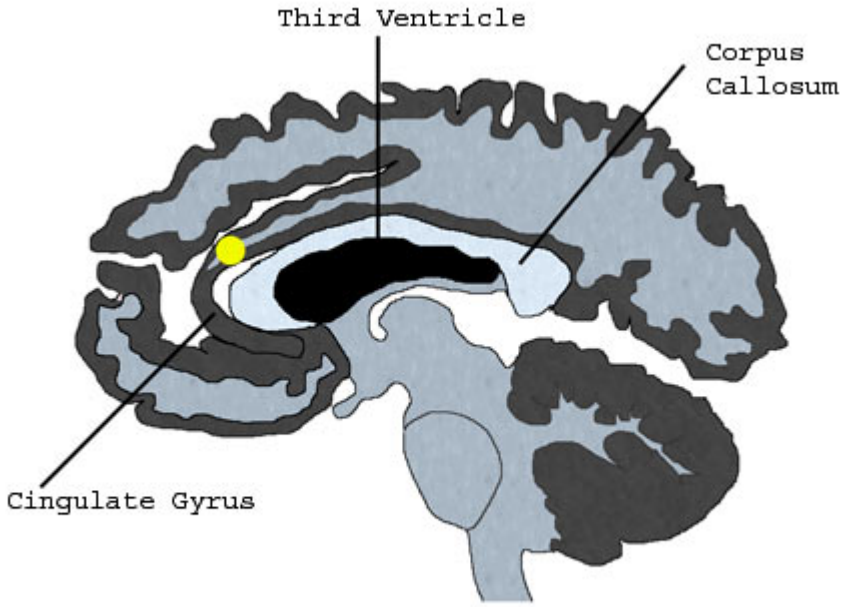

Figure 2. The relationship between the Cingulate and the rest of the brain.