making sense

neurosurgery for mental disorder
Making sense of neurosurgery for mental disorder

This booklet explains what NMD is, what the operation is like, possible side effects and alternative surgical treatments. It also covers the law around consent to treatment by NMD.
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What is neurosurgery for mental disorder (NMD)?

Neurosurgery for mental disorder (NMD) is the medical term for a type of brain surgery which may be performed to treat severe, incapacitating mood disorders.

Key facts about NMD

- NMD is only performed extremely rarely. For example, during 2012–13 only 4 people in the UK received NMD; in 2013–14 only 5 people were referred, although some of these people may have received an alternative treatment instead of NMD.
- NMD is only offered if all other treatments have failed, including psychiatric medication and electroconvulsive therapy (ECT).
- NMD is not a cure. Anyone who has NMD is likely to need continued psychiatric support afterwards, even if the surgery is considered to be successful.
- The surgery cannot be reversed.
- NMD is not available if you're under 20 years old.
- NMD cannot be performed without your consent (in England and Wales).
- There are two reversible alternatives to NMD available: deep brain stimulation (DBS) and vagus nerve stimulation (VNS).

Is NMD the same as lobotomy?

No. NMD is not lobotomy – the techniques used today are very different. In the past, brain surgery for mental health problems was called 'psychosurgery' and involved controversial techniques such as lobotomy, but this practice has not been used in the UK for many years.
What problems can NMD treat?

NMD can be used to treat:

- severe depression
- obsessive compulsive disorder (OCD)

However, if you've already tried both medication and electroconvulsive therapy (ECT), and nothing has worked, it's possible that NMD won't work for you either.

NMD is not used specifically to alter behaviour (although some change in behaviour may be one outcome), and is not offered for: personality disorders; schizophrenia; or anorexia (an eating problem) – although NMD is sometimes offered for anorexia outside the UK.

How does NMD work?

In NMD, an operation is carried out on the frontal lobes of your brain, which are behind your forehead. This area includes the limbic system, which is concerned with your emotional responses such as joy, fear and rage, and some physical responses you are not usually aware of, such as changes in your heart rate and blood pressure.

The aim of the operation is to disrupt connections between nerves in tiny areas of the limbic system which might be creating or contributing to your mental health problem.

How successful is NMD?

It's very difficult to measure how successful NMD is because so few people receive it, and it's only ever used for people with very severe illness for whom all other treatments have failed.
According to one study, which looked at a total of 25 cases of people who were treated with bilateral anterior cingulotomy (a type of NMD technique) collected over a period of years, 15 people (60%) showed improvement in symptoms of depression, and 5 people (20%) were no longer depressed after the operation. But there is no indication of how long this improvement lasted.

**What happens in the operation?**

There are three NMD techniques currently used in the UK:

**Subcaudate tractotomy**
Two probes are inserted via small holes made in your forehead, and guided to a part of your brain called the caudate nucleus. A very small part of this target area is then destroyed using an electrical current.

**Bilateral anterior capsulotomy**
Two probes are passed via incisions on each side of the midline on the top of your head into a part of the brain called the internal capsule, which is close to the caudate nucleus. A very small part of this target area is then destroyed using an electrical current.

**Bilateral anterior cingulotomy**
This procedure involves a similar technique to bilateral anterior capsulotomy, but targets an area of your brain called the anterior cingulate gyrus.

There is no international agreement on which of these techniques is the best way of performing NMD, and different techniques are used at different treatment centres.
About the procedure

Regardless of which specific NMD technique is being performed, the operation itself is likely to follow this procedure:

• Your hair is shaved in small areas on your scalp where the surgery will be performed.
• You are given a general anaesthetic, so you are unconscious during the operation.
• A special apparatus called a stereotactic frame is attached to your skull through tiny cuts in your scalp, using skin folds wherever possible. The purpose of this frame is to hold the delicate surgical tools in place. ('Stereotactic' means that the tools can be guided precisely in three dimensions, so that the surgery can be very exact.)
• A small hole (called a burr hole), is made in your skull using a special drill.
• A very fine probe is put through this hole. Computer software is used alongside brain imaging technology, such as magnetic resonance imaging (MRI) scanning, to guide the probe precisely to the target spot within your brain (to an accuracy of one millimetre).
• When the probe is in the right place, an electrical current is passed through it. This generates heat to destroy a very small area of brain tissue at the end of the probe.
• The probe and the frame are then removed, and the cuts in your scalp are stitched and/or glued.

The operation usually takes about 90 minutes, most of which is taken up by scans to monitor the position of the probe.

How soon will I recover after the operation?

Two days after the operation you should be able to sit out of bed; on the third day, you should be able to start moving about. But recovery is a slow process, so you'll need to take your rehabilitation gradually in the following weeks and months.
It's important to remember that NMD alone is not a cure for severe depression or OCD, but it could help lift your symptoms so that you are able to benefit from other forms of treatment, such as talking treatments.

What are the side effects?

NMD can cause:

• **headaches**, which may be severe and last for some days
• **weight gain** (this is associated with subcaudate tractotomy and bilateral anterior capsulotomy, but not with bilateral anterior cingulotomy; no one knows why)
• **apathy** (a lack of emotion, interest or concern). One study on people who received subcaudate tractotomy for depression suggested that although they were not depressed afterwards, they seemed not to care any more about difficult issues that might have upset them in the past. This effect is not seen in people who have more common treatments for depression.

In addition to this, all brain surgeries carry a risk of causing:

• **damage to the blood vessels** (which may result in stroke, although this is very rare in NMD)
• **confusion**
• **epilepsy** (a neurological condition which causes seizures)
• **pressure in the front of your brain**, caused by fluid produced in the brain tissues as part of the healing process; this can make you feel confused, and can last for up to a month after the operation
**Could NMD affect my mental capacity or personality?**

- **Mental capacity** – there is no evidence that NMD causes any loss of thinking ability. It might actually have the outcome that you’re able to think more clearly, probably because of the relief of symptoms that had previously made it hard for you to concentrate.
- **Personality** – personality changes following NMD have been reported in some people, but are considered rare.

**Who decides if I receive NMD?**

The law relating to consent to receiving NMD is different depending whether you are being treated in Wales or in Scotland (there are no NMD treatment centres in England).

**The law in England and Wales**

In England and Wales NMD is covered by section 57 of the Mental Health Act, which applies to all voluntary patients and everyone who is currently detained under section.

This law says that you can only be given NMD if all three of the following statements are true:

- You consent (agree) to the treatment.
- A second opinion appointed doctor (SOAD) and two other people appointed by the Care Quality Commission in England, or the Healthcare Inspectorate Wales, certify that: The SOAD also certifies that it is appropriate for you to receive this treatment.
- you have the capacity to consent, AND
- you do consent.
Could it ever be performed without my consent?

No. In England and Wales, NMD cannot be performed without your consent, even if you lack the capacity to consent. The Mental Capacity Act may not be used to authorise a treatment which comes under section 57 of the Mental Health Act.

For more information about mental health law in England and Wales, see our legal pages on consent to treatment, sectioning, the Mental Health Act and the Mental Capacity Act.

The law in Scotland

Procedures performed in Scotland, including NMD, come under the provisions of the Mental Health (Care and Treatment) (Scotland) Act 2003. They are overseen by the Mental Welfare Commission for Scotland, which provides independent clinical assessments for all patients.

In Scotland, NMD can only be carried out if all the following are true:
- A designated medical practitioner, appointed by the Mental Welfare Commission, has given an independent opinion that it will be beneficial for you.
- Two lay people appointed by the Commission have certified whether or not you are capable of consenting.
- If you are capable of consenting, you do give your consent; OR if you are not capable of consenting, you do not object to the treatment.

Could it ever be performed without my consent?

Yes. In Scotland NMD can be performed if you lack the capacity to consent, but only if both the following are true:
- You do not object to the treatment.
- The Court of Session (the Supreme Court in Scotland) has made an order declaring that NMD may be lawfully given.
How do I access NMD?

NMD is very rare. It would not usually be offered unless you are severely ill and all other treatments have failed, including psychiatric medication and electroconvulsive therapy (ECT).

If you are in this situation, your psychiatrist can refer you to a psychosurgical team for an assessment. The psychosurgical team is made up of everyone who would be helping to look after you, including the anaesthetist and the neurosurgeon. Good practice guidelines state that:

- The psychosurgical team should review your full hospital notes during the assessment.
- A close relative should accompany you to the assessment, and they should be interviewed as well.

Where is NMD performed?

Assessments can be done at the Maudsley Hospital in London, but there are only two hospitals in the UK where the operation can be performed. These are:

- (Wales) University Hospital of Wales, Cardiff – this hospital uses the bilateral anterior capsulotomy technique.
- (Scotland) Ninewells Hospital, Dundee – this hospital uses bilateral anterior cingulotomy for treatment-resistant depression, and either capsulotomy or cingulotomy for treatment-resistant OCD.

There are no NMD treatment centres in England, so if you live in England you would have to travel to Wales or Scotland for the operation. It's important to be aware that the law on consent to treatment with NMD is different in Scotland to Wales.
What alternatives are there?

There are two surgical alternatives to NMD, neither of which involves permanent damage to brain tissue (this means they can be reversed). These are:

• deep brain stimulation (DBS)
• vagus nerve stimulation (VNS)

Deep brain stimulation (DBS)

DBS involves a procedure similar to the NMD operation. A stereotactic frame is used to implant electrodes (insulated wires that conduct electricity) in your brain, but, instead of destroying the cells, the electrodes are left in place and used to stimulate a small area of your brain. Wires lead just under your skin from your brain to a stimulator (similar to a pacemaker), which is set in your chest wall, and is programmed to deliver high frequency electrical stimulation. It uses a special battery to work, which is sometimes rechargeable.

This technique is likely to improve, and DBS may eventually replace NMD.

The Care Quality Commission has expressed concern that DBS is currently unregulated in England and Wales, and could therefore theoretically be given to someone who has not given consent or who lacks capacity. This is not the case in Scotland, where DBS is covered by the same rules as NMD.

What is it used for?

Studies on DBS have involved only small numbers of people, but this research suggests it can treat:
• most cases of severe depression
• long-term OCD that has not been helped by other treatment
• movement disorders such as Parkinson's disease

With both depression and OCD you might find DBS very helpful while the stimulation is turned on, but your problems could return when it is turned off. The National Institute for Health and Care Excellence (NICE) has produced clinical guidelines for the use of DBS in Parkinson's disease, but not for depression or OCD.

DBS has sometimes been used in China to treat anorexia (an eating problem), but it is not performed as a treatment for eating problems in the UK.

**What are the side effects?**

Possible adverse effects from DBS include:

• infection after the operation
• complications if the equipment goes wrong

Also, having the DBS implants means that you cannot be treated with electroconvulsive therapy (ECT).

**Where is it performed?**

DBS is performed in Frenchay Hospital, Bristol, as well as the NMD centres in Cardiff and Dundee.
Vagus nerve stimulation (VNS)

VNS is a surgical treatment in which a device similar to a pacemaker is implanted in your chest wall, with electrodes connected to the vagus nerve in your neck area. The device sends timed pulses to your vagus nerve, which has branches from many organs of your body to your brain.

What is it used for?

VNS can be used to treat:

- severe, treatment-resistant depression
- epilepsy (a neurological disorder that can cause seizures)

No one knows exactly why targeting the vagus nerve can relieve depression or epilepsy, but research shows that up to half of people who have tried it found it helpful. However, NICE has issued this guidance saying that there is not much evidence about how well it works for treating depression, or how safe it is.

What are the side effects?

Possible adverse effects of VNS include:

- coughing
- shortness of breath
- changes in your voice
- changes to your heart rhythm
- hypomania or mania
- your depression could get worse

Where is it performed? As it's used most commonly to treat epilepsy, VNS may be more likely to be performed in centres where there is a specialist epilepsy clinic.
Useful contacts

Mind
Mind Infoline: 0300 123 3393 (Monday to Friday, 9am to 6pm)
email: info@mind.org.uk
text: 86463
web: mind.org.uk
Details of local Minds, other local services and Mind's Legal Line.
Language Line is available for languages other than English.

Care Quality Commission
tel: 03000 616161
web: cqc.org.uk
Inspects hospitals, care homes and health care services, and works to protect people receiving treatment under the Mental Health Act.

Depression Alliance
web: depressionalliance.org
Provides information and support for people with depression.

Healthcare Inspectorate Wales
tel: 029 2092 8850
web: hiw.org.uk
The independent inspectorate and regulator of all healthcare in Wales.

Mental Welfare Commission for Scotland
tel: 0131 313 8777 or 0800 389 6809
web: mwcscot.org.uk
Organisation which safeguards the rights and welfare of everyone with a mental health problem in Scotland. Provides information on the law relating to treatment in Scotland.

National Institute for Health and Care Excellence (NICE)
web: nice.org.uk
Provides guidelines for treatment within the NHS, including guidance on vagus nerve stimulation (VNS)

OCD-UK
tel: 0845 120 3778
web: ocduk.org
Organisation supporting people with obsessive compulsive disorder. Provides information about neurosurgery for mental disorder as a treatment for OCD.
Further information

Mind offers a range of mental health information on:
• diagnoses
• treatments
• practical help for wellbeing
• mental health legislation
• where to get help

To read or print Mind’s information booklets for free, visit mind.org.uk or contact Mind Infoline on 0300 123 3393 or at info@mind.org.uk

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This information was written by
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