



**The Leeds
Teaching Hospitals**
NHS Trust

Adult Epilepsy Surgery

Information for patients



Leeds Centre for
Neurosciences

You have been given this leaflet as you may be considering a surgical treatment for your epilepsy. This leaflet aims to help you understand what this means and what may happen in the future.

The Epilepsy Surgery team will help to support you through the process of epilepsy surgery and in making a decision about surgery. During the process to see if epilepsy surgery is possible, if at any point you decide that you do not want to have epilepsy surgery you will be supported in this decision.

What is Epilepsy Surgery?

The term Epilepsy surgery means an operation to remove part of the brain or disconnection of part of the brain from another.

It is only considered if:

- Several anti-epileptic drugs have been used at therapeutic dose but have failed to control seizures.
- Seizures are found to start from the same place in the brain (this is called a seizure focus).
- Surgery can be undertaken with a low risk of causing permanent damage to important structure.
- There is good chance of becoming seizure free after surgery.

No surgery is without risk and so there are several investigations that may be needed in order to establish if surgery is possible.

It can take 2-3 years to have all the investigations needed to ensure we have gathered all the information needed to make a judgement about whether surgery is possible.

The purpose of the assessment is to:

- Identify the part of the brain where seizures are generated from.
- To establish how epilepsy is affecting the brain's ability to function.
- To determine if the area of the brain where seizures are generated can be safely removed.
- To assess the risks and benefits of an operation.

What tests/investigations might be needed?

Various investigations may be needed to establish if epilepsy surgery is possible. Each person may need different investigations. These may include:

EEG (electroencephalograph or brain wave test)

This is a test that records your brain waves. This is carried out as an outpatient appointment. You could have an awake or asleep test. It involves having small electrodes attached to the scalp to monitor your brain wave activity. In the awake test you may be asked to close your eyes, breathe fast, and look at flashing lights. This takes about 30 minutes. In an asleep test you will be asked to sleep deprive the night before the test and try to sleep during the recording. This can take up to 2 and a half hours.

Most people will also need Video Telemetry.

Video Telemetry (VT)

This is the same as an EEG but you stay in hospital for up to a week. During this test you are monitored by a video continually whilst recording an EEG recording at the same time.

This helps to identify what seizures look like and how they affect you. Whilst you are in hospital your medication may be reduced to ensure that you have some seizures during this test.

MRI (Magnetic Resonance Imaging)

This is a detailed study of the brain that needs to be done within 12 months of surgery. This scan can help to identify any abnormalities in the brain that may be the focus of your seizures.

This is done as an out-patient appointment and your head is placed within a scanner that is within a long tube that you enter. It uses high powered magnets to help produce images of the brain. You may require an injection into the vein of dye during this scan as this can help to see any abnormalities of the brain more clearly.

fMRI (Functional Magnetic Resonance Imaging)

This is an MRI scan but it shows how the brain functions when certain tasks are carried out. You will be asked to perform certain activities whilst the scan is being carried out. For example; thinking of a word, tapping your thumb and finger together or looking at a picture.

Neuropsychological Assessment

This is an assessment carried out by a psychologist to understand how your brain works and what impact your epilepsy may be having on functions such as memory, emotions, language and attention. You may have a number of appointments. The first appointment will be a discussion about how your epilepsy affects your life. Other sessions may include tests of memory or other thinking skills. This will be discussed in detail with you first.

Once all the assessments are complete you will be given another appointment to discuss the test results and what impact surgery may have. The risk to brain function and surgery varies from person to person.

A further assessment is usually carried out 12 months after surgery has taken place.

Whilst these are the most common investigations used for epilepsy surgery others may be required, these include:

PET - Positron Emission Tomography

This scan uses a radioactive substance called a tracer. This is injected into a vein before the scan. The special scanner then measures subtle changes that can help to identify areas that may be causing epileptic seizures. The radiation dose given is extremely small and disappears from the body very quickly.

WADA test

This is usually one of the last tests that might be needed and is usually carried out as a day case. If you need this your Consultant Neuropsychologist will go through what to expect.

Intracranial EEG

This is similar to the Video Telemetry test but instead of putting the electrodes on the scalp a delicate neurosurgical operation is performed to insert electrodes into/onto the brain. This is not currently provided in Leeds, so if this is needed you will be referred to Kings College Hospital in London. The Consultant Neurologist in Leeds will go through the reasons for this before the referral is made.

Upon completion of investigations

Once these tests are complete your individual case would be discussed in the meeting with all the specialists involved in your care. This is called a multi-disciplinary meeting or MDT. The team will decide whether surgery is possible from the results of the investigations. You will be advised of the outcome of the meeting and then asked for your opinion.

Making your own decision about surgery

The thought of surgery can be daunting. However, if surgery is possible your consultant will help you with your decision. The final say is yours so you need to be well informed of the risks and benefits. You will probably have lots of questions, but you will have the opportunity to go through these. Writing them down can help you cover everything. If you decide not to proceed with surgery, you will still be reviewed by a neurologist.

Epilepsy Surgery

If you do decide to go ahead with surgery it is performed at Leeds General Infirmary unless you have been referred to London. You will usually be in hospital for 3-5 days.

Potential complications of Epilepsy Surgery

Any operation carries a degree of risk. However, even with neurosurgery these are relatively small. The risk of surgery depends upon the place of surgery, your age, other health issues and these will all be discussed with you.

The most serious complications of surgery include:

- Risk of death is about 1%.
- Risk of bleeding in the brain (stroke).
- Infection.

There are also specific risks depending upon the site of surgery these include:

- Loss of part of the field of vision. This can be temporary or permanent and may be only small or can be more severe meaning that you would never be able to drive.
- Memory can be affected.
- Speech can be affected.

Usually, the specific potential risks to sight, memory and speech can be evaluated prior to surgery, and every care is taken beforehand to ensure that these risks are at a minimum, hence the need for extensive investigations.

After Brain Surgery

It is common to feel tired and have some swelling and bruising in the first few weeks after surgery. The tiredness can last for weeks to months but this is very individual.

Most people remain on their epilepsy medications for 1-2 years after surgery. If you become seizure free in that time then you might be able to consider reducing your medications under supervision of your neurologist. There is a possibility that even though you are seizure free on medication you may start to have seizures if your medication is reduced. This happens in about a third of people who have had epilepsy surgery. However, seizures do usually (but not always) stop when medications are restarted.

If Brain Surgery is not possible or not wanted

If you do not want to have brain surgery or the investigations show that it is not possible in your case, then you would continue to be cared for by your Neurologist. However, in some cases you may be considered for a Vagus Nerve Stimulator (VNS).

Vagus Nerve Stimulation (VNS)

VNS therapy is an implanted device like a pacemaker. The battery sits in the upper portion of the chest, usually on the left-hand side and a lead connects the battery to a nerve in the neck (called the Vagus Nerve). The device regularly delivers a mild electrical pulse to the vagus nerve which is then carried to the brain. This can be implanted as a day case.

The stimulation level is gradually increased over time to a level that is considered to be at therapeutic range.

Different settings can be adjusted to try to obtain a more significant effect from the VNS.

Over time the VNS may time help to reduce seizures, reduce severity of seizures and may help with memory and concentration. It will not make someone seizure free and can take 2-5 years to reach peak effect.

When the VNS stimulates it can cause a tickle in the back of the throat and may also cause vocal hoarseness. This only occurs during stimulation and at all other times your voice would be normal. If the VNS was not effective for you it could be switched off and left in place.

If VNS is not possible or desired

If you do not want a VNS you will continue to be cared for by your Neurologist. If you become stable or seizure free you may be discharged back to your own GP.

Useful resources

Epilepsy Action

- **Telephone: 0808 800 5050** (UK Freephone helpline).
Opening hours: (Monday to Friday 8.30am-5pm, Saturday 10am-4pm)
- **Website: www.epilepsy.org.uk/**
- **Text Epilepsy Action on 0747 963 8071**
- **Use the email helpline: helpline@epilepsy.org.uk**
- **Tweet Epilepsy Action a question @epilepsyaction**
- **Contact Epilepsy Action via Facebook**

The Epilepsy Society

- **Telephone: 01494 601 400** (Opening hours Monday to Friday 9am to 4pm, Wednesday 9am to 7.30pm).
- **Website: www.epilepsysociety.org.uk/**
- **Email: helpline@epilepsysociety.org.uk**

The Epilepsy Surgery team

Consultant Neurologists

- Dr Melissa Maguire
- Dr Zeid Yasiry
- Dr Ana Garcia

Consultant Neurosurgeons

- Mr Paul Chumas
- Mr John Goodden
- Mr Gnanamurthy Sivakumar

Neurophysiologist

- Dr Munni Ray

Neuropsychologist

- Dr Catherine Derbyshire

Neuroradiologist

- Dr Daniel Warren
- Dr Ian Craven

Epilepsy Specialist Nurses

- Elizabeth Wright
- Jo Geldard
- Caroline Armstrong

Secretaries

- Lynette Silverwood
- Sue Jackson
- Lisa Farley

Contact us

- **Epilepsy Surgery Coordinator - Sue Jackson**
Telephone: **0113 392 8127** (Monday to Friday)
- **Dr Maguire's Secretary- Lynette Silverwood**
Telephone: **0113 392 8118** (Monday to Thursday)
- **Dr Yasiry's Secretary- Sue Jackson**
Telephone: **0113 392 8127** (Monday to Friday)
- **Dr Garcia's Secretary- Lisa Farley**
Telephone: **0113 392 8132** (Monday to Friday)
- **Epilepsy Nurses office**
Telephone: **0113 392 8128** (Monday to Friday)

Usual office hours are 9am - 4pm, all telephones have an answering machine. Please leave a message with your name and telephone number to ensure your call is returned.



What did you think of your care?

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Your views matter

