

Surgery for Epilepsy

Information for families

**Alder Hey Children's and Central
Manchester NHS Foundation Trusts**

This booklet explains about the epilepsy surgery programme at Alder Hey Children's Hospital and Manchester Children's Hospital and what to expect while your child is being assessed for surgery.

In 2012 the NHS Commissioners approved Alder Hey and Manchester Children's Hospitals as one of only four centres in England that would operate on children with epilepsy. This is known as the Children's Epilepsy Surgery Service (CESS). Alder Hey and Manchester is known as the 'NorCESS' – and provides a surgical service for children with epilepsy from the North of England

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How can surgery help my child's epilepsy?

The aim of the surgery is to remove the underlying cause of the seizures and therefore cure the epilepsy. In some cases, however, it may only be possible to reduce the frequency of seizures as the cause cannot totally be removed.

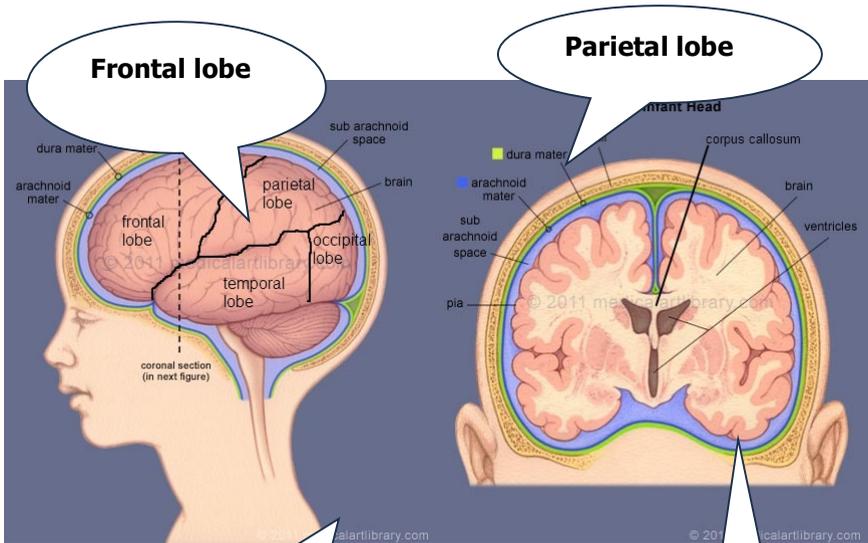
Who can be considered for an operation?

Surgery should always be considered for children with focal epilepsy. This is particularly important for children with a focal epilepsy that has not been controlled by medical treatment. Surgery is usually considered after one or two years of epilepsy. However, surgery may be considered and done earlier if it is clear at an early stage that seizures are particularly difficult to control or if a lesion is seen on the MRI scan. Due to modern methods of investigation, it is now possible to offer surgery much earlier in the course of the epilepsy and to younger children. Children with focal epilepsy may have additional problems with

learning and behaviour and/or special educational needs, and this may also contribute to a decision about surgery. NorCESS is a service that is provided over two sites – at Alder Hey and Manchester Children's Hospitals. Your child will usually be seen and treated in the hospital which is closest to where you live.

The structure of the brain

The brain is made up of two hemispheres connected in the centre by the corpus callosum. There are four lobes in each hemisphere; these are the frontal, temporal, parietal and occipital lobes. Most focal seizures start in the temporal or frontal lobes. The types of things that happen in your child's seizures will help the doctors decide which lobe the seizures may be coming from. It is important that you give as much information to the doctors as what exactly happens in your child's seizures and particularly how it starts. It can also be very helpful for you to video some of your child's seizures.



Frontal lobe

Parietal lobe

Temporal lobe

Occipital lobe

How will the MDT (NorCESS Team) decide whether any operation is suitable for my child?

When your child is referred to us, the NorCESS MDT will decide what happens next. There are two possibilities:

- a) We may need to ask the doctor who referred you to give us more information and possibly do some more tests.
- b) We will arrange for your child to have an outpatient visit. This will be with one of the paediatric neurologists or in a joint clinic with a paediatric neurologist and paediatric neurosurgeon. During this visit your child's history will be discussed and your child examined. This is to see which type of epilepsy your child has, ask about any learning or behaviour problems and review their treatment. It may be decided that your child needs more tests. These tests may be done as an outpatient or as an inpatient over a few days.

After this the neurologist will discuss your child with the NorCESS MDT. A decision will then be made as to whether your child is able to undergo surgery.

What tests will my child need?

Your child may need some special tests to decide exactly where their seizures are coming from, and whether that part of the brain is performing any vital function. Not all children will need to have the same tests. Which tests are performed will depend on the type of epilepsy your child might have. This will be decided by the neurologist and neurosurgeon.

EEG

This is the brain wave test. Your child will have had one or more of these before, either at Alder Hey or in Manchester Children's Hospital or elsewhere. An EEG usually takes half an hour to an hour. This test shows whether there is abnormal seizure activity in certain areas of the brain between seizures.

Video – EEG telemetry monitoring

This is an EEG which is performed continually over a longer period of time, sometimes several days and nights with a video camera. This test is used to record some seizures. If the seizures are not very frequent, we may need to reduce or occasionally stop your child's

anti-epileptic medicines while he or she is in hospital. We need to find out whether the seizure(s) recorded are your child's usual seizures and look at the EEG to see where the seizures start from electrically and how they spread.

Magnetic Resonance Imaging (MRI)

This is a type of brain scan that uses magnetic signals rather than x-rays to obtain a very detailed picture of the brain. This is to see whether there is an abnormality in a part of the brain that may be causing the seizures. Although your child may have had an MRI previously, it may need to be repeated. This is because either our scans will be more detailed, or because we need more information. There is another part of the scan that enables us to get more information about the chemical structure of certain parts of the brain. This is called Magnetic Resonance Spectroscopy (MRS). The MRI scan takes about 40 minutes to do.

PET and SPECT scans

PET stands for Positron Emission Tomography and SPECT for Single Photon Emission Computed Tomography. They are known as 'functional brain scans'.

Both these scans give a picture of blood flow within the brain. The

pattern of this blood flow may show where your child's seizures are coming from. Both scans are undertaken after an injection of a radio-labelled dye which shows up the blood flow in the brain.

The PET scan is done when your child is not having a seizure; this is called an inter-ictal scan.

The SPECT scan is made up of two separate scans. The first SPECT scan is done where the injection has been given at the beginning of a seizure; this is called the ictal SPECT scan. The second SPECT scan is done on a different day and is done when your child has not had a seizure; this is the inter-ictal SPECT scan. These scans can give us more information as to where the seizures are coming from. The two SPECT scans are looked at separately and also compared with each other to give us this information.

Neuropsychology

Tests are performed to see whether your child has any learning difficulties. The tests involve a number of hours of games and puzzles split into several sessions. The tests can also tell us whether the part of the brain from which we think

the seizures are coming is performing any useful function. This will help us decide whether removing it would cause problems. Your child's short- and long-term memory will also be tested.

Neuropsychiatry

A psychiatrist with experience of epilepsy surgery will sometimes see most children and their families as part of the surgical assessment. This is in part to see what difficulties or problems the epilepsy may be causing and whether surgery may help to relieve them.

Other assessments

Your child may need other types of assessment, for example, speech and language, occupational and physiotherapy. These will depend on the types of problems your child has. This will give us some information to compare with following your child's surgery. Your child may also need a test of their peripheral vision, also called visual field assessment. This will be required if the part of the brain which is causing your child's epilepsy is involved in vision. All these tests take place as an outpatient or sometimes as an inpatient.

Discussing the results of these tests and scans

Once the NorCESS team has seen all the test results, they will discuss whether surgery is possible. They will discuss whether all the seizures come from one area of the brain and whether the operation would make any existing physical or learning problems worse. The NorCESS team will make one of four decisions:

- **Surgery will be offered without needing to do more tests**
- **Surgery may be possible but further tests are required**
- **Surgery may be a possible in the future but not at the present time**
- **Surgery is not possible.**

If surgery is not possible or further tests are required, you will be asked to come to the epilepsy or the Joint Epilepsy Surgery clinic to discuss this. If your child is offered surgery, you will be given an outpatient appointment at the Joint Epilepsy Surgery Clinic. You will be able to meet the paediatric neurologist and neurosurgeon and they will explain which operation is likely to be undertaken. The neurosurgeon will also discuss the details of the

operation and the risks and benefits to your child.

The epilepsy surgery team will ask you to think about the information given to you and to decide whether you want your child to have the operation. When you have decided, you can ring the NorCESS coordinator. The team will then decide a date(S) for the operation and will contact you to discuss which date would suit you best.

What types of operation are there?

Different types of operation are used for different types of epilepsy. More detailed leaflets are available to explain more about these operations. The operation planned for your child will be discussed with you in detail by the neurosurgeon.

The plan may be to disconnect the two hemispheres of the brain (hemispherotomy or corpus callosotomy) or remove part of the brain – called focal resection (lobectomy or lesionectomy). Implantation of vagal nerve stimulator (VNS) may be done in some cases where a focal resection is not possible or appropriate.

Hemispherectomy or hemispherotomy

This operation disconnects or removes one half of the brain from the other. Children who may benefit from this operation usually have a long history of weakness down one side of the body – called a 'hemiparesis'. This is usually the result of severe damage to the opposite side of the brain, which may have been present from birth. The child's general development may have been slow. If the seizures are considered to arise from the damaged part of the brain, it is removed or disconnected to stop the seizures. This may not lead to any further weakness as the brain has usually re-organised other functions to the normal, unaffected side.

Corpus callosotomy

This is considered for children who have many different seizure types, including 'drop attacks'. Drop attacks occur when the child suddenly drops to the ground, either stiff or floppy and may harm themselves. Drop attacks may happen many times a day. The operation disconnects the two sides of the brain from each other in a more straightforward way than with a hemispherotomy and no tissue is removed. The aim of this procedure is to stop these 'drop attacks' but it

will not affect the other seizure types.

Focal resection

This is considered when one part of the brain is thought to be responsible for the seizures. The operation removes the abnormal part of the brain that is causing the epilepsy. It doesn't remove those parts that are still serving useful purposes. If the part of the brain causing the seizures is in the temporal lobe, the surgeon will perform a type of focal resection called a 'temporal lobectomy. Most focal resections are done in the temporal lobe. The next most common focal resections are done in the frontal lobe.

Invasive EEG

In this operation a special 'grid', 'strip' or 'depth' electrode is placed directly on to the surface of the brain, it is like an internal EEG. This will help to confirm exactly where your child's seizures are coming from. This type of EEG only needs to be undertaken in a small number of children before they have an operation to remove a small part of their brain.

Vagal nerve stimulation (VNS)

This is often used alongside medicines to reduce the

number or severity of seizures. A pulse generator, implanted into the chest, sends electrical signals to the vagus nerve in the neck. The vagus nerve transmits these signals to the brain, stopping the burst of electrical activity that causes seizures.

What are the risks of the operation?

Healthy children usually cope well with the general anaesthetic that your child will need for the surgery. The risk increases if your child has other problems.

Any surgery carries the risk of infection or bleeding. When operating on the brain there is also the risk of damage to the brain causing a 'stroke'. The effect of the stroke will depend on the part of the brain removed during the surgery but may include weakness down one side of the body. This will be discussed in more detail with regard to your own child. The risk of complications is small however if one occurs your child may have to stay in hospital longer than expected.

Are there any alternatives to an operation?

The neurologists could continue to try to control your child's seizures with different anti-epileptic medicines or combination of medicines. However, although there will always be new medicines to treat epilepsy, children who have not responded to the older ones will probably not respond to the new medicines. This means that there is only a small chance that medicines will control your child's seizures in the long-term. It is also important to understand that only surgery offers the possibility of 'curing' your child's epilepsy. Anti-epileptic medicines can never do this.

There is also a dietary treatment, called the 'ketogenic diet'. This is a very special and quite strict diet. If you would like more information on this treatment ask your child's local paediatrician or paediatric neurologist. You can also read more about it on the internet – at the 'Matthew's Friends' website.

How successful is surgery for epilepsy generally?

The epilepsy surgery team will discuss the expected results of surgical treatment with you and your child. These will vary according to the child's particular circumstances. The results are often excellent in commonly performed operations and particularly those that are on the temporal lobe. Seizures will stop in 75% of children who have temporal lobe surgery. However, for a small number of children surgery is unsuccessful. The main reason why children often have a large number of tests before surgery is to reduce the number of children for whom surgery is unsuccessful. The results of these tests will also allow the epilepsy surgery team to give you as much information as possible about the chance of success.

What about follow-up?

When you and your child leave hospital, we will arrange an appointment in the neurosurgery clinic. This is likely to be about 2 to 4 weeks after your child leaves the hospital. This is to check that

the wound is healing and all is well.

In most children, the anti-epileptic medications they will have been taking before the surgery will continue to be taken. This will usually be for at least 6 months after your child's surgery.

Six to 12 months after the operation, your child will need to have a few more tests and check-ups in clinic. The tests may include an MRI brain scan, an EEG and neuropsychology. Depending on the operation your child had, they may also need a repeat visual field test and assessments by speech and language, occupational and physiotherapists.

Your child will be reviewed at regular intervals by your local paediatrician or paediatric neurologist (or both) who will liaise closely with the epilepsy surgery team and NorCESS. If your child has had no seizures for 6 months after their surgery, your local paediatrician or paediatric neurologist will discuss with you and your child whether they need to continue to take their anti-epileptic medication

We may also invite you and your child to take part in some long-term follow-up research. This will

help the NorCESS improve what we do.

Your child and your family will go through a period of adjustment after the operation. We encourage you to discuss this as much as possible. We can make appointments for you with other specialists if necessary.

Notes

The Epilepsy Surgery Team

The Epilepsy Team is highly-specialised and also multi-disciplinary. Members of the team include neurologists, neurosurgeons, neuroradiologists, neurophysiologists, neuropsychologists, psychiatrists, EEG physiologists, clinical nurse specialists, nurses, speech and language therapists, occupational therapists, play specialists, physiotherapists and administrative staff.

You may need to contact the following people at some point during the process:

For queries about your child's care, including outpatient or clinic appointment details please phone your consultant's secretary.

For queries about your child's admission to Alder Hey or Manchester Children's Hospital, please contact the NorCESS Co-ordinator (Emily Tolno) on:

Alder Hey:	0151 252 5851
Manchester:	0161 701 0769

For questions about surgery, medications and communicating with your local team, contact the NorCESS Lead Nurse (Andrea McLaren) on:

Alder Hey:	0151 252 5851
Manchester:	0161 701 5072

NorCESS website and links to Alder Hey and Manchester Children's Hospital websites here ...