Children's Epilepsy Surgery Service (CESS) in England

epilepsy.org.uk
Epilepsy Helpline: 0808 800 5050

Epilepsy Action aims to improve the quality of life and promote the interests of people living with epilepsy.

Our work...

- We provide information to anyone with an interest in epilepsy.
- We improve the understanding of epilepsy in schools and raise educational standards.
- We work to give people with epilepsy a fair chance of finding and keeping a job.
- We raise standards of care through contact with doctors, nurses, social workers, government and other organisations.
- We promote equality of access to quality care.

Epilepsy Action has local branches in most parts of the UK. Each branch offers support to local people and raises money to help ensure our work can continue.

Your support

We hope you find this booklet helpful. As a charity, we rely on donations to provide our advice and information. If you would like to make a donation, here are some ways you can do this.

- Visit epilepsy.org.uk/donate
- Text ACT NOW to 70700 (This will cost you £5 plus your usual cost of sending a text. Epilepsy Action will receive £5.)
- Send a cheque payable to Epilepsy Action.

Did you know you can also become a member of Epilepsy Action from less than £1 a month? To find out more, visit epilepsy.org.uk/join or call 0113 210 8800.

Contents

Introduction

In England, around 340 children each year could benefit from epilepsy brain surgery. However, in recent years, only around 110 children each year have had surgery on their brain to try to treat their epilepsy. Epilepsy brain surgery is done to help stop a child's seizures, or reduce the number of seizures they have.

Since November 2012, following a successful campaign by Epilepsy Action, a new Children's Epilepsy Surgery Service (CESS) has been providing epilepsy brain surgery for many more children in England. For children aged five years and under, this surgery is done at one of four specialist CESS centres. For children aged six years and over, surgery may be done at a CESS centre, or locally.

This information gives an overview of what is involved before, during and after epilepsy brain surgery. If you have already been told that surgery could help your child, the CESS centre will be able to give you more information, and answer any questions you have.

Epilepsy Action's online community, forum4e (forum4e.com) has some members who have had epilepsy surgery. They will be able to share their experiences of what to expect when surgery is being considered.

Further information on many of the different aspects of epilepsy mentioned in this booklet is available from Epilepsy Action. See page 31 for contact details.

The CESS centres

- Birmingham Children's Hospital NHS Foundation Trust
- North Bristol NHS Trust, transferring to University Hospitals Bristol NHS Foundation Trust during 2014
- Great Ormond Street Hospital for Children NHS Foundation Trust and King's College Hospital NHS Foundation Trust, London
- Alder Hey Children's NHS Foundation Trust (Liverpool) with Central Manchester University Hospitals NHS Foundation Trust

The four centres will treat children from all over England, not just those in their local area. Contact details are on page 24.

If you live in Northern Ireland, Scotland or Wales

The CESS is funded by NHS England and is therefore a service for children living in England. If you live in Northern Ireland, Scotland or Wales and your child is being considered for epilepsy brain surgery, there are a number of options as to where they might be referred. Your child's epilepsy specialist will discuss this with you.

Wherever your child is referred for epilepsy brain surgery, the information in this booklet about what is involved before, during and after surgery will still be relevant for you.

About the CESS

The CESS aims to improve the quality of epilepsy brain surgery for children. It also aims to review more children, to see if they would benefit from epilepsy surgery. All children being considered for epilepsy brain surgery will be assessed by the CESS. They may go on to have surgery at a CESS centre. Or the CESS centre may advise that they should have the surgery locally.

Each CESS centre has an expert team of surgeons, doctors, healthcare professionals, and specialist facilities needed for epilepsy brain surgery.

The centre will make sure you and your child have access to support and services, as listed below. This includes during the assessment, when your child goes in for surgery, and after their surgery.

Support and services

- A chance to visit the centre and meet the team who would do the operation, before the surgery takes place
- Support for your family for the period your child would be in hospital. This should be in a child-friendly environment with toys, books and activities that are right for your child
- A management plan, to be agreed with you and your child, and shared with you both, on an ongoing basis. This plan will include details about your child's follow-up care, and the monitoring and review process
- A named lead doctor or healthcare professional responsible for coordinating your child's care. They will act as a link between you and the people treating your child
- 24 hours a day access to a member of the team for advice, information and support
- Access to an epilepsy specialist nurse
- Clear information about your child's condition, which should include
    - A description of their epilepsy
    - How their epilepsy will be managed
    - Medicines and other treatments they might receive
    - How you and your child can get the best from their treatment
    - Emotional and behavioural support
    - Information about appropriate patient support groups and charities
    - Contact details of your child's named nurse

Referral to a CESS centre

The National Institute for Health and Care Excellence (NICE) is the independent organisation responsible for providing national guidance on treatments and care for people using the NHS in England and Wales. The guidance is to help healthcare professionals, patients and their carers make decisions about treatment and healthcare. NICE says that children with epilepsy should have regular reviews of their epilepsy and treatment.

When your child has their epilepsy review, or if they are having problems with their epilepsy at any other time, they may be referred to a CESS centre. At this point, they may be considered for epilepsy brain surgery. To be referred, they would need to be in one of the groups mentioned below.

- Children with severe epilepsy that started in the first few years of life, and which is thought to come from one part of the brain
- Children with epilepsy where a magnetic resonance imaging (MRI) brain scan has shown an abnormality in one or more parts of the brain. These abnormalities could include benign tumours, and hypothalamic hamartomas
- Children with focal epilepsy (also called partial epilepsy) that has not been controlled with two epilepsy medicines. These medicines could have been used singly or together. These children may, or may not, have an abnormality on an MRI scan
- Children with a weakness down one side of the body and epilepsy that has not been controlled with two epilepsy medicines, used either singly or together. A one-sided weakness is called hemiplegia
- Children with Sturge-Weber syndrome or Rasmussen's syndrome
- Children with drop attacks
- Children with tuberous sclerosis with epilepsy that has not been controlled by two epilepsy medicines, used either singly or together

Tests before epilepsy brain surgery

To find out if your child would be suitable for surgery, the epilepsy specialist, and a number of other specialists at the CESS centre, would thoroughly assess them. At the end of the assessment, the CESS centre would advise if surgery is possible, and also recommend where it should take place.

As part of the assessment, they would ask your child to have a number of tests. These may include some of the following.

- Electroencephalogram (EEG)/video telemetry
- Computed tomography (CT scan)
- Magnetic resonance imaging (MRI scan)
- Functional MRI scan (fMRI)
- Positron emission tomography (PET scan)
- Single-photon emission computed tomography (SPECT scan)
- Magnetoencephalography (MEG scan)
- Neuropsychology tests
- Neuropsychiatry tests

Information about the tests

You will want to know more about what the various tests involve. What follows is some brief information. Your child's paediatrician, or staff where your child is going for tests, should be able to give you more detailed information.

Electroencephalogram (EEG)/video telemetry

The EEG tells doctors about the electrical activity in the brain. During the EEG, a technician places harmless electrodes on the scalp, using a special glue or sticky tape. The electrodes are then connected to the EEG machine, which records the electrical signals in the brain on a computer.

In video telemetry, a video recording is done at the same time as an EEG. This means that if your child has a seizure, doctors can see exactly what happens. An EEG/video telemetry can be done while your child is awake or asleep, or both.

Computed tomography (CT scan)

This is a type of X-ray that shows the structure of the brain. It wouldn't show if your child has epilepsy. However, it might show if there is an abnormality that could cause epilepsy. CT is now an old investigation, which has mostly been replaced with magnetic resonance imaging (MRI scan).

Magnetic resonance imaging (MRI scan)

The MRI uses radio waves and a magnetic field, rather than X-rays. It can show if there's a structural cause for someone's epilepsy. The MRI is more powerful than the CT scanner, so it can pick up small or subtle abnormalities that the CT scanner can't find (see above).

Functional MRI scan (fMRI scan)

This works in a similar way to an MRI scan but, during the scan, your child would be asked to do something. For example, they might be asked to tap their thumb against their fingers. Or they may be asked to look at pictures, or answer questions, on a computer screen. These activities increase the flow of oxygen-rich blood to a particular part of the brain. This type of MRI scan will help to show exactly which part of the brain manages important tasks such as thought, speech, movement, and sensation.

Positron emission tomography (PET scan)

This scan uses a radioactive substance, called a tracer, to look for information about how the brain is working. It can also show any abnormalities.

Single-photon emission computed tomography (SPECT scan)

This scan shows different parts of the brain in different colours. Your child would be given an injection of a radioactive dye, which would go to their brain. The different colours show how much blood flow is in each part of the brain. Usually, blood flow is higher in the part of the brain where seizures start. There are two sorts of SPECT scans. One is the inter-ictal SPECT scan, which is done between a child's seizures. 'Inter' means between and 'ictal' refers to a seizure. The other is the ictal SPECT scan, which is done just after a child has had a seizure.

Magnetoencephalography (MEG scan)

This is a new type of scan, and is only available in very special circumstances. The scanner would sit outside your child's head and measure their brain activity. It can tell which parts of a child's brain are active during a certain task.

Neuropsychology tests

These tests would show if your child has any memory and learning problems. The tests may take up to eight hours, split into different sessions, and involve a number of games and puzzles. They can show whether the part of the brain that will be operated on is responsible for any functions that other parts of their brain can't take over. This is to try to make sure your child would not have problems after surgery that they didn't have before.

Neuropsychiatry tests

A psychiatrist with experience of epilepsy brain surgery would see you and your child, as part of the initial assessment. Emotional and behavioural problems are common in children with epilepsy. Because of this, the psychiatrist would consider whether your child has these types of problems. They would also be able to suggest any treatment your child might need for these problems. This treatment would be available, whether or not your child goes on to have surgery.

The psychiatrist would also be one of the people who checks with you and your child what your aims and expectations are for surgery.

Other assessments

Other types of assessment might be organised, depending on the type of epilepsy, and the type of problems, your child has.

These may include the following.

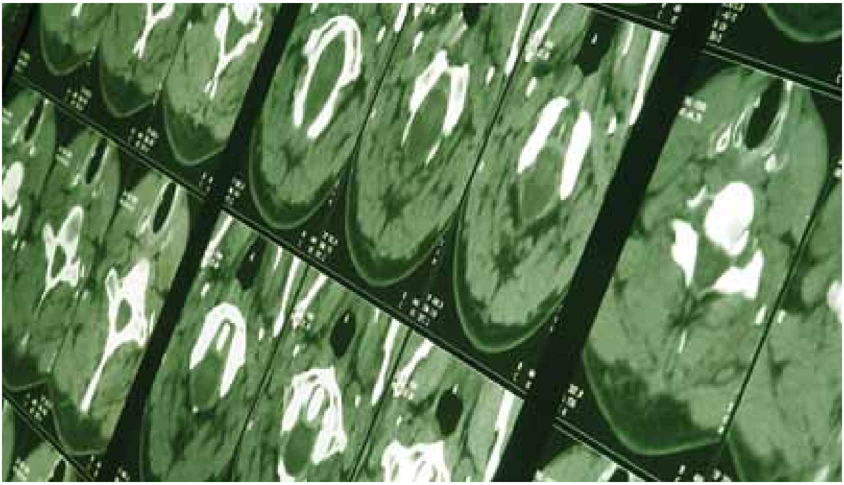
- Speech and language
- Development
- Vision, particularly peripheral vision
- The need for occupational therapy
- The need for physiotherapy

Types of epilepsy brain surgery

There are many different types of epilepsy brain surgery. The type your child might have depends on their type of seizures, and where the seizures begin in their brain. Here are some of the most commonly performed types of epilepsy surgery.

Focal resection

This is done when surgeons are sure which part of the brain the seizures start in. Children having this type of surgery have a



small part of their brain removed. Although this sounds worrying, the surgeon would only take away damaged parts that aren't needed. If the part of the brain causing the seizures is in the temporal lobe, the surgery is called a temporal resection. If the part of the brain causing the seizures is in one of the other lobes, it is an extra-temporal resection.

Multiple subpial transection

This surgery is not very common, but is performed when it's not possible to remove the part of the brain that's causing the seizures. The surgeon will make a series of cuts to separate the damaged part of the brain from the surrounding area. This stops seizures moving from one part of the brain to other parts.

Corpus callosotomy

This surgery separates the two hemispheres (halves) of the brain. It is mainly used for generalised seizures, particularly frequent drop attacks. It is sometimes used for myoclonic seizures that affect the whole body. It is also sometimes used for severe focal seizures that start in one hemisphere and spread to the other.

Hemispherectomy/Hemispherotomy

This is major surgery to separate, or remove, one half of the outer layer of the brain from the other. It is performed in children who have seizures because one half of their brain is badly damaged or not working properly. Sometimes the hemisphere is not removed, but completely disconnected from the rest of the brain. This is called 'hemispherotomy'.

What happens during epilepsy brain surgery

What happens during brain surgery for epilepsy will depend on the type of surgery. Most surgery involves making a small opening in the skull to get to the brain. The surgeon may remove some bone.

Children are put to sleep with a general anaesthetic. On rare occasions, the surgeon may wake the child up during part of the operation. This is so they can find the part of the brain that controls language and movement. The surgeon would explain this to the child. Waking children up during the operation is only usually done in children older than 12 years. After the surgery, the bone is replaced and fixed to the skull for healing.

Most epilepsy brain surgery takes at least four to six hours.

After epilepsy brain surgery

After surgery, your child's head and face would be swollen and painful, and they would need to take painkillers for a few days. The pain and swelling should settle after a few days, or a week or two.

Your child would need to rest and relax in the first few weeks after the surgery, and gradually become more active. It's usual for children to stay off school for around two to three months. Children should not play any contact sports for about four to six months.

Leaving hospital

Once your child leaves hospital, their care will be shared between the CESS centre and the doctor who referred them for surgery. If your child has surgery locally, there will be an agreed plan with the CESS about your child's follow-up care.

Generally, children continue to take epilepsy medicine for between six months and two years after the epilepsy surgery. The exact length of time will vary, depending on whether your child has stopped having seizures completely. It will also depend on what you and your child's epilepsy specialist think is best for your child. They may be able to reduce, or even stop the medicine after a while. If your child's epilepsy medicine does need reducing, their doctor will tell you how to do this. They will also keep in regular contact with you during this process.

Your child will have a follow-up appointment with their healthcare team to check on their progress after surgery. The team will keep in touch, to see how your child is doing, possibly for several years. If your child needs any further development, emotional or behavioural assessments, they will arrange these. The healthcare team will also stay in contact with you, to make sure your child is well, and that any local services they need are made available.

Success rates for epilepsy brain surgery

The success rate depends on the type of surgery. Many children stop having seizures after epilepsy surgery. If they do still have seizures, they usually have a lot fewer than before. If seizures continue, most children will usually continue to take their epilepsy medicine. Children who have a temporal resection usually do better than those who have an extra-temporal resection. (See **Focal resection** on page 15.)

Benefits and risks

Although the tests before epilepsy brain surgery are very thorough, it's still not always possible to predict what the risks are for each child. However, the test results will help the doctors decide whether to recommend surgery for your child. They will be able to discuss this with you fully before any decision about surgery is made.

Doctors will only go ahead with epilepsy brain surgery if the tests show that the benefits are likely to be higher than the risk of complications. The risks depend on the type of epilepsy brain surgery. Here are some possible risks.

Memory problems

The temporal lobes handle memory and language. This means that any surgery on the temporal lobes can cause difficulties in remembering, understanding and speaking. The memory problems can be for things that a child has seen ('visual memory') or for things that a child has heard ('verbal memory').

More seizures than before

Cutting the connections between the two hemispheres (sides) of the brain in corpus callosotomy stops seizures spreading from one hemisphere to the other. However, it doesn't stop all the seizures, only the drop attacks. In fact, some children may have more focal (partial) seizures, but they are less severe.

Visual symptoms

After hemispherectomy (where the outer layer of one half of the brain is removed), a child's vision may be reduced or they may have double vision. This is usually temporary. They may also have some difficulties with their peripheral vision. This may be temporary or permanent and will depend on how much of the brain has been removed.

One-sided paralysis

After hemispherectomy (where the outer layer of one half of the brain is removed), a child may have limited use of one side of their body. This one-sided paralysis is called a hemiparesis or hemiplegia. Physiotherapy and occupational therapy can help with this.

Behavioural problems

Some children may have had behavioural problems before the surgery. Or they may have had problems communicating or relating to other people. Epilepsy surgery itself will probably not help these problems. It is even possible that in a very few children, these problems may become a little worse.

Contact details for the CESS centres

Birmingham Children's Hospital
NHS Foundation Trust
Steelhouse Lane
Birmingham
B4 6NH
Tel: 0121 333 9999
Website: bch.nhs.uk

North Bristol NHS Trust
Frenchay Hospital
Frenchay Park Road
Bristol
BS16 1LE
Tel: 0117 970 1212
Website: nbt.nhs.uk
Transferring to University
Hospitals Bristol NHS
Foundation Trust during 2014.
The phone number will
change to 0117 342 0185.

Great Ormond Street Hospital
for Children NHS
Foundation Trust
Great Ormond Street
London
WC1N 3JH
Tel: 020 7405 9200
Website: gosh.nhs.uk

King's College Hospital NHS
Foundation Trust
Denmark Hill
London
SE5 9RS
Tel: 020 3299 9000
Website: kch.nhs.uk

Alder Hey Children's NHS
Foundation Trust
Eaton Road
West Derby
Liverpool
L12 2AP
Tel: 0151 228 4811
Website: alderhey.co.uk

Central Manchester
University Hospitals NHS
Foundation Trust
Royal Manchester Children's
Hospital
Hathersage Road
Manchester
M13 0JH
Tel: 0161 276 1234
Website: cmft.nhs.uk

About this publication

This booklet is written by Epilepsy Action's advice and information team, with guidance and input from people living with epilepsy and medical experts. If you would like to know where our information is from, or there is anything you would like to say about the booklet, please contact us.

Epilepsy Action makes every effort to ensure the accuracy of information in its publications but cannot be held liable for any actions taken based on this information.

Date: May 2013; Due for review: May 2015; Code: B157.01

Acknowledgements

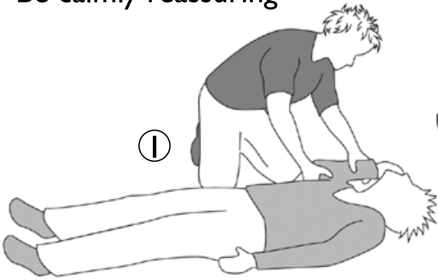
Epilepsy Action wishes to thank Dr Richard Appleton, consultant paediatric neurologist at Liverpool's Alder Hey Children's Hospital, for his contribution. Dr Appleton has declared no conflict of interest.

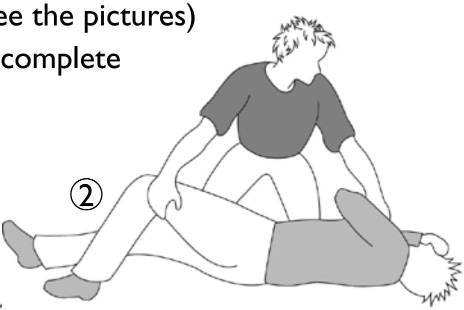
First aid for tonic-clonic seizures

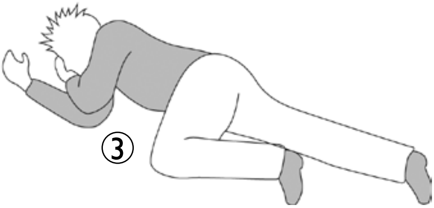
The person goes stiff, loses consciousness and falls to the floor.

Do...

- Protect the person from injury (remove harmful objects from nearby)
- Cushion their head
- Aid breathing by gently placing the person in the recovery position when the seizure has finished (see the pictures)
- Stay with them until recovery is complete
- Be calmly reassuring







Don't...

- Restrain the person's movements
- Put anything in their mouth
- Try to move them unless they are in danger
- Give them anything to eat or drink until they are fully recovered
- Attempt to bring them round

Call 999 for an ambulance if...

- You know it is the person's first seizure
- The seizure continues for more than five minutes
- One seizure follows another without the person regaining consciousness between seizures
- The person is injured
- You believe the person needs urgent medical attention

First aid for focal (partial) seizures

The person is not aware of their surroundings or of what they are doing. They may pluck at their clothes, smack their lips, swallow repeatedly or wander around.

Do...

- Guide the person away from danger
- Stay with the person until recovery is complete
- Be calmly reassuring
- Explain anything that they may have missed

Don't...

- Restrain the person
- Act in a way that could frighten them, such as making abrupt movements or shouting at them
- Assume the person is aware of what is happening, or what has happened
- Give them anything to eat or drink until they are fully recovered
- Attempt to bring them round

Call 999 for an ambulance if...

- You know it is the person's first seizure
- The seizure continues for more than five minutes
- The person is injured
- You believe the person needs urgent medical attention

Further information

If you have any questions about epilepsy, please contact the Epilepsy Helpline.

Epilepsy Action has a wide range of publications about many different aspects of epilepsy. Information is available in the following formats: booklets, fact sheets, posters, books and DVDs.

Information is also available in large text.

Please contact Epilepsy Action to request your free information catalogue.

Epilepsy Action's support services

Local meetings: a number of local branches offer support across England, Northern Ireland and Wales.

forum4e: our online community is for people with epilepsy and carers of people with epilepsy. For people aged 16 years or over. Join at www.forum4e.com

Epilepsy awareness: Epilepsy Action has a number of trained volunteers who deliver epilepsy awareness sessions to any organisation that would like to learn more about epilepsy. The volunteers are able to offer a comprehensive introduction to epilepsy to a range of audiences.

If you would like more information about any of these services, please contact Epilepsy Action. Contact details are at the back of this booklet.

B157.01

Children's Epilepsy Surgery Service (CESS) in England

Please complete this form to tell us what you think of this publication.

How useful have you found this publication?

☐ Very useful ☐ Useful

☐ Quite useful ☐ Not at all useful

Is the language clear and easy to understand?

☐ Very clear and easy to understand

☐ Clear and easy to understand

☐ Quite clear and easy to understand

☐ Not at all clear or easy to understand

Does this publication cover all you want to know about the topic?

☐ Completely ☐ Mostly ☐ Not quite ☐ Not at all

What do you think of the design and general layout of this publication?

☐ Excellent ☐ Good ☐ OK ☐ Poor

Please let us have your comments:

____

____

____

____

____

Date: ______________________

Please return the completed form to:

Epilepsy Services, Epilepsy Action, FREEPOST LS0995, Leeds LS19 7YY epilepsy action

Epilepsy Action
FREEPOST LS0995
LEEDS
LS19 7YY

Registered charity in England (No. 234343)

How to contact the Epilepsy Helpline

Telephone the Epilepsy Helpline freephone **0808 800 5050**
Monday to Thursday 9.00 am to 4.30 pm Friday 9.00 am to 4.00 pm
Our helpline staff are Text Relay trained

Write to us free of charge at
FREEPOST LS0995, Leeds LS19 7YY
Email us at **helpline@epilepsy.org.uk** or visit our website:
epilepsy.org.uk Text your enquiry to **0753 741 0044**
Send a Tweet to **@epilepsyadvice**

About the Epilepsy Helpline

The helpline is able to offer advice and information in 150 languages.

We provide confidential advice and information to anyone living with epilepsy but we will not tell them what to do. We can give general medical information but cannot offer a medical diagnosis or suggest treatment. We can give general information on legal and welfare benefit issues specifically related to epilepsy. We cannot, however, take up people's cases on their behalf.

Our staff are trained advisers with an extensive knowledge of epilepsy related issues. Where we cannot help directly, we will do our best to provide contact details of another service or organisation better able to help with the query. In doing this, Epilepsy Action is not making a recommendation.

We welcome comments, both positive and negative, about our services.

To ensure the quality of our services we may monitor calls to the helpline.

epilepsy action

B157.01

Epilepsy Helpline:

freephone 0808 800 5050
epilepsy.org.uk

The Information Standard
Certified member

This organisation has been certified as a producer of reliable health and social care information.
www.theinformationstandard.org

Epilepsy Action
New Anstey House, Gate Way Drive, Yeadon, Leeds LS19 7XY
tel 0113 210 8800 **email** epilepsy@epilepsy.org.uk

Epilepsy Action is a working name of British Epilepsy Association.
A company limited by guarantee (registered in England No. 797997)
Registered charity in England (No. 234343)

Date: May 2013; Due for review: May 2015

FSC
www.fsc.org
MIX
From responsible sources
FSC® C005110

Environmental statement
All Epilepsy Action booklets are printed on environmentally friendly, low-chlorine bleached paper. All paper used to make this booklet is from well-managed forests.