Children’s Epilepsy Surgery Service (CESS) in England
**Epilepsy Action – together we can change lives**

Together we can help more people gain the knowledge and confidence to live better with epilepsy. We can raise awareness, so that more people understand epilepsy.

Together we can:

- Provide expert information and advice, so everyone affected by epilepsy can get the support they need to live better with epilepsy
- Run local events and support groups, so that fewer people have to face epilepsy alone
- Campaign to help make sure health services and national policies take into account the needs of everyone living with epilepsy

**It’s only donations like yours that make this life-changing work possible.**

**Please donate today.**

Text ACT NOW to 70700 to give £5 (message will cost £5 plus your usual cost of sending a text, Epilepsy Action will receive 100% of your donation).

You can also join Epilepsy Action and add your voice to the UK’s biggest epilepsy movement. Together we can campaign for change, support each other and fight for a better future.

Find out more by calling the Epilepsy Action membership team on 0113 210 8800 or visit epilepsy.org.uk/join

Thank you.
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About CESS

The Children’s Epilepsy Surgery Service (CESS) in England is a specialist service that aims to improve the quality of epilepsy brain surgery available for children. It does this by reviewing children with difficult to control epilepsy, to see if they would benefit from epilepsy surgery.

The CESS is funded by NHS England for children with epilepsy in England. There are four specialist CESS centres that will treat children from all over England, not just those in their local area.
Each CESS centre has an expert team of surgeons, doctors, healthcare professionals and specialist facilities needed for epilepsy brain surgery.

Around 340 children each year could benefit from epilepsy brain surgery. This surgery is done to help reduce, or even completely stop seizures.

Children aged six years and over will have their surgery at one of the CESS centres. Children aged five years and younger will have their surgery at Great Ormond Street Hospital for Children NHS Foundation Trust or Central Manchester University Hospitals NHS Foundation Trust.

To see some children talking about their epilepsy surgery go to epilepsy.org.uk/childrenssurgery

**The CESS centres**

- Birmingham Children’s Hospital NHS Foundation Trust
- Great Ormond Street Hospital for Children NHS Foundation Trust and King’s College Hospital NHS Foundation Trust, London.
- Department of Paediatric Neurology, Bristol Royal Hospital for Children
- The Northern Children’s Epilepsy Surgery Services (NorCESS) Alder Hey Children’s NHS Foundation Trust (Liverpool) and Royal Manchester Children’s Hospital (Central Manchester University Hospitals NHS Foundation Trust)
Although CESS is funded by NHS England, it will also treat children who live in Wales but are registered with a GP in England. And they will provide services for children or families in Scotland, Wales or Northern Ireland if their child lives or goes to school in England.

Other children from Wales and Northern Ireland will be referred to the CESS centres for assessment. This is arranged on an individual basis by the local consultant paediatrician or neurologist.

Contact details for the CESS centres are at the end of this booklet.

This information looks at what is involved before, during and after epilepsy brain surgery. If your child is already being considered for surgery, the CESS centre will be able to give you more information, and answer any questions you have.

**Support and services**

The centre your child is referred to will make sure you and your child have access to the support and services listed below. This includes during the assessment, before, during and after their surgery:

- The chance to visit the CESS centre and meet the surgery team before surgery
- Support for your family for the time when your child is in hospital
• A child-friendly environment with toys, books and activities that are right for your child
• A management plan that you and your child agree with – updated as needed – including details about follow-up care and the monitoring and review process
• A named doctor or healthcare professional who will coordinate your child’s care and act as a link between you and the people treating your child
• Access to a member of the team for advice, information and support 24 hours a day
• Access to an epilepsy specialist nurse

You will also be given clear information about your child’s condition including:

• 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
• Details of patient support groups and charities
• Contact details for your child’s named nurse
Referral to a CESS centre

The National Institute for Health and Care Excellence (NICE)

NICE says that children with epilepsy should have regular reviews of their epilepsy and treatment. At their review, or if they are having problems with their epilepsy at any other time, they may be referred to a CESS centre. This is most likely if they:

- Have severe epilepsy that started in the first few years of life, and is thought to come from a single part of their brain or
- Have had a magnetic resonance imaging (MRI) brain scan which has shown an abnormality in one or more parts of the brain. An example might be a benign tumour or an hypothalamic hamartoma or
- Have focal epilepsy (also called partial epilepsy) that has not been controlled with two epilepsy medicines, used either singly or together. These children may, or may not, have an abnormality on an MRI scan or
- Have a weakness down one side of the body (hemiplegia) and epilepsy that has not been controlled with two epilepsy medicines, used either singly or together or
- Have Sturge-Weber syndrome or Rasmussen’s syndrome or
- Have drop attacks or
- Have tuberous sclerosis complex (TSC) with epilepsy that has not been controlled by two epilepsy medicines, that have been used either singly or together

For information about different seizure types and epilepsy syndromes, go to epilepsy.org.uk/syndromes
Tests before epilepsy brain surgery

To find out if your child will be suitable for surgery, the epilepsy team at the CESS centre will thoroughly assess them. As part of the assessment, they will ask for your child to have a number of tests, which could include:

- Electroencephalogram (EEG)/video telemetry
- Invasive EEG telemetry
- 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 assessment
- Other assessments
Electroencephalogram (EEG)/video telemetry

The EEG tells the doctors about the electrical activity in the brain.

During this test, your child will sit or lie down. The person doing the test will attach the electrodes to your child’s head with a sticky gel. They may ask them to breathe deeply for some minutes and also to look at a flashing light. These activities can change the electrical activity in your child’s brain, and this will show on the computer.

In video telemetry, a video recording is done at the same time as the EEG. This means that if your child has a seizure, doctors can see exactly what happens. It will help to show exactly which part of the brain the seizures are coming from. An EEG/video telemetry can be done while your child is awake or asleep, or both.

Invasive EEG telemetry

Some children might need to have more detailed EEG telemetry. This is called invasive EEG telemetry. This can be done with subdural grids/strip electrodes or stereo-EEG.

Subdural grids/strip electrodes

These are placed directly on the surface of the brain. They are good for showing seizures starting on the surface of the brain, but not as good for showing seizures in deeper parts of the brain. They are also good for ‘cortical mapping’. Cortical mapping shows which part of the brain controls a person’s speech and hand or leg functions. Cortical mapping is done to reduce the risk of any complications after the surgery.
**Stereo-EEG**

This is good for looking deeper into the brain, and also for seeing what is happening in both sides of the brain. After some careful planning, the neurosurgeon identifies the areas of the brain where stereo-EEG electrodes need to be placed. They then place the electrodes in the brain, through small holes in the skull.

The information from invasive EEG telemetry will be reviewed and a decision made about whether epilepsy surgery should go ahead.

**Are there any risks in having invasive EEG telemetry?**

There are some risks from both types of invasive EEG monitoring. These are not common, but can include a loss of speech or paralysis down one side of the body.

**Magnetic resonance imaging (MRI scan)**

MRI stands for magnetic resonance imaging. An MRI scan uses a strong magnetic field and radio waves to create pictures on a computer, of tissues, organs and other structures inside your child’s body.

**Functional MRI scan (fMRI)**

This is similar to the MRI scan but, during the scan, your child will be asked to do something, such as:

- Tap their thumb against their fingers or do other more difficult finger movements
- Look at pictures
- Answer questions on a computer screen
These activities increase the flow of oxygen-rich blood to a particular part of the brain. From these activities it will be possible to see which part of the brain manages important tasks such as thought, speech and language, 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 if there’s a structural cause for the epilepsy.

**Single-photon emission computed tomography (SPECT scan)**

This scan shows different parts of the brain in different colours. Your child will be given an injection of a radioactive dye, which will go to their brain. The different colours show how much blood flow is in each part of the brain. Usually, blood flow is highest in the part of the brain where seizures start.

There are two sorts of SPECT scans: one is the inter-ictal and the other is the ictal. ‘Inter’ means between and so the inter-ictal SPECT scan is done between seizures. Ictal means seizure, so the ictal SPECT scan is done just after a child has had a seizure.

**Magnetoencephalography (MEG scan)**

This is a newer type of scan, and is only available in very special circumstances. The scanner sits outside your child’s head and measures their brain activity. It can tell which parts of your child’s brain are active during a certain task.
Neuropsychology tests

These are tests that show if your child has any memory or learning problems. They can take up to six, or sometimes eight hours, split into two or three different sessions, and involve a number of games and puzzles.

The results of the tests may help the surgeon to plan the type of surgery your child might need. They can also show whether the surgery will affect any functions that can’t be taken over by other parts of the brain. This is to try to make sure your child will not have any problems after surgery that they didn’t have before.
Neuropsychiatry assessment

Your child will see a psychiatrist with experience of epilepsy brain surgery as part of their initial assessment. They will check whether they have any emotional and behaviour problems, as these can affect some children with epilepsy. And they will be able to suggest any treatment your child needs.

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

Other assessments

Your child might have some other types of assessments, depending on the type of epilepsy, and problems they have. These assessments might include some of 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 has depends on their type of seizures, and where the seizures begin in their brain. Some of the more common types are listed below.

**Focal resection**

This is done when surgeons know 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 will 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 called an ‘extra-temporal’ resection.

**Corpus callosotomy**

During this surgery the two hemispheres (halves) of the brain are separated. It is mainly used for generalised seizures, particularly frequent drop attacks (tonic and atonic seizures), and myoclonic seizures that affect the whole body. It is also used for severe focal seizures that start in one hemisphere and spread to the other.
**Hemispherectomy/hemispherotomy**

This is major surgery to remove or separate (disconnect) one half of the outer layer of the brain from the other. It is for children who have seizures because one half of their brain is badly damaged or not working properly. Removing one hemisphere is called ‘hemispherectomy’. Sometimes the hemisphere is not removed, but completely disconnected from the rest of the brain. This is called hemispherotomy.
What happens before, during and after epilepsy brain surgery?

**Before surgery**

Your child will be very carefully prepared for surgery in the operating theatre. They will be put to sleep with a general anaesthetic. Altogether, this part of the operation may take up to two hours.

**During surgery**

What happens during surgery will depend on the type of surgery your child is having. Most children will have a small cut made in their skull, so that the surgeon can see their brain. The surgeon may then remove some bone. On rare occasions, and only usually in children older than 12 years, the surgeon may wake the child up during part of the operation. This is done so that they can find the part of the brain that controls language and movement. The surgeon will explain to your child why this happens. Afterwards, the bone is replaced and fixed to the skull for healing.

Most epilepsy brain surgery takes at least four to six hours, and sometimes longer.
After epilepsy brain surgery

After their surgery, your child:

• Will have a swollen and painful head and face from a few days to two weeks. One or both eyes may be swollen and difficult to open
• Will need to take painkillers for a few days
• Will need to rest and relax for a few weeks, but gradually become more active
• Will probably stay away from school for a few weeks, but most children are back by six weeks. This should be discussed with your child’s surgery team
• Shouldn’t play contact sports for at least four to six months
After surgery care
Once your child leaves hospital, their care will be shared between the CESS centre and the doctor who referred them for surgery.

Epilepsy medicine after surgery
Your child will usually need to continue taking their epilepsy medicine for between six months and two years after their epilepsy surgery. The decision about reducing or stopping it will depend on whether or not they are still having seizures, and your thoughts and feelings. If their medicine is reduced, this will be done gradually. You will be told how to do this, and will be supported during the process.

Follow-up appointments
Yours child’s local healthcare team will:

• Arrange follow-up appointments to check their progress after surgery
• Keep in touch with your child, possibly for several years after surgery
• Arrange any development, emotional, behaviour or local services your child needs
Success rates for epilepsy brain surgery

The success rate depends on the type of surgery. Many children no longer have seizures after epilepsy surgery. If they do, they usually have a lot fewer than before, and will need to carry on taking their epilepsy medicine.

Children who have a temporal resection usually do better than children who have an extra-temporal resection. Approximately seven out of every 10 children who have had surgery will stop having seizures after their surgery.
Benefits and risks

The tests and assessments done before epilepsy surgery are very thorough. They are to make sure that the benefits of surgery are higher than the risk of any complications. And you will be able to discuss them with the surgery team before the final decision is made about surgery for your child. Here are some possible risks.

Memory problems
The temporal lobes handle memory and language, so any surgery on the temporal lobes can cause problems with 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 (‘auditory’ or ‘verbal memory’).

More seizures than before
Cutting the connections between the 2 hemispheres (sides) of the brain in corpus callosotomy stops seizures spreading from one hemisphere to the other. But 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 removing one hemisphere of the brain in hemispherectomy, a child’s vision might be affected for a few days or weeks. Their vision might be reduced, or they might have double vision. They might also have some problems with their peripheral vision. This could be temporary or permanent, depending on how much of the brain has been removed.
One-sided paralysis
After hemispherectomy or hemispherotomy, a child may have limited use of one side of their body. This paralysis is called a ‘hemiparesis’ or ‘hemiplegia’. Physiotherapy and occupational therapy can help children affected with this.

Behaviour problems
Some children may have had behaviour 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 a very few children will have worse problems than before.
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

Department of Paediatric Neurology
Bristol Royal Hospital for Children
Level 6 Research & Education Centre
Upper Maudlin Street
Bristol
BS2 8AE
Tel: 0117 342 0185
Website: uhbristol.nhs.uk
Email: ubh-tr.bristolcess@nhs.net

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

The Northern Children’s Epilepsy Surgery Services (NorCESS) is a joint service between Alder Hey Children’s NHS Foundation Trust (Liverpool) and Royal Manchester Children’s Hospital (Central Manchester University Hospitals NHS Foundation Trust)

Alder Hey Children’s NHS Foundation Trust
Eaton Road
West Derby
Liverpool
L12 2AP
Tel: 0151 228 4811
Website: www.norcess.nhs.uk

Royal Manchester Children’s Hospital
(Central Manchester University Hospitals NHS Foundation Trust)
Hathersage Road
Manchester
M13 0JH
Tel: 0161 276 1234 or 0161 701 5072
Website: cmft.nhs.uk
About this information

This information is written by Epilepsy Action’s advice and information team, with guidance and input from people living with epilepsy, and medical experts. If there is anything you would like to say about the information, please contact us at epilepsy.org.uk/feedback

If you would like to see this information with references, visit the *Advice and Information references* section of our website. If you are unable to access the internet, please contact our Epilepsy Action Helpline freephone on 0808 800 5050.

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

**Our thanks**

Epilepsy Action wishes to thank Prof. Richard Appleton, honorary professor in paediatric neurology and Dr Tim Martland, consultant paediatric neurologist at Royal Manchester Children’s Hospital and Lead Clinician for NorCESS for their contributions.

Prof. Appleton and Dr Martland have declared no conflict of interest.

**Date:** April 2017  
**Due for review:** April 2020  
**Code:** 157.02
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 on their side (in the recovery position) when the seizure has finished (see picture)
- 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 or
- The seizure continues for more than five minutes or
- One seizure follows another without the person regaining consciousness between seizures or
- The person is injured or
- 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 *or*
- The seizure continues for more than five minutes *or*
- The person is injured *or*
- You believe the person needs urgent medical attention

Epilepsy Action has information on what to do if someone has a seizure in a wheelchair
Further information

If you have any questions about epilepsy, please contact the Epilepsy Action 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. Or download a copy at epilepsy.org.uk/catalogue

Epilepsy Action’s support services

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

Coffee and chat groups: these give people living with epilepsy the chance to meet new people, share experiences and learn more about life with epilepsy.

forum4e: our online community is for people with epilepsy and carers of people with epilepsy. You have to be aged 16 or over to join. Go to forum.epilepsy.org.uk

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.
Children’s Epilepsy Surgery Service (CESS) in England

We would like to know if you have found this booklet helpful.

As a result of reading the information, please let us know if you agree (tick yes) or disagree (tick no) with any of the following statements.

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<td>I feel more informed about issues to do with epilepsy</td>
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<td>I have talked to my employer/colleague/teacher/family/other (cross out those that don’t apply) and they have improved how well they support me</td>
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<td>I have used other Epilepsy Action services, such as the website, the Epilepsy Action Helpline, support groups or forum4e</td>
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Please tell us how you think we can improve this information

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Please return the completed form to:
FREEPOST RTGS-LEYK-XGCK, Epilepsy Services, Epilepsy Action, New Anstey House, Gate Way Drive, Yeadon, Leeds LS19 7XY

You can also give us feedback online. Visit epilepsy.org.uk/feedback

Thank you.
FREEPOST RTGS-LEYK-XGCK,
Epilepsy Action
New Anstey House,
Gate Way Drive,
Yeadon,
Leeds LS19 7XY

Registered charity in England (No. 234343)
Ways to contact the Epilepsy Action Helpline

**Telephone: freephone 0808 800 5050**
We are usually open 8.30am to 5.30pm, Monday to Friday. Our helpline staff are Text Relay trained and we are able to offer advice and information in 150 languages. To ensure the quality of our service, we may monitor calls.

**Email: helpline@epilepsy.org.uk**
Email us your question about epilepsy. We aim to reply within 48 hours (on work days)

**Text: 0753 741 0044**
Text us and we aim to send a text reply back to your phone within 24 hours (on work days)

**Twitter: @epilepsyadvice**
Tweet us with your question and we will tweet back (on work days)

**Post: New Anstey House, Gateway Drive, Leeds, LS19 7XY**
Write to us and we aim to reply within seven working days

About the Epilepsy Action Helpline

We do:
• Provide confidential advice and information about epilepsy to anyone
• Give general medical information
• Give general information on legal and welfare benefit issues related to epilepsy

We do not:
• Tell people what to do
• Offer a medical diagnosis or suggest treatment
• Take up people’s legal cases on their behalf

If we cannot help you directly with a query, we will do our best to provide details of other organisations that may be able to help. In doing this, Epilepsy Action is not making a recommendation.

We welcome feedback, both positive and negative, about our services.
Epilepsy Action Helpline:
freephone 0808 800 5050
epilepsy.org.uk

Epilepsy Action
New Anstey House, Gate Way Drive, Yeadon, Leeds LS19 7XY
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A company limited by guarantee (registered in England No. 797997)
Registered charity in England (No. 234343)

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low-chlorine bleached paper. All paper used to make this booklet is
from well-managed forests.