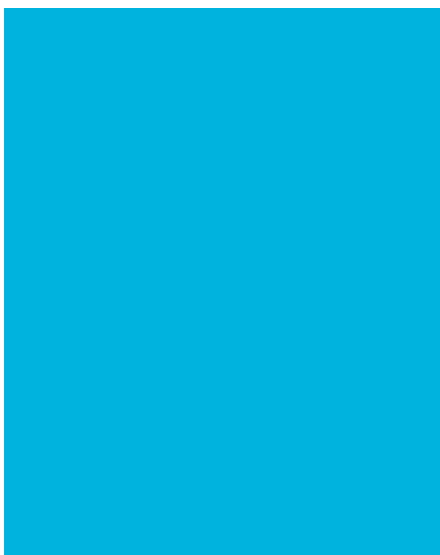


A guide for
Paediatricians:
Children's Epilepsy
Surgery Service
(CESS)

Guidelines for
children's epilepsy
brain surgery
referrals in England



Children's Epilepsy Surgery Service (CESS)

*Guidelines for children's epilepsy
brain surgery referrals in England*

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1. Introduction

In England, an estimated 340 children each year could benefit from brain surgery for epilepsy. However, in recent years, only around 110 children each year have undergone brain surgery for epilepsy.

In November 2012, a new Children's Epilepsy Surgery Service (CESS) was set up to provide high quality brain surgery for many more children with epilepsy in England.

Surgery will be predominately undertaken by four centres but for children aged six years and over surgery may be appropriately performed locally with the agreement of the relevant CESS. All cases being considered for epilepsy surgery should be discussed by the multidisciplinary team (MDT) in the relevant CESS centre. The service is available to children from any part of England.

2. CESS centres

There are four CESS centres at the following locations:

- 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.

This information is for you if you are a paediatrician who treats children with epilepsy. It outlines the reasons why you should refer some children with epilepsy to a CESS centre for pre-surgical evaluation.

It has been produced by Epilepsy Action, in association with the National Clinical Coordinating Group for Children's Epilepsy Surgery Services.

3. About the Children's Epilepsy Surgery Service (CESS) in England

The aim of the CESS is to improve the quality and uptake of, and access to, epilepsy surgery for children who could gain an improvement in, or complete control of, their seizures.

The CESS centres will do this by:

- providing an MDT review for all children with epilepsy who meet the criteria for pre-surgical evaluation (as listed below);
- providing a comprehensive pre-surgical evaluation service;
- providing and coordinating epilepsy surgical procedures for children in line with the CESS specification;
- identifying and supporting local care within the children's network, where this is appropriate;
- providing expert advice and services within the network;
- providing leadership for research, audit and training in assessment and management of epilepsy through surgery;
- advising local services on individual cases of children aged six years and over who may appropriately receive their surgery locally.

This service is commissioned and funded by NHS England.

4. What is epilepsy brain surgery?

Epilepsy brain surgery is the removal or modification of part of the brain aimed at alleviating epileptic seizures. The aim of surgery is seizure freedom without detriment to function.

Children will be carefully evaluated, to determine whether seizures are coming from one area of the brain, and whether that area is required for useful functions. In many children, an abnormality causing the seizures is evident on MRI. In most children, a portion of the brain is removed; procedures that may be considered include lesionectomy, lobectomy, and hemidisconnection. In a limited number of children part of the brain may not be removed but disconnected, such as in corpus callosotomy, performed for the treatment of 'drop attacks'.

5. Why it is important to refer to a CESS centre

Two thirds of children with seizures will respond to anti-epileptic drugs, or have a type of epilepsy that will remit spontaneously¹. However, this leaves one third of children who continue to have seizures. The chance of seizure freedom after two drugs have failed is less than 12 per cent.

Early onset epilepsy is associated with poor seizure control and poor neurodevelopmental outcomes. Studies have shown² that, at the very least, neurodevelopment is maintained following surgery, whereas if seizures continue, the developmental trajectory will slow, the gap widening between an individual and their peers with an apparent reduction in developmental quotient. Cessation of seizures allows optimal developmental outcome, as it is presumed that ongoing seizures in part have an impact on the developing brain. Ongoing convulsive seizures, however, are also not without risk of injury or death. A referral to a CESS centre for children with early onset epilepsy offers them a chance of seizure freedom and better long-term quality of life.

If you have a child who you think could benefit from epilepsy surgery, you should discuss this possibility with your regional paediatric neurology service or directly with the CESS centre. The CESS centres provide evidence-based pre-surgical evaluation and surgical treatment for children with uncontrolled epilepsy. They will provide all epilepsy surgery for children aged five years and younger. They will do this in designated in-patient services and make sure that there is an effective, safe and timely discharge to local services, giving specialist professional advice to referrers and other agencies, where needed. They will also provide a specialist multi-disciplinary team that will advise whether surgery may be appropriately provided locally for children aged six years and over, or be provided at a CESS centre.

Advances in technology have enabled detailed non-invasive assessments allowing many more children to be assessed for surgery. A referral, however, doesn't mean surgery will take place. The service expects to see 1,050 referrals each year, across the four CESS centres; around 350 of these children will have surgery. An early referral to a CESS centre means children have an appropriate pre-surgical assessment and gives families and carers the opportunity to make an informed choice as to whether or not to go ahead with surgery.

¹ Arts WF, Brouwer OF, Peters AC, Stroink H, Peeters EA, Schmitz PI, van Donselaar CA, Geerts AT. Course and prognosis of childhood epilepsy: a 5 year follow-up of the Dutch study of epilepsy in childhood *Brain* 2004;127:1774-84

² Freitag H, Tuxhorn I. Cognitive function in preschool children after epilepsy surgery: rationale for early intervention. *Epilepsia*. 2005 Apr; 46(4):561-7

Battaglia D, Chieffo D, Lettori D, Perrino F, Di Rocco C, Guzzetta F. Cognitive assessment in epilepsy surgery of children. *Childs Nerv Syst*. 2006 Aug; 22(8):744-59

6. Referral criteria

NICE³ says that children with epilepsy should have regular reviews of their epilepsy and treatment. At their review, you should refer children with epilepsy in any of the following groups to a CESS centre for a review of their epilepsy. They then may be considered for epilepsy brain surgery.

Children should be referred for assessment by a CESS centre if they meet one of the following criteria.

- i Children with catastrophic early onset epilepsy with evidence of lateralisation of the seizure onset
- ii All children under 24 months old with evidence of focality of seizure onset, with or without an MRI evident lesion
- iii Children of any age with evident focal epilepsy, or lateralised seizures associated with congenital hemiplegia, resistant to two appropriate anti-epileptic drugs (AEDs)
- iv Children who have epilepsy associated with a lateralised abnormality seen on a brain scan
- v Children with epilepsy associated with Sturge Weber syndrome, benign tumours with developmental issues and/or ongoing seizures, or Rasmussen's syndrome
- vi Children of any age with epilepsy associated with tuberous sclerosis resistant to two AEDs where seizures may arise from a single focus (probably from a single tuber)
- vii Children who have 'drop attacks' as part of a more complex epilepsy
- viii Children with epilepsy associated with hypothalamic hamartoma

7. Pre-surgical evaluation

Once children have been referred to a CESS centre, they will have a clinical review, including a review of their EEG and MRI scans. A plan for further evaluation will then be made. This will usually include an inpatient assessment for video telemetry to record seizures. Neuropsychology and neuropsychiatry assessments will also be done. A multidisciplinary team will then review the test results and make the decision about whether surgery can be offered, and on the appropriate location of the surgery. Children and their parents or carers will then be seen in outpatients, to discuss the decision. If surgery is offered the risks and benefits are fully discussed so the children and families and carers can make an informed decision as to whether they wish to proceed.

³ National Institute for Health and Care Excellence, 2012. *Clinical Guideline 137* [online] Available at: <http://publications.nice.org.uk/the-epilepsies-the-diagnosis-and-management-of-the-epilepsies-in-adults-and-children-in-primary-and-cg137> [Accessed 21 December 2012]

8. The risks of epilepsy brain surgery

The risks depend on the type of epilepsy brain surgery performed, but overall risks are low. Such risks need to be carefully considered against the risk of an individual child continuing with seizures, such as interference with neurodevelopment and learning, behaviour difficulty, injury and even death.

The CESS centres will discuss the risks and benefits of surgery with the parents and carers and the children and these will be put in the context of each individual case.

Sometimes it is necessary to perform further investigations and this may include invasive recording. This is when electrodes are placed in or on the surface of the brain to enable very detailed recording and possibly also stimulation of the brain. Once again the risks and benefits of this approach will be discussed in detail with the family.

9. Following epilepsy brain surgery

Once the patient has been discharged from hospital, after-surgery care will be shared with the CESS centre and referring team. Where the CESS has advised that surgery may be appropriately performed locally there will be agreed protocols between the CESS and the local service on post-surgery review, follow up and care.

A decision will be made in consultation with the family about drug reduction and this will take place in a gradual way under close medical supervision.

It will be important for the CESS centre to follow up the child to assess progress after surgery; this will include developmental and neuropsychological follow up where appropriate.

The local paediatric team will keep in contact with the family to ensure continuity of care and access to the relevant local services.

10. Further information and support

If you are considering referring any children to a CESS centre, Epilepsy Action has a leaflet for parents and children explaining the CESS service, epilepsy brain surgery and the assessment process. This is available from epilepsy.org.uk/childrensurgery or by calling the Epilepsy Helpline on freephone 0808 800 5050.



11. Referral contact information

If you have a child who you think could benefit from epilepsy surgery, you should discuss this possibility with your regional paediatric neurology service or directly with a CESS centre.

North Bristol NHS Trust
Frenchay Park Road
Bristol
BS16 1LE
Tel: 0117 970 1212
epilepsy.coordinator@bristol.nhs.net

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 ext 5594
epilepsy.coordinator@gosh.nhs.uk

King's College Hospital NHS
Foundation Trust
Denmark Hill
London
SE5 9RS
Tel: 020 3299 8305
kch-tr.EpilepsySurgery@nhs.net

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

Alder Hey Children's NHS
Foundation Trust
Eaton Road
West Derby
Liverpool
L12 2AP
Tel: 0151 252 5163
epilepsy.coordinator@alderhey.nhs.uk

Central Manchester University
Hospitals NHS Foundation Trust
Hathersage Road
Manchester
M13 0JH
Tel: 0161 701 2346
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The information is correct at the time it was produced.

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.

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