



NHS

Great Ormond Street
Hospital for Children
NHS Foundation Trust

After your child has had epilepsy surgery: information for families

Your child has recently had epilepsy surgery. We are happy that your child has now recovered from their operation and is ready to go home. This information sheet from Great Ormond Street Hospital (GOSH) is designed to give you the advice and support you need when you take your child home.

Your child's name and DOB

Date and details of operation

Follow up appointments

Date for hair wash, bath or shower

Recommended time off school/nursery

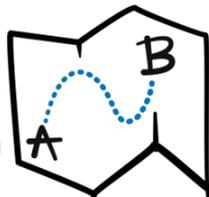
Contact details for the Epilepsy Surgery team

Nicky Barnes – Advanced Nurse Practitioner: 020 7405 9200 ext. 1592 or email nicola.barnes@gosh.nhs.uk

Sarah Carter – Clinical Nurse Specialist: 020 7405 9200 ext. 5814 or email sarah.carter@gosh.nhs.uk

Out of hours, please call Koala Ward on 020 7829 8826 or 020 7813 8313 or 020 7829 8827

Commented [BM1]: Can you also be contacted through MyGOSH once family have registered? Standard now to add short para about this.



Looking after the operation site

Swelling and bruising is normal after epilepsy surgery, particularly around the face and eyes. It can take a few days for all the swelling to go down and can sometimes appear worse in the mornings or after your child has been lying down.

The stitches your child has are dissolvable and can take several weeks to go. You may find they will begin to fall out when you wash or brush your child's hair. Avoid scratching or touching the wound site, we recommend keeping finger nails short and brushing hair gently.

Some children may complain their wound site is itchy, this should gradually ease off. An oral antihistamine such as Piriton® can help with this. Please follow the instructions on the box.

Your child's wound will have a dressing in place, you should keep this dry for five days. After this you should wash your child's hair with shampoo (do not use conditioner).

We recommend washing your child's hair every other day while gently rubbing the wound with a clean flannel. Your child's dressing can be removed after five days, using warm soapy water can help loosen these dressings.

Your child's scar should look like a "marker pen line". If the wound appears swollen, red, or begins to ooze you should contact the Specialist Epilepsy Nurses or Koala ward if out of hours.

Sometimes you may notice scabs forming along the scar line, this is normal. If the scab begins to get bigger or smelly then again you should contact the Specialist Epilepsy Nurses or Koala ward if out of hours.

You should avoid the wound becoming sun burnt. If it is sunny please use a high strength sun cream or sun block and to keep your child's scar covered with a hat.

Getting back to normal

We would recommend a 'quiet life' for four weeks after surgery. Knocks and bumps are a normal part of childhood life, a simple fall will not be too harmful. However, rough and tumble play should be avoided. If your child has had a severe fall or bang, then take them to your local health services just as you would for any other child.

Nursery or school

Depending on your child's operation, they may need time off school, nursery or playgroup. This may be up to a few weeks. We have given a recommendation for time off on the front of this information sheet but please discuss this with the nurses before you go home.

When your child returns to school or nursery you may need to ease them back in gently. Start with a few mornings, then increase as they recover their energy.

Swimming and sports

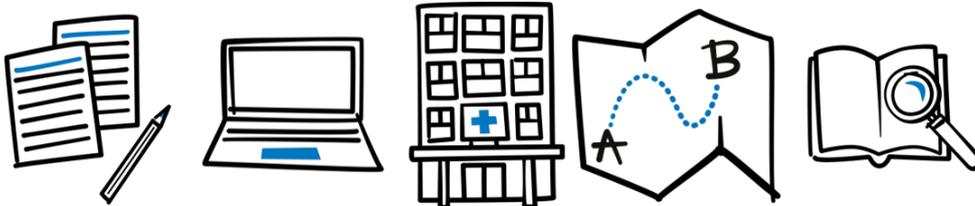
Children should avoid swimming, contact sports or bike riding until reviewed by their specialist nurse or doctor in clinic. This is normally in six weeks' time.

Immunisations

If your child is due any immunisations around the time of surgery, you should check with your nurse whether they should have them or wait for a while after the operation.

Flying

If you are planning to fly soon after your child's surgery, please let your doctor know. Your child may require a check X-Ray and a fit to fly letter.



Follow up appointments

We will have arranged follow up appointments at regular points after the operation. The timings below are approximate – we will let you know when these are booked.

Epilepsy surgery

Six weeks after the operation: Follow up appointment with Nurse Practitioner

Three months after the operation: Repeat EEG and MRI scan

Six months after the operation: Follow up appointment with Neurology Consultant

12 months after the operation: Repeat Neuropsychology or Developmental Epilepsy Service assessment. Follow up with Neurosurgeon and Neurology Consultant

SEEG implantation

Four to six weeks after the operation: Follow up appointment with Neurosurgical and Neurology Consultants. They will discuss the results of your child's SEEG at this appointment.

Vagus Nerve Stimulation (VNS)

Two weeks after the operation: Wound review and switch on VNS

Resective (removal) or disconnective epilepsy surgery

Seizure medication

In general, we would not make changes to your child's seizure medications until at least six months after the operation. However, depending on your child, we may wish to make alterations earlier. Your Neurology consultant will discuss any medication changes at your child's six month follow up appointment.

Behaviour

After the operation, your child's behaviour is likely to be similar to how it was before surgery. Some children are more subdued for a while. Very rarely, older children or teenagers become low in mood or depressed – if this happens you should contact your GP and/or the epilepsy nurse.

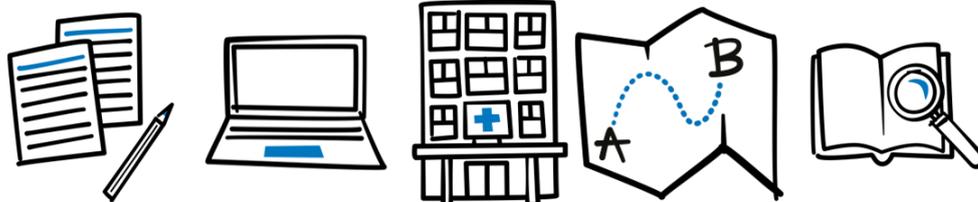
A few children become more active and challenging. This may be due to seizures stopping and your child becoming more alert and awake. We would expect your child's behaviour to settle back to normal in time. If you are concerned about your child's emotions or behaviour, we recommend liaising with your child's nursery/school/SENDCo. You can also contact the specialist epilepsy surgery nurses who may direct you to the correct team for advice and help.

Cognitive ability – understanding and learning

We do not expect to see significant changes in learning or understanding in the post-operative period. A repeat neuropsychology assessment will be carried out 12 months after your child's surgery.

If you are concerned about your child's learning or developmental progress following surgery, please contact your child's medical consultant in the first instance. They can then make an additional referral to Neuropsychology as needed.

If you are seeking advice relating specifically to a previous assessment completed by the



Neuropsychology Team, please contact their administrator on 020 7405 9200 ext. 0146.

Sleep

Your child's sleep pattern and the quality of sleep can become affected after surgery, this may be due to the reduction of seizures. The sleep charities below may be helpful for managing longstanding sleep difficulties with your child.

cerebra.org.uk/help-and-information/sleep-service

Sleep information resources and sleep workshops are available. Parents can also receive advice over the phone for any particular sleep issue.

www.sleepscotland.org/

Sleep Scotland gives advice on managing sleep in children with both developmental and physical health conditions

www.thechildrenssleepcharity.org.uk/

The Children's Sleep Charity provide sleep resources and workshops for parents

kidssleepdr.com/

'Kids Sleep Dr' helps parents understand and improve the sleeping and waking patterns of their child via an app (from newborn in to the teenage years)

contact.org.uk/

Contact has a sleep booklet for managing sleep in disabled children

Further information and support

If you have any questions or concerns when you get home, please call the Epilepsy Surgery nurses. Out of hours, call Koala Ward.

