



For more information

Our epilepsy surgery nurse specialist will be the best person to talk to about recovery after epilepsy surgery.

If the epilepsy surgery nurse specialist is not available, a message can be left, and you will be contacted as soon as possible.

Epilepsy surgery nurse specialist: 0131 312 0608
07976 582 367

Scottish Paediatric Epilepsy Surgery Service

Going home from hospital after epilepsy surgery

Information for patients and families



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Annual review appointments with the epilepsy surgery nurse specialist for 5 years

The epilepsy surgery nurse specialist will continue to be in contact with you and your child for five years following the surgery for annual review appointments to gather information about your child's progress and provide support to your family. This is called the Epilepsy Surgery Nurse Specialist (ESNS) Clinic.

These appointments can be in-person when the epilepsy nurse specialist conducts the clinic at a hospital close to your family's home, or by a NHS Near Me video consultation. We aim to see children in the ESNS clinic as close to the yearly anniversary of your child's surgery so you can review the past year together.

What happens next

Clinic appointment with the epilepsy surgery team

The epilepsy surgery team will arrange to see you and your child the next time they are at a hospital close to you. This is an opportunity for the epilepsy surgery team and your child's local consultant neurologist or paediatrician to find out how recovery at home has been going and to explain what happens next. This can involve talking about any investigations (medical tests or assessments) that will need to be carried out in future, such as MRI and neuropsychology evaluations, and what the plan is for your child's anti-epileptic medication. Your child's usual medication will likely need to continue for at least a year or more after surgery and the reasons for this will be explained to you. The neurosurgeon will also have a look at your child's wound to make sure it is healing well.

Often following this appointment, your child will be discharged from review with the epilepsy surgery team. If this is the case for your child, this will be discussed during the appointment and you can ask any questions. At this time, the epilepsy surgery team will largely step back from ongoing involvement, though our epilepsy surgery nurse specialist will be available to talk to for support and advice at any time, and will review your child annually for five years after their surgery to collect data and review seizure status.

Your local healthcare team has been informed of everything that has happened with your child's epilepsy surgery by the epilepsy surgery team and our epilepsy surgery nurse specialist, so they will be knowledgeable about your child's situation and healthcare needs following surgery.

Recovery at home should involve doing a little bit more each day and resting when required; tiredness can still be significant during this period. If your child has a good or busy day, it would not be uncommon to feel more tired the following day.

Try to ensure that your child drinks plenty of fluids, eats regular meals, and sleeps or rests when they feel the need without turning their sleep cycle upside down. This will aid their recovery. Building back up physical fitness and adjusting to fatigue can take several weeks.

Seizures

Do not be alarmed if your child has seizures; this is not uncommon at this stage and is no indication of the surgery outcome.

For seizures that are focal and non-urgent please -

- Phone your local epilepsy nurse specialist

- Update the epilepsy surgery nurse specialist after speaking to your local team.

If your child has a generalised convulsive seizure, please -

- Phone 999 for an ambulance and attend your closest A&E (Accident and Emergency) for review.

Wound care

A wound infection can occur up to two weeks after surgery or longer if the wound is re-opened by picking or scratching the scab. This can lead to infection of the fluid in and around the brain, which though rare can lead to life-threatening illness. Picking the scab too early also disrupts the granulation process of healing and can lead to more noticeable scarring. Your child should not scratch or pick the wound. Keep your child's fingernails short and use dressings.

Around 2-3 days after surgery, the wound can be lightly washed with a light showering of water and patted dry.

Around 5 days after surgery, the wound can be washed lightly with neutral/baby shampoo with minimal scrubbing, light showering and dry patting.

Wound infection is rare, but if you notice **leakage** from the wound of any colour, any redness, heat or increased swelling to area surrounding any surgical sites, or if your child is experiencing any headaches, ongoing temperature, vomiting or increased lethargy, please -

Phone Borthwick Ward **Ph:** 0131 312 1333
Phone or text the epilepsy surgery nurse specialist
 Ph: 0131 312 0608
 Ph: 07976 582 367

A wound review will be organised for your child, either at home, on Borthwick Ward or at your local hospital.

Other times to get in touch

There will be good days and challenging days, and adjusting is different for everyone. Parents can often feel very tired, stressed, emotional, depressed and not able to cope. A positive routine can help to normalise and reduce anxiety. If there is anything that feels out-with your comfort or control, do not worry alone - please speak with us.

Who to contact if your child is experiencing any headaches, ongoing temperature, vomiting or increased lethargy within the first month of going home

Phone Borthwick Ward **Ph:** 0131 312 1333
Phone or text the epilepsy surgery nurse specialist
 Ph: 0131 312 0608
 Ph: 07976 582 367

Who to contact for non-urgent messages

If you have non-urgent messages or would like to update/chat things through, please -

Phone or text the epilepsy surgery nurse specialist
 Ph: 0131 312 0608
 Ph: 07976 582 367

Who to contact for anything urgent

Attend your closest A&E
Phone Borthwick Ward (24 hour advice) **Ph:** 0131 312 1333
Attend your GP.

Activities

When your child feels able, return to light activities that do not carry risks of bumps to the head (it is understood that not all risks can be eliminated, but they should be minimised).

After 4-6 weeks, begin a phased return to school. Some children are ready to return to school sooner than this. This should be discussed with the school and the epilepsy surgery team. The epilepsy surgery nurse specialist will phone the school prior to your child returning.

Scooter and bikes should be avoided for 12 weeks.

Swimming is okay after 12 weeks if the wound is water tight.

Contact sports should be avoided for 6 months after surgery, and returning to contact sports should always be discussed with the epilepsy surgery team first.

Fluid between the skull and the skin is not uncommon and should go away with time but can be discussed if you are concerned. Please -

Phone Borthwick Ward **Ph:** 0131 312 1333

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Medication

It is essential to continue with anti-epileptic medication and not miss doses as your child's seizure threshold can be very low after surgery.

For pain relief, give your child pain relief as explained by the nursing team (and guidance on bottles). After a few days, try to spread out the doses to give pain relief when needed rather than in a set routine.

If you have concerns about pain relief and pain management, please -

Phone or text the epilepsy surgery nurse specialist

Ph: 07976 582 367

Or contact your GP.

Sleep

Sleep can often be disturbed, broken or back-to-front after surgery. Whilst rest periods and day naps can be required and important, if your child is having disrupted overnight sleep try not to let them sleep too much during the day. It can be helpful to give pain relief right before your child goes to bed for the night.

Emotion and behaviour

Your child has been through a time in the hospital where their control over the situation was extremely limited. There will be a lengthy adjustment for them to reflect on all that has happened, adapt to how different they may feel and accept the limitations that recovery places on them. Your child may have difficulty expressing emotions, which may cause frustration that they may struggle to control. Try to help them focus on the positives and encourage activities that make them happy or laugh.

There will be difficult days, which is normal, but good days will hopefully outnumber the bad days.

If you have concerns about your child's mood or behaviour, especially uncontrollable behaviour or marked changes to mood, please -

Phone or text the epilepsy surgery nurse specialist

Ph: 0131 312 0608

Ph: 07976 582 367

Rehabilitation

Try to follow a routine. To gradually build up fitness, you should aim to help your child be up and active for a short part of every day and gradually build this up as they start to feel they have more energy. This can be walking around the house and garden, going out for lunch or short walks and so on, with rest periods like a mid-afternoon snooze or watching a movie scheduled in.

Socialising is of great importance and even when your child is not yet ready to return to school, a social visit to join friends for lunch or a special event can be very good for rehab.

Do not panic if your child is doing really well then has an off day; this can be common – rest and reassess the following day. If they had a busy day, the next day, they might have to relax and not do very much. Your child and their behaviour will guide you.