



### For more information

Our epilepsy surgery nurse specialist will be the best person to talk to about the epilepsy surgery options available to your child. They are contactable by text message and by phone, and their mobile phone details will be provided at or soon after your clinic appointment with the epilepsy surgery team.

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

### Scottish Paediatric Epilepsy Surgery Service

## Epilepsy Surgery

### Information for patients and families



## Contents

- 3 Getting ready for surgery
- 5 Borthwick Ward
- 8 Staying with your child
- 9 The day before epilepsy surgery
- 10 Consent
- 11 On the day of surgery
- 12 After surgery
- 14 Going home from hospital
- 16 For more information

There may be some time between feeling ready to go, and everything being arranged and finalised on the day, but we will do our best to make things run as smoothly and efficiently as they can.

When your child is home from hospital, you can contact your child's local consultant neurologist or paediatrician, local epilepsy nurse specialists, or the epilepsy surgery nurse specialist for advice and support.

## Going home from hospital

Most children stay in hospital after surgery for around 7 to 10 days, but this depends very much on the epilepsy surgery your child had and their needs after surgery. Children who have a type of surgery with known rehabilitation needs will stay in hospital for longer. You will be kept fully informed of what is happening by the teams involved in your child's care and will be welcome to ask questions at any time.

The first thing that is considered when planning a discharge is if all the teams involved in your child's care are happy that your child has recovered to an extent where they will do well at home. Sometimes, this is when your child's general health meets certain criteria, and sometimes when their progress with rehabilitation has reached a certain point. You can speak to anyone involved with your child's care about your child's specific considerations if you like.

The second thing that is considered for discharge is that other healthcare professionals know your child's needs so you can continue to receive support after leaving the hospital. Planning for this will start on, or soon after, arriving at the hospital. You and the teams involved with your child's care will be involved in discussions about your child's needs. The epilepsy surgery nurse specialist will ensure that your local consultant neurologist or paediatrician and health professionals are well informed.

You will be provided with a 'Going home from hospital' information booklet.

## Getting ready for surgery

The exact type of epilepsy surgery recommended for your child will be discussed with the family at a clinic appointment.

Your epilepsy surgery nurse specialist will be your first contact point in the lead up to surgery and is the best person to ask if you have any questions. You can phone or text them. If the epilepsy surgery nurse specialist is not available, a message can be left and you will be contacted as soon as possible.

## Appointments and home visits

The epilepsy surgery nurse specialist will meet you after you decide that you would like your child to have epilepsy surgery. Meetings can be at home or in the hospital, and are for families to talk about any worries about coming to the hospital or the surgery, and to ask any questions. They will discuss the anticipated admission and recovery.

The epilepsy surgery nurse specialist has access to the information about your child that was gathered from discussions with the multi-disciplinary team and investigations so that they can understand more about each child's general health. They often like to learn more about each child and discuss family circumstances to ensure that patients and their families have the right support.

## Opportunity for a hospital visit

It can be helpful for some children and families to see the ward where they will be staying. The epilepsy surgery nurse specialist can arrange a tour of the Borthwick Ward at the Royal Hospital for Children and Young People (RHCYP) in Edinburgh, so you can see where your child will be staying during their surgery and recovery.

## Talking about expectations of surgery

Every child and family has different expectations about what epilepsy surgery can change for their child. The epilepsy surgery nurse specialist will discuss what differences you may see in your child if they undergo surgery. It is important to note every child is different, and their reaction and adjustment to surgery is also different.

This is also an opportunity for you to mention any problems or concerns you may have regarding your child and discuss if these will change or worsen after surgery. You will be asked to complete a questionnaire about this.

## Making plans for your child's admission and recovery

It is important to plan your child's admission for surgery and recovery carefully. The epilepsy surgery nurse specialist and your local epilepsy nurse will give you as much help and advice as possible and work with you to make sure things are ready in a way that is right for you and your family.

## Forms and paperwork

Our epilepsy surgery nurse specialist will go through some paperwork with you. These forms allow us to measure the effectiveness of surgery and its role in improving a child's quality of life. We use this information to evaluate the effectiveness of surgery as a treatment and to prepare future families. We repeat these forms yearly for 5 years in the nurse-led clinic to get a full picture of each patient's progress. These questionnaires are completed by family members, teachers, and the child themselves (if they are at an age and stage to be able to) and relate to their strengths, difficulties and quality of life. There is also a questionnaire for families about the impacts their child's epilepsy might be having on family life.

When your child is on Borthwick Ward, you will be able to spend as much time with them as you want. Please check with the nursing team about the visiting policy for other family members and visitors.

Seizures may occur after surgery, and this does not mean that the surgery has been a failure. Your child's anti-epileptic medication will not change for at least 12 months, but your local consultant neurologist or paediatrician will manage this.

If your child needs to be seen by the Physiotherapy, Occupational Therapy, or Speech and Language Therapy teams to help with their recovery, they will come to the ward.

## After surgery

Your child will wake up in the recovery room and either be transferred back to the ward or to the Critical Care area to be watched closely, depending on what is best for them. They will be given regular pain relief (analgesia) to help keep them as comfortable as possible and medicine to help if they feel sick (anti-emetics).

Often, children wake up with a headache, and the degree of this varies from patient to patient. The team caring for your child will review this regularly and administer pain relief. They are in touch with the pain management team and can contact them if your child is not coping with the discomfort. If all is well, your child will be back on the Borthwick Ward as soon as possible, if they are not already. Your child will be looked after by our experienced Borthwick Ward nursing team, and the neurology team will visit every day.

During the first few days, your child is likely to feel very tired and sleepy. This is the effect of the anaesthetic and the surgery. Your child may have days when they feel better or worse than others, which is entirely normal. We should see a small improvement each day, but it is not uncommon for recovery to be up and down. If you are concerned, speak to the Borthwick Ward nursing team, who will explain everything and answer your questions.

The epilepsy surgery nurse specialist will be able to provide more information about anticipated recovery and expected challenges after surgery that are specific to your child and the surgery they had.

## Borthwick Ward

Children with problems affecting their brain are looked after on the Borthwick Ward at the RHCYP in Edinburgh so that all of the specialists they need can care for them in one place. If you need to come to the Borthwick Ward and stay overnight, important details about meal times, the daily routine and visiting times will be explained to you when you arrive.

## Who will care for my child in the hospital?

You will likely meet a lot of people during your appointments and while staying on the ward. Staff should always introduce themselves, with their name and what they do. Please remind them if they forget!

You may not need to meet everyone introduced in this section.

**Neurology team:** Your child will be looked after by a consultant paediatric neurologist who will lead a team of other doctors, including specialist neurology registrars, registrars and junior doctors.

**Neurosurgical team:** The two consultant neurosurgeons from the epilepsy surgery team will perform your child's surgery together. Other paediatric neurosurgeons and specialist neurosurgery registrars may also be involved in your child's care before and after their surgery.

**Epilepsy Surgery Nurse Specialist:** The epilepsy surgery nurse specialist will continue to see you and your child, and provide information, guidance and support throughout your hospital stay.

**Borthwick Ward nursing team:** A Senior Charge Nurse manages each ward. Day-to-day care is provided by staff nurses, nursery nurses, student nurses, and clinical support workers. All are experienced in caring for neurosurgical patients.

**Neurophysiology team:** The neurophysiology team do investigations to help diagnose and monitor epilepsy and other neurological (brain) conditions by looking at how the brain and the nerves work. They can also provide helpful information during epilepsy surgery in the form of intra-operative monitoring.

**Play specialists:** Play specialists have lots of toys and games to occupy children in the playroom or bed on weekdays. Play specialists may also help prepare your child for procedures (like blood tests) that they may have and offer distraction during the procedure.

**Anaesthetic doctor and pain management team:** The anaesthetic doctor will see your child before and after your child's surgery. Your child will be asleep during the surgery and be woken up by the anaesthetic doctor afterwards. The anaesthetic doctor is also part of the pain management team, who help make sure your child is comfortable and pain-free after their surgery while they are in hospital.

## On the day of surgery

On the day of surgery, your child will have a bath or shower and have their hair washed with an antibacterial scrub, which reduces the chances of infection.

You may have decided with the anaesthetic doctor that a sedation medicine to help relax your child would be beneficial. If so, this will be given, and your child will rest on a trolley bed before being called. If your child is unwell on the day of surgery, the anaesthetic doctor will review them and advise if surgery can go ahead.

The nursing team will complete a surgery checklist and take you to the theatre when the neurosurgery team is ready. You and your child will go together to the anaesthetic room, and you can stay with your child until they go to sleep.

Usually, some hair will be shaved at the time of the surgery, where the incision (surgical cut) is going to be made on your child's head. The neurosurgeon will have shown you where this will be when they explained the surgery to you. The hair will re-grow after the surgery.

The length of each surgery depends on the type of surgery being carried out. Surgery may take several hours, but this will be discussed with you before surgery. The epilepsy surgery nurse specialist will keep you updated whilst your child has surgery by sending you text messages to let you know how things are going. The neurosurgeons will aim to give you a brief update on how things went after the surgery is finished. The epilepsy surgery team or Borthwick ward nursing team will contact you when your child is awake and stable, and you will be able to go and see them.



## Consent

No surgery can be performed without the parent or carer's consent, and the neurosurgery team will visit you with the consent forms for you to sign. This usually takes place on the day of surgery. Consent needs to be an informed decision, so the neurosurgeon will repeat the potential risks and benefits of the surgery discussed in the clinic before you sign the consent form. This is the best time to ask any final questions you may have.



**Physiotherapy team:** The Physiotherapy team will see your child before, during and after their epilepsy surgery to determine if there are any differences in their strength or ways of moving after surgery. The Physiotherapy team will assess and work on any rehabilitation needs your child may have after their surgery and help them adjust. Some days this could be direct, hands-on treatment and some days, it could be a discussion with the team.

**Speech and Language team:** The Speech and Language team may see your child before and after their epilepsy surgery to determine if there are any differences in how your child communicates or swallows food and drink after surgery. They will give individual, tailored support if rehabilitation in these areas is needed.

**Occupational Therapy team:** The Occupational Therapy team is mostly involved after your child's epilepsy surgery to make sure your child feels confident doing day-to-day activities that are important to them. Occupational Therapists will assess your child's needs and can recommend approaches or techniques, teach new skills and suggest changes to equipment or how rooms are arranged to help everyday life.

**Dietician team:** If your child is sleepy or having issues eating and drinking, the Dietician team will oversee things to make sure your child is getting the nutrition they require.

## Staying with your child

Every patient bed on the Borthwick Ward has a fold-down bed for a parent or carer to sleep next to their child. Accommodation can also be available at Ronald McDonald House on the top floor of the hospital. A member of the ward team can check whether a room is available.

Theatre pyjamas can be ordered from:

[www.pyjamafairies.org](http://www.pyjamafairies.org)



## Family Support

Having a child in the hospital can be a worrying time for all the family. Family Support is available with a range of services, including help with travel costs, a place to get away from the wards, financial and benefits advice or sometimes just a listening ear. Find out more about the support available at:

[www.children.nhslothian.scot/parents-and-carers/](http://www.children.nhslothian.scot/parents-and-carers/)



## Edinburgh Children's Hospital Charity

Edinburgh Children's Hospital Charity supports children, young people and their families using the hospital and other healthcare settings in the wider community. They aim to ensure children and young peoples' lives are less interrupted by illness and their families are supported. They have a base in the hospital that families are welcome to go to.

Get in touch on 0131 6684949 or visit:

[www.echcharity.org](http://www.echcharity.org)



## Kindred

It is a hospital-based charity for parents of children with complex medical needs or conditions. They can give help, support and advice, including advocacy. Find out more about Kindred at:

[www.children.nhslothian.scot/parents-and-carers/kindred/](http://www.children.nhslothian.scot/parents-and-carers/kindred/)



## The day before epilepsy surgery

Your child will be admitted one or two days before the surgery to complete the final preparations. This is an opportunity for you to ask any further questions you may have.

After some surgeries, children are admitted to Critical Care. You will have the opportunity to visit the Critical Care areas, where your child may be in the first 12 to 24 hours following their epilepsy surgery if staff need to keep a very close eye on them. In the Critical Care area, it is impossible to sleep at the bedside but it has a family sitting room and two-parent/carers bedrooms are available for short term stays on the ward. Usually, the decision regarding the need for a critical care bed will have made before admission. On occasion, the neurosurgeons and anaesthetic doctor may decide this is necessary during surgery and discuss the reasons for this with you.

Both the neurology team and the nursing team will complete their paperwork. The play specialists on the ward may be able to support the doctors or nurses to do a blood test that must be done before surgery. The Physiotherapy team and Speech and Language team may want to carry out pre-surgery assessments if required.

The anaesthetic doctor will visit your child before surgery to discuss your child's general health with you and explain what the general anaesthetic will involve, including risks. They may prescribe some sedation to make your child a little sleepy before they come down for the operation. Your child will not be allowed to eat for six hours before surgery, but they will receive their regular anti-epileptic medication as usual. They can drink clear fluids up until two hours before surgery.

The epilepsy surgery nurse specialist will do their best to see you to offer support and answer any queries you have.