For more information

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

Department of Paediatric Neurosciences · Royal Hospital for Children and Young People
· 50 Little France Crescent · Edinburgh Bioquarter · Edinburgh EH16 4TJ

Scottish Paediatric Epilepsy Surgery Service

Investigation Surgery (SEEG)

Information for patients and families

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Contents

What happens next

There is a lot of information to review and report from SEEG which may require discussion with the multi-disciplinary team, so follow-up may be several weeks or months later. The epilepsy surgery team will arrange to see you and your child the next time they are at a hospital close to your family's home. This is an opportunity for the epilepsy surgery team to talk to you about the findings from the SEEG and to explain what happens next – one of three options:

1. We can offer epilepsy surgery.
2. We are still unsure exactly where the seizures are coming from and we may need further investigations or tests
3. We cannot offer a surgery because the area involved with seizures is not possible to operate on or there is not suitable evidence to support epilepsy surgery.

Whatever the next steps, your child's doctor will discuss it fully and answer any questions.

Recovery at home

Your child should be back to feeling themselves on the day of discharge, and a restful weekend is advised. Stitches from each electrode site will dissolve themselves. Hair can be washed as normal, and the small wounds should not be touched or picked.

Who to contact about wound infection

Wound infection is rare, but if you notice leakage from the wound of any colour, any redness, heat or increased swelling to the wound, 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 (phone number provided at appointment)

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 (phone number provided at appointment)

Who to contact for anything urgent

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

About investigation surgery

Investigation surgery looks at your child's brain activity to find out where the seizures start in their brain with as much detail as possible.

This is called Invasive Monitoring SEEG (Stereo-EEG). Your child will need a surgery to put in small electrodes (thin wires that measure brain waves) directly into the brain through small holes in the skull. Your child will stay in the hospital and we will monitor their brain activity for around one week and video at the same time. At the end of the week, the neurosurgeons take out the electrodes with a second, shorter surgery. All children will need a general anaesthetic for the two surgeries. We do all SEEGs at the Royal Hospital for Children and Young People in Edinburgh, and your child will be looked after by the epilepsy surgery team.

The possible outcomes of an SEEG are that:

1. We can offer epilepsy surgery. If the monitoring gives us good information about where the seizures are coming from in the brain and it would be safe to do a surgery there, we can then propose an epilepsy surgery. This discussion would usually take place a few weeks or months after the SEEG to ensure the evidence gathered is reported and reviewed by the epilepsy team and discussed with the multi-disciplinary team from around Scotland
2. We are still unsure exactly where the seizures are coming from and we may need further investigations or tests
3. We cannot offer a surgery because the area involved with seizures is not possible to operate on or there is not suitable evidence to support epilepsy surgery.

Renishaw Neuromate® robot

This robotic aid is a state-of-the art robotic 'arm' used during surgery to guide the electrodes used for SEEGs. It is programmed by our consultant neurosurgeons with your child's most up-to-date MRI images to very accurately and safely insert electrodes into the brain without the need for open surgery. This helps patients recovery and the quality of information gathered from this investigation.

Going home from hospital

Most children will be discharged the day after their implants are removed, but this can vary. You will be kept fully informed by the teams involved in your child's care and will be free to ask questions at any time. The epilepsy surgery nurse will keep in contact with you once home and inform your local medical teams of your discharge. Children usually go back to school the Monday after they leave the hospital.

Brain mapping

During the monitoring period, we sometimes perform a “mapping” of brain. This involves passing a small electrical current through some electrodes, which can help us find out what parts of the brain do important functions like speaking and moving. This can help the surgeons plan a surgery with less risks.
During this monitoring there will be a number of people in the room including neurophysiologists, neurology nurse specialists and sometimes other professionals.

The electrical current should not be painful but some children report odd sensations. Some children do not like the experience and it causes them anxiety and upset, and others deal with this fine or sleep through it. The epilepsy surgery team will prepare your child and support you through this.

When the current is running, it temporarily interferes with what that part of the brain normally does. We can learn that a part of the brain is important for:

- Language, if your child stops speaking when the current is running
- Movement, if your child’s limbs, body or face start and stop moving when the current is running
- Sensation, if your child feels tingling or numbness in a body part when the current is running.

This helps the neurosurgeons know areas to avoid during any future surgeries, or if epilepsy surgery involving that area of the brain would cause problems for your child.

Electrode stimulation

Sometimes the epilepsy surgery team will pass a small electrical current through some of the electrodes to purposefully try to provoke a seizure, which also provides important information about where your child’s seizures may be coming from.

The surgery date

Because the monitoring part of the SEEG happens for a week, the epilepsy surgery team works with many other teams to arrange a time when everyone is available. We usually plan for 6 SEEGs per year. We will offer you the date of the next available SEEG period to see if this will fit in with you and your family. Because of the way SEEGs are planned, the next available SEEG period may be much later, especially if many children are waiting. If the dates offered are not suitable, it may also be some time before the next dates become available. You may be prepared some time before your allocated date so you could take a late cancellation.

The epilepsy surgery nurse specialist will keep you informed about the potential dates and plans for invasive monitoring periods that can be offered to you, and can answer any questions you may have.

When a family accepts a surgery date, it will be confirmed in writing by a patient admission letter from the Royal Hospital for Children and Young People in Edinburgh.

Getting ready for surgery

Your epilepsy surgery nurse specialist will be your first point of contact in the lead up to an SEEG and is the best person to ask if you have any questions. They can be contacted by text message and by phone. 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 the SEEG. Meetings can be at home and in the hospital, and are for families to discuss any worries about coming to the hospital or the SEEG, and ask any questions. The epilepsy surgery nurse specialist has access to the information 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 in Edinburgh, so you can see where your child will be staying during their surgery and recovery.

After this, if your child is still not experiencing any seizures, the neurology team may discuss reducing your child's medication. It is important to get as much information about their seizures as possible. Medication reduction can increase the risk of a longer seizure that could be bigger than your child's usual seizures, and there will be emergency medication prescribed should this happen.

There is also a risk of status epilepticus where a big seizure continues and is difficult to stop. If this happens, your child may have to be transferred to the Critical Care unit for further medication and further observation. This is rare and will all be discussed with you in full before any decisions are made. We will seek your consent and ask you to sign a further form that says you have understood these conversations and consent to the medication reduction.

We understand you may find longer or bigger seizures frightening and difficult to watch. Please be reassured that the nursing staff are very experienced in dealing with these seizures and have access to doctors for advice and treatment at all times. There are many safety precautions in place for SEEGs. The staff will talk you through this should longer or bigger seizures occur. Medication will be increased back up to full doses as soon as possible so there is no delay to your child being able to go home.

During the monitoring period

After the first surgery is done, the monitoring period is similar to video telemetry but is more restrictive in terms of walking around. Your child will always have a designated one-to-one nurse or a trained staff member who will supervise your child both day and night to ensure their safety and observe for seizure activity. Parents can come and go during the week, and we encourage parents to take regular relief breaks and rest overnight.

Your child's head will be bandaged to keep the electrodes comfortably in place. The electrodes are held in place by a stitch so they are secure, but pulling on them should be avoided and care should be taken when they are handled. Electrode wires should be only handled by staff. The leads (wires) from these electrodes will be connected to a small recording box (headbox) that will remain near your child. The leads remain plugged into this box for the week-long monitoring period. The staff will handle the wires and box when your child needs to stand to use the toilet and wash, and help from parents and carers with this is encouraged.

The nursing and neurophysiology staff will show you where the best place to position the small box, particularly when your child is asleep, to avoid injury to them or damage to the leads. This helps the information from the investigation be as good as it can be.

Sometimes having anaesthetic can result in children having fewer seizures for a little while, so there is nothing to worry about if your child does not experience seizures for the first few days.

Making plans for your child's admission and recovery

It is important to plan your child's admission for their SEEG and recovery carefully. The epilepsy surgery nurse specialist will provide you with 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.

As monitoring is continuous, your child will have to stay in their hospital room bed for most of the week. This helps us capture their seizures on video and record seizure activity with minimal interference. It is useful to bring activities to help your child pass the time. Borthwick ward has a portable DVD player and a small DVD library, but please feel free to bring along your own and any toys from home.

Borthwick Ward

Children with problems affecting their brain are looked after on the neurosciences ward called 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!

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 the surgeries to put in and take out the electrodes for your child's SEEG together. Other paediatric neurosurgeons and specialist neurosurgery registrars may also be involved in your child's care before and after their surgery.

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 play an important role in SEEG and you will see them every day of the monitoring period.

The neurophysiology team will be in the room setting up the leads when your child returns. Nursing staff will carry out observations.

Surgery to remove the implants usually happens a week after the implant. This is a much shorter surgery, and children are usually only in the theatre for a few hours. If lots of information from the monitoring is gathered early, there may be the opportunity to take the implants out sooner. If not enough information is gathered, the monitoring period may have to be extended. The epilepsy surgery team will keep you updated over the week and discuss any changes to the plan.

How will my child feel when they wake up?

Your child will wake up in the recovery room and will be transferred back to the ward. 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, who can help if your child is not coping with the discomfort. Your child will be looked after by our experienced Borthwick Ward nursing team, and the neurology team will visit every day.

During the first evening, your child is may feel sleepy. This is the effect of the anaesthetic and the surgery. Children often feel well within the first day, and the biggest challenge can be to keep them occupied whilst in bed and helping them cope emotionally with the week-long monitoring period.

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.

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 speak to you about the surgery's potential risks and benefits before signing the consent form. This is the best time to ask any final questions you may have.

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 helpful. 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 proceed.

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.

The length of each surgery is different for each child. It could 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 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.

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. During the SEEG, your child with have a 1:1 member of staff in the room at all times.

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.

Physiotherapy team: The Physiotherapy team will see your child before, during and after their SEEG to determine if there are any differences in their strength or ways of moving after surgery. Your child will be in bed for the week, and the Physiotherapy team will assess your child's chest and muscles daily. Some days this could be direct, hands-on treatment and some days, it could be a discussion with the team.

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 third floor of the hospital close to Borthwick Ward. A member of the ward team can check whether a room is available.

Theatre pyjamas can be ordered from:
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/

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

Kindred

Kindred 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/

The day before the surgeries

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

When you arrive at Borthwick Ward, you will be shown your designated room.

Both the neurology team and the nursing team will complete their paperwork. The play specialists on the ward may be available to support the doctors or nurses to do a blood test that must be done before surgery. The Physiotherapy team may want to carry out pre-surgery assessments if they have not done so already.

The anaesthetic doctor will visit your child before surgery to discuss your child's general health with you and explain to you 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.

This can feel like a lot of information. Your child's epilepsy surgery nurse specialist will do their best to offer support and answer any queries you have.