



Scottish Paediatric Epilepsy Surgery Service

About the Scottish Paediatric Epilepsy Surgery Service (SPRESS) & the First Clinic Appointment

Information for patients and families

About the Scottish Paediatric Epilepsy Surgery Service (SPRESS)

SPRESS is a specialist service made up of experts from across Scotland who all help decide if surgery will benefit children with epilepsy.

SPRESS is a 'multi-disciplinary team' which means many different health professionals all work together. This includes the epilepsy surgery team based in Edinburgh, and consultant paediatric neurologists, epilepsy nurse specialists, neurophysiologists, radiologists, psychologists, occupational therapists, speech and language therapists and physiotherapists from around the country.

The epilepsy surgery team works with local teams at district general hospitals who are involved in epilepsy care and specialists from Tayside Children's Hospital in Dundee, the Royal Hospital for Children in Glasgow, the Royal Hospital for Children and Young People in Edinburgh, and the Royal Aberdeen Children's Hospital in Aberdeen. Our patients can come from all over Scotland, so we try to treat young people as close to home as possible before and after any surgery. Most of the investigations are carried out locally. All surgeries and some specialist investigations take place at the Royal Hospital for Children and Young People in Edinburgh under the care of the epilepsy surgery team.

When are children considered for surgery?

Children are considered for epilepsy surgery if they have seizures that are not well controlled by anti-epileptic medication, they experience unacceptable side-effects from treatment, or their investigations (medical tests or assessments) show that a part of the brain has an abnormality that is a likely cause of the seizures.

Epilepsy surgery is usually recommended for a child with focal epilepsy. Modern methods of investigation mean it is now possible to offer surgery much earlier and to younger children so we may consider surgery for children if it is clear at an early stage that seizures are particularly difficult.

How can surgery help with epilepsy?

The aim of surgery is to remove the underlying cause of seizures in the brain or to interrupt the pathways that seizures take. Surgery can be helpful in situations where epilepsy is caused by a specific abnormality in part or parts of the brain, or when there may be some form of scarring, tumour or lesion on the brain.

In some cases, it may not be possible to remove the cause of the seizures but it may still be possible to reduce seizure frequency and severity by interrupting the pathways they take in the brain or reducing how far seizures spread in the brain. In some cases, your care team may be able to reduce or stop epilepsy medication after a period of being free from seizures.

The epilepsy surgery team

The Consultant Paediatric Neurologists

Our two consultant paediatric neurologists are specialists in looking after children with neurological problems, and are especially knowledgeable about epilepsy and seizures. When a child has epilepsy surgery at the Royal Hospital for Children and Young People in Edinburgh, one of our consultant paediatric neurologist will oversee their care during their stay and to keep their local consultant neurologist or paediatrician informed.

The Consultant Neurosurgeons

Our two consultant neurosurgeons (*brain surgeons*) are skilled experts in epilepsy surgery for children. When a child has epilepsy surgery, they work together to plan and do the surgery, and will explain everything that is involved to children and families. They will also make sure the surgery wound is healing well afterwards alongside the epilepsy surgery nurse specialist.

The Epilepsy Surgery Nurse Specialist

Our epilepsy surgery nurse specialist has many years of experience and will help inform you about the processes involved in epilepsy surgery, from discussion and assessment, to the surgery itself and all the way through to follow-up care. When a child has epilepsy surgery, our epilepsy surgery nurse specialist's job is to talk to children and families about what is happening at each stage and to provide support.

The Service Coordinator

Our service coordinator is the person who looks after arrangements for the epilepsy surgery team. If you wish to contact the service about appointments, they are the person to call.

Ph: 0131 312 0631

What does it mean to be referred to SPESS?

The consultant paediatric neurologist at your specialist centre or the consultant at your local hospital will have talked to you about the potential for surgery to see if you would be happy for your child to be referred to SPESS.

If you agree for your child to be referred, your child will be discussed at a national epilepsy surgery multi-disciplinary team meeting, where the epilepsy surgery team and specialists from all over Scotland will carefully review your child's medical history and current diagnosis of epilepsy. They will help decide if epilepsy surgery is a suitable option for your child.

After this discussion, the team will decide one of the following “outcomes”:

- 1) That surgery is not a suitable treatment option for your child
- 2) That surgery is a suitable treatment option for your child and can be offered based on the results of investigations already done by your child’s local team
- 3) That surgery may be a suitable option for your child but further investigations are required.

Discussion and assessment can be a lengthy process, and your child may be discussed at more than one meeting.

Throughout this process, your child’s own local epilepsy team will continue to be responsible for managing your child’s epilepsy.

How will I be updated on what is happening with my child’s discussion and assessment?

Your child’s local consultant neurologist or paediatrician will be the best person to talk to about the epilepsy surgery journey for your child. They will arrange the large majority of the investigations your child may need to have, and will present the findings from these for discussion at the national epilepsy surgery multi-disciplinary team meeting.

After meetings, your local consultant neurologist or paediatrician will feedback the outcome and will let you know about what might happen next. They will also let you know if the epilepsy surgery team would like to have an appointment with you to discuss your child’s options for surgery or specialised investigations.

Steps on the epilepsy surgery journey

In addition to the included information, we also have a short video that you can view through the below link or QR code.

<https://vimeo.com/1023240373/22673571cc?share=copy>



1. Discussion and assessment

This is the stage you are at now.

After your child is discussed at the multi-disciplinary team meeting, your local consultant neurologist or paediatrician will feedback the outcome and will let you know if particular investigations are needed to build up as full a picture as possible of your child’s seizures.

There are many tests and investigations but your child may not need them all.

If previous tests were inconclusive (not clear) some other investigations might be recommended. The team will identify which investigations are best suited to your child. Your child’s local consultant neurologist, paediatrician or the epilepsy surgery team will contact you with more information if any of these investigations are recommended.

Most investigations may be carried out at your local hospital, but some specialised investigations have to be done in Edinburgh or another specialist centre.

Once the investigations have been done, the team will discuss your child and the results at another epilepsy surgery multi-disciplinary team meeting and use this information to consider if epilepsy surgery is a suitable treatment option for your child.

2. Clinic appointment with the epilepsy surgery team

If the team decides that surgery is a suitable treatment option for your child or that your child would benefit from a specialised surgical investigation, you will be invited to attend an appointment to meet the epilepsy surgery team. This appointment is explained in detail on the next page of this leaflet.

This appointment will be at your local Children's Hospital or at Royal Hospital for Children and Young People in Edinburgh. The epilepsy surgery team will discuss your child's epilepsy treatment options, the results of the discussion, and the aim of the epilepsy surgery or surgical investigation proposed. This is an opportunity to ask questions and discuss how you feel about surgery.

Afterwards, you will be able to take your time to think about the options discussed, and can contact the epilepsy surgery nurse specialist to talk about any thoughts or questions you may have.

3. Epilepsy surgery

If you decide to proceed with surgery, the surgery will take place at the Royal Hospital for Children and Young People in Edinburgh. Your child will be looked after by the epilepsy surgery team you met during the clinic appointment.

Before the surgery, the epilepsy surgery nurse specialist will spend time with you and your child to help you prepare for surgery.

4. Follow-up care

After surgery, your child will have a wound review and an outpatient appointment with the epilepsy surgery team. Following this appointment, your child's epilepsy and post-surgery (after surgery) treatment and management will go back fully to your child's local consultant neurologist or paediatrician and local healthcare professionals.

The epilepsy surgery nurse specialist will continue to be in contact with you and your child for five years following surgery for annual review appointments and to provide support to your family.

If you are invited to a First Clinic Appointment with the Scottish Paediatric Epilepsy Surgery Service

Some of the epilepsy surgery team from Edinburgh will be at this appointment.

The epilepsy surgery team will discuss your child's epilepsy treatment options, the results of the discussion at the national epilepsy surgery multi-disciplinary team meeting, and the aim of the epilepsy surgery or specialist investigation proposed.

The consultant neurosurgeon will explain the surgical procedure or investigation and the risks and benefits involved. You will be able to ask the epilepsy surgery team any questions you may have and discuss any concerns. It is good to remember that no two patients are the same and so the discussion that you will have will be specific to your child.

There may be tests or investigations that are needed before the surgery takes place, and these will be discussed with you.

Your child does not have to join for the entire duration of the appointment. We believe that if your child is at an age and stage where they can participate, it is important they are present for at least part of the appointment because their input, questions, and feelings are of great importance. Ultimately, when deciding if you wish for your child to come to this clinic appointment, you should do what is right for your child and your family.

You do not have to make a decision about surgery at this clinic appointment; the epilepsy surgery team will ask you to think about the information given to you and read over the summary letter that will follow the appointment. It is important to take your time to decide whether you want your child to have the surgery.

You will be given the contact details for the epilepsy surgery nurse specialist at or soon after this appointment and can contact them to discuss or ask further questions.



After this appointment

You will receive a letter from the neurosurgeon summarising the conversation you had in clinic, including the risks and benefits of surgery for your child. At or soon after the clinic, the epilepsy surgery nurse specialist will give you their mobile phone number so you can contact them at any point, and they will call you to talk about the clinic summary letter that will follow your appointment and any thoughts and questions you have relating to it.

If you would like to talk to the epilepsy surgery team about your child's surgical options further, we can arrange another clinic appointment for you and your child. This would usually be at the Royal Hospital for Children and Young People in Edinburgh.

When you feel you have enough information, you can take time to make a decision as a family as to whether you would like your child to have the surgery or not. When you have decided, please ring or text the epilepsy surgery nurse specialist.

For more information

Your child's local consultant neurologist or paediatrician will be the best person to talk to about how your child's discussion and assessment is progressing, as well as any thoughts you have about the epilepsy surgery journey. Your epilepsy nurse specialist is also a very helpful source of information and guidance.

Your child's local consultant neurologist or paediatrician and epilepsy nurse specialist are all connected to the epilepsy surgery team and can ask us to get in touch with you if you need more information.

If you would like more general information about the Scottish Paediatric Epilepsy Surgery Service (SPESS) or the epilepsy surgery journey please contact:

SPESS Service Coordinator: 0131 312 0631

