

# Children and Young People's Epilepsy Services

**This leaflet explains more about children and young people's epilepsy services at St. George's Hospital and what to expect while your child is receiving treatment. If you have any further questions, please speak to a doctor or nurse caring for your child.**

## What is epilepsy?

Epilepsy is one of the most common disorders which affect the brain in children. Different types of epilepsy have different causes but all epilepsy causes repeated seizures.

Once epilepsy is diagnosed, the first line treatment is antiepileptic drugs (AEDs) taken daily to prevent seizures.

## Who are the children and young people's epilepsy team?

The team at St. George's Hospital includes different types of health professionals to ensure the best care for your child. Some members of the team are:

- consultant paediatricians specialised in epilepsy
- specialty doctors
- neuropsychologist
- epilepsy nurse specialist
- neurophysiology consultants
- EEG physiologists
- neuro-radiologists
- clinical geneticists
- speech and language therapists
- occupational therapists
- physiotherapists
- administrative staff.

## What epilepsy services can my child access at St George's Hospital?

### Paediatric epilepsy clinic

This is a clinic for children who have seizures.

Once the child is under our service, we share the care with your General Practitioner (GP) and school nurse by providing up-to-date information on your child's progress. The GP will work with the paediatric epilepsy team to provide repeat prescriptions.

## Young people's epilepsy clinic

This is a clinic for teenagers under the age of 16, where your child will be able to see the paediatric epilepsy consultant in a more adult environment, to help prepare them for changing to adult services.

## Transition epilepsy clinic

This is a clinic for young people over the age of 16, where they will be seen by both the paediatric and adult epilepsy teams at the same time, before transferring fully to adult services.

## Who can use the service?

Children who are registered with a GP in the London Borough of Wandsworth and children living within London Borough of Wandsworth can attend.

Children already under the care of a developmental or community paediatrician at another hospital or centre because they have other needs which may be related to epilepsy should be referred to the epilepsy paediatrician at that hospital. This will help to make sure their care is well coordinated.

## Where do I need to go?

The **paediatric epilepsy clinic** is based at the Child Development Centre, Lanesborough wing, St George's Hospital alongside the Dragon Children's Centre.

It is held weekly on a Monday and two Fridays a month (not including bank holidays).

The team also runs a weekly telephone clinic for anything you would like to talk through without the need for your child to actually attend the clinic.

The **young people's epilepsy clinic** is held in the Child Development Centre, Lanesborough wing, St George's Hospital alongside the Dragon Children's Centre.

The **transition epilepsy clinic** runs four times a year at the adult neurology outpatient department in the Atkinson Morley wing of St George's Hospital.

## How do we make sure your child gets the right diagnosis?

Sometimes it takes a long time to get the right diagnosis for your child. It is important that we take this time to get it right, so your child can get the best treatment for them.

Things you can do to help are:

- take your child to the GP as soon as possible after a seizure
- write down what happens before, during and after each of your child's seizures
- be ready to talk through your written record of the seizure(s) at your child's appointment
- if you can, film the seizure so you can show it to the medical team
- watch your child closely after the seizure and note down anything unusual in the way they are acting. Ask them to try and notice if they have any unusual feelings and to tell you if they feel 'funny' in any way.

Things we will do include:

- taking a detailed medical history of your child and other family members
- giving your child the right tests if they need them.

## **What tests might my child have in order to help decide if they have epilepsy or to help with their condition?**

### **Electroencephalogram (EEG)**

This is a test to see how the brain is working. Small sensors are attached to the top of your child's head and the electrical signals produced by their brain cells are recorded and checked.

The test is painless and may take up to an hour.

A normal EEG does not rule out epilepsy.

### **Sleep-deprived EEG**

This test is done in the same way as a normal EEG but the child sleeps during the test.

This can help to get a more useful reading because the type of brain activity which can show epilepsy is more common when your child is tired or going to sleep.

### **Video-EEG telemetry**

This is a test made up of an EEG together with a video recording of your child's movements, so if they have a seizure during the test, what is happening to their body can be looked at alongside their brain activity.

It is only carried out in certain cases, for example when it is not clear if your child has epilepsy or to decide if surgical treatment might help.

The test happens in hospital, usually over a few days. A video camera will record your child's activity and they will have an EEG test at the same time. The equipment cannot be moved and the child has to stay on camera around the bed area. You can stay with your child the whole time.

### **Magnetic resonance imaging (MRI)**

This is a scan which creates pictures of the brain to help diagnose the causes of epilepsy.

It takes approximately 30 minutes, and your child will be given headphones or earplugs because the scanner makes a loud noise.

Sometimes a dye is injected into a vein as part of the scan to make things show more clearly.

The scan is painless but it is important for your child to stay very still so preschool children may be given a light general anaesthetic.

Because the scanner uses a very powerful magnet to produce images, it is very important that the medical staff ask some safety questions. They will check if your child has any medical implants or metal fragments anywhere in their body. If you or another carer will be going into the scanning room with your child you will be asked these safety questions too. If you know this information beforehand you should tell the doctor in the outpatient clinic at the time you are

referred for your scan or tell the booking clerk at the time you make your appointment for the scan.

## What if treatment does not help with my child's epilepsy?

In a small number of people, the epilepsy can be difficult to treat with medication. If this happens, we can suggest other treatment options and may arrange for your child to see a paediatric neurologist, who will offer further advice.

## Useful sources of information

**Epilepsy Action** has produced the following information:

- Children with epilepsy leaflet: [www.epilepsy.org.uk/info/children/children-with-epilepsy](http://www.epilepsy.org.uk/info/children/children-with-epilepsy)
- What to do when someone has a seizure: [www.epilepsy.org.uk/info/firstaid](http://www.epilepsy.org.uk/info/firstaid)
- First aid for tonic clonic seizures: [www.epilepsy.org.uk/info/firstaid/what-to-do](http://www.epilepsy.org.uk/info/firstaid/what-to-do)
- Photosensitive epilepsy information: [www.epilepsy.org.uk/info/photosensitive-epilepsy](http://www.epilepsy.org.uk/info/photosensitive-epilepsy)

**NHS Choices** has more information on EEGs and NRIs:

- [www.nhs.uk/Conditions/EEG/Pages/Introduction.aspx](http://www.nhs.uk/Conditions/EEG/Pages/Introduction.aspx)
- [www.nhs.uk/conditions/MRI-scan/Pages/Introduction.aspx](http://www.nhs.uk/conditions/MRI-scan/Pages/Introduction.aspx)

Other useful epilepsy websites are:

- [www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/epilepsy12-audit/about-epilepsy12-audit](http://www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/epilepsy12-audit/about-epilepsy12-audit)
- [www.epilepsysociety.org.uk](http://www.epilepsysociety.org.uk)

## Contact us

If you have any questions or concerns about your child's outpatient or clinic appointment, including planned admission, please contact your consultant's secretary or the Child Development Centre main desk on 020 8725 1896 (Monday to Friday, 9am to 5pm).

If you have questions or concerns about your child's medication and day to day management, please contact our epilepsy clinical nurse specialist on 020 8725 2829 or 07917 172730 (Monday to Friday, 9am to 5pm).

If you have any immediate concerns about your child's epilepsy, outside of these hours, please contact your GP or NHS direct or bring your child directly to A&E.

**For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit [www.stgeorges.nhs.uk](http://www.stgeorges.nhs.uk)**

## Additional services

### Patient Advice and Liaison Service (PALS)

PALS can offer you on-the-spot advice and information when you have comments or concerns about our services or the care you have received. You can visit the PALS office between 9.30am and 4.30pm, Monday to Friday in the main corridor between Grosvenor and Lanesborough wings (near the lift foyer).

**Tel:** 020 8725 2453 **Email:** [pals@stgeorges.nhs.uk](mailto:pals@stgeorges.nhs.uk)

### NHS Choices

NHS Choices provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health.

**Web:** [www.nhs.uk](http://www.nhs.uk)

### NHS 111

You can call 111 when you need medical help fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones.

**Tel:** 111

### AccessAble

You can download accessibility guides for all of our services by searching 'St George's Hospital' on the AccessAble website ([www.accessable.co.uk](http://www.accessable.co.uk)). The guides are designed to ensure everyone – including those with accessibility needs – can access our hospital and community sites with confidence.



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