

Epilepsy

Information and advice for parents and carers

Paediatrics

What is epilepsy?

Epilepsy is a brain condition that causes repeated seizures (also known as fits). 1 out of 103 people in the UK has epilepsy.

What are the symptoms of epilepsy?

The symptom of epilepsy is repeated seizures. In an epileptic seizure, abnormal electrical activity in your child's brain disrupts the normal messages passing between their brain cells, causing a seizure. What happens in a seizure depends on which part of the brain is affected by the abnormal electrical activity.

There are two main types of epileptic seizure:

1. **Partial seizures (also called focal seizures)** – where only part of the brain is affected. During a partial seizure a child may be conscious (aware of what is going on) or unconscious (not aware of what is going on). They may also experience one or more of the following:
 - Twitching in their face or one of their hands which spreads to their arms and legs.
 - Feeling strong emotions.
 - Making unusual noises.
 - Unusual behaviour such as fiddling with things, smacking their lips or turning their head.
 - Changes in the way things look.

Children who have partial seizures may experience strange tastes or smells, tingling in their limbs or a strange feeling in their tummy before the seizure starts. This is called an aura.

2. **Generalised seizures** – where most or all of the brain is affected. During a generalised seizure a child may still be conscious or unconscious. They may also experience one or more of the following:
 - Their muscles suddenly relax and they fall to the floor.
 - Their body becomes stiff and their limbs shake.
 - They stare into space and seem vacant or confused.

Sometimes epileptic seizures can happen if your child has not had enough sleep or if they see flashing lights.

For more detailed information about what happens during the different types of epileptic seizure visit www.epilepsy.org.uk/info/seizures.

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What causes epilepsy?

We don't know what causes epilepsy in 2 out of 3 people who have the condition. In 1 out of 3 people with epilepsy their epilepsy is caused by one of the following:

- not getting enough oxygen during birth
- a head injury
- a problem with the development of part of the brain or the blood vessels or nerves in the brain
- a stroke
- a brain tumour
- brain surgery

Around 3 out of 10 people with epilepsy have a close family member with epilepsy so there may be a genetic link.

How is epilepsy diagnosed?

To diagnose epilepsy your child's doctor will ask you to describe in detail what happened before, during and after the seizure. It is helpful to take a video recording of one of their seizures if you can. Your child will then need some of the following tests to check that the seizure was caused by epilepsy and not something else:

- Blood tests.
- Urine (wee) tests.
- An ECG – this is a recording of the electrical activity of your child's heart. This involves leads being attached to your child by sticky pads, which are then attached to a computer that picks up the reading. It only takes a few minutes and your child will not feel anything from it.
- An EEG – this is a recording of the electrical activity in your child's brain. This involves leads being attached to your child's head by sticky pads, which are then attached to a computer that picks up the reading. You can find out more about having an EEG from our leaflet 'What is an EEG?' and our story for children called 'Emily's having an EEG'.
- An MRI or CT scan of your child's brain – this involves lying down on a bed that moves through a tunnel where images of your child's brain are taken.

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How is epilepsy treated?

Epilepsy is treated with medication to prevent seizures. These are called anti-epileptic drugs (AEDs). There are many different AEDs and your child's doctor will prescribe the one that is most appropriate for your child. You may also be given medicine to give to your child to stop a seizure when they have a seizure that lasts for more than 5 minutes.

What are the benefits of anti-epileptic drugs?

The benefit of anti-epileptic drugs is that they can prevent epileptic seizures in up to 7 out of 10 people.

What are the risks of anti-epileptic drugs?

The risks of AEDs are as follows:

- They can change the level of other medications in your child's blood, meaning that there is too much or too little of the medicine in their blood.
- Some people can be allergic to them.
- 3 out of 10 people still have seizures when taking them.
- If the child is female, when they are able to have children they should only do so under specialist advice because AEDs can cause problems with the baby during pregnancy or breastfeeding.

Your child's doctor will discuss the risks of AEDs with you before your child starts taking them. You can also find a full list of possible side effects in the manufacturer's leaflet that comes with the medication.

Are there any alternative treatments to anti-epileptic drugs?

For some children AEDs do not work well enough and one of the following treatments may be suitable for them:

- Surgery to put a small electric device into the body just below the neck, which has wires wrapped around a nerve in the neck (called the vagus nerve). The device passes regular pulses of electricity to the nerve to stimulate it, which can reduce the amount of seizures and how severe they are.
- Surgery to remove the part of the brain causing the problems.
- Surgery to put electrodes into the brain to control seizures.

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What are the risks of not having treatment?

If your child does not have treatment for epilepsy then their seizures cannot be prevented.

Follow-up

Your child will have regular follow-up appointments with their specialist every 3 – 12 months and you will be sent appointments for these.

What to do when your child has a seizure

If your child loses consciousness, falls to the ground and their body is shaking:

1. Keep calm and note the time that the seizure started.
2. Move any harmful objects like furniture away from your child. If this is not possible, move them away from any danger.
3. Cushion their head with something soft or with your hands to protect it.
4. Stay with your child and wait for the seizure to stop.
5. If the seizure doesn't stop after 5 minutes or it is your child's first seizure call 999 for an ambulance.
6. After the seizure has stopped check that they are breathing normally and there is nothing in their mouth.
7. Put your child into the recovery position:
 - Lay them on their side.
 - Tilt their head back to keep their airway open.
 - Position their arms and legs to stop them rolling over.
8. Stay with them until they have fully recovered.
9. If they have another seizure before they fully recover, call 999 for an ambulance.
10. Check your child for any injuries they may have got during the seizure.

If your child is not aware of what is happening but has not fallen to the ground and is not shaking:

1. Keep calm and note the time that the seizure started.
2. Move any harmful objects like furniture away from your child. If this is not possible, move them away from any danger.
3. Stay with your child and wait for the seizure to stop.

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4. If the seizure doesn't stop after 5 minutes or it is your child's first seizure call 999 for an ambulance.
5. Stay with them until they have fully recovered.
6. Check your child for any injuries they may have got during the seizure.
7. If your child has another seizure before they fully recover, call 999 for an ambulance.

Once the seizure stops your child may be confused, sleepy and upset so give them reassurance.

During a seizure DO NOT:

- Restrain your child.
- Place anything in your child's mouth.
- Shake or slap your child.

Contact details

There are four ward areas that look after children within the trust. If your child has recently been discharged and you need to get in touch with staff, they can be contacted on the following numbers:

Priory Ground

0121 507 3927

Lyndon Ground

0121 507 3717

Lyndon 1

0121 507 3800

Children's Emergency Care Unit (CECU)

0121 507 4019

Further information

Epilepsy Action

Helpline: 0808 800 5050

Monday - Thursday: 8.30am - 7pm

Friday: 8.30am - 4.30pm

Saturday: 10am - 4pm

www.epilepsy.org.uk

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Epilepsy Society

Helpline: 01494 601 400

Monday, Tuesday, Thursday & Friday: 9am-4pm

Wednesday: 9am - 7.30pm

www.epilepsysociety.org.uk

(Websites and information checked 01 March 2021)

For more information about our hospitals and services please see our website www.swbh.nhs.uk, follow us on Twitter @SWBHnhs and like us on Facebook www.facebook.com/SWBHnhs.

References:

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- Patient (2015) *Epilepsy in children and young people*. Available at: <https://patient.info/doctor/epilepsy-in-children-and-young-people> (Accessed 01 March 2021).
- National Institute for Health and Care Excellence (2020) *Epilepsies: diagnosis and management*. [CG137]. Available at: <https://www.nice.org.uk/guidance/cg137> (Accessed 01 March 2021).
- National Institute for Health and Care Excellence (2021) *Epilepsy*. Available at: <https://cks.nice.org.uk/topics/epilepsy/> (Accessed 01 March 2021).

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