

## Information for parents and carers

First seizure  
First safety-net

### Introduction

Seeing a child or young person having a seizure can be frightening. Most seizures do not cause serious harm.

This leaflet has been given to you because you are a parent or carer of a child or young person who has had a first seizure that was **NOT** considered to be a 'febrile convulsion'.

### What is a seizure?

A seizure is a sudden disturbance in the brain that affects how a person appears or acts. Seizures, and how your child recovers after them, can vary from one child to another.

Sometimes, people call seizures fits, convulsions, attacks or episodes. They vary from child to child, from being quite noticeable events for some to 'going blank and staring' for others.

One type of seizure is an epileptic seizure. There are many different types of epileptic seizures, and sometimes children can have events that look very similar to an epileptic seizure, but they are not. These include faints, tics, daydreams, sleep disorders and breath-holding attacks.

### Is it epilepsy?

If your child has had only one seizure, it does not always mean they have epilepsy. Some children will never have another one.

If your child goes on to have more seizures, then further medical review with a paediatrician will be needed to confirm epilepsy. An appropriate plan of care can then be agreed and started.

### First aid for a convulsive seizure

A convulsive seizure is where the child is stiff or shaking. The information below can help you to focus when your child is having a seizure. It can help you to give first aid to keep them safe.

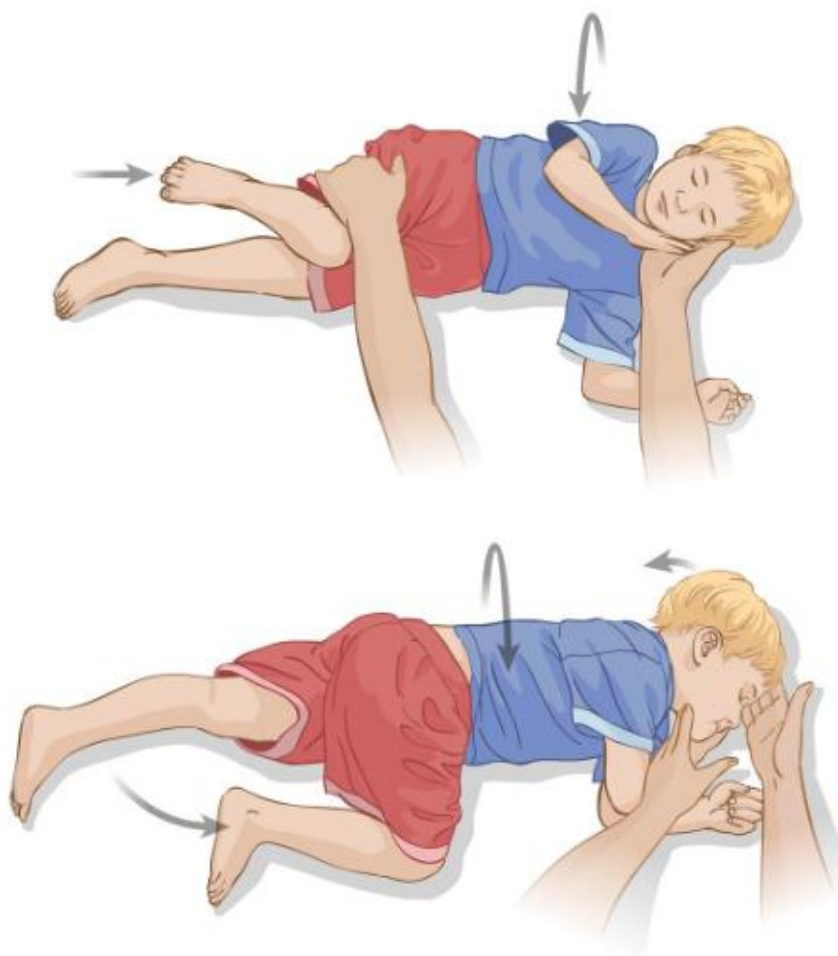
#### Do

- Stay calm
- Protect them from injury (remove harmful objects from nearby)
- Cushion or gently hold your child's head to protect them from head injury
- Note the date and time the seizure started – if stiffness and / or jerking continues for **5 minutes or more** you should call 999 for an ambulance

- Turn your child onto their side, into the recovery position, as soon as you are able (as shown in Image 1). This can help with their breathing and help if they vomit or have other types of fluid in their mouth. Some noisy breathing and slight colour change is common
- **If possible, try to video the seizure on a mobile phone** as it can provide a lot of useful information to your child's doctor or nurse. Video can help confirm the type of seizure, which then helps decide which tests and treatment may be needed. Try to capture the whole child in the video, say out loud what you are seeing and show how they respond to you
- Stay with your child until they are fully recovered
- Your child may be confused, drowsy or fall asleep after a seizure – reassure them if they are confused, let them rest or sleep if they are drowsy, make sure you keep an eye on them until they are fully recovered

### Do not

- Restrain or restrict your child's movements
- Move your child unless they are in danger
- Put anything in their mouth
- Give your child anything to eat or drink until they have fully recovered



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**Image 1:** Moving a child into the recovery position

## Call 999 for an ambulance if:

- You are concerned or need help
- You feel that your child needs medical attention for any reason
- The stiffness and / or jerking continues for **5 minutes or more**
- One seizure follows another before your child has fully recovered
- Your child is injured or you are worried about their breathing

## Do I need to do anything differently after this first seizure?

It is **important** to let your child go back to nursery or school and enjoy their normal hobbies and activities.

As your child has had a seizure recently, it is important to take extra care with some activities until your child has had their initial assessment. Each of these activities should be reviewed over time:

- **Bathing:** A shower, or shower attachment, is better than a bath. They should be **supervised at all times** by a responsible person if having a bath
- **Climbing:** Your child should not climb anything taller than their own height unless they are wearing a harness and being supervised
- **Cycling:** Your child can still ride a bicycle or scooter, but they should wear a helmet and you should consider whether they are allowed to ride on roads or need to be supervised
- **Swimming:** Your child can still go swimming and do water sports as long as they are **supervised at all times** by a responsible person
- **Driving:** Older teenagers who hold a driving license have a legal responsibility to stop driving and tell the Driver and Vehicle Licensing Agency (DVLA) (or DVA in Northern Ireland) that they have had a seizure. For advice visit [www.gov.uk/epilepsy-and-driving](http://www.gov.uk/epilepsy-and-driving)

## Who else should I tell?

It is a good idea to tell your child's school, family and close friends that they have had a seizure. Sharing the first aid information in this leaflet is a good way to help keep your child safe.

## What will happen next?

It is usual for your child to have at least one assessment with a paediatrician, neurologist or another specialist.

Your child may have a heart rhythm trace (electrocardiogram, ECG) if they have not had one already. After initial assessment they may also have a brain rhythm trace (electroencephalogram, EEG), a brain scan and / or blood tests.

## Who has my child been referred to?

*The local team should complete details here:*

## Who else can I contact in the meantime if I am worried?

- Phone NHS 111, who can help if you have an urgent medical problem and you are not sure what to do
- GP or out of hours service
- Your child's doctor, nurse or local team may be able to give you information about helplines, local groups and online forums:

*The local team should complete details here:*

- If epilepsy has been confirmed, then organisations such as Young Epilepsy and Epilepsy Action can provide more help and support

## What can I do in the meantime?

### Video of further seizures

If your child has another seizure, **try to video any further seizure on a mobile phone.**

While it may seem disrespectful, scary and not a natural thing to do, recording the seizure using video can give a lot of useful information to your child's doctor or nurse. For example, video can often help confirm the type of seizure, which then helps decide which tests and treatment may be needed.

Remember to try to capture the whole child in the video, say aloud what you are seeing and show how they respond to you.

## Make notes

Make a note of the date and time the seizure happened and anything about your child's seizure that could be useful for their doctor or nurse to know, for example:

Stage	Information to note	Notes
	<ul style="list-style-type: none"><li>• Date:</li><li>• Time:</li></ul>	
Before seizure	<ul style="list-style-type: none"><li>• What was your child doing?</li><li>• Did your child mention any unusual sensations, such as odd smell, funny feeling or taste?</li><li>• Did you notice anything happen before the seizure?</li><li>• Has your child had a recent fever or been unwell?</li><li>• Were there any triggers?</li></ul>	
During seizure	<ul style="list-style-type: none"><li>• Was there staring, lip smacking, head turning or eye rolling? Were the eyes open or closed?</li><li>• Was there any colour change? Did your child become pale, flushed or blue?</li><li>• Did any parts of your child's body stiffen, jerk or twitch? Did they drop anything?</li><li>• Which side was affected, left or right or both?</li><li>• Did the seizure change pattern (for example, start in one area and then spread to involve other areas)?</li><li>• Did your child make any sounds?</li><li>• Were they responsive or confused?</li><li>• Did they wet or soil themselves?</li><li>• How long did the seizure last?</li></ul>	
After seizure	<ul style="list-style-type: none"><li>• Did your child look drowsy? Did they go to sleep? (if so, for how long)</li><li>• How long did it take your child to return to their usual self?</li><li>• Was any part/side of the body slow to return to normal than the rest and how long did it take?</li></ul>	

## Where can I find other information?

### NHS website

<https://www.nhs.uk>

### Patient

<https://patient.info>

St John Ambulance (search for 'Seizures (fits) in children')

<http://www.sja.org.uk>

Epilepsy Action

[www.epilepsy.org.uk](http://www.epilepsy.org.uk) | Tel: 0808 800 5050

Young Epilepsy

[www.youngepilepsy.org.uk](http://www.youngepilepsy.org.uk) | Tel: 01342 832 243 / 01342 831 342

## Notes

Endorsed by:



**This leaflet aims to provide accurate information. Individual patient circumstances may differ, which might alter both the advice and course of therapy given by your doctor**

Produced by a working group of clinical experts and ratified by the RCPCH Epilepsy Programme Board | For details on source materials used please contact the Royal College of Paediatrics and Child Health's Quality Improvement team ([qips@rcpch.ac.uk](mailto:qips@rcpch.ac.uk))

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# Information Provision Checklist for Healthcare Providers

Please print or save this page and retain in patient records

**Leaflet name: Following a first seizure without a fever in children and young people (information for parents and carers)**

This leaflet is designed for emergency departments, general practice and initial paediatric services to give to parents and carers of children and young people after they have been initially assessed post first afebrile seizure. In some circumstances, it may be suitable for older child over 6 years with a seizure and fever.

It is designed to be appropriate whether the seizures are single or recurrent, epileptic, non-epileptic or uncertain and whether associated with other problems and provides information in the gap between initial assessment and first specialist paediatric assessment.

*Key words: Seizure, Fit, Epilepsy, Convulsion*

**Patient name:** \_\_\_\_\_

**NHS number:** \_\_\_\_\_

**Date issued:** \_\_\_\_\_

**Issued by:** \_\_\_\_\_

**Leaflet version:** Produced: November 2019 (Version 1.2)

I confirm the following (where appropriate):

- This leaflet has been given to parents / carers
- Appropriate advice has been given about bathing and water safety
- Referral made for paediatric outpatient department (if needed)