

Information for children and young people

First seizure
First safety-net

Introduction



Having a seizure can be frightening. It is important to remember that most seizures do not cause serious harm.

You have been given this leaflet because you have had a first seizure that was **NOT** connected with a fever (unusually high body temperature). This leaflet will answer some of the questions you may have, but if you have more questions please ask your doctor.

Your parents / carers have also been given some information so that they know how to care for you during this time. You should talk to your parents / carers about who you wish this information to be shared with.

What is a seizure?

A seizure is a sudden disturbance in the brain that affects how a person appears or acts. Your brain is like a very powerful computer. It controls everything you do. When your brain starts sending too many messages, this can make different things happen to your body. Seizures, and how you recover after them, can be different for everyone.

Sometimes, people call seizures, 'fits', 'convulsions', 'attacks' or 'episodes'. They can range from 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. Sometimes people 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.

Some seizures are convulsive, usually involving the whole body. These are the most dramatic type of seizure where there is stiffness or shaking.

Is it epilepsy?

Epilepsy is a common condition that affects the brain and causes frequent seizures. If you have only had one seizure, it does not always mean you have epilepsy. Some people will never have another seizure.

You may have been told that you are being referred to see a paediatrician (a doctor who works with children and young people) who will be able to confirm if it is epilepsy. They will then work out the best care for you.

First aid for a seizure – what should I tell others?

The people who look after you at home and at school will need to know that you have had a seizure and how to look after you if you have another one.

Showing your family, friends and the relevant people at school the below information, and giving them a copy of the '*Information for Parents and Carers*' leaflet, will help them to know what to do if you have another seizure. It can help them to give first aid to keep you safe.

If I have a seizure, please:

Do

- Stay calm
- Protect me from injury (remove harmful objects from nearby)
- Cushion or gently hold my head to protect me from head injury
- Note the time the seizure started – if stiffness and / or jerking continues for **5 minutes or more** you should call an ambulance
- Turn me onto my side, into the recovery position, as soon as you are able, as shown in Image 1. This can help with my breathing and help if I vomit or have other types of fluid in my 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 my 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 person in the video, say out loud what you are seeing and show how I respond to you
- Stay with me until I am fully recovered
- I may be drowsy or fall asleep after a seizure – let me rest or sleep if I am drowsy, but make sure a responsible person looks after me until I am fully recovered

Do not

- Restrain or restrict my movements
- Move me unless I am in danger
- Put anything in my mouth
- Give me anything to eat or drink until I have fully recovered

Call 999 for an ambulance if:

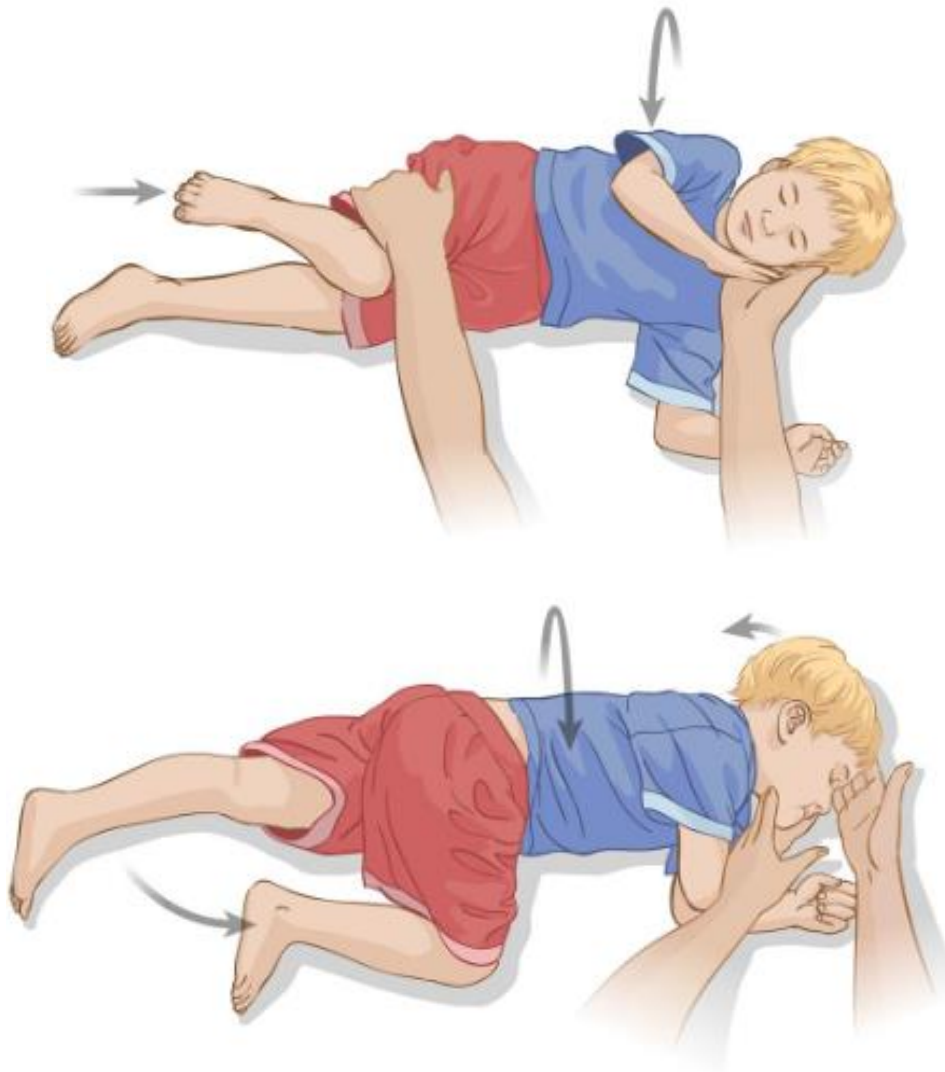
- You are concerned or need help
- You feel that I need medical attention for any reason
- The stiffness and / or jerking continues for **5 minutes or more**
- One seizure follows another before I have fully recovered
- I am injured or you are worried about my breathing



The **DR. ABC** procedure will also allow you to establish what level of first aid you need to give and if you need to call for an ambulance.

DR. ABC stands for **D**anger, **R**esponse, **A**irway, **B**reathing and **C**irculation.

If you are a First Aider, when you encounter a casualty you will need to do the initial **DR. ABC** procedure, also known as the primary survey.



Courtesy of www.aboutkidshealth.ca
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Image 1: Moving a person into the recovery position

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



It is important that you go back to school and enjoy your normal activities. As you have recently had a seizure, it is important that you and the grown-ups around you know the best ways to keep you safe.

Each of these activities should be reviewed over time:



Bathing: A shower, or shower attachment, is safer than a bath and is recommended. Make sure the door is left unlocked, as there can be concern around drowning if you are alone and have another seizure



Climbing: You should not climb anything taller than your own height unless you are wearing a harness and are supervised – this is in case you have another seizure and fall and hurt yourself



Cycling: You can still ride a bicycle or scooter, but will need to wear a helmet. It is best if you do not cycle on busy roads, so always check with a responsible person



Swimming: You can still go swimming and do water sports as long as you are **supervised at all times** by a responsible person



Driving: If you hold a driving license, or provisional license, you have a legal responsibility to stop driving and tell the Driver and Vehicle Licensing Agency (DVLA) (or DVA in Northern Ireland) that you have had a seizure. For advice visit www.gov.uk/epilepsy-and-driving

If you are worried about any other activities that you enjoy doing, please ask a doctor.

What will happen next?

You will usually have at least one assessment with a paediatrician, neurologist (a doctor who diagnoses and treats brain and nervous system problems) or another specialist doctor.

They may test your heart's electrical activity (electrocardiogram, ECG) if you have not had one already. After your first assessment you may also have a test which assesses electrical activity of your brain (electroencephalogram, EEG), as well as a brain scan and / or blood tests.



Your doctor will explain to you about the tests you will need, but please ask them if you are worried.

Who have I been referred to?

The local team should complete details here:

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

If you are worried or have any questions, you can speak to the following people:

- Talk to a parent / carer, teacher or school nurse
- You can phone (or ask an adult to phone):
 - NHS 111, who will be able to give you information and help if you have an urgent medical problem and are not sure what to do
 - Your doctor or out of hours service
- Your hospital may be able to give you information about helplines, local groups and online forums:

Local helplines, local group details and online forums:

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

If you want to talk to someone confidentially, you can also contact an online counselling service such as:

- Kooth: www.kooth.com
- MeeTwo: <https://web.meetoo.com>

What can I do in the meantime?

Video of further seizures

To help the doctors understand what is happening to you, if you have another seizure you should ask your family, friends and teachers to **video any further seizure on a mobile phone**.

This should remain a confidential video and can be helpful to your doctor or nurse. If possible, ask your family, friends and teachers to say aloud what they are seeing and show how you respond to them. They should also note the time when the seizure starts and how long it lasts.

Video can often help confirm the type of seizure, which then helps decide which tests and treatment may be needed.

Make sure your parent / carer is given the '*Information for Parents and Carers*' leaflet, so they can read more about seizures and make a note of anything about your seizure that could be useful to your doctor or nurse. They can also share the leaflet with school, family members and friends in addition to this leaflet.

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>

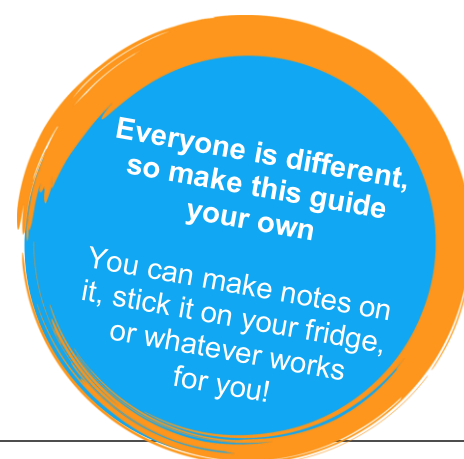
Epilepsy Action

www.epilepsy.org.uk | Tel: 0808 800 5050

Young Epilepsy

www.youngepilepsy.org.uk | Tel: 01342 832 243 / 01342 831 342

My notes



My information

Name:

Next of kin:

Name: _____ Tel. number: _____

Details of my emergency care plan (if in place):

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 | For details on source materials used please contact the Royal College of Paediatrics and Child Health's Quality Improvement team (gips@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 children and young people)

This leaflet is designed for emergency departments, general practice and initial paediatric services to give to 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: July 2020 (Version 1.0)

I confirm the following (where appropriate):

- ☐ This leaflet has been given to the child / young person
- ☐ The accompanying parent / carer information leaflet has been given
- ☐ Appropriate advice has been given about bathing and water safety
- ☐ Referral made for paediatric outpatient department (if needed)