



Healthcare  
Improvement  
Scotland

**SIGN**  
Evidence-based  
clinical guidelines

# Epilepsy

## A booklet for young people up to the age of 18



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Additional images from the original SIGN publication Epilepsy: A booklet for young people up to the age of 18 who are affected by epilepsy.

## Who is this booklet for?



This booklet is for young people up to the age of 18 who:

- have been diagnosed with epilepsy
- or are being assessed



Diagnosed means a doctor has decided what your illness or health condition is.

An assessment is how doctors and healthcare staff make that decision.

## What is epilepsy?



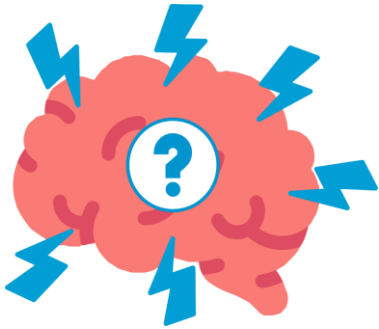
Epilepsy is a condition where you have seizures.

Seizures stop the brain working in the usual way.

It can make your body do things that you cannot control.



Most seizures last less than 5 minutes and will stop on their own.



There is information about the different types of seizure on the Epilepsy Scotland website.

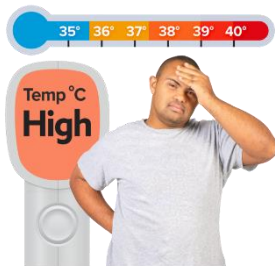
[www.epilepsyscotland.org.uk/here-for-you/publication](http://www.epilepsyscotland.org.uk/here-for-you/publication)

## Why does a seizure happen?



We do not always know why a seizure happens.

Some things that can make a seizure happen are:



- being ill or having a fever



- forgetting to take medicine



- not getting enough sleep



- being very hot or very cold



- being stressed or worried



- missing meals or not drinking enough



- changes in your hormones  
An example is when you have a monthly period.



- drinking a lot of alcohol



- taking street drugs



- having a lot of caffeine  
Caffeine is in things like coffee and energy drinks.



- flashing and flickering lights

## How do healthcare staff find out if I have epilepsy?

Healthcare staff will ask you and people who have seen your seizures questions like:



- what were you doing before the seizure started?
- did you know a seizure was going to happen?



- what happened as the seizure stopped?
- how did you feel after the seizure?

### When the seizure happened:



- did you know where you were?
- could you respond to people talking to you?



- were your eyes open or closed?
- were your eyes staring or fluttering?



- did any parts of your body stiffen, twitch or jerk?



- did your skin go pale or a bit blue?

## What information should I get when I am diagnosed?

Your epilepsy specialist should talk to you about:



- what epilepsy is
- the different kinds of seizures
- what has caused your epilepsy if they know this



- different treatments and tests
- how to stay safe



- how to get in touch with your epilepsy nurse specialist
- where to get more information

Your parents and carers should be given information about:



- first aid advice
- what to do when you have a seizure
- when to call an ambulance





## How can I help healthcare professionals decide what type of epilepsy I have?



You could ask your parents, carers or family members to make videos of you having a seizure.

## What tests might I get?



You may get an EEG - a type of brain scan.

Small wires are attached to your head. It does not hurt.

It takes around 30 minutes.



You may get an MRI.

You lie on a table and slide into a machine that takes pictures of your brain.

It does not hurt.



You can see videos of young people having these tests at:

<https://www.whatwhychildreninhospital.org.uk/>



You may get a blood test.

## What treatment can I get?



### Medication

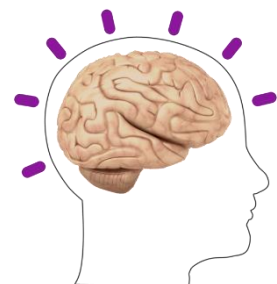
You will be able to try different medicines to see what works best for you.



### Ketogenic diet

A ketogenic diet uses the food you eat to help you have less seizures or stop them.

Healthcare staff will make sure the diet includes foods you like.



### Having an operation

If medication has not helped your epilepsy you may get an operation on your brain.

Your epilepsy specialist will talk about this with you and your family.



You would get tests to see if surgery would be right for you.

You would meet the epilepsy surgery team before you have an operation.

## What should I know about the risk of dying?



It can be scary to think about dying but it is important for you to know what the risks are.

21 people with epilepsy die every week.



Children and young people with epilepsy can have more risk of dying because of:

- seizures that last a long time
- accidents or drowning



- suicide – people killing themselves
- SUDEP. This stands for ‘sudden unexpected death in epilepsy’. This is when someone dies with no obvious cause.
- other conditions that may have caused epilepsy such as a brain tumour



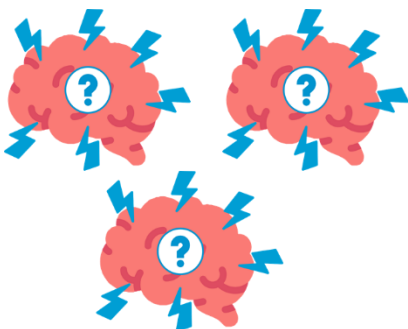
Talk to your epilepsy team about your risks.

They will give you and your family information and support.

## What are the risks linked to sudden unexpected death in epilepsy?



The strongest risk for SUDEP is having a lot of seizures that affect your whole body.



Other things that are risky are:

- seizures that happen one after the other



- seizures that happen at night or when you are sleeping



- seizures that are difficult to control with treatment

- seizures that last more than five minutes



- not taking your medicine as often as you should or not taking it at all

- other health conditions you have had for a long time

## Things that can help reduce epilepsy risks



Always take your medication on time.

Go to healthcare appointments about your epilepsy.

Have a regular epilepsy review – a meeting to check if things are going well.



Write down when your seizures happen.

You could use a diary to do this.



Try not to sleep on your stomach.  
This means do not lie face down.



Try to sleep on your side or on your back.



If you have seizures at night or when you are asleep, think about using a monitor to alert your parents or carers.



Talk to people about your epilepsy.

Tell them what to do or not to do if you have a seizure.



Make sure they know when to call an ambulance.

## Will my epilepsy mean I have problems with learning and how I behave?



Some children and young people with epilepsy have more chance of:

- having a type of autism
- having a condition where you have lots of energy but find it difficult to concentrate



If you or your parent or carer are worried about these things tell your healthcare staff.

Healthcare staff may ask you if you would be happy speaking to a specialist service.



You can read more about this in our [booklet for young people](#).



If you have problems with learning or thinking your healthcare staff should speak to a teacher who knows you well and talk about how the school could help you.



Your healthcare staff could arrange for you to have a test to check how you finish tasks, answer questions, write and draw.

## **What if I have problems with how I feel?**



People with epilepsy may feel very sad or worry more.



Your healthcare staff could refer you to mental health services.

This service is called CAMHS.

CAMHS stands for Child and Adolescent Mental Health Service.

## **What will happen when I move to adult services when I am 18?**



This is called 'transition'.

It will help you start to look after your condition yourself.

Transition should be planned with you and your parents.





Your epilepsy specialist should tell you:

- what will happen
- when it will happen
- who will be involved and support you



- the differences between child and adult services
- the names of your doctors



- how to make an appointment
- how to order a prescription



- information about:

- staying well if you are having sex

This includes information about contraception to stop you having a baby you do not want.

- drugs

- driving



Your epilepsy specialist should:

- arrange for you to meet healthcare staff and a specialist nurse
- tell you where you can find information online about transition and epilepsy advice

## Where can I get more information?

**Epilepsy Action** [www.epilepsy.org.uk](http://www.epilepsy.org.uk)

**Epilepsy Connections**

[www.epilepsyconnections.org.uk](http://www.epilepsyconnections.org.uk)

**Epilepsy Scotland**

[www.epilepsyscotland.org.uk](http://www.epilepsyscotland.org.uk)

**Epilepsy Society**

<https://epilepsysociety.org.uk/>

**Matthew's Friends**

[www.matthewsfriends.org](http://www.matthewsfriends.org)

Specialists in ketogenic diet therapies.

**NHS Inform** [www.nhsinform.scot](http://www.nhsinform.scot)

National health information service

**SUDEP Action** [www.sudep.org](http://www.sudep.org)

**The Daisy Garland**

[www.thedaisygarland.org.uk](http://www.thedaisygarland.org.uk)

**Young Epilepsy**

[www.youngepilepsy.org.uk](http://www.youngepilepsy.org.uk)





## Useful reading

[Getting on with life – Teenage Guide](#)

SUDEP – [reducing your risk: information for teenagers and young adults](#)



## Useful video

Muir Maxwell Epilepsy Centre – [Me and My Epilepsy](#)



There is more information online at: [www.sign.ac.uk](http://www.sign.ac.uk)

If you want our booklet '[SIGN guidelines: information for patients, carers and the public](#)'



email: [sign@sign.ac.uk](mailto:sign@sign.ac.uk)  
or call: 0131 623 4720.



If you need this information in a different language or format

email: [sign@sign.ac.uk](mailto:sign@sign.ac.uk)  
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