



Healthcare
Improvement
Scotland

SIGN
Evidence-based
clinical guidelines

Epilepsy

A booklet for young people up to the age of 18 who are affected by epilepsy



PLAIN
LANGUAGE
COMMISSION
**CLEAR
ENGLISH
STANDARD**

© Scottish Intercollegiate Guidelines Network
ISBN 978-1-909103-81-8

First published 2021

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Infographics on pages 15-17 and information on page 21 have been adapted from sudep.org/sites/default/files/sudep_childrens_lo_0.pdf

We would like to thank all the young people and voluntary organisations who helped to develop this booklet.

The image used on the front cover was inspired by a young person with epilepsy.



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Who is this booklet for?

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

- have been diagnosed with epilepsy, or
- may be going through assessment.

What is this booklet about?

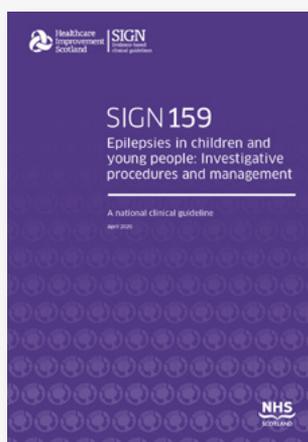
This booklet explains advice that we have written for healthcare professionals on how to investigate and treat epilepsy in children and young people. The advice is published in a guideline called SIGN 159.

The advice is based on what we know from current medical research. It also gives advice based on the opinion of healthcare professionals who are trained on how best to manage your care.

There are details of where you can get more information about epilepsy at the end of the booklet on pages 23–25.

On page 26 you can find out how we produce guidelines.

If you would like to read the guideline for healthcare professionals, please visit www.sign.ac.uk.

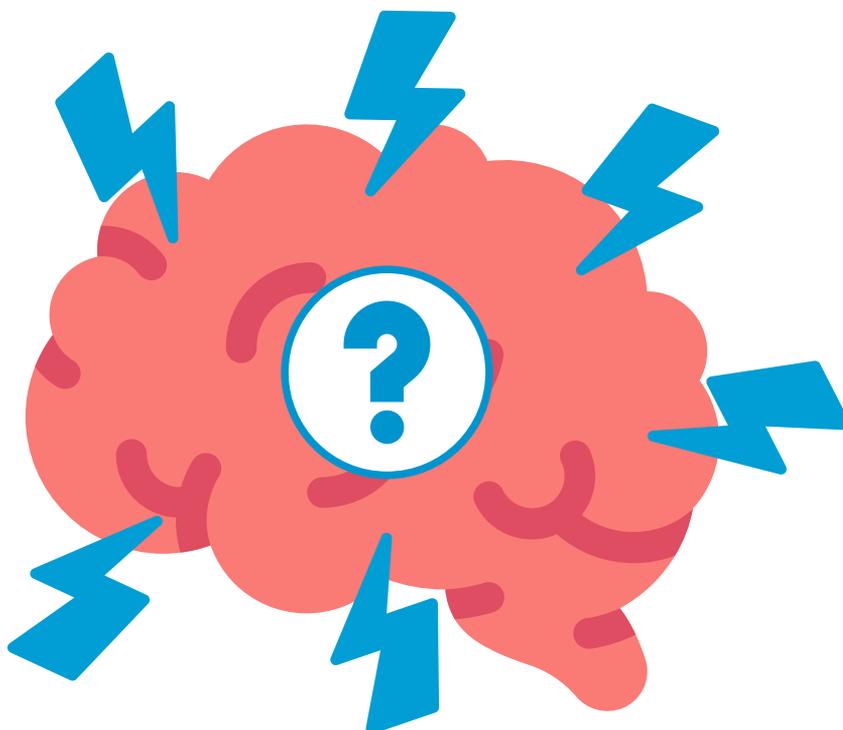


What is epilepsy?

Epilepsy is a condition where you have repeated seizures. Seizures happen when your brain sends too many electrical messages. This stops the brain working in the usual way. It can make your body do things that you can't control.

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

There are many types of seizure. You can find detailed information about them on Epilepsy Scotland's website. www.epilepsyscotland.org.uk/about-epilepsy/epilepsy-and-seizures-explained



Common seizure triggers

Many people have seizures for no obvious reason, but some common triggers are listed below.



Information

Common seizure triggers include:

- feeling unwell, running a fever
- forgetting to take medication
- lack of sleep
- being really hot or really cold
- stress and anxiety, sometimes even boredom or excitement
- missing meals
- dehydration
- hormonal changes, such as during a monthly period
- drinking alcohol, particularly binge drinking
- taking street drugs
- high caffeine intake
- flashing and flickering lights.



“ Try to stay away from known triggers. Emotions are triggers so you need to keep calm...

How do healthcare professionals find out if I have epilepsy?

Assessment and diagnosis

Diagnosing epilepsy can be difficult, so it's important that healthcare professionals know every detail to make sure they get the right diagnosis and treatment for you.

Doctors may ask you several times to repeat the story of your seizures.



Information

Here are some questions that healthcare professionals might ask you and those who have seen your seizures.

- What were you doing and what happened just before and at the time the seizure started?
- Did you feel you had any warning it was about to happen?
- What order did things happen in?
- What happened as the seizure ended?
- What were you like after the seizure and for how long?
- During the seizure:
 - were you aware of your surroundings?
 - were you able to respond to people talking to you?
 - were your eyes open or closed? Were they staring or fluttering/jerking?
 - did any parts of your body stiffen, twitch or jerk?
 - did your skin go pale or slightly blue?

Healthcare professionals will base their diagnosis on what you and others who saw your seizures have told them.

Epilepsy should be diagnosed by an epilepsy specialist. This is a doctor who has had training in epilepsy. They will also have had plenty of experience of working with young people who have epilepsy.

“ You can't hide it [diagnosis] from people, be honest because it's a big responsibility for them when you're out with them.

“ Tell people that need to know and who you are comfortable with, not everyone needs to know.

What information should I get when I am diagnosed?



Information

Your epilepsy specialist should talk to you about:

- what epilepsy is and different seizure types
- the most likely cause of your epilepsy, if known
- possible tests that may be carried out
- what the future may hold for you
- treatment options
- how you can stay safe
- how to get in touch with your epilepsy nurse specialist, and
- where you can find out more.

“ I got a book to read about my condition and that helped.

“ My epilepsy nurse came to explain what happened [seizures] and that helped a lot.



Information

Your parents and carers should be given information too, such as:

- first aid advice
- when and how to take action
- when to call an ambulance.

How can I help healthcare professionals to find out what type of epilepsy I have?

A good way to help healthcare professionals diagnose and treat your epilepsy is to show them videos of your seizures as these will tell them a lot. You could ask your parents, carers or family members to help make the videos.

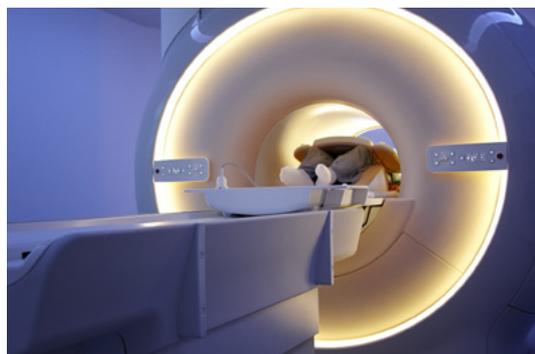
What tests might I get to help healthcare professionals find out what type of epilepsy I have?

You may need a number of tests as there is no single way of diagnosing epilepsy.

You may receive a brain wave test called an electroencephalogram (EEG) or a brain scan known as a magnetic resonance imaging (MRI) scan to help healthcare professionals find out what type of epilepsy you have.



To do an EEG, small wires are attached to your head. These monitor your brain's electrical activity. It's painless. A routine EEG test usually takes between 20 and 30 minutes.



An MRI is a painless scan of your brain using strong magnetic fields and radio waves. You lie on a table and slide into a machine. The machine takes pictures of your brain and shows if there is anything that may help to explain why you're having seizures.

“ It’s important to be involved in conversations about epilepsy.

You may find it helpful to watch videos of young people having these tests. See them here www.whatwhychildreninhospital.org.uk

Sometimes if no causes are found for your epilepsy, you may be offered blood tests for genetic testing.

The blood test looks to see if there are any changes in your **genes** that explain why you have epilepsy.

Genes

Genes carry information that makes you who you are. They set things like your eye and hair colour. Your genetic make-up is passed to you from your parents when you are conceived.

What treatments are available?

Medication

The most common treatment for epilepsy is anti-epileptic medication.

You will be able to try different medicines or a combination of medicines to see what works best for you. Your epilepsy specialist will talk to you about medication before giving it to you.



Medication should be given to you by a specialist epilepsy doctor. This may happen at a specialist epilepsy clinic at hospital, but it might not be your local hospital.

Ketogenic diet

A ketogenic diet is a way of treating epilepsy by using the food you eat to reduce your seizures or stop them altogether.

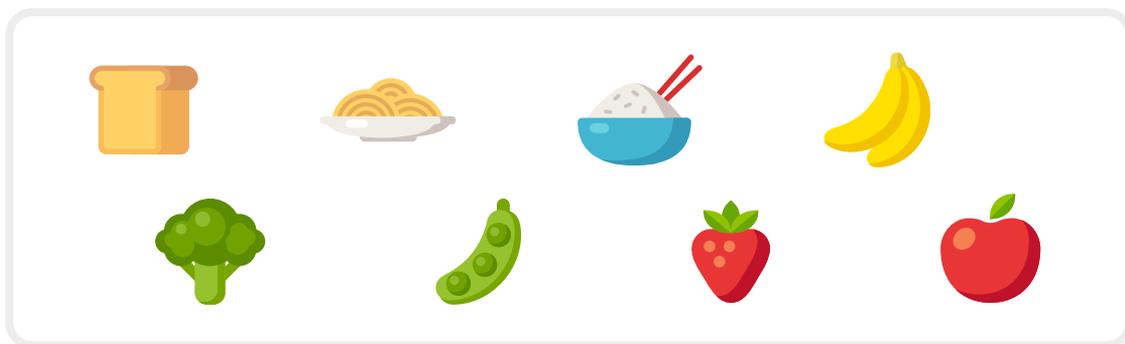
Examples of food included in ketogenic diet



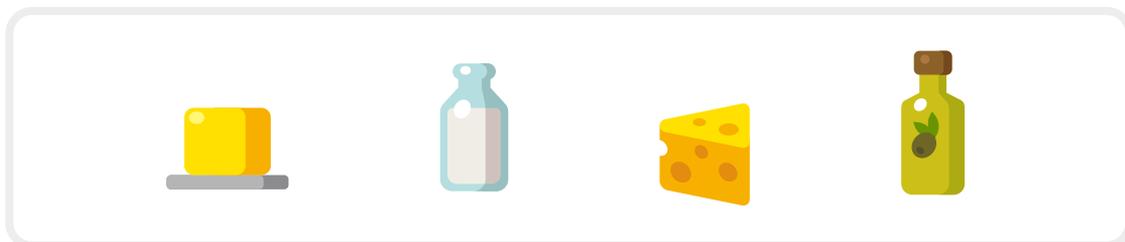
What treatments are available? continued

Food is the fuel that gives our brain and body energy. There are two types of fuel we can use in our bodies:

Glucose, which we get from foods like bread, pasta, rice and fruit and vegetables (these are called carbohydrates).



Ketones, which we get from things like butter, milk, cheese and oils (these are called fats).



Our brain picks glucose first for its fuel as there is usually plenty of it. If our bodies don't have enough glucose, our brain starts using ketones from any fat we have in our body. These ketones can reduce or stop seizures so this diet is a way of making your brain use ketones and not glucose. You just need to eat foods that help your body use fat for energy so it can make the ketones.

What treatments are available? continued

You will be asked to try a ketogenic diet if your epilepsy has not responded to treatment with medication (known as drug-resistant epilepsy) or has not responded to two anti-epileptic medications. You should try a ketogenic diet for at least three months to see if it is helping. Healthcare professionals will discuss its risks and benefits with you at your appointments to see if you should stay on it.

The ketogenic diet is created just for you. Professionals will work with you to make sure your diet includes foods you like.

“ I like the idea of it but I’m just not sure how it would work, especially when I go out with friends

Epilepsy surgery

An operation on your brain may be an option for you if medication has not helped. Your epilepsy specialist will discuss this with you and your family.

For some people, epilepsy surgery can stop or reduce the number of seizures they have.

If you have tried two or more anti-epilepsy medications and they haven't helped, you may be referred for assessment to find out if surgery would be an option for you. This should happen as soon as possible.

Your epilepsy specialist will discuss with you whether more tests would be needed to try to find out what type of seizures you usually have.

Your epilepsy specialist will discuss your epilepsy with a large team of other epilepsy specialists. If the whole team agrees that surgery might help you, you will be invited to meet the epilepsy surgery team.

What should I know about the risk of dying?

Over 600,000 people (children and adults) in the UK have epilepsy. Sadly, approximately 21 people die each week because of it. Although it can be scary to think about, it is important you know this. Being aware of the risks linked to epilepsy means you can do things to reduce them.

Why do some children and young people with epilepsy die early?

Children and young people with epilepsy can be at increased risk of dying early because of:

- things going wrong during seizures
- seizures that last a long time
- accidents or drowning
- suicides
- sudden unexpected death in epilepsy (SUDEP), and
- other conditions that may have caused epilepsy such as a brain tumour.

Your epilepsy team can also give you advice on risk that applies to you and your specific epilepsy. It's important you talk to them about this regularly, especially as risks can change over time.

What is sudden unexpected death in epilepsy (SUDEP) and what are the risks linked to it?

Each year about 1 in 4,500 children with epilepsy in the UK will die suddenly with no obvious cause of death. This is called SUDEP.

Risks (including SUDEP) and safety issues should be discussed regularly with you and your family. This should happen when you are diagnosed and at follow-up visits with healthcare professionals.

What increases the risk of SUDEP?

The strongest risk factor for SUDEP is having frequent convulsive seizures (a type of seizure affecting your whole body).

Other risk factors include:



Seizures that happen one after the other (cluster)



Night-time seizures and seizures that happen when you are sleeping



Seizures that are difficult to control with treatment



Seizures that last more than five minutes



Not taking your anti-epileptic medication regularly as prescribed, or stopping it completely



Other long-term health conditions



Information

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.

As you get older, there will be other risk factors to think about (see page 21).

Special thanks to SUDEP Action for the information in this section.

Things that can help reduce epilepsy risks (including risks linked to SUDEP).

Care



Attend regular appointments with your healthcare professional. You should have a regular epilepsy review.

Take your medication regularly.



Take extra care near water, including swimming and bathing.

Choose showers rather than baths.

Lifestyle



Carry important information about your epilepsy with you.

A medical ID bracelet or card could help if you have a seizure when you are on your own.

Put emergency contact details into the lock screen of any mobile phone you have.

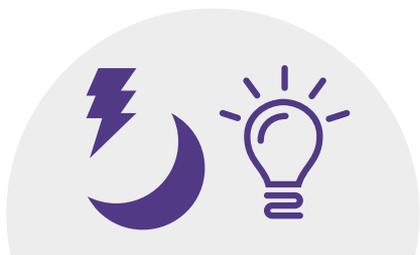


Talk to your healthcare professional about concerns such as:

- how often you're having seizures
- medication side effects
- changes to your moods
- sex and contraception (when appropriate).

Things that can help reduce epilepsy risks (including risks linked to SUDEP).

Seizures



Identify and try to avoid seizure triggers (see page 4).



Keep a seizure record or diary.



Avoid sleeping on your stomach.



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

“ If I have a seizure when I’m out with friends, I’ve told them to sit me down and if the seizure lasts long, they should call my parents. It means giving them my phone password.

Special thanks to SUDEP Action for the information in this section.

Do difficulties with learning and behaviour happen alongside epilepsy?

Epilepsy can be associated with conditions that affect how the brain works and develops in children and young people.

It is important for your epilepsy specialist to monitor your general development as well as manage your epilepsy. This should include asking you and your family about difficulties you may have at home and school and how you get on with other people.

Some children and young people with epilepsy have more chance of having conditions that affect development, for example **autism spectrum disorder (ASD)** and **attention deficit hyperactivity disorder (ADHD)**.

ASD

A lifelong condition causing difficulties with social and communication skills and behaviour. It is a term used to describe a group of similar conditions including autism and Asperger's.

ADHD

A condition where people have lots of energy but difficulty concentrating. Sometimes people may only have difficulty with paying attention (this is called attention deficit disorder).

If you, or your parent or carer, are worried about your development, healthcare professionals can ask you questions to gather information about any symptoms of (ASD) or (ADHD) you may have noticed.

If this identifies symptoms of ADHD or ASD, your epilepsy specialist should consider making a referral to a specialist service for a more detailed assessment. They will discuss this with you and ask your permission for a referral to be made.

You can read more about getting assessed for ASD or ADHD in our booklet for young people www.sign.ac.uk/media/1160/pat145_young_people.pdf

What if I have problems with my learning?

Some children and young people with epilepsy can have difficulties with learning and some thinking skills, for example memory, paying attention, and language. They may also have difficulty solving problems and controlling their thoughts and behaviours.

Your epilepsy specialist will want to find out about any difficulties you have, whether they have changed over time and what help you may be getting at school.

They may ask for more information from your school, including your school reports or exam results.

If it looks like you are having difficulty with learning or thinking skills, your healthcare professional should contact a teacher who knows you well to discuss this and what the school may be doing to help.

If you are having more severe problems with learning, your healthcare professional may ask for a specialist assessment (called a neuropsychological assessment).

Neuropsychological assessments are done by psychologists in Paediatric Neuropsychology services or Child and Adolescent Mental Health Services (CAMHS). Assessment can involve completing tasks, answering questions, and writing or drawing.

What if I have difficulties with how I feel?

Feelings of low mood and increased worrying are common in people who have epilepsy. We know that children and young people with epilepsy may be at increased risk of depression or anxiety. This can increase the difficulty of going to school, seeing friends and taking part in social and leisure activities. So it's important to get help as soon as possible.

“ I worry and get embarrassed. It's hard telling people that I have epilepsy.

You should be asked about your mood at your epilepsy review appointments. This may include asking about symptoms of depression and anxiety.

Your epilepsy specialist should consider using questionnaires to ask you about symptoms of depression and anxiety.

If they think you may be at risk of depression or anxiety, they should consider referring you to specialist mental health services. This may be your local Child and Adolescent Mental Health Service (CAMHS). You will get treatment if you need it.

“ When I finally got support, I opened up, I expressed my emotions. When holding back, I had more seizures.

What should happen when I move from child to adult services?

It's called 'transition' when you move from child to adult services. Transition may help you in starting to look after your condition yourself, rather than your parents being the first point of contact for your care.

“ It's important for me to be able to talk to the doctor on my own.

It is important that you know the best ways to look after your condition but also how to stay safe.

Medication side effects

Be honest with your healthcare professional to help them find a balance between seizure control and minimising any side effects.

Taking medication regularly

This can help seizure control and help reduce the risk of injury.

Driving a vehicle

To drive, it is vital to have your seizures under control.

Alcohol and use of street drugs

This can affect epilepsy and medication, and could have serious consequences.

Sex and contraception

You can discuss this with your healthcare professional. It's important to be honest and ask questions, so you can make informed choices.

“ You should talk to your doctor yourself and with your parents.

What should happen for a good transition?

Transition should be planned, with you and your parents. Your epilepsy specialist nurses will help you a lot during transition. The process could include:

- educating both you and your parents on epilepsy
- making sure you know the names of the doctors involved in your care
- giving you information about things like how to make an appointment and order a prescription, as well as advising about sexual health, drugs and driving
- offering advice to you that suits your gender, for example about taking contraception while on epilepsy medications
- organising one-to-one meetings with a healthcare professional/specialist nurse
- directing you to websites with information about transition and specific epilepsy advice
- explaining the differences between adult and paediatric care to you and your parents/carers.



Information

During transition, your epilepsy specialist should tell you:

- what will happen
- when it will happen
- who will be involved and support you, for example your epilepsy nurse specialist.

Where can I find out more information?

If you haven't found what you're looking for, here are some further sources of information.



Websites

Epilepsy Action

www.epilepsy.org.uk

The aim of Epilepsy Action is to raise awareness about epilepsy, and to bring about permanent change for people with epilepsy so they can have a better life.

Epilepsy Connections

www.epilepsyconnections.org.uk

Epilepsy Connections runs various projects and services in the Greater Glasgow & Clyde, Forth Valley and Ayrshire & Arran Health Board areas. They offer information, advice and support to people with epilepsy, their families, friends and carers, and the professionals working with them.

Epilepsy Scotland

www.epilepsyscotland.org.uk

Epilepsy Scotland is the national organisation representing people living with epilepsy in Scotland. They provide services, support and information for people of all ages.

Epilepsy Society

epilepsysociety.org.uk

The Epilepsy Society provides epilepsy services throughout the UK. Through research, awareness campaigns, information resources and expert care, they work for everyone affected by epilepsy in the UK.

SIGN accepts no responsibility for the content of the websites listed.



Websites continued

Matthew's Friends

www.matthewsfriends.org

Matthew's Friends are specialists in medical ketogenic dietary therapies for epilepsy that doesn't respond to medication, and other neurological and metabolic conditions.

NHS Inform

www.nhsinform.scot

Scotland's national health information service provides patient information on medical conditions, self-help advice and a directory of local support groups.

SUDEP Action

sudep.org

SUDEP Action aims to increase awareness of epilepsy risks and tackle all epilepsy-related deaths, including sudden unexpected death in epilepsy. They provide information on seizures and risks, lifestyle and risks and how you can take action to reduce risks.

The Daisy Garland

www.thedaisygarland.org.uk

The Daisy Garland is a charity working for children and families whose lives are affected by epilepsy that doesn't respond to medication.

Young Epilepsy

www.youngpilepsy.org.uk

A children and young people's epilepsy charity.

SIGN accepts no responsibility for the content of the websites listed.

Useful publications specifically for young people



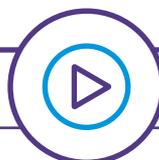
Getting on with life

www.epilepsyscotland.org.uk/wp-content/uploads/2021/08/Teen-guide.pdf

SUDEP - reducing your risk: information for teenagers and young adults

www.sudep.org/sites/default/files/9153d_sudep_action_leaflet_a5_4pp_reducing_your_risk_ds_44_170gsm_silk_x_200.proof1_.pdf

Useful video



Muir Maxwell Epilepsy Centre - Me and My Epilepsy

www.youtube.com/watch?v=MO7xXL2ZXP8

How are SIGN guidelines produced?

Our guidelines are based on the most up-to-date scientific evidence. We read research papers to find evidence for the best way to diagnose, treat and care for patients. If we cannot find this out from the research evidence, we ask healthcare professionals to use their clinical experience and judgment to suggest treatments.



1

Gather lived experience



2

Identify the questions



3

Search for the evidence



4

Look at the evidence



5

Make judgements and recommendations



6

Ask people for feedback



7

Publish



8

Let everybody know about our guidelines

You can read more about us by visiting www.sign.ac.uk or you can phone 0131 623 4720 and ask for a copy of our booklet 'SIGN guidelines: information for patients, carers and the public'.

The Scottish Intercollegiate Guidelines Network (SIGN) writes guidelines which give advice for healthcare professionals, patients and carers about the best treatments that are available. We write these guidelines by working with healthcare professionals, other NHS staff, patients, carers and members of the public.

We are happy to consider requests for other languages or formats. Please phone 0131 623 4720 or email sign@sign.ac.uk



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