



Healthcare  
Improvement  
Scotland

**SIGN**  
Evidence-based  
clinical guidelines

# Epilepsy

A booklet for parents, carers and families of children and young people affected by epilepsy



PLAIN  
LANGUAGE  
COMMISSION  
CLEAR  
ENGLISH  
STANDARD

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Infographics on pages 20-22 and information on page 29 have been adapted from [sudep.org/sites/default/files/sudep\\_childrens\\_lo\\_0.pdf](https://sudep.org/sites/default/files/sudep_childrens_lo_0.pdf)

**We would like to thank the parents, carers and the voluntary organisation representatives who helped us to develop this booklet.**



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# Who is this booklet for?

**This booklet is for parents, carers and families of children and young people up to the age of 18 who:**

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

We have written another booklet especially for young people, and there are details about this on page 35. Both booklets are based on a national guideline on epilepsy in children and young people. The full guideline is available on our website [www.sign.ac.uk/media/1844/sign-159-epilepsy-in-children-final.pdf](http://www.sign.ac.uk/media/1844/sign-159-epilepsy-in-children-final.pdf).



# What is this booklet about?

## This booklet explains:

- what epilepsy is
- what tests your child may get
- information on risks and safety issues in epilepsy
- what treatments your child may be offered
- what happens when your child moves from child services to adult services
- where you can get more information.

This booklet explains the recommendations in a guideline, produced by the Scottish Intercollegiate Guidelines Network (SIGN), about investigating and managing epilepsy in children and young people.

The guideline is based on what we know from current medical research. It also gives advice based on the opinion of healthcare professionals who are trained in how best to manage your child's care. On page 37 you can find out how we produce guidelines.

Some information in this booklet will not be relevant to the type of epilepsy your child has. Your child's healthcare professional can help you decide which sections of the booklet would be most helpful for you to read.

## There are two different types of recommendations in this booklet.



**Recommendation  
based on the research evidence**

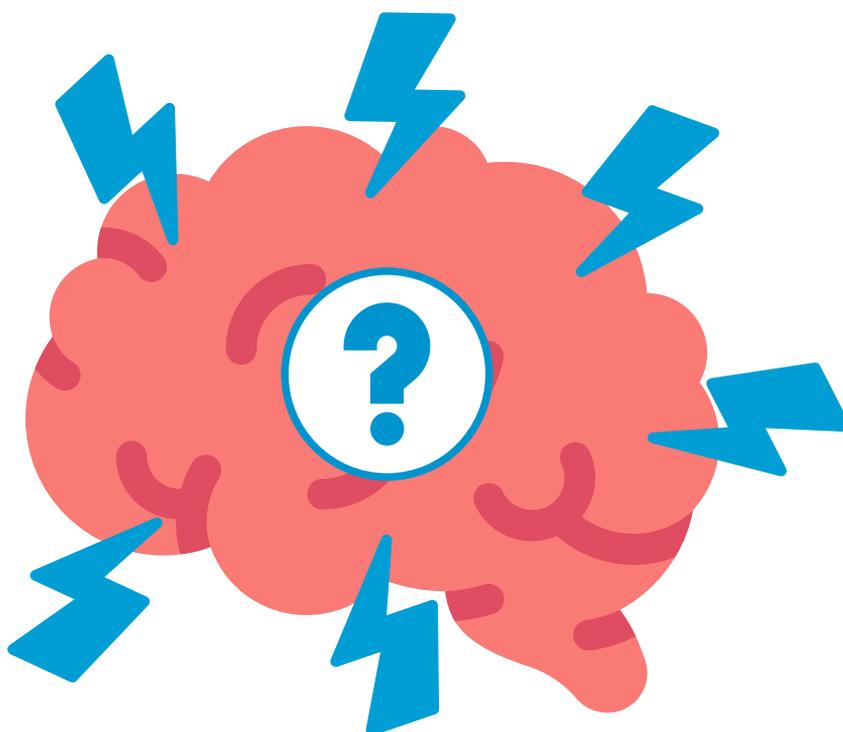


**Recommendation  
based on clinical experience**

# What is epilepsy?

Epilepsy is a condition that affects the brain. It causes a person to have repeated seizures because of a sudden burst of electrical activity in their brain. This stops their brain from working in the usual way and causes the brain's messages to become mixed up. Seizures can involve a sudden burst of electrical activity on just one side of the brain (known as focal seizures) or they can involve a sudden burst of electrical activity on both sides of the brain (generalised seizures). Most seizures last less than 5 minutes, and will stop on their own.

There are over 40 different 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](http://www.epilepsyscotland.org.uk/about-epilepsy/epilepsy-and-seizures-explained)



### Common seizure triggers

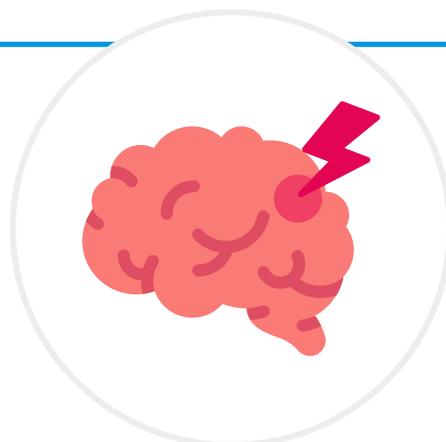
For some people, seizures are triggered by events such as the ones below. Not every person has a seizure trigger and seizures can happen for no obvious reason.



#### Information

Common seizure triggers include:

- feeling unwell, running a fever
- forgetting to take medication
- lack of sleep
- temperature extremes
- 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 (healthcare professionals can explain this to you).



# How do healthcare professionals find out if my child has epilepsy?

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

This is why they may ask you several times to repeat your child's history of seizures. It may feel like they have not read your child's notes, but they are checking to see if there is any new information, or if there have been any changes in your child's condition. Even small details can tell them a lot.



## Information

Here are some questions that healthcare professionals might ask you, to help them make a diagnosis:

- What was your child doing and what happened just before and at the time the seizure started?
- Were there any symptoms that seemed like a warning, and what were they?
- What was the sequence and timing of events?
- What happened as the seizure ended?
- What was your child like after the seizure and for how long?
- Were they:
  - aware during the event
  - unresponsive
  - staring.
- Did they have:
  - open or closed eyes
  - eyelid flutter
  - eyeball jerking or staring to one side (in what direction?)
  - facial twitching
  - body stiffness
  - chaotic jerking of legs and arms
  - rhythmic jerking of legs and arms
  - paleness, or a blue tinge to their skin, lips, fingers or toes.
- If there was more than one seizure, how similar were they?

## How do healthcare professionals find out if my child has epilepsy? continued

Healthcare professionals will base their diagnosis on what you tell them about your child's seizures.



### Recommendation based on clinical experience

Epilepsy should be diagnosed by an epilepsy specialist.

## How can I help healthcare professionals to find out what type of epilepsy my child has?



### Recommendation based on clinical experience

Although it may seem strange and not easy, filming your child during seizures is very helpful. It can give your child's epilepsy specialist useful information that can help in diagnosis and treatment. You could film on a smart phone or tablet.

## What tests might my child have, to help professionals find out what type of epilepsy it is?

Your child may need a number of investigations or tests as there is no single way of diagnosing epilepsy.

Test	How it can help
 Brain wave test (electroencephalogram (EEG))	Looks at the electrical activity in your child's brain
 Brain scan (magnetic resonance imaging (MRI))	Looks at the structure of your child's brain
 Blood test	Looks at changes in your child's <b>genes</b> that may explain why they have epilepsy and to see if any other conditions may be causing their symptoms

### Genes

Genes determine your characteristics, for example your eye colour. For most characteristics, we inherit one gene from our mother and one from our father.

Tests are usually done at a hospital outpatient clinic during the day. The results are usually discussed at your child's next specialist epilepsy doctor appointment.

### EEG

In all brain wave tests, small wires are attached to your child's scalp with gel or glue. The test is painless. The wires are removed at the end of the test.

A standard EEG takes about 20-30 minutes.

Ambulatory EEG - wires are put on your child in hospital and then your child goes home for 24 hours.

Sleep EEG - this test is done when your child is asleep. You may be asked to keep your child awake the night before the test to make sure they sleep during the test. This is called sleep deprivation.



Videotelemetry EEG - your child will be admitted to hospital for continuous EEG monitoring alongside video recording. This may last for several hours to days if required.



### Recommendation based on clinical experience

You should be given an explanation of what each test involves. The type of brain wave test your child will have depends on:

- what type of epilepsy the specialist thinks your child may have
- what time of the day your child has their seizures.



### Recommendation based on the research evidence

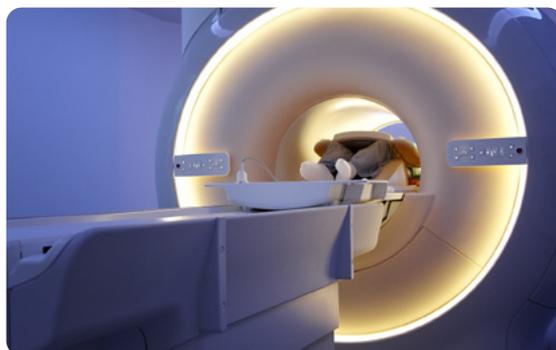
If your child's standard EEG is normal, professionals will consider doing an ambulatory EEG or sleep-recorded EEG. If a sleep EEG is needed, professionals may give your child a medicine called melatonin to help them sleep.

## MRI



### Recommendation based on the research evidence

If your child has epilepsy starting on one side of their brain and is not responding to medication, an MRI scan can be done. If a standard MRI scan does not detect anything unusual, a more detailed MRI scan may be needed.



## Blood tests



### Recommendation based on clinical experience

Sometimes if no causes are found for your child's epilepsy, blood tests for genetic testing may be offered. This should be discussed fully by your child's epilepsy specialist and explained before the test is done. Reasons for referring your child to a specialist doctor in genetics include:

- first seen to have epilepsy as a baby or infant
- learning difficulty or disability
- problems with co-ordination and movement
- blood tests that are not normal
- brain scan results that are not normal
- medications have not helped.

## What information should I get when my child is diagnosed?



### Recommendation based on clinical experience

You should be given information in a way that suits you and your child. You should be given enough time to ask any questions you may have. Information should be repeated over time, for example at follow-up appointments to make sure you understand. You should also be given information to take home in a style that suits you and your child, for example a leaflet.



### Information

Your child's healthcare professional should talk to you and your child about:

- what epilepsy is and different seizure types
- possible causes of your child's epilepsy, if known
- possible further tests that could be done
- what the future may hold for you and your child
- treatment options for your child
- safety and first aid
- risks, including death (see page 18)
- who will manage your child's epilepsy - for example reviews should be with your child's epilepsy specialist
- how epilepsy affects people's lives
- how to help others understand epilepsy
- possible learning problems, including with their memory and attention
- emotional wellbeing (mood and anxiety)
- concerns about behaviour
- concerns about development
- how to access further information
- availability of advice and support from professionals in health, social care, education and voluntary organisations.



It's all new to parents and I don't think there is enough information given. I don't think I was prepared for the journey ahead. It's important to ask for information to take away.



### Recommendation based on the research evidence

At or around the time of diagnosis, you should be given information (both face-to-face and written) about risks and safety to help your child live with this long-term condition. Information you are given should include:

- the risk factors of sudden unexpected death in epilepsy (SUDEP)
- action that can be taken to reduce risks (see pages 18-22)
- where to find further information and support (see pages 32-36).

“ There is nothing worse than losing a child but to feel that [our son] did not have all the information he needed to make informed decisions makes it especially cruel.

See pages 18-22 for more information on the risks that come with epilepsy and what can help reduce them.

# What treatments are available?

## Medication

The most common treatment for epilepsy is anti-epileptic medication. Anti-epileptic medication aims to stop or reduce the number of seizures your child has. What type of medication your child is given depends on:

- their age
- the type of seizures and epilepsy they have
- gender
- how well they tolerate the medicine.

Medication should be fully discussed by your child's epilepsy specialist before being prescribed. Some medications are specialised to the type of epilepsy they are trying to treat. These medications may require specialist monitoring through a blood test.

A range of medicines are available that can help reduce seizures. Your child will be able to try different medicines or a combination of them to see what works best.



### Recommendation based on the research evidence

Medication should be prescribed by a specialist epilepsy doctor and this may be in a specialist epilepsy service at hospital. The service may not be at your local hospital.



### Recommendation based on clinical experience

Some medications affect females only and should only be used if other medications are not effective. Sodium valproate, for example, should not be used in girls who could become pregnant. It can harm an unborn child.

## What treatments are available? continued

### What if my child's epilepsy does not respond to medication?

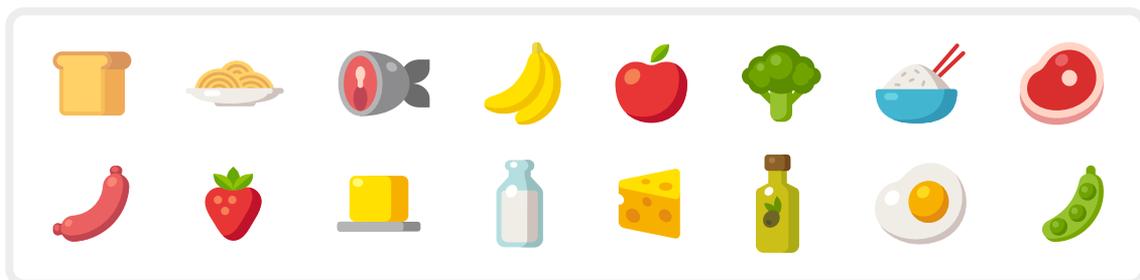
Sometimes, if children have complex epilepsy that does not respond to medication, other treatment options need to be explored and discussed with your child's specialist epilepsy team. These treatments may include a ketogenic diet, epilepsy surgery and vagus nerve stimulation.

### Ketogenic diet

The ketogenic diet is a medical diet that is **high in fat** but **low in carbohydrate**. Examples of fat are foods like oil, butter and cream. Examples of carbohydrate are foods like bread, pasta, fruit and vegetables. Carbohydrates provide the 'fuel' for our brain and body, which is commonly known as glucose.

By replacing most of the carbohydrates with fat, the body is forced to burn the fat to get energy and this switch in 'fuel' makes ketones. Ketones can reduce or even stop seizures. This is also why the diet is called ketogenic.

A ketogenic diet can be effective in managing epilepsy that does not respond to medication, and it must be managed by a qualified ketogenic dietitian in partnership with your medical team.



#### Recommendation based on the research evidence

A ketogenic diet should be offered if your child's epilepsy has not responded to:

- treatment with medication (known as drug-resistant epilepsy), or
- two antiepileptic medications.



### Recommendation based on the research evidence

A ketogenic diet should be started as soon as possible after diagnosis and should be tried for at least 3 months to see if it is helping. Healthcare professionals will discuss the risks and benefits with you and your child to decide if it should be continued. Usually children stay on the diet for up to 2 years but this is reviewed at each visit with the **neurologist** and dietitian. It can be stopped before 2 years if the diet doesn't seem to be helping.

**Neurologist** - a doctor who specialises in diagnosing and treating conditions of the brain and nervous system.



### Recommendation based on clinical experience

If successful, a ketogenic diet should be continued into adulthood (lifelong treatment) in children with epilepsy that does not respond to medication or certain rare types of epilepsy.

## Epilepsy surgery

For children and young people whose epilepsy does not respond to medication, there may be an option for epilepsy brain surgery. There is a way of assessing whether your child may be suitable for surgery and this would be discussed between you and your child's epilepsy specialist.

The main aim of epilepsy surgery is to stop or reduce the number of seizures. Other benefits may include better quality of life.



### Recommendation based on the research evidence

If your child's epilepsy has not responded to two or more anti-epilepsy medications, they may be referred for assessment to find out if surgery would be an option. If so, this should take place as soon as possible.



### Recommendation based on clinical experience

Children who have been identified as suitable for surgery should be referred to an epilepsy surgery programme.

The Scottish Paediatric Epilepsy Surgery Service holds frequent referral meetings around Scotland. Your child's epilepsy specialist will discuss your child's condition with a large team of other epilepsy specialists. If the whole team agrees that surgery is an option, you will be invited to meet the epilepsy surgery team.

## Vagus nerve stimulation



### Information

Vagus nerve stimulation is a treatment that involves electrical stimulation of the vagus nerve (long nerve that stretches from the brain all the way down through the body). Your child's epilepsy specialist will discuss this in detail with you if it is a suitable treatment for your child.

You can read more about it here [www.epilepsy.org.uk/info/treatment/vns-vagus-nerve-stimulation](http://www.epilepsy.org.uk/info/treatment/vns-vagus-nerve-stimulation)

If your child's epilepsy has not responded to medication or any other treatments, their epilepsy specialist may discuss the possibility of vagus nerve stimulation with you.



### Recommendation based on the research evidence

Vagus nerve stimulation could be considered because it may reduce the number and intensity of seizures over time.

# Epilepsy deaths – what do I need to know and can I help reduce risks?

Over 600,000 people (children and adults) in the UK have epilepsy. Sadly, 21 people (adults and children) die each week because of their epilepsy. This can be worrying but it's important to know about it. Being aware of the risks linked to epilepsy means you can take positive steps to reduce them.

As with other long-term health conditions like asthma or diabetes, it's important to understand the risks and discuss them regularly with your child's epilepsy team, as often things can be done to manage or reduce them.

## Why do some people with epilepsy die early?

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

- complications from seizures
- seizures that last too long (status epilepticus)
- accidents or drowning
- suicides
- sudden unexpected death in epilepsy (SUDEP)
- other conditions that may have caused their epilepsy such as a brain tumour or other neurological conditions.



### Information

Although it can be difficult, talking to your child about risks and encouraging them to take responsibility (where possible) is very important for when they gain independence.

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

SUDEP is when someone with epilepsy dies and no other cause of death can be found. SUDEP is rare. It happens in about 1 in 1,000 people with epilepsy (1 in 4,500 children) each year in the UK. The cause is not yet known.

Researchers have found key risk factors that can increase the risk of SUDEP. In many cases, positive things can be done to reduce these risks (see pages 20–22).

### Recommendation based on clinical experience

Risks (including SUDEP) and safety issues should be discussed regularly with you and your child at follow-up visits with healthcare professionals.

### Recommendation based on clinical experience

If there is a risk of SUDEP, healthcare professionals should discuss the advantages and disadvantages of using listening devices, night-time supervision or sharing the same bedroom with your child.

The risk of SUDEP increases if children have a more complex, rare form of epilepsy. This is something you should be aware of and discuss with your healthcare professional who can discuss your child's individual level of risk (which varies between people with epilepsy).

## What are the risk factors for SUDEP?

The strongest risk factor for SUDEP is having frequent convulsive seizures (a type of seizure affecting the whole body). The more frequent these seizures, the higher the risk of SUDEP.

Other risk factors include:



Seizures that happen one after another



Night-time seizures and seizures that happen during sleep



Seizures that are difficult to control with treatment



Seizures that last more than five minutes



Not taking anti-epileptic medication (AEDs) regularly as prescribed, or stopping AEDs completely



Other significant long-term health conditions

It is important to remember that epilepsy risks are very individual, can change over time, and should be discussed with your child's healthcare professionals.

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

## Positive steps you and your child can take to live safely and reduce epilepsy risks (including risks linked to SUDEP).

### Care



Attend regular appointments with your child's healthcare professional. They should have a regular epilepsy review (even when moving from child to adult care).

Encourage your child to take medication regularly.



Take extra care near water, including swimming and bathing.

Encourage your child to choose showers rather than baths.

### Lifestyle



Your child should carry key information about their epilepsy with them.

A medical ID bracelet or card could be helpful in case they have a seizure when they are on their own.

Put emergency contact details into any mobile phone they have.



Talk to your child's healthcare professional about such concerns as:

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

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

## Positive steps you and your child can take to live safely and reduce epilepsy risks (including risks linked to SUDEP).

### Seizures



Identify and try to avoid seizure triggers.



Keep a seizure record to help spot patterns and changes.



If possible, your child should avoid sleeping on their stomach.



If your child has seizures at night or during sleep, consider using a monitor to alert you (for example an alarm device or audio monitor such as a baby monitor).

Your child's healthcare professional can discuss this and advise on options.

#### Information

Be open and encourage your child to be open about their epilepsy. Let all those around your child know. Tell them what to do or not to do in the event of a seizure and know when to call emergency services.

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 can affect brain function and development. Children and young people with epilepsy are at greater risk of having conditions that affect development.

These conditions are known as **neurodevelopmental disorders**.



## Recommendation based on clinical experience

It is important for your child's epilepsy specialist to monitor and assess their general development as well as manage their epilepsy. This should include asking questions about their social skills, play, language, learning, attention and behaviour.

## Neurodevelopment disorders

These are conditions that relate to the development of the brain and nervous system. They can affect language and social skills, behaviour, learning and thinking skills. The conditions include **autism spectrum disorder (ASD)** and **attention deficit hyperactivity disorder (ADHD)** (see page 24).

## What happens at a developmental assessment?

- Your child's epilepsy specialist will find out about any difficulties your child is having, how these have changed over time and your family situation. This is called history taking.
- The specialist will gather information about your child's strengths and difficulties in different settings, including home and school.
- The specialist may use questionnaires to do this.



### Recommendation based on clinical experience

The same questionnaires can be used to gather information about symptoms of autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD) in children who have epilepsy and those who don't.

Questionnaires should only be used alongside a detailed description of your child's development and history taking.



### Recommendation based on the research evidence

Because symptoms of ASD can vary, specialist assessment should be done by healthcare professionals from different professional backgrounds (called a multidisciplinary team). This is because they are skilled in different types of assessment, for example speech and language.

Therapists will assess language and communication skills. Psychologists and psychiatrists will assess behaviour. The team should have experience of assessing children and young people with ASD.

#### ASD

A lifelong developmental disability affecting social and communication skills and other behaviours. It describes a group of similar conditions including autism and Asperger's.

#### ADHD

The core symptoms of ADHD are difficulty concentrating, hyperactivity, and acting impulsively (such as doing things without thinking about the consequences). Sometimes they may only have difficulty with paying attention (this is called 'inattentive subtype' or attention deficit disorder).



### Recommendation based on clinical experience

If your child's epilepsy specialist believes your child has difficulties with attention or concentration, they may ask for a specialist assessment of ADHD symptoms. This assessment should be done by a professional with specialist skills in assessing ADHD. They may be your local Child and Adolescent Mental Health Services (CAMHS) or a paediatrician who specialises in ADHD.

You can read more about assessing and managing ASD or ADHD in our booklet for parents and carers [www.sign.ac.uk/media/1166/pat145\\_parents\\_and\\_carers.pdf](http://www.sign.ac.uk/media/1166/pat145_parents_and_carers.pdf)

## How will my child's learning ability be assessed?

Some children and young people with epilepsy can have difficulties with learning and thinking skills. These skills include memory, attention, the language and skills involved in problem solving, and controlling thoughts and behaviours. Sometimes a child can have these difficulties even when their epilepsy is well controlled and they are not having seizures.



### Recommendation based on clinical experience

It is important for your child's epilepsy specialist to ask about their learning and thinking skills at review appointments. They will find out whether they have any difficulties, whether this has changed over time and what help your child may be getting at school.

They may ask your child's school for more information including school reports, or ask about exam results or school-based assessments.



### Recommendation based on clinical experience

If there are signs that your child is having difficulties with learning or thinking skills, their epilepsy specialist should contact education staff (teachers, learning support staff or guidance teacher if they are at high school) to find out more about these concerns and what support is already in place.

If there are signs of more severe difficulties with learning or these are not well understood by the school, your child's epilepsy specialist should refer your child for a specialist assessment (called a **neuropsychological assessment**).

### Neuropsychological assessment

This is a way of measuring someone's ability to carry out mental tasks or thinking skills (including memory, attention, talking and language skills, planning and problem-solving skills). This provides information about a person's strengths and difficulties. Assessment can involve completing different tasks, answering questions, and pencil-and-paper activities.

## What happens if my child is diagnosed with a neurodevelopmental disorder?

If a diagnosis of ASD or ADHD is made, your child's specialist multidisciplinary team should discuss what is available to help. You should be given information about ASD or ADHD and how it may affect your child. Learning about what support is available can help you and your child cope with their condition.



### Recommendation based on the research evidence

The medication methylphenidate can be considered as a treatment for children and young people with epilepsy to manage ADHD symptoms.



### Recommendation based on clinical experience

Before starting methylphenidate, healthcare professionals should keep a careful record of your child's seizure activity (how often they have seizures, how severe they are). They should continue to monitor this once your child has started taking the medication. This will help to check for any changes in seizures or other physical or emotional side effects. This information should be written down in a seizure log or diary.

## What should happen if there are concerns about my child's mood or behaviour?

Feelings of low mood and increased worrying are common in people who have long-term health conditions such as epilepsy. Studies have shown that children and young people with epilepsy may be at increased risk of depression or anxiety. It is important to get professional help when those symptoms continue for long periods of time or affect a child's way of life. Depression and anxiety can increase the difficulty of going to school, seeing friends and taking part in social and leisure activities. So it is important to seek help as soon as possible.



### Recommendation based on the research evidence

Your child's healthcare professional should ask about your child's depression and anxiety symptoms at their review appointments.



We always encourage [our daughter] to talk to us about how she feels. We do keep a close eye on her mental health, some days are worse than others.



### Recommendation based on clinical experience

When finding out about your child's mood, healthcare professionals should consider using questionnaires that ask about symptoms of depression and anxiety. Some questionnaires will be completed by you but older children may complete these themselves.

The same questionnaires that are used to look for depression and anxiety in children and young people who don't have epilepsy can also be used with those who do.

If questionnaires show that your child may be at risk of depression or anxiety, your child's healthcare professional should consider a referral to specialist mental health services for further assessment. This may be your local Child and Adolescent Mental Health Service (CAMHS).



### Recommendation based on the research evidence

**Cognitive behavioural therapy (CBT)** should be considered to manage depression in children and young people who also have epilepsy.



### Recommendation based on the research evidence

For older children with more severe depression, an antidepressant medication may be considered in addition to psychological therapy.

### **Cognitive behavioural therapy (CBT)**

This is a type of psychological therapy (also called 'talking therapy') that has been found to be effective in treating depression in older children and young people.

# What should happen when my child moves from child to adult services?

It's called 'transition' when your child moves from child to adult services. Transition leads to a change from you, as their parent or carer, managing their epilepsy to your child taking responsibility for it. This encourages them to become independent.

It is important that your child knows the best ways to gain independence but also stay safe.

## **Medication side effects**

Encourage your child to be honest with their healthcare professional to help them find a balance between controlling seizures and minimising any side effects.

## **Taking medication regularly**

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

## **Alcohol and use of street drugs**

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

## **Driving a vehicle**

To do this, it is vital to have seizures under control.

## **Sex and contraception**

This can be discussed with your child's healthcare professional. It's important that they are honest and ask questions, so they can make informed choices.

Gaining full independence may be hard for those with learning disability or exceptional healthcare needs. Transition is also important in empowering families to manage issues such as capacity (the ability to make informed decisions) and consent (parental legal guardianship). If you become your child's legal guardian, this gives you legal rights to make informed decisions about your child beyond the age of 16 years in Scotland.



### Recommendation based on the research evidence

Transition should be approached in a planned, structured and educational way that involves you and your child. Epilepsy specialist nurses have an important role in it. The process will vary in different health board areas but could include:

- educating both you and your child on epilepsy
- educating your child about lifestyle and self management
- offering gender-suitable advice to your child, for example about taking contraception while on epilepsy medication.
- organising one-to-one meetings with a healthcare professional/specialist nurse
- directing your child to web-based resources for advice about transition and their specific condition
- explaining to you and your child the differences between adult and children's care.

Ideally, transition will:

- be suited to your child's needs and preferences
- be co-ordinated between children's and adult services
- include regular reviews of how well services are working for your child.



### Information

When your child is moving from child to adult services their epilepsy specialist should tell you:

- what will happen
- when it will happen
- who will be involved and support the transition, for example an epilepsy nurse specialist.



**Recommendation based on clinical experience**

Ideally, transition will be followed up jointly by child and adult health services over a longer time period while your child is within adult healthcare services.



**Recommendation based on clinical experience**

Ideally, transition would be reviewed before and afterwards to make sure it works well for your child.

# Where can I find out more information?

If you haven't found what you're looking for, here are some further sources of information. The organisations we have listed may be able to answer your questions and offer support.



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## National organisations

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### NHS 24

[www.nhs24.scot](http://www.nhs24.scot)

Freephone 111

NHS 24 is an online and out-of-hours phone service providing the Scottish people with access to health advice and information 24 hours a day, 365 days a year.

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### NHS Inform

[www.nhsinform.scot](http://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.

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### Epilepsy Action

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

Helpline: 0808 800 5050

Email: [helpline@epilepsy.org.uk](mailto:helpline@epilepsy.org.uk)

The aim of Epilepsy Action is to raise awareness about epilepsy, and to bring about permanent change for the social and medical benefit of people with epilepsy.

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



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## National organisations continued

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### Epilepsy Connections

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

Phone: 0141 248 4125

Email: [epilepsyconnections.org.uk](mailto: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. Information and advice is available in English, Urdu, Punjabi, Cantonese and Polish.

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### Epilepsy Scotland

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

Helpline: 0808 800 2200

Phone (office): 0141 427 4911

Email: [enquiries@epilepsyscotland.org.uk](mailto:enquiries@epilepsyscotland.org.uk)

Epilepsy Scotland is the national organisation representing people living with epilepsy in Scotland. Services include Lighthouse Outreach, Community Support and Activity Groups; youth groups and social work support; campaigning and lobbying; policy; and the provision of information and training. There is also a very experienced contact team who provide guidance, support and information on the telephone, via social media, email or text and in over 170 languages via a telephone interpretation service.

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### Epilepsy Society

[epilepsysociety.org.uk](http://epilepsysociety.org.uk)

Helpline: 01494 601400

Email: [enquiries@epilepsysociety.org.uk](mailto:enquiries@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.

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## National organisations continued

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### Matthew's Friends

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

Phone: 01342 836571

Email: [enq@matthewsfriends.org](mailto:enq@matthewsfriends.org)

Matthew's Friends are specialists in medical ketogenic dietary therapies for drug-resistant epilepsy and other neurological and metabolic conditions. They cover all aspects of ketogenic therapy for children and adults, providing support services, training and education for families and professionals, funding for clinical research as well as funding for NHS posts and ketogenic teams. They work with the European Reference network for rare and complex epilepsies and the international consensus group for ketogenic therapy.

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### Quarriers Epilepsy Services (Scottish Epilepsy Services and Epilepsy Fieldwork Services)

[www.quarriers.org.uk/epilepsy](http://www.quarriers.org.uk/epilepsy)

Phone: 0141 445 7750

Email: [Scottishepilepsycentre@quarriers.org.uk](mailto:Scottishepilepsycentre@quarriers.org.uk)

The William Quarrier Scottish Epilepsy Centre is an independent hospital run by Quarriers charity. It offers a multidisciplinary inpatient assessment and treatment to people with complex diagnostic and treatment needs, as well as outpatient and telemedicine clinics.

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### SUDEP Action

[sudep.org](http://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.



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## National organisations continued

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### The Daisy Garland

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

Phone: 01803 847 999

Email: [thedaisygarland@btinternet.com](mailto:thedaisygarland@btinternet.com)

The Daisy Garland is a family-run, national, UK-registered charity. Their aim is to offer help and support to those whose lives are touched by drug-resistant epilepsy.

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### Young Epilepsy

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

Helpline: 01342 831342 open Monday–Friday, 9am to 3pm

Phone (office): 01342 832243 open Monday–Friday, 8.30am to 5pm

Email: [info@youngpilepsy.org.uk](mailto:info@youngpilepsy.org.uk)

Young Epilepsy is a UK charity that provides diagnosis, assessment and rehabilitation for children and young people with epilepsy. Its specialist services include a school, college and residential services providing education and healthcare. The charity also provides a range of support and information for parents, children and young people, as well as training for professionals.



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## Useful publications

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

[www.sign.ac.uk](http://www.sign.ac.uk)

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**SUDEP: What you need to know, parent and carer guide**

[www.sudep.org/sites/default/files/sudep\\_roll\\_fold\\_lo\\_0.pdf](http://www.sudep.org/sites/default/files/sudep_roll_fold_lo_0.pdf)

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## Useful video



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### Muir Maxwell Epilepsy Centre – Me and My Epilepsy

[www.youtube.com/watch?v=MO7xXL2ZXP8](https://www.youtube.com/watch?v=MO7xXL2ZXP8)

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## Websites



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### Citizens Advice Scotland

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

The Citizens Advice Bureau (CAB) can give free, confidential, impartial and independent advice and information on a wide range of subjects: benefits, debt and money advice, consumer issues, work-related problems and housing.

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### Scottish Paediatric Epilepsy network (SPEN)

[www.spn.scot.nhs.uk](http://www.spn.scot.nhs.uk)

The Scottish Paediatric Epilepsy Network (SPEN) is a nationally managed clinical network. SPEN brings together people involved in paediatric epilepsy from all over Scotland to agree the way forward for epilepsy services. The SPEN membership includes: patients, parents and carers, paediatric neurologists, epilepsy nurse specialists, paediatricians, voluntary sector organisations, neurophysiologists, GPs, dieticians, NHS managers, social workers.

The aims of SPEN are:

- to promote the delivery of high-quality care to children and adolescents with epilepsy in Scotland
- to be patient centred and deliver seamless care between organisations and professional groups involved in epilepsy care
- to contribute to the setting of standards for epilepsy care and to audit the care provided
- ensure equity of services for all children and young people with epilepsy wherever they live in Scotland.

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

# 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](http://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](mailto:sign@sign.ac.uk)



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