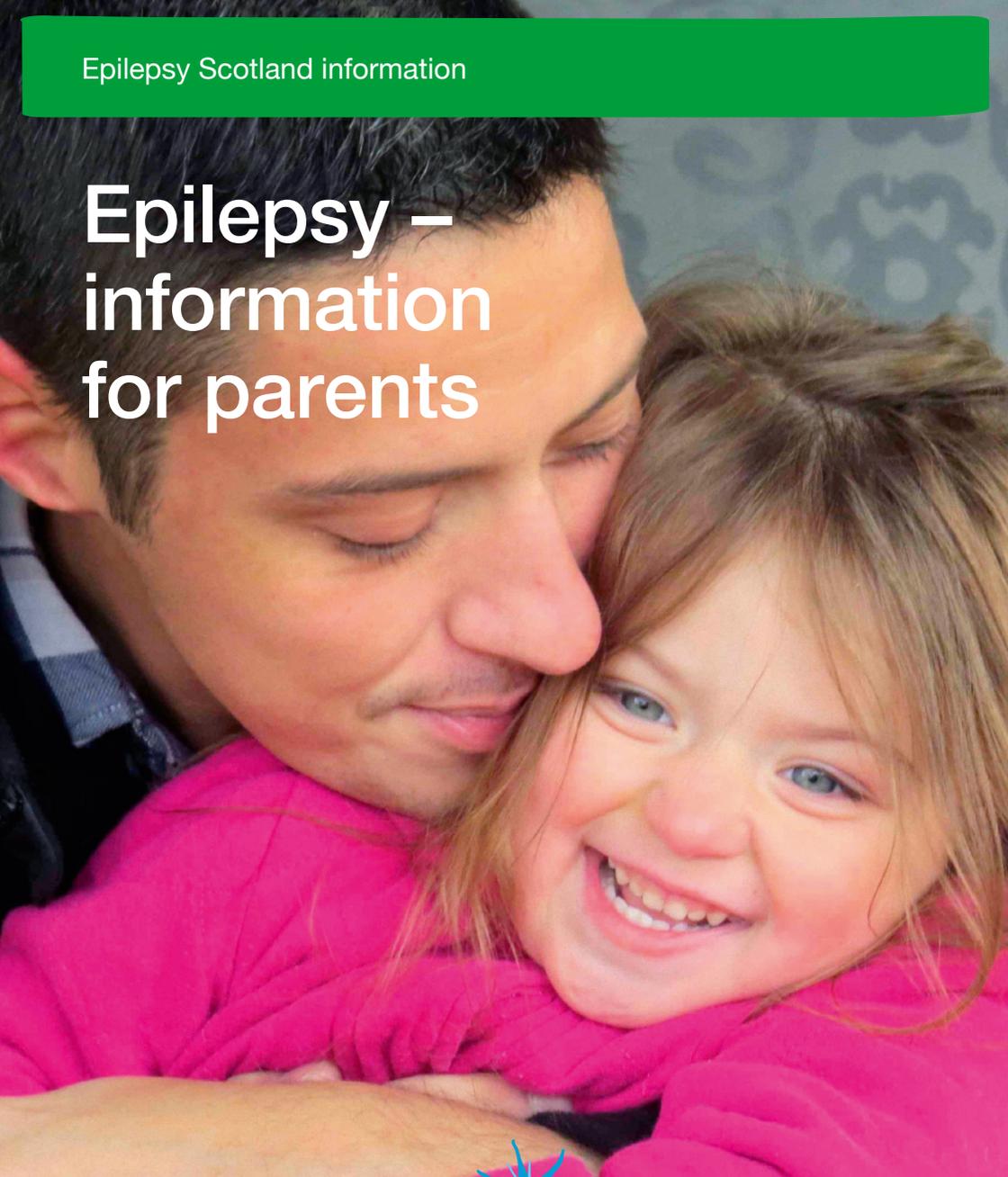


Epilepsy Scotland information

# Epilepsy – information for parents



  
epilepsy scotland



With thanks to the Glasgow paediatric epilepsy nursing team for their valued input and advice - October 2021

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## About this publication

This publication is for parents who are new to epilepsy. It covers general information on epilepsy and how it may affect a child. Your child's specialist and epilepsy specialist nurse will work with your family to get your child's epilepsy under control. If you have any questions about your child's medical care, always speak to your child's medical team.

You can also phone our freephone helpline on 0808 800 2200 if you have any questions, or just want to talk.



# Understanding epilepsy and seizures

There is no cure for epilepsy, but in around two thirds of children diagnosed with epilepsy anti-seizure medication will provide good seizure control. Most children will grow out of their epilepsy by the time they reach adulthood depending on the type and cause of their epilepsy. Your child's specialist may be able to you give you more detailed information on what to expect.

## How common is epilepsy?

Around 55,000 adults, young people and children in Scotland have epilepsy, an estimated 4,200 of which are children and young people under 18<sup>1</sup>.

## What is epilepsy?

Epilepsy is a neurological condition which affects the brain. It can affect anyone at any age, but children and young people are more likely to develop epilepsy. Epilepsy is defined as the tendency to have more than one seizure which starts in the brain.

The word epilepsy is often used as an umbrella term for many different types of epilepsies, including epilepsy syndromes.

Approximately 1 in 20 people will have a one-off seizure during their lifetime. This does not necessarily mean they have epilepsy. There could be many reasons for this such as having a high temperature.

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1 SIGN, No 159 Epilepsies in children and young people: investigative procedures and management, May 2021

# Understanding epilepsy and seizures

## What causes epilepsy?

A combination of brain scans and modern genetic testing can identify a cause for epilepsy in a large proportion of children, particularly in those who have their first seizures in early childhood. Some genetic causes of epilepsy are inherited, and others arise as a result of a new genetic change in the child. Epilepsy can also occur if the brain has been damaged due to trauma, infection (including meningitis), or a stroke.

## What is a seizure?

An epileptic seizure is best explained as a temporary disruption to the brain's electrical activity. Billions of brain cells pass messages to each other via electrical and chemical signals. If there is too much electrical activity, the brain mixes up messages resulting in a seizure.

## What does a seizure look like?

There are many different types of seizures. What they look like will depend on where in the brain the seizure starts. Sometimes a seizure can start in one part of the brain and spread to another part, or across the whole brain. How often seizures happen, how long they last and what happens before or after a seizure differs from child to child.



Some seizures are obvious, the child suddenly falls down and starts jerking. Others are less visible and only someone who knows a child well may notice the seizure. This could look like an unexpected brief change in behaviour, repetitive movements or staring into space as if in a daydream. Sometimes, the seizure can be so subtle that not even a parent may notice.

Your child's specialist will tell you what type of seizure your child has. Children can have more than one type of seizure. Most seizures are self-limiting and stop on their own.

## Main types of seizures

A seizure can be **focal** or **generalised**. A focal seizure affects just one part of the brain, whereas a generalised seizure affects the whole of the brain.

### Focal (partial) seizures

Focal seizures start and remain in one part of the brain and can be the result of a brain injury from accidents, an infection or malformation of the brain. However, it is often not possible to identify a cause for this type of seizure.

A seizure can sometimes start in one part of the brain and then spread across the whole of the brain. This is called a 'focal to bilateral tonic-clonic seizure' (or 'secondary generalised seizure').

# Understanding epilepsy and seizures

What a focal seizure looks like depends on the area of the affected brain:

**Focal aware seizure:** The child may be aware of unusual sensations, movements (such as an arm twitching), feelings or seeing things. They may also talk about feeling ‘dreamy’ or sick or show strong emotions such as anger or fear. The child remains fully conscious during this kind of seizure.

**Focal seizure with impaired awareness:** The child may appear confused or lose their sense of time. They are usually unaware of what is happening around them. The child may make repetitive movements or display unusual behaviour such as lip smacking, pulling at clothes, speaking strangely, or moving aimlessly around a room. There will be some loss of, or change in, consciousness.

## Generalised seizures

These seizures affect the whole brain:

**Tonic–clonic seizure:** This type of seizure can start with a cry. The child suddenly becomes stiff (tonic phase), falls and becomes unresponsive. Legs and arms start jerking (the clonic phase) and breathing may become noisy and shallow and/or colour draining from the lips.

The child may also make grunting noises, bite their tongue or cheek, or lose control of their bladder. The jerking usually stops after a couple of minutes and the child slowly comes round. They may feel groggy and complain of a headache. Most children want to sleep afterwards. These seizures used to be known as ‘grand mal’.

**Absence seizure:** This is a brief period of the child being unaware of what is happening and appears as a blank stare for a few seconds, remaining unresponsive to speech and touch, then continuing with activities. The child's posture may slightly change. These seizures can occur many times a day and can be confused with daydreaming. Girls tend to be more affected by this type of seizure than boys. An absence seizure used to be known as 'petit mal'.

Absence seizures can be **typical or atypical**: A typical absence seizure usually means an abrupt stare which lasts for approximately five to ten seconds with immediate recovery. An atypical absence seizure usually lasts longer, and the child often cannot immediately continue with what they were saying before it. There may be a change in muscle tone with a slight nodding of the head.

**Tonic seizure:** Muscles suddenly stiffen, the child will usually fall backwards but there is no jerking. The child will be unresponsive. Recovery from this type of seizure tends to be quick.



# Understanding epilepsy and seizures

**Atonic seizure:** The body very suddenly becomes limp because of a sudden loss of muscle tone and the child falls immediately to the ground, unable to put out hands to break the fall. These seizures are often called ‘drop attacks’ and recovery is usually quick.

**Myoclonic seizure:** These seizures often look like an electric shock with an abrupt, sudden jerk of the arms, head and sometimes the whole body. These seizures are most common in the morning, just after waking, or when the child is tired, and can occur in clusters.



# How is epilepsy diagnosed?

After a suspected first seizure, your child will usually be seen by their GP or by A&E at your local hospital.

A detailed account of what you observed before, during and after the suspected seizure, including a mobile phone recording of the episode, can help with a diagnosis. Write down everything you observed while it is still fresh in your mind.

Videos of seizures can be really helpful to your child's epilepsy specialist team and can speed up diagnosis and treatment.

You can use a secure and free NHS video sharing platform called vCreate Neuro, which allows you to directly upload any videos of seizures and share with your child's medical team from any device. Your child's epilepsy specialist or specialist nurse will explain how to register and use the video platform.

Your child's GP or A&E doctor will also want to rule out other medical causes for the suspected seizure before your child is referred to an epilepsy specialist.



# How is epilepsy diagnosed?

## Appointment with a specialist

This is usually a paediatric neurologist or paediatrician with expertise in epilepsy at your hospital or nearest paediatric clinic. Children over 16 will usually be seen at an adult first seizure clinic.

The specialist will take your child's medical history and will ask detailed questions such as:



- Where was your child, what was your child doing just before the episode?
- What time of day was it?
- Was your child tired?
- Did your child have a fever or other illness?
- Did you notice a change in your child's mood before the episode, i.e. unusually quiet, anxious or excited?
- Did your child tell you they were feeling unwell?
- Did they mention anything else to you, such as an unusual smell or taste, or hearing something unusual?
- What happened during the episode?
- What happened afterwards?
- How long was it before your child felt well again?

## Testing for epilepsy

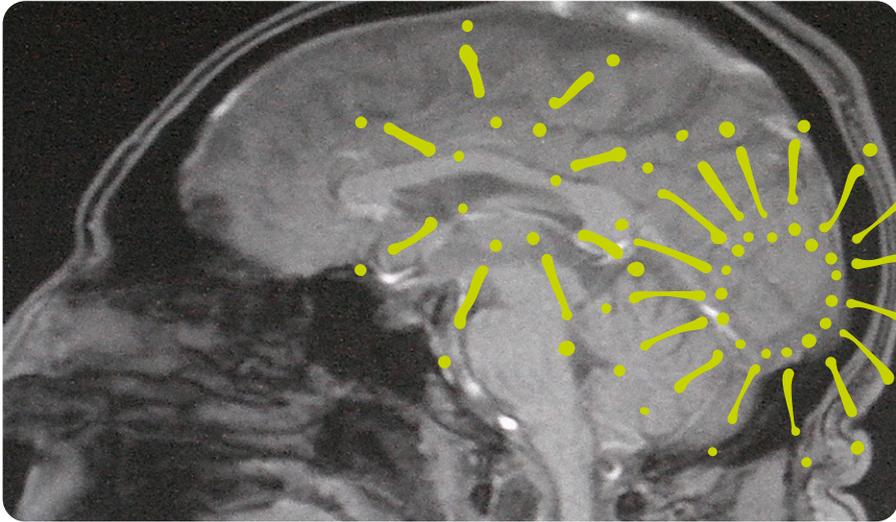
There is no single test to diagnose epilepsy. Your child's specialist will largely base a diagnosis on your description of what happened before, during and after the episode. Some of the following tests can sometimes be helpful to confirm a diagnosis and the possible type of epilepsy. Even if any or all of these tests come back negative, a diagnosis of epilepsy can still be made. None of these tests are painful.

**ECG (electrocardiogram):** An ECG test is sometimes done to rule out other causes of seizures, such as an irregular heartbeat.

**EEG (electroencephalogram):** This routine test can help with a diagnosis. It records the electrical activity in the brain and usually takes around 45 minutes. You may also be asked to keep your child awake in the run up to a sleep-deprived EEG, as tiredness can sometimes show up additional useful information on the recording. During video telemetry a camera records a suspected seizure while the EEG machine records the brain's electrical activity.



## How is epilepsy diagnosed?



**Brain scans:** These scans look at the structure of the brain to identify possible causes or type of epilepsy, or rule it out. A brain scan is not always necessary.

Some children will have an MRI (magnetic resonance imaging) scan, which is much more detailed than a CT scan (computed tomography/computer-assisted tomography), formerly known as a CAT scan

A brain scan will last approximately 15 to 35 minutes during which time the child needs to lie very still in an enclosed space. Children can often watch videos or listen to music during the scan to keep them calm and to help drown out the noise of the scanner.

## Not epilepsy

Other medical conditions can sometimes be confused with epilepsy, such as fainting, migraines or even breath-holding attacks, which are common with young children.

### **Non-epileptic seizures:**

These seizures usually have a psychological cause and should be managed by talking therapies. Non-epileptic seizures can look very similar to epileptic seizures to the untrained eye, and it sometimes takes a while for this to be diagnosed. These seizures are more common in teenagers and can also occur in children who also have epileptic seizures.

**Febrile seizures:** A high temperature can trigger a seizure in some young children, also known as febrile seizures. These common seizures are the same as epileptic seizures, but they are not classified as epilepsy. Most children who experience febrile seizures will never go on to develop epilepsy.



# Treating epilepsy

Treatment options will always aim to reduce or prevent seizures altogether. By far the most successful way to treat epilepsy is with anti-seizure medications.

## Anti-seizure medications (ASMs)

The aim is to reduce seizures with the smallest dose necessary and without causing any side effects.

ASMs come in many forms such as tablets, dispersible tablets, slow-release pills, liquid, capsules, sprinkle capsules and tiny granules making it easier for your child to take the medication.

ASMs should be taken exactly as prescribed, at around the same time each day. Missing a dose is more likely to increase seizures.

The medication's package can sometimes look different or have a different name when you pick up your child's prescription from the chemist, but they are the same medicine. With some ASMs it is important that your child always gets the same brand (name), with others it is less important. Your child's epilepsy specialist nurse will give you more information about your child's medication. If you are concerned about getting a different looking package or the drug has a different name, always speak to your child's GP or epilepsy specialist nurse.



## **What to do if you forget to give a tablet**

Do not automatically give your child a double dose next time. Do not stop giving the medication or change the dosage unless advised to do so by a medical professional.

Find out from your child's specialist or specialist nurse in advance what to do as this could be different for each medication. As a general rule, if your child only takes one tablet a day, give the dose as soon as you remember. If your child takes tablets twice a day, it is usual to only give the missed dose if you remember within four to six hours of when your child should have taken the medication. If this is longer, then your child's epilepsy specialist nurse may advise you to wait until the next dose is due.

## **What to do if you have given more than the usual dose**

If you have accidentally given your child more than the prescribed dose, phone your child's epilepsy specialist nurse, GP or NHS 24 on 111 outside clinic hours. The most likely effect of an overdose will be drowsiness.

## **What to do if your child has been sick**

If your child has been sick within an hour of taking their ASM, phone your child's epilepsy specialist nurse or NHS 24 on 111 outside clinic hours for advice.

As a general rule, if your child has been sick within an hour of taking their ASM, give another dose. However, if it is more than one hour, wait for the next scheduled dose.

# Treating epilepsy

## Side effects of ASMs

Side effects usually occur at the start of treatment or when changing to a different ASM but often improve over time. Common side effects include feeling sick, sleepiness, dizziness, headaches, or weight gain but this depends on the medication prescribed for your child. Your child's epilepsy specialist nurse will make you aware of what to look out for.

## Interaction with other drugs

Tell your child's specialist if your child takes any other prescribed or over-the-counter medication including vitamins, supplements, or herbal remedies. This is to ensure that the prescribed medication will not interfere with any other medications and vice versa.

## Are ASMs forever?

Your child's medical team will usually want to see your child seizure free for around two years before considering taking your child off their ASMs.

This should always be a clinical decision based on the type of epilepsy, the risk of seizures returning, how your child and you feel about this risk, and the best time to do this. For example, it might be better to delay coming off medication around exam times or around the time when an older child wants to apply for a provisional driving license.

## Other treatment options

For around one third of children, anti-seizure medication is not effective but there are other treatment options which may be suitable:

The **Ketogenic diet** is a medically supervised and prescription only diet high in fat with just enough protein and very low in carbohydrates. It works by burning fat for energy instead of carbohydrates which produces ketones. This state of 'ketosis' can have a positive effect on seizure control.

**Surgery** can be an option for a small number of children with medication resistant epilepsy. It is usually only considered as an option if the first two to three ASMs have been ineffective.

## Vagal Nerve Stimulator (VNS)

is a small device inserted under the left collar bone and connected to the left vagus nerve in the neck. It is programmed to send regular electrical impulses to the brain which can help reduce seizures.



# First aid for seizures

Seizure first aid will help to keep your child safe during and after a seizure.

## First aid for tonic-clonic seizures:

- Time the seizure from when it starts and how long it lasts
- Turn the child on their side during the seizure if possible, or once the jerking has stopped so that saliva can drain away
- Slide something soft under the child's head if possible
- Loosen tight clothing around the neck and remove glasses
- Once the jerking has stopped, tilt the head slightly backwards to support the child's airways
- Clear a space around the child and prevent others from crowding round
- Talk quietly and calmly during the recovery period and tell the child what has happened
- If the child sleeps after a seizure, let them wake up naturally

## What not to do

- Do not try to lift or move the child while the seizure is happening unless the child is in danger (for example, the child is at the top of stairs)
- Do not try to stop the jerking or restrain the child
- Do not put anything in the child's mouth or between their teeth
- Do not give any medication while the seizure is happening unless this is prescribed medication
- Do not offer anything to eat or drink until the child is fully conscious and recovered

## When to call an ambulance

Your epilepsy specialist nurse will give you a seizure management plan which is specific to your child's epilepsy. This plan will clearly state when to call an ambulance.

As a general rule, only call an ambulance if:

- one seizure follows another without full recovery in between
- the jerking part lasts for more than five minutes or for longer than is usual for the child
- the child has been injured during the seizure, and the injury requires more than first aid
- the child may have inhaled food or water
- the child is having problems breathing after the seizure has stopped

## First aid for any other types of seizure

- Time when the seizure starts
- Stay with the child to make sure there is no risk of injury or further seizure activity
- Talk gently and reassuringly during a seizure
- There is no need to call an ambulance unless they last longer than five minutes or longer than usual

Tell the child what has happened after the seizure and offer reassurance. A child often wants to sleep after a seizure.



# Keeping your child safe

This chapter describes the most common scenarios which may require some intervention to stop a seizure. Remember, most seizures are short, will usually last two to three minutes, will stop on their own and will not require any medical intervention. Some children, however, have seizures which will go on for longer and they are often given emergency medication, such as midazolam, to stop the seizure.

## Prolonged seizures and status epilepticus

Prolonged seizures are defined as seizures which last two minutes longer than what is usual for a child, or five minutes in total if you don't know yet how long your child's seizures usually last. Each child should have a seizure management plan which will clearly state after how many minutes to give emergency medication, and/or when to call an ambulance.



Image credit: flickr.com/photosavvy

A prolonged seizure can turn into **status epilepticus**. This is defined as a seizure which continues for more than 30 minutes, and which does not stop on its own, or several seizures without recovery in between.

Status epilepticus is rare. It is more commonly linked to seizures which involve jerking but can also occur with any other type of seizure, which can be more difficult to detect. If a convulsive seizure continues for a long time, it can affect breathing.

If your child has had one prolonged seizure, your child's specialist may prescribe emergency medication which you can give at home to stop the seizure.

Your child's seizure management plan will clearly state what you need to do, such as:

- what to look out for
- when to administer emergency medication
- how much of the medication to give
- when to phone 999

Your epilepsy specialist nurse will show you how to administer emergency medication.



# Keeping your child safe

## Serial seizures

These are seizures that happen one after another. If there is no emergency medication or seizure management plan in place, call an ambulance.

## A cluster of seizures

Some children can have clusters of seizures over a day or few days. A child's seizure management plan will address clusters and tell you what to do if this happens. This might also mean additional prescribed medication to stop these clusters.

## Sudden Unexpected Death in Epilepsy (SUDEP)

The risk of SUDEP is very low for children without other underlying disabilities. It is also very low for absence and myoclonic seizures, and low if seizures are controlled. To put it in context, sudden unexpected death can also happen with other medical conditions such as diabetes or asthma.

Your child's epilepsy specialist nurse can give you specific information about your child's risk and usually allay any concerns you may have. For more general information on SUDEP, please phone our helpline on 0808 800 2200.

# Managing your child's epilepsy and seizures

We do not entirely understand why seizures happen when they do, in many cases, they just happen without a cause. However, some factors or events may make a seizure more likely, such as a high temperature.

## Keep a seizure diary

A seizure diary can help you look for any pattern and will help you manage your child's seizures. Your child's consultant or epilepsy specialist nurse will also appreciate a record of seizures to monitor the medication's effectiveness.

## Give medication exactly as prescribed

Not taking ASMs exactly as prescribed can trigger a seizure. Establish a daily routine by linking medication time with a regular task or set a reminder on a mobile phone or smart speaker.

You can also use a dosette box which can be a helpful prompt for teenagers who sometimes forget to take their medication.

Never reduce or stop your child's medication unless advised by your child's specialist or epilepsy specialist nurse.



# Managing your child's epilepsy and seizures

## Encourage your child to stay active

For most children, epilepsy is a small part of their life. Encourage your child to continue with their usual routines. Risks associated with specific activities can often be reduced with some precautions.

**School trips:** A school cannot exclude a child from educational trips or other school leisure activities for having epilepsy. Exclusion can only happen on specific health and safety grounds following a detailed risk assessment, and only if risks cannot be safely minimised. If your child has been excluded from a trip, contact your epilepsy specialist nurse who can liaise with the school over this.



**Swimming:** If seizures are well controlled, or seizure patterns are predictable, swimming can be a relatively risk-free activity. Use a swimming pool which is supervised by a qualified lifeguard who has been made aware of the child's epilepsy. If seizures are more frequent, an adult may need to be present in the pool who can keep the child's head above water during a seizure.

**Riding a bike:** Always ask your child to wear a cycle helmet. How much supervision is needed depends on the age of the child or how busy the roads are. If your child is out with friends, encourage them to explain to their friends what to do if they have a seizure.

Cycling on off-road cycle paths tends to be safer than busy roads. Avoid routes along canals or rivers.



Image credit: Richard Masoner flickr.com/bike

## Stress, anxiety and sleep

Stress and anxiety can often affect sleep, and the tiredness from disrupted sleep can make seizures more likely.

A new diagnosis of epilepsy can often create anxiety and stress for parents, and children can very easily pick up on this. Too many restrictions can also create a stressful environment for children.

Remain positive and supportive to help your child adjust to living with epilepsy. For example, if your child experiences any issues at school, speak to your child's epilepsy specialist nurse who can liaise with the school to reduce any school-related stress factors.

# Managing your child's epilepsy and seizures

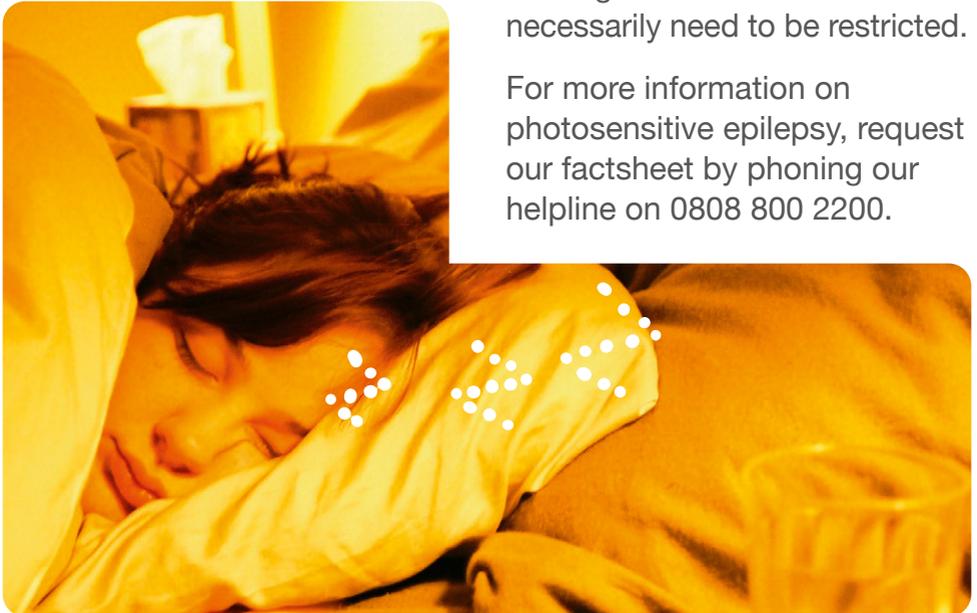
Your child's epilepsy specialist nurse can also make a referral to clinical psychology or local child mental health services if anxiety is becoming an issue for your child.

Sleep problems can also sometimes be a side effect of some ASMs. If you suspect this might be the case, seek advice from your child's epilepsy specialist nurse.

## Photosensitive epilepsy

Contrary to popular belief, only around two to three percent of children and adults with epilepsy will be affected by flashing and flickering lights. A specialist will usually have checked for photosensitive epilepsy via a routine EEG test. If your child has photosensitive epilepsy, your child's specialist will try and control this with ASMs, so that regular activities do not necessarily need to be restricted.

For more information on photosensitive epilepsy, request our factsheet by phoning our helpline on 0808 800 2200.





## Alcohol and recreational drugs

Drinking in moderation is usually ok but always refer to the medication's information leaflet or seek advice from your child's epilepsy specialist nurse as some medications do not mix well with alcohol.

Teenagers need to understand that binge drinking and taking recreational drugs can make ASMs less effective and seizures more likely. Some recreational drugs can also trigger seizures even in people who do not have epilepsy. Drinking alcohol can also affect the quality of sleep making your child more tired, which can increase the risk of seizures.

Some teenagers may want to skip their medication before a night out. Your child needs to understand that a seizure resulting from skipping medication can sometimes be more serious than a seizure resulting from mixing ASMs with alcohol or recreational drugs.

## Hormonal triggers

Occasionally, for some girls, their seizures can be more common around their monthly periods. Keep a diary of seizure and period dates to look at a likely link and seek medical advice. Prescribed 'booster' medication can help with an increase in seizures around these times.

## Health triggers

For some children, seizures are more likely if they feel unwell or are running a temperature. Always seek medical advice if you notice an increase in seizures due to feeling unwell.

# Safety around the house

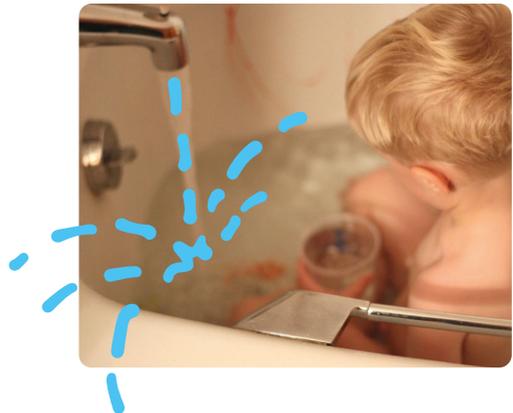
If your child's seizures are well controlled, safety issues will be less of a concern. Your child's epilepsy specialist nurse will always aim to have seizures controlled by medication, which will make most of what is mentioned in this chapter not relevant.

If your child's seizures are not under control yet, some precautions can reduce the risk of injury. An assessment of these risks should always take into account frequency and type of seizure, and whether a child gets a warning before a seizure. Your child's epilepsy specialist nurse or an occupational therapist can help you risk assess your home.

If you want to receive more general information on safety, download our 'Staying safe with epilepsy' guide from our website [www.epilepsyscotland.org.uk](http://www.epilepsyscotland.org.uk) or call our helpline 0808 800 2200 for a free copy.

## Bath and shower time

Never leave your young child alone in or near water. Accidental drowning is a risk for any young child, but particularly for children who may have a seizure while bathing. A shower with level access or wet room is usually safer as it reduces the risk of drowning.



## Epilepsy alarms

Epilepsy alarms can give parents peace of mind, but be aware that alarms will not always pick up genuine seizures or may trigger occasional false alerts. Once alerted, you can assist your child with basic first aid and keep them safe.

Not all types of alarms are suitable for all types of seizures. Your child's epilepsy specialist nurse will be able to advise on the right type of alarm for your child's seizures and how to obtain an alarm. Often your local social work department will fund and install an alarm.

## Seizures during sleep

A carpet or something soft at the side of the bed can cushion a possible fall. Keep the bed away from any furniture with sharp edges. Anti-suffocation pillows with small holes can also support a child's breathing during a seizure but they are not generally suitable for any child under the age of two.

## Medical identification jewellery

A medical bracelet or necklace can contain helpful information about your child's epilepsy. Not every child will want to wear visible medical jewellery. A card containing similar information such as emergency contact details and medication to be carried on the person may be an acceptable alternative. Epilepsy Scotland can provide you with such a free wallet size card.

## School and learning

If seizures are well controlled, children with epilepsy are unlikely to need formal additional support. A child's seizure management plan will contain useful information for teachers allowing them to effectively support a child with epilepsy.

Some children with epilepsy can have issues with their memory, particularly their short-term memory, or learning. A referral can be made for a neuro cognitive assessment to identify potential issues and provide tailored support.

Short-term memory is commonly affected before, during and after a seizure. As the brain builds up to a seizure, information may not be processed well enough to pass to the long-term memory.

Occasionally, some ASMs can also have an effect on concentration and learning. Always seek advice from your child's epilepsy specialist nurse who can liaise with the school if there are any learning issues.

Our 'Epilepsy – a guide for teachers' publication provides lots more information for teachers on what to look out for, and how to effectively support a child with epilepsy. Refer your child's teachers to our website, download this guide at [www.epilepsyscotland.org.uk](http://www.epilepsyscotland.org.uk) or request a free copy (or multiple copies) by phoning our helpline 0808 800 2200.

## Explaining epilepsy to your child

Most children are initially more concerned about the impact epilepsy may have on their life. Provide reassurance and answer any of their questions as much as you can. Staying positive around your child can make your child more ready to talk. An older child may prefer to speak to their epilepsy specialist nurse or someone else they trust.

Storybooks can also be an effective way of starting a conversation about epilepsy. We have a number of resources for younger children and teens on our website [www.epilepsyscotland.org.uk](http://www.epilepsyscotland.org.uk). You can also request free copies by phoning 0808 800 2200.



Our Epilepsy Scotland Youth Service can help and support young people understand and accept their epilepsy. For more information about our Youth Service, please contact 0808 800 2200.

Siblings also need support. Spend time with each of your children on their own giving them an opportunity to talk about how they feel and ask questions they may be too frightened or embarrassed to ask in front of someone else. Specific support to siblings of disabled children and adults is available from the charity Sibs [www.sibs.org.uk](http://www.sibs.org.uk).

## Emotional wellbeing

Children often have an amazing ability to bounce back and adapt. Give your child time to understand and get their head around living with epilepsy and what it may mean for them. Living with the uncertainty of seizures and a feeling of being different can affect a child's confidence and self-esteem. Encourage your child to talk about how they feel and seek help if you think your child is struggling.

Low mood is common in all teenagers, but epilepsy can make this more likely for teenagers. Occasionally, medications can also affect mood. If you have any concerns, speak to your child's epilepsy specialist nurse, who can make an appropriate referral if necessary.



# Growing up with epilepsy

Many children will grow out of their epilepsy but for others, their epilepsy will continue into adulthood. As a child grows older, seizure frequency and patterns may change. Keep a seizure diary and seek medical advice if you notice an increase in seizure activity or change in seizure pattern.

A child approaching adolescence may also become more sensitive about how others view them and may find it more difficult to cope with seizures. It is also a time when your child will want more independence.

## Attending youth groups

Youth groups can support a young person through the challenges of growing up and help them make informed decisions about their epilepsy. Our own Youth Service works with children and young people one to one and provides social activities in a group setting to increase confidence and independence. To find out more, please phone our helpline on 0808 800 2200.



# Growing up with epilepsy

## Transition to adult hospital services

Transfer to adult epilepsy services will usually happen around the ages of 16-19, or when a child leaves school. A child aged 15 or 16 at diagnosis will often be referred directly to an adult neurologist cutting out the transition phase.

The move to adult services sometimes means travelling to a different hospital. Some hospitals have a transfer clinic where families can get to know medical staff of the adult team.

Transitioning into adult epilepsy services is usually a good opportunity to review a child's epilepsy care and medication taking into account a child's physical, emotional and psychological changes.

Any child attending a teenage clinic will be entitled to see their consultant or other specialist without their parents and make their own decisions about their health.

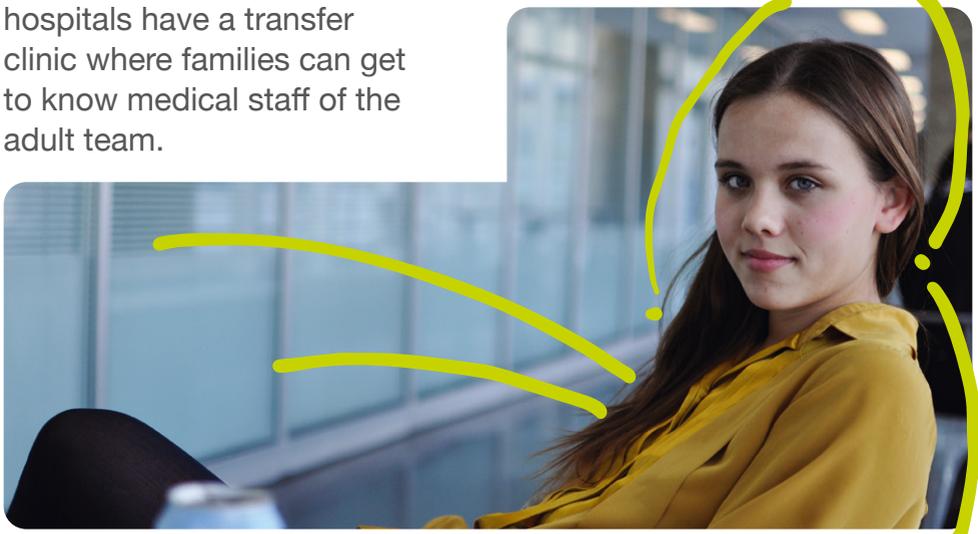


Image credit: Andréa Portilla flickr.com/andreyah-pictures

## Lifestyle choices

Older children need to be well informed to make safe decisions about their life. Skipping medication, taking recreational drugs and drinking alcohol can put them at risk of seizures. Encourage them to talk to their epilepsy specialist nurse.

Our teen guide 'Getting on with life' addresses many of these issues. You can download this from our website [www.epilepsyscotland.org.uk](http://www.epilepsyscotland.org.uk) or request a free copy by phoning our helpline 0808 800 2200.

Any sexually active girl needs to seek contraception advice from her epilepsy specialist nurse. Not every contraceptive method is suitable and effective for a young woman taking ASMs.

## Further or higher education

Epilepsy doesn't stop a young person to go to college or university. Student disability services can help students address any practical issues and help liaise with the college/university over adjustments. This could, for example, be a longer deadline for assignments and essays if concentration is affected by medication.

We have a dedicated guide for students covering many of the issues relevant to young people in further and higher education. You can download this from our website [www.epilepsyscotland.org.uk](http://www.epilepsyscotland.org.uk), or phone our helpline 0808 800 2200 for a free copy.

## Entitlement to benefits

Entitlement to benefits will depend on how well a child's seizures are controlled, and whether a child has any other support needs. Always seek advice from a professional welfare rights service before applying for any benefits including any Scotland specific benefits and payments administered by Social Security Scotland.

For a full benefits check, advice and help with benefits applications contact:

- Advice Direct Scotland  
0808 800 9060
- Your local Citizens Advice Bureau  
[www.cas.org.uk](http://www.cas.org.uk)
- Disability Information Scotland  
[www.disabilityscot.org.uk](http://www.disabilityscot.org.uk) 0300 323 9961
- Epilepsy Scotland's Welfare Rights Service  
0141 427 4911



# Contact us!

If you would like more information about anything mentioned in this guide, have further questions, or just want to talk, please contact our helpline on 0808 800 2200.

Our friendly helpline and information officers are here to listen, support and help.



Image credit: Alex. Alexi flickr.com/131365673@N02

**Helpline: 0808 800 2200**  
**Text: 07786 209 501**  
**[www.epilepsyscotland.org.uk](http://www.epilepsyscotland.org.uk)**

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