Parent Guide

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What is this resource and how do I use it?

This helpful guide is written to help parents understand more about epilepsy and how they can support their child, from learning about the types of seizures your child might experience to practical tips for keeping your child safe around the house.

What is the focus of this resource?

- Empowering Parents of Children with SEND
- Support for Children with Epilepsy
- Epilepsy Awareness
- Practical Support

Further Ideas and Suggestions

We have lots of parent support guides in **this category** at the **Parents' Hub**. In this category, you'll find support for a range of diagnoses, including **dyscalculia**. This **Parent Guide to SEND Support in School** explains how schools target support for the children in their care.

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Supporting a Child with Epilepsy

A Guide for Parents

Supporting a Child with Epilepsy

If your child or a child in your care has epilepsy, use this guide to find out a bit more about the symptoms of epilepsy and how you can support your child at home.

What is epilepsy?

Epilepsy is a disorder that affects the brain, causing seizures. While it can start at any age, it's common for epilepsy to begin in childhood. Epilepsy is a lifelong condition but symptoms can improve gradually over time, for example seizures may become less frequent.

What causes epilepsy?

It is not always clear as to what causes the sudden burst of electrical activity in the brain, which is the cause of the seizures. There is a chance that genes play a part in epilepsy but this is not always the case. Sometimes, a severe head injury, brain tumour or infection can cause damage to the brain which can lead to epilepsy.

Signs and Symptoms

The main symptom of epilepsy is seizures. There are many types of seizures, which can present in different ways. It's important to recognise the signs of your child's seizures so you can tell family members and school staff what they should look out for. Some signs of a seizure can include:

- Staring blankly into space with no awareness of what is happening
- Experiencing strange sensations, such as tingling arms and legs or getting a 'rising' feeling in the stomach
- 'Fitting' (where the person jerks and shakes uncontrollably)
- Collapsing or becoming rigid
- Twitching of limbs
- Loss of sight

If you think your child (or anyone) is experiencing a seizure for the first time, you should call 999 for emergency medical assistance. It may be a one-off or it may be the first of many; regardless, it is important to find out why it happened.

Types of Seizures

It's important to know what type of seizure or seizures your child usually experiences. They can be put into two groups: focal seizures (which start in one side of the brain) and generalised seizures (which start affecting both sides of the brain immediately).

Your child might experience one or more of the following types of seizures if they have

epilepsy:

Focal aware seizures - your child remains fully aware of what is happening around them, even if they can't respond. These usually last for up to two minutes but can only be for a few seconds. Your child may experience different symptoms depending on which lobe of the brain the seizure occurs in. These can include loss of sight, twitching, thrashing, difficulty with understanding and loss of bladder control.

Focal impaired awareness seizures - your child loses awareness of what is happening around them, whether for a moment or for a whole seizure. These are usually seizures which occur in the temporal lobes and have symptoms that include lip smacking, feeling frightened and hearing things that aren't actually there. Your child may be confused after this type of seizure.

Atypical absence seizures - your child seems to become floppy or clumsy. These seizures last for around 30 seconds and usually occur in people who have other conditions that affect the brain too.

Typical absence seizures - your child will be unconscious for up to 10 seconds but won't fall down. They may suddenly stop what they are doing or appear to be daydreaming. There may be some other signs such as eyelid fluttering and, while each seizure only lasts for up to 10 seconds, these seizures are often clustered together. Your child may feel confused after a cluster of seizures but may continue as they were before it started.

epilepsy:

Tonic-clonic seizures - this is what people most typically associate with epilepsy. During a tonic-clonic seizure, your child will experience a tonic phase where they lose consciousness and go rigid, falling to the floor. This is followed by a clonic phase where their limbs jerk quickly and rhythmically and they may lose bladder control. Most tonic-clonic seizures last between one and three minutes. If your child has a seizure for longer than five minutes, they may need emergency medical help. Your child could feel very tired or unwell after a tonic-clonic seizure and may not feel better for several days.

Myoclonic seizures - these can be focal or generalised and are very short seizures, not usually affecting consciousness. They cause jerks in one or more parts of the body. These jerks can be a small twitch or a large movement, perhaps causing your child to throw what they are holding or fall over. Your child will usually be able to carry on as normal after a myoclonic seizure.

Focal to bilateral tonic-clonic seizures - someone may experience a focal aware seizure before a tonic-clonic seizure, which they often describe as an ‘aura’ or a sense that they are about to have a tonic-clonic seizure. The ‘aura’ is the focal aware seizure starting in one side of their brain before they lose consciousness as the seizure spreads to both sides.

If you are unsure about what sort of seizures your child experiences, ask your child’s doctor or epilepsy nurse.

Childhood Epilepsy Syndromes

Things like the age your child begins having seizures, the types of seizures they have and whether they have any other medical or learning needs might indicate a particular medical syndrome. If your child is diagnosed with a particular syndrome, it can help you and your child's doctors predict what might happen with their epilepsy in the future based on others' experiences. It can also help the doctor plan the most appropriate treatment for your child.

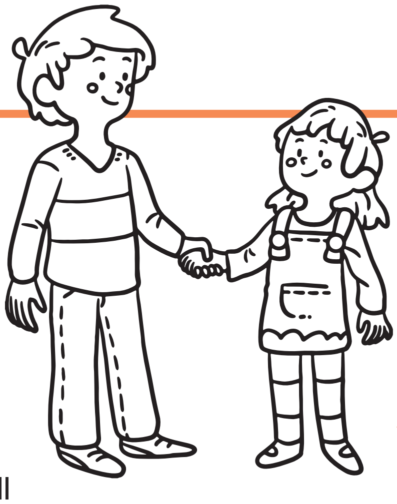
Possible Triggers

Seizures can appear to occur randomly for some people but others may notice that they occur after certain 'triggers'. You might find your child experiences seizures following triggers such as:

- Stress
- Lack of sleep
- Missed medication
- Illness
- Flashing or flickering lights
- Hormonal changes

Diagnosis of Epilepsy

If your child has experienced a seizure, they should be referred to a neurologist (brain and nerve specialist) who will ask some questions and run some tests to see what caused it. Your child should get an appointment within two weeks of referral. There is a chance that they may experience more seizures while they wait for their appointment and, if you can, you should try to limit potentially dangerous activities during this time (swimming being a good example). If they do have another seizure during this waiting time, contact your GP.



Tests that may be used include an EEG (electroencephalogram), where small sensors are placed on the scalp to pick up unusual electrical activity in the brain, or a brain scan, which helps the doctors look for things such as tumours, damage or scarring that could be affecting the electrical activity in the brain. An MRI (magnetic resonance imaging) scan is usually used for this.

The neurologist will also need to know what happened during your child's seizure or seizures. You may find it helpful to record anything you notice before, during and after their seizures to help with this. Thinking about some of the following questions may help with this:

Before the seizure:

- Did anything seemingly trigger the seizure?
- Did they mention tasting or smelling something unusual?
- Did their mood change?
- What were they doing?

During the seizure:

- Were they conscious or unconscious?
- Did their body become stiff or floppy?
- Did they fall down?
- Did they do something out of character for them (for example mumble or fiddle with things)?
- Did they appear to be daydreaming?
- Did they wet themselves?

After the seizure:

- Were they tired?
- Were they confused?
- Were they able to carry on as normal?
- Did they notice something had happened to them?
- Did they need to sleep? How long for? How were they when they woke up?
- How long until they felt like they were back to themselves?

The Next Steps

As previously mentioned, epilepsy is a lifelong condition. However, there are treatments that can help reduce the frequency of your child's seizures. In some cases, these treatments can stop seizures from occurring at all and your child might be able to come off their treatment over time.

Following diagnosis, your child's doctor will recommend the best course of treatment. The most common form of treatment is anti-epileptic drugs but sometimes doctors might recommend switching to a ketogenic diet that can help control seizures or surgery. NICE guidelines state that epilepsy medication should be reviewed annually to make sure it is still the best course of action.

If your child attends nursery or school, you should inform them of your child's seizures even if you are still waiting for epilepsy to be diagnosed. This can help keep your child safe while they are at school. Once diagnosed, you can request a meeting with school staff to discuss your child's needs. They may record information such as triggers, medication and how to deal with a seizure in an individual healthcare plan (IHP) for your child. The plan should be unique to your child and based on their needs, including what should happen after a seizure. For example, does your child need to come home (as they are usually very tired afterwards) or are they able to stay at school? If your child does have a seizure at school, this should be recorded and the school should make you aware. The IHP should be reviewed and updated annually or earlier if there are any changes in your child's needs.

What can I do to support my child?

Support Them to Do What They Love

In most cases, children with epilepsy can continue to do the activities they enjoy including playing sports and taking part in school activities. However, you will need to think carefully about how you can help them do things they love but keep them safe at the same time. This will be different for each child depending on the frequency and type of seizures they have. For example, your child could still go swimming but you should make sure there is someone in the water with them who knows how to recognise their seizures and what to do.

Talk to Them

Discuss epilepsy as openly and honestly as you can. This will help your child to feel confident talking about their epilepsy with others, which can help them feel more confident generally and also help keep them safe.

What can I do to support my child?

Help Them Help Themselves

As your child gets older, help them learn to risk assess situations and make plans that allow them to do things they want to but still ensure they are safe. They might have a checklist they can run through (physically or just in their mind) before undertaking an activity. This can help increase their independence, which is really important for self-esteem.

A checklist might seem a bit much to some but, in reality, we all use mental checklists every day to keep us safe. We get so used to them that we don't always notice we are doing them - things like crossing the road, locking our doors and checking (and double-checking) the oven is off all require a safety checklist!

Try to Stay Positive

This might involve problem-solving and you may find this difficult at times!

Establish Routines

Making things like taking medications part and parcel of daily life is a good idea to help your child get used to regularly taking their medication. It can also help them build independence and establish some ownership of this situation. Building a regular bedtime into this routine can be helpful, as getting enough sleep can lower your child's risk of seizures.

Create a Safe Space

There may be certain measures you take around the home to help prevent your child from getting hurt if they have a seizure at home. Where possible, you might try to have carpets rather than hard floors. You might want to take locks off bathroom doors and use a sign to let people know if it is occupied instead. This means you can get in easily if your child has a seizure whilst in the bathroom. Keep your child's bed away from the wall and radiator to prevent them from bumping or burning themselves if they have a seizure whilst in bed.

The measures you take might depend on the type and frequency of seizures your child has.

What can I do to support my child?

Keep an Eye on You

Your child needs you to be their biggest fan and their advocate. It's important not to let epilepsy become the thing they think you focus on. To nurture a positive relationship with your child, you could:

- Find out what they love doing.
- Engage in play with them.
- Show them how much you love them.
- Be there to cheer them on.
- Have fun together.

It can be easy to forget yourself due to the necessary considerations you need to give your child - you also need to look after yourself. Time away from your child can be beneficial so you don't feel overwhelmed and so that you can replenish your energy. Never feel that you are 'failing' because you're frustrated by your child's needs - all parents feel this at some point. You'll never get everything right and nobody would ever expect you to - you're learning too! But remember, there is support for you too. Talking to another parent of a child with epilepsy might help to see what things work for them or even just to discuss your thoughts and feelings with them.

Disclaimer: We hope you find the information on our website and resources useful. As far as possible, the contents of this resource are reflective of current professional research. However, please be aware that every child is different and information can quickly become out of date. The information given here is intended for general guidance purposes only and may not apply to your specific situation.

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