



## Epilepsy and Seizures in children

### What is Epilepsy?

Epilepsy is a name given to a group of disorders where children have recurrent epileptic seizures. It is a relatively common condition effecting 1 in every 200 children. Epilepsy is usually well controlled with medication.

### What exactly are “Epileptic Seizures”?

Your brain controls your body and your thinking by electrical messages. An epileptic seizure occurs when your child’s brain has temporary abnormal electrical activity that causes unusual movements, behaviour or funny feelings for your child. Normal brain function cannot continue until this abnormal electrical activity stops.

Sometimes this abnormal electrical activity starts only in certain areas of the brain, which is why only certain body parts may twitch or shake. These types of seizures are called **focal seizures**. When the abnormal electrical activity involves the whole brain these seizures are called **generalised seizures**. It may seem like the epileptic seizure goes on forever but most epileptic seizures last less than 5 minutes. Although they can be very frightening and awful to watch, epileptic seizures of this duration do not cause any damage to the brain.

There are many different kinds of focal and generalised seizures. Some seizures can be quite subtle. For example, a seizure may consist of only blank staring for a few seconds. Seizures can also sometimes be quite bizarre and children can have quite inappropriate behaviour or feel very scared. Other seizures have obvious movement changes where one part or the whole body can go stiff and/or jerk quite violently.

Some older children may experience an unusual feeling of an “aura” just prior to the beginning of a seizure. This feeling may be a funny smell, a headache, a taste in their mouth or a stomach pain. If they have an aura before their seizures they may have time to tell you how they feel, or be able to lie on the floor so they are less likely to injure themselves.

Certain environmental influences such as flashing lights or deep breathing can trigger an epileptic seizure in some types of epilepsy. Tiredness, illness, fever, stress or excitement can also increase the chance of an epileptic seizure.

Even though your child experiences his/her own particular kind of seizure, seizure types can change from time to time. So it is important that you know what to do if a major seizure should ever happen.

### Types of Epileptic Seizures

	Name of Seizure Type	What you might see and/or your child might feel
Focal seizures	<i>Focal aware seizure</i>	Your child will be completely aware during this seizure. They may have an unusual feeling inside, feel unusual sensations or see funny things. They may have jerking of just one part of their body. These seizures usually last less than 2 minutes.



	<b>Name of Seizure Type</b>	<b>What you might see and/or your child might feel</b>
<b>Focal seizures</b>	<b><i>Focal impaired awareness seizure</i></b>	Your child may have similar features to a focal aware seizure but they then lose awareness and cannot respond to questions or commands normally. They may just stare ahead. These seizures usually last for 30 seconds to 2 minutes. After the seizure your child may be confused or tired and want to sleep for several hours.
	<b><i>Focal to bilateral tonic clonic seizure</i></b>	These seizures start like focal aware and impaired awareness seizures but they progress to involve shaking of the whole body. These seizures usually last less than 5 minutes. After the seizure your child may be confused or tired and want to sleep for several hours.
<b>Generalised seizures</b>	<b><i>Absence seizure</i></b>	Your child will suddenly stop what they are doing. They will not respond appropriately to questions or commands. Tickling them does not result in a normal response. They may just stare ahead and have eye blinking. These seizures are brief lasting between 5 and 45 seconds. When the seizure is over your child will simply carry on doing what they were doing before it started. They will not be confused or tired after the seizure but may wonder what just happened.
	<b><i>Myoclonic seizure</i></b>	Sometimes when your child goes to sleep at night they can have sleep jerks – this is normal. Myoclonic seizures look like these jerks but occur when your child is awake. They are more likely to happen in the morning and are brief rapid jerks of the whole body which last less than a second.
	<b><i>Generalised tonic clonic seizure</i></b>	Your child will suddenly with no warning become stiff all over. If standing they will fall to the ground. After a brief period of time (1 to 15 seconds) they will start to have jerking of their whole body and their limbs. At first this may be small fast jerking but it becomes larger slower jerks. At the end of this seizure the jerking will stop and you may hear a big sigh and noisy funny breathing. Your child will be confused and sleepy for several hours.
	<b><i>Tonic seizure</i></b>	Your child will suddenly and with no warning become stiff all over. If standing they will fall to the ground. These seizures will last from several seconds to minutes. When the seizure is over your child may be sleepy.
	<b><i>Atonic seizure</i></b>	Your child will suddenly and with no warning fall to the ground– they will be very floppy during the fall and may injure themselves. These seizures can be very brief and your child may quickly get up and carry on.



## Why does my child have epilepsy?

The cause of most epilepsy is genetic. We all have genetic material (DNA) in each of our cells. This DNA codes for proteins which make us who we are. As we start off life as a single cell and grow into a person with over 30 trillion cells the DNA has to be copied many times. Sometimes there can be a mistake when the DNA is copied resulting in a protein that doesn't do what it is supposed to do. This can lead to a disease such as epilepsy. The genetic abnormality that causes epilepsy in your child may be an inherited genetic change and other members of the family may also have epilepsy or it may be a genetic change only in your child with epilepsy.

Epilepsy can also occur when there is an injury to the brain cells such as:

- a severe injury to the head
- an infection in the brain like meningitis
- a maternal infection which has affected the growing brain during pregnancy

## What should I do if my child has a seizure?

1. Try to stay calm – remember it will stop, your child is not going to die and it is not damaging his/her brain.
2. Move your child to a safe space. You may need to lie your child down on the floor (or move furniture away from them) and protect the head if there is jerking movements.
3. Turn your child on their side so they will not choke on saliva or vomit – you may need to wait until the jerking stops to do this.
4. Loosen tight clothing. Do not put anything in or near their mouth.
5. Stay with your child until the seizure stops. Tell them quietly that you are right beside them and you will keep them safe.
6. Do not restrain their movements.
7. Take note of the time the seizure started. If the seizure lasts more than 5 minutes call an ambulance.
8. If you are able to (or there is someone else with you) try to get a video of the seizure with your phone to show your doctors.
9. Once the seizure is over, let your child rest for a while. They may remain confused, feel strange and experience sore muscles and a headache for some time afterwards.
10. If your child has bitten their tongue Panadol and an ice block can be helpful (when they are awake enough to take them).
11. Write down the details of what happened to your child (before and during the seizure) so that you can remember what to tell the doctor.

## Myths about Epilepsy

You do not need to worry about your child swallowing their tongue – this is a myth. Do not try to put your fingers in your child's mouth as you are likely to get them bitten or break your child's teeth.



## When do I need medical help?

When an epileptic seizure occurs it is not usually necessary to immediately call a doctor or an ambulance. You may need to consult your GP however to inform them a seizure has occurred.

If your child has regular seizures but begins having them more frequently than usual please make an appointment to see your GP.

## When do I call an ambulance?

- If an epileptic seizure continues for more than 5 minutes.
- If your child has two or more seizures in a row without waking properly between them.
- If your child has had a head injury or another injury has occurred during the seizure.

## Will my child require tests and investigations?

If your child has had an epileptic seizure they will probably require an EEG (electroencephalogram) which is a recording of their brain's electrical activity. This can be done as an outpatient.

A "CT" or an "MRI" scan is sometimes necessary to look at the structure of the brain. These can be helpful in determining a cause for the epilepsy.

Very rarely blood tests may be required for the monitoring of your child's anti-epileptic medication. Medications are absorbed from the stomach into the bloodstream where they travel to the brain to take effect. Blood tests are usually only necessary if the seizures are not well controlled or if your child appears to be experiencing some of the more severe side effects of the medication. The rate at which drugs are absorbed and eliminated from the body can vary from child to child. That is why the amount of medication your child takes may vary from other children taking similar medication for similar types of seizures.

## Do I need to do anything differently now that my child has epilepsy?

It is important to treat your child normally, just as you did before they had epilepsy. Having said that there are some situations where having a seizure could be dangerous. For six months after your child has had a seizure we recommend:

- Showers are safer than baths. If your child has a bath someone should be close enough to help if your child has a seizure. For older children that might mean the door to the bathroom is ajar and someone is listening outside.
- Swimming is an important skill to learn for all children. However if a child has had a seizure it is important to take extra care near water. There should be someone who is watching your child closely while they are in the water. The observer should be close enough (and have the skills) to be able to get your child out of the water if they have a seizure.
- Your child should always be wearing a helmet while on a bike. Biking off road is fine but they should not bike on the road.
- Your child should avoid climbing trees. Playing in a playground is fine as even children without seizures fall off this equipment and they are designed with that in mind (safety mats etc.).



## What happens in Status Epilepticus?

When seizures go on for prolonged periods of time (30 min or more) we call this ***status epilepticus***. It is either a single seizure that continues non-stop or many seizures occurring one after the other without the child recovering in between. Long seizures can be bad for the brain. It is unclear exactly how long a seizure needs to be to cause damage but it is likely to be 60 min or more.

You should call an ambulance if your child's epileptic seizure occurs for more than 5 minutes so that further treatment can be given in hospital.

If your child has an epileptic seizure which lasts for more than 5 minutes, your doctor may prescribe a medication to stop these at home or school. This is called "rescue" medication and comes in two forms. One is called midazolam and is given into your child's cheek and the other is called diazepam (Stesolid) and is given rectally to stop the seizures. Give these to your child and if they continue to seizure for a further 5 minutes please **call an ambulance**. While you are waiting for the ambulance, continue to lie your child on their side in the recovery position and stay with them.

The majority of children will not experience "status". Why status occurs is not clear but it depends on the child's type of epileptic seizure, how well they are controlled by medication and the reason for their epilepsy.

## How long will my child need to take medication for?

Many types of childhood epilepsy only occur in childhood and a child will outgrow their seizures. Some types of childhood epilepsy will continue throughout life. If your child remains seizure free for two years they may be able to come off their medication. The decision as to when to wean medications needs to be made in consultation with your doctors. **NEVER** just stop your child's medication suddenly. This can result in serious seizures and status epilepticus which can be hard to stop. It is important to make sure you do not run out of medication for your child.

## Can my child die from epilepsy?

Sudden Unexplained Death in Epilepsy (SUDEP) is a very rare but sad event. In any 1 year, SUDEP affects 1 in 4,500 children with epilepsy; in other words, annually, 4,499 of 4,500 children will not be affected by SUDEP. The best way to prevent SUDEP is to stop convulsive seizures and this is one of the reasons your doctor may recommend medications for your child.

## Who to contact for more information or support

Epilepsy New Zealand has educators who can answer any questions you may have and can act as a support person for you. You can contact your local educator at **0800 37 45 37**.