

When your child has Epilepsy

For carers whose child has been recently diagnosed



EPILEPSY ACTION
AUSTRALIA

Newly Diagnosed Epilepsy



“You just call Epilepsy Action and say ‘**I need some advice.**’ They know what they’re talking about. To me, that’s worth a lot.”
Debbie Marrum, Taniesha’s mum.



Epilepsy Action provides education and support services to children and adults with epilepsy across Australia

Witnessing your child experience a first seizure or series of seizures is a confronting situation. Not knowing what is happening; fearing for your child’s safety and wellbeing can leave parents feeling anxious, upset or frightened. This is a common reaction and it is often a relief to be given a diagnosis. However, when the time comes and you hear the word *epilepsy* a multitude of feelings and emotions may be evoked.

Many people have little knowledge or experience of epilepsy. You may wonder what this diagnosis means to you and your family, and how it will affect your child’s life. Accurate information can bring a greater sense of confidence and control, and provide strategies to manage life with epilepsy. How parents react and respond at the time of diagnosis can greatly affect their child’s response, feelings and future. Learning about epilepsy, talking openly with your child, accepting the diagnosis and treating your child as you treat any other will positively affect your child’s outlook.

Generally, children with epilepsy cope well after the initial period of adjustment. The majority of people achieve good seizure control with medication and can live a full and active life. Epilepsy need not necessarily limit expectations or achievement.

What is epilepsy?

Epilepsy is common, affecting about 2% of Australians during their lifetime and can affect anyone regardless of age, gender, level of intelligence, culture or background. Epilepsy is a disorder that causes a disruption of the electrochemical activity of the brain resulting in recurrent, unprovoked seizures.

There are several types of seizures depending upon the area of the brain involved during the seizure. For example some children will experience changes in sensation, movement and behaviour during seizures. Other seizures begin with a sudden loss of consciousness and muscle stiffening. Seizures can last from a few seconds to minutes.

Your doctor will speak with you about the type of seizures your child is experiencing.

The three most common are:

- ◆ Generalised tonic clonic.
- ◆ Complex partial.
- ◆ Absence.

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“Through wonderful doctors and early diagnosis Isaac’s medications are at a level where his **seizure control** is excellent.”

Gary Washbourne, Isaac’s dad

Generalised tonic clonic seizures

Previously called ‘grand mal seizures’, which some people still use. They begin with a sudden loss of consciousness. If standing the person may fall to the ground. The body stiffens (tonic) followed by rhythmic jerking of the muscles (clonic). Breathing becomes shallow or temporarily suspended causing the lips or complexion to change colour. Some people have an excess of saliva which may be slightly bloodstained if the tongue is bitten. Others may experience urinary incontinence.

The seizure usually lasts less than two minutes followed by a period of confusion, agitation or sleep. Headaches or muscle soreness are also common afterwards.

Complex partial seizures

These seizures vary widely. The child may feel the seizure starting with a particular sensation or emotion called an aura. As the seizure goes on, consciousness or awareness is altered producing a vague, confused or dreamlike appearance. The person may not respond to you or may respond inappropriately. They may also display behaviour such as chewing, repetitive movements, fiddling with clothes and wandering aimlessly.

The child does not usually collapse to the ground like a tonic clonic seizure. After the seizure there may be a short period of confusion and the person may need to sleep.

Absence seizures

Usually these seizures start in childhood but they can be experienced by adults and consist of a brief loss of awareness lasting 10-30 seconds. They may occur many times a day. The person appears to stare vacantly and their eyes may flutter or turn upward. While the person is unaware of their surroundings during the seizure, they recover immediately afterwards. Absence seizures are often mistaken for daydreaming or lack of concentration and can disrupt learning by creating gaps in the information a person receives.

Seizure triggers

Certain circumstances can trigger (or set off) seizures, which vary between individuals. The level at which this occurs will depend on a person’s seizure threshold or sensitivity. Everyone has a seizure threshold, however this is lower in some people and they are more susceptible to seizures.

Avoiding identified triggers can help to reduce seizure frequency.

Common triggers include:

- ◆ Lack of sleep.
- ◆ Missed medication/s.
- ◆ Extreme fatigue or physical exhaustion or stress.
- ◆ Consumption of too much alcohol or illicit drug use such as amphetamines or ecstasy.
- ◆ Fever associated with colds and infections or gastric upsets.

Recording seizures

Few doctors see their patients’ seizures. An accurate eyewitness description or video of seizures will help the specialist make decisions about investigations, diagnosis and treatment.

If you are observing someone’s seizures, write a description of what you saw happen before, during and after the seizure. When the person has recovered, ask them to describe what they felt and remembered.

Medication

Medication is the first treatment of choice once a diagnosis of epilepsy has been established. Medication cannot cure epilepsy however in the majority of people it can prevent seizures with minimal side effects. The doctor will choose which medication to use based upon the type of seizures or epilepsy syndrome, the child’s age, gender, lifestyle, other health conditions and individual factors.

Medication is introduced slowly with the dose built up over days or weeks. During this time, its effectiveness in controlling seizures will be closely monitored as well as any unwanted effects.

These may occur in some children while their body becomes accustomed to the medication. A few weeks after starting medication, most people find the unwanted effects tend to lessen or disappear.

If the medication is unsuccessful, a second may be trialled and the first slowly withdrawn during a stabilising period.



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“Our local preschool had no more idea than we had. Epilepsy Action came and did a great presentation to staff. **It was a relief.**”

Tim Shelton, Erynne's dad.

It is important that the medication is taken at regular times as prescribed. Altering dosage or daily routine may provoke unexpected seizures or unwanted effects. Missing medication doses may sometimes trigger a seizure. The goal is to keep a constant level of the medication in the bloodstream.

Tips for taking medication:

- ◆ Establish a regular routine to help avoid forgetting medication.
- ◆ Take medication with meals or use a tablet dispenser.
- ◆ Maintain supplies to avoid running out of medication at the last minute, particularly if away from home.
- ◆ If a dose is missed it can generally be taken as soon as remembered.



- ◆ Do not double up on doses. It is important not to take the missed dose if it is close to the next one.
- ◆ Keep a record of doses that have been missed.

It is important to never stop or alter the dose of a drug without medical advice. Any withdrawal from antiepileptic medication should be done slowly and under medical supervision. Suddenly stopping these drugs can provoke seizures, often more severe than usual.

Who should we tell?

Parents may wonder how they explain epilepsy to their child, their other children and their friends. Who needs to know? How much do they need to know? It helps to speak with the child and explore what they already know, what questions they may have and how they feel about the diagnosis.

It is important to talk to the child's teacher so they can gain an understanding of the types of seizures the child may experience and any strategies to minimise any potential effect upon the child's learning. A seizure management plan is useful to help teachers recognise the child's seizures and know what to do should a seizure occur in the playground or classroom.

Protecting your child

Many parents struggle against the desire to over-protect their child. It is important to let children lead as normal a life as possible. Being exposed to some risks is an ordinary part of growing up.

Staying safe

For the majority of people with epilepsy, seizures will be well-controlled by medication. However it is worth being prepared in case a seizure does occur. Tell your family, close friends and babysitters about your child's type of epilepsy, what to expect should your child experience a seizure and how they can help. Have seizure first aid posters displayed in easily accessible places at home or school.

With a few extra precautions, people with epilepsy can safely enjoy a full range of sporting and recreational activities both inside and outside the home.

While accidents can happen to anyone at any time, the risks for people with epilepsy can be different. This is due to the unpredictable nature of epilepsy. Try to gain an awareness of potential risks and how these can be lessened.

Injuries can occur as a result of seizures such as cuts and abrasions, broken teeth, burns, fractures or even drowning. As with many other conditions, loss of life can

result although this is very rare indeed. It may occur because of an injury sustained during a seizure or as a direct result of seizure activity.

Improving management of seizures, being compliant with medication regimes and avoiding circumstances or identified triggers that increase seizure frequency will reduce potential risk factors.

It is important to remember that the majority of children with epilepsy gain good seizure control and live full and active lives.

Accurate information and knowing what to do can give you a greater sense of confidence and control.

Need help?

It is often helpful to discuss your concerns with someone who understands. Seeking support from a community group can help if your child has recently been diagnosed with epilepsy. Learn as much as you can because knowledge gives you choice and control.



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A U S T R A L I A

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This information is given to provide accurate, general information about epilepsy. Medical information and knowledge changes rapidly and you should consult your doctor for more detailed information. This is not medical advice and you should not make any medication or treatment changes without consulting your doctor.