

## Fact Sheet 5

# Children and Epilepsy

- Epilepsy affects 1 in 100 people, and most have their first seizure in childhood. The largest group of people with epilepsy is children under the age of five (see “What is epilepsy?” fact sheet).
- There are many types of seizures with varying degrees of severity. Some types of childhood seizures are benign (the child grows out of them and their development and intellect are usually normal). Some types are more serious and are associated with other problems.
- Some children are diagnosed with a syndrome. Here is the list of syndromes. These syndromes are age-related and may have different causes. The diagnosis of a likely syndrome will guide the pediatrician in choosing the best treatment plan possible.

Aicardi syndrome

Angelman syndrome (AS)

Benign myoclonic epilepsy in infancy

Childhood absence epilepsy (CAE)

Childhood epilepsy with centro-temporal spikes (CECTS)

Dravet syndrome

Electrical status epilepticus during slow wave sleep

Early myoclonic encephalopathy

Epilepsy and limbic encephalitis (LE)

Epilepsy of infancy with migrating focal seizures

Epilepsy with myoclonic absences

Eyelid myoclonia with absences

Generalised epilepsy with febrile seizures

GLUT1 deficiency syndrome

Gelastic epilepsy

Juvenile absence epilepsy

Juvenile myoclonic epilepsy

Landau Kleffner syndrome

Lennox Gastaut

Mitochondrial disorders

Myoclonic astatic epilepsy (Doose syndrome)

Ohtahara syndrome

Panayiotopoulos syndrome

Rasmussen syndrome  
Rett syndrome  
Ring syndrome  
Self-limited neonatal convulsions  
Self-limiting and pharmaco-responsive focal epilepsy in infancy  
Self-limiting late-onset occipital epilepsy  
Sturge-Weber syndrome  
Unverricht-Lundborg syndrome  
West syndrome

For more information on these syndromes visit [www.epilepsy.org.uk/info/syndromes](http://www.epilepsy.org.uk/info/syndromes)

- Children with epilepsy have a wide range of learning abilities. Epilepsy does not necessarily hinder learning and skill development, but many children do experience learning issues which may include ongoing motor skills or cognitive functions, as well as a difficulty acquiring new skills or knowledge.

Some children have problems with global delay, adaptive behaviours, such as learning to walk, talk or getting dressed, etc, and they will have significant problems in sleep. They may also have significant difficulties with social and emotional development as featured in ADHD and autism.

Seizures are common in children with ASD (Autism spectrum disorder) and ADHD (Attention deficit hyperactivity disorder). Both are neurodevelopmental conditions and have a range of symptoms: [www.understood.org/articles/en/the-difference-between-adhd-and-autism](http://www.understood.org/articles/en/the-difference-between-adhd-and-autism)

- Anti-seizure medications (ASMs) are commonly used for the treatment of epilepsy and most children's seizures are controlled with their use. The choice of ASM depends on the individual child and the epilepsy diagnosis, particularly if there is a likely syndrome. A paediatrician or paediatric neurologist should always start this medication process.

ASMs are designed to stop seizures from happening rather than treat any underlying cause.

All medication needs to be taken regularly every day, and compliance in taking them is essential in maintaining seizure control.

- All ASMs can cause unwanted side effects and a paediatrician will work to alleviate them where possible (see "Epilepsy Medication" fact sheet). Report all side effects, especially if there is an accompanying rash or significant mood change, to your paediatrician. It is important that your child remains on their medication at all times unless directed otherwise.

Your paediatrician should prepare a comprehensive care plan for your child. You should be given information on your child's seizure type and if there is a possible epilepsy syndrome.

You should receive treatment and emergency management plans which may include the use of midazolam.

For those children with uncontrolled seizures, the ketogenic diet (which is high fat, adequate protein, low carbohydrate) can be used to treat seizures once a child has been trialled on two or more medications.

Whilst on the ketogenic diet, the body burns fat, not sugar, for energy (ketosis). The ketogenic diet is rigid, and strictly calculated, and requires commitment by both the parent and child.

Children on this diet cannot deviate from it. Specialist advice and support are essential before starting on this diet with your child.

There are a number of reputable websites that help with up-to-date information, and Ketogenic diet recipes:

The Daisy Garland - [www.thedaisygarland.org.uk/Pages/FAQs/Category/what-we-do](http://www.thedaisygarland.org.uk/Pages/FAQs/Category/what-we-do)

Matthews Friends - [www.matthewsfriends.org](http://www.matthewsfriends.org)

Atkins for Seizures - [atkinsforseizures.com/how-to-start/](http://atkinsforseizures.com/how-to-start/)

- Some children with uncontrolled seizures may be candidates for surgery, or the use of a vagal nerve stimulator. Your epilepsy professional can advise about these options.
- Some children living with epilepsy will experience depression or anxiety, and some of these children will have suicidal thoughts. Mood disorder symptoms may look different from child to child. Many will have low self-esteem and negative thinking but some will show irritability and disruptive behaviours, poor school performance, changes in sleep patterns or appetite.

Parents and teachers are to be aware of mood changes in children especially if seizures worsen, or after a medication change. Medical help and mental health support will be needed.

For more information on epilepsy and mood changes please visit our Epilepsy and Mood Disorders fact sheet: [ewct.org.nz/epilepsy-and-mood-disorders/](http://ewct.org.nz/epilepsy-and-mood-disorders/)

- Safety in the home (see “Safety in the home” fact sheet) and at school is important for all children with epilepsy. A risk management plan should be formulated with your child’s classroom teacher and school (see “Risk management” fact sheet). There should always be direct supervision by an adult around water activities including bathing and eating. Children should avoid biking in any traffic and climbing to heights greater than one metre, with the exception being playgrounds with safety mats.

- Ask for information, help and support from your EWCT epilepsy advisor. Your epilepsy advisor will explain the following:
  - What is epilepsy?
  - What are the different types of seizures?
  - Explain the difference between epilepsy and non-epileptic seizures
  - Discuss medications and how they work
  - Explain seizure triggers and how to manage them
  - Show you how to fill out a free EWCT seizure diary
  - Create an epilepsy action plan so you know what to do in the event of a seizure. It can be shared at schools/residential homes, etc
  - Discuss lifestyle issues and how to overcome them
  - Explain what happens in an EEG
  - Connect you with other social services
  - Explain what benefits you can receive and information on Ministry of Health funding
  - Give epilepsy-awareness talks to schools etc.
  - Give you children's books on epilepsy
  - Advocate on your behalf

By becoming informed you will feel empowered to manage your child's epilepsy.

- Many children with epilepsy can lead a good life and many will outgrow their condition. Ensure positive social interactions at home, at school and with family and friends. Please remember that having epilepsy is only a small part of who your child is.

Disclaimer: this fact sheet is for education purposes only. Please consult your doctor or other health professional for advice regarding your epilepsy.