

## Living with epilepsy in your family

Take some time to absorb the information you have been given by your doctor. Because your child has epilepsy, you may have to make some minor adjustments in your family lifestyle. Generally your family routines and experiences should remain the same as usual. The main changes that need to become part of your daily lifestyle involve the introduction of a regular medication regimen and promoting your child's safety if a seizure does occur. The following advice is important.

### Medication

Ensuring your child takes their medication every day will give them the best opportunity of becoming seizure free. It is a good idea to use a weekly medication box as this makes it really easy to tell if you have missed a dose by mistake. Smart phone alarms can be set to remind you and your child to take their medication.

### Friends and family

Experiencing an epileptic seizure can be stressful on the family. Brothers and sisters may be frightened at the time. Keep family members, teachers and friends well informed about your child's epilepsy. If they happen to be present during a seizure, it is important they know what to do or how they can help. The more people are aware and understand, the more acceptable it will become for your child and their friends.

### Sleep

Tiredness and sleep deprivation can lead to an increase in seizures. The occasional late night should do no harm, however repeated late nights are best avoided.

### Eating habits

A healthy, well balanced diet enhances general well-being and good health in children. Illness and inability to fight infection can lead to poorer seizure control.

### Exercise

Encourage childhood sports and activities to promote good health. Epilepsy should not limit your child's sporting participation.

### Realistic Precautions

Children with epilepsy should not be restricted in their activity with the exception of the following:

- **Swimming**  
Learning to swim is an important skill for New Zealand children. Children with epilepsy should be carefully watched when they are swimming by a responsible adult who knows what to do should a seizure occur and is close enough to reach the child quickly. A seizure while swimming could be fatal if there is nobody there to help. Remember to always supervise bath times if your child is having a bath. Showering is safe.
- **Bike riding**  
Until your child's epilepsy is well controlled by medication, we advise not to cycle on public roads. All children should wear an approved cycling helmet when cycling.

## School

To begin with some children may be afraid to do things they normally do, such as swimming, going to school or even going to sleep. They need understanding and time to adjust to their epilepsy. School attendance should be the same as for anybody else. Apart from additional supervision during certain activities such as swimming, children with epilepsy should be treated as normal children. Encourage them to be as independent as possible.

Teachers are able to deal with seizures if they are well informed. As epilepsy is common there is likely to be other children in the school with epilepsy.

It is important for the teacher to keep a record of seizures occurring during class for your benefit.

## Recording information

It is very helpful to keep an up to date record of your child's seizures. The following information is helpful:

1. What were they doing when it started?
2. How did it start? Which part of the body was first involved?
3. How did it progress? Did it include both arms and legs?
4. Were they aware of it happening? At what point did they lose awareness?
5. Did they lose consciousness? Was there a change in colour?
6. How long did it last?
7. Were they sleepy or disorientated afterwards?
8. Afterwards did they have trouble moving one side of their body?
9. Did they miss any medication today? Has the medication been changed recently?
10. How did they feel about it?

It is really helpful for your doctor to see your child's seizure so if you can video it on your phone that can be very valuable. Make sure your child is safe before you start videoing – or get someone else to video for you while you attend to your child. When you video a seizure it is good to get your child's whole body in the screen not just their head.

## Teamwork

As parents you are responsible for how your child's epilepsy will affect your day to day family life as a whole. Be well informed so your child's self-esteem and confidence develops normally - they will learn from you. Help them to communicate fears openly. Interaction with friends and gaining social ease amongst peers should be a natural behaviour regardless of their epilepsy. Encourage them to be responsible for taking their own medication when old enough although you will still need to check they are actually taking the medication appropriately. Your participation and the information exchange between you, your GP and specialist, plays an important part in achieving the common goal of maximum seizure control. Sometimes parents feel it helps to talk to other parents who have learned to live with epilepsy in their family.

**Epilepsy New Zealand** is a valuable resource for information and support. They can provide contact with other families of children who also have epilepsy. Epilepsy New Zealand has Epilepsy Educators who can provide more information for you, your child, other family members or your child's teacher.