

## How do I talk to my child about epilepsy?

### Your child will feel:

**Anxious:** about having seizures, getting accustomed to medication, constant visits to doctors or hospitals for special tests, this may temporarily affect your child's development. They will also worry about what others will think of them.

**Fear:** of dying, of losing control and the unpredictability of the seizures themselves.

**Grief:** because they have a changed lifestyle.

Encourage your child:

- to learn, explore and try new situations
- to have realistic, not pessimistic, expectations
- to express their feelings openly
- to accept seizures as a normal part of his or her life
- to find ways to explain epilepsy to others
- to focus on personal triumphs and other concerns, besides epilepsy.

## Talking to the Child about Epilepsy

- It is very important for parents to inform their child about their epilepsy. In order to do this you need to understand epilepsy yourself.
- How much parents tell their child depends on how much they think their child can handle. Make the information suitable for their age level and ability. Books and videos are available from your local epilepsy associations.
- Parents should discuss what epilepsy is; what happens during a seizure; what a person looks like during a seizure; how to manage epilepsy in terms of diet, lifestyle, medications and medical care; and how the child can tell others about their epilepsy.
- Your child with epilepsy may never have witnessed a seizure, give them a realistic description of what they look like during a seizure. Reassure children that although some seizures look dramatic it is very rare for a person to die or experience pain during a seizure.
- Encourage children to ask questions and talk about any concerns they have.
- Involve them in the management of their own epilepsy, eg. taking medications, becoming aware of their own triggers and talking to their doctor. Encourage them to research epilepsy themselves by using libraries and epilepsy associations.

## What do I need to tell other care givers?

- A clear explanation of what epilepsy is.
- A list of the medications the child is taking (including the dosages), who should administer it, and when it should be administered.
- Mention any side effects which the child may experience.
- Mention any triggers that may provoke seizures for your child (e.g. fever, flashing lights etc).
- A description of the type of epilepsy the child has, any auras or warnings the child experiences, what a seizure looks like and the usual duration and frequency of the seizures.
- Appropriate first aid to the child experiencing a seizure, both during and following the seizure, including how long the child may need to rest.
- If any activities need to be limited.
- If the child has any other medical conditions.
- Any other relevant information, including emergency phone numbers.

An example of an Epilepsy Information Form is included in this kit and will be helpful in a variety of situations.