How do I tell my child about his/her seizures?

As children are learning labels associated with experiences during the preschool years it is very important to provide your child with a label for his/her seizures.

Children with generalised seizures are unaware that a seizure is occurring, but are aware afterwards that something has happened. They may be confused following a generalised tonic clonic seizure, have dropped things during myoclonic jerking or missed something during an absence seizure.

Giving the event a name relating to how the child feels as he/she regains awareness helps them to understand that something occurred (“a sleepy/jumpy arm”). The child learns to associate the name with the consequence of the event.

Children who have simple or complex partial seizures may be more aware of what is occurring during the event.

Parents and children often use names that describe these feelings or actions (“dizziness or shakes”). This helps the parent and child communicate about what is occurring.

Giving these concrete references to the child’s experience is helpful early in the preschool years. As your child grows it will be important to let him/her know that they have seizures that are responsible for these events.

You can start between the ages of three and four to associate the word “seizure” with the child’s terms of events (“You had a sleepy seizure.” or “You had a dizzy seizure.”)

Parents can gradually progress to referring to the events only as seizures. As this term grows in meaning the child learns to use it as well.

From the age of three to four years they can begin to understand more about seizures.

How do I explain to my child why they need treatment for seizures?

Giving seizures a label makes it possible to talk about the treatment. A child at this age can understand: “You take medication for your seizures (‘dizzies/shakes’).”

Children are also learning about minor body parts and a child with epilepsy needs to be introduced to three important body parts:

- The stomach or tummy where food and medicine goes;
- Blood which moves around the body and “soaks up” food and medicine from the stomach (tummy) to take it to all parts of the body, including the brain; and
- The brain which makes our bodies work and also makes seizures happen.

Once your child has learned these important body parts you can start to explain how epilepsy is treated.

1. A three-year old needs to know that medicine helps his/her seizures (using the child’s term for the seizures). A four- to five-year old can understand that the medication goes to the tummy, gets soaked up by the blood and is carried to the brain to help control the seizures.
2. A three-year old needs to know that “pokes” (blood tests) tell the doctor how the medicine is working while a four- to five-year old can understand that blood tests show the doctor “how much medicine you have soaked up”.

3. A three-year old can begin to understand that the EEG tells the doctor “how the brain is working” while a four- to five-year old can begin to understand that seizures happen when the brain makes “too much electricity” and that the EEG is checking “the electricity in your brain”.

How can I help my child through medical treatment?

Children master events in their lives (including medical treatment) through their play. Your child will be visiting the doctor more often than most children of the same age. A toy medical kit is a good investment.

This allows your child to give “pokes” to their dolls, teddy bears or action figures, check their reflexes and listen to their hearts. You can make electrodes for your child to use EEGs on their toys by attaching buttons to strings and allowing them to use tape to attach these to the stuffed animals.

You can use the same play materials to practice medical procedures with your child. When your neurologist orders a medical procedure, ask what will be involved for the child. While playing with your child you will learn what they are thinking and feeling.

For example, make a tunnel with blocks and practice having a stuffed animal slide into the tunnel, lie very still, have a brain picture taken and then slide out.

Children in this age group also master events in their lives through story books. For a two- or three-year old child make sure that the book has only one sentence per page. Attention has grown for a three- to five-year old child to the extent that he/she can stay involved with stories that have three to four sentences per page.

Once you have a book, read it to your child a number of times as children needs repetition to gain mastery. Remember that Epilepsy South Africa can help you to acquire suitable material for your child.

How will I find a preschool for my child?

Many preschool children with epilepsy are developing language, intellectual and fine motor skills at the same rate as other children their age.

When looking for a preschool for your child you will want to interview the preschool staff about their experience with disability and chronic medical conditions in general and epilepsy in particular. Just as you educated the parents of your child’s peers, you will need to provide teachers with a fact sheet to help understand your child’s needs. Epilepsy South Africa can provide material and epilepsy sensitisation training at preschools.

Children with epilepsy can be at an increased risk for delay in the development of skills needed for succeeding in school. If you have concerns about your child’s development discuss these concerns with the preschool and neurologist.

Depending on your child’s needs he/she may receive occupational, physical and/or speech and language therapy in addition to the classroom programme.

(Source/reference: Growing up with epilepsy - L Blackburn, 2003)