



epilepsy

SOUTH AFRICA

Parenting a child with Epilepsy

You and Your Child

It is always a shock for a family to learn that a child has epilepsy. However, out of the initial shock and dismay you can build an understanding, loving and accepting environment in which your child can grow, believing in his/her own ability to succeed in life.

Your feelings

Like most parents you're concerned about your child's future. You may find it difficult to accept the word "epilepsy" or to talk about it. You may feel angry, depressed, inadequate and even guilty. It may seem to you that in some obscure way you have failed as a parent.

You can overcome these feelings and your anxiety by educating yourself. The more you learn about epilepsy, the easier it will be to accept the condition.

Why my child?

Understanding epilepsy and why seizures occur still doesn't explain why this happened to your child. You may be concerned that something in the genetic make-up of your family (you or your spouse) may be the cause and that the condition is therefore someone's fault. In fact, unless an individual's family history shows a strong recurring pattern of epilepsy, it is very unlikely that an inherited factor was responsible.

Possible causes of epilepsy

In approximately 66% of cases the underlying cause(s) of epilepsy is unknown. This is referred to as idiopathic

epilepsy. In the remaining cases the underlying causes can be identified which is known as symptomatic epilepsy.

There can be a verity of underlying causes such as:

- The result of a head injury that can occur at any age;
- A birth injury such as a lack of oxygen during birth;
- Fever convulsions, encephalitis or meningitis (but even childhood measles may lead to a child developing seizures); and
- Metabolic or biochemical disturbances or imbalances. Some known causes of epilepsy are unlikely to occur in children such as alcohol and drug abuse or degeneration (getting older).

Visits to the doctor

An experienced professional specialising in children with epilepsy probably knows that you tried to block out the word "epilepsy" from the first moment that he/she mentioned it. The doctor is well aware that you have received a major shock and probably have many questions. Before subsequent visits to the doctor (while you are relatively calm) write down the questions you would like to ask. This will guide you in your interaction with medical professionals.

The doctor will prescribe medication based on the age, physical condition and type of seizures of your child. Remember that anti-convulsant medication does not cure epilepsy, but will (in most cases) reduce the frequency and severity of seizures. As your doctor is the only person to decide if and when to change or decrease your child's medication you should never do so without medical advice. Remember that you have the right to seek a second or even a third opinion.

What do I tell my child?

Make your child aware of his/her condition. Children (as young as three) can understand that the brain controls the body, sometimes sending an incorrect message to the body. Older children should be given a more comprehensive explanation.

Older children may well ask “Why me?”

You will need to answer openly and honestly that you don't know. However, ensure that your child understands that it has nothing to do with anything he/she may have done.

You and your family

The anger, depression and possible guilt you are experiencing will pass. Husbands and wives should be a source of strength and comfort to each other at this time. You both need to be equally involved in your child's medical and social progress at all times.

Tension within the family is the last thing your family needs at this time. Children quickly pick up on parental tension and the child does not need the additional burden of knowing that his seizures are causing a rift in the family or between his parents. Inform close relatives and your child's friends. Epilepsy South Africa can assist you with information and material.

Do I tell his/her teacher?

Never hide your child's seizures (epilepsy) from the teacher and other responsible school officials. You will not be at school to assist during a seizure and teachers should thus be educated to deal with such situations.

The teacher may be apprehensive and it is therefore all the more important that you take the time to explain the condition and any possible first aid procedures. Don't forget that the teacher is your stand-in while your child is at school.

Epilepsy South Africa can assist you by supplying information and/or training, including age-appropriate material for children.

Useful hints on parenting a child with epilepsy

- Ensure that your child receives a comprehensive medical assessment by a qualified professional, ideally a neurologist.
- Always emphasise your child's abilities and concentrate on what he/she can do rather than on what he/she can't.
- Learn as much as possible about the condition.

- Be open and honest about the condition, both with yourself and your child.
- Emphasise any activity that will improve your child's self-acceptance, self-worth and self-confidence.
- Ensure adult supervision for some activities (e.g. climbing trees or swimming) without restricting your child unduly.
- Educate family and friends as epilepsy is only an “illness” when viewed through the eyes of the uninformed.
- Equip your child with the correct information about his/her seizures so that they can respond with confidence when questioned.
- Assure your child that proper care is administered while he/she has a seizure as this will allay unnecessary fears.
- Always ensure that medication is administered and taken regularly as prescribed.
- Provide a set routine with plenty of rest, three balanced meals per day and regular exercise. A regular routine helps to limit seizures.
- When explaining seizures use words that your child will understand. This will remove some of the mystery surrounding epilepsy.
- Always remember that there are 365 days in a year. If your child has one seizure per week, that leaves 313 days for your child to live a full life.
- Never allow your child to use seizures as an excuse for getting out of doing chores or accepting responsibility.
- Never use epilepsy as an excuse for lowering your expectations of your child.
- Don't talk about your child behind closed doors or as if he/she is not present.
- Don't use or encourage the use of negative words such as ‘epileptic’, ‘suffer’, ‘attacks’ and ‘fits’.
- Don't overprotect your child. Overprotection will stifle and smother the child's initiative and abilities.

