



epilepsy

SOUTH AFRICA

Living with Epilepsy

www.epilepsy.org.za

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You are likely to feel rather stunned and confused when first told that you have epilepsy. However, this is not a disaster. You may certainly need to make some small changes in your lifestyle, but the most important thing is to know and understand as much as possible about epilepsy and how it affects you. Life with epilepsy can have its ups and downs no matter how well controlled your seizures are. Accept the limitations the condition may impose on you from time to time and live life to the fullest. Living with epilepsy may have its problems, but with the right attitude these can be overcome.

What is Epilepsy?

Epilepsy is a tendency to have recurrent seizures. Seizures (or convulsions) occur when there are abnormal electrical discharges in the brain which may be triggered by chemical imbalance or a structural abnormality. The term “epilepsy” covers a variety of seizure types which differ in cause, nature, severity, management and long-term outcome.

What causes Epilepsy

Some people develop epilepsy because of brain damage brought on by injury, infection (e.g. encephalitis or meningitis), hormonal problems, circulatory problems or tumours. This is known as symptomatic epilepsy.

However, in most cases the cause remains a mystery (idiopathic epilepsy). It appears that people diagnosed with epilepsy have a lower resistance to seizures than the rest of the population.

Some people with epilepsy may identify factors (triggers) which bring on seizures. These could include stress, hormonal changes or illness. A particular type of epilepsy is triggered by visual stimulation such as flashing lights or a flickering TV or computer screen. This is called photosensitive epilepsy.

Types of Seizures

There are many types of seizures and a person may have more than one type and people don't have the same symptoms. The type of seizure depends on which part of the brain is affected. Seizures affecting the entire brain are known as “generalised”

which usually results in a loss of consciousness, however brief. Seizures affecting only a part of the brain is known as “partial” or “focal” and although consciousness may be affected the person usually stays conscious. In the same way that people's seizures vary, so do recovery times. This can be from a few seconds to a few minutes.

How is a diagnosis made?

The diagnosis of epilepsy is largely clinical. Therefore an accurate description of the seizures and the circumstances in which these occur is very important. Persons experiencing seizures are generally not able to describe their seizures. As such, such descriptions will probably be provided by friends or family members who have witnessed the seizure(s). These descriptions help in the diagnosis and may determine the need for further investigations such as:

Blood tests which will help your doctor assess your general health and eliminate other potential causes of seizures. CAT scans (Computerised Tomography) may be required to determine any structural changes in your brain.

EEGs (Electroencephalograms) measure changes in your brain's functioning, detected by alterations in electrical activity.

It is quite possible that any or all of these investigations will record “normal” results, but on the basis of observed symptoms, a diagnosis of epilepsy can still be made.

Medication: When and Why?

The majority of people with epilepsy control their seizures through anti-epileptic medication. A great deal of progress has been made in this field over the years and currently between 70% and 80% of people with epilepsy is able to control their seizures completely or greatly reduced seizure activity by using these drugs. The choice of drug depends not only on the type of seizure but also on you as an individual. As such, it may take some time to achieve the right dose for you.

Medication strengthens resistance to seizures and it is critical to take the prescribed dose at the prescribed time. The aim of drug therapy is to maintain the level of medication in your blood at the level needed to prevent or reduce seizures. Never stop taking anti-epileptic drugs suddenly without medical advice. If you forget to take a dose you should not “double dose”. Note and report any changes or side effects which may result from

your medication (though often minor and short-lived) to your doctor.

People who can Help

Your family doctor and neurologist

The person you see most often will be your family doctor or general practitioner (GP) who (together with you and your neurologist) will manage your epilepsy. You can help the medical professionals to identify the best treatment for you by keeping a record of your seizures, noting how you feel before a seizure and the circumstances surrounding it. Your neurologist will know most about your condition. Find out as much as you can because understanding your epilepsy will help you explain it to others.

You may find it useful to prepare a list of questions before you visit your doctor such as:

- Which type of epilepsy do I have?
- Is there an identifiable cause?
- Will I have to take medication?
- How long will I have to take the prescribed medication?
- What does the medication do?
- Are there any side effects?
- Will I be able to control my seizures?
- How will epilepsy and the treatment affect my life?

The social worker

You can get practical advice from your clinic/hospital social worker while advice and information about epilepsy is also available from Epilepsy South Africa and our social workers and other professionals.

Your family and friends

Openly discuss your epilepsy and treatment if at all possible as the support and understanding of your family and friends is invaluable. Make sure they have correct facts about your condition so that they can understand it. Remember, it is no disgrace to have epilepsy and it would be a tragedy to let it dominate your life. It is important that your family and friends respect your independence and not try to over-protect you.

Your employer and work colleagues

While most people with epilepsy are successfully employed in a wide variety of jobs many are afraid to disclose their condition to their employer and/or work colleagues. This is not advisable as keeping this secret will increase your stress which is likely to trigger seizures. Employers and colleagues need to know about epilepsy, how it affects you and what to do if you have a seizure. Epilepsy South Africa can help you by facilitating awareness and educational talks at your workplace.

Teachers and other learners

While teachers can be very helpful to your child with epilepsy this is only possible through regular and open communication between the teacher, you as parents and the child with epilepsy. Ensure that the teacher understands your child's condition by providing accurate information, particularly if he/she needs to assist your child to take medicine during the school day.

To avoid teasing and bullying also ensure that other learners understand your child's condition. Remember that Epilepsy South Africa can help you with age-appropriate material and information sessions which can be incorporated into the curriculum.

A child with epilepsy should not be treated differently from his/her peers and should be able to participate in most school activities and sport (with the necessary precautions taken). Never allow your child to be the source of limitations being placed on his/her class.

Helping Yourself

Safety is important for persons with epilepsy, but if you remember some basic, common sense rules you will minimise the likelihood of injury should you have a seizure.

Fires and stoves: Never come too close to an open fire.

Keep guards around open fires (e.g. fireplaces) and primus/gas stoves.

Bathrooms: Leave the bathroom door (which should ideally open outwards) unlocked. It is generally safer to shower than bath. However, if a shower is not available keep your bath water shallow. Turn the taps off before getting into the bath. Avoid bathing while alone at home (if possible).

Sleep: Some people have seizures during their sleep (nocturnal seizures) and are advised to sleep without a pillow.

Sport: With adequate precautions you should be able to participate in most sporting activities. Always wear a helmet when horse-riding or cycling. Swimming, mountain/rock climbing and sailing should not be done alone. Make sure that whoever is with you are aware of your condition and know what to do if you have a seizure.

Identification: Ensure that you carry identification with you, including the contact details of a family member or friend to contact in the event of a seizure. It is also good to include the name and contact number of your doctor. Remember that you may not be able to provide this information at the time. It is also a good idea to wear a MedicAlert disc identifying you as a person with epilepsy. These are available from Medic Alert (www.medicalert.co.za).

Self-help and support groups: Some people find enormous support in belonging to a self-help or support group. For more information about a group in your area contact your nearest Epilepsy South Africa Branch. It might also be a good idea to start a support group to suit your needs. Again, Epilepsy South Africa can assist you with this.

Looking to the Future

Improved medical treatment and better understanding of the condition in recent years enable most people with epilepsy to lead full and active lives. While the initial diagnosis may be a shock and require some changes to your lifestyle try to come to terms with it as quickly as possible so that you can get on with your life!

If this seems difficult, the following tips should be helpful:

- Educate yourself and others about epilepsy and help to dispel the myths and misconceptions about the condition. If you would like to participate in the awareness activities of Epilepsy South Africa contact your nearest Branch.
- Find a doctor in whom you have confidence. It is important that you have a good working relationship with your doctor which starts by following his/her advice.
- Be open with others and try to ignore any negative reactions. These often result from a lack of knowledge and understanding.
- Don't let the fear of having a seizure keep you at home.
- Remember that with the right approach, qualifications and skills, epilepsy need not be a major barrier to employment.
- Help is available from your doctor/clinic or the nearest Epilepsy South Africa Branch.