



## **EPILEPSY SUPPORT ASSOCIATION UGANDA**

Plot 695, Gombe B Village off Kayunga - Kinoni – Wakiso Rd  
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### **LIVING WITH EPILEPSY**

When you are first told that you have epilepsy you are likely to feel rather stunned and confused. But it is not a disaster. Certainly, you may need to make some small changes in your life. The most important thing is to know and understand as much as possible about epilepsy and how it affects you.

No matter how well controlled your epilepsy is, life with epilepsy can have its ups and downs. Accept the limitations it 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 they can be overcome.

#### **WHAT IS EPILEPSY?**

The word epilepsy means a tendency to have recurrent seizures. Seizures (or convulsions) occur when there is abnormal electrical discharge in the brain. This may be triggered by chemical imbalance or a structural abnormality. The term epilepsy is used to cover a variety of seizure types. These differ in cause, nature, severity, management and long-term outcome.

#### **WHAT CAUSES EPILEPSY?**

Some people will develop epilepsy because of brain damage brought on by injury, infection (e.g. Encephalitis or meningitis), hormonal problems, circulatory problems or tumours (Symptomatic Epilepsy).

However, for most the cause remains a mystery (Idiopathic Epilepsy). It appears that those who develop epilepsy have a lower resistance to seizures than the rest of the population.

Some people with epilepsy may identify factors 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 flickering TV.

#### **TYPES OF SEIZURES**

There are many types of seizures and a person may have more than one type. No two people will have the same symptoms. The type of seizure depends on which part of the brain is affected. If the whole brain is affected then the seizure is known as “generalized” and there is a loss of consciousness, however brief.

If only part of the brain is affected, then it is known as “partial” or “focal” and consciousness although affected may not necessarily be lost.

Just as people’s seizures vary, so do recovery times. This can be from seconds to minutes.



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### **HOW IS A DIAGNOSIS MADE?**

The diagnosis of epilepsy is largely clinical; therefore an accurate description of the seizures and the circumstances in which they occur is most important.

These descriptions will probably be provided by friends or relatives who have witnessed the seizure. This will help in the diagnosis and may determine the need for further investigations such as:-

- Blood tests – which will help the doctor assess the general health of the person and will eliminate other potential causes of seizures.
- CAT Scans (computerized Tomography) may be taken to determine whether or not there are any structural changes in the brain.
- EGG (Electroencephalogram) will measure changes in the 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 have their seizures controlled by anti-epileptic medication. A great deal of progress has been made in this field over the years and now about 80% of people with epilepsy will have their seizures totally controlled or greatly reduced thanks to these drugs.

The choice of drug depends not only on the type of seizure but also on the individual and it may take some time to achieve the right dose for each person.

Medication strengthens the resistance to seizures. It is most important to take the prescribed dose at the prescribed time. The aim is for the amount of medication in the bloodstream to be maintained at the level needed to prevent or reduce seizures. Anti-epileptic drugs should not be stopped suddenly without medical advice. If a dose is forgotten, it is not advisable to “double dose”. Any changes or side-effects which may result from your medication (though often minor and short lived) should be noted and reported.

### **PEOPLE WHO CAN HELP**

#### **FAMILY DOCTOR AND NEUROLOGIST**

The person you see most often will be your GP who together with you and your neurologist will manage your epilepsy. You can help them to help you by keeping a record of your seizures noting how you feel before a seizure and the circumstance 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.

### **SUGGESTED QUESTIONS:-**



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- 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 it?
- What does the medication do?
- Are there any side effects?
- Is control possible?
- How will it affect my life?

### **SOCIAL WORKER**

You can get practical advice from your clinic or hospital social worker. Advice and information about epilepsy is also available from the Epilepsy Support Association.

### **RELATIVES AND FRIENDS**

Be as open as possible with people. The support and understanding of family and friends is invaluable. Make sure they have the correct facts about your condition. It is no disgrace to have epilepsy and it would be a tragedy to let it dominate your life.

It is important that family and friends respect the independence of people with epilepsy and do not try to over-protect them.

### **EMPLOYERS**

Most people with epilepsy are successfully employed in a wide variety of jobs. Many people are afraid to disclose to their employers that they have epilepsy. This is not advisable. Employers and colleagues need to know about epilepsy and how it affects you and what to do should you have a seizure.

### **TEACHERS**

Teachers can be very helpful. One cannot stress strongly enough the importance of regular and open communication between the teacher, the parents and the child with epilepsy.

### **HELPING YOURSELF**

Safety is important. If you remember some basic, common sense rules, you will minimize the likelihood of injury should you have a seizure.

Fires and stoves: - Never come too close to an open fire. Keep guards around hearth fires and primus and gas stoves.

### **BATHROOMS**

Doors should be left unlocked and if possible should open outwards. A shower is often preferable to a bath, but if not available, bath water should be kept shallow and the taps should be turned off before getting in. Avoid bathing while alone at home.



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**Sleep:** - Some people have seizures during their sleep. Sleeping without a pillow may be advisable.

**Sports:** - With adequate precautions, no sport need be barred. When horse riding, always wear a helmet. Swimming, mountain climbing and sailing should not be done alone. Make sure that whoever is with you is aware of your condition and knows what to do if you have a seizure.

**Identity Discs:** - It is an excellent idea to wear a Medic Alert Identity Disc at all times. It is also a good idea to keep an identity Card containing your name and address and your doctor's name and telephone number in your purse or wallet.

**Self-Help Groups:** - Some people find enormous support in belonging to Self-Help Groups.

### LOOKING TO THE FUTURE

Thanks to better medical treatment and improved understanding of the condition, most people with epilepsy lead full and active lives. Yes, the diagnosis may come as a shock and you may have to make some changes to your lifestyle. But 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 of the past.
- Find a doctor in whom you have confidence and follow his/her advice.
- Be open with other and try to ignore any negative reactions.
- 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 to be a major barrier to employment.