



# EPILEPSY SUPPORT ASSOCIATION UGANDA

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## CHAPTER 1: UNDERSTANDING EPILEPSY

### 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.

### 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.



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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.

## ***SUGGESTED QUESTIONS:-***

- *Which type of epilepsy do I have?*
- *What does the medication do?*
- *Are there any side effects?*
- *Is control possible?*
- *How will it affect my life?*
- *Is there an identifiable cause?*
- *Will I have to take medication?*

## **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.

### **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.



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## **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.

**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.

## **FACTS ABOUT EPILEPSY**

- *Epilepsy is the most common neurological condition.*
- *About 1 in every 100 people has epilepsy.*
- *A single seizure does not necessarily mean you have epilepsy.*
- *Epilepsy can affect anyone, at any age.*
- *75% of people with epilepsy have had their first seizure before the age of 20.*
- *Up to 80% of people will have their epilepsy controlled by medication.*
- *Many children with epilepsy will outgrow it.*
- *Epilepsy is not a mental illness or psychiatric disorder.*
- *Epilepsy is not infectious or contagious.*
- *1 in 20 people have a seizure at some time in their lives.*
- *A seizure is caused by abnormal chemical activity of the brain.*
- *Slightly more males than females have epilepsy.*
- *There are different forms of epilepsy and types of seizures.*
- *Some people's seizures follow a definite pattern while others have unpredictable seizures.*
- *Some people get a warning before a seizure.*
- *Most seizures are over quickly and are easily dealt with.*
- *Epilepsy affects people of all levels of intelligence and from all racial and social backgrounds.*
- *Anyone can develop epilepsy at any stage of life.*
- *For most people with epilepsy, the biggest problem they have to face is other people's attitudes to epilepsy.*
- *What people with epilepsy most need is understanding and acceptance from the public.*

## **FIRST AID FOR SEIZURES**

Medical help is usually not necessary, but should be sought if:-

- Repetitive seizures occur without the regaining of consciousness in between.
- The seizure shows no sign of stopping after a few minutes, or



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- There is a physical injury during the seizure.

## 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.

## HOW TO RECOGNIZE A SEIZURE AND WHAT TO DO

The following table should be helpful in recognizing seizures and assisting a person when a seizure occurs.

SEIZURE	WHAT IT LOOKS LIKE	HOW YOU CAN HELP
<b>Generalised (previously Petitmal)</b> <b>absence named</b>	<ul style="list-style-type: none"> <li>- The person looks blank and stares.</li> <li>- There may be blinking or slight twitching. It lasts a few seconds then normal activity continues</li> </ul>	<ul style="list-style-type: none"> <li>- Be reassuring. The person may be unaware of the seizure. Note that it has occurred.</li> </ul>
<b>Generalised tonic clonic (previously Grandmal)</b> <b>tonic clonic named</b>	<p>The common sequence is: staring; stiffening of the body; possible blue colour around the mouth; jerking movements. As breathing restarts normal colour returns.</p> <p>There may be blood flecked saliva and incontinence (rare). Last a few minutes.</p>	<p>Protect the person from injury. Cushion the head. Do not restrict movement or put anything in the mouth. Help breathing by putting the person on to the side. Stay with him or her until fully recovered.</p>
<b>Complex (affecting a specific area of the brain)</b> <b>partial</b>	<p>May start with a warning or “aura” The person may appear confused or distracted. There may be repetitive movements, eg Plucking at clothes.</p>	<p>Remove harmful objects and guide the person away from danger. Talk quietly to reassure him or her.</p>

## CHAPTER 3: MEDICAL MANAGEMENT OF EPILEPSY

### MEDICATION FOR EPILEPSY

The standard modern treatment for epileptic seizures is the regular use of one or more chemical substances called anti-convulsant or anti-epileptic drugs.

Treatment with anti-convulsants has dramatically changed the kind of life that people with epilepsy can expect to live. For hundreds of thousands of people these drugs have meant the difference between a fearful, isolated existence and a confident life and successful employment based on the knowledge that the chances of having a seizure are small.

There are a number of different anti-convulsants available. None of them can cure epilepsy, but they have become increasingly successful in preventing seizures as long as they are taken regularly.

An anti-convulsant may be prescribed as a single drug or in combination with other drugs. If a person has more than one kind of epileptic seizure, he or she may have to take more than one anti-convulsant to maintain control. This is because drugs that prevent one type of seizure may not necessarily be effective for another type. However, physicians try, wherever possible to limit the number of drugs prescribed and to use a single drug if they can.

### FINDING THE RIGHT DRUG

People react individually to drugs just as they do to food or other substances that enter the body. One person may experience side effects from anti-convulsants, while another person may not. Some drugs reach an effective (that is, seizure-preventing) level in the person's blood more quickly than other drugs do. (Anything from 3 days) That is why it may take some time to "customize" the dosage and/or the choice of drug. A doctor tries to strike a balance when prescribing an anti-convulsant drug to achieve the greatest degree of seizure control in the patient with the smallest number of side effects.

### NEW TESTS HELP

In the old days it might have taken many weeks, even months, to achieve the right drug, or combination of drugs, and dose for an individual patient. Now doctors treating epilepsy have a tool which shows them what is happening to the medication after it enters the patient's body.

This technique is called anti-epileptic level monitoring. It examines a sample of the patient's blood to find out how much of the medication is present. If the level of the drug in the blood is too low, seizures may occur and the doctor will increase the amount the patient takes. If the drug level is too high, the patient may also experience an increase in seizures as well as undesirable side effects, such as feelings of drowsiness, confusion or unsteadiness (sedation is a common side effect). In such cases the dose will be reduced to arrive at an optimum level.

Medical experts suggest that drug level tests be performed as a treatment programme progresses and subsequently when clinical changes take place or are contemplated, or if seizures suddenly begin again after a period of good control. Blood samples are usually obtained before the early morning dose. It has been found that the quantity of enzymes, which the liver will produce to break down medicines, varies from individual to individual and within each individual as his circumstances change.

### DRUG INTERACTIONS





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Once a person is stabilized on an anti-convulsant, the addition of another anti-convulsant or other medication may either increase or decrease the concentration of the original anti-convulsant in the blood stream. If an additional anti-convulsant is given to a stabilized patient, he may show symptoms of medicine toxicity or of altered seizure activity. Some examples of interactions include.

Anti- convulsant	Medication which may affect blood level concentration of certain anti-epilepsy drugs.
Phenytoin	Phenobarbitone, valproic acid, diazepam, aspirin, some oral contraceptives, propranolol
Carbamazepine	Phenytoin/phnobarbitone, propoxyphene, erythromycin
Phenobarbitone	Valproic acid, phenytoin, carbamazepine
Valproic acid	Phenytoin. Phenobarbitone, Carbamazepine

Apart from ant-convulsant blood level interactions, it should be remembered that several medicines can themselves precipitate seizures. Sometimes another drug, prescribed for an unrelated medical problem, will intensify the effect of an anti-convulsant drug. On the other hand, the anti-convulsant drug may intensify the effect of a drug not being taken to control seizures. This phenomenon is called drug interaction and it is the reason that patients are urged to tell their doctors what other medications they are taking whenever a new drug is prescribed. When purchasing an over –the counter product, a person taking anti-convulsants should check with the pharmacist as to the nature of possible drug interactions.

You should also consult with your doctor or pharmacist before taking any other medication eg. anti-depressants, anti- nausea, oral contraceptives, and anti-motion sickness drugs, cough and cold preparations.

## SIDE EFFECTS

Like all drugs, anti-convulsants may have some side effects. The appearance of these depends on each person’s individual response to the drug as well as much of it he or she is taking. With only a few exceptions, side effects associated with anti-convulsant drugs are mild and usually occur at the beginning of therapy, usually disappearing as the person becomes used to the drug.

Depending on the type of drug involved, the most frequent side effects are drowsiness, irritability, nausea, rash, thickening of facial features, increase in the body hair, physical clumsiness, and hyperactivity in children. Some drugs may produce emotional changes; occasionally a drug will actually increase rather than decrease the number of seizures a person experiences.

However, many people are able to take the medication for years without experiencing any of these effects. If side effects do occur, they should be reported.

## DRUGS AND PREGNANCY

While there is a slightly higher than normal risk of birth defects in the babies of women who have epilepsy, the greater majority of mother (92%) on anti-convulsant medication give birth to normal, health babies.

When pregnancy occurs, the question for a woman with epilepsy and her doctor becomes one of balancing the risks and the benefits. Is the risk of the mother having a seizure and possibly falling, or experiencing an oxygen shortage, greater to a developing child than the risk of some defect developing as the result of anti-convulsant medication? Is the risk of seizures during pregnancy a greater hazard to the mother than the risk



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of a defect in the child? Unfortunately these questions are not easy to answer given current levels of knowledge. At present most medical experts would say that the risk of having a child with a defect is so low, that the possibility of having a seizure offers the greater potential harm. It is not yet certain, when defects occur, that the drug is necessarily the cause; family history may also be involved.

What is certain is that sudden withdrawal of anti-convulsants may cause non-stop severe seizures which may injure the mother and or interrupt the supply of oxygen to the developing child. In any case withdrawal of medication after the pregnancy is detected would not necessarily prevent a possible defect since by that time (usually about six weeks after conception) any malformations in the foetus would already have occurred. Thus women with epilepsy are being advised to continue their drug therapy during pregnancy under close supervision by a doctor.

The best solution for a woman who has epilepsy and who is taking anti-convulsants is to discuss the whole question of anti-convulsants during pregnancy with her doctor before she becomes pregnant. At that time the doctor may evaluate her continuing need for the drugs. If she has been seizure-free for a number of years and other tests show no sign of epilepsy, her doctor may decide before pregnancy begins to try a slow withdrawal from the medication. If the woman still needs medication but is taking a drug which has been closely associated with birth defects, the doctor may decide to see whether another medication could be successfully substituted.

## **ANTI-CONVULSANTS AND CHILDREN**

Early recognition of seizures and regular consistent treatment with anti-convulsant drugs offer the best chance of normal development and a positive future for the child with epilepsy.

Because of the many physical changes that take place as the child grows, it is not unusual for a seizure-free child to suddenly begin having seizures again. This does not mean that medication is not working or that the condition is getting worse; usually a change of dosage by the doctor will take care of the problem.

Because of the differences in the way in which the physical systems of children and adults process drugs, it takes a relatively larger dose of the anti-convulsant to control seizures in the average child than in the average adult. At the onset of puberty (adolescence stage), the body chemistry changes over from that of childhood to adulthood. It can happen in a matter of months. This may necessitate a change in dosage.

Children should be encouraged as early as possible to be responsible for taking their own medication. In most cases this will give them a sense of being in control of their condition. The decision on whether or not to allocate responsibility to the child should depend on his or her maturity and intelligence level.

If medication is being given in liquid form, the bottle should be taken well before the dose is poured. If this is not done, the effective part of the medication may sink to the bottom, making the first doses too weak and the last ones too strong.

When medication is prescribed, the doctor should be asked if it should be taken before, during or after meals. Sometimes medication on an empty stomach can increase the possibility of stomach upset. On the other hand, taking certain drugs after food may affect the rate at which the drug is absorbed into the blood stream.

## **ANTI-CONVULSANTS AND DRUG ABUSE**

Parents often worry that children who take anti-convulsants may become addicted to them or be more susceptible to drug abuse.

Although it is true that barbiturates e.g. phenobarbitone are subject to abuse, the doses in which they are prescribed for epilepsy are not habit-forming. In fact, a more common reaction on the part of the adolescent with epilepsy is to express his rebellion against drugs rather by taking more of them.

## **DRUG THERAPY: A PERSONAL RESPONSIBILITY**

Successful drug therapy involves more than care by a skilled physician. It also requires the active co-operation of the patient.

### ***Important points to remember if you or someone in your family takes anti-convulsants***

- ❖ *Don't take less or more than prescribed. You may have a seizure.*
- ❖ *Don't stop your medication abruptly. You could risk a medical emergency in the form of non-stop seizures which could be life threatening.*
- ❖ *Attend all follow-up appointments. Anti-convulsant drugs are safe and generally effective but careful monitoring is advisee.*
- ❖ *Don't try other people's pills even if a friend has better control with a different medication, check with your doctor instead.*
- ❖ *Alcohol and medication can be a dangerous combination. Both are depressants and one may affect the other.*
- ❖ *Don't drive or operate power tools when starting a new medication until you know how it affects you. It may make you drowsy at first.*
- ❖ *Don't assume that if you've missed a few doses of your medication you can then make them up safely by taking them at once. What you need is a certain amount of medication taken at regular intervals.*
- ❖ *If you have trouble remembering to take your medication in sequence (this may be necessary if you are taking more than one type of drug), try counting out each days' supply of pills and storing them in special containers you can buy from a pharmacy.*
- ❖ *Don't let yourself run out of medication. If you are going on a trip, make sure you have enough to last until your return and carry a copy of your prescription with you. If you are going overseas find out from your doctor what the medication is called abroad (drugs often have different names in different countries).*
- ❖ *Keep all medication locked up and away from children. If you plan to carry medication in a container other than a pharmacy bottle, make sure your prescription label is fixed to it.*

*In conclusion, anti-convulsants drugs are successful in preventing seizures in the majority of people who take them as prescribed. It is estimated that at least 50% of all people with epilepsy gain complete control of their seizures.*



## CHAPTER 4: EPILEPSY AND WOMEN

Our bodies experience many physical changes throughout our lifetime, and there's no evidence to suggest that epilepsy interferes with this process. Epilepsy has specific implications for women in respect of their gynaecological health and child bearing

### FEMALE BIOLOGICAL CHANGES

**Menstruation:** - There is no evidence to suggest that women with epilepsy experience any major differences in their menstrual patterns. Some women may find a change in seizure pattern, with an increase in seizures either during their period or at the time of ovulation.

**Menopause:** - The menopause usually occurs between your mid 40's to mid 50's and may have unpleasant symptoms such as hot flushes and night sweats. Hormone replacement Therapy (HRT) may be prescribed to relieve these symptoms.

There is no medical proof to indicate an association between epilepsy and menopausal changes or that HRT influences seizure control or the absorption of anti-epileptic drugs. If you suffer from osteoporosis and if seizures are a problem, this could be a problem.

### YOU AND YOUR PARTNER

**Relationships:** - It is understandable that women with epilepsy may be anxious about establishing intimate relationships but many do form satisfying stable relationships. To do this it is important that both of you are open with each other and discuss your epilepsy and its implications for your life together.

**Sex drive:** - In a small number of people, epilepsy and anti-epileptic drugs may cause a slightly lower sex drive. For most people this is not a problem and they are able to enjoy sexual intercourse.

**Fertility:** - Research has shown that a limited number of women may have a lower fertility rate due to epilepsy. But there is no reason to believe that anti-epileptic drugs will reduce your fertility.

**Contraception:** - Women with epilepsy can choose from all the contraceptive methods available. Your doctor will be able to advise which is the most suitable for you. It's important to note that the effectiveness of some forms of the pill can be reduced by anti-epileptic drugs and higher doses may be necessary to provide adequate contraception.

**Heredity:** - The chance of passing epilepsy on to your children will depend on the type of epilepsy you have and other factors. If you've had it since birth there's about a 6% chance that your child will also have it too.



## PREGNANCY AND BIRTH

**Family planning counseling:** - If you are thinking about having a baby, its best to discuss the matter with your doctor before becoming pregnant. This will allow you to gather all the information you need in order to decide on planning your family.

Your partner should join you in counseling to share his concerns and to be informed of the possible risks to you and your baby's health.

**Anti-epileptic medication:** - Before becoming pregnant it is important to discuss your medication with your doctor as it may need to be changed to minimize the risks to your baby. Some drugs can affect the growing fetus so it is essential that this be checked out with your doctor as soon as possible. Generally it is preferable to remain on medication with the small risks this may carry rather than to withdraw all drugs and risk losing control of your seizures.

**Seizure patterns:** - Some women experience changes in their seizure pattern during pregnancy. There may be a slight increase or decrease in frequency.

**Diet:** - Some anti-epileptic drugs may reduce vitamin K in the bloodstream which can affect the clotting mechanism in the blood. In such cases the doctor may recommend that vitamin K is taken by the mother before delivery and by the baby for a short while after birth. Some drugs are known to increase the risk of neural tube defect such as spina bifida.

It is advisable that all pregnant women but in particular those with epilepsy should take a folic acid supplement during pregnancy.

**Medical check-ups:-**It's important to see your doctor regularly during pregnancy. You should report any seizures or incidents which have occurred such as falls, vomiting, illness or injury.

## DELIVERY & CARING FOR YOUR BABY

**Labour:** - Your labour and the delivery of your baby is not likely to be different from that of other mothers. By taking your medication correctly and getting as much rest as possible, you will reduce the risk of having a seizure during labour.

Remember that you will not be alone during this time and immediately after the birth.

**Breastfeeding:** - The likelihood of your baby being affected by anti-epileptic drugs present in your milk will depend on the medication you take. In the majority of cases very little of the drug is passed on to the infant and should not pose a problem. In fact, this may be a way of weaning your baby of the medication that would have been absorbed during pregnancy.



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If you tend to have seizures without warning, it is advisable that you take precautions while feeding your baby. You could try sitting on the floor with your back on the wall surrounded by cushions.

**Bathing and changing your baby:** - Using a bath stand could be risky so its best to put the baby bath on the floor. If you feel this is still too risky and there is no one to assist you, it may be best to sponge your down on a waterproof sheet. Changing your baby in the cot or on a blanket on the floor is a good idea. By kneeling to the side, you will fall away from your baby should the seizure occur.

**Sleep:** - Having a new baby in the home is physically and emotionally draining. Make sure to get plenty of rest and accept any offers of assistance you get from friends and relatives.

**Parenthood:** - Like all new parents you and your partner will find parenthood exciting and challenging. The pleasure you get from your baby should not be affected in any way by the fact that you have epilepsy.

### CHAPTER 5: *LIVING WITH EPILEPSY*

#### *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*



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There are a number of procedures available to assist the doctor in making an accurate diagnosis of the type of epilepsy a person has. The names can be confusing and what follows is a brief summary of the various tests which might be recommended.

## **The EGG**

An electroencephalogram or EGG is a written record of the brain's electrical rhythms. To record these rhythms a number of small metal discs, called electrodes, are placed against the scalp at various points. They are held in place by a glue-like substance which can easily be washed off later. With the electrodes in place, the person will either sit or lie down in a restful state with his/her eyes closed. The test takes about thirty minutes. During this time the person will be asked to perform certain simple tasks, such as blinking, breathing deeply or some form of mental activity. The test usually includes a series of flashing lights at various frequencies since some forms of epilepsy may be stimulated in this way. When testing young children who may become restless, it is necessary to give them a mild sedative. Sometimes it is necessary to obtain a recording over a period of hours or days. A portable EEG machine can be attached to be person to perform the test while carrying out normal activities, including sleep. This is called EEG telemetry. In certain circumstances it is necessary to admit the person to hospital and monitor the brain's activity through EEG telemetry and continual video recording at the same time. This enables the doctor to match brain rhythms with behaviour and seize activity.

## **The CT scan**

Computerized Tomography (CT) provides cross sectional images or slices) of the brain. The person lies on an X-ray table which is moved slowly into the CT unit, which contains the scanner. Only the upper part of the head moves within the scanner. At X-ray device rotates around the person's head in an arc formation, recording a number of images of the brain. To make the images clearer, a dye is injected into a vein in the person's arm. The whole procedure takes about 45 minutes and provides valuable information for diagnosing epilepsy. The procedure is painless.

## **The MRI scan**

Magnetic resource imaging (MRI) is a method of scanning the brain without using X-rays. During the MRI scan the person's head is surrounded by a magnetic field. Radio frequency waves are produced to stimulate the brain. The energy changes that result are used to produce computer images which look like two-dimensional slices through the brain. The magnetic field and radio frequency waves are completely painless and cause no known physical harm. At worst the person may feel some discomfort from having to lie still in the "tunnel" while the machine is scanning their head. To minimize discomfort, a fan circulates air and a mirror at the end of the tunnel allows the person to see the room and scanner operator. An intercom call button is right beside the person's hand so verbal communication can be maintained throughout. Some people choose to wear ear plugs to block out the metallic thumping noise of the machine. The MRI scan takes about an hour and a half.

## **Pet scanning**



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Position Emission Tomography (PET) is a non-invasive imaging technique that creates a three-dimensional image of the brain. Short-acting radioisotopes are injected into the blood. The person then rests for about 30 minutes. During the scan a mask is placed gently over the person's face to limit movement. An EEG recording is taken at the time. There are microphones in the scanner so the person can communicate with the operator at all times. The images are produced by analyzing the uptake of glucose in the brain. For this to happen, it is necessary that the person must fast for a certain period prior to the PET. The scan takes between 30 and sixty minutes. PET scanning is extremely costly and has been largely replaced by the SPECT scan.

## **SPECT Scanning**

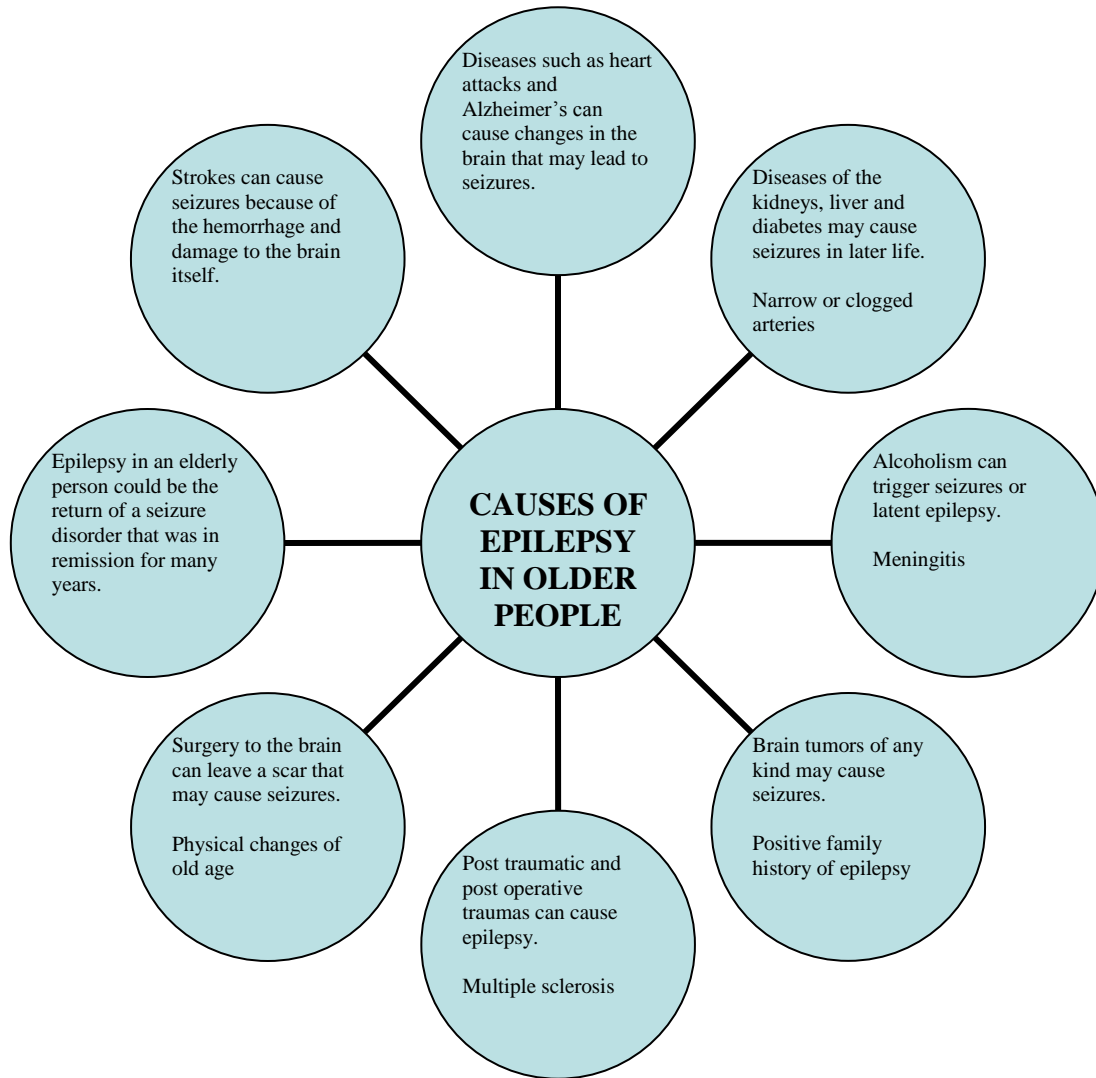
Single Photon Emission Computed Tomography (SPECT) is similar to PET scanning. It uses different radioisotopes which are able to hold the image of the blood flowing through the brain for up to 24 hours. The SPECT Scan looks at blood flow through the brain during a seizure (ictal phase) and compares this with the inter-ictal (seizure free) scan. This highlights the "hot spot" or origin of the seizure in the brain. The scan can be performed anytime from an hour after the radioisotopes have been injected, up to 24 hours later. A mask is not required and an EEG is not taken. The actual scan usually takes about 20 to 30 minutes.





## **CHAPTER 7: EPILPESY AND THE ELDERLY PERSON**

Of the total population who are diagnosed with epilepsy for the first time, only 2% are elderly people for the first time, only 2% are elderly people. The physical changes related with ageing are most likely the cause of epilepsy.



## EPILEPSY AND THE PROCESS OF AGING

Decrease in mental alertness, mood changes and memory loss can be caused by several health problems associated with ageing. There may also be other explanations for the change in behavior of the elderly person

### ❖ TOXICITY

The therapeutic levels of anti-convulsant medication need to be monitored through regular blood tests. If the levels are too high it could cause toxicity, which could, in turn, manifest as dizziness and confusion.

### ❖ DRUG INTERACTION

The elderly person is most likely taking a variety of medication for different medical reasons. These drugs can interact and produce negative side effects. It is therefore of utmost importance to discuss possible drug interactions with the doctor and/or pharmacist.

## ❖ SENSITIVITY

A negative reaction to drugs may result in depression, agitation, confusion or loss of memory. Monitor any changes in sleeping eating patterns. It is possible that the person is sensitive to specific drugs. Consult with the doctor and never change or stop medication without the doctor's advice.

- *The first seizure is a very traumatic experience with far reaching social consequences*
- *An elderly person may feel useless and of little value to society. Loneliness, physical changes, the fact that they cannot live independently or drive a vehicle can cause depression. This is even worse for the elderly person with epilepsy*
- *The elderly person has a higher risk of sustaining head injuries or fractures due to frequent falls.*
- *They may feel as if they have lost control over their own lives and feel uncertain about their future*
- *The elderly person with epilepsy can become socially isolated*
- *If the person does not experience an aura (a warning sensation that occurs prior to a seizure) the person will need to adjust accordingly to the DOs and Don'ts.*

## MEDICATION

Memory problems often affect people with epilepsy. Epilepsy medicine works best when blood levels remain steady. The correct dosage must be taken at specific times to maintain blood levels and to achieve optimum therapeutic results.

It can be difficult to keep track of when to drink what medication and therefore we suggest:

- A pillbox/ dispenser divided into segments according to the time and day is useful
- Pills can also be packed in sachets marked with the specific hour of the day and day of the week
- A wristwatch with an alarm can be helpful to remind someone when to take their medication
- A friend or family member can be asked to assist in keeping track of reordering dates and mark the calendar accordingly.

## DOs & DONTs

- Remember fire, heat and water are dangerous to any person with epilepsy
- Do not smoke or abuse alcohol if you have epilepsy
- Avoid carrying hot dishes or boiling water in a kettle
- Set the water temperature on the geyser lower to prevent the water from burning you.
- Do not bath or shower in excessively hot water as it may bring on seizures
- Avoid ironing if at all possible
- You can drown in very little water. If possible shower instead of taking a bath and do not lock the bathroom door.
- Wear rubber gloves when handling or washing glassware
- Place a screen in front of open fires and do not carry hot ashes
- If possible avoid staying in a house or flat with stairs. You may fall down on the stairs while having a seizure
- Carpeted floors and padded furniture provide more protection.
- Protective and padding can be used on sharp corners of tables to prevent injuries.
- Keep in touch with family or friends with beepers and/or portable phones.
- A medic Alert bracelet can be useful to identify a person while having a seizure enabling the public to be of assistance.

## *THE SOCIAL IMPACT OF EPILEPSY ON THE ELDERLY*

### **IT IS IMPORTANT TO REMEMBER:**

- Do not emphasise what the elderly can do, not what he or she cannot do (while at the same time taking sensible precautions).
- Do treat the elderly person like everyone else in the family.
- Do help your elderly integrate into as many social activities as possible, with the necessary precautions, enabling a health social life.
- Do allow the elderly person to make his/her own decisions where possible.
- Don't over protect the elderly. Allow the person to identify his or her own strengths and weaknesses.
- Don't blame the elderly's epilepsy if the family experiences difficulties.

Should you have any further concerns about taking care of the elderly you can contact an Epilepsy Support Association Uganda which offers advice on various issues concerning the elderly.



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## **CHAPTER 8: PARENTING THE CHILD WITH EPILEPSY**

### **You and your child**

It is always a shock for a family to learn that a child has epilepsy. But 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 own ability to succeed in life

### **HOW YOU FEEL**

Like most parents you are concerned about your child's future. You may find it difficult to accept the word "epilepsy" or talk about it. You may feel angry, depressed, inadequate and even guilt. It may seem to you that in some obscure way you have failed as a parent. Overcome your anxiety by becoming informed- the more you learn about epilepsy, the easier it will be to accept the condition

### **WHY MY CHILD?**

Knowing what epilepsy is and why a seizure occurs still doesn't explain why it has happened to your child. You may be concerned that something in your or your spouse's genetic makeup may have caused the epilepsy to develop 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 most that an inherited factor was responsible.

### **POSSIBLE CAUSES OF EPILEPSY**

A common cause of epilepsy is head injury. This may occur during childbirth or from a blow to the head sustained in infancy or childhood. Fever convulsions, encephalitis or meningitis are the culprits in some cases but even childhood measles may lead to the child developing seizures. However, in most cases the cause is totally unknown aka idiopathic epilepsy.

### **VISITS TO THE DOCTOR**

An experienced professional who specializes in children with epilepsy probably knows that your mind tried to block out the word "epilepsy" from the first moment that he mentioned it. The doctor is well aware that you have received a major shock. You probably have a hundred questions so before subsequent visits to the doctor, while you are relatively calm, you should write down questions that need to be asked. The doctor will prescribe medication based on the age, physical condition and type of seizures experienced by your child. Remember that anti-convulsant medication does not cure epilepsy, but in most cases reduce the number of seizures or the severity of the seizures. Only your doctor can decide when and if to change or decrease your child's medication, but you are more than welcome to seek a second or even third opinion.

### **WHAT DO I TELL MY CHILD**

The child should be made aware of the condition. Children as young as three can understand that the brain is in control of the body and that sometimes the brain sends an incorrect message to the body. Older children should be given a more comprehensive explanation. If the child is old enough he will probably ask you "why me?" and you will have to answer openly and honestly that you



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don't know. It must however be made very clear that it has nothing to do with anything that the child did that was 'bad'

## YOU AND YOUR FAMILY

The anger, depression and possible guilt that you are experiencing will pass. Husbands and wives should be a source of strength and comfort to one another 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 that the family needs at this time. Children 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.

## DO I TELL HIS TEACHER?

The fact that child experiences seizures should under no circumstances be kept hidden from the teacher and other responsible school officials. The teacher may be apprehensive and it is therefore all the more important that you take 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.

## USEFUL HINTS ON PARENTING THE CHILD WITH EPILEPSY

- *Ensure that your child receives a comprehensive medical assessment by a qualified professional*
- *Always emphasize your Child's abilities. Concentrate on what your child can do rather than what he can't.*
- *It is your duty to learn as much as possible about the condition*
- *Be open and honest about the condition both with yourself and with your child*
- *Emphasize any activity that will improve your child's self-acceptance, self worth and self-confidence*
- *Educate family and friends –epilepsy is only an 'illness' when viewed through the eyes of the uninformed*
- *Equip your child with the correct information about their seizures so that proper care is administered to them while they are in seizure. This will allay unnecessary fears*
- *Always ensure that medication is administered and taken regularly*
- *Provide a set routine with plenty of rest, three balanced meals per day and regular exercise.*
- *A regular routine helps to limit seizures*



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- *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.*
- *Don't ever allow your to use seizures as an excuse for getting out of doing chores or accepting responsibility*
- *Don't ever use epilepsy as an excuse for lowering your expectations of your child*
- *Don't talk about behind closed doors or as if they are 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 initiatives.*

## CHAPTER 9: EPILEPSY & RELATIONSHIPS

### Relationships in general

Most of us have many different types of relationships such as family, school friends, colleagues, intimate friendships and life partner. Relationship of any kind can be very rewarding, giving a sense of belonging, security and love. However, when a person has a pre-existing medical condition or is newly diagnosed, problems can occur even in a strong, loving relationship. Although there is general awareness that all relationships need to be nourished, there are times within a relationship when the partners need to work harder to develop or strengthen the bond. Below we cover possible areas of concern, which could occur in relationships where epilepsy is a factor.

### To disclose or not to disclose

Most people with epilepsy have normal healthy relationships in which their epilepsy causes no problems.

This may be because their seizures are well controlled or because they have a lifestyle where they are very open about their epilepsy, giving simple explanations and practical guidance to their friends etc. Forming new relationships can be a difficult time for any of us. Some people are shy, lack confidence or may not have had much experience in forming relationships. When a person has any medical condition it can be a difficult decision as to when and how to disclose their condition.

As epilepsy can still be misunderstood by most people who have not come into contact with the condition before, disclosing details of your own condition may cause concerns. Some people with epilepsy are very open, talking freely their condition, while others feel better giving their relationship time to bond before disclosing their condition. The choice in disclosure is a personal one and needs to be made according to what is best for the individual.

### Understanding your partner's epilepsy



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Although 70% of people with epilepsy can have their seizures controlled with medication, just the fact that the person has epilepsy can in itself cause problems. Partners may respond to epilepsy in much the same way as the individual themselves: with denial, guilt or by searching for a reason. It may be tempting for the partner to overprotect, something which may affect the relationship. Therefore, it is advisable for both members of the relationship to understand epilepsy, talk to one another about their concerns and where relevant seek help or advice.

## **Social aspects**

Some people with epilepsy may not have had the experience of forming relationships and the reasons for this will vary from person to person. This may be due to the lack of opportunities in developing social skills. For example:

- Frequent seizures causing worries about being in public places.
- Over protection as a child.
- The general public's attitude to epilepsy.
- One's own acceptance and understanding of epilepsy.

Epilepsy developing in adulthood can also have a debilitating effect on some individuals, potentially restricting social activities which could result in difficulties in meeting suitable life partners. The fact that they may not be able to drive could for some people be a social problem.

## **Sexual Drive**

In general, most people will need the comfort, pleasure and closeness that human contact can bring. Sexuality is a normal expression for men and women. And for people with epilepsy this is no different. In general sexual activity can be fulfilling, allowing an individual the potential to experience the same pleasure as other. The main anxiety for some people with epilepsy and their partner is that a seizure may occur during sexual intercourse. In fact, a seizure is no more likely to occur at this time than at any other any. Research does suggest a seizure is less likely to occur when a person with epilepsy is occupied or doing something they enjoy

In general, health sexuality relies on harmony of the body and mind. It is therefore known that sexual behaviour can be disturbed in many people with any chronic (i.e long-term) condition, including epilepsy. Such sexual problems may be as a result of an individual's emotional state, side effects of medication or dysfunction of the part of the brain concerned with mood feeling and instinct.

It is unclear at present whether some anti-epileptic medication causes alteration in several of the hormones which are responsible for our ability to become sexually aroused as the information in this area is limited and controversial.

Some doctors believe there is a connection between medication and its effect on our hormones which deal with our sexual desires, therefore suppressing these desires. When hypo sexuality (or low sex drive) occurs due to epilepsy or the medication it often causes concern which in turn could lead to difficulties in the relationship. Should anyone believe they are experiencing problems due to their epilepsy or its treatment, it is advisable to discuss this possibility with their neurologist.

Alternatively there are organizations unrelated to epilepsy which you may wish to contact. Contact Epilepsy Support Association Uganda their contact details.





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## **Impotence**

Most men at some time experience impotence and there can be various reasons for this, for example: stress, tiredness, illness, and alcohol. Your GP can arrange any necessary tests, treatment or referrals to a specialist if appropriate. It is unlikely that epilepsy will be directly responsible for impotence. However, as impotence could be due to psychological and /or physical problems, some individuals with epilepsy who experience these symptoms could find these factors having an effect on their sexual ability. In some instances, talking the situation over with their partner and /or GP can help. With regards to the possibility of anti-epileptic medication being the cause, some anti-epileptic drugs affect the liver and can therefore, theoretically cause a drop in testosterone level. If your doctor thinks that there is some connection between your impotence and your epilepsy or medication, she/he may decide to refer you to your epilepsy specialist.

## **Fertility**

There is limited information about the effects of epilepsy on fertility. One of the most recent population studies in Iceland showed that there was no difference in rates of fertility between men and women who had epilepsy and those without epilepsy. Other research does suggest that fertility rates appear to be slightly reduced in both men and women with epilepsy compared to the general population.

There are many couples, who successfully conceive and have perfectly health children irrespective of their epilepsy or anti-epileptic medication. Reduced fertility rates can be due, for example to life styles and seizure types (temporal lobe epilepsy). Some women may experience menstrual irregularities and also experience polycystic ovary syndrome, which could interfere with their ability to conceive. Should a person experience problems with fertility they should seek advice from their GP or neurologist.

## **Heredity**

Epilepsy itself is only inherited in a few very rare instances. However, people with a low seizure threshold may be more susceptible to epilepsy and this threshold may be passed down in the genes. Even if your child does inherit a low seizure threshold however, it is by no means certain that she/he will develop epilepsy.

## **Parenting**

Many people with epilepsy successfully care for and bring up their children, irrespective of the many practical steps that can be taken in order to ensure that the care of a young child is carried out as safely as possible. As with any parent some may need support in their parenting role, but this should be assessed on an individual basis. Any parent with concerns about coping with any aspect of the care of their young child should discuss these with any Social Worker.

Alternatively you can contact any nearest organization which offers support and advice on various parenting issues.

Most people with epilepsy can and do enjoy the pleasure of having relationships. We hope this information will help individuals overcome their concerns and consequently feel more comfortable in forming relationships.



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