



EPILEPSY SUPPORT ASSOCIATION UGANDA

An Epilepsy Handbook For Volunteers, Teachers and Parents.

Epilepsy Support Association Uganda
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About Epilepsy Support Association Uganda (ESAU)

The Epilepsy Support Association is a registered national organization that brings together persons with epilepsy with the main aim of fighting for their rights. It started as a small initiative in 1998 in Mbarara; the association is a user-governed non-governmental organization that works to improve the quality of life of people with epilepsy. The Association has branches in 42 districts of Uganda.

The vision of ESAU

A Ugandan society in which epilepsy is understood and persons with epilepsy are treated with dignity so that they can exercise their full potential and participate in all development processes

The mission statement of ESAU

To become the leading organization that empowers people with epilepsy to participate in development processes through advocacy, networking and lobbying for their rights in achieving dignity and equal opportunities

Objectives

- To build an association in which persons with epilepsy (PWE), their parents and guardians are empowered and participating in advocacy and lobbying for their rights in achieving of dignity and equal opportunities
- To empower ESAU structures engage decision makers at the district and sub county levels for effective service delivery
- To create awareness among PWE, their relatives, health workers, opinion leaders and the community so they understand epilepsy and are able to support PWE.
- To build networks and alliances through which ESAU can advocate for the rights of PWE

What we do

Mobilization and sensitization

Epilepsy Support Association Uganda (ESAU)'s main activity is to mobilize people with epilepsy, their parents and guardians to form support groups. Through support groups, persons with epilepsy learn from each other and share experiences on how to live positively with epilepsy.

Capacity building

ESAU organizes its members to elect its leaders both at sub county and district levels. In these groups members are trained in leadership skills and income generating activities. ESAU trains volunteers in financial management skills, group dynamics, records management, mobilization skills and simple counseling.

Lobbying and advocacy

ESAU lobbies and advocates for the rights of people with epilepsy i.e. the right to regular medication, education, ownership of property etc. In this capacity ESAU engages districts, and central government agencies to take epilepsy as a priority and to accept persons with epilepsy in the communities as important citizens who should be involved and consulted in all planning processes.

Networking

ESAU is a member of Voices for Health Rights coalition (VHR) and is a member of NUDIPU (an umbrella organization that brings together all disabled persons organizations in Uganda. ESAU is also a member of International Alliance of Patients Organizations, International Bureau for epilepsy and currently holds the post of the vice chairperson of the IBE African Regional Commission. ESAU has become a vibrant member of civil society in Uganda.

Counseling and referral at the Secretariat

ESAU staff offer counseling about epilepsy, seizure management and how PWE can positively live with epilepsy. We also provide information on education and employment. At the secretariat we refer PWE to public hospitals and health centers for diagnosis and treatment. The secretariat also has a small documentation centre.

Definition of Epilepsy

It is a condition caused by abnormal functioning of the brain which may lead to loss of consciousness or abnormal behavior.

Causes of Epilepsy

- Un known causes or hereditary causes
- Birth injury
- Febrile convulsions during childhood
- Infections(Syphilis, HIV/AIDS, tape worms, ochocerciasis, meningitis)
- Head injury
- Brain tumors
- Alcohol abuse
- Measles
- Drug abuse

NOTE: Witch craft or curses do not cause epilepsy. Epilepsy is not contagious.

DO's & DONTs IN EPILEPSY CARE & MANAGEMENT

What people with Epilepsy should do:

1. People with epilepsy must take their medications daily as prescribed by a clinician/doctor
2. Persons with epilepsy should not share their medications with others
3. Such people are encouraged to attend school with other learners in an inclusive setting
4. Persons with epilepsy should keep their appointment with the doctor and inform him about any side effects they may be experiencing. They should never take un prescribed medicines
5. They should eat three meals a day
6. Persons with epilepsy need to drink three to four liters of water a day
7. Treat any ailment they get as they trigger seizures

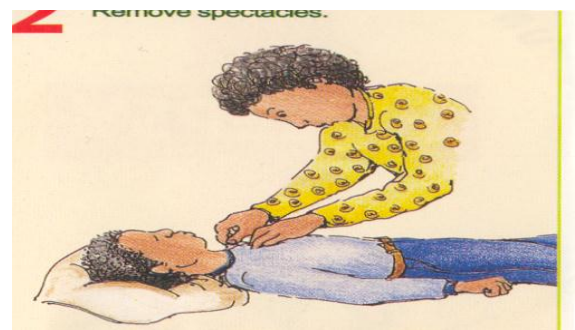
What they should not do

- *Persons with epilepsy should never stop taking their medications unless advised by their doctor*
- *They should not drive vehicles, motorbike operate heavy machinery*

- *Do not smoke or abuse alcohol or take any intoxicants if you have epilepsy.*
- *Avoid carrying hot dishes or boiling water in a kettle*
- *Do not bath wash or shower in excessively hot water as it may bring on seizures.*
- *They should not go out swimming or fishing alone*
- *When cooking, they should cook from a raised platform so that they do not fall in the fire*
- *You can drown in very little water. If possible, shower instead of taking a bath and do not lock the bathroom door*
- *Persons with epilepsy of the opposite sex are not advised to marry each other as this increases the risk of producing children with epilepsy.*
- *People with epilepsy should never fast or starve*
- *They should not climb heights or trees. If possible, avoid living in a house or flat with stairs. You may fall down the stairs while having a seizure. Carpeted floors and padded furniture provide more protection. Protective 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 or identification/ medical card can be useful to identify a person while having a seizure enabling the public to be of assistance*

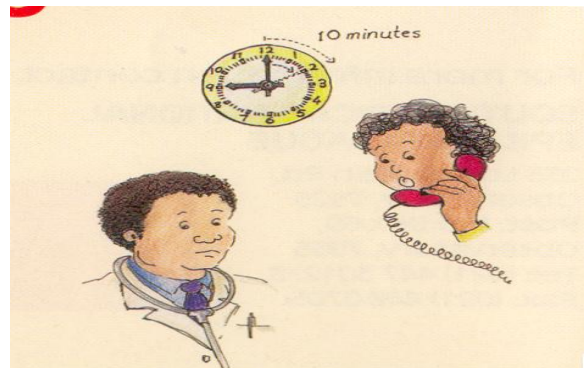
First Aid

- **Recovery position**
- **Loosen tight clothing**



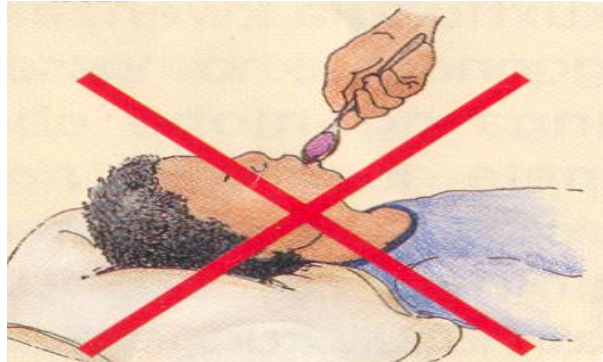
First Aid

- **Give comfort and Care**
- **Refer to a nearby health centre**

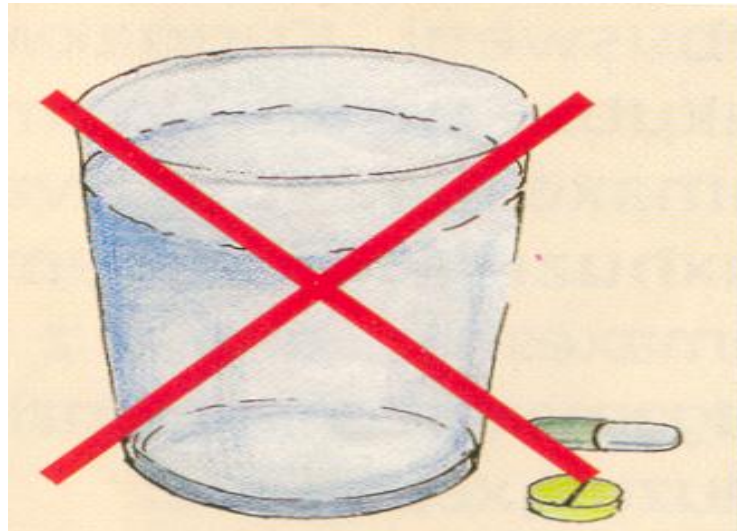


First Aid

- **Never lift the person**
- **Don't give anything to eat**



First Aid



- **Never give medication to a person who is having a seizure**

FIRST AID- WHAT YOU SHOULD DO

- Protect the person's head with your hands or a cushion so as to prevent further injury to the head.
- Loosen tight clothing so that the person may not suffocate
- When the seizure is over, turn the person into a recovery position so they may be able to breathe with ease.
- Stay with the person until they recover completely
- Explain to them what happened to them during the seizure.
- Refer them to a nearby health facility or walk them home.

FIRST AID- WHAT YOU SHOULD NEVER DO

- ❖ Never give the person something to eat or drink during a seizure as you may choke them
- ❖ Do not fear the seizure. Stay with the person and help them as epilepsy is not contagious
- ❖ Do not restrain the leg and arms as you may break them
- ❖ If they are in a dangerous place like a road or they are hitting their head against an immovable object, pull them away from such an object

INCLUSIVE EDUCATION & EPILEPSY

It is universally recognized that the main objectives of the education system is to provide quality education for all children. This is to enable them attain full potential and be able to meaningfully contribute to, and participate in society throughout their life.

Inclusive education is a vision of schools that are underpinned by the following beliefs:

- All people can learn
- People might learn in different ways and at different rates but can learn from each other and alongside one another
- We all have strengths and weaknesses and at different rates but can learn from each other and alongside one another.
- We all have strengths and weaknesses and experience barriers to effective learning at times
- Children with epilepsy have all the rights to attend a school close to his/her home, in the company of his or her friends/siblings.
- This would create a more tolerant and caring society.
- Many children are disabled due to the inflexible system in which they are forced to live and learn and not by their own difference and difficulties
- Remember the person with epilepsy only experiences loss of consciousness during a seizure and their brain functions normally during other times.

WHY INCLUSIVE EDUCATION?

Until now, children with physical and intellectual disabilities have been placed in separate specialist schools. Whilst such schools do offer highly qualified teachers and specialized programmes, children tend to become segregated from their neighborhood, peers and from the opportunity to interact within the mainstream society. In areas where there are no special schools, children with disabilities have often remained at home and are further deprived of education and opportunities for social interaction and stimulation

WHAT IS NEEDED TO MAKE INCLUSIVE EDUCATION WORK?

- A full commitment to the philosophy of inclusion
- A culture of caring and respect towards everybody in the school
- Creative and flexible teachers
- A team of special needs advisers who can support individual schools and teachers where needed
- Parents who participate and who are actively involved
- A flexible curriculum that meets the needs of children
- Assessments that focus on the strengths and specific needs of children with epilepsy, instead of their deficiencies

How school administrators should handle children with epilepsy

- Accept the child
- Foster a culture of acceptance in the classroom
- First aid training for classmates
- Improve the child's self-image
- Help with the development of confidence
- Concentrate on what the child can do

Do not

- Rush in to help unless the child obviously needs it
- Restrict the activities of the rest of the class because of the child with epilepsy
- Treat the child with epilepsy differently from other children
- Allow the child to think of him/herself as an invalid or use epilepsy as an excuse to avoid difficult situations.
- Be afraid to involve colleagues, parents and medical professionals in your classroom management

Note: Teachers need to recognize that some types of epilepsy may cause slow behavior, temporally loss of concentration and forgetfulness. Children with epilepsy may require more time to deliver on their work or assignments and surely need more time to do their exams (already taken care of by UNEB regulations). During stressful times like exams, such learners will need reassurance and counseling so as to attain the best achievement from them

Tips for parents of children with epilepsy

- Meet with the class teacher as soon as your child is placed at the school
- Explain the condition to the teacher and be willing to train other pupils and staff about epilepsy
- Focus on the handling of a seizure, triggers and types of seizures. Also stress that epilepsy is not contagious.
- State your expectations and your contributions
- Provide information with regard to the medication your child is taking and obtain the teachers commitment to administer medication when needed
- Ask that your child be treated exactly the same as his/her peers

Myths regarding epilepsy and education

Many people wrongly believe that

- Having an ordinary seizure kills brain cells
- Children with epilepsy have intellectual disabilities
- Children with epilepsy need to attend special schools

Epilepsy and the impact on behavioral and emotional development

It is important to note that psychological and social problems are often more significant than the condition itself. This is mainly due to ignorance, fear, and stigmatization on the part of onlookers that cause greater distress than the condition itself.

EPILEPSY IN THE CLASSROOM

School administrators need to have knowledge about the following in epilepsy management

- Epilepsy and what it is
- Seizure management
- Recording time, duration and types of seizures
- Factors that trigger seizures
- Medication the child takes and be on the lookout for side effects

Tips for teachers

Dos:

- Accept the child for what he/she is
- Foster a culture that you and all the children in the class/school receive adequate training regarding epilepsy and epilepsy management
- Encourage participation in activities that improve the Child's self-image
- Support the child and help him/her to develop confidence to deal with different situations
- Concentrate on what the child can do rather what he can't do

DONTs

- Rush in to help unless the child obviously needs it
- Restrict the activities of the rest of the class with epilepsy
- Treat the child with epilepsy differently from other children
- Allow the child to think of himself/herself as an invalid or use epilepsy as an excuse to avoid difficult situations e.g. did not do his/her homework
- Be afraid to involve colleagues, parents and medical professionals in your classroom management.

Epilepsy management for a child with epilepsy in the family

- Important to develop positive attitude to epilepsy and child's future
- Communicate fears and knowledge to spouse and all children in the family
- Its important for family members to be supportive
- The child should not be treated as an invalid but as a normal child
- Help the child integrate in social activities
- Don't make the child a center of attraction
- Don't blame children's epilepsy for family difficulties

Parenting

Many people with epilepsy successfully care for and bring up their children irrespective of the level of seizures. As with any parent, some may need help in their parenting role, but this is assessed on an individual basis.

Useful hints on parenting a child with epilepsy

- Ensure that your child receives a comprehensive medical assessment by a qualified medical professional
- Always emphasize your child abilities, concentrate on what the child can do rather than what he can't do
- 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
- Ensure that your child does not climb trees etc, does not swim without adult supervision
- 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 seizures so that they can respond with confidence when questioned
- Always ensure that medication is administered and taken regularly

- Assure your child that proper care is administered to them while they are in seizure. This will allay unnecessary fears
- Provide a set routine with plenty of rest, three balanced meals per day and regular exercise. A regular routine helps to limit the 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 full life.
- Don't talk about your child 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 over protect your child. Over protection will stifle and hinder the Childs initiatives

PARENTING A CHILD LIVING 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 guilty. 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 you 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 may be 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 ie 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 reduces 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.

It is important to note that no herbal remedy, traditional ritual or religious practice can heal epilepsy. In many situations it has been found that actually many parents worsen the conditions of their children by undertaking such practices and ultimately waste the resource that they would need for the treatment of their children on modern medicine. Remember that a simple scan (EEG) of the brain will confirm whether your child has seizures and even where resources cannot allow, if your child has experienced three familiar seizures, then that will be confirmed as epilepsy. When seizures are treated early, recovery is very fast. If one type of medication doesn't work well with your child, please ask your doctor to prescribe a better one. Please keep counting how much time the child has gone without a seizure. If they do two years, it may be possible to gradually withdraw them from medication with the physicians guidance.

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 can send 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 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 the 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

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 313days for your child to live a full life.

Don't ever allow your child 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 your child 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 initiative

Epilepsy Treatment Options

Anti-convulsants	Medication which may affect blood level concentration of certain anti-epileptic drugs
Phenytoin	Phenobarbitone, valproic acid, diazepam, aspirin, some oral contraceptives, propranolol
Carbamazepine	Phenytoin/phenobarbitone, prooxyphene, erythromycin
Phenobarbitone	Valproic acid, Phenytoin, carbamazepine
Sodium Valproic acid	Phenytoin, phenobarbitone, carbamazepine

Each of these medications may have some side effects on your child so please watch your child very well and never get scared of some side effects. Get back to your doctor and explain these side effects. They will normally give you an anti-dote with the medication which will help with the side effects.

Medication for epilepsy should not be withdrawn quickly or frequently as this may interrupt the treatment plan

For more Information on epilepsy and how to live with it please refer to the nearest health facility or the Epilepsy Support Association Uganda (ESAU).