

EPILEPSY & RELATIONSHIPS

Editorial

Dear Readers, Epilepsy is the worst understood disease since biblical times. Those who live with it live in fear of getting seizures and are often neglected by their families. The social stigma surrounding epilepsy influences the way individuals relate with others.

In this issue of the Epilepsy torch, we are pleased yet again to share with you information that will enable you appreciate that epilepsy is not contagious, it can be treated and that those who live with it are individuals that have feelings and emotions like any others. That they can love and be loved and that individuals with epilepsy will meet their social functions normally if they receive appropriate and regular medication.

Although it is true that epilepsy can run in families, only 6% of those that have epilepsy actually inherit it from their parents. More so epilepsy rarely causes sexual dysfunction. It is indeed in order for such individuals to marry and form families. It is true that people with epilepsy may need to take extra caution and care during pregnancy and while caring for young ones. The Epilepsy Support Association Uganda exists to demystify epilepsy and will continue to bring you as much information as possible. Our best wishes for a prosperous 2008

Relationships in general

Most of us have many different types of relationships such as family, school friends, colleagues, intimate friendships and life partners. Relationships 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 condition, 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 about 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

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.

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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 the 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 if you require such or related information..

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The editorial team welcomes questions on epilepsy and how to cope with the condition

EPILEPSY AND WOMEN

From page 1

Impotence

Most men at some time experience impotence and there can be various reasons for this, for example: stress, tiredness, illness, and alcohol. Your Doctor 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.

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 as 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 foetus so it is essential that this be checked out with your doctor as soon as possible.



A pregnant mother attends an epilepsy clinic at a health centre in Apac

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 mind 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.

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 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.

EPILEPSY DRUG BANKS IN PARTNERSHIPS WITH FAITH BASED HEALTH

Since its inception in 1998 in Mbarara, the Epilepsy Support Association Uganda (ESAU) could not avoid running outreach clinics for its members. This was inevitable as public services were weak or non-existent and yet the association could not mobilize patients/clients and family members without controlling the seizures of sufferers. The other reason was actually to demonstrate that those who took regular drugs would be able to significantly improve or even have their seizures controlled.

Epilepsy clinics were therefore opened both in private and public health units in Mbarara, Bushenyi, Ntungamo and Kabale districts. The first challenge the association faced was how to sustain these clinics when government abolished cost sharing in public health units. Although the association bought and distributed free drugs to public health units, there would be no money to restock the drugs when they run out.

Two outreach clinics for persons with epilepsy at Rubindi Health Centre II and at Mushanga Health Centre have however continued to run since 1998. The success of these units has been dependent on the fact that since these units belong to the Catholic Church all clients pay for the medical care they receive. These two units have therefore provided a sampling ground for the ESAU community drug bank concept. The idea behind this scheme is that there is a cost to any free health service; clients actually spend money and resources to access these drugs. They pay transport, lose a lot of time commuting 10 to 20 km to access these services and wait long periods before they can be treated. ESAU has been testing the idea that if a clinic was opened in a rural area where persons with epilepsy can walk not more than 5km, then 50 to 80 people could put together the money they would each have spent to commute to a public health unit and instead contributed to a "drug bank" where they would each replace the drugs that they receive. ESAU normally provides the start up drug kit.

The success of this 'drug bank' idea at Rubindi and Mushanga has led ESAU to roll out this idea to 12 other faith based health facilities. ESAU hopes that when these units begin to treat up to 80 persons with epilepsy or more, they will then realise that treating epilepsy is viable and sustainable. The epilepsy Support Association Uganda provides the drugs to start such a clinic and run it for the first three months. ESAU also mobilizes its members to come for the clinic and pay for the drugs at 2,500/= for any type of drug they receive. The charges at such a clinic are consolidated and are normally exempt from consultation charges and stationery.

So far ESAU has drawn up Memorandas of Understanding with the following health units which have started running the clinics. These include;

Comboni Hospital Centre, Kyamuhunga	Bushenyi
Mushanga Health Centre	Bushenyi
Motherchild Rescue, Nyakashaka Buhweju	Bushenyi
Rubindi Health Centre	Mbarara
St. Lucia Kagamba	Ntungamo
Teboke Mission Health Centre	Apac
Aduku Mission Health Centre	Apac
Ngora Fred Carr Hospital	Kumi
Lwala Hospital	Kaberamaido
Amuria Church of Uganda H/C III	Amuria
Toroma Health Centre III	Katakwi
Kidetok Health Centre III	Soroti

Reports ESAU is getting from these units indicate that the numbers of clients collecting the drugs is very high. At Aduku Mission for example more than 100 people are getting treated while at Kagamba 87 clients. It is encouraging to note that persons with epilepsy are willing to take care of their lives and that where drugs are available they will pay for the services.

The drug bank therefore offers an alternative to persons with epilepsy. Where they cannot access free medicine in public health units, they can be able to access them at a private health unit at an affordable cost and within easy reach. The association will continue to lobby district Administrations and health centre IV's to buy drugs for free distribution in public health units but where recourse allow, ESAU will continue to engage faith based health units to run epilepsy clinics at a fee.

"EPILEPSY IS NOT THE END OF THE ROAD"

This is a story of Ndyomugenyi, a member of Kabale Epilepsy Support Association.

My name is Ndyomugenyi and I got epilepsy in 1994 when I was 30 years of age, officially married with 2 children. By that time I was working in a bakery in Kabale town. I was the sole bread winner of my family, but after getting epilepsy I started getting seizures almost every day. I could not disclose my condition to my boss and workmates because I feared to be sacked. However, as the seizures became severe I decided to abandon my job because I could not manage working near the fire place while baking bread since fire is a trigger factor for seizures.

"Life without a job"

My wife was a house wife and that meant that we had to improvise on other means of getting income to run the family. My wife was supportive. She did not abandon me at that trying moment instead she started petty trade where she would get some money to support the family. By that time epilepsy was a strange condition to me and to my family, I thought I was bewitched because I had never experienced it and not even seen some one with it.

"Treating my epilepsy using witch doctors"

By the time I was working I had managed to save some money (over a million Uganda shillings) but this saving was spent on settling bills with witch doctors while looking for epilepsy treatment and cure.

I moved almost in the whole of Uganda trying to get a cure for epilepsy by using different witch doctors but the strange condition continued. I spent all the one million shilling buying herbal medicine but still the seizures would continue.

Life after the formation of Epilepsy Support Association Uganda (ESAU) Kabale branch

The Epilepsy Support Association came to Kabale in 1998, by that time I had been with epilepsy for 4 years. Mr. Augustine Mugarura the National Director had his first mobilization and sensitization meeting in Kabale Regional Referral Hospital. I was among the first people to become members of the association in Kabale. After the sensitization I started modern medication (Anti Epilepsy Drugs) and it was my first time to know that such drugs exist and that they can help.

Since I started medication, the seizures disappeared. After stabilizing on the medication, I went back to my job and since I was hard working my boss gave me back my job and even promoted me to supervisory level. I now have 3 children and have started a business for my wife. She is now dealing in buying and selling of maize and beans in Kabale town and she is financially independent. One of my children has completed primary school and will be joining secondary school in February 2008. We are now a happy family and financially stable and life has never been the same. However, I still take my medication.

I would like to take this opportunity to thank the founder members of the Epilepsy Support Association Uganda (ESAU) for restoring my hope and for being inspired to start this association. Fellow members I had lost hope and saw no future in my life but due to Epilepsy Support Association Uganda, my hope has been restored. I would like to appeal to all people living with epilepsy that they can live a normal life and be financially independent as long as one keeps on medication. There is no witch doctor that can cure epilepsy and no herbal medicine for epilepsy. Let us not be deceived. Let us work together to build a strong association so that we can mobilize and sensitize more persons with epilepsy to join the association, lead normal and meaningful lives while contributing to society and lobby for services such as adequate and regular medication. Together we shall "Bring Epilepsy in Uganda out of the shadows".

Ndyomugenyi Wilber, Kabale

ABOUT ESAU

The Epilepsy Support Association Uganda is the only registered national organizational 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; ESAU is a user governed NGO that works to improve the quality of life of people with epilepsy. The association is in operation in 25 districts of Uganda. The Association is democratically governed by the members who elect a local executive committee at sub-county and district levels. Each district branch sends two delegates to a national assembly that elects a national board. All officers at the secretariat are appointed by the board which is the policy making organ of the association.

Vision

“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”.

Mission

To become the leading organization that empowers people with epilepsy to participate in development processes through advocacy, networking ,research and documentation.

Objectives

- To build an association in which 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 in decision makers at the district and sub-county levels for effective service delivery.
- To create awareness among PWE, their relatives, health workers, professionals opinion leaders and the community so they understand epilepsy and are able to support PWE.

NOTE: The offices of ESAU in Kampala do not operate a medical clinic for epilepsy. If you need any medical treatment please refer to the nearest health unit. ESAU will only refer those who require specialized treatment.

For more information, comments, questions, experiences and counseling please write or e-mail us at the address below.

ACTIVITIES

Mobilization and sensitization

ESAU's main activity is to mobilize people with epilepsy, their parents and guardians in support groups. Through support groups, persons with epilepsy learn from each other and share experiences on how to positively live with epilepsy. The Association has 139 support groups in total.

Capacity building

ESAU organizes it's 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 skills, groups dynamics, records management, mobilization skills and simple counseling.

Advocacy and Lobbying

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 bodies to take epilepsy as a priority and to accept PWE in the communities as important citizens who should be involved and consulted in all planning processes.

Networking

ESAU became a member of NUDIPU in 2004 and is represented on its board and has participated in drafting the Disability Act, National policy on PWDs and the Equal opportunities Act. ESAU has dynamic partnerships with other Disabled Peoples Organizations like; Mental Health Uganda, Uganda Parents of Children with learning Difficulties, Uganda National Association of the Physically Disabled, Deaf Blind and the new initiative on persons with brain injuries.

Counseling & referral at the Secretariat

ESAU staff offer counseling about epilepsy, seizure management and how PWE can positively live with epilepsy. We also offer 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 resource center.



ESAU's Board of Directors, Management and staff at their offices in Bukoto