

**A PRESENTATION BY MRS. ANGELA ASEMOTA, PRESIDENT; ANGIE
EPILEPSY FOUNDATION
AT THE SEMINAR HELD AT SAGAMU COMMUNITY TOWN HALL,
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. In trying to impact the knowledge of epilepsy in the Society, We have done Seminars in many places in other parts of the country like Auchi, Benin, Asaba, Abuja, Dagbala, Lagos, Onitsha, Ekiti, Enugu and in Several Parishes in Warri. Educating people about Epilepsy is very important because people need to know what to do if they see someone having a seizure and they need to know that there are different types of seizures and that they don't have to be afraid of epilepsy or the people who have it. Education also help people with epilepsy know that they are not alone I really hope that other people around the world don't feel alone.

We yearn for a Society in which all persons with Epilepsy will be aware of the treatment of Epilepsy and when they can combat and overcome the stigma associated with it. This can be done through a holistic propagation of campaigns against the stigmatization of persons with Epilepsy. we are through these campaigns trying to improve the social status of these persons by getting more and more persons to know about the Causes and Treatment of Epilepsy.

First of all, let us get one thing clear, Epilepsy is not a spiritual problem, it is not caused by Witches and Wizards, and it is not a mental illness. Persons with epilepsy should not be relegated, they should be encouraged and be supported they get to School age or a marriageable age.

Persons with Epilepsy suffer alone with no one/government to care for them. Persons with epilepsy in Nigeria are suffering due to the acute stigmatization. The social stigma encountered by school children with epilepsy needs to be addressed by the Church/Mosque, government and the society in general. Because of the myths and misconceptions surrounding epilepsy. Children with epilepsy that of school age shy away from school because they are frequently teased by their friends, parents are afraid of the stigma so they are not sent to school. What can the Society do to support this correct these problem? *Doctors on their part are concerned about the Treatment of Epilepsy in Nigeria. They explain more about epilepsy and argued that Nigeria may not be able to improve the lives of patients with epilepsy, unless it is ready to do 3 things:*

1: Increase public awareness about epilepsy

2: Reduce the cost and improve availability of anti epileptic drugs and

3: Increase the numbers and improve access to specialists available in the country.

What about you? what can you do to support these persons? Help to support them and give them a hope that is beyond stigma and shame.

What is epilepsy?

Historically, epilepsy has been neglected, feared and misunderstood. A veil of secrecy surrounding it has resulted in myths, superstitions and a general lack of knowledge. This has really impeded scientific and social progress towards finding answers to one of the most prevalent neurological disorders. It is estimated that about 80% of patients with epilepsy do not have complete control. The need for cure is clear. many of the patients are children who can experience more than 20 seizures a day. During the dark days, before the birth of Angie Epilepsy Foundation my Dear son use to have over 30 seizures at night over 20 a day and these were his daily seizure activities. Today confidence is back to my family but still on medication. The impact on the developing brain ranges from learning disabilities to retardation and in a disturbing large number of patients, there is an increasingly large incidence of onset epilepsy in the aging population as a result of stroke Alzheimer's disease and for many suffering traumatic injury in the battle field, epilepsy will be a long term consequences.

Epilepsy is truly best regarded as a disorder of the brain and can be caused by many diseases. The medical definition of epilepsy is 'repeated seizures or convulsions (or fits) due to a brain problem'. This means that the seizures originate from the brain. But in my own terms, Epilepsy is a sudden cessation of normal activity in a person at a particular time.

In normal brain functions millions of tiny electrical charges passes from nerve cells in the brain to the rest of the body. A seizure occurs when the normal pattern is interrupted by sudden and unusually intense bursts electrical energy which may cause strange sensations, emotions, behaviors or convulsions, muscle spasms and loss of consciousness. these unusual bursts are called seizures. When a person has two or more seizures which have not been provoked by a specific effect such as trauma, infection, fever or chemical change, he or she is considered to have epilepsy.

What are the myths and misconceptions about epilepsy?

There are many myths surrounding this disease. Many persons think it is madness or acquired by eating certain food, some people also think that it is infectious i.e. it can be contacted by touching the saliva of persons suffering from this disease. These are myths and they are false.

Some people believe that epilepsy is due to a spiritual attack and that the demon must be cast out of the patient. Needless to say, this is irrespective of educational background or level in the society. Educated and even well travelled people also fall for this big misconception. Some of the patients have been to church, mosque,

spiritual healers and herbalists and of course numerous hospitals looking for an explanation and treatment. Demons have been thought responsible and therefore 'beaten' out of sufferers in many churches and herbalist homes, by unskilled people. In this regard, many patients have been subjected to massive cruelty and even death. Epilepsy is not contagious. It has never been and it will never be. You cannot contract epilepsy by touching the sufferers or coming in contact with their saliva. It is not an infection and is not caused by a virus or a germ.

Epilepsy is not a mental illness. Experts say that Seizures are mainly symptom that there is a physical problem, like a scar, on the brain. Some people with epilepsy are extremely clever, others are of average intelligence and some have learning difficulties. Just like normal people in the population, really. Epilepsy does not have to be a bar to success in life. Many people with epilepsy enjoy highly successful lives.

Most persons with epilepsy and some general public are absolutely unaware that epilepsy is a medical condition that can be treated and cured.

CAUSES OF EPILEPSY

Genetic and Environmental

It may seem obvious that heredity (genetics) plays an important role in many cases of epilepsy in very young children, but it can be a factor for people of any age. For instance, not everyone who has a serious head injury (a clear cause of seizures) will develop epilepsy. Those who do develop epilepsy are more likely to have a history of seizures in their family. This family history suggests that it is easier for them to develop epilepsy than for others with no genetic predisposition.

Epilepsy in which the seizures begin from both side of the brain at the same time is called primary generalized epilepsy. Primary generalized epilepsy more likely to involve genetic factors than partial epilepsy, in which the seizures arise from a limited area of the brain.

Are the Brothers and Sisters of Children with Epilepsy more likely to Develop it.

Their risk is slightly higher than usual, not because they will "catch" it (that can't happen) but because there may be a genetic tendency in the family that makes seizures and epilepsy more likely. Even so, most of them will not develop epilepsy. Epilepsy is more likely to occur in a brother or sister if the child with epilepsy has primary generalized seizures. Depending on the type of epilepsy and the number of family members who are affected, only about 4% to 10% of the other children in the family will have epilepsy.

Not everyone who carries genes making them more likely to develop epilepsy will do so. Even if the genes are passed on, not every generation in a family will have seizures. And so, like diabetes, epilepsy may skip a generation.

Is Epilepsy Inherited?

While there are certain medical conditions that are associated with developing epilepsy, you might wonder if epilepsy is inherited.

However, in some cases, epilepsy can be inherited from a parent, and scientists are in the process of trying to determine the different genetic abnormalities associated with epilepsy in order to have a better understanding of what happens during some seizures and possible future treatments of this. Due to the advancement of technology, our understanding about this disorder and active research, scientists and clinicians have identified several genes that could classify epilepsy as an inherited disorder. These mutated genes include defects in various channels involved in transporting chemicals used to help area in the brain communicate with one another. The defects in these genes could contribute the abnormal communication between neurons in the brain that cause seizures to occur. The anticonvulsant medications currently available to help you manage your seizures target these specific areas in the brain involved with communications.

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Environmental Factors

Faulty conception, Uncompleted abortion, Partial miscarriage, Sporting and bleeding in pregnancy Untreated malaria, Typhoid in pregnancy, Fall in pregnancy, Stressful labor and prolonged labored, Jaundice, Baby delivery by forceps, Baby injury when delivered by vacuum extractor, Baby injured when delivered b caesarean section and injured in the head with a scissors, Delivered by local midwife, Mismanagement of labor, improper handling of infants, Hard/bad fall in infants, Metabolic imbalance, Trauma etc.

Diagnoses And Treatment Of Epilepsy

Diagnosing epilepsy can only be done by giving your physician the right information. your Doctor will first try to figure out if it was a seizure you had or something else with similar symptoms. For example, a muscle tic or a migraine headache may look or feel like a kind of seizure. Your Doctor may need to speak to an eye witness, to know what happened to you before, during and right. He will also examine and request that you do some tests. such as an egg, calcium, phosphate, fasting blood sugar, he may also need to check on

your family history, issues at birth, if there was an accident, a long term illness. these information will help your Doctor decide the kind of seizure you have and if you have epilepsy.

However, medicine controls seizures in many people who have epilepsy ,it may take time, careful and controlled changes by you and your Doctor to get the right combination, schedule and dosing of medicine to best manage your epilepsy. The goal is to prevent seizure and to reduce side effect to the berets minimum. After you get the drug that works for you, take it exactly as prescribed. The best way to prevent more seizures is to keep the right amount of the medicine in your body system. to do this is, you need to take the medicine in the right dose and at the right time every day. Epilepsy can make you feel miserable, make you feel like your world is fast shifting beneath your feet, but the truth is epilepsy does not have to rule your life. Even with the unpredictability of not knowing when a seizure will strike, there are resources that can help you and your love ones navigate epilepsy. I believe we have mentioned severally that treatment of epilepsy is different from when you are treating malaria. Treatment of epilepsy runs between 3 to 5 years. Don't get discouraged because of this but do the following and you will get better. Epilepsy is curable if treated correctly.

1. Change your mind set: Don't spend money on false prophets and herbalists because what they will do for you will not work. Focus your mind on what the Doctor will tell you.

Adherence to medication: This is a continuous process. Don't stop, change your mind set, know that adherence to medication is permanent. Be medication complaint. Just like the persons living with HIV will take their medication for life, you will take it until you are gradually weaned off it and not until you get to that stage, you still have to take your medications. If you flout this you will continue to fall.

Finally stabilization is not a one day affair. It is a gradual process. If you are patient you will get there.

Epilepsy is not always a lifelong condition. Many people who have been seizure free for three or four years have their medications carefully withdrawn under close medical supervision and remain free for the rest of their lives. Surgery can also be successful in eliminating certain types of seizures. Epilepsy can be prevented, treated, controlled and more often than not cured. THE EASIEST AND MOST IMPORTANT TREATMENT IS PREVENTION. THE MOST IMPORTANT WAY TO PREVENT EPILEPSY IS TO OFFER EARLY DRUG TREATMENT

TO PATIENTS WITH HEAD INJURY, MENINGITIS AND THOSE UNDERGOING BRAIN SURGERY.

Are the drugs within reach and what's the cost implication?

Many of the drugs are available in Nigeria and there are many reputable local manufacturers. The drugs available may cost up to N300 per day for effective treatment. More expensive drugs may be necessary to control is not adequate. Many really expensive drugs are not available in Nigeria.

In Nigeria today many people do not believe that epilepsy can be treated they still hold on to the old believe that epilepsy is something that comes as a result of evil. But I put it to you that epilepsy is as a result of the mistakes of years ago. Some of these mistakes are; untreated malaria/typhoid, bleeding in pregnancy, brain trauma etc. many people living with epilepsy tend to hide the disease from people. The truth about this is that the more we hide it from people the more problem we have. The best cure for epilepsy is education because if I have epilepsy and I tell my loved ones that I have it and let them know that to do when I have a seizure the better for me. Many people hide their seizures status from their intending partner; this creates more chaos in relationships. Genevieve, a woman in her forties narrates her story.

“Being an attractive young lady, men flocked around me, each asking for a date with me. I accepted a few; and when a young bachelor among them expressed serious intention about marriage, I accepted. Not long after, he was transferred to another state; so, our relationship assumed a new shape, as we mostly communicated by letter. Phones were rarity then. As such, my fiancé only knew what I told him about myself, though I must confess that I withheld the most vital information about my health, fearing that it could make him change his mind if he knew that I was epileptic.

“Though I had regular epileptic seizures once every month, he didn't get to know about it, as everybody seemed to be cautious about being accuse4d of breaking our relationship. We married after my service year almost immediately, I became pregnant. Six weeks into the pregnancy, I had a seizure. It was late n the night. Of course, having lived with the disorder since I was a child, knew that the seizure was coming, but there was no how I could prevent it.

The shame that it portends made it compulsory to guard my health condition it utmost secrecy, but it back fired. I had a seizure, but being ignorant of what was really happening, my husband could only rally neighbours to come see what was happening to his new bride. The neighbours, mostly adults, immediately recognized what was going on and they tried so hard to stop me from injuring myself. But then as I came out of the seizure, I started bleeding and the doctor later

confirmed that I had lost the baby. He also explained to my husband that I was suffering from epilepsy, which really angered him. He was angry especially because I kept the information from him and led him by the nose, so to say, into marriage. He simply walked out of the union and that was it.”

Now a single mother of a 10-year-old boy whom she had through a casual relationship, Genevieve said she wished she knew better than she did when she was growing up. “But then, what do you expect from a youngster when even my parents talked about my condition in low tones, guarding the secret from neighbours and distant relations. Worse still, I didn’t know any other person who had epilepsy all the time I was growing up; nor do I know anyone who does shield from the prying world.” Wow look at what secrecy does people. Why must we hide epilepsy? Many people in the society today are guilty of this same offence. They have destroyed their children and loved ones all for the fact of hiding their children. Many of them still lock up their children even as we speak.

What is the prevalence of epilepsy in Nigeria and where do we have the highest cases?

As with most diseases and conditions in Nigeria, we do not have any reliable statistics. Epilepsy as a disorder is prevalent and many people suffer in silence. However, people in rural areas are more vulnerable because of ignorance, poverty and belief

How should people treat someone having a seizure?

Patients having seizure or a fit can jerk around, lose consciousness and foam the mouth. The fit can last seconds or a few minutes as long as 5 minutes. In close to 90% of cases, the fit stops by itself and the patient recovers as if nothing happened. The best management for the patient at the time of a fit is to make sure they do not come to harm or injure themselves during the period of loss of consciousness. Move objects that can harm the person, out of the way. If possible, place a pillow under the person’s head so that the head doesn’t bang against the floor causing injury. Keep calm and do not panic. Let the seizure run its course and do not hold them down. If possible move them to a comfortable place and let them sleep or least have a good rest once the seizure is over. If the seizure does not stop or is repeated often without the person waking up in between, please get medical help immediately. Take the person to the nearest hospital where they can be helped.

Thing you must do

People trying to help can cause untold suffering, pain, lifelong disability and death. We have heard of some communities where burning the feet of the sufferer is supposed to be helpful! Please do not do this. Also, the practice of putting a stick or spoon in their mouth is not necessary and can be damaging. Finally, in some

communities, various concoctions (urine, drugs and alcohol) are poured down the throat of the sufferer. This can lead to choking, aspiration, pneumonia and death.

How can we position our health system to better respond to epilepsy?

Remove ignorance and increase access to the right information and specialists. The three most important ways we can help people with epilepsy are as follows:

1. Create more awareness about epilepsy, this is vital and of real benefit by removing ignorance about the disease and making it understood by ordinary people, educated and otherwise. This is why we have created the PURPLE DADY AND WORLD EPILEPSY DAY to promote more enlightenment about the condition. That is why the Angie Epilepsy Foundation is committed to creating awareness about epilepsy and we urge you to contribute your quota to this laudable project of creating awareness.
2. Make the drugs more available and cheaper to obtain by patients. The drugs can be expensive and so patients stop taking their medications leading to their seizure. The government MUST talk to the big manufacturers to make the drugs widely available for Nigeria and also reduce the cost.
3. There are few neurologist and even fewer neurosurgeons in Nigeria and the number of specialists available to manage the large number of patients is small. Efforts must be made to train more specialists and position them in all the six geopolitical zones for wider coverage.

Finally I want to thank everyone here present and everyone in the society who has taken it upon themselves to help those with epilepsy and humanity in general. According to one of our spiritual directors, "when you give to those in need, you give to God and in turn, He shall repay". Carrying out awareness campaign is faced with a lot of challenges; you can assist this foundation in many ways ranging from human support, material support, sponsorship on TV and Radios.

NOTE THAT LIKE THE CHURCH CANNOT SURVIVE ON PRAYERS ALONE, WE CANNOT STAND ON GOOD WISHES ALONE.

THANKS FOR SUPPORTING ANGIE EPILEPSY FOUNDATION

God bless you all.

Mrs. A. O. Asemota
President- Angie Epilepsy Foundation