

**A WELCOME ADDRESS DELIVERED BY MRS. ANGELA
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THE SEMINAR HELD AT SAPELE OKPE COMMUNITY TOWN
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CAUSES OF EPILEPSY IN NIGERIA

I welcome you all to this seminar organised by the Angie Epilepsy Foundation (AEF) here in Okpe Community Town Hall 2, Sapele. We have also had some in other parts of the country like Auchi, Benin, Lagos, Onitsha and Sapele and in several Parishes in Warri

When a baby is born into a home there is usually so much joy and celebrations. As the baby grows and matures, the parents are filled with joy and great, tall and high expectations for the future. But how sad it would be to say that this baby that has been a bundle of joy and gladness should have epilepsy.

Educating people about epilepsy is so 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 kinds of seizures. They also need to know that they don't have to be afraid of people who have epilepsy. Education also helps people to know that they are not alone.

People living with Epilepsy suffer alone with no one/government to care for them. People living with epilepsy in Nigeria are suffering due

to the acute stigmatization. The social stigma encounter by school children living with epilepsy needs to be addressed by the Church/mosque, government and the society in general. Because of the myths and misconceptions surrounding epilepsy, Doctors are concerned about the management of Epilepsy in Nigeria. They explain more about epilepsy and argue 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 epilepsy drugs and

3: increase the number and improve access to specialists available in the country.

What is epilepsy?

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 in of normal activity in a person at a particular time.

What are the myths and misconceptions about epilepsy?

There are so 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 or contagious i.e. it can be contracted 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, mosques, 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 sufferer or coming in contact with their saliva. It is not an infection and is not caused by a virus or germ.

Epilepsy is not a mental illness. Seizures are mainly a 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 people living with epilepsy and some general public are absolutely unaware that epilepsy 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 sides of the brain at the same time is called primary generalized epilepsy. Primary generalized epilepsy is 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 areas 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 communication.

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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 labour and prolonged laboured, Jaundice,

Baby delivered by forceps, Baby injured when delivered by vacuum extractor, Baby injured when delivered by caesarean section, Baby delivered by unskilled nurses, Baby delivered by caesarean section and injured in the head with a scissors, Delivered by local midwife, Mismanagement of labour, Improper handling of infants, Hard/bad fall in infants, Metabolic imbalance, Trauma etc

Treatment and management

This part is most times left to the Doctors to handle but because many people tend to believe that epilepsy is not curable I have this to say

1. Change your mind set. Don't send 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

2. Adherence to medication. This is a continuous process. Don't stop, change your mind set, know that adherence to medication is permanent. Be medication compliant. 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 rarely, 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. The hardest treatment to achieve is cure. Epilepsy can be best controlled and managed rather than talk about cure. Patients may have to be on the medications for the rest of their lives.

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 main drugs mentioned above are available and may cost up to N300 per day for effective treatment. More expensive drugs may be necessary if 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 what to do when I have a seizure the better for me. Many people hide their seizure status from their intending partners; this creates more chaos in relationships. Genevieve, a woman in her forties, narrates her story.

”When I resumed at the media house where I was posted to do my primary assignment as a 22-year old youth corps member, it was the best thing that could happen to me, what with the extra allowance the medium paid corps members posted to serve there. Indeed, it was approximately 95 per cent of the stipend the Federal Government was paying corps members then. So, life was good—at least on the surface of it.

”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 a 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 accused of breaking our relationship. We married after my service year and almost immediately, I became pregnant. Six weeks into the pregnancy, I had a seizure. It was late in the night. Of course, having lived with the disorder since I was a child, I 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 in utmost secrecy, but it backfired. I had the 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 recognised 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 now. It is simply a dark world that people with the disorder and their relations prefer to further shield from the prying world.”

Wow look at what secrecy does to 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.

How should people treat someone having a seizure?

Patients having a seizure or a fit can jerk around, lose consciousness and foam from 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 at 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.

Things you must not 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 DAY 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 recurrence of their seizure. The government **MUST** talk to the big manufacturers to make the drugs widely available for Nigeria and also reduce the costs.

3: There are few neurologists and even fewer neurosurgeons in Nigeria and so 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 living with epilepsy and humanity in general. According to one of our spiritual directions- 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

Co-ordinator Angie Epilepsy Foundation