

Let's

Talk
Epilepsy!

youth
on the
move
emPOWER talents with EPILEPSY

LET'S TALK EPILEPSY!

**2nd Edition, August 2015 by:
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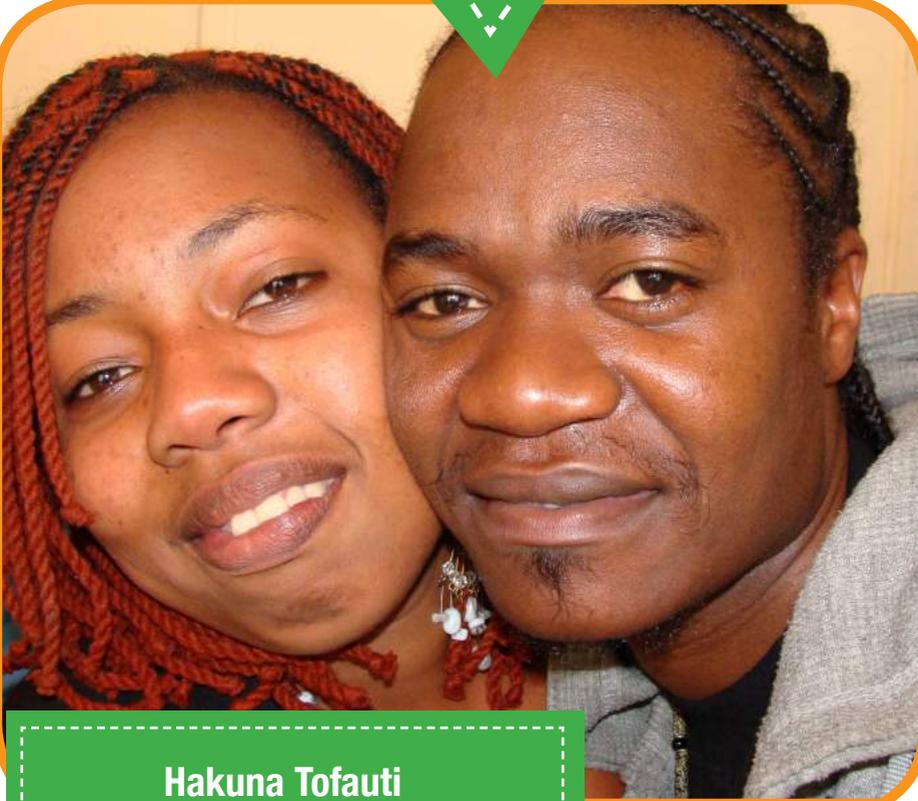
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**Kuna ugonjwa noma
inaitwa kifafa,
Si mchezo kila mtu
anaweza kuipata,
Tajiri, maskini, mkubwa,mdogo,
Mrefu, mfupi, mkonda, mnono,
Watu wengi sana wanaumia,
Lakini sio mwisho ya maisha.**



**Hakuna Tofauti
Jua Cali posing with Mover
Daphne**

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1.

FOREWORD

Youth on the Move welcomes you to our epilepsy training. Through this training we will prepare you to contribute in creating awareness about epilepsy and positively transform the lives of the approximately 70 million people worldwide who are living with the condition. Knowledge is power; having the basic facts about epilepsy, gives one the power to change the lives of people who live with it.

Epilepsy has existed for many years and through the years scientists have gained more insight in the causes and control of the seizures. However, people still face challenges in living with the condition. We therefore appreciate your efforts to expand your knowledge on how people with epilepsy can effectively deal with the condition. During the training we encourage participants to share their own views and experiences concerning epilepsy, because we believe that we can also learn from each other. Your stories will make the classes lively and give us more insight as the training goes on.

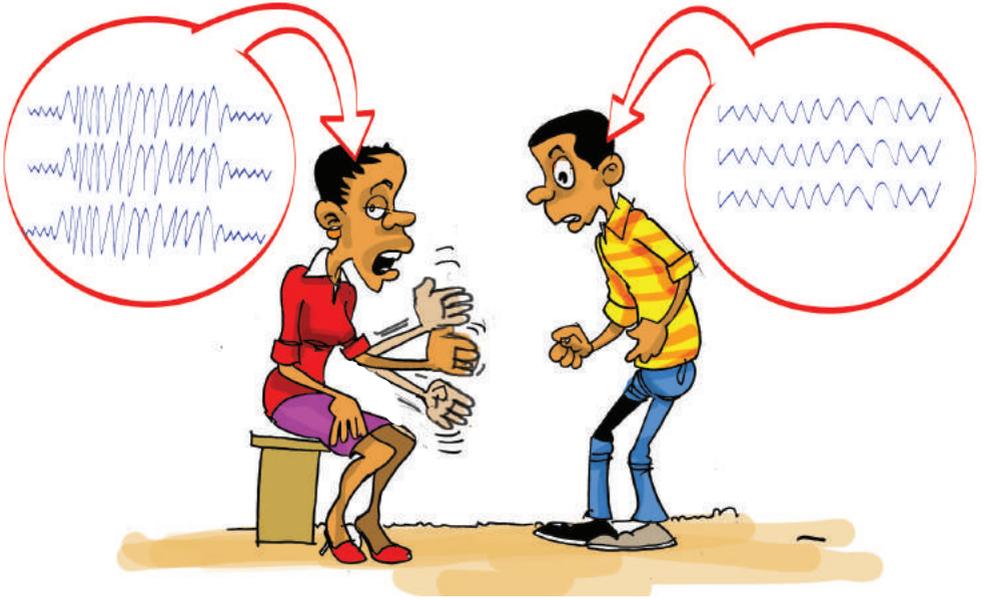
Epilepsy is a condition which may be difficult to understand. You cannot always visibly see it like albinism or polio. Until a seizure occurs, a person with epilepsy looks the same as everyone else. When doctors explain to you what epilepsy is, they may often use complicated words that could make the subject of epilepsy even more confusing. In this manual we share our knowledge on epilepsy in layman's terms. This will make it easier for you to pass on the information to your peers. Once we understand our epilepsy, we will be able to make informed decisions about our lifestyle and live an active life like anyone else.

The Movers Team,
Nairobi, 2016



2.

MEDICAL ISSUES IN EPILEPSY



2.1 What is it?

Epilepsy is a disorder in the brain which makes a person prone to seizures. Seizures, also known as fits, spells, attacks, convulsions or spasms are sudden and temporary electrical disturbances in the brain which cause changes in sensation, awareness or behaviour. There are many types of seizures with different manifestations. One may fall and jerk; others may only stare or fumble with clothes and smack lips. Epilepsy cannot be cured like malaria, but can be effectively controlled in the majority of cases with anti-epileptic drugs which need to be prescribed by a doctor. Just like seizures, epilepsy is quite varied. One person may live with epilepsy throughout their lives, but in many instances the person outgrows the condition. For the prescribed drugs to be effective they need to be taken consistently and any change in the drug combinations or amount must be done in consultation with the doctor.

Anyone can get the condition regardless of their country, their

age, their social class or their religion. Most people with epilepsy can live an active life; work, go out and have a family as long as they take their medication as prescribed.

Aura (warning signs)

In most cases people get the seizure unexpectedly, but some people feel a warning sign just before the seizure starts. Sometimes this feeling may be a headache, a rising feeling in the stomach or a feeling of déjà vu (a feeling of familiarity- like you have experienced the same situation before).

2.2 Causes

The cause of epilepsy can be defined as the initial reason for which someone has epilepsy. In many instances, the cause of the condition is unknown. These are called idiopathic epilepsy. If the doctors have found the cause of the seizures, then we speak of symptomatic epilepsy.

The following conditions can lead to epilepsy:

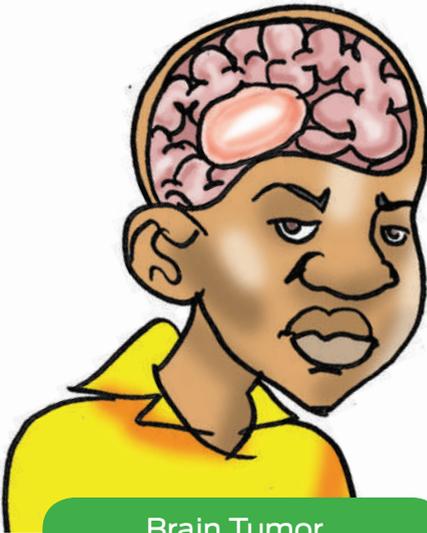
1. **Brain damage or injury:** The level of brain damage or injury determines the effects on a person's health. Sometimes the injury doesn't bring any change in your functioning. But in some cases it can lead to physical challenges, such as epilepsy seizures.
2. **Brain tumor:** A tumor is an uncontrolled growth of a part of the body. Sometimes it can spread to other parts of the body, but it can also stay in place and cause damage by putting direct pressure on other parts. Some tumours in the brain cause epilepsy while others don't. This means that not everyone who has a brain tumour gets epilepsy.
3. **Infections:** Infections like cerebral malaria, meningitis, HIV/AIDS and tuberculosis can especially affect the brain. Sometimes, even when treated in time, you can get epilepsy from these infections.
4. **Stroke:** A stroke is a blood clot that blocks the vessel which carries blood from the heart to the head, or the vessel breaks open. In some cases this can lead to epilepsy.

Causes of Epilepsy

MATERNITY
4000 KMs



Birth complications



Brain Tumor



Excessive use of alcohol
and drugs over a longer
period of time

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Head Injury



Malaria



5. **Birth complications:** When there are complications at birth, such as prolonged labor, the baby may lack oxygen and this could lead to brain injuries. These injuries may result in epilepsy that appears immediately during babyhood or in later life.
6. **Alcohol or drugs:** When one takes alcohol or drugs inappropriately over a long period of time, it may harm the brain and lead to epilepsy
7. **Inheritance:** if other people in the family have epilepsy, then there may be an increased chance for the siblings to develop epilepsy compared to people without a genetic tendency.

Whatever the cause of epilepsy, one thing is clear: nobody chooses to have epilepsy. It can happen to anyone at any age and in any community.

2.3 Prevention of epilepsy

In developing countries the chances of getting epilepsy are higher. The latest research suggests that the chances of getting epilepsy in Kenya are three times higher than in developed countries. Fortunately there are ways we can reduce the number of people affected with epilepsy. Let's take a look at how we can contribute to reducing the chance to get epilepsy:

1. **Increase use of maternity care:** About four out of ten women nationwide give birth in a hospital (Ministry of Planning, 2008). When women give birth outside the hospital, they often do not receive the required assistance. The advantage of hospital delivery is that health care providers can identify complications in time. Once identified they may be in a position to avoid these complications which can lead to birth traumas or injuries that may cause epilepsy.
2. **Prevent infectious diseases:** Infectious diseases such as HIV/AIDS, cerebral malaria, meningitis and tuberculosis can cause epilepsy. Taking preventive measures for these infections greatly reduces the chances of getting epilepsy. For example, sleeping under a mosquito net will reduce

your chances of getting malaria.

3. Head Trauma: Brain damage is one of the causes of epilepsy, therefore anything that prevents head trauma consequently reduces chances of epilepsy. About 9 out of 10 accidents worldwide occur in developing countries. Safe driving reduces the chances of accidents and consequently reduces the risk of head trauma.

2.4 Triggers

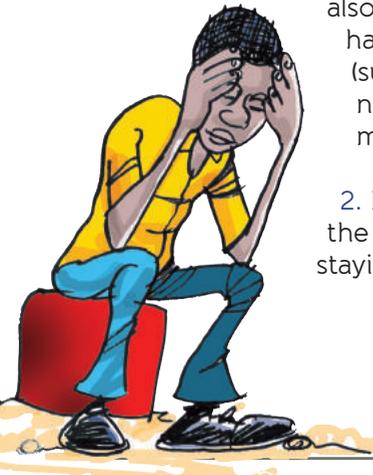
There are various triggers that can provoke epilepsy seizures. They include:

1. Missed medication
2. Lack of sleep
3. Stress
4. Menstruation
5. Missed meal
6. Illness (especially diarrhea or vomiting)
7. Drinking alcohol
8. Taking of illicit drugs
9. Extreme temperatures
10. Flickering lights or patterns
- 11 High body temperature

These are the most common triggers. However some people have very unique triggers, like listening to a special kind of sound or eating a certain food. Exposure to triggers increases the chances of experiencing a seizure. Being well informed about these triggers can help reduce the number of seizures. For instance, if missing a meal is a prominent trigger for one person, then they understand the importance of taking meals. In time this will reduce the number of seizures.

1. Missed medication: Forgetting to take your medication or taking it a bit late can trigger a seizure. It is important to take another dose if you vomit half an hour after taking your medication because the other one may not have been absorbed by the body. It could also happen that you take your drugs, but they have not been adjusted to your bodily changes (such as increased body weight). In this case you need to consult your doctor so that they can make adjustments.

2. Lack of sleep: Getting adequate rest reduces the chances of getting seizures. This doesn't mean staying away from activities but finding a good bal-



ance between being active in the daytime and getting adequate sleep at night to gain energy for the next day.

3. Stress: You can experience negative stress (anxiety) and positive stress (excitement), both of which can provoke a seizure.

4. Menstruation: Some women have more seizures during menstruation; it is essential for them to inform their doctor about it. There are medications that can be taken to reduce the number of seizures. Like other anti-epileptic drugs, they have to be prescribed by the doctor and can't be bought over the counter. They also need to be taken every month to be effective.

5. Missed meal: Missing a meal or eating later than usual can cause the body to get out of balance and could consequently trigger a seizure. It is therefore very important to eat regularly in the morning, afternoon and evening.

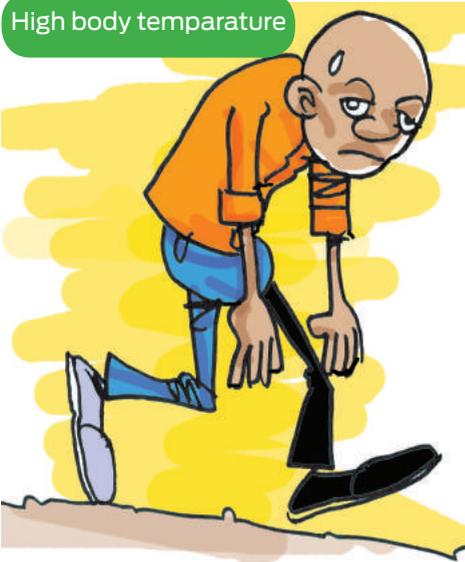
6. Illness: A seizure can be triggered by illnesses such as fever, flu, malaria, and diarrhea. It is important to inform a doctor that you are being treated for epilepsy before they treat you for any other illness. This is because:

- a. Fever makes the brain more likely to have an electrical disturbance
- b. The stress associated with illness may trigger more seizures
- c. The illness may have symptoms that can trigger seizures, such as poor feeding, fatigue etc.
- d. If you're given a drug for the illness, then it may affect the use of your anti-epileptic drugs

7. Drinking alcohol: When you have epilepsy, drinking alcohol may affect your body more than it does to others. The alcohol usually takes effect faster and may even trigger a seizure. Alcohol may not provoke a seizure straight away, but about 6 to 72 hours after the alcohol intake. Ask yourself if the effect of the alcohol intake is worth the pleasure of drinking it.

8. Taking of illicit drugs: Illicit drugs such as cocaine, marijuana and ecstasy do more than only make you high for a moment. They also affect

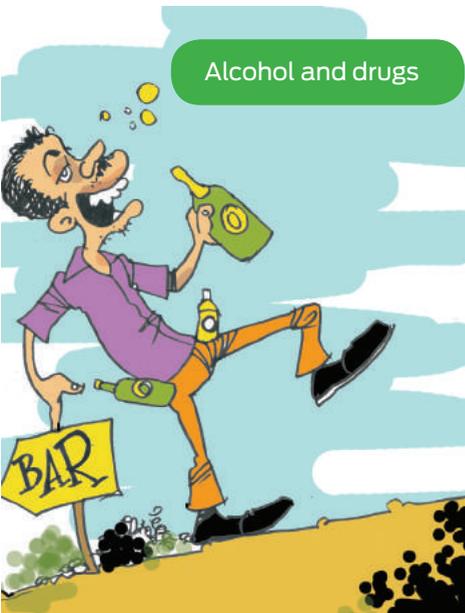
High body temperature



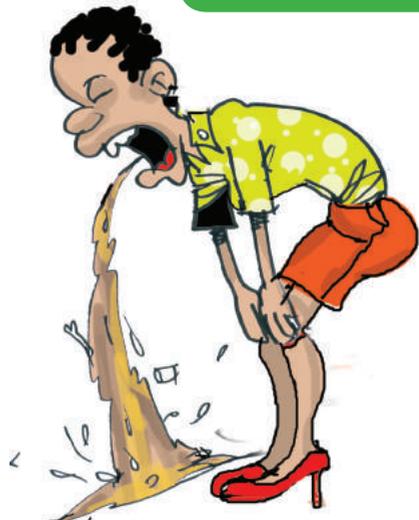
Flickering lights



Alcohol and drugs



Diarrhoea or vomiting



the body in the long term. For some people, taking illicit drugs leads to epilepsy. If you already have epilepsy, the illicit drugs can make your epilepsy worse as well as trigger seizures. Therefore we strongly advise you to avoid them.

9. Extreme temperatures: Staying in the sun for long can cause a body to overheat and can lead to a seizure for people with epilepsy. This doesn't mean that one has to stay indoors all the time to avoid the warm sunshine. When it's very warm indoors, then catch a fresh breeze outside. If overheating is a major trigger, find ways to get fresh air. You can also consider protecting your head from the warm sun with a hat, just as walking in the shade can keep you fresh.

10. Flickering lights or patterns: Only 3 to 5 % of people with epilepsy are sensitive to flickering lights or patterns. This is for example when they watch television, work on the computer, or sit under the tree where the sunlight shines through the leaves as the wind rustles them.

It's important to understand that these triggers cannot give you epilepsy. They can only provoke a seizure if you already have epilepsy.

Triggers are not the same for everyone and it can take some time to recognize them, especially if seizures are not frequent. Although trigger reduction is crucial, it is important to know that epilepsy is not caused by it. We recommend that people with epilepsy discuss the seizures with their doctor to ensure that the medical treatment offered is the right one.

2.5 Types of seizures

People with epilepsy have different types of seizures. One person may fall and jerk, whereas someone else may only appear absent or non-responsive for a while and stare.

For some people the seizure affects only a part of the brain. This type of seizure is called a partial seizure. A generalized seizure occurs when the whole brain is affected by the seizure and one loses consciousness.

Most people have only one type of seizure, but in some instances they experience several types of seizures. These include:

Partial Seizures

During a partial seizure, only a part of the brain is affected. The signs and symptoms will depend on the part of the brain where the seizure occurs and which body functions are controlled by that part of the brain.

The following seizures are partial seizures:

1. **Simple partial seizures:** In this type of seizure, the person remains conscious but experiences sensations or uncontrolled movements. The seizure can cause rhythmical twitching of one limb or a part of the limb, or unusual tastes or feelings such as pins and needles in a specific part of the body. These unusual sensations or movements are sometimes the beginning of a generalized seizure with eventual loss of consciousness; they are known as 'warning signs' or 'auras'.

2. **Complex partial seizures:** These seizures differ from simple partial seizures in that consciousness is reduced and the person will remember nothing or very little of what happened during the seizure. The seizure can begin with an odd taste in the mouth or smell like rotten eggs, a rising feeling in the stomach, or a sense of déjà vu. Then the awareness slowly reduces and the person may fiddle with clothes or objects, mumbling or wandering about in a state of general confusion. The person may respond if spoken to. The person is often tired, briefly confused after the seizure and may have a headache.

3. **Partial seizures secondarily generalized:** These seizures start as partial seizures, then spreads to the whole brain, leading to a seizure such as the tonic-clonic seizure that involves the loss of consciousness.

Generalized Seizures

In generalized seizures, the whole of the brain is affected during the seizure and the person loses consciousness. These seizures mostly come without a warning sign (aura) and afterwards the person will not know what had happened during the seizure.

1. **Tonic clonic seizure:** It is the most common type of seizure, also known as grand mal seizure. In the first part of the seizure, the person becomes stiff and may fall. The muscles then relax and tighten rhythmically caus-

Partial Seizure



Complex Partial Seizure



Tonic-Clonic Seizure



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ing the person to convulse. At the start of the seizure the person may bite their tongue or cry out. In some cases they may urinate. After the seizure they might be tired, confused, have a headache and may need some rest to recover fully.

2. Absence seizure: This is common in children, also known as petit mal. The person briefly loses consciousness and doesn't respond to anything. They appear blank and make no movements, except for maybe fluttering of the eyelids or swallowing movements. Absence seizures often last for only a few seconds and usually go unnoticed. Absence seizures are regularly confused with day dreaming. However, children who daydream tends to respond if someone pushes them or talks to them, whereas children who are experiencing an absence don't.

3. Tonic seizure: General stiffening of the muscles without rhythmical jerking is characteristic for this type of seizure. The person may fall to the ground with a consequent risk of injury, however recovery is quick.

4. Atonic seizure: Also known as drop attacks, they involve a sudden loss of muscle tone, causing the person to fall. The risk of getting injured during this seizure is high, but recovery is generally quick.

5. Myoclonic seizure: This involves brief and abrupt jerking of one or more limbs. This often happens within a short time of waking up. The seizures can happen on their own or with other forms of a generalized seizure

2.6 Lookalikes: seizure or no seizure?

Epilepsy is a condition which is often confused with other conditions. These include:

1. Fainting
2. Psychogenic seizures
3. Breath holding spells
4. Febrile convulsions
5. Daydreaming
6. Sleepwalking
7. Tics
8. Tourette's syndrome
9. Diabetes

1. Fainting: Fainting is a temporary loss of consciousness. Unlike a seizure, the person who faints usually regains alertness soon after regain-

Daydreaming



Absence Seizure



ing consciousness. Fainting is caused by a temporary decrease in the brain's blood supply. It mostly results from an abnormal reflex. The heart pumps more forcefully and the blood vessels relax, but the heart rate does not compensate fast enough to maintain the flow resulting in fainting. The main distinguishing point is that it has a short duration of loss of consciousness and that the person is not confused after the fainting.

2. Psychogenic seizures: These are seizures which look like epilepsy seizures, but they are caused by a psychological disturbance. One of the types of psychogenic seizures is known as hysteria. People who experience a hysteric attack often lose self-control due to an overwhelming emotion such as fear or anger. This can happen in events where crowds are excited into a state of frenzy. This may lead to mass hysteria, hyperventilating (breathing fast) and consequently the brain gets less oxygen. Once the level of oxygen goes down, people can have a seizure which looks like an epileptic seizure, when it's really a hysteria attack.

3. Breath holding spells: This could occur when a young child cries intensely, mostly after some minor upset, and holds their breath, leading to a lose in consciousness and getting limp. The attack mostly takes 30

to 60 seconds. With longer spells, the eyes might roll up; the entire body may become rigid and jerk, as the lack of oxygen to the brain actually triggers a seizure. Although the seizure looks like an epilepsy seizure, the child may not have epilepsy.

4. Febrile convulsions: This is a convulsion that is caused by a rise in body temperature common among children aged 6 months to 6 years. This is not necessarily epilepsy but a temporary condition which needs to be examined by a doctor.

5. Daydreaming: Daydreaming can be easily confused with an epileptic seizure; however, while lip smacking, eye blinking, or stiffening of muscle groups is common during seizures, they are not common during daydreaming. Daydreaming can be stopped by calling the person's name, making a startling noise, touching or tickling the person. However if it is an epilepsy seizure, then the person will not respond until the seizure passes.



6. Sleepwalking: During sleepwalking the person is completely unaware of what is happening, and it is understandable that people confuse it with epilepsy, as it presents like some types of seizures. It is important to know that sleepwalking can also happen to people who do not have epilepsy.

7. Tics: Tics are brief, involuntary, and repetitive movements. The most common tics are eye blinks, facial grimaces, shoulder shrugs, and head movements. Although people can

make the same movements during an epilepsy seizure, these tics are not necessarily caused by epilepsy.

8. Tourette's syndrome : Someone with Tourette's syndrome has a specific type of tic which is chronic repetitive movements and voice tics. The voice tics range from grunts and throat-clearing sounds to involuntary cursing and other embarrassing noises. These tics are also commonly confused with epilepsy.

9. **Diabetes:** People with diabetes usually have low or high blood sugar; this can trigger a seizure which looks like an epileptic convulsive seizure. Even though the first aid they need during the convulsive seizure is the same, people with diabetes require a different medical treatment from that given to people with epilepsy.

2.7 Diagnosis

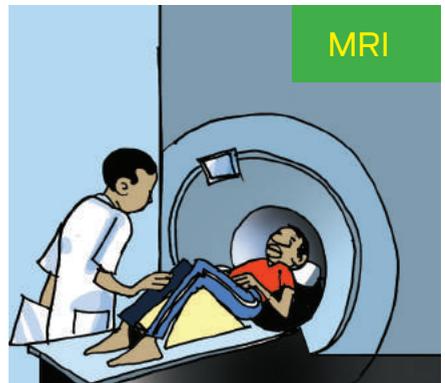
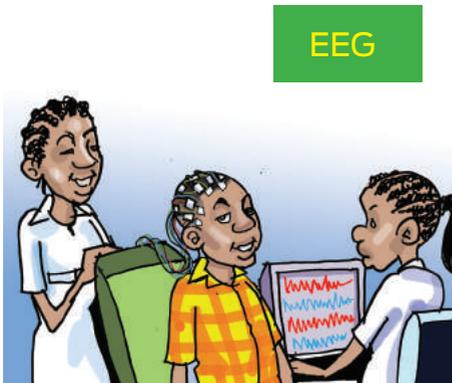
Everyone who has epilepsy, or thinks that they have epilepsy, must visit a doctor for consultation. It will help the doctor if you take someone with you who was present during your seizure, as they can explain what it looked like.

The doctor will ask various questions, like:

1. What do the seizure look like?
2. How long do the seizures take?
3. How do you feel before and after the seizure?

Usually a doctor can draw a conclusion about the types of seizures you experience from the answers given. If they are still not sure, they may request medical tests such as an EEG or MRI, which give definitive information about what happens in your brain.

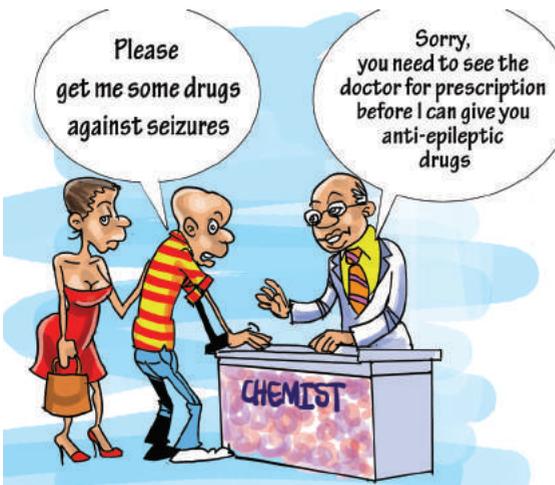
Electroencephalogram (EEG): An EEG is a test that records the electrical activity of the brain. Special sensors (electrodes) are attached to the head and connected by wires to a computer. The computer records the



brain's electrical activity on the screen as wavy lines. The person may be asked to hyperventilate or to look at flashing lights so as to activate brain discharges. A seizure can be seen by the changes in the normal pattern of the brain's electrical activity. Most EEGs can be run in about an hour or less.

Magnetic Resonance Imaging (MRI): To search for the cause of your seizures, the doctor may request for an MRI scan. The MRI takes pictures of the inside of your brains with the help of a magnetic field. The images are extremely precise, and may for example show a tumor or damage in the brain which could be the cause of the seizures.

It may be necessary to get an injection (contrast) before the test, to help the MRI scans reveal more. Afterwards, you will be asked to lie down on a narrow bed. They will position cushioned pads on either side of your head to keep it still. It is important that you lie as still as possible during the test so as to get clear pictures without movements. The technician will roll the bed inside a shaped tube and they will give you guidance through each step. Once in the tube, you will not feel anything except for the cushioned pads around your head, but you will hear a series of knocking sounds. The duration of the scan depends on the area in the brain which the doctor wants to examine. This could take twenty minutes or longer.



2.8 Treatment

Epilepsy is a condition which can be treated with anti-epileptic drugs after the doctor has made a diagnosis. Once the doctor has diagnosed you with epilepsy, you will need to be treated with anti-epileptic drugs (AEDs). AEDs are tablets which are taken daily as prescribed by the doctor.

Seven out of ten people that make use of AEDs become seizure free; the other

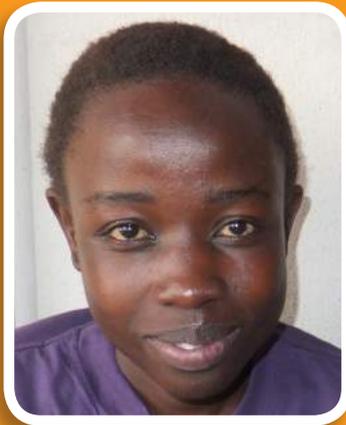
three out of ten may still experience seizures though in reduced numbers. It is important to know that the condition cannot be treated over the counter.

Typically a doctor will not prescribe any treatment after a single seizure; at least two seizures are necessary to begin treatment. If seizures are very rare, the doctor may question the necessity of the treatment. It is a matter of weighing the challenges of your seizures against the challenges of the treatment (such as the costs and side effects of the drugs).

To stay healthy, you need to continue the treatment until the doctor suggests a change. They do not cure the epilepsy but can con-

Rhoda Anyango's life experience with epilepsy

I have lost so much in my life that it led me to ask if God is still really there because epilepsy was not a good thing in my life. When I was 10 years old, I got my first fit and I was in primary school at the time. My friends were laughing at me saying that I had reached the end of my life. In school, even my teachers were not happy with my state of health. Anytime I got a seizure, it was considered a curse and my family members would quarrel amongst themselves, especially my family and my grandparents. They believed it was the moon that caused my seizures. When my condition did not improve, I was taken to witch doctors who gave me dog meat to eat as a medicine. They also put



different kinds of medicines inside my nose. I would sneeze and sweat until I felt I was going mad. They also used razor blades to cut my body and they would rub ash on these wounds as a way of curing me. It didn't change anything because I still had the seizures. I later started going to the epilepsy clinic in Mathare and received anti-epileptic drugs. The drugs controlled my seizures and gave me hope again. Now I know I can live an active, healthy life when I take my drugs. I don't worry much these days; God can raise one person from nothing to something.

trol the seizures for as long as you take them. This means that if you stop the treatment without doctor's consent, it may bring back the seizures and even make them worse.

Usually the consultation and the drugs in public hospitals in Kenya do not cost more than Ksh 300 per month (Ksh 100 for consult and Ksh 200 for the drugs).

Ten rules for your treatment:

1. Inform your doctor if you still have seizures despite taking your drugs
2. Do not experiment with your drugs, your doctor needs to guide the changes
3. Tell your doctor if you have any doubts about your prescription
4. Don't stop the drugs suddenly, even if you do not have seizures any more, consult your doctor first!
5. Remember to take your drugs in time, ask your doctor what to do if you forget
6. Use a medicine box if you find it hard to remember taking medication

There is something in this world that is affecting people. Epilepsy is not the end of life. If you have it, seek medical advice

Kapsabet Movers



7. Tell your doctor if side effects occur. Sometimes, changes can be made
8. Plan ahead so you do not run out of drugs, always take drugs with you
9. Diarrhea and vomiting may affect the absorption of medication. If you throw up shortly after taking the medication take another dose. Consult your doctor if vomiting continues.
10. If you are planning to get pregnant, discuss it with your doctor in case any changes on your treatment need to be made

2.9 First aid

The type of first aid that needs to be given during seizures depends on the type of seizure. With convulsive seizures, others can assist by:

1. Staying calm
2. Removing any sharp or harmful objects or moving the person away from danger
3. Supporting or placing something soft beneath the head
4. Loosening any tight clothing at the neck
5. Rolling the person onto their side (recovery position) when jerking stops
6. Staying with the person until fully recovered and oriented
7. Seeking medical help if the seizure takes longer than 5 minutes

Know the don'ts

1. Do not restrain the person when they're jerking, it can cause bruises
2. Do not put anything in the mouth, you cannot prevent the person from biting their tongue
3. Do not give food or drinks before the person is fully recovered as they might choke on it
4. Do not pour cold water or anything else on the person

If the person experiencing the seizure is on a wheelchair or car seat, they can remain seated if secure and safely strapped in. When the seizure is happening it is important to support the head. When the jerking stops and they are still unconscious, they can be removed from the seat and rolled on their side to allow excess saliva to come out.

DO NOT put anything
in the mouth



DO NOT give food
or drinks

3.

LIFESTYLE



3.1 Accepting epilepsy

The degree to which people accept their epilepsy varies from person to person. Some people easily face it and learn to deal with it while others experience confusion. When the doctor informs you that you have epilepsy, a lot of questions may go through your mind:

1. Did they say epilepsy or leprosy?
2. Am I going to die now?
3. What did I do wrong?
4. How can I get rid of this?
5. Why me and not someone else?
6. How can I hide this from others?

Understanding epilepsy is an important step in your effort to acknowledge and accept the condition. For this, you need knowledge about it. This can be given by the doctor, but you can also search for literature or ask other professionals to tell you more about it. Their information can reassure you that epilepsy is nothing to be ashamed of and that you can live beyond it.

It is advisable for you to participate in trainings where you can share experiences and knowledge. This can be achieved at various epi-

lepsy organizations that organise meetings for people with epilepsy. Once you have enough knowledge, you will understand how you can live an active life.

Epilepsy Opening Up Model

Sometimes people with epilepsy are advised that they should just accept their condition, even before they understand what it is. It is more important to check how someone with epilepsy perceives their condition before giving advice how to deal with it.

Below is the Epilepsy Opening Up Model indicating the various stages people with epilepsy can experience and what support is most appropriate at that moment:

State	Thought of the person	Appropriate action
State of ignorance	"I fainted and I don't know why"	Referral to a doctor for diagnosis and prescription.
State of denial	"The doctor says that I have epilepsy, but I'm not convinced"	Provide knowledge about epilepsy.
State of acknowledgment	"I acknowledge that I have it, but I can't accept it; why me?"	Provide personal coaching and interaction with peers, getting to understand epilepsy is a condition you can live beyond.
State of acceptance	"I accept that I have epilepsy, but I don't want to open about it"	Meeting with peers who have experienced the same, getting to understand epilepsy is nothing to feel ashamed about.
State of utilisation	"I accept that I have epilepsy, and I am ready to share my knowledge and experiences with people around me to empower them"	People with epilepsy take responsibility to educate others in their own areas.

3.2 Informing others

When you have epilepsy, do you have to inform others about it? Some say that it's important to share it with the people you deal with; others choose to keep it quiet. The good thing is that the choice is yours. You can choose to share or to keep it private.

When you tell others about your condition you:

1. help them to understand what epilepsy is and reduce the prejudices
2. teach them how they can give you first aid during a seizure
3. share your challenges and get their moral support to overcome it
4. encourage others not to feel ashamed about their epilepsy

To avoid prejudices, most people with epilepsy don't tell others about their condition. But when you sense that a seizure is about to come, it is wise to open up about it. People who are close to you may feel betrayed because you haven't been open about your epilepsy. They will also not be prepared in the event of a seizure.

3.3 Getting treatment

It is important to get treatment to control the seizures. However, the majority of people with epilepsy in Kenya do not make use of it. Research done in Kilifi reveals that, 8 out of 10 people with epilepsy don't take anti-epileptic drugs (Edwards, 2008). Some people deliberately avoid the treatment, whereas others unintentionally don't take drugs. Let's take a look at reasons why people could not be taking their drugs:

1. **Diagnosis:** The person may not have gone to the doctor for a diagnosis, or may have visited a doctor but received a misdiagnosis. As a result, a patient may be prescribed a treatment that is meant for another condition.
2. **Stigma:** Sometimes people who have epilepsy

Isitoshe
ninawezajichagulia,
Ukuinicheki
unanikimbia,
Napitia hosi, kuna dawa
Nafanya shughuli
zangu bila haya
Au sio?



LET'S
TALK
EPILEPSY!

seizures feel embarrassed about it, and even avoid visiting the doctor. Some prefer to deny the condition rather than face the doctor.

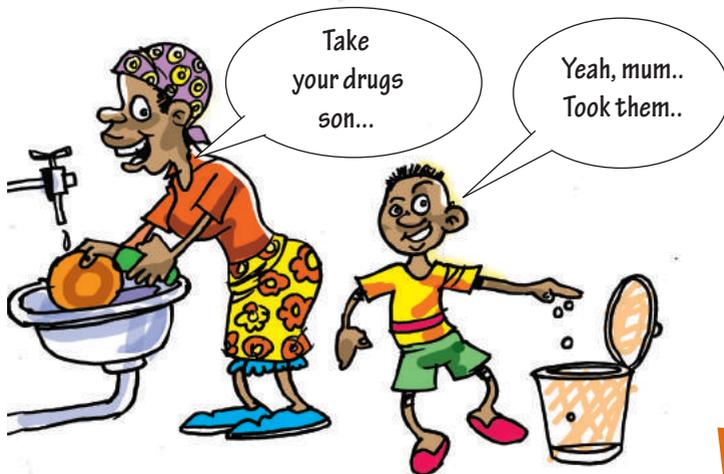
3. Confidence in Doctors: Many Kenyans have little or no confidence in the local healthcare providers due to past malpractice. According to the Community Strategy (2005) many doctors do not pay proper attention when diagnosing and prescribing treatment or explaining medical conditions.

4. Availability of Drugs: Even in the cases where epilepsy is correctly diagnosed, the availability of drugs still remains a major challenge. It is therefore important to maintain an adequate stock of the drugs.

5. Finances: In developing countries where a good number of the population live under a dollar a day accessing treatment is difficult for many people.

6. Ignorance: In some cases the patient doesn't know just how essential the drugs are. But sometimes they may simply forget to take the medication

7. Side effects: Anti-epileptic drugs usually have extensive side effects; in an effort to alleviate these side effects some may possibly stop taking the medication all together.

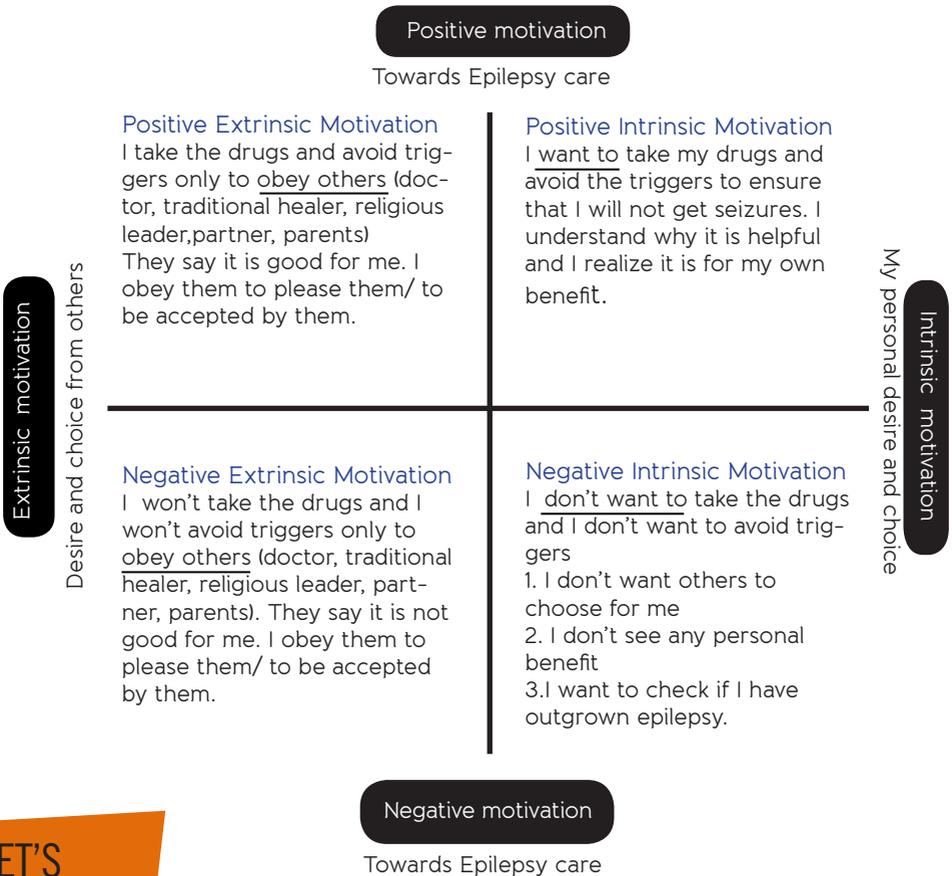


8. **Rebellion:** Young people are often resistant of authority figures, more so in their teen years. For the youth with epilepsy this rebellion can have untold consequences when it leads them to skip medication.

Epilepsy Care Motivation Model

Due to the stigma that surrounds epilepsy it is common practice for people with this condition to reject assistance even when it is offered. There are various attitudes that you can have toward your anti-epileptic drugs and preventing seizures.

We distinguish positive, negative, intrinsic and extrinsic motivation to take the AEDs and to avoid triggers of seizures. By making use of ACT (Acceptance and Commitment Therapy) we provide knowledge on epi-



CASE STUDY

Annette: My parents are very concerned about my health given that I have seizures. Therefore they regularly remind me to take my drugs, especially when I need to take them. This drives me crazy, because it seems that they don't have faith in my ability to take care of myself. I sometimes just don't take the drugs to be rebellious, to have the feeling that I live my life for myself, not for them. It's my life and my choice to do what I want to do with it, not theirs. It is therefore advisable to encourage young people to take responsibility for their well being by informing them of the negative impact of skipping drugs.

lepsy and guidance which helps people with epilepsy to acknowledge and accept the condition and understand the need for the treatment. Once you have the positive intrinsic motivation for your treatment, you will be able to independently take good care of yourself.

3.4 Misuse of epilepsy

Some people feel that epilepsy is an excuse to let others assist them even when they can do something perfectly well by themselves. Taking advantage of epilepsy can lead to passiveness and stronger dependence than required. The disadvantage is that the person with epilepsy is not creating opportunities to become independent and free.

Some also use epilepsy as an excuse for their temper. They may say that they cannot help it that they are sensitive and incapable of peacefully handling confrontations. The disadvantage is that people will lose the pleasure of socializing with them, and even avoid seeing them.

This means that misusing epilepsy works against you rather than for you. We therefore encourage people not to take advantage of their epilepsy. Instead of asking others to do things for you, you can ask them to be supportive as you make an effort to do things by yourself, unless it's too risky.

3.5 Education

Education is an essential aspect of life and epilepsy does not in any way prevent an individual from successfully attaining it. However, the condi-

tion has been classified by some as a mental challenge. As a result some people with epilepsy have been denied the right to access education even though they can attend classes and gain knowledge like anyone else.

On the other hand it is important to note that the condition places an additional challenge upon those who live with it. Epilepsy presents with symptoms such as memory loss and seizures which can interfere with the normal learning process. It is essential not to let it limit or deny access to education. Staying at home would not only take away one's chance to advance in the labor market but also take away the chance to interact with peers. You would also be missing out on socializing and this may lead to isolation and loneliness.



3.6 Work

The ability to work and be productive opens doors for people to achieve their goals. People living with epilepsy have the same opportunity to attain anything they set their minds on. However, when choosing a job it is important to take into account your condition. In most cases, people with epilepsy can work just like anyone else. However, if you have regular seizures or extensive side effects from medication, it may make it difficult for you to fulfill your duties.

Here's a check list that can help to assess the relevance of your work:

1. The place of work is safe (you and your colleagues won't be at risk in case of a seizure)
2. The work doesn't have triggers for your seizures such as:
 - a. Too much stress
 - b. Sunlight (which can cause overheating)
 - c. Lack of sleep due to long working days
3. Your duties and responsibilities can be postponed or taken over by someone else if a seizure occurs

Nonetheless the jobs that can be termed as risky are a minority. We encourage you to find a way to get educated for the job you want. Com-

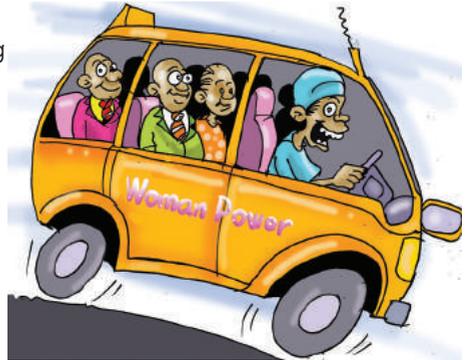
binning education and volunteer work will help you broaden your network and improve on your skills. This will in turn make it easier to find a job.

3.7 Driving

Everyone who wants to drive a car needs to pass the tests for a driving license. But is it wise to drive if you can have a seizure? How can you decide if you can safely drive a car? Can you drive yourself from home to work? Or is this too dangerous due to the chance that you may get a seizure? In many countries people who experience seizures during the daytime lose the legal right to drive.

Some people think they can drive safely because they get an aura before the seizure occurs. However, what will you do when you are driving along a superhighway as you get the aura? You may not have enough time to drive to a safe place to park your car.

The risk of having an accident because of your seizure is greatly reduced in people who have been seizure free for 12 months. Therefore many countries allow you to drive if you are seizure free for a year.



In Kenya, there are no clear published rules on your right to drive a car when you have seizures. However, we highly encourage you to make a wise decision. If you drive a car and you can have a seizure, you risk not only your own safety, but also the safety of other people on the road.

3.8 Exercise

Exercise is a great way to make ourselves feel better. It makes us feel energetic and boosts our self-esteem. It enables us to sleep better and keeps us from being depressed. When we exercise, the body produces hormones called endorphins which give us a feeling of happiness. These hormones are usually addictive, so once you start with exercise, it's hard to stop.

For most people with epilepsy exercises don't trigger seizures, but in fact reduce the occurrence. It is therefore not common for people to experience an attack while engaging in sports. Everyone has a type of ex-

ercise that they like most. One person may like dancing; someone else may love soccer. Another might enjoy walking more, or riding a bicycle instead of public transportation. When you have epilepsy, you need to consider which exercise is best for you as some types of exercises can be risky, such as swimming. If you get a seizure while swimming you could drown if you don't get immediate assistance. Therefore you must have someone who can accompany you, so as to assist you if you get a seizure in the water. It is also recommended that you inform the lifeguard about your epilepsy and how they can assist you if you get a seizure.

As you participate in sports, you need to protect yourself from exhaustion, dehydration and low blood sugar. These can trigger seizures. Do not cross your limits, and ensure that you drink enough water and eat enough food.



3.9 Alcohol & drugs

Some people get epilepsy because of extensive alcohol intake over a long period of time. People who have epilepsy can be sensitive to alcohol. Only half a beer can make a person with epilepsy feel drunk. Alcohol can also trigger a seizure.

Consumption of drugs (like smoking weed) and alcohol is associated with behavior that is risky for people living with epilepsy.

Most people with epilepsy can have one or two glasses of alcohol without increasing the chances of having a seizure. For some a small amount of alcohol provokes a seizure and they therefore must choose not to drink alcohol at all.

Just like all other lifestyle issues, when youth are told what they should and shouldn't do it generally has a negative impact. If they are

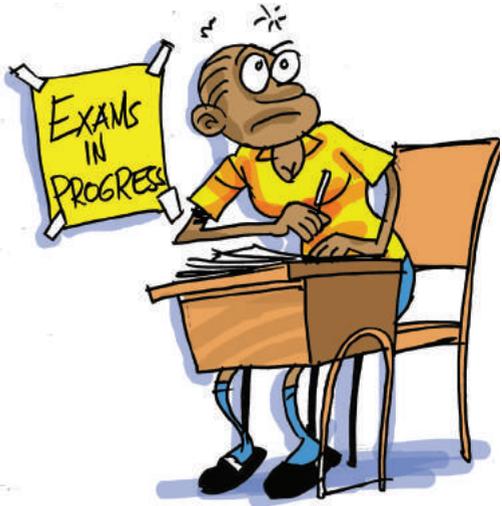
told not to drink alcohol, they may feel the urge to rebel and drink excessively. It is therefore recommended that they are given the facts and the chance to make the choice for themselves.

3.10 Stress (Anxiety and Excitement)

When we think about stress, it's negative pressure that mostly comes to mind; the stress for exams or work, or the stress of how to get enough money to put food on the table or to pay school fees on time.

There is however another form of stress: the positive stress, excitement. Think about the moment you get a positive message; you've gotten the job of your dreams. You might feel energy bursting from your toes to your head; the adrenaline kick goes through your body. Or imagine when you are celebrating your birthday and your friends and family are visiting you. You are excited to see them together. This can be described as positive stress.

Both positive and negative stress in an extreme form can trigger a seizure for people with epilepsy. So this seizure can be triggered during exciting events and during events when you are negatively stressed. For example, you could get the seizure after a tough day at work, just when you got home to relax. We advise you not to completely exclude the stress in your life, as this could mean that you avoid any activity. Instead, we advise you to weigh the consequences of the stress actions: is it worth risking a seizure?



3.11 Dating

Like anyone else, people with epilepsy have feelings, desires and go out on dates in the hope of meeting someone that they can love. As you go for the first date, you could be anxious and doubtful of what you should

share about yourself. Will you only share the nice things in your life? Or will you also share your challenges? When will you inform your date about your epilepsy? Do you do it during the first encounter, or do you



wait a bit longer, maybe even wait until they see you having a fit? The choice is yours, although we encourage you to be open about your health, as epilepsy is nothing to feel embarrassed about. We believe that a person who truly loves you will take you with all your strengths and challenges. Take your time to explain what epilepsy is. You can explain to your date that you are not a victim of epilepsy, as long as you have access to your treatment and as long as people

treat you like a normal human being. Just remember that epilepsy is only a small part of you. It's not your character, it's not your personality, and it is only a disruption in your brain when you have a seizure. Take your time to explain what it is, so that the person can understand you better and be there for you, for better and worse.

3.12 Sex and family planning

Living with epilepsy cannot prevent one from having a successful marriage and bear children. People with epilepsy can make love and have children like anyone else. Therefore you also need to take measures to avoid pregnancy if you are not ready to become a parent.

For women with epilepsy, it's important to know that birth control pills may not fully protect against pregnancy, as some anti-epileptic drugs reduce the effect of the pill. However, condoms work the same for everyone and prevent pregnancy and the transmission of Sexually Transmitted Diseases .

When you are ready to become a parent, we advise you to first consult your doctor. They may change your prescription during pregnancy to reduce the chance of complications for the baby. In most cases, people with epilepsy have perfectly healthy children. During the pregnancy you could experience a difference in your epilepsy. The number of seizures could increase or decrease. This is different for every person.

However, if you have a seizure during your pregnancy, we encourage you to inform the doctor about it so that they can check if there is need to change your treatment. In some very rare cases the seizure may harm the baby. Therefore it is important to check how to reduce the chances as much as possible.

Commonly Asked Questions

[Can epilepsy be transmitted through sex?](#)

In some areas people believe that epilepsy can be transmitted through sex or even by touching the person with epilepsy. Fortunately this is not true. Epilepsy is not contagious, and therefore it's not a reason to exclude anyone from social interaction and intimacy.

[Can you get pregnant when you have epilepsy, or impregnate someone else?](#)

Another myth is that people with epilepsy can't have children. This is also not true, as a woman with epilepsy can easily get pregnant and a man with epilepsy can easily impregnate a woman. Therefore, if you are not ready to have children, it is important to engage in the services of a family planning clinic.

[Might I have a seizure when I make love?](#)

Sometimes, people with epilepsy and their partners worry that a seizure may occur while they make love. In fact, a seizure is no more likely to come at this time than at any other time. But it is true that it could happen to you. This is not a reason to be nervous about it, and even less a reason to walk away from the physical intimacy. Having a seizure as you make love cannot do any harm, as we already know that epilepsy cannot be transmitted through sex. As you are intimate with your partner, (s)he is close enough to give you the support and assistance that you need.

Can you get infected by HIV or any other STD?

If you have epilepsy, you need protection from HIV and any other STD as much as anyone else. Epilepsy does not prevent you from getting infected when you have sex or through any other way.

3.13 Faith and belief

As people grow up they are socialized into various spiritual and moral beliefs. For every faith and belief, there are views of epilepsy which have an impact on the way people relate to it. While some religions view epilepsy as a curse, others view people with epilepsy as a divine spirit.

Religious institutions sometimes offer more services than only spiritual guidance. We see religious institutions running their own schools and clinics that assist in creating awareness about health issues. This way they greatly contribute to the quality of health of their members.



Whereas many religious leaders encourage their members to seek medical assistance from conventional doctors, some prohibit or discourage their members from seeking conventional treatment but to solely seek spiritual guidance instead. Some people make use of both; they take the treatment as prescribed by the doctor while they also ask their pastor or a faith healer to pray for God's intervention. In some cases, religious leaders or

faith healers claim to heal epilepsy and discourage the use of anti-epileptic drugs. This can be a risk to your health. Seizures can come back in an even greater form than before if you abruptly quit using your drugs without your doctor's consent.

3.14 Rights

What rights do you have when you have epilepsy? Many people are not aware of their rights, whereas it's important to know what you deserve in life, so that you can stand up for your rights when others abuse or violate them.

When we think about rights, we think about the law, and in particular the highest law of the land: the Constitution. The Constitution gives you the same rights as every other citizen. We have basic human rights such as:

1. The right to life
2. The right to human dignity
3. The right to your security
4. The right to be treated equally with others
5. The right not to be discriminated against
6. The right to education
7. The right to health
8. The right to fair conditions of work

You also have extra rights if you are hindered in carrying out your day-to-day activities due to your epilepsy, or any other 'physical, sensory, mental, psychological or other impairment, condition or illness.

When you are hindered in carrying out day-to-day activities, you have:

1. The right to be treated with dignity and respect and to be addressed and referred to in a manner that is not demeaning
2. The right to be educated in schools and other institutions that are integrated
3. The right to reasonable access to all places, public transport and information
4. The right to have materials and devices to overcome challenges arising from your physical challenge
5. The right to participate in all matters taking place in Kenya, including standing for Parliament or county governments

As a person with epilepsy, the right to health is particularly important, and you need to always remember and insist on your rights as a client when you go for a check-up to a hospital. Now it is your responsibility to recognize when people do not treat you according to your rights. When

you realise that people are abusing your rights, you can start a dialogue about it and set your boundaries. You may be initially scared and wonder: What will they say or do when you say that you want to be treated differently? They may laugh at you or take it seriously and offer their apologies. Sometimes it can be of help to discuss with your peers when you feel uneasy about the way people treat you. If you have the feeling that people treat you with disrespect, your peers can give you support and advice on how to stand up for your rights. Remember, these rights are not 'given' to you: they belong to you as a citizen of Kenya by the fact that you are a human being. They cannot be taken away from you either by the government or its officers, or anyone else. You must remember, however, that you must also respect the rights of others.

Serious violation of rights

When people attack you in a way that threatens your security and health, it is important you take action. If people do not respect your rights, you can report the case to the police, so that they can take action. If they think the case is serious enough, they may take the person to court. You can also approach an advocate to ask for legal advice. They will tell you if and how to take the matter to court and how this can be of help to you. This is, however, time consuming and often expensive. Therefore they usually only do this for serious cases.

Human Rights organisations that can be of assistance include: the Kenya National Commission on Human Rights (KNCHR), the National Cohesion and Integration Commission (NCIC), the Kenya Human Rights Commission (KHRC), Kituo Cha Sheria and the Federation of Women Lawyers (FIDA-K) for assistance or advice on what to do.

For more information about your rights, we refer you to our website where we share facts about the rights for people with epilepsy in Kenya: www.yotmkenya.com/rights

Kati ya mi nawe,
Hakuna tofauti,
Tuko sawa nawe,
Hakuna tofauti,
I have a voice in so-
ciety, Please don't
take it off of me.



4.

YOUTH ON THE MOVE'S ACTIONS

4.1 Epilepsy Education

To create awareness about epilepsy, yearly, we give trainings in forty places all over Kenya. Our trainers are youth with and without epilepsy. They have the knowledge and experience of what epilepsy is and how you can live beyond it. With openness they share this with you and also welcome you to tell your story and ideas about epilepsy.

Would you like to learn more? Come to our Training Centre at the Birongo Square in Nairobi West to take part in our trainings.

Are you a group and you'd like us to come to your area? Contact us, where possible we would love to come to your place to share our knowledge and experiences on how to live a pro-active life with epilepsy.

Email or call Epillose Musimbi with your request:

Email address: epillose@yotmkenya.com

Phone: 0712623681

4.2 Youth Coordination Training

Every year Youth on the Move trains twelve youths (of which six are youth with epilepsy) as professional peer educators. They get classes and exams from February until the beginning of December on the following topics:

1. February: Epilepsy
2. March: Culture & Identity, Presentation Skills
3. April: Personal Development Plan
4. May: Coaching
5. June: Youth Participation
6. July: Teamwork
7. August: Personal Development Plan
8. September: Lifestyle
9. October: Entrepreneurship
10. November: Personal Development Plan
11. December: Graduation

4.3 Take part in the awareness creation!

Do you want to be one of the youths in training? Apply online to get an interview with the trainers. Every January we have interviews and final selection, the training starts in the beginning of February.

Visit our website to apply for the training: www.yotmkenya.com or send an email with your request to info@yotmkenya.com.

4.4 Movers Meeting

Would you like to exchange experiences with other youths with epilepsy? Come to our weekly Movers Meeting in Nairobi which takes place on Saturday from 11 am to 2 pm (except for the last Saturday of the month). Every week we prepare the upcoming activities and evaluate the last events. Do you have any good ideas of how to empower youths with epilepsy? Any plans of how we can create awareness about epilepsy? Become a Mover and bring it in during the meeting so that we can be inspired by you and even reach out to many more people.

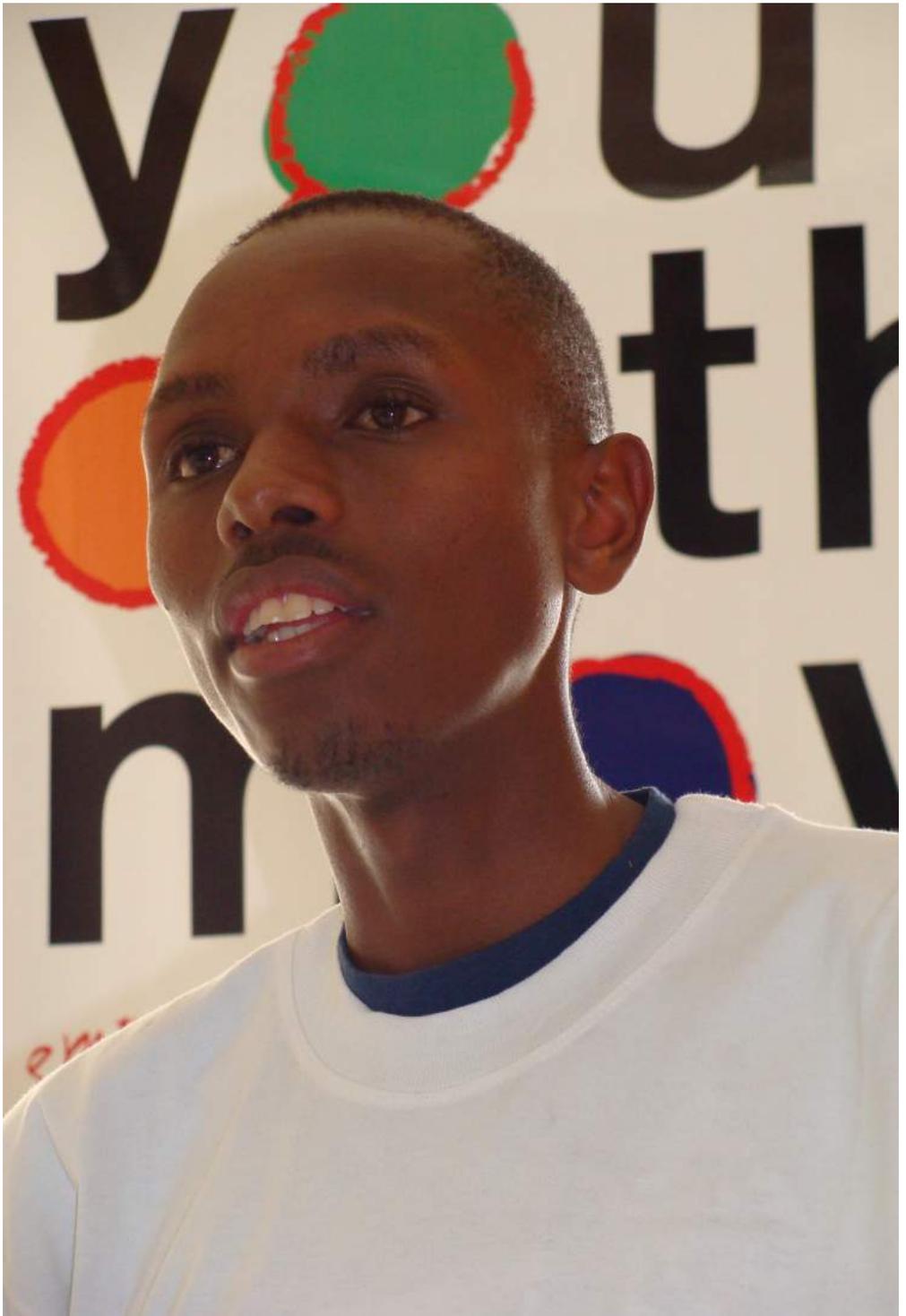
After the preparations of our Awareness Actions, we hold the Sikika Talk where the Movers share knowledge and experiences about different topics and encourage each other to develop our own opinion and to freely share it with the team.

4.5 Movers Picnic

Every last Saturday of the month (except for December) we have our Movers Picnic in Nairobi and Kisumu starting from 8.30 am. You want to join in? Communicate with our Movers Coach for more information about where you can find the team.

4.6 Parents Meeting

Every last Saturday of the month, when the youth go out for the picnic, the parents meet at Youth on the Move's centre from 11 am to 2 pm. They discuss their challenges and opportunities in raising their daughters and sons living with epilepsy. They share experiences and discuss together on how to find a good balance between protecting them from potential harm and stimulating them to become independent confident adults who are capable of taking good care of themselves.





**youth
on the
move**
emPOWER talents with EPILEPSY

The Voice of Youth and Adolescents
**Straight
TALK**

**Youth on the Move Office
& Training Centre:**

New Life Church Building, Birongo Square,
Nairobi West. Reachable with matatu 14b to
Nairobi West Shopping Centre.

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