

FACILITAOR

MUSIMBI EPILLOSE

YOUTH ON THE MOVE, EMPOWER TALENTS WITH
EPILEPSY

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Content of training

1. Introduction – Epilepsy defined, statistics, myths
2. Medical Facts on Epilepsy
 - ❖ Causes
 - ❖ Types of epilepsy seizures
 - ❖ Triggering factors
 - ❖ Conditions confused with epilepsy
 - ❖ Diagnosis and treatment
 - ❖ First aid
3. Lifestyle issues
4. Evaluation

Locals names for EPILEPSY

Kenya:Kifafa, Kebaba, Ndulme, Kiptaleit, Indulume, Mng'atuko,Kumagaka, Kufitka,

- Nigeria – Warapa (Yoruba)
- Gambia – Wayoo (Mandinka)
- Uganda – Esimbu (Luganda)
- Malawi - Chithu cha waka (Tumbuka)
- Rwanda – Igicuri (Kinyarwanda)

Epilepsy is one of the world's oldest recognized conditions, with written records dating back to 4000 BC

FACTSHEET WHO 2019:

- Epilepsy is a chronic non communicable disease of the brain that affects people of all ages. is the most common serious brain disorder worldwide. It has no age, racial or social class, national, or geographic boundaries
- Around 50 million people worldwide have epilepsy, making it one of the most common neurological diseases globally.
- Nearly 80% of people with epilepsy live in low- and middle-income countries.
- It is estimated that up to 70% of people living with epilepsy could live seizure- free if properly diagnosed and treated.
- The risk of premature death in people with epilepsy is up to three times higher than for the general population.
- Three quarters of people with epilepsy living in low-income countries do not get the treatment they need.
- In many parts of the world, people with epilepsy and their families suffer from stigma and discrimination.

FACT SHEET

- The estimated proportion of the general population with active at a given time is between 4 and 10 per 1000 people.
- Globally, an estimated five million people are diagnosed with epilepsy each year
- In high-income countries, there are estimated to be 49 per 100 000 people diagnosed with epilepsy each year. In low- and middle-income countries, this figure can be as high as 139 per 100 00

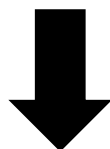
IN KENYA

- There are approximately 1,000,000 people living with epilepsy
- About 77 new cases in every 100, 000 people are diagnosed every year.

(KEMRI)

Challenges

1. Ignorance on epilepsy; confusion, treatment gap
2. Being talked about as a sufferer, victim, patient, child, disabled
3. Epilepsy in the centre of their lives:
focus on what they don't have and can't do



LOW SELF-ESTEEM, LOW PARTICIPATION IN SOCIETY

2. Medical Facts

1. What is epilepsy?
2. What are the causes?
3. How can it be prevented?
4. What are triggers?
5. Types of seizures
6. Lookalikes
7. Diagnosis
8. Treatment
9. First aid

What is epilepsy?

- Epilepsy is a disorder in the brain which makes a person prone to seizures/fits. Seizures are sudden and temporary electrical disturbances in the brain which causes changes in person's sensation, awareness or behaviour.
- There are many types of seizures with different manifestations
- Epilepsy is defined as having two or more unprovoked seizures
- Epilepsy is not contagious
- Epilepsy cannot be cured but controlled with treatment
- When one no longer experiences seizures we say the person has outgrown the condition
- Mostly seizures are unexpected but some experience aura sign

Synonyms:

1. Fits
2. Spells
3. Attacks
4. Convulsions
5. Spasms

Causes – Risk factors

What is a cause?

The initial reason why someone has epilepsy.

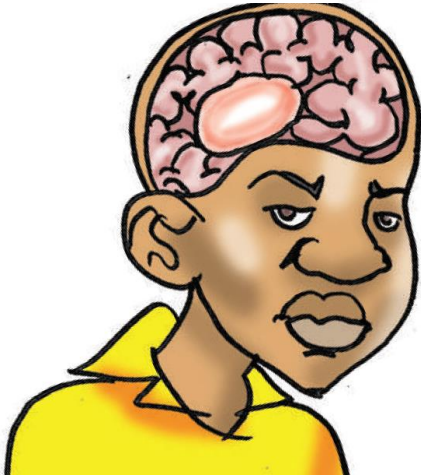
In most cases it is unknown, then we speak of *idiopathic epilepsy (WHO 50%)*

If cause is known, then we speak of symptomatic epilepsy

Causes – Risk factors

1. Head Injuries (birth related, accidents etc)
2. Brain tumours
3. Infections – HIV Aids, cerebral malaria, TB, meningitis etc
4. Stroke (restricts amount of oxygen to brain)
5. Birth complications (oxygen, trauma etc)
6. Alcohol and drugs
7. Inheritance/Genetics

Causes – Risk factors

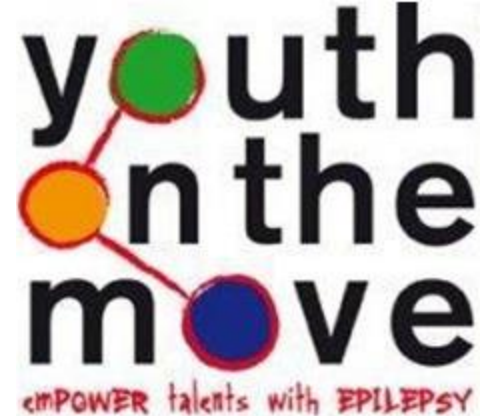


Prevention of epilepsy

An estimated 25% of epilepsy cases are preventable.

The prevalence of epilepsy could be reduced by:

1. Improving maternity care pre and post natal care
2. Preventing infectious diseases through Elimination of parasites, education on how to avoid infections and vaccinations
3. Head injuries to prevent post-traumatic epilepsy
4. cardiovascular risk factor reduction, e.g. measures to prevent or control high blood pressure, diabetes and obesity, and the avoidance of tobacco and excessive alcohol use can reduce epilepsy related to stroke
5. Education on alcohol and drug use



Cause vs Trigger

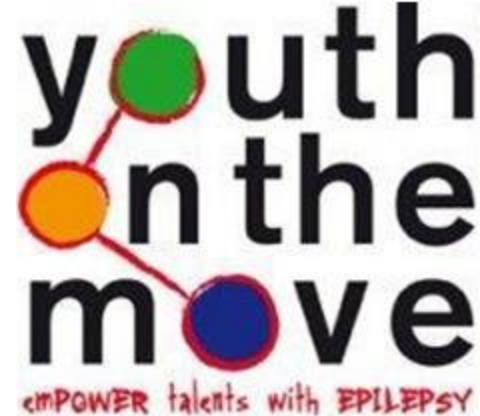
CAUSE: the initial reason why one has epilepsy

TRIGGER: the event that provokes a seizure for people who have epilepsy



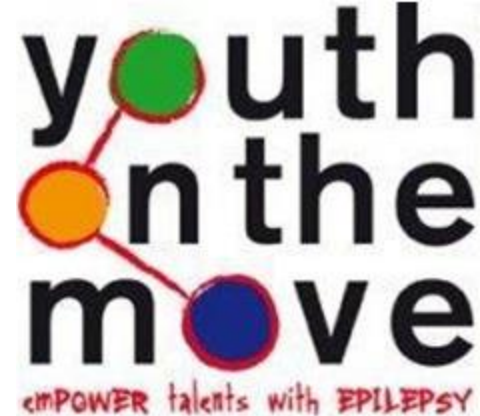
Triggers of seizures

1. Missed medication
2. Lack of sleep
3. Stress (anxiety and excitement)
4. Menstruation
5. Missed meal
6. Illness
7. Drinking alcohol
8. Taking of illicit drugs
9. Extreme temperatures
10. Flickering lights or patterns



Triggers of seizures





Types of Seizures

1. Convulsive Seizures

The whole brain is affected

2. Non Convulsive seizures

Only a part of the brain is affected

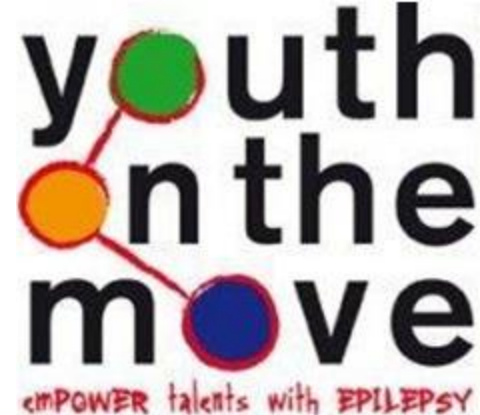
Convulsive Seizures

The whole brain is affected. A person loses consciousness

- **Tonic- clonic** seizure (Grand mal): The person may cry out, become stiff and may fall, shake or jerk and become unaware of what's going on around them. At start may bite tongue and may urinate.
- **Myoclonic**: brief and abrupt jerking of one or more limbs. Common within a short time of waking up.
- **Tonic**: General stiffening of muscles without rhythmical jerking
- Epileptic spasms: in infants. Episodes of stiffness and tightness



Non-Convulsive Seizures



Present with abnormal behaviour like blank stares, sudden falls and abnormal sensation.

Absence (petit mal): briefly lose consciousness and don't respond to anything. Remains blank. Common in kids.

Atonic (Drop attacks): sudden loss of muscle tone causing the person to fall

Other behaviours

Running in a state of confusion

Holding onto clothes or objects

Chewing lips

Repeated actions

Lookalikes

There are several conditions confused with epilepsy:

1. Fainting- temporary loss of blood supply caused by decrease in the brain's blood supply
2. Psychogenic seizures eg hysteria
3. Breath holding spells
4. Febrile Convulsions
5. Daydreaming
6. Sleepwalking
7. Tics – brief involuntary and repetitive movements eg shoulder shrugs and facial grimaces
8. Tourette's syndrome – specific chronic movement eg voice tics
9. Diabetes

Lookalikes

Daydreaming



Absence Seizure



Sleepwalking



Diagnosis

MEDICAL HISTORY

The doctor will ask various questions like:

- How do the seizures look like?
- How long do the seizures take?
- How do you feel before and after the seizure?

Diagnosis

Sometimes extra tests are required for proper diagnosis and prescription.

EEG



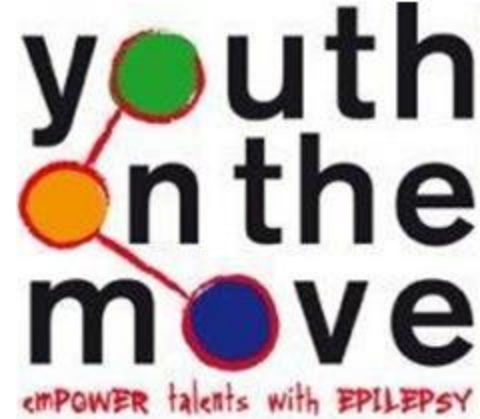
MRI



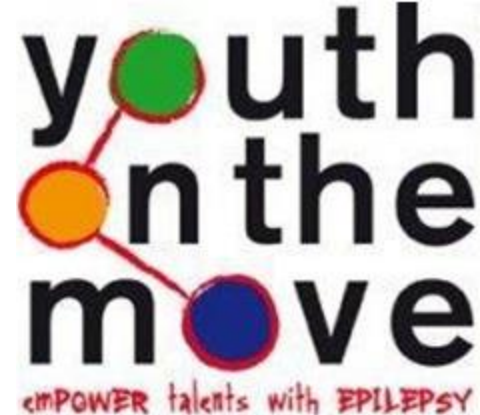


EEG

Electrocephalogram



An EEG is a test that records the electrical activity of the brain. Special sensors are attached to the head and connected by wires to a computer. The computer records the brain's electrical activity as wavy lines. A seizure can be seen by the changes in the normal pattern.



MRI

Magnetic Resonance Imaging

It 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 tumour or damage in the brain which could be the cause of the seizure.

Treatment

Up to 70% of people living with epilepsy could become seizure free with appropriate use of anti-seizure medicines (WHO 2019)

Anti-Epileptic Drugs

1. They do control seizures for 70%
2. They do not cure epilepsy

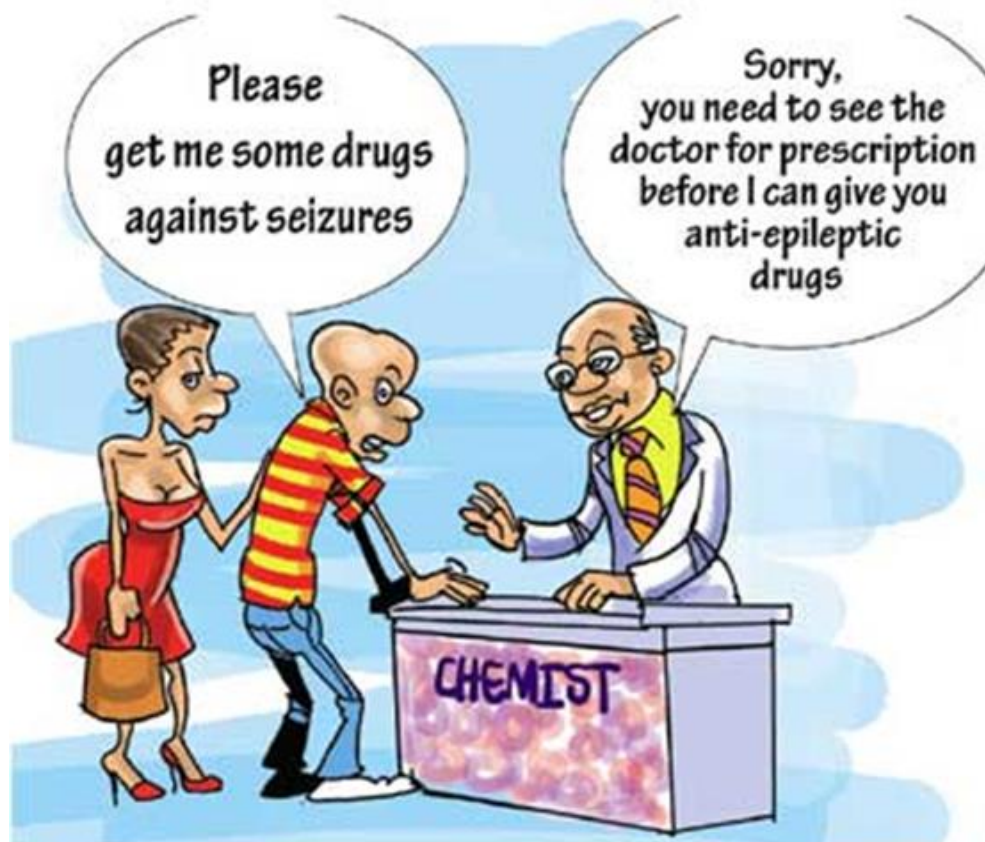
Not recommended to be administered across the counter without proper diagnosis

Brain surgery

Depends on which part of the brain is affected

In some cases people can outgrow epilepsy, then they need to slowly reduce the drugs, only recommended in consult with the doctor. Abrupt change of drugs can sometimes even be fatal.

Treatment



First Aid (Do's)

1. Stay calm
2. Remove any harmful object
3. Move the person away from danger
4. Support or place something soft beneath head
5. Roll them onto their side (recovery position) when jerking stops
6. Stay with them until they are fully recovered and oriented
7. Seek medical help if it takes longer than 5 minutes

First Aid (Don'ts)

1. Do not panic
2. Don't restrain them, it can cause bruises
3. Don't put anything in the mouth
4. Don't give food or drinks
5. Don't pour cold water or anything else

Socio –economic impact

Epilepsy accounts for 0.5% of the global burden of disease,

- The economic impact of epilepsy varies significantly depending on the duration and severity of the condition, response to treatment, and the health-care setting. Out-of-pocket costs and productivity losses create substantial burdens on households
- the stigma and discrimination that surround epilepsy worldwide are often more difficult to overcome than the seizures themselves

4. Lifestyle Issues

1. Accepting Epilepsy
2. Informing others
3. Getting treatment
4. Education
5. Work
6. Driving
7. Exercise
8. Alcohol & Drugs
9. Stress

Accepting epilepsy

When diagnosed, confusion can follow:

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?

Accepting epilepsy

Phases that people with epilepsy may experience:

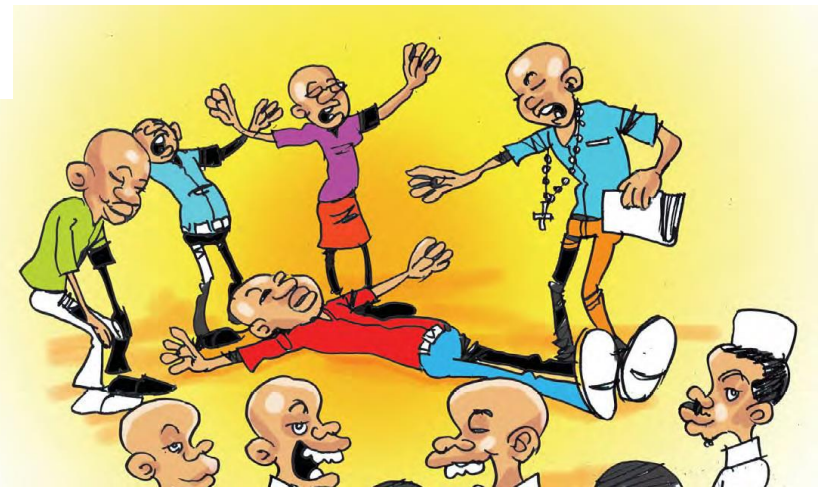
1. State of ignorance (I don't know what I have)
2. State of denial (I'm not convinced it's epilepsy)
3. State of acknowledgement (I acknowledge but can't accept)
4. State of acceptance (I accept but can't open up)

Getting treatment

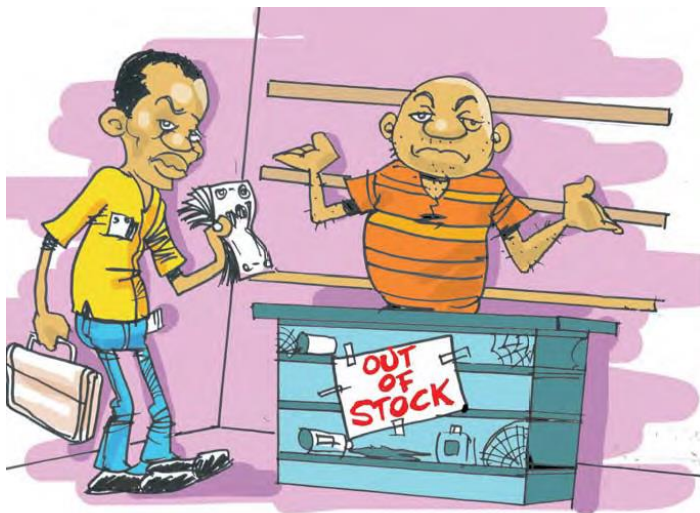
What could stop a person from taking treatment?

1. No diagnosis or misdiagnosis
2. Stigma
3. Lack of confidence in doctors
4. Drugs are not in stock
5. Lack of finances
6. Ignorance or forgetfulness
7. They dislike side effects of drugs more than seizures
8. Rebellion

Treatment gap



Treatment gap



Education

1. Affected concentration
2. Affected memory
3. Low esteem, fears to get a seizure and fail

Support that may be required when faced with challenges:

Challenges that people with epilepsy may experience at learning institutions:

1. Focus on their strengths instead of weaknesses
2. Help them to accept that they have to work harder than others to achieve the same
3. Check if they can get extra time for their exams
4. Guide them to be patient in their learning process

Work

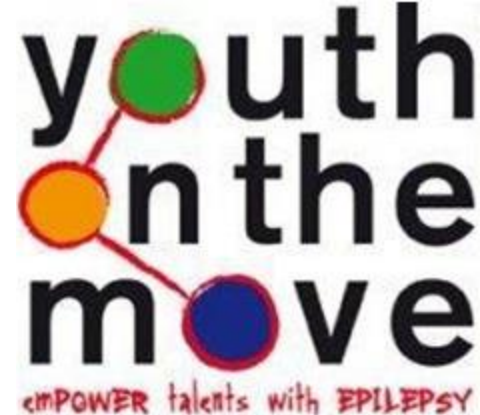
Most people with epilepsy can work like anyone else.

However, it's important to check if:

1. The place of work is safe (no risk in case of a seizure)
2. The work doesn't trigger seizures
3. Duties can be postponed in case of a seizure

How can you help?

1. Encourage people with epilepsy to apply for jobs
2. Assist them in practicing their skills for an interview
 - confidence, motivation to show their reliability in taking up responsibilities
3. Encourage others to employ PWE
4. Also encourage them to protect their rights



Driving

What will you advise if they ask if they can drive?

1. They risk their safety and the safety of others
2. They can be found guilty if they caused an accident due to a seizure if they were aware that it could happen

Best thing: no driving until the person is seizure free for one or two years (specific advice needs to be given by doctor for each person individually)

Exercise

What will you advise if they ask if they can do sports?

1. They need to consider if the sports is not risky (like swimming alone)
2. They need to check if the exercise improves their wellbeing.

Most people with epilepsy gain fitness and confidence through exercise. This can reduce their anxiety and therefore even reduce their number of seizures.

Alcohol & Drugs

What will you advise if they ask if they can drink use drugs?

1. It can trigger seizures
2. They need to check what it does to them and whether it's worth the taste of the beer or drugs

Check if they drink out of peer pressure and if it's affecting their ability to give their boundaries. Make them aware of this risk involved.

Discouraging drinking can lead to rebellion - > more drinking

Stress

Both negative and positive pressure in extreme form can trigger epilepsy attacks.

Negative – lack of money, work related, studies related etc

Positive – excitement eg good news – you might feel energy bursting from toes to head and could trigger an attack

Prof. Stephen Hawking

“We have a **moral duty to remove the barriers to participation**, and to invest sufficient funding and expertise **to unlock the vast potential of people with disabilities** who are denied access to health, rehabilitation, support, education and employment, and never get the chance to shine”

World Report on Disability (WHO,
2011)

5. Questions & Evaluation session

How did you experience the training?

- What impressed you most?
- What did you miss most?
- What is your resolution for people with epilepsy?
- How are you going to contribute towards reducing epilepsy burden in general?

Time for a break!
Thank you!

