Epilepsy Training Manual for Health Committees
Understanding Epilepsy in Community

UCT School of Public Health and Family Medicine
Health and Human Rights Programme

LEARNING NETWORK

COMMUNITY SYSTEMS STRENGTHENING PROJECT

The Learning Network is a collection of 5 civil society organisations based in Cape Town:

1. The Women's Circle,
2. Ikamva Labantu,
3. Epilepsy South Africa,
4. Women on Farms Project and the
5. Cape Metro Health Forum

The **Learning Network** serves as the umbrella body in the Western Cape and includes 3 higher education institutions:

1. University of Cape Town (UCT)
2. University of the Western Cape (UWC)
3. Maastricht University, in the Netherlands

Training for Transition

Capacity Development for Organisations Working with Vulnerable Groups

This project is funded by the European Union

The contents of this publication is the work of the
Community Systems Strengthening Partnership
It can no way be taken to reflect the views of the European Union.

Curriculum Developed by: Fundiswa Kibido
Health and Human Rights Programme
Department of Public Health and Family Medicine
University of Cape Town

Tel: 021 406 6429
Email: Fundiswa.kibido@uct.ac.za

Published: March 2017

Head of Department: Professor Leslie London
Email: leslie.london@uct.ac.za

TABLE OF CONTENTS

Page

Section 1: Understanding Epilepsy

Section 2: Management of Epilepsy

Section 3: TB Prevention

Section 4: Health Committee Support to Community

Background

Epilepsy is a chronic non-communicable illness of the brain that affects people of all ages. Approximately 50 million people worldwide have epilepsy, making it one of the most common neurological illnesses globally. WHO and its partners recognize epilepsy as a major public health concern. WHO International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) are carrying out a global campaign – "Out of the Shadows" – to provide better information and raise awareness about epilepsy and strengthen public and private efforts to improve care and reduce the impact of the illness.

Stigma associated with having epilepsy, which is common to many cultures, can be a negative effect on the social identity of people with the illness, particularly those living in resource-poor communities. Although WHO projects on epilepsy have shown that there are simple, cost-effective ways to treat epilepsy in resource-poor settings, education and awareness raising events need to reach out to the whole community.

Although the social effects vary from country to country, the discrimination and social stigma that surround epilepsy worldwide are often more difficult to overcome than the seizures themselves. People living with epilepsy can be targets of prejudice. The stigma can discourage people from seeking treatment for symptoms, so as to avoid becoming identified with the illness.

.

Learning Outcomes

By the end of this session, participants will be able to

1. Understand what epilepsy is
2. Know what are seizures and how the brain works
3. Understand the types of seizures and epilepsy
4. Know the signs and symptoms of epilepsy
5. Understand the risks for seizures in epilepsy and what to do during the seizures
6. Know how to treat and prevent seizures
7. Understand the role that health committees can play to support community organisations in management and prevention of epilepsy

Reflection Activity:

Read the poem and highlight the most important aspects reflected about epilepsy and the seizures. When reading this poem, how do you understand living with epilepsy to be?

A mother's promise
By Wanda Musto

I cry, I beg, I plead, I pray
that one day your seizures will go away
Just when you think the storm has passed
It sneaks back up on you oh so fast
With no warning at all
as i watch my precious child fall
The feeling of despair
thinking this is just not fair
As you awake from your sleep
my emotions so deep
these seizures i know you will beat
I try to understand why God's plan
was to put this special child in my hand's
I guess he knew i'd be your biggest fan
I will never lose sight of hope
as each day i learn how to cope
Never knowing when the next storm will hit
Next to you is where i will always sit
My promise to you my child is this
No matter how hard the road we travel
or how scary it may seem
we will always be on the same team
I will stand by you forever
Me give up on you.....
NEVER!!!

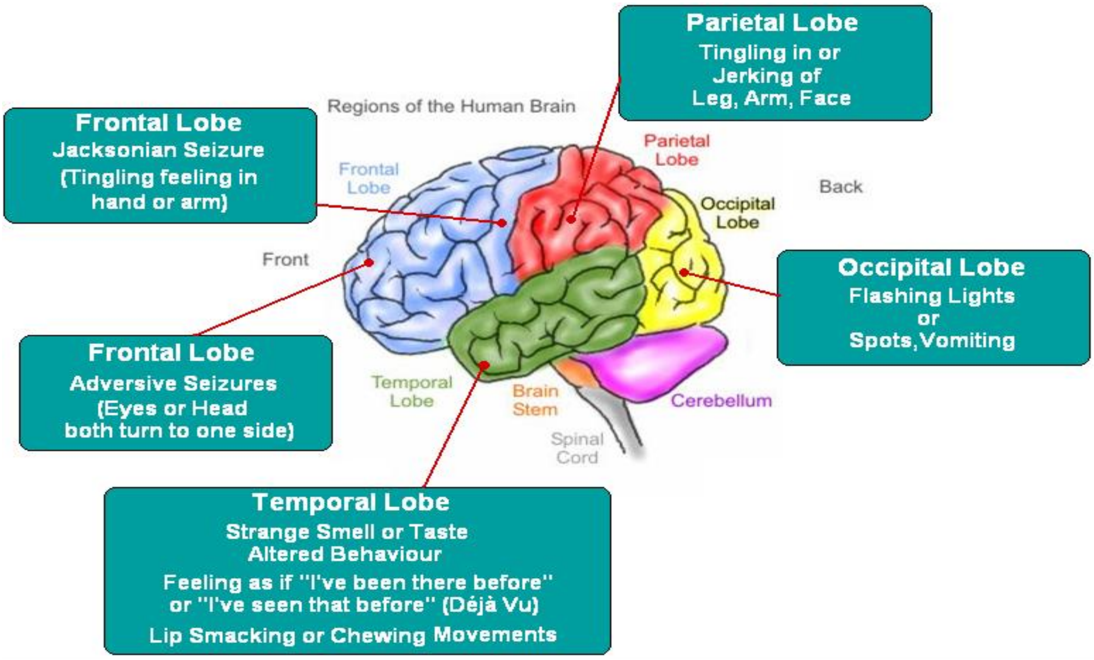
1. What is Epilepsy; How is it defined

The word epilepsy comes from the Greek word “epi” meaning "upon, at, close upon", and the Greek word “Leptos” meaning "seizure". Epilepsy is defined as a neurological condition which affects the central nervous system. People with epilepsy tend to have recurrent seizures (fits). Epilepsy is not infectious or contagious. The seizures occur because of a sudden surge (wave) of electrical activity in the brain - there is an overload of electrical activity in the brain. This causes a temporary disturbance in the messaging systems between brain cells. During a seizure the person's brain becomes "halted" or "mixed up". Every function in our bodies is triggered by messaging systems in our brain, and the human brain is the source of human epilepsy. What a person with epilepsy experiences during a seizure will depend on what part of the brain that epileptic activity starts, and how widely and quickly it spreads from that area.

1.1 Seizures and how the brain works

To understand what a seizure is, let us first understand how the brain works. As the brain goes about its daily functions, millions of electrical and chemical signals pass from its nerve cells out to the body. These electrochemical messages are necessary for almost everything we do and feel. Your brain is comprised of thousands of neurons – cells that process and transmit information by interacting with each other.

Different parts of the brain have different functions required to lead a normal life, these are:

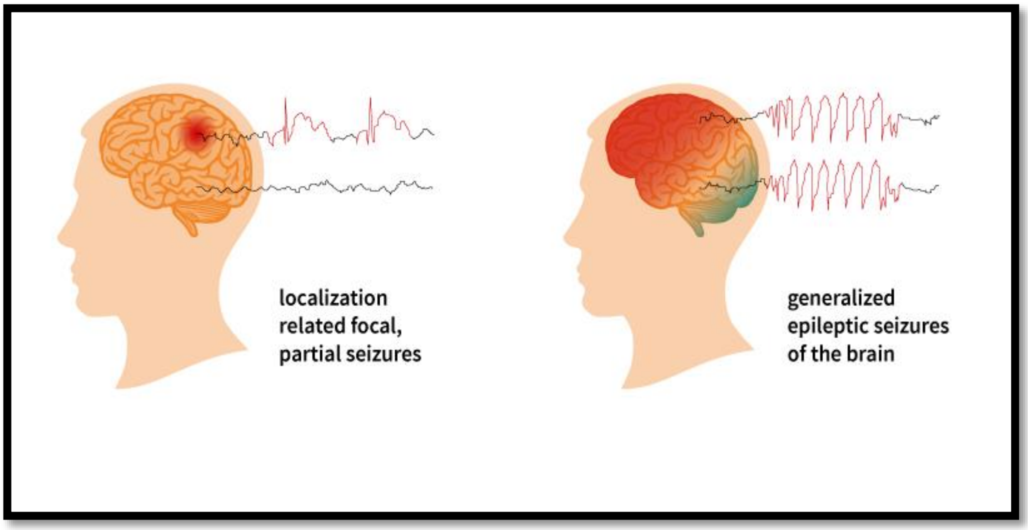


https://za.pinterest.com/pin/106538347412946458

In most brains, neuron interactions occur in a confused but balanced, orderly fashion with few disruptions. Occasionally, small disruptions (neuron misfires) may occur with little consequence. When various cells misfire at the same time, depending on the seriousness and location in the brain, it may cause muscle twitches and spasms. This is a seizure. A seizure is defined as a sudden, electrical discharge in the brain causing alterations or changes in behaviour, sensation (feeling), or consciousness.

It can take many different forms and can affect different people in diverse ways. Some seizures are mild; the person may just feel absent for a second or two and not even notice that they have had a seizure. In other, more major seizures, the individual may lose consciousness, their body may become rigid or stiff and they may make fast jerking movements. There is approximately an 80% chance that an individual who has had two seizures will have more.

1.2 Types of Seizures



Royalty free images

One of the most common seizure types is a convulsion. This may be called a "tonic clonic" or "grand mal" seizure. In this type of seizure, a person may stiffen and have jerking muscle movements; during the muscle-jerking, the person may bite their tongue, causing bleeding or frothing at the mouth. Other seizure types are less dramatic. Shaking movements may be isolated to one arm or part of the face. Alternatively, the person may suddenly stop responding and stare for a few seconds, sometimes with chewing motions or smacking the lips.

Seizures may also cause "sensations" that only the person feels. As an example, one type of seizure can cause stomach discomfort, fear, or an unpleasant smell. Such subjective feelings are commonly referred to as auras. A person usually experiences the same symptoms with each seizure aura. Sometimes, a seizure aura can occur before a convulsive seizure.

1.3 The difference between “epilepsy” and “seizures”

Plenary: Do you think people in your community know the difference between having epilepsy and seizures? Do you think there is any difference between the two?

Many people in communities cannot tell the difference between having a seizure and having epilepsy, these terms are commonly used as meaning the same thing. Although the two terms are often used simultaneously, they are not the same. An epileptic seizure is a brief occurrence of signs and or symptoms due to abnormal excessive neuronal activity in the brain. A seizure is viewed as an event and epilepsy is the illness involving continuing (recurrent) unprovoked seizures. Up to 10% of people worldwide have one seizure during their lifetime. Epilepsy is defined as having 2 or more unprovoked seizures, this means two seizures that were not caused by some known medical condition. Epilepsy is not a mental illness or psychiatric disorder.

A person is considered to have epilepsy if they meet any of the following conditions.

- At least two unprovoked (or reflex) seizures occurring greater than 24 hours apart.
- One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years.

If the cause of the seizure is not associated with a withdrawal from drinking alcohol or other factors that may cause seizures such as blood sugar problems, the person may be diagnosed with epilepsy. The word "epilepsy" does not indicate anything about the cause of the person's seizures or their severity.

1.4 Different Types of Epilepsy

Seizures have many differing causes and are a feature of various states of ill-health. They may be the only manifestation of disease, caused by a specific brain disorder, or are part of a more generalised bodily illness.

Primary	**Secondary**	**Isolated**
Seizures where the brain is abnormally prone to seizure activity, probably due to an inherited tendency. These are often seen in children and teenagers**.**	Typically due to spread from a seizure focus (a scar).	Related to an underlying brief medical condition, and will stop as soon as the underlying condition is effectively treated. Examples include organ failure (liver or kidney failure), infections such as meningitis, head injury, brain surgery, drug and alcohol abuse.

2. How common is epilepsy in S.A. and globally

Approximately 50 million people currently live with epilepsy worldwide. The estimated proportion of the general population with active epilepsy (i.e. continuing seizures or with the need for treatment) at a given time is between 4 and 10 per 1000 people. However, some studies in low- and middle-income countries suggest that the proportion is much higher, between 7 and 14 per 1000 people. Globally, an estimated 2.4 million people are diagnosed with epilepsy each year. In high-income countries, annual new cases are between 30 and 50 per 100 000 people in the general population. In low- and middle-income countries, this figure can be up to two times higher.

It has been estimated that approximately one South African in 100 will suffer from epilepsy at some point in their lifetime. Epilepsy impacts hundreds of thousands of people of all races and backgrounds in South Africa. People should learn about this medical condition and what to do in the event that someone they know has a seizure. National Epilepsy Week runs from the 15th to the 21st of June in South Africa. Many of the nation's most loved and highly successful individuals are epileptic." South Africans should keep this in mind before judging those who suffer a seizure or from epilepsy

Conditions such as higher incidence of road traffic injuries; birth-related injuries; and variations in medical infrastructure, availability of preventative health programmes and accessible health care, is related to the increase in the incidents of epilepsy.

3. The history of Epilepsy

Epilepsy is one of the world’s oldest recognized conditions, with written records dating back to 4000 BC. The earliest mention of epilepsy found begins with the Babylonians, and is almost as old as civilization. The Greeks also have records of epilepsy and called it the Sacred Disease.

Did You Know? The Greeks believed that epilepsy was the result of a curse from the gods delivered for the offense of the goddess Selene. It was believed that if you spent a night in the temple of Selene she would come to you in a dream and tell you how to remove the curse. What other beliefs are there in your community about epilepsy?

In 400 B.C. Hippocrates, the father of medicine, offered another view of epilepsy, that it was just another natural disease and could be treated through natural methods. He supported the use of medicine and control of the diet in order to cure this disease based on his theories of medical methodology. While his methods were hardly scientific he was the first to consider epilepsy to be a natural disorder and would be the only one to do so for centuries. The first surgical procedures on epileptic patients were performed during the 19th century.

4. Signs and Symptoms of Seizures in Epilepsy

Before a seizure, many people experience a warning sign called an aura, which may involve a particular smell, feeling, or visual effect. After a seizure, a person may be confused, tired, or sleepy, may experience muscle aches or soreness, and may not remember what happened.

Signs and symptoms before the seizure include:

Awareness, Sensory, Emotional or Thought Changes:

- ✓ A feeling of being there before but never have
- ✓ A feeling that something is very familiar but it isn't
- ✓ Smells
- ✓ Sounds
- ✓ Tastes
- ✓ Visual loss or blurring
- ✓ "Strange" feelings
- ✓ Fear/panic (often negative or scary feelings)
- ✓ Pleasant feelings
- ✓ Racing thoughts
- ✓ Physical Changes:
- ✓ Dizzy or lightheaded
- ✓ Headache
- ✓ Nausea or other stomach feelings (often a rising feeling from the stomach to the throat)
- ✓ Numbness or tingling in part of the body

During the seizure:

Awareness, Sensory, Emotional or Thought Changes:

- ✓ Loss of awareness (often called "black out")
- ✓ Confused, feeling spacey
- ✓ Periods of forgetfulness or memory lapses
- ✓ Distracted, daydreaming
- ✓ Loss of consciousness, unconscious, or "pass out"
- ✓ Unable to hear
- ✓ Sounds may be strange or different
- ✓ Unusual smells (often bad smells like burning rubber)
- ✓ Unusual tastes
- ✓ Loss of vision or unable to see
- ✓ Flashing lights
- ✓ Formed visual hallucinations (objects or things are seen that aren't really there)
- ✓ Numbness, tingling, or electric shock like feeling in body, arm or leg
- ✓ Out of body sensations
- ✓ Feeling detached

After the Seizure:

Awareness, Sensory, Emotional or Thought Changes:

- ✓ Slow to respond or not able to respond right away
- ✓ Sleepy
- ✓ Confused
- ✓ Memory loss
- ✓ Difficulty talking or writing
- ✓ Feeling fuzzy, light headed or dizzy
- ✓ Feeling depressed, sad, upset
- ✓ Scared
- ✓ Anxious
- ✓ Frustrated, embarrassed, ashamed

Many people believe that someone having an epileptic seizure is in danger of swallowing his or her tongue and choking. In reality, this almost never happens. If you try to prop the mouth open of someone who is experiencing a seizure, you can damage their teeth or lose a finger. (See section 8.5 on how to assist during a seizure).

An exception is in status epilepticus, when a seizure either keeps going for more than 5 minutes or recurs many times in a short period. It may be provoked after abruptly stopping anti-seizure medication. You should call an ambulance if this happens.

5. Risks for seizures in Epilepsy

The underlying cause of the epilepsy is unknown. Causes of epilepsy vary by age of the person. Epilepsy is not a disease but rather a symptom of disturbed brain function, which can be caused by many different disease processes. But what's true for every age is that the cause is unknown for about half of everyone with epilepsy. A risk is something that makes a person more likely to develop seizures and epilepsy. The risks for epilepsy include:

In New-borns:

- Brain malformations
- Lack of oxygen during birth
- Low levels of blood sugar, blood calcium, blood magnesium or other electrolyte problems
- Inborn errors of metabolism
- Intracranial haemorrhage
- Maternal drug use

In Infants and Children:

- Fever (febrile seizures)
- Brain tumour (rarely)
- Infections (e.g. meningitis)

In Children and Adults:

- Congenital conditions (Down's syndrome; Angelman's syndrome; tuberous sclerosis and neurofibromatosis)
- Genetic factors
- Progressive brain disease (rare)
- Head trauma

In Seniors:

- Stroke
- Alzheimer's disease
- Trauma

Other risks for epilepsy include:

- ✓ Infections of the brain such as meningitis and encephalitis
- ✓ AIDS and AIDS-related neurological conditions
- ✓ Withdrawal from alcohol
- ✓ Exposure to toxins, such as lead or carbon monoxide

Mild head injuries, such as a concussion with just a very brief loss of consciousness, do not cause epilepsy. Yet the effects of repeated mild head injuries and epilepsy are unknown.

5.1 What triggers the seizures?

Even though you may not know the cause of your epilepsy, you can look at whether there are factors (often called ‘triggers’) that trigger or provoke seizures. These triggers may make a person with epilepsy more likely to have a seizure in certain situations.

- ✓ Missed medication
- ✓ Lack of sleep or disrupted sleep
- ✓ Illness (both with and without fever)
- ✓ Psychological stress
- ✓ Heavy alcohol use or seizures after alcohol withdrawal
- ✓ Use of cocaine and other recreational drugs such as Ecstasy

- ✓ Over-the-counter drugs, prescription medications or supplements that decrease the effectiveness of seizure medicines
- ✓ Nutritional deficiencies: vitamins and minerals
- ✓ Poor eating habits, such as long times without eating, dehydration or not enough fluids
- ✓ The menstrual cycle or hormonal changes
- ✓ Flashing lights or patterns
- ✓ Specific activities, noises or foods

The triggers could change the number or seriousness of seizures. Learning if you have any triggers can help you learn what to do next. Sometimes people can learn how to modify their lifestyle or environment to lessen the risk of triggers.

6. Test and Diagnosis of Epilepsy

https://123rf.com

The doctor needs to recognise features that suggest a seizure and distinguish it from events such as fainting spells, behavioural problems and a range of involuntary movements.

Seizure Diagnosis: If you have a seizure and have never had one before, your healthcare provider will want to get as much information about the seizure as possible. He or she will want to know a detailed description of the episode, if you lost consciousness, stared blankly, or twitched and jerked violently. You may be asked about your history of seizures, how long they last, when they occur, and how you feel afterwards. The family history may also be relevant. The more information your healthcare provider has about your seizure, the better able he or she will be to make the right diagnosis. A witness to the seizure is also very important in making a diagnosis.

Tests and procedures — Depending on the circumstances of your seizure, your age, and your individual situation, your healthcare provider may order one or more tests, including:

Test	Check For
Blood tests	Check for problems such as: Low or high blood sugar) that may have caused your seizure Certain things that could tell them the type of seizure you had.
Lumbar puncture (spinal tap)	May be done after a seizure to check for signs of infection. (done in emergency room)
Electroencephalography (EEG)	A recording of the brain's electrical activity as measured by electrodes placed on the outside of the scalp.
Brain Imaging studies – MRI or CT scans	Check for tumours, strokes, or other structural problems in the brain. However, these tests are often normal in people with epilepsy.

7. Consequences and complications of having seizures in epilepsy illness:

The types of problems people may have range from injuries, the effect of repeated seizures on the brain, seizure emergencies, and death. Some seizures rarely cause problems for people, but overall, the chance of injury is higher for people with uncontrolled seizures. The type of injuries a person may get depends on the type of seizure, how long the seizure lasts, where the seizure occurs, and if it develops into an emergency.

Some common injuries may include:

- Bruises
- Cuts
- Burns
- Falls

More serious problems, such as:

- Breathing problems; are usually seen in people who have generalized seizures with falls, long seizures or repeated or clusters of seizures.

- Brain Injury: People with epilepsy are at risk for having a status epilepticus attack. This is a condition of uninterrupted seizure activity that lasts for more than five minutes or recurrent seizures without a return to consciousness between each one. Status epilepticus may cause brain damage or death.

- Memory Loss: Patients with epilepsy may develop problems with memory over the long term. People can lose memories during a seizure which may not return after the seizure ends. Memories of events that occur before a seizure may also be lost after a seizure. Medications used to treat epilepsy may interfere with memory as well. The damage to memory may affect a patient's life in a variety of ways; the patient may have to find ways to adjust to function in everyday life

- Death from drowning is more common among people with epilepsy. Drowning can even occur in a tub with only a few inches of water, so people who have seizures probably should stick to showers instead of baths.

- Choking from vomit: People with epilepsy can also die from problems that occur during or after a seizure, such as inhaling vomit and choking. This problem can be prevented if the person is turned onto one side as soon as possible. This allows saliva, vomit or other fluids to drain out of the mouth and not go back into the lungs.

- Broken bones: Even when seizures do not directly threaten life or limb, the condition can be damaging.

- Learning disability: If absence seizures are not recognised in children, these brief interruptions of attention throughout the day can lead to learning disability.

- Permanent injury or death: If seizures can’t be stopped or repeated seizures occur one right after another, permanent injury or death can occur.

- Accidents while driving: Accidents while driving or using machinery are very common: If you have epilepsy, your doctor and the officials responsible for licensing drivers will help you decide whether it is safe and legal for you to drive.

- Withdrawal from the world: Older children and adults may find the prospect of seizures so socially embarrassing or frightening that they withdraw from the world.

- Side effects: All anti-epileptic drugs have side-effects

.Section 2: Management and treatment for epilepsy

8. Epilepsy Management and Care

The first goal in epilepsy management and care is to control the seizures. When a diagnosis of seizures or epilepsy is made, (that is ongoing tendency to have seizures), the health care provider will then discuss with the person or the person’s family what the best treatment options are. The majority of people with epilepsy control their seizures through seizure-preventing drugs or anti-epileptic medication. Over the years, great progress has been made in this field. Between 70% and 80% of people with epilepsy is able to control their seizures completely or greatly reduced seizure activity by using these drugs. If an underlying correctable brain condition was causing the seizures, sometimes surgery may stop them.

Many seizures are the direct result of an underlying brain or bodily disorder. In such a case, treatment of the underlying condition will often be sufficient to prevent seizures from recurring, and the seizures themselves will need no specific management. In general, seizures that have only occurred once are not treated unless they recur. Once seizures are recurrent, specific anti-epileptic medication will generally be needed. Some epileptics will only have seizures in certain settings, or find that their seizures are reliably provoked by specific triggers. Alcohol use and sleep deprivation are frequently responsible.

8.1 Medicine for Epilepsy

There are many different type of medicine for epilepsy, examples of widely-used established medications are Carbamazepine, Phenytoin, Phenobarbital, and Valproic acid. The neurologist who is an expert in epilepsy decide which medicine should be given to a person. The choice will rest on the type of seizure, the effectiveness of the medication and how well it is tolerated by the individual person with epilepsy. As such, it may take some time to achieve the right dose for you. Most people use a single medication to control seizures, if necessary, medications in various combinations are used.

The aim of drug therapy is to maintain the level of medication in your blood at the level needed to prevent or reduce seizures. Medication strengthens resistance to seizures and it is critical to take the prescribed dose at the prescribed time. Illness, pregnancy, sleep deprivation, skipping medication doses and using drugs, alcohol or certain medications may cause seizures in someone with previously well-controlled epilepsy.

People with epilepsy should be advised to wear Medic-Alert bracelets, and family members should be instructed in how to assist during a seizure.

Surgery: Some people may be advised to do surgery, but is reserved for patients with a seizure focus that can be precisely identified, and for some people who continue to have seizures even after trying several medications. Surgery removes the portion of the brain causing the seizures or severing the connection between the two halves of the brain can reduce or eliminate seizures in some people. This may render patients seizure-free without having to use medications

8.2 What are common side effects of epilepsy medicines?

Epilepsy medicines may cause unwanted side effects in some people which can affect each person differently. Anyone taking an anti-seizure medication should be aware of some side-effects. Most of the time, the effects are mild and do not last long. Often they can be treated by adjusting the dose or how a person takes it. Some common side effects that may occur in the first few weeks of taking seizure medicines include:

- Feeling tired

- Stomach upset or discomfort
- Dizziness, or blurred vision
- Allergic reactions.

8.2.1 Some unpredictable side effects that can occur

Many side effects are unpredictable and are not related to the dosage or level of medication in the blood. They may also be called ‘idiosyncratic’ side effects. These can include:

- Rash
- Problems with the pancreas
- A serious drop in the number of white blood cells in your body (needed to fight infection)
- A serious drop in the number of platelets in your body (needed to control bleeding)

- Aplastic anaemia (severe damage to bone marrow so blood cells aren’t produced normally)
- Liver failure:

- An increased risk of becoming suicidal: If you start to become depressed or have thoughts of harming yourself or others while taking an anti-seizure medication, speak to your healthcare provider right away.

- Stevens-Johnson syndrome: A rare but serious skin disorder called Stevens-Johnson syndrome, which can cause fever and a painful, sometimes blistering, rash that eventually kills the top layer of skin. This side effect is most likely to happen in people taking carbamazepine, oxcarbazepine, phenytoin, and lamotrigine, and it is mostly likely to occur within the first two months of use. If you notice a severe rash while taking an anti-seizure medication, you should report this to your healthcare provider right away.

- Weakening of bones (osteoporosis): This can occur after long-term use of anti-seizure medications. There are steps you can take to protect and strengthen your bones. If you are concerned about your bone health, or are at risk for osteoporosis, ask your healthcare provider what you can do to keep your bones as healthy as possible. You should take Calcium and vitamin D for bone health.

Read the following story: What lesson learnt on how to live and cope with epilepsy.

Debbie's story

Epilepsy is a neurological disorder that can cause unusual activities such as loss of consciousness or seizures. Looking at this definition, you probably think my disease is one that someone would have to live with forever. I can tell you from first-hand experience that it is not just another one of those diseases that is looked at, treated, and then cured; it was an uphill battle everyday. I dealt with Epilepsy for most of my life, but today I am cured. It wasn’t easy, and let me tell you I have seen many doctors and had my fair share of seizures. But, today I am not only cured of epilepsy, but I am an independent woman and stronger because of my experience.

The earliest signs of my seizures occurred due to the many high temperatures I had when I was a baby. My first seizure happened when I was 12 years old. My fall off of a balance beam triggered my seizures. During my years of epilepsy, my seizures ranged from temporal lobe seizures to grandmals. My body would quickly get immune to the medications my doctor prescribed me. I was having 2–3 seizures everyday, and I was not happy that my doctors could not control them.

During my years of seizures, I would always worry about being stared at or judged. I also thought people would not like me because of my seizures. Because I was very unhappy, I decided to do something about it. I read and studied everything I could about epilepsy surgeries. My doctors could not control the seizures because, when they would change my medicine every few months, my body would get immune to the medication. With all of the trouble I was having with my body getting immune to medication, I read about surgery for people with epilepsy.

I had a great doctor talk to me about epilepsy surgery, and he explained everything about testing for the surgery and the surgery itself. So, the only thing that I could think of was how could epilepsy surgery help me?! So, I read all about it and watched any tapes I could possibly get my hands on about the procedure. All the knowledge I obtained about the epilepsy surgery came from books, magazines, articles, and tapes. Everything I could possibly read about the epilepsy surgery I did. At that time we were not as fortunate to have the resources to study and research seizures as we are so privileged to have now.

When my doctors gave me the option to either change my medication or go through the testing for the procedure, I did not hesitate for even a second. I was definitely ready to go through the testing for surgery. Through the two and a half years leading up to the surgery, I went through many tests including EEG, MRI, PET Scan and Wada testing (a procedure performed during angiography that assesses which side of your brain has your language and memory functions), as well as many hospital visits. Finally, in August of 2000, I was set to have my surgery. What a good feeling, I screamed!!

8.3 The role of the person with epilepsy in treatment of epilepsy

A positive attitude….goes a long way!!

Even though I have been living with epilepsy for most of my life, I try every day to have a positive attitude towards life. If you ask my family or my friends, they will probably tell you that I try not to let the negative things bother me. I guess I have always been a positive, determined, kind, respectful, smart, wise, and strong women. I give most credit to my family and friends. Without them, I wouldn't be the person who I am today!

Even though I have epilepsy and a learning disability. I have accomplished a lot of things throughout the years. My hardest subject in school was Maths and this past semester I actually accomplished of going to the next level of maths!

Although there has been many accomplishments, there has been some disappointments. This past January I found out that I was not a qualified candidate for epilepsy surgery. So I am on medication for now, but so wanted to get rid of this illness! I have not given up, my life and my attitude towards my illness has improved tremendously. Epilepsy is part of who I am!!

REFLECTIVE ACTIVITY: PLEASE A MOTIVATIONAL PIECE OF WORK TO ENCOURAGE PEOPLE LIVING WITH EPILEPSY AS WELL AS THE COMMUNITY TO EMBRACE THEM

A newly diagnosed person with epilepsy has to make some adjustment to be able to manage his or her condition. These adjustments will have a big impact on how well the anti-seizure medication works, here are some things you could do:

- Take your medication exactly as directed, at the right times, and at the right doses. Ask your healthcare provider to write down any special instructions.
- Have seizure calendar, especially when you first start taking a new medication, it's a good idea to keep a record of seizures as they occur. On a calendar, note any seizures you may have had, and ask those around you to help you keep track. You should also write down any seizure triggers, such as days when you were sleep-deprived, stressed, drank alcohol, or (if you are a woman) had your period.
- If medication side effects are a problem for you, use the calendar to record them as well. Then bring this calendar with you when you see your healthcare provider.
- Keep appointments: Your healthcare provider may ask to see you on a regular basis, especially soon after you start taking anti-seizure medication. These visits are important because they allow your healthcare provider to:
  - Check how well your medication is working
  - Find out whether you are having troubling side effects

  - Make sure that your kidneys and liver are working properly (anti-seizure medications can sometimes strain these organs)
  - Monitor the level of medication in your blood
- Pregnancy: Women who may become pregnant and who require anti-seizure medications should talk to their healthcare provider about their plans for pregnancy. Anti-seizure medications can affect the health of a developing foetus, and they can interfere with the effects of certain birth control methods.
- Ask what side effects you can expect and what to do about them. Even if you develop uncomfortable side effects, don't stop taking your anti-seizure medication without first speaking to your healthcare provider.
- Be careful not to let your prescription run out. Stopping anti-seizure medication abruptly can put you at risk of seizure.
- While taking an anti-seizure medication, do not start taking any other medications including over-the-counter medications and herbal supplements without first checking with your healthcare provider. Anti-seizure medication can interact with prescriptions, over-the-counter medications, and herbal supplements, so mixing them can be dangerous.
- Be careful on train or subway platforms and when walking near busy streets.

8.4 Factors that influence treatment outcomes in epilepsy treatment

Did you know? People with epilepsy were regarded as “being chosen” or “being possessed,” depending on the prevailing popular belief; this affected treatment and society’s attitudes towards people with epilepsy. Any other beliefs that have been around in your community about epilepsy

Patient related factors

- Forgetfulness
- Inconvenient work schedule
- Socio-economic factor: education status, economic class
- Psychosocial factors: Beliefs (myths),Motivation, Attitude of the patients

System Factors

- Poor relationship between patient and health professionals/physician
- Irregular or poor drug supply

Medication Factors

- Feeling sick, side effects
- Poly-pharmacy (Drugs are too many)
- Medication complexity

Socioeconomic factors

- Local beliefs or beliefs about the origin of illness
- Long distance from treatment setting

Condition related factors

- Duration, and previous treatment failures

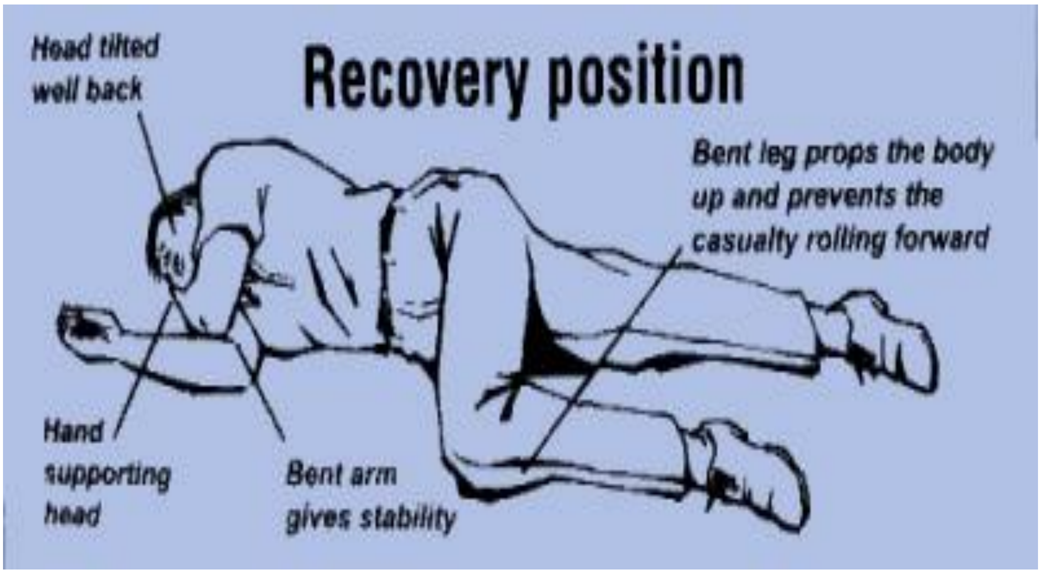
8.5 Emergency first-aid treatment for a convulsive seizure

1. **Stay calm**. Understanding what is taking place should help you to do this.
2. **Protect the person from injury**. Clear the area of objects that may cause injury.
3. **Cradle the head with a pillow**, (you can use whatever is available if it is happening on the road, e.g. clothing item), but don't restrain the person's movements.
4. **Be sure to keep yourself out of harm's way**.

- **Do not try to restrain anyone who is having a seizure**. When seizures continue, or consciousness is not regained between seizures, call emergency services.

5. **Do not put anything in the person's mouth**.
6. **Once the individual's seizure has stopped place them in the recovery position**. Turn the person's head so that any vomit can easily drain from their mouth and make sure they are breathing normally.
7. **Do not give the person liquids, medication or food until they are fully alert**.
8. **Stay with the person until he or she recovers,** which should be five to 20 minutes.

Activity: With a partner, take turns to practise recovery position on one another



Royalty free images

Section 3: Epilepsy Prevention:

9. Strategies for prevention of seizures and epilepsy

Prevent traumatic brain injuries	•Ride safely. Use safety belts, child passenger seats, airbags, bicycle helmets, and motorcycle helmets to reduce motor vehicle and traffic injuries. •Step carefully. Falls are the leading cause of brain injury. Get help for traumatic brain injuries if they happen
Preventive services	•Regular health checkups for you and your family may help you prevent and find diseases. •Lower the chances of stroke and heart disease, these include eating well, exercising, and not smoking. These health actions may prevent epilepsy later in life.
Get vaccinated	•Immunizations (also known as vaccines or shots) lower your chances of infection that can sometimes lead to epilepsy
Wash your hands and prepare food safely	•An infection called cysticercosis is the most common cause of epilepsy world-wide. •It is caused by a parasite and it is prevented through good hygiene and food preparation practices.
Stay healthy during your pregnancy	•Some problems during pregnancy and childbirth can lead to epilepsy. Follow a prenatal care plan with your health care provider, like your doctor or nurse, to keep you and your baby healthy.

Section 4: Health Committee Support to Community Organisations

“The epileptic is avoided to isolation. Everywhere he goes, intimidating and challenging obstacles arise to his obtaining a position, to his establishing himself, to his relationships, and to his very livelihood; he has to say goodbye to his dreams of success, for the masters even refuse him work in their shops; goodbye to his dreams of marriage and fatherhood, goodbye to the joys of the domestic hearth. This is death to the spirit.”

Reflection: Do you think this perfectly describes the effects of stigma on the quality of life of people with epilepsy today?

10. Health committees and understanding of stigma in epilepsy

In many communities people with epilepsy face many stereotypes about their illness. Because of different ways in which communities views or understand epilepsy, people with epilepsy, including children and adolescents are not readily accepted socially, even when seizures are infrequent or fully controlled. In some cultural settings, epilepsy is not generally disclosed to friends or extended family. Some children are not sent to school if seizures are uncontrolled. All of these prejudices may further impair social and academic function in children with epilepsy. Despite laws guaranteeing people with disabilities and medically impaired people full access to socioeconomic opportunities, people with epilepsy still face exclusion. For school going children, fear of teasing, exclusion or bullying may cause adolescents to hide their epilepsy diagnosis.

Stigma as "an undesired differentness". People are stigmatised because they have an attribute that is undesired and so "deeply discrediting". This attribute represents a discrepancy (disagreement) between the person they might be and the person they are, between their virtual and actual social identity.

Reflection Activity

Three different types of stigma:

- The tribal stigmas of race and religion
- Blemishes of individual character, and
- Abominations of the body.

Read above types of stigma and critically reflect on your community views of them. What stereotypes do community people have of people with epilepsy?

10.1 Components of a stigma

1. People differentiate and label socially important human differences
2. Dominant cultural beliefs link label people with negative stereotypes (e.g. people with mental illness are a danger to others)
3. People who have been labelled are placed in distinct categories (e.g. "fat", "disabled", "epileptic") to separate them from others
4. People who have been labelled experience status loss and discrimination (e.g., unequal health and socioeconomic outcomes)

5. Social, economic, and political power enables components 1–4 (i.e., those in positions of low power cannot impose labels, stereotypes, separation, or status loss)

10.2 What HCs can do to reduce Stigma associated with illness

Efforts to reduce stigma need to focus both on those contributing to and those perceiving stigma in epilepsy. This must include educating people with epilepsy and their families to address the relation between knowledge, stigma, and adjustment.
Targeting the general public and the various organisations with which people with epilepsy connect.
Health committees should use all platforms including the media, social gatherings and health events to raise this awareness. The role of the media in perpetrating misconceptions about epilepsy among the different groups must be addressed, perhaps with the help of multi stakeholders and health professionals and through advocacy campaigns.

Because of certain societal beliefs about the condition, all sectors including sectors providing alternative medications, religious groups should be part of the advocacy campaigns to raise awareness of the illness and the stigma associated with it.

It is important for health committee membership to include all sectors especially people practicing in alternative medication, which is sometimes used instead of western medication. These parties should have same understanding of the illness.

Recent research shows that conducting public education and comprehensive treatment programmes in an African community successfully changed attitudes to epilepsy: traditional beliefs about epilepsy were weakened, fears about epilepsy were diminished, and community acceptance of people with epilepsy increased.

Health committees should also participate to reduce stigma associated with epilepsy worldwide by prioritising participation in initiative such as "Epilepsy: Out of the Shadows"

To advocate for relevant and appropriate services for people with epilepsy and educate them of their right to health.

Epilepsy Support Groups: Health committees and health activists should encourage interaction between those who have epilepsy and their families to help not only to cope with their epilepsy, but also help them to live and manage it too.

Health committees should encourage people with epilepsy to wear a medical identification bracelet stating that they have epilepsy to let others know for medical emergencies.

11. Assessment: Taken from Epilepsy website

1. Epilepsy is a disorder of the Central Nervous System

○ True ○ false

2. People with epilepsy are usually Intellectually Disabled

● True ● false

3. A child with epilepsy can be identified at sight by certain physical characteristics

○ True ○ false

4. Epilepsy is contagious… you can catch it from someone who has it

○ True ○ false

5. Most seizures last from a few seconds to a few minutes

○ True ○ false

6. Some people have seizures only in their sleep

○ True ○ false

7. Heredity plays a major role in getting epilepsy

○ True ○ false

8. A person with epilepsy cannot work until seizures are totally controlled

○ True ○ false

9. Some people experience a “warning” before a seizure, allowing them to move to a safe area

○ True ○ false

10. Children with epilepsy cannot participate in sports

○ True ○ false

11. People with epilepsy can predict the future

○ True ○ false

12. Children with epilepsy have more accidents at school than other children

○ True ○ false

13. Epilepsy affects about 1 out of 100 people in South Africa

○ True ○ false

14. People with epilepsy have very similar personalities

○ True ○ false

Reference

1. http://www.epilepsy.com/learn/epilepsy-101/what-epilepsy
2. http://www.ilae.org/
3. http://epilepsy.org.za/new/