EPILEPSY

A MANUAL FOR HEALTH AND SOCIAL SERVICE WORKERS IN ZIMBABWE

2019 Version

EPILEPSY
a manual for health and social service workers

Republished by
Epilepsy Resource Centre Zimbabwe, 2019
Republished by
Epilepsy Support Foundation, 2010
Republished, 2003
First published, 1995

Readers should note that advances in medical science occur rapidly and some of the information contained in this book about drugs and treatment may change.

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PREFACE

This manual was initially compiled as part of the Zimbabwe Demonstration Project of the Global Campaign against Epilepsy - a joint partnership of the International League against Epilepsy (ILAE), International Bureau for Epilepsy (IBE) and the World Health Organisation (WHO). It was primarily aimed at those health workers manning primary health clinics in Zimbabwe but it was realized that it is suitable for all health and allied workers. We are glad to have this book based on the knowledge and experiences of key people in the medical and social management of epilepsy in Zimbabwe notably Professors N. Buchanan (Australia), L. F. Levy, J. Mielke and Dr. D. Ball.

Epilepsy should basically be defined as a medical condition and social disease.

Chapter 1 addresses the medical aspects of epilepsy such as the causes, prognosis and prevention. The causes are varied, as you will see, and it is normally hard to pinpoint the actual cause or causes. In other cases, the causes are not known. In prevention lies the future of managing epilepsy. It is essential to promote prevention since most of the causes lie within the realms of human interaction. If we manage to prevent epilepsy, we will reduce its physical, psychological, economic and social impacts which are too strong to bear with. Further, the chapter discusses the types of epilepsy and the different forms of diagnosis. A detailed section follows on the medical treatment of epilepsy, focusing on management at primary health settings. It is important to note that nurses at primary health care settings can now treat epilepsy within their limits. The book clearly lays out what they should do and how to refer using very simple charts. We hope this book will help these workers who are usually hesitant to initiate epilepsy treatment due to limited information. Use of diazepam for status epilepsy, treatment of children, application of first aid, and management of pregnant women are also discussed. The control of epilepsy currently hinges on anti-epilepsy drugs. The final sections of this chapter deal with drug types, drug choices, side effects, commencement, compliance, withdrawal and triggering factors.

Chapter 2 addresses the social aspects of epilepsy. As a social disease, its social symptoms must be diagnosed and treated socially. Social therapy mainly addresses triggering factors. This chapter then discusses ignorance, myths and stigma and how to address these as part of social treatment. Health workers should contribute to social treatment and where necessary should seek the assistance of social workers, psychologists, counselors and related professionals. A drug such as phenobarbitone is not effective if the social environment is not conducive. Therefore, this chapter concludes by discussing different lifestyle situations and advising workers on how to deal with them.

Chapter 3 discusses epilepsy in Zimbabwe with a lengthy discussion on services offered by ESF and the Government of Zimbabwe. Roles of various stakeholders are discussed. Finally, a list of very useful addresses is provided. We trust this book will help all health workers in applying their knowledge and experiences to deal with epilepsy.

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ACKNOWLEDGEMENTS

Portions of this book have been based on a manual produced by Professor Neil Buchanan in 1995 for the Epilepsy Support Foundation of Zimbabwe entitled: Epilepsy - an introduction for health care workers. Chapter 1 was co-authored by the late Professor Jens Mielke and Doctor Douglas Ball in 1997, and Gladys Saburi reviewed and added more information in 2010. We are very indebted to them. The initial editorial board (composed of Professor Lawrence Levy, Iris Chagwedera, Roy Dhlamini and GCAE committee members) is thanked for its immense contribution. The 2010 editorial team's contribution is greatly acknowledged. The WHO through the Ministry of Health and Child Welfare assisted with printing and we are very grateful for their support. The contribution made by Dr Mugumbate, notably on the social aspects of epilepsy and compilation of chapters 2 and 3 and putting the book together and reviewing the book in 2019 is acknowledged.

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ABBREVIATIONS

AEM	ANTI-EPILEPSY MEDICINE
CBZ	CARBAMAZEPINE
CPS	COMPLEX PARTIAL SEIZURES
CT SCAN	COMPUTERIZED TOMOGRAPHY SCAN
EAA	EPILEPSY ALLIANCE AFRICA
EEG	ELECTROENCEPHALOGRAPHY/ELECTROENCEPHALOGRAM
ESF	EPILEPSY SUPPORT FOUNDATION
ERCZ	EPILEPSY RESOURCE CENTRE ZIMBABWE
GCAE	GLOBAL CAMPAIGN AGAINST EPILEPSY
IBE	INTERNATIONAL BUREAU FOR EPILEPSY
ILAE	INTERNATIONAL LEAGUE AGAINST EPILEPSY
MRI	MAGNETIC RESONANCE IMAGING
PWE/PLWE	PEOPLE WITH EPILEPSY/PEOPLE LIVING WITH EPILEPSY
WHO	WORLD HEALTH ORGANISATION
ZLAE	ZIMBABWE LEAGUE AGAINST EPILEPSY

Chapter 1 MEDICAL ASPECTS OF EPILEPSY

Professor Jens Mielke, Dr. Douglas Ball and Gladys Saburi

Epilepsy may be defined as *a* tendency to recurrent seizures. Seizures are episodes of abnormal synchronous (i.e. occurring at the same time) electrical activity in the brain leading to different behavioural changes depending on the site of the seizure.

SECTION 1 UNDERSTANDING EPILEPSY

Overview of epilepsy and seizures

Epilepsy is a recurrent seizure disorder caused by abnormal electrical discharges from brain cells, often in the cerebral cortex. It is not a distinct disease, it is a group of disorders for which recurrent seizures are the main symptom. Different forms of epilepsy are either secondary to a particular brain abnormality or neurological disorder, or are said to be “idiopathic,” without any clear cause. Epilepsy is a symptom not a disease. A symptom is something experienced by patients, indicative of an underlying disease. Thus, a seizure is a symptom of other diseases like meningitis.

Normally, nerve transmission in the brain occurs in an orderly way, allowing a smooth flow of electrical activity. A seizure occurs when these neurons generate uncoordinated electrical discharges that spread throughout the brain. This can occur with both normal and abnormal nerve cells.

Physiology of epilepsy

To get a better understanding of epilepsy, it is important to first understand the physiology of seizures. The first thing to understand is that the brain works on electricity. Normally, the brain continuously generates tiny electrical impulses in an orderly pattern. These impulses travel along the network of nerve cells, called neurons, in the brain and throughout the whole body via chemical messengers called neurotransmitters. A seizure occurs when the brain’s nerve cells misfire and generate a sudden, uncontrolled surge of electrical activity in the brain.

Another concept important to epilepsy is that different areas of the brain control different functions. If seizures arise from a specific area of the brain, then the initial symptoms of the seizure often reflect the functions of that area. The brain in responsible for our emotions, thoughts, memories, movement and sensations (sounds, smells, tastes, feelings and sight). It is divided into 2 halves, left and right hemispheres. Each half is further divided into 4 lobes with specific functions as shown on Figure 1. The right half of the brain controls the left side of the body, and the left half of the brain controls the right side of the body. So if a seizure starts from the right side of the brain, in the area that controls movement in the thumb, then the seizure may begin with jerking of the left thumb or hand.

Figure 1 Functions of the brain

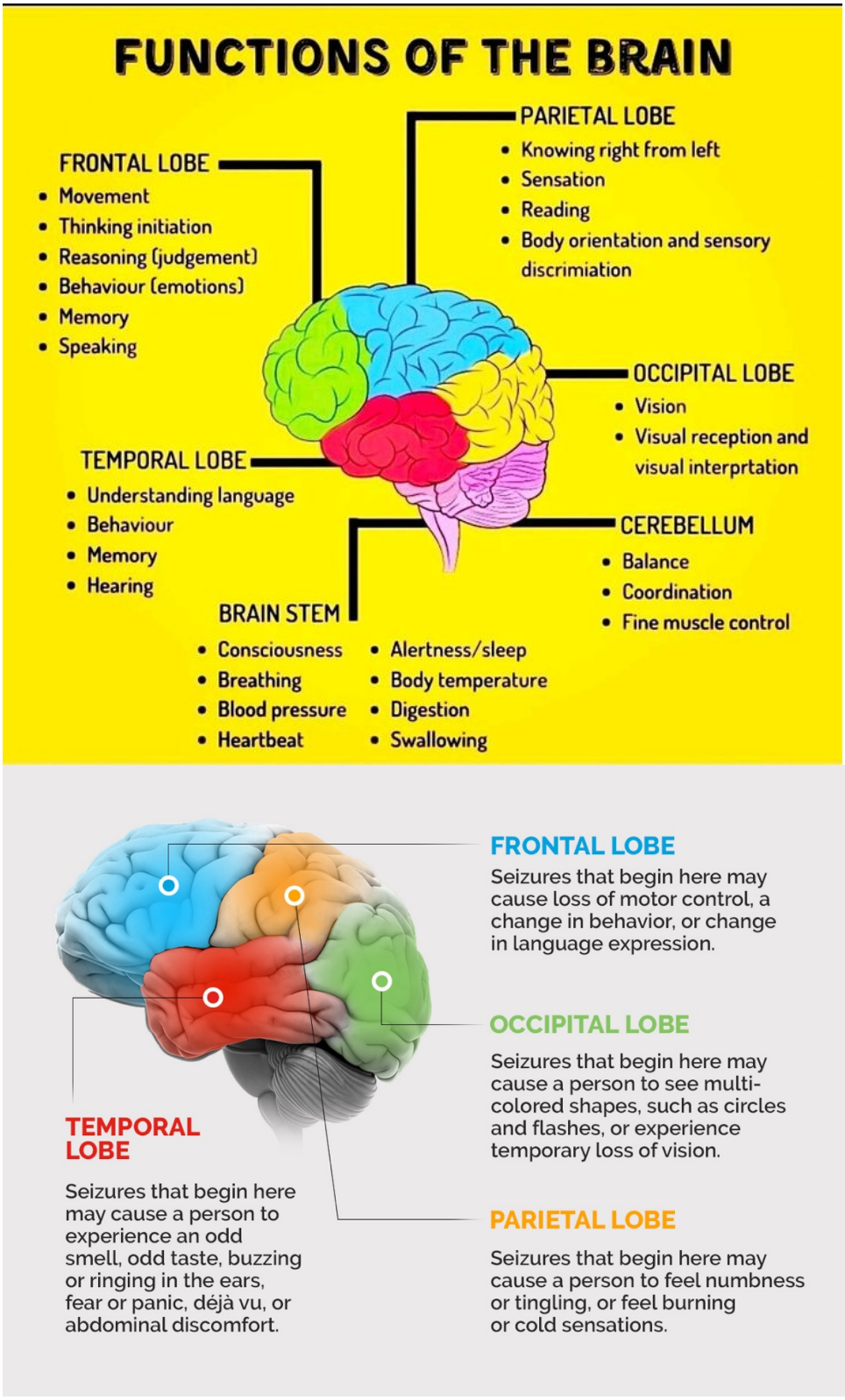


Figure 1 Functions of the brain and epilepsy
Public images

Causes of epilepsy

Epilepsy is due to some abnormality of the brain of which there can be many causes. Causes for epilepsy vary between countries and across age groups. However, a cause may only be found in 20-40% of patients with epilepsy and then only when advanced diagnostic facilities are available. The brain functions due to electrical signals passing from cell to cell through axons. Some signals excite (make them active) the neurons yet others inhibit (make them inactive) them. Actually, if they are all active or all inactive, a person will experience seizures or an 'electrical storm'. There should be a balance of active and non-active neurons. In partial seizures, imbalance between active and inactive cells may result from damage to some cells. This damage could have resulted in lack of oxygen at birth, infections (meningitis, encephalitis or brain abscesses), febrile convulsions, birth or head trauma/injury, tumour (gliomas or meningiomas), stroke, cerebral hemorrhages, dementia (Alzheimer's) or defect in brain development.

In generalized seizures, the imbalance affects both halves of the brain. The brain itself shows no obviously abnormal structures. Generalized seizures may therefore result from body chemistry imbalances (low calcium, magnesium or glucose), alcohol and drugs (cocaine, amphetamines, ecstasy) or other inherited conditions.

In most cases (70%), causes for epilepsy are unknown. Such types of epilesy are referred to as idiopathic. Epilepsy symptoms may be seen many years after the cause has occurred. Primary generalized epilepsy may be inherited. Diseases like tuberous sclerosis or other conditions causing epilepsy may be inherited.

Prevalence

Epilepsy is a very common medical condition. According to WHO epilepsy affects 50 million people worldwide, a prevalence of less than 1%. Prevalence is low in developed nations around (0.5%) and very high in developing economies. Indeed, in many African countries prevalence approaches 1%. In Zimbabwe, it is estimated that the trend will be the same as in other African nations, with a prevalence of about 1%. A study is Hwedza found a treatment gap of 13.4/1000 or 1.34% (Madzokere and Mielke, 2005).

Incidence

Incidence of epilepsy is the number of newly diagnosed cases over a specific period of time (e.g., one year), depends somewhat on the age of the individual. The risk of epilepsy from birth through age 20 is approximately 1 percent. Within this group, the risk is highest during the first year of life and increases somewhat at the onset of puberty. From age 20 to 55 it decreases again but increases after age 55. The prevalence of epilepsy (defined as the total of the population suffering from a disorder at a particular time) has been estimated to be about 5 to 8 in every 1000 people.

Diagnosis

It seeks the probability that someone will have another seizure. This increases if one has had more than one seizure within a year. If one has, say 2 seizures in one year, there is over 80% likelihood they will have another, so they should be treated. People with a likelihood of having more seizures are therefore diagnosed as having epilepsy. In life, everyone has a chance of having a seizure. There are life situations that increase these chances, like accidents and trauma. A single seizure is normally not treated

because it has a fifty-fifty chance of recurring and if treated, there is the possibility of side effects to deal with. According to EDLIZ (2006), a single seizure is not epilepsy. Further information about the types of diagnosis is given on later on Section 3.

Treatment gap
This is the number of people with epilepsy who are not on medical treatment, divided by the total number of epilepsy multiplied by 100 or the ratio of people who are not on treatment and those on treatment. In most African countries the estimate is 70%, meaning 7 out of 10 people with epilepsy are not on treatment. A study in Hwedza found a gap of 80% (Madzokere and Mielke, 2005).

Epilepsy and health
Epilepsy may result in poor mental and physical health. Mental health is a state of mental wellbeing in which the individual realizes his or her abilities, where one can work productively and fruitfully and be able to contribute to his/her own community and not simply the absence of detectable mental disorder (WHO, 1996). Mental disorder is maladaptive response to stressors from the internal or external environment, evidenced by thoughts, feelings and behaviors that are incongruent with local or cultural norms, and interfere with the individual's social, occupational and or physical functioning (Townsend, 1996). Epilepsy does not kill but conditions such as status epilepticus and injury may result in death. A phenomenon known as Sudden Unexpected Death in Epilepsy (SUDEP) is still being studied but is believed to be responsible for more deaths in patients with epilepsy than expected.

People with epilepsy have higher mortality rates, especially in early adult life and in those with severe epilepsy. Common causes of death in people with epilepsy include: accidents (e.g. drowning, head injury, road traffic accidents), *status epilepticus,* stroke, pneumonia and suicide. Sudden unexpected death (SUDEP), a condition which remains unexplained, is common particularly in young males.

Prognosis and overall outlook
In developing countries, between 0.5-1% of the population may have a seizure at some time in their lives but most patients who develop seizures do not develop epilepsy. Of those who do, about 75% can become seizure-free with medicines. After 2 years or more on treatment without seizures, the risk of further seizures is greatly reduced and some patients can be taken off their medication. About 60% can be successfully withdrawn from medication. Effective early treatment is important in improving the long-term outlook of the condition. In withdrawing from medication, the benefits of withdrawing and the costs in the event of a recurrence must be considered carefully. About 30% of patients will have epilepsy which is difficult to treat. Patients with symptomatic epilepsy, partial or mixed seizure types, associated mental retardation, or neurological or psychiatric disorders are more likely to have a poor outcome. Most patients are entirely normal between seizures, but in a minority of patients with severe epilepsy, physical, mental or intellectual deterioration may occur.

Traditional teaching says a single seizure does not make a diagnosis of epilepsy and so should not be treated. Overall, this view is correct, but recurrences are in fact quite

common with 65-80% of people who have had one fit having another. However, although second seizures are quite common, in most people, the total number of seizures is small and their epilepsy is short lived. Many people have seizures as a result of acute infections (e.g. malaria), metabolic derangement (e.g. uraemia) or drug intoxication (e.g. alcohol). They do not have epilepsy unless the seizures reoccur in the future without the previous cause still being present.

Prevention of epilepsy

Not all cases of epilepsy are preventable. However, there are some steps which can be taken which might help to reduce the incidence of epilepsy. Some of these are:

- Adequate perinatal care to decrease incidence of perinatal haemorrhage, eclampsia etc
- Optimising the treatment of childhood infections
- Immunisation against pertussis, measles, rubella and tuberculosis to reduce the cerebral damage caused by these infections
- Appropriate management of febrile convulsions
- Preventative programmes against parasitic and infectious diseases
- Improved public safety at work and on the roads to prevent head injuries
- Public health initiatives to reduce smoking and obesity (stroke risk factors)
- Genetic counselling for those where epilepsy runs in families.

Other neurological conditions

- Infections of the nervous system
- Meningitis
- Neurocysticercosis
- Headache
- Acute confusional states
- Stroke
- Progressive generalized
- weakness
- Peripheral sensory symptoms
- Involuntary movements
- Essential tremor
- Parkinsonism
- Cerebellar tremor

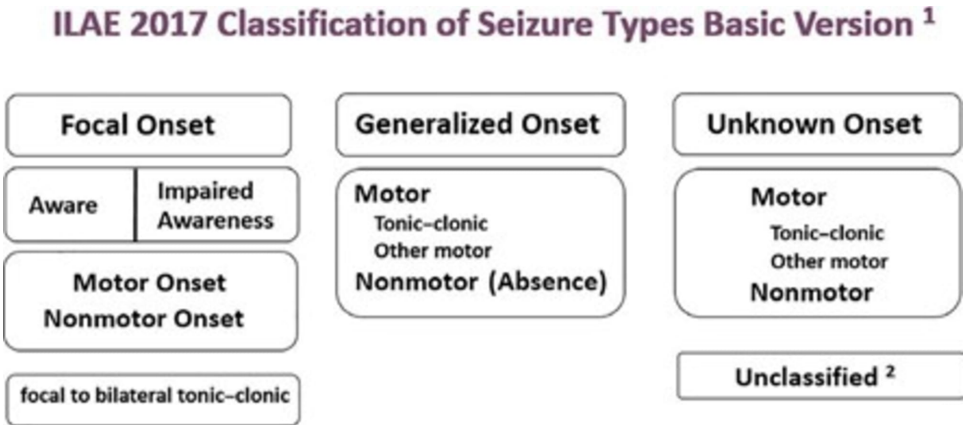
Mental health conditions

- Psychoses
- Mood (affective) disorders
- Depression
- Anxiety disorders
- Treatment of alcohol dependence

SECTION 2 TYPES OF EPILEPTIC SEIZURES

Epilepsy is a tendency for recurrent seizures. First we should consider the different types of seizures that can occur with epilepsy. Careful history taking is essential before one can be quite sure what type of fit any one patient may be experiencing. Take your time talking to relatives, and ask questions several different ways to be quite sure what is meant. Some of the more common seizure types will be considered in a bit more detail to assist in diagnosis. Seizures can be classified according to an international scheme

as detailed below.



ILAE 2017 Classification of Seizure Types Basic Version

From Fisher RS, et al. Instruction manual for the ILAE 2017 operational classification of seizure types. Epilepsia, 58(4):531–542, 2017.

___ Focal Onset

(if focal onset, choose one or leave blank if unknown)

__ Aware
__ Impaired Awareness

(if focal onset, choose one or leave blank if unknown)

__ Motor Onset
__ Nonmotor Onset
__ Focal to bilateral tonic-clonic

___ Generalized Onset

(if generalized onset, choose one or leave blank if unknown)

__ Motor
__ Nonmotor (absence)

___ Unknown Onset

(if unknown onset, choose one or leave blank if unknown)

__ Motor
__ Nonmotor

Figure 2 International classification of seizure types (basic)

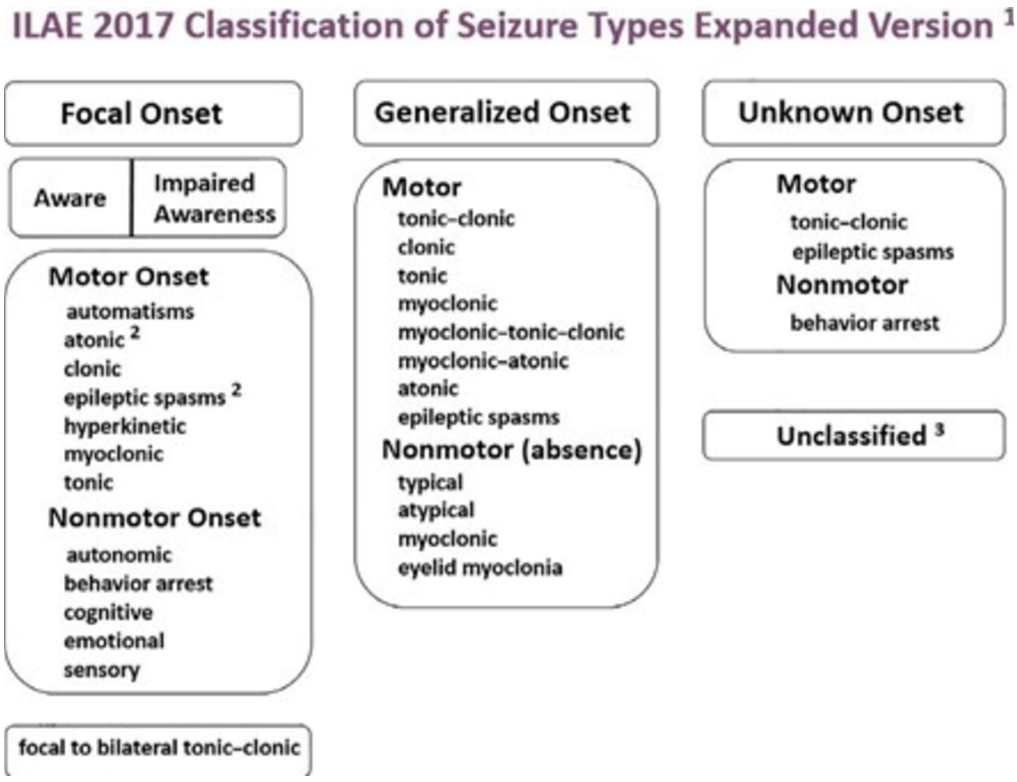
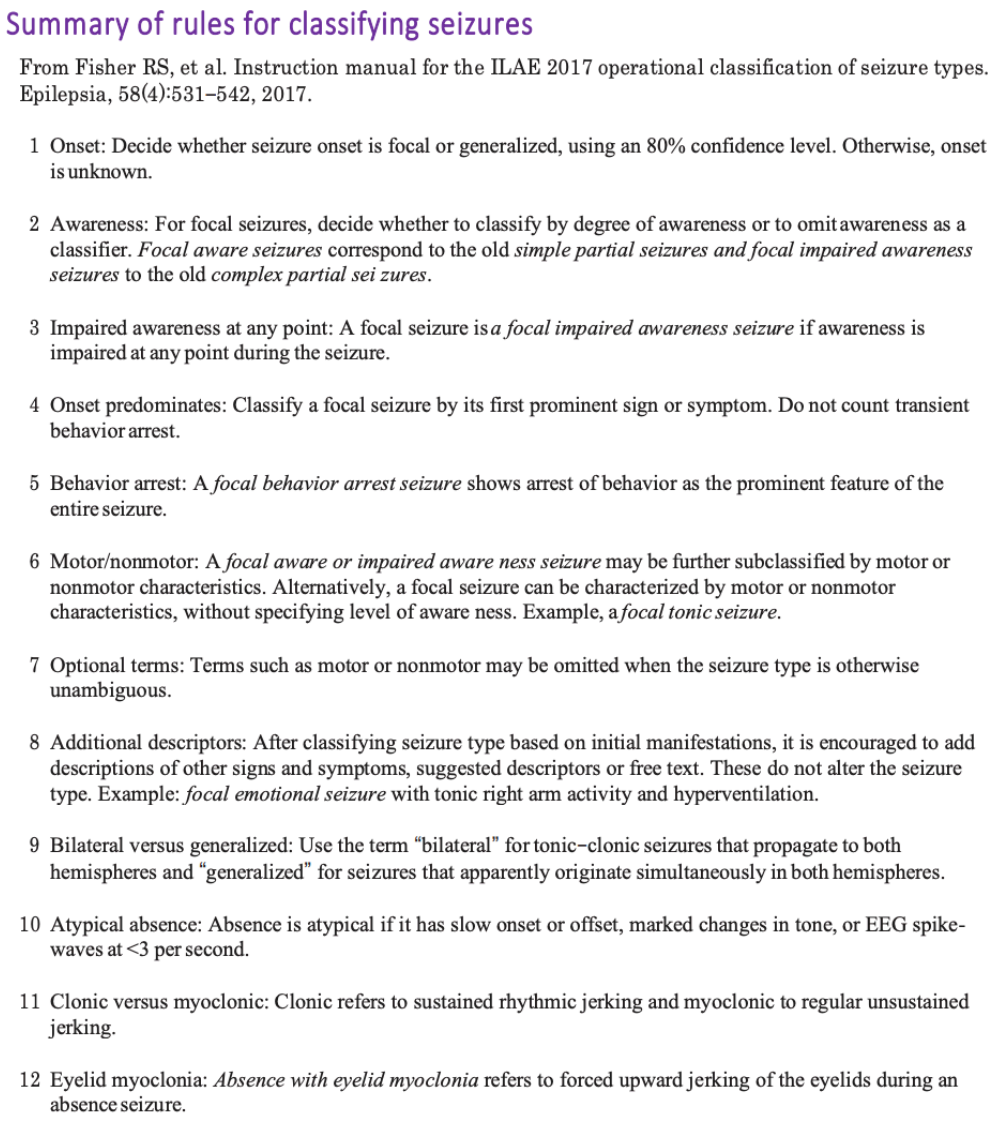


Figure 3 International classification of seizure types (expanded)



Summary of rules for classifying seizures

From Fisher RS, et al. Instruction manual for the ILAE 2017 operational classification of seizure types. Epilepsia, 58(4):531–542, 2017.

1 Onset: Decide whether seizure onset is focal or generalized, using an 80% confidence level. Otherwise, onset is unknown.

2 Awareness: For focal seizures, decide whether to classify by degree of awareness or to omit awareness as a classifier. *Focal aware seizures* correspond to the old *simple partial seizures and focal impaired awareness seizures* to the old *complex partial sei zures*.

3 Impaired awareness at any point: A focal seizure is *a focal impaired awareness seizure* if awareness is impaired at any point during the seizure.

4 Onset predominates: Classify a focal seizure by its first prominent sign or symptom. Do not count transient behavior arrest.

5 Behavior arrest: A *focal behavior arrest seizure* shows arrest of behavior as the prominent feature of the entire seizure.

6 Motor/nonmotor: A *focal aware or impaired aware ness seizure* may be further subclassified by motor or nonmotor characteristics. Alternatively, a focal seizure can be characterized by motor or nonmotor characteristics, without specifying level of aware ness. Example, a *focal tonic seizure*.

7 Optional terms: Terms such as motor or nonmotor may be omitted when the seizure type is otherwise unambiguous.

8 Additional descriptors: After classifying seizure type based on initial manifestations, it is encouraged to add descriptions of other signs and symptoms, suggested descriptors or free text. These do not alter the seizure type. Example: *focal emotional seizure* with tonic right arm activity and hyperventilation.

9 Bilateral versus generalized: Use the term "bilateral" for tonic–clonic seizures that propagate to both hemispheres and "generalized" for seizures that apparently originate simultaneously in both hemispheres.

10 Atypical absence: Absence is atypical if it has slow onset or offset, marked changes in tone, or EEG spike-waves at <3 per second.

11 Clonic versus myoclonic: Clonic refers to sustained rhythmic jerking and myoclonic to regular unsustained jerking.

12 Eyelid myoclonia: *Absence with eyelid myoclonia* refers to forced upward jerking of the eyelids during an absence seizure.

Figure 4 Summary of rules of classifying seizures

SECTION 3 DIAGNOSIS OF EPILEPSY

How to make a correct diagnosis

First - Be aware of the possibility of a seizure.

Epilepsy may present in funny ways. Sometimes there is a clear history of a fit of some sort as described above. Sometimes no fit has been witnessed. Yet the patient may have an unexplained yet severe and deep burn that no normal patient would allow himself to suffer. Or there may have been a fall or peculiar behaviour. Keep asking yourself "could this patient have had a fit?"

Second - Be clear what kind of seizure is.

Rarely will you see the seizure yourself. You are dependent on the witnesses. So get the description exactly, even if it takes time to be sure of what the witness is describing. The witness (the mother for instance) may be tearful and confused. Put her at her ease. Don't get cross with her for being difficult to understand. In the end you may have to be satisfied with a diagnosis on "the balance of possibilities". You can't always be 100% sure. Find out whether an aura occurs, biting of tongue, loss of consciousness, automatisms, duration of the seizure and inconsistence of urine and stool.

Third - Be clear that there has been more than one seizure.
An isolated fit does not of itself diagnose epilepsy, though a strong family history might just support such a diagnosis. For instance, a child may have a fit or fits just because it has a severe fever. It does not have to be epilepsy. To diagnose epilepsy, there must have been repeated fits. Febrile convulsions are the commonest kind of fits under the age of 3 but may be seen up to the age of 5.

Conditions similar to epilepsy
How can you differentiate a fit from a faint or fall? There are clues in the onset and type of history. A faint has a slow onset - the patient can feel it coming on, but seizures start suddenly, unless there is an aura. There will probably be memory for events leading up to a faint and even for the fall itself. (After an epileptic seizure there is often confusion or tiredness afterwards and no memory for the event).

Psychiatrically induced "fits", which used to be called "hysterical", and are now called pseudo-seizures, are not epileptic seizures. The movements are not typical tonic-clonic movements but more of a writhing about and the eyes may be held tight shut, although the patient is often able to talk during the fit. There may be some stressful situation which brought about the "fit", or a felt need to draw attention to oneself.

Table 1 Conditions that mimic epilepsy

DISORDER	HOW IT IS DIFFERENT FROM EPILEPSY
Syncope (fainting)	feels dizzy before, never while lying down, awake again straight away, often remembers everything
Migraine	headache before, lasts longer, often with nausea and vomiting
Vertigo/dizziness	lasts longer, without confusion or lost consciousness
Pseudo-seizures	often after an upset, bizarre movements, last long
Narcolepsy	falls asleep but can be woken, sleeps for minutes to hours
Breath-holding	in small children: cries then stops, turns blue , jerks

Types of diagnosis
Diagnosis is mainly clinical or history taking. The objective is to determine whether the person is having seizures or false seizures. An eyewitnesses will help since most people can not recount what happened. Since epilepsy may at times be a symptom of an

underlying significant illness, it is important to be quite clear on certain points. History taking is important.

a) Clinical diagnosis

As part of clinical diagnosis, the health worker should take and record down a detailed history including:

- An eyewitness account of the seizure (if possible but very important)
- Prior trauma (e.g. accident), infection, alcohol or other drugs
- History of family seizures or other neurological disorders
- Record of other medication used recently
- Ask if patient has been using medication correctly and adequately if it is status epilepticus
- Birth history
- Age at onset of seizures
- How often have seizures happened, how many times, what type and what time of day
- Any tests done before like EEG, CT scan, MRI, blood tests etc. If not done, these may be recommended to aid diagnosis.
- Impact of family in life: home, work, community, school etc
- Examine the person for scars, brain abnormality and check heart (to rule out fainting or syncope)
- Do a neurological examination (checking eyes, face, coordination, power and sensation in limbs, arm, leg and feet reflexes.
- This information must be recorded and kept confidential. It might not necessary to have the patient to carry the information since this may be lost, affecting treatment. Always have a copy of each patient's diagnosis at the health centre.

b) EEG (electroencephalography/electroencephalogram)

The EEG helps to determine type of seizure and pinpoint seizure focus. It records the electrical movement within the brain. It is harmless and painless. Wires attached to the head record electrical activity from the brain, which is amplified and recorded on paper with a printer. The paper shows waves which are slow in sleep and speedy when alert. If the paper shows spikes, there is a 99% chance the person may have epilepsy. Spikes are most likely picked during sleep. A video telemetry is an EEG with video monitor which carries tests for a lengthy y period. It helps deal with seizures where it is not sure where they start. It is also necessary to recommend patients for epilepsy surgery. It is very helpful if it records the patient during the actual seizure.

c) CT (computerized tomography) scan

A computer is used to give pictures of slices of the brain using x-rays fired at different angles. It can pick up abnormalities as tumors, strokes, brain hemorrhage or Alzheimer's. During this procedure, the person lies painlessly in a scanner for minutes. A dye may be injected in one arm to highlight certain areas of the brain.

d) MRI (magnetic resonance imaging)
This is replacing the CT scan because it is more sensitive and gives clearer pictures. It does not use x-ray but a large powerful magnet is placed around the head. Actions between the brain and the magnetic field are recorded by computer to give detailed brain pictures. The patient lies in scanner for 10-20 minutes. People with metal implants can not use an MRI because of the powerful magnets. It is very useful for recommending surgery.

SECTION 4 TREATMENT OF EPILEPY

About 60-70% of people with epilepsy will get good seizure control with medical treatment using anti-epilepsy medications. About 30-40% will not respond very well to medication, and a very small number may be helped by surgical means. Complex partial seizures respond less well to medication than do generalized seizures. About 60-80 of people with epilepsy who can be controlled by medication need only one drug and this is called monotherapy. There are some who need more than one drug (polytherapy) but they are few and they rarely need more than two drugs.

Treatment of epilepsy (from 7th EDLIZ, 2015)

The treatment information came from EDLIZ 2015. *Always use the most recent version of EDLIZ.*

Epilepsy

This is defined as a tendency to recurrent (unprovoked) seizures. **A single seizure is NOT epilepsy.** One or more seizures in the presence of fever, brain infection, medicine intoxication (including alcohol), at the time of trauma and during an episode of metabolic derangement (hypoglycaemia, uraemia, liver failure) is not epilepsy, although the brain damage caused by some of the above may lead to epilepsy. Look for provoking factors like the ones listed above when faced with a patient with a first seizure.

Seizures are distinguished from other transient neurological episodes by the history, especially the description provided by an eyewitness. **Do not start anticonvulsant treatment without an eyewitness description of a seizure.**

A typical generalised seizure has a sudden onset with abrupt loss of consciousness. There are often involuntary movements of the limbs, urinary incontinence or tongue biting. Afterwards the patient is often confused, sleepy and complains of headache. Partial seizures do not involve loss of consciousness but present as recurrent twitching or abnormal sensations in one body part. Complex partial seizures include reduced awareness, aimless movements and memory loss for the event afterwards.

First line treatment

Health workers who have undergone training in the recognition and management of epilepsy may initiate treatment at primary care (C) level. Otherwise refer to District level.

- If two or more typical seizures in the past 12 months in a patient over 2 years

plus

- normal physical examination, no neurological signs, start:

Medicine	Codes	Adult dose	Frequency	Duration
phenobarbitone po	**C V**	120mg Paed = 5mg/ kg	once a day, at night	2 weeks until review

Review after 2 weeks. Check compliance and side effects (very sleepy, loss of balance, rash, poor concentration, hyperactive). If side-effects, reduce phenobarbitone dose by 30mg. Review again after 4 weeks.

Second line treatment

For the patient with persistent seizures despite phenobarbitone check the diagnosis, compliance, medicine interactions, and intercurrent illness.

- Increase:

	Medicine	Codes	Adult dose	Frequency	Duration
	phenobarbitone po	**C V**	120mg	every night	4 weeks then review

- If seizures persist (one or more in four weeks):

	Medicine	Codes	Adult dose	Frequency
add	**phenytoin po**	**B V**	300mg	bedtime

- If seizures persist, increase:

	Medicine	Codes	Adult dose	Frequency	Duration
	carbamazepine po	**B V**	400mg Paed = 10mg/kg	twice a day	4 weeks, then review

- Review in 4 weeks
- If seizures persist, intolerable side effects, patient maintained on more than one anticonvulsant: refer for **tertiary level care or specialist care.**
- Other indications for referral to **tertiary level / specialist care**: neonatal epilepsy, progressive neurological deficit, absence seizures (momentary loss of consciousness without involuntary movements)

Tertiary/Specialist care

Decisions will include whether further investigations (EEG, CT scan) are indicated, and the use of phenytoin sodium, sodium valproate, ethosuximide, diazepam or clonazepam.

Figure 5 Treatment of epilepsy (EDLIZ 7th edition, 2015)

Status epilepticus

A seizure or a series of seizures continuing for more than 30 minutes, or recurrent seizures without regaining consciousness in-between, for more than 30 minutes. Many cases do not occur in known epileptic patients – always consider possible underlying causes such as stroke or brain abscess.

The above description should be strictly adhered to. **The practice of prescribing diazepam 10mg i.v. every time a seizure occurs should be resisted.** It is preferable to use a regular anti-convulsant during the in-patient stay.

Adults:

Management at primary level:

- Protect the airway and give oxygen if available,
- Give 50ml bolus of *dextrose 50%* intravenously (children: 10-20ml)
- While making arrangements to transfer the patient to a hospital, **give:**

	Medicine	Codes		Adult dose	Rate
	diazepam slow iv (or pr) (not im)	**C**	**V**	10mg	Given over 2-3 minutes. May be repeated **once** after 5mins.

Management at district level:

- Diazepam as above may be repeated twice (max dose 40 mg) if seizures persist, but watch for respiratory depression (ambu-bag must be available).
- **If seizures persist after 30 minutes, give:**

	Medicine	Codes		Adult dose	Frequency	Duration
	phenobarbitone iv/im	**B**	**E**	10-15mg/kg	30-50mg per minute infusion(iv over 10 mins)	

- Commence oral medicines as soon as fully conscious: by naso-gastric tube if unrousable for more than 6hrs.
- If seizures persist, **transfer** to provincial or central level for:

	Medicine	Codes		Adult dose	Frequency	Duration
	phenytoin sodium iv	**A**	**E**	15-20 mg/kg then 100mg	At a rate of 50mg/min, 6 hourly	

- If seizures still persist after 30 minutes, and ICU facilities and anaesthetist available, give:

	Medicine	Codes		Adult dose	Frequency	Duration
	thiopentone sodium iv	**B**	**V**	7mg/kg	assess/review	
and	**suxamethonium chloride iv**	**B**	**V**	100mg	assess/review	

- intubate and ventilate; consider thiopentone infusion.

Children:

- Protect the airway and give oxygen if available.
- At primary level (C) give:

	Medicine	Codes		Paed dose	Frequency	Duration
	dextrose 50% iv	**C**	**V**	10-20ml	once only	-
and	**diazepam pr ***	**C**	**V**	5mg	may be repeated once	

**use a syringe without a needle*

- Further management at district (B) level:

Medicine	Codes	Paed dose	Frequency	Duration
diazepam iv slow	**C V**	1mg/year of age	May be repeated once	

Febrile convulsions should be treated with tepid sponging, paracetamol and diazepam as above if necessary. They do not require long-term anticonvulsants unless recurrent and with neurological deficit.

Figure 6 Treatment of status epilepticus (EDLIZ 2015)

Treatment chart

Management (treatment) of epilepsy

According to EDLIZ (2006), primary health care workers who have received such training can diagnose and treat convulsive or generalized tonic-clonic seizures. Be clear that there has been more than one fit. An isolated fit does not of itself diagnose epilepsy, though a strong family history might just support such a diagnosis. For instance, a child may have a fit or fits just because it has a severe fever. It does not have to be epilepsy. To diagnose epilepsy, there must have been repeated fits. Febrile convulsions are the commonest kind of fits under the age of 3 but may be seen up to the age of 5.

Once you have decided that patient has had one or more seizures, the next step is to decide to start treatment right away or to refer (see chart below).

Management (treatment) chart: Department of Pharmacy (UZ) and Ministry of Health

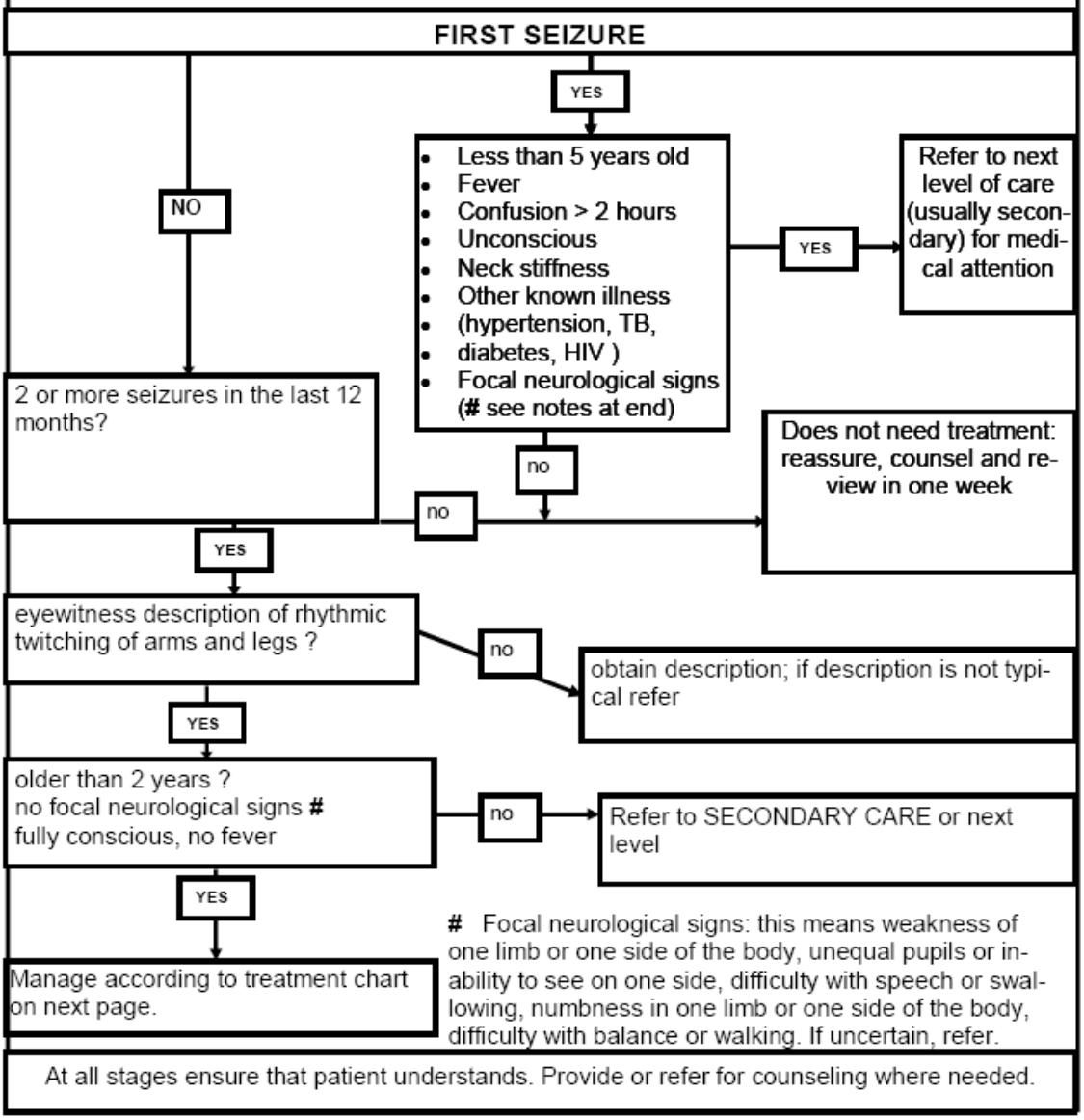


Figure 7 Management of epilepsy (treatment chat) Department of Pharmacy and Ministry of Health. ***Chart based on EDLIZ 2006***

Treating febrile (fever) convulsions

These are generalised tonic-clonic seizures which occur in children between the ages of six months and five years, when the temperature has risen quickly. The child must have a fever. They are benign but may be confused with much more serious conditions like cerebral malaria or meningitis. Febrile convulsions are common, occurring in up to 5% of children. It is a mistake to treat children with febrile convulsions as if they were epileptic. They do not need drug prophylaxis unless the child has existing neurological damage and more than 2 febrile seizures, or in the case of a child who has the first convulsion while very young (less than ten months old). Their management consists of the following:

- Prevent the convulsion before it even happens by tepid sponging or cool bathing a susceptible child, or by giving paracetamol (not aspirin which can induce a potentially fatal syndrome - Reye's syndrome)
- If a convulsion does occur give rectal diazepam (using the iv solution) five mg in a plastic syringe without a needle. This can be repeated (once) if necessary. Cool the child as above, of course, and place in a semi-prone position because vomiting often occurs after a convulsion.
- Reassure the parents and explain about febrile convulsions. They probably think the child is dying - the convulsion is so dramatic.
- If the child is dehydrated, treat that actively.

Treatment of status epilepticus

The term "*status epilepticus*" is applied to the situation where there are prolonged seizures longer than 30 minutes or repeated seizures without regaining consciousness in between. This is a medical emergency; patients should be referred to a hospital where incubation and ventilation are possible immediately. The mortality rate and the chance of permanent brain damage both increase the longer the attacks are. The management is as for an ordinary fit at first. Then oxygen is given If you can't get an open airway and the patient is having difficulty with respiration, use an oral airway and an ambu-bag to help with ventilation, incubate with an endotracheal tube if possible.

Treatment during pregnancy

At this stage, both the baby and mother must be protected. 30% of pregnant people with epilepsy report an increase in seizures, 20% a decrease and 50% no change. There is a possibility the baby may be injured physically during tonic clonic seizures or by medication. High doses and polytherapy increase the probability of foetal damage. It is therefore recommended that the patient is put on lower doses once or before pregnancy. Common abnormalities include cleft/lip palette, spina bifida (more common with valproate or carbamazepine). Folic acid tablets should be given before conception and in the first 3 months of conception to avoid child malformations and miscarriage. In the last month the mother should receive vitamin K supplement (epilepsy drugs decrease in the body) and the same must be given to new baby. In very high doses of phenobarbitone and ethosuximide, breastfeeding may result in baby drowsiness. Most mothers with epilepsy on drugs can safely breastfeed though.

Epilepsy surgery

Seizures which are difficult to control with anti-epileptic drugs are called refractory seizures. Some of patients with this type of seizures may benefit from epilepsy

surgery. Although surgery is not widely used because of cost and inadequate personnel, it has been proven to be effective for people with refractory seizures. Epilepsy surgery is an operation during which either a portion of the brain is removed or connections in the brain are cut. As epileptic seizures originate in the thin outer layer of the brain (the cortex), the most commonly performed operations are directed at removing part of the cortex. Just as in any other aspect of life, the treatment of epilepsy requires careful consideration of all options and a selection of the best treatment option for patients. For any patient whose seizures are not controlled by other treatment, epilepsy surgery should be considered. For some patients whose seizures are controlled by medication, surgery may sometimes be considered if: the side-effects of medication are unacceptable, a pregnancy without exposure to anticonvulsant medication is desired or life-long anticonvulsant therapy appears inevitable and the patient wishes to avoid this.

SECTION 5 FIRST AID CARE

Tonic-clonic seizure

Do:

- Keep calm, do not be afraid, do not run away, reassure others and be ready to help
- Prevent injury! Remove dangerous objects/places, loosen tight clothing, and put a cushion to prevent head or limb injury. Ensure saliva is drained out to avoid choking.
- After seizures have stopped, let person lie down on left side with right hand as a pillow. Put his head on one side (recovery position)
- Remain with person until they are fully recovered and tell them what has happened. Educate about epilepsy and encourage to seek treatment. Ensure they record in their diary.
- If convulsions last more than 5 minutes or happen repeatedly without regaining consciousness, then call an ambulance.
- For health workers, knowing how to administer diazepam is important. Where family members or school are going to administer it, there should be adequately trained.

Do not:

- Do not restrain ‘fitting” as you may injure them or yourself.
- Do not move the patient unless they are in danger.
- Do not put anything in mouth or between teeth (you will break his teeth and get your fingers bitten- tongues heal but teeth do not and they may get inhaled.
- Do not slap face, try to bring him round or pour water.
- Do not give food, water or tablets during a seizure.

First aid in other seizures

Other seizures are not this severe but it is necessary to assist the person so that they

feel comfortable. It is often embarrassing to have a 'blackout' in front of other people. When this happens the person needs reassurance that 'we understand your condition, you are still part of us, feel very comfortable'. Some people with absence seizures may injure their tongue. Yet some become unstable, aggressive or unaware. In most cases, after such instances people do not remember that anything has happened. In such cases, gently tell them what has happened so that they record in their seizure diary. It is critically important to ensure that after the seizure, the person will arrive home safely.

SECTION 6 TREATMENT COMPLIANCE

At first diagnosis it is important to take time to talk to the patient and his family or the people whom he stays with. A simple explanation of what epilepsy is and what it is not will help them to understand the reasons for taking medications and the importance of taking regularly. Some points that are useful to include are:

- Epilepsy is the result of an abnormality in the brain, like a scar which continues to itch for a long time after the wound has healed. Many different things can cause epilepsy, but not witchcraft.
- Epilepsy is not contagious; it cannot be contracted by touching people with epilepsy, or from the foam at their mouth, or from their eating utensils
- Most people with epilepsy can learn and think normally, although some also have other brain injury which can make them slow or have behavioral problems. So almost all children with epilepsy should go to normal schools
- Epilepsy is common especially in children, but many grow out of it and do not have seizures when they are adults
- The medicines can make the seizures occur far less often, in two thirds people can become free of seizures, but they must continue to take the medications, otherwise the seizures will probably recur
- The medicines do not cure the epilepsy but make the seizures occur less often
- When you first start taking the medicines they can make you feel sleepy and weak, but that usually stops even if you continue to take them. So it is important not to stop taking them, and to come to the clinic before they run out.
- No special treatment has to be given if a seizure does happen (see First Aid care)

Make a note on a separate piece of paper of the date every time a seizure does happen and bring the paper with you to the clinic when you come for review, because it is important to find out how many seizures there have been and when they happened. People with epilepsy must be encouraged to take medicine always at right time and dose. Poor compliance may result in seizures whilst overdose may be fatal. If a dose is missed, it should be taken immediately as long as it is not within time for the next dosage. Tablets vomited must be retaken whilst in diarrhea situations, higher doses are needed. Family members, teachers and employers must help the person to remember. Before dismissing the patient, ensure they understand their dosage.

Monitoring and review

Epilepsy drugs and the patient must be monitored. The treatment charts clearly show

that. To ensure this process is effective, the patient should have a record of their seizures. This should be mandatory. Also, treatment records must be kept at the clinic. In some cases the patient carries the card in form of sheets or booklet.

SECTION 7 DRUG COMMENCEMENT, MAINTENANCE AND WITHDRAWAL

Anti-epileptic drugs (AEDs) are a key component in the management of epilepsy. Drugs used to treat epilepsy in Zimbabwe include phenobarbitone, phenytoin, carbamazepine, sodium valproate, ethosuximide, diazepam and others. Treatment is mainly through anti-epilepsy drugs, avoiding triggers and surgery. The first drug, potassium bromide, was discovered by Sir Charles Locock in 1857 and was stopped (due to severe side effects) when phenobarbitone was introduced in 1912. Brain surgery can treat some types of epilepsy but is not readily available and risky (involves removing part of brain responsible for seizures). It is suitable for drug resistant, refractory or pharmaco-resistant cases. Research is ongoing on traditional treatment. Spiritual or faith healing has been ruled out by scientists. Other forms of treatment like relaxation therapy, physiotherapy, occupational therapy etc are helpful to manage stress and reduce tension. Detailed information on these drugs, their indications, side-effects, drug interactions and important information for the patient is contained in the formulary of C-list drugs available from Pharmacy Services in the Ministry of Health. Some information is provided below from the British Medical Association.

Drug action

When an epilepsy tablet is swallowed, it is absorbed into the bloodstream and passed onto the brain. Drugs should be taken just after meals to aid absorption. Drugs do not stay in the body for ever; they are broken down or passed out as urine. Drugs control epilepsy by balancing chemicals in the brain and also by stabilizing the work of neurons.

When to commence AEDs?

Once the diagnosis of epilepsy has been made, drug treatment should be started. A single seizure does not warrant treatment except in certain special circumstances e.g. progressive brain disorders, obvious neurological deficits, a clearly epileptic EEG.

Certain factors which might suggest not treating a patient with drugs include:

- Seizures widely separated in time, such as once a year.
- A previous history of not taking medication as directed (non-compliance).
- Provoked seizures - alcohol and drugs for example. The provoking factors are best avoided, if possible, rather than taking AEDs.
- Patient/parental opinions.

How to commence AED treatment?

The choice of AED should ideally be based on type of seizure or epilepsy. This choice is more limited in Zimbabwe than in developed countries. Phenobarbitone is used locally

since it is cheaper, effective and allows more patients to be treated than if we only used more expensive drugs like carbamazepine.

First treat with phenobarbitone increasing the dosage until seizures are controlled or until side-effects are a problem. If seizures are not controlled, then introduce phenytoin while slowly withdrawing phenobarbitone. Again, increase the phenytoin dose until seizures are controlled or side-effects are not tolerated. If seizures are still not controlled then introduce carbamazepine while slowly withdrawing phenytoin. Increase dose until seizures are controlled or side-effects are a problem. If still not controlled, refer for specialist advice.

About 70% of patients will have their seizures controlled effectively with one drug (monotherapy). About 30% of patients with epilepsy will need to be on more than one AED (polytherapy). Unnecessary polytherapy can actually worsen seizure control and increase the incidence of side-effects mainly due to drug interactions. Patients are likely to mix up dosages.

How long to treat for and when to stop?
This is an important issue which must be discussed with the patient / carers at the outset of treatment. Ideally treatment should be as short as possible but in many cases it will continue for many years and will be life-long in some. Treatment is continued until the patient is free of seizures for at least 2-3 years (generalised seizures) or 5 years in the case of partial seizures. The patient should not stop treatment on their own.

How to withdraw AEDs?
Since the brain has become accustomed to antiepileptic drug, withdrawal must be slow to prevent a rebound effect with excess seizures. Withdrawal over 6-12 months by progressive lowering of dose is normal, with longer periods required when patients have been treated for many years.

SECTION 8 TYPES OF ANTIEPILEPSY DRUGS

Phenobarbitone
In rich countries this drug is getting unfavoured because of side effects but in poor nations it is favoured because it is cheap. It was originally used as a sleeping tablet which is why it can make some patients drowsy although in children it may make then hyperactive or aggressive. Other side effects include rash, drowsiness, cognitive impairment, irritability, loss of balance, impotence, depression and poor memory in high doses and in the long term it may give coarse facial features and decrease store of vitamins like folic acid and vitamin D in the body.

Carbamazepine
Found safe and effective in partial seizures in the 1950s but may worsen absence and myclonic seizures. If it results in rashes, it has to be stopped. High doses lead to double vision, imbalance, nausea, headache, drowsiness and neutropenia (low, white blood cell count).

Ethosuximide
Only useful in absence seizures. Can cause rashes, stomach ache, tiredness, headache and dizziness.

Phenytoin
Compared to phenobarbitone, it causes less drowsiness. It was started in 1938 and is effective on partial and tonic conic seizures. Possible side effects: gingival hyperplasia (overgrowth of the gums), hirsuitism/hypertrichosis (excessive hair growth), imbalance, lethargy, anemia, and, in long-term use, peripheral neuropathy (weakness), rash (must be stopped if it happens), dizziness, increased seizures, unsteadiness, double vision, a course face, acne, and a decrease in the body of folic acid and vitamin D. As such, young people are not keen to use it.

Valproate
Discovered to be useful in epilepsy in France, 1960s. Treats light sensitive epilepsy, myoclonic seizures and absences. May cause severe liver damage in under 3 years children. Possible side effects: hepatotoxicity (liver damage), stomach upset, allopecia (hair loss), tremor, swelling of the angles, weight gain and drowsiness which increases if combined with phenobarbitone.

Primidone
In the body this drug is broken down to phenobarbitone and works just like it with the same possible side effects.

Clonazepam
Suitable for absences but may apply on other seizures. This drug may cease to be effective in some patients after 3 months of use (tolerance). It may result in drowsiness and behavioral changes.

SECTION 9 SIDE EFFECTS

The treatment of epilepsy is a balance between seizure control and drug side effects. Side effects can be dose relate, individual related (idiosyncratic) or chronic.

Dose related side effects
These are seen in patients when dose is too high (drug intoxication). These include dizziness, double vision, drowsiness, sleepiness, slowness, stomach upset, headache, lack of concentration and poor intellectual ability. In other patients these happen as they start drugs but disappear; which is why it is not necessary at times to discontinue a drug with mild effects less than a month after introducing it. Some side-effects e.g. drowsiness and lethargy are only a problem when starting therapy and the patient gets over them after 2-3 weeks. Patients should be warned about this so that they do not stop taking their medicines.

Idiosyncratic side effects

They happen on specific patients only mainly due to allergies and should be discontinued immediately. Some of the effects include rash, liver failure, psychosis/depression or some blood disorders.

Chronic side effects
Occur after taking a drug for too long. These may include gum bleeding in the case of phenytoin or problems with teeth. Other chronic effects include weight gain, vitamin deficiencies, face changes, acne, mood changes or sedation.

Drug interactions
Anti-epilepsy drugs may interfere with other treatments and they may interfere with each other as well. Interference means breakdown, absorption and excretion are affected. This may result in a shortage of the drug in the blood resulting in seizures or more drug in the blood resulting in side effects. When a second drug is introduced, the old one must be monitored and also change dosage. Of the more important drug interactions with phenobarbitone are (a) it reduces the effectiveness of oral contraceptives and (b) it can cause respiratory depression when combined with other CNS depressants such as alcohol or diazepam. In fact, many epilepsy drugs increase the breakdown of the pill resulting in it being ineffective to control pregnancy and may result in breakthrough bleeding. Higher doses of the pill may be necessary. Other substances interacting with epilepsy drugs include warfarin (used which prevents blood clotting), aminophylline (asthma), antacids, asprin, erythromycin, folic acid and cotrimoxazole.

SECTION 10 TRIGGERING FACTORS

At times patients and clients keep having seizures despite having the best drug and dose for them. This could be as a result of triggering factors. Health workers should know these and be able to treat them. Most of them require social techniques of therapy and they are discussed in the following chapter on social therapy. Here some of them will be highlighted. Triggers normally compete with drugs in the brain and blood stream. Resultantly, the drug is defeated resulting in seizures. Most triggers affect compliance to medication and they work hand in glove.
Please note triggers do not affect all patients in the same way. Most triggers do not happen to most patients. Some of these factors are alcohol, drugs, menses, caffeine, stress, pregnancy, other medicines, other sicknesses/fever, lack of sleep, lights (photosensitivity), sounds and patterns (reflex epilepsy), missing medication, taking a very low dose (a higher dose may give side effects that may in turn cause more seizures), getting tired, hunger, depression, high temperatures from fire or sun etc.

Solutions: stress management, aroma and relaxation therapy may help reduce stress. Having work to do and leisure are necessary. Most of these triggers may be reduced by counseling so health workers must provide it or refer. Adequate sleep and small jobs at a time e.g. shift work are recommended. Night vigils are not recommended. Before taking other medicines e.g. for family planning, see your doctor. People with epilepsy on certain drugs may not take aspirin. There are many solutions to all the triggers. The family must be involved and where necessary colleagues.

SECTION 11 EPILEPSY AND HIV/AIDS

There is still very little literature on this topic. Mielke et al (2007) argued that there is need for research into the interaction between antiretroviral drugs and anti-epilepsy drugs. The argument was that there is high risk of interactions resulting in one form of drug being less effective or giving side effects. It is a well known factor however that antiretroviral drugs (ARVs) may be a triggering factor as well as related factors like stress, further infection and loss of liquids. On the other hand, HIV may result in bran cell damage, resulting in epilepsy. The major relationship between these two conditions is possibly the high level of stigma attached to both. There is need for more studies in this area.

SECTION 12 PATIENT AND FAMILY EDUCATION

To ensure success of treatment and reduction of side effects, it is important to involve the family. The best way to do this is to ensure that they are educated on the following:

- Types, causes and prevention of seizures
- Need for adequate rest and exercising
- Stress management
- Keeping regular appointments
- Use of community resources such as support groups, Epilepsy Support Foundation, social workers, disability groups, religious groups and counselling services.
- Getting the medic alert bracelet
- Avoiding excessive alcohol and caffeine intake
- Talking openly about epilepsy to increase support.
- Involving males in care giving

Chapter 2 SOCIAL ASPECTS OF EPILEPSY

Rugare J. Mugumbate

Epilepsy is a social disease and medical condition characterized by lifelong stigma and recurrent seizures. This might be the definition closest to the reality of epilepsy, at least for social scientists. Although medically, some consider it improper to term it a disease, socially it might be one. It is argued that any diagnosis of epilepsy that leaves out the social aspects is inadequate. Therefore, any treatment that ignores the social aspects of epilepsy is incomplete. All epilepsy diagnosis must consider the symptoms of social problems and try to lay them bare for treatment. In most cases treatment goes beyond the person to include the family and community.

SECTION 1 SOCIAL DIAGNOSIS OF EPILEPSY

Medical diagnosis is well documented and quite clear. Not so with social diagnosis. Social diagnosis seeks to achieve basically 3 things: ascertain the availability of social problems, clarify and classify the problems. As a social disease epilepsy has the following among other numerous symptoms:

- Myths, misunderstanding, ignorance of epilepsy and treatment.
- The unavailability of resources needed for chronic medical epilepsy treatment.
- Stress, depression, mood and behavior disorders.
- Stigma and discrimination.
- Denial, not accepting treatment and poor compliance.
- Dependence on others for support.
- Overprotection.
- Being feared by other people.
- Low self esteem.
- Poor memory.
- Low IQ and learning abilities.
- Poor physical ability.
- Poor sensation.
- Social development abnormalities e.g. not married, not employed etc.
- Biological abnormalities e.g. problems with sexuality, conception, pregnancy etc.
- Risk of injury, death, abuse etc.

These challenges can be classified into economic, psychosocial, biomedical and social, educational and political (e.g. the feeling that policies neglect people with epilepsy) categories.

Ways to do a social diagnosis

- All professionals should be able to diagnose. Social diagnosis should be made a compulsory component in every training curriculum. A professional who does a social diagnosis should write all non-confidential matters in the client/patient booklet in the same manner they do a medical diagnosis. This is primary social diagnosis normally achieved using interview or counselling as the main tools.
- Secondly, a professional who is unable to do a social diagnosis must refer the client to a Social Worker who then communicates with the medical professionals using the patient booklet, letter or share notes in a meeting. A professional Counselor might be useful where a Social Worker is not available. In fact, seeing a Social Worker, especially Clinical or Medical Social Workers must be compulsory for people with epilepsy where these professionals are available. This is secondary diagnosis.

Any treatment plan must have prescriptions for social therapy. This is the only way neurologists; neurosurgeons, physicians, nurses, psychiatrists, physicians, pediatricians, social workers and many other professionals will be able to move people

with epilepsy from an undesired quality of life to a desired quality of life. Most people with epilepsy desire to compete in life against anyone else, without the hindrance of stigma and seizures. To achieve this high quality of life, medical and social treatment should balance. Medical treatment may give people with epilepsy a better quality of life, but may fail to give the best quality of life. Medical and social care professionals are strongly urged to adopt social diagnosis as it builds a much firmer background to defeat stigma.

SECTION 2 SOCIAL TREATMENT OF EPILEPSY

After a successful diagnosis, the social problems will now be known, clarified and classified. It will be time for solutions. The solution finding process involves the client to a larger extent. This is an easy process. The most difficult task in treating the social disease of epilepsy is indeed to uncover the social problems because most people do not open up so easily. Social workers and counselors are trained to 'open up' people and activate them to solve their own problems to enhance social functioning.

Social treatment strategies
There are several solutions to each of these problems. The following table summarizes possible treatment options although this varies from client to client based on support systems available.

Table 2 Options for social management of epilepsy

CATEGORY OF SOCIAL PROBLEM	POSSIBLE SOLUTIONS
Economic	• Explore all possible forms of support e.g. self, family, friends, employer etc • Refer to department of Social Service, NGOs, churches, companies etc. • Try income generating ventures • Finding employment according to ability. This can be part time.
Educational/informational	• Give client information on epilepsy in appropriate language and media e.g. pamphlets, books, videos etc. • Talk to teacher and arrange for awareness at school. • Give teachers literature. • Give parents skills to help child learn better. • Refer to community health worker. • Ensure epilepsy sensitive literature.

Psychosocial	• Refer to Psychologist if severe. • Refer to Social Worker or Counselor e.g. marriage Counselor. • Try to remove stressor e.g. stop alcohol etc. • Refer to elders. • Arrange for education and awareness for family, community, workplace etc using the best technique agreed. • Ensure protective devices like helmets where necessary, help join Medic Alert, ensure support by an adult where necessary etc. • Give memory aids like seizure diaries. • For fear of medication, consider monotherapy or withdrawal where possible.
Biological/medical	• Refer to appropriate professional e.g. gynecologist etc based on needs. • Treat related conditions. • Diagnose and manage triggers.
Political	• Refer to advocacy organizations. • Build self esteem and assertiveness through group therapy. • Write petition letters in the event of discrimination
Emotional	• Refer to church. • Refer to elders.

It is strongly argued that treatment of epilepsy focusing on one therapy model is inadequate. If, as professionals, we focus on medical treatment only, we will not give people with epilepsy the quality of life they desire. If on the other side, we focus on social treatment only, we will not achieve the best quality of life. Those managing epilepsy today will not be forgiven for taking a thin treatment approach when opportunities for treating stigma and seizures are now available. It will also be necessary to consider other forms of therapy, normally termed alternative therapies. I do not consider social treatment an alternative therapy, but rather a therapy that can compete well with medical therapy and complement well with medical therapy. Social therapy treats the disease of epilepsy while medical therapy treats the condition of epilepsy. Without a stop to seizures, there is no stop to stigma. Stigma will only end when the best quality of life is given to people with epilepsy. The best quality of life will only be achieved when we, as professionals successfully treat the social disease and medical condition of epilepsy.

SECTION 3 PSYCHOSOCIAL ISSUES

As already mentioned, there is more to the management of epilepsy than purely seizure control. The unpredictability of seizures, the loss of control over one's body and

environment, the embarrassment that may be associated with a seizure and the stigma associated with the condition all go towards shaping the epileptic's view of the world. In addition, it is accepted that there is an increased incidence of anxiety, psychosis, sexual dysfunction, affective disorders, behavior problems and psychopathology in general, in people with epilepsy. This is particularly the case in those with chronic epilepsy which is difficult to treat. It is often these factors, rather than the seizures as such, which explain how the individual functions in society.

Behavior disturbances associated with seizures
Behavior changes before a fit include irritability, depression, headache, a "funny feeling" and confusion. These may last for minutes to several days and disappear after the seizure. During and after the seizure there may be changes in memory and thought processes. There may also be automatic behaviors, illusions and delusions, especially with complex partial seizures.

Emotional disorders
Mood problems such as anxiety and depression are common in people with chronic epilepsy. Suicide is about 4 times greater in people with epilepsy than in the general population and even more frequent in those with complex partial seizures.

Personality
There is no evidence for an "epileptic personality", but as has already been pointed out personality problems are not uncommon. An unusual (different) personality is most often seen in those with complex partial seizures. Again from a social point of view, it is not uncommon for people with epilepsy to say "I want to be normal like everyone else". Their feeling is that with seizure control, all will be well. This is not always the case. In addition, some of the behaviors exhibited before, during and after seizures, do not favour epileptics being seen as normal.

Cognitive (thinking/brain function) problems
Cognitive changes are more common in people with chronic epilepsy than those with mild epilepsy. They include problems with memory, intellect, language and learning difficulties. The commonest complaint is that of a deteriorating memory. Some AEDs affect cognitive function too.

Sexuality
Patients with complex partial seizures have been shown to have a higher incidence of decreased sexuality (libido) than those with generalised seizures. In addition, the psychological problems already mentioned plus unemployment and poor self confidence may also contribute. The contribution of AEDs to this is probably small.

Pregnancy
Inheritance: There is a small risk, but at least five times greater than in the general population (about one in forty or 2.5 %), that epilepsy will occur in the children born of parents, where one or both have epilepsy (Walker and Shorvon, 1999). This does not apply to those with post-traumatic epilepsy.

Effect of pregnancy on seizure control: About 50% of women will show no change in

seizure frequency, 35% a deterioration and 15% an improvement. The deterioration in seizure control is probably due to AED changes in the body. It is difficult to predict which patients will deteriorate, although those with difficult seizure control prior to pregnancy are more likely to be affected.

Effects of epilepsy on the pregnancy: An increased bleeding tendency in the neonate has been reported, especially when the mother has been taking phenytoin and phenobarbitone. Vitamin K should be given to the newborn infant.

Drug effects on the foetus (teratogenicity): Neonatal malformations occur 2-3 times more often in the children of epileptic mothers taking AEDs than in the general population (Walker and Shorvon, 1999). This is especially the case where there is poor seizure control and several AEDs are being used. Abnormalities consist of minor and major congenital abnormalities, some degree of growth retardation and developmental delay. Abnormalities have been reported with all the AEDs and spina bifida occurs in 1-2% of pregnancies where sodium valproate is used. Spina bifida has also been reported with exposure to carbamazepine. Folic acid 5 mg/day should be given for a month before and throughout the pregnancy to lower this risk.

Breast feeding: All the AEDs get into breast milk to some degree, but rarely cause any clinical problems. It is safe to breast feed.

Treatment compliance
It must be obvious that starting treatment without the consent of the person of their guardian might prove futile. There is need for their cooperation and it comes after informing them about correct issues related to epilepsy, treatment and medication. This will enhance drug compliance.

Drug compliance
Many patients with a chronic disorder, such as epilepsy, will be non-compliant from time to time. Taking medication twice or thrice daily for years on end is boring and we are all forgetful. With epilepsy, significant non-compliance leads to a seizure or several seizures. This is usually unpleasant and few people enjoy having seizures. So, most people with epilepsy are compliant most of the time. The patient and family must be informed that epilepsy is chronic and medication will be taken for long, if not life long. They should also know that medication might not work instantly, it might take time and they should be patient. Educate patients on what to do when they miss medication and the dangers of missing medication.

Fear of seizures
A fear of seizures and their consequences is quite common and often unspoken. These fears include that of actually having a seizure, possible injury, brain damage, having a brain tumour, a mental illness or dying during a seizure. For many people these fears are short-lived, but for others they may lead to anxiety or depression, a fear of being alone and a general obsession with their health.

SECTION 4 ACCEPTANCE AND STIGMA

These are important issues and will be discussed in some detail. There are two forms of acceptance related to epilepsy. There is the individual person's acceptance of their epilepsy and there is society's acceptance of someone who has epilepsy. These issues are separate, but linked. The individual who has not accepted their epilepsy is likely to have more problems in, and with, the general community.

With respect to the matter of acceptance of epilepsy by the individual, parents and the family, it has already been suggested that at the time of diagnosis of epilepsy (and many other conditions) a grief reaction occurs; grief for a "loss of health". Whatever the process that people go through, the final objective is acceptance. Families should be helped to build acceptance that their child or themselves have epilepsy and that this is part of their life in the same way that they might have asthma, a heart condition or some other problem. No one wants to have epilepsy, or anything else that causes a 'loss of health" and it is not surprising that it takes a while, sometimes a very long time, for acceptance to occur. In some people this never happens, leaving them in state of anger and denial. This stops them from relating with others and getting on with their lives. When acceptance happens, something changes in the individual or family's life which puts their epilepsy in a different perspective. It is now only a nuisance, rather than being the main issue in their lives.

This leads to the issue of acceptance of people with epilepsy in, and by society, and the problems of discrimination and stigma. Why should society not accept people with epilepsy? According to those with epilepsy, there are a number of reasons:

- Public ignorance about epilepsy. Studies over the years have shown this to be less of a problem than is generally thought by people with epilepsy.
- A view that the public is intolerant of people with epilepsy. There is little evidence to support this.
- A view that the public discriminates against people with epilepsy. As will be argued below, this is probably more perceived than real, but the perception continues.
- The perception that the public recognises an epileptic "identity". Studies have shown that society sees people with epilepsy as "nervy", highly strung, aggressive or withdrawn. There is not, however, a general view of an epileptic "identity". Whilst it has been shown that not all people with epilepsy feel discriminated against (stigmatised), many do. The relationship between the severity of seizures and the perception of stigma has been shown to be related to other characteristics in the individual with epilepsy, such as the perception of employment discrimination, the perception of limitations imposed by the disorder and the extent of the individual's education. If stigma does exist, why should it? It may well be that people with epilepsy threaten the social order. Why might this be?

One view is that there may be a prejudice against epilepsy based on a fear that the epileptic is liable to a sudden and unpredictable loss of body control, of "going berserk". Another view is that each fit represents a loss of control which in turn suggests that the individual cannot be relied upon. If people with epilepsy cannot be relied upon and

cannot be cured, then they should be set apart (isolated), so the world seems to think.

SECTION 5 BELIEFS, MYTHS AND MISUNDERSTANDING

To be successful in communicating with the patient and their family, you need to have some idea of their background and beliefs. There are many beliefs which make it difficult for families to seek medical treatment and these must not be ignored, nor must the family be driven away or blamed because of them. Rather they must be recognised and ways found to work around them:

- *If the patient is burned by a fire they cannot be treated*: this is not true from a medical stand-point and tends to come from traditional healers who say that such patients are more difficult for them to treat
- *If the patient is cut by the traditional healer (nyora in Shona) they must not take medicines*: regular taking of antiepileptic medication is important to control seizures. Stress to the family that even if they take the patient to the traditional healer, they must continue with the medicine regardless.
- *Epilepsy can be caught from the patient's saliva*: this is not the case; epilepsy is not an infectious disease
- *Epilepsy is caused by evil spirits and witchcraft*: this is a common belief in some communities and is difficult to overcome.
- *People with epilepsy are mad:* Epilepsy is not a mental illness. However some epileptic patients present with symptoms that mimic mental illness or confusion.

SECTION 6 LIFESTYLE ISSUES

It is not helpful to provide a long list of do's and don'ts for people with epilepsy. The majority of problems can be solved with commonsense, bearing in mind that most people have infrequent seizures, while others are more severely affected.

Fires and hot areas
Fires are a major concern for people with epilepsy. It may result in serious burns and even death. People with epilepsy should not sleep too close to an open fire. It is advisable to have all fires protected. Extremely hot areas cause by irons, elements, machines and many other things must be avoided for people with uncontrolled epilepsy.

School
A person with epilepsy should not be prevented from attending school. In most cases there is no need for special education. There is need for the school, teacher, health workers, family and person with epilepsy to work together to overcome any challenges.

Water bodies
Water presents a big challenge to people with epilepsy as it may result in drowning. Water in wells, tubs, swimming pools and deep stagnant and flowing water must be

avoided for people with epilepsy which is not well controlled.

Swimming
People with epilepsy should never swim alone, and the companion should know that the person has epilepsy and what to do if a seizure should occur.

Bathing
Showering is preferable to bathing, but if the individual wishes to have a bath, they should not be left alone in the house.

Bicycle riding
The person with epilepsy who is not having frequent seizures can ride a bicycle, but should wear a helmet.

Climbing
Some people with epilepsy may have a phobia or fear of heights. Mountain climbing for example should probably be avoided.

Cooking
There is always concern that people with epilepsy might have a seizure whilst at the stove or at the open fire. For the individual with quite frequent seizures it would be wise to invest in a microwave cooker, if that is possible or affordable. It is also advisable to use protected fires or stoves.

Driving
Road accidents claim several lives. It is therefore prudent that any person with a seizure disorder informs the Vehicle Inspection Department when they want a licence or at the time they start having epilepsy even if they already have a licence. This applies even for a single seizure. In the UK, in such a case, the licence is withdrawn and only reissued after a year without a seizure or aura. Those who continue to drive or apply for a licence silently are committing an offence. In the UK, in the event of an accident, the insurance is invalidated if one had not disclosed. The general rule is that individuals need to be seizure free for one year prior to obtaining a private driving licence. Further seizures even after obtaining the licence will result in it being withdrawn. When applying, it is necessary to give evidence from hospital or doctor and the issuing office may request this. To drive heavy or passenger vehicles, minimum seizure free period is 10 years in UK. Seizure free means no aura or actual seizure. Exceptions may be given where these happen during sleep. Where the person feels unfairly treated, they must approach the courts. In Zimbabwe, when applying for a driver's licence one has to disclose whether they have epilepsy. The procedures are currently not clear on what happens to those with epilepsy.

Employment
Because of the nature of the condition, some occupations are simply not suitable for people with epilepsy e.g. driving a public transport vehicle, working with heavy or dangerous machinery or working at heights. In the UK, people with epilepsy are by law prohibited from becoming pilots, ambulance drivers, taxi drivers, train drivers, merchant

seaman, army, fire brigade or police. The possibility of sustaining an injury during a seizure and that of causing harm to others needs to be considered. Apart from that, people with epilepsy can do anything that anyone else can do and the discrimination often encountered in the workplace is unjustified. When applying for a job, it is best to mention about epilepsy when asked. If asked by a form, this may be left blank or indicate this shall be discussed in interview. The best point to mention about epilepsy is just before accepting the job or in final interview. It is best to disclose to the employer than having them find out on their own. Telling a workmate may help so that they may administer first aid.

Sleep deprivation

Sleep deprivation is a strong seizure provoking factor in all age groups. It is important for people with epilepsy to get reasonable amounts of sleep and, for example, if they are expecting a late night, to have a nap during the day. This is especially important for mothers with epilepsy with infants who wake in the night and during adolescence. Spouses should be made aware of this. Normally people are deprived of sleep due to worship, fasting, work, funerals, entertainment and other reasons.

Alcohol

Drugs and alcohol are not good for people with epilepsy. People with epilepsy should drink alcohol modestly if they choose to drink, as it will increase drowsiness and may provoke seizures. Otherwise, it is recommended not to take alcohol.

Stress

There is little evidence that epilepsy starts as a result of stress, but there is a lot of evidence that stress makes seizures more frequent. As a general rule, stress associated seizures do not respond to more medication. In fact, increasing the dose may increase drowsiness and decrease functioning which in turn increases the stress and makes the seizures worse. Hence the need for relaxation therapies.

SECTION 7 ADMINISTRATION OF EPILEPSY SERVICES

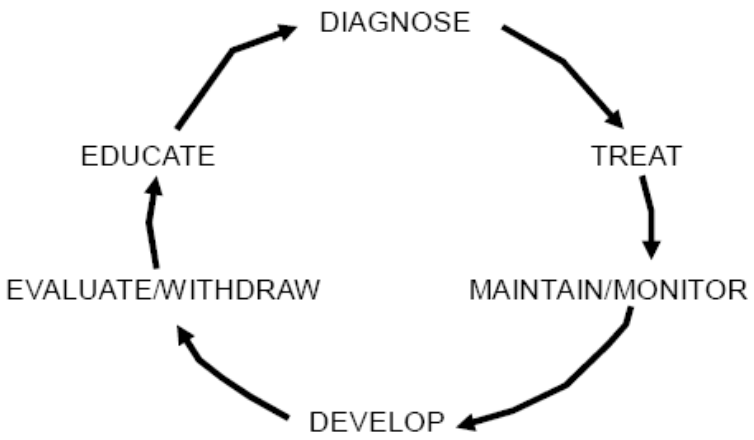
Most health workers are managing health services and the information below is best for you. The Epilepsy Support Foundation's model for management of epilepsy is as follows:

- Educate the public about epilepsy, publicize that epilepsy is treatable and treatment is available. Ensure adequate supplies of drugs and treatment workers. Ensure information in understandable language in fliers, pamphlets, banners, books, billboards etc for the public and professionals.
- Educate those who come for treatment about epilepsy, diagnosis and treatment and related issues.
- Ensure adequate diagnosis clinically and with the EEG for every patient unless otherwise.
- Start treatment with phenobarbitone because it is cheaper. Mono-therapy should be encouraged to lessen cost and side effects.

- Treatment should start at primary care level and referred with adequate diagnosis notes only where necessary e.g. when patients do not respond to maximum doses of major drugs.
- Keep patient records securely and safely and always have the diagnosis and treatment record for each patient and avoid them carrying their information as it can easily get lost.
- Have a register for new patients each year and close it at the end of the year with totals.
- Have another register for re-attendances each year and close it with totals at the end of the year.
- Ensure each patient has a seizure diary to indicate the dates of seizures, time, what they were doing, possible trigger, length and description of seizure. and its recorded and communicated to the health worker.
- Treat all patients and supply drugs at no charge.
- Ensure each patient has a booklet or card, which is dated and recorded each time they see a health or social care professional and next date clearly labeled. Each patient should also have a seizure record diary or can use their patient booklet from the back.
- Ensure there are monthly review clinics with a Doctor and that patient always sees one health worker if possible.
- Ensure patients are withdrawn from medication at least after 2 years after treatment by referring them to a doctor or specialist. Mostly those who would have been seizure free for this period and without neurological signs or symptoms, unacceptable behaviour change or adverse reaction to drugs may qualify to withdraw. It is expected that for above 70% patients, at this time they would have been fully treated and a withdrawal plan must be worked out. However, a good number may need to remain on medication for longer. Keeping people on medication when in actual fact they can be withdrawn may reduce their quality of life when they have a chance to lead a life free of medication.
- Provide mobile clinics to reach those without transport money, the disabled, the aged and others.
- Work with other departments like Social Services, non-government organisations, community programmes, private sectors, traditional institutions and many others to improve awareness and provide basic needs.
- Research and use newer diagnosis methods, drugs (where approved feasible) and social management techniques like group work.
    - It is important to supply epileptic patients with at least a month's supply of phenobarbitone. If they have to walk 15 km to collect 3 days' supply they will not come to the clinic often. Therefore you should order enough phenobarbitone tablets for all the epileptic patients in your area, and practice good stock control to always have adequate unexpired stocks.
- Blood level monitoring of AEDs was very popular in the 1980’s, but it has become apparent that this has been overdone. It is not easily available in Zimbabwe and probably the only AED worth measuring is phenytoin as it may be difficult to find the right dose for any one patient. Therapeutic drug monitoring may on occasion be useful with carbamazepine.
- Government takes the overall responsibility over the welfare of people with

epilepsy since it is a chronic condition and often costly to manage. Non-government agencies complement government effort by filling the gaps and advocating for those gaps to be covered by government.

This model can be summarized by the following framework:



The six stage epilepsy management framework: Epilepsy Support Foundation.

Figure 8 Epilepsy management framework

Notes: Epilepsy education is important since it helps the individual, their family and society to appreciate treatment. Diagnosis should be thorough and all treatment options must be explored, including surgery where feasible. At this stage, availability of medication must be ensured. To deal with side effects and compliance, monitoring should be ensured. Evaluation precedes withdrawal and includes diagnostic methods. At the 'develop stage' the patient, the family, the community, services, professionals and all stakeholders must be enhanced to deal with epilepsy. The individual needs skills to enable them to be independent socially and economically. The stages are interlinked and may happen at once.

Chapter 3 EPILEPSY IN ZIMBABWE

Rugare J. Mugumbate

All health and allied workers must know epilepsy services available in Zimbabwe. They should know who their providers are and should be able to provide information for the benefit of their patients. Some of them are provided in this chapter. A directory of these and related services is provided at the end.

SECTION 1 GOVERNMENT SERVICES

Ministry of Health and Child Welfare

Epilepsy in Zimbabwe falls under this Ministry. It is directly under the Mental Health Department. This department is headed by the Deputy Director who reports to the Principal Director for Policy and Planning. The Principal Director reports to the Secretary for Health who in turn reports to the Minister. The Deputy Director-Mental Health normally has subordinates in the form of the Mental Health Officers. There is a supporting team of various professionals to this department. At provincial level, the Provincial Mental Health Coordinator heads mental health issues, with a District Mental Health Coordinator and at community level, the Nurse-In-Charge. Psychiatric nurse practitioners are to be found at every central, provincial, psychiatric hospital or at local authority level according to the Mental Health Act. The Deputy Director and a Chief Government Psychiatrist advise the Minister on mental health issues.

The Mental Health Department's mandate is stated in the Mental Health Act (1996), Mental Health Regulations (1999) and the Mental Health Policy (which succeeded the Zimbabwe National Mental Health plan of Action). These 2 instruments are silent on epilepsy, seizure disorders or neurological conditions but rather stress mental disorders (psychosis, schizophrenia, alcoholism etc). The policy 'provide(s) a framework within which mental health programmes, projects and activities can be designed, implemented, monitored and evaluated…'

This department is one of the least funded within the Ministry. The WHO recommends that this department must have at least 15% of the national health budget. However, this has never been achieved in Zimbabwe.

The Ministry runs psychiatric units where people with acute problems related to epilepsy are admitted and rehabilitated together with those with psychosis and related mental health challenges. The major ones being the Annex at Parirenyatwa, Harare Hospital and Ingustheni in Bulawayo.

At each hospital the government has a psychiatric department where people with epilepsy are normally treated by personnel trained in psychiatry. This presents mismanagement possibilities. In previously reported cases, patients with epilepsy were treated as psychiatric patients and psychotropic drugs were administered. This may result in death or acceleration of the problems related to seizures.

At primary health centres epilepsy is mainly managed by psychiatric nurses and general nurses with limited training on this condition.

In the community, community-based health systems support the national health system. However, home based health workers have inadequate information about epilepsy.

On another level, the Ministry trains nurses in Zimbabwe at all central hospitals and provincial health centres. It supervises nurse training at mission hospitals. Of special

note is the training of psychiatric nurses at Ingustheni Psychiatric Hospital in Bulawayo. The Ministry also trains Rehabilitation Technicians at Marondera Hospital.

The Ministry has a role to ensure medication is available in health centers and is administered according to guidelines provided in its essential drugs list in Zimbabwe (EDLIZ). Copies of EDLIZ may be obtained from the Ministry's Pharmacy Services. In most cases though, there is inadequate supply of anti-epilepsy medication and it is the duty of health workers to advocate for adequate supplies.

The Ministry has another department responsible for health education. When health workers request IEC material, they should also request some on epilepsy.

Social Services Department
This department administers various instruments that improve the life of disadvantaged groups in our society. Currently, it has these programmes among others in relation to people with epilepsy:

- Assisted medical treatment which is given in the form of a certificate valid for one year and renewable. This is normally called an AMTO-assisted medical treatment order. This is proof that government will pay for treatment services given to the person at a government hospital. It is obtained after means testing-interviews to find out how needy one is-carried out at a social welfare department.
- Children below 5 years and the elderly above 65 years of age do not pay at government hospitals. This applies to all citizens.
- Payment of rentals or rates people of limited means after vetting (means testing).
- Payment of schools fees through the BEAM-basic education assistance module-to needy children in school.
- Provision of bus warrants to travel to hospital or rehabilitation centres.
- Public assistance through various programmes including a monthly $20 grant.
- Department of Disability Affairs
- They coordinate the National Disability Board which represents the interests of people with disabilities in government.

The support from this department is often very small and in most cases not available. There is great competition for social welfare benefits. It is important that health workers know about these services so that they are able to refer appropriately. The same ministry is responsible for supervising welfare institutions, among them homes and rehabilitation centres and thus will be able to provide information to health workers about institutions that can help people with epilepsy. The ministry runs special rehabilitation schools offering skills and courses to people with disabilities including people with epilepsy like Ruwa Rehabilitation Centre.

Ministry of Education, Sports and Culture
This ministry runs schools in Zimbabwe. It has a psychological services department that evaluates children with epilepsy. This is helpful to ensure that they get schools suitable for them. Most children with epilepsy learn in mainstream but a sizeable number require special schools. It is recommended that for every child with epilepsy, they get a psychologist's evaluation. This will improve their learning even if they are in mainstream.

The Ministry also supervises special schools. These come in two forms. There are special classes within mainstream schools. Then there are special schools. Most special schools are run by charitable trusts like the ZIMCARE. Other schools have boarding facilities yet others offer day service only.

The Ministry trains special education teachers at United College of Education. The school often is short of literature to adequately train special teachers on the needs of children with epilepsy.

Parirenyatwa Hospital-Epilepsy Clinic and EEG Department
Of special note is the epilepsy clinic/neurology clinic running every Tuesday. These are run by a specialist neurologist. With an EEG department just near this clinic, it represents the best we have so far to epilepsy management in the country. It is also at the same site with the medical school. Patients with epilepsy referred from district hospitals normally go to this clinic. It is therefore important for health workers to know how it functions.

Patients are diagnosed at primary health level and treated there. Those who, by nature of their condition, can't be treated at primary level are referred to the district or provincial hospital. From this secondary level, they are referred to tertiary level for further management if need be. At the ESF we believe if seizures have not stopped each person with epilepsy must reach tertiary level as indicated on the treatment chart. The same applies even if seizures have stopped but there are side effects. At the tertiary level, each patient normally ends up having an EEG or CT scan taken. The EEG costs $50 and the scan costs $150. There is normally a $10 registration fee at the hospital. Those over 65 years and children under 5 years do not pay the registration fee. Those with the social welfare treatment order may not pay for all fees, including EEG and scan.

For a patient to be attended at the epilepsy clinic, they must have their treatment records and inside it must indicate that they have been referred from a lower level. Booking may be done from the clinic or home. Call 04-701555 and ask for OPD then ask to be booked at epilepsy clinic. They will give the patient a date to come. Before the time to see the doctor, ensure you register at the hospital and obtain a patient number and make necessary payments. Encourage patients to comply with treatment, including having tests done, coming for reviews and taking medication.

There is a social work department for counseling, home visits and reference to social welfare or other supporting organizations within the hospital. People with epilepsy must utilize the department.

Parliamentary Committee on Health and Social Services
Parliament has a committee to deal with health and social services. Issues related to epilepsy for parliamentarians may be addressed through this committee.

Health Advisor to President and Cabinet
It is worth noting that in Zimbabwe we have a Health Advisor to the President and Cabinet. Currently, Dr. Timothy Stamps, former Health Minister occupies this position.

The role of this Department, which falls under the Office of the President and Cabinet, is to give advice to the President and Ministers on health issues.

SECTION 2 EPILEPSY SUPPORT FOUNDATION (ESF)

The ESF wishes to see every person with epilepsy diagnosed, treated, rehabilitated and with minimum income required to meet basic needs. The consequences of untreatable epilepsy are severe: death, disability, poor quality of life, stigma, exclusion, discrimination, isolation, no opportunities and many others. The major strategies used to achieve this:

- Seeking charitable and development funds to provide treatment, offer social assistance and build income generating capacity for disadvantaged people with epilepsy.
- Advocating for more government intervention in epilepsy management mainly through provision of medication for free or at affordable prices and ensuring availability of adequately trained personnel.
- Lobbying for affordable private sector services especially diagnosis and treatment.

History

The ESF is a registered (1190) voluntary welfare organization established in 1990 to support the welfare of people living with epilepsy through treatment, education, awareness advocacy, networking, medication, diagnosis, counseling and social support services. The ESF founding member Nicholas George lived more than 40 years of his life with epilepsy. At 12 years, Nicholas was forced out of a government school because of epilepsy. He inspired laypersons and professionals to form the association in 1990. The ESF now has regional branches and support groups across the country. It offers membership to people living with epilepsy (PLWE), friends, relatives and corporate membership to organizations. The Foundation has an epilepsy centre in Hatfield, Harare - the Nicholas Arthur George Epilepsy Centre offering counseling, social, nursing and fundraising services. The Foundation is a member of the International Bureau for Epilepsy (IBE) and its Regional Committee in Africa and works closely with the International League Against Epilepsy (ILAE) through its local chapter, the Zimbabwe League Against Epilepsy (ZLAE). The ESF cooperates closely with government and non-government agencies in Zimbabwe.

Vision

A better quality of life for all people living with epilepsy in Zimbabwe.

Mission

The Foundation endeavors to capacitate people living with epilepsy to overcome the many challenges that they encounter by assisting them to secure diagnosis, treatment, social assistance, education and awareness and empowerment activities.

Services, activities and programmes

Social assistance

The Foundation believes that epilepsy as a chronic condition is costly to manage for individuals and their families. Although it is the responsibility of government to cater for people of limited means, our government has not been able to adequately do so. The result has been unmet medical and social needs for the majority of people with epilepsy through a lack of resources or ignorance. The Foundation fills this gap by mobilizing charity resources and applying them to meet the needs of people with epilepsy directly or indirectly. Among other things, the Foundation freely treat epilepsy at its centre with nurses and doctors, gives free medication, trains professionals, semi-professional and community members and also tries to meet the non-medical basic needs like payment of school fees, food handouts, training for income generating projects and initiating them to give people with epilepsy income.

Epilepsy education, training and awareness campaigns

Most people do not know the true facts about epilepsy and so they do not seek or promote medical treatment. Therefore, education and awareness programmes are targeted at families, PLWE, teachers, employers, government and the public. When people know the facts about epilepsy, PLWE will find a supportive environment to rehabilitate them and become productive and valuable citizens for socio-economic development. Some of the campaigns include the commemoration of the national epilepsy awareness week, public education, and production of materials and publications to raise awareness and media coverage. We have a library with epilepsy resources (books, magazines, cds and cassettes) and health workers can borrow material or request more pamphlets, fliers and posters.

Medical support through epilepsy clinic

Diagnosis, treatment and rehabilitation are core precedents for a better quality of life for all PLWE. At the centre we offer these with the support of full time nurses and volunteer doctors. One focus is the effectiveness of medical care, emphasizing the importance of drug compliance if medication is to be effective. Another focus area is the reduction of side effects of medication. It is important to note that the Foundation acquired an EEG machine with support from the British Embassy in 2010 and it will be operational towards the end of 2010.

Social work (Counselling, Psycho-Social support and Referrals)

Counseling, support groups, education and awareness provide a social environment that is conducive for the rehabilitation plan. Family support services are also aimed at ensuring that families are empowered to help through the rehabilitation process. Needy clients are interviewed and appropriately referred (where we can not assist ourselves) to assisting organisations, including government agencies like social welfare.

Research, Advocacy and Lobbying

Research into medical, social, economic, psychological and educational areas will ensure that there are research-based facts to lobby and advocate for better services in the areas of policy development and implementation, drugs availability and affordability, social services and inclusion for people with epilepsy.

Education, Training and Employment

The Foundation ensures that the needs of children with special learning needs are met, vocational training for young persons with epilepsy is available and suitable employment for people living with epilepsy is available.

Networking, Fundraising and Membership
The Foundation seeks affiliation with other organisations within and outside the country to strengthen organizational development and improve the Foundation's capacity to assist PLWE. Fundraising is an important component in ensuring sustainability of the program. Membership is offered to people with epilepsy, caregivers, members of the community, corporate and organizations.

Future plans
Development of the Epilepsy Centre in Hatfield, Harare into a multi-disciplined epilepsy centre offering medical and social services and opening of epilepsy resource centres in all provinces of Zimbabwe.

SECTION 3 ZIMBABWE LEAGUE AGAINST EPILEPSY (ZLAE)

This is the local chapter of the ILAE. It is composed of professionals mainly from the medical field and those from other sectors-social, economic, business and related professions. Among its founders were Professors L. Levy and J. Mielke who worked hard to improve epilepsy service in Zimbabwe. Professor Levy was the first neurosurgeon in the country around 1950 and among one of the first ones in Africa. He treated the first epilepsy patient in Zimbabwe. Among his first patients was Nicholas George, the man who is credited with founding the ESF in 1990. The League is responsible for advancing epilepsy treatment, research and training. It was instrumental in the Demonstration Project (Hwedza) in 1997 under the Global Campaign Against Epilepsy (GCAE), an initiative of the IBE, WHO and ILAE. The League currently operates from the Epilepsy Centre.

SECTION 4 EPILEPSY RESOURCE CENTRE ZIMBABWE (ERCZ)

History (Nhoroondo)

The Epilepsy Resource Centre of Zimbabwe (ERCZ) was formed in 2018 and registered in 2019 after the founders realized a gap in services and support for people with epilepsy in Zimbabwe in general and in Chitungwiza and surrounding areas in particular. In 2019 the ERCZ became a member of the Epilepsy Alliance Africa (EAA).

Our Aim (Vavariro Yedu)

- To address the barriers that prevent people with epilepsy from living a seizure free life (Kubvisa matambudziko anoita kuti vane pfari varambe vachigwinha).

Our Work (Basa Redu)

- Research, evidence use and promotion (Tsvakurudzo)
- Information generation, dissemination and training (Ruzivo)
- Social work and support services (Rubatsiro)
- Medical support services (Rubatsiro rwezvekurapwa)
-

Objectives (Zvatinoita)

The objectives of the organisation are:

1. Create a forum for organisations, support groups and people with epilepsy to share ideas;
2. Provide resources to people affected by epilepsy to enable them to overcome challenges associated with the condition;
3. Support the collaboration, upskilling and networking of professionals dealing with epilepsy;
4. Capacity building of organisations and support groups for persons with epilepsy;
5. Support the collaboration of medical and non-medical professionals to promote the use of research and evidence-based treatment of epilepsy in Zimbabwe;
6. Advocate for legislation and policies which advance the rights and interests of persons with epilepsy in Zimbabwe.

Social Work (Kushanda neVanhu)

Our social work services are:

- Social Assessment and Support (Bvunziridzo neRubatsiro)
- Community Work (Kushanda neNharaunda)
- Counselling (Nhaurirano)
- Research (Tsvakurudzo)
- Awareness (Shambadzo)
- Training (Dzidziso)

Research (Tsvakurudzo)

We do research in collaboration with investigators from different institutions on:

- Epilepsy and employment
- Children with epilepsy
- Employment and epilepsy
- Epilepsy policy

Research teams

Children and Epilepsy Research Alliance (CHERA)

Research internships available for students doing honours, masters and PhD research and those who want to further their research skills after graduation.

Medical Support (Batsiro yekuRapwa)

Our medical support services are:

- Training health workers (Kudzidzisa vashandi veutano)

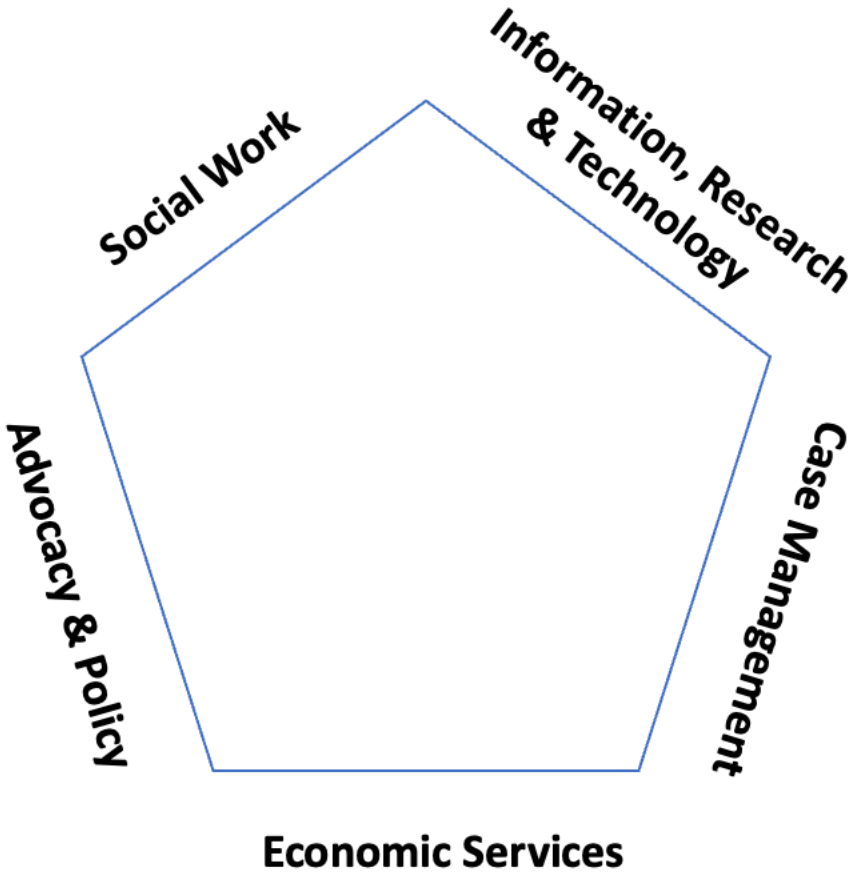


Figure 9 ERCZ model of managing epilepsy

SECTION 5 OTHER PVOs, HOMES & REHABILITATION CENTRES

Zimbabwe has a number of homes offering specialist services. There is no home or centre that is specifically dedicated to epilepsy. Although it is now strongly recommended to use community approaches to providing care, other homes are offering respite and therefore play a significant role. One such home is the Tose in Prospect Harare offering a residential facility to children with severe intellectual and physical impairments. These include children with epilepsy although most of them have multiple conditions. Other institutions include Cheshire Zimbabwe Trust in Westwood Harare, Larche in Waterfalls, Zimcare Trust Schools, King George IV in Bulawayo, St Giles in Harare, Danhiko School, Jairos Jiri and many others.

SECTION 6 LOCAL COUNCILS AND MUNICIPALITIES

They run clinics and most of them treat people with epilepsy for free. This is important because, being a chronic condition, epilepsy can drain all family resources. Without resources, people with epilepsy will end up not getting treatment. Most have health departments or committees. These are encouraged to ensure that they prioritize epilepsy treatment and awareness. Some councils have special facilities, rates and services for people with epilepsy and health workers need to know these so that their patients or clients with epilepsy benefit from such services.

SECTION 7 UNIVERSITY OF ZIMBABWE (UZ)

College of Health Sciences (formerly Medical School)
This is the premier medical training institution in the country. Of particular interest is training in neurology and neurosurgery. These are critical in epilepsy management. However, currently Zimbabwe has a limited number of neurosurgeons (maybe less than 7) and neurologists (may be only 1). The school runs numerous other courses at graduate and postgraduate level and health workers must find out their prospectus and further their studies in areas promoting epilepsy management. Of special note is the training of psychiatrists. These professionals are currently doing a lot of tertiary treatment for epilepsy patients. The college might not have programmes tailor made to epilepsy but other external universities and hospitals do. It is better to find out about these. The college is located at Parirenyatwa Hospital.

School of Social Work
This arm of the University of Zimbabwe trains social workers in areas like rehabilitation, clinical social services, community health, social policy and many others.

SECTION 8 PRIVATE SECTOR INCLUDING PHAMACEUTICAL COMPANIES

This is composed of businesses, parastatals and individuals. These fund welfare initiatives and even support government programmes. Pharmaceutical companies are some of them. In your area of jurisdiction, you need to approach them to support people with epilepsy who require assistance. Often, they are very socially responsible. Of importance are private surgeries. One such is the Gelfand Medical Centre which has an EEG and CT scan. It was founded by the late Professor Levy.

These play a significant role in manufacturing, importing or distributing drugs. For the government, this is done by National Pharmacy (NatPharm) located at Harare Hospital. Varichem currently manufactures phenobarbitone together with CAPS. CAPS also manufactures carbamazepine. Much of our anti-epilepsy drugs are imported from

Europe and India. Some African countries do produce these drugs and they are often found in some of our pharmacies.

SECTION 9 EPILEPSY ALLIANCE AFRICA (EAA)

It is with great pleasure that we introduce you to Epilepsy Alliance Africa (EAA). EAA was formed to bring together all partners fighting seizures and stigma on the African continent, with the theme Together, WE CAN GO FAR, motivated by the African proverb *If you want to go fast go alone if you want to go far go together*.

Purpose
The EAA is a pan-African alliance of individuals, families, institutions, organisations, and groups interested in preventing and addressing challenges caused by epilepsy on the African continent.

Objectives and activities
1. Engage the African Union (AU), regional and sub-regional organisations with a view to improve epilepsy policies and programs.
2. Engage in conversation and dialogue with governments in regard to epilepsy matters and assist members with skills to advocate their governments for improved epilepsy policies and services.
3. Become a reference group for epilepsy issues on the continent.
4. Engage international partners interested in epilepsy.
5. Become a leading voice for epilepsy on the continent.
6. Develop training programs to capacitate alliance members.
7. Initiate regular meetings online or face-to-face.
8. Mobilise resources.
9. Promote meetings, seminars, symposia, webinars and conferences at local, national and regional level.

Values
1. Unity of purpose across all the sub-regions of the continent.
2. No separation of programs for persons with epilepsy, medical and social professionals.
3. Homegrown solutions.
4. Independence.
5. Inclusion and participation.
6. Effective and sustainable partnerships.

Main services
1. Tele-health: Free weekly clinic available to people with epilepsy from any African country
2. Tele-education and training: Webinars for professionals, advocates and people with epilepsy. This includes nurse training.
3. Research, documentation and information on epilepsy: We promote, support, carry out research and publish on epilepsy related topics. We coordinate the Global South Epilepsy Research Group (GSERG).

4. Advocacy and policy: We advocate for improved and new policies for epilepsy on the African continent and help members achieve the same in their countries
5. Capacity building and coordination: We support epilepsy associations and their leaders in Africa to maximise their potential.
6. African Day Indaba: 25 May
7. Conference: annual epilepsy conference in June each
8. Awareness: annual epilepsy awareness week (Stripes Week) 3rd week of September
9. Voice Indaba – held 2 times a year to recognise the voices of people with epilepsy and providers of care. Organised by people with epilepsy.
10. Annual survey on the status of epilepsy in Africa

Members ('Alliancees')

1. Organisations, trusts, clubs or groups, including online groups interested in epilepsy, disability and health.
2. Associations of people with epilepsy or families of people with epilepsy.
3. Professional associations.
4. Institutions like government department, schools, health units, centres, clinics or facilities, research centres or universities.
5. Partners including non-government organisations, international organisations, development organisations, corporates and funders.

SECTION 10 WORLD HEALTH ORGANIZATION (WHO)

The WHO is an important partner in the fight against epilepsy at local and global level. It gives advice on crucial issues related to epilepsy. It gives resources ranging from medication to funds for epilepsy awareness. Its partnership with the IBE and ILAE, the WHO has resulted in the formulation of a global strategy against epilepsy called the Global Campaign Against Epilepsy (GCAE). More information about this campaign is appended. The WHO also has a library at its offices.

SECTION 11 GAPS IN THE MANAGEMENT OF EPILEPSY IN ZIMBABWE

Despite the availability of all these role players in managing epilepsy, several gaps still remain. These are indicated below:

Low funding

Both government and non-government programmes to deal with epilepsy suffer from a chronic shortage of resources, financial, human or otherwise. The Mental Health Department should be afforded the capacity to play its oversight role in the management of epilepsy. Organisations like the Epilepsy Support Foundation and the Zimbabwe League Against Epilepsy must have their capacity enhanced to deal with epilepsy. To

win the fight against epilepsy in Zimbabwe, resources must be made available for medication, training, supervision, research, documentation and personnel.

Medication
Medication has not been available in adequate quantities in public facilities. This is a challenge given that over 75% of people with epilepsy live in poverty and can not manage to buy medicines.

Free treatment
Free treatment has remained a dream for people with epilepsy. This has resulted in non-compliance.

Community based services
Community based health initiatives have failed to reach people with epilepsy. There is need for home based care givers to be trained in community based epilepsy management.

Nurses training
Although the EDLIZ firmly give nurses authority to treat generalised epilepsy, it indicates that they should be appropriately trained. This training has not been adequate and it should be extended to all nurses who need it. Although some nursing schools have strengthened their training in epilepsy, some are still to respond firmly. Those nurses trained years back before EDLIZ introduced epilepsy management by nurses, must surely be given the opportunity to train adequately. Nurses are critical in the management of epilepsy and if they are adequately trained, they will treat successfully the majority of people with epilepsy and refer appropriately for secondary and specialist treatments.

Doctors training
There is need for more focused training for doctors to manage epilepsy. This recommendation has been made by doctors at various forums.

Specialist services
More neurologist, neurosurgeons, EEG technicians and related specialist professionals are needed to provide specialized services.

Pregnancy
There is need for services aimed at addressing the challenges of pregnant women with epilepsy. In other countries they have a register for pregnant women with epilepsy. This helps to monitor side effects of medications to the mother and child as well as to deal with complications. The ESF has found out that although it is an international recommendation that pregnant women with epilepsy should take folic acid as prescribed, in Zimbabwe only a few women are lucky to get it. This may mean that more children of parents with epilepsy are susceptible to birth defects.

Neurologists
With only 1 neurologist known to be working in Zimbabwe at the publication of this book, specialist services for patients with epilepsy is a challenge.

Diagnostic machines
EEG machines and CT scans are not adequately in Zimbabwe. This affect treatment at secondary and tertiary levels.

Literature
Literature is a key element in managing epilepsy. Books are critical for the training of health workers. Without adequate books learning becomes difficult. Nurses, teachers, social workers, rehabilitation workers, doctors and many other workers in this field require adequate printed, audio and related material. Locally produced literature on epilepsy is rare.

Awareness
There is need for more awareness to reduce stigma, misunderstanding, myths and exclusion. If communities understand epilepsy, there will be acceptance, understanding, inclusion and opportunities will be equal and available to everyone, including PWE.

Unified approach
There is need for an approach that involves all stakeholders like the GCAE. Such campaigns have worked well for HIV and AIDS because resources were unlocked.

A neurological health approach
Zimbabwe follows a mental health approach to deal with epilepsy yet other countries, including many in Africa, deal with epilepsy as a neurological condition. People with epilepsy should not be treated as psychiatric patients but it should be clear that they have a physical brain condition although a small percentage may also become psychiatric patients.

Policy Framework
It is quite evident that both the Mental Health Act and Mental Health Policy were crafted for mental illnesses and neurological conditions have no place in them whatsoever. Ultimately, it is important for Zimbabwe to have a law aimed at improving the quality for life for people with epilepsy. This may be Epilepsy or Neurological Health Act and a Policy.

Rural areas
The most disadvantaged people with epilepsy are in the rural areas and the most ignorant people about epilepsy are possibly in the rural areas. It follows without saying that the rural inhabitants in Zimbabwe should be prioritised in improving the quality of life of PWE.

DIRECTORY OF EPILEPSY SERVICE PROVIDERS

Epilepsy Support Foundation (PVO11/90): 43 St. David Road, Hatfield, Zimbabwe, Cellphones: 0773595241/5/6/8 Tel: 04-2922806 04-571225, Fax: 04-571233, email: epilepsyzimbabwe@gmail.com

Epilepsy Resource Centre Zimbabwe: Number 12899, Unit N, Seke, Chitungwiza, Zimbabwe, Mobile/WhatsApp, 0781198841; 0713079544, Facebook https://www.facebook.com/pfari.epilepsy, @pfari.epilepsy, Email, pfari.epilepsy@gmail.com, Website www.ercz.africasocialwork.net

Epilepsy Alliance Africa (EAA): For awareness support through Stripes Week, telehealth and networking and webinars. Phone/WhatsApp: +250784115806, Email: epilepsyallianceafrica@gmail.com, Instagram: epilepsyallianceafric, YouTube: Epilepsy Alliance Africa EAA, Twitter: AfricaEpilepsy, Facebook: Epilepsy Alliance Africa, Website www.epilepsyalliance.africasocialwork.net

Ministry of Health and Child Welfare: Kaguvi Building Cnr 4th Street/Central Avenue P. O. Box CY1122 Causeway, Harare. Tel: 04-798558/70/85/44/69, 04-730011-19 Mental Health Dept. 3rd Floor Tel: 04-723147 Fax 04-700960

Zimbabwe League against Epilepsy (ZLAE): The Coordinator, 43 St. David Road, Hatfield, Zimbabwe, Cellphones: 0773595241 Tel: 04-2922806 04-571225, Fax: 04-571233, email: epilepsyzimbabwe@gmail.com

School of Social Work: Corner Chinhoyi and Grant Streets, Harare. Tel: 04-752965

Department of Social Development: Contact the nearest social services office in your district or the social work department at your hospital.

Parirenyatwa Hospital: Mazowe Street P. O. Box CY198 Causeway Harare. Tel: 04-701555-7 Epilepsy and Neurology Clinic: To book patients at epilepsy clinic ask for OPD then bookings.

Harare Hospital: Lobengula Road P. O. Box ST14 Southerton Harare Tel: 04-621111/4, 04-621100, 04-664601/2

Mpilo Hospital: P. O. Box 2096 Bulawayo Tel: 09-205078

United Bulawayo Hospitals: P. O. Box 958 Bulawayo Tel: 09-252111 Fax: 237284/250038

Zimbabwe National Association for Mental Health (ZIMNAHM): P. O. Box A196 Avondale Harare Tel: 04-731272, 04-728538 Fax: 04-792946 zimnahm@mweb.co.zw

Ingustheni Hospital P. O. Box 8363 Belmont Bulawayo Tel: 09-466463-5/472420/463413

Dr. Ngwende (Neurologist) 3rd Floor Medical Chambers, 60 Baines Avenue, Harare. Tel: 04-707111, 04-2911578, 0712866919, giftngwende@yahoo.co.uk

Dr Kandawasvika, Pediatric (Child) Neurologist, Suite 3, 37 Baines Avenue, Harare, +263 24 2790244, gwenkandawasvika@gmail.com

World Health Organisation (WHO) 82 Enterprise Road Highlands Harare Tel: 04-253730

APPENDIX 1 PHYSIOLOGY OF SEIZURES

In order to understand the process of electrical transmission within nerve cells, it is important to review the structure and function of a nerve. A nerve cell can be thought of as a tube, having an inner section, and bounded by a cell wall (membrane). Importantly, the chemical composition of the inside of the cell and the outside of the cell are very different. Specifically, there is a difference in the concentration of sodium and potassium salts, with sodium being much higher on the outside, and potassium being much higher on the inside. In a normal resting state, special pumps (called membrane pumps) are continually at work to maintain each salt in its proper location.

When a nerve is called upon to transmit an electrical signal, a sudden movement of these salts from one side of the cell's membrane to the other occurs. This movement spreads like a wave from one end of the nerve to the other, until it reaches the end. At this point, the nerve's signal may be transmitted to the next nerve cell either by a direct extension of this process, or, more commonly, by releasing a special chemical called a neurotransmitter.

According to Schachter (2006) some of the major neurotransmitters in the brain shut off or decrease brain electrical activity. They cause nerve cells to stop firing. These neurotransmitters are called "inhibitory" because they inhibit the activity of the cells. A neurotransmitter called GABA is the best-known example of this type. Other neurotransmitters stimulate or increase brain electrical activity. That is, they cause nerve cells to fire. These are described as "excitatory." Glutamate is an example of this type. According to one theory, epilepsy is caused by an imbalance between excitatory and inhibitory neurotransmitters. If the inhibitory neurotransmitters in your brain are not active enough, or if the excitatory ones are too active, you are more likely to have seizures. Many of the new medicines being developed to treat epilepsy try to influence these neurotransmitters. They try to increase the activity of the inhibitory ones, which turn cells off, or reduce the activity of the excitatory ones, which turn cells on. Either way, the idea is to have less uncontrolled electrical activity in your brain, and therefore fewer seizures.

Interestingly, certain areas of the brain are more likely than others to be the source of a seizure. These include the motor cortex (responsible for the initiation of body movement) and the temporal lobes (including a special deep area called the hippocampus, which is involved in memory). The reason for this likelihood may be that nerve cells in these areas are particularly sensitive to certain situations that can provoke abnormal electrical transmission. Examples include sensitivity to decreased oxygen levels, metabolic changes, and infection, any of which may lead to a seizure.

Many types of brain abnormalities can be responsible for producing seizure activity. Abnormal discharges may spread to other cells in a local area or to remote areas of the brain, resulting in intermittent disturbance in the brain's normal functions. Changes in brain biochemistry and communication between brain cells occur. These basic neurofunctional abnormalities that lead to epilepsy produce the clinical symptoms that are seen. In turn, recurrent seizures or prolonged seizures can cause injury to the brain. Seizures that last longer than 20 to 30 minutes can damage the brain's neurons. A

seizure is often divided into different parts. The aura is a period or warning prior to a seizure. Patients may experience unusual smells, visual symptoms, or feelings. The seizure itself is known as the ictus. The period of time after the seizure is called the postictal state. *Extracts from www.healthcommunities.com article by Stanley J. Swierzewski, M.D.*

APPENDIX 2 GENERIC AND BRAND NAMES OF DRUGS

Generic Names	Brand Names
acetazolamide	Diamox
acetazolomide modified release	Diamox SR
carbamazepine	Tegretol
carbamazepine modified release	Tegretol Retard
clobazam	Frisium
clonazepam	Rivotril
ethosuximide	Emeside; Zarontin
eslicarbazepine acetate	Zebinix
gabapentin	Neurontin
lacosamide	Vimpat
lamotrigine	Lamictal
levetiracetam	Keppra
oxcarbazepine	Trileptal
phenobarbital (phenobarbitone)	N/A
phenytoin	Epanutin
pregabalin	Lyrica
primidone	Mysoline
rufinamide	Inovelon
sodium valproate	Epilim; Episenta
sodium valproate modified release	Epilim Chrono Epilim Chronosphere
tiagabine	Gabitril
topiramate	Topamax
valproic acid	Convulex Depakote
vigabatrin	Sabril
zonisamide	Zonegran

Source: British National Formulary (*BNF*) Number 59 (March 2010). Published by the British Medical Association and the Royal Pharmaceutical Society of Great Britain. *Please note: not all these drugs are registered for use in Zimbabwe*

APPENDIX 3 GLOBAL CAMPAIGN AGAINST EPILEPSY (GCAE)

This is the worldwide project to deal with epilepsy. The most crucial thing about this campaign is that it brings together all the role players in epilepsy work discussed below. It was established in 1997 as a joint project of the World Health Organization (WHO), International League Against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE).

Objectives:

- Increase public and professional awareness of epilepsy as a universal, treatable brain disorder;
- Raise epilepsy to a new plane of acceptability in the public domain;
- Promote public and professional education about epilepsy;
- Identify the needs of people with epilepsy on a national and regional basis;
- Encourage governments and departments of health to address the needs of people with epilepsy including awareness, education, diagnosis, treatment, care, services, and prevention.

Mission statement:
To improve acceptability, treatment, services and prevention of epilepsy worldwide.

Campaign tactics:

- To generate Regional Declarations on Epilepsy, produce information on epilepsy for policy-makers, incorporate epilepsy care into National Health Plans, and facilitate the establishment of national organizations of professionals and lay persons who are dedicated to promoting the well-being of people with epilepsy;
- To help organize Demonstration Projects that illustrates good practice in the provision of epilepsy care. In Zimbabwe this project was carried out in Hwedza from 1997 to 2005 as one of the demonstration sites worldwide. The outcome is that epilepsy awareness improves treatment rates and treatment improves quality of life.

Campaign strategy:
Working along two parallel tracks, the Campaign will:

- Raise general awareness and understanding of epilepsy;
- Support Departments of Health in identifying needs and promoting education, training, treatment, services, research and prevention in their countries.

APPENDIX 4 HWEDZA-ZIMBABWE GCAE DEMONSTRATION PROJECT

Overall aims
The project's main aim was to demonstrate that it is possible to improve the quality of life of people with epilepsy in rural Zimbabwe by:

- Establishing the prevalence of epilepsy and its treatment gap in a rural area.
- Discerning the influence of epilepsy on the quality of life of people with epilepsy in such an area.
- Positively influencing the physical quality of life of these people with epilepsy through a pharmaco-economic intervention (ensuring availability and accessibly of medical care and medications).
- Positively influencing the social quality of life of these people with epilepsy through a psychosocial intervention (a health education campaign for health staff, patients and their families, and the public).

Methodology
The project consisted of three phases:

- Epidemiological survey
- Intervention to improve treatment
- Education

Epidemiological Survey
The questionnaire used for the prevalence survey was based on the survey used in the demonstration project for China. People identified as possibly having epilepsy were evaluated by Primary Health Care Workers at the local clinics and given a confirmatory diagnosis if appropriate. One of the principal investigators randomly reviewed a sample of those found to have epilepsy by the Primary Health Care Worker, as a quality assurance.

A rural community prevalence for epilepsy of 13.3/1,000 was found, which is similar to other African countries. A treatment gap of 93% confirmed clinical impressions. The vast majority of people with epilepsy in the district were not receiving treatment.

- Number of people randomly sampled: 6,274
- Number screened as possibly having epilepsy: 636
- Number screened as positive for epilepsy: 84
- Prevalence: 84/6274 (13.4/1000) or 1.34%
- Attendance before intervention: 83
- Attendance after intervention (2003): 198
- Previous treatment gap: 93.1%
- Treatment gap after intervention: 83.6%
- Increase in persons with epilepsy being treated: 138.5%
- Estimated reduction of persons with epilepsy not treated: 10.2%

Intervention to Improve Treatment
People found to have epilepsy were asked to fill out a questionnaire about their quality of life. In addition, interviews with people with epilepsy and their caregivers were conducted to correlate with the questionnaire results, and two focus group discussions were held.

Education
Primary healthcare nurses and environmental health technicians attended a one day workshop, which included sessions related to background knowledge, diagnosis, management of epilepsy, psychosocial issues and attitudes. Subsequently they were involved in public talks both in health centres and villages. The technicians trained village health workers (lay members in the community with an interest in health and health care) and supplied them with literature in the local language. The nurses and the district health education officer gave presentations in schools. In addition, a seminar was held with participation of one teacher from each school in the area, to enable this teacher to act as an epilepsy resource person for the school and for parents. Each of these teachers was asked to organise at least one activity related to epilepsy in the school (i.e. produce a play, speak at a public function, organise a competition, etc.).

Quality of Life (QOL) Survey
There were fewer responses for this study, as many people were not attending clinics due to two factors, which were the unavailability of medicines at most of the clinics and in some areas people had migrated due to the land reform program.

- PHC played a huge role because there were no doctors.
- Patients did not go to Hwedza Hospital or Harare where they were referred for further treatment because of cost
- Medication was not available at clinics
- It was not clear if the following had improved for patients:
    - Seizure frequency or severity
    - Side effects
    - Functional impact – improved work or not
    - Carer improvement as a result of treatment
    - Contribution to household and community
    - Relationships
    - Overall health
    - Future plans and ambitions
    - Standard of living

Conclusions
Four major conclusions were reached and shared with the government and the African and global community. (1) Training primary health care workers to diagnose epilepsy (generalised convulsive seizures) is effective and safe. In quality assurance visits by the principal investigator no patients were found to have been treated inappropriately. Recommendations were made to the National Drug and Therapeutic Committee as well as the Ministry of Health and Child Welfare to adopt a national policy of primary health care worker training to diagnose and treat forms of epilepsy. (2) It was proven to be possible to apply training and public education interventions in the most unfavourable environments (shortages of health workers for example). (3) Training and awareness

increase attendance for treatment. (4) Regular availability of medicines and health staff will improve quality of life.

APPENDIX 5 AFRICAN DECLARATION ON EPILEPSY

Under the aegis of the Global Campaign Against Epilepsy of the World Health Organization (WHO). International League Against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE), a meeting "Epilepsy: a Healthcare priority in Africa" was held in Dakar, Senegal, Africa on 5 and 6 May 2000. Professionals from Health and Social Sciences sectors and representatives from universities coming from every African Region unanimously agreed to the following Declaration:

Considering that:

- Epilepsy is the most common serious chronic brain disorder, estimated to affect at least 50 million people in the world of which 10 million live in Africa alone, irrespective of race, religion, sex, age or socioeconomic groups.
- Epilepsy is not an infectious disease and seizures are not contagious.
- All people with epilepsy can be effectively and inexpensively treated.
- Three quarters (¾) of people with epilepsy in Africa have no access to healthcare provisions and are not appropriately treated.
- General information about epilepsy, trained expertise, diagnostic facilities, antiepileptic drugs and surgery are not available to – or affordable by – the majority of people with epilepsy, for geographical, financial or cultural reasons.
- Beliefs in supernatural causes and traditional treatment of epilepsy in Africa contribute to the under-utilization of the medical health services, to discrimination and social isolation.
- Because of these factors, disability and mortality are greater in Africa than elsewhere.
- Epilepsy has serious physical, psychological and social consequences for the affected and their families.
- The impact of epilepsy is most severe in children and adolescents.
- In Africa preventable causes of epilepsy are more frequent than elsewhere including infectious diseases, head trauma, insufficient per natal care and consanguinity.
- 10. Epilepsy does not receive adequate attention in existing national health plans.

We proclaim the following:

Epilepsy is a healthcare priority in Africa requiring every government to develop a national plan to:

- Address the needs with respect to epilepsy in terms of access to trained personnel, modern diagnostic equipment, antiepileptic medication and surgical treatment, information communication, prevention and social integration.
- Educate and train health care and other relevant professionals about epilepsy.
- Educate those affected by epilepsy and the general public about epilepsy as a universal neurological, non communicable and treatable condition.

Eliminate discrimination in all spheres of life particularly at school and the workplace.

- Encourage incorporation of prevention and treatment of epilepsy in national plans for other relevant healthcare issues such as maternal and child health, mental health, infections, head trauma, neurovascular diseases and community-based

rehabilitation programs.

- Encourage the public and private sectors and NGOs to get involved in the local activities of the Global Campaign against Epilepsy.
- Promote interaction with traditional health systems.
- Encourage basic and applied research on epilepsy.
- Proclaim a National Epilepsy Day.
- Encourage regional and continental cooperation.

Dakar, Senegal, 6th May 2000

APPENDIX 6 WHO RESOLUTION ON EPILEPSY 2015

SIXTY-EIGHTH WORLD HEALTH ASSEMBLY WHA68.20
Agenda item 13.5 26 May 2015

Global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications

The Sixty-eighth World Health Assembly,

Having considered the report by the Secretariat on the global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications;

Considering resolution WHA66.8, in which the Health Assembly adopted the comprehensive mental health action plan 2013–2020, and resolution WHA67.22 on access to essential medicines;

Acknowledging United Nations General Assembly resolution 68/269 and resolution WHA57.10 on road safety and health, resolution WHA66.12 on neglected tropical diseases, resolution WHA67.10 on the newborn health action plan, resolution WHA67.15 on strengthening the role of the health system in addressing violence, in particular against women and girls, and against children, and the discussions on the control of neurocysticercosis and its association with epilepsy at the Fifty-sixth World Health Assembly;2

Noting the Political Declaration of the High-level Meeting of the United Nations General Assembly on the Prevention and Control of Non-communicable Diseases,3 in which Heads of State and Government recognized that mental and neurological disorders are an important cause of morbidity and contribute to the global noncommunicable disease burden, necessitating provision of equitable access to effective programmes and health care interventions;

Considering the health-related Millennium Development Goals, the outcome document of the United Nations Conference on Sustainable Development entitled “The future we want”,4 and the report of the Open Working Group on Sustainable Development Goals, established pursuant to United Nations General Assembly resolution 66/288, which proposes Goal 3 (Ensure healthy lives and promote well-being for all at all ages) and target 3.4 (by 2030 reduce by one-third premature mortality from non-communicable diseases through prevention and treatment, and promote mental health and well-being);1

Recognizing that epilepsy is one of the most common serious chronic neurological diseases, affecting 50 million people of all ages globally, and that people with epilepsy are often subjected to stigmatization and discrimination because of ignorance, misconceptions and negative attitudes surrounding the disease, and that they face serious difficulties in, for example, education, employment, marriage and reproduction;

Noting with concern that the magnitude of epilepsy affects people of all ages, gender, race and income levels, and further that poor populations and those living in vulnerable situations, in particular in low- and middle-income countries, bear a

disproportionate burden, posing a threat to public health and economic and social development;

Cognizant that large differences exist in the level of epilepsy management in different countries, with, for example, the median number of neurologists in low-income countries standing at only 0.03/100 000 population, that the essential antiepileptic medicines are often unavailable, that the treatment gap is estimated to be over 75% in low-income countries and to be substantially wider in rural areas than in urban areas;

Noting that the majority of people with epilepsy can be kept free from seizures if appropriately treated with cost-effective, affordable antiepileptic medicines;

Recognizing in addition that certain causes of epilepsy can be prevented and that such preventive action can be promoted in the health sector and in sectors outside health;

Aware that in 1997, WHO and two international nongovernmental organizations, the International League Against Epilepsy and the International Bureau for Epilepsy, launched the Global Campaign against Epilepsy – "Out of the Shadows", and that in 2008 WHO launched its mental health gap action programme, which provided a sound basis for WHO to further lead and coordinate global development work on epilepsy;

Aware also that practice in China and some other low-income countries has proved that country-level coordinated action may be very effective in controlling the disease and improving the quality of life of millions of people with epilepsy at little cost;

Recognizing the remarkable progress made recently in the technology of epilepsy management, from basic research to diagnosis and treatment;

Considering that international governmental organizations, nongovernmental organizations, academic societies and other bodies have recently enhanced their investment in epilepsy management and have undertaken a significant amount of work in collaboration with national governments, such as the International League Against Epilepsy and the International Bureau for Epilepsy, which are in official relations with WHO and have been collaborating with WHO in epilepsy management for several decades;

Recognizing the role of WHO to demonstrate further leadership and coordination and take effective action for epilepsy management, in view of the large public health impact,

1. URGES Member States

And, where applicable, regional economic integration organizations.

(1) to strengthen effective leadership and governance, for policies on general health, mental health and noncommunicable diseases that include consideration of the specific needs of people with epilepsy, and to make the financial, human and other resources available that have been identified, as necessary, to implement evidence-based plans and actions;

(2) to introduce and implement, where necessary and in accordance with international human rights norms and standards, national health care plans of action for epilepsy management, aiming to overcome inequalities and inequities in health, social and other related services, paying special attention to people with epilepsy

living in conditions of vulnerability, such as those living in poor and remote areas, including by strengthening public health care services, and by training local human resources with proper techniques;

(3) to integrate epilepsy management, including health and social care, particularly community-based services, within the context of universal health coverage, including community-based rehabilitation, into primary health care, where appropriate, in order to help to reduce the epilepsy treatment gap, by training non-specialist health care providers in order to provide them with basic knowledge for the management of epilepsy so that epilepsy can be diagnosed, treated and followed up as much as possible in primary health care settings, as well as by empowering people with epilepsy and their carers to make greater use of specified self- and home-care programmes, by ensuring a strong and functional referral system and by strengthening health information and surveillance systems to routinely collect, report, analyse and evaluate trends on epilepsy management;

(4) to support the establishment and implementation of strategies for the management of epilepsy, particularly to improve accessibility to and promote affordability of safe, effective and quality-assured antiepileptic medicines and include essential antiepileptic medicines into national lists of essential medicines;

(5) to ensure public awareness of and education about epilepsy, in particular in primary and secondary schools, in order to help to reduce the misconceptions, stigmatization and discrimination regarding people with epilepsy and their families that are widespread in many countries and regions;

(6) to promote actions to prevent the causes of epilepsy, using evidence-based interventions, within the health sector and in other sectors outside health;

(7) to improve investment in epilepsy research and increase research capacity;

(8) to engage with civil society and other partners in the actions referred to in subparagraphs 1(1) to 1(7) above;

2. INVITES international, regional, national and local partners from within the health sector and beyond to engage in, and support, the implementation of the actions set out in subparagraphs 1(1) to 1(8) above;

3. REQUESTS the Director-General:

(1) to review and evaluate the actions relevant to epilepsy that WHO has been leading, coordinating and supporting in order to identify, summarize and integrate the relevant best practices with a view to making this information widely available, especially in low- and middle-income countries;

(2) to develop, in consultation with relevant stakeholders, on the basis of work requested in operative paragraph (1), a set of technical recommendations guiding Member States in the development and implementation of epilepsy programmes and services, and to provide technical support to Member States in actions for epilepsy management, especially in low- and middle-income countries;

(3) to report to the Seventy-first World Health Assembly on progress in the implementation of this resolution.

Ninth plenary meeting, 26 May 2015 A68/VR/9

APPENDIX 7 EPILEPSY STRIPES WEEK

#EpilepsyWeek #StripesWeek #Epilepsy #Kifafa

The Epilepsy Alliance Africa (EAA) is an Africa-wide alliance of epilepsy associations that was formed in December 2019. The EAA and its members have been doing different awareness activities but realized there was no single epilepsy awareness event that resonated with the African situation. As such, we agreed to dedicate a whole week each year to epilepsy awareness. The 3rd week of September each year was agreed.

We searched for a common colour, and common animal on the continent that could help us send a strong message. We found the zebra and its colours very attractive. Zebra stripes represent belonging, oneness, strengths, shining and visibility. That is why they have been selected to represent epilepsy week. In Africa, where the epilepsy week idea originated from, zebras are well known and liked.

There are many suggestions of what can be done by individuals, families, communities, organisations, schools, workplaces and government during epilepsy week: Wear or use zebra stripes during the Epilepsy Week, e.g. a hat, scarf, headcover, shirt, dress, blouse, trousers, bag, belt, t-shirt and tie or cushion or hair. Arrange an awareness event face to face or online. Share information by word of mouth or social media. Tell your story or family's story with epilepsy. Listen to a story of someone with epilepsy. Change the status or profile picture for your social media pages.

Why is Epilepsy Week necessary? Because the burden of epilepsy is still huge in Africa, and globally. We are cognisant and worried that of the estimated 10 million people with epilepsy in Africa:

- The knowledge gap or misunderstanding of epilepsy stands at about 70%, meaning only about 30% view epilepsy as a neurological disorder that can be managed medically or surgically. Most people think epilepsy is contagious or infectious, yet it is not.
- Only about 25% (2.5 million) are on medical treatment, giving a treatment gap of 75% (7.5 million).
- Out of those 2,5 million who are on medical treatment, we estimate that only about 25% (625 000) have access to medicines and
- Only 5% (125 000) have access to specialist treatment.
- About 25% of epilepsies are easily preventable.

Through the Epilepsy Week, we hope to share stories and experiences of living with epilepsy, encourage people to listen or read the stories, and think about how we could all work together, because **Together we will defeat Epilepsy!**

APPENDIX 8 NATIONAL STRATEGIC PLAN FOR MENTAL HEALTH SERVICES 2019- 2023 (SUMMARY)

Context and Situation Analysis

Zimbabwe is a sub-Saharan country sharing borders with Zambia to the north, Mozambique to the East, Botswana to the West and South Africa along its southern border. According to the inter- censal demographic survey of 2017, Zimbabwe has a population of over 13 million people, 40% of whom are below the age of 15. Zimbabwe has an agro-based economy and the majority of the population reside in non urban areas. Zimbabwe is faced with significant disease burden of communicable and non communicable disease and mental health disorders contribute significantly to this burden.

Historically, prior to independence in 1980, mental health care was a low priority and services were inaccessible to the majority of the population. Inguthseni was established in Bulawayo in 1908 as an asylum mainly for the black population and was changed into a mental health hospital in 1933 after a psychiatrist was assigned to run it from the United Kingdom. Training of a small number of specialist psychiatric nurses only started in 1970. At this time there was little mental health education included in general nurse training or the medical undergraduate curriculum. (MOHCC, 1984).

Independence came with significant changes to the structure of health services with emphasis on primary healthcare and improving access to healthcare for all. The intake for psychiatric nurses was increased and mental health care was included as mandatory in the general nurse training and undergraduate medical training. A diploma in psychiatric health was started in 1982 for doctors going to work at district hospitals, a Masters of Science in Clinical Psychology began in 1982 and in 1984 a specialist Masters of Medicine in Psychiatry degree was established at the University of Zimbabwe. From 1984 a program to decentralise healthcare was set up with upgrading of infrastructure at provincial and district level. In 9 of the 10 provinces a provincial hospital was built or refurbished and district hospitals were also built or refurbished. Local clinics and rural health centres were established at primary health care level allowing for a referral system to be set up. Mental health services were to be part of care at every level of care. Socioeconomic challenges interfered with the decentralisation process however and only 2 Provincial units were established. (MOHCC, 1984)

Zimbabwe currently has four tertiary psychiatric units namely Inguthseni in Bulawayo, Harare Hospital Psychiatric Unit and Parirenyatwa Annexe in Harare and Ngomahuru Hospital in Masvingo. There are four psychiatric units at provincial level in Chinhoyi, Gweru and Marondera as well as in the district of Mutoko. There are also two forensic psychiatric units, Chikurubi Special and Mlondolozi Special Institutions. Harare Hospital Psychiatric Unit was recently refurbished through partnership with Medicines San Frontiers, with renovations to the original acute admission unit and sub acute unit as well as construction of a new outpatient facility. MSF further supported staff services, training and helped to set up a community psychiatry outreach team to support mental health services in Harare City clinics. This work greatly improved the service provision

at Harare Hospital Psychiatric Unit and motivated the staff in their work. All the other units are however in dire need of refurbishment. There is a lack of admission facilities for children and adolescents, and lack of suitable services for effective occupational therapy. There is also need to improve the living conditions for forensic patients.

There are currently 917 registered mental health nurses in the country and 17 psychiatrists. There are 6 Clinical psychologists, 13 Clinical Social Workers and 10 Occupational Therapists working in the government sector. There is high patient to staff ratio across all disciplines, highlighting a need to recruit and retain mental health professions and to increase numbers in all available training programs (see table 1).
Patient numbers are currently very high at tertiary units indicating possible recentralisation of services (see table 2). Major diagnoses reported to be seen in the last year include Alcohol and substance related conditions, Schizophrenia, Organic Psychosis and Depression. A concerning number of attempted suicides where also reported by some units as well.

There is a critical shortage of drugs country-wide. The Health Levy directed partly towards psychotropic drug procurement has had a limited effect on drug supplies as most units still have between 1 to 3 months stock of even the most basic drugs, primarily first generation antipsychotics with minimal stocks of antidepressants and mood stabilizers (see Table 3).

Mental Health Care in Zimbabwe is governed by the Mental Health Act of 1996 and guided by the Mental Health Policy of 2007. There is a need to review the Mental Health Act to bring it in line with contemporary approaches to mental health care and protection of human rights. Given the increased prevalence, policies to address alcohol and substance use are needed. Moreover, the lack of finances within the mental health sector calls for possible tax legislation to fund mental health services. Funding of mental health activities is a major facilitator for this mental health plan. To implement this plan effectively, there is an urgent need for public funding and partnership with private and non-governmental organisations.

Mission, Vision and Guiding Principles

The mission of the mental health services in Zimbabwe as stated in the mental health policy continues to be:
To provide for all Zimbabweans, a comprehensive, coordinated, quality mental health service that is integrated into the general medical health system with the aim of improving the mental health of the nation.
The objective of the strategic plan is to provide a detailed, time bound, feasible action plan to achieve this mission

The principles as highlighted in the mental health policy by which this plan is guided include:

1. Mental health as a fundamental human right
2. Provision of the highest possible quality of care
3. Professionalism in service provision and ethical treatment of patients

4. Decentralisation and integration of services to allow accessibility and sustainability
5. Multidisciplinary approach to mental health care
6. Multisectoral approach to mental health care
7. Community involvement and empowerment
8. Partnership and Collaboration with local and international partners

MOHCC Mental Health Strategic Plan 2019- 2023

During the next five years we aim to focus on following five key areas within the mental health service:

1. **Improve Quality of Patient Care and Service delivery:** this will involve developing and implementing standard operating procedures and quality of care protocols within the service. This will require in service training of staff in SOPs, professionalism, ethics and human rights and developing a culture of self reflection, self appraisal and self care in order to improve the quality of our services. Other critical areas in this objective will be to improve our infrastructure and ensure consistent medication supply.
2. **Improving mental health awareness and community empowerment**: this will focus on increasing awareness of mental health issues through a focused media drive, annual commemorations of key mental health related events, a school mental health awareness program and community led mental health programs such as the Friendship Bench
3. **Research and Data Management**: this will tackle the gap in local research data that is needed to inform policy in mental health and will involve formation of a coordinating multidisciplinary research taskforce, formation of a mental health research database compiling all researches done on mental health issues nationally and coordination of relevant national studies on pertinent mental health issues. The mental health data collection system will also be reviewed to allow routine data to inform policy and planning as well as to aid in monitoring and evaluation.
4. **Review of Legislation:** this will focus on reviewing and updating our mental health act, development of policy recommendations and guidelines for treatment and rehabilitation of alcohol and substance use disorders as well as a proposal for a levy to be taken from alcohol sales tax to go towards funding mental health activities in Zimbabwe.
5. **Mental Health Training, Human resource development, administration of mental health services:** this key area will involve strengthening the mental health workforce through improved training of mental health nurses, psychologists and psychiatrists as well training of non specialist health workers in mental health through the WHO mhGAP program.

Funding and partnerships

Financing health is key in provision of quality health services. Health is generally funded through public finances (taxes, levys and user fees), grant assistance and private out of pocket payments (WHO, 2003). How health is financed affects equity; efficacy and effectiveness of service provision. Mental health is

mostly funded by public finance, 60% of funding for mental health comes from taxes worldwide (WHO, 2003).

Patients with mental health challenges are often disadvantaged financially and out of pocket payments can become an unnecessary barrier to treatment. The WHO recommends that where possible governments aim for mandatory coverage of mental health services which Zimbabwe has attempted to do. This however is difficult to achieve in low income settings where mental health often receives less than 1% of the health budget (Dixon, 2018). This tends to then result in lower quality of service being provided. Developing and protecting dedicated funding for mental health services would improve the quality of service we provide to those affected by mental health problems.

The WHO recommends that planning should drive the budgeting process and a budget should generally reflect priority objectives (WHO, 2003). We have aimed to this during this strategic plan where we have planned based on local data and developed a budget based on national priority areas (See Appendix 3, the calendar and approximate budget for 2019 as the template we would be using each year).

In this strategic time period we hope to partner with private and non-governmental organisations to help fulfil the key objectives of this plan. We however also aim at this juncture to develop a sustainable financial model for Zimbabwe's mental health services through a dedicated mental health levy taken from alcohol sales. This would ensure a consistent form of income for mental health services and allow longer term planning in the future.

Implementation Plan

We aim to implement this strategic plan in 2 phases as follows:

Phase 1(Initial 30 months) - Improving quality of care and empowering the community

- Improving Accessibility to mental health services and Quality of Care within mental health services through QOC and mhGAP training
- Ensuring availability of psychotropic medications
- Addressing the growing alcohol and substance use problem through establishing a Treatment and rehabilitation taskforce; guidelines for treatment and rehabilitation of alcohol and substance use disorder; developing and implementing training on addictions management for staff
- Community empowerment through commemorations, a media drive, school mental health and Friendship Bench modelled community programs
- Establishment of the research taskforce and setting a research agenda

Phase 2 (Subsequent 30 months) - Ensuring sustainability, securing the future

- Reviewing our legislation in line with current approaches, establishing an alcohol levy to finance mental health services
- Improving human resources establishment, improving training and refresher courses
- Infrastructure development and refurbishment

Outputs will be measured quarterly to allow monitoring of this plan and each year a review of the strategic plan will be done at departmental level together with experts in policy and planning from the MOHCC. An interim review with stakeholders will be done after 30 months at the halfway point. A situational analysis will be done towards the end of the strategic plan and a final review with stakeholders will be done at the end of the 60 month period.

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