

# Epilepsy Namibia

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## Information For Teachers

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# Right to Inclusion and Full Participation

Compiled by Ranjini Govender

Presented at the National Epilepsy Conference

Inclusive education is concerned with providing appropriate responses to the broad spectrum of learning needs in formal and informal education settings which, focuses on the diversity of learners.

## **Ten Reasons for inclusion**

1. It is a human right
2. It makes good educational sense
3. It makes good social sense
4. It promotes the right to learn and live together
5. It builds respect for one another
6. It builds acceptance of diversity
7. It builds a uniform and responsive education and training system
8. It removes the elements of elementary discrimination
9. It supports positive interaction and learning from one another
10. It helps to build a rehabilitative and supportive society

## **Ten Challenges for the educator**

1. Support inclusion
2. Advocate and raise awareness
3. Embrace diversity
4. Change perceptions and attitudes
5. Address the needs of all learners
6. Accept people who are facing challenges
7. Accept people who are different
8. Stop discrimination
9. Support family needs
10. Be informed

## Aim of Epilepsy Awareness in Schools

- School (normal/special education)
- Professional nurse(s)
- Medical services
- Nursing services
- Clinical services
- Occupational therapy
- Physio therapy
- Management: epilepsy

- Full participation in academic curriculum
- Physical (basic needs)
- Psychological
- Social
- Vocational
- Recreational
- Structure & discipline
- Stimulation

*available*

*needs*

Learners with Epilepsy reach full potential in schools

*involved*

*achievable*

- Case history & data
- Individual care plan
- Treatment
- Problems / challenges
- Interests
- Friends
- Families
- Epilepsy education: family and the child with epilepsy
- Advocacy

- Change of attitude to epilepsy
- Normal schooling
- Maintain good health to enable good learning/work performance
- Maintain social skills and relationships
- Acceptance – controlled Epilepsy
- Work according to abilities

## What is Epilepsy?

### **EPILEPSY**

.....is a symptom of a structural or chemical disorder, which occasionally produces uncontrollable electrical discharges in the brain, resulting in a wide variety of different kinds of **SEIZURES**:

Seizures:

Can be mild or severe	⇒	Major convulsions
Usually lasts only for a short while	⇒	Brief periods of “absences”
Manifests itself in many different forms	⇒	Muscular rigidity, Agitation, Mental confusion

<i><b>Epilepsy is not....</b></i>	<i><b>Epilepsy is.....</b></i>
A mental illness	The tendency to have repeated seizures
Indicative of intellectual impairment	Caused by a disturbance in the electrical activity of the brain cells
Totally uncontrollable – most cases can be managed successfully with medication	The most common serious neurological condition affecting at least 1 in 200 people
A barrier which prevents people from leading a full life	Common in childhood, but can start at any age
Contagious or hereditary	A disorder or condition – not a disease

## First aid for major seizures

### **STAY CALM**

**Don't try to restrain the person**

- If he is seated when the seizure starts, ease him down to the floor.

### **TIME THE SEIZURE**

- By counting, wrist watch, wall clock, cellphone, etc.
- Note down duration.

### **REMOVE HAZARDS**

- Such as hard, hot or sharp objects that can cause injuries if a person falls against it .

### **DON'T MOVE THE PERSON.....**

- Unless the area is clearly dangerous, such as a busy street.
- Don't attempt artificial respiration unless respiration has ceased.

### **CHECK THE AIR PASSAGE**

- Never force the mouth open or attempt to place anything into the mouth.
- When the seizure ends, turn the person onto his side.

### **DON'T CALL A DOCTOR**

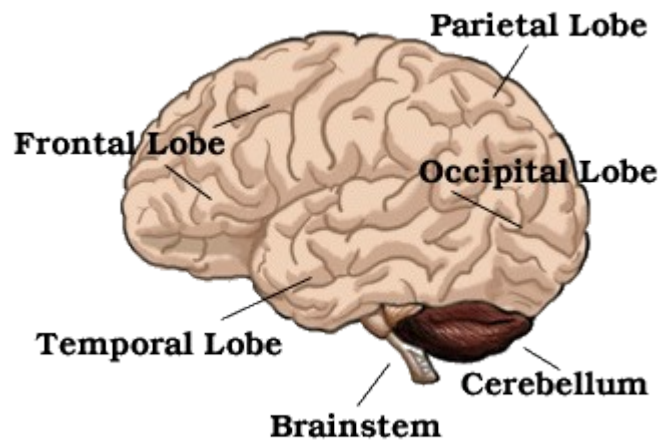
.....Or an ambulance unless the person seems to have one seizure after another without gaining consciousness. Let the seizure run it's course.

### **WHEN THE SEIZURE ENDS**

- Let the person rest or sleep if necessary.
- Be calm and reassuring as the person might feel embarrassed or disorientated afterwards.

# Functions of the brain

Epilepsy manifests in the brain and can influence certain functions:



## **1. Brain stem**

Neurological functions located in the brainstem include those necessary for survival (breathing, digestion, heart rate, blood pressure) and for arousal (being awake and alert).

## **2. Cerebellum**

Coordinate movement (balance and muscle coordination).

- Damage may result in ataxia, which is a problem of muscle coordination. This can interfere with a person's ability to walk, talk, eat, and to perform other self-care tasks.

## **3. Frontal Lobe**

Involved in planning, organizing, problem solving, selective attention, personality and a variety of "higher cognitive functions" including behavior and emotions.

## **4. Occipital Lobe**

Processes visual information. Not only is the occipital lobe mainly responsible for visual reception, it also contains association areas that help in the visual recognition of shapes and colours. Damage to this lobe can cause visual deficits.

## **Parietal Lobe – 2 lobes**

**Right** –Damage to this area can cause visual-spatial deficits (e.g., the person may have difficulty finding their way around new, or even familiar, places).

**Left** –Damage to this area may disrupt a patient's ability to understand spoken and/or written language.

## Holistic Service Approach

### The following services form part of the effective management of epilepsy:

1. Person (learner with Epilepsy)
  - Training in the management of Epilepsy.
  - Guidance and support to face the challenges and affect of Epilepsy on him.
  - Acceptance of Epilepsy, the treatment thereof and self representation.Strengthening positive behaviour.
2. Family
  - Domestic situation: basic and nutritional care, support, discipline, affection.
  - Provide a healthy life style.
  - Self support.
2. Health services (clinics)
  - Nursing care – personal hygiene, medicine management, minor ailment treatment, psychiatric care, record keeping.
  - Medical services.
  - Epilepsy treatment.
3. Social support services
  - Family support.
  - Life skills development.
  - Stimulation programs (pre-school programmes)
  - Group work
  - Interpersonal relationships
  - Awareness programs
  - Epilepsy educational programs
4. Education, training and skills development services

**80 % of people with Epilepsy can manage to live a normal life if given the opportunity.**

  - Early stimulation and intervention programmes.
  - Formal education (in the mainstream system if possible).
  - Special education and supportive training programmes where necessary – usually for the 20% of people who have another condition which has a limiting effect on the learning ability of the person.

### Why do people need all these special services?

1. Epilepsy is a non visible disability.
2. Epilepsy has been a reason for discrimination against people who are affected by it in society, schools, workplaces.
3. Epilepsy is a stigmatised condition.
4. People with Epilepsy and their families, care givers, educators, communities have limited knowledge of Epilepsy and the management thereof – therefore are isolated in most cases and the condition poorly controlled.

## Interdisciplinary team

### Conduct a case study

Team involved: Teacher and/or other responsible person, Health services, Social services/assisting NGO, Parents, Learner with Epilepsy.

<u>Teacher contribution</u>	<u>Medical Contribution</u>	<u>Social services contribution</u>	<u>Parents Contribution</u>	<u>Learner contribution</u>
Identified needs of the learner	Short overview of health	Families social history and needs	Identified needs of the family	Communicate his/her feelings
History of academic progress	Short overview of the mental health condition	Social knowledge of Epilepsy – providing training programs	Knowledge and understanding of the condition and treatment	Identified needs
Identified needs of the teacher in class	Epilepsy information and seizure pattern:	Social support	Involvement of a traditional healer	Personal goals
Identified needs of the other learners in the classroom and school overall	Present health situation	Family's socio economic situation and support available	Observations of seizure patterns and behaviour at home	Knowledge and understanding of own condition and needs
Knowledge and understanding of the condition, treatment and management	Emotion and behaviour patterns	Ability to access clinical or medical services	Understanding of their responsibilities in respect of the child	Willingness to comply to program
Observations in respect of seizures and other relevant behaviour patterns in the classroom	Latest reports: Neurological Psychiatric Blood levels Treatment plan and effects.	Myths and misunderstanding		
Updating of seizure diaries	Updating of seizure diaries	Updating of seizure diaries	Updating of seizure diaries	Updating of seizure diaries



## The way forward

Use all relevant information to draw up a plan to include the following :

- Do not lower the standards and expectations set for the learner.
- Decide what each role player's contribution should be.
- Plan classroom/school training re. epilepsy (what is epilepsy, what causes epilepsy, who gets epilepsy, how do you help the person when a seizure occurs, what the person can do and cannot do, building positive relationships).
- Plan a way/action that will ensure compliance to treatment.
- All people involved with the person with epilepsy should be trained to manage the seizures and the condition.
- Remember: we are dealing with a whole person and the team will have to draw up a plan that takes this into consideration – (physical, mental, psychosocial).

## Challenges encountered in the management of Epilepsy within the educational set-up

### 1. Prognosis

- Approximately 75% of seizures are controlled effectively with AED's (Anti Epileptic Drugs)
- 25% becomes chronic, intractable Epilepsy and needs special services and care.

### 2. Differential diagnosis

- Imitations of seizures – most common types: syncope (poor nutrition, reflex or cardiac diseases).
- Pseudo-seizures and hyperventilation syndrome.

### 3. Principals of drug therapy

- A proper diagnosis of the condition is extremely important to apply the most effective treatment.
- Medication must be administered strictly according to instruction of the medical practitioner.
- AED's cannot be changed suddenly or frequently without careful monitoring – this disturbs the level of concentration of medicine in the blood and usually causes uncontrolled seizures and generally ill health.
- Single drug therapy is accepted as the best method.
- Multiple drug therapy often makes treatment programs extremely complex.
- Reluctance of family/patients to accept the challenge of mono drug treatment due to a fear of seizures.

#### **4. Drug toxicity and drug interactions**

- Drug interaction often causes an AED to reach toxic levels in the blood and causes toxicity (dizziness, sleepiness, disturbed co-ordination, behaviour problems etc.).
- Addition of an acute medication (anti-histamines, antidepressants, headache medication, erythromycin), alcohol and other drugs etc.).

#### **5. Poorly controlled seizures**

- Sudden withdrawal of a drug due to poor delivery from the supplier.
- Non-compliance by some patients.
- Poor administration systems.
- Undiagnosed inter-cranial diseases.

#### **6. Status Epilepsy**

- Usually caused by a sudden withdrawal of AED's or an underlying acute condition and needs urgent medical intervention.

#### **7. Cluster seizures**

- Frequently occurring seizures.

#### **8. Social, psychological and emotional problems**

- The result of misunderstanding, family issues, lack of support and rejection.
- People with Epilepsy are slow starters early in the morning.
- Most of the time people with Epilepsy experience social isolation.
- They feel that they are different and lose motivation to better themselves.
- Many brilliant brains go to waste because they feel that their situation is hopeless, they leave school and find themselves perceived as people who cannot do anything worthwhile.

### **Possible solutions for the above challenges**

Most people need to change their mind set and attitude towards Epilepsy and the management of the condition. Never lower your expectations of the possible achievements set out in the goals for the person with Epilepsy. Never give up or isolate the person with Epilepsy of normal learning/training activities. Like anyone of us, they need maximum input into their education in order to achieve their goals.

**Try the following:**

1. In some instances the teacher might be the first person to observe strange behaviour in the classroom – e.g. “day-dreaming” might be a sign of “absent seizures”.
2. Gain knowledge of Epilepsy and the management of the condition – pass this knowledge on to the learners, your colleagues and other role players.
3. Know the seizure type to be able to manage the sudden disruption in the classroom or playground.
4. Know the first aid for seizures.
5. Children grow and changes happen in their bodies and therefore monitoring of seizures and observation of behaviour changes should be reported.

## **Behavioural disturbances in Epilepsy**

### **Sources of behaviour disturbances**

<b><u>Daily life</u></b>	<b><u>Mood disorders</u></b>	<b><u>Treatment related</u></b>
Other problems in daily life	Depression	Wrong treatment
Chronic illness – uncontrolled seizures	Anxiety – when the causes for epilepsy are misunderstood	Sudden change of medication
Social consequences – how people treat the person with epilepsy	May be seizure related: pre – seizure disturbances (autonomic behaviour) during a seizure (uncontrolled behaviour) after a seizure (confusion and disorientation)	Additional medication causing interactions
Brain diseases – tumours etc.		Toxicity – over dosage of medication
Drugs and interactions		

### **TREATMENT**

Counselling, psychotherapy, anti-depressants, anxiolytics. Limit suicide risk.

### **Personality disorders in Epilepsy**

- For many years people with Epilepsy were branded with a term that indicated they had an “epileptic personality” THIS IS NOT ACCEPTED TODAY.
- People with epilepsy react to the attitude, behaviour and acceptance of other people of their condition and themselves as a human being.
- In some cases people with epilepsy are treated in the most bizarre ways and as if they have no feelings at all.
- Children are most prone to this type of treatment and in most cases the outcome of this has an affect on their development, future and behaviour in adulthood.

## **Psychosis of epilepsy**

“Psychosis is a lack of contact with reality” (schizophrenia).

- Ictal psychosis – in status epilepticus (continued, persistent, uncontrolled seizures).
- Post ictal psychosis – latent internal psychosis and lasts for days or weeks.
- Psychosis unrelated to the above named seizure related psychosis:
  - long history of uncontrolled seizures
  - temporal lobe seizures(psychosis in these are uncommon and rare)

## **TREATMENT:**

- Anti-psychotic drugs and counselling.

## **Stress in Epilepsy**

- Stress increases the risk of having a seizure .
- Stress is not a primary cause of epileptic seizures .

## **Learning disability**

- Epilepsy is more common with learning disability.
- Learning Disability is due to the underlying disorder.
- No evidence that isolated seizures cause Learning Disability.
- Prolonged status epileptics may cause brain damage.
- AED's may impair thinking ability.
- Rarely occurs with 'epileptic encephalopathy' in young children with multiple daily seizures and ongoing cerebral electrical activity on EEG.

## **AED's (anti-epileptic drugs) and behaviour**

- **Negative effects**
  - Drowsiness is caused by all AEDs.
  - Psychiatric depression caused by Phenobarbitone, Phenytoin.
  - Mood changes, psychosis caused Vigabatrin, Topiramate.
  - Polytherapy with AEDs – more than one AED “confuses” the effectiveness of the drug.
- **Positive effects**
  - Mood elevation by Carbamazepine, Valproate, Lamotrigine.

## **Aggression and violence in epilepsy**

- Mood disorders – irritability, temper outbursts.
- Brain damage – cause of both aggression and epilepsy.
- Aggressive behaviour alone is not a seizure “Episodic dys-control”.
- Violence – before, during and after a seizure.
- Directed violence does not occur in seizure.

**Treatment** : Drugs for anger control.

# Management of Epilepsy

Knowledge is power!

## **Know ...**

- What types of seizures can occur
- What factors may trigger seizures
- The correct first aid for seizures
- How to record time, duration and patterns of seizures
- What pre- seizure signals to look out for
- What feelings to expect of the person with Epilepsy
- That Epilepsy affects daily activities in several ways

## **To manage Epilepsy effectively we need.....**

- Awareness of the condition of Epilepsy
- Generosity of mind and a spirit of understanding in our role as care givers, colleagues, friends and family
- High expectations of the person with Epilepsy
- Undertake to support and assist the person with Epilepsy

**Some effects of Epilepsy on the capacity of the person to perform** Epilepsy, its treatment and the associated level of self image/confidence of the person may have significant effects on:

- Speed of information processing - Memory recall
- Vigilance - Alertness
- Sustained and focussed attention
- Motor fluency - Language fluency

## **The impact of epilepsy on behaviour and emotional development**

*“Children require a stable upbringing to develop emotionally and anything that threatens that stability may have negative consequences for subsequent development and psychological health*

Epilepsy with the unpredictable and at times intense nature of its symptoms poses such a threat” PAMELA J JONSON



Management of Epilepsy...

**At home/work/school**

1. Be informed and unprejudiced.

2. Be prepared for a seizure.
3. Deal appropriately with the emotions of the person with Epilepsy.
4. Foster a culture of acceptance.
5. Be prepared to administer/supervise the treatment of a person with Epilepsy.
6. Don't lower your expectations and standards for the person.
7. Don't impose blanket restrictions.
8. Encourage participation in activities that improve his self image.
9. Be aware of the side effects of certain "over" the counter medication.
10. Be aware of all safety aspects at school, home and in the workplace.

**Management of Epilepsy...**

## **And the needs of other members in the home/workplace/school**

Inform people around the person with epilepsy about the condition.

1. Prepare for seizures and train learners/colleagues in first aid for seizures.
2. Reassure other people around the person.
3. After the seizure has ended, place the person in a recovery position or allow the person to rest for a little while afterwards if necessary.
4. Consider a simple explanation to the people around.
5. Record information on the persons diary.
6. Continue with normal activities as soon as possible.

**Management of Epilepsy**

## **Implications at home/work/school**

**Parents/people are sometimes over-protecting /rejecting.**

- ➡ **This causes instability in the relationship**
  - The condition is hidden from other family, friends, acquaintances.
- ➡ **This results in uncertainty, low self-esteem and a lack of confidence**
  - People with epilepsy are send home after a seizure/ refused entry in schools or not given opportunities to work.
- ➡ **This results in a lack of training and the person becomes de-motivated to do anything for himself and starts to believe that he is not able to achieve anything.**

**(People with epilepsy can normally continue activities after a rest period!)**

This has a major influence on the person's development, academic achievement and preparation for a career.

## **Turn this around .....**

- Create an open trusting relationship.
- Motivate family to change their attitude.
- Train people with Epilepsy and those around them to manage epilepsy effectively in order to create support and understanding.

- Stress the importance of regular use of medication to improve life style.
- Be willing to listen to people with epilepsy and their challenges.
- Create a willingness to report regularly to family.
- Motivate people with Epilepsy to obtain training and to participate in activities.
- Install a structure of routine and discipline.
- Encourage people with Epilepsy to discuss their condition.
- Build a relationship that includes partnerships with all role players and professionals.

Management of Epilepsy

## Preparing for work

- Positive attitudes towards people with Epilepsy and related disabilities.
- An atmosphere of appropriate high expectations, high quality planning and professional support on an individual basis.
- Encouragement of reasonable and safe risk taking.
- Commitment in a partnership.
- Motivation to improve skills.
- Support when working in a group situation.
- Organize the workplace to be safer and create a suitable and acceptable working environment.
- The person with Epilepsy will regain self confidence, trust and acceptance.

Management of Epilepsy

## Relationships with colleagues and friends

- Understanding the need to learn more about Epilepsy awareness and the potential stigmatising effect that it has on some people.
- Awareness of the potential isolating effects the people with Epilepsy face.
- Awareness of the potential dangers they face
- Willingness to confront work challenges.
- Willingness to deal with safety issues.
- Willingness to go on listening, learning and responding to the person with Epilepsy.
- Responding to individual needs and the way Epilepsy affects them.

The only time a person has epilepsy is during an Epileptic seizure – for the rest they are normal people who just have a higher tendency than most other people to have a seizure