

POUT S L youth en POWER talents with EPILEPSY

MIND YOUR RIGHTS

First published in April 2014 by: Youth on the Move

1st floor, New Life Christian Church Building, Birongo Square, Nairobi West

P.O. Box 20689 - 00100

Nairobi - Kenya Tel: +254 (20)605723

Fax: +254 (20)605723 E-mail: info@yotmkenya.com © 2014 by Youth on the Move



Permission will generally be granted when sought but all rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form, or by means, electronic, mechanical, photocopying, recording or otherwise, without prior written permission from Youth on the Move.

MIND YOUR RIGHTS February 2014

2

CONTENTS

Abbreviations	4
Acknowledgements	5
Foreword	6
Executive summary	10
Chapter 1: What is epilepsy?	12
Chapter 2: Justice: rights and obligations	16
Chapter 3: Where can we find our rights?;	19
Chapter 4: Stand up for your rights	20
Chapter 5: Equal rights for people with epilepsy	28
Chapter 6: Right to health	31
Chapter 7: Right to freedom	43
Chapter 8:Right to security	44
Chapter 9: Right to Housing	45
Chapter 10: Freedom of opinion, expression and choice	46
Chapter 11: Freedom of conscience and religion	47
Chapter 12: Education	48
Chapter 13: Social Interaction	50
Chapter 14: Love, sex and marriage	52
Chapter 15: Work	58
Chapter 16: Driving	62
Chapter 17: Rights in politics	64
egal help	66

ABBREVIATIONS

AEDs: Anti-Epileptic Drugs

ANPPCAN: African Network for the Prevention and Protection against

Child Abuse and Neglect

CAJ: Commission on Administrative Justice

CLAN: Children's Legal Action Network

CoE: Committee of Experts for Constitutional Review

CoK: Constitution of Kenya 2010

CRPD: Convention on the Rights of Persons with Disabilities

COVAW: Coalition on Violence Against Women

FIDA: Federation of Women Lawyers

KHRC: Kenya Human Rights Commission

ID: Identity

OB: Occurrence Book

KLRA: Kenya Law Reporting Authority

KNHREC: Kenya National Human Rights and Equality Commission

STD: Sexually Transmitted Disease

PWDs: Persons with Disabilities
MP: Member of Parliament

NGO: Non-Governmental Organization
NHIF: National Hospital Insurance Fund

WRAP: Women's Rights Awareness Programme

MIND YOUR RIGHTS February 2014

4.

ACKNOWLEDGEMENTS

This publication would not have been possible without all the contributors who have assisted us in the production of this manual. They include an incredible network of friends, colleagues, partners and most of all youth with epilepsy. They have given their time and efforts to facilitate our advocacy for epilepsy through this manual.

First and foremost we would like to thank the Movers. They are the youth living with epilepsy. It is truly remarkable to see their talents and abilities brought to the limelight. This incredible Movers Team remind us every day why we do what we do. They include Moses Waweru, Annie Arogo, Jane Wahome, Epillose Musimbi, Peter Nyette, Nelson Ondari, Kenneth Omwandho, Haniph Aasman, David Karanja, Purity Sipilon and Raymond Safari.

We would also like to extend our appreciation to the Ambassadors Bernice Mugambi, Fred Wambugu, Edwin Masenge and Sitawa Wafula. They are role models for people living with epilepsy, and we are glad that the media is taking note. They bear witness to the fact that epilepsy doesn't stop us from becoming true shining stars.

We are indebted to the honorable Lady Justice Mumbi Ngugi who inspired us with her activism for equal rights for vulnerable, marginalized groups in society. Her role as the former Chairperson for the Albinsim Foundation of East Africa has given us the motivation to advocate for justice and for the implementation of the rights of people with physical challenges. She was truly resourceful in helping us find and use the right information.

We are humbled by Bobby Mkangi's participation. A Member of the Committee of Experts for Constitutional Review, he voluntarily offered himself to assist in writing the manual and ensured that the content was accurate. His optimism and sense of responsibility in achieving justice for persons with epilepsy in Kenya is truly remarkable.

The "National Epilepsy Coordination Committee" (NECC) has continuously supported our efforts to produce this manual. We are eternally thankful to the Chairman Prof. Paul Kioy and the Secretariat member Dr Samson Gwer.

Dr. Samson Gwer has been invaluable both as a secretariat member of the NECC and as a board member for Youth on the Move. Other board members include: Nelson Chege, Nashon Odhiambo, Tiberry Nyakwana, Elizabeth Shiakamiri. We thank you for overseeing our work and continuing to chip in when your insights are needed. The Dutch board members: Lianne Belt, Astrid Ogelo, Elizabeth Njeru, Danielle Ringoir and Josefien de Kwaadsteniet, thank you for your assistance in resource mobilization. You have helped us to keep growing in our endeavor to assist youth with epilepsy.

We are equally obliged to our editorial contributors Msanii Kimani wa Wanjiru, Taylor Krohn and our designer Kenny Kaburu for his illustrations. We are particularly grateful for the financial assistance of ASN Bank, Haella Fonds and the income of our Movers Cyber which enabled us to develop this manual.

Karijn Aussems **Epilepsy Activist**

MIND YOUR RIGHTS February 2014





The Movers attend the Purple Day for Epilepsy on 26th of March 2013 at Arboretum Park, Nairobi

FOREWORD

August 27th 2010 shall for ever remain one of the most memorable days in my life and I believe the same applies to many Kenyans. After a tough fifteen months of drafting and preparing the new Kenyan constitution, which Kenyans approved through a referendum earlier that month, the document that I had helped to churn out as a member of the Committee of Experts for Constitutional Review (CoE) was indeed my country's new constitution.

That day was very special to me. That day and the experiences leading up to it presented me with ambivalent emotions— great pride and distinction for being one of the Kenyans in the eleven member committee that provided stewardship during the successful writing process and profound humility for the opportunity and support that Kenyans had accorded my colleagues and me during that journey.

The new Kenyan Constitution provided a fresh blueprint through which Kenyans could navigate themselves out of an old disappointing order to a new dispensation full of ambition, hope and fulfillment – a belief that many Kenyans had on that day as the president led the country in promulgating the new document.

However for me, a voice of restraint and objectivity kept on whispering in the ear of my mind. It hauntingly said (and still does!) – 'this was the easy bit, a battle has been won but the war continues – bado mapambano!' I was well aware that inasmuch as we were celebrating (and rightly so considering

the twenty-plus-years the struggle had taken) the arrival of a new constitution, it was just a document or simply, words on paper and would remain so if we, as Kenyans did not employ full effort to implement it.

I was counseled by the Kiswahili saying that says – kumzaa mwana si kazi, kazi ni kumlea, which translates to – giving birth to a child is not hard work, hard work is in bringing up the child. The baby had been born safely and received with pomp by many during that wonderful 'baby shower', but now the hard work of bringing the baby up was just starting.

As I watched the mammoth crowd that had turned up at Uhuru Park to witness the president officially sign the new document into law, I could not help but wonder if those Kenyans seated in front of me and millions of others following the proceedings from home via various media were up to the task and were aware that it would take the effort of ALL Kenyans to bring to life those beautiful words in the constitution so as to make them useful to us. We wanted a better life, had gone ahead and written a manual on how to get that better life, but I pondered, were we really going to read and follow it?

I digress a bit to bring the point home. Benjamin Franklin, one of the writers of the American constitution is famously quoted to have told Americans: "The American Constitution only guarantees the right to pursuit of happiness. It is up to you to pursue happiness." What Benjamin Franklin implied was that the American Constitution only provided a platform for Americans to use in the quest for a happy life. This could only be achieved by a proactive use of that platform by the citizens and not by the words in the Constitution on their own.

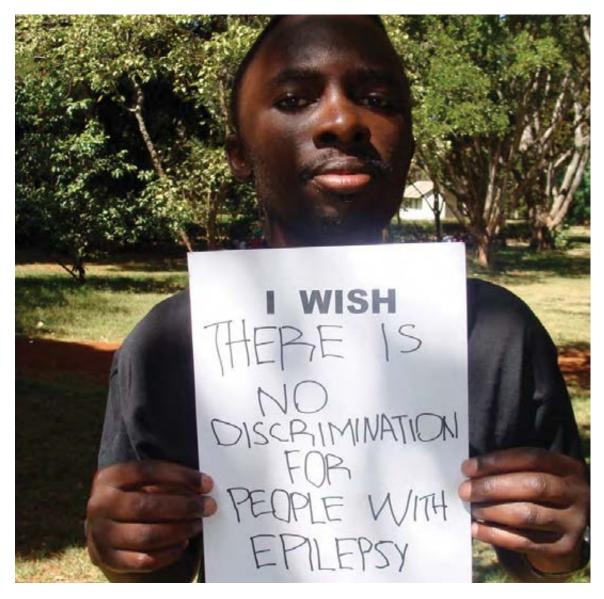
Happiness cannot be realized by the mere fact that the Constitution guarantees it. It can, through actions aimed at achieving it that are recognized, protected and inspired by the Constitution. In other words, the Constitution would only be useful if Americans made use of its content by taking appropriate and relevant action and not by them sitting back and expecting the words to get them results magically. The Constitution is the map and not the destination.

I was reminded that similar wisdom to Benjamin Franklin's is applicable in Kenya. Kenyans need constant reminding that the content of the new Constitution of Kenya 2010 (CoK 2010) is only words on paper and that the gains in it are not realizable unless wananchi themselves make use of them. However, in order to do this, knowledge of the content of the Constitution is the starting block to its effective use.

To this end, enter Mind your Rights!, an important and foundational publication that primarily targets people with epilepsy in Kenya. This essential empowerment tool is not only useful for those living with epilepsy, who represent two per cent of Kenya's population but also to all Kenyans.

Mind Your Rights! is first and foremost an educational and informational tool on

Allan Okello has epilepsy and shares his desire for equality for people with the condition



epilepsy, both as a medical condition and its socio-economic and cultural impacts. It provides information on the care framework (or its inadequacy); institutional and normative, available in Kenya. In doing so, it gives information on the medical and other care institutions for persons with epilepsy which are largely hospitals and other medical facilities in the country.

It also gives the legal and policy framework that governs issues of epilepsy in Kenya – both local and international. It does this by outlining the laws and policies touching on epilepsy, primarily the CoK 2010. It appropriately personifies epilepsy by presenting the day to day challenges that a person with epilepsy faces in Kenya on a constant basis, information which is critical not only for those affected by the condition directly but also indirectly, which as it successfully shows, is everyone.

However, what tops in this book is the call-to-action content that targets mostly Kenyans living with epilepsy. Beyond the useful information it provides, it outlines practical steps that a person with epilepsy can take to claim his or her rightful place and space in society. It shows how the rights outlined in the CoK 2010, which belong to all Kenyans including those with epilepsy, can be made use of and the institutions to be approached to

push for the full enjoyment of those rights. It places the individual as both the agent and beneficiary in the triggering and realization of positive action.

The title of the document — Mind Your Rights!, literally presents the idea that it is the bearer or owner of rights (with capacity), that has the fundamental duty of 'minding' or taking care of his or her rights by first knowing what those rights are and taking action to ensure that they enjoy those rights fully. This proactive approach is inspired by what Kenyan politicians have in the recent past been quoted as saying — 'The Government is like a wheel-barrow. It has to be pushed to move.'

This echoes what the late American President John .F. Kennedy said – 'Things do not just happen. They have to be made to happen.' It therefore reminds people with epilepsy that, for their rights to be realized, they have to stand up for them. Inasmuch as government has the primary responsibility to ensure that their rights are fulfilled as Article 20 of the CoK 2010 proclaims, this shall only be realized if the same government is pushed to act – an unfortunate but realistic picture of things. It is therefore the trigger through the action(s) of people with epilepsy that will help secure and bring to life the rights contained in the constitution and other laws and policies.

Mind Your Rights!, however, does not only present a mwananchi vs. government call-to-action dialogue that most publications of this nature do. It wisely reminds persons with epilepsy that violations of rights can also be inter-personal or from individuals to individuals and that action against those is also important. In essence, it is in standing up against the inter-personal everyday or 'small' violations that breeds the habit and culture of taking action against bigger players like the government. People living with epilepsy are also reminded that they must recognize and respect the rights of others: that it is only in an environment where care and concern for each other is integral in day to day interactions that rights are most secure.

Mind Your Rights! seeks to start the journey of transforming persons living with epilepsy in Kenya from victims or survivors to gadflies. It is a journey towards entrenchment of the constitutional values and principles through empowerment of sovereignty, which the CoK 2010 proclaims belongs to all people of Kenya (Article 1) – a journey that I humbly seek through this endorsement of Mind Your Rights!, to be a 'fellow traveler', especially as a member of the Committee of Experts for Constitutional Review.

May we live happily ever after!

Bobby Munga Mkangi, **Nairobi, Kenya**



MIND YOUR RIGHTS February 2014

EXECUTIVE SUMMARY

I have a dream that one day people with epilepsy will live in a nation where they will not be judged by their epilepsy but by the content of their character!

Paraphrase Inspired by Martin Luther King

aving epilepsy doesn't make one less human; people with epilepsy have desires, dislikes, opportunities and challenges like anyone else. "Hakuna tofauti, tuko sawa"— there's no difference, we're all the same. That's the motto that the youth with epilepsy sung in their song recorded in 2008. People living with epilepsy have human rights as much as anyone else. The Universal Declaration of Human Rights supports them in living their lives to the fullest, in a safe environment where opportunities are offered to live beyond challenges.

It's important that we know our rights; however, knowledge alone is not enough. It's equally important to understand how to make use of these rights. We need to learn what we can do if someone crosses our boundaries. Do we just let it happen? Do we defend ourselves? Do we ask for help?

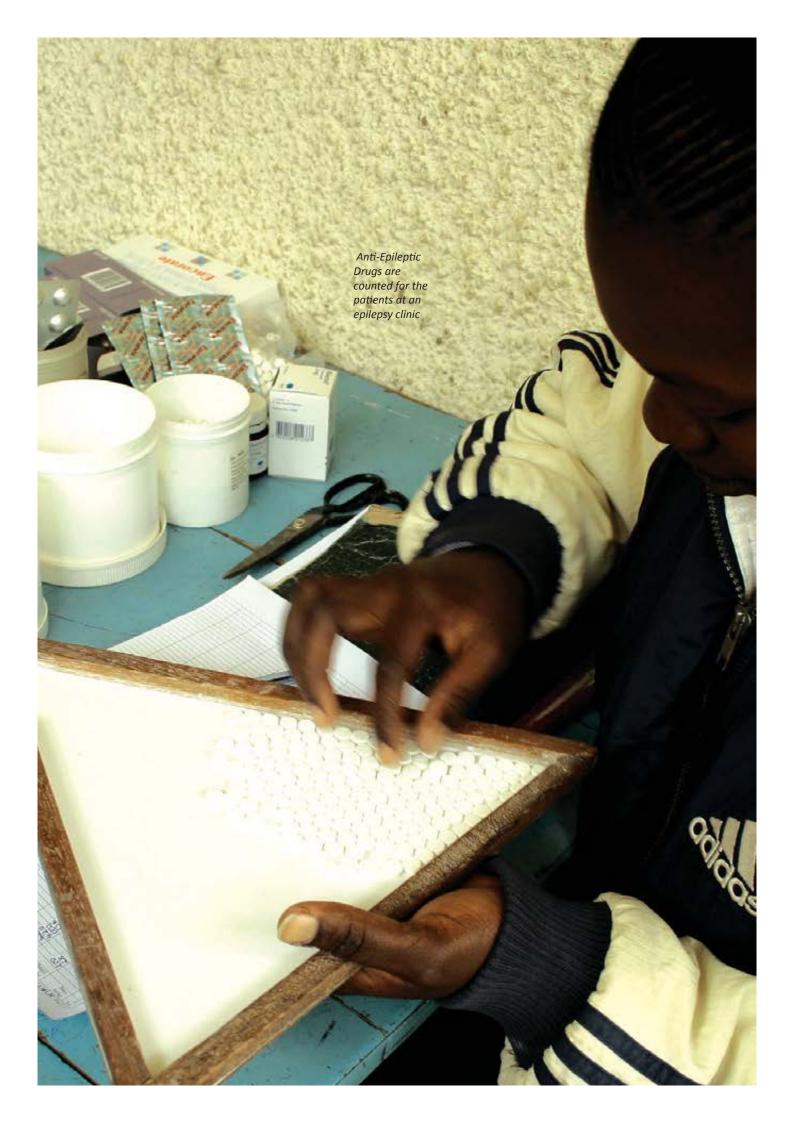
In this manual, we'll discuss why we have rights and obligations, who makes them and where we can find these rights. We also give advice on how to defend Human rights and what to do when they are violated.

People living with epilepsy have more to contend with beyond the medical condition. This manual gives a variety of rights that are important to deal with these challenges. Like anyone else, they learn values and norms as they grow up. They learn how to relate with others. They go to school, fall in love, search for work, and participate in social activities. Therefore it is essential to provide rights not only in health care, but also in areas such as education, work, relationships and politics.

When we know our rights, we can either look at the rights which are not fulfilled and complain about them, or we can decide to take charge and look for ways to achieve them. Most rights can be fulfilled by taking responsibility: by daring to speak for ourselves, taking initiative and asking for the encouragement of others in achieving our desires. In some cases, we need the assistance of others, especially when others do not respect our boundaries. It's our hope that this manual will be a tool to encourage people to see more opportunities and to be assertive in situations where they need to seek support to stand up for their rights.

Movers Team, Youth on the Move





CHAPTER ONE

WHAT IS EPILEPSY?

Epilepsy is a brain disorder which makes a person prone to seizures. Seizures are sudden and temporary electrical disturbances in the brain which cause changes in sensation, awareness or behavior. They are also known as fits, spells, attacks, convulsions or spasms. There are many types of seizures with different manifestations. One person may fall and jerk, another may only stare or fumble with clothes and smack lips.

Epilepsy cannot be cured like malaria, but it can be effectively controlled. In the majority of cases, Anti-Epileptic Drugs (AEDs) are an effective control. They do, however, have to be prescribed by a doctor. Just like seizures, people with epilepsy have different experiences. While some people have to live with epilepsy throughout their lives, some outgrow the condition. For the prescribed drugs to be effective they need to be taken consistently and any change in medication must be done in consultation with the doctor. Most people with epilepsy can live an active life: work, go out and have a family as long as they take their medication as prescribed.

What is the Cause?

Anyone can get the condition, in any country, age and in any social class or religion. In many instances, the cause of the condition is a mystery. However, there are times when a doctor can determine the cause, such as brain damage or injury, brain tumors, infections, stroke, birth complications, alcohol or drugs, malnutrition and inheritance.

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

Treatment and First Aid

Epilepsy cannot be treated over the counter. The doctor will first need to make a diagnosis. This means that they must ascertain that you have the condition. Once the doctor has diagnosed you with epilepsy, you will need to be treated with AEDs (Anti-Epileptic Drugs). AEDs are tablets which you need to take daily as prescribed by the doctor. About 7 out of 10 of people who make use of AEDs are seizure free, while the other 30% may still experience seizures though in reduced numbers.

Kuna ugonjwa
noma inaitwa kifafa,
Si mchezo kila mtu
anaweza kuipata,
Tajiri, maskini, mkubwa,mdogo,
Mrefu, mfupi, mkonda, mnono,
Watu wengi sana wanaumia,
Lakini sio mwisho ya maisha



Jua Cali - Hakuna Tofauti Kenyan musician

A doctor will rarely prescribe treatment after a single seizure; at least two seizures need to have occurred to be diagnosed with epilepsy. When seizures are very rare, the doctor may question if treatment is really necessary. It is a matter of weighing the challenges with your seizures against the challenges of the treatment (such as the costs and side effects of the drugs).

To stay healthy, you need to continue the treatment until the doctor suggests a change. The Anti-Epileptic Drugs (AEDs) control the seizures as long as they are taken as prescribed, but they do not cure the epilepsy. This means that if you stop the treatment without the doctor's consent, the seizures could relapse and even make the condition worse.

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

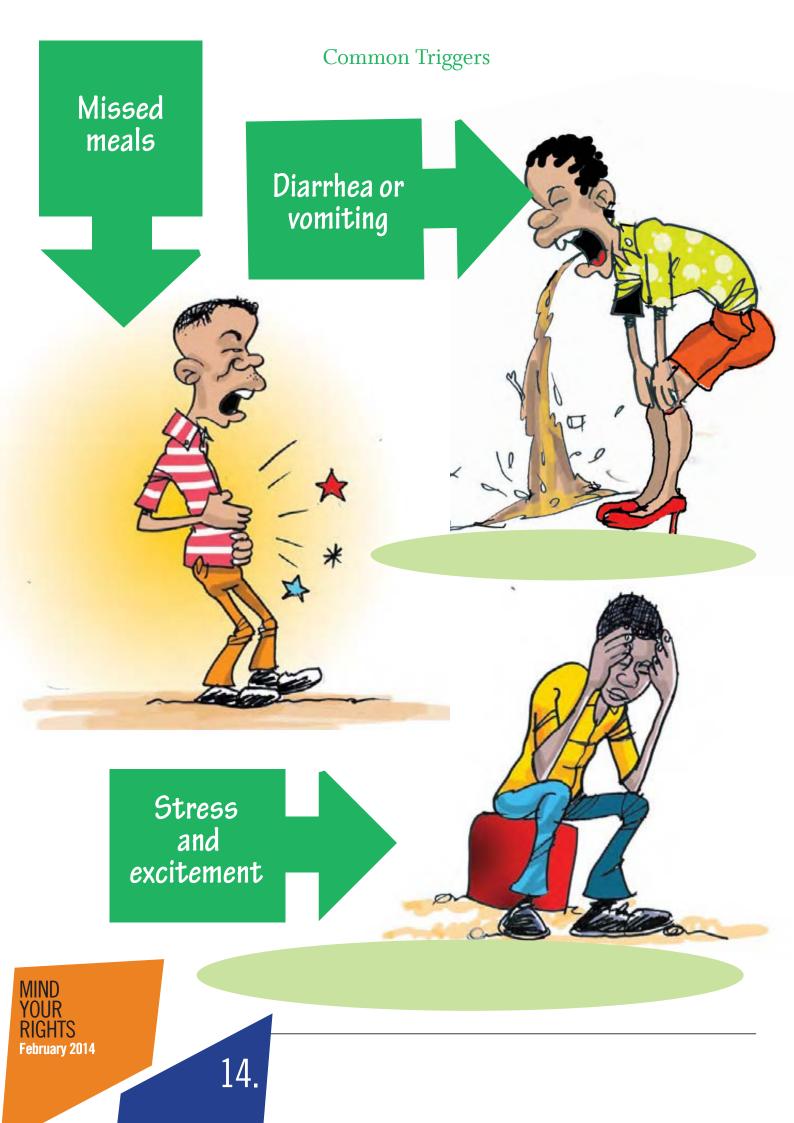
Lifestyle

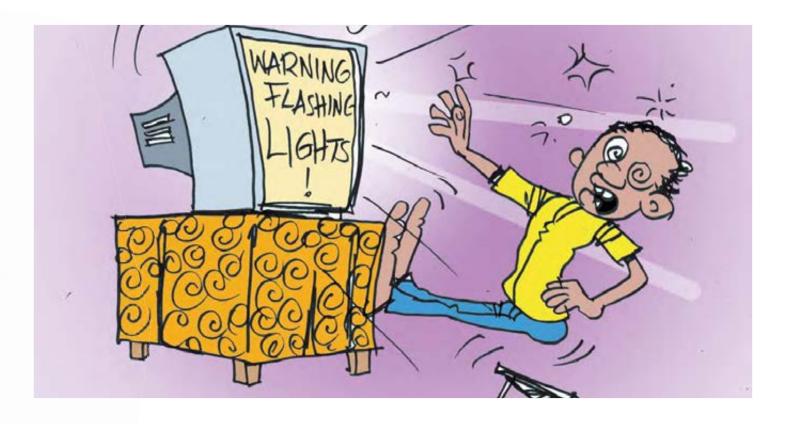
We all create our own way of life; the way we decide to live our lives is greatly determined by our choices. The opportunities that others provide, the environment we live in, and our health status also play a vital role in this lifestyle.

People with epilepsy are not different in this respect. They have their own personality, and preferences on how they choose to live their lives. Their daily life does not have to be determined by a condition like epilepsy, but by preferences and opportunities. However, it is useful to recognize that lifestyle helps in reducing the number of seizures and triggers. When you have epilepsy, there are common triggers that can provoke a seizure. They include:



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





Some people have very unique triggers, like listening to a special kind of sound or eating something specific, among others.

Some people get more seizures when they drink alcohol. They therefore need to question if the taste and temporary delight of the beer is worth the extra seizures. On the other hand, it's essential not to let epilepsy take charge of your or someone else's life. Epilepsy is only one of the many factors that determine the opportunities and choices in life. The talents and desires of people with epilepsy are more important to focus on than the challenges faced when having to live with it. For example, it may be harder to study for exams, as the stress of it may trigger seizures, but that doesn't mean that a person with epilepsy is not capable of studying. Sometimes it may take extra time to get all the grades, but that doesn't make it less of an opportunity to make use of the talent to learn a profession and to put it into practice.

It's important for people with epilepsy to take charge of their lives. They may feel as if they are victims but they can live with it, as long as they take charge of their lives. When you have epilepsy and you feel that people restrict your chances in life, you need to stand up for your rights which others must respect. By reading this manual, you will learn how to take charge and ensure that you can make use of your rights.



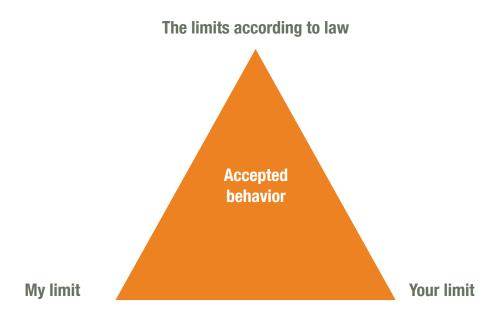


JUSTICE: RIGHTS AND OBLIGATIONS

Every country has rights and obligations for their citizens in order to achieve justice. Justice is the behavior or treatment that people deserve that protects them from harm and gives them opportunities.

Behavior beyond your Boundaries

Even when it harms us, we sometimes let things happen against our will without expressing our boundaries. For some people it's because they are not aware of their rights. For others, the reasons may vary: they may not dare stand up for their rights, or they may not know how to establish boundaries. Think about the right to an opinion; you are allowed to have your own opinion and to speak it freely. But when you think that you should always agree with your parents, you may have missed the opportunity to learn to think for yourself and to speak your mind. Rights are also about the limits that we have, for instance if you do not want to make love to someone, the other person shouldn't push you into it. It's your right to say no and everyone else needs to respect this. It's therefore important that we all learn about our rights.



Our Responsibility

Inasmuch as we all have the right to have our own opinion we also bear the responsibility to give others freedom to voice their own opinions even when it differs from our own. Rights co-exist with responsibilities such as paying taxes and obeying traffic rules.

When people shun their obligations, they do so intentionally or unintentionally. They may simply want to rebel and do the opposite of what they're allowed to do. They may also fail to achieve their responsibility as they either do not know about it or due to other prevailing limitations. An example would be a parent's responsibility to take good care of their child by providing them with food and shelter. Would you blame them for not providing these needs if they didn't have the financial resources to do so?

We can say that rights do not directly offer us solutions, but they are like guidelines to achieving a fulfilling life by bringing together personal and societal efforts. When someone fails to offer you what you deserve, you can refer to your rights and ask for the treatment that is rightfully yours. If necessary you may need to seek the help of other people, e.g. friends, police, activists or lawyers.

Before we share more information about your rights and how to make use of them, let's first question who exactly decides what our rights are- who decides what we are allowed and obliged to do? Is it your parents, your teachers or maybe the president? Take a look at the table below and fill in who you think has the powers to decide what your rights and obligations are.

Do these people decide what your rights are?	Yes	No	Do these people decide what your rights are?	Yes	No
You			The Faith Healer		
Your Parents or Caretakers			The Minister of Justice		
The Members of Parliament			The Religious Institutions		
Your Boss at work			Your teacher		
The most popular Class mate			The American President		
The Kenyan President			Your neighbor		
The Attorney General			The UN Boss		
The Police Officer			The City Council Officer		
The Village Elders			Your Elder Brother or Sister		
The County Governor			Your Best Friend		

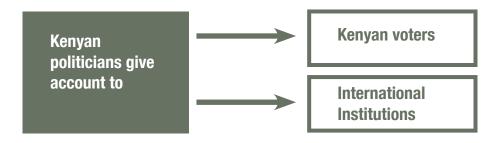


Politicians aren't our bosses but our representatives.



Rights in politics

Various people have powers to make laws and regulations that recognize and protect our rights. First of all, everyone who is eighteen and above has a voting right; when we cast our ballot during elections, we select who is going to serve as President, MPs, Governors and Senators. This means that politicians aren't our bosses, rather they are our representatives. Their role is to make decisions for the benefit of the people who elected them. When they make decisions for the country, they not only have to give an account of their choices to the people whom they represent, but they also have to give an account of their choices to international institutions such as the UN which makes rules and regulations for the member states.



MIND YOUR RIGHTS February 2014

WHERE CAN WE FIND OUR RIGHTS?

The current Kenyan Constitution was approved by Kenyans during the referendum in 2010. It contains the rights and obligations that politicians need to respect as they make decisions. Kenya is a signatory to several International Declarations and the decisions of the politicians must also fulfill and obey the rights and obligations contained therein. Declarations and Conventions can be described as formal agreements between countries on matters involving them; an example is the Universal Declaration of Human Rights, which was adopted by the United Nations General Assembly on 10th December 1948 to guarantee the rights of every individual all over the world.

The Kenyan Constitution and the Universal Declaration provide general information about the basic rights of people but they do not give specific details. We also have Acts of Parliament. These are written laws which give detailed information about specific issues, they are approved by parliament. They include the Persons with Disabilities Act (2003), the Sexual Offences Act (2006) and the Employment Act (2007).



With technology, it has become very easy to find detailed information about one's rights. With the help of search engines such as Google and Bing one can download the Kenyan Constitution and the various Acts.

CHAPTER FOUR



Get up, stand up,
Stand up for your rights
Don't give up the fight,
Life is your right,
Get up, stand up,
So we can't give up the fight,
Stand up for your rights,
Get up, stand up,
Keep on struggling on,
Don't give up the fight.



Bob Marley,Jamaican musician

STAND UP FOR YOUR RIGHTS

What should we do if someone crosses our boundaries? Should we discuss this with the person or report these occurrences to the police? Rights help us understand what we can and cannot do, and hence what to expect and not expect of others. When one doesn't respect these rights, we can demand them in an attempt to ensure they change their behavior.

In this chapter, we'll discuss the following steps that you can take to secure your rights:

- 1. Inform yourself about your rights
- 2. Speak up
- 3. Dialogue, find a compromise
- 4. Seek security
- 5. Seek medical assistance
- 6. Report to police
- 7. Seek support from Human Rights Advocates
- 8. Take someone to court

1. Inform Yourself about your Rights

Without knowledge of one's rights, it's impossible to know what to stand up for and so it is essential for everyone to learn about their rights.

Once in a while, laws that uphold rights change, like when the New Constitution was introduced in Kenya. It gave extra rights to vulnerable groups to be represented in parliament. Once in a while new Acts are endorsed (approved) by the parliament; updates of this are always available in the media. Following the media makes one well informed and enhances the ability to share information with others. Those who have access to the internet can search and access new laws by following the parliament or the Kenya Law Reporting Authority (KLRA) websites www.parliament.go.ke or www.kenyalaw.org respectively.

Another way of keeping yourself up to date is by regularly taking part in meetings of **advocacy groups**; they are usually the first to know about changes in law and they exist to share the knowledge with you. A good example is the Kenya Human Rights Commission (KHRC) which advocates for rights and creates awareness in communities; these groups also exist at local/grassroots levels. It is therefore important to find which advocacy group operates in your local area and to participate or support their activities and efforts.

2. Speak Up

Once you're well informed about your rights, it becomes easier to recognize a violation of rights or situations in which rights are not being fully exercised. When people cross someone's boundary, we can speak of confrontation. Confrontation can happen at any place and at any time: it can be a conflict in the family, in a love relationship, a conflict at college or work, with a good friend or with public officers. It can take place on the streets between strangers, individuals or opponents of political parties. It is important that everyone feels free to speak up and to share their opinion without any fear. Opinions cannot kill; it is the way people respond to them that matters. It's our right to speak up and set our boundaries. It is also our obligation to give others space to speak for themselves and to respect their rights.

3. Dialogue, Finding Compromise



Sometimes when you speak up and express your boundaries, the other person may disagree and present a counter argument. There are those who are of the opinion that a disagreement is an excuse for violence. However, there is no excuse for violence.

Steve Biko, the late human rights activist from South Africa, was a campaigner for resolving conflict without violence. He believed that conflict and confrontation doesn't have to lead to violence. This is portrayed in the biographical movie Cry Freedom.

I object to violence because when it appears to do good, the good is only temporary; the evil it does is permanent — Gandhi

A dialogue between Steve Biko and the State Prosecutor in Court (Movie Cry Freedom):

Steve Biko: "We have to fill the black community with our own pride. We have to teach our black children black history; tell them about our black heroes, our black culture, so they don't face the white man believing they are inferior. Then we'll stand up to him in any way he chooses. Conflict, if he likes, but with an open hand, too, to say we can all build a South Africa worth living in; a South Africa for equals, black or white, a South Africa as beautiful as this land is, as beautiful as we are."

State Prosecutor: Your own words demand for direct confrontation!

Steve Biko: That's right, we demand confrontation. **State Prosecutor:** Isn't that a demand for violence?

Steve Biko: Well, you and I are now in a confrontation, but I see no violence.

There are instances in which people cross the line: you set your boundaries, but people don't respect them. For example someone may want to be intimate with you and consequently act inappropriately. If these occurrences are consistent and the perpetrator persists violently, then dialogue alone is not enough. In such a case you have the right to defend yourself physically. There are various organizations that offer training in self-defense. Participating in these trainings will help you to learn how to respond effectively when you are assaulted, and this can give you more confidence.

MIND YOUR RIGHTS February 2014

When a violation of rights leads to physical harm, it is important to seek medical assistance.

4. Seek Security

It is essential to seek the safety of public areas, like a shop when you're in a threatening situation and you feel that you cannot defend yourself. These places offer safety in numbers because you can walk in and ask for assistance. Avoid areas that put you at risk of being beaten, pushed, scratched, kicked, or even sexually abused. After an attack, the most important thing is to seek a safe place that reduces the chances of a repeat attack. If you can, approach someone who can stay with you until your safety is assured.

5. Seek Medical Assistance

When a violation of rights leads to physical harm, it is important to seek medical assistance. A medical officer will need to examine you and give you the treatment that you need. It is advisable not to wash yourself or change clothes before you go for treatment. In rape cases, there may be traces of the rapist's DNA left on your body or clothes. DNA is a chemical in the human body that can identify an individual. The doctor can take samples of the DNA, as evidence against the person who assaulted you. The doctor may also prescribe emergency contraception and anti-retroviral, which can prevent pregnancies and infections such as HIV/AIDS respectively. The doctor will conduct a medical exam after which a report will be filed detailing the harm caused to you and you will have access to that report.

6. Report to the Police

When you are assaulted you are encouraged to report the matter at the nearest police station where they fill out a P3-form. This is a form which you need to take with you to the police station to report a crime where there is harm or injury to the body. They may ask you to go to a cyber café to download and print out the P3-form, or they may give you the form and ask you to make a copy.

The police will need your ID number (if you are an adult) and the doctor's report. They will question you, write your report into the Occurrence Book (OB) and thereafter give you an OB-number. It is important that you don't lose this number so that you can produce it when the case is taken to court. If there was a witness, then they will be asked to record their statement.

If you were assaulted and there are traces of the person left on your clothes (e.g. blood or sperm), then you need to give these clothes wrapped in newspaper (not nylon or plastic) to the police so that they can use them for examination and as evidence. You need to go back to the doctor for them to fill in their medical report on the P3-form. After that, deliver the P3-form to the police. We encourage you to keep a copy for yourself in case you want to follow up on the case.

inform Yourself







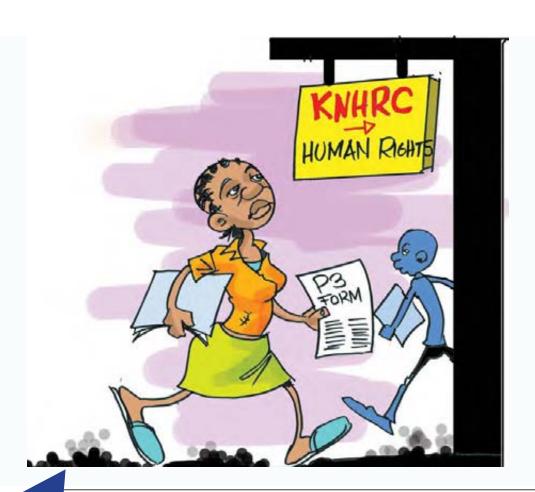
Often people feel uncomfortable identifying the accused because they fear that the accused will contradict their statement or may even want revenge. Take your time deciding what to do, and ask for support from someone you trust. You can report the case without giving details about the person until you feel confident enough about your security. You can ask for support in making the decision on how to follow up on the accused. All in all, it is advisable to report the case so the police can take action on the perpetrators to alleviate the threats they pose to you and society.

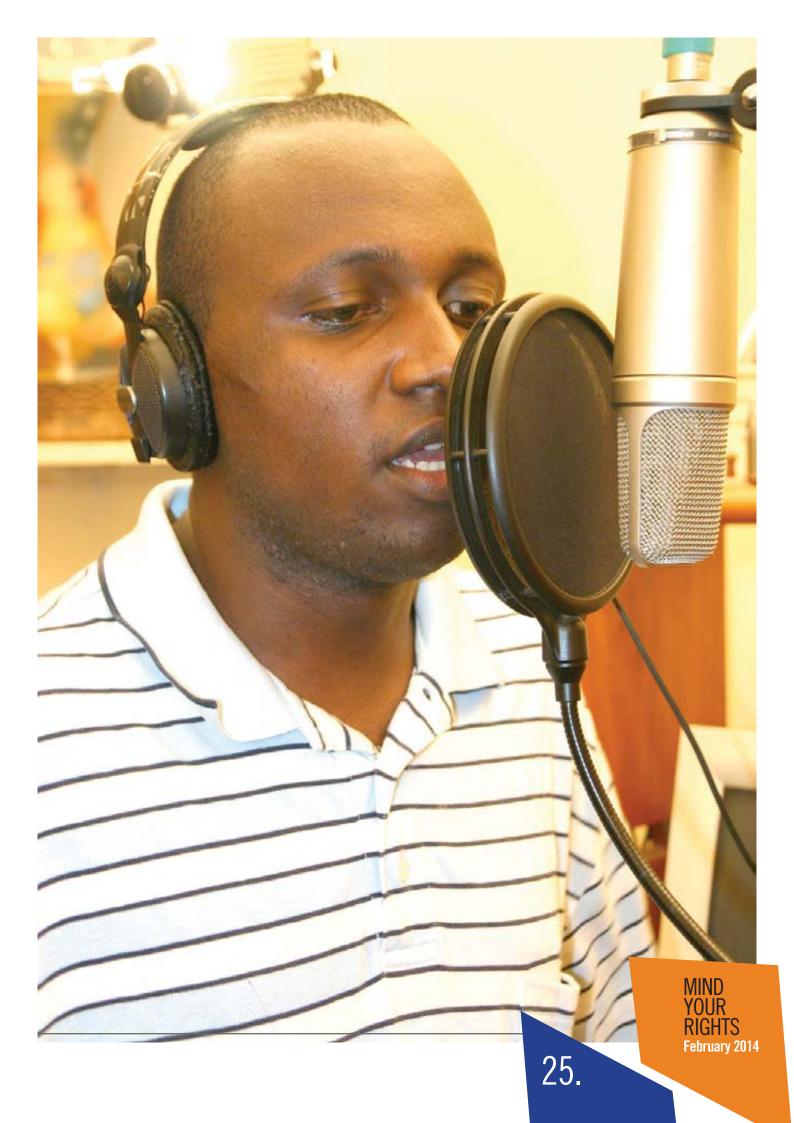
7. Seek Support from Human Rights Advocates

When you realize that people do not respect your rights and you cannot sort it out with them personally or with the help of the police, then there are various institutions where you can seek assistance.

There are public and private institutions that offer free legal assistance. The KHRC (an NGO) and Kenya National Human Rights and Equality Commission (KNHRC, a constitutional commission) are focused on all Human Rights issues, while others provide legal support (legal assistance in achieving your rights) to special groups, like women and children. Some organizations such as the "Child line" are easy to reach through over the phone (dial for free 116). At the last page, you can find information about the existing human rights advocacy organizations in case you wish to get in touch with them to receive support.

You could also seek the assistance of a lawyer who can inform you of your rights and how to seek justice when your rights are violated. A lawyer can represent you and take the case to court. However, most lawyers will require payment/compensation for their assistance necessitating one to first check on their charges and consider the affordability of such action.





8. Taking one to Court

Universal Declaration of Human Rights:

Article 7: All are equal before the law and are entitled without any discrimination to equal protection of the law.

Article 10: Everyone is entitled in full equality to a fair and public hearing by an independent and impartial tribunal.

When your rights have been violated and you have adequate evidence, you can proceed to court. A lawyer is able to explain the challenges and opportunities of filing the case. It is your personal right to decide whether or not you want to go to court.

All human rights cases are free to file at the High Court. This, however, does not mean that the lawyer (should you choose to use one) will represent you in court for free. You have to agree on a fee with him or her. Everyone has the right to effective access to justice (Article 48). This even goes further, where extra assurance of this right is given for Persons with Disabilities people hindered in their day-to-day activities due to physical and mental

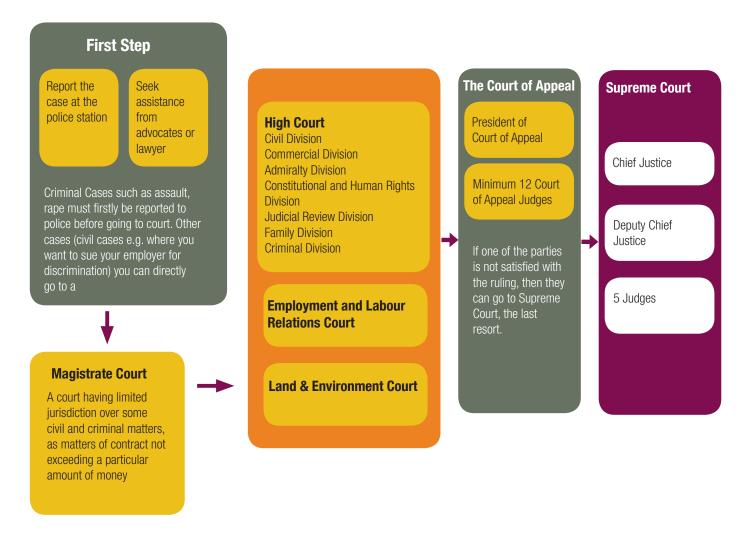
Judgments in Kenya are made by Magistrates and Judges of the Industrial Court, the Land & Environment court, the High Court, the Court of Appeal and the Supreme Court. The Supreme Court is Kenya's highest court which hears appeals (a request to change a previous decision) from the Court of Appeal.







System of Courts



System of Courts

Magistrate Courts: The Magistrate Court Judges deal with criminal and civil matters in their area. When the accused or victim is not satisfied with the decision of the Magistrate, they can appeal to the High Court.

High Court: The Judges of the High Court can answer the question of whether a right or fundamental freedom has been denied, violated, infringed or threatened. They hear appeals of cases handled by the Magistrate Courts.

Court of Appeal: This court hears appeals from the High Court and any other court or tribunal as prescribed by an Act of Parliament.

Supreme Court: This court hears cases relating to presidential elections and cases brought on appeal from the Court of Appeal. The appeals will involve the interpretation or application of the Constitution and anything else the Supreme Court or the Court of Appeal certifies as of general public importance. All courts, other than the Supreme Court, are bound by its decisions.

YOUR RIGHTS February 2014

5. CHAPTER FIVE

EQUAL RIGHTS FOR PEOPLE WITH EPILEPSY

Article 1 of Universal Declaration of Human Rights

All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood

Article 27 of the Kenyan Constitution, 2010

Every person is equal before the law and has the right to equal protection and equal benefit of the law

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

People with epilepsy share the same rights and obligations as anyone else. And the most important right may be Article 1 of the Universal Declaration of Human Rights, which states that we are all born free and equal in dignity and rights. This means, for example, that the right to have an opinion counts for the president of Kenya, as it does for you or any other global citizen.

However, there are groups in society that need some extra attention to be able to live a healthy fulfilling life.

These groups often miss out on chances to make use of their rights. For instance women only take 15 to 16 percent of top positions in business (Sheryl Sandberg, 2012), only ten percent of people with physical challenges go to school as children, and of whom only twenty percent would have a job in some countries (UNESCO, 2012). People with epilepsy are among the most vulnerable in society not only because of the condition itself, but also due to the stigma; this leads to discrimination and limitations in economic, political, social and cultural rights. (IBE, ILAE, WHO, 2012).

Therefore, both international institutions and countries have made special laws to give extra protection to vulnerable groups.

According to the Kenyan Constitution, Acts of Parliament and the International Conventions, people with epilepsy belong to various groups with special rights, such as:

1) Persons with Disabilities

According to the Kenyan Constitution and the Convention on the Rights of Persons with Disabilities, a person is disabled when they are hindered in their common day-to-day activities due to a physical and/or a mental challenge.



Wyre Kenyan musician

This means that a person with epilepsy is 'disabled' when their seizures hinder their day-to-day activities. However, when the same person with epilepsy takes medication which controls the seizures and enables them to undertake day-to-day activities, they are no longer viewed as disabled.



"I choose to not place "dis" in my ability."

Daddy Owen, Kenyan musician

Is Samson disabled?

Samson has epilepsy but doesn't let this condition stop him from being very active and hardworking. Last year he cleared form four and now studies and works. With the money he earns, he can pay for his visits to the doctor and the drugs he takes daily. As long as he takes his drugs and eats and drinks well, he is perfectly healthy and fit to work, study and socialize.

However, sometimes he forgets to take good care of himself and doesn't eat or drink enough. This causes dehydration which is a trigger of his seizures. In June 2012, he had to be admitted to hospital due to this dehydration. For more than a month he couldn't go to class and do his work because he needed to recover in hospital.

Is Samson disabled? Yes, he is disabled when he forgets to take good care of himself and has seizures. It hinders him in undertaking his day-to-day activities of work, study and socialization. But no, he is not disabled when he drinks and eats well while he takes his treatment, because then he is as active, or maybe even more active than any other person without epilepsy.

People who are hindered in their day-to-day activities due to physical challenges have equal rights to people who are not. Like anyone else, they have the right to be treated with dignity and respect and to be addressed and referred to in a manner that is not demeaning.

However, they have some extra rights: they have the right to reasonable access to all places, public transport and information. They especially have the right to access educational institutions and facilities for persons with disabilities that are integrated into society according to the interests of the person. They even have the right to access materials and devices to overcome constraints from their disability. Some people need more assistance than others to achieve this; therefore, it's a very useful right in the Kenyan Constitution.



2) Children

When you are 0 to 18 years old, you can make use of children's rights in Article 53. The most important right of children is the right to parental care and protection, basic nutrition, shelter and health care and the right to free and compulsory basic education (compulsory means that you must do it because of a rule or law).

3) Youth

You can make use of the youth rights when you're between 18 and 35 years old (Article 55). The rights of youth include the right to access education, training and employment and to associate, be represented and participate in political, social, economic and other spheres of life. In addition they also have the right to protection from harmful cultural practices and exploitation.

4) People with Non-Communicable Diseases

Epilepsy is a non-communicable disease; it is not infectious. People with epilepsy can make use of the statements in the Declaration on the Prevention and Control of Non-communicable Diseases (2011). This declaration states that these conditions are a serious threat to people's health and that the Government must respond effectively to their health care needs. The Kenyan Government needs to create access to efficient programs and health care interventions. According to the Declaration, the current resources for the treatment and prevention of non-communicable diseases do not address the seriousness of the problem.

CHAPTER SIX

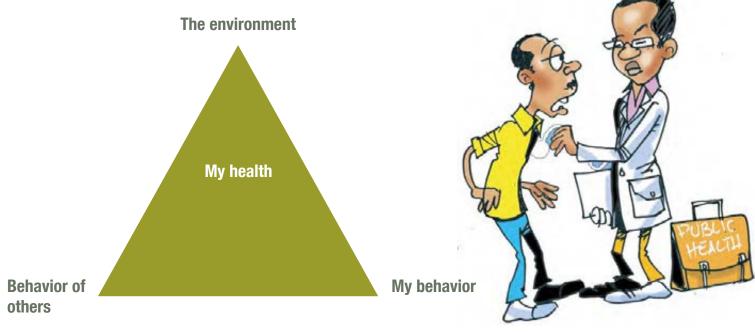
RIGHT TO HEALTH

Perhaps the most important right is the right to health: how important would the other rights be if we are not healthy enough to make use of them? You can't easily make use of your right to education if you cannot even think clearly due to the epileptic seizures. However, who is responsible for your health? You cannot only hold the Kenyan Government responsible for the state of your health.

Your health depends on various factors, such as the environment where you live: whether there is fresh air, clean water, safe roads, good security, food, whether you have the chance to get enough rest. It also depends on your own choices. There are people who live in a healthy environment but choose to live an unhealthy lifestyle; they may eat unhealthy, smoke, drink alcohol and decide to sleep late etc. Therefore, we can say that you are partly responsible for achieving your right to health.

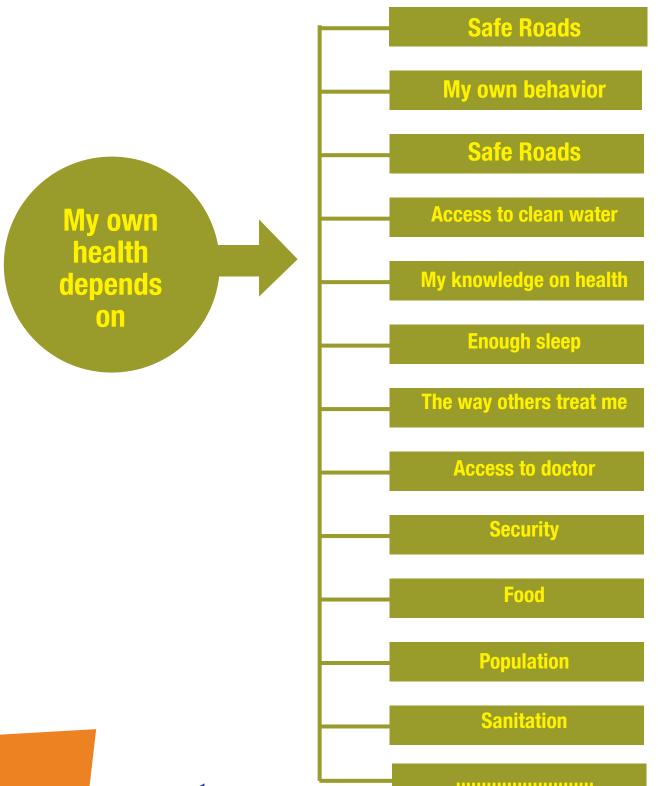
The environment may offer you the chance to live a healthy life and to take charge of your health. But in some cases it may hinder a healthy lifestyle, by for example denying you the chance to go to bed on time, or preventing you from going to a professional health provider.

When you miss out on one of the factors that contribute to good health, you need to ask yourself who is responsible for this. Could it be because you didn't take responsibility for taking good care of yourself? Did someone choose to deny you this? Or is the Government responsible as they do not provide an environment in which you can fulfill your rights?



Take a look at the following cases and mention who fails to ensure a healthy environment: the Government, the person with epilepsy or people in their direct environment.

- 1. Victor was taking anti-epileptic drugs as prescribed by his doctor, but the pastor of his church advised him to stop taking it, and to instead pray to God.
- 2. Viola has epilepsy. She sells vegetables but cannot get her anti-epileptic drugs because they're not in stock at the district hospital.
- 3. John needs to take his anti-epileptic drugs every evening. His parents pay for the drugs, but he secretly doesn't take them, because he's not convinced of their effectiveness.



Whose Responsibility is it to pay for your Epilepsy Care?

According to Article 43 CoK, you have the right "to the highest attainable standard of health, which includes the right to health care services."

The right to health includes the right to prevention and cure of diseases, as well as the right to the control of disorders such as epilepsy. It is your right to have available and accessible facilities of good quality.

The Constitution also says that the State shall give priority to ensuring the widest possible enjoyment of this right, considering the current situation for the vulnerable groups or individuals. According to Article 21 CoK, the State has the primary duty to observe, respect, protect, promote and fulfill these rights. This means that the Government has to give evidence that they have no money before they are allowed to shirk their duty. In the case where the government can prove it does not have the resources (which means that it is bankrupt and should get out of office), the court cannot then excuse it. However, it does need to give directions aimed at ensuring that the government fulfils its constitutional responsibilities (Articles 20. 1-4 and 23. 3 CoK). Article 21 does not allow the government (executive, legislature and judiciary) to be excused from its duties.

Access to Care

When you go to a hospital to receive treatment for your epilepsy, you are expected to pay. Most hospitals will ask you to pay first before you receive any consultation and/or treatment. However, if you urgently need care and arrive at the hospital while, for example, having a seizure, then the hospital has to give you treatment even before you pay (in such emergency situations).

When you go to a private hospital and you cannot afford treatment, then they have the right to refer you to a public hospital if you are not in acute danger. A private hospital is a hospital which is not from the government, but owned by individuals, a faith based institution, an association or NGO. The Public hospital instead is owned and governed by the State using public funds.

The private hospital can only deny provision of treatment without payment when it doesn't risk your health (Article 43.2 CoK). This means that a person with a status seizure (a seizure which continues unless doctors administer an injection) must be treated by each hospital where they are brought for first aid, even if the person cannot afford this.

What if I need treatment, but the drugs are not in stock or there is not enough medical staff?

A public health facility may be inadequately staffed or lack the type of drugs you need in stock. The Constitution makes it the duty of the government to ensure that all Kenyans enjoy 'the highest attainable standard of health' (Article 43.1 CoK). This means that it is the government's responsibility not only to ensure that you receive health care but that this care is of the appropriate quality. The quality is measured by such things as availability of health facilities, access to those health facilities, the number of health care practitioners including specialized ones like in the case of epilepsy, availability of drugs and cost.

Who has to pay for the health services you need? Your parents? Insurance? NHIF? Your employer? The one responsible for the fact that you need medical care?

Many people and/or institutions bear this responsibility (as has been seen above). The government has the primary responsibility of ensuring that health facilities, appropriate







adequately staffed and that all relevant drugs are available at an affordable price if not free of charge. If this is not the case and the problem is persistent in your local or nearest public health facility, it is important to enquire from the person in charge of the facility why this is so If the problem continues and an adequate answer or explanation is not forthcoming from the person in charge, you can report the matter to the health administrators such as the District or County Health Officer or Medical Officer for action.

The government must therefore ensure that all public health facilities are well-equipped. If the problem continues and an adequate answer or explanation is not forthcoming from the person in charge, you can report the matter to the health administrators such as the District or County Health Officer or Medical Officer for action.

If the problem is not resolved, it is advisable to raise the issue with your area representative, such as your County Assembly

Representative or Member of Parliament (MP). They, on your behalf, need to follow up the issue with the relevant county or national ministry in charge or raise the issue in the County Assembly or National Parliament as the case may be. Ultimately, through the Constitution of Kenya, you can also sue the health facility, county government and/or the national government in the High Court for failing to adequately staff the health facility and provide drugs which is a violation of your rights (Article 22.1 CoK)

Who has to pay for the health services you need? Your parents? Insurance? NHIF? Your employer? The one responsible for the fact that you need medical care?

Many people and/or institutions bear this responsibility (as has been seen above). The government has the primary responsibility of ensuring that health facilities, appropriate health and medical personnel and drugs are available to all Kenyans. By providing these, it is in a way paying for the health services you need. The

government must also ensure that these services are reachable, in terms of distance and affordability.

In an attempt to make health and medical care accessible to Kenyans, the government has set up the NHIF (http://www.nhif.or.ke/healthinsurance/). The NHIF membership is open to all employed Kenyans and their dependants. Therefore if you are a member, part or all of your medical costs shall be met through NHIF according to the terms and conditions.

Alternatively, if you have private medical insurance cover, then the company that has covered you should meet the costs according to the terms and conditions of your cover. If you are a child, then obviously beyond the government, your parents or guardians have the responsibility of meeting your health care costs if they can afford it. That is why it is important for the government to ensure that the costs of health and medical care are free or kept at a minimum.

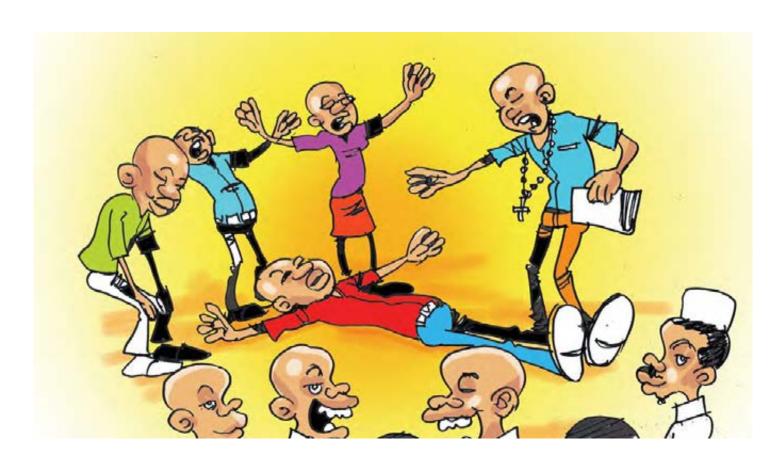
Finally, if a person causes you to be in need of medical care, for instance if a motorist hits you with his vehicle, then the motorist should be responsible for your medical care to the extent agreed or determined by a court of law.

What if the ones responsible do not want to take ownership? What if they say that they cannot afford it?

Where an institution or a person neglects their duty of care, it is important to report them to the relevant authority. For instance parents who willfully fail to provide medical care to their children can be reported to the area Children's Officer. In their absence, the area Chief of Police can take up this responsibility. If it is a public institution, then those in charge of health in the area such as the Health Officers or Medical Officers should be notified. Ultimately a person, even the government, can be taken to court to explain why they have failed in their duty. If the claim is that they cannot afford it, they must clearly show (and especially for the government) why. This must be looked at in the context of what they have already tried to provide with the available resources. It needs to be questioned whether this is truly the best they can do at that moment and what they plan to do in the future to improve the situation.



YOUR RIGHTS February 2014



Right to First Aid

In most cases, a person with epilepsy needs to get assistance during a seizure to ensure their safety. For example, when the seizure happens on the streets, they need to be guided or even carried to the side of the road to avoid any harm. But are people obliged to assist? We know that many people do not know how to give first aid to someone with an epilepsy seizure. You therefore cannot blame people for not assisting as long as they are not on duty. A stranger on the streets can assist, but is not obliged to do so, whereas if you have a seizure in a hospital and trained medics deny you first aid, then you can hold them accountable. This is because they have the obligation to perform their duty during working hours.

Instead of blaming people for not knowing how to assist someone during a seizure, it is more useful in the long-term to take charge and teach them how to give first aid during a seizure.

When someone purposely refuses to give First Aid

If you need medical care, but someone purposely keeps you away from the provision of health services, you can hold them responsible for denying health services.

In 2011, Salim got a status seizure, which made him unconscious and in need for emergency care from a professional medic. Salim was trained on how to give first aid, and he knew that if the seizure lasts longer than five minutes, the person needs to be brought to a doctor for medical care. However, when he had the status seizure, his mother didn't want to take him to hospital because she didn't trust the efforts of the doctors. Even the social worker at the Ministry of Youth Affairs couldn't convince her to take him to hospital. Therefore they had to call the Chief who ordered people to take him to hospital. The chief was authorized to do this because when somebody cannot make choices for themselves anymore and their immediate family refuses to take them for emergency care in hospital, the Government then takes this responsibility. Unfortunately it took too long to get Salim to hospital, and he died of the seizure.

If a person with epilepsy cannot choose for them self whether to be admitted when their life is in danger, and the family doesn't want to take them to hospital, then the chief or other authorized officers (e.g. Children's Officer), is responsible for taking them to hospital if notified. These officers therefore need to be informed of the situation. We encourage you to inform the chief or other authorized officer if you are witnessing a situation where a person with epilepsy is denied health services and cannot choose for themselves.

What if the hospital took too much time to take the necessary measures?

If a hospital unnecessarily takes too much time to take necessary measures, this amounts to negligence and is a violation of your rights. The hospital can be sued in a court of law for liability and compensation if it fails to accept liability and compensate adequately in the first place.

Health Insurance

Every working citizen has the obligation to be insured with NHIF, a national health insurance which covers a part of your health care costs. Monthly contributions depend on your income and whether it is from formal or informal employment or from self-employment. Typically the employer deducts the NHIF contribution from your salary.

Besides the NHIF, you can also get extra health insurance which covers more of your health care costs. However, people sometimes experience challenges seeking health insurance when they have epilepsy. Most companies take you through a medical test before providing insurance coverage. This is actually not legal because health insurance companies are not allowed to exclude you from any services their health insurance offers based on your medical background.

Article 27 (4) CoK protects a person against discrimination on the basis of health status amongst other grounds. Therefore, an insurance company would be violating the rights of a person with epilepsy if they refused to cover them on that basis. They are not allowed to give you insurance where they exclude some medical services in the coverage.

Quality of Care

Having access to care is not enough. It is very important that the care offered to you is of good quality. Going to a hospital and being treated makes you the customer of the hospital.



Doctors can only practice if:

They are certified for their profession. Without certification they are not allowed to treat you as a patient. You can confirm their registration online.

The private and public hospitals therefore, have the obligation to respect your consumer rights. One of these rights is that their goods and services are of reasonable quality, and that they protect your health and safety (Article 46 CoK).

One of the ways that the Kenyan Government protects your health and safety in health care is by allowing doctors and other medical practitioners to practice only if they are certified. Doctors who do not have the certification are not allowed to treat you as a patient.

What are your rights when a doctor has given you the wrong treatment?

If a doctor knowingly or unknowingly misdiagnoses and consequently gives you the wrong treatment, then that is professional negligence and should be prosecuted in a criminal court. They may be ordered to compensate you. Depending on the gravity of their actions, they may have their license withdrawn. Other wrongdoings include sexual violations, where the practitioner can be arrested and charged under the Sexual Offences Act.

Who has the Right to give you Epilepsy Care?

When a person gets epilepsy seizures and needs to get treatment, there are various types of practitioners that they can choose to go to. There are professional health practitioners who have received training which is acknowledged by the Kenyan Government. We also have people who learned it through other ways, for example taught by a family member or as some say that God gave them the skills. Does that give them a right to treat your epilepsy? Let's take a look at the list below, and give your thoughts of who is qualified to prescribe treatment for people living with epilepsy.



Do they have right to decide what Epilepsy Care you need?	YES	NO	Do they have right to decide what epilepsy care you need?	YES	NO
Your Parents			Traditional healer		
Religious Leader			Foreseer		
Community Health Worker			Social Worker		
Witchdoctor			Yoga Teacher		
Psychologist			Counselor		
Dentist			Neurologist		
The Shopkeeper			Gynecologist		
Herbalist			Astrologist		
Grandparents			The Chemist		
The Neighbor who works as a cleaner at the hospital			Nurse		
General Practitioner			Village Elder		
Your Teacher			Income		
Spiritual Healer			Youth Leader in Church		

Whereas most non-medics encourage others to seek medical assistance from professional doctors, some prohibit or discourage others from seeking conventional treatment and may encourage one to seek spiritual or other guidance instead. Some people make use of both; they take the treatment as prescribed by the doctor while they also ask their religious leader for divine intervention.

In some cases, non-medics can tell you that they can cure your epilepsy, or that a person with epilepsy doesn't need to take Anti-Epileptic Drugs anymore. This can be a risk to your health. Seizures can come back in an even greater form if you abruptly quit using your drugs without your doctor's consent.

To avoid these practices, the Kenyan Government has set up rules for people to get permission to work as medical practitioners. When they have completed the required studies, they receive a license which must be prominently displayed at their place of practice. However, some doctors also practice outside their offices, and therefore cannot show their license everywhere they work.



You have the right to ask for:

The diagnosis;
The cause of your condition;
The various options for
treatment;

The side-effects of treatment; When you need to get back for follow up .consult If you have doubts about your doctor's qualifications, you can search online to confirm if they are licensed for their profession. The website that gives you the list with licensed doctors in Kenya is www.medicalboard.co.ke.

Can you demand money back if someone gave you treatment, but you find out the person is not licensed? YES. It is also your responsibility to report this person to the Health or Medical Officers and to the Police.

Can you demand compensation for provision of wrong information? YES.

Provision of wrong professional information (it could be that you asked for directions to a place!) can also amount to professional negligence and compensation can be demanded for this. The ultimate way of doing this is through court especially where personal responsibility is not forthcoming from the provider of the information.

Can you demand a health provider's license of services be revoked if they gave wrong treatment? YES and this can happen as explained above if a court of law sees this fit. Alternatively they may be asked to compensate and have their licenses suspended for a period.

Right to Information

When you visit the doctor to be treated for your epilepsy (or any other condition), you have the right to ask the doctor questions about their diagnosis and prescription. They are responsible for answering these questions even when they are overwhelmed with patients. You deserve an explanation about the condition you have and about the treatment options. You have the right to be involved by the doctor in the planning of your epilepsy treatment (Article 25, CRPD).

When the doctor shares information about the condition with you, you will be able to understand it and know how to take good care of yourself. Being involved in the decision of your treatment may also make you feel more motivated to consistently take the medication.

Doctors are responsible for the keeping of clinical records. Sometimes they give them to you to keep while others keep them at their medical facility. If they keep the records at their facility, then you have the right to free and full access to it (Article 35 CoK).

What is your right when doctors say that they lost your documents?

All that a doctor or medical practitioner does in the course of treating you amounts to the required professional duty of care including keeping your documents safe and secure. A loss of your documents can therefore amount to professional negligence and can attract legal action and consequences, if proven.

Right to Respect

Every person has an inherent dignity and the right to have that dignity respected and protected (Article 28 CoK). Also a person with a disability (someone who is hindered in day-to-day activities due to physical and/or mental challenges) must be addressed and referred to in a manner that is not demeaning (Article 54 CoK). This means that everyone needs to show appreciation for who you are and what you stand for, including your doctor. The doctor needs to take what you tell them seriously and respond to it by giving their feedback.

When you feel that people do not respect you, by for example ignoring you or not taking your opinion seriously, then you have the right to ask for your rights to be respected. The doctor may know more facts about epilepsy, but that doesn't make you less important. The doctor can only make a good diagnosis with your involvement. The doctor needs information about your medical history, and that includes your own experiences and opinions about the condition and how you have dealt with it so far.

We encourage you to ask the doctor for clarifications about the diagnosis and treatment, so that you can understand their prescription better. When you do not have faith in their treatment, you need to share with the doctor why that is so. In most cases you will achieve much more with the doctor if you engage them in a dialogue about the treatment.

Right to a Second Opinion

In any work environment people make mistakes and medical practitioners are no exception. A doctor may therefore make an incorrect diagnosis and prescribe treatment that doesn't help control your seizures.

You have the right to question their performance if you doubt the diagnosis or prescribed treatment of your doctor. It may be useful to visit another doctor for a second opinion, to get their views about your health status and what treatment you need. A second opinion is the diagnosis of a second doctor who conducts a medical examination and compares their diagnosis with the diagnosis of another doctor.

The second doctor may confirm the diagnosis and prescription of the previous doctor, and by doing so give you confidence in the initial treatment. In case there is a change, it is important to ask for clarifications as to why they changed the diagnosis, and if they understand why the other doctor came up with the other diagnosis.

Article 31

Every person has the right to privacy, which includes the right not to have— (a) their person, home or property searched; (b) their possessions seized: (c) information relating to their family or private affairs unnecessarily required or revealed; or (d) the privacy of their communications infringed.

Kenyan Constitution

> MIND YOUR RIGHTS February 2014



Right to confidentiality:

Sometimes people avoid going to a doctor as they feel embarrassed to open up about their epilepsy seizures. They may fear that it can affect their reputation if people learn what they have. There's no reason to feel embarrassed about epilepsy because it can happen to anyone, anywhere and at any time. However, it may encourage people to know that the doctor is expected to keep information about their patients confidential.

As we have the right to access information about our treatment, we also have the right to confidentiality. This means that the doctor is not allowed to disclose any information about your treatment to anyone else except to you and their colleagues. They are not allowed to share it with anyone who is not involved in the provision of the health services offered to you.

This confidentiality is important to make you feel comfortable to share your private challenges with the doctor. It helps you to open up about your experiences when you know that people in your community will not learn about your private issues.

Even when you move to another doctor, your initial doctor still has to keep your information confidential. However, your new doctor may require your medical history from your previous doctor. They are only allowed to provide your information to third parties with your informed consent.

CHAPTER SEVEN

RIGHT TO FREEDOM

Besides our right to health, it is important to have the right to freedom (Article 29 CoK). This means that nobody has the right to lock someone up. There are instances where people with epilepsy are kept indoors; this violates their right to freedom and movement (Article 39 CoK). This may take place if family members feel embarrassed about the condition, or if they are afraid that something bad will happen outdoors when the person with epilepsy has a seizure. It is important for them to get educated that most people with epilepsy live an active life as long as they take their medications as prescribed by the doctor, and that epilepsy is nothing to feel embarrassed about. It can happen to anyone at any place and time. People with epilepsy need their interaction outdoors as much as anyone else and deserve to have the freedom to choose what they want to do with their lives.



Atieno was taken to a traditional healer in the hopes of being cured of epilepsy. The traditional healer put her in a hut for several days. In the hut was a fire burning, and she had to stay in the hut with smoke while being naked. When she couldn't handle it anymore, she escaped and ran to one of the nearest homes to ask assistance. These are practices that are a form of torture and denial of freedom, and are therefore not allowed.

CHAPTER EIGHT

RIGHT TO SECURITY

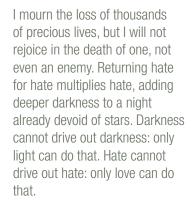
While we make use of our freedom, we also have the right to security wherever we spend our time (Article 29 CoK). This means that nobody has the right to torture anyone in any manner, whether physically such as beating or pinching) or psychologically (such as humiliating or scaring someone with words).

There are various reasons why people carry out attacks. Some do it for criminal purposes, such as during a robbery. Others do it out of disagreement: on a small scale, a fight between two people or on a larger scale, the Post-Election Violence in 2008 that involved the whole country.

We all have the right to security, not only when we are outdoors at school, work, in church or when you visit friends, but also indoors. This means that you are not allowed to be beaten or spanked by your parents, even if it's with the intention to discipline you. This is an argument which is often given- that spanking is necessary to teach children, youngsters or even a partner morals. However, according to Article 29 CoK this is no longer legal.

While we have the right to security, we also have the obligation not to attack people. This means that when you're annoyed, you don't express your anger through aggression, but through dialogue. Violence doesn't solve conflict, but dialogue helps in creating understanding with each other and assists in finding a solution together. In order to resolve conflicts amicably it is advisable to wait until tempers cool down before confronting your contender.

People above eighteen are eligible to report to the police, because they are capable of giving an account of what happened. However, when one is bellow eighteen, the police can arrest the offender based on the evidence of other witnesses who are older than eighteen.





- Martin Luther King



CHAPTER NINE 9

HOUSING

According to the Kenyan Constitution, every person has the right to accessible and adequate housing, and to reasonable standards of sanitation (Article 43.1b CoK). However, you are expected to arrange your own housing, but if you are a minor, then it's your parents' responsibility.

While we have the right to accessible housing, we also have the right to have our privacy in this housing (Article 31 CoK). People with epilepsy who are hindered in their day-to-day activities can make use of Article 19 and 22 of the Convention on the Rights of Persons with Disabilities (CRPD). It states that they have the right to live independently and to be included in the community while they also have the right to conduct their lives in private as their privacy must be honored and protected. This same Convention requires that people with epilepsy have the right to choose their place of residence, where and with whom they live, on an equal basis with others, and they are not obliged to live in a particular living arrangement (Article 19a, CRPD).



According to the Kenyan Constitution, every person has the right to accessible and adequate housing, and to reasonable standards of sanitation (Article 43.1b CoK).

MIND YOUR RIGHTS February 2014

CHAPTER TEN

FREEDOM OF OPINION, EXPRESSION AND CHOICE

As we grow up, we're taught values and norms: what is right and what is wrong. These values and norms are not fixed, they are different in every culture and even among individuals.

There is a difference between facts and opinions. Facts are fixed and can't be negotiated. We do not need to discuss if red is a color. It's a fact that red is a color. Instead, we can discuss if red is a beautiful color, because this is just an opinion, and not a fact. You may love the color red, while someone else may strongly dislike it. The good thing is that we have the right to have our own opinion, to disagree with people and to speak this out (Articles 19 and 33 CoK).

The fact that you have a different opinion doesn't have to create a problem. It would only become a problem if someone denies another person their right to speak for themselves. It's important that everyone has the space to share their opinion inasmuch as it's everyone's role to give space to others to also share theirs.

Finally, whatever other people's opinion is, you have the right to choose for yourself what you stand for and what you want to do in life. The right to choice doesn't mean that everything is offered to you to achieve your wishes. Your choices need to be realistic and achievable as they shouldn't conflict with the rights of others either.

Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.

Article 19, Universal Declaration of the Human Rights



CHAPTER ELEVEN

FREEDOM OF CONSCIENCE AND RELIGION

Just as we are allowed to have our own opinion, each of us also has the right to have our own conscience and religion. There are various views of what is the right conscience and religion, but conscience and religion is something you can choose for yourself, it's not something you are born with. In the Constitution every person has the right to freedom of conscience, religion, thought, belief and opinion. Nobody can deny anyone access to any institution, employment or facility because of a belief, just as nobody can force you to act, or engage in any act that is contrary to your beliefs (Article 32 CoK).

We, the people of Kenya-

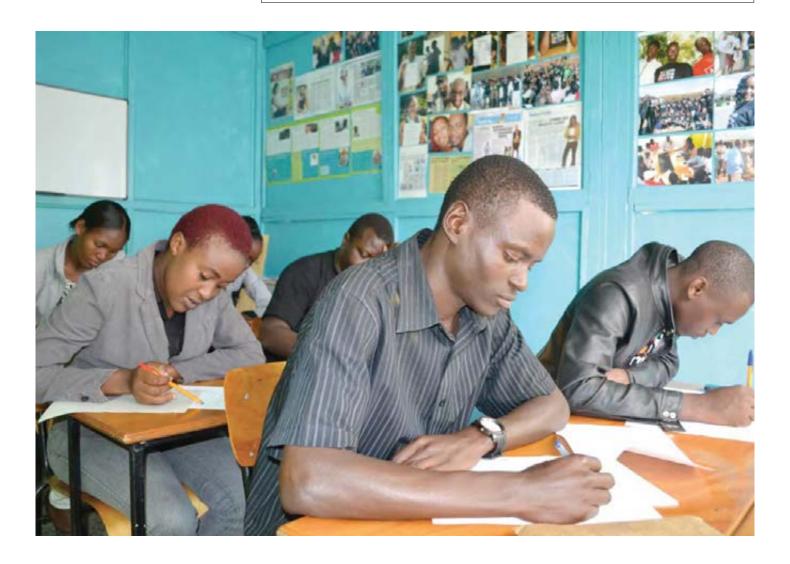
PROUD of our ethnic, cultural and religious diversity, and determined to live in peace and unity as one indivisible sovereign nation

Kenyan Constitution, 2010



12. CHAPTER TWELVE

RIGHT TO EDUCATION



According to Articles 53 and 55 CoK, the state has a responsibility to ensure that youth (between the ages 18 and 35) have access to relevant education and training. If you want to get an education, you have equal rights as others to attend school. This means that you have the right to free primary education as a child (until the age 18). Therefore, nobody is allowed to deny you access to education; teachers at school and care takers need to encourage and support a young person's attendance at school. While primary education is free for children, you may have to pay for Secondary education and other forms of schooling. The Kenyan Government is obligated to ensure that the required costs don't hinder your access to education.

Schools are required to give equal chances to attend classes to all children and youth. This means that they are not allowed to deny anyone admission because of their epilepsy. However, when teachers feel someone needs extra assistance in their education, they may refer them to a special school.

When you are hindered in your day-to-day activities due to your epilepsy, you have the right to access educational institutions and facilities that are integrated into society with your interests (Article 54 CoK). This means that the Kenyan Government has a responsibility to provide you with the chance to attend a school where they can give you the right assistance during seizures and also where you have the chance to get good education.

Let's take a look at Mutwiri who knows that he has the right to education:



Mutwiri wants to go to school, but his father wants him to stay home because of his seizures.

Dad: Mutwiri, you had better not go to school, you may get a seizure again. People will gossip about the wrongdoings of our family.

Mutwiri: But I need to go to school to learn, otherwise I won't pass the exams.

Dad: No! It would be an embarrassment if you get a seizure and everyone watches.

Mutwiri: But it's my right to go to school, and it's my teachers' duty to give me first aid if I have a seizure at school. I don't think my epilepsy is an embarrassment, it's not our choice and it's not our wrongdoing, it can happen to anyone.

Dad: Yes, but it's also your right to be protected from harm. It's too much of a risk to you if you go to school while you can have a seizure. You're not sure if people will assist you during the seizure.

Mutwiri: We can speak with the teacher, and tell them how they can help me during the seizure. I can go to school together with my friend Sam, if I have a seizure we know that he will help me.

Dad: Well, let's see what the teacher has to say. Let's consult them next week to find the best solution where we do not take too many risks.

MIND YOUR RIGHTS February 2014

CHAPTER THIRTEEN

Eniloney is

Epilepsy is not a reason for people to be excluded in social gatherings. People with epilepsy can participate in education, sports, religious meetings and all other sorts of social gatherings just like anyone else.

SOCIAL INTERACTION

Social interaction is one of the most important needs in life. Social interaction is what we all need to achieve all our other rights, such as the right to have a family, the right to express your opinion and the right to education. Epilepsy is not a reason for people to be excluded in social gatherings. People with epilepsy can participate in education, sports, religious meetings and all other sorts of social gatherings just like anyone else. The condition doesn't take away one's right to take part in these meetings. The right to community integration is even specifically protected in the International Bill of Rights. Whose responsibility is it then to have people with epilepsy participating in all social gatherings? Is it the Government's, the people who don't have epilepsy, or is it the responsibility of the people with epilepsy? According to the constitution, all people have the right to be treated equally. Therefore, people with epilepsy need to take initiative to be socially active as much as anyone else and other people have a responsibility to not deny their attempts to take part in social events.

We mentioned earlier that, in some cases, people with epilepsy are encouraged to stay indoors, as the family may feel embarrassed about the condition. This is not accepted since "every person has the right to freedom" (Article 29 CoK). In cases where the family is not open about the condition and wants to hide the family member with epilepsy, we encourage them to seek advice from the doctor and maybe even counselors to get to know that epilepsy is nothing to feel embarrassed about and that they can easily participate in social activities just like everyone else.

Another reason they stay indoors is that people with epilepsy sometimes have low self-esteem because of the seizures they experience and may lack the courage to take the initiative to socialize.

According to the CRPD (article 26), the Government is responsible for taking effective and appropriate measures. This includes peer support to enable persons with disabilities to attain and maintain maximum independence and full inclusion and participation in all aspects of their life. Fortunately, there are various local initiatives where people with epilepsy can take part in and be encouraged to overcome the challenges in order to take part in social interactions.





MIND YOUR RIGHTS February 2014

CHAPTER FOURTEEN

Whether or

Whether or not you have epilepsy, you have the choice to allow or deny intimacy.

LOVE, SEX AND MARRIAGE

The Constitution states that everyone, including people with epilepsy, has the right to equality (Article 27 CoK). This means that everyone has the right to decide whether they want to be close with someone. Whether or not you have epilepsy, you have the choice to allow or deny intimacy.

When you get to know someone well and you feel that the person is the type you'd like to be close with, it's advisable to be open about who you are, your strengths and challenges. It is your right not to tell them you have epilepsy, but how can they assist you during a seizure if you do not tell them about it? They may feel disappointed that you kept it a secret from them, and they may decide to leave you.

The choice is yours, although we encourage you to be open about your health since epilepsy is nothing to feel embarrassed about. We believe that a person who truly loves you will take you with all your strengths and challenges. Just remember that epilepsy is a small part of who you are. It's neither your character nor your personality; it is only a disruption in your brain when you have a seizure. Take time to explain what it is, so that people can understand you better and be there for you, for better and worse.

Intimacy and intimidation

In our interaction with people, we all have our preferences about who we want to spend our time with. There are people with whom we want to be close to and people we'd rather keep at a distance. People may get close to you with or without your consent. Intimacy is being close out of your own choice; intimidation is being harassed by someone.

Sometimes people say that girls actually mean YES when they say NO. Nonetheless, the reality is that everyone has to respect and accept someone's 'no' to intimacy.

Intimidation is not allowed by law - nobody is allowed to get intimate with you against your own will. When someone begins to get physically close to you against your will, you can start by being assertive and speaking out where your boundary is, you can say:

- 1. I like you as my friend, but I don't want you to touch my thighs.
- 2. I know that the matatu is full, but I still don't want you to hang so much over my shoulders.

- 3. I think you are standing very close to me, I prefer more distance.
- 4. I know we are "brothers and sisters in Christ", but you don't have to hug me.

The person to whom you speak may offer apologies and avoid doing it again, or they may do it again. If it happens again, you can be more clear and firm in your statement. Your own boundary must be appreciated regardless of their opinion.

If the person doesn't respect your boundary, then the person doesn't respect your right. When you miss the chance to defend yourself, it's important to seek assistance.



Triza and Sam are good friends, but Sam likes Triza so much that he wants to be closer to her. He starts hugging her and wants to kiss her.

Triza: Hey, I don't want you to kiss me.

Sam: But I like you, I need to express my love.

Triza: You can also express your love through words. If I don't want you to hug and kiss me, you need to keep off of me. I have the right to set my boundaries and you have the obligation to respect that.

Sam: Why are you being so difficult? Can't you just simply enjoy it? You are really fragile!

Triza: I know I'm not fragile, but simply telling you what I want and don't want. I know it's my right to choose when I want to get intimate. When I set my limits, you need to respect them to be able to be my friend.



Remember to always and very carefully ask yourself if you are certain that you want to have sex. Don't have sex just because you think that everyone else is doing it or to give in to pressure from friends or adults.

Sex

People have various reasons for having sex. They may want to have sex to show their love for someone. Other people may do it out of curiosity to know how it feels. These are examples of those who want to do it out of free will. Unfortunately sometimes people do it for other reasons such as peer pressure to be a 'real man' or to be an 'experienced woman'. Or they may give in to having sex out of fears of losing the person they love; fearing that he or she will take off if they postpone sexual intercourse.

Remember to always and very carefully ask yourself if you are certain that you want to have sex. Don't have sex just because you think that everyone else is doing it or to give in to pressure from friends or adults. If you are uncertain about what you should do in such a situation, wait and speak about it with an adult who you trust and ask their advice.

Sex is only allowed when you both agree to it, and legally when both of you are above 18 years old. When you are 18 years or older, and have sex with someone who is younger than 18, you can be prosecuted and jailed for this, even if both of you had agreed to it.

NB: The Sexual Offences Act requires that everyone take reasonable steps (for instance asking for I.D. especially where the age cannot be ascertained just from looking) to ensure that the person they have sex with is over 18.

Marriage

According to the Kenyan Constitution, every adult has the right to marry a person of the opposite sex, based on the free consent of the parties (Article 45 CoK). This right cannot be hindered due to someone's ethnicity, nationality, religion or health status (Article 27 CoK).

The Constitution also states that every person, which includes a person with epilepsy, is equal and has the right to equal protection and benefit of the law (Article 27 CoK). Having epilepsy doesn't take away the right to be treated with dignity and respect and to be addressed in a manner which is not demeaning (Article 54 CoK). Therefore people with epilepsy have equal rights to get married and to start a family.

When you're married, both partners have equal rights; both are responsible for taking good care of each other. This means that having epilepsy doesn't change your position.

Pregnancy and abortion

Most people with epilepsy can have children. Like anyone else, they have





the legal right to have sex from the age of 18, and therefore the right to become parents from 18 years of age. In most cases, epilepsy doesn't affect the health of the children. Epilepsy is therefore no reason to be denied the chance to have children. When planning to become a parent, seek medical advice. This is because anti-epileptic drugs sometimes need to be adjusted to ensure that the baby is not affected.

Protection from pregnancy

It is your right to choose when you're ready to become a parent. It's not your parents or your spouse alone who tell you when the timing is right. Both you and your partner must





feel ready to take on the responsibility of pregnancy and the upbringing of the children. When you do not feel ready to have children, you need protection from pregnancy as much as anyone else. You can decide to abstain from sex until you feel ready to have children. If you do not want to abstain from sex, you can choose other ways to prevent pregnancy:

- 1. Male or female condom
- 2. Contraceptive coil (IUD, intrauterine device)
- 3. Contraceptive pill
- 4. Contraceptive injection

Even though they all work to prevent pregnancy, it is only the first that can also prevent infection from STDs. The last three options can be used in a relationship where the couple is faithful and don't sleep with other people.

Unplanned pregnancy

A couple may have unprotected sex, or they may use a condom, but it breaks. In such a case the woman may conceive within the first 72 hours after intercourse/having sex.

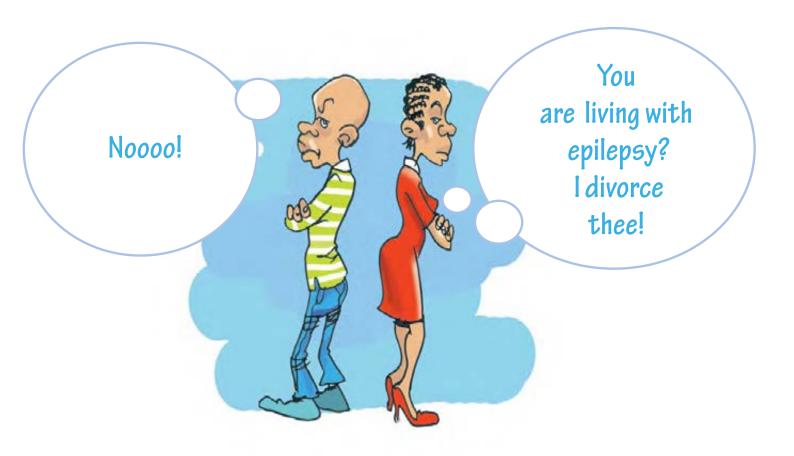
In such cases there are various measures the woman can take to avoid an unplanned and unwanted pregnancy. One of the options is the emergency contraceptive, which must be taken within 72 hours after sexual intercourse. When no action is taken within the first 72 hours, then there is only the option of abortion to end the pregnancy in countries and situations where it is legally accepted.

According to the Kenyan Constitution, abortion is not permitted unless there is need for emergency treatment in the opinion of a trained health professional or the life or health of the mother is in danger (Article 26.4 CoK).

Divorce

People who are married may experience challenges in their relationship, which can lead them to consider divorce. The court can approve a divorce if both parties show that there is no love between them anymore, after a minimum of three years of marriage.

According to the Matrimonial Causes Act (Section 8), a person is not allowed to divorce you because of your epilepsy. A person would only be allowed to leave you if you have become of incurable unsound mind while you've been under care and treatment for a period of at least five years. Most people with epilepsy are not mentally challenged, and it can therefore not be



said that they are of unsound mind. When you are in a marriage where you are not secure, for example because you are denied your freedom or good care by your partner, then you have the right to leave the house. Safety comes first. If you cannot find a solution together, it may be better to file for divorce than to stay in a situation where your safety is not assured. The person requesting divorce must prove to the court that the divorce is justified. The party must prove that their case fits within one of the few grounds for divorce. A divorce can be approved if the partner has:

- 1. Committed adultery
- 2. Left their partner without cause for a period of at least three years
- 3. Treated their partner with cruelty or
- 4. If the partner is incurably of unsound mind and has been continuously under care and treatment for a period of at least five years

CHAPTER FIFTEEN

WORK

Article 23,

Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment.

People with epilepsy can work just like anyone else and therefore have equal rights to be employed or start their own business. According to the Persons with Disabilities Act, 2003, every employer (both private and public) is required to provide 1 out of 20 jobs to persons with physical or mental challenges (Persons with Disabilities Act, 2003). This is in accordance with the Kenyan Constitution which guarantees the right to work for every person. It's the responsibility of the Kenyan Government to provide equal opportunities for appointment, training and advancement at all levels of the public service. They also need to promote employment in the private sector and to ensure that reasonable accommodation is provided in the workplace (CRPD, Article 27).

Avoid jobs that are risky when you have seizures in daytime

It's your duty to avoid jobs that are too risky in case of a seizure. If you know that you can get a seizure at any time, then it will be risky to be a driver or to work in construction at great heights. Imagine if you're constructing on the 15th floor and you collapse due to the seizure. Or you're on the highway and you get a seizure before you get the chance to park the car, you would not only risk your own life, but also the lives of others. However, if you know that you only get seizures at night, then it shouldn't be a problem to do these jobs in daytime.

Safety and reasonable accommodation at work

Your employer is expected to ensure safety and a work environment that is open and accessible to persons with physical challenges. According to the Convention of the Rights of Persons with Disabilities, appropriate changes need to be made to ensure that persons with physical challenges can enjoy and exercise their duties on an equal basis with others.

Frequently Asked Questions (FAQs)

Can I be forced by others to work?

It is not legal to force anyone to work (Article 30 CoK). When you do work, it needs to be with your approval and that of the employer. However, this right is not an excuse to avoid any employment in life. You expect others to

financially take care of you if you don't take advantage of the available opportunities to work and earn your own income.

Do you have the obligation to inform your boss about your epilepsy?

It is your own choice whether to disclose your epilepsy during an employment interview. However, you may need to discuss with your potential employer whether your seizures could affect your ability to do the job safely and effectively. If the employer is not aware that you can have a seizure, they will not be able to prepare themselves to give you the right assistance when you have a seizure. While you're informing them about your epilepsy, also explain how they can give you first aid in case you have an attack.

If you apply for a job, are they allowed to do a medical examination?

This really depends on the job's nature and the reasons for the medical examination. For instance in piloting, several medical examinations including eyesight tests might be appropriate. Jobs requiring certain mental and physical fitness might require preemployment medical examinations testing the respective attributes. For example, it would be inappropriate and irrelevant to conduct thorough physical tests for a job where a person will largely be required to sit behind a desk and stamp documents. At times the medical examination might be in your interests because the employer wants to provide you with the appropriate work environment and medical coverage. However, if the medical examination is proven to be solely used to negatively affect your chances of getting the job, then this amounts to discrimination and is illegal and unconstitutional (Article 27 (4) CoK). You can sue the potential employer for discrimination and for denying you your right to work.

Are people allowed to deny you a job due to your epilepsy?

When you apply for a job, and you inform them about your epilepsy, they are not allowed to deny you employment because of your condition. Article 27 (4) CoK protects a person against discrimination on the basis of health status amongst other grounds and consequently a potential employer would be violating the rights of a person with epilepsy if they refused to employ them on that basis. This is also covered in the National Social Security Fund Act: physical and mental disabilities shall not be considered as leading to work incapacity. This would only be allowed if your seizures can be a risk to others or if it will affect the quality of your work. However, the challenge is that they can give other reasons for selecting someone else for the job. Therefore, it can be hard to prove that people do not give you work due to your epilepsy, and you cannot easily blame them or take them to court for it.

Are employers allowed to end your contract due to your epilepsy?

If you are working under a contract for longer than one year, the employer is not allowed to



A person with epilepsy cannot be dismissed from an employment because of their

epilepsy.

terminate your contract without fair reasons such as misbehavior. However, if you have been working for less than a year, and they find out that you have epilepsy, they may give other reasons for the termination (other than your epilepsy). One of the reasons could be that they are not satisfied with your performance regardless of your epilepsy.

What do I do if my contract was terminated unfairly?

According to the Employment Act, the termination of an employee's contract should not be based on "race, color, tribe, sex, religion, political opinion or affiliation, national extraction, nationality, social origin, marital status, HIV status or disability". This means that a person with epilepsy cannot bezz dismissed because of their epilepsy.

When you think that your employment was unfairly terminated for one of the above reasons, then you can deliver a complaint to a labour officer of the Ministry of Labour within three months of the date of dismissal.

The labour officer is required to ask both parties to explain their side of the story. Thereafter they may recommend that the parties seek the best means of settling the dispute. If the labour officer concludes that the termination of a contract was unjustified, they may rule that the employer pay the employee for the lost income.

In addition to filing a complaint with the labour officer, you also have the right to take the case to the Labour Court if you cannot arrive at an amicable resolution of the dispute with your employer. The court is normally the institution of last resort if all else fails. The court would then give directions and make orders to end the dispute.

Do you have a right to sick leave? How many days per year? If you take sick leave, are you allowed to do anything else besides visiting a doctor and staying indoors to recover?

Sick leave is a right to all employees in Kenya (s. 30 of the Employment Act). This can be given for a minimum of seven days. You must, however, produce evidence from a medical practitioner proving that you are sick and need such leave. Sick leave is available after you have worked for over two consecutive months whereby it is given for at least seven days with full pay and for seven days with half pay every contractual year thereafter. Obviously sick leave is given as part of treatment and therefore towards recovery from sickness. When people are sick, they are required to rest and are not expected to do

anything else other than those things that contribute to their getting better e.g. taking a walk around the neighborhood as part of rehabilitation of an injured foot. It would be in bad faith and perhaps fraudulent and therefore illegal for you to get sick leave and do other personal things like running your business or harvesting your "shamba".



Peter Nyette worked as an intern in a restaurant, and gained the skills as a waiter. The boss was satisfied with his performance and provided him a job. While he worked at the restaurant, he asked leave for one day to go to the doctor for treatment of his epilepsy. His boss was shocked to hear he had epilepsy and told him he didn't have to come back anymore. According to the Employment Act, it wasn't legal for him to get fired due to his epilepsy, but as he was still in his probation term, the boss had the right to terminate his job without giving a reason.

CHAPTER SIXTEEN

If you get a seizure while driving, you risk not only your own safety, but also the safety of other people on the road.

DRIVING

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

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

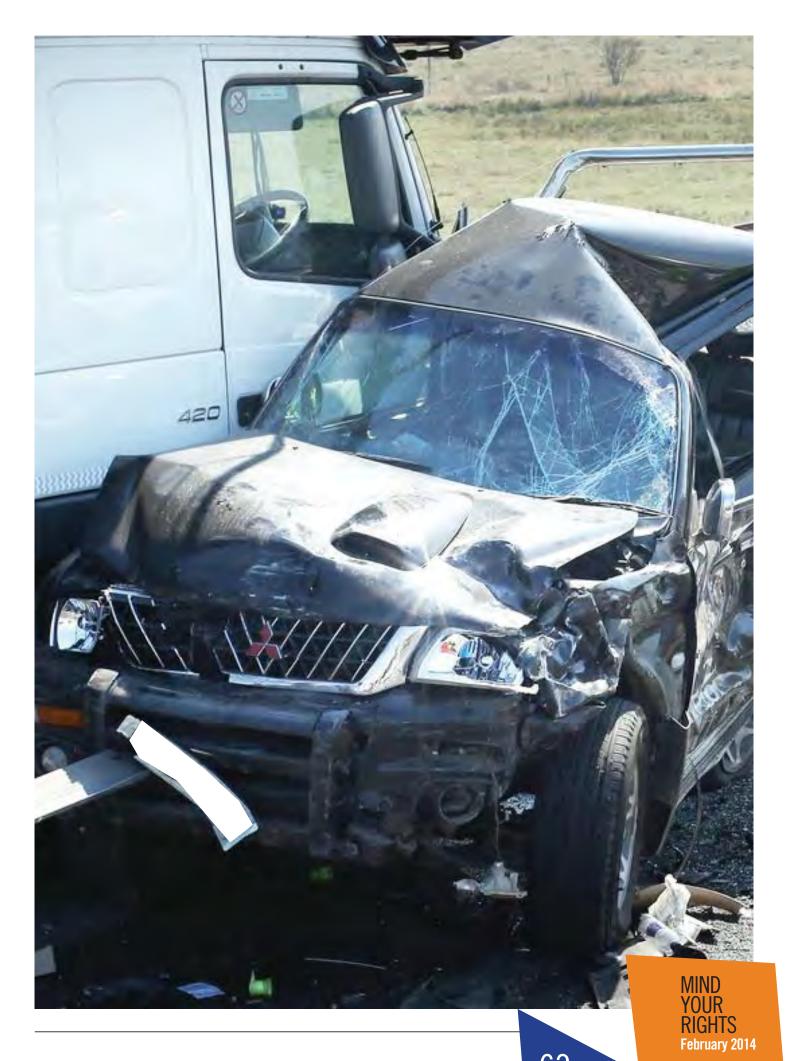
The risk of having an accident because of your seizure is greatly reduced in people who have been seizure free for 12 months. Therefore many countries allow you to drive if you've been seizure free for a year.

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

Is it punishable if your epilepsy seizure leads to a traffic accident and harms people?

You're taking a great risk if you decide to drive when you know that you may have a seizure. If you have an accident because of your seizure, and you knew of the chance of having a seizure, you can be held accountable for this despite the fact that you did not choose to have the seizure. You are expected to be responsible enough to make wise decisions such as whether or not to drive a car. Therefore people can take you to court.





CHAPTER SEVENTEEN

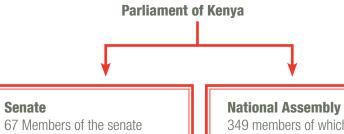
Article 38.3, Every adult citizen has the right, without unreasonable restrictions

- (a) To be registered as a voter;
- (b) To vote by secret ballot in any election or referendum; and
- (c) To be a candidate for public office, or office within a political party of which the citizen is a member and, if elected, to hold office.

RIGHTS IN POLITICS

People with epilepsy also have equal rights to participate in politics. Everyone above the age of 18 has the right to vote during elections or during a referendum (Article 38 CoK).

The Kenyan Constitution now requires that Parliament promote the political representation of vulnerable communities in Parliament. These vulnerable communities involve women, persons with disabilities, youth, and some ethnicities as well as other minorities and marginalized communities (Article 100 CoK) states (View Diagram):



67 Members of the senate of which 47 senators and 16 nominated female women representatives, 2 members representing youth (one man, one woman) and 2 members representing persons with disabilities (one man, one woman).

349 members of which 290 are elected from the constituencies, 47 female women representatives and 12 nominated members who represent special interests including youth, persons with disabilities and workers.

In addition, everyone also has the right to form a political party or to be active in a political party (Article 38.1). Every political party has the obligation to respect the right of all persons to participate in the political process, including minorities and marginalized groups (Article 91.e).

People with epilepsy have the right to take part in active politics, a position that gives them power to not only represent the minority of people living with epilepsy but also to be part of the policy makers of a country. This means that people with epilepsy or any disability (visible or invisible) can hold public office and represent the masses if nominated or elected by following due process as required by the legitimate electoral body.

Right to petition Parliament

If you do not agree with the current laws, you have the right to petition Parliament to consider any changes. This means that the MPs are requested to think about enacting (making law), amending (making minor changes) or repealing (officially cancelling) any legislation (Article 118 CoK). Once Parliament approves the proposed changes, they are responsible for ensuring that this right will be exercised.

Just like any other minority or vulnerable group, people with epilepsy can actively take part in petitioning for changes in policy areas regarding epilepsy. When people with epilepsy are empowered, they are able to take action and stand up for their rights and consequently bring epilepsy out of the shadows.



LEGAL HELP

Kenya National Commission for Human Rights (KNCHR): a constitutional (and hence a public institution) – accessible via walk-in, phone call, SMS and email. According to the Kenyan constitution "Every person has the right to complain to the Commission, alleging that a right or fundamental freedom in the Bill of Rights has been denied, violated or infringed, or is threatened." Kenya Human Rights Commission (KHRC): This NGO is not to be confused with it's governmental counterpart (KNCHR). The non-governmental Commission (KHRC) can act on cases and they have accessible reporting and follow-up channels.

The Commission on Administrative Justice (CAJ): They receive and act on complaints of inadequate services from public institutions and officers (meaning that a person can complain even about the Human Rights and Equality Commission).

However, these are large organizations and they represent a huge group of people; therefore it may be not as easy to reach them in person through phone or mail. It may be more helpful to approach smaller organizations with more specific target groups. Here are a few of them:

Institutions for Girls and Women:

FIDA (Federation of Women Lawyers):
Nairobi: 020-3870444 or 020-3873511
Mombasa: 041-222- 4500 or 041-231-3611
Kisumu: 072 425 6658 or 073 444 4448

COVAW (Coalition on Violence Against Women): COVAW offers access to justice to at least 400 women annually, who have been violated physically or sexually.

WRAP (Women's Rights Awareness Programme): offers services that address the needs of abused and violated women and children such as provision of alternative accommodation and related supportive services like legal aid/advice, medical care, trauma counseling, marital counseling, mediation, reconciliation, resettlement and re-integration.



INSTITUTIONS FOR CHILDREN:

Childline Kenya: this is a free national hotline for issues concerning children. At any time of the day you can call them at 116 (free of charge) in case you need assistance

CLAN (Childrens Legal Action Network): promotes and provides high quality legal aid services that improve the lives of children in Kenya.

Cradle: protects and promotes the rights of the child by providing legal assistance to child abuse victims.

ANPPCAN (African Network for the Prevention and Protection against Child Abuse and Neglect): Promotes the legal rights of the child and provides legal assistance and protection to children or those acting on their behalf.

Some NGOs and CBOs also operate in certain localities and can be very helpful if approached; at times they are more effective than the national ones since they can respond with speed and an appreciation of local nuances.

LABOUR ISSUES

Ministry of Labour: Social Security House, Bishops Road

RAPE CRISIS CENTRES

Nairobi Women's Hospital Gender Violence Recovery Centre

Landline: 0386-2772/3-9 or 020-2726821/4/6/7

Mobile: 072 169 6214 or 072 176 0146

Urgent Action Fund-Africa Life Ministry Centre: 020-2731095

Liverpool VCT Centre, Nairobi: 0/33 - 333268/0/22203610





