



# PERSONAL SHORT STORIES



**ESF**

**THE DILEMMA OF EPILEPSY**



**[The Dilemma of Epilepsy ]**

**List of Abbreviations:**

*CT*                      *Computed*  
*Tomography*

*EEG*  
*Electroencephalogram*

*Phenobarb*              *Phenobarbitone*

*PWE*                      *People with Epilepsy*

## Preface

This booklet was compiled to inspire people with epilepsy [PWE] and general public that anyone with epilepsy can live a normal and productive life. The book is made up of five success stories written by PWE sharing their success stories and other motivational life experiences. The stories take us through how the writers got know that they have epilepsy, managed to stand against stigma and discrimination, how they sought to include themselves in environments designed to exclude them, how they were diagnosed, counseled, treated and ultimately rehabilitated to lead, live and fully participate in the development of society on an equal basis with others. They express the challenges they encountered and how they overcame them. This book will provide a link between persons with epilepsy, health professionals and the community at large. Although PWE face challenges it does not have to result in an inability to have a full rewarding life.

# My Grace Is Sufficient For You



*Anyone with epilepsy  
can live a normal and  
productive life*

## Clotilda Chinyanya

### Introduction`

January the 11<sup>th</sup>, 1999 marked a turn in my life. Waking up in the morning with no memory of recent events was not only devastating, but frightening as imaginations of the worst case scenario raced through my head. Could it be a brain tumor? Could it be Epilepsy? What had caused this memory loss?

My spouse immediately rushed me to hospital. The casualty officers in attendance were also confused. They decided to rule out brain tumor, of which I went

for a CT scan. The scan revealed that I did not have a brain tumor. They then referred me to a physician for further investigations and management.

### **THE CHALLENGE OF DIAGNOSIS**

It took long for the physician to conclude that what I had suffered was an epilepsy seizure. Even then, he was not very sure if it was really epilepsy or not. The EEG results were not conclusive and he just decided to start me on epilepsy medication. On enquiring from the physician whether I was really suffering from epilepsy, his response was not convincing. He only said he needed to try me on epilepsy medication to see if my condition would improve.

What happened on the 11<sup>th</sup> of January is still a mystery to me. I did not feel anything safe to wake up with compromised memory. Within two weeks, I was commenced on epilepsy medication. I took my medicine faithfully as prescribed, but after two weeks, I decided to do my research on the particular medicine I was taking, and just told myself that I was not going to accept this condition, hence stopped taking medication. The other reason was that my physician had indicated that he was just trying the medicine to see if I would respond as he was also not sure what my actual problem was.

From the moment I stopped taking medication, I started having real auras and seizures. I was now confused whether the seizures were a result of the abrupt withdrawal of medication or I was really living with the condition of epilepsy.

### **THE CHALLENGE OF FAITH**

As a born-again Christian, my pastors and fellow congregants visited me quite often to pray and support me and my family. The way epilepsy presents is like a demonic attack and even Matthew 17:15 says, “For oftentimes he falleth into the fire, and oft into the water”. This falling into the fire and water is what people with epilepsy go through; hence most Christians associate it with demons which were cast out by Jesus in the quoted text.

If one is a Christian and starts having epilepsy seizures, many people in the church regard that as a sign of weak faith or not being born-again. It then puts pressure on the individual who is going through this unknown phenomenon. In-order to demonstrate that I had faith; I stopped taking medication and increased my prayer times. Together as a family, we fasted and prayed, but the condition did not improve. I became frustrated, desperate and confused. I would ask myself, “what exactly should I do?” No answer

was forthcoming except different people presenting their different views.

One particular morning after a seizure, I phoned our senior pastors' wife and asked her what exactly I was supposed to do. She gave me an answer that healed me spiritually. She said, "Do not worry, God is in control. Do not be concerned about the causes and when it will end, just know that your God is faithful and He will see you through." From that day onwards, my attitude changed, but I did not resume taking my medication.

### **The experience of pregnancy and epilepsy**

In May of that year, I deliberately stopped taking my contraceptives and became pregnant. All this while, I was no longer taking my seizure medication. I visited my obstetrician when I was about six weeks pregnant.

I explained to him that I had been diagnosed of epilepsy, but I think he never noted it in his notes. I continued visiting my doctor for ante-natal, but he never suggested anything to address issues to do with pregnancy and epilepsy. I continued having seizures of different types throughout the pregnancy.

At one time, I only remember catching a lift to work just next to my house and arriving at work. To get to my place of work, I needed to use two lifts. The first

one dropped me in town, but I do not know where. I walked to catch the second lift which dropped me at my workplace unknowingly. I only regained consciousness when I walked into my office. My boss went to ask the security officer manning the gate how I had come to work and he confirmed that I had been dropped by a commuter omnibus at the gate. As I was trying to establish how I had got to work, whilst standing in my boss' office, had another seizure. She rushed me home and this became the norm throughout my pregnancy.

A week before I delivered my baby, I had a major seizure which caused me to be admitted for four days in hospital as no one was quite sure what I was going through. My obstetrician had to call my physician to get his opinion, but the physician only caused more confusion than before. Eventually my obstetrician decided to do what he knew best in the given state and a week later, I safely delivered my baby.

### **The challenges with memory**

A week after delivering my baby, I had another major seizure and ended up forgetting my newly born baby. It was very frustrating to hear my maid saying the baby she was bathing was mine. I was taken back to my obstetrician who eventually agreed with my spouse to seek the opinion of another physician.



The new physician counseled me and highlighted the importance of taking my medicines at stipulated times.

Memory continued to be a challenge as I was taking Phenobarb, but the seizures disappeared within a week.

I was employed as a buyer for medicines and related products. My job required me to be very alert as it involved preparing tenders documents, comparative schedules, inviting experts to evaluations, notifying the winning bidders, preparing contracts, facilitate payments for foreign suppliers and inspecting delivered goods against specifications. This became too involving for me. At times I would forget to send the messenger to collect tender documents from the Tender Board, or to do the contracts or anything very critical to ensure continuous supply of medicines in the hospitals.

The frustration from under-performing got the better of me. My superiors were very supportive, especially my immediate boss, but it could not bring back the confidence I had before epilepsy. According to Bandstra (2008:437), “Seizures are unpredictable and often quite dramatic” and this causes discomfort around colleagues. When you see two people talking,

you think they are discussing your last seizure, yet this might not be the case.

I was eventually retired on grounds of poor health and this opened another window for me.

### **The challenges with taking different brands**

From the time my new physician counseled me on compliance to medication, I never took chances again. I was convinced in my heart that if the medication kept the “demons” away, then it was okay.

As a Pharmacy Technician, I had always regarded people who insist on a particular brand as a problem, but I was going to experience it personally. From the time of diagnosis, I had only taken one brand of Phenobarb, but on a particular day, I went to Harare Hospital Pharmacy to take my supplies. The person who served me in the pharmacy explained to me that a number of patients had been complaining of seizures after taking the brand they had in stock. I told her that it would not happen with me because I was well controlled. I never took it to heart, but went home and started taking the new brand. After a week of taking this new brand, my husband woke me in the morning to tell me I had had seven seizures in a row. He was convinced I had stopped taking my medication.

I tried hard to explain that compliance was no longer an issue with me as I had accepted my condition. He continued trying to establish the cause of this setback. I then remembered what the lady at the pharmacy had told me. He immediately rushed to a private pharmacy to buy the brand I had been using all along. Once I started taking this brand, everything returned to normal. This brand has been discontinued and I had to migrate to another brand. Auras were experienced during the transition phase, but after a week or two, I had adjusted to the new brand. This has caused me to be very particular about the brand I use as seizures can be triggered by these small changes.

### **Life after retirement**

I was retired on the 30<sup>th</sup> of June 2001. Staying at home brought its own challenges as I had been employed ever since I left school.

In August 2001 as I was doing a locum at a certain pharmacy, I discovered that there was a general shortage of sanitary pads on the market. I went home and communicated the findings to my spouse. We eventually approached a certain company that I knew from my background as a buyer had a machine to make sanitary pads. The directors warmly welcomed us and agreed to give us distributorship for the pads as

they were concentrating mainly on hospitals and the consumer market was not an area of interest to them.

This is how our company started. Within three weeks of operation, we were listed in all the major chain shops and were supplying nationwide. In nine months, we registered our pharmaceutical wholesale and started supplying medicines to pharmacies and hospitals.

In 2003, I was awarded the Zimbabwe National Chamber of Commerce (ZNCC) Businesswoman of the Year. It was a great honor to me, especially when I consider the condition I have. It was still vivid to me that I had been retired on grounds of poor health and here I was being given such a prestigious award. I just gave God all the glory.

2005 became a very important year to us as we bought our own sanitary pads manufacturing machine. The company has continued to grow and our vision is not limited by the condition I have.

Prayer and compliance to medication have helped me live a seizure-free life and if I did not tell people that I have epilepsy, they would never know. I live a normal healthy life. I drive; I cook and do all the things every other woman does.

In 2007, I enrolled for a Bachelor in Business Administration with UNISA. I completed the program in 2010 and graduated with 6 distinctions. I feel I could have done even better as at times I would just go blank in an exam. My doctor suggested changing Phenobarb to another medicine, but I was scared of having seizures should the new drug fail to address my particular seizures. I was on a dilemma. Phenobarb controlled my seizures, but affected memory, but this new medicine which my doctor was suggesting was foreign to me. Though it had the advantage on the memory side, I decided not to take chances. To me seizure control was more important than memory.

My vision is to have a doctorate soon as I am now working towards my Masters degree. Epilepsy will not and cannot stop me.

### **Everything works together for good**

I have now resolved to do all I can to make the life of people with epilepsy better by making myself available whenever I am needed especially in my area of expertise. Parents of children with epilepsy sometimes lose hope when their children start having seizures. They need someone with the condition to encourage them rather than hearing theory from experts.

I have developed an interest in the condition and try to enlighten my colleagues in the profession about this condition. Many health professionals regard epilepsy as a mental illness yet it is a neurological condition. This is worsened by the fact that the Ministry of Health and Child welfare has also categorized Epilepsy under mental illnesses. Though they have valid reasons for keeping it like this, I personally feel that the negative effects outweigh the benefits. According to Bandstra et. al. (2008:437), stigma whether “enacted” or “felt” is a major issue in PWE.

### **Conclusion**

Through the years, I have discovered that Epilepsy is a mysterious condition even to medical personnel. Diagnosis is not very easy as most people are not quite sure. There is heavy reliance on EEG yet according to our own expert in the country, epilepsy is a clinical condition and should not wait for an EEG to diagnose. Furthermore, we have about three machines in the country. This then causes people to go untreated for some time and in the process worsening the situation.

This lack of knowledge even in medical personnel causes poor compliance to medication as people are never given proper counseling concerning the condition. It is true that you cannot give what you do

not have, meaning one cannot be expected to give the information they do not have, and therefore more needs to be done towards training of personnel.

What makes epilepsy very difficult unlike other conditions like hypertension is that it is usually associated with witchcraft or demonic attacks depending on what one believes. This delays proper treatment as people waste time consulting traditional healers and “prophets” in the hope of having the problem resolved, and many times the problem persists

Kale (1997:2) summarizing the history of epilepsy puts it as, “4,000 years of ignorance, superstition and stigma followed by 100 years of knowledge, superstition and stigma.” This just shows that despite all the efforts people are making towards seizure control, stigma is unrelenting.

Like Paul I said, “LORD, may you take this epilepsy away from me”, but His word was re-assuring, “My grace is sufficient for you: for my strength is made perfect in weakness” (2 Cor. 12:9).

## **Bibliography**

Bandstra, N.F, Camfield C.S and Camfield P.R. 2008. “Stigma of Epilepsy” in: *The Canadian Journal of Neurological Sciences*. 35/4: 436-440

Kale, R. 1997. “Bringing Epilepsy out of the Shadows: Wide Treatment Gap need to be reduced” in: *BMJ*. 1997/315: 2-3

## **ALL BIBLE REFERENCES ARE FROM THE FOLLOWING VERSION:**

Barton, B.B., ed. 1989. *Life Application Study Bible: King James Version*. Wheaton: Tyndale Publishing House



## A BLESSING IN DISGUISE



**MARY GOWE 10-10-1968**

My name is Mary Gowe; I am a 43 years old widow with three children. I have epilepsy. I am a teacher by profession; I attained my diploma in education in 1993. I never had any health problems until 1999 when epilepsy started. When this condition started I got so worried, I felt out of place and lost self esteem. People said a lot of things like I had been bewitched to the extent that I avoided places where there were many people.

With this condition I consulted many doctors, prophets and spiritual healers but I got no help. Some of the doctors send me for many tests to do with my head and even to the extent of being tested for HIV but all the results were negative. One of the doctors after seeing my negative results went to an extend of

referring me to a certain doctor who was by then holding a high post at training medical practitioners. Still I got no help until the time he died .For all these consultations I paid a lot of money.

I was directed to Epilepsy Support Foundation not even by a doctor but by someone who saw me having an attack. On the 13<sup>th</sup> of April 2011 I visited Epilepsy Support Foundation and I was sent for an EEG test. On the 14<sup>th</sup> I went back with my results, I received counseling, I had been diagnosed with partial epilepsy caused by too much thinking and I was put on treatment. When I started taking medication the problem came to an end.

This problem came to an end after just paying US\$1 membership joining fee, no any other payments up to now. As I said above that I had visited many places for help and paid lots of money to the extend that my mother sold cattle to help me but nothing worked. Just imagine after suffering for 11 years, I am now fine .Surely it is a blessing. Blessings come in different ways.

I had taken epilepsy as a serious problem not knowing that it was a blessing in disguise. It gave me the chance to learn a lot, to meet many people from different professions with the same problem and share ideas .I am also able to help others with epilepsy after

attending conferences and educational meetings. This really relieved me because that's when I accepted the problem after knowing that anyone can have it despite who you are. I learned that epilepsy is not a disease and it's not infectious.

My appeal to doctors and all health workers is to quickly refer patients with epilepsy to Epilepsy Support Foundation where they will get immediate help. Also to those who would have received tablets from the Foundation is to take them as instructed and comply with treatment. I was put on treatment, complied with treatment now I am well after having suffered for 11 years .I have also directed other people to Epilepsy Support Foundation. It's a blessing in disguise.

# The Successful Escape



## **Tineyi Mavhunga 23 August 1979**

I had a deep desire to change myself because I was tired of making changes in my life. It was on a Friday in 2002 when I was called by my mother for a discussion in the sitting room along the way in the corridor, I saw darkness in my eyes, rotations which pulled my mind to the left side. I fell on the floor my forehead was bleeding, my tongue was bleeding and

my body was in pain. Everyone was surprised; I didn't know where I was. My mother grabbed me and said 'Tineyi what is happening to you can you see me, talk to me, talk to me' By then I had started to regain consciousness.

I was a nurse in the intensive care unit at one of the best hospitals in Zimbabwe. I was well paid to the extent that I was given a nickname which was called Papa homie. The following Monday I went to work night duty. During that night I was left to monitor the intensive care unit whilst the other nurses went to have supper. After going for patient rounds there was darkness, rotations. When I woke up I had been admitted the doctor explained what had taken place. After two days I went back to work but upon my arrival at my work station, my work mates ignored me. They just greeted me and they all disappeared. My supervisor called me to his office where I was told that I had to quit my job. I had no option but to leave nobody said goodbye, they didn't show any interest into my new born problem.

My parents were supportive however my wife decided to leave by that time I had been cancelled on pay roll. My life changed I was now depended on my parents' I continued having recurrent seizures everyday .My mother decided to find a solution we went to see a self proclaimed prophet ,I had no choice but to just go.

The prophet said I was carrying a big black snake on my back; he began splashing water on my body. I was told that I had demons.

I started having seizures for at least 3 times a day. My mother came up with another plan because nothing had changed from our previous visit after two years of having seizures. We went to a traditional healer. I was given opaque beer which was meant to cleanse me .The traditional healer did not find any problem with me and I was dismissed. I started to drink alcohol excessively and become an addict. One day as I was at home I was attacked by a major seizure. I was told I had a serious attack. When I regained consciousness I had a deep cut on my chin, the t-shirt I was wearing was covered with blood. My aunt is the one who suggested taking me to the hospital.

Since I started having black outs I had never been to the clinic .That was the first time I entered the doctor's rooms after two years of seizures. The doctor explained that I had a condition called epilepsy and I had to go on treatment. I was put on medication phenobarbitone.I went back to school to study Community Based Rehabilitation and Massage Therapy for two years. I did my attachment at Epilepsy Support Foundation where I helped a group of young people with the condition.

We came up with a successful album which was called **Debunking the myth of epilepsy**. The aim of the album was to address the myths and misconception to address stigmatization and discrimination people with epilepsy face. This album rocked the on Zimbabwe national radio charts of on popular station radio 3 when our song was number one for a month. Now I am fully employed and married with a wife who knows and understand my condition. We are happily married and we work together.

I successfully escaped the myth of epilepsy I am now 8 years old without a seizure.

# The Day My Life Change

Ronald Mabaso

I was born able bodied just like other babies. However my able bodiedness didn't last long due to an accident .It was on the 24<sup>th</sup> of December 1980 when the horrific car accident happened. I was told that when it happened I was only 8 months old. We were three of us my uncle, my mom and I. The car veered off the road and hit a tree. I got permanent injuries to my leg, hand and my head all of the left side. We were coming from Harare to Masvingo when accident happened and my mom died on the spot. We were going to take my grandmother from Masvingo to come and see my aunt who had come from Sweden.



I was admitted at Harare hospital then I was transferred to Parirenyatwa hospital. My grandmother looked for me for two weeks without success. At Parirenyatwa I was seen by a doctor named Professor Levy. The Doctor worked wonders on me ,he had



three successful operations .I stayed at Parirenyatwa hospital for 6 months .From there my grandmother used to carry me on her back to Jairos Jiri Center where I went through physiotherapy ,I was taught to identify colours ,identify similar objects and to use my left hand.I was taught how to crawl,sit,stand up and finally to walk.I later went to school ,in 1993 while in grade 7 I started to have uncontrollable seizures and I was taken to Parirenyatwa hospital to see Professor levy and he used a machine called an EEG to detect the function of my brain cells. He diagnosed me with epilepsy and I was put on medication called phenytoin.

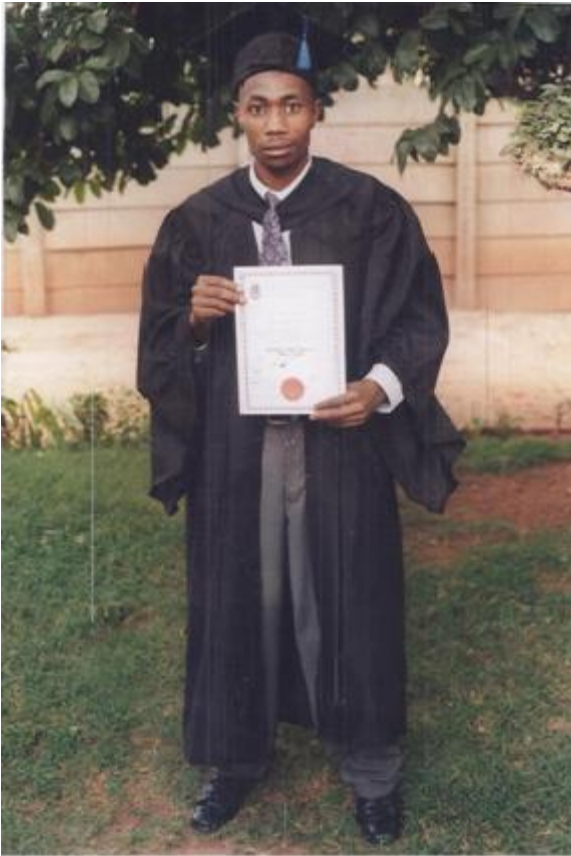
At one time epilepsy drugs were scarce so we went to the Epilepsy Support Foundation where I was given medication. I started going to the Foundation as a volunteer and there are doctors who have dedicated their time to come and see us for free at the center. At one time epilepsy drugs became scarce that I was forced to change from phenytoin to phenobarbitone.Now I am better seizures don't happen frequently .I want to tell people without this condition not to violate our rights People with epilepsy are entitled to the right to go to school, the right to food, shelter, health and the right to go to work. As long they have suitable qualifications they are capable of competing and are even better than

those without this condition. People with epilepsy must make decisions on their own and not to be overprotected.

I am in the process of forming an organization called Road Victims Association Zimbabwe that will cater for those who would have been involved in road accidents. Especially the less fortunate, marginalized and disadvantaged in our communities. That's my wish and may my dream come true one day.

# After The Sunday

*Epilepsy is not contagious*



**Walter Chiradza**

## **After The Sunday**

I grew up in a church going family and learnt from an early age that Sunday was the day of the Lord .It was

a day devoted to the praise and worship of the Lord who blessed us with life and everything else have grown into the man that I am today with this value in me and to this day Sunday is the day where I go to church and thank God for everything that he has blessed me with ;I mean ,my job, my family and friends and that gorgeous girl in my life. That is how I woke up that beautiful, sunny, a bit windy spring Sunday morning.

2008 was supposed to be my year. I was a few months from graduation for my Bachelors degree with a local distance learning inistitute.I had just passed my first level course in short term insurance and had already enrolled for the diploma level class. Having started working for huge insurance broking firm the previous year, I had just been made permanent and I was enjoying my work while my superiors were quite pleased with my efforts. There was a talk of a promotion to underwriting in the not so distance.

At home, things couldn't be any better. My parents were busy with their small plot just outside Harare where they into small scale market gardening **while** my siblings ,two brothers and sister lived happily with their spouses .My sister had since left for South Africa with her husband while I remained at home being the youngest and still single as I am. Financially, socially and even emotionally, I was safe and in a comfortable

position. Except maybe for a bit more money-human as I am, I wouldn't have traded my life for anything. My friends adored me and we had lots of great times together. I was the kind of guy everyone sought. The guy everyone relied on in good or bad times because for some reason I was fulfilled greatly when I was with my many friends. I was the man with his feet firmly on the ground. Occasionally I floated but still managed to land on my feet. I believed, no, I knew the lord was watching over me –until that Sunday of course.

It was a typical Sunday morning and like every other Sunday for me; I prepared to go to church to catch my favorite morning service. The morning service remains my personal favorite because it is a two hour service, which leaves me with time to catch up with friends and most importantly watch my favorite soccer teams do what they know best. I am a huge Caps United fan locally, Manchester United in England and Real Madrid in Spain. My Sundays were as routine as my weekdays, wake up at 8, be at church by 10, meet up with the boys at 2 and be home by 9 the latest to prepare for Monday.

There has always been this smell that had bothered me for a couple of months prior to the Sunday. I can not really explain it but it's like a mixture of burnt rubber, freshly mowed grass and manure. I had not put much

thought into this and each time I had brushed it aside assuming that it was probably some allergic reaction I was having. So it was then that as I neared the main entrance to the church hall that's when the smell hit me, I tried to ignore it as I had successfully done over the last few months. But I didn't know, did I? That it wasn't a smell but an aura. A sign that all was not well, a knock that should never have been ignored in the first place. However that Sunday, the smell, hard as I tried to fight it, wouldn't go away. It was as if it was fighting back-and it was winning. I found myself lost in an empty space. I tried to shout, but didn't have the voice. I tried to run but I couldn't feel my legs and then .....darkness .Complete darkness don't know how long or what happened between that time and the time I came to .

The first thing I remember was some distance singing. As I forced my tired limbs to focus, I finally opened my eyes. At first I didn't know where I was and worse still, what happened. I was in church, the singing now louder and clearer. Still the piercing stares from the congregation told me something was amiss. My mother sat by my side, her tear stained face blank as she stared into space. I noticed I had no shoes and that my clothes were very dirty. I felt thirsty and tried to lick my lips but my tongue was very painful as if somebody had cut it with a blade or something.

In my confusion, I tried to recall what happened but it was all blank became self-aware and assumed that the reason people were staring so piercingly at me was the dirt. I shook my mother and asked her to take me home .She didn't say anything, but simply stood up went up to a friend who together with some other person I cant remember helped me to my feet ,out of the church and back home. All the way home, I tried hard to remember what had happened to me or how I had got so dirty. I was so confused that I just wanted to be alone .I didn't know that I had just had my first episode of epilepsy.

Once at home I managed to get myself cleaned up, albeit with much effort than normal .I got into bed and lost myself in a deep slumber. The next time I woke up, I was at Baines Avenue clinic and the doctor was talking with my elder brother and mother while I lay confused on the bed. 'I am not certain, but from what you've just described and what his been saying, it could be epilepsy. We can only know for sure after the EEG scan that I've booked him for tomorrow" I could hear the doctor tell my family, but wait, she said I had spoken to her. I didn't remember talking to anyone after I got home. What was happening to me? Anyway, I was sent home to come back the next day for the scan.

Somebody once wrote that good news hops on one leg while bad news runs like the hare. He wasn't lying. As I prepared to go for my scan the next day, a family friend came by while my mother was bathing. She knocked and was rather taken aback when I answered the door. She composed herself as she asked for my mother. I told her she was taking a bath and that she could come in and wait for her if she wished. I could see her uneasiness as her eyes ran over our lounge. She jerked up suddenly when I tried to close the door and said quickly, 'Leave it open it's a bit hot and the gentle breeze will do me some good' I thought this rather odd considering she was wearing a heavy coat and to be frank, it was a bit of a chilly morning.

As I sat down opposite her, I noticed her eyes running back and forth from me to the door every few seconds. She tried in vain to make polite chit chat by asking me about work before she finally asked me about the events of the previous day. Honestly I had dreaded that question the moment she came in but now that she had asked I had to tell her the truth which was that I didn't know. This made her shift uneasily in her seat. She warmed up a little when my mother came in and I felt relieved to let mama explain what had happened. This is when our visitor shocked us both. She confessed that the only reason she had come was because she had heard that I had lost my



mind and wanted to confirm the rumour. I was shattered. It had happened in church for crying out loud. Everyone had been there and seen it for themselves. So why would anyone, a church going member for that matter, want to spread such pathetic and humiliating lies about me? And if it was so, were they wrong? I mean, I didn't even know what had happened to me which in itself was confirmation enough that I had lost my marbles.' Keep calm, Keep calm,' I tried to assure myself, "no one will ever believe that you've gone mad'

But later as my mother and I walked to the bus stop to get a kombi into town, I realized I was lying to myself that no one would believe I had gone mad, because it was as if everyone wanted to catch a glimpse of the boy who had lost his marbles at church. I could feel them, I could hear them. The stares and the whispers. What had happened? Why me? Suddenly there were more questions I could not answer. People looked at me as a mad man. Even people I didn't know seemed to notice there was something wrong with me.

After the scan, we were told I could only get my results on Wednesday and so we made the weary seemingly long way back home. While in the kombi, there it was again. The smell, this time even more powerful I didn't even get the opportunity to try and fight it.....darkness. I had collapsed in

the kombi and scared the living daylights out of the other passengers. My mother had to pay the driver to drive us home while some passengers refused to get into the vehicle for fear of catching whatever it is I had. I knew then that was doomed .Questions.Where were my friends? Most importantly, where was my girlfriend?

Friendship is the greatest gift of all. You can have all the wealth in the world, but no one to share it with; it's just not that fancy. A friend is not that person you hang around with every other day. I found myself asking the inevitable, where were my friends? No visits, no calls, hell not even a text message.Noone but except one.Bradely is that kind of friend to me. He is the brother I never had and apart from my family, is probably one of the only two people who have really understood what I have gone through. The other is Tendai who has seen most of my seizures intensified, I usually collapsed mostly on the way to work. However she always went out of her way to make sure I was either rushed to the nearest clinic or back home, sometimes getting into trouble at her workplace,.

Their support was a breath of fresh air. Their visits brought some cheer to my quickly diminishing morale. However it still did nothing to stop me from questioning the true nature of my other friends. This

was perpetuated by my girlfriends continued silence. After two years, I thought she was my soul mate. None the less I had to face the fact that no one wanted to hang around a mental case .a fact which the world seemed to believe was true. This was compounded by the fact that the scan results came out negative meaning there was no evidence of epilepsy in me. This also meant we had to find out what was causing my seizures.

There came possible explanations from friends, family, relatives, strangers and enemies alike. The most popular explanation was witchcraft.I had been bewitched. But by who? My aunt in Mbare could be a likely suspect, I mean I've been doing quite well of late; in fact I've done exceptionally well compared to her failures of sons. I mean she could've been jealous and sought juju to get back at my family. Maybe its evil spirits, someone offered their thoughts. Or maybe we haven't been appeasing our ancestors and they are showing their anger through me, another person came up with this theory. And I can tell you there were more explanations that I care to explain.

And yet the seizures continued, at first once every week or so then once every few days. At work I became a burden to my colleagues as they had to cover my work load as well because each time I had a seizure., I had to take a few days off.Roumors of my

imminent dismissal were doing rounds. This did nothing to help my already dampened self esteem. By mid -2009, they were ready to fire me but were advised by the company lawyers against such action as it was tantamount to some form of discrimination. And so I continued working while the seizures kept tormenting me.

I remember one particular Wednesday afternoon when I was walking from the bank. Of course by now I Knew what the inexplicable smell meant, and yet even when I knew, I was still clueless as to what to do when I smelt it. Right there on the pavement, I collapsed and had another seizure No one had the guts to help or were simply scared. Many people saw me. A guy who rented a room in my street saw me and all he did was call my neighbor and tell him what he had seen. A woman who worked in the same building with me saw me and all she did was to tell the security personnel on the buildings front desk what she had witnessed. A former schoolmate who lived in my neighborhood saw me and all she did was watch as the people wrestled among the shocked crowd to catch a glimpse of the man who wriggled on the pavement. None could help-none at all.

The worst of my seizure episodes was when I collapsed in front of a neighbor's gate. The neighbors' dog, probably in a panic attack at seeing a man

wriggling and kicking at their gate attacked and bit me senseless. It was sundown and a lot of people were walking by. All people could do was watch in horror as the mad man was viciously attacked by the equally mad dog. No one helped. I spent the whole month in hospital as the dog had given me quite some serious injuries on my legs, right arm and more seriously my testicles where I had to have six stitches. Something had to be done, and done fast. The situation was getting out of hand and I could see the effects on my parents. The plot was failing because I now needed constant monitoring. The company I worked for finally let me go sighting that I had become a danger to myself. Money became tight and although my brothers and sister were helping as best they could ,travelling around the country in search of a cure meant we needed a bit more.

We went to the various sects dotted around the country where prophet upon prophet had his own explanation. One said I was under the control of evil spirits and that I need only drink and bath with holly water he gave me and the evil spirits would leave. Two days later, I had another seizure. Another prophet said I had fits and she took us to Binga where we spent three days in the middle of nowhere near a puddle of water where she prayed and poured bucketful upon

bucketful of the puddle water. On our way back, I had another seizure.

My gorgeous girlfriend-remember her/well she decided to send me a text message six months after the Sunday and I quote, ' I am sorry, but I don't see our relationship working ,ever!' I loved the girl with all my heart, I still do actually. I knew she had probably been under pressure to leave me from friends and family. I understood the reasons why she wouldn't want to be with me. She was everything I had hoped my future wife would be- well almost everything. Love knows no boundaries, but here was a boundary she was not willing to cross and I understood and forgave her, but breaking up with me over a text message .that just plain cruel. I forgave her, but I never forgot.

The whole family went on another escapade to Gurube, this time with my sister who had to leave her job in S.A and come to the aid of her little brother. This time we were to see a spirit medium that had his own explanation apparently I had my great grandfathers' name that had to be bestowed upon me for the seizures to stop. Goats were bought, traditional beer brewed, relatives gathered, the spirit medium paid and the initiation ceremony held. A month later, another seizure and this time everyone could not hide

the fact that they saw no hope of my ever being back to normal.

In Chiweshe, a popular healer apparently a specialist in cases such as mine gave me a concoction which had a live crab and chicken blood to drink for two weeks. I had to drink it all while the crab was alive. There were strict conditions that I would never eat chicken and fish for the rest of my life. Desperately, I drank the sour medicine religiously following strict instructions with the support of my ever devoted mother who seemed to be getting better by the day. I withdrew from the rest of the world and decide to spend my time locked up in my room, away from the stares and whispers. I hated my life and everything about it. The worst of it all was that I lost all hope and self-belief,

*Not good enough for the rest, I am trying but can't seem to do my best. Life is complicated and full of pain and nothing to gain. I want to be loved, cuddled and held by someone who cares and takes away my nightmares. Somebody who cares only for me. I want to be in a comfortable and safe place that will keep me happy for the future. Who will take away my pain inside that I have to hide in this place where I take up too much space. What is the purpose of my life/and why does this happen to me? I have had enough! Can't you see?*

*Had I known that knowledge is power, I would have had the power to fight it all. I would never have spent four years of my young adult life on fruitless endeavors to rid myself of an evil that I didn't have in the first place. I would have known what begins on Sunday ends on Sunday. I would have known what begins at church ends at the church. But no! Oh no didn't know did I? We were all busy being scared and running around pointing fingers at one another when the real disease was our ignorance.*

Yes, ignorance. It led us to Mhondoro where an old man in his nineties-also touted as a specialist in conditions such as mine, mixed some herbs with a cow hoof and made me it the whole lot all of it without leaving anything except the bones After that I had to drink up all the soup and then inhale some more herbs and eat some other herbs mixed with porridge for a whole fortnight. There were conditions as well, no cats, no cat fish, no white meat, no okra and get this, I was told that I should eat anything that would have been cooked in a pot that would have previously been used to cook anything that I wasn't supposed to eat .We paid him \$USD200 and came back to Harare a hopeful lot.....Two week's letter, well need I tell you?



*We love, we care, we watch, we keep, we nurse, we heal, we teach, we know, we help, we laugh, we weep. And all through life we grow.* Somehow I found myself with a new hunger to live. These words sang to me. They were my first immeasurable feat of magic as it were, after the Sunday. They liberated me from ignorance and self –pity and reminded me that I had to grow out of my shell. I had been through a lost of these past few weeks and it was now time to learn from these years and grow into a man who got what he wanted. I wanted to be free from the seizures and I made it public that I was tired if fighting and that if there was anyone out there, who could help, then please be my guest. And sure enough, help came.

It was a typical Sunday morning when my aunt called us and invited us to her church in Hatfield. It is there that we first learnt about the Epilepsy support Foundation from a member of the church we went there the next day and were greeted with a very friendly counselor who explained to us about the evil that we thought I had. He explained that epilepsy was a medical condition which was caused by a malfunction of the electrical brain impulses. I have learnt a lot over the past few months. What I thought was a smell that always heralded my seizures is in fact an aura and that people with epilepsy have different auras.

Most importantly, I met people like me. People who really know what a seizure is. People who have felt the pain in their limbs days after a seizure. People who have lost friends, relatives all because of epilepsy .as I sat down on the many occasions that I have been at ESF,I felt relieved of the heavy burden that I once carried. Sharing our stories of what we have been through has shown me that I am not alone- we are never alone. It pains me that while I've been moping and wishing this had never happened to me (but who?) there are others, some children, barely teenagers who face this all on their own. Why do we people do this to ourselves? How do we live with ourselves? With all this suffering? Are we really scared, so ignorant, so proud that we cannot take that risk, take that chance and make a change? Why can't we open our minds and see beyond the physical? Let us get out of the darkness and come into the sun and not forget that we are after all human. Let us now and for all time extract from our societies the decadency that is ignorance to our social maturity and open our minds.

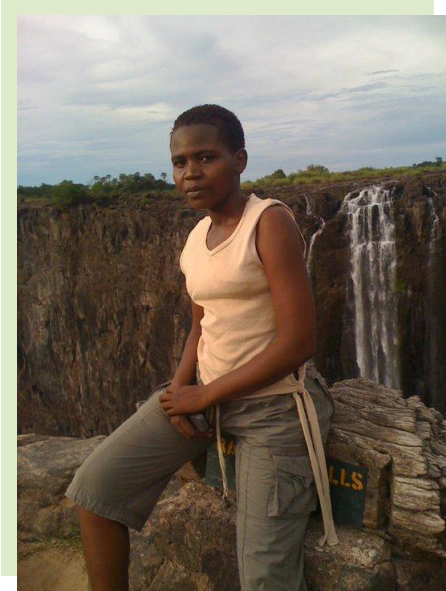
*Minds are like parachutes-they wont work unless they're open. What's the purpose of having a parachute that won't work? It allows for only one possibility and not a bright one at that. So keep your mind in working order-keep it open. How can you*

*have a broader vision of life if you refuse to raise your eyes at a new horizon? How can you hear new ideas if you don't listen to them? You are a student of life; open your mind to a world of greater wisdom, knowledge and new ideas. Read broadly, have discussions about current events with interesting and diverse friends, watch educational programs, open yourself to others who are bright 'with it' and you know you'll have solid advice. When you do these things, your mind stays open and you are sure to land safely wherever the winds of life take you. **Many who took the wrong road blame the road.***

I haven't had a seizure in close to six months now. After I registered with ESF, I was booked for another EEG scan that also came out negative but the doctor prescribed some medication which has helped a lot. The medication is free for all members, which has lifted a huge financial burden for the family. My health improvement has heralded a new era in my family we've learnt the value sticking together, through thick and thin. Let it rain cats, dogs, hounds and even horses, but however the storm, we've vowed to be together through it all. When times are rough, friends are few, but the fewer the truer. What is more important /having a thousand friends who just want you for their selfish gains or just two who want you

just for you? This is just one of the many lessons I learnt after The Sunday.

Four years ago after that Sunday, I took the wrong road towards finding a ‘cure’ for my condition, and have spent those years blaming the road all because I refused to open my mind. It has been a bumpy ride, these last few years. But those years are part of me. A part of me which for many I should put behind me and focus on the future. But what is a future without a past? My past memories have given me experience to deal with these issues and nothing beats experience through which, practiced and achieved. Knowledge without wisdom is dead just as wisdom without knowledge. If you have knowledge about a particular subject but don’t have the wisdom to apply it then what use is that knowledge .Four years have gone by since that Sunday morning, but as I write this piece, I smile at what I’ve accomplished .I now have the knowledge and wisdom to declare that its not what happened on Sunday that matters, but rather what happened **after the Sunday**



## My Journey with Epilepsy

### Nobunle Shumba

I was born in Chirumanzu at St Theresa's hospital, according to my mother nothing wrong was detected so I grew up as a normal doing what was expected from a normal child. I grew up staying with my grandparents and I never lacked anything ,I would see my mother maybe two to three times a year and my mother also did not even of see any sign of epilepsy on me and all was well with us .My grandparents and my mother were expectant ,they anticipated that I will become a very successful person in life since I was very intelligent and I also felt that I was going to make it in life ,I desired so much to have a brighter future ,it was my wish to have a good job, a husband ,kids and a happy family since I grew up not staying with my mother due to reasons beyond my control.

On the 28<sup>th</sup> of October 1998 I woke up on the other side of the mountain, this day brought so many changes in my life positive and negative .When I woke up I felt so much pain in my body ,my tongue was swollen and I could not speak properly, my bed was wet my head was aching and I was confused. A lot of people were surrounding my bed .It was early in the morning between 1am and 3 pm when I woke up I could not understand what was happening to me. My grandmother asked me if I wanted to go to the hospital and I agreed to go but did not know why I wanted to go the hospital.

Everyone around me was showing signs of sympathy and pity but I did not understand why, since I was in pain and I was feeling very weak did not ask questions. My aunt and her niece who had witnessed what had happened to me cleaned me up and also accompanied me to St Theresa hospital which is about one and half kilometer away from home .

When we arrived at the hospital my aunt explained to the nurses what had happened to me and I could not believe what I heard ,I was still very weak and I wanted to sleep so I was admitted .When the doctor came to see me ,he then explained to me that I might have epilepsy. They told me it was a possibility they were not sure if it could be it but still they had to give me some medication and continue to monitor me.

I had my first dose of phenobarbitone on this day which was a few hours after my first seizure. It was very difficult for me to believe that I might have epilepsy .Epilepsy was one condition I had never imagined to have because what I grew up hearing about epilepsy was disturbing all I knew were myths about it.News about epilepsy was a bitter pill for me to swallow .Most people that I knew with epilepsy in my village lived a very miserable life ,they were treated like inhuman and possessed people .They could not live a life of their choices and were abused and this alone brought fear in me.

When this happened I was a teenager and I was in form three at Hama High School, so as a teenager what bothered me was what my schoolmates and friends would think about me. I felt like my world was falling apart before my own eyes, all my dreams ,my hopes and desires were destroyed at this point I was no longer the same person. I wished I could just die than to face this new condition. The nurses and the doctors tried to help as much as possible to understand what was happening to me and what to expect as well.

The news did not only affect me only but it also affected my family .When I was discharged from the hospital my grandmother felt that the doctors

diagnosis and treatment was not enough, so she also sought other alternatives from the native doctor who was believed to be a specialist in treating epilepsy using herbs, this was done in agreement with other family members, I also had no choice despite the fact that I was on phenobarbitone I had to get other alternative medicine so I accepted.

The herbs were terrible I could not stand the taste and the running stomach after drinking the herbs ,nut what could I do I wanted to get rid of epilepsy so I had to soldier on despite that the herbs were not good there were also conditions attached to the herbs ,I was not supposed to eat meat during the period I was using the herbs and also I was not allowed to eat anything that is cooked in a pot which was used to cook meat and this meant I could not visit any relatives. This lasted for one year but nothing changed.

Development of seizures caused me to leave the rural areas to urban areas where my mother lived since she could not afford to visit me after every seizure .The seizures were severe she thought I might die. I was fortunate that my friends did not reject me or stigmatize as I expected them to do especially my best friend Memory Manhova,she would accompany me to the hospital. If I had a seizure at school and she would be on my bedside whenever she had a chance. Coming to leave with my mother did not help to stop seizures, seizures continued and my mother took me for an EEG scan and it was confirmed that I had 2% epilepsy now that it was confirmed .It also induced fear in me and the fear of the unknown provoked seizures .The dosage of phenobarbitone was increased and the native herbs period of consumption ended but nothing changed but I refused to get on to another one year course and those tough conditions and I had to stick to my medication from the hospital.

After confirmation of results my relatives consulted traditional healers because they could not believe that a young, beautiful and intelligent girl can develop epilepsy from nowhere. A Lot was said and it was disturbing and this also provoked my seizures .I was an O level student and these continuous seizures affected my performance at school. When I wrote my

final exams my results they were not what I expected because I was affected with seizures.

Due to so much pressure and confusion I got pregnant and I got married in the year 2000. The seizures did not stop leading me to give birth to a premature baby thank God he survived. I was so happy to be a mother. My husband understood my condition but his parents did not. He would take care of me after every seizure but it did not work out, we separated and went back to leave with my mother.

I had my child but I was jobless, I did not have a profession. I got a job at local township and I was later transferred to town but the job was still not paying well I discovered that the people I was working with were criminals so I did quit the job. After quitting my job I got married again, I told him about my condition and child he went ahead and married me. I praise the lord thinking this man was from heaven. I got married to Kombo in 2003 I had my second son. We lived happily though my seizures were occurring once in a while, my in laws accepted my condition. We lived peacefully up to May 2005 when the lightning of life started.

I had a terrible seizure which left me unconscious for three days and this man took me to my parent's place who took me to the hospital. I was admitted at Chitungwiza Central Hospital, I lost my memory and this man thought I was mentally ill so he left me and his child. I lost my memory for two months until things normalized. I had lost hope and didn't know what the future held for me, I was empty and confused.

One day when I was discharged from hospital waiting for the Doctor to process my report my mother saw the late Remigio Mutete holding a book which was written Epilepsy Support Foundation. He gave us all the details about the ESF. The next day I visited ESF. This opened a new chapter in my life. My visit made me to understand that I'm not alone and meeting other people with epilepsy gave me hope.



I started visiting the foundation regularly to be actively involved in all the activities which were taking place at the center and this alone changed my life. I realized that I can make a difference in other people with epilepsy. My visit to the center resuscitated the real me. Reading the books in the library talking to other members made me realize that epilepsy is not me but it's just something that I have and should never determine who I am who I should be. Participating in activities at ESF healed me and I realized that epilepsy was no longer my prime concern but to help others and other disadvantaged people.

Monica Mutasa , Taurai Kadzviti are the main people who opened my eyes and made me realize that I was wasting my time. I joined ESF in 2006 and computer in-house training. I trained with others and I passed this was an achievement because I never imagined using a computer. I also got involved in NASCOHS program on policy formulation through ESF during these workshops realized that disability does not mean inability. Most of the disable people I met had decent professionals.

Through these workshops I got my first decent job as a secretary because I was empowered by ESF through computer courses. I also worked as administrators at another company where I was trained in pastel accounting. In December 2009 I was nominated as the worker of the year. I then went to the University of Zimbabwe where I did a monitoring and Evaluation course I passed with a credit .I am still looking forward to pursuing my studies.

I have also joined a multi-level business and network marketing and I am now running my own shop as an independent distributor. I am now a business lady and happy .I am a mother who is taking care of her children.

I have realized that everything happens for a reason and it works together for good, it just needs one to realize that epilepsy to me is no longer a prime concern but it is my desire to make others see the light and live a happy and better life despite the fact that one has epilepsy. There is no point to be

controlled by epilepsy but one has to control epilepsy. If seizures are controlled it makes it easier for one to live a normal healthy life.

