What Epilepsy Took from Me Cannot Be Measured Only by Seizures

My Journey with Epilepsy

By Noleen Munetsi – June 12, 2026

For many years, epilepsy was a word surrounded by fear, stigma, myths, and misunderstanding in my life. Before I understood what was happening to me, other people had already decided what my seizures meant. Some said I was bewitched. Others believed I was possessed by evil spirits. At one point, I was even told that my late mother's spirit was haunting me. While people searched for explanations, I was simply a frightened young girl trying to understand why I kept losing control of my own body.

> "What epilepsy took from me cannot be measured only by seizures. It took away my confidence, my sense of belonging, my independence, and at times, my hope."

Yet through all the pain, confusion, and setbacks, epilepsy also taught me resilience, courage, self-advocacy, and empathy for others facing similar battles. Today, I am no longer the scared little girl who suffered in silence. I am an epilepsy advocate, a support group founder, a student, a professional and a woman who has learned that a diagnosis does not define a person's worth or limit their potential.

✦ This is my story

My name is Noleen Munetsi, and I was born in 1996. When I look back on my childhood, I see a sweet little girl, just like any other, unaware of what life had in store for me. I would sometimes stare blankly into space for a few seconds without realising it. I would stop talking in the middle of a sentence, become unresponsive, or experience involuntary movements. I paid little attention to these episodes and assumed they were normal.

Everything changed after my mother passed away in December 2006. I was only ten years old. The following year, I began experiencing tonic-clonic seizures, causing me to lose consciousness completely two or three times a week, both at home and at school. Today I know those earlier episodes were focal unaware seizures, but at the time, I had no idea what was happening to me.

✦ Stigma, fear and misunderstanding

My guardians initially sought help from faith healers and traditional healers. Each person had a different explanation. Some said it was an evil spirit. Others blamed witchcraft. The most painful and traumatic thing I heard was that my mother's spirit was haunting me because she was not resting in peace and wanted to take me with her. As a frightened child, I believed much of what was being said about me.

At school, many students stopped associating with me because they believed epilepsy was contagious. I withdrew from my peers and spent much of my time alone, overwhelmed by stress and sadness. I cried often and silently carried a burden that few people understood. Eventually the school urged my guardians to seek medical help.

My aunt took me to a public hospital in Harare, where I underwent an EEG and was diagnosed with epilepsy. I was prescribed Phenobarbital, but when the one-month supply ran out, it was never refilled. Everyone assumed the condition had disappeared. It hadn't. The seizures continued.

> "I lost count of the herbal concoctions I drank, the rituals I participated in, and the sacrifices performed to cure me. To this day, my hand remains permanently dislocated from repeated falls during seizures."

As a teenager, my seizures began to follow a pattern linked to my menstrual cycle; years later I would learn this was catamenial epilepsy. I was also told my seizures were happening because I did not know my father, and that finding him would make everything stop. I found him. Nothing changed. Depression became a constant companion. I dreamed of becoming an air hostess or a lawyer, but epilepsy seemed to have stolen those dreams before I even had a chance to pursue them. I cried in private because I believed nobody would understand and nobody could help.

✦ Finding hope: Doctor G

As I grew older, I realised that epilepsy does not come with a roadmap. I would have to learn how to navigate life myself. That realisation led me to Doctor G. He was the first doctor who saw more than my seizures. He saw a young woman carrying years of emotional wounds, unanswered questions, grief, fear, and trauma. He listened. He explained. He educated. He encouraged. Most importantly, he helped me believe in myself again. Doctor G restarted me on Lamotrigine, which worked well until I developed allergic reactions. We then switched to Levetiracetam, a medication more suitable for me. Although my seizures did not disappear completely, my perspective changed. I learned to recognise my triggers, identify my warning signs, advocate for myself, and accept my reality. Acceptance did not mean I liked having epilepsy. It did not make seizures less painful or frightening. It simply meant acknowledging my condition and choosing to build a meaningful life despite it. That acceptance gave me hope for tomorrow.

✦ Building a community

Because of everything I experienced: the stigma, isolation, misinformation, discrimination, and lack of support; I made a promise to myself that no other person with epilepsy should have to feel as alone as I once did. That promise led me to help establish a support group alongside Doctor G, and today it has been running for approximately four years.

The group provides a safe space where people can share their experiences without fear of judgment, ask questions, find support, and remind one another that they are not alone. Together, we celebrate International Epilepsy Day, Purple Day, and Stripes Week. In 2024, I shared my story with the Epilepsy Alliance Africa during Stripes Week, and it was published to encourage others with epilepsy.

✦ A disability does not define my ability

Looking back, I am proud of how far I have come. I obtained a driver’s licence; something I once believed would never be possible. I work as a Sales and Marketing Executive. I first studied Supply Chain Management and am currently pursuing a Bachelor of Commerce in International Supply Chain Management, majoring in Transport and Logistics.

Many people advised me to choose Procurement instead, believing my condition and Transport and Logistics were incompatible. Their doubts only strengthened my determination because I wanted to prove that a disability does not define a person’s ability.

“Epilepsy is not a life sentence. It is a medical condition that can often be managed and controlled with the right treatment, support, and understanding.”

I share my story today because I know there is someone reading this who is struggling to accept what life has handed them. Perhaps you are questioning why this happened to you. Perhaps you feel alone. If that is you, I hope my story finds you exactly when you need it and reminds you that your diagnosis is not the end of your story.

Every conversation creates awareness. Every act of awareness brings us closer to understanding. As long as I can, I will continue sharing my story, raising awareness, and standing proudly with my purple family.