


epilepsy[™]
SOUTH AFRICA

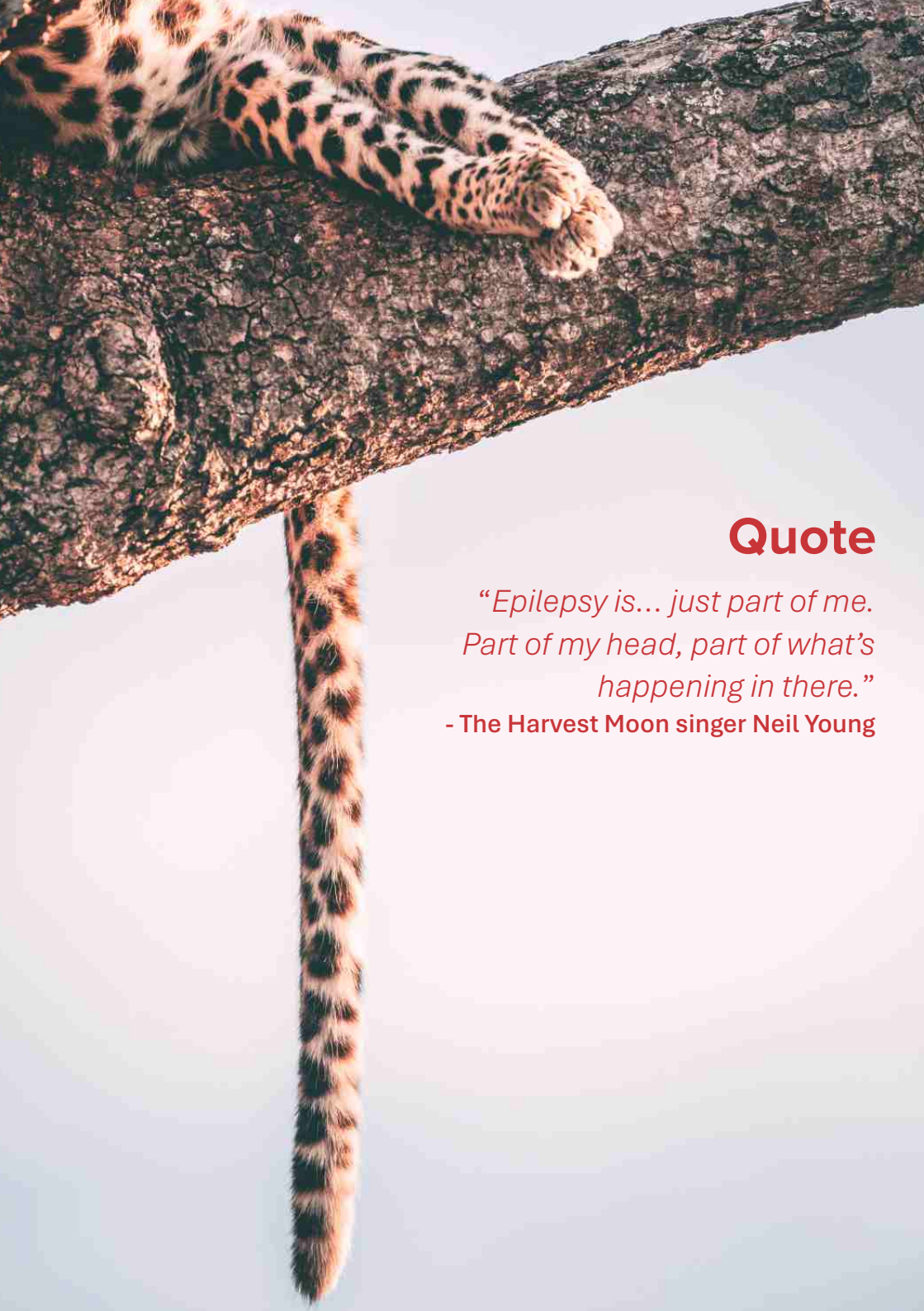
EPINEWS

Edition One 2026



epilepsy.org.za

Igniting the Flame of Potential



Quote

*"Epilepsy is... just part of me.
Part of my head, part of what's
happening in there."*

- The Harvest Moon singer Neil Young

Contents



6

**Why words matter
when talking
about epilepsy**



8

**A miracle
named
Mangaliso**



13

**Emergency
Seizure
Management**

04 Editorial with Tim de Villiers

05 Epilepsy Facts

06 Why words matter when we talk about epilepsy

08 A miracle named Mangaliso by South Cape / Karoo Branch

10 Gladys & Khutso's story by Gladys Napo

12 Me vs Epilepsy - a poem by Darshmika Reddy

13 Emergency Seizure Management: a guide

17 I didn't fit in, so I endured - by Obakeng Pelle

19 Epilepsy – The Invisible Disability by Laurianne Brown

21 Epilepsy and Work: Confidence, Safety, and Knowing You Belong

**24 Epilepsy SA Branches: Social Work and the Carers Who Hold Our
Communities Together**

26 Epilepsy South Africa Branches - Contact Info

Editorial by Tim de Villiers

It is our pleasure to present to you
Epinews Edition 1 of 2026.

Epilepsy is known as an invisible disability, as it may not be outwardly visible, yet it can significantly affect a person's life.

Seizures can occur at any time, often without warning, and can impact both individuals and those around them in different emotional ways.

I can relate to this. It wasn't easy, but I learned to manage my condition step by step, turning obstacles into opportunities.

As I prepare to retire in September after nearly 45 years in engineering, I reflect on a career I once thought impossible for me to achieve. It took determination, and I refused to let my condition get in the way.

We proudly share inspiring stories from and about people with epilepsy, alongside valuable knowledge, insights, and information on treatment and recovery. Each contribution is a reminder of resilience, hope, and the strength found in shared experiences.



In this edition:

- ♥ We unpack the **importance of minding one's use of words** when speaking about or to persons with epilepsy, in a way that adds respect and fosters understanding.
- ♥ We **meet young Mangaliso**, whose parents show us that in spite of great challenges, love for their child can inspire us all.
- ♥ **Gladys Napo** shares her own story as a parent of a child with epilepsy, and we commend her for her love and dedication to raising a wonderful young woman with epilepsy.
- ♥ We ask the important question: **is epilepsy an invisible disability?**

♥ We share crucial **Emergency Seizure Management** info that can have profound impact for persons with epilepsy.

♥ We print to print **employment guidance** for young persons with epilepsy.

Epinews is a bi-annual magazine compiled by people with epilepsy, for people with epilepsy.

Our aim is to offer our readers a platform to share their life experiences with epilepsy, express how they feel, be inspired by others and broaden their knowledge.

To our team, Laurianne Brown, Zubair Slamdien, Sharlene Cassel (National Director of Epilepsy SA) Jason Fiddler (who designed this edition) for their "brainstorming" and putting in so many hours of creative work to bring you this inspiring Edition – thank you!

Epinews is something we're immensely proud to publish.

Yours, Tim

You do not need to be a writer to share your experiences with Epinews, simply write to us care of the following:

Epilepsy South Africa National Office
by email at **marketing@epilepsy.org.za**,
or visit our informative website:
www.epilepsy.org.za


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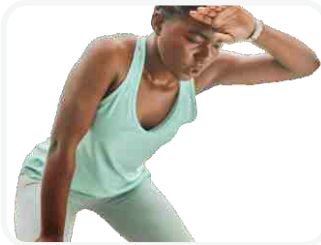
Epilepsy Facts



Epilepsy affects both
men and women
of any age



A healthy and
physically active
lifestyle can support
overall well-being and
seizure management



Stop exercising if you
feel faint, nauseous,
or dehydrated



People with epilepsy
can work successfully
with the right support



Managing seizures
effectively is
important in the
workplace



Alcohol can increase
the risk of seizures -
some anti-seizure
medications should not
be taken with alcohol

**You can learn more about epilepsy, find other useful resources and
get in touch with our Branches by visiting our website**





Why words matter when we talk about epilepsy

Language is one of the most powerful tools we have. It can open doors or close them. It can affirm dignity or reinforce stigma. For people living with epilepsy in South Africa, the words used to describe their condition often shape how they are treated long before anyone understands the medical facts.

This is why Epilepsy South Africa continues to emphasise the importance of respectful, accurate and person-first language.

The UN Convention on the Rights of Persons with Disabilities (UNCPRD), which South Africa has ratified, provides a clear foundation for this work. The Convention does not define disability as a defect within a person. Instead, it recognises disability as an evolving concept created when society fails to remove barriers that prevent full participation.

These barriers can be physical, social, psychological or attitudinal. Language sits squarely in this last category. When we use words that reduce a person to their diagnosis, or rely on outdated and harmful terms, we reinforce the very barriers that we are called upon to dismantle.

Historically, epilepsy has been surrounded by misunderstanding. Terms like “fits”, “attacks”, “falling sickness” or “epileptic” have been used casually for generations, often without awareness of the harm they cause.

These words carry echoes of fear, superstition and exclusion. They can make people feel unsafe, ashamed or defined by their condition.

They also undermine the modern understanding of epilepsy as a neurological disorder that affects people in diverse ways.

We prefer you to say

Please don't say

Seizures

Fits, convulsions, episodes, attacks, bad turns

Person with epilepsy

Epileptic

Person with epilepsy

Sufferer/suffer

Epilepsy

Falling sickness

Neurological Disorder

Disease/illness

Anti-epilepsy drugs (AEDs), anti-seizure medication

Epilepsy pills

Tonic-clonic seizure

Grand mal seizure

Absence seizures

Petit mal seizure

Changing our language is a simple but meaningful act of solidarity, or true community spirit. When we say “seizures” instead of “fits”, we use terminology that is medically accurate and free of judgement.

When we speak about a “person with epilepsy” rather than an “epileptic”, we affirm that a person's identity is not their condition.

These shifts may seem small, but they align directly with the principles of the UNCRPD: respect for inherent dignity, non-discrimination, full inclusion and accessibility.

They remind us that people with epilepsy are rights-holders, not passive recipients of care. They also help create environments where individuals feel seen, heard and valued.

“Mind your language” is not about policing speech. It is about choosing words that reflect empathy, accuracy and respect.

It is about recognising that stigma is not inevitable – it is learned, and therefore it can be unlearned.

Each of us has a role to play in creating a South Africa where people with epilepsy can participate fully and confidently in every aspect of life.

By speaking with care and mindfulness, we help build the inclusive society that South Africa is inherently capable of.

In doing so, we send a clear message: that people with epilepsy are people first, and they deserve to be treated with dignity in every conversation. 🔥



A miracle named Mangaliso

by South Cape/Karoo Branch

In the heart of Dam Se Bos, Knysna, on the southern shores of the Western Cape, lives a courageous 12-year-old boy named Mangaliso, whose name means "miracle." He lives with both his parents in a small home that, despite its challenges, overflows with love and determination.

Mangaliso developed epilepsy at the age of seven, following two traumatic accidents: a fall from a swing and, later, a car accident.

At his lowest point, he was experiencing between four and six seizures every day. Yet through it all, his gentle smile and playful spirit remained undimmed.

His mother, Patricia, has been in a wheelchair since contracting Polio at the age of four. The family's living conditions are difficult; when it rains, their home floods completely.

Although authorities have been alerted and work on the home is ongoing, only temporary measures have been provided so far. Still, Patricia and her husband remain resilient – facing every storm, quite literally, together.

When our Community Social Worker, Abigail September, and Community Development Worker, Cherolize van Aswegen, first visited the family in October 2025, Patricia expressed immense gratitude for their care and concern.

They found a mother who, despite immense hardship, radiates love and hope.

Since that first visit, contact with the family has been consistent and ongoing – ranging from phone calls and planned visits to regular check-ins – reflecting a commitment to walking alongside them every step of the way.

Our branch worked closely with several partners to ensure the family received the support they needed, and the results are already being felt.

One of the most significant early interventions was fast-tracking Mangaliso's hospital appointment. Rather than waiting months for a routine review, our team went the extra mile to bring the date forward. In preparation, the family made excellent use of an epilepsy diary, carefully recording each seizure to give the medical team an accurate picture.

The impact has been remarkable: Mangaliso, who was once having up to six seizures a day, is now experiencing a maximum of one – and on many days, none at all.

The partners supporting this family include:

Knysna Municipality: To address the flooding and improve wheelchair access to the home – a process that remains ongoing.

Western Cape Department of Health: Mangaliso's medical review has been successfully expedited, with his medication assessed and adjusted, contributing directly to his dramatically reduced seizure activity.

Western Cape Department of Education: Continuing to provide educational and therapeutic support for Mangaliso, who attends a local primary school's special needs class.

FAMSA (Families South Africa): The family has recently been referred for professional counselling, offering them a dedicated space to process their experiences and strengthen their emotional resilience.

Epilepsy South Africa – South Cape/Karoo Branch Social Work Support: Abigail September (pictured below with Mangaliso) continues to provide support, helping the family develop coping strategies and navigate the various systems working on their behalf.

Despite their many obstacles, this family's strength is inspiring. Patricia and her husband work as a team – he takes on piecemeal jobs close to home to remain nearby in case Mangaliso has a seizure, while she continues to nurture and care for their son with unwavering faith and gentleness. They are not seeking handouts, but rather understanding, dignity, and sustainable support. Their story is a reminder of how important it is to work together as a community – to ensure that families affected by debilitating epilepsy and other associated neurological disabilities are not forgotten.

At Epilepsy SA – South Cape/Karoo Branch, we are proud to walk alongside this remarkable family. Their story is one of love, perseverance, and hope that is a reflection of what is possible when compassion meets action. 🔥





Gladys & Khutso's story

by Gladys Napo

I am Gladys Napo, born on the 30th of April 1965 at Allmans Drift in what is now Mpumalanga. I am mother to Khutso Elhazor Mabele who was born on the 15th of February 1993, as a child with Epilepsy.

My story begins when I was abused physically and emotionally by my husband during my pregnancy with Khutso in 1992.

While I was still 8 months pregnant, in January 1993, I got sick one morning. My body was freezing from the hips, down to my toes; I tried sitting down but it was too late then I passed out and woke up at the Waterval clinic around 1pm.

I asked myself what could have happened to me, how I ended up at the local hospital. I was in hospital then until on the 15 February, when I gave birth to Khutso.

After giving birth, she did not cry, she did not breathe, she just came out quiet... the nurses tried their best to save her life until they called ambulance to take us to another hospital.

The doctors from this hospital tried to save her upon our arrival and it was very tough going until the arrival of certain doctor from Democratic Republic of Congo who saved my child's life!

He put her on an incubator machine, with lots of drips and using oxygen to help her breathe.

We stayed together in hospital for about 3 months; my child started to open her eyes on day 21 after birth.

After 2 months they took her off the incubator machines, which was a huge relief to me.

All the doctors gave me support so that they could prepare me to begin to understand her condition – they needed to tell me that my child had epilepsy and that there were possibilities of having seizures for the rest of her life.

Learning this was very difficult for me, as I began to understand how serious this was for her, and for me.

I remember when, in July of 1994, Khutso got her first seizure - she was 1 year 5 months old. I took her to our local clinic to get help. It was about 3 years before she had another seizure. On her second seizure I took her to doctor at Vaalbank where the doctor confirmed that it was epilepsy and gave her medication. This is where Khutso started with follow-up care and treatment.

In 2002 Khutso attended her grade 1 at Phakgamang primary school but she was unable to continue with her studies as she was having learning difficulties. I felt overwhelmed but then a social worker was called to help me with looking for special schools for Khutso.

The social worker then helped the family with the process of applying for a special school placement that was eventually successful. She attended that school until she had to move on due to her age.

Khutso has since accepted her epilepsy. You do not need to remind her to take her medication. She leads a full life, attending workshop training at Epilepsy South Africa Mpumalanga Branch satellite offices in Siyabuswa, with the support of social workers. I am so proud of my beautiful daughter and glad that she has all this support, for which I am deeply grateful! 🔥



Me vs Epilepsy

A poem by Darshmika Reddy

Round 1 !

*3, 2, 1 and fight !
Epilepsy attacks !
I take the beating ,
I fall ,
but I stand up.*

Round 2 !

*3, 2, 1 and fight !
Epilepsy attacks again !
Stronger than ever before !
I cannot and will not win...
Out of sheer luck ,
I dodge a punch and counter
with an uppercut to the face !*

*Epilepsy is shocked ,
but unwilling to accept defeat.
Once the bell rings ,
it throws a kick to my stomach.
This time I do not fall ,
I stand strong.*

*No matter what illegal attacks it throws ,
I will always stand strong!*

Round 3 !

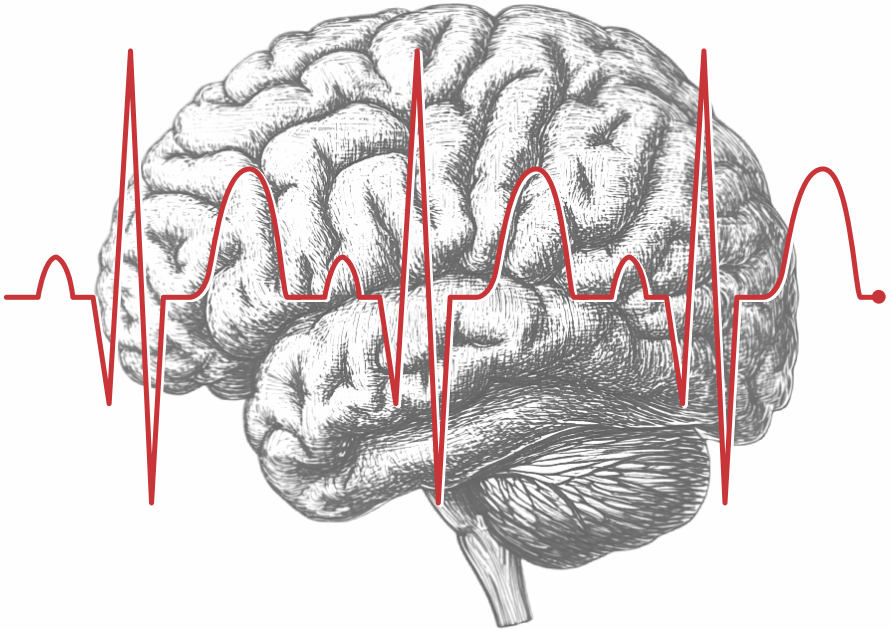
*3, 2, 1 and fight !
As Epilepsy runs towards me ,
I throw a sweeping leg kick ,
successfully ending the fight !*

Winner !

*I am the winner !
Epilepsy is the loser !*

*To all people with Epilepsy, you are the winners !
To those people who passed away from
epilepsy, you are the fighters !*





Epilepsy and Emergency Seizure Management

**A guide for persons with epilepsy,
their families and caregivers**

What is epilepsy?

Epilepsy is a neurological condition in which a person has a tendency to experience recurrent, unprovoked seizures. A seizure happens when there is a sudden burst of abnormal electrical activity in the brain that briefly disrupts how the brain works.

Epilepsy is not a single condition. It affects each person differently, depending on the type of seizure and the underlying cause. With the right diagnosis and treatment, many people with epilepsy gain good seizure control and lead full, active lives.

Understanding seizure types

Seizures are grouped according to where they begin in the brain and how they affect a person. The table below shows the main types, what you might see, and how to help.

Seizure type	What you might see	How to help
Focal seizures <i>(begin in one area of the brain)</i>	The person may stay aware or have reduced awareness. Jerking or stiffness in one part of the body; unusual smells, tastes or sensations; a rising feeling in the stomach; confusion; repeated movements such as lip-smacking; wandering or behaving strangely.	Stay calm and reassure them. Do not restrain them. Gently guide them away from danger such as a road. Speak softly; they may be confused and could react if grabbed. Stay until they are fully aware.
Generalised seizures <i>(involve both sides of the brain)</i>	Usually affect awareness and the whole body. Tonic-clonic (stiffening then jerking, often with a fall); absence (brief blank staring); myoclonic (sudden jerks); atonic (sudden loss of muscle tone and a fall).	For tonic-clonic seizures, follow STAY – SAFE – SIDE and time the seizure. For brief or absence seizures, stay with the person and guide them away from hazards. Check for injury after any fall.
Unclassified seizures	In some cases a seizure cannot yet be clearly classified.	A healthcare provider will assess the seizure type over time and guide treatment.

Important: Some people experience prolonged seizures, or repeated seizures close together (seizure clusters). These can become a medical emergency and may need urgent treatment.

What is status epilepticus?

A seizure that lasts **5 minutes** or longer, or repeated seizures without recovery in between, is called status epilepticus. A prolonged convulsive (tonic-clonic) seizure is a medical emergency. The sooner treatment is started, the better the outcome, so call for emergency help without delay and follow the person's emergency plan if they have one.

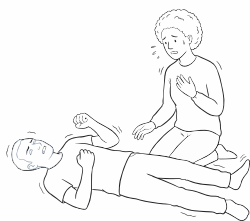
What to do during a seizure

Stay calm and focus on safety. Time the seizure. Protect the person from injury by moving objects away and cushioning their head. Loosen tight clothing and allow the seizure to run its course. When the active jerking has settled, or if the person is not aware, gently place them on their side to help keep the airway clear. Stay with them until they have fully recovered.

Seizure first aid: **STAY – SAFE – SIDE**

Most seizures stop on their own.
If you see someone having a seizure, follow 3 simple steps:

1 STAY



- Stay with the person and remain calm. Note the time the seizure starts so you can time how long it lasts.
- Keep them company until they are fully awake and aware. Look for a medical bracelet, card or other identification.

2 SAFE



- Keep the person safe. Move away anything hard or sharp and cushion their head with something soft.
- Loosen anything tight around the neck.
- Do not move them unless they are in danger.

3 SIDE



- Once the active jerking has settled, or if they are not awake and aware, place them in the recovery position. This helps keep the airway clear.
- Stay with them until they have fully recovered.

Do NOT

- ✗ Do not hold the person down or try to stop their movements.
- ✗ Do not put anything in their mouth – a person cannot swallow their tongue.
- ✗ Do not give food, drink or oral medicine during a seizure.
- ✗ Rescue medicine may be given only if it has been prescribed and you have been trained to give it.

After the seizure

How to place someone in the recovery position:

1. Kneel beside the person. If they are pregnant, kneel on their left and roll them onto their left side.
2. Place the arm nearest you out at a right angle to their body, palm facing up.
3. Bring their far hand across to rest against their near cheek, and bend their far knee up.
4. Gently pull the bent knee towards you so they roll onto their side, facing you.
5. Tilt the chin slightly to keep the airway open and check nothing is blocking the mouth. Stay with them.

The person may feel confused, tired or emotional, and may not remember the seizure. Offer reassurance, let them rest, and keep them safe and comfortable. Do not give them anything to eat or drink until they are fully alert. Some people recover quickly; others may take longer to feel themselves again.



When to get emergency help

Call an ambulance – 10177 (landline) or 112 (any cellphone) – if:

- The seizure lasts longer than 5 minutes.
- One seizure follows another without the person recovering in between.
- The person has difficulty breathing.
- The person does not wake up or regain awareness.
- The person is injured during the seizure, or is pregnant or unwell.
- The seizure happens in water.
- It is the person's first-ever seizure.
- You are worried for any reason.

Emergency medicine (rescue treatment)

Some persons with epilepsy are at risk of prolonged seizures or seizure clusters. For them, a healthcare professional may prescribe an emergency medicine, also called a rescue medicine, to help stop a seizure quickly – often outside hospital. The rescue medicines most commonly used belong to a group of medicines called benzodiazepines. They are designed to act quickly during a prolonged seizure or cluster. Depending on what has been prescribed, they may be given:

- as a spray into the nose (intranasal);
- into the side of the mouth, between the cheek and gum (buccal);
- rectally; or
- by injection, in a hospital setting.



A rescue medicine is always part of an individual seizure management plan. The choice of medicine, the way it is given, and when to use it are decided by the prescribing healthcare professional. Anyone who may need to give the medicine – including family members, caregivers or school staff – should be trained by a healthcare professional and should follow the written plan. The South African Standard Treatment Guidelines support the use of rescue medicine in specific situations, such as prolonged seizures or seizure clusters, including where a drip (intravenous access) is not available.

Safety

A responsible adult should watch over the person as advised by the healthcare professional and seek emergency help if there is any concern. Keep any prescribed rescue medicine in a safe place, away from children, and check the expiry date.

When to speak to your doctor

Ask your doctor:

- Do I, or does the person I care for, need a rescue medicine?
- What should I do if a seizure lasts longer than 5 minutes?
- Can my caregiver, family or school be trained to help?
- Can we write a seizure action plan together?

www.epilepsy.org.za

References

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- International League Against Epilepsy (ILAE). Operational classification of seizure types.
- National Department of Health, South Africa. Standard Treatment Guidelines and Essential Medicines List, Primary Healthcare Level – Chapter 15: Central Nervous System Conditions (2020 edition, Version 1.0, 26 May 2025).
- Epilepsy South Africa.

I didn't fit in, so I endured!

by Obakeng Pelle

My name is Obakeng Pelle and I am 28 years old. I grew up with epilepsy (it started at the age of 2), which affected many parts of my childhood, especially my school life. From a young age, I experienced seizures that were frequent and unpredictable. School was not always safe or supportive place for me.

Some teachers did not understand my condition. Instead of support, I was treated differently, excluded or underestimated. I was often made to feel like I was less capable than others. This made my learning journey harder, not because I could not learn, but because the environment was not accommodating or understanding.

Sadly, discrimination did not only come from school. Some members of my extended family also treated me differently because of epilepsy.



I was judged, misunderstood and at times made me feel like a burden. This affected my confidence and emotional well-being.

Despite all these challenges, I did not give up; I learned to be strong even when I was left alone. I pushed through fear, stigma and discouragement.

Having epilepsy taught me resilience, patience and empathy for others who face invisible struggles.

Today, I am proud of how far I have come. My journey was not easy, but it has shaped me into a determined and compassionate person.

I want my story to be understood not as a story of weakness but of strength and perseverance. 🔥

Epilepsy – The Invisible Disability

by Laurianne Brown

**Is epilepsy a disability?
It's a constant debate and
a difficult one to answer.**

Generally, people living with epilepsy don't show any outward signs of having a condition until they have a seizure. Physical disabilities are evident from the outset but epilepsy “hides” away leading people to believe you are completely normal and healthy.

This is one of the biggest challenges that epilepsy sufferers face. Taken at face value there is absolutely nothing wrong.

This often creates misunderstanding of the real, tough, life struggles.

Because of the unseen nature of the condition, it can become something that people fear...



*Should I employ this person?
Will they be able to do the job,
or will they become a
burden?*

*Should I allow this person to join
our sports team? Could their
seizures affect our team's performance?*

*Is this person just using this as an excuse to
try and make their lives easier? I mean, they
look totally fine.*

Has this person been cursed by witchcraft?

All these doubts and concerns create misunderstanding and further cement the stigma around epilepsy.

This makes the decision to disclose your diagnosis genuinely difficult.

In the South African work environment, epilepsy can be classified as a disability under the Employment Equity Act, but only when it significantly impacts a person's ability to perform their job or participate in everyday activities.

The struggle for people living with epilepsy is that the decision process around this is very subjective.

Who gets to decide what qualifies as impacting "a person's ability to perform their job or participate in everyday activities"?

Each person's experience of living with epilepsy is as unique as their own fingerprint.

No two people will have exactly the same difficulties, symptoms, post seizure struggles, abilities, recovery time from seizures and so forth. Then there's the other side of the coin where people decide they're not going to let this affect them negatively.

They fight with all they've got to achieve their dreams and overcome the hurdles. They refuse to be seen as someone with a disability, not willing to accept any concessions in the school, work or the sporting world. Kudos to them! It's highly admirable and absolutely doable for some but unfortunately not all.

So, in the end, is epilepsy a disability?

I don't think we'll ever have a definitive answer but all we can do is keep having honest conversations and raising awareness of the condition and how it impacts our lives on a personal level and hopefully, that way we can create better understanding and empathy from those around us. 🔥

This article has been repeated for this print edition from a previous electronic-only edition.





Epilepsy and Work:

Confidence, Safety, and Knowing You Belong

If you're a young person with epilepsy, you might think: how can I navigate the workplace and make sure you I everything I need to succeed? Well, you're in the right place for some good advice!



Flexible Work Schedules

Imagine this: You had a rough night with a seizure, and you're feeling exhausted. Instead of stressing about getting to work on time, how about having a flexible work schedule?

Let's dive into reasonable accommodation in the working world and how you can educate yourself and have open conversations with your employer or maybe someone thinking of hiring you.

What is Reasonable Accommodation?

First things first, let's break down what reasonable accommodation means. It's all about making adjustments or changes to your job or work environment to help you perform your tasks effectively and safely.

Think of it as levelling the playing field so you can shine just like anyone else.

You can talk to your employer about starting a bit later or having regular shifts that don't mess with your sleep. It's all about finding a balance that works for you.

Safety First

Safety is super important, especially when you have epilepsy. Picture this: Your workplace has safety devices around machinery, carpets over concrete floors, and a hazard-free environment.

These small changes can make a big difference in reducing the risk of injury during a seizure. It's all about creating a safe space where you can thrive.

Educate and Raise Awareness

Now, let's talk about your colleagues and supervisors. They might not know much about epilepsy, and that's okay! You can take the lead in educating them.

Imagine having a "buddy system" where a colleague is trained in first aid for seizures and knows how to support you. It's all about building a supportive and understanding work environment.

Tech to the Rescue

Technology can be your best friend. Think about using tools that help you work remotely or make your workspace more comfortable. For example, glare guards for computer screens, reducing colour intensity, and replacing flickering lights can make a huge difference if you have photosensitive epilepsy. It's all about finding the right tech solutions that work for you.

Why Inclusion Matters

Inclusion isn't just a buzzword; it's a game-changer. When employers create an inclusive environment, everyone benefits.

Research shows that businesses with diverse teams have better morale, longer retention rates, and improved attendance. Plus, it minimizes costs related to early medical retirement and work-related injuries. It's a win-win for everyone!

Empower Yourself

Epilepsy South Africa has been advocating for people with epilepsy since 1967. They're all about empowering individuals like you to understand your rights and access opportunities. By knowing your rights and implementing reasonable accommodation, you can achieve your greatest potential in the workplace and beyond. Visit our social media or website www.epilepsy.org.za

So, there you have it! Reasonable accommodation is your ticket to a successful and fulfilling career. By having open conversations with your employer, educating your colleagues, and using the right tools, you can create a supportive work environment where you can thrive. Remember, you have the power to shape your future and make a difference. Go out there and show the world what you're capable of! 🔥





Have you made your Epilepsy Pledge?

Across the country, something powerful is taking shape – one promise, one commitment, one act of solidarity at a time.

This year, EpilepsySouthAfrica launched **Epilepsy Pledge: Epilepsy In Action**, a bold national movement calling on every South African to take **one meaningful step** to support people living with epilepsy. It's simple, human, and profoundly impactful: choose one action you can complete in 2026, and let that action help build a safer, more informed, more inclusive South Africa. The campaign forms part of the global Epilepsy Pledge initiative leading up to International Epilepsy Day 2027, where countries around the world will showcase the real, tangible actions taken to challenge stigma and strengthen understanding.

What makes the #EpilepsyPledge powerful is its accessibility. Not everyone can rewrite policy or fund a research programme – but everyone can take one action. One myth corrected. One story shared. One moment of speaking up when stigma appears. One person learning seizure first aid. One community choosing inclusion over fear. Each pledge is a reminder that change doesn't begin with institutions – it begins with people. Ordinary South Africans choosing to act.

In this edition of EpiNews, we celebrate that spirit by highlighting a selection of pledges already received from across the country. These commitments are diverse, heartfelt, and deeply practical. Some come from individuals living with epilepsy. Others from parents, teachers, nurses,

librarians, business owners, sports coaches, and allies who simply want to make a difference. As you read through these pledges, we invite you to reflect on your own role in shaping a more epilepsy-aware South Africa. Whether your action is big or small, public or personal, it matters, and it counts! Change begins when someone chooses to act. This year, South Africa is taking action.

Make your pledge at www.epilepsy.org.za 

- I pledge to increase awareness and understanding of epilepsy, to stand against stigma and discrimination, and to support those living with epilepsy with compassion, respect, and inclusion.*
- By 01 December 2026, I will take concrete action so that Epilepsy is recognized as an invisible disability, reasonable accommodation is provided and first aid lessons to as many people as possible.*
- As a person with epilepsy, I pledge to keep sharing my story so others can see that life with epilepsy can still be full of possibility, dignity, and hope. I pledge to keep working alongside families, communities, and partners across South Africa to ensure SAINAP becomes a reality and reaches the people who need it most. Real change happens when we walk this journey together. This is my promise – to keep showing up, keep speaking out, and keep choosing hope. This is my #EpilepsyPledge.*

#EpilepsyPledge 

Jabu's Story

by Epilepsy SA Mpumalanga Branch

Jabu Ngobeni from Athol in Bushbuckridge was born on the 19th of April 1989. He was born without epilepsy. He started experiencing seizures in 2008. That's when he was diagnosed with epilepsy after experiencing consistent, regular seizures

Jabu was taking traditional medication to deal with the seizures. However, the seizures never stopped, rather they became worse.

In 2012, he heard about a support group of persons with disabilities at the Bushbuckridge satellite office of Epilepsy South Africa Mpumalanga Branch and he opted to join and attend the meetings.

He indicated that the support group is where he got knowledge and information about epilepsy and its medication.



He stated that he then started taking his Epilepsy medication and saw a difference in his seizures.

He mentioned that since he started taking the medication in 2012, he experiences far fewer seizures and can live a normal life. Jabu has struggled to find a long-term relationship and shared that people rejected him because of his condition. He has now found a partner who also has epilepsy. They understand each other well. They've been together for 8 years and have 2 children, aged 8 and 5.

Jabu is a Master of Ceremonies at his local church and he enjoys being an MC during awareness campaigns where he can teach others about acceptance and getting support for persons with disabilities. 🔥



EPILEPSY SA BRANCHES: Social Work and the Carers who hold our communities together

Across the country, Epilepsy South Africa's branches carry out work that is both profoundly practical and deeply human. While national advocacy shifts public understanding, it is the branches and their social workers, carers, community teams, and volunteers who translate rights into lived experience.

They are the ones who sit with families in crisis, who help residents rebuild confidence, who stand in the gap when stigma isolates, and who ensure that no person with epilepsy is left behind. The three branch directors interviewed for this edition – **Rebecca Mashigo (Mpumalanga), Aileen Langley (Gauteng), and Solly Mokgata (Free State and North West)** – each describe a landscape of need that is vast, complex, and deeply personal.

For Rebecca, who has spent most of her professional life at Epilepsy SA, social work begins with humility and presence. She explains that there is no single approach that fits every person, because each individual arrives with their own aspirations, challenges, and cultural context.

Empathy, attentive listening, unconditional acceptance, love, and a non judgemental stance form the foundation of her practice. Her years working in rural communities have shaped her understanding of language, tradition, and the importance of meeting people where they are.

Aileen, with 35 years in social work, describes a similar reality. Many who reach out to the Gauteng branch do so at a point of deep discouragement. Access to nutrition, healthcare, and psychosocial support is often limited, and stigma remains a powerful barrier.

She speaks of the relief that comes when persons with epilepsy are connected to the right services, the renewed confidence that grows when someone stabilises on appropriate medication, and the sense of belonging that emerges when a person attends the protective workshop rather than being left alone at home. For many residents in Gauteng, the branch is a permanent home, and the relationships built there shape the rest of their lives.

Solly brings a philosophical depth to the conversation, grounding his reflections in the African principle of shared humanity. “*Umuntu ngumuntu ngabantu*” – a person is a person through other people – is not simply a proverb for him, but a daily reminder that healing and dignity are never achieved in isolation.

He describes the emotional and social burdens carried by many persons with epilepsy: stigma, rejection, unemployment, and a profound sense of isolation. For him, social work is the practice of seeing beyond the condition and restoring a person's sense of belonging. Healing, he says, is found not only in treatment, but in acceptance, advocacy, and restoring hope.

“Healing is not only found in treatment, but in acceptance, advocacy, and restoring hope.”

*Solly Mokgata,
Branch Director:
Free State & North West*



Across all branches, carers and residential staff emerge as the quiet backbone of daily life. Their work is relational, steady, and often invisible to the outside world. Many residents live at branches for the rest of their lives, thus carers, nurses, cleaners, and cooks build relationships that extend far beyond their formal duties.

In Mpumalanga, Rebecca describes the constant balancing act of ensuring food, clean clothing, medical care, and daily support are always prioritised, even during periods of financial strain. These are the acts of devotion that rarely make headlines but define the heart of Epilepsy SA's branch work.

“There is no single approach that fits every person. Each individual deserves to be seen, heard, and supported on their own terms.”

*Rebecca Mashigo,
Branch Director: Mpumalanga*



The challenges facing branches are significant. Funding shortfalls remain a constant pressure, with government subsidies appreciated but insufficient to cover full operational costs, where ageing buildings require major refurbishment and improved security.

Access to specialised public healthcare such as neurology, psychiatry, speech therapy, physiotherapy, and occupational therapy is limited, with long waiting periods. Stigma and misinformation continue to isolate persons with epilepsy, making community awareness an ongoing necessity.

“Every person assisted is a success story. Every moment of dignity restored matters.”

*Aileen Langley,
Branch Director:
Gauteng*



Yet despite these pressures, each director describes a deep sense of purpose. Success, in branch terms, is rarely dramatic. It is found in the person who regains confidence after joining a support group, the resident who stabilises on the right medication, the family who finally understands epilepsy and stops living in fear, the young person who discovers purpose in a protective workshop, and the community that begins to replace stigma with understanding.

Their words remind us that Epilepsy South Africa's branches are not just service points, but lifelines. They are places where dignity is protected, where carers and social workers hold space for healing, and where persons with epilepsy are seen, supported, and empowered to live full, meaningful lives. 🔥

This article marks the first of a two part interview feature, with three more branch director interviews to follow in Edition Two.

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Quote

*“epilepsy is a challenge,
but it’s also a journey
of growth and empowerment.”*

- Michael Lee



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