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World Epilepsy Day in Malawi: A Doctor's Story from the Frontlines and the Legal and Policy Imperatives to Act in Malawi

Date: 17th February 2026

The following account is based on a real-life experience (anonymous; names have been changed).

Dr. Senga walks into the medical clinics at Blantyre's busiest public hospital. Before the sun rises over Blantyre, the first patients are already waiting. Parents with children who just awakened from a night of seizures, adults admitted after injuries sustained during uncontrolled fits, and school going children whose education has been disrupted not by epilepsy itself but by the absence of consistent treatment.

Dr. Senga explains that the majority of his patients travel over 50 km to reach the public hospital because their nearest clinics have no anti-epileptic drugs left. Others are advised to buy medication privately, often in several weeks supply at costs far beyond what their families can afford. While Carbamazepine and phenobarbital are usually available in public hospitals, these often cause side effects such as dizziness and behavioral changes. Newer medications with fewer side effects are rarely available. Supply chains are unreliable and stock-outs remain common, forcing patients either to interrupt therapy or to purchase medicines privately at costs many families cannot sustain.

What is Epilepsy?

The World Health Organisation defines epilepsy as a chronic noncommunicable disease of the brain. [1]It is characterized by recurrent seizures, which are brief episodes of involuntary movement that may involve a part of the body or the entire body, and are sometimes accompanied by loss of consciousness and control

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[1] World Health Organization, 'Epilespy' https://www.who.int/news-room/fact-sheets/detail/epilespy accessed on 6 February 2026

of bowel or bladder function. Persons with epilepsy have up to three times higher risk of premature death, including from accidents, fires, and sudden death than the general population. [2]Epilepsy is neither contagious nor a mental illness. With appropriate treatment, people with epilepsy live full, healthy and productive lives.

The Health Burden of Epilepsy in Malawi

Epilepsy is amongst the most prevalent neurological conditions in Malawi. Community surveys indicate that active epilepsy affects around 2.8% of the population. [3]However, the actual numbers on the ground are likely double the figure as many hide in the shadows and data collection is poor. [4]Malawi's health strategic plan of 2023-2030 acknowledges neurological disorders as a significant component of the non-communicable disease burden, with epilepsy accounting for the largest share. Despite this recognition, access to effective treatment remains deeply inadequate.

Systematic Gaps in Care and Specialist Capacity

Malawi's health system is not yet structured to manage epilepsy effectively. Epilepsy care is fragmented across the mental health department and general medical services, often without standardized, up-to-date clinical guidelines or sustained specialist oversight. Interrupted anti-seizure therapy increases the risk of status epilepticus, traumatic injury, cognitive decline in children, and sudden unexpected death in epilepsy (SUDEP).

The shortage of neurologists is particularly acute. The World Health Organisation recommends **one neurologist for every 50,000 people**. [5] In stark contrast, Malawi currently has **two adult neurologists and one pediatric neurologist** for a population of **over 20 million** resulting in an approximate ratio of **one neurologist to 6.7 million people.** Therefore, the vast majority of Malawians living with epilepsy will never be assessed or managed by a clinician with formal neurology training, relying on overstretched general practitioners and intermittent visiting neurologists. [6]

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[2] Advocate's Toolkit for Making Epilepsy A Priority in Africa <https://www.ibe-epilepsy.org/wp-content/uploads/2021/09/Epilepsy-Advocacy-Toolkit_WE.pdf

[3] Dream Sant'rgidio 'Epilepsy Program in Malawi' (2023) https://www.dream-health.org/approfondimento/epilepsy-program-in-malawi accessed on 7 February 2026

[4] Alister Munthali, Stine H. Braathen, Lisbet Grut, Yusman Kamleri, Benedicte Ingstad, 'Seeking care for epilepsy and its impacts on households in a rural district in southern Malawi' (2013) *African Journal of Disability.*

[5] Yohane Gadama, Joseph Kamtchum Tatune, Laura A Benjamin, Patrick Kamalo, Mac Mallewa, 'Neurological letter from Malawi' (2019) *Practical Neurology* Volume 19, Issue 4.

[6] Thengo Kavinya, 'Thengo Kavinya talks to Dr Yohane Gadama, Neurologist on his career' (2025) *Malawi Medical Journal*

The Human Rights Implications

The consequences of untreated epilepsy extend beyond the health system. Children with epilepsy are frequently withdrawn from school due to fear, or stigma undermining their right to education. Adults face unfair dismissal from work, or exclusion from economic opportunities undermining their rights to fair labour practices, economic freedom, and development. Research across Africa indicates that households affected by epilepsy spend almost 50% of their income on epilepsy treatment and related care, reflecting the broader economic and social cost of systematic neglect. [7]

Prevention of Epilepsy

It is estimated that up to **25% of epilepsy cases are preventable**.[8] Higher burdens of epilepsy in Malawi and across Africa are attributed to higher rates of pre and perinatal complications, central nervous system infections such as malaria, meningitis, and traumatic brain injury resulting from road traffic accidents or falls, pork tapeworms, and strokes. Effective prevention requires strengthening health systems across the life course by improving maternal and neonatal care, ensuring universal immunization, preventing and promptly treating malaria and other infections especially in children. These are legal and policy obligations tied to the right to health.

International Legal and Policy Obligations

Malawi's responsibility to address epilepsy is grounded in binding international commitments. As a Member State of the United Nations and the World Health Organization (WHO), Malawi has endorsed several global instruments that recognize epilepsy as a public health priority.

World Health Assembly (WHA) Resolution 68.20 (2015) and Resolution 73.10 (2020) urge Member States to strengthen leadership and governance in addressing epilepsy, improve access to anti-seizure medicines, integrate epilepsy care into primary health systems, and develop national action plans.

In May 2022, the 75th World Health Assembly adopted the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022–2031 (IGAP). [9] This 10-year framework sets measurable global targets, including reducing the treatment gap, strengthening workforce capacity, promoting brain health, and safeguarding the human rights of persons living with neurological conditions. The IGAP emphasizes an intersectoral approach requiring coordination between health, education, labor, finance, and justice

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[7] See n 2

[8] Ibid

[9] World Health Organization, *Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022–2031* (2022). https://www.who.int/publications/i/item/9789240076624

sectors recognizing that epilepsy cannot be addressed solely within hospital walls but requires systemic reform.

However, without domestication, commitments to reduce the treatment gap, strengthen primary-level epilepsy care, and safeguard human rights cannot be systematically implemented. Domestication involves translating international commitments into national policies, budget allocations, monitoring frameworks, and accountability mechanisms. To date, Malawi has not adopted a dedicated national epilepsy strategy aligned with the 2022–2031 Global Action Plan. International recognition of epilepsy as a public health imperative therefore places a corresponding obligation on Malawi to move beyond acknowledgment toward structured implementation.

Domestic Legal Framework and Structural Gaps

At the domestic level, epilepsy exists within a fragmented legal and policy landscape. It is often subsumed under broad categories such as non-communicable diseases, mental health, or disability.[10] While these classifications may provide partial protection, the lack of specific recognition creates ambiguity in planning, and service delivery, diffusing responsibility and weakening accountability.

The Persons with Disabilities Act No. 4 of 2024 provides an important legal foundation. The Act defines disability to include long-term physical, mental, psychosocial, intellectual, neurological, developmental, or other sensory impairments which, in interaction with various barriers, may hinder full and effective participation in society. Under this definition, epilepsy qualifies as a disability where it substantially limits participation. The Act prohibits degrading treatment in healthcare, education, and employment, and protects against discrimination.

In practice, however, the lack of a dedicated national epilepsy policy or implementation strategy limits the operationalization of these protections. There are no standardized national guidelines for epilepsy care at all levels of the health system, and no ring-fenced budget for anti-seizure medicines. Where legal recognition exists without implementation frameworks, these rights risk remaining symbolic rather than substantive. For persons living with epilepsy in Malawi, the gap between legal protection and lived experience remains wide.

The Way Forward

Epilepsy is not a curse or an untreatable disease. It is a neurological disorder for which effective, low-cost treatment exists. When persons with epilepsy in Malawi are left without medicine, or dignity, it is not a failure of science but a failure of health systems, policy, and the law. From a clinical and legal

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[10] See n 2

perspective, the reforms required include the following: Explicitly integrate epilepsy into national health and NCD policies with clear targets, domesticate the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022-2031, increase funding and accountability, strengthen specialist training, invest in sustained civic education to address stigma, and ensure uninterrupted access to essential anti-epileptic medicines at all levels of care.

World Epilepsy Day in Malawi demands more than awareness. It demands accountability, deliberate legal and policy reform that recognises it as a public health priority, allocates resources accordingly, and ensures that protections on paper translate into services in practice.