MIND MATTERS

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EDITORIAL

EPILEPSY: FROM MYSTICISM TO MEDICAL SCIENCE TO HOLISTIC CARE

How many of you know how to help someone who suddenly has an epileptic seizure in a public place?

How will you give first aid to the person experiencing the 'fit'?

A young boy with epilepsy was often teased, bullied and excluded at school because his classmates did not understand his condition. When a newly recruited teacher noticed this, she educated the class about epilepsy and encouraged the students to respond with empathy instead of fear. She also worked with the parents, school staff, and school nurse to ensure the child's medication and emergency support were always available. Over time, the classroom environment changed. His classmates learned how to support and keep him safe during seizures, and the boy—once withdrawn and fearful—slowly became confident, social, and actively involved in school life. **Sometimes, awareness from just one person can change an entire life.**

While awareness programs exist for many health conditions like cancer, diabetes, brain stroke, heart attack; and have been popularized, epilepsy comparatively seems to be neglected.

Though **modern medicine has transformed epilepsy care** through better diagnosis, anti-seizure medications, brain imaging, surgery, neurostimulation, and personalized treatments; **it continues to be less discussed, leading to persistent stigma, misconceptions and limited understanding.**

Throughout history, epilepsy was often misunderstood and linked to superstition or spiritual beliefs, until thinkers like Hippocrates recognized it as a disorder of the brain. However, **epilepsy is not just neurological**. **It is a complex that affects physical health, emotional well-being, relationships, education, work, and daily life.**

The condition strongly intersects mental health, and the real burden of epilepsy often lies in the invisible struggles. The constant worry of seizures, the hesitation in sharing one's condition; the quiet fear of being judged; leads to depression and anxiety disorder, low self-esteem, and discrimination. Socio-psychological pressure leads to social withdrawal, isolates the patient and often delays diagnosis and treatment. **In many cases, mental health challenges impact quality of life more than the seizures themselves.**

And it doesn't stop with the individual. Families and caregivers carry their own silent load — constant worry, disrupted routines, emotional fatigue. . Their mental health matters too, yet it is rarely addressed. Supporting family mental health is therefore essential.

So, what needs to change?

We have come a long way from mysticism to scientific understanding to treatment modalities and even awareness of human rights and dignity. **Purple Day on March 26th** each year since 2008 has been designated as epilepsy day.

Yet more needs to be done.

Because epilepsy still remains less talked about.

We need to start talking. Openly. Accurately. Compassionately. Epilepsy care must go beyond seizure control. **Mental health support should be routine, not optional**. Mental health screening, counseling, and psychoeducation should be part of routine care.

Schools, workplaces, and communities must be educated. Myths must be challenged with knowledge. Conversations must replace silence. **Because awareness is not just about information — it is about empathy and taking action. It's also about human rights.**

When we understand epilepsy, we reduce fear. When we support mental health, we restore confidence. And when we challenge stigma, we create space for dignity.

The goal is simple yet powerful: a world where people with epilepsy are not defined by seizures, no one must hide their condition; but empowered to live without fear, fully, freely, and with dignity.

-Dr. Aabha Pimprikar
Co-Editor

DAGMHI 3030 AT PETS – SETS RID 3030

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LIVING WITH EPILEPSY

Epilepsy (seizure disorder) is a medical condition that essentially affects neurons and manifests with physical, mental, autonomic, and behavioural symptoms. For ages, it has remained a feared diagnosis, often carrying the heavy burden of possible life-threatening outcome, long treatment duration, biased cultural perceptions, financial stress, poor recovery, and overall impact of comorbidities.

Numerous **factors cumulatively affect 'kindling' of seizure onset** and span across a person's lifetime, from conception of life to diagnosis – ranging from genetic vulnerability, intrauterine atmosphere, perinatal asphyxia, adverse neonatal incidents, major childhood events, brain injury, psychoactive substance use, or advancing age, to superadded iatrogenic causes. **Childhood onset of seizures irreversibly damages a set of neurons** with each episode, and hampers the brain's physiological neuroplasticity, further restricting cognitive adaptation. The evolution of epilepsy can hence be viewed from a neuro-developmental aspect, which explains initiation of pathological changes during foetal development, and slow progression throughout a child's growing years, gradually integrating into their baseline health parameters.

Clinically diverse presentations in epilepsy and **lack of commonplace knowledge about them** often delay patients' primary contact with healthcare, and make timely diagnosis and early intervention a challenge for health professionals. This inadvertently increases perceived burden in patients through longer duration of untreated illness, resisting acceptance of chronicity, fear of relapses and associated stigma. Stigma for secondary epilepsy (attributed to treatable causes such as CNS infections, drug withdrawal, or space occupying brain lesion) seems to be decreasing over the years, as evidenced by better remission rates, and smoother return to functioning and quality of life standards. However, **in cases with genetic predisposition or acquired irreversible conditions,** a diagnosis poses a significant threat to the patient's self-esteem, friend circle, relationships, marriage prospects, and family planning. This is an even greater ordeal for female patients of epilepsy, or those with refractory seizures or need for lifelong pharmacotherapy.

The chronic course of epilepsy is historically linked with enduring behavioural traits, **referred to as 'epileptoid personality.'** Described as 'sticky' or viscous in nature, these individuals tend to fixate on certain topics, show excessive need for structure/routine, with slower cognitive processing and reduced mental flexibility. They seem to be overly sensitive and dependent in relationships, and show high levels of irritability and emotional volatility as seen in unexpected aggressive episodes. Although traditionally linked with epilepsy, **this term today is obsolete** and warrants deeper neuropsychiatric evaluation to guide symptom-based treatment models.

Epilepsy and mental health fall on a wide neuropsychiatric interface where seizures are commonly encountered in Psychiatric settings in cases of organic mental disorders, post-head trauma or post-neurosurgical sequelae, acute psychotic episodes, high dose neuroleptic administration, drug withdrawal states (alcohol and benzodiazepines), and/ or neurocognitive disorders such as vascular dementia. Microvascular damage caused by age-related noncommunicable diseases accelerates neurodegenerative processes in epilepsy, further impeding patients' cognitive reserve. Additionally, **antiepileptic medications ill-famed for their adverse effects (sedation, cognitive dulling) can also present with secondary psychiatric symptoms. Women of the reproductive age group taking anti-epileptics** especially bear the brunt of weight gain and PCOS-related fertility issues and potential teratogenic effects on the unborn fetus even after successful conception of pregnancy. These patients often need to make informed decisions – choosing between embryo safety against congenital anomalies and risk of seizure relapse, which by itself can endanger the viability of pregnancy. However, scientific advances have propagated **relatively safer antiepileptic medications for expecting mothers as** well as closer fetal monitoring during the antenatal period under supervision of an Obstetrician.

While the sliver of hope must stay on the horizon in our pursuit of healthy living, each person living with epilepsy remains unique to their combination of biological, psychological, and social factors and must make informed decisions at various times in life to maximise their health potential.

-Dr Bhakti Murkey
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EPILEPSY AND CULTURAL BELIEFS

Epilepsy is a chronic neurological disorder **manifested by repeated epileptic seizures**. The word **'seizure'** comes from an old French term '*seisir*' - which means to take control of. In the medical field, this term is used to suggest the disorder taking over the body and resulting in uncontrolled activity.

People, especially in rural India think that this is because of a ghost taking over the patient's body or the patient being under some witchcraft. **This is the most common misconception about epilepsy is that it is not a neurological disorder but a supernatural activity.** In some countries and cultures, epilepsy is referred to as "**pig madness**" which increases the stigma.

Some people think that this is a mental health disorder and that the person having epileptic seizures "has gone mad". **Another common myth is that these seizures are contagious**, and if someone with this disorder touches you, you will get it too.

This often results in the patient being isolated and family members and relatives choosing to stay away from the patient when patients need them the most.

All such misconceptions often lead to the patient being isolated; or worse, beaten up in some cases. People often think that they can "beat the ghost out of the patient's body". **Family members ask the patient to act "normal"** in front of other people so that people don't start talking about them.

This leads to the deterioration of the patient's mental health. When the patient needs proper medical attention, they are left alone, told that this is their fault, or that they have been possessed by a ghost; they are told to "act normal".

For the patient (where their normal is different); everyone telling them to fit in someone else's definition of normal, may lead to severe **anxiety disorders** and **depression**. For some patients, fear, misunderstandings, aggression and violence (being beaten up because of epileptic seizures) can lead to **post-traumatic stress disorder**.

Some people believe that the patient can swallow their own tongue during a seizure, or that holding them in place or restraining them will help, these myths actually interfere with the first-aid that the patient needs.

Epilepsy is not possession, punishment, or madness—it is a medical condition!

Awareness, timely treatment and 'understanding' can save lives.

-Sara Pimprikar
Mental Health Ally, Member-DAGMHI 3030 India

THE HAUNTING SILENCE OF DEPRESSION IN EPILEPSY

During our recent train journey, a young man hastily awakened when his stop arrived. In seconds, he gathered his belongings, stepped down… and collapsed on the platform. Strangers rushed and shouted for help. Can hear someone loudly saying, "Poor boy got seizures." Not just time and tide; even the train didn't wait. With a heavy heart inside the train, my thoughts moved back. It brought back memories of Arun.

Arun was a bright engineering graduate who declined a campus job opportunity outside his hometown because of fear. A few years back, he had a seizure in a crowded public bus, unpredictable, unforgettable. Though his seizures were later controlled, his confidence was not. He avoided travel, refused relocation, and slowly, opportunities faded. What held him back was **depression caused by fear, unpredictability, and lack of autonomy**.

Nandhini, a young girl, was brought in by her parents as she refused to talk about marriage and her future. Medically stable, she resisted marriage. Pregnancy and childbirth were her major fear factors. "I don't want to spoil someone else's life," she once said. T**he depressive self-doubt marks** left by episodes of seizures had narrowed her world and vision. **Depression whispered limitations into every possibility.**

Faizal, once socially vibrant, gradually withdrew from his business and relationships. He felt persistently tired, disconnected, and unmotivated. Missed medications led to breakthrough seizures, intensifying a cycle of depression and poor adherence, which in turn worsened seizures. "**I don't feel like myself anymore,"** he shared.

Depression in epilepsy does not always look like sadness. It often looks like **decisions that slowly and gradually reduce the quality of life.**

These case vignettes reflect a consistent finding **in epilepsy, depression often determines quality of life more than seizures themselves.**

The World Health Organisation states that epilepsy affects nearly **50 million people worldwide.** Depression occurs in 20–55% of individuals, significantly higher than in the general population. Importantly, the relationship is bidirectional—each increases the risk of the other (Hesdorffer et al., 2012).

Depression in epilepsy isn't only reactive; it is a neurobiological mechanism including neurotransmitter imbalance (serotonin, GABA), limbic dysfunction, HPA axis activation, and neuroinflammation. It may appear as fear, avoidance, irritability, or apathy, often without obvious sadness, and frequently mistaken for medication outcomes or "adjustment."

Its impact is deep, emotional distress and loss of self-worth, Cognitive slowing and poor concentration, Social withdrawal and stigma, Reduced occupational functioning, Poor treatment adherence, Increased suicide risk (3–5 times higher). A vicious cycle often follows: depression → poor adherence → more seizures → worsening depression. Yet, this remains underdiagnosed.

Routine screening, integrated care (neurology, psychology, and nutrition), and evidence-based interventions such as CBT and appropriate antidepressants will help improve quality of life. Nutritional approaches such as omega-3 fatty acids, gut–brain modulation, and stable glycaemic patterns offer support.

As Professor Sameer Zuberi a prominent consultant paediatric neurologist reminds us, "**each increment in knowledge, every marginal gain, when added together can make big differences to the lives of people with epilepsy.**"

-Dr Sripriya Shaji Ph D
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THE SILENT STRUGGLE: WHY TREATMENT ADHERENCE IN EPILEPSY ISN'T JUST MEDICAL

Seizures and other neurological symptoms define the pathology; however, the disease's impacts extend far beyond the neurological aspects and affect psychological functioning and sociocultural dynamics. The main determinant of effective seizure management and the prevention of associated complications is the consistent intake of anticonvulsants. However, treatment is often undermined by psychological barriers (WHO, 2023).

Firstly, the **patients' response to the epilepsy diagnosis is emotional.** It may include denial, fear, and other feelings that lead to avoiding treatment or forgetting to take prescribed drugs. Daily taking anticonvulsants may remind patients about their illness and cause emotional discomfort. Consequently, it becomes difficult to adhere to the treatment regimen (Epilepsy Foundation, 2023).

Moreover, co-occurrence of mental disorders, including anxiety and depression, is quite common among those suffering from epilepsy. **Depression negatively affects patients' motivation to follow the treatment plan** and decreases the level of cognitive functioning. Thus, patients may fail to remember to take pills regularly. **Anxiety is also likely to increase patients' fears** associated with medication. Moreover, some patients **might decide to abandon the therapy** because of negative experiences, which increases the risk of developing seizures (International League Against Epilepsy, 2022).

Another important psychological barrier is related to the **stigmatisation and discrimination experienced** by those who suffer from epilepsy. Misconceptions regarding the nature of the disease lead to social withdrawal and avoidance. It decreases the likelihood of patients seeking professional help and expressing difficulties experienced while undergoing treatment (WHO, 2023).

A 19-year-old college athlete with epilepsy said he didn't always take his medicine because he was worried about feeling tired and not performing well in sports. He didn't tell his coach about his condition because he feared being kicked off the team. Over time, irregular medication use led to more seizures, which increased his anxiety and reduced his confidence. Psychological intervention emphasising psychoeducation, cognitive restructuring, and incremental disclosure facilitated improved adherence and emotional well-being. Similar patterns of non-adherence associated with stigma and emotional distress have been documented in young adults with epilepsy (Modi et al., 2012).

Stigma is still a big problem. People who have epilepsy may not want to talk about their problems or get help because they are ashamed or embarrassed about it (WHO, 2023). For athletes suffering from the condition, psychological barriers are even harder to overcome. Athletes might be concerned about potential performance deterioration and about coaches' unwillingness to accept patients as team members. They might choose not to inform anyone about their illness to protect themselves from being discriminated against. In addition, treatment might be discontinued due to patients' beliefs about its effects on performance (International Epilepsy Centre of Excellence, n.d.).

To conclude, a comprehensive care approach should be developed to ensure proper treatment adherence in patients suffering from epilepsy. Understanding is better than judgment; adherence will be better not only as a practice but also as a way to regain control over one's life.

-Akanshaa Hirraani
Founder & Head Psychologist, Calmfit Counselliing (https://calmfitcounselliing.com/)

Epilepsy Support Groups
https://epilepsyindia.org/support-groups/

BEHAVIOURAL SIDE EFFECTS OF ANTIEPILEPTIC MEDICATIONS

Anti-seizure medications are the cornerstone of treatment for conditions like Epilepsy and other seizure-related disorders. While these medications are often highly effective in controlling seizures, they can sometimes produce behavioural and psychiatric side effects that significantly impact quality of life.

Behavioural side effects of AEDs can range from mild mood changes to severe psychiatric disturbances. These effects may depend on the specific drug, dosage, patient vulnerability, and pre-existing mental health conditions. Common behavioural symptoms include: Irritability and agitation, Anxiety, Depression, Mood swings, Aggression or hostility, Impulsivity, cognitive slowing or attention difficulties and in rare cases, more severe effects such as psychosis or suicidal ideation may occur.

The exact mechanisms are complex and not fully understood, but several factors are implicated like Neurotransmitter modulation, Genetic factors and pre-existing psychiatric conditions which can increase risk. Rapid dose escalation leading to sudden changes in drug levels can trigger behavioural symptoms and drug interactions in cases where more than one anti-epileptic medication is used.

Certain patients are more vulnerable to behavioural side effects especially those with a history of depression, anxiety, or other psychiatric disorders. Pediatric and adolescent populations and people with intellectual disability may be more prone to develop side effects. Patients receiving higher-dose or multiple anti-epileptic medications at the same time may develop more side effects as compared to ones on mono-therapy.

It is important for **caregivers to be aware of the potential side effects** that may occur so that they can be managed effectively and in time. Monitoring of mood and behaviour regularly after initiating or changing medication and reporting immediately to the clinician is helpful. In children, behavioural changes may be mistaken for developmental issues or discipline problems while Elderly patients who develop Cognitive and mood changes may be mistaken as dementia or late onset depression.

Behavioural side effects of antiepileptic medications are clinically significant but often manageable with careful monitoring and individualized treatment strategies. A balanced approach that prioritizes both seizure control and mental well-being is essential. Early recognition, patient education, and timely intervention can greatly improve outcomes and quality of life for individuals undergoing antiepileptic therapy.

-Dr Rucha Sule Khot
Consultant Psychiatrist, Nashik

EPILEPSY: MISSING THE BIG PICTURE

As a therapist, I have worked with many people living with Epilepsy who quietly express thoughts of not wanting to continue living in the same way. These are not always crisis statements, but often emerge after months or years of adjustment, limitation, and uncertainty. What stands out is how long these thoughts remain unspoken.

In consultations, the focus often stays on physical symptoms and seizure patterns. Yet **what unfolds beyond seizure counts matters just as much**: how the week has felt, what parts of life have gradually faded, how often the mind anticipates the next episode, and whether, at times, everything begins to feel overwhelming.

For many people living with Epilepsy, **the risk of suicidality may develop long before a visible crisis. It often builds within the ongoing experience of unpredictability, loss of control, and living between seizures**. Over time, social participation, confidence, independence, and identity may gradually narrow. Added to this are neurological changes, medication effects, emotional stress, and the burden of stigma. **What remains concerning is how easily these experiences stay outside routine care.**

Screening tools such as the **Neurological Disorders Depression Inventory for Epilepsy (NDDI-E)** and the **Patient Health Questionnaire-9 (PHQ-9)** can help identify depression and suicide risk, yet they are not consistently included in follow-up care.

Understanding epilepsy therefore requires more than tracking seizures. **It requires attention to how a person is adapting, withdrawing, or continuing to engage with life, and how long someone has been carrying that weight alone.**

-Anjali Anil Salani, Therapist

CAREGIVERS & FAMILY HEALTH: HOLDING THE HOLDERS

Epilepsy is not experienced in isolation-it quietly reshapes the emotional landscape of an entire family. Beyond visible medical care, there is an invisible layer of alertness that caregivers carry. Even during moments, a part of the mind remains watchful, anticipating the uncertainty seizures can bring. Over time, this state of "**always being prepared**" becomes emotionally draining.

Caregivers move into roles that demand consistency, responsibility, and strength. They track medications, ensure safety, and adjust routines - all while trying to maintain normalcy. Yet beneath this are emotions that rarely find space,fear during unpredictability, helplessness in moments of loss of control, and quiet guilt. Thoughts like "**Am I doing enough**?" or "**What if I miss something**?" linger and deeply felt.

Within families, these emotional shifts are subtle but significant. Parents may become more protective, driven by concern. Siblings adapt quickly, sometimes suppressing needs or emotions to "**not add to the stress**." These patterns influence relationships and the emotional climate at home. Over time, unexpressed feelings can surface as irritability, withdrawal, or emotional fatigue.

What often helps is small, intentional shifts. When families **create space for honest conversations**-not just about epilepsy, but about how it feels - there is relief. Naming emotions reduces their intensity. Understanding the condition through psychoeducation can replace fear with preparedness and control.

Equally important is acknowledging that caregivers need care too. Taking short breaks, maintaining social connections, or engaging in something meaningful can restore emotional balance. **Support systems** and **shared family responsibility**,reduce the sense of carrying everything alone.

Caregiving, especially in conditions like epilepsy, is as much an emotional journey as a practical one. When the focus expands to include the well-being of caregivers and family members, the environment becomes more supportive and sustainable.

Because behind consistent care, there is a human being who also needs space to breathe, feel, and be supported!

– Aditi Sethi
Counseling Psychologist |Trauma informed practitioner