A Free Guide for People Living with Epilepsy, Caregivers, and Those Seeking Understanding

WHAT I WISH I KNEW ABOUT LIVING WITH EPILEPSY

Living with epilepsy is often more complicated than people realize. This guide shares lessons, insights, and encouragement drawn from lived experience to help others feel more informed, understood, and supported.

The information provided in this guide is for educational and informational purposes only and is not intended to replace professional medical advice, diagnosis, or treatment. Always consult with a qualified healthcare provider regarding questions about any medical condition, symptoms, or treatment decisions. If you believe you are experiencing a medical emergency, call 911 or seek immediate medical attention.

Purple is a color widely associated with epilepsy awareness and other neurological and invisible health conditions. Wear purple with pride as a symbol of awareness, strength, support, and resilience.

1. Epilepsy Does Not Always Look the Same

Not all seizures involve falling to the ground or convulsions. Some seizures are quiet and may appear asstaring spells, confusion, memory lapses, emotional shifts, or moments where time seems to disappear.

2. You May Spend Years Trying to Explain Experiences You Don't Yet Have Words For

One of the hardest parts of living with epilepsy can be trying to describe experiences that feel difficult to explain—even to yourself. You are not imagining these experiences.

3. Stress, Fatigue, and Change Matter

Many people living with epilepsy notice patterns connected to lack of sleep, stress, illness, hormones,overstimulation, or changes in routine.

4. Invisible Illness Can Affect Identity

People living with epilepsy often become skilled at hiding symptoms in order to appear normal. Over time,this can become emotionally exhausting.

5. Advocay Matters

Your voice matters. Asking questions, seeking second opinions, tracking symptoms, and communicatingyour experiences are important parts of self-advocacy.

6. Caregivers and Support Systems Matter Too

Support is not only about emergencies. Sometimes support looks like patience, listening, flexibility,understanding, and reducing judgment.

7. You Are Not Alone

There are millions of people living with epilepsy and invisible neurological conditions. Connection,education, and understanding can make a powerful difference.

> “You are not strange.
> You are not broken.
> You are not alone.”

Continue the Journey

Rain Down Purple: Because Epilepsy Ain’t for Punks

A memoir by C.S. Edwards exploring epilepsy, identity, advocacy, and resilience.

Visit: **raindownpurple.com**

Download updates, previews, speaking information, and future resources.

EPILEPSY FOUNDATION

Epilepsy & Seizures 24/7 Helpline:
1-800-332-1000
en Espanol:
1-866-748-8008

epilepsy.com/helpline