

# Hope, Hesitancy, and Hard Truths

A PATIENT AND PROVIDER PERSPECTIVE ON EPILEPSY TREATMENT



Epilepsy affects nearly **3.4 million people in the U.S. alone**, and while advances in medicine have made seizure control possible for many, about **one-third of patients** continue to experience seizures despite treatment.

## The Hope Gap



**78% of patients** don't believe they will ever be seizure-free.



**One in four** say it's not worth trying a new treatment because they've accepted the fact that they will be living with seizures for the rest of their lives.



**63% of doctors** believe 75–100% seizure reduction is realistic, while **fewer than half of patients (46%)** believe such a reduction is possible.

## Treatment Hesitancy



**Nearly 90% of patients** would ask about switching/adding medication.



Yet, **88% of doctors** report encountering resistance from patients or their loved ones when proposing a change.



**Over half of patients** surveyed (**52%**) believe having more information about alternatives could help them have better conversations with their doctors about changing or adding medications.



While **65% of epileptologists** report they regularly talk about alternate treatments as part of routine care, only **44% of advanced practice physicians and 35% of neurologists do so**.

## Why are you afraid to change medications?



Side effects



Effectiveness of the medication



Cost/affordability



Drug interactions



The time it will take to experience additional seizure reduction/less side effects



Dosing (e.g., once a day, twice a day, etc.)

## Seizure Transparency

**72% of patients** don't report all seizures.



**31%** fear losing driving independence



**21%** forget to keep track of their seizures



**30%** don't think seizures are significant



**18%** unsure how to effectively track or describe their seizures



**25%** don't think it will change treatment

## SUDEP Awareness Gaps

### Sudden Unexpected Death in Epilepsy (SUDEP)

is the leading cause of death among people with epilepsy. While there are no preventive treatments for SUDEP, physician-patient discussions are critical for understanding the risks and how to reduce them.

**88% of doctors** say they discuss SUDEP,



**Almost one-fifth of patients**

who experience one or more daily seizures have either not heard of SUDEP or not heard about it from their physician.