



Understanding SUDEP

The leading cause of death in uncontrolled epilepsy — and what you can do about it

By: Wafaq Alshami

LET'S START HONEST — RAISE YOUR HAND

Has a doctor ever talked to you about SUDEP?



- Yes — they brought it up on their own
- Yes — but only after I asked
- They said it was rare and not to worry
- No — never
- I'd never heard of SUDEP before today

Remember the show of hands — we'll compare our room to 500 patients nationwide in a few minutes.

What Is SUDEP?



Sudden Unexpected Death in Epilepsy

A person with epilepsy — otherwise healthy — dies suddenly and unexpectedly, and death investigation finds no other cause.

It occurs far more often in people whose seizures are poorly controlled, and most often during or right after a seizure — frequently at night, unwitnessed.

By definition, SUDEP is NOT:



An accident, injury, or drowning



A seizure emergency like status epilepticus



Explained by anything found at autopsy

Source: Epilepsy Foundation, “Ask Questions about SUDEP” (117SFS, 2022)

What We Think Happens



1



A seizure occurs

Often tonic-clonic (grand mal) — frequently during sleep

2



Body systems falter

Problems with consciousness, breathing, and heart function during and after the seizure — long pauses, dangerous rhythms

3



Often unwitnessed

Most events happen during sleep — face-down (prone) in bed, with no one aware a seizure is happening

4



Cardiorespiratory collapse

Breathing and heart function fail to recover — this is SUDEP

The exact causes are still not well understood — which is exactly why prevention focuses on the one thing we can measure: seizures.

Source: Epilepsy Foundation (117SFS, 2022); SK Life Science, “Hope, Hesitancy, and Hard Truths” (2025)

The Numbers — No Sugarcoating



1 in 1,000

adults AND children with epilepsy
die from SUDEP every year



1 in 150

every year, when epilepsy
remains uncontrolled — ~7× higher



#1

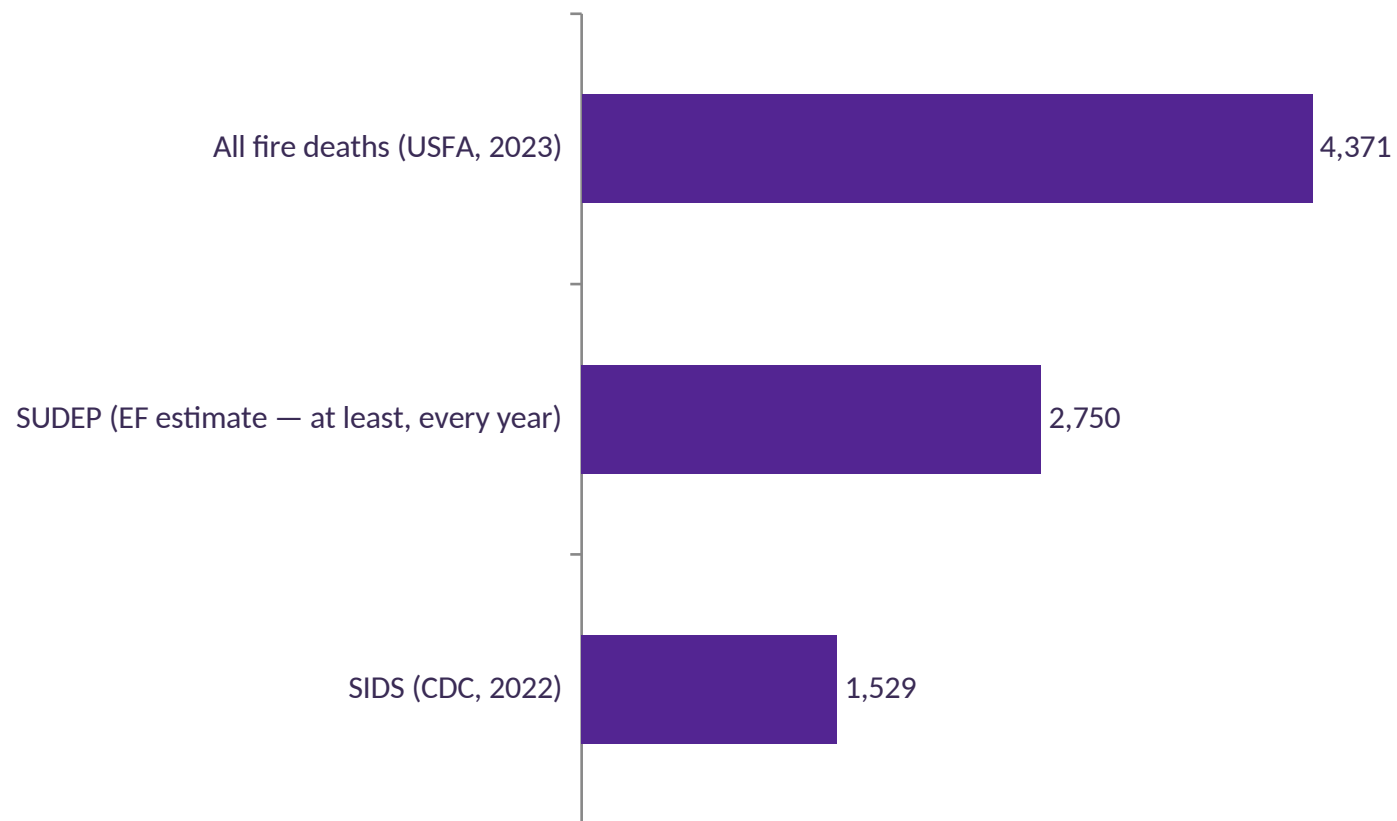
leading cause of death in young
adults with uncontrolled epilepsy



That is roughly 2,750+ American lives lost to SUDEP every single year — and the risk is not spread evenly: it follows uncontrolled seizures.

Sources: Epilepsy Foundation (117SFS, 2022); Orrin Devinsky, MD — NYU Langone Comprehensive Epilepsy Center

More Deaths Than SIDS — None of the Awareness



“Epilepsy-related mortality should be a public health priority. There are at least 2,750 U.S. cases of SUDEP every year.”

— Orrin Devinsky, MD
NYU Langone • SUDEP Advisory Board

Sources: Epilepsy Foundation $\geq 2,750$ /yr SUDEP estimate (117SFS, 2022) • CDC SUID/SIDS data, 2022 • U.S. Fire Administration, 2023

Who Is at Highest Risk



Frequent or uncontrolled seizures — the dominant driver. Every breakthrough seizure is another roll of the dice.



Grand mal (tonic-clonic) seizures — the convulsive type carries the highest SUDEP risk.



Nighttime seizures — seizures in sleep are the classic SUDEP scenario: prone, dark, unwitnessed.



Irregular seizure-medication use — inconsistent levels leave the brain unprotected exactly when it matters.

If any of these sounded familiar, today applies to you directly.

Source: Epilepsy Foundation / SK Life Science, “Hope, Hesitancy, and Hard Truths” (2025)

TALK TO YOUR NEIGHBOR — 2 MINUTES

What does “controlled” mean for YOUR epilepsy?



- How many seizures did you have last month?
- Do you personally call that “controlled”?
- Would your neurologist agree with you?

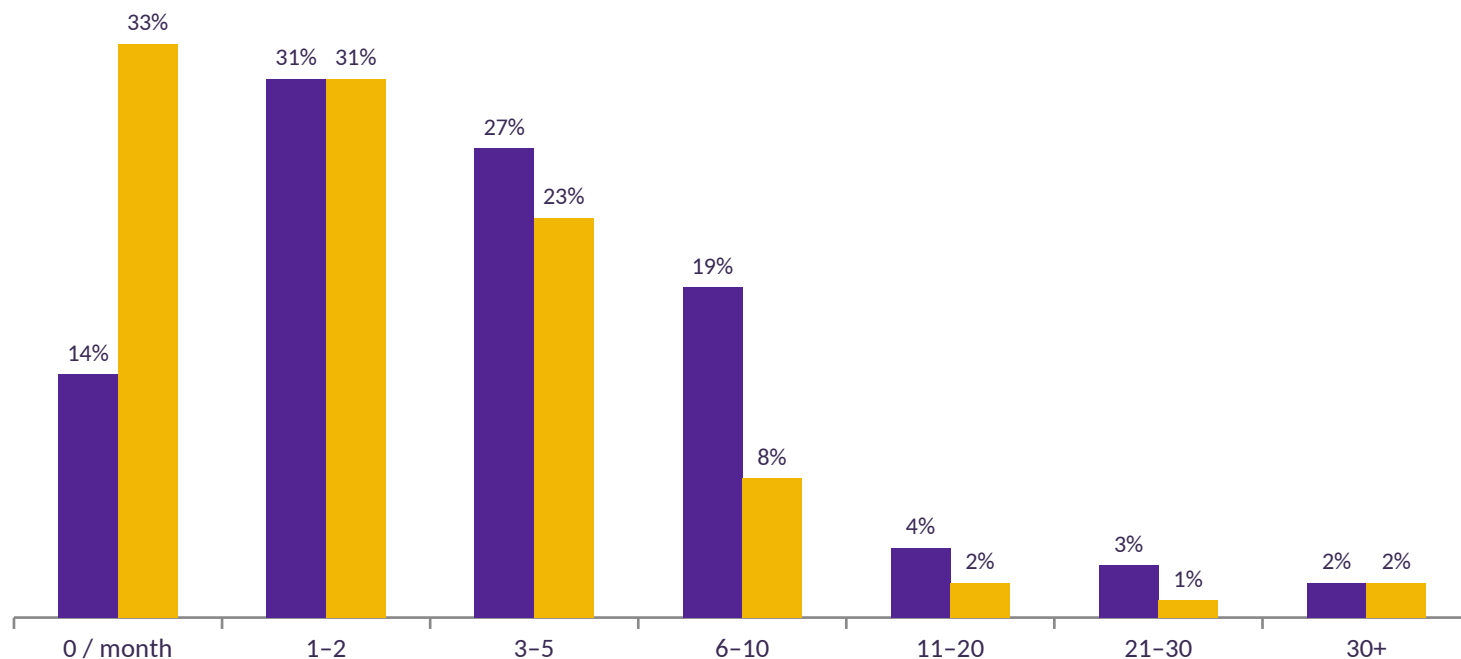
Keep your number in mind — next slide is what 500 U.S. patients said.

The Hope Gap — What Patients Call “Control”



“How do you define seizure control?” — patients, by share of answers

■ Men ■ Women



78%

of patients don't believe they'll ever be completely seizure-free

1 in 4

say a new treatment isn't worth trying — they've accepted seizures for life

25%

call 3-5 seizures a month “under control”

Source: SK Life Science / Wakefield Research, “Hope, Hesitancy, and Hard Truths” — 500 U.S. patients, July 2025

Your Doctor Believes More Is Possible



63%

of physicians say it's realistic to expect treatment to cut seizures by 75–100%



46%

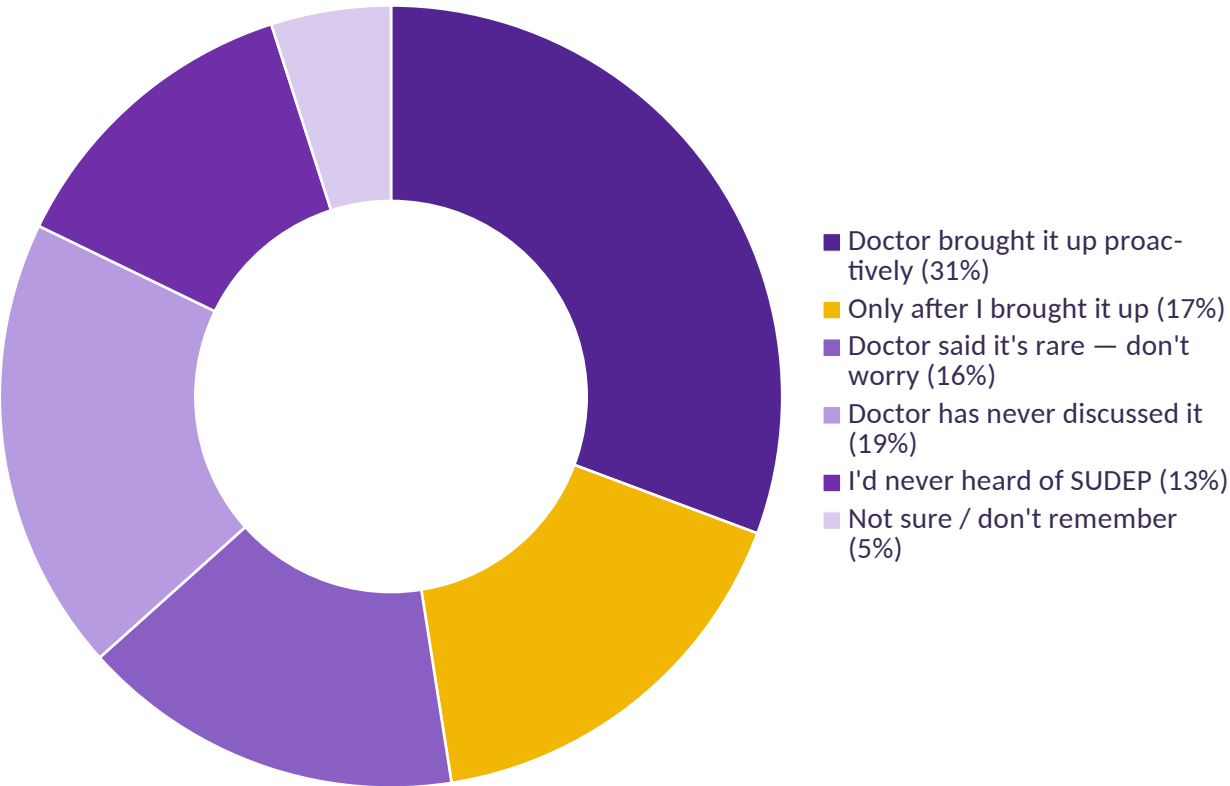
of patients believe a reduction like that is even possible

“We, as specialists, need to show patients and non-specialist providers that seizure freedom is achievable for some, even after years of uncontrolled seizures.”

— Pavel Klein, MD

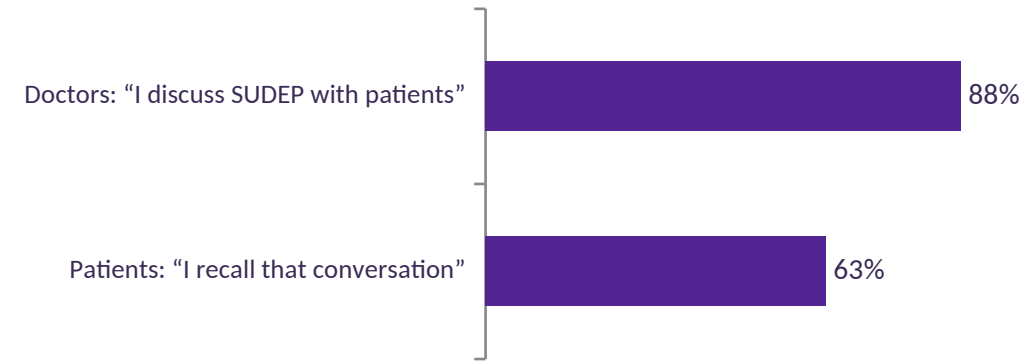
Source: SK Life Science / Wakefield Research, 2025 — 450 healthcare providers, 500 patients

The Awareness Gap — Measured



Answer categories as published in the survey — they total 101% because each value was rounded to the nearest whole percent.

The same conversation — said vs. remembered:



A quarter of these conversations vanish between "said" and "heard."

18% of patients with DAILY seizures have never heard of SUDEP — or not from their doctor

2× rural patients are twice as likely as city patients to never be told (30% vs 15%)

Source: SK Life Science / Wakefield Research, 2025. "Has your doctor discussed the risk of SUDEP?" — 500 U.S. patients

YOUR TURN — PICK TWO

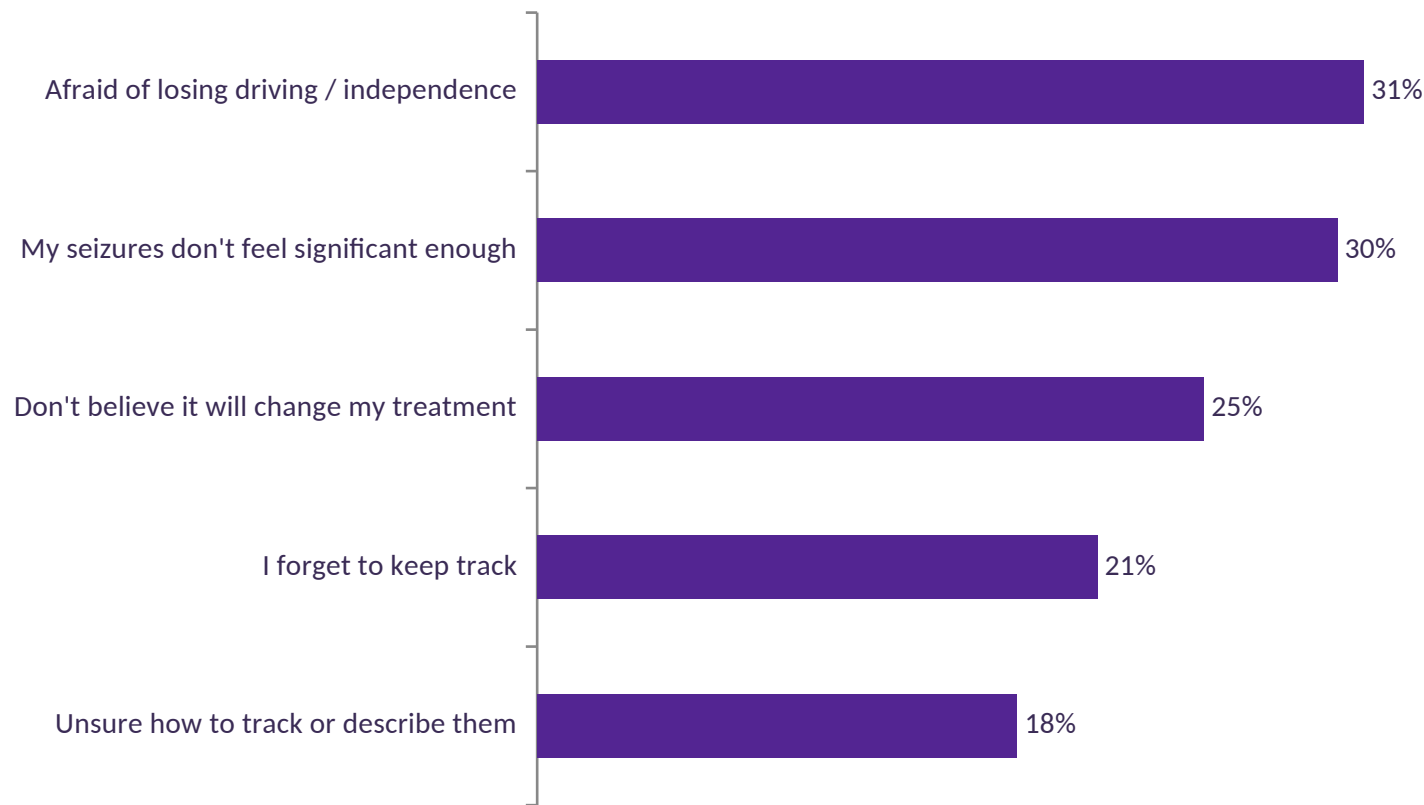
Which two will you ask at your next appointment?



- 1 How can I lower my SUDEP risk?
- 2 What should I do if I have another seizure?
- 3 How can we prevent future seizures?
- 4 Could surgery, a neurostimulation device, or dietary therapy reduce my seizures?
- 5 What should I do about seizures at night?
- 6 Should I consider a seizure-alert device?
- 7 Should I consider sharing a bedroom?
- 8 Is my current medication really working hard enough?

Write your two down now — phone notes count. Questions 1–7 are the Epilepsy Foundation's own recommended list; #8 is ours.

The Silence Problem — 72% Don't Report Every Seizure



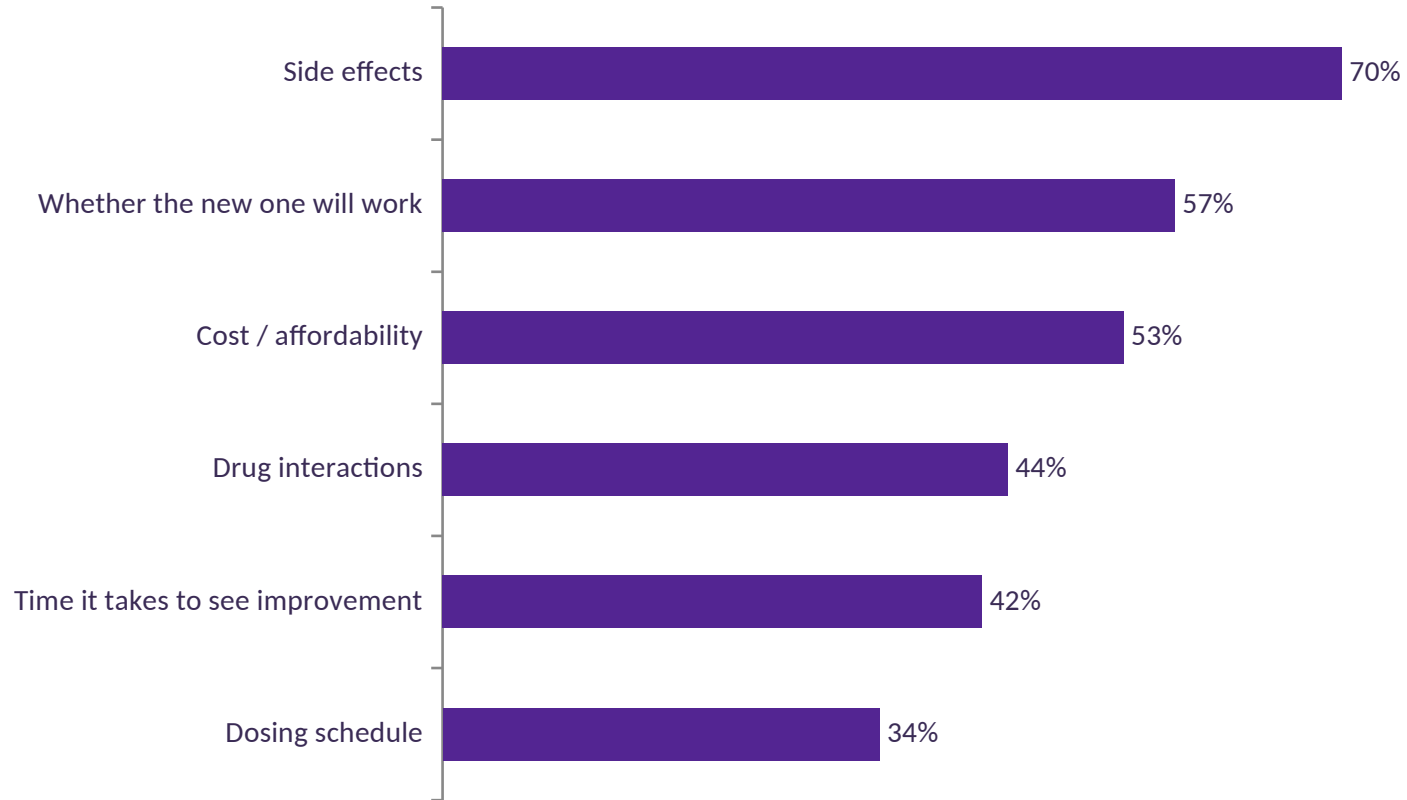
A seizure your doctor never hears about is a risk nobody is treating.

"Patients often hide seizures out of fear of losing independence... 'help me help you' — so they feel safe being open about every seizure."

— Lucretia Long, DNP, CANP, F-AES

Source: SK Life Science / Wakefield Research, 2025 — 72% of 500 U.S. patients don't report all seizures

Why We Fear Changing Treatment



~90%

of patients would ask about switching or adding a medication

88%

of doctors report resistance when they propose a change

65% vs 35%

epileptologists routinely discuss alternatives — most general neurologists don't

Source: SK Life Science / Wakefield Research, 2025. Dr. Dawn Eliashiv notes many side effects are transient, and slow titration eases the change.

Strive for Seizure Control — Six Habits



Meds on time, every day

Exactly as prescribed — alarms, pill boxes, whatever it takes



Protect your sleep

Sleep deprivation and seizures are directly linked



Limit alcohol & substances

Both lower the seizure threshold



Know your triggers

And build concrete plans to minimize them



Keep a diary

Seizures, test results, questions for your doctor



Share a Seizure Response Plan

So the people around you know exactly what to do

The best way to prevent SUDEP is to work with your health care team to have as few seizures as possible. — Epilepsy Foundation

Source: Epilepsy Foundation, “Strive for Seizure Control” (117SFS, 2022)

Beyond Pills — And Be Prepared



If two medications haven't controlled your seizures, ask about:



Epilepsy surgery evaluation



Neurostimulation devices (VNS · RNS)



Dietary therapies (ketogenic, modified Atkins)



Night strategies — alert device, shared bedroom, supervision

Emergencies find us — be ready:



Emergency kit with EXTRA anti-seizure medication



Seizure Action Plan in a waterproof bag



Free seizure first-aid course: learn.epilepsy.com



24/7 Helpline: 1.800.332.1000 · español 1.866.748.8008

Sources: Epilepsy Foundation “Ask Questions about SUDEP” (117SFS) & “Emergency Preparedness” (EFA150, 2022)

BEFORE YOU LEAVE — WRITE IT DOWN

Your three commitments



- 1 The date of my next neurology appointment
- 2 The SUDEP question I picked today — the one I WILL ask
- 3 The one habit I'm fixing this month (med alarms · sleep · diary)

Tell the person next to you what you wrote — they're your accountability partner until next month's meeting.



Any Questions?



Thank you for listening

No one should face epilepsy alone. · support@beyondepilepsy.org · 559-466-7713