

# What Does It Mean to Live With Epilepsy? Burden of Illness From the Patient Perspective

Wagner JM, Oak B, Smith B, Athavale A, Skaar JR, Ong A, Harden C. *Epilepsia Open*. 2026. doi:10.1002/epi4.70222

## OBJECTIVE

Examine the real-world experience, comorbidities, and mental health of patients with epilepsy (PwE) currently receiving antiseizure medications (ASMs).

## BACKGROUND

- The primary treatment goals for epilepsy are to maximize seizure control, reduce side effects of medication, and improve quality of life.
- Real-world data on quality of life, mental health, work productivity, and caregiver impact can illuminate unmet needs despite ongoing treatment.

## METHODS

**Design:** Web-enabled survey of PwE in the United States (July-September 2023)

**Recruitment:** Patient panels and physician referrals

**Eligibility:** US residents; 18-80 years old; physician-confirmed epilepsy  $\geq 1$  year; self-reported focal seizures;  $\geq 1$  seizure/month; past/present use of  $\geq 2$  ASMs; currently receiving an ASM  $\geq 1$  month

**Assessments:** Treatment journey and disease burden; validated self-reported PROs—QOLIE-10, PHQ-9, GAD-7, WPAI; healthcare resource utilization; caregiver burden

## RESULTS

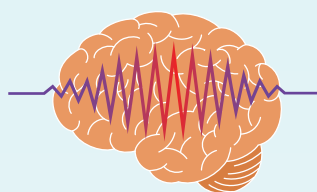
### Participants



170

Adults with epilepsy (US) reporting focal seizures

### Seizure Burden



66.5%

Reported  $>1$  seizure/month

75.3%

Rated seizures as moderate-to-high severity

### Comorbidities<sup>a</sup>



49.4%

Anxiety

40.6%

Migraines

40.0%

Depression

<sup>a</sup>Self-reported physician diagnosis

### Nonseizure Symptoms



72.9%

Reported  $\geq 3$  nonseizure symptoms despite ASM treatment

#### Top Symptoms

76.5%

Mood issues

72.4%

Fatigue/lack of energy

68.8%

Problems with sleep

### Quality of Life & Mental Health



44.5  
(SD 17.5)

QOLIE-10 notable impact on QoL

70%

Report trouble driving

63.5%

PHQ-9 with moderate-to-severe depression

46.5%

GAD-7 with moderate-to-severe anxiety

### Work Productivity



60.6%

WPAI Mean work productivity loss (driven by presenteeism<sup>a</sup>)

<sup>a</sup>Reduced performance due to health problems

### Caregivers



60.6%

Required caregivers

68.9%

Of PwE with caregivers agreed that day-to-day and emotional demands negatively impacted family/caregivers

### Healthcare Use (Annual)



9.4

Outpatient visits

2.8

Emergency visits and/or hospitalizations

## CONCLUSION

PwE reporting focal seizures who were on ASMs report substantial ongoing burden—including persistent seizures, nonseizure symptoms, mental health challenges, impaired work productivity, high healthcare utilization, and caregiver impact—highlighting unmet needs for therapies that meaningfully reduce disease burden.