

# Have you heard of sudden unexpected death in epilepsy?

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Sudden unexpected death in epilepsy (SUDEP) is concerning and many—even those with seizure disorders—may not be aware of this condition. New research published in *Epilepsia*, a journal published by Wiley on behalf of the International League Against Epilepsy (ILAE), reports that 76% of caregivers are more likely to have heard of SUDEP compared with 65% of patients with epilepsy.

Dr. Barbara Kroner, an epidemiologist with RTI International in Rockville, Maryland and lead author of the study says, "When someone with [epilepsy](#) dies suddenly we want to understand why. Our research calls attention to SUDEP and provides important knowledge to help neurologists have open discussions with patients, especially those at greatest risk of epilepsy-related death."

While it is obviously an overwhelming loss, SUDEP is uncommon, occurring in about 1 in 1,000 individuals with epilepsy each year. However, a study by Dr. David Thurman and colleagues also published in this issue of *Epilepsia* suggests that "comparing years of potential life lost from SUDEP with selected other neurologic diseases, SUDEP ranks second only to stroke." Moreover previous evidence shows that only 5% of neurologists discuss SUDEP with their all patients and 69% discuss it with few or none of their patients. One of the main reasons for this lack of communication is that doctors do not want to raise fears or anxiety in patients.

For the Kroner et al study, researchers surveyed close to 1,400 patients

with epilepsy and more than 600 caregivers. Surveys were conducted via the web or in a clinical setting. The survey included questions about type of seizure, epilepsy treatment plans, fear of death, and familiarity with SUDEP. If respondents had not heard of SUDEP, a definition was provided, and questions about the initial reaction to the condition were asked.

Findings indicate that internet survey respondents were more likely to have heard about SUDEP than patients in the clinical setting at 71% and 39%, respectively. Those caring for epilepsy patients were more likely than the epilepsy patient to have heard about SUDEP (76% vs. 65%), with prior awareness associated with increased education level, more severe and longer epilepsy duration, and having an epilepsy specialist as the primary care provider.

Fear, anxiety, and sadness were often reported by epilepsy patients at caregivers upon first learning about SUDEP, with most wanting to discuss these feelings with their doctor. Knowledge of SUDEP and increase in epilepsy severity escalated the concern of death among patients and caregivers. However half of respondents thought that knowledge of SUDEP would influence management of epilepsy.

"Preventing seizures in patients with difficult to treat epilepsy may help avert sudden [death](#)," concludes Dr. Kroner. "It's important for the neurological community to continue to focus our attention on SUDEP, determining which epilepsy patients are at greatest risk and how best to educate them and their caregivers."

Drs. Gary Mathern and Astrid Nehlig, Editors-in-Chief of *Epilepsia*, along with Associate Editor, Dr. Dale Hesdorffer agree, "SUDEP continues to gain considerable attention, with increasing pressure from the epilepsy community to encourage dialog between clinicians, patients and their families. In a series of SUDEP articles we start this important

conversation and invite readers to participate in a SUDEP survey at <http://surveys.verticalresponse.com/a/show/1539433/a6bed9de39/0>. Together we can advance understanding of SUDEP and how best to communicate with those challenged by this tragic outcome."

**More information:** "Characteristics of Epilepsy Patients and Caregivers Who Either Have or Have Not Heard of SUDEP." Barbara L. Kroner, Cyndi Wright, Daniel Friedman, Kim Macher, Liliana Preiss, Jade Misajon and Orrin Devinsky. *Epilepsia*; Published: October 16, 2014 [DOI: 10.1111/epi.12799](https://doi.org/10.1111/epi.12799)

"Sudden Unexpected Death in Epilepsy: Assessing The Public Health Burden." David J. Thurman, Dale C. Hesdorffer and Jacqueline A. French. *Epilepsia*; Published: October 16, 2014 [DOI: 10.1111/epi.12666](https://doi.org/10.1111/epi.12666)

"Knowing the Risk of SUDEP: Two family's perspectives and The Danny Did Foundation." Mark J. Stevenson and Thomas F. Stanton. *Epilepsia*; Published: October 16, 2014 [DOI: 10.1111/epi.12795](https://doi.org/10.1111/epi.12795)

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