



# SUDEP DISCUSSION GUIDE

**SUDEP—Sudden Unexpected Death in Epilepsy—is the leading cause of epilepsy-related deaths.<sup>1</sup>**

Take steps that may lower the risk of SUDEP. Arm your patients with the knowledge they need.

Use this guide as a starting point for discussing SUDEP with patients and their caregivers.

**According to the Epilepsy Foundation:** Every year, 1 in 150 people who have uncontrolled seizures dies from SUDEP, the leading epilepsy-related cause of death.<sup>1</sup> However, in a 2016 survey, **only 18% reported having discussed the risk of SUDEP with their doctor.**<sup>2,3</sup>

## Increased SUDEP risk during the preceding year<sup>4</sup>



## Some tactics that can make discussions easier:

- Taking a moment to make your patient feel comfortable
- Having a straightforward discussion in which you outline:
  - What breakthrough seizures are, and why it's important for the patient to let the doctor know when they occur
  - How SUDEP is thought to happen (disrupted brain, heart, lung, and arousal system function and other mechanisms)<sup>1</sup>
  - The patient's likely risk of SUDEP (for most patients small, but rising with the frequency of convulsive seizures)<sup>5</sup>
  - Ways to mitigate that risk (effective seizure control, seizure detection devices, nocturnal monitoring, changes to pillows and bedding, taking prescribed anticonvulsants consistently, avoiding triggers, and preventing convulsive seizures)<sup>1,5</sup>

## Keep in mind when planning a discussion about SUDEP:

- The discussion doesn't have to be long to be effective
- Patients and caregivers might feel more motivated to take treatment seriously once they know what they're up against
- You may prefer to talk to them about SUDEP before they hear about it from a less trustworthy source

**“People with epilepsy have the right to know that SUDEP exists, and they have the right to be responsibly counseled about how to reduce the risk. And actually, that doesn't have to be a painful conversation.”<sup>6</sup>**

—Dr. Elizabeth Donner, Neurologist, Hospital for Sick Children, Toronto; co-founder, SUDEP Aware

## Some steps that may help minimize the risk of breakthrough seizures—especially convulsive seizures—and SUDEP:

**For patients who present with a higher frequency of seizures:** Establish seizure frequency and severity baseline at intake. Monitor as needed, especially where seizure frequency is high.<sup>1</sup>

**For patients who are sensitive to drops in AED plasma levels:** Avoid prescribing short-acting AEDs that require multiple doses daily at specific times. Consider prescribing an AED with a longer half-life.<sup>7</sup>

**For patients who may miss doses:** Assess to determine likely obstacles to adherence and create an appropriate treatment plan.

**For patients who menstruate:** Because changing hormone levels may make AED plasma levels less stable, consider prescribing an AED with a longer half-life.<sup>8</sup>

**For patients who encounter multiple triggers in their daily lives:** Probe for ongoing issues that could make seizure control more challenging, including stress, difficulty sleeping, alcohol consumption, and comorbidities. Counsel patients on ways to manage triggers.<sup>9</sup>

**For patients who are not well controlled on their current medication(s):** Determine whether it's the medication itself, adherence, side effects, or some other issue that is getting in the way of treatment.

**References:** 1. Elmali AD, Bebek N, Baykan B. Let's talk SUDEP. *Noro Psikiyatir Ars.* 2019;56(4):292-301. 2. Epilepsy Foundation SUDEP Institute. "Aim for Zero." *Epilepsy Foundation*, November 2017, <https://www.epilepsy.com/make-difference/public-awareness/aimforzero-striving-toward-future-free-sudden-unexpected-death>. Accessed November 2, 2020. 3. Epilepsy Foundation. "New SUDEP Resources for Families in English and Spanish." *Epilepsy Foundation*, 14 May 2018, [www.epilepsy.com/article/2018/5/new-sudep-resources-families-english-and-spanish](http://www.epilepsy.com/article/2018/5/new-sudep-resources-families-english-and-spanish). Accessed October 29, 2020. 4. Nashef L, Rugg-Gunn F. Reducing the risk of SUDEP: From uncertainty to reality. *Neurology.* 2020;95(18):807-808. 5. Hesdorffer DC, Tomson T, Benn E, et al. Do antiepileptic drugs or generalized tonic-clonic seizure frequency increase SUDEP risk? A combined analysis. *Epilepsia.* 2012;53(2):249-252. 6. Baruchin A. "Unmasking Silent Killer in Epilepsy." *The New York Times*, 26 July 2010, [www.nytimes.com/2010/07/27/health/27epil.html](http://www.nytimes.com/2010/07/27/health/27epil.html). Accessed October 30, 2020. 7. Ettinger AB, Adiga RK. Breakthrough Seizures—Approach to Prevention and Diagnosis. *US Neurology*, 2008;4(1):40-42. 8. Schachter S, Devinsky O, Cramer J. Discussion Guide. *Epilepsy Therapy Project*. [https://www.epilepsy.com/sites/core/files/atoms/files/discussion\\_guide.pdf](https://www.epilepsy.com/sites/core/files/atoms/files/discussion_guide.pdf). Accessed November 2, 2020. 9. Epilepsy Society. "Seizure Triggers." *Epilepsy Society*, 14 May 2020, [www.epilepsysociety.org.uk/living-epilepsy/epileptic-seizures/seizure-triggers](http://www.epilepsysociety.org.uk/living-epilepsy/epileptic-seizures/seizure-triggers). Accessed October 29, 2020.