



What Health Care Providers Need to Know: **SUDDEN UNEXPECTED DEATH IN EPILEPSY (SUDEP)**

Why Should I Talk to My Patients About SUDEP?

SUDEP is the term used when a person with epilepsy dies without warning signs and no cause of death can be found.

New York State law requires physicians, nurse practitioners, and physician assistants to educate patients about SUDEP if:

- (1) the patient has been diagnosed with epilepsy and is at high risk of SUDEP, and
- (2) the provider has primary responsibility for the treatment and care of that patient for epilepsy. Treatment in an emergency situation is not covered by this new law.

But this is more than a legal requirement: information from a trusted medical source helps to combat fear and puts the power to address the issue back in patients' hands. Growing evidence shows that patients would rather learn about SUDEP from their health care provider at the time epilepsy is diagnosed, or very soon thereafter, rather than search for information on their own.¹ Providers can serve as the most trusted, reliable source of initial information for their patients.

Providers should take a personalized approach with each patient based on their individual SUDEP risk. The goal of each SUDEP conversation is to reduce fear and anxiety about SUDEP, while empowering the patient with information tailored to them to reduce their risk.

Who is at greatest risk of SUDEP?

While SUDEP is not common – it affects 1 in 1,000 adults with epilepsy and 1 in 4,500 children with epilepsy per year. These are some high-risk factors:

- People who have frequent or uncontrolled seizures.
- People who miss taking seizure medications or who do not take their medicines as prescribed.
- People who have tonic-clonic seizures (grand mal).
- People with nighttime seizures.



**1 OUT
OF EVERY
1,000
ADULTS**



**1 OUT
OF EVERY
4,500
CHILDREN**

Actions Health Care Providers Can Take



- **Talk with your patients and their caregivers about SUDEP.** Most people do not know what SUDEP is.

These conversations can be hard to have, but there are resources to help providers start the conversation and to effectively convey the most important information, such as using the SPIKES Strategy framework: https://www.dannydid.org/assets/1/6/SUDEP_Pocket_Folder_Handout_FINAL.pdf or the Empowering Conversations Guide-Preventing Epilepsy Deaths: Clinician Toolkit <https://preventingepilepsydeaths.org/clinicians/empowering-patients-through-effective-conversations/>

- **Discuss the following strategies with patients to reduce their seizure risk, because the best way to prevent SUDEP is to have as few seizures as possible or to be free from seizures:**



- **Keep regular health care appointments.**

Help patients build a trusting relationship with you to encourage appointment regularity.

- **Take seizure medications as prescribed.** Remind patients that they can come to you with questions or concerns about their medication regimen.
- **Establish healthy lifestyle choices, like getting enough rest, exercising, eating healthy, and avoiding stress.** Encourage patients to avoid choices that can cause seizures like alcohol and drug use, or not getting enough sleep.
- **Keep a journal of things that happened before a seizure.** This task will help patients better understand their seizure triggers, including where and when the seizure occurred.

¹ See e.g., Gayatri NA, Morrall MC, Jain V, et al. Parental and physician beliefs regarding the provision and content of written sudden unexpected death in epilepsy (SUDEP) information. *Epilepsia* 2010;51:777–782. 10 [In this study, a survey of 67 parents of children with epilepsy revealed that 91% of parents wanted to know about SUDEP, and the majority, 67%, wanted to be informed of SUDEP at the time of their child's diagnosis.]; Ramachandranair R, Jack SM, Meaney BF, et al. SUDEP: what do parents want to know? *Epilepsy Behav* 2013;29:560–564 [In this study, all parents reported that they wanted to know about SUDEP soon after diagnosis].

- **Print and share the educational SUDEP**

Patient Fact Sheet developed by the New York State Department of Health available at <https://www.health.ny.gov/diseases/conditions/epilepsy/>.

- **Connect patients with an Epilepsy Specialty**

Center. These distinct hubs provide focused, expert care to epilepsy patients. Centers can offer:

- A team approach to diagnosis and treatment, including different types of providers.
- Advanced testing.

- Information about new treatments, therapies, clinical drug trials, and research.
- Guidance and education about epilepsy and pregnancy.

- **The National Association of Epilepsy Centers (NAEC)** can help patients find an epilepsy specialty center near them. Search by state or zip code at: <https://www.naec-epilepsy.org/about-epilepsy-centers/find-an-epilepsy-center/>

- **Connect patients with a regional Epilepsy Support Organization**, such as those listed at the end of this fact sheet.

Regional Epilepsy Organizations in NYS

- **Epilepsy Foundation of Northeastern New York, Inc.**

Albany, NY 12205
(518) 456-7501
<https://www.efneny.org>

- **Epilepsy Foundation of Long Island**

East Meadow, NY 11554
(516) 739-7733
<https://www.epicli.org/>

- **Epilepsy Association of Western New York**

Buffalo, NY 14222
(716) 883-5396 ext. 407
<https://epilepsywny.org/>

- **Epilepsy Alliance of West Central NY, a part of EPI (Empowering People's Independence)**

Rochester, NY 14620
(585) 442-4430 ext. 2741
<https://www.epiny.org/>

- **Epilepsy Society of Southern NY/Capabilities Partnership, Inc.**

West Nyack, NY 10994
(845) 627-0627 ext. 112
<https://cpiny.org/>

- **Epilepsy Foundation of Metropolitan New York**

New York, NY 10006
(212) 677-8550
<https://www.efmny.org/>

National Epilepsy Organizations and Resources

- **American Epilepsy Society (AES)**

<https://www.aesnet.org/>

- **Partners Against Mortality in Epilepsy (PAME)**

<https://pameonline.org/>

- **SUDEP Action Day**

<https://sudepactionday.org/>

- **U.S. Centers for Disease Control and Prevention**

<https://www.cdc.gov/epilepsy/about/sudep/index.htm>

- **Epilepsy Foundation of America**

<https://www.epilepsy.com/programs/sudep-program>

- **Epilepsy Alliance America**

<https://www.epilepsyallianceamerica.org/>

- **Danny Did Foundation**

<https://www.dannydid.org/epilepsy-sudep/about-sudep/>

- **CURE Epilepsy**

https://www.cureepilepsy.org/signature_programs-sudep-sudden-unexpected-death-in-epilepsy-overview/

- **SUDEP Action "SUDEP and Seizure Safety Checklist"**

<https://www.sudep.org/checklist>

- **Preventing Epilepsy Deaths Toolkit, from the Child Neurology Foundation**

<https://preventingepilepsydeaths.org/>

