

SUDEP: when Sudden and Unexpected Death occurs in a person with EPilepsy

SUDEP came to the forefront of the world's mind in 2019 when Disney star Cameron Boyce tragically passed away from SUDEP at the age of 20. While this was the first time many people heard about SUDEP, many others continue to face the risk of SUDEP every day. For people living with epilepsy, SUDEP is the leading cause of death.

SUDEP affects 1 in 1,000 people with epilepsy, and 1 in 150 people with uncontrolled seizures. SUDEP takes more lives in the United States than sudden infant death syndrome every year.

Efforts to educate the public and individuals with epilepsy continue. In 2013, the Danny Stanton SUDEP Act mandated that SUDEP be considered when examining deaths of individuals with epilepsy.

The best defense is to manage epilepsy well:

1. Avoid missing medications

- Take medications as prescribed
- On time, every time



2. Avoid missed sleep

- Lack of sleep is a common trigger for seizures
- The majority of SUDEP cases occur at night



3. Limit alcohol and illicit substances

- Alcohol increases the risk of seizures
- Illicit substances may have unknown effects



4. Find support for uncontrolled seizures

- Consider your options
- Speak to an epilepsy specialist about risk and precautions



Why does SUDEP occur?

Research suggests that SUDEP, while not fully understood, may occur in certain conditions. Most often, SUDEP occurs during or immediately after a seizure - but not always. SUDEP can happen many ways:

- Interruptions in breathing (e.g., apnea, airway obstruction)
- Interruptions in heart rhythm or by heart failure
- A combination of these or other causes

How can I help my loved one?

- Discuss SUDEP with your loved one's doctor
- Get trained in seizure first-aid
- Address uncontrolled seizures with your loved one's doctor
- Educate yourself, your loved one and others.

SUDEP action day is October 23 - But you can take action everyday



Resources and additional reading:

[Sudden Unexpected Death in Epilepsy \(SUDEP\)](#)
[SUDEP Information for Parents of Children with Epilepsy](#)
[Managing Epilepsy Checklist](#)
[CDC Parent's Guide](#)