





The Role of Clinicians in Preventing Epilepsy Deaths: Three Steps to Save Lives

Epilepsy is a neurological disease that doubles or triples the risk of premature mortality. Important causes of death among people with epilepsy include injuries, status epilepticus, and SUDEP, some of which may be preventable with access to high-quality specialty healthcare and compliance with effective treatment plans.





Step 1: Assess

-  Understand seizures and syndromes associated with increased risk of mortality
-  Inquire into lifestyle, occupational/recreational activities or major life changes that increase the risk of seizures and accidents
-  Assess supervision during seizures (especially nocturnal seizures) and in dangerous environments such as water
-  Assess for high-risk medical comorbidities (including mental health) using standardized instruments and labs

Barriers to quality care include

- Complications with medication management and adherence
- Access to comprehensive epilepsy services
- Frequent use of emergency services





Step 2: Act

-  Review all medications at each visit
-  Develop and review the treatment plan and treatment options
-  Order genetic testing if there is a worsening of seizures or diagnostic uncertainty
-  Routinely evaluate the need for laboratory studies to screen for comorbidities and long-term complications from medical therapies when appropriate

Additional actions to consider

- If the patient is not responding to treatment, refer to specialists as appropriate
- If multiple clinical care providers see the patient, develop mechanisms for communication and coordination of care
- Develop a Seizure Action Plan, and include rescue meds when appropriate

Step 3: Empower

-  Educate people with epilepsy and their caregivers
-  Describe seizure types and risk factors for increased mortality
-  Explain comorbid conditions and symptoms to watch for
-  Regularly evaluate and explain the individual's current risk factors for death and actions they can take to reduce risk

Additional actions to empower people

- Ask about barriers to care and suggest solutions
- Provide resources, including connection with appropriate advocacy organizations
- Provide handout to people with epilepsy and their caregivers

TO LEARN MORE:

Visit [preventingeplepsydeaths.org](https://www.preventingepilepsydeaths.org) for information and to learn more about actions clinicians can take to reduce risk.

Talk about the risk of death with people with epilepsy.

Connect people with **advocacy organizations** to learn more about epilepsy and join a supportive community.

