

Epilepsy Can Be Life-Threatening: Steps to Decrease Your Risk

People with epilepsy are at significantly higher risk of death, but the good news is that there are steps that can lower the risk. Seizures can increase the chance of fatal accidents. Other life-threatening complications can include status epilepticus (seizures longer than 5 minutes or multiple seizures within a single 5-minute period), sudden unexpected death in epilepsy (SUDEP), and other health conditions that do not appear directly related to epilepsy.

Things that increase risk of death:

-  Having more than one convulsive seizure in a year
-  Accidents related to seizures
-  Unsupervised seizures
-  Having additional chronic health conditions
-  Frequent visits to the emergency room
-  Mental health challenges, such as depression or substance dependence

How to decrease risk of death:

- Reduce the number of seizures
 - Take medications on time every day, exactly as prescribed. Use pill boxes, alarms, or other reminders to help.
 - Discuss different treatment options with a trusted doctor. These may include rescue medications, surgery, neurostimulation devices, or dietary therapy.
 - Get a referral to see an epilepsy specialist who will be familiar with the latest treatment options.
 - Keep a seizure diary, which can help identify seizure triggers or changes.
- Create a seizure action plan. Share it with family, friends, school staff, and co-workers to teach them how to help during a seizure.
- Minimize the risk of accidental injury during a seizure, such as drowning or falling, by arranging oversight.
- Arrange for supervision as appropriate for one's age and living situation.
- Consider a seizure detection device when supervision is not available, especially while asleep, when SUDEP risk is increased.
- Notify your healthcare team of any health or medication changes.



It is important to understand that even with the best care available, not all epilepsy-related deaths can be prevented.

TO LEARN MORE:

Visit preventingepilepsydeaths.org for information and a simple form to prepare to talk to your doctor about your risk.

Ask your **health care team** how to decrease your risk of dying from epilepsy.

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



Epilepsy Can Be Life-Threatening: Preparing to Talk to Your Doctor

Fill out this form and bring a printed copy to your neurologist visits. Be sure to keep an electronic or paper copy for yourself—this will be a valuable tool in assessing serious or life-threatening risks associated with epilepsy and working with your doctor to decrease the risks.

What is currently your primary type of seizure? _____

Note: Seizure types include Generalized Seizures (tonic-clonic, clonic, tonic, myoclonic, atonic, epileptic spasms, absence), Focal Seizures (focal with impaired awareness, focal aware, and epileptic spasms), and Infantile Spasms.

If you experience other seizure types, list them here: _____

When was the last seizure? _____

At what age did the seizures begin? _____ Years _____ Months

How often do you typically have seizures? (check one)

- Yearly Monthly Weekly Daily

How many minutes do the seizures usually last? _____ minutes

Is there a known trigger(s)? (check one)

- Yes No Don't Know

If yes, what triggers the seizures? _____

Is there a known warning sign(s)? (check one)

- Yes No Don't Know

If yes, what is the warning sign? _____

What time of day are the seizures? (check one)

- Morning Midday Afternoon Evening During Sleep

Have you noticed a recent change in your seizure type or frequency? (check one)

- Yes No Don't Know

Do you have a seizure action plan? (check one)

- Yes No Don't Know

If yes, please describe: _____

Do you take your medication as prescribed? (check one)

- Always
 Very Often
 Sometimes
 Rarely
 Never

If not always, explain why: _____

Are there any side effects from the medications? (check one)

- Yes No Don't Know

If yes, please describe: _____

Have you started any new medications since your last visit? (check one)

- Yes No Don't Know

Is your doctor aware of all medications you are currently taking? (check one)

- Yes No Don't Know

Have you had any major illnesses or visits to the emergency room or urgent care in the past year? (check one)

- Yes No Don't Know

If yes, please describe: _____

Have you been diagnosed with the following? (check all that apply)

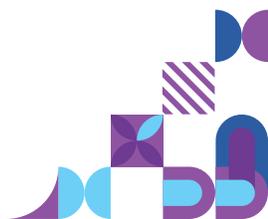
- Heart disease Kidney disease
 Liver disease Lung disease
 Cancer Diabetes
 Other _____

If you selected any of the above, please describe: _____

How many hours do you typically sleep at night? _____ hours

Are you satisfied with your sleep? (check one)

- Yes No



What hobbies do you participate in? (e.g., art, sports, etc.) _____

What is your profession? _____

Do you typically do any of the following? (check as many as apply)

- Take baths without supervision
- Swim without supervision
- Approach open flames, such as candles, fireplaces, campfires, etc.
- Use ladders or other activities that might increase the risk of falling
- Bicycle or engaging in contact sports without wearing a helmet
- Trip or fall in your home or at work
- Use heavy equipment, including driving cars

Do you spend time in a home where a gun is kept? (check one)

- Yes
- No

Have you experienced any of the following? (check as many as apply)

- Loss of health coverage
- Significant household changes
 - Getting married or divorced
 - Having a baby or adopting a child
 - Death in the family
 - Other _____
- Changes in residence
 - Moving to a different home (including a student moving to or from school)
 - Moving to or from a shelter or other transitional housing
- Beginning puberty
- Difficulty attending school or work
- Other stressful situations

During the past two weeks, how often have you been bothered by the following problems:

Feeling down, depressed, irritable, or hopeless? (check one)

- Not at all
- More than half the day
- Several days
- Nearly every day

Little interest or pleasure in doing things? (check one)

- Not at all
- More than half the day
- Several days
- Nearly every day

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