

People who have epilepsy are at greater risk of a number of complications, which is why managing and preventing seizures is so important. The most serious complications are injuries and dying from seizures. Although the occurrence is rare, it's important to know about the risk of dying from epilepsy.

Lived Experience

We recognise all people living with epilepsy and the impact it has on their lives. We take a moment to acknowledge the lived experience they have shared with us. In sharing their stories, we acknowledge the #bravery people living with epilepsy have shown in the face of not getting a fair go.

What is SUDEP?

Sudden Unexpected Death in Epilepsy (SUDEP) occurs when a person with epilepsy dies prematurely. SUDEP is defined as sudden, unexpected, witnessed or unwitnessed non-traumatic, non-drowning death of people with epilepsy. The instance of death is classified as SUDEP when a post-mortem examination does not reveal another cause of death, and occurs with or without evidence of a seizure.

What causes SUDEP?

Each year more than one in 1,000 people with epilepsy die from SUDEP, yet little is known about the underlying causes. Some studies suggest the part of the brain that controls breathing may be involved, while other studies indicate cardiac dysfunction and changes in brain function. There may be no single cause but a combination of things occurring at once. Several risk factors have been identified; some of which are modifiable (able to be changed) while others are not.

What are the risk factors for SUDEP?

Risk factors are certain circumstances someone experiences that may increase the likelihood of SUDEP occurring. Without a known cause, it is difficult to determine whether an individual is predisposed to SUDEP, however it seems some people may be more at risk than others.

These risk factors include people who:

- have generalised tonic-clonic seizures.
- have generalised tonic-clonic seizures during their sleep.
- are aged between 20-40 years.
- are not taking their epilepsy medications regularly or as prescribed.
- have had epilepsy for a long time.
- live alone/have no shared bedroom.
- are not monitored/supervised at night.

What can you do?

While there is no proven prevention program for SUDEP, gaining control of your seizures and lowering your exposure to the above risk factors is the best course of action. These are some measures you can take to try to reduce the risk of SUDEP.

- **Maximise seizure control:** If your seizures are not well controlled, you could request a referral to an epilepsy specialist for your epilepsy and medication to be re-assessed. This would also give you the chance to discuss with your specialist whether any other treatment options would help to control your seizures.

- Regular medication: Make sure that you never run out of your prescribed antiseizure medication and never stop or make changes to your medication without talking to your doctor first.
- Reduce/avoid seizure triggers: This may include lack of sleep or poor sleep hygiene. Look at a bedtime routine to improve sleep. Consider using monitors/alarms while sleeping.
- Practice healthy habits: Eat well, have adequate rest and exercise. Consider things you can put in place to help decrease triggers like stress.
- Keep a seizure diary to help track seizure triggers and activity.
- Ensure those around you know seizure first aid.
- Limit alcohol consumption and recreational drug use.
- Talk with your family and friends about SUDEP and consider telling colleagues about your epilepsy.

Why haven't I heard more about SUDEP?

Doctors and other health professionals can find it difficult to discuss SUDEP due to a lack of clarity and research around it. Discussion of SUDEP can empower people living with epilepsy to make appropriate decisions that help lower their risk. Communicating about SUDEP can help increase awareness of the condition and ensure ongoing research.

If SUDEP hasn't been raised, you can start a discussion with your specialist. Being aware of SUDEP, discussing your risk factors and what you can do to reduce those risks, are positive ways to face this difficult subject.

Epilepsy Support

The National Epilepsy Support Services (NESS) is available Mon – Sat, 9.00am – 7.00pm (AEST) to provide support and information across Australia.
Phone: 1300 761 487
Email: support@epilepsysmart.org.au

A medical note

The information contained in this publication provides general information about epilepsy. It does not provide specific advice. **Specific health and medical advice should always be obtained from a qualified health professional**

Other Resources

www.epilepsysmart.org.au

www.sudep.news

www.sudep.org

<https://www.epilepsy.com/complications-risks/early-death-sudep>

<https://www.epilepsy.org.uk/info/sudep-sudden-unexpected-death-in-epilepsy>

Related Documents

External (including Legislation)

The burden of premature mortality of epilepsy in high-income countries: a systematic review from the Mortality Task Force of the International League Against Epilepsy, [Epilepsia. 2017 Jan 1; 58\(1\): 17–26.](#) 2017 ([David J. Thurman](#), Giancarlo Logroschino, [Ettore Beghi](#) et al)

Sudden Unexpected Death in Epilepsy: what every neurologist should know, *Epileptic Disord.* 2017, 19:1 (3) 1-9. (Shankar R, Donner E, McLean B, et al)
www.ile.com/en/revues/epd/sommaire.phtml?cle_parution=445

Sudden Unexpected Death in Epilepsy: continuing the global conversation, 2011 Epilepsy Australia Ltd, Epilepsy Bereaved & SUDEP Aware.
<https://www.cdc.gov/epilepsy/about/sudep/index.htm>
<https://www.sudep.news/>