
Sudden unexpected death in epilepsy



People living with epilepsy should discuss SUDEP with their neurologist.

What is SUDEP?

Sudden Unexpected Death in Epilepsy (SUDEP) occurs when a person with epilepsy dies without warning, and no other cause of death can be found. Most recorded SUDEP cases occur at night or during sleep. Therefore, people living with epilepsy should discuss SUDEP with their neurologist – preferably early during the diagnosis stage of their epilepsy. By being well-informed from the start and understanding the risk factors for SUDEP, mitigating strategies can be implemented to reduce the risk.



How common is SUDEP?

Each year, 1 in 1000 people with epilepsy pass away from SUDEP, making it the leading cause of death from epilepsy. However, in people with poorly controlled convulsive seizures, the risk can be as high as 1 in 150 people.



What causes SUDEP?

There is likely more than one cause of SUDEP, but more research is needed. Most SUDEP cases happen immediately after a convulsive seizure which, can impact a person's brain, heart and breathing function. These causes are described below:

- **Altered brain activity:** Convulsive seizures can be followed by disruptions in brain activity, which may cause SUDEP.
- **Altered breathing:** Seizures often affect areas of the brain that control breathing. Altered breathing can cause pauses in breathing (apnea) and sometimes cause oxygen levels to drop. In some seizures, the airways may also become physically obstructed, affecting a person's breathing.
- **Altered heart rhythm:** Seizures can also trigger irregular heart rhythm or cardiac arrest and lead to SUDEP.

Who is most at risk?

The most important risk factor for SUDEP is having convulsive or tonic-clonic seizures. This risk increases with the number of convulsive seizures.

Individual risk of SUDEP varies – people living with epilepsy should discuss SUDEP with their neurologist. Being informed about SUDEP can help you and your loved ones manage known risk factors.

How can I lower my risk of SUDEP?

Achieving the best possible seizure control can lower your risk of SUDEP. For most people with epilepsy, this is through anti-seizure medications and following their Epilepsy Management Plan as prescribed by their neurologist. In people who can't achieve seizure control with medication alone, your neurologist may recommend other treatments such as epilepsy surgery, seizure alert devices, or dietary therapies.

Below are a list of strategies to help manage seizures and lower the risk of SUDEP:

- Take your anti-seizure medication as prescribed
- Avoid any seizure triggers
- Get enough sleep
- Eat well, drink enough water, and get enough rest
- Minimise stress where possible
- Avoid excess alcohol consumption or recreational drugs
- Look into seizure first aid training for caregivers
- Visit your neurologist for a review and develop/ update your Epilepsy Management and Emergency Medication Plans.
- Talk to your neurologist about improving your overall health and practical ways to reduce the risks of harm or injury from epilepsy. These may include having your heart and breathing checked to rule out any potential problems.

- Check to rule out any heart problems, or a sleep test to rule out any sleep or breathing problems at night.

What should I ask my neurologist?

- What is my risk of SUDEP?
- What can I do to reduce my risk?
- What should I do if I miss a dose of my anti-seizure medication?
- Can we consider a change in treatment towards the goal of freedom from seizures?
- What are my Epilepsy Management Plan and Emergency Medication Management Plan, and do they need updating?
- Is a seizure monitoring device at night suitable for me and my caregivers?
- Where can my caregivers be trained in seizure first aid?
- I have seizures in my sleep; should I consider sharing a bedroom?
- How should I speak to loved ones about SUDEP?

What else can I do?

- Contact your local state or territory epilepsy organisation to discuss education and training options for yourself and your family, your school, childcare centre, and to access local epilepsy support services and information resources. The National Epilepsy Support Service can refer you – Phone 1300 761 487 or email: support@epilepsysmart.org.au.

Mental health support

Discussing SUDEP can be a difficult topic for people living with epilepsy and their loved ones. Below are links to helpful support services:

- **Lifeline Australia**
Phone: 131114
Web: lifeline.org.au
- **Kids Helpline**
Phone: 1800 55 1800
Web: kidshelpline.com.au
- **SUDEP Action**
SUDEP Action raises awareness internationally about the risks of epilepsy-related harm to prevent epilepsy-related injuries and deaths.
Web: sudep.org

Annual SUDEP awareness

SUDEP Action Day in October is a worldwide initiative raising awareness of this most prominent cause of death among people with epilepsy. SUDEP Action Day is a campaign to empower people living with epilepsy through increased awareness, education about risk reduction and SUDEP research. SUDEP Action Day takes place annually on the third Wednesday in October.

For more information visit: sudepactionday.org

Other resources

- **Seizure alert devices booklet**
Epilepsy WA's online interactive seizure alert devices booklet - www.epilepsywa.asn.au/wp-content/uploads/2023/07/Seizure-Alert-Technology-booklet_download-Jul2023.pdf
- **Seer seizure diary application**
Phone: 1300 869 888
Web: www.seermedical.com/au/health

Epilepsy support

The National Epilepsy Support Service (NESS) is available Mon – Sat 9am – 7pm (AEST) to provide support and information across Australia. Phone: 1300 761 487. Email: support@epilepsysmart.org.au

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 strength and resilience people living with epilepsy have shown in the face of not getting a fair go.

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

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Epilepsy Smart Australia Program

National Epilepsy Support Service 1300 761 487

Website epilepsysmart.org.au



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