

# Sudden Unexpected Death in Epilepsy (SUDEP)



Sudden Unexpected Death in Epilepsy (SUDEP) is when an otherwise healthy person with epilepsy dies suddenly and prematurely and no reason for death is found. This does not include those who die in status epilepticus and those who die from a seizure-related accident.

In general, people living with epilepsy have a risk of up to 1.2 in 1,000 of SUDEP per year. Among Australia's estimated 142,740 people living with epilepsy, this would equate to approximately 171 SUDEP-related deaths per year across the general population with epilepsy.

Among children, SUDEP is an even rarer occurrence with the risk as low as 1 in 4,500. Most, but not all, cases of SUDEP occur during or immediately after a seizure.

To date we do not know what causes SUDEP. Researchers are currently investigating a variety of possibilities, such as respiratory (breathing) or cardiac (heart) dysfunction.

October 18 is international SUDEP Action Day.

## SUDEP RISK FACTORS

- Uncontrolled or frequent seizures
- Tonic-clonic seizures, particularly if these happen at night or during sleep
- Frequent seizure activity
- Seizures that begin at a young age
- Many years of living with epilepsy
- Missed doses of medication

- Drinking alcohol.

Yet risk factors only tell part of the story. Sometimes people who have with infrequent seizures pass away, while others with more frequent and apparently more severe seizures do not. Some people may be at greater risk because of lifestyle choices or poor self-management, such as drinking alcohol to excess or stopping medication against the advice of doctors.

## REDUCING RISK

- Speak to your doctor about the risk of SUDEP
- Take your AED as prescribed
- Avoid [triggers](#), if known
- Get adequate sleep
- Avoid drinking too much alcohol (or taking illicit drugs)
- Learn how to best manage your seizures through information, speaking to doctors and seeking support
- Ensure that your family and carers are trained in [seizure first aid](#).

## TALKING TO YOUR DOCTOR

If you are concerned about SUDEP, whether that is for yourself or someone you care for, it is a good idea to talk to your doctor. This will provide you with a chance to talk about risks and ways of lowering these in relation to SUDEP.

When talking to your doctor about SUDEP, you may want to discuss the following:

- What is my risk for SUDEP?
- What can I do to reduce my risk?
- What should I do if I forget to take my AED?
- Would a change in medication assist me to gain better seizure control?
- Are there any activities I should avoid?
- How should I speak to my family and friends about SUDEP?

## GETTING SUPPORT

The Epilepsy Foundation is here to assist and counsel anyone who has lost a loved one to SUDEP, or any other epilepsy-related deaths. Please feel free to contact us for confidential support.

You may also want to consider talking to your doctor or another healthcare professional. External crisis counselling and support can be found through:

[Beyond Blue](#) – (1300 22 46 36)

[Lifeline](#) – (13 11 14)

[Kids Helpline](#) – (1800 55 1800)

## SUDEP RESEARCH

[SUDEP Action](#), based in the United Kingdom, is focused on providing information on SUDEP and sponsoring research to prevent further deaths. SUDEP Action also manages an international [Epilepsy Death Register](#) which gathers information about epilepsy-related deaths so that more can be learned and risks can be reduced. If a loved one has passed away you may want to consider sharing information in the Epilepsy Death Register.

## FREQUENTLY ASKED QUESTIONS

### Q. What is SUDEP?

Sudden Unexpected Death in Epilepsy (SUDEP) is when a person living with epilepsy passes away unexpectedly, and the cause is not known.

### Q. How common is SUDEP in people with epilepsy?

Approximately every year, there is about 1 case of SUDEP for every 1,000 people living with epilepsy.<sup>1</sup> While in children, the risk of SUDEP is around 1 case for every 4,500.<sup>2</sup>

### Q. What are the causes of SUDEP?

Currently, the exact cause of SUDEP is not clearly understood by researchers. However, they have found that certain types of seizures increase a person's risk. That is why the best way to reduce the risk of SUDEP is to learn how to manage your seizures. Please follow your Epilepsy Management Plan (EMP) and talk to your neurologist if you have any concerns about SUDEP.

While little is known about SUDEP, it is thought to occur during or immediately after a seizure.

Some potential causes for SUDEP may include:

- Respiratory problems

A seizure may cause the breathing of a person with epilepsy to stop. This could be more prevalent during a generalised tonic-clonic seizure if a person's breathing stops.<sup>3</sup>

- Heart-related issues

A seizure may cause problems to the heart, causing it to stop pumping blood, therefore, leading to cardiac arrest<sup>3</sup>

### Q. What are the main risk factors for SUDEP?

The main risk factors for SUDEP include:

- The onset of epilepsy seizures at a young age 4
- Many years lived with epilepsy 4
- Uncontrolled or frequent seizures 3
- Uncontrolled generalised tonic-clonic seizures 3
- Developmental disabilities (during childhood) 4
- Resistant to anti-seizure medication (ASM) 3
- Seizure triggers (e.g., sleep deprivation, flashing lights, recreational drug use, heavy alcohol consumption) 1

## Q. How can a person with epilepsy reduce the risk of SUDEP?

If you have epilepsy, you should speak with your GP and neurologist about your concerns regarding SUDEP. You can also learn more about SUDEP by visiting the SUDEP Action website.

Other steps you may take that could reduce the risk of SUDEP include:

- Manage and follow your ASM as discussed with your neurologist
- Develop and regularly update your EMP
- Avoid any seizure triggers. To learn more about potential seizure triggers that could affect your epilepsy condition, [click here](#)
- Manage your sleep
- Avoid alcohol intoxication
- Talk to your GP about any cardiovascular or respiratory problems you may have that could increase the risk of SUDEP
- Take appropriate precautions if you are someone that experiences uncontrolled or generalised tonic-clonic seizures. Make sure your family and friends are well trained and equipped in seizure first aid (EFA). To learn more about EFA, [click here](#)

To also learn more about education and training for families, click [here](#).

If you would like to stay up to date with the latest research about SUDEP, then please visit <https://sudep.org/>

## References

1. Thurman DJ, Hesdorffer DC, French JA. Sudden unexpected death in epilepsy: assessing the public health burden. *Epilepsia*. 2014;55(10):1479-85.
2. Harden C, Tomson T, Gloss D, Buchhalter J, Cross JH, Donner E, et al. Practice Guideline Summary: Sudden Unexpected Death in Epilepsy Incidence Rates and Risk Factors: Report of the Guideline Development, Dissemination, and Implementation Subcommittee of the American Academy of Neurology and the American Epilepsy Society. *Epilepsy Curr*.

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3. Szucs A, Lalit N, Rásonyi G, Barcs G, Bóné B, Halász P, et al. [Sudden death and mortality in epilepsy]. *Ideggyogy Sz.* 2006;59(9-10):321-8.
4. Tomson T, Nashef L, Ryvlin P. Sudden unexpected death in epilepsy: current knowledge and future directions. *Lancet Neurol.* 2008;7(11):1021-31.