

SUDEP

(SUDDEN UNEXPECTED DEATH IN EPILEPSY)

FACT SHEET



SUDEP: Sudden Unexpected Death in Epilepsy

SUDEP happens in approximately 1 per 1000 people with epilepsy



What is SUDEP?

SUDEP is when a person with epilepsy dies suddenly & prematurely and no reason for death is found. SUDEP deaths are often not witnessed with many of the deaths occurring overnight during sleep. There may be obvious signs a seizure has happened, though this isn't always the case.

Why does it happen?

We don't know exactly what causes SUDEP to happen. Researchers are looking at a range of possibilities such as the effect of seizures on breathing, the heart and state of arousal.

What is my risk?

- **Having active seizures** can put you at higher risk of SUDEP.
- **Your risk increases if you have tonic-clonic seizures**, especially if they are frequent, happen at night or when you are asleep.
- **If you live or sleep alone** and have tonic-clonic seizures, you are at higher risk.
- **Not taking medications as prescribed** or frequently forgetting to take medications may also be a risk factor.

Although SUDEP is more common in people with frequent seizures it has also occurred in people who have had very few seizures.

Risk levels vary between people with epilepsy, and they can change over time.

Seizure types, such as absence and myoclonic seizures, are not known to be associated with increased SUDEP risk. However, if you have these seizures and do not take your medication as prescribed, the you may be at risk for tonic-clonic seizures.

Talk with your doctor or epilepsy nurse about any risks or concerns you have. They can help you understand your personal risks and work with you to take steps to reduce them.

Go through the [SUDEP and Safety Checklist](#) with your GP or Epilepsy Nurse to help determine your risk.

Disclaimer: This information is given to provide accurate, general information about epilepsy. Medical information and knowledge changes rapidly and you should consult your doctor for more detailed information. This is not medical advice, and you should not make any medication or treatment changes without consulting your doctor.

WHAT YOU CAN DO

Knowing about risks means you can take steps to reduce them

Steps you can take to reduce seizure related risks, injury or death are:

Get the best seizure control possible.

- Take your medication as prescribed
- Speak to your doctor if you are not happy with your current medication or side effects
- Have regular reviews with your doctor

Be involved in managing your seizures

- Avoid any known seizure triggers for you
- Avoid drinking too much alcohol or taking illicit substances
- Know when your seizures are most likely to occur
- Get enough sleep
- Be healthy
- Manage stress

Make sure those close to you know what to do when a seizure happens

Go to [Epilepsy and Risk](#) for more information

Contact us on:

Phone: 1300 37 45 37

Email: epilepsy@epilepsy.org.au

[Book a telehealth appointment with an epilepsy nurse](#)

