

## What is SUDEP?

**SUDEP** stands for **Sudden Unexpected Death in Epilepsy**

SUDEP is when a person with epilepsy dies suddenly and 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.

**SUDEP happens in approximately 1 per 1000 people with epilepsy.**

## Why does it happen?

We don't know exactly what causes SUDEP to happen, or who will be affected. 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 of SUDEP?

- 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 be a risk factor.

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.

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.

**It is important you discuss your risks and concerns with your doctor who can help you assess your own risks and put steps in place to reduce them.**



## Knowing about risks means you can take action against 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 in case of a seizure

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

### For more information

[SUDEP – reducing your risk: Information and guidance for people with epilepsy](#)

[Epilepsy and Risk](#)

For further information or to go through the SUDEP and Safety Checklist with an Epilepsy Nurse, call us on 1300 37 45 37 or email [epilepsy@epilepsy.org.au](mailto:epilepsy@epilepsy.org.au)