

SAFETY, SUDEP & MORTALITY IN PAEDIATRIC EPILEPSY

**FACT SHEET FOR HEALTHCARE
PROFESSIONALS**



SAFETY, SUDEP & MORTALITY IN PAEDIATRIC EPILEPSY

Epilepsy affects around 1 in 200 Australian children. About one-third of these children have drug-resistant epilepsy, which significantly increases the risk of seizure-related injuries and early mortality.

SEIZURE RELATED INJURIES



The most common injuries include soft-tissue and head injuries, but may also involve dental injuries, burns, fractures and near drowning.

Deaths can be due to trauma, accidents, suffocation, drowning, status epilepticus, and suicide, but the leading cause of epilepsy-related deaths in children and adults with epilepsy is Sudden Unexpected Death in Epilepsy (SUDEP).

WHAT IS SUDEP?



SUDEP is when a person with epilepsy dies suddenly and prematurely and no reason for death is found. There is often evidence of a seizure.

Around 170 Australians die from SUDEP each year, or 1.2 in 1000 people with epilepsy, with rates similar in both children and adults.

Although SUDEP is most common in people with drug-resistant epilepsy, findings establish that SUDEP affects the full spectrum of epilepsies, and can even occur in children who have good seizure control or never had a tonic clonic seizure and no co-morbidities.

Although the exact cause is unclear, SUDEP may result from cardiac, respiratory, or autonomic dysregulation, all of which may occur independently or in combination. It is likely that SUDEP arises from a variety of causes

SUDEP affects 1 child in every 1000

SUDEP RISK FACTORS

Although not all risk factors are modifiable, knowledge that they are associated with SUDEP can help when counselling parents and families about SUDEP.

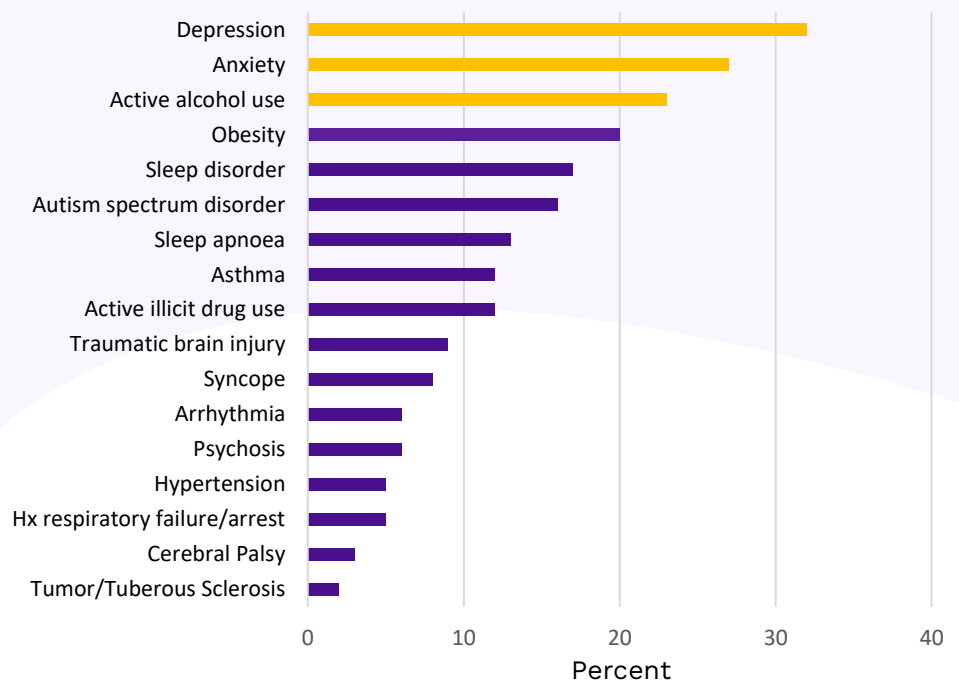
The two strongest risk factors for SUDEP are:

- Frequent tonic-clonic (convulsive) seizures
- Nocturnal seizures

Other risk factors include:

- Prolonged or cluster seizures, or status epilepticus
- Drug resistant epilepsy
- Subtherapeutic antiseizure medication levels
 - not taking antiseizure medication as prescribed,
 - frequent medication changes, or
 - stopping medication
- Intellectual disability
- Genetic factors - epilepsy-related and cardiac genes (including cardiomyopathies and long QT syndrome) may be implicated.
- Early age of onset of epilepsy
- Alcohol and drug use
- Other conditions particularly psychiatric comorbidity (see Figure1)

Comorbid conditions reported in cases of SUDEP



SUDEP PREVENTION

It is important to discuss SUDEP with all patients with epilepsy

Because SUDEP can occur in children who are seizure-free, have never had a tonic-clonic seizure, or diagnosed with a “benign” epilepsy syndrome, it is important to discuss risks with all families.

In the paediatric population, discussing SUDEP risk has been associated with improvement in epilepsy-related behaviour, such as administering medications on time, using rescue medications, and having a seizure action plan.

The Paediatric SUDEP and Seizure Safety Checklist can greatly aid this discussion. ([LINK](#))



A good number of SUDEP cases can be prevented by medication adherence & lifestyle changes (sleep hygiene, limited/no alcohol), & possibly by monitoring to detect seizures to provide prompt seizure first aid.

Improving Seizure Control and Medication Adherence

Effective seizure control is key to reducing a person’s risk.

Suggestions for improving seizure control include:

1. Timely referral to an epilepsy centre for assessment of other epilepsy treatments such as surgery, vagus nerve stimulation or ketogenic diet. [Drug Resistant Epilepsy](#)
2. Providing patient education/advice on lifestyle measures and avoiding seizure triggers
3. Enhancing the ability to detect seizures and cardiorespiratory distress with seizure, respiratory, and heart rate with monitoring devices. [Seizure Safety Products](#)
4. Preventing airway obstruction through nocturnal supervision and lattice safety pillows.

Nocturnal Supervision and Seizure Detection Devices

Lack of seizure detection or nocturnal supervision puts a child with nocturnal seizures at a higher risk.

Increasing nocturnal supervision; sharing a bedroom, using a seizure detection device appears to be protective and linked with reduced SUDEP risk because someone is alerted and present to provide assistance in the vulnerable post-seizure period. Even tactile stimulation and repositioning can decrease post-seizure respiratory dysfunction.

While direct evidence is limited, seizure detection devices may enhance night-time supervision and reduce SUDEP risk.



It is important to have that difficult conversation about risks that come with epilepsy.

USE OUR PAEDIATRIC SUDEP & SEIZURE SAFETY CHECKLIST

Discussion of SUDEP should be part of comprehensive epilepsy education given to all families of children with epilepsy.

See [Children and Risk](#)

A Paediatric SUDEP and Seizure Safety Checklist has been developed to determine SUDEP risk factors and provides a guide to a conversation about this topic with the families of children with epilepsy.

See [SUDEP and Seizure Safety Checklist](#)

Using this checklist can greatly aid your conversation about seizures risks and SUDEP. You can download an interactive version from the above link.

Our epilepsy nurses are also available to have this discussion with your patients – [Click Here to book a telehealth appointment](#) with an epilepsy nurse.



KEY ACTIONS



It is important to have that difficult conversation about risks that come with epilepsy. Knowing risks generally improves treatment adherence and self-management practices.

People with drug resistant epilepsy should be referred to a comprehensive epilepsy centre to review their epilepsy, gain a clearer diagnosis for more targeted management as soon as possible to improve their seizure control.

Visit our website



- **Discuss SUDEP with all families**
 - **Use the Paediatric SUDEP & Safety Checklist tool OR**
 - **refer to an epilepsy nurse**
- **Encourage Epilepsy Management Planning**
- **Recommend nocturnal supervision or seizure monitors**
- **Suggest basic life support training**

Contact us on:

Phone: 1300 37 45 37

Email: epilepsy@epilepsy.org.au

Patient Information

[Parent safety factsheet](#)

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

[Seizure first aid and video](#)

[Epilepsy Essentials online course](#) – free for families