



SUDEP

(Sudden unexpected death in epilepsy)

What is SUDEP?

Sudden unexpected death in epilepsy (SUDEP) is defined as an unexpected or unexplained death in a person with epilepsy in whom no clear causes for death are after a post mortem examination.

What causes SUDEP?

SUDEP is a baffling condition with little known about the underlying causes. Some studies suggest the part of the brain that controls breathing may be involved. Other studies indicate cardiac dysfunction and changes in brain function. There may be no single cause but a combination of things occurring at once. Although research continues, it is impossible to predict who may be affected. There is a great need for further research on SUDEP to increase understanding and educate people about SUDEP.

Who is at risk of SUDEP?

Many people with epilepsy live a full life span. Although it is known that people with epilepsy have an increased risk of death compared to the general population (ref: making sense of SUDEP).

Without a known cause, it is not possible to accurately determine whether or not an individual may be predisposed to SUDEP. However, it seems some people may be more at risk than others. These may include people who:

- have uncontrolled seizures
- have generalised seizures during their sleep
- have frequent tonic-clonic seizures
- are not taking their prescribed antiepileptic medication
- are having frequent or sudden changes to their antiepileptic medication.

What can you do?

There are measures you can take to try to reduce the risk of SUDEP. Maximise seizure control. If your seizures are not well controlled, you could ask to be referred to an epilepsy specialist for your epilepsy and medication to be re-assessed. This would also give you the chance to discuss with your specialist whether any other treatment options would help to control your seizures.

- Make sure that you never run out of your prescription medication and never make changes to, or stop your medication without talking to your doctor first.

- Avoid known seizure triggers, especially sleep deprivation.
- Look after yourself: eat well, have adequate rest and exercise.
- Talk with your family and friends about SUDEP and consider telling colleagues about your epilepsy.

Why haven't I heard more about SUDEP?

Doctors and other health professionals can find it difficult to discuss SUDEP. For people living with epilepsy it can be difficult to find reliable information about SUDEP.

We encourage you to visit the sites listed below to learn more. If you feel comfortable, you may also initiate a discussion with your specialist, if SUDEP hasn't been mentioned. It is important to discuss how you can reduce the risks of SUDEP.

Links for more information:

www.epilepsyaustralia.net.au/SUDEP/SUDEP.aspx

www.sudep.org

www.epilepsyfoundation.org/epilepsyusa/

www.epilepsy.org.uk

www.sudep.org

References:

Sudden Unexpected Death in Epilepsy: continuing the global conversation, 2011
Epilepsy Australia Ltd, Epilepsy Bereaved & SUDEP Aware.

SUDEP: information for People with Epilepsy, 2012 Making sense of SUDEP.

Although every effort has been made to ensure accurate and up to date information is provided, Epilepsy Queensland cannot accept any liability in relation to the information provided. It is strongly recommended that you discuss any information with your doctor.