



# Risks & SUDEP

**It would be unrealistic to believe we can live our lives without risk. Some risks are foreseeable, others less so.**

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People with chronic conditions face a range of risks associated with their health status. Those with severe obesity are more likely to develop diabetes and heart disease. People with diabetes can experience visual impairment and loss of limbs from untreated infections. Asthma sufferers can experience life-threatening asthma attacks.

Although we may be aware of the general risks, it does not mean every person's risk is equal nor can we predict the risk for any given individual. However, being educated about the factors that increase the likelihood of these events empowers people to have some control over their quality of life and health outcomes. The obese, for example, are informed of the dangers of their condition, and a whole industry has emerged

to assist with weight loss and risk minimisation. People with diabetes are given tools to measure and maintain their blood sugar levels, and people with asthma are taught to monitor their 'peak flow' and regularly use their prescribed medication.

You may ask what all this has to do with epilepsy. Epilepsy, too, carries inherent risks. The seizure type and situation in which it occurs will determine the level of risk and potential injury. Education about risks helps minimise the chance of negative outcomes. Safety messages are readily available from epilepsy support organisations and cover a wide variety of circumstances – from water activities to mothers with epilepsy caring for their babies.

Some risks are not quite so obvious. How many times have you, in hindsight, said that if you had only known, you would have done things differently?

In epilepsy (like asthma and diabetes), there are those rare and extreme situations where there is a loss of life. Sometimes the cause may be obvious, while other times the doctors and family are left baffled and the cause remains unknown. This is called Sudden Unexpected Death in Epilepsy or SUDEP.

### **What is SUDEP?**

This is a rare but recognised syndrome where a person with epilepsy suddenly dies and no clear cause of death is found. It can occur in people with frequent and infrequent

seizures, although the risk is negligible for anyone who is seizure-free. It is almost twice as likely in males than females. Although it can occur at any age, it is very rare in under 16s.

### What causes SUDEP?

Little is known about SUDEP. It is thought to relate to a number of factors, rather than just one. Studies have suggested that parts of the brain controlling heartbeat or breathing are affected. It is known that some people experiencing seizures can stop breathing temporarily.

A recent US study – published in the journal *Science Translational Medicine* in

and studies before the findings have any relevance for the everyday practice in the doctor's office."

This finding, although in its infancy, sheds a glimmer of light on the mystery surrounding SUDEP.

### Patient and family education

In the UK in 2004, the National Institute for Clinical Excellence issued guidelines stating: "individuals with epilepsy and their families should be given and have access to information on SUDEP." This step was motivated by advocacy from families of those who had died without warning.

Although SUDEP is rare, it has a very real

include:

- Frequent or sudden changes in medication
- Not taking antiepileptic medication as prescribed
- Regularly missing doses of antiepileptic medication
- Poorly controlled generalised seizures at night

By knowing about your type of epilepsy, antiepileptic medications and the individual situations that make you more vulnerable to experiencing a seizure, you can implement strategies to avoid those situations or triggers – and be empowered to live more confidently. Speak with your neurologist

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October 2009 – found mice with a mutation in the KvLQT1 ion channel, which is usually associated with prolonged and irregular heart rhythms, also experienced frequent epileptic seizures. This finding is the first evidence of a molecular connection between the heart and the brain and could open up new avenues for exploring SUDEP.

Dr Robert Mittan, a renowned US epileptologist, explained that these new findings relate "to genetic-based benign familial neonatal convulsions – a specific, uncommon generalised type of epilepsy."

While affirming that "most people with epilepsy will have a normal lifespan," the study's author, Dr Jeffery Noebels of Baylor College of Medicine in Texas, hopes the discovery translates to humans. He believes it may eventually lead to the use of preventative treatments – like beta blockers and cardiac pacemakers for heart abnormalities – for those people identified through genetic screening with this form of epilepsy and the KvLQT1 mutation.

Although the research is speculative at this stage, Mittan says it "does raise the possibility that one particular genetic variant, if shown to play a role in a limited selection of human epilepsy, may be a useful line of scientific enquiry." However he anticipates there will be "considerable time

impact on families. The impact is intensified when families only find out later that people can lose their lives as a result of SUDEP. Often the mystery surrounding SUDEP leaves grieving relatives hunting for answers about what happened and what they could have done to prevent it.

There are many reasons why people do not talk about SUDEP. Many parents fear their child is dying when they witness their first seizure. Others are distressed about the diagnosis of epilepsy and their preconceptions of what that may entail.

Patients and their families are told of the risk of injury and avoidance of seizure triggers. However, SUDEP is very rare. So why tell people something that in high probability will never happen, and could create fear and unnecessary restriction of activity?

Because knowing about risk – all risks, no matter how remote – allows the person the choice and opportunity to manage their own medication and take personal responsibility for their own health and wellbeing. Even then, although rare, SUDEP can still occur.

### Preventative measures

To be honest, nobody really knows the cause of SUDEP and scientists continue the search. Some events associated with SUDEP

about your seizure management and do not be afraid to ask the hard questions.

### References:

- i "Sudden Unexpected Death in Epilepsy (SUDEP)" fact sheet, Epilepsy Action UK. [www.epilepsy.org.uk](http://www.epilepsy.org.uk)
- ii Burford, J. "Sudden Unexpected Death in Epilepsy (SUDEP): A Review"
- iii [www.sudep.org/contactus2.asp](http://www.sudep.org/contactus2.asp)
- iv [www.sudep.org/contactus2.asp](http://www.sudep.org/contactus2.asp)
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- vi [www.sudep.org/contactus2.asp](http://www.sudep.org/contactus2.asp)
- vii <http://www.bcm.edu/news/item.cfm?newsID=1568>
- viii National Institute for Clinical Excellence. Diagnosis and care of children and adults with epilepsy. London: NICE, 2004
- ix "Sudden Unexpected Death in Epilepsy (SUDEP)" fact sheet, Epilepsy Action UK. [www.epilepsy.org.uk](http://www.epilepsy.org.uk)

### For support or information

If you would like to find out more about SUDEP, call Epilepsy Action Australia on 1300 37 45 37, or visit our website – [www.epilepsy.org.au](http://www.epilepsy.org.au) – and search for 'SUDEP'.

Other helpful resources are:

[www.sudep.org/default.asp](http://www.sudep.org/default.asp)

[www.epilepsysupportgroup.co.uk/sudep.htm](http://www.epilepsysupportgroup.co.uk/sudep.htm)

[www.epilepsy.com/EPILEPSY/sudep\\_epilepsy](http://www.epilepsy.com/EPILEPSY/sudep_epilepsy)