

SUDEP : reducing risk

SUDEP is sudden unexpected death in someone with epilepsy, who was otherwise well, and in whom no other cause of death can be found, despite thorough post mortem examination and blood tests. This does not include those who die in status epilepticus and those who die from a seizure-related accident.

In general, the risk of SUDEP for an adult with epilepsy is low, at one in 3000 persons over a one-year period. For persons with poorly controlled seizures the risk is one in 100 persons over one year. In children, SUDEP is an even rarer occurrence with the risk as low as one to two in 10,000 over one year.

To date we do not know what causes SUDEP. Current research leads to respiratory or cardiac dysfunction, but the cause of this dysfunction still eludes us and we cannot know who will be affected.

However, over the years some possible risk factors have been suggested including:

- Young adulthood
- Early age of onset of seizures
- Presence of tonic clonic seizures
- Increased frequency of seizures
- Frequent changes of dose and type of antiepileptic medication (AED)
- Poor compliance with AEDs
- Alcohol abuse
- Certain epilepsy syndromes

Yet risk factors only tell part of the story. Sometimes individuals with infrequent seizures die, while others with more frequent and apparently more severe seizures do not. Some may be more at risk because of social factors, lifestyle or sub-optimal management; others may have additional biological susceptibility.

Communicating risk

In the UK in 2004, the National Institute for Clinical Excellence issued guidelines stating that 'healthcare professionals should provide a person with epilepsy and their family or carers with general information about SUDEP, to show why controlling seizures is important. They should also discuss with the person with epilepsy (and their family or carers, as appropriate) their individual risk of SUDEP'.¹

Epilepsy Australia affiliates have been proactive in communicating the known

facts and possible risks of SUDEP since 1998 and in 2005, with partner Epilepsy Bereaved, published the highly regarded book *Sudden Unexpected Death in Epilepsy: a global conversation*. This book brought the SUDEP conversation into the public domain and continues to be widely distributed both in soft and hard versions.

Despite the NICE guidelines there are still widely divergent views on what defines best practice in communication of risk with people with epilepsy and their families. Ethical, legal and practical arguments have all become points of debate. But in 2010, when an internet search produces 538,000 results for SUDEP, perhaps some of these views are now out of step with community expectations of full disclosure of health risks of epilepsy by the treating doctor.

Reducing risk

People with epilepsy can take a very positive approach to reducing risk by making seizure freedom a high priority. Good control of seizures is often achieved quite simply by taking the medication prescribed, at the correct dose on a regular basis.

It is generally agreed that seizure frequency is the factor most strongly associated with an increased risk of SUDEP, and that the 'unknown' category of seizure frequency, that where seizure frequency is not known or disclosed, showed the strongest association with risk of SUDEP of all seizure-frequency groups.

Life is precious, and while the risk of SUDEP is low, all factors that may lead to injury or loss of life should be included in any risk management discussion. Informed decisions about treatment and lifestyle can only be made if all the information is provided and consequences discussed.

Call for more research

Research into SUDEP is developing but has attracted almost no support in Australia. Unfortunately a world first pilot research project of death scene investigation in SUDEP by Victorian Institute of Forensic Medicine, modelled on Sudden Infant Death Syndrome (SIDS) research has not been able to develop due to a lack of funding.

SIDS provides a very interesting comparison to SUDEP with striking similarities between the two phenomena. Both have no identified cause; only risk factors are suggested. In the case of SIDS, action on risk factors has reduced deaths. A comparison of research funding provides a stunning contrast. Whereas SUDEP has received virtually no Australian research funding, SIDS has accessed more than \$15m for research. The Australian death rate of SIDS has fallen from 563 in 1986 to 87 in 2005. This is far below the current estimate for SUDEP of 150 deaths per year, and Epilepsy Australia believes with the same level of support and focus a similar reduction could be achieved in relation to SUDEP.²

150 deaths per year to SUDEP is unacceptable, indeed one death is one too many. The issue of SUDEP was the keynote address at the inaugural 2008 meeting of the Parliamentary Friends of Epilepsy and this statistic surprised and shocked them. All agreed more needed to be done.

8th AOEC & SUDEP

The latest SUDEP research will be presented during the scientific program of the 8th Asian & Oceanian Epilepsy Congress and the Epilepsy & Society day program to be held in Melbourne in October.

Dr Elson So will examine what SUDEP is and who seems to be at risk, while Dr Rosemary Panelli will review the global, local and individual perspective. This will be an extremely interesting and informative session, with time for questions from the floor.

Epilepsy Australia's **SUDEP Research and Education Fund** facilitates research and community education into SUDEP. If you would like more information about this fund or you would like to contribute please contact dchapman@epilepsyaustralia.net

1. National Institute for Clinical Excellence. Diagnosis and care of children and adults with epilepsy. London, 2004.
2. A Fair Go for People Living with Epilepsy. Joint Epilepsy Council of Australia. p24. 2009



The full text of *Sudden Unexpected Death in Epilepsy: a global conversation* is available at

www.epilepsyaustralia.net/publications