

SUDEP

What is SUDEP?

SUDEP refers to the unexplained death of an individual, with a diagnosis of epilepsy, who dies suddenly, in benign circumstances, without a structural or toxicological cause for death being found at autopsy.

It is not a condition or disease, per se, but rather the category to which these types of unexplained deaths are assigned.

What causes SUDEP?

The precise mechanism, or cause, of death is, as yet, not understood. Most sudden deaths of people with epilepsy are unwitnessed and this makes it difficult to determine what, exactly, occurs in the last moments of life. By definition, the autopsy does not reveal a cause of death suggesting that the terminal event is due to disturbance of function, not structure. Most frequently, but not always, there is evidence for seizure activity prior to death and recent studies strongly support a close relationship between seizure episodes (especially generalized convulsions) and SUDEP.

Various potential mechanisms have been proposed and these mainly involve the cardiac and/or respiratory systems. It is unknown whether mechanisms are jointly or severally responsible, what leads to the fatal cardiac event and/or the cessation of breathing, what role the brain and/or seizure plays in the whole process or, indeed, whether the same events trigger SUDEP in each person.

“Sudden, unexpected, witnessed or unwitnessed, nontraumatic and nondrowning death in patients with epilepsy, with or without evidence for a seizure and excluding documented status epilepticus, in which postmortem examination does not reveal a toxicologic or anatomic cause for death.”

Nashef 1997

Risk factors for SUDEP

Without a known cause, it is not feasible to accurately determine whether or not an individual may be predisposed to SUDEP. Investigations of SUDEP circumstances have identified several associated or contributory factors which do serve to indicate some extent of risk to the individual (that is, whether at higher or lower risk of SUDEP). The factors most consistently identified in case studies include those which are deemed unmodifiable, such as early onset of epilepsy and young adult age, and those which are deemed modifiable with the potential to lower SUDEP risk. These include, but are not limited to, poorly controlled seizures (especially generalised tonic-clonic seizures), poor compliance with the anti-epileptic drug (AED) regime and the number of different types of AEDs used.

For further SUDEP information:

SUDEP Aware, Canada www.sudepaware.org

Epilepsy Bereaved, UK www.sudep.org

Epilepsy Australia www.sudep.org.au/SUDEP/SUDEP.aspx

References:

Dasheiff (1991) “Sudden Unexpected Death in Epilepsy: A Series from an Epilepsy Surgery Program and Speculation on the Relationship to Sudden Cardiac Death.” *J Clin Neurophysiol* 8:216–222

Langan et al (2002) “Certification of Deaths Attributable to Epilepsy.” *J Neurol Neurosurg Psychiatry* 73(6):751–2

Lhatoo et al (2001) “Mortality in Epilepsy in the First 11 to 14 Years after Diagnosis: Multivariate Analysis of a Long-Term, Prospective, Population-Based Cohort.” *Ann Neurol* 49:336–344

Nashef (1997) “Sudden Unexpected Death in Epilepsy: Terminology and Definitions.” *Epilepsia* 38 (Suppl. 11):S6–8

Schraeder et al (2006) “Coroner and Medical Examiner Documentation of Sudden Unexplained Deaths in Epilepsy.” *Epilepsy Research* 68:137–143

SUDEP

SUDEP Aware: promotes knowledge and understanding of Sudden Unexplained Death in Epilepsy (SUDEP) through support, education and collaboration.

For more information, please contact us at:

Tel: (416) 964-9095 Ext 236

Email: sudepaware@gmail.com

Web: www.sudepaware.org

What is the incidence of SUDEP?

SUDEP is estimated to account for up to 18% of all deaths in patients with epilepsy.

Consistent, and comparable, data on the incidence of SUDEP and its risk factors is proving difficult to ascertain. This is due to differences in research methodologies (including, definition of SUDEP, study type and reference populations) and inevitable methodological limitations. Most studies are restricted to smaller sample sizes and select epilepsy groups (such as tertiary care clinics or residential homes) because of the relatively rare incidence of SUDEP in the population and the impracticality of studying large numbers of individuals with epilepsy from diagnosis to death.

The alternative research approach, conducting retrospective studies of those identified as having died from SUDEP, is hampered by the apparent underuse of the term SUDEP as a cause of death on death certificates, as found in the UK (*Langan et al 2002*) and the USA (*Schraeder et al 2006*). Instead, the cause may be registered as, for example, ‘respiratory failure’ or ‘unascertained’ and would thereby be erroneously excluded from SUDEP case studies or statistics.

Epidemiological data from research conducted to date has demonstrated substantial variance in incidence depending on the epilepsy cohort studied. This has been shown to range from 0.09 per 1000 person-years in a community-based study (*Lhatoo et al 2001*) to 9 per 1000 person-years in candidates for epilepsy surgery (*Dasheiff 1991*).

Minimising the risk of SUDEP

In the current absence of a proven SUDEP prevention method, the recommended approach is to attempt to keep modifiable contributory factors to a minimum.

As research indicates that SUDEP is largely a seizure-related phenomenon, optimisation of seizure control is highly important. Recommendations to achieve this include:

- seeking regular medical consultation to re-evaluate epilepsy diagnosis, review medication and the possibility of new treatments, discuss implications of lifestyle changes etc;
- maintaining good adherence/compliance with medication regime;
- identifying possible triggers for seizures and determining an effective strategy for keeping these to a minimum. For example, maintaining regular and adequate sleep patterns or learning ways to better manage stress.

It is also prudent for family, friends and caregivers to be informed of what to do during and following a seizure. This includes knowledge of the recovery position and cardiopulmonary resuscitation techniques. In addition, the necessity of calling an ambulance if the seizure lasts for more than five minutes or repeats without full recovery and of staying with a person for 15-20 minutes after the seizure to ensure that recovery continues.