

# SUDEP: global, local and individual perspectives

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**S**udden Unexpected Death in Epilepsy (SUDEP) is not a recent phenomenon but historically, when treatments rarely provided good seizure control, deaths were accepted as a sad outcome of a difficult medical condition. Those who died suddenly were often assumed to have suffocated during a seizure. As modern treatments improved seizure control, epilepsy became less conspicuous in the community and many began to regard it as a minor health issue. Epilepsy information increasingly focused on the positive aspects of modern care, and death slipped from the discussion of risk. In this modern setting, the sudden unexpected death of a young person who is apparently healthy, apart from epilepsy, is rarely expected or accepted by family and friends. It is a totally shocking event aggravated by the fact of not knowing such deaths are possible. More comprehensive investigation of the deaths by post mortem has also revealed that suffocation is rarely the cause of death, adding to the bewilderment of bereaved families and leaving them with many unanswered questions.

Not surprisingly bereaved families felt that action was needed. In 1993 Epilepsy Bereaved was formed in the UK, and SUDEP finally began to attract international attention. Several such organisations now exist internationally and epilepsy specific web sites frequently include SUDEP information.

Two core questions have emerged about SUDEP. Firstly, what causes it and secondly, what should we tell people with epilepsy? There is a reluctance amongst many health workers to talk to patients about SUDEP. If we do not know the cause, it is suggested, how can it help people to know about this risk? Others have argued that despite the fact that SUDEP has no known cause, or guaranteed method of prevention, patients have a right to know that it occurs. This is in line with the contemporary style of Western medicine with its patient-centred approach, and the expectation that patients will be well informed and able to participate in decisions. Risks are routinely disclosed and the community has come to expect this. Families bereaved by SUDEP have felt betrayed in this setting, where they

have not been fully informed.

The identification of possible risk factors for SUDEP through epidemiological research has eased this situation slightly as doctor-patient discussions can now take on the character of a personalised risk assessment. Risk factors can be considered in light of a patient's individual diagnosis and circumstances. As with SIDS, it is hoped that although the cause is not yet known, educating the community about risk factors might prevent some deaths. For example, there are negligible risks associated with certain seizure types and this allows the doctor to provide some reassurance to lower risk patients. Seizure frequency is also a risk factor, which leads well into a discussion with all patients about the importance of striving for the best seizure control possible. Nevertheless, deaths still occur in apparently low risk patients, so while trying to minimise fear it is also important not to create false assurances. Concerns about raising anxiety in patients can be balanced by consideration of the benefits which can accrue from an open discussion. Many patients and parents already harbour fears for themselves or their children which they do not express. Epilepsy educators working in this field argue that careful discussion with a realistic appraisal of an individual's situation often helps to reduce anxiety.

Also important to consider is the ready availability of internet information, much of which is not correct and certainly not tailored to the individual circumstances of the reader. Personal discussion with their own doctor is the best way for people to appraise their risk, and frank, open discussion will facilitate the building of trust in the therapeutic relationship. A recent UK study in a paediatric setting found that 91% of parents studied, expected their doctor to provide SUDEP information, and that it did not have significant immediate or longer term negative impacts on the families. Interestingly one third of the participants had already heard about SUDEP.

A discussion of SUDEP can sit well in the overall consideration of risk, which is an important aspect of the diagnostic phase. Treatment decisions involve a

comparison of risks and benefits, and although death may not be a common outcome, the catastrophic nature of the event warrants consideration when the diagnosis is explained. Complacency about medication adherence is a common problem in epilepsy. Also, life circumstances can change and a person may decide to reduce or cease treatment without consulting a doctor; unexpected pregnancies can occur for example. If a full disclosure of risk has not been provided early, people with epilepsy may not have sufficient understanding to make safe choices over the passage of time.

It is understood that patients vary in personality and coping styles, and therefore in their attitude to information and how they use it to navigate health issues. In settings where risk is introduced to epilepsy patients it would be advantageous to provide additional support workers, to allow for extended discussion where it is desired.

SUDEP continues to be an important topic of discussion and research internationally. Some promising scientific research is starting to emerge and from the clinical perspective SUDEP is a positive influence on the approach to epilepsy management. Guidelines for epilepsy care published in the UK recommend a discussion of SUDEP as part of general epilepsy information and something to be considered when decisions are made regarding antiepileptic drug treatment. In the US an epilepsy taskforce is looking at the priorities for a public health agenda on epilepsy and the blueprint includes a special focus on SUDEP. The epidemiology of risk factors underlines the need to strive for the best possible seizure control in all epilepsy patients and this is a very positive influence on epilepsy care worldwide.

Epilepsy Australia (EA) continues to promote discussion of SUDEP and other epilepsy-related risk. In partnership with bereaved families, people who have epilepsy, Epilepsy Bereaved UK, and colleagues worldwide, EA continues to strive for quality epilepsy care and a reduction in all epilepsy-related deaths. A taskforce has recently been created with epilepsy-related deaths as its focus.