

Sudden Unexpected Death in Epilepsy (SUDEP): Global, local and individual perspectives

Brief summary of presentation to the 8th Asian and Oceanian Epilepsy Congress, Melbourne 2010

Sudden Unexpected Death in Epilepsy (SUDEP) is not a recent phenomenon.(1) However, historically, when treatments rarely provided good seizure control, deaths were frequently 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 became more effective in limiting seizures, epilepsy became less conspicuous in the community and increasingly perceived as a very manageable health condition. Epilepsy information predominantly focussed on the positive aspects of modern care, and death slipped from the discussion of risk.(1) 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. Despite comprehensive investigation of the deaths, including autopsies, a clear explanation of the cause remains elusive(2) adding to the bewilderment of those who are bereaved and leaving them with many unanswered questions.(3, 4)

Not surprisingly many who experience sudden and unexpected bereavement due to epilepsy respond to the experience by calling for research and action to prevent or reduce SUDEP, and in 1993 the first consumer agency dedicated to reducing epilepsy-related deaths (Epilepsy Bereaved) was established in the UK. The organisation quickly initiated an international scientific meeting (5), followed by a very significant national audit of epilepsy-related death in the UK.(6) Around the world several similar organisations have sprung into existence and, in addition, the web sites of most epilepsy agencies now include SUDEP information. Awareness of SUDEP has increased amongst clinicians, researchers, and health administrators, resulting in diverse research, education, and policy initiatives targeting SUDEP.

Two crucial, interrelated questions have emerged about SUDEP. Firstly, what is the cause and, secondly, what should we tell people with epilepsy? Research has not yet been able to reveal the cause, or causes, of SUDEP and consequently, there is reluctance amongst some health workers to discuss SUDEP with patients. If we do not know the cause, they ask, how can it help people to hear about this risk? Others argue 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.(7, 8) Families bereaved by SUDEP have felt betrayed in this setting, where they perceive that they have not been fully informed.

The gradual identification of possible risk factors for SUDEP through epidemiological research has facilitated improved risk communication in epilepsy, as doctor-patient discussions can now take on the character of a personalised risk assessment.(9) Risk factors can be considered in light of a patient's individual diagnosis and circumstances. Where there are negligible risks associated with certain seizure types this allows the doctor to provide some reassurance to lower risk patients. On the other hand, seizure frequency is significant risk factor, and this leads well into a discussion with all patients about the importance of striving for the best seizure control possible. As with SIDS, a

fatal occurrence in children, for which the cause is also not yet known, it is hoped that community education about risk factors might prevent some deaths.(10) Nevertheless, deaths still unfortunately occur in apparently low risk patients, so while trying to inform, and minimise the fear factor, 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.(11)

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. The community use of internet sites to obtain health information is escalating(12), and whilst some web sites do provide useful general material, personal discussion with their own doctor is the best way for people to appraise their unique risk. Frank, open discussion will also 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.(13) Although current practice regarding the discussion of SUDEP amongst doctors is evolving, it may not be changing as rapidly as patient expectations. A UK study published in 2006 comprising neurologists and medical practitioners working with epilepsy found that whilst 30.3% of respondents reported discussing SUDEP with the majority or all of their patients, 68.7% discussed the issue with very few or none of their patients. Those with a special interest in epilepsy were significantly more likely to discuss SUDEP. (14) Similar figures were noted in an Italian study published this year.(15)

A discussion of SUDEP can sit well in the routine overall consideration of risk, which is an important aspect of the diagnostic phase.(2) 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.(16) Complacency about medication adherence is a common problem in epilepsy.(17) Also, life circumstances can change and a person may decide to reduce or cease treatment without the benefit of timely medical counselling; for example, when an unexpected pregnancy occurs.(18) 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. Nonadherence to prescribed medication regimens in epilepsy has been found to be associated with a more than threefold increased risk of mortality.(17)

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 with scientific studies yielding some promising results.(19) From the clinical perspective, SUDEP is exerting a positive influence on the approach to epilepsy management. The epidemiology of risk factors underlines the need to strive for the best possible seizure control in all epilepsy patients(2), and this is an important message for epilepsy care worldwide. Guidelines for epilepsy services published in

the UK now recommend a discussion of SUDEP as part of general epilepsy information and something to be considered when decisions are made regarding antiepileptic drug treatment.(20, 21) Formal inquiries into epilepsy-related deaths have endorsed the provision of SUDEP information to patients.(22, 23) 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.(24)

Epilepsy Australia continues to promote discussion of SUDEP and other epilepsy related risks.(25, 26) In partnership with bereaved families, people who have epilepsy, Epilepsy Bereaved UK, and colleagues worldwide, Epilepsy Australia 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.(27)

1. Epilepsy Bereaved. The SUDEP story. [Online]. 2010 [cited 2010 December 9]; Available from: <http://www.sudep.org/whatwedo/the-sudep-story/>
2. Tomson T, Nashef L, Ryvlin P. Sudden unexpected death in epilepsy: current knowledge and future directions. *Lancet Neurol* 2008;7(11):1021-31.
3. Epilepsy Bereaved. Keeping their memories alive. [Online]. 2010 [cited 2010 December 5]; Available from: <http://www.sudep.org/how-we-can-help-you/case-studiestestimonials/>
4. Kennelly C, Riesel J. Sudden death and epilepsy - the views and experiences of bereaved relatives and carers: Epilepsy Bereaved; 2002.
5. Wiley online library. *Epilepsia*: November 1997. [Online]. 1997 [cited 2010 November 25]; Available from: <http://onlinelibrary.wiley.com/doi/10.1111/epi.1997.38.issue-s11/issuetoc>
6. Hanna NJ, Black M, Sander JWS, Smithson WH, Appleton R, Brown S, et al. The national sentinel clinical audit of epilepsy related death: epilepsy - death in the shadows: The Stationary Office; 2002. Available from: <http://www.archive2.official-documents.co.uk/document/reps/nscaerd/nscaerd.pdf>
7. General Medical Council. Consent: patients and doctors making decisions together. London: General Medical Council; 2008. Available from http://www.gmc-uk.org/static/documents/content/Consent_0510.pdf
8. Nunes V, Neilson J, O'Flynn N, Calvert N, Kuntze S, Smithson H, et al. Clinical guidelines and evidence review for medicines adherence: involving patients in decisions about prescribed medicines and supporting adherence. London: National Collaborating Centre for Primary Care and Royal College of General Practitioners; 2009. Available from: <http://www.nice.org.uk/nicemedia/pdf/CG76FullGuideline.pdf>
9. So EL, Bainbridge J, Buchhalter JR, Donalty J, Donner EJ, Finucane A, et al. Report of the American Epilepsy Society and the Epilepsy Foundation joint task force on sudden unexplained death in epilepsy. *Epilepsia* 2009;50(4):917-22. Available from: <http://www.cureepilepsy.org/downloads/SoEL-SUDEPTaskForceReportEpilepsia.pdf>
10. SIDS and kids. Education [Online]. 2010 [cited 2010 December 9]; Available from: <http://www.sidsandkids.org/offices/western-australia/education/>
11. Mittan RJ. How to discuss SUDEP with patients and families. In: *The Epilepsy Report: Epilepsy Australia*; 2010. p. 10-11. Available from <http://www.epilepsyaustralia.net/userData/docs/The%20Epilepsy%20Report%20Oct%202010.pdf>
12. Fox S. The engaged e-patient population. [Online]. 2008 [cited 2010 November 25]; Available from: http://www.pewinternet.org/~media/Files/Reports/2008/PIP_Health_Aug08.pdf.pdf
13. Gayatri NA, Morrall MC, Jain V, Kashyape P, Pysden K, Ferrie C. Parental and physician beliefs regarding the provision and content of written sudden unexpected death in epilepsy (SUDEP) information. *Epilepsia* 2010;51(5):777-82.

14. Morton B, Richardson A, Duncan S. Sudden unexpected death in epilepsy (SUDEP): don't ask, don't tell? *J Neurol Neurosurg Psychiatry* 2006;77(2):199-202.
15. Vegni E, Leone D, Canevini MP, Tinuper P, Moja EA. Sudden unexpected death in epilepsy (SUDEP): a pilot study on truth telling among Italian epileptologists. *Neurol Sci* 2010.
16. Macdonald A. Rogers v Whitaker: duty of disclosure. In: *Bioeth Res Notes*; 1993. Available from <http://www.bioethics.org.au/Resources/Online%20Articles/Opinion%20Pieces/0503%20Rogers%20v%20Whitaker%20duty%20of%20disclosure.pdf>
17. Fought E, Duh MS, Weiner JR, Guerin A, Cunnington MC. Nonadherence to antiepileptic drugs and increased mortality: findings from the RANSOM study. *Neurology* 2008;71(20):1572-8.
18. Lewis G, editor. The Confidential Enquiry into Maternal and Child Health (CEMACH). Saving mothers' lives: reviewing maternal deaths to make motherhood safer - 2003-2005. The seventh report on confidential enquiries into maternal death in the United Kingdom. London: CEMACH; 2007. Available from [http://www.cemach.org.uk/getattachment/26dae364-1fc9-4a29-a6cb-afb3f251f8f7/Saving-Mothers%E2%80%99-Lives-2003-2005-\(Full-report\).aspx](http://www.cemach.org.uk/getattachment/26dae364-1fc9-4a29-a6cb-afb3f251f8f7/Saving-Mothers%E2%80%99-Lives-2003-2005-(Full-report).aspx)
19. Tomson T, Nashef L, Ryvlin P. Sudden unexpected death in epilepsy: current knowledge and future direction. *Lancet Neurol* 2008;7:1021-1031.
20. Scottish Intercollegiate Guidelines Network (SIGN). Diagnosis and management of epilepsy in adults; 2003. <http://www.sign.ac.uk/pdf/sign70.pdf>
21. Stokes T, Shaw EJ, Juarez-Garcia A, Camosso-Stefinovic J, Baker R. Clinical guidelines and evidence review for the epilepsies: diagnosis and management in adults and children in primary and secondary care, CG20 full guideline; 2004. Available from <http://www.nice.org.uk/nicemedia/live/10954/29533/29533.pdf>
22. Taylor JA. Determination of Sheriff James Taylor, Sheriff of the Sheriffdom of Glasgow and Strathkelvin at Glasgow. Inquiry held under fatal accidents and sudden death inquiry (Scotland) Act 1976 into the death of Colette Marie Findlay.; 2002. Retrieved from: <http://www.sudep.icuc.co.uk/FAIdetermination.doc>
23. Scottish Public Services Ombudsman. Case 200700075; 2009. Available from: http://www.spsso.org.uk/webfm_send/2134
24. Epilepsy Foundation. Living with epilepsy: a task force update - a blueprint for the future; 2009. Available from: http://www.cdc.gov/epilepsy/pdfs/living_with_epilepsy.pdf
25. Epilepsy Australia. Welcome to Epilepsy Australia. [Online]. 2010 [cited 2010 November 25]; Available from: <http://www.epilepsyaustralia.net/default.aspx>
26. Chapman D, Moss B, Panelli R, Pollard R, editors. Sudden unexpected death in epilepsy: a global conversation. Camberwell: Epilepsy Australia; 2005. Available from: <http://www.epilepsyaustralia.net/userData/docs/SUDEP%20A%20Global%20Conversation.pdf>
27. Epilepsy Australia. New research project to examine epilepsy death in Australia. In: *The Epilepsy Report*: Epilepsy Australia; 2010. p. 5. Available from: <http://www.epilepsyaustralia.net/userData/docs/The%20Epilepsy%20Report%20Oct%202010.pdf>