



How to discuss SUDEP with patients and families

I must say I am surprised at the extent of controversy regarding whether or not physicians should discuss SUDEP with patients and families. Fear of dying from seizures is nearly universal among patients and families. Most patients and families are reluctant to bring the topic up. They don't ask their physicians because they are afraid their worst fears will be confirmed. These fears are substantial. In our original UCLA study (Mittan, 1986), two-thirds of patients were openly afraid they could die with their next seizure and nearly three-fourths were afraid seizures would cause further brain damage. The fact is that for the vast majority of persons with epilepsy and their families, raising the topic of SUDEP is not going to harmfully introduce fear that was not there to begin with.

For 27 years I have presented the Seizures & Epilepsy Education (S.E.E.) program. This has given me the opportunity to speak with nearly 40,000 patients and families with epilepsy in Australia, Canada, New Zealand, and the U.S. I have found patients and families are almost universally afraid of death from seizures. So is the general public. It makes sense – even non-convulsive seizures frighten people. In 27 years of asking, all but one parent thought that their child was going to die when they first witnessed the child's seizures. The one exception was an epilepsy nurse specialist whose daughter started having absence seizures.

When these universal patient and family fears are not discussed, these fears are left unchecked by the true facts of the risk. Each of us know from our own experience what is not said in a conversation can speak more loudly than what is said. When the doctor fails to discuss the potential death from epilepsy, patients and families naturally interpret the physician's behavior as confirmation that the risk of death is

real and too uncomfortable for him or her to discuss or for the family to hear. While physicians debate the wisdom of bringing up the topic of SUDEP and status epilepticus for fear of "unduly alarming" their patients, their behavior is actually confirming alarming fears in the minds of most patients and their families.

With the lack of facts and the apparent lack of "courage" to discuss death and epilepsy on the part of the physician, these fears can, and often do run rampant, to the serious ruin of quality of life. Fear is the force behind developmentally disabling overprotection and overcontrol of the person with epilepsy. Fear is the force leaving people afraid to be alone and afraid to go out by themselves because of seizures. Fear shrinks life to the house and social contact to the immediate family for far too many.

Rather than alarming families, discussing causes of death in epilepsy gives them a more realistic appreciation of the risk – which is often much to their relief! Just the fact that the physician feels comfortable in discussing the topic is comforting to the patient. If the physician can talk about the risk of death without alarm, patients and families see a real life human model that they can openly discuss this concern without alarm as well. For 27 years the S.E.E. program has taught patients and families about SUDEP, status epilepticus, and fatal accidents in epilepsy, including relative risk and circumstances for each. Two controlled outcome studies (Helgeson, et al, 1990, and Shore, et al, 2008) showed significantly reduced fear as a result – and equally important, significantly improved compliance. While there is much debate over the potential causes of SUDEP, there is virtually universal agreement on one prevention – seizure control (Hughes, 2009.) And seizure control is thought highly dependent upon compliance.

During every S.E.E. program I poll

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The S.E.E. program is designed to give people with epilepsy, parents of children with epilepsy and family members the information and skills needed to get the best chance of becoming seizure free – without letting treatment become part of the problem.

Dr Mittan has presented this program to over 30,000 people with epilepsy and their families in Australia, Canada, New Zealand and the USA.

the audience to find out how many have discontinued their medications on their own and have gone into status epilepticus. Consistently 10-15% will raise their hands. They protest they were “never warned” of the danger. Nearly all were angry with their physician about it. In fact, they undoubtedly were warned with “you should never stop taking your medications!” Some recall hearing this demand, but never recall hearing why.

However, telling people what to do is rarely effective in changing behavior. It is essential to tell people why to do it. Every prescription patients receive is accompanied with some version of “take this exactly as directed.” Patients hear this so often it stops being meaningful. After all, how often have they failed to take all of their antibiotics or other medication and nothing bad happened? Why should it be any different with seizure medications? However, if the patient knew they risked status and possibly death by stopping their medication – that would get their attention. But to do this, the physician has to talk about status, SUDEP, and their lethal potential.

The benefits of talking about SUDEP, status epilepticus, and other risks in epilepsy not only fulfills patients’ and families’ right to know, but can significantly contribute to reducing fear. It may save a life. Rather than threatening the emotional wellbeing of patients and families (who already assumed a fear death), the discussion of SUDEP offers a therapeutic opportunity. It is a chance to significantly improve quality of life and reduce harm from seizures. The methods used in disclosing this information can strongly influence medical and psychosocial outcomes.

So how does one go about the process of talking about SUDEP, status epilepticus, accidents, and other potential sources of harm from seizures? Very often, how a message is given is more important than the content of the message itself. How many times have you been upset with someone, not for what they said, but how they said it? The same is true when talking about SUDEP. How it is discussed often has a greater impact on the result than hearing of SUDEP itself.

Let’s say a man falls off a ferry into

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the ocean. His life is at risk. He knows it and the ferry captain knows it. If the ferry captain frantically shouts to the man “Swim or you might drown!” the man is likely to become alarmed and thrash more violently out of fear he might die.

If instead the captain calmly yells, “People fall overboard sometimes. I’m going to tell you what you can do to keep yourself afloat. You don’t need to drown when you can do things to prevent it. First, take off your shoes, jacket, and heavy clothing because those will weigh you down. Next, lie on your back and try to float on the water. Fighting against the water will only tire you out. I have stopped the boat. Just paddle gently to it. Take your time. That way you will reach the boat without spending yourself and getting into trouble.”

Telling persons with epilepsy and their family members about SUDEP is similar to the wise ferry captain coaching the passenger. The captain does not avoid discussing death – the risk is obvious to everyone. What the captain does is reassuring and useful. He focuses his message upon providing the passenger with the practical skills the passenger needs to have the best opportunity to preserve his life.

We have advantage over the captain regarding SUDEP. The crisis has not occurred yet. The conversation can (and must) begin with specific positive steps persons with epilepsy and their families can take to improve their overall seizure control. These would include explaining how medications work, their behavior in the bloodstream, therapeutic ranges, and the challenges to be faced in maintaining proper blood levels day in and day out. These include talking about first aid, about how lifestyle habits can improve the chance of seizure control,

and the importance of identifying and avoiding seizure triggers. These include the unambiguous goal of good seizure control, with a clear plan for further diagnostic workups and / or treatment changes if current efforts are not successful. These include educating the person about medication side effects and how to recognize toxicity so these can be reported – and especially so these do not cause poor compliance.

Once patients and families possess the knowledge and skills they need to help protect life, then the physician is in the ideal position to introduce SUDEP as constructive therapy. SUDEP provides the physician with a compelling opportunity to illustrate why proper medical self-management skills are so valuable to the person and family. While these skills are designed to prevent seizures, they also afford important protections against more rare and serious complications in epilepsy, including SUDEP and status. The take home message, “Practicing these skills daily can reduce your risk of harm from epilepsy. That puts your future in your control.”

References

- Helgeson, D., Mittan, R., Tan, S. & Chayasirisobhon, S (1990), Sepulveda Epilepsy Education (S.E.E.): The efficacy of a psychoeducational treatment program in treating medical and psychosocial aspects of epilepsy. *Epilepsia*, 31(1), 75-82.
- Hughes, J (2009) A review of sudden unexpected death in epilepsy: Prediction of patients at risk. *Epilepsy & Beh*, 14: 280-287.
- Mittan, R. (1986). Fear of seizures. In S. Whitman and B. Hermann (Eds.), *Psychopathology in epilepsy: Social dimensions*. (pp. 90-121). New York: Oxford University Press.
- Shore, C., Perkins, S. & Austin, J. (2008), Efficacy of the S.E.E. program on quality of life, seizure management and cost savings for adolescents with epilepsy and their parents. *Epilepsy & Beh* 12: 157-164.