



EPILEPSY & The Facts

SUDEP

What is SUDEP?

SUDEP stands for Sudden Unexpected and Unexplained Death in Epilepsy. It is a category of uncommon sudden death, used when a person with epilepsy dies unexpectedly, without apparent cause. In a typical case of SUDEP, an otherwise healthy person with active epilepsy dies suddenly, unobserved, while in bed. For this reason SUDEP reminds some people of Sudden Infant Death Syndrome (SIDS) in newborns.

What causes SUDEP?

Research indicates that there is likely more than one explanation for SUDEP. According to one theory, electrical discharges in the brain may change the electrical status of the heart, affecting its rhythm. Another theory is that breathing is stopped by a seizure. In either case, a post-mortem examination reveals no anatomical cause of death.

What are the chances of dying from SUDEP?

The actual risk of SUDEP remains uncertain, and more research is badly needed. It has been estimated that fewer than One in 1,000 people with epilepsy will die of SUDEP each year.

Could SUDEP happen to me?

When people with epilepsy are told about SUDEP, they ask, "Will it happen to me?" The chances of dying from SUDEP are remote. Some people may be more at risk than others, especially young people aged 20-40 with tonic-clonic (grand mal) seizures which are not fully controlled by medication. Not taking medication correctly or regularly, being alone during seizures and using alcohol or street drugs may also be factors.

What can I do to lower the risk of SUDEP?

No one knows for sure, but seeking treatment regularly to get the best possible seizure control, avoiding sudden drug withdrawal, and taking one's medication regularly are recommended. Avoiding alcohol, maintaining regular and adequate sleep patterns, exercising, eating nutritious meals and learning to manage stress are simple things that may make a difference. Concerned relatives should know that staying with someone for 15 to 20 minutes after a seizure to ensure they are breathing easily would be useful. Family members may want to learn CPR.



Should people with epilepsy live differently because of SUDEP?

It is important for people with uncontrolled epilepsy to balance the awareness of their slightly increased risk of death with the need to live as normal a life as possible. There are usually very few things that people with epilepsy cannot do.

Do doctors have a role to play with regard to SUDEP?

The risk of SUDEP, while relatively small, is nevertheless real. We believe it should be discussed openly by doctors with patients and their families. Direct and reasoned discussion may improve compliance with medication and lifestyle regimens. It may also prevent the family feeling betrayed by the doctor should a sudden death ever occur. “Why weren’t we told?” is a common reaction of family members bereaved by SUDEP.

Some victims of sudden death syndrome are found to have sub-therapeutic blood levels of anti-epileptic drugs. It is prudent to try to predict those who might be most susceptible to SUDEP, particularly young people aged 20 to 40 with poorly controlled tonic-clonic seizures. It may be beneficial for these patients to be monitored by their physician with increased frequency during this period and compliance assessed more frequently.

If a SUDEP death should occur, we believe it is important that it be formally identified as SUDEP. In addition to information, families bereaved by SUDEP need to be offered a compassionate ear and grief counselling.

Where can I get more information about SUDEP?

SUDEP Aware is a network and support group for families impacted by SUDEP and can offer more information. Contact Tamzin Jeffs at 416.964,9095 x236.