

SUDEP

Sudden, Unexpected Death in Epilepsy

What is SUDEP?

SUDEP is an acronym for Sudden Unexpected Death in Epilepsy. It thus describes a category of uncommon and sudden death 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 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 believes that breathing is stopped by a seizure. In either case, a postmortem 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 urgently needed. It has been estimated that fewer than one in 1 000 persons with epilepsy will die of SUDEP every year.

1/1000

Could SUDEP happen to me?

When people with epilepsy are told about SUDEP they generally ask, "Will this happen to me?" However, the chances of dying of SUDEP are slim.

Some people may be more at risk than others, especially young people in the age group 20 to 40 years with tonic-clonic seizures which are not fully controlled by medication. Not taking medication as prescribed (i.e. the right dosage at the right time), being alone during seizures and the consumption of alcohol or recreational (street) drugs may be risk factors.



You can contact Epilepsy South Africa for more information.
info@epilepsy.org.za | www.epilepsy.org.za

Should people with Epilepsy live different because of SUDEP?

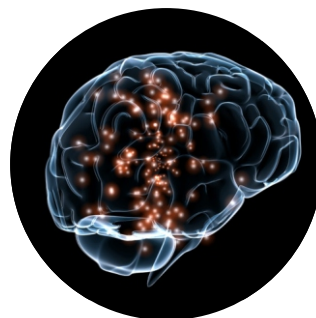
Nobody knows for sure how to reduce the risk of SUDEP. However, seeking treatment regularly to achieve the best possible seizure control, avoiding sudden drug withdrawal and taking your medication regularly as prescribed are recommended.

A number of lifestyle choices may further the risk of SUDEP. 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 a person for 15 to 20 minutes after a seizure to ensure that he/she is breathing easily, would be useful.

Family members may also want to learn CPR (cardiopulmonary resuscitation).

Should persons with epilepsy change their lifestyle because of SUDEP?

It is important for persons with uncontrolled epilepsy to balance an awareness of their slightly higher risk of SUDEP with the need to live as normal a life as possible. There are usually a very limited number of things that people with epilepsy are not able to do.



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

The risk of SUDEP (while relatively small) is nevertheless very real.

As such, medical personnel should openly discuss this with patients and their families. Direct and reasoned discussion may improve compliance with medication and lifestyle regimes. It may also prevent families feeling betrayed by medical staff should a sudden death occur. "Why were we not told?" is a common reaction of family members bereaved by SUDEP.

Some victims of SUDEP are found to have sub-therapeutic blood levels of anti-epileptic drugs. It is prudent to try to predict those cases most susceptible to SUDEP, particularly people between the ages of 20 and 40 years with poorly controlled tonic-clonic seizures.

It may be beneficial for high-risk patients to be monitored by their doctor(s) more frequently during this period and treatment compliance equally monitored more often.

What should happen in the event of SUDEP?

In the event of SUDEP it is important that it be formally identified as SUDEP.

In addition to information, families bereaved by SUDEP must be offered compassionate bereavement/grief counselling.



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