

SUDEP

INFORMATION FOR People Bereaved by Epilepsy



The sudden, unexpected and unexplained loss of a loved one can unleash a wide range of emotions, from anger and frustration to despondency and despair. Coping can be extremely difficult, especially while so many questions about SUDEP remain unanswered.

The grieving process is a very challenging journey and you may feel isolated and without hope at times. Know that you are not alone. There are other families like yours, that have gone through a similar experience and who wish to offer their support through your time of healing.

For ways to connect with these families, or to find support agencies near you, see the Making Sense of SUDEP website or contact us toll free on: 1-855-85-SUDEP (78337).

WHAT IS SUDEP?

Sudden Unexpected Death in Epilepsy (SUDEP) refers to the death of a person with epilepsy, without warning and where no cause of death could be found. It is a category of unexplained death. There are no proven ways to prevent SUDEP, but research is ongoing to understand how and why these deaths occur.



HOW COMMON IS SUDEP?

Recent studies estimate the rate of SUDEP at about one death per 1,000 people with epilepsy per year. In people with frequent epileptic convulsions, the rate is believed to be about 1 in 100 per year.

These figures may be an underestimate because of poor case identification due to lack of awareness, and inconsistencies in the investigation and recording of the deaths. Low autopsy rates make it difficult to know the exact incidence of SUDEP.

IDENTIFICATION OF SUDEP

SUDEP can only be accurately determined after an autopsy examination rules out other causes of death. Without an autopsy, deaths can only be classified as 'probable' or 'possible' SUDEP, so autopsies play a vital role in the true identification of SUDEP. Families should be encouraged to permit or request autopsies.

For most families, a SUDEP death is their first experience with the death investigation process, which can be a difficult and intimidating one. The investigation of the death is an essential step in the identification of SUDEP deaths and families play a key role by disclosing the deceased's history of seizures and epilepsy; providing a detailed medical background; describing the circumstances prior to and surrounding the death; and consenting to the autopsy.

It is not yet known what causes SUDEP. It usually occurs at night or during sleep, and this makes it hard to find out exactly what happened during the last moments of life. There is often, but not always, evidence of a seizure before death. A seizure at the time of death is not needed for a diagnosis of SUDEP.

It is unlikely that a single cause will explain all SUDEP deaths. Advances in research are identifying critical risk factors and a number of possible mechanisms for SUDEP.

Researchers are investigating problems with breathing, heart rhythm and brain function as possible causes of SUDEP. During seizures, there is often a change in breathing and heart rhythm. In most people living with epilepsy, this is not dangerous. Sometimes, a more serious drop in blood oxygen levels or changes in heart rhythm may occur. Seizures may also affect the brain's influence on breathing and heart function. In addition, researchers are exploring genetic links between seizures and heart rhythm abnormalities.

Further research is urgently needed to learn more about SUDEP. The medical history, tissue and blood from your loved one can be used for this research. Visit the Making Sense of SUDEP website for more information.

Continued on next page

SUDEP



INFORMATION FOR

People Bereaved by Epilepsy (continued)

THE POSITIVE STEPS YOU CAN TAKE

At the time of death:

Sometimes families are not aware of SUDEP until later on. When possible:

- Request a complete autopsy examination to help identify the cause of death as SUDEP.
- Authorize the death investigation team to collect autopsy samples for donation to SUDEP research.
- Provide information to the North American SUDEP Registry, to enable researchers to better understand the causes and risk factors for SUDEP. Call them at 1-855-432-8555.

Once SUDEP is determined:

- Learn about SUDEP and discuss it with your healthcare provider, especially if others in your family have epilepsy or died a sudden death.
- Seek support from other SUDEP-bereaved families, SUDEP/epilepsy organizations or grief counsellors in the know about SUDEP.

When the time feels right:

- Keep up-to-date with evolving news and research about SUDEP and share this information with friends and family.
- Help raise awareness of SUDEP through sharing your experience, organizing an event or helping your local epilepsy organization with their SUDEP support work.
- Advocate for, and participate in, research that investigates the causes and prevention of SUDEP.

Contact the campaign for further information and help with finding local resources.

AWARENESS IS THE FIRST STEP TOWARDS FINDING THE CAUSE AND PREVENTION OF SUDEP

- Raising awareness and encouraging discussion between people with epilepsy and their healthcare providers is the main aim of the Making Sense of SUDEP campaign.
- Increased awareness will advance research by making more information available to scientists and doctors studying SUDEP.

© SUDEP Aware 2012

Photos of models used as illustrative content.

PBE/APR 12



**Making Sense
of SUDEP**

Epilepsy is More
Than Seizures

A collaboration to raise
awareness of SUDEP

www.MakingSenseOfSUDEP.org
Toll free: 1-855-85-SUDEP (78337)



EPILEPSYAZ.ORG
**EPILEPSY
FOUNDATION**
Arizona

www.epilepsy.com
Toll free: 1-800-332-1000