



Sudden Unexpected Death in Epilepsy (SUDEP)

Although sudden unexpected deaths can occur in the population of people without epilepsy, some people with epilepsy are at higher risk of this occurring. It is estimated that around 500 people a year die from sudden unexpected death in epilepsy (SUDEP) in the UK.

SUDEP is said to have occurred when someone with epilepsy dies suddenly and unexpectedly for no known reason with, or without, evidence of having had a seizure. It usually occurs at night when there are no witnesses.

There is no obvious explanation for the death, even with a post-mortem examination. Most deaths occur in bed, presumably during sleep and often there is evidence to suggest a seizure had occurred around the time of death.

Although it is not fully understood why SUDEP occurs, it is thought that it is most likely due to seizure activity spreading to areas that control the heartbeat or the part of the brain responsible for respiration thus resulting in the heart and/or breathing ceasing to function.

Whilst SUDEP can occur in those with infrequent seizures as well as those with severe epilepsy, the risks are negligible for anyone who is seizure-free.

Although rare and unpredictable, certain factors increase the risk of SUDEP.

Risk factors that may increase the risk

- young adults (particularly males) who live alone
- poorly controlled tonic clonic seizures
- seizures that occur during sleep
- the need for more than one antiepileptic drug to control seizures
- abrupt and frequent changes in medication
- a sudden withdrawal of medication
- having learning disabilities

Reducing the risk of SUDEP

- optimizing seizure control and preventing seizures as much as possible
- being aware of potential risks at night
- medication compliance
- sensible lifestyle

For more on information on SUDEP visit www.sudep.org.

Epilepsy Bereaved (Tel 0800 282 986) offers support and information to those who have been directly affected by epilepsy and sudden death.

CRUSE (Bereavement Care) (Tel 0870 167 1677) offers help to people bereaved in any way.

The Compassionate Friends (Tel 0845 123 2304) offers help to bereaved parents whose son or daughter (of any age, including adult) has died from any cause.

Better futures for young lives with epilepsy

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