

Fact Sheet 27

SUDEP (Sudden Unexpected Death by Epilepsy)

SUDEP (Sudden Unexpected Death by Epilepsy) is a very sensitive topic because it highlights the fact that epilepsy, as a condition, carries a small risk of premature death. To die from SUDEP is uncommon but it is the single-most important cause of death in people with epilepsy, and it happens suddenly and without warning. American studies suggests that SUDEP occurs in approximately 1 in 1,000 adults and 1 in 4,500 children, accounting for 8-17% of deaths of people living with epilepsy and therefore it is a very real burden to those living with the condition. SUDEP is usually targeted to those under the age of 40 years and whose seizures are largely difficult to control, but the mortality rates in older adults may be underestimated.

SUDEP is defined as 'the sudden and unexpected, non-traumatic and non-drowning death of a person with epilepsy and with no other known medical conditions.' It can be witnessed, or unwitnessed, and generally happens during or after a seizure. In most cases, SUDEP occurs during sleep and may involve a nocturnal generalised convulsive seizure and a disruption of the autonomic system contributing to respiratory disturbance and heart failure. Lying in a prone position is also a contributing factor. The mechanisms of SUDEP remain uncertain but there is ongoing world-wide research to try to find answers, and a cure, for this devastating event.

A neurologist should explain if you are at risk of SUDEP but it is often a difficult subject to broach with some people. Because there are many potential burdens associated to living with epilepsy, the idea that the condition may also reduce life expectancy could be overwhelming for some. It is often necessary to have a frank discussion to help allay any unnecessary fear and anxiety, remembering that the risk of dying from SUDEP is very small.

At present the only strategy available to help prevent SUDEP is to minimise risks.

The following steps are advisable:

- Take medications as prescribed by a neurologist. Medications are designed to control seizures and should be taken routinely each day. If there are unpalatable side effects then it may be possible to change one medication for another. Always get immediate advice in the event of worsening seizures during a medication change. This is always a potentially hazardous period from the point of view of SUDEP.

More information: See fact sheet 7 on [epilepsy medication](#).

- Do not stop taking your medications for any reason. Adherence to taking medications is important in controlling seizures. It is likely that any drug therapy which reduces the frequency of convulsive seizures will reduce the incidence of SUDEP.

More information: See fact sheet 24 on [taking anti-epileptic medication](#).

- Keep a record of your seizures and discuss any changes with your neurologist.

Contact us if you wish to receive a free copy of our seizure diary.\

- Supervision at night should be considered when there is a risk of uncontrolled seizures occurring.

Use a mattress alarm, a baby monitor or surveillance camera to alert loved ones of a seizure taking place at night.

<https://www.samialert.com/>

http://www.reidtechnology.co.nz/site/reidtech/files/Emfit_Epileptic_A4_web.pdf

There is even the Embrace watch that alerts people of a generalised seizure happening.

An [epilepsy assistance dog](#) may also help give comfort and support.

- Manage seizure triggers such as alcohol/drug abuse and sleep deprivation.

A particular feature of sudden death is the need to understand why it happened. Some of that pain is perhaps associated with the fact that there is a general lack of SUDEP awareness in our community which can leave bereaved families feeling socially isolated and uncared for.

There are various online support groups for SUDEP to help raise awareness and to support research in this area.

For further support and advice please contact your EWCT epilepsy advisor.

Disclaimer: this fact sheet is for education purposes only. Please consult your doctor or other health professional for advice regarding your epilepsy.