Sudden Unexpected Death in Epilepsy (SUDEP)

Sudden Unexpected Death in Epilepsy (SUDEP) is when an otherwise healthy person with epilepsy dies suddenly and prematurely and no reason for death is found. This does not include those who die in status epilepticus and those who die from a seizure-related accident.

In general, people living with epilepsy have a risk of up to 1.2 in 1,000 of SUDEP per year.

Among children, SUDEP is an even rarer occurrence with the risk as low as 1 in 4,500. Most, but not all, cases of SUDEP occur during or immediately after a seizure.

To date we do not know what causes SUDEP. Researchers are currently investigating a variety of possibilities, such as respiratory (breathing) or cardiac (heart) dysfunction.

October 23rd is international SUDEP Action Day – read more about it here

SUDEP RISK FACTORS

- Uncontrolled or frequent seizures
- Tonic-clonic seizures, particularly if these happen at night or during sleep
- Frequent seizure activity
- Seizures that begin at a young age
- Many years of living with epilepsy
- Missed doses of medication
- Drinking alcohol.

Yet risk factors only tell part of the story. Sometimes people who have with infrequent seizures pass away, while others with more frequent and apparently more severe seizures do not. Some people may be at greater risk because of lifestyle choices or poor self-management, such as drinking alcohol to excess or stopping medication against the advice of doctors.

REDUCING RISK

- Speak to your doctor about the risk of SUDEP
- Take your ASM as prescribed
- Avoid triggers, if known
- Get adequate sleep
- Avoid drinking too much alcohol (or taking illicit drugs)
- Learn how to best manage your seizures through information, speaking to doctors and seeking support
- Ensure that your family and carers are trained in seizure first aid.

TALKING TO YOUR DOCTOR

If you are concerned about SUDEP, whether that is for yourself or someone you care for, it is a good idea to talk to your doctor. This will provide you with a chance to talk about risks and ways of lowering these in relation to SUDEP.

When talking to your doctor about SUDEP, you may want to discuss the following:

- What is my risk for SUDEP?
- What can I do to reduce my risk?
- What should I do if I forget to take my ASM?
- Would a change in medication assist me to gain better seizure control?
- Are there any activities I should avoid?
- How should I speak to my family and friends about SUDEP?

GETTING SUPPORT

Epilepsy New Zealand is here to assist and support anyone who has lost a loved one to SUDEP, or any other epilepsy-related deaths. Please feel free to contact us for confidential support.

You may also want to consider talking to your doctor or another healthcare professional

GRIEF AND LOSS- SUPPORT WEBSITES IN NEW ZEALAND

Sklylight -Based in Wellington- A hub/website offering personalised information, support, counselling services and library

Mental Health Foundation -Grief and Loss

Health Navigator – Grief

Grief Centre – Services which are designed to offer grief and loss support to children, youth, adults, families, or whanau experiencing any form of significant loss.

NATIONAL HELPLINES

Need to talk? Free call or text 1737 any time for support from a trained counsellor.

Lifeline – 0800 543 354 (0800 LIFELINE) or free text 4357 (HELP).

Suicide Crisis Helpline – 0508 828 865 (0508 TAUTOKO).

Healthline – 0800 611 116

Samaritans – 0800 726 666

SUDEP RESEARCH

SUDEP Action, based in the United Kingdom, is focused on providing information on SUDEP and sponsoring research to prevent further deaths. SUDEP Action also manages an international Epilepsy Death Register which gathers information about epilepsy-related deaths so that more can be learned and risks can be reduced. If a loved one has passed away you may want to consider sharing information in the Epilepsy Death Register.