

SUDDEN UNEXPECTED DEATH IN EPILEPSY (SUDEP)



BRAINWAVE
THE IRISH EPILEPSY
ASSOCIATION



INTRODUCTION

We all face risks in our daily lives. The challenge is to have a balanced understanding of these risks and how best to manage them.

Epilepsy Bereaved and Brainwave The Irish Epilepsy Association hope this leaflet will help you gain a better understanding of Sudden and Unexpected Death in Epilepsy (SUDEP). It is aimed at helping you to assess whether this is a risk worth considering in relation to your own type of epilepsy. It also offers practical advice about all the things you can do to reduce any risk.

SUDEP is a known risk to people with epilepsy. In the past it has been poorly understood and not really talked about. It has been ignored, understated and exaggerated at different times.

It is not surprising that people with epilepsy and their families increasingly ask for accurate information about SUDEP.

Being aware of risk factors and ways to reduce them may help you to manage your epilepsy so you can get on with your life.

WHAT IS SUDEP?

If a person with epilepsy dies suddenly and no other cause of death is found, this is called SUDEP (Sudden Unexpected Death in Epilepsy).

About 60 - 80 people die from epilepsy each year in Ireland. Accidents and status epilepticus (an uncommon type of severe seizure) account for some of these, but the most common cause of death is SUDEP.

WHAT CAUSES SUDEP?

SUDEP is connected to seizures but what exactly causes SUDEP is unknown. The most likely explanation is that a seizure interferes with the part of the brain that controls breathing or the heart.

WHO IS AT RISK?

Just as there are many different types of epilepsy, the risk of SUDEP will vary from low to very low (about 1 in 1000 people with epilepsy), but for a small number of people the risk may be higher.

This is why it is important to understand your own type of epilepsy and how best to manage it.

The most significant risk factor for SUDEP is the occurrence of seizures (particularly tonic-clonic). Therefore the better your epilepsy is controlled, the more your risk is minimised.

Common sense precautions include avoiding binge drinking and taking recreational drugs which may trigger seizures.

Other risk factors include:

- having seizures during sleep
- being a young adult
- frequent seizures
- having seizures when no-one is around to help
- untreated epilepsy
- abrupt changes in your epilepsy medication or not taking medication as prescribed

SUDEP is rare, but can happen in children under 16.

HOW CAN THE RISKS OF SEIZURES BE MINIMISED?

Here are some ways to reduce any risk:

- You have the best knowledge of what triggers your seizures. Be aware of these triggers and consider to what extent you can avoid them.
- Ask your doctor what type of epilepsy you have and check for any specific risks associated with it.
- If you are not seizure-free, ask your GP to refer you to a doctor who specialises in epilepsy.
- Keep taking your medication. You should never make changes to or stop taking your medication without discussing it with your doctor or epilepsy specialist nurse first.
- Your doctor will need accurate ongoing information about the number, frequency and type of seizures you have. This helps them give you the right medication and the best dose for you. They will also need to know if you have any side effects from your medication.
- If you have seizures while you are asleep, think about getting a seizure alarm.
- Get enough sleep.
- Avoid binge drinking and recreational drugs.

It is a good idea to raise any possible concerns about SUDEP with your consultant or epilepsy specialist nurse.

If you care for someone with epilepsy and you are with them while they are having a seizure you can do the following things to reduce their risk of SUDEP:

- Try and stay with them for about 20 minutes after the seizure has finished so you can check their breathing is regular and their colour is back to normal.
- Put them into the recovery position when the seizure has finished. Moving the person could encourage breathing to restart if it has stopped.



You may already have a plan worked out with your Doctor or Epilepsy Team for when to call an ambulance. Please follow this.

Other reasons to call can include:

- if the person is injured
- if the seizure does not stop after a few minutes
- if one seizure follows another
- if the person is having trouble breathing.

Barbara's story



Barbara Doyle, from Keadue, Co. Roscommon was a spirited, fun loving 30 year old teacher and talented musician with a love of travel and the outdoors. Barbara was diagnosed with epilepsy when she was almost 13 years old but never let this condition prevent her from living her life to the full.

Barbara achieved both bachelor and masters degrees before going on to qualify as a primary teacher. She won the All-Ireland Senior Harp championship in 1998. After teaching for several years she fulfilled a long held ambition when she travelled around the world from August 2006 to February 2007 taking in as much as possible on the way, including kayaking on the white-waters of the Zambezi in Africa and climbing Mount Kinabalu, the highest mountain in South East Asia. Barbara returned to take up a teaching position near her home town.

Sadly, Barbara died in her sleep in November of 2007. Needless to say, her sudden and unexpected death shocked and devastated her family, work colleagues and large circle of close friends.

Before her death, Barbara had planned to complete a hike to raise funds for 'Brainwave'. As a tribute to Barbara, her family and friends proceeded with this in June of 2008 encompassing the final five hikes that Barbara had completed. The money raised has made possible the publication of this leaflet. Her family and close friends are hopeful that this will help promote awareness of SUDEP and prompt patients and the medical profession in general to appreciate more fully the risks involved.

REMEMBER

Epilepsy is a long term chronic condition and the outlook for most people is very good. With a clear understanding of your epilepsy and good management of your seizures, the risk of SUDEP can be minimised. Research is also continuing so we can improve our understanding of the cause of SUDEP and further prevention measures.

The photographs on the cover of this leaflet are of loved ones who have died from epilepsy. We would like to thank the bereaved relatives who have provided these photos.

This is a joint publication between Epilepsy Bereaved and
Brainwave The Irish Epilepsy Association



www.sudep.org



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Epilepsy Bereaved works to prevent SUDEP through research; education and awareness and through providing services to people affected by SUDEP and other seizure-related deaths.

Brainwave The Irish Epilepsy Association is the national association representing people with epilepsy in Ireland. Brainwave operates through a network of regional offices, staffed by Community Resource Officers.

Dublin T: 01 – 4557500
E: imurphy.brainwave@epilepsy.ie

Cork T: 021 – 4274774
E: brainwavecork@epilepsy.ie
E: brainwavecork1@epilepsy.ie

Dundalk T: 042 – 9337585
E: brainwavedk@epilepsy.ie

Galway T: 091 – 568180
E: crogalway.brainwave@epilepsy.ie

Kilkenny T: 056 – 7784496
E: southeast.brainwave@epilepsy.ie

Letterkenny T: 074 – 9168725
E: donegal.brainwave@epilepsy.ie

Limerick T: 061 – 313773
E: brainwavelk@epilepsy.ie

Tralee T: 066 – 7119507
E: crokerry.brainwave@epilepsy.ie

Sligo T: 071 – 9154625
E: donegal.brainwave@epilepsy.ie

Tullamore T: 057 – 9346790
E: midlandbrainwave@epilepsy.ie