

Please contact us for further information:

Head Office:	SUDEP Action Scotland:	Support (direct line):
01235 772850	0131 516 7987	01235 772852
info@sudep.org	www.sudep.org	support@sudep.org

SUDEP.ORG

SUDEP Action 

Making every epilepsy death count



HAVE YOU BEEN BEREAVED BY EPILEPSY?

There are around 1200 epilepsy deaths
a year in the UK

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SUDEP Action, registered charity 1164250 (England & Wales), SC047223 (Scotland)

Epilepsy Bereaved (founded 1995) is part of SUDEP Action

SUDEP Action is a UK based charity providing specialist services designed for people bereaved by epilepsy. The charity is committed to helping you in this most difficult time.

People with epilepsy can die from accidents, drowning, suicide, status epilepticus (where there is evidence of a seizure lasting for 30 minutes or more), or from SUDEP (Sudden Unexpected Death in Epilepsy), which is when a person with epilepsy dies suddenly and no other cause of death is found. Epilepsy is a very complex condition and after a death people may have many questions.

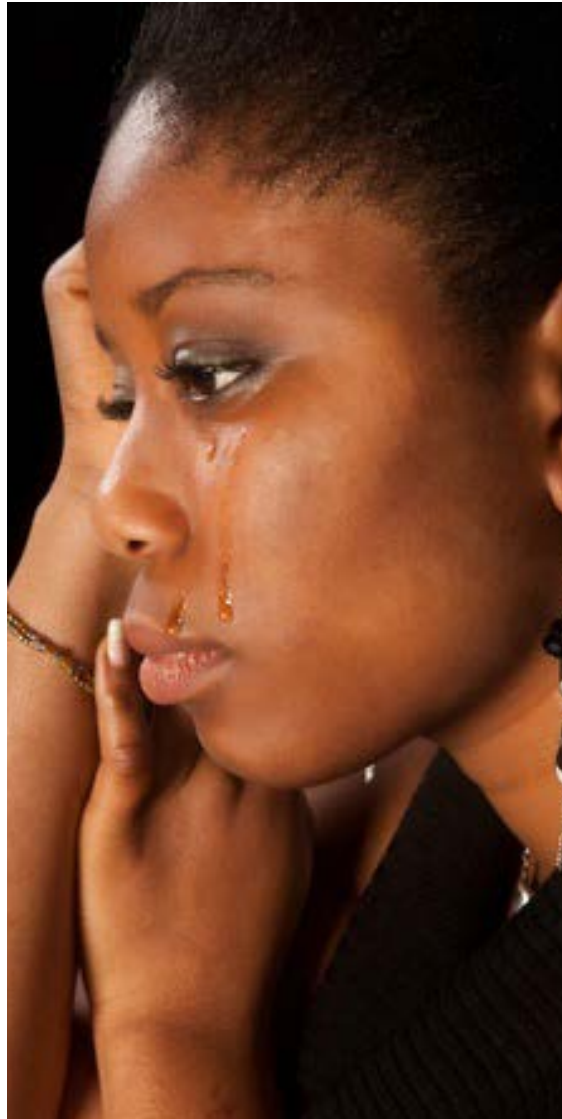
After a death we provide:

- A dedicated support line offering valuable listening space
- Help in understanding what may have happened
- Support and information on coronial investigations, leading up to and after an inquest
- Information on how you can help research by providing information
- Information on brain and tissue donation
- Opportunities to meet others similarly bereaved
- Counselling

What you can do at this stage:

- Contact us immediately if you would like information on brain or tissue donation
- Report the death to the Epilepsy Deaths Register on 0330 088 1220 or via sudep.org
- Learn to look after yourself, as you will need a lot of strength
- Try to understand as much as possible about what happened
- Ask for our information pack
- Talk to us, as there are many ways we can support you, or that you can get involved: 01235 772852

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All epilepsy deaths are devastating and often they are unexpected. We provide services based on what the bereaved tell us they need. We have been working with people bereaved by epilepsy for over 20 years. We campaign for change and work with experts in the field of epilepsy and epilepsy mortality to find answers to reduce epilepsy-related deaths. If there is anything you feel we may be able to help you with, please contact us. Our team is supported by a panel with expertise in SUDEP, status epilepticus, suicide and all causes of epilepsy related deaths.

SUDEP deaths are particularly difficult to understand as many people have not heard of it prior to a death. It is therefore important that you are able to access the support and information you need as you try to understand what may have happened and why.

What is SUDEP?

SUDEP is when a person with epilepsy dies suddenly and no other cause of death is found. Almost half of all epilepsy deaths in the UK are from SUDEP. These deaths usually occur at night or during sleep and many are not witnessed. There may have been a seizure just before death, although this isn't always the case.

It is only possible to confirm SUDEP through a post mortem, when other causes of death are ruled out. Families and carers can play a key role in the process with the coroner, by giving the history of seizures and information about the events leading up to a person's death.

What Causes SUDEP?

Although we don't fully understand why these deaths occur, they are known to be related to seizures, although there is not always evidence of this. Several different mechanisms may be involved and there is unlikely to be a single explanation.

The two most likely causes of death are cardiac and respiratory. During a seizure there is often a change in breathing and heart rhythm. In most people with epilepsy, this is not dangerous but sometimes a more serious drop in blood oxygen levels or changes in heart rhythm may occur.

For further information contact:

01235 772852 email support@sudep.org

The uniqueness of our bereavement service recognises the emotional impact that an epilepsy-related death can have and we understand that people bereaved in this way may have complex information needs. We can provide answers and help break the isolation, helping you to feel less anxious and more in control at a time when nothing seems to make sense.

Coping with the death of someone close can be difficult, and the range of feelings that you experience can be enormous. Not only can you feel isolated; anxious and confused, there may be an overwhelming need for answers. You may find it helpful to visit: www.sudeptheglobalconversation a global information site which has information from professionals and stories from the bereaved.