

## About Epilepsy Bereaved (registered charity number 1050459)

Founded in 1993, Epilepsy Bereaved (EB) is the only charity in the UK dedicated to preventing sudden unexpected death in epilepsy (SUDEP) and other seizure related deaths.

Core to the work of the charity is providing information and support to bereaved families, friends and carers who have lost a loved one through epilepsy.

We offer;

- someone to listen
- a confidential service within the charity
- information specific to epilepsy deaths and SUDEP
- opportunities to meet other people bereaved by epilepsy

Epilepsy Bereaved is advised by a panel of epilepsy experts and specialist pathologists. We therefore have access to information and advice to assist the bereaved to understand the cause of death.

Aims of Epilepsy Bereaved;

- To reduce the number of avoidable deaths from epilepsy
- Raise awareness and influence health professionals and policy makers
- Develop research into the causes of sudden death in epilepsy

The risks of SUDEP and other epilepsy deaths are still not fully acknowledged. This means that people with epilepsy are still at risk of dying suddenly, prematurely and unnecessarily. Without Epilepsy Bereaved, awareness of SUDEP and epilepsy related deaths would be minimal.

### Key facts

- There are approximately 1,000 deaths from epilepsy each year in the UK. More than 500 are attributed to SUDEP. This is greater than the total number of AIDS related deaths annually.
- 1 in 130 people in the UK have some form of epilepsy.
- EB led the National Sentinel Clinical Audit of Epilepsy-Related Death in 2002. This revealed that 42% of these deaths were potentially avoidable.
- The report also revealed that people with epilepsy have a risk of premature death that is 3 times higher than that of the general population.
- 79,000 people with epilepsy in the UK are having seizures that could be prevented.

### What do we do?

- EB provides a contact line enabling people who have been bereaved by epilepsy related deaths to get initial support and information. Currently there are over 1,000 calls per annum.
- EB provides support to people individually and the opportunity to meet each other in regional peer support groups. Last year EB hosted two national and six regional meetings. In addition, EB provides opportunities for bereaved families and others to become involved in our work. Last year, EB enabled over 300 people to take part in campaigning for improved epilepsy services along with fund-raising activities.
- EB lobbies clinicians, health managers and policy makers with the aim of raising awareness and ultimately reducing the risk of epilepsy related death.
- EB carries out and supports research into the causes of SUDEP and other epilepsy deaths. We are currently working in partnership with Kings College Hospital London with the aim of finding ways to prevent SUDEP and other epilepsy deaths.

### Contact details;

PO Box 112, Wantage, Oxford, OX12 8XT

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[www.sudep.org](http://www.sudep.org)

**Bereavement support line 01235 772 852**

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