

SUDEP Action is the only UK charity dedicated to raising awareness of epilepsy risks, tackling epilepsy deaths and supporting those bereaved by the condition

Although almost entirely funded by bereaved families, we helped **11,000 people** and **278 organisations** in the last year alone. We provide:

- ✓ **Specialist service and care pathway for families after a sudden death**
- ✓ **Unique on-line research platform for over 600** bereaved families since 2013
- ✓ **Dedicated research programme** pump-priming research collaborations with leading UK experts on risk factors, life-saving devices and impact on families
  - Resulting in a **2million euros grant** to the lead researcher of a wearable device project (see press release for details) and another included in the NHS Innovation Accelerator Programme
- ✓ **Standardised clinical checklist for risk and digital self-management tool** to support people with epilepsy
- ✓ **SUDEP and Seizure Safety training tools** for GPs and Ambulance crews
- ✓ **Our information and services are model and used internationally:** so far supporting organisations in USA/Australia

## Why we are calling for an inquiry

**1 in every 103 people live with epilepsy in the UK** – yet alarmingly many of these people and their clinicians are not aware the condition kills as many people each year as Asthma, a condition with a population **9x larger**.

**21** Epilepsy deaths a week  
(3 a day)

Which means from 1996→2017  
**21,000**  
 Epilepsy deaths

**42%** could potentially be avoided = 9000 lives

- **Sudden Unexpected Death in Epilepsy (SUDEP) accounts for 50% of epilepsy deaths;** accidents, drownings, suicides & Status Epilepticus are the other causes of death.
- There are **over 600 SUDEP** each year (over **4x more** than the number of babies who suffer cot death).
- Many epilepsy deaths are in the young – the number of potential years of life lost is significant.
- Research has identified key risk factors which increase risk of death in people with epilepsy.
- **Many of these factors can be reduced if actions are taken**, such as improved seizure control, better medication taking, increased awareness of risk and better engagement with services.
- Investigation into the development and the benefit of alarms & monitors is ongoing. Currently there is **no evidence** that an alarm or device can guarantee safety. We hope in time this changes; meanwhile SUDEP Action provide free tools to help reduce risks.
- A Charity report of 300 families shows **52% were not told about SUDEP risks**. In some areas, communication rates about risk between patient and clinician are **less than 20%**. Leaving a huge number of people unaware of the dangers they face & of the importance of managing risk alongside their clinicians.
- Epilepsy annual reviews were removed from QOF in 2013, leaving little incentive for them to happen. However, other long-term conditions eg: Asthma, have well developed & attended risk reviews systems.

## How you can help – 3 steps

### Preventing Unnecessary deaths

Who in government can meet with the charity to help speed up the spread of good practice across the NHS? Show your support for an enquiry into avoidable deaths.

### Helping families after a death

Who in government can meet the charity to help with coronial and professional signposting after a death so that no family is left to search the internet?

### Share our press release & have a photo taken today, helping support the charity through your media channels

SUDEP Action Day also takes place on October 23<sup>rd</sup> – can you retweet our messages & raise awareness of the day & SUDEP Action in your constituency? [www.sudepactionday.org](http://www.sudepactionday.org)