

## People with epilepsy are dying prematurely and avoidably: help us to prevent this

Neurology deaths are increasing, but deaths from other conditions have fallen. **At least 21 people with epilepsy die each week**; yet we know things can be done to stop this.

This letter speaks on behalf of the **families left behind**.

It is supported by key neurology and epilepsy organisations and individuals who support the call to action from Government - to prevent these untimely deaths.



In February 2018, SUDEP Action wrote to the Secretary of State for Health and Social Care to request a meeting with us; this has yet to happen.

In November 2018, SUDEP Action brought together over 60 experts in epilepsy & epilepsy deaths for a **Summit on Tackling Epilepsy-related deaths** (<http://bit.ly/P21Summit>). This led to key recommendations regarding preventing future epilepsy deaths being agreed by consensus. We plan to work collaboratively to achieve these but need the support of policy makers & Government.

**Will you stand with us and help us to save lives?**

**Attend the All Party Parliamentary Group for Epilepsy on 28th November to hear more & find out how you can help**

### EPILEPSY DEATHS INCREASE

A recent report from Public Health England shows an alarming increase in numbers of deaths in people with neurological conditions. This 14-year progression demands action.

Epilepsy affects 600,000 people in the UK, along with their families and their communities. Deprivation is associated with poor seizure control, increased emergency admissions and sudden and early death. This report highlights that people in deprived areas with epilepsy are three times more likely to die than those from elsewhere.

Many of these untimely deaths can be avoided: 90% of those dying from Sudden Unexpected Death in Epilepsy (SUDEP) in a population with high deprivation had demonstrated an increase in convulsive seizures and other risks in the previous three to six months. The 2014 removal of a financial incentive for GPs to annually monitor people with epilepsy has cost a valuable safety net, losing the ability to identify and manage those at highest risk.

This report is another call for action from government to protect society's most vulnerable. We hope that the secretary of state for health and social care has time to meet a delegation led by the bereaved community.

*Jane Hanna OBE, CEO SUDEP Action; Dr John Hirst CBE, chair SUDEP Action; Professor Mary M Reilly, president and on behalf of the Association of British Neurologists; Professor Phil E M Smith, immediate past president of the Association of British Neurologists; Dr John Paul Leach, President of the British Branch of the International League Against Epilepsy; Joe Korner, chief executive, Neurological Alliance; Dr Craig Newman, consultant neuropsychologist, NHS Innovation Accelerator Fellow, Plymouth University; Dr Paul Morrish, consultant neurologist, Great Western Hospital, Swindon; Professor Leone Ridsdale, professor of neurology and general practice, King's College, London; Dr Arjune Sen, consultant neurologist and associate professor, John Radcliffe Hospital, Oxford; Dr Rohit Shankar MBE, consultant in adult developmental psychiatry, Cornwall Partnership NHS Foundation Trust*

## What you need to know:

**600,000** people with epilepsy in the UK (**1 in 103**)  
Sudden death is **24x** more likely

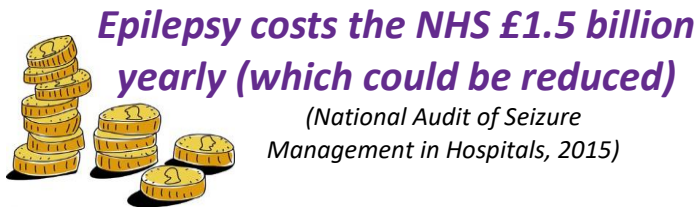
21 people with epilepsy die each week in the UK



**Nearly HALF of all epilepsy deaths  
are potentially avoidable**

*(National Sentinel Audit of Epilepsy Deaths 2002)*

**But we KNOW steps can be taken  
& tools are available to prevent this!**



***Epilepsy costs the NHS £1.5 billion  
yearly (which could be reduced)***

*(National Audit of Seizure  
Management in Hospitals, 2015)*

**Yet the cost to families bereaved by  
epilepsy is incalculable:**

*“I keep hoping I’ll wake up & realise it  
was a bad dream. Although I knew  
epilepsy was a serious illness, I never  
thought she would die.”*

**SUDEP Action**   
*Making every epilepsy death count*

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

Almost entirely funded by bereaved families – we’ve helped **11,000  
people** and **278 organisations** in the last year alone with:

- ✓ **A free specialist support service and care pathway for bereaved families**
- ✓ **A unique on-line research platform reaching over 700 bereaved families**
- ✓ **A dedicated research programme** pump-priming UK expert led research collaborations on epilepsy risk factors, life-saving devices & bereavement  
Resulting in:
  - ✓ **A €2million grant** to research on a potentially life-saving wearable alert device for people with epilepsy
  - ✓ **Another project** backed by the NHS Innovation Accelerator Programme
- ✓ **Free checklist on epilepsy risks** to support clinicians ([SUDEP & Seizure Safety Checklist](#)) and **digital self-management tool** to support people with epilepsy ([EpSMon](#))
- ✓ **Free training tools** for GPs and Ambulance crews
- ✓ **Our information and services are modelled and used internationally** (supporting organisations in USA/Australia)

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