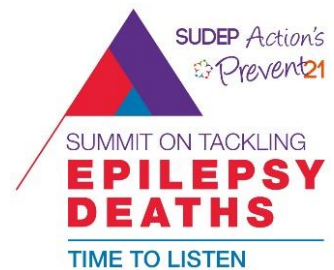


Tackling Epilepsy Deaths: MP Briefing



SUDEP Action

Leader of PREVENT21 movement to tackle epilepsy-related deaths and lever potentially life-saving improvements to epilepsy services on the ground.

Founded in 1995, over 50% of SUDEP Action's Trustee Board and Staff Team (7 FTE) have direct family experience of the impact of epilepsy-related deaths, Sudden Unexpected Death in Epilepsy (SUDEP) or Sudden Death. The Charity has a proven track record of changing guidance and practice at global, national and local levels, helping over 11,000 people last year.

They provide innovating solutions and services to meet gaps in provision; achieving this through collaborating with research, clinical and policy champions, and through using digital tools to support relationships between health professionals and patients.

www.sudep.org

Epilepsy Deaths - Key Facts

At least **21 epilepsy-related deaths a week** (9x riskier than asthma). Sudden Unexpected Death in Epilepsy (SUDEP) accounts for about 50% and other causes are accidents, suicide and prolonged convulsive seizures (Status Epilepticus)

Epilepsy is in **top ten of all causes of mortality** as many years of life lost as deaths in children & young

3% increase in people living and dying with epilepsy per annum. Death **varies 3-fold with deprivation** (high prevalence and poor control means more deaths) - *Public Health England: Deaths from Neurological Conditions Report, 2018.*

At least 42% of all epilepsy-related deaths avoidable. Epilepsy risk are often underestimated in decision-making between patients and health professionals, despite evidence that many can be reduced. There is wide variation in disclosing these potentially fatal risks to patients, with UK discussion rates varied from 4% - 80%. **Epilepsy has no regular monitoring** in contrast with asthma.

UK has 60,000 A&E attendances and 40,000 admissions due to epilepsy per year. Poor care was demonstrated by National Audit with 63% not seen in previous 12 months and 56% with no follow up.

Cost of epilepsy in the UK >£1Billion/year

Epilepsy is not yet included in the NHS 10-year plan – neither was it prioritised in the 5 Year Forward plan.

National research grant giving bodies in the UK have a poor track record on funding relevant research

SUDEP Action's Prevent 21 Summit on Tackling Epilepsy Deaths

71 delegates representing **43 different organisations** participated in a collaborative two-day Summit to tackle deaths at Corpus Christi, Oxford November 2018. MPs participating included Paula Sherriff MP; Norman Lamb MP, Ed Vaizey MP and Ivan Lewis MP.

7 key recommendations were agreed by consensus at the Summit. These recommendations were underpinned by **recommendations from bereaved families** who have lost a loved one to Epilepsy:

Families bereaved by epilepsy have outlined the following recommendations as being important to the Bereaved Community:

1. Timely signposting of bereaved families to specialist support services and the Epilepsy Deaths Register after a death
2. The roll out of tools that accelerate putting guidelines into practice on conversations about risk
3. Increased research funding being made available and prioritised to support projects on epilepsy deaths and the implementation of interventions to support clinicians and people with epilepsy, & avoid future deaths
4. Neurological Conditions (specifically highlighting Epilepsy and Epilepsy deaths) to be included in the upcoming NHS 10-year plan

Findings from the Epilepsy Deaths Register research registrations, consulted on by bereaved families at the SUDEP Action National Conference 2018

What is happening already to tackle epilepsy deaths?

- **Prevent21 Summit Recommendations Report** published and is being shared with supportive organisations & policy makers
- **One Day Workshop on Epilepsy-Related Deaths for Epilepsy Organisations** in planning (Spring 2019)
- **Epilepsy & Behaviour Journal Supplement** highlighting key presentations & outcomes from the Summit (Published early 2019)
- **A series of Parliamentary Questions tabled** EG: Who is the Minister responsible for Epilepsy? Will Neurology / Epilepsy be prioritised in the upcoming NHS 10-year plan?

Next Steps

- **Letter to Health Select Committee** asking for an inquiry into epilepsy-related deaths
- **APPGE to seek/push for a meeting with Secretary of State for Health and Social Care**
To highlight the Summit recommendations & the need for Gov. to meet with the bereaved community and support those tackling epilepsy deaths.
- **Epilepsy-related deaths to become a standing APPGE Agenda Item**
With SUDEP Action updating the APPGE on work relating to Epilepsy-related deaths at future APPGE meetings – coordinating with other Epilepsy organisations, supportive MPs and APPGE Chair in-between meetings to progress actions and achieve outcomes
- **SUDEP Action will be reporting on this APPGE & the Prevent21 Summit shortly** – could you share this information in your constituency newsletter?

Can you support this work moving forward & help us raise awareness of this in your constituency?

Please contact Sammy Ashby: samantha.ashby@sudep.org