

## Tackling avoidable epilepsy mortality – 3 asks to Government

**21 epilepsy deaths each week in the UK is 21 deaths too many. We are calling for:**

1. **A Government inquiry into avoidable epilepsy deaths**
2. **A funded annual risk check for all people with epilepsy**
3. **Government to meet SUDEP Action to show how increasing epilepsy risks and rising avoidable mortality can be addressed**

### Why is a Government inquiry into avoidable epilepsy deaths needed?

Currently Neurology is not an NHS priority and epilepsy remains highly stigmatised. Epilepsy is excluded from the majority of NHS plans at both national and local levels. But we know there are:

- **21 epilepsy deaths weekly**, many in young and otherwise healthy people
- **42% of all epilepsy deaths are known to be potentially avoidable**
- **Up to 50% of epilepsy deaths are due to SUDEP (Sudden Unexpected Death in Epilepsy)**

Neurology is the ‘Cinderella service’ of the NHS, facing geographical and socio-economic inequalities highlighted in the 2016 Public Accounts Committee inquiry<sup>i</sup>, the 2018 Public Health England report on Neurology Mortality<sup>ii</sup> and the Neurological Alliance’s recent Patient Experience Survey findings<sup>iii</sup>. This report **flagged increasing neurology deaths**, (*increasing* by 39% between 2001-2014), despite general deaths rates *falling* by 6% during the same time period; and that people with epilepsy facing deprivation are at least 3x more likely to die prematurely<sup>iv</sup>.

There is much ‘Transformation’ work happening at national and local levels to improve health services. Yet national and local service planning are not considering epilepsy (& neurology in general) as a priority; despite significant evidence of epilepsy deaths and the potential to reduce avoidable mortality and despite epilepsy being the focus of high-profile news coverage due to current issues such as medicines shortages, Sodium Valproate & medical cannabis. **However, Epilepsy & deaths from the condition are a prominent aspect of any national work on Neurology & are often cited as a driver for proposed change; creating a juxtaposition where epilepsy deaths are simultaneously used and neglected.**

**Epilepsy deaths are not decreasing** despite deaths from other conditions (such as SIDS) falling<sup>v</sup>. Epilepsy-related maternal deaths (in women who are pregnant or who have recently given birth) are in fact increasing<sup>vi</sup>, and there have been multiple high-profile epilepsy deaths in people with learning disabilities in recent years.

Preventing **unnecessary and untimely deaths is possible** by improving patient pathways, by having open & routine communication of risk information, and by improving access to services<sup>vii</sup>. Risk management is critical to reducing avoidable epilepsy-related deaths; highlighted throughout research, national guidelines, and Coronial reports (Prevention of Future Death reports and Fatal Accident Inquiries).

Epilepsy deaths has been debated many times since it was first debated as urgent issue in 1998; most recently with a 2015 epilepsy mortality debate, a 2019 debate on the potentially catastrophic impact of Serious Shortage Protocols for medicines on people with epilepsy. **Debates help raise profile, but action must now be taken, and urgent attention given by Government if lives are to be saved and improved for the better. An inquiry into tackling avoidable epilepsy deaths would shine a light on key issues, highlight available solutions and identify on record what actions must be taken and by who in order to prevent further unnecessary lost lives.**

## Why is an annual Government funded risk check for all people with epilepsy needed?

Prevention of a health crisis is critical in improving the efficiency of the NHS and **improving both quality of life and overall outcomes** for people with epilepsy. **Research has demonstrated however that actions *can* be taken to reduce epilepsy risks**, and if adopted nationally could lead to a reduction in preventable epilepsy deaths<sup>viii</sup>.

Research in the South West of the UK exploring epilepsy risk by examining death records found that:

- only 20% of people with epilepsy who had died had been in contact with specialist services in the previous year
- In 90% of the deaths their epilepsy worsened in the 3-6 months before their death
- Many also had other risks linked to worsening seizures & increased mortality risk (which can be reduced if **care is patient-centred**<sup>ix</sup>)

Because of this knowledge SUDEP Action created a free award-winning clinical tool (the [SUDEP and Seizure Safety Checklist](#)) to support clinicians to discuss, monitor and put steps in place to help reduce their patient's epilepsy risks. The Checklist has demonstrated potentially fatal risks can be reduced<sup>x</sup> and over 730 UK clinicians have the tool.

There is no other method widely used to review people with epilepsy in a standardised way. The Quality Outcome Framework (QoF) for a yearly epilepsy review in General Practice was dropped without consultation in 2014; despite the known avoidability of many epilepsy deaths, and despite 'prevention of amenable mortality' being a priority in the NHS Outcome Framework<sup>xi</sup>. In light of existing successful interventions providing such a check (SUDEP Action's Checklist and its patient app version [EpSMon](#)), **Government re-evaluating this decision to no longer incentivise or fund an annual epilepsy review could address this issue by providing a national patient 'safety net' with a view to reducing deaths**<sup>xii xiii</sup>.

There is a national push for more integrated care – so who locally is best placed to conduct a risk check may vary. SUDEP Action's Checklist fits this model as it is designed for use by any clinician engaging with epilepsy patients, regardless of clinical setting; but a national steer is needed to take it beyond a best practice tool being adopted by motivated clinicians, to a tool integrated and supported by NHS systems across the UK. **Integration of this Checklist into national patient record systems could give all UK clinicians instant access to an intervention which can help reduce risks, improve patient outcomes, reduce burden on health services and could even save lives.**

This potential has been recognised by the **NHS Innovation Accelerator Programme & during the NHS 70<sup>th</sup> birthday celebrations**<sup>xiv xv</sup>. However, despite their potential to prevent deaths being recognised by health bodies such as the BMJ, HSJ, NHS NIA, Cochrane & NIHR, it is incredibly difficult to gain implemented and adoption across the NHS. Asthma has a successful annual review model (including risk review) which shows such interventions can be successfully adopted by both clinicians and patients.

Non-specialists can play a pivotal role in reducing burden on overstretched specialist epilepsy services, particularly in risk management<sup>xvi xvii</sup>. But with less than ½ a day in most medical training courses on Neurology (let alone on epilepsy) there is Neurophobia among medical students and some non-neurology specialist clinicians. **Increased training and support for non-epilepsy specialists is needed to support them with epilepsy risk management. Helping to reduce variation in care provided by non-specialists, which will in turn help reduce burden in the system**<sup>xviii xix</sup>.

## **Why must Government meet with SUDEP Action to show how they can address increasing epilepsy risks and rising avoidable mortality?**

**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 – they helped over 13,500 people and nearly 300 organisations in the last year alone.

They are a user-led charity offering bespoke services in the aftermath of epilepsy deaths. Their staff and trustee board are led by people with lived experience of epilepsy or suddenly bereavement providing unique insight to support bereaved families and people living with epilepsy. They also work with a UK wide clinical & research network to support them in their work on tackling epilepsy deaths.

### **Expertise in tackling epilepsy mortality**

SUDEP Action have a long history working with the Government, Department of Health, NHS England & Ministry of Justice on this issue eg:

- The National Clinical Audit on Epilepsy Deaths in 2002, led by SUDEP Action CEO, Jane Hanna OBE;
- the Government Action Plan on Epilepsy Deaths (2003);
- Royal College of Pathology guidelines (2003 & 2019);
- NICE guidelines in epilepsy (2004),
- The inclusion of the epilepsy review QOF quality marker (2004)
- NHS England's Specialised Commissioning Epilepsy Pathway and NHS RightCare's Epilepsy Toolkit (2019)

**In November 2019 SUDEP Action led a Prevent21 Summit on Tackling Epilepsy Deaths<sup>xx</sup>** – attended by over 45 stakeholder organisations, including clinical, research and policy stakeholders (including NHS England & Ministry of Justice representatives). The event focused on solutions both available and required to meet the gaps in preventing epilepsy deaths, first identified over 21 years ago. A report on actions needing to be taken has been endorsed by the Neurological Alliance and the All Party Parliamentary Group for Epilepsy<sup>xxi</sup>.

The Charity's free information and services are already being utilised in pockets across the NHS. helping complement and support a hugely overstretched workforce. Their services and support can be instrumental in helping to prevent escalation to potentially fatal crisis among people living with epilepsy and help reduce the long-lasting legal and service provision burden on the NHS caused by avoidable epilepsy bereavements.

### **Expertise after an epilepsy death**

SUDEP Action fill a gap for bereaved families who at most vulnerable time of lives have to negotiate coroners' inquests, medical complaints and other traumatic systems following their loved one's often unexpected death. The charity is led by needs of these families and works alongside them through these processes; continuing to provide life-long bespoke support and involvement for families bereaved by epilepsy.

As an organisation specialised in supporting bereaved families following often avoidable epilepsy deaths, they have observed rising demands on NHS resolution of complaints and claims. Improving NHS digital channels, such as NHS Choices, to better **digitally signpost** to third sector sources of support who have a wealth of expertise would hugely benefit patients, and in particular bereaved families who are often left traumatized with no empathetic support system following a death. This alone could save the NHS significant time and funds by helping these groups access support via the voluntary sector and help reinforce the NICE guidance on supporting epilepsy bereaved families<sup>xxii</sup>.

SUDEP Action have a wealth of expertise which could support the Government in taking action to prevent future avoidable epilepsy deaths – if they are willing to meet to discuss what can be done.

- <sup>i</sup> <https://www.parliament.uk/business/committees/committees-a-z/commons-select/public-accounts-committee/inquiries/parliament-2015/services-to-people-with-neurological-conditions-progress-review-15-16/>
- <sup>ii</sup> Public Health England, report into [Deaths Associated with Neurological Conditions](#), March 2018
- <sup>iii</sup> <https://www.neural.org.uk/wp-content/uploads/2019/07/neuro-patience-2019-1.pdf>
- <sup>iv</sup> Thornton J. [Data show big rise in deaths of people with neurological disorders](#). British Medical Journal. 2018; 360.
- <sup>v</sup> Thurman DJ. [How common is SUDEP: reconsidering the data](#). In: Hanna J, Panelli R, Jeffs T, Chapman D, editors. Continuing the global conversation [online]. SUDEP Action, SUDEP Aware & Epilepsy Australia; 2014.
- <sup>vi</sup> Nashef L. [SUDEP and pregnancy](#). In: Hanna J, Panelli R, Jeffs T, Chapman D. Continuing the global conversation. SUDEP Action, SUDEP Aware & Epilepsy Australia; 2014.
- <sup>vii</sup> Hanna N J, Black M, Sander JWS, Smithson WH, Appleton R, Brown S, Fish DR (2002) [The National Sentinel Clinical Audit of Epilepsy-Related Death: Epilepsy—death in the shadows](#). The Stationery Office
- <sup>viii</sup> Shankar, R., Newman, C., Hanna, J. et al, [Keeping patients with epilepsy safe: a surmountable challenge?](#) *BMJ Qual Improv Rep*. 2015;4
- <sup>ix</sup> Shankar R, Jalihal V, Walker M et al. [A community study in Cornwall UK of sudden unexpected death in epilepsy \(SUDEP\) in a 9-year population sample](#). *Seizure* 2014;23(5):382-5.
- <sup>x</sup> Shankar, R., Henley, W.H., Boland et al, [Decreasing the risk of SUDEP: structured communication of risk factors for premature mortality in people with epilepsy](#). *Eur J Neurol*. 2018;
- <sup>xi</sup> Rusk, L [www.bmj.com/content/350/bmj.h718/rapid-responses](http://www.bmj.com/content/350/bmj.h718/rapid-responses); NHS Employers. 2014/15 General Medical Services (GMS) Contract Quality and Outcomes Framework (QOF). Guidance for GMS Contract 2014/15.
- <sup>xii</sup> Shankar R, Newman C, McLean B, et al [Can technology help reduce risk of harm in Patients with Epilepsy?](#) *BJGP*, 09/2015; 65 (638): 448 -449
- <sup>xiii</sup> Page R, Shankar R, McLean BN, et al (2018) [Digital Care in Epilepsy: A Conceptual Framework for Technological Therapies](#). *Front. Neurol*. 9:99.
- <sup>xiv</sup> <http://sudep.org/article/epsmon-app-joins-nhs-innovation-accelerator-programme>
- <sup>xv</sup> <https://nhsaccelerator.com/people-encouraged-go-digital-new-nhs-short-films/>
- <sup>xvi</sup> Ridsdale L. [Avoiding premature death in epilepsy: General practice is the place to start, and much can be done](#) *BMJ* 2015;350:h718.
- <sup>xvii</sup> Gales, A; [Applying the SUDEP Checklist to a General Practice Population](#); Learnings and Outcomes. RCGP, Bright Ideas, 2016.
- <sup>xviii</sup> Ridsdale L, Massey R, Clark L.; [Preventing neurophobia in medical students, and so future doctors](#), *Practical Neurology* 2007;7:116-123.
- <sup>xix</sup> Ridsdale, L. [Closing the gap between neurologists and GPs](#), *BMJ Opinion*; 16/4/18
- <sup>xx</sup> <https://sudep.org/sudep-actions-prevent21-summit>
- <sup>xxi</sup> [https://sudep.org/sites/default/files/sudep\\_action\\_prevent21\\_summit\\_report\\_-\\_outcomes\\_recommendations\\_1.pdf](https://sudep.org/sites/default/files/sudep_action_prevent21_summit_report_-_outcomes_recommendations_1.pdf)
- <sup>xxii</sup> <http://www.nice.org.uk/guidance/cg137/chapter/1-guidance#information> (Section 1.3.14)