

Overview of Epilepsy Mortality – Valproate Stakeholders Network (May 2019)

About SUDEP Action:

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 – the charity has helped over 15,000 people and nearly 300 organisations in the last year alone. SUDEP Action has developed award winning digital tools (BMJ Education, HSJ Patient Safety) to support clinicians and people with epilepsy reduce risks and learn from avoidable deaths. They charity also supports international organisations to model our services to tackle epilepsy deaths worldwide.

As the only specialist organisation focusing specifically on epilepsy mortality, the Charity has a long history working with Government, for example during the National Clinical Audit on Epilepsy Deaths (2002), led by SUDEP Action CEO Jane Hanna OBE; the Government Action Plan on Epilepsy Deaths (2003); Royal College of Pathology guidelines (2003 & 2018); NICE guidelines in epilepsy (2004), and the inclusion of the epilepsy review in Quality Outcome Framework (QoF) (2004).

Epilepsy Mortality – increasing, preventable and devastating

Currently, Neurology is not an NHS priority and epilepsy remains highly stigmatised. But **21 people with epilepsy die weekly in the UK**, many of which are in young and otherwise healthy people. With **42% of all epilepsy deaths are known to be potentially avoidable**; there is an urgent need for epilepsy to become an NHS priority. 50% of epilepsy deaths are due to Sudden Unexpected Death in Epilepsy (SUDEP). Similar to SIDS/SADS, we know much can be done to prevent these deaths.

Neurology is referred to as the ‘Cinderella service’ of the NHS, facing geographical and socio-economic inequalities highlighted both in the 2016 Public Accounts Committee inquiry¹ and the Public Health England’s 2018 report on Neurology Mortality². This report flagged rising neurology deaths, (*increasing* by 39% between 2001-2014), despite general deaths rates *falling* by 6%; and that people with epilepsy facing deprivation are at least 3x more likely to die prematurely³.

Epilepsy deaths have remained static in recent years despite deaths from other conditions (such as SIDS) falling⁴. **Epilepsy-related maternal deaths** (in women who are pregnant or who have recently given birth) **are increasing**^{5 6 7}, and there have been multiple high-profile epilepsy deaths in people with learning disabilities in recent years. Research has demonstrated however that actions *can* be taken to reduce epilepsy risks, and therefore if adopted nationally could lead to a reduction in preventable epilepsy deaths^{8 9 10}.

Prevention of a health crisis is critical in improving NHS efficiency and **improving both quality of life and overall outcomes for people with epilepsy**. 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 suddenly, had been in contact with specialist services in the previous year. In 90% of the deaths, there was increased seizure frequency 3-6 months prior to death, half had a record of alcohol misuse, and a quarter had been taking drugs to treat depression or anxiety; all of which can be better managed if care is patient-centred¹¹, risks are openly discussed, and people are better supported to self-manage their condition.

¹ House of Commons Public Accounts Committee, [Services to people with neurological conditions: progress review](#), 2016

² Public Health England, report into [Deaths Associated with Neurological Conditions](#), March 2018

³ Thornton J. [Data show big rise in deaths of people with neurological disorders](#). British Medical Journal. 2018; 360.

⁴ 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.

⁵ Nashef L. [SUDEP and pregnancy](#). In: Hanna J, Panelli R, Jeffs T, Chapman D, editors. Continuing the global conversation. SUDEP Action, SUDEP Aware & Epilepsy Australia; 2014.

⁶ Knight M, Nair M, Tuffnell D, Shakespeare J, et al (Eds.) on behalf of MBRRACE-UK. [Saving Lives, Improving Mothers' Care - Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2013-15](#). Oxford: National Perinatal Epidemiology Unit, University of Oxford 2017

⁷ SUDEP Action, [A closer look at the MBRRACE Maternal Deaths Report](#), 2017.

⁸ Shankar, R., Newman, C., Hanna, J. et al, [Keeping patients with epilepsy safe: a surmountable challenge?](#) *BMJ Qual Improv Rep*. 2015;4

⁹ 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

¹⁰ Shankar, R. Henley, W. Boland, et al (2018), [Decreasing the risk of sudden unexpected death in epilepsy: structured communication of risk factors for premature mortality in people with epilepsy](#). *Eur J Neurol*, 25: 1121-1127. doi:10.1111/ene.13651

¹¹ 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

Preventing unnecessary and untimely deaths is possible by improving patient pathways, open communication of risk information and improving access to services. Risk management is vitally important to reducing avoidable epilepsy-related deaths, as highlighted in research & NICE Guidelines, but also via Prevention of Future Death reports, and Fatal Accident Inquiries held by those investigating sudden and unexpected epilepsy deaths¹².



Samantha died on the 4th December 2004. She was 25 years old and was seven months pregnant with our first grandchild. We only found out it was a little boy after she had died, and we were able to give him a name as she had chosen the name Regan for if it was a boy.

From 16, Samantha developed epilepsy. She only ever had a seizure as she was coming out of sleep and they only occurred two or three times a year. We made sure she slept in a low bed and that there was no furniture around, so she could be safe. She was determined to not let the epilepsy control her life and was in the final year of a nursing degree.

When she became pregnant the seizures became more frequent and she was referred to the local hospital. Only a week before we found her, she received a letter from the consultant to say she was a low-risk patient and had nothing to worry about.

The day we found her was the worse day of my life. Everything changed. Nothing meant anything anymore and it was dark all of the time. The first time we heard of SUDEP was when the coroner gave it as the cause of death. We had no answers and so many questions. As I started searching frantically for answers, I came across a website for Epilepsy Bereaved (now SUDEP Action). They returned my call and I was offered bereavement support. They also provided all the information I needed to understand more about SUDEP.

Solutions are available to help save lives & learn lessons to prevent future deaths

SUDEP Action has created a free [award-winning](#) clinical tool to support clinicians, both specialist and non-specialist, involved in epilepsy patient care to support discussion and management of these risks (the [SUDEP and Seizure Safety Checklist](#)). Currently used in varied clinical settings by over 700 clinicians UK wide, the tool helps clinicians work with their patients to identify risks and put actions in place to reduce them; enabling people with epilepsy to make informed choices about their care. Research has demonstrated these fatal risks can be reduced, and patients are empowered to make informed choices about their epilepsy through repeated use of the Checklist¹³. **Updated annually, the Checklist could in future signpost clinicians (and therefore patients) to the Pregnancy Prevention Programme (PPP); while also setting such discussions for those whose need to have them, within the context of mitigating wider epilepsy mortality risks.**

SUDEP Action's [Epilepsy Death register \(EDR\)](#) research project holds over 700 experiences from bereaved families and clinicians to **help learn lessons from deaths**. The EDR has shown many of those who died (including reports of women with epilepsy who were pregnant or undergoing medication changes for example) were not informed of epilepsy fatality risks and likely made uniformed choices about their care. **The EDR project could play a role in working with the MHRA on monitoring the impact of the PPP, by gathering information from bereaved families on epilepsy deaths in women with epilepsy either:**

- **Under the PPP and taking Sodium Valproate (or taking the AED but not aware of the PPP)**
- **Previously taking Sodium Valproate but medication was switched due to MHRA guidance**
- **Pregnant of who had recently had a baby and taking Sodium Valproate**
- **Who may have been taking Sodium Valproate but was medicine non-adherent or stopped taking their medication**

¹² Hanna J & Wannamaker BB. [Judicial reports on avoidable deaths](#). In: Hanna J, Panelli R, Jeffs T, Chapman D, editors. Continuing the global conversation. SUDEP Action, SUDEP Aware & Epilepsy Australia; 2014.

¹³ 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;

While some people with epilepsy require specialist clinical support for their conditions, community care can also play an important role in preventing epilepsy deaths. Better equipping GPs to recognise and manage epilepsy is essential, especially since the incentivised QoFs for annual epilepsy review, and pre-conception counselling for women with epilepsy were retired. **GP screening** for example, could be easily developed now to identify people at risk and cut deaths^{14 15}. By facilitating notifications within patient record systems to review risks among all patients, some preventable deaths may be avoided. **If community-based clinicians also play a vital role in implementation of the PPP, notification of both the need for risk reviews, and to review the PPP (when applicable), could help ensure women with epilepsy are receiving balanced information on all risks they may face, and can then make informed choices about their care.**

Technology can play a significant part in creating a **person-centered model of care** by improving engagement with, and access to; services for people with epilepsy, and also supporting their clinician with increased efficiency, knowledge and access to data.

Though not currently widely adopted, **Telehealth** is a solution to supporting engagement in healthcare for people with epilepsy, who can struggle to attend appointments. The SUDEP & Seizure Checklist was successfully piloted in this way; showing increased engagement by patients with their clinicians and promoting early clinical intervention when potentially fatal risks were flagged¹⁶. **This may be a model which could be encouraged to support the implementation of the PPP where engagement is patchy (especially if the PPP review was integrated as part of a wider epilepsy risks review).**

82% of neurology patients do not have a care plan, and the QoF for a yearly epilepsy review in General Practice was dropped without consultation in 2014. This was despite epilepsy mortality being known to have potential avoidability, and prevention of amenable mortality being a priority listed in the NHS Outcome Framework¹⁷. There is some clinical perception that care planning is time-consuming and without significant value; yet use of the Checklist and its patient version [EpSMon](#) (an **NHS Innovation Accelerator endorsed app** promoting self-management of risk^{18 19}) has demonstrated this needn't be the case. Integration and wider adoption of such systems as part of existing NHS technology could prove beneficial in the reduction of epilepsy deaths^{20 21}. **This holistic method of risk communication and review, could also act as a vehicle to support the implementation and education about the Pregnancy Prevention Programme.**

There is a shortage of neurologists and epilepsy specialists (across clinical settings) and those in post manage complex and ever-increasing caseloads. Many people with epilepsy are managed by clinicians in the community, or engage with healthcare in sporadic ways, so may be difficult to reach (eg: only picking up repeat prescriptions). Better **training and support for non-neurological specialists** helps encourage a holistic approach to care, helping patients effectively self-manage their conditions, in conjunction with more community-based healthcare support²². Research has also highlighted **Neurophobia** among medical students and non-neurology specialist clinicians, indicating that further training regarding neurology and prevalent conditions such as epilepsy, could benefit patient experience and engagement with services, as well as reduce burden on secondary services²³. **Given these factors, increasing awareness of the PPP across clinical settings could help increase uptake and implementation of the programme, as well as supporting non-specialists to engage with it, especially if they are the only touchpoint for some people with epilepsy.**

¹⁴ Ridsdale L. [Avoiding premature death in epilepsy: General practice is the place to start, and much can be done](#) BMJ 2015;350:h718.

¹⁵ Gales, A; [Applying the SUDEP Checklist to a General Practice Population](#); Learnings and Outcomes. RCGP, Bright Ideas, 2016.

¹⁶ Shankar, R., Newman, C., Hanna, J. et al, [Keeping patients with epilepsy safe: a surmountable challenge?](#) *BMJ Qual Improv Rep.* 2015;4

¹⁷ Rusk, L [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.

¹⁸ <http://sudep.org/article/epsmon-app-joins-nhs-innovation-accelerator-programme>

¹⁹ <https://nhsaccelerator.com/people-encouraged-go-digital-new-nhs-short-films/>

²⁰ 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

²¹ Page R, Shankar R, McLean BN, et al (2018) [Digital Care in Epilepsy: A Conceptual Framework for Technological Therapies](#). Front. Neurol. 9:99.

²² Ridsdale, L. [Closing the gap between neurologists and GPs](#), BMJ Opinion; 16/4/18

²³ Ridsdale L, Massey R, Clark L.; [Preventing neurophobia in medical students, and so future doctors](#), Practical Neurology 2007;7:116-123.



My daughter Katy was 21 when she died and had given birth to a much-wanted daughter just two weeks before her death. Katy was first diagnosed with epilepsy at the age of 7. The medication she was on originally caused weight gain which caused her severe anxiety when she went into her teenage years. She was unable to drive; her seizures also limited her choice of employment.

The year before she died she miscarried a much-wanted baby. She was told by a gynaecologist that her medication probably caused her to miscarry and this really upset her. When I was told the cause of Katy's death was SUDEP I had no idea what it was. I would advocate anything and everything possible to stop even one family going through what has happened to us.

As an organisation specialised in supporting bereaved families following often avoidable epilepsy deaths, SUDEP Action have observed **rising demands on NHS resolution of complaints and claims**. Improving **digital signposting** 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 could save the NHS significant time and funds as well as help reinforce the NICE guidance on supporting families bereaved by epilepsy²⁴. **SUDEP Action work with the Coronial service, Ministry of Justice and the Royal College of Pathologists to raise awareness of epilepsy mortality and in supporting families after a death. There may be opportunities to work alongside the MHRA to target these organisations further in highlighting both the Pregnancy Prevention Programme and the work of SUDEP Action, which can support their work on epilepsy-related deaths.**

²⁴ <http://www.nice.org.uk/guidance/cg137/chapter/1-guidance#information> (Section 1.3.14)