

Facing the issues with Epilepsy care in the UK: not just time and money saving but LIFE saving **A response to the Public Accounts Committee for their review into neurological services in the UK**

Background: The Issues

1. The number of people in the UK diagnosed with epilepsy has risen sharply in recent years, with an estimated 600,000 people living with the condition in the UK.(1)
2. Misdiagnosis of epilepsy is common (20–31% of patients are wrongly diagnosed and treated) and can have important consequences in terms of patient outcomes and cost to the NHS.(1)
3. Over 1000 people with epilepsy die each year in the UK, with this figure rising, despite 42% of epilepsy-related deaths being potentially avoidable.(2)
4. Epilepsy costs the NHS £1.5 Billion yearly – a figure which could be reduced from improved services, care & signposting to and collaboration with the third sector. (5) This public health burden of epilepsy is 2nd only to stroke (among neurological conditions).
5. Epilepsy is responsible for a high number of emergency department visits. Reducing non-elective epilepsy admissions may offer significant cost savings. The key is understanding which admissions are avoidable.(4)

The problems not being challenged:

Neurology Data:

At present there is no UK-wide register for epilepsy so it is unknown how many people with epilepsy there are in total or the numbers in many specific regions of the country. While data points such as the Neurology Intelligence Network and the NHS Fingerprint Profiles are available and appreciated by the third sector, there is uncertainty over their future & the data is quickly out of date if not maintained. Although some CCGs do maintain registers for people over 18yrs old, this provides only a snapshot and is not a consistent portrait of epilepsy across the UK. So, if there are only an estimated number of people with epilepsy in the UK, how are healthcare teams able or expected to provide accurate care for their patients with the condition?

This void in cohesive data makes it easier for people with epilepsy to slip through the gaps and drop out of the system; something SUDEP Action knows is a significant risk factor for epilepsy related mortality. A recent study in Cornwall investigated Cornish epilepsy deaths over a 9 year period found that 90% of epilepsy deaths showed deterioration of engagement with clinical services in the 3-6 months prior to their death, with only 20% of patients having engaged with an epilepsy specialist in the year previously (6). Coupling this with the fact that the number of epilepsy deaths in the UK still rising, it is even more critical to ensure people with epilepsy are known by healthcare teams, so measures can be put in place to monitor and manage their patients' epilepsy and epilepsy risks.

While statistics for epilepsy related deaths are available from the databases mentioned above and via public records such as the ONS, they can be buried amongst other statistics, incomplete or not grouped among other neurological conditions, reducing their efficacy. There are also no registries monitoring the impact of epilepsy deaths on those left behind, other than SUDEP Action's [Epilepsy Deaths Register](#). Although there is significant burden on the NHS for the care of people with epilepsy, the current failings result in additional burden supporting those who have been bereaved by epilepsy who require long term support and/or medication following the death of their loved one (which in some cases could have been potentially avoided if appropriate care management strategies and interventions had been put in place during their lifetime).

Adding to this issue is the lack of a 'red-flagging' system within General Practice to monitor their patients with epilepsy, as they currently do for those with stroke, heart disease or cancers. A recent article in the British Medical Journal raised this issue, that by following a similar method already available, a significant step up in care could be implemented for people with epilepsy across General Practice in the UK (7). Professor Ridsdale who led the pilot suggests:

"Whilst GPs are having funds cut for reviewing people with epilepsy, we know from this research that the risks for many deaths might be identified, and potentially reduced. Screening for risk has halved deaths from cervical cancer. Epilepsy causes more deaths and could benefit in the same way. If health services research funding is provided, an electronic risk assessment tool can be developed that would help GPs identify people at risk of death in epilepsy, just as they do in heart disease and cancer. If a risk-assessment tool were developed, and GPs funded to use it by the Quality & Outcome Framework, then premature deaths might be avoided, just as they have been for cervical cancer."



Erin

I could talk all day about Erin, telling you how beautiful, clever, kind, caring, popular, fun loving, annoying and special she was. Due to leave home for university, she was diagnosed with tonic-clonic seizures and put on anti-seizure medication following a nocturnal seizure. I remember the neurologist saying, 'This will just be a minor nuisance in Erin's life'. Five months later she had a second review, when her medication was reduced because Erin was worried about putting on weight and tiredness.

Erin was 19 when she died in her sleep some six weeks after starting University. She was getting used to university life. She was not taking her medication as she should have been; she was missing doses.

I first heard of SUDEP when it appeared on Erin's death certificate. The hospital had not contacted us and we had to search the Internet for death in epilepsy and discover what SUDEP was. We rang the neurologist and told him we were coming to see him. When asked, he explained that his practice was not to routinely inform about SUDEP because he did not want to cause distress and there was nothing Erin could have done.

We believed that Erin would have taken her condition more seriously, taken her medication properly and we could have supported her. At least she would have had the chance to. The risk might have been remote but it was the most serious risk she faced. Scottish national guidelines recommended SUDEP as essential information for people with epilepsy and in 2002 a judge determined in the Findlay Fatal Accident Inquiry that people with epilepsy should be told, unless there was a good reason not to.

Driven by the attitude of the neurologist, I decided to challenge. A complaint to the hospital was dismissed. I contacted the Scottish Public Services Ombudsman. Two years later the Ombudsman's final report concluded that as there was no record of the decision not to tell Erin, and because no written information was provided, the hospital had failed to provide patient-centred care. She wrote to the government urgently recommending research into communication about SUDEP - this is now being funded.

Independently, the Scottish Government ordered a Fatal Accident Inquiry (FAI) into Erin's death and into the death of another young woman, Christina, who also died from SUDEP. The two Inquiries, which have been joined together, have involved evidence taking over many months and will report during 2011.

I feel we have achieved what we set out to do; the hospital has recruited a specialist nurse and is providing written information. Regardless of the outcome of the FAI, we have been listened to and the arguments have been carefully considered by independent professionals. This has taken years now and at great personal cost to our family. It was not a matter of courage or bravery; it was about the need to make sense of what happened. As time passed I also came to appreciate that, in her name, changes could come about that would mean that Erin did not die for nothing.

Janet Casey

Care Planning:

By improving epilepsy data/records to help health professionals keep people with epilepsy engaged in the system, increased self-management & primary care interventions for epilepsy becomes a more manageable aim for the healthcare system to achieve. This is something greatly needed for epilepsy care, as highlighted by the 2012 and 2015 rounds of the National Audit of Seizure management in Hospitals (5).

With epilepsy currently costing the NHS £1.5 Billion yearly – it is vital that improved care services are put in place to not only lower this figure but also to relieve the burden epilepsy has on the already overstretched NHS. Increased collaboration with the third sector and the implementation of care tools and initiative that promote self-management and targeted clinical care such as [EpsMon](#) (a mobile app for people with epilepsy to self-manage & monitor their condition in between medical appointments) and the [SUDEP and Seizure Safety Checklist](#) (for clinicians to review & monitor their patients' epilepsy and wellbeing) offer potential relief.

While reducing spends and burden on the NHS are for many significant motivations to encourage NHS England to improve neurological care, the impact of the 1000 plus people with epilepsy who die each year, and on those suddenly left behind is SUDEP Action's driving force in asking the Public Accounts Committee to do all they can to hold NHS England to account for their failings and push for reform.



David

My cousin threw her arms around my neck. 'David's died,' she was repeating. It didn't register. She sobbed into my shoulder. What was she saying? 'David's died.' The words formed a sentence with meaning. What? It must be a joke. Who would joke about something like that? No one, I realised. Sickened, I pushed her away in horror and disbelief and started choking out the word, 'No, no, no...'.

On that terrible day in 2003, my brother's housemate arrived home to find David dead in the shower. David was just 30 – and he was my closest friend.

As David had a history of epilepsy, my parents and I imagined he had fallen during a seizure and hit his head, drowning in the running water. We had no idea that epilepsy can kill directly. David's autopsy found no obvious cause of death. It was something called SUDEP, the pathologist said. Something we'd never heard of before, something that kills without leaving a trace.

I've since discovered that David, though unique in so many ways, was typical of someone who dies from SUDEP. He was a young, fit and healthy man with epilepsy. He took medication to control his tonic-clonic seizures, but sometimes after a late night he'd forget to take it. My parents and I had seen him have a handful of seizures over the years, in bed or as soon as he got up, and we thought they occurred only when he missed a tablet or was extremely over-tired. It now appears David may have been having more seizures than anyone knew. He didn't remember the ones we witnessed, and it's likely more took place in bed. His friends have since mentioned either seeing seizures occurring or noticing suspicious bruises. David swore others to secrecy, both because of the stigma associated with epilepsy and his reluctance to modify his fun-filled and friend-filled lifestyle. He worked long hours, travelling between states, and he studied hard and socialised harder.

I know now what David's doctor had never told him – that the risk of SUDEP is considered low for people whose epilepsy is well controlled. Preventing seizures, by complying with medication or getting enough rest for example, may reduce the risk. I wish David had been given this knowledge. And so my wonderful friend, my smart, entertaining, charismatic brother with his wide grin and infectious enthusiasm, was given no choice about modifying his behaviour, and we'll never know if that choice may have saved his life.

David's Sister

Improving Neurology Commissioning:

Only 22% (1 in 5) Health and Wellbeing boards in the UK have epilepsy as a specified section of their Joint Strategic Needs Assessments (JSNAs), with 77% stating they had no plans in place of any intention to do so; even though in a significant number of NHS England Commissioning for value reports, epilepsy was noted as an area for potential improvement among many CCGs (9). Without appropriately planned for and commissioned epilepsy services, there is a lack of cohesion across UK care, adding to the inconsistencies noted in care and good practice across the country. The adoption and promotion of the [Epilepsy Commissioning Toolkit](#) could provide a ready-made answer to this challenge. The Toolkit is a resource created by leading epilepsy charities (SUDEP Action included) and epilepsy/neurology experts for CCGs to provide best practice information, advice and resources for the commissioning, updating and improvement of epilepsy care services.

The question SUDEP Action would like the Public Accounts Committee to ask on our behalf:

With the voluntary sector and many clinicians striving for and supporting initiatives to help the healthcare services improve and standardised epilepsy care across the UK, why are NHS England and the Department of Health not at least equalling this commitment in order to not only save time and money, but the lives of hundreds of people with epilepsy each year?

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