

## **Key Facts**

### **STATISTICS & SUDEP**

- Epilepsy accounts for more deaths now than cervical cancer and is in the top ten of all causes of amenable mortality (7).
- A myth persisted in the epilepsy community itself as recently as the 1990's that epilepsy was a benign condition, from which people did not die. This is not true.
- According to the Official Public Records, in 2013 there were 1041 epilepsy-related deaths in England & Wales, 105 in Scotland and 41 in Northern Ireland (2) It is thought that around 50% of these are from SUDEP (6)
- SUDEP (**S**udden **U**nexpected **D**eath in **E**pilepsy), is the most common cause of epilepsy-related death, being twenty fold higher than in the general population. SUDEP is when an otherwise healthy person with epilepsy dies without warning and no other cause of death can be found at post mortem.

### **MORTALITY RATES**

- Epilepsy deaths have remained static in recent years despite deaths from other conditions (such as SIDS) falling (6).
- Epilepsy-related maternal deaths (in women who are pregnant or who have recently given birth) appear to be increasing (3).
- In a 2013 report into epilepsy mortality, the RCPCH (Royal College of Paediatrics & Child Health) noted 173 incidents in childhood of deaths and prolonged seizures were in children whose first seizure occurred under 4years old (5).

### **AVOIDABILITY & RISK**

- The National Sentinel Audit of Epilepsy Deaths in 2002 found that 42% of deaths were potentially avoidable (4).
- Patients who have been seizure-free in the previous 12 months have also been found to have a 22% reduced risk of dying (1). This can be achieved through:
  - improved seizure control by providing people with epilepsy access to treatments,
  - supporting adherence to medication
  - encouraging lifestyle changes which reduce their risks.
- Children with multiple comorbidities (medical conditions) and those classed as ethnic minorities and more deprived socio-economic areas were also found to be of high risk of mortality which could potentially have been avoided with prior intervention.
- People with mental health problems and those that misuse alcohol and drugs are at high risk of epilepsy-related deaths and interventions are required to reduce their risks. Access to services supporting mental well-being and addiction services are important steps in this process.
- Risk management has been highlighted as vitally important to reducing avoidable epilepsy-related deaths, both in research & reporting but also via Prevention of Future Death reports and Fatal Accident Inquiries held by those investigating sudden and unexpected deaths (4).
- People with epilepsy want information on risk (14) and there is some evidence that communication of risk is very slowly improving (15).
- GP screening could be developed now to identify people at risk and cut deaths (1, 7, 12, 17).

**Raising awareness of epilepsy mortality & risk – it's a hard job but one that cannot be avoided**

SUDEP Action is the working name for Epilepsy Bereaved, which was founded in 1995. They led a world-wide movement which has established the facts on epilepsy mortality and the potential for avoidability. They currently work with leading research teams both in the UK and internationally to tackle epilepsy mortality by supporting investigations into:

- epilepsy risk,
- the cause of SUDEP & epilepsy-related deaths and
- the search for a proven intervention of all causes of mortality.

They also contribute their expertise on mortality issues in working with the other epilepsy charities and as part of the Neurological Alliance.

**SUDEP Action and their new branch SUDEP Action Scotland, is the voice of over 1000 bereaved families in the UK and asks MPs to:**

- **Raise awareness of the public health burden of epilepsy-related deaths**
- **Promote the urgent need for development of screening of risk in primary care**
- **Raise awareness of the need for the bereaved to access recommended support**

**Public health burden of epilepsy-related deaths**

- The public health burden of SUDEP alone is estimated as second only to stroke amongst neurological conditions (4). An estimated 1.16 per 1000 people with epilepsy die suddenly each year.

This puts unnecessary strain onto the already struggling NHS, particularly in the under-resourced and under pressure Neurology departments and General Practices. A new BMJ editorial on epilepsy mortality (7) has highlighted this burden and has been welcomed by doctors who report neurology waiting times are long; that there is pressure to discharge patients from review who are relatively stable and that GPs QOF payments have been reduced for epilepsy (10) – all impacting on the care for those with epilepsy.

- In their current publication of the NHS Outcomes Framework, the Government prioritises in public the prevention of amenable mortality, making it a core focus for NHS services. Epilepsy mortality also features in new NICE Standards as well as NICE Clinical Guidelines.

However, the continuing shake-ups and reshuffling of primary and specialized care for patients with epilepsy is having a detrimental impact on outcomes and will continue to add to the burden unless measures are put in place to ensure standardised levels of care that meet these guidelines effectively.

**Interventions are needed for change to happen**

- Screening for risk is needed in primary care if epilepsy is to benefit from reductions in death seen for other causes of mortality (7).

Research has highlighted the need for risk management and reduction for people with epilepsy and for the introduction of interventions and strategies at a primary care level. For example, a 2011 study suggested that risks of fatality could be flagged up in general practice with development of existing NHS systems and infrastructure (1).

- In a research project based across the South West of the UK exploring epilepsy risk, it was found that only 20% of people with epilepsy who died suddenly had been in contact with specialist services in the previous year (9). For those with tonic-clonic seizures (a risk factor for SUDEP), in about 90% of the deaths there was a noted increased in seizure frequency 3-6 months before their death. One half had a record of alcohol misuse, and a quarter had been taking drugs to treat depression or anxiety.

Being open and honest with patients about their level of risk, allows them to make educated choices as to their ongoing care and management of their condition. However, primary care lacks confidence with epilepsy (6) and specialist services do not routinely discuss risk with patients (11). Many of the bereaved families who contact SUDEP Action support the view that people with epilepsy should be made aware of the risks: "There is nothing worse than losing a child but to feel that [our son] did not have all the information he needed to make informed decisions makes it especially cruel." (13)

Information resources such as SUDEP Action's 'Be Smart Be Safe' and 'SUDEP – Understanding your risks' leaflets are some of the resources available to patient organisations in UK and worldwide to support these discussions, but practical support tools for professionals are also needed to translate research into practice.

In the UK, progress on epilepsy-deaths stops short of any proven intervention, but there are initiatives that, if promoted and supported, are on the cusp of doing this.

### **The needs of the bereaved – their voices should be heard**

- The NICE Guideline states: 'where family and/or carers have been affected by SUDEP, healthcare professionals should contact families and/or carers to offer their condolences, invite them to discuss the death and offer referral to bereavement counselling and a SUDEP support group'. (16)

Yet, this is not happening and we are aware that many people bereaved by epilepsy find no specialist support and are often left struggling to understand what happened and why. Early intervention after a sudden death is known to help with the long term effect of grief and often people look for ways to use their experience to help others bereaved in a similar way.

- 2013 saw the launch of the Epilepsy Deaths Register, a central reporting system for epilepsy-related deaths, endorsed by government and UK policy makers.

Since the register was launched in 2013, it has received over 340 reports containing vital information for researchers and a database of families willing to be contacted for research. The register not only sheds light on epilepsy deaths and ways that risks can be minimised, but also helps us understand more about their impact and how to develop services for people bereaved in this way.

- The unexpectedness of SUDEP, accidents; suicide and other causes of epilepsy-related death impacts on how people deal with grief. The bereaved families are robbed of the chance of saying goodbye; of saying the things that they always wanted to, and didn't. They are robbed of opportunities, future hopes and dreams (8).

The Epilepsy Deaths Register is an important outlet for most families. It is somewhere to leave their story; a way to feel that the information they give will be used for the benefit of others for years to come. The impact of these deaths is not yet fully understood, but in our experience is captured by one of the families reporting to SUDEP Action's Epilepsy Deaths Register:

*"The physical pain and guilt are overwhelming, and we are only just becoming able to talk about him to each other after 16 months has passed. The impact is total and devastating, and has affected both the physical and mental health of the whole family".*

- Bereaved families who have provided information about an epilepsy-related death to the Epilepsy Deaths Register have shown that the top three things needed by those bereaved are:
  - Ways to find answers to their questions
  - Someone to talk to and
  - Being able to learn more about epilepsy-related deaths (7).

These are all services SUDEP Action provides for those bereaved by epilepsy. They have been doing so for the past 20 years as the only UK charity specialising in epilepsy bereavement. It is vital however, that those bereaved by epilepsy are made aware of the services available to them for support shortly after a death as this can influence the impact on their future mental wellbeing.

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