

## *THREE people die from epilepsy each day in the UK*

### *At least ONE death could have been avoided*



*The excess death rate in epilepsy is 10 times that found in asthma<sup>1</sup>*

*In chronic epilepsy the main cause of death is SUDEP – Sudden Unexpected Death in Epilepsy is a syndrome where a person with epilepsy dies suddenly and no other cause of death is revealed<sup>2</sup>*



*Adults with epilepsy have a sudden death rate 24 times higher than the background population*

*SUDEP occurs in people with active epilepsy including those reporting only one seizure in the previous year*



*The group most at risk of sudden death are young people between the ages of 20 and 40*

*Epilepsy Bereaved estimates that there are at least 22,500 'lost years' per annum due to SUDEP (assuming average age of death from SUDEP is 30 years and average life expectancy is 75 years)*

**Our Manifesto for Life and Action Plan for MP's is focused on priorities for prevention and management of avoidable deaths.**

### **A Manifesto for Life**

- 1. A care plan and case management for people with epilepsy who are not known to be seizure-free**
- 2. Communication of risk and ways to reduce risk**
- 3. A national standard of investigation into epilepsy deaths and monitoring of deaths**
- 4. Post death access for the bereaved to specialist information and support**

### **Action Plan for MP's**

**Seek a response from government on avoidable deaths from epilepsy**

**Support Epilepsy Bereaved- The charity will be organising a meeting for MP's following the summer recess**

**Ask your PCT and SHA to respond to our Briefing for Commissioners (available at [www.sudep.org](http://www.sudep.org))**

(Please keep us informed of any response)

Epilepsy Bereaved (EB) exists to prevent avoidable epilepsy-related deaths and to support families affected.

We work closely with researchers and are currently collaborating with Kings College Hospital NHS Foundation Trust and Kings College, London in a bid to the National Institute for Health Research aimed at supporting strategies to reduce risk. EB is a stakeholder in the implementation of the recent reforms to the Coroners system. We support Joint Epilepsy Council and All Party Parliamentary Group on Epilepsy requirements of prompt access to high quality epilepsy services through implementation of NICE guidelines.

#### **Contact Epilepsy Bereaved**

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#### **Selected Key References-**

1 Hanna et al, 2002 The National Sentinel Audit of Epilepsy Related Death, The Stationary Office, London.

4 ALL Party Parliamentary Group on Epilepsy 2007. The human and economic cost of epilepsy in England.

20 Kennelly, C. & Riesel, J. 2002. Sudden death and epilepsy – the views and experiences of bereaved relatives and carers. Epilepsy Bereaved

**A full reference list is available on [www.sudep.org](http://www.sudep.org)**

## 1. Care Plan and Case Management for people with active epilepsy

Medical knowledge of the epilepsies has improved greatly over the years and effective treatments have been developed yet the provision of services and access to them has never been adequate.

The most significant risk factor for SUDEP is the occurrence of seizures involving a lack of consciousness. Therefore the better seizures are controlled, the more the risk is minimised.

The NICE National Sentinel Audit of Epilepsy Related Deaths, led by Epilepsy Bereaved drew attention to this important problem. The Audit revealed that; **42% OF DEATHS WERE POTENTIALLY AVOIDABLE.**

### The Audit found:

**A lack of management plans and poor record keeping.**

**41% with no record of monitoring in two years before death.**

**A lack of re-referral.**

**Significant problems of access to and quality of care.**

**Epilepsy management frequently did not meet national criteria.**

**There were deficiencies in communication between clinical staff and with patients and families both in life and after death.**

**In 99% of deaths there was no recorded discussion of risk.**

### Where are we now?

Progress has been made with the development of NICE Guidelines on the Epilepsies (2004) and epilepsy is now included in the GP Contract. However, an inquiry by the All Party Parliamentary Group on Epilepsy on the human and economic cost of epilepsy in England in 2007 found that the National Health Service was failing people with epilepsy;<sup>5</sup>

**69,000 people were living with unnecessary seizures**

**74,000 people were taking drugs that they did not need.**

**£189 million was needlessly spent each year.**

The APPGE report found evidence of non-implementation of NICE and problems with the quality of review process at primary care. Primary Care Trusts report finance and other priorities as barriers to implementation. Furthermore, most trusts in England still fall far short of some of the key recommendations made by NICE in 2004 and subsequently reinforced in the 2008 epilepsy commissioning guide.<sup>6</sup>

The number of reported deaths from epilepsy are rising from 1071 in 2007 to 1105 in 2008.<sup>7,8,9.</sup>

Epilepsy is also responsible for a high level of emergency admissions. Epilepsy scored the highest for the percentage of patients who had two or more emergency admissions for the same condition in the year 2006/07.<sup>10</sup>

The EB Priority for improving standards of care is aimed at the NHS focusing attention on people with epilepsy who are at risk of A & E Admission and Death. This would involve the introduction of a case management approach supporting people who have experienced a seizure in the last year which involved a loss of consciousness.

A Fatal Accident Inquiry was held in 2007 into the sudden death of a young woman of 17 who had four to five seizures yearly, varying in frequency and severity, but there was no annual review or re-referral for specialist care.

Sheriff Taylor suggested that all the key issues would have been addressed if a care plan, '...shared or otherwise' had been produced, and '... it might have saved her life' <sup>11</sup>

## 2. Communication of risk

The NICE Audit of Epilepsy Deaths found that in 99% of deaths there was no recorded discussion of risk.

NICE guidelines recognise the importance of seizure freedom and being aware of the dangers of night seizures and recommend that SUDEP should be part of essential information to patients following diagnosis.<sup>12</sup>

Whilst epilepsy specialists and epilepsy specialist nurses are most likely to include communication of risk,

there is significant evidence of non implementation of national guidelines on discussion of risk with patients.<sup>13,14,15</sup>

In the short-term the devolved administrations in Scotland and Wales have funded a SUDEP booklet to provide patients with accurate information based on what is known about SUDEP (Copies are available from Epilepsy Bereaved).

It is important that people with epilepsy are allowed to live as normal a life as possible. However, individuals are entitled to know the facts about their condition. Information that epilepsy can present acutely and sometimes fatally is part of the information package that needs to be shared with people with epilepsy so that they can make decisions on a day to day basis about lifestyle and management of their condition.<sup>16</sup>

People who are diagnosed with, for example, diabetes or heart problems, are made aware of the risk of death if their condition is not well managed. Epilepsy should be in this category and dealt with in the same way.

### Research

NICE Guidelines<sup>17</sup> and the Scottish Public Health Ombudsman<sup>18</sup> recommend further research on communication of risk of SUDEP.

During 2010 Kings College, London and Epilepsy Bereaved are co-applicants to the National Institute for Health Research for a project on Prevention of avoidable death and injury in Epilepsy: Patients and carers perceptions, causes, and coaching to reduce Risk.

EB is funding research into the General Practice Database to identify and confirm risk factors in people dying from epilepsy compared with a control group.

**Research into the cause and prevention of SUDEP continues to be urgent. Eight years on from the Audit, our understanding of sudden death in epilepsy is greater, but we still need to reduce the number of such deaths.**

**We must continue to promote research into this neglected medical syndrome.**

## ERIN'S STORY

Erin, aged 19, was in her sixth week at university. She had been diagnosed with epilepsy seven months previously and was taking anti-epileptic medication.



The drug began to interfere with her contraceptive pill and as a result she asked her GP for a different one. Meanwhile, she was gaining weight and feeling tired. Erin may have taken the decision to stop taking her anti-epileptic medication for a while or she may simply have forgotten to take it.

Either way, had Erin been informed about the risk of SUDEP, she may have been able to make a more informed choice about taking her medication if she knew epilepsy could prove fatal. Erin's family, boyfriend and friends are convinced that she would have continued her medication above all else.

Erin died in her sleep from Sudden Unexpected Death in Epilepsy (SUDEP)

The Scottish Public Health Ombudsman has reported on this case and during 2010 there will be a Fatal Accident Inquiry court hearing.

## 3. National Standard of investigation

The NICE Audit found a high level of post-mortem investigation into epilepsy-related deaths, but that only 13% of epilepsy-related deaths were adequately investigated and reported. The implementation of the Coroners Act 2009 will include the development of standards in some areas. Epilepsy urgently needs to be one of the priority areas.

There is no national monitoring of epilepsy deaths, but other investigatory bodies continue to highlight the issues identified in the NICE Audit in 2002:

We hope recent reforms to the Coroners system together with the Child Death Overview Panels will bring an increased profile to avoidable deaths in the future.

## 4. Post-Death service for the bereaved

NICE state that 'Where families 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'.<sup>19</sup>

Bereavement affects people uniquely, but there is evidence that sudden bereavement can complicate the grieving process and early intervention can reduce associated morbidity.<sup>20,21</sup>

Parallels have been drawn between the trauma of cot death and SUDEP. This is because most individuals die from SUDEP during sleep and because families experience bewilderment, isolation and prolonged distress as the death is sudden and unexpected. Research into SIDS found acute distress and long-lasting damage, in particular; relationship conflict, difficulties with surviving children, and anxiety about future children becoming victims.<sup>22</sup>

In both SUDEP and SIDS the death is wholly unexpected, the cause is unknown and families face the bewildering interventions of police, a post mortem examination, ongoing enquiry, and uncertainty. Some families experiencing SUDEP have other family members with epilepsy.<sup>23</sup> Like SIDS families, they can fear a recurrence.

The impact of SUDEP can be exacerbated if families were not aware that epilepsy can be fatal. Further, unlike SIDS which is well publicized, SUDEP may create an additional burden on the grieving family in explaining the death to the police, family, friends and the local community who are ignorant of SUDEP.<sup>24</sup>

Following a sudden death from epilepsy, bereaved relatives have reported difficulties in accessing medical professionals, particularly the specialist responsible for managing the care of the person with epilepsy.<sup>25</sup>

Epilepsy Bereaved is the only organisation providing specialist SUDEP support and is currently funded mainly by bereaved families. The charity supports about 100 newly bereaved people each year and ongoing support to over 1000.

In 2009 the majority of referrals were from the internet and other epilepsy organisations reflecting a lack of referral from statutory agencies or professions. The support needs have increased in complexity from requests for epilepsy-related information and SUDEP peer group (identified by College of Health Research in 2002)<sup>26</sup> to more complex information requests on SUDEP and requests for specialist advocacy in negotiating a range of agencies following a death including coroners and the NHS.

The Coroners Act 2009 includes a Charter for the Bereaved, but EB would like the implementation of these reforms to include information and training to those involved in the investigation of epilepsy deaths on sign-posting to Epilepsy Bereaved.

**Epilepsy Bereaved recommends our Manifesto for Life and asks you to take action now.**

## Becky's story

*"We lost our lovely young daughter Becky in May 2004. She was a victim of Sudden Unexpected Death in Epilepsy. Despite having suffered seizures since September 2001, she was only finally diagnosed a few days before she died.*



*We had no knowledge of SUDEP and in fact heard the term for the first time some three days after Becky died.*

*Nothing can bring Becky back to us but, in her memory, we support the efforts of the charity Epilepsy Bereaved. They were there for us following our enormous loss and actively promote the raising of awareness of both Epilepsy and SUDEP"*

Roger Scrivens, father of Becky who died of SUDEP in May 2004, three months short of her 12th Birthday.