

THREE PEOPLE DIE FROM EPILEPSY EACH DAY IN THE UK

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 Ombudsman has reported on this case (SPSO, March 2009) and during 2010 there will be a Fatal Accident Inquiry court hearing.

Epilepsy Bereaved exists to prevent avoidable epilepsy-related deaths and to support families affected. The NICE National Sentinel Audit of Epilepsy Related Death (Hanna et al 2002), led by Epilepsy Bereaved revealed that;

42% OF DEATHS WERE POTENTIALLY AVOIDABLE.

We are collaborating with Kings College Hospital NHS Foundation Trust and Kings College, London in a SUDEP research initiative aimed at producing an evidence base to support action to prevent unnecessary deaths.

EB has been a stakeholder and supports the recent reform to the Coroners system which aims to bring the attention of the NHS to individual avoidable deaths.

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. PCTs report barriers to implementation as finance and other priorities. 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 (Epilepsy Action, 2009).

Epilepsy Bereaved priorities for Commissioners are the recommendations from NICE that the epilepsy care pathway include;

- 1. A management plan for each person with epilepsy**
 - 2. Communication about Risk**
- Post death management to include;
- 3. An invitation to meet with the bereaved family**
 - 4. A letter of condolence and signposting of people bereaved through epilepsy to SUDEP support.**

Implementation of these areas would be cost-effective requiring resource dedicated to coordination, training and information.

Deaths from epilepsy

The excess death rate in epilepsy is 10 times that found in asthma (Hanna et al, 2002).

In chronic epilepsy the main cause of death is SUDEP – a sudden unexpected death in people with epilepsy, with or without evidence of seizure, where no other cause of death is revealed at post-mortem (Nashef et al, 1997)

Priority One: A Management Plan

The most significant risk factor for SUDEP is the occurrence of seizures-particularly tonic-clonic). Therefore the better epilepsy is controlled, the more the risk is minimised.

The major findings of the National Sentinel Audit of Epilepsy-related death were that nearly all deaths were in people not known to be seizure-free and that;

→42% of deaths were potentially avoidable.

→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.

In 2003 the Chief Medical Officer and NICE wrote to Primary Care Trusts recommending that local NHS clinicians and organisations should establish or review policies and practices regarding the management of epilepsy & epilepsy-related death.

Where are we now?

Progress has been made with NICE Guidelines on the Epilepsies, however the number of deaths are increasing; **Reported deaths from epilepsy in the UK rose from 1071 in 2007 to 1105 in 2008** (NISRA, 2009. ONS 2009, General Register Office for Scotland, 2009)

The 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 and that a much improved service can be delivered at the same time as making significant savings (APPGE, 2007). For example;

→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 presented evidence of non-implementation of NICE and problems with the quality of review process at primary care.

The urgent need for improved monitoring of people with epilepsy is reflected in the findings of a Health Needs Assessment for Long Term Neurological Conditions in North East England which reported on the number of episodes where neurological conditions were the main reason for admission 2007/08. This indicated that admissions due to epilepsy were the second largest in the region.

Furthermore, epilepsy scored the highest for the percentage of patients who had two or more emergency admissions for the same conditions in the year 2006/07 (Whiston et al, 2009).

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

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' (Taylor, 2002,18).

Recent reforms to the Coroners system together with the Child Death Overview Panels are likely to bring an increased profile to avoidable deaths in the future.

The Confidential Enquiry into Maternal and Child Health (CEMACH) 2007 stated that:

“SUDEP is known to be more common in patients who do not take prescribed anticonvulsants and many women are reluctant to take anticonvulsants when pregnant or breast-feeding for fear of harming their babies”.

Case study from CEMACH;-

A woman died from SUDEP in mid-pregnancy. She had had epilepsy with tonic/clonic seizures for many years but had intolerable side effects from anticonvulsants which did not seem to affect seizure frequency. Because of this she had not taken any anticonvulsants for a year and was reluctant to try newer ones because she was concerned about teratogenicity.

Although she attended the antenatal clinic at her GP's surgery very early in pregnancy she was not able to be fully "booked" until four weeks later because the midwives were too busy. Although she was referred to a neurologist she did not attend her appointment because she did not receive the appointment letter. As she was having regular fits she was referred again to the neurologist but, the repeat appointment was delayed by more than one month and she died before she could attend.

Priority Two: Communication about 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 (Stokes et al, 2004).

There is significant evidence of non implementation of national guidelines on discussion of risk with people with epilepsy (Morton et al, 2006. Lewis et al, 2008. Brodie & Gregory, 2008. Gayatri, N.A. et al, 2010).

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 particularly as this may affect important day-to-day decisions.

When giving general guidance on epilepsy, information on SUDEP can be given in the context of other risks from seizures e.g. accidents. Being aware of risk factors and ways to reduce them may help people with epilepsy and their carers to manage their condition so that they can get on with their life.

A wide range of information for people with epilepsy, health professionals, Strategic Health Authorities, Primary Care Trusts, Coroners etc is available from Epilepsy Bereaved.

NICE Guidelines (2004) recommend further research on communication of risk of SUDEP.

During 2010 Kings 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.*

As part of the SUDEP Research Initiative with Kings College, London and King's College Hospital, EB is funding research into the General Practice Database to identify risk factors in people dying from epilepsy compared with a control group.

Priority 3: An invitation to meet with the bereaved family

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'* (Stokes et al, 2004).

Following a sudden death from epilepsy, bereaved relatives need information from medical professionals to help them come to terms with the death. However they have reported difficulties in accessing medical professionals, particularly the specialist responsible for managing the care of the person with epilepsy (Kennelly et al, 2002).

Priority 4: Sign-posting the bereaved to SUDEP support

Bereavement affects people uniquely, but there is evidence that sudden bereavement can complicate the grieving process and early intervention can reduce associated morbidity (Raphael 1977; Yates, Ellison and McGuinness 1990).

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 Sudden Infant Death Syndrome found acute distress and long-lasting damage, in particular; relationship conflict, difficulties with surviving children, and anxiety about future

children becoming victims (Woodward 1985).

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 (Kennelly and Riesel 2002). 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 (Sudden Unexpected Death in Epilepsy: A global conversation 2005).

The National Audit recognised the need for support to the bereaved (paras 1 b & c) and the 2004 NICE guidelines further recommended referral of families affected by SUDEP for specialised SUDEP support.

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

Epilepsy Bereaved is the only organisation providing specialist SUDEP support. The charity supports about 100 newly bereaved people each year and ongoing support to 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, Kennelly & Riesel, 2002) 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.

Epilepsy in context

The outlook for most people with epilepsy is very good. Evidence suggests that with a clear understanding of the condition and good management of seizures, the risk of SUDEP can be minimised (Hanna et al. 2002).

Our knowledge of the condition 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 (CMO, 2001).

Equity of services with other long-term conditions would require a significant investment in epilepsy services.

It is also clear, however, that a number of NICE guidelines, which would **not** require significant funding to implement, are currently not put into practice.

In conclusion, Epilepsy Bereaved recommends that the following improvements ought to be progressed as a matter of priority.

1. **A management plan for each person with epilepsy**
2. **Communication about Risk**
3. **An invitation to meet with the bereaved family**
4. **A letter of condolence and signposting of people bereaved through epilepsy to SUDEP support.**

Epilepsy Bereaved can assist in developing training programmes and provide information and resources.

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