

# South Wales East Regional Committee

## SWERC(2) 01-07 (p2)

<b>Date:</b>	9 <sup>th</sup> March 2007
<b>Venue:</b>	Pontypool Active Living Centre, Pontypool
<b>Title:</b>	Epilepsy Bereaved

## Epilepsy Services - Sudep And Epilepsy-Related Deaths

### 1. SUDEP (Sudden Unexpected Death in Epilepsy) and Epilepsy Deaths

There has been a steady increase of reported epilepsy deaths each year from 849 in 1993 to 1174 in 2005. The majority of these deaths are SUDEP (Sudden Unexpected Death in Epilepsy) which like SUDI (Sudden Unexpected Death in Infancy) and SADS (Sudden Arrhythmia Deaths) tend to occur out of the blue in the otherwise healthy young population and are traumatic deaths for families.

	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
England and Wales	753	762	785	832	816	842	867	845	934	960	1088	990	1050
Scotland	77	89	101	113	99	99	115	99	114	120	134	96	93
N Ireland	19	22	23	26	19	22	17	23	23	26	27	32	31
UK total	849	873	909	971	934	963	999	967	1071	1006	1249	1118	1174

Source: General Registrars for England and Wales; Scotland and Northern Ireland, Annual Reviews, 1993-2005

### 2. Families affected by SUDEP and other seizure deaths in Wales

Statistics are not reported separately for Wales, but there are approximately 40 epilepsy-related deaths in Wales each year. Epilepsy Bereaved exists to reduce risks of SUDEP through research and education and currently provides information and support services to 36 families in Wales.

Although NICE guidelines recommend that families are signposted to SUDEP support, in Wales this does not appear to be implemented. Coroners and GPs are likely to be the agencies most engaged with families at this time, yet we have evidence of very low levels of awareness or interest in SUDEP amongst these agencies. Firstly, we sent a letter and questionnaire to all Coroners in Wales but only 2 of 11 responded. Secondly, 10% of all GP practices in Wales responded to a questionnaire but 98% had never attended any training on SUDEP and 85% positively requested training in this area.

Whilst there is a statutory obligation on the police to assign a Family Liaison Officer and provide specialist information packs to relatives bereaved through murder or road deaths, no provision is made at all for victims of medical accidents. Epilepsy Bereaved would like some support from the Assembly in engaging with Coroners and GPs in order that bereaved families can easily access our services.

Families accessing our service are provided with tailored information and support including national good practice on investigation of epilepsy deaths; NICE epilepsy guidelines. This is vital information to some families given the evidence from the National Audit of Epilepsy deaths that 87% of post-mortems were considered inadequate; that GPs were not referring all sudden deaths to the Coroner and that 400 of 1000 deaths were potentially avoidable. Across the UK, 208 bereaved families were active in 2006 in raising awareness of SUDEP through complaints or education and awareness. Whilst there is a statutory obligation on the police to assign a Family Liaison Officer and provide specialist information packs to relatives bereaved through murder or road deaths, no provision is made at all for victims of medical accidents.

### **Some examples of families we help in Wales**

Brenda Burt and her family became involved with Epilepsy Bereaved after the death of her daughter Joanne a staff nurse aged 26, who died of SUDEP on 18 August 2005. The family knew nothing of SUDEP despite Brenda working with people with learning difficulties, many of whom have epilepsy, and her other two daughters also being staff nurses. Through involvement with Epilepsy Bereaved they have come to realise that the risks associated with epilepsy were not widely known, and that even within the medical profession staff were often unaware that epilepsy could be fatal. The family have found it helpful attending charity meetings where they have been able to discuss their loss with others in a safe environment, helping to normalise their grief feelings. The sisters Leanne and Claire have also been able to access sibling support. The family have become active in campaigning for better epilepsy services. Being members of Epilepsy Bereaved has given them a sense of purpose at this difficult time.

Christine & Graeme Muggeridge became involved with Epilepsy Bereaved after the death of their daughter Claire aged 17, who died of SUDEP on 22<sup>nd</sup> February 2004. Claire died hours after her second seizure, before being diagnosed. Christine and Graeme took their daughter to the A&E department of their local hospital after her second seizure, she was admitted and due to see a consultant the next morning. She appeared back to her normal self when her parents left her in the early hours of the morning but, when they returned 7 hours later she had died. Christine and Graeme have accessed support and information from Epilepsy Bereaved and have found that attending local meetings has been beneficial to their grieving process. They are determined that Claire's death should

mean something and as members of Epilepsy Bereaved have campaigned to improve access to adequate services and to increase the number of specialist staff.

### **3. Health policies aimed at preventing epilepsy-related deaths**

Rhodri Glyn Thomas (Carmarthen East and Dinefwr):

Will the Minister confirm whether the directive on epilepsy services is the action plan in response to the Audit on epilepsy deaths 2002. (WAQ48695)

Brian Gibbons: The Service Development and Commissioning Directives for Epilepsy will include a number of key actions to help improve the health and quality of life of people living with epilepsy. The work was initiated in response to a number of issues including the growing pressures on services and the National Sentinel clinical Audit of Epilepsy-Related Death. Prior to Designed for Life this work was referred to as a policy and action plan but has developed into commissioning directives taking account of the growing agenda to tackle chronic conditions in Wales.

Experience in England on the implementation of the Government Action Plan on Epilepsy is that most PCTs have reported financial constraints in being able to implement the Plan. We are pleased that an action plan is due to be published shortly, but need reassurances that there are levers in place that will mean that in practice the plan in Wales will not suffer the implementation deficit experienced elsewhere in the UK.

### **3. Use of the medico-legal system to drive service improvements.**

In Scotland significant advances in development of epilepsy services occurred following the Fatal Accident Enquiry into the death of Colette Findlay aged 17 from SUDEP. The FAI process found serious public interest concerns raised by non-implementation of national epilepsy guidance and was an important catalyst in Scotland to the funding of epilepsy clinical networks. In England, Wales and Northern Ireland bereaved families have not been able to make use of the coronial system to drive improvements in service delivery because the system is designed to identify whether deaths are natural or unnatural. The Smith Report into the Harold Shipman incident and the Luce Report of the Fundamental Review of Death Investigation and Certification recommended a major overhaul of the archaic system and the introduction of a nationally funded system for coroners. The Government proposals for reform (Draft Coroners Bill 2006, June 2006) have rejected calls for a national coroners' service, opting instead for a local service headed by a chief coroner and have been widely criticised. The requirement of local resourcing (by local authorities and the police) of Coroners is a major problem as it will not only hinder accountability to a Chief Coroner or any national standards, but will continue the serious funding problems in the existing system. Most significantly there are endemic staff shortages in police, coroner, pathology, hospital and community bereavement and trauma services. See Early Day Motion 392, Westminster.

In January 2007 a ministerial statement from Harriet Harman announced proposals for new legal powers for Coroners focused on public health concerns and helping closure for the bereaved. These powers are not sufficient on their own to make any difference. For sudden medical deaths there

would need to be a positive duty on the Coroner to lodge details of any criticisms/recommendations with the National Patient Safety Agency and the Healthcare Commission so that a national database can be constructed and interventions made and a national protocol on SUDEP and other sudden unexplained medical deaths (addressing the public interest issues raised by these deaths) and for the Chief Coroner to be responsible for the implementation of this.

**For further information e.g. National Audit of Epilepsy Deaths/ Draft Coroners Bill 2006 please contact**

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