

Dianne and Colette Findlay

1956-1989

1981-1998



SUDEP

- Sudden Unexpected Death in Epilepsy (SUDEP).
- SUDEP is likened to an adult cot death because there is no warning and often a person may simply die in their sleep.
- 1996 - over 1,000 people died from epilepsy in the UK
- most of these epilepsy related deaths were of children and young people who, although in otherwise good health, died suddenly
- many cases of SUDEP are not recognised and are recorded inaccurately
- SUDEP has been acknowledged in medical literature for over 100 years; a major book on death in epilepsy appeared in 1990; articles have appeared in the Lancet and the British Medical Journal; and a major special edition of a medical journal, Epilepsy, clearly outlining risk factors and possible precautions, appeared in 1996.

Risk factors

- young adults
- mainly but not solely generalized seizures
- poor seizure control
- nocturnal seizures
- unwitnessed seizures
- abrupt and frequent changes in medication
- non-compliance
- people with epilepsy whose seizures are not recorded in medical notes

Possible prevention

- the importance of remaining seizure free, especially for people in high risk groups
- supervised sleeping
- non-suffocation pillows
- use of breathing monitors/apnea alarms
- learning of resuscitation techniques

Fatal Accident Inquiry

- legal procedure in Scots Law which looks at the causes of certain deaths where there is a public interest
- Held at Glasgow Sheriff Court under first Sheriff Daniel Convery and then Sheriff James Taylor
- Determination was published in September 2002
- Key findings:
 - Death could have been avoided
 - ‘Catalogue of errors’
 - There should have been a ‘care plan’
 - Patients and/or their families should be informed of risk
- GP’s should set up specialist epilepsy clinics

Practical impact of the FAI Determination

- media – information and awareness raising
- Local GP practice
 - specialist epilepsy clinic
 - local GP now involved in group drafting clinical guidelines for Scotland
- Scotland wide
 - discussions at Parliament
 - monitoring of implementation of recommendations by Deputy Chief Medical Officer
 - establishment of Managed Clinical Network to co-ordinate provision of epilepsy treatment in line with clinical guidelines