Coroners' rulings on avoidable epilepsy-related deaths

(Ashby, S & Hanna, J; 2014)

In England all sudden deaths should be investigated by the Coroner. Recent reforms in the coronial system have meant Coroners have the power to make a special ruling under regulation 28 (formally known as rule 43). This is where the coroner considers a death may be avoidable and where future deaths could be prevented if specific actions are put in place. The aim of a regulation 28 is to draw the attention of local health bodies or other agencies to an area of concern and to seek their response by completing a report to prevent future deaths (also known as PFD reports).

These documents are publically available on the Office of the Chief Coroner's website and a summary of PFD reports highlighting epilepsy related deaths for 2013-14 can be found below:

Personal Details	Cause of Death	Why the PFD report was raised	Who the PFD was sent to for action to be taken	Date for expected response regarding PFD	Further details
Thomas aged 22	1. Brain Swelling & Infarction 2. Glioblasoma	Inadequate and incomplete record keeping of Mr Burchell's seizures (which developed while in hospital while under investigation and treatment of the tumor) by the staff involved in his care, even though he was in a neurosurgical unit used to dealing with seizures and difficult to treat epilepsy.	Royal Devon and Exeter NHS Trust	29-02-16	https://www.judiciary.gov.uk/wp-content/uploads/2016/02/Burchell-2016-0002.pdf
Connor aged 18	Drowning following an epileptice seizure in the bath, contributed to by neglect.	• Connor was under the care of Southern Health NHS Foundation Trust, however drowned in the bath while in one of their homes. • He was known to like long baths. • The Trust policy permits patients with epilepsy to bath with sight/sound observations: sight causing dignity issues, sound not felt by the coroner to be sufficient to prevent drowning, especially as in a busy ward context as close observation is unlikely to be maintained. • Secondly, issues regarding RIO note taking (available space & prompts to do so) about patients' epilepsy/history were flagged up.	Southern Health NHS Foundation Trust	Jan-16	https://www.judiciary.gov.uk/wp-content/uploads/2015/12/Sparrowhawk-2015-0445.pdf **Response:** https://www.judiciary.gov.uk/wp-content/uploads/2015/11/2015-0445-Response-by-Southern-Health-NHS-Trust.pdf
Jorge aged 50	1. SUDEP 2. Post-Traumatic Epilepsy 3. Old Traumatic Head Injuries 4. Alcoholic Ketoacidosis	• Following a head injury in August 2013, the deceased developed post-traumatic epilepsy & prescribed medication. • The last instance of collecting this prescription was on 3rd July 2014 but this was not raised during subsequent medical appointments, even though concerns had been raised about his adherance in a letter from an external person to the GP. • Jorge was known to be vulnerable, drinking alcohol excessively and treated sporadically for depression since the injury. • There is no system in place at the GP surgery to flag up people not collecting prescriptions, especially those who are vulnerable or reliant on medication to control a condition such as epilepsy.	Springfield Medical Practice.	24/06/2015	https://www.judiciary.gov.uk/wp-content/uploads/2015/07/Castro-2015-0170.pdf

Rasharn aged 9	1a hypoxia 1b generalised seizure 1c univentricular cyanotic congenital heart disease with pulmonary hypertension (Natural Causes)	• The deceased had a heart condition which was known to be life-limiting, however participated in many normal activities. • School staff noticed him becoming unwell during a disco & administration staff members looked after him while his mother was called. • He appeared to have an absence style seizure during this time (suspected by a junior staff member) but the other supervising staff member (a trained first aider) did not think an ambulance was needed – even though he did not have epilepsy. • An ambulance was not called until 27 minutes after he first became unwell (7 minutes after the seizure began). He died later in hospital. • Concerns raised over the unclear nature of his school care plan & school processes for identifying & caring for children with complex health issues (potentially requiring emergency care).	Headteacher of the primary school	26/06/2015	https://www.judiciary.gov.uk/wp-content/uploads/2015/07/Williams-2015-01681.pdf
Eve aged 52	Open – Cause unascertained	• The deceased suffered seizures & fluctuating peri-ictal confusional states following brain surgery in 2011. • She was urgently referred by psychiatrists at her hospital on separate occasions to the local Community Mental Health Team but this was not actioned (records showed no notes of this & there was found to be a lack of agreement as to what constitutes as an 'urgent' referral). Instead an appointment was made for later in the month. • The deceased went missing in a peri-ictal confusional state a few days later and was not found until she was found deceased the following month.	Worcestershire Health and Care NHS Trust	05/03/2015	https://www.judiciary.gov.uk/wp-content/uploads/2015/03/Cullen-2015-00021.pdf
Jason aged 38	SUDEP	• The deceased suffered from epilepsy & schizophrenia & was imprisoned at the time of his death. He had limited intellectual ability and was known to not take his medication reliably. • The welfare checks were inadequate & failed to notice the deceased had died until hours after it occurred. • The set-up of the medical centre & its systems to see inmates was found to defer prisoners from attending & procedures were not adequately in place to chase non-attendees requiring medication). • There was also no policy in place to deal with situations where prisoners require 24hour observation from medical staff (even though this was recommended).	NHS England The Prison Service	09/03/2015	https://www.judiciary.gov.uk/wp-content/uploads/2015/03/Lawson-2015-0006.pdf
Aimee aged 21	SUDEP	• While undergoing investigations into epilepsy, an urgent referral was not made, resulting in lost opportunities to diagnose & treat the condition. • That the NICE Guidelines for referring a patient with suspected epilepsy to a Specialist Tertiary Centre were not followed.	University Hospital Trust	June 2014	http://www.judiciary.gov.uk/wp-content/uploads/2014/07/Varney-2014-0249.pdf

Dafyyd aged 34	Pericarditis; Drug reaction with eosinophilia & systematic symptoms (DRESS); Epilepsy treated with Levetiracetam.	• The medication used to treat epilepsy was changed from Carbamazepine to Levetiracetam due to the symptoms caused. • This is the 4th death documented which shows that the possibility of such a reaction to the epilepsy medication Levetiracetam, while rare, is not drawn to physicians attention in the drug literature or in the BNF entry.	Pharmaceutical Companies	June 2014	http://www.judiciary.gov.uk/wp-content/uploads/2014/07/Watts-2014-0194.pdf
Caroline aged 30	Propranalol Toxicity	• The attending ambulance service had insufficient training to safely move the patient whilst still having a seizure. The police were called to assist. While police can assist with restraint techniques, they are not adequately trained to deal with patients who are mentally/physically unwell. • This resulted in inappropriate removal of police officers from their core policing duties, but also potentially results in harm to patients being caused by delaying their removal to hospital.	Secretary of State for Health Ambulance Service	May 2014	http://www.judiciary.gov.uk/wp-content/uploads/2014/08/Pilkington-2014-0269.pdf
Adrian aged 48	Pulmonary thromboembolism; Deep vein thrombosis; epilepsy & diabetes	• The trust policy dealing with the staff response to patients with epilepsy (& still having seizures) being cared for under the Mental Health Act did not include a clear set of guidance to ensure appropriate care. Nor did the policy include the need, as part of the emergency response, to request the duty doctor. • Some of the nursing staff were not able to act in a calm coordinated manner & were not able to apply the training they had received in basic life support.	Mental Health Trust	April 2014	http://www.judiciary.gov.uk/wp-content/uploads/2014/06/Cowan-2014-0111.pdf
Russell aged 54	Open conclusion	• There was a failure for staff at the care home to provide accurate information and medical documentation to the ambulance service following an unwitnessed potential seizure. • There was a failure to accompany the patient (who was unable to communicate) to the hospital making it difficult for A&E to treat him quickly & effectively.	Residential Care Care Authority	March 2014	http://www.judiciary.gov.uk/wp-content/uploads/2014/06/Felstead-2014-0016.pdf
Billy aged 20	Hypoxic Ischaemic Encephalopathy; Cardiac arrest; Epilepsy	• The policy regarding detainee processing was not effective, meaning the deceased was in custody overnight & for an unnecessarily prolonged time. • Attending staff were aware of the deceased's epilepsy yet there was a lack of communication regarding the level, purpose & procedure of observations required to ensure proper care. There was also a lack of communication between staff. • Records should be accurately kept for visits regarding those in custody requiring observations. Risk assessments & all other supporting documentation should also be recorded once completed with any changes noted.	Police Authority	March 2014	http://www.judiciary.gov.uk/wp-content/uploads/2014/06/Salton-2014-00021.pdf

Rosemary aged 55	SUDEP	• The deceased was hospitalised but later discharged by a clinician (based on NICE guidelines & clinical issues) to the care of a friend. Social workers were not informed so no support measures were in place. • The clinician called the friend but it was not made clear that constant supervision was required for 24hours. Therefore, while in the same place, the deceased was not watched constantly. There is a concern this could easily occur again if measures are not put in place. • The Hospital Notes were brief with vital information & discussions found to have been omitted. This resulted in confusion & miscommunication regarding this case.	NHS FOUNDATION TRUST 2 more unnamed recipients	March 2014	http://www.judiciary.gov.uk/wp-content/uploads/2014/05/Ferguson-2013-0365.pdf
Kate aged 7	Acquired cerebral palsy; epilepsy; chronic lung complications following meningitis	• When examined in hospital, the Doctor failed to deal correctly with the diagnosis of the deceased's condition & potentially mislead the parents into thinking he had sought a second opinion. • From a witness statement, doubt is cast onto the fitness of the Doctor to continue to practice and it is a 'grave concern' for the coroner.	General Medical Council	February 2014	http://www.judiciary.gov.uk/wp-content/uploads/2014/05/Pierce-2013-0363.pdf
Sandra aged 64	Intracerebral Haemorrhage	• The deceased was put to bed in the nursing home in an unconscious state after a suspected epileptic fit. No medical opinion was sought even though she remained unconscious throughout the night for a far longer period than would be expected after an epileptic fit. • Residents in an unconscious state who are treated in future in the same way as she may be at risk of unnecessary death or injury if measures are not put in place to prevent this.	Residential Care	February 2014	http://www.judiciary.gov.uk/wp-content/uploads/2014/06/Wordingham-2013-0373.pdf
Daniel aged 35	SUDEP	• The arrangements for the deceased to take his ant-convulsant medication were insufficient, resulting in a failure to manage the risks associated with his medication management. • The supervision provided to the deceased whilst in residential care was insufficient to safeguard his safety & wellbeing.	Residential care	November 2013	http://www.judiciary.gov.uk/wp-content/uploads/2014/05/Onley-2013-0208.pdf
Clive aged 51	Epilepsy related to Parkinson's Disease	• Concerns regarding the care home accurately providing medication & ensuring attendance at medical appointments. • Failings with the complaints system within the care home meant complaints were not escalated for appropriate action to be taken in time.	Residential Care	July 2013	http://www.judiciary.gov.uk/wp-content/uploads/2014/05/Clinton-2014-0238.pdf
Unknown	Unknown	• To consider whether more awareness could be made available in respect to epilepsy.	Department of Health	Unknown	http://www.judiciary.gov.uk/wp-content/uploads/JCO/Documents/coroners/pfds/Summary+Report+of+PFD+Reports+Apr+-+Sep+2013.pdf

NB: The Chief Coroner's Office is currently working to upload all reports completed since 25 July 2013 and suggest checking regularly for new reports. The above table is accurate as of **August 2015**.