SHERIFFDOM OF TAYSIDE CENTRAL AND FIFE
AT DUNDEE

UNDER THE FATAL ACCIDENTS AND SUDDEN DEATHS INQUIRY
(SCOTLAND) ACT 1976

Determination by

Sheriff Alistair JM Duff

In respect of

Fatal Accident Inquiry

Into the deaths of

Erin Casey

and

Christina Fiorre Ilia

Dundee 24th August 2011

The Sheriff, having considered the evidence adduced, Determines in terms of Section 6(1) of the Act:-

In respect of the death of Erin Casey (Erin)

(1) That in respect of section 6(1)(a) Erin died on 27th October 2006 within her bedroom, Room 5, 22 Fife Park, St Andrews, Fife;

(2) That in respect of section 6(1)(b) the cause of death was sudden unexpected death in epilepsy (SUDEP);

(3) That in respect of section 6(1)(c) the reasonable precautions whereby the death might have been avoided were

(a) if Erin and her parents had been advised of the risk of SUDEP;

(b) if Erin had adhered to the regime of anti-epilepsy medication prescribed to her; and

(c) if Erin had been subject to supervision while asleep during the night of 27th October;

(4) That in respect of section 6(1)(d) the defect in any system of working which contributed to the death was:-

Erin's response to her initial diagnosis, understanding of that diagnosis and compliance with medication was not effectively monitored and appropriate further advice was not provided in the period immediately after 12th April 2006 and before her next appointment on 5th September 2006 and between then and her death;

(5) That in respect of section 6(1)(e) other facts which were relevant to the circumstances of the death were:-

No system was in place within Erin's GP practice to monitor her uptake of the repeat prescription of her anti-epilepsy medication

In respect of the death of Christina Fiorre Ilia (Christina)

(1) That in respect of section 6(1)(a) Christina died on 23rd March 2009 at 19 Newmonthill, Forfar, Angus;

(2) That in respect of section 6(1)(b) the cause of death was sudden unexpected death in epilepsy;

(3) That in respect of section 6(1)(c) the reasonable precautions whereby the death might have been avoided were:-

(a) if Christine and her parents had been advised of the risk of SUDEP;

(b) if Christina had been subject to supervision while asleep during the night of 23rd March;

(4) That in respect of section 6(1)(d) there were no defects in any system

of working which contributed to the death;

(5) That in respect of section 6(1)(e) other facts which were relevant to the circumstances of the death were:-

Officers of Tayside Police who attended at Christina's home on the morning of her death referred to the house as "a crime scene" in speaking to her parents. This was insensitive and, if it accords with procedure, should be reconsidered in future.

The inquiry

In this inquiry the following parties were represented:-

the Crown

Erin's family

Christina's family

Fife Health Board

Tayside Health Board

Dr Martin Kirkpatrick (by Tayside Health Board's counsel)

The inquiry commenced hearing evidence on 1st November 2010 and concluded for the first time on 24th November having sat more or less every court day. Thereafter further evidence was heard between 17th and 21st January 2011 and final submissions were made on 8th March.

The witnesses

The following witnesses gave evidence:-

(1) Janet Casey, mother of Erin

(2) Graeme Casey, father of Erin

(3) Shauna Casey, sister of Erin

(4) Daniel Casey, brother of Erin

(5) Lynn Wheeler, mother of Christina

(6) Dr Brian Adamson, pathologist employed by Fife Health Board based at Victoria Hospital, Kirkcaldy

(7) Markos Ilias, father of Christina

(8) Michael Brodie, paramedic with Scottish Ambulance Sevice, based at St Andrews

(9) Stuart Falconer, ambulance technician with Scottish Ambulance Service, based at Forfar

(10) Heather Smith, flatmate of Erin in St Andrews

(11) Abigail Erdman, flatmate of Erin in St Andrews

(12) Lee McPherson, Erin's boyfriend

(13) Dr Ian Cruikshank, Erin's GP, based at Leven Health Centre

(14) Dr Douglas Burt, Christina's GP, based at Forfar

(15) Dr Martin Zeidler, consultant neurosurgeon, based at Victoria Hospital, Kirkcaldy

(16) Dr Claire Evans, pathologist, Royal Hospital for Sick Children, Yorkhill, Glasgow

(17) Detective Sergeant Ian Thomson, Tayside Police, Dundee

(18) Detective Constable Scott Carswell, Tayside Police, Perth

(19) Detective Inspector Iain Wales, Tayside Police, Forfar

(20) Dr Martin Kirkpatrick, consultant paediatric neurologist employed by Tayside Health Board, based at Ninewells Hospital, Dundee

(21) Dr Robert McWilliam, consultant paediatric neurologist, Royal Hospital for Sick Children, Yorkhill, Glasgow

(22) Dr Jonathon McCormick, consultant in paediatric respiratory illness, based at Ninewells Hospital, Dundee

(23) Dr Susan Duncan, consultant neurologist with a special interest in epilepsy, based at Western General Hospital, Edinburgh

(24) Dr Richard Roberts, Reader in Medicine at Dundee University and honorary consultant in neurology at Ninewells Hospital, Dundee

(25) Professor Judith Cross, Professor in Paediatric Neurology and Head of Neurosciences Unit, UCL-Institute of Child Health, University College, London, holder of Prince of Wales' Chair of Childhood Epilepsy UCL-Institute of Child Health, Great Ormond Street Hospital for Sick Children, NHS Trust and National Centre for Young People for Epilepsy

(26) Professor Matthew Walker, Professor of Neurology at Institute of Neurology, UCL and National Hospital of Neurology and Neurosurgery, London

(27) Dr William Henry Smithson, Senior Clinical Lecturer, Academic Unit of Primary Care, University of Sheffield and part-time GP

(28) Professor Stephen Brown, Chair of Trustees of Epilepsy Bereaved, previously consultant psychiatrist in learning disability, Cornwall Partnership NHS Trust and Honorary Professor of Developmental Neuropsychiatry and Chair Develpomental Disability Research and Education Group, University of Plymouth and Peninsula Medical School

(29) Jane Hanna, OBE, Director of Epilepsy Bereaved

I do not propose to rehearse the evidence of the witnesses. Thanks to the way the inquiry was conducted before me parties focused on a number of distinct issues arising out of the deaths of Erin and Christina. There was much common ground. I intend to address the principal areas of concern or dispute and indicate the view I have reached referring to relevant evidence where appropriate.

Erin's family circumstances and the events leading to her death

Erin was born on 11th June 1987, so that she was 19 when she died on 27th October 2006. Prior to leaving home to attend St Andrews

University in September 2006 she lived with her parents, Graeme and Janet Casey, in Lundin Links, Fife. She had a younger brother, Daniel, and a younger sister, Shauna, aged 15 and 17 respectively in October 2006. At the time of her death she had a boyfriend, Lee McPherson, whom she met at college in Kirkcaldy when she undertook a drama course between 2005 and 2006.

Erin enjoyed good health and lived a full, normal young woman's life. She was intelligent and gained a place at university to study French and Spanish. Prior to going to university she had lived at home where she shared a bedroom with her sister, who went off to Dundee University at the same time. On going to St Andrews she secured accommodation in a shared student house at 22 Fife Park where she occupied Room 5. She shared the house with 5 other girls.
At university she attended classes and went to the gym. She drank alcohol, but only occasionally to the point where she appeared drunk. She smoked a little. There was no evidence that she led a lifestyle dominated by regular excessive drinking and late nights.
Lundin Links being no great distance from St Andrews, Erin maintained regular contact with her family and her boyfriend. Her sister and boyfriend visited her in St Andrews.

In March 2006 when Erin was in bed at home she suffered an episode which was later diagnosed as a generalized tonic-clonic epileptic seizure. Her sister was asleep in the same room and was woken up when Erin started throwing her arms around. This lasted for a few seconds. She then lay still and Shauna could not hear her breathing. She went over, touched Erin and said her name. Erin took a big breath and began snoring. In the morning Erin could not remember this event taking place but complained of a sore back and painful teeth. She had also bitten her cheeks. Erin, her sister and mother discussed this episode and recalled that from about the age of 13 Erin had occasionally experienced "absences" or blanks, later described as "déjà vu" episodes.

Erin consulted her GP and was referred to Dr Martin Zeidler, consultant neurologist at the Victoria Hospital in Kirkcaldy. She attended the appointment with her mother and boyfriend on 12th April 2006. On the basis of the history narrated above Dr Zeidler was able to make an immediate diagnosis of epilepsy. Erin was prescribed medication, carbamazepine, and specifically was given a prescription for 200mg tablets which she obtained that day at the hospital pharmacy. Initially for 5 days she was to take half a tablet twice daily, ie 100mg twice per day, but every 5 days she had to increase the dosage by half a tablet until eventually she was taking 300mgs twice per day, ie one and a half tablets twice daily. According to Dr Zeidler in his evidence he told Erin about her medication regime. He said she was an intelligent girl and was dismissive of any suggestion that she might have had difficulty understanding the instructions. He did not write anything down for her but she took some notes herself. It is perhaps telling that in subsequent weeks members of Erin's family saw her trying to halve tablets and could not understand why she was doing this, even though the medication regime clearly required such a process. As far as Erin's family was concerned there were times when she seemed confused about her medication regime. Only during the course of Dr Zeidler's evidence did he manage to obtain a copy of the label which would have been attached to the bottle or packet of drugs. This label contained the description of the regime set out above but was printed in small, dense type.

Dr Zeidler gave Erin advice about safety issues related to swimming, bathing, heights and driving. He also discussed the issue of contraception and the potential for her anti-epileptic medication reducing the effectiveness of the contraceptive pill.
I am satisfied that he advised Erin that her epilepsy would be no more than "a minor nuisance" in her life. He denied using that phrase. Mrs Casey was clear that he did. His demeanour during his evidence

suggested to me that this phrase is exactly the sort of language he would have used.

Erin collected her first prescription that day and it would have lasted 28 days if taken properly. She collected a repeat prescription on 25th May and, taken properly, it would have lasted 56 days. In other words, had Erin taken her medication as she should have done she should have picked up the repeat prescription to begin using it around 12th May and that repeat prescription should have lasted her until around mid July. She did not collect any other repeat prescription until 25th September 2006 but she did not obtain further medication from any pharmacist.

After the appointment on 12th April Dr Zeidler wrote to Erin's GP, Dr Cruikshank, reporting the diagnosis, medication and advice given. A copy of that letter was sent to Erin though her parents were not aware of that having been done.

Between 12th April and her next appointment with Dr Zeidler on 5th September Erin had further déjà vu episodes and one probable generalized tonic-clonic seizure just after going to bed.

At the appointment on 5th September Erin did not report to Dr Zeidler any of the déjà vu episodes nor the tonic-clonic seizure. She also did not give any indication that she was failing to comply with her medication regime. She reported feelings of tiredness and weight gain and the dosage of carbamazepine was reduced. The interaction of the medication with the contraceptive pill was discussed. Dr Zeidler said he would see her again in one year. After the appointment he again wrote to Erin's GP, this time not copied to her, reporting on the outcome of the appointment.

Between 5th September and her death on 27th October Erin was seen to have a probable 2 or 3 further déjà vu events. None of these was reported to Dr Zeidler or her GP.

On the evening of 26th October Erin was in her student house. One of her housemates spoke to her. Erin went to bed and exchanged text messages with her boyfriend until after midnight. She was due to have an exam on the morning of 27th October and was due to go home to Lundin Links in the late afternoon or early evening. Eventually, when she did not come home, her father went to the student house in the evening of that day and, alongwith one of the housemates, found Erin dead in her bed. On post mortem examination there was, according to Dr Brian Adamson, “clear evidence” of Erin having had a seizure around the point of death.

A subsequent toxicology report disclosed that at the time of her death Erin had a level of carbamazepine in her blood which was well below a therapeutic level.

In her approach to her condition Erin did indeed seem to regard epilepsy as no more than a minor nuisance. She did not make an issue of it with her family, her boyfriend or her housemates. Lee McPherson gave evidence that Erin did not seem properly to understand how to take her medication and as far as he knew she was “hardly taking her medication at all”. He spoke to her about it. She did mean to take it. He wasn’t worried as she was not having “serious” fits. In his view had she been told of the risks associated with not taking medication she would have taken it and she would have modified her lifestyle where appropriate. Lee McPherson thought that Erin’s approach to her epilepsy was “tainted” by Dr Zeidler’s apparent “blasé” attitude to her condition.

When Erin’s family saw her death certificate they discovered for the first time the term SUDEP. At no stage had the risk of SUDEP been mentioned to Erin or her family or boyfriend. They carried out some research into the phenomenon and had meetings with Dr Zeidler and Dr Richard Roberts at Ninewells Hospital. They complained to Fife

NHS Board about aspects of Erin's treatment and, feeling dissatisfied with the outcome, complained to the Scottish Public Services Ombudsman, The Ombudsman reported on the complaint around July 2008 and in broad terms upheld the complaint. I will refer to the Ombudsman's report in a little more detail later.

Christina's family circumstances and the events leading to her death

Christina was born on 8th April 1993 and was therefore 15 when she died on 23rd March 2009. She lived with her parents, Lynne Wheeler and Markos Ilias, at 19 Newmonthill, Forfar. Christina was born with various health difficulties and at aged 2 was diagnosed as suffering from asthma. This condition persisted throughout her life and at times was sufficiently severe to require hospitalisation. However these conditions had no bearing on Christina's death, though her experience of them meant that during her whole life Christina and her parents had significant regular contact with health professionals.

Christina lived the normal, active life of a child and then teenage girl. She participated in the same activities as her friends at school including going abroad on a school trip.

In December 2005 Christina suffered a tonic-clonic type seizure. No investigation of the seizure was undertaken at this time. In October 2006 she had another tonic-clonic seizure while on holiday in the USA. She was treated at a local hospital and prescribed an anti-epileptic drug, phenytoin. On her return to Scotland she was referred to the Paediatric Neurology Clinic at Ninewells Hospital where she was first seen in January 2007. Her medication was changed to lamotrigine. After various procedures and reviews a diagnosis of epilepsy was confirmed by Christina's consultant Dr Martin Kirkpatrick.

Christina had a further tonic-clonic seizure in October 2007, but thereafter remained seizure free until June 2008 when there were two episodes in one day. These were different from the other tonic-clonic seizures and Dr Kirkpatrick thought that they might have been focal or partial seizures. Christina's dosage of lamotrigine was increased.

In July 2008 there were two further partial seizures.
In September 2008 another seizure occurred after Christina had forgotten to take her medication. Her dosage was increased again. At this time Christina's father expressed concern that her seizure control was deteriorating.

She had another seizure in December 2008.

In the weeks prior to March 2009 Christina's parents had become particularly concerned about her suffering from excessive tiredness. She would come home from school and sleep. Mr Ilias met Dr Shetty, one of Dr Kirkpatrick's colleagues at the beginning of March and said in his evidence that he communicated this concern. There is no note to that effect in the records of the consultation and no such information was passed on to Dr Kirkpatrick. Mr Ilias misrecollected what occurred at the consultation in relation to medication. While I am sure he is doing his best to remember what happened I believe he is mistaken in recollecting that he advised Dr Shetty about tiredness.

On the evening of Sunday 22nd March 2009 Christina was in bed watching TV when her parents went to bed. On the Monday morning when Mr Ilias went into her room he found her dead in bed. Her fists were clenched as sometimes happened when she had a seizure.

After a long delay the cause of death was certified as SUDEP but in the meantime Christina's parents had been told by their police liaison officer that the pathologist felt that the cause of death would relate to her epilepsy. This took them aback and they began to research the

relationship between epilepsy and mortality. During this they found out about SUDEP. They had meetings with, inter alia, Dr Kirkpatrick at which they raised their concerns, particularly about not having been advised of the risk of SUDEP at any point during the management of Christina's condition. Dr Kirkpatrick's view was that the cause of death was unlikely to be SUDEP and he advised the family that they had not been told of the risk because Christina was at low risk and because of the detrimental effect on patients or their families which could result from being given the information.

Epilepsy and Sudep

"An *epilepsy* is defined as a neurological condition characterised by recurrent epileptic seizures unprovoked by any immediately identifiable cause. An *epileptic seizure* is the clinical manifestation of an abnormal and excessive discharge of a set of neurons in the brain.

Epilepsy should be viewed as a symptom of an underlying neurological disorder and not as a single disease entity."

("The diagnosis and management of epilepsies in adults and children in primary and secondary care" National Collaborating Centre for Primary Care (NICE) Guidelines October 2004. Production No. 1 for the families)

Clinicians sometimes refer to the "*abnormal and excessive discharge of a set of neurons in the brain*" as "abnormal electrical activity in the brain".

At any time approximately 450,000 people in the UK suffer from epilepsy. It is the most common neurological condition treated by the medical profession. The way in which the condition is manifested, in other words the type of seizure experienced, varies according to a number of factors including, *inter alia*, the parts of the brain affected, the pattern of spread of the abnormal

electrical activity through the brain, the cause of the epilepsy and the age of the individual. Types of seizure include absences or *déjà vu* episodes where the patient experiences a few seconds or so of “blankness”. There may be an actual sense of *déjà vu*, an inability to take things in, a feeling of fear or panic, a sensation of something “rising upwards” through the body or a combination of these phenomena. Such a seizure is typical of temporal lobe epilepsy. To an observer the person seems to be pre-occupied, staring, not speaking. Afterwards the patient may well be unaware such an episode has occurred. Another type of seizure, described as a focal seizure, may comprise a tingling or numbness felt by the patient in a single part of the body, eg one arm. Yet another type of seizure, and the one most commonly thought of by the public at large as an instance of an epileptic seizure, is a generalized or tonic/clonic seizure where the patient may emit a cry or sound, become rigid (the tonic phase) and then commence convulsive shaking of the limbs and body (the clonic phase). The tonic phase is usually accompanied by the patient apparently stopping breathing and perhaps turning blue. After a few minutes the seizure stops. The patient breathes once more, often noisily like snoring, becomes still and may lapse into sleep or, if asleep when the seizure began, may remain asleep. During such a seizure the patient may bite his/her tongue and/or the inside of the cheeks. On waking the patient may be unaware that the seizure has occurred unless there are physical signs of it such as a sore tongue or cheeks or pain in the muscles.

One form of epilepsy is temporal lobe epilepsy where the patient suffers only *déjà vu* type seizures but on occasion the abnormal electrical activity may spread to other parts of the brain and cause a generalised tonic/clonic seizure. On the other hand the patient may have a form of epilepsy affecting all of the brain and almost always experience such generalised seizures. It is often not known why, in an individual patient, this abnormal electrical activity is taking place. Sometimes there is identifiable an aspect of the patient’s history which may contribute to a greater risk of epilepsy such as brain damage, a head injury, a brain infection, a history of febrile convulsions or a history of epilepsy in the family. Some forms of epilepsy may be genetic or hereditary, such as juvenile myoclonic epilepsy. The diagnosis of epilepsy is

not always straightforward. It is not uncommon for patients to be wrongly diagnosed as suffering from epilepsy. It is important to take a detailed history from the patient and to follow that up with other investigations such as an EEG examination.

A seizure may occur at any time, although there are certain recognised risk factors which make the occurrence of a seizure more likely. Seizures can happen during sleep, including when going to sleep or waking up from sleep. These are called nocturnal seizures.

While it is possible to reduce the risk of seizures by avoiding or modifying risk factors, often associated with lifestyle, by far the most effective method of controlling seizures is by adhering to an appropriate regime of anti-epilepsy medication. There are various types of such medication. 70% of those with epilepsy who adhere to appropriate epilepsy medication become seizure free. Some people “grow out” of their epilepsy, in that with appropriate medication they become seizure free and then after some years can stop taking medication and suffer no more seizures. For those whose condition is not controlled by medication (and usually two or three different types of medication in varying dosages will have been tried) and who continue to suffer generalised tonic/clonic seizures, one option is to consider surgery on the affected part of the brain. After such surgery, if successful, the patient will not suffer seizures.

I heard evidence from various professional witnesses about the risk factors which may make seizures more likely for someone with epilepsy. There was not absolute unanimity on these factors but it appeared to me, based on the evidence which I accepted, that there was a fairly broad consensus around certain matters, namely:-

(1) **Non compliance with medication** For several witnesses this was by far the most important risk factor.
(2) **Alcohol** Excessive alcohol consumption was a clear risk factor, normally associated with the stage of withdrawal from alcohol after a

"binge". Even people who do not have epilepsy can suffer seizures in these circumstances. Persons with juvenile myoclonic epilepsy are particularly prone to seizures when withdrawing from an alcohol "binge".

(3) **Sleep deprivation** This can be caused by a number of factors associated with lifestyle including excessive alcohol consumption and irregular sleep patterns, but, however caused, sleep deprivation or drowsiness seems to be recognized as a risk factor.

(4) **Stress/depression** Several witnesses referred to stress as a risk factor. It was not clear why, although stress contributing to sleep deprivation may be relevant.

(5) **Drugs** The consumption of certain controlled drugs appeared to be a risk factor, but it was not clear to me whether this was because of a heightened risk of suffering disrupted sleep, or forgetting to take medication or for some reason inherent in the chemical properties of the drugs.

(6) **Carbamazepine** This is a commonly prescribed anti-epilepsy drug. There seemed to be some support for the proposition that in some circumstances, for some forms of epilepsy carbamazepine may increase the risk of seizures.

(7) **Photosensitivity**

There was evidence about the risks associated with epilepsy. Once again there appeared to me to be a broad consensus on these all of which relate to risks associated with seizures:-

(1) **Driving** Newly diagnosed patients are advised that they cannot drive. Driving with poorly controlled epilepsy and continuing seizures is dangerous. The DVLA requires to be informed and the patient will not be permitted to drive until there has been a year free of seizures.

(2) **Drowning** Epilepsy sufferers are advised that they should take showers rather than baths and should not swim alone.

(3) **Heights** Epilepsy sufferers are warned of the dangers of being at a height from the ground whether up a ladder, working at height or otherwise.

(4) **Injury** There are two aspects to this. Firstly there is the risk of unwittingly undertaking something dangerous while disorientated because of a seizure, eg crossing the road in the face of traffic. Secondly, because of the nature of a generalised tonic/clonic seizure there is the risk of injury by falling or by striking out at objects.

It is immediately obvious that all of these risks could result in injury or even death, but such death or injury could not be said to have been caused by the epilepsy but rather by an accident arising out of a seizure in a situation where the risk of accident exists.

According to the evidence which I accepted, based on the current state of medical knowledge, it appears to me that the risk of death from the condition of epilepsy does exist in two particular sets of circumstances.

The first is *status epilepticus*. Where a patient suffers a generalised tonic/clonic seizure which lasts for 30 minutes or longer or suffers repeated such seizures over a 30 minute period without recovery of consciousness between each convulsion the patient is suffering *status epilepticus* and is at risk of death through impairment of either or both of the cardiac and respiratory functions. Intervention is possible to relieve the condition, including securing the patient's airway, providing oxygen and administering particular forms of anti-epilepsy medication designed to stop the seizure.

The second is **Sudden Unexpected Death in Epilepsy**, known as SUDEP. SUDEP is defined as

"Sudden, unexpected, witnessed or unwitnessed, nontraumatic and nondrowning death in individuals with epilepsy, with or without evidence for a seizure, and excluding documented status epilepticus, in which post-mortem examination does not reveal a toxicological or anatomic cause for death".

This definition, now accepted across the medical profession as the classic definition of the phenomenon, was provided by Lina Nashef, a consultant neurologist, in her paper “Sudden unexpected death in epilepsy: Terminology and definitions” presented at an International Workshop on “Epilepsy and Sudden Death” held at the Royal College of Physicians in London in October 1996 and published in Epilepsia, the Journal of the International League Against Epilepsy in 1997 (Production No 7 for the families).

I was told that the notion that people with epilepsy could die “from epilepsy” unexpectedly, without trauma or drowning and in circumstances short of status epilepticus, was well recognised 100 to 150 years ago. However, eventually in the 1970’s, 80’s and into the 90’s there had developed a trend in the medical profession to deny the existence of this phenomenon. One witness, Professor Stephen Brown, discovered that in his health area (Cornwall) such deaths were being attributed mainly to status epilepticus and, in one case, drowning, without the full circumstances of the particular deaths being looked at properly by pathologists.
Typically such deaths were unwitnessed (although not always), occurred during the night when the patient was asleep (although not always) and, on post-mortem examination no mechanism for death could be identified. Various experts in the field engaged in research into such deaths and, with the publication of the Nashef paper, 1996/97 could be seen as something of a watershed with the concept of SUDEP achieving greater recognition and acceptance. Research has continued with the result that there is now a greater but by no means perfect understanding of the condition and a very wide, if not universal, acceptance of the existence of the concept amongst the medical profession. During the evidence certain witnesses hinted at there continuing to be a small number of clinicians who doubt the validity of SUDEP as a cause of death. There is no doubt that it is really a diagnosis “by exclusion” as some witnesses put it. However, all of the medical witnesses who gave evidence before me expressly or impliedly accepted the concept of SUDEP to be a valid diagnostic tool in assessing and reviewing the circumstances of some deaths amongst epilepsy sufferers.

The most typical example of an epilepsy sufferer succumbing to SUDEP will involve the patient going to bed and then being found deceased in bed in the morning. There may be physical/medical indications that there has been a seizure, but not necessarily. However the evidence before me was that SUDEP deaths most commonly occur during or in the immediate aftermath of a seizure. Post mortem examination will disclose no clearcut mechanism of death and there will be no toxicological explanation.

Occurring usually at night, during sleep, most SUDEP deaths are unwitnessed, but not all. Some deaths have occurred amongst patients in hospital while subject to monitoring by video and EEG. In some cases where such monitored patients have suffered a seizure during sleep and their EEG has "flatlined" or breathing has apparently ceased intervention by nursing staff has been unsuccessful in reviving them. However, in some such instances intervention, by moving or stimulating the patient, has led to the patient being resuscitated. It is not clear why this has happened in these cases.

Statistically, taking the entire cohort of epilepsy sufferers, which covers the whole range of types and severity of epilepsies, I was told that the risk of experiencing SUDEP was 1 in 1000. However the risk was "vanishingly small" for those whose epilepsy was of the less severe type involving only "*déjà vu*" or focal seizures and also for any epilepsy sufferer whose seizures were well controlled with medication. For those with refractory epilepsy (continuing to experience generalised tonic/clonic seizures, resistant to medication and being considered for surgery) the risk was much higher than the mean, 1 in 100 or even 1 in 75. I was told that about 600 epilepsy sufferers succumb to SUDEP annually in the UK.

I heard much evidence about the **risk factors for SUDEP**. In the submissions on behalf of Erin's family reference is made to the NICE guidelines (Family Production 1) at page 278 on the matter. I agree that this section of the guidelines accords with the bulk of the expert evidence which I heard and accepted. Dr Zeidler's evidence on the question of risk I will refer to later. Once again I could not say that, on the evidence, there was absolute

unanimity on what the risk factors might be but, on the basis of the evidence which I accepted, I believe that the following can be identified as factors which, if they are present, leave the individual epilepsy sufferer at a greater risk of SUDEP than the mean figure mentioned above:-

(1) Continuing generalised tonic/clonic seizures;
(2) Young age;
(3) Uncontrolled or poorly controlled epilepsy;
(4) Learning disability;
(5) Seizures occurring during sleep;
(6) Unwitnessed seizures;
(7) Poor adherence to anti-epileptic medication regime.

I have referred above to the factors which might increase the risk of a seizure occurring (alcohol, drugs, stress, sleep deprivation etc) so that these issues would also have to be taken into account when considering the risk of SUDEP, since the incidence of seizures is in general terms a risk factor for SUDEP.

On the question of risk factors for SUDEP Dr Zeidler was referred to Family Production 5, an article from the Lancet published online in September 2008, "Sudden unexpected death in epilepsy: current knowledge and future directions" by Torbjorn Tomson, Lina Nashef and Philippe Ryvlin, described as a review of "SUDEP rates, risk factors, triggers and proposed mechanisms" and a critical assessment of potential preventive strategies. He was asked about various matters identified as risk factors in that article and, according to my notes, responded as follows:-

(a) **Non-compliance with medication** – *Some say it's a risk factor, some not. No convincing evidence that it is a risk factor – maybe it is. Compliance may reduce the risk of SUDEP. Maybe taking medication is a risk factor. There is some evidence to this effect in relation to carbamazepine. It is possible compliance with medication may prevent SUDEP but the evidence for that is so poor as to be non-existent. By definition taking a sub-optimal dose of medication would increase the*

risk of seizure. Better to take the "correct" dose but there may be different "correct" doses. There is uncertainty about whether non-compliance increases the risk of SUDEP given the risk of carbamazepine contributing to a heightened risk of SUDEP.

(b) **Frequency of seizures** – *Some people say that's a factor. I don't know. Though I can see the logic. More seizures means you're more likely to suffer death in a seizure.*

(c) **Lack of supervision and use of alarms** – *Maybe these are risk factors. I don't accept there is sufficient evidence. It is possible night supervision may prevent SUDEP but the evidence for that is so poor as to be non-existent.*

(d) **Alcohol** – *I've not seen evidence alcohol is a risk factor. Alcohol presents a risk factor. Too much drink and lack of sleep might bring on a seizure. There is a paper which has looked at alcohol and has not found it to be a significant risk factor in SUDEP.*

(e) **Stress** – *could be a risk factor.*

(f) **Sleep deprivation** – *Is uncertain as a risk factor. It is in relation to juvenile myoclonic epilepsy. It may be in relation to other types. I have not got a feel for the evidence.*

(g) **Teenage years/transition to independent living** – *that is not a special case giving rise to special considerations.*

In general Dr Zeidler said *"Maybe these are risk factors, maybe not. They may be artefacts of studies"* and "*Unless the evidence is of high quality you have to judge the situation as you see fit".*

I found his evidence very unsatisfactory and his attitude dogmatic. He had a position that nothing was sufficiently certain and every answer he gave appeared to me to be framed so as not to dislodge that dogma. At times he contradicted himself. At times his answers bordered on the flippant or dismissive.

Unlike the other professional witnesses he appeared unfamiliar with certain of the literature. He was unwilling, it seemed to me, to allow any published studies to affect or inform his clinical judgement unless the evidence was, in

his view, overwhelming and none of it was. On the other hand he repeatedly referred to the risk posed by carbamazepine use, despite the fairly isolated evidence (not otherwise supported) for this approach. All of this flew in the face of almost every other professional witness who gave evidence, all of them expert witnesses with much more experience than Dr Zeidler.

Reducing the risk of SUDEP

All of the professional witnesses agreed that the risk of SUDEP cannot be entirely eliminated in any patient. At one end of the epilepsy spectrum the risk is “vanishingly small” and at the other end the risk is much higher.
Apart from Dr Zeidler all of the witnesses agreed that the single most important factor in reducing the risk of SUDEP was to reduce the risk of seizures and the optimum route to achieving that goal was to comply with the regime of prescribed medication.

In addition all of the professional witnesses, other than Dr Zeidler, were prepared to accept, on the basis of the available literature, that there were certain potential triggers for seizures and were therefore accustomed to advise patients about these triggers and avoiding them. These triggers clustered around the notion of lifestyle and were matters capable of modification by the patient, namely alcohol consumption, controlled drugs, tiredness and stress.

All of the witnesses, other than Dr Zeidler, recognised that these “lifestyle” issues were of particular relevance in respect of young people and in particular young people about to leave home and lead an independent life whether at university or otherwise. Indeed Professor Cross indicated that in her clinical practice there was a paediatric epilepsy clinic and an adult service but there was also a transition or teenage clinic to care for and advise young people moving between the paediatric and adult service so that they could learn how to look after their condition themselves and readjust to how decisions are made.

Dr Zeidler expressed himself reluctant to adopt a “lecturing” approach to his patients, including young people. He believed that any attempt to build a relationship of trust and confidence between himself and a patient would be undermined if he seemed to be telling them what to do, whether it be in terms of complying with medication, avoiding excessive alcohol consumption, avoiding controlled drugs or adopting a regular sleep regime. He stated for example that he would only discuss the impact of controlled drug consumption if the patient asked about it. This struck me as a wildly unrealistic expectation in respect of almost any patient, let alone a teenager.

As was submitted to me on behalf of Erin’s family Dr Zeidler was highly dismissive of an article entitled “Pressure on Freshers” by Leach and others, Epilepsy Professsional 2008 10:10 (Family Production 13) which set out the particular problems likely to be faced by a new student away from home. This article seemed to me to reflect the sorts of issues a reasonably informed lay person would recognise to be relevant to a young student patient and certainly reflected the clinical practice of the other professional witnesses.

No other professional witness expressed any reluctance to discuss these topics and give appropriate advice, although whether the patient would ultimately follow that advice was less easy to predict.

Intervention to prevent SUDEP

Professors Cross, Walker and Brown all gave evidence to the effect that, based upon the published studies available, it was possible to conclude that in respect of a patient who has a seizure it may be possible to avoid SUDEP by the intervention of another person, possibly by simply moving the patient and thus providing stimulus. Thus night supervision might be a precaution which could reduce the risk of SUDEP. Intervention would not always avoid SUDEP and the mechanism by which intervention might make a difference was not

understood although there were theories on the matter. I found their evidence reliable and compelling.

Dr Zeidler and Dr Kirkpatrick would not accept that there was convincing evidence of the effectiveness of intervention. Dr Kirkpatrick criticized the 2 studies which suggested otherwise and stated that another 7 or 8 studies had not found night supervision to be a factor. In his view if it was a protective factor then this would be “getting shouted from the rooftops”. Even in hospital people cannot be resuscitated. Dr Zeidler thought that the research was flawed although Professor Walker had no such fundamental reservations and stated, as has been submitted to me, that “a consultant neurologist could feel comfortable” relying on the research.
I was impressed by the evidence of Professors `Cross, Walker and Brown and given the view I had formed of their expertise and careful consideration of the published literature I preferred their evidence recognising the possibility that intervention might be capable of averting SUDEP.

The question of the possible effectiveness of intervention raises the related issue of night supervision. For intervention to take place it will obviously be necessary for someone to be aware that the epilepsy sufferer is experiencing a seizure.
A seizure may involve noise and it may involve movement. It may involve neither. It may also involve compromise of the respiratory function. Someone sleeping in the same room or very close by may see or hear the sign of a seizure. Erin’s sister was disturbed by her first tonic-clonic seizure. On the night of her death Christina’s parents were close enough to hear her cough, although they were awake at this point.
On the other hand there are available alarms which can detect sound or movement and therefore alert a carer. Some, apnoea alarms, can detect cessation of breathing. The evidence disclosed that of those who use alarms the majority use sound alarms (like baby monitors) rather than movement alarms. A number of the professional witnesses were not enthusiastic about the use of alarms. Their experience was that of the patients who started using them many gave up because of the incidence of false alarms leading to

disturbed sleep for everyone. On the other hand, as has been submitted to me on behalf of Christina's family, Professor Walker was very clear that studies supported the notion that the risk of SUDEP was reduced for those subject to supervision by sharing a room and those subject to remote monitoring. Professor Brown gave evidence that in his clinical experience the use of alarms was routinely discussed with patients and their families and, while some did not opt to use alarms, some did and of those who did some took the view that they were helpful.

Telling patients/carers about the risk of SUDEP

Drs Zeidler and Kirkpatrick did not tell Erin and Christina or their parents about the risk of SUDEP. This was a deliberate decision on their part.

Dr Zeidler explained his judgement on the issue at length. He said SUDEP was a "jargon" term. It meant different things to different people. However he then gave his understanding of the concept and it corresponded fairly closely to the recognized classic definition given above. He would not "force" information about SUDEP on a patient. He would not tell a patient about it unless the patient asked. He said 95% of neurologists would do the same. He said that, as of now, his threshold for telling a patient about SUDEP has lowered, but he would still not tell a patient like Erin. In his view Erin was at low or no risk of succumbing to SUDEP. He then appeared to indicate that in fact he would still not tell the vast majority of patients about SUDEP but he understood that they would now, in the Victoria Hospital, usually be told, since there was a now an epilepsy specialist nurse service to whom patients were referred. He understood the nurse might discuss SUDEP. He then said he thought the nurse discussed SUDEP with the majority of patients. In his view telling a patient about the risk of SUDEP was likely to cause distress and for no good reason, given that there was nothing which could be done to prevent or reduce the risk of SUDEP occurring. There was no evidence telling patients did any good and it might do harm. Erin could have found out about it for herself. A lot of information was and is publicly available. She was an

intelligent girl, about to go to university (and therefore, by implication, intelligent enough to research her own condition and find out about SUDEP). Dr Zeidler's assessment of the risk of distress being caused by telling about SUDEP appeared to be based on an example he had heard of at Ninewells Hospital where a patient had been told of the risk and had committed suicide. His widow blamed this on his being told of SUDEP. He mentioned female epilepsy patients becoming upset when advised of the risk to the unborn child posed by their condition. He also gave examples of other conditions where, in his judgement, he would withhold information about certain risks because of the lack of any method of reducing the risk.
He was adamant that even if he had known that Erin was not taking her medication properly and was still having seizures he would still not have told her about SUDEP. He had no way of knowing, he said, whether she would have been more likely to take her medication or more likely to report further seizures if she had known about SUDEP. On the other hand he agreed that it was possible that if she had taken her medication properly she might have eliminated further seizures and she might not have had the seizure leading to her death in October 2006. He also agreed that if she had been supervised during the night she died she might have avoided death. He agreed that if she had had information about SUDEP then she might have taken steps which might have been such that she would not have died. His overall position however was that she was at very low risk of SUDEP and that whether she would have taken her medication properly or opted for some form of supervision was unknown. If she had then whether that would have reduced the risk of SUDEP was also speculative.

Dr Kirkpatrick's position was that he did not tell Christina or her parents about the risk of SUDEP because of the potential for causing distress and, as it emerged, also because in his view Christina was at very low risk of suffering SUDEP and in any event there were no steps which could be taken to minimise or reduce the risk. He would only discuss SUDEP with such a patient if asked about it. If he thought a patient was at risk he would discuss SUDEP even if he thought they would find it difficult to cope with the information. It is necessary to balance the risk of telling and causing distress

against the risk of not telling and having to deal with the distress of a family if SUDEP occurs. Telling Christina and her parents would have made no difference to the issue of risk. Despite the recurrence of seizures during the second part of 2008 and her reported tiredness Christina was not at heightened risk of SUDEP as at March 2009. He would take the view that the risk of SUDEP was increased if seizures were occurring daily or weekly. In the event of a sudden cluster of seizures, as had taken place with Christina in late 2008, that would be addressed within the normal process of monitoring, as was done.

In 2002 there had been a Fatal Accident Inquiry into the death of Collette Findlay. While there were characteristics of Miss Findlay's death which were unique to that inquiry some very similar issues were raised and the presiding sheriff, Sheriff James Taylor as he then was, stated that the risks of sudden death in epilepsy should have been explained to her carers and also said:-
"I stop short of recommending that the risk of sudden and unexplained death from epilepsy (SUDEP) should be discussed with every epilepsy sufferer or their family, as submitted by Mr Carr. Discretion must be left with the medical profession to form a view. There may well be families who are of an extreme disposition or perhaps who have learning difficulties, where such a discussion would do more harm than good. I do, however, accept that in the vast majority of cases there should be a discussion".

In Scotland in 2003 the Scottish Intercollegiate Guidelines Network (SIGN) produced guidelines aimed at health professionals in respect of the diagnosis and treatment of epilepsy. In England the National Institute for Clinical Excellence (NICE) produced similar guidelines in 2004. Both sets of guidelines referred to the issue of SUDEP. The SIGN guidelines recommended the use of a checklist "*to help healthcare professionals to give patients and carers the information they need in an appropriate format*". An "*example checklist*" was provided and listed information about SUDEP as essential.
The NICE guidelines state, as submitted by counsel for Erin's family:-

"The risk of SUDEP can be minimised by:

-optimising seizure control

-being aware of the potential consequences of nocturnal seizures.

Tailored information and discussion between the individual with epilepsy, family and/or carers (as appropriate) and healthcare professionals should take account of the small but definite risk of SUDEP."

Dr Zeidler was dismissive of these guidelines. In his view the recommendations in respect of advising about the risk of SUDEP were not (unlike other recommendations) evidence based and in any event the guidelines were, at most, precisely that. It was up to clinicians to reach their own judgement.

Dr Zeidler did not agree with the conclusion of Sheriff Taylor. He said the outcome of the inquiry, like the SIGN and NICE guidelines, was something to be considered. He thought that Sheriff Taylor's conclusion was "not evidence based" and in any event Ms Findlay's position was quite different to Erin's.

Dr Kirkpatrick stated that the guidelines were not "the Bible" but were merely guidelines. He criticised the evidence base. He did not agree that the risk of SUDEP could be minimised by being aware of the potential consequences of nocturnal seizures. Being aware was not enough. There had to be something you could do about it and there wasn't. He did not agree that, given the recommendations of the SIGN and NICE guidelines, the default position should be that there should be a discussion of SUDEP with a newly diagnosed patient. He did not agree that the effect of the determination in the Findlay inquiry (mentioned below) was that he should have discussed SUDEP with Christina and/or her parents.

The other professional witnesses conceded that there had been at times a debate within the neurology community about the appropriateness of telling patients about SUDEP. At one time the concept of SUDEP was itself not the subject of universal recognition. There is no uptodate reliable information about current practice. One study was co-authored by Dr Susan Duncan, one

of the witnesses. The results of this study were contained in an article "Sudden Unexpected Death in Epilepsy (SUDEP) : Don't ask, don't tell" published in 2006 which was Crown Production 6. Dr Zeidler relied on this article for his assertion that his approach to advising patients about SUDEP was shared by 95% of other neurologists in the UK. A copy of the article was sent to Erin's mother by NHS Fife. In evidence Dr Duncan agreed that, as was submitted to me, "there were statistical and methodological weaknesses" in the research. Indeed that was relatively obvious to me in the broad nature of the questions forming the basis of the research study. The Scottish Public Services Ombudsman who considered Mrs Casey's complaints about Erin's care also criticised the methodology and reliability of this research.

However in trying to form a view of the practice of neurologists I found it far more instructive to have regard to the evidence given before me by experienced medical professionals as to their practice or the practice in institutions in which they worked.

Dr Smithson was chair of the Guideline Development Group for the NICE guidelines and was not aware of any suggestion that they were not founded in evidence. His view was that the NICE guidelines were "tools not rules" and that there was scope for a clinician to depart from the guidelines in a particular case. The appropriateness of this would depend on the particular guideline. However his view was that in relation to the recommendation in respect of SUDEP the scope for departure was "very limited". A clinician would have to have a very good reason not to follow the guideline and would have to be prepared to justify it.

Professor Cross was also one of the NICE Development Group. She was of the view that practitioners were expected to be aware of and follow the NICE guidelines unless they had "just cause" for not doing so. Even if based on expert opinion rather than empirical evidence the body of opinion would reflect the views of several experts. Clinicians could not just follow the guidelines they liked and ignore others. The recommendations on SUDEP were not driven by the determination of patients' groups.

Dr Duncan was not keen on the view that clinical advice should be given on a "tick box" basis. Despite the existence of the NICE guidelines clinicians had to be allowed "a degree of leeway". The guidelines reflected the views of "a few

doctors in London and patients' representatives". Nevertheless her actual practice was to tell "the vast majority" of her patients about SUDEP, albeit partly for what she called "self protection".

Dr Richard Roberts was chair of the Guideline Development Group for the SIGN guidelines. His view and the view of the group was that most or the majority of patients would be told about SUDEP, if not by name then as part of a discussion about death occurring in the context of a seizure. There had been some debate about including discussion of SUDEP as "essential information", but the Chief Executive of Epilepsy Scotland, who was part of the Group, made strong representations for its inclusion and there was "not much disagreement" about including it.

Drs McWilliam, Duncan and Roberts all gave information about SUDEP very early in the process of diagnosis. Professors Cross, Walker and Brown all stated that the issue of SUDEP would be discussed with a new patient within the first few months after diagnosis. None of these witnesses had any difficulty in providing the information and none had experienced any distressed reactions. Indeed there was evidence that the provision of clear information about the risk of death in epilepsy was in fact reassuring to many patients or their families some of whom thought the risk was actually much greater.

The general attitude of these witnesses was that the risk of SUDEP was an important aspect to the patient's condition and that therefore the patient had a "right" to know.

In addition none of these witnesses took the view that nothing could be done to reduce the risk of SUDEP occurring so that all recognised the value of emphasising for patients the importance of compliance with medication and avoiding triggers for seizures such as alcohol binges, controlled drug use, stress, lack of regular sleep. None of these witnesses saw any difficulty in taking an approach to giving advice which might run the risk of seeming "schoolteacherly", even though some were philosophical about the extent to which young persons might take on board the advice.

Equally, none was prepared to exclude the possibility, apparently vouched by some evidence, that intervention in a seizure might avert SUDEP and thus none was dismissive of the notion that patients or their carers might want to

address the question of night supervision and the use of alarms, even if the assessment of the efficacy of alarms varied.
Most of these professional witnesses worked or had worked in institutions where there was an epilepsy specialist nurse service and the information about SUDEP might be given by the diagnosing doctor or might be left to the specialist nurse. Either way the provision of the information did not depend on the patient asking and the patient was not left to research the topic via leaflets or the internet.

Erin – the Ombudsman's report

The report was Crown production 8. The report summarises Mrs Casey's complaint as relating to a failure to provide Erin with information about her newly diagnosed condition generally and in particular the provision of inadequate information about her medication regime and a failure to advise her about the risk of SUDEP. In respect of this last aspect of the complaint Mrs Casey is reported as being particularly concerned that Dr Zeidler failed to follow the SIGN and NICE guidelines and the recommendation of the Findlay Fatal Accident Inquiry. She also complained that he failed to record his decision not to follow the guidelines.
In the report the Ombudsman sets out the views of Dr Zeidler as represented to the Ombudsman during the investigation. Dr Zeidler took the view that Erin was not in a heightened risk group for SUDEP. He placed much reliance on the paper "Sudden Unexpected Death in Epilepsy patients: Don't ask, don't tell", referred to above, as supporting the notion that the vast majority of neurologists at least at that time (2006 and into 2008 presumably) did not routinely advise epilepsy sufferers of the risk of SUDEP for fear of causing anxiety. He, and Fife Health Board, took the view that the SIGN and NICE guidelines were only guidelines, that the so-called check list of information to be given to a patient was only provided as an example and, in respect of SUDEP, was not evidence based.
It was noted by the Ombudsman that no written information about her condition was supplied to Erin on first diagnosis "*which would have allowed her to make further enquiries as she wished*, *and should have ensured she properly understood the potential risks of not taking her medication"* (page 15,

para 37). There was no epilepsy specialist nurse service at the Victoria at that time.

There was "*no evidence of person-centred decision making"* for Erin. This latter conclusion appeared to be founded on the Ombudsman's view that a decision not to follow SIGN or NICE guidance or a sheriff's recommendation should be recorded in the patient's notes and that General Medical Council guidance issued in 2008 provided :- "*You should not withhold information necessary for making decisions for any (other) reason unless you believe that giving it would cause the patient serious harm. In this context "serious harm' means more than that the patient might become upset or decide to refuse treatment"* and "*If you withhold information from the patient you must record your reason for doing so in the patient's medical records and you must be prepared to explain and justify your decision*". The Ombudsman noted the differing views about advising patients about SUDEP or not. No concluded view was reached about whether Erin was at heightened risk of SUDEP. It could not be concluded that Dr Zeidler acted improperly in not telling her about SUDEP but the reasons given for not telling (the risk of upset) were not "in step with the direction of travel of NHS Scotland towards a mutual NHS" (page 15 para 36). This reference to "a mutual NHS" was an acknowledgement of a concept of involving patients as "partners" in their care, rather than just recipients of care, set out in a Scottish Government action plan launched in December 2007.

Thus the Ombudsman (a) held that Fife NHS Board should apologise to Mrs Casey for the failure to provide general written information about Erin's condition but refused to criticise Dr Zeidler for not advising about SUDEP; (b) held that that the decision not to advise about SUDEP should have been noted, a view largely based on subsequent literature; and (c) recommended that consideration of creating a specialist nurse post should be prioritised.

It appeared to me that the report set out various of the competing arguments on issues such as risk factors, amenability to change, telling (or not) about SUDEP, but stepped back from expressing a concluded view about most of them. It seemed to me that the Ombudsman had not had the benefit of anything like the very clear body of expert opinion which I heard.

My determination

The death of Erin Casey

It seems to me that my findings in terms of **sections 6(1)(a) and (b)** are uncontroversial and I do not propose to expand upon them. I am satisfied that around the time of her death, probably very shortly before, Erin suffered an epileptic seizure.

In terms of **section 6(1)(c)** I require to consider whether there were any reasonable precautions which could have been taken whereby the death might have been avoided. In the submissions made to me on behalf of Fife Health Board I have been asked to address myself to the question of whether there were any reasonable precautions which "**would have prevented"** the death. This is the wrong criterion and sets too high a test.

"*Certainty that the accident or death would have been avoided by the reasonable precaution is not what is required. What is envisaged is not a "probability" but a real or lively possibility that the death might have been avoided by the reasonable precaution"* Carmichael, *Sudden Deaths and Fatal Accident Inquiries* 3rd Edition page 174 para 5-75.

Having regard to the evidence which I found credible and reliable:-

(1) SUDEP is normally associated with a seizure;
(2) The risk of SUDEP occurring is reduced if, inter alia, the frequency of seizures is reduced;
(3) The frequency and incidence of seizures can be reduced by a number of factors, some related to lifestyle, but the most important related to proper compliance with a regime of anti-epileptic medication;
(4) Erin did not comply properly with her regime of medication and, as it happens, continued to have seizures;
(5) Had Erin been told of the risk of SUDEP she might have complied more assiduously with her regime of medication which might have prevented the seizure suffered by her on the night of 27th October 2006;

(6) If a seizure occurs intervention by another person might prevent SUDEP taking place;
(7) Had Erin been told of the risk of SUDEP she and her family would have discussed and considered the possibility of changing her university accommodation arrangements with a view to providing night supervision for her;
(8) Had Erin been subject to supervision on the night of 27th October her supervisor might have been able to intervene and death might not have resulted;

I have no doubt whatsoever that Erin should have been advised of the risk of SUDEP at or not long after her first diagnosis, albeit provisional, in April 2006. Dr Zeidler's reasons for not telling her were not convincing and were contradicted by the professional witnesses whom I held to be credible and reliable. Dr Zeidler's approach did not take account of the circumstances of the individual patient. He made no assessment to be able to judge if the patient was likely to suffer distress by being told of SUDEP, although he claimed to have assessed Erin as intelligent enough to understand her regime of medication without elaborate explanation and intelligent enough to carry out her own research into her condition if she wished. There was at that time no epilepsy specialist nurse service at the Victoria Hospital so until her next appointment in September Erin would have no monitoring of her condition or access to advice unless she sought it out herself. In addition Dr Zeidler had little or no evidential basis beyond one or two anecdotes for concluding that advising about the risk of SUDEP was such a distressing event that the advice was likely to be harmful and should be withheld. His concern was not supported by the experience of those who do tell. Underlying all of this of course was his assessment of the available published literature which in his view did not support the idea that there were any steps which could be taken to reduce the risk of SUDEP. While his view was shared by Dr Kirkpatrick, it was contradicted by all of the other witnesses from whom I heard. His assertion, based on Dr Duncan's research, that 95% of UK neurologists take the same approach as him to telling about SUDEP was in my opinion unreliable. If such a statistic was even close to being accurate I would have

expected some of the 95%, apart from Drs Zeidler and Kirkpatrick, to give evidence.

I believe that Dr Zeidler exercised appropriate clinical judgement at the first appointment with Erin in assessing her risk of SUDEP as low. As I will explain later I believe that there were deficiencies in the care of Erin but for which her non-compliance with medication and continuing seizures might have been discovered and addressed. However, having regard to Dr Zeidler's *de facto* state of knowledge at the time of the second appointment, I do not believe he was wrong to continue to assess her risk of SUDEP as low, assuming he considered the issue at all.

It is of course quite possible that, even had she known of the risk of SUDEP, Erin would not have complied to any greater extent with her regime of medication and might have continued to suffer seizures and not disclosed these. She and her family might not have considered issues of supervision or might have considered but rejected any change to her student accommodation requirements. I heard from various professional witnesses that even when their young patients are told of the risk of SUDEP some do not comply properly with taking their medication. Night supervision for a young student might be highly impractical. The efficacy of alarms is patchy and some patients give up on them. However the evidence of her family and her boyfriend, which I accepted, was that had Erin known of the risk of SUDEP her behaviour would have been affected and supervision would have been considered.

It also has to be acknowledged that even if Erin had complied with her medication and even if she had been subject to supervision she might nevertheless have succumbed to SUDEP on the night of 27th October. I am sympathetic to the submission made on behalf of Fife Health Board that in this area I am being invited to speculate. However I disagree that the conclusion that there were reasonable precautions which might have resulted in the avoidance of death is so speculative as to be remote. Having regard to the test which I must apply it seems to me that the precautions I have identified were reasonable and there was a real or lively possibility that their adoption might have resulted in the death being avoided.

I now turn to **section 6(1)(d)** and whether there were any defects in any system of working which contributed to the death. In April 2006 there was no epilepsy specialist nurse service at the Victoria Hospital in Kirkcaldy. There is now. Dr Zeidler's evidence, while not always consistent on the point, suggested that he would still in most cases, including someone like Erin, not tell the patient about the risk of SUDEP. However it appeared to me that he felt content maintaining this "purist non-telling" approach confident in the knowledge that a nurse would thereafter decide whether to inform the patient or not and would probably decide to tell. Thus he could preserve the integrity of his position while the trend for telling could be satisfied by someone else. In 2006 however, after Erin's first appointment in April, she would receive no further input into her newly diagnosed condition and its treatment until September unless she sought it out herself. As already explained Dr Zeidler took the view that his role was not to tell Erin what to do or what not to do. She was intelligent. She knew it was important to take her medication. This did not need reinforced. She knew what seizures consisted of. He did not want to lecture her about drugs, alcohol, lifestyle. He did not believe that her age and her pending removal from the family home to take up life as a student put her in any special situation deserving particular advice. He did not want to "force" information about SUDEP on her. As already noted, no other witness (Dr Kirkpatrick aside) felt the least compunction in addressing these matters with patients. Additionally however within the practice of all or most of these other witnesses there was an epilepsy specialist nurse service to which the newly diagnosed patient was referred. Very quickly that patient would meet the nurse who would, *inter alia*, reinforce or supplement the advice already provided, monitor issues related to medication and enquire about seizures. Witnesses saw this service as extremely valuable in supporting patients and taking pressure off consultants. Patients could access quickly and easily expert specialist advice about all aspects of their condition without having to book an appointment with their consultant or rely on generalist advice from their GP.

There was no such nurse service available to Erin. Thus, having had her first appointment with Dr Zeidler, unless she chose to contact him or her GP, there was no further contact until September. I was surprised that after the April

appointment, with or without my criticism of Dr Zeidler's approach to the giving of advice, Erin was effectively left to her own devices in managing her condition. She was 18. The diagnosis was potentially psychologically devastating for her. Her regime of medication was not straightforward. She was at a small risk of death. My surprise was confirmed when I heard that in the practices of the other witnesses this would not have happened. Had Erin been referred to an epilepsy specialist nurse service (had one existed in Fife) there is, in my view, a real possibility that she would have been provided with more advice and information, informed about the risk of SUDEP and that her seizure frequency and compliance with medication would have been monitored. She might have complied better with taking her medication. Seizures might have been eliminated. She might not have succumbed to SUDEP.

I appreciate that I could be accused of indulging in speculation on this issue. I have considered carefully whether the absence of a specialist nurse service can properly be described as a defect in a system of working which "**contributed**" to Erin's death or whether this is better dealt with as a circumstance relevant to the death in terms of section 6(1)(e). In my view having regard to the evidence which I heard of the widespread availability of such a service in other areas, including Tayside, and of the effectiveness of the service, its then absence in Fife must be seen as properly falling within the ambit of section 6(1)(d).

Finally I address **section 6(1)(e).**

I have detailed above the history of Erin's prescriptions. To recap, Erin received a 28 day supply of medication at hospital on 12th April. She collected a repeat prescription on 25th May and, taken properly, it would have lasted 56 days. So had Erin taken her medication as she should have done she should have picked up the repeat prescription to begin using it around 12th May and that repeat prescription should have lasted her until around mid July. She did not collect any other repeat prescription until 25th September 2006 but she did

not obtain further medication. At post mortem she had in her blood a level of medication well below the lowest therapeutic level. I heard no evidence as to anyone finding any residual supply of her medication after her death. When her GP, Dr Cruikshank, gave evidence he said that there was a practice in his surgery of chasing up patients who had requested a repeat prescription and had then failed to collect it. It was also likely that if someone accustomed to ordering repeat prescriptions went for a period of time without ordering one and then suddenly did, when that patient attended to collect the prescription enquiries might be made as to why there had been a gap. If there was a consultation with a patient on a repeat prescription then a failure to collect prescriptions would be noticed and addressed. Epilepsy patients were on a register. Every six months a review letter was sent to epilepsy patients asking various questions including questions about taking medication. If the letter was returned with the questions answered those answers were generally accepted as true. If there was no response a further letter would be sent and if there was still no response the patient's records would be referred to a doctor. Because Erin had gone to St Andrews and was registering with a GP there no six month review letter would have gone out.

Dr Cruikshank agreed that if there had been a system for monitoring whether Erin had ordered, collected and used her repeat prescriptions then any failures would have been identified and pursued with her. Thus her non-adherence to medication might have been discovered, she could have been consulted with and given advice, so that she might have thereafter adhered to her medication. Her seizures might have been better controlled and she might not have died.

I have considered whether this inability to monitor the uptake and use of repeat prescriptions could be regarded as a defect in a system of working contributing to the death. I do not feel I can go so far. I have no idea of the feasibility of initiating such a system. I heard no evidence on that matter and no evidence of any such system in operation elsewhere.

The death of Christina Illia

As in relation to Erin it seems to me that my findings in terms of **sections 6(1)(a) and (b)** are uncontroversial and I do not propose to expand upon them. I am satisfied that around the time of her death, probably very shortly before, Christina suffered an epileptic seizure. The evidence for a seizure was less clearcut than in respect of Erin. Dr Evans the pathologist could not say categorically that there had been a seizure but there were signs of a hypoxic mode of death, indications that Christina had bitten her tongue and her father saw that her fists were clenched.

S**ection 6(1)(c)**

Having regard to the evidence which I found credible and reliable:-

(1) SUDEP is normally associated with a seizure;

(2) The risk of SUDEP occurring is reduced if, inter alia, the frequency of seizures is reduced;

(3) The frequency and incidence of seizures can be reduced by a number of factors, some related to lifestyle, but the most important related to proper compliance with a regime of anti-epileptic medication;

(4) If a seizure occurs intervention by another person might prevent SUDEP taking place;

(5) Had Christina and her parents been told of the risk of SUDEP they would have discussed and considered the possibility of providing night supervision for her, possibly by use of an alarm;

(6) Had Christina been subject to supervision on the night of 23rd March her supervisor might have been able to intervene and death might not have resulted.

Christina's parents were caring, loving and supportive of her. They had had a lifetime of dealing with her serious medical conditions, taking advice from medical professionals, weighing it and acting on it. Once Christina was old enough to do so she had also cooperated well with her treatment whether for her birth problems, her asthma or her epilepsy. Dr Kirkpatrick had no basis for concluding that they or Christina were likely to experience inappropriate

distress if advised of the risk of SUDEP. It was far more objectively likely that they would have taken the news in their stride and dealt with it. In my view Dr Kirkpatrick, in withholding the information for this reason without consideration of the particular patient and her family, was evincing the “blanket” approach he professed to dislike when it was put to him that all patients should be advised of the risk of SUDEP unless there was a good reason for not so doing. His approach was not reflected in the practice of Dr Roberts, also a consultant at Ninewells, who discussed SUDEP with adult patients who were having generalised tonic-clonic seizures. Likewise his approach was not reflected in the practice of any other medical witness other than Dr Zeidler.

Like Dr Zeidler Dr Kirkpatrick’s view of the published literature was that there were no steps which could be taken to reduce the risk of SUDEP assuming seizures were controlled. As I have already explained I found overwhelming the evidence of the other witnesses who regarded the evidence as supporting the notion that intervention might prevent a patient who has had a seizure from succumbing to SUDEP. They could not assert why this was but they were quite relaxed about tailoring their clinical judgement and advice to patients around the acceptance of the potential efficacy of intervention. Similarly they or their epilepsy specialist nurses had no difficulty discussing with patients the pros and cons of the use of alarms to monitor nocturnal seizures, thus potentially allowing a carer to intervene. Christina’s parents were used to putting her in the recovery position if she had a seizure. Mr Ilias had had first aid training. The evidence was that merely moving a patient having an epileptic seizure and putting her/him in the recovery position might be sufficient to resuscitate.

In the latter half of 2008 Christina suffered a number of seizures. The last of these was in December 2008. She had no seizures in 2009 prior to her death in March. Nevertheless Professor Cross believed that because of the occurrence of these seizures Christina was at heightened risk of SUDEP, that the seizures should have been investigated and a change to her medication should have been considered. Alongwith her father she attended for a review of her epilepsy on 4th March. She saw Dr Jay Shetty, specialist registrar to Dr

Kirkpatrick. According to Christina's father he told Dr Shetty about Christina's extreme tiredness and Dr Shetty said this might be due to her medication. Mr Ilia said he was surprised because Dr Shetty then increased the dosage of her medication. Mr Ilia thought that if the doctor considered that medication might be causing the tiredness then he should have changed the medication rather than increasing the dose. After the appointment Dr Shetty wrote a letter to Christina's GP in which he reported the outcome of the consultation. There was no mention in the letter of the report of tiredness and no suggestion of any concerns. The letter also recorded that at the consultation Christina's dosage of medication was not changed. Dr Kirkpatrick's evidence was that if Christina was suffering extreme tiredness and that was reported to him he would have investigated the cause. I was urged by counsel on behalf of Christina's family to conclude that the facts were as set out above and that, because of the increased frequency of seizures during the second half of 2008 and Christina's tiredness she was at greater risk of SUDEP. It was also put to me that the failure to record and report the assertion of tiredness and to act on it was a significant failure. I was urged to hold that investigation of her seizures and her lack of sleep should have taken place, her medication should have been reviewed and that these would have been reasonable precautions which might have avoided her death.

The opinion of Dr McWilliam was that the care provided to Christina in relation to her epilepsy was appropriate and of a high standard, including during the period covering the second half of 2008 and 2009. Professor Cross was of the view that Christina's less well controlled experience of seizures during that time up to December 2008 merited investigation. However the evidence was that the seizures, when reported, were assessed for their significance and medication was sometimes adjusted. The seizures stopped. I am not satisfied that the issue of Christina's tiredness was mentioned to Dr Shetty at the appointment on 4th March. There is no note of it and Mr Ilias' recollection that her medication was increased is wrong.

As one witness said, risk assessment is not fixed at one point. It will vary throughout the history of the patient according to events. Professor Cross

thought that Christina's risk of seizure and therefore SUDEP increased in late 2008 because of her experiencing less well controlled seizures. She did not think that the seizure free period between December and March lessened that assessment of risk. She expressed the level of risk in a negative way – she would struggle to say that Christina had no higher risk than the general population and also – one cannot say such a patient is not at a raised risk. Dr McWilliam assessed Christina's risk of SUDEP as low throughout the entire history of her epilepsy. Whatever distinction there is to be drawn between these two expressions of opinion it is not in my view quantifiably significant. On no view of the evidence could Christina's perceived risk of succumbing to SUDEP be described as anything other than relatively low at any stage. I am certainly not satisfied that there was any failure in her care and treatment during late 2008 and early 2009 the rectification of which could be described as a reasonable precaution by which death might have been avoided.

In terms of **section 6(1)(d)** I do not find that there were any defects in any system of working which contributed to Christina's death.

In terms of **section 6(1)(e)** I require to consider whether there were any other facts which were relevant to the circumstances of Christina's death. I have been urged to consider the issues of the provision of information about SUDEP, supervision and the use of alarms. I have nothing further to add about these matters to what I have said above. I have been asked to consider the issue of communication and note taking by medical professionals. I do not believe that any significant concerns arose in respect of this and I have nothing to say about it.

I have also been asked to make comment on the behaviour of officers of Tayside Police when they attended at Christina's parents house on the morning of her death. Despite having no substantial basis for suspecting let alone concluding that a crime had been committed an officer or officers referred to the house as a "crime scene" and, on the basis of that analysis, tried to hurry Christina's parents out of the house. This included walking in on

Lynne Wheeler when she was getting dressed and trying to get Mr Ilias to tell Ms Wheeler to hurry up and get dressed. Detective Sergeant Thomson said the expression “crime scene” was used at all unexpected deaths and its use was a matter of national practice. I heard no further evidence on the matter. I have been told by the Crown that the issue is being addressed by the police and I have been urged to make no formal recommendation. I do not understand why I should refrain from making a recommendation if I think one is appropriate. The use of the phrase “crime scene” was inappropriate and grossly insensitive. While police officers attending the scene of an unexpected death require to approach their investigations with open minds until the facts can be established the reality was that they were presented with two clearly distraught parents and should have dealt with them with sensitivity and compassion. It would be a function of the same virtue of an open mind to err on the side of treating the parents with compassion until the truth can be determined. If the police attitude on the morning of 27th March was truly the manifestation of a nationally established practice, and I have no reason to doubt that, then the practice should be changed.

Recommendations

As was submitted to me “the practice of the medical profession is a matter for the profession itself”. The medical profession may, in its wisdom, issue guidelines but ultimately the question of clinical practice and the provision of information to patients has to be a matter for the exercise of the professional judgement of the clinician concerned.

However, having presided over this inquiry I have the duty and responsibility to make such recommendations as I see appropriate in relation to the issues raised in the inquiry. Insofaras my recommendations relate to questions of clinical health practice I do of course put them forward as a layman. I would not presume to dictate to health professionals in areas of medical practice. However I believe that it is my duty to articulate my recommendations clearly and trust that they will be considered seriously by the relevant authorities and professional bodies. In particular I hope that my recommendations will come to the attention of the Cabinet Secretary for Health and Wellbeing, the Chief Medical Officer for Scotland, NHS Scotland including the various local NHS

Boards, the General Medical Council, the Nursing and Midwifery Council, the General Pharmaceutical Council, the various medical Royal Colleges and those responsible for the issuance of guidelines to the health professions such as the SIGN and NICE guidelines. There is also one specific recommendation relevant to Tayside Police and perhaps other police forces.

I recommend the following:-

(1) The vast majority of patients with epilepsy, or their parents or carers where appropriate, should be advised of the risk of SUDEP on first diagnosis or if , in the particular circumstances of that patient, there are exceptional circumstances for delaying immediate provision of the information, then within a very short time thereafter. Advice about the risk of SUDEP should only be withheld if there is assessed to be, in the case of a particular patient, a risk of serious harm to the patient in providing the information or the patient has learning difficulties.

I accept the evidence of many of the witnesses that patients have an entitlement to be informed about a significant aspect of their condition regardless of the particular applicable risk, though I would expect the information to be provided against the background of, inter alia, a description of that risk. Additionally, in my assessment of the evidence which I accepted, there are good practical reasons for informing the patient about the risk of SUDEP. It may underline the need to comply with the regime of medication and it may reinforce the merit in adopting modes of lifestyle which could reduce the risk of seizure and therefore of succumbing to SUDEP. Finally it would give the clinician, the patient and his or her family the opportunity to consider issues of night supervision, the use of seizure alarms and the practice of resuscitation techniques all of which, on the evidence which I accepted, might reduce the risk of SUDEP.

(2) A decision <u>not</u> to inform a patient or his or her family about SUDEP should be recorded in the patient's medical records alongwith an explanation, however brief, for the decision.

(3) After a consultation with an epilepsy patient the consultant or, where appropriate, the specialist epilepsy nurse, should send a letter to the patient and to the patient's GP summarising the findings of the consultation and any care or treatment decisions taken.

(4) The information and advice about SUDEP should be provided directly by the consultant in charge of the patient's case or, where appropriate, by an epilepsy specialist nurse.

The majority of the expert witnesses stated that this was the course followed by them and their nurses. None had any experience of significant adverse reactions. None found any difficulty in imparting the information. It was suggested that the more clinicians engaged in telling patients about SUDEP the easier it became. It was not left to patients to ask about SUDEP or risk generally and patients were not simply given information leaflets and expected to carry out their own research. The witnesses were, it should be said, fairly confident that patients, particularly those with internet access, would engage in their own research. It was at least partly for this reason that the witnesses thought it important personally to give information and advice about SUDEP, so that patients would be properly informed and not made excessively anxious by something read online.

(5) All NHS Boards should prioritise consideration of their arrangements for the care of epilepsy patients, whether a post of epilepsy specialist nurse is required, if not already in place, in any particular hospital and, if there is such a post, whether the current arrangements are adequate.

I did not hear definitive evidence about the nationwide use of epilepsy specialist nurses. Ninewells Hospital in Dundee has had such a post for some time. Since a point after Erin's death Victoria Hospital in Kirkcaldy has had an epilepsy nurse thought Dr Zeidler's evidence suggested that there was some doubt about covering the post. All of the other expert witnesses had the benefit of such a service and its merit was clear. It appeared that the nurse usually had almost as much expertise in the practical care and treatment of patients as the

consultant. The nurse worked in a fashion complementary to the consultant's role. The consultant often had much pressure on his or her time. The nurse could devote more time to the patient's information and other needs and was generally more accessible by telephone or otherwise to give advice and answer questions about care, treatment and medication.

(6) Current arrangements for the provision of written information packs to newly diagnosed epilepsy patients and their families should be reviewed to ensure that they are adequate and meet the needs of patients for information and access to services and support at a distressing time.

Dr Zeidler was vague about the information packs currently given to patients at his hospital.

(7) Where a patient is prescribed medication both the prescribing doctor and the dispensing pharmacist should provide the patient with clear and easily understood instructions as to how the medication is to be taken. If the regime of medication is relatively complex the doctor should take time to explain it and should, in particularly complex cases, provide written instructions. In the case of all prescriptions pharmacy labels should be clearly printed in easily read, jargon-free text.

This recommendation may seem obvious and unnecessary. However there was clear evidence from Erin's family, which I accepted, that Erin did not properly understand the way she was supposed to take her medication in the period after first diagnosis. When Dr Zeidler had explained the medication to her she had made notes on a scrap of paper. To begin with at least she had required to halve tablets. The pharmacy label provided with her medication was printed in a small, dense typeface. If, for various other reasons (the casual attitude of a teenager, denial of her condition, side effects), she was reluctant to take her medication, this confusion and lack of confidence would not have helped. There were thus strong practical reasons for Erin to have her medication explained properly.

(8)Consideration should be given to the feasibility of introducing a system in GP practices (possibly in conjunction with pharmacies) whereby the uptake of repeat prescriptions by patients can be monitored.

(9)Those responsible for the issuance of guidelines on the care and management of epilepsy patients should consider the adequacy of existing guidelines in the light of this inquiry and the evidence led. They should consider the recommendations made, any resultant revision of the guidelines which might be appropriate and the need for clarifying for medical professionals the status of the guidelines in clinical practice.

There was unanimity amongst the medical witnesses that the SIGN and NICE guidelines are “tools not rules”. They exist to assist clinicians in identifying what is perceived as best practice but decisions about the care and treatment of individual patients are entirely for the judgement of the relevant consultant. Dr Zeidler, at least in relation to the issue of informing patients about SUDEP, declared himself entitled to analyse what he saw as the evidence base for the apparently clear guideline that information about SUDEP was “essential” and concluded that the guideline was not evidence based and therefore could be ignored. Having regard to his view of the status of the guideline he also did not feel that his decision not to follow it required to be noted in the patient’s medical records, as on the face of it required by another guideline. His decisions in this area were not informed by any particular assessment of Erin’s circumstances but represented his general view, just as his decision not to inform Erin about SUDEP represented his policy rather than being informed by a judgement that she as an individual would be excessively distressed or put at risk of serious harm by the information. The other medical witnesses who had much more experience than Dr Zeidler and who appeared less trammeled by dogma than him, accepted the guidelines for what they seemed to be – an informed and uncontroversial guide to best practice, to be followed unless a patient’s circumstances suggested otherwise in which case clear notes should be maintained of the reasons for that decision. Their view was that

clinicians could not simply select those parts of the guidelines of which they approved and ignore the other parts.

(10)It may be that some of my recommendations, if adopted, would have ramifications for training of medical professionals. Regardless of such consequential issues of training it appeared to me that this inquiry revealed other areas of clinical practice in respect of which I recommend that consideration be given to the training needs of medical professionals:-

(a) the assessment of published research literature;

(b) the status of published guidelines on care and treatment;

(c) the provision of potentially distressing information to patients;

(d) methods for obtaining information from patients, particularly teenagers or those who may be reluctant to be honest with their doctor or nurse;

(e) the provision of information and advice about modifying behaviour to achieve lifestyle changes which may contribute to the relief of a condition or minimise a risk associated with that condition;

(f) recognising the particular circumstances of a patient and tailoring advice and information as appropriate with particular emphasis on teenagers or young adults moving towards independence, engaging in risky activities or beginning to take responsibility for themselves.

My recommendations in this area are largely driven by the view I formed of the evidence of Dr Zeidler. I have referred to his evidence above. He was reluctant to regard any published research as so definitive or convincing that it would impact on his clinical judgement, unless it supported his views that patients should not be told about SUDEP because of possible distress and that SUDEP was unpreventable. He felt himself able to pick and choose those parts of the SIGN and NICE guidelines of .which he approved. He seemed to be of the view that he could not probe patients to test the reliability of their claims to be taking their medication or experiencing no seizures, despite recognising that some patients were tempted to be less than honest. He was not prepared to give firm advice to

patients about moderating their behaviour in any way which might reduce the risk of seizures or SUDEP for fear of appearing “paternalistic” or “schoolmasterly”. He was not prepared to acknowledge that some patients, on the cusp of adulthood, might suitably be given robust advice about the particular issues this might throw up in managing their condition. The other medical witnesses had no such problems in their attitude to the literature or the guidelines. They also had no difficulty in acknowledging the importance of getting accurate information from patients and providing suitably tailored advice to patients. As already mentioned one witness had the benefit of a clinic, a “transition” service, specifically aimed at young adults with epilepsy moving towards independence.

On behalf of Erin’s family I was urged to recommend specifically that Dr Zeidler should undergo some training in these areas. I do not feel it appropriate or necessary to personalise my recommendations.

(11) I recommend that Tayside Police and, if appropriate, other forces, review their practice in relation to their approach to the location of a sudden unexpected death and in particular the practice of, *ab initio,* describing it as a “crime scene”.

SHERIFFDOM OF TAYSIDE CENTRAL AND FIFE
AT DUNDEE

UNDER THE FATAL ACCIDENTS AND SUDDEN DEATHS INQUIRY
(SCOTLAND) ACT 1976

Addendum to

Determination by

Sheriff Alistair JM Duff

In respect of

Fatal Accident Inquiry

Into the deaths of

Erin Casey

and

Christina Fiorre Ilia

Dundee 26th August 2011

Following the publication of my determination dated 24th August I received representations from solicitors acting on behalf of the parents of Christina Ilia. They requested permission to listen to the record of proceedings of the inquiry to ascertain whether I had misrepresented the evidence of Marcos Ilias in relation to a consultation with Dr Shetty on 4th March 2009. This consultation

and the evidence of Mr Ilias is referred to at pages 11 and 40 of the determination.

I have checked my notes of evidence and I am satisfied that I have not accurately recorded Mr Ilias' evidence on the issue. My notes disclose that in evidence Mr Ilias stated that he advised Dr Shetty that Christina was experiencing disrupted sleep patterns. According to Mr Ilias Dr Shetty indicated that she should try to avoid that. Dr Shetty then went on to advise that her medication would be reviewed in three months and the dosage **might** (my emphasis) then be increased. Mr Ilias thought this was odd.
I am therefore wrong in noting in my determination that the evidence of Mr Ilias was that the medication **was** increased by Dr Shetty at this consultation.

I apologise to Mr Ilias for this.

However I remain not satisfied that the issue of Christina experiencing disrupted sleep patterns was raised with Dr Shetty at this consultation. Even if it was I would not take a different view of the quality of Christina's care and treatment during this period, nor would I amend my formal determination or my recommendations.