A microscopic image of a neuron, showing a central nucleus and branching processes, overlaid with a teal color filter.

# Sudden Unexpected Death in Epilepsy

a global conversation

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**Edited by  
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ISBN 0-9758011-0-4

First published 2005 by:

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Typeset in Arial/Garamond

Cover Image by Jenny Solomon Dreamstimes.com

Printed and bound by Pegasus Printing

Blacktown NSW 2148 Australia

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# Contents

<b>Acknowledgements</b>	<b>v</b>
-------------------------	----------

<b>Foreward</b> <i>Ann Jacoby, UK</i>	<b>vi</b>
---------------------------------------	-----------

<b>Part 1: facing the questions</b>	<b>1</b>
-------------------------------------	----------

What is SUDEP? <i>Gail Bell &amp; Ley Sander, UK</i>	<b>2</b>
------------------------------------------------------	----------

Why the need for action? <i>John Lipetz, UK</i>	<b>4</b>
-------------------------------------------------	----------

<i>Becky aged 11</i>	<b>7</b>
----------------------	----------

Does SUDEP occur in children? <i>J Helen Cross, UK</i>	<b>8</b>
--------------------------------------------------------	----------

Who is at risk? <i>Jose F. Téllez-Zenteno &amp; Samuel Wiebe, Canada</i>	<b>10</b>
--------------------------------------------------------------------------	-----------

How does SUDEP occur? <i>Lina Nashef, UK</i>	<b>12</b>
----------------------------------------------	-----------

<b>Part 2: facing the facts</b>	<b>15</b>
---------------------------------	-----------

An audit of epilepsy-related deaths <i>Jane Hanna, UK</i>	<b>16</b>
-----------------------------------------------------------	-----------

<i>Kristen aged 25</i>	<b>19</b>
------------------------	-----------

SUDEP and the post mortem <i>Marjorie Black, UK</i>	<b>20</b>
-----------------------------------------------------	-----------

<i>Celene aged 31</i>	<b>22</b>
-----------------------	-----------

Certifying SUDEP <i>Noel Woodford &amp; Matthew Lynch, Australia</i>	<b>24</b>
----------------------------------------------------------------------	-----------

Guidance for SUDEP in clinical practice <i>Henry Smithson, UK</i>	<b>26</b>
-------------------------------------------------------------------	-----------

<b>Part 3: facing the uncertainties</b>	<b>29</b>
-----------------------------------------	-----------

<i>David aged 30</i>	<b>30</b>
----------------------	-----------

Supporting the bereaved <i>Patricia Johnston, UK</i>	<b>31</b>
------------------------------------------------------	-----------

Responding to community need <i>Paul L Schraeder, USA</i>	<b>34</b>
-----------------------------------------------------------	-----------

Managing fear <i>Robert Mittan, USA</i>	<b>36</b>
-----------------------------------------	-----------

Accessing information <i>Jennifer Preston, UK</i>	<b>38</b>
---------------------------------------------------	-----------

Empowering the global community <i>Steven C Schachter, USA</i>	<b>40</b>
----------------------------------------------------------------	-----------

# Contents

<i>Peter aged 27</i>	42
Communicating risk <i>Robert Mittan &amp; Catalina Rofloc Mittan, USA</i>	44
Telling young people? <i>Charlotte Lawthorn &amp; Phil EM Smith, UK</i>	46
<i>Matthew aged 26</i>	48
Reflecting on my clinical experience <i>Mark Cook, Australia</i>	49
Educating health professionals <i>Patricia Osborne Shafer &amp; Joan K Austin, USA</i>	51
Living with the risks <i>Maree Kearton, Australia</i>	54
Considering medico-legal issues <i>Roy Beran, Australia</i>	55
<i>Dianne aged 31 &amp; Colette aged 17</i>	58
Determining the right to know <i>Robert Carr, Scotland</i>	59

## **Part 4: facing the future** 63

Australia <i>Rosemary Panelli, Denise Chapman, Brendon Moss</i>	64
Canada <i>Lionel Carmant</i>	66
Chile <i>Tomás Mesa, Carlos Acevedo &amp; Keryma Acevedo</i>	68
China <i>Shichuo Li &amp; Yongqing Zhao</i>	73
Cuba <i>Salvador González Pal &amp; Erick González Delgado</i>	75
Germany <i>Robert Bauer</i>	76
Greece <i>Athanasios Covanis</i>	77
India <i>H.V. Srinivas</i>	79
Ireland <i>Mike Glynn</i>	80
<i>John aged 19</i>	82
Kenya <i>Charles Gachenia Woiye &amp; Anne Gathoni</i>	83
Niger <i>D. Douma Maiga &amp; A. Alzouma</i>	84
Pakistan <i>Syed Wasim Akhtar</i>	85
Romania <i>Gelu Stanculescu</i>	86
Scotland <i>Susan Douglas Scott</i>	88

## **Bibliography** 90

## **Websites – SUDEP links** 96

# *Acknowledgements*

We embarked upon this project not knowing how it would be received. From our experience we felt there was a need for a resource that could present a succinct picture of SUDEP bringing together both the science and the human experience in an accessible form for all interested readers. We distributed invitations far and wide via email and we were overwhelmed by the positive responses. As the number of acceptances grew so did the number of pages.

We were delighted when Epilepsy Bereaved chose to partner Epilepsy Australia in this endeavour and to incorporate the publication into their ten-year anniversary celebrations. A special note of appreciation to Jane Hanna for her invaluable assistance with this project. Epilepsy Bereaved has been inspiring and supporting our SUDEP work in Australia for nearly ten years and we thank Jennifer Preston for her tireless efforts. We congratulate the charity on its very significant contribution to the epilepsy community.

We thank the authors for their considered observations – each a unique perspective on SUDEP. While diverse in content and style, the articles have come together to construct a compelling mosaic of global experience. The willingness of the authors to make time in their busy lives for this project is much appreciated. This book could not exist without their generosity and enthusiasm.

The contributing families, especially, deserve our gratitude for entrusting us to tell their stories. We feel privileged to be given this opportunity to share your stories and we respect your courage.

We invite all readers to join us in this ongoing conversation and welcome your comments at *[info@sudep.org.au](mailto:info@sudep.org.au)*

**Denise Chapman**  
**Rosemary Panelli**

**Brendon Moss**  
**Russell Pollard**

# Foreward

My first real encounter with the problem of SUDEP was at the official launch, in 2002, of the UK National Sentinel Clinical Audit of Epilepsy-Related Deaths, which took place in very grand surroundings in the Houses of Parliament. I knew about the risk of death in epilepsy before then, of course, but only as a subject for academic study. Suddenly, I was hearing the stories of people who had suffered SUDEP and beginning to understand the terrible sense of loss their deaths brought to their families and friends. There are more stories such as theirs in this new publication and it is, as then, a great privilege to read them.

As Chair of the 3<sup>rd</sup> International Commission on Risks and Insurability in Epilepsy, I was honoured to be asked to write the foreword to this 'global conversation' about SUDEP. The 3<sup>rd</sup> Commission and its predecessors have laboured hard to gather together high quality information about the various kinds of risk people with epilepsy face and to make it accessible to them and all those involved in their care. Thanks to research over recent years, we now understand a considerable amount more than we did about the risk factors for SUDEP and the importance of making people with epilepsy aware of this particular type of risk. Where previously there was considerable reluctance to do so, there is now much more openness – and as Bob Mittan comments in his piece, the conversation need not be a negative one since knowledge, however potentially threatening, can help people with epilepsy take control of their condition and improve the outcome.

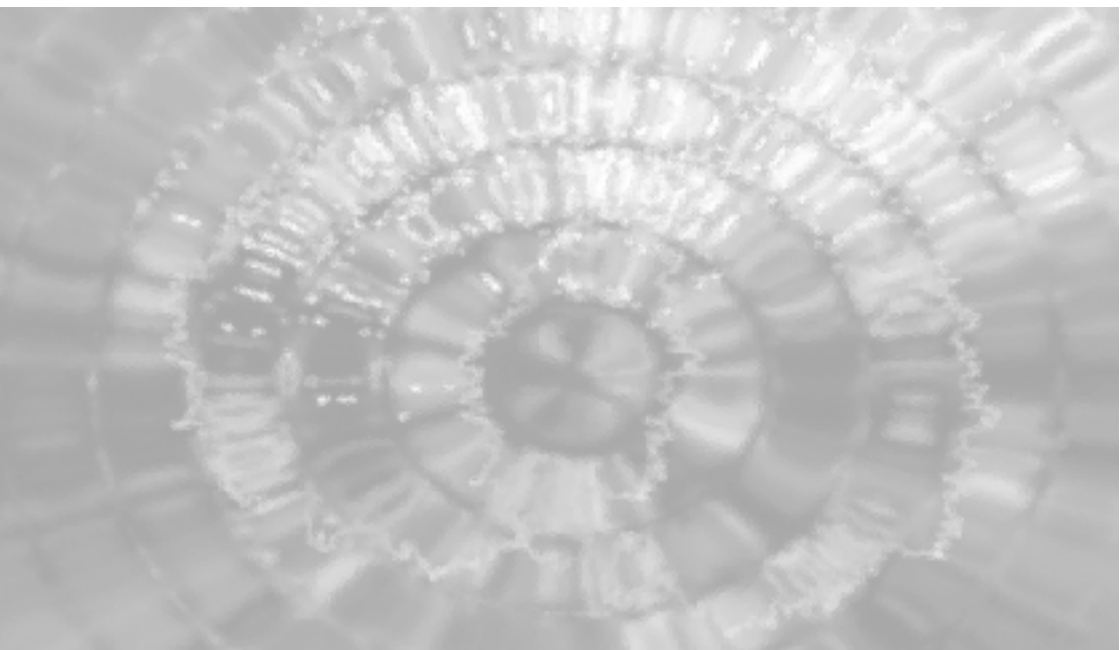
Presenting information about risk in a way that is meaningful to patients and families is a challenge for all health and social care professionals working with them. This publication raises some difficult and painful questions, but also begins to provide some answers in a way that will make it an invaluable asset to many, both people with epilepsy and those supporting people with epilepsy. I congratulate the authors and the editors on its production.

***Ann Jacoby***

***Chair, 3<sup>rd</sup> International Commission on Epilepsy Risks and Insurability  
August 2005***

# Part 1.

*facing the questions*





# What is SUDEP?

In 1868 Bacon, an eminent physician, noted the occurrence of ‘sudden death in a fit’ and almost 40 years later Spratling, one of the earliest American neurologists, recognised epilepsy as ‘a disease which destroys life suddenly and without warning through a single brief attack.’ Despite this, in the 1960’s it was suggested that ‘there is no reason why ...*someone with epilepsy*... should not live as long as he would if he did not have epilepsy’ (Livingstone 1963).

SUDEP is sudden unexpected death in someone with epilepsy, who was otherwise well, and in whom no other cause for death can be found, despite thorough post mortem examination and blood tests. The definition excludes people dying in status epilepticus and those who drown.

Awareness of SUDEP has increased over recent years, yet in many countries the medical profession has been reluctant to consider SUDEP. Indeed, there is little information on the number of cases in different countries. It has been estimated that the risk of sudden death is almost 24 times higher than for someone without epilepsy.

Most people with newly diagnosed epilepsy will stop having seizures, and SUDEP is very rare amongst them. Searching for risk factors in this group would require meticulous follow up of large numbers of people. Studies of SUDEP have therefore usually been conducted in groups of people with more severe forms of epilepsy, such as specialist clinic populations, hospital inpatients or residential groups. The risk of SUDEP is elevated in these populations. It is estimated as between 1:500 and 1:1000 patient-years in community based populations with epilepsy, and even higher in people considered for surgery.

The cause of death in SUDEP is currently, by definition, unknown, but various risk factors have been suggested. These include young adulthood, presence of convulsive attacks, poor seizure control and poor adherence with antiepileptic drugs (AEDs). Other suggested risk factors are male

gender, use of more than one AED, frequent changes of dose or type of AED, alcohol abuse and certain epilepsy syndromes.

Studies of age at death in SUDEP can be problematic because its definition requires negative findings at post mortem examination. Many elderly people have evidence of vascular disease and it is often difficult to exclude this as a cause of death. Most studies have found young adults as the group at higher risk. The age of onset of seizures is lower in people with epilepsy who died of SUDEP than in those dying of other causes.

SUDEP is usually unwitnessed but, when witnessed, often follows a convulsion. Evidence for a seizure prior to death is frequently, but not always, found at post mortem examination. Studies have found that most cases of SUDEP in whom the seizure type was known, had a history of convulsions. Many people dying of SUDEP are found in or near the bed. A recent study found that supervision at night appears to be protective.

Higher rates of SUDEP are found in studies of people with severe epilepsy, suggesting that people with frequent, severe seizures are most at risk. Some authors have suggested that seizure frequency is not a risk factor but a recent study found it to be the most significant risk factor.

There is conflicting evidence concerning the use of more than one AED as a risk factor. One study which showed increased risk associated with multiple AEDs suggested this may be because these people have more severe seizures, while another found the increased risk associated with more than two AEDs was still significant after adjusting for seizure frequency. Other studies have not found any association.

People have debated whether SUDEP is more likely in men than women, but a recent study found the rate of SUDEP to be identical in men and women.

***Gail Bell & Ley Sander***  
***Institute of Neurology, Queen Square, London, UK.***

# Why the need for action?

The UK-based organisation Epilepsy Bereaved works to inform and raise awareness of SUDEP and other epilepsy-related deaths, promote research, and provide information and support to people affected by an epilepsy-related death. Ten years of work has seen a dramatic shift in thinking and practice on SUDEP in the UK. The context of overwhelming lack of recognition and interest in SUDEP during the early 1990's has changed to a situation today where there are numerous initiatives from government and professional bodies. Epilepsy mortality is now addressed and people who are bereaved through epilepsy have ready access to specialist information and support from Epilepsy Bereaved.

Epilepsy Bereaved began with a campaign by five women – Catherine Brookes, Jane Hanna, Sheila Pring, Sue Kelk and Jennifer Preston. Jennifer's son William died in 1988 (aged 22); Jane's partner and Sheila's son Alan died in 1990 (aged 27); Catherine's son Matthew died in 1991 (aged 21) and Sue's daughter Natalie died in 1992 (aged 22). All were young and active people who died suddenly and unexpectedly. Neither doctors nor professionals involved in the investigation of the deaths could adequately explain why or how they had died nor identify ongoing research to answer these questions. Families affected by SUDEP were left searching for answers to the question 'why did they die?' All thought they were completely alone and due to the lack of recognition of SUDEP it took four years for the founding members to discover each other. The breakthrough came when the national media featured a story in 1992 about the sudden death of Alan and provided a contact point for the families to write and to finally meet. Out of this basic need for togetherness, Epilepsy Bereaved was formed.

In 2005 Epilepsy Bereaved provides an ongoing service for 700 families across the UK and Ireland.

In 1995 the families created the charity Epilepsy Bereaved. In the early 1990's the subject of SUDEP was not being addressed except by a hand-

full of clinicians and the work of Epilepsy Bereaved was sometimes viewed as controversial and taboo. It was the partnership between these dedicated clinicians and Epilepsy Bereaved that made the campaign not only possible, but also highly successful.

In 1996 Epilepsy Bereaved, with the support of an educational grant from Glaxo, convened a workshop of international epilepsy experts and epilepsy organisations to address sudden death and epilepsy. The workshop produced a series of published papers on SUDEP addressing issues of definition, mechanisms, risk factors, information, and prevention (Epilepsy & Sudden Death 1997). The years following saw increased research activity on SUDEP including important new studies highlighting optimum seizure control as a key preventative measure.

The workshop also called for governments to urgently investigate what proportion of epilepsy deaths were potentially avoidable. A lobby, led by Epilepsy Bereaved between 1997 and 1999, involved petitions, written questions, an epilepsy debate in the United Kingdom parliament (Hansard 1998), and meetings with ministers and civil servants. Governments commented that the most effective part of the campaign was the involvement of bereaved families:

'In that regard, we owe a debt of gratitude to Epilepsy Bereaved and all those who have given their time, efforts and energy to support its valuable work for having raised the consciousness of the House and Hon. Members about sudden, unexpected death from epilepsy. The stream of correspondence that has come into my Department from families who are living with the reality of bereavement and who are determined ... that their loved ones shall not have died in vain has helped to make the whole House conscious of the importance of this issue'.

*Paul Boateng, Minister,  
Parliamentary Debate*

Most significantly, one bereaved mother met with her local Member of Parliament Stephen Twigg who re-established, and became the leader of,

a group of politicians keen to support the campaign. The outcome of the SUDEP campaign was funding for a national investigation into epilepsy deaths and in 1998 Epilepsy Bereaved became the first voluntary sector organisation to lead a national clinical audit. The National Sentinel Clinical Audit of Epilepsy-Related Deaths was the first national and international report to address the preventability of SUDEP deaths establishing in 2002 that 42% of epilepsy deaths in the UK are potentially avoidable (Hanna 2002). The audit led to a series of national initiatives. In parallel, the charity commissioned research into the views and needs of families affected by epilepsy deaths.

The charity relies heavily on the power of individual experiences. One example of this was support to the Findlay family leading to the first judicial determination relating to SUDEP prevention and information on risk (Taylor 2002). This judgement prompted the government in Scotland to seek action from Health Boards on prevention of SUDEP and by 2004 all but two Health Boards in Scotland had developed a new model for delivery of epilepsy services through the use of clinical networks.

The charity's work has been presented at international epilepsy conferences in Australia (1998, 2004), Ireland (1997), Poland (1999), Brazil (1999), Malta (2004), Paris (2005), and Romania (2005), and our campaign work is used as a model of good practice in a resource for European epilepsy organisations in the EUCARE Epilepsy Action Pack – a Tool for Change 2004.

***John Lipetz***  
***Chair, Epilepsy Bereaved, UK.***

# BECKY

On a wet spring morning in May 2004, just three months short of her twelfth birthday, Becky became a victim of SUDEP.

Becky suffered her first seizure in September 2001 and was promptly seen by a registrar at the local hospital. We were soon sent on our way with 'nothing to worry about, it's probably migraine, we can't do anything more unless the seizures become more regular and frequent'.

Over the next two years Becky had sporadic night time fits, however those words of comfort turned to concern when the seizures became more frequent during the first weeks of January, February, and March 2004. We pushed for a referral to a paediatrician who thought that Becky might be having epileptic seizures in addition to migraine and arranged for her to undergo EEG and MRI scans. But seizure medication was 'out of the question for a child this age'. There was no mention of SUDEP.

Becky died three days before we were due to visit the hospital to discuss the test results. Three days after her death we heard about 'sudden unexpected death in epilepsy' for the first time in the form of a passing reference from the Coroner's Office. Some web searching uncovered the Epilepsy Bereaved website and our first viewing of the acronym SUDEP...and the horror associated with it.

In hindsight, her earlier life had given clues to her epilepsy. She appeared to have early learning difficulties and was investigated for dyslexia. The results confirmed she actually was a very bright girl who just 'drifted off' for brief periods. These absences were probably the early signs of her epilepsy. In fact, during the last months of Becky's life she experienced brief 'flashing light/colour' visual disturbances on a daily basis that continued to be diagnosed as migraine.

Beautiful, fun loving, intelligent, and creative, Becky was much loved by all who knew her. How we miss not having the chance to see her grow into adulthood. Our beautiful Becky is no longer with us, but her memory always will be.



# Does SUDEP occur in children?

There has been much recent discussion as to whether SUDEP exists as an entity in children. Two epidemiological studies have suggested this to be rare; however, the National Sentinel Clinical Audit of Epilepsy-Related Deaths (Hanna, 2002) in the UK found a possible 81 children of 791 total deaths over a twelve month period, although only the records of 22 could be reviewed in full. Many of us involved with complex epilepsy are aware of this apparent phenomenon occurring in younger as well as older children within the clinic, albeit infrequently (personal experience of 2-3/year). Although, of course, it appears a much rarer occurrence to the general paediatrician.

Much focus has been placed on risk factors for SUDEP – in adults the type of epilepsy has probably not been as relevant as continuing seizures. Studies have suggested that children with symptomatic epilepsy are at higher risk. A possible explanation of this higher risk is a relationship between epilepsy and an associated comorbidity, but it could equally relate to the reduced likelihood of seizure control. Emerging data suggests that it is ongoing seizures that may pose the greater risk. Children with a probable diagnosis of what are regarded as the more benign syndromes (e.g. benign epilepsy with centrotemporal spikes) have been reported as likely SUDEP. This supports an argument for treating such syndromes sooner rather than later, in view of their usually prompt response to anticonvulsant medication. It appears unlikely that children with only typical absence seizures are at risk.

A key question often posed by families and professionals, if a possible risk of SUDEP is discussed, is how do we prevent or guard against it. Of course this question is virtually impossible to answer with our current knowledge although ongoing generalised tonic clonic seizures do appear to be a risk factor. This would provide an argument for optimal seizure control, aiming for seizure freedom where possible, and emphasising the need for compliance with regular medication.

Often clinicians are reticent to discuss SUDEP with families, primarily because of concern about unknown risk factors, expressing the likelihood of risk, and being unable to give information of cause and how to prevent it. There is concern about frightening parents and children alike, which is probably more of an issue with the clinician than the families themselves. Often when a child first presents with a generalised tonic clonic seizure, a parent who has witnessed the event may already have experienced a feeling that they thought the child had died. Discussion of the possibility, and the apparent lower risk than is perceived, is often easier at the outset – at time of diagnosis – rather than when a child has been established on treatment. Discussion of such may also aid decision making as to whether treatment is warranted in the benign syndromes. Older children themselves may express the fear that they could die at any time they have a seizure. An explanation that the risk is actually low may alleviate rather than enhance anxiety in some individuals.

Expression of risk, in terms which are comprehensible to the family, carers and child may be difficult. This is a recurrent problem within medicine, particularly in a condition where treatment will involve discussions based on probabilities rather than hard fact. We can only be open with the facts we know, and explain to the best of our ability.

***J Helen Cross***

***Institute of Child Health and Great Ormond Street Hospital for Children  
NHS Trust, London, UK.***



# Who is at risk?

A systematic review was performed to provide evidence-based estimates about risk factors and incidence of SUDEP (Tellez-Zenteno, Ronquillo & Wiebe 2005). We searched Index Medicus, Medline, EMBASE, and the Cochrane database, for retrospective or prospective cohort and case-control English language studies exploring the risk factors and incidence of SUDEP in adults and children from 1966 to 2003. Of 83 potentially eligible articles 36 fulfilled eligibility criteria (29 cohort and 8 case-control studies). Salient findings follow:

**Researchers do not use standard definitions of SUDEP.** Standard definitions are essential for meaningful communication about clinical conditions. Some authors did not state a definition, some crafted their own, and others adhered to published definitions. A definition of SUDEP was explicit in 65% of studies, not clear in 29%, and not given in 6%. In many studies, the diagnosis of SUDEP was probable, not definite, because the most used definitions require post mortem data, and autopsies are performed infrequently in many settings. This suggests that the requirement of post mortem examination for a definitive SUDEP diagnosis may require revision. Specifically, how much certainty and precision does the post mortem examination add to the diagnosis of SUDEP?

**The risk factors for SUDEP depend on the type of comparison.** Studies exploring risk factors use one of two main comparison groups, i.e. non-SUDEP epilepsy deaths, and live people with epilepsy (PWE). Comparisons with non-SUDEP deaths explore best the circumstances surrounding death (e.g. seizures preceding death, place of death, AED levels at the time of death). Comparisons with live PWE explore best the lifestyle and clinical variables related to SUDEP (e.g. frequency of seizures, number of AEDs, use of other drugs). Therefore, the seemingly disparate risk factors found in these studies are really complementary.

**High-risk and low-risk groups for SUDEP are identified.** The risk of SUDEP is expressed as number of deaths per 1000 person-years. The risk is highest in studies of candidates for epilepsy surgery and epilepsy referral centres (2.2 to 10 per 1000), intermediate in studies including patients with mental retardation (3.4 to 3.6 per 1000), and lowest in children (0 to 0.2 per 1000). The incidence was similar in autopsy series (0.35 to 2.5 per 1000) and in studies of epilepsy patients in the general population (0 to 1.35 per 1000). PWE in the high-risk group typically suffer from more severe epilepsy, have frequent seizures, and require many AEDs. These factors are consistently associated with SUDEP (Langan & Nashef 2003; Lhatoo & Sander 2002; Stollberger & Finsterer 2004). The reasons for a lower risk in children require further investigation.

**The contribution of SUDEP to overall mortality varies by risk group.** As expected, in higher-risk groups SUDEP is a more frequent cause of death than in lower-risk groups. In studies of children, general population, epilepsy registers and autopsy series, SUDEP explained from 0 to 14% of deaths. In studies of epilepsy clinics, drug trials, epilepsy surgery or surgical candidates, and registers of patients with refractory epilepsy SUDEP explained from 29 to 75% of deaths.

**Several aspects of SUDEP require further research.** Prospective studies from seizure monitoring units could be fruitful. Standardisation of case ascertainment, definitions, and description of population sources is necessary to improve the analysis and interpretation of data. International panels could review the SUDEP definition and scientific journals could encourage researchers to adhere to standard definitions. Finally, researchers need to assess the impact that learning about SUDEP has on patients and their families, while exploring optimum risk communication and coping strategies for this infrequent but devastating event.

*Jose F. Téllez-Zenteno and Samuel Wiebe  
Department of Clinical Neurosciences, University of Calgary,  
Alberta, Canada.*

# How does SUDEP occur?

People with epilepsy may die unexpectedly without a clear structural or pathological cause for death. We call this SUDEP. Often, but not always, there is evidence to suggest an epileptic seizure around the time of death. SUDEP is a category not a condition. It may represent more than one entity and different mechanisms may operate in different individuals. A final common pathway for death is cardiorespiratory compromise. Understanding mechanisms involved is necessary to formulating prevention strategies.

A number of studies suggest that SUDEP is largely a peri-ictal event. These include case-control studies and accounts of witnessed deaths and detailed circumstances of death. They also include incidence studies showing an association with less well controlled epilepsy, particularly where there is a history of generalised tonic clonic seizures.

Risk factors identified so far, however, only tell part of the story. Sometimes individuals with infrequent seizures die, while others with more frequent and apparently more severe seizures do not. Some may be more at risk because of social factors, lifestyle or sub-optimal management; others may have additional biological susceptibility.

Of particular interest are risk factors we can influence or prevent, such as tonic clonic seizures. One study also identified polytherapy and frequent treatment changes as independent risk factors. While these risk factors may still be surrogate markers for epilepsy severity, theoretically, both could make SUDEP more likely. Medication changes, prescribed or otherwise, particularly if abrupt, could result in instability, while (poly)therapy could, theoretically, affect post ictal respiratory depression and/or cardiac autonomic function. Of note, however, is that one study found untreated epilepsy to be a risk factor, with those who had never had drug therapy at increased risk.

Another consistent observation is that most deaths occur in bed, presumably from sleep. Again, are nocturnal seizures different pathophysiologically – for example, associated with increased vagal tone or respiratory depression – or is it simply that assistance is not to hand, as Delasiauve wrote a century and a half ago? There is some evidence to suggest that he was at least partly right. A study looking at position in death found 71% prone and only 4% supine. Another case control study showed decreased risk associated with using listening devices or sharing the room with someone capable of giving assistance. Respiratory compromise frequently occurs in more severe seizures. Central and obstructive apnoea, excess bronchial and oral secretions, pulmonary oedema and hypoxia are all well documented. That assistance in the community provides some protection favours a role for respiratory factors which, to some extent, can be influenced by relatively unskilled intervention such as airway protection, re-positioning or stimulation.

Primary or secondary cardiac mechanisms are also likely to be important. One can postulate a number of hypotheses, which are not mutually exclusive:

- That malignant cardiac tachy/brady arrhythmias or cardiac failure occur secondary to the ictal discharge and/or apnoea/hypoxia. A study of long-term cardiac rhythm monitoring using an implanted device resulted in 4/19 patients with intractable epilepsy being paced because of recorded periods of asystole, thought to have occurred in a very small proportion of seizures reported.
- That long-term cardiac changes secondary to uncontrolled epilepsy may occur. Pathological studies provide limited support for this.
- That, theoretically, the same underlying process which causes epilepsy could predispose to sudden cardiac death in a proportion of people with epilepsy. For example, ion channel disorders are implicated in genetic epilepsies and in conditions predisposing to sudden cardiac death; many are co-expressed in heart and brain.

- That some individuals with epilepsy may have a co-existing *unrelated* ‘mild’ genetic susceptibility to sudden death, through cardiac conduction/ion channel disorders, which then manifests because of uncontrolled seizures. Advances in the studies of complex minor genetic susceptibility may further research into SUDEP.

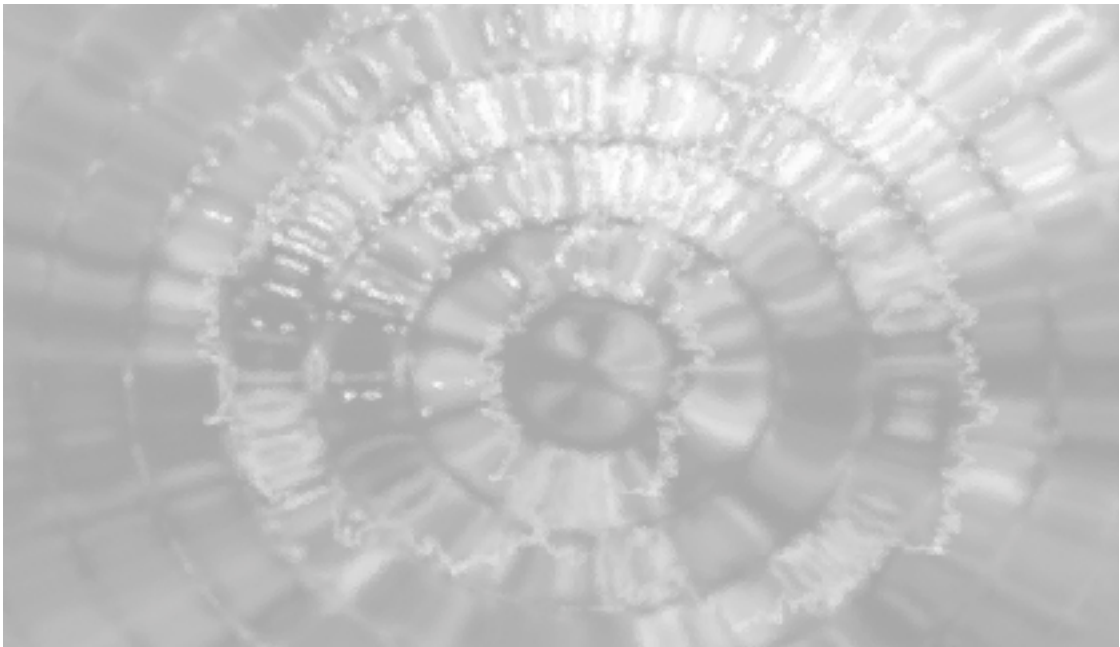
Strategies to reduce SUDEP include focusing on seizure prevention, optimising medical and surgical management and assistance during seizures, aided by future advances in seizure prediction/detection. Further research into mechanisms exploring the above hypotheses may also lead to specific interventions. An analogy between SIDS and SUDEP is often drawn. Success in preventing some potential SIDS cases followed advice on optimal positioning of infants. More recently individual susceptibility in a small proportion of cases (‘SIDS’ genes which include channelopathies) is being addressed. How important these turn out to be remains to be seen. Many lessons can be learnt from the SIDS story.

***Lina Nashef***

***Kings College Hospital, London, UK***

# Part 2.

*facing the facts*



# An audit of epilepsy-related deaths

'Because primary-care providers manage most patients with epilepsy in the USA and Canada, results of a similar audit in North America would probably only differ in degree. The UK audit should be a wake-up call to the medical profession and result in a targeted campaign for people with epilepsy. While there remains a critical need for more effective treatments ... the UK audit emphasises that many patients with epilepsy – perhaps most – could benefit substantially if only current knowledge and available therapeutic options were applied effectively'. *Timothy Pedley, W. Allen Hauser, Lancet 2002*

The National Sentinel Clinical Audit of Epilepsy-Related Deaths (Hanna 2002) was led by Epilepsy Bereaved in partnership with medical professional organisations in the UK and with the support of the Joint Epilepsy Council.

'This is an emotive topic and groundbreaking study. Firstly, it tackles an important problem that has lain in the shadows far too long. Secondly, it delivers a loud wake up message that demands immediate and vigorous action. Thirdly, it demonstrates a seismic shift in the way we do medical studies – the bereaved families have real ownership of the work ... The main role of professionals has been to ensure sound methods and robust analysis. This partnership has allowed key questions to be addressed that have previously been thought too sensitive and remained hidden from view'.

*Professor David Fish*

The audit looked at the medical care and post mortem investigation of patients who had died and in whom epilepsy was considered the main cause of death between September 1999 and August 2000. During this time 812 deaths were identified including 81 children under 18 years. A total of 595 deaths were audited for the investigation of death and medical records of 225 were made available and audited to review pre-mortem care. A key aim of the audit was to establish whether deficiencies in the standard of clinical management or overall package of healthcare could have contributed to deaths. A key finding was that 42% of deaths were potentially avoidable.

A majority of adults (54%, 84/158) had inadequate care, which led to the conclusion that 39% of adult deaths were considered potentially or probably avoidable. The main deficiencies identified were (in descending order of frequency): inadequate access to specialist care, inadequate drug management, lack of appropriate investigations, no evidence of a package of care, inadequate recording of histories, adults with learning difficulties “lost” in transfer from child to adult services, and one or more major clinical management errors.

A majority of children (77%, 17/22) had inadequate care, which led to the conclusion that 59% of deaths in children were considered potentially or probably avoidable. The main deficiencies identified were (in descending order of frequency): inadequate drug management, inadequate access to specialist care, and inadequate investigations. There was concern that documentation was poor in both primary and secondary care; only 1% of hospital records for adults showed that SUDEP had been discussed.

‘Perhaps the most dismaying disconnect is between doctor and patient — the failure by doctors to discuss with the patient the risks of epilepsy and how to minimise them ... or to point the patient in the direction of support from voluntary organisations ... I am sorry to say that this part of the report spoke to me of a basic lack of willingness on the part of doctors to involve patients in decisions about their own care and a ducking out of confronting unpleasant truths ...’

*Lord Howe in Parliament, May 2002*

The audit also examined the management of processes following death. 1023 cases were subject to post mortem and the audit reviewed two-fifths of these cases and a tenth of cases which did not go to post mortem. Less than 1 in 8 deaths were fully and properly investigated. In almost half the certificate was incomplete or inappropriate in some way. Communication by the medical profession with bereaved relatives was inadequate. Only 7% of GP notes and 10% of hospital notes indicated contact with the family.



In 2004 as a result of the audit, SUDEP is recognised as a syndrome by national and local policy makers in the UK. In a recent survey of neurologists 66% reported that there had been a definite or probable improvement in managing the risk factors for SUDEP. The audit has a high citation rate with SUDEP highlighted in a wide range of health professional journals and in new NICE epilepsy guidelines in England and Wales (2004). In England there has been an increase in national initiatives on epilepsy including the first epilepsy action plan published by the government in England in response to the audit and in Wales a national implementation group working on an action plan. In Scotland the audit alongside the Findlay Inquiry (Taylor 2002) were important factors in all but two Health Boards creating a new model of integrated epilepsy services.

New guidelines have also been produced on the investigation of epilepsy deaths by the Royal College of Pathologists in 2005 as part of the government action plan. These guidelines and all documents mentioned in this article can be accessed at [www.sudep.org/national\\_report.asp](http://www.sudep.org/national_report.asp)

***Jane Hanna***

***Director, Epilepsy Bereaved, UK***

# KRISTEN

My daughter Kristen was diagnosed with epilepsy when she was nearly 15 years old. For ten years her epilepsy had been fairly well controlled with medication, having one or two seizures a year on average. That changed when she became pregnant. When her seizures became more frequent she was told that this was nothing to be alarmed about as this often happens during pregnancy. Not only did her seizures become more frequent, but they also occurred during sleep rather than during the day which was the norm. This gave me a sense of security – at least she couldn't hurt herself or the baby while having a seizure in bed. I couldn't have been more wrong.



One the morning of July 2, 1999 Kristen got up to see her partner Neil off to work. Having worked until 10pm the night before she told Neil she was going back to bed. Neil was the last person to see her alive. When he returned from work that evening he found her dead in bed.

The news of her death was devastating. With no obvious signs of cause of death, her death was treated with suspicion. The next time I saw my daughter was on a mortuary slab. With her hair bound in a white sheet, Kristen was covered with a purple velvet cloth with gold fringes. The first thing I saw when I entered the room was her heavily pregnant belly; Kristen was 8 months pregnant. I could not touch her because of the circumstances of her sudden death. All I could see of her was her tiny blackened face which I kissed when leaving. I withdrew quickly as she was as cold as marble. The memory of this day will stay with me forever. I sincerely hope no mother has to witness such a sight.

Six weeks later we learned that Kristen had died from epilepsy. How could she possibly just die? I did not know that having epilepsy could be fatal. Nobody warned me of the risks of SUDEP and now my daughter and grandson are lost forever.

*father*

# SUDEP and the post mortem

We all recognise that most individuals would probably rather not have a post mortem examination performed on themselves, a relative or friend. It can however, be a valuable source of information to society and the medical profession but most importantly to those close to the deceased.

Historically, many sudden deaths occurring in people with epilepsy were attributed by the certifying doctor as being a consequence of choking on vomit or other asphyxial processes. It is now recognised that this is not necessarily the case. The term SUDEP recognises that these deaths can fit a pattern but the exact cause or mechanism of the death is uncertain.

There are no diagnostic features of a SUDEP death; the diagnosis requires exclusion of any other potential cause of death, in association with a typical history and circumstances of the death. Thus a full post mortem examination including toxicology and histology is essential to identify any other natural disease, intoxication or trauma. Deaths could wrongly be attributed to epilepsy when there is another natural disease e.g. cerebral haemorrhage, or drug overdose. Studies have also shown that a neuropathological examination of the brain can provide additional information.

It is important that these deaths are properly investigated to establish the true incidence of SUDEP deaths and to document the findings. The recent National Sentinel Audit of Epilepsy-Related Deaths (Hanna 2002) in the UK sadly identified that there were still many deficiencies in the quality of the examination and in the manner in which the deaths were certified.

The majority of the deaths will undergo a medico-legal post mortem examination, on the instructions of the relevant authority, to determine the cause of death. This should include the retention of small pieces of major organs for processing into histological blocks and slides. It may also involve retention of the brain but pathologists have adapted practice such that a neuropathology opinion can often be obtained either by sampling at the time of the examination or after short fixation and return

of the brain before the funeral. In many countries the recent controversy and concerns regarding organ retention have led to changes in the law. Relatives will now be informed of any organ retention. In the UK any research on organs or tissues will now be illegal without the explicit, fully informed consent of the next of kin.

The post mortem examination may provide answers that can help in the grieving process. I am aware from speaking to relatives and support groups that feelings of guilt are not uncommon. For example, if a death is certified as due to inhalation of vomit or asphyxia this may imply that it was preventable. The medical profession must recognise that such a conclusion requires incontrovertible evidence. The mere presence of food in the airways is meaningless (it can occur after death); a histologically proven vital response is required. Similarly petechial haemorrhages within hypostasis in someone found face down is of no diagnostic value. Recognition that these deaths are sudden and unexpected can alone provide some comfort – the carer could not have altered the outcome.

A full post mortem examination will identify any other natural disease or pathology – this may answer some questions and raise others. In some instances a cause for the epilepsy may be identifiable e.g. traumatic injury or a genetic disease, the latter uncommon but of considerable importance to a family. The pathologist may find another potential cause for the death e.g. ischaemic heart disease. The information available regarding the circumstances of the death may then allow the pathologist to assess whether this, rather than epilepsy, is the likely cause of death.

**Marjorie Black**  
***Forensic Medicine and Science, University of Glasgow, Scotland***

# CELENE

The autopsy report of Case No 3251/2003 stated that “the body was that of a well nourished adult Caucasian female” and that her death was consistent with Sudden Unexpected Death in Epilepsy (SUDEP).

Case No 3251/2003 was our daughter, Lieutenant Celene Harris B.Sc. (Hons), RAN, aged 31, a beautiful, vivacious, loving and generous young woman.

In 1991, at age 19, Celene saw a neurologist after she complained about strange ‘déjà vu’ feelings which she described as ‘a tingling sensation that started from her toes, travelled slowly through her body to her head, was accompanied by vivid images of earlier experiences, and left her with a headache’. These episodes occurred about every two weeks, or so. Investigations revealed nothing. The neurologist concluded that Celene was probably suffering from stress relating to her university studies.

Ten years later, when she described her first experience of waking to find she had been incontinent in bed, bitten the inside of her mouth, fallen out of bed, grazed her cheek, bruised her side, and was feeling very sore all over, we were alarmed. By that time, Celene had become an officer in the Royal Australian Navy, in the Hydrographic Service, a role that involved regular duty at sea.

Six months after her first significant experience, Celene had 3 tonic clonic seizures while asleep. Her boyfriend, who witnessed the seizures, took her to hospital and provided a description of the events, which helped in her diagnosis. Celene was diagnosed with epilepsy in 2001 and was prescribed medication. As a result, Celene was classified by the Navy as being ‘unfit to go to sea’, an outcome that was very distressing for her. She was posted to shore duties, while under observation by a neurologist. She was very upset at the likely prospect of not being fit again for duty at sea, but eventually settled into a role in recruiting which she enjoyed, where she made close friendships and, as an officer, earned the respect of her staff and peers.

She never did return to sea.

Celene died in her sleep and when she was found, she appeared to be sleeping peacefully on her stomach. There was no evidence of a seizure. Celene did not like the side-effects of her medication. It ‘slowed her brain’ and made her groggy and



she hated that. She did not take her pills as prescribed. Celene did not want to be an epileptic.

Celene was never told that she could die from epilepsy. She was never told that if she did not take her medication correctly, she could die. Nor were we ever told.

As a family, we had not previously heard of anyone dying from epilepsy. It may be that the medical profession takes the view that Celene and her family and friends were spared the constant prospect that any day may have been her last. Now, having lost our beautiful daughter, we feel cheated, not only at our loss, but that we would have taken her illness that much more seriously. Celene would have suffered us ‘bugging’ her; but she might be with us today, because of that ‘bugging’. We will never know.

The message — taking epileptic medication is critical — may be one of her lasting legacies to her fellow sufferers.

***mother & father***

# Certifying SUDEP

Epilepsy has long been recognised and invoked as a significant ingredient in the mechanism of sudden unexpected death, particularly in the setting of status seizures, trauma, drownings and aspiration of gastric content. However, a wider appreciation that epilepsy *per se* may be a major cause of rather than contributory factor to death, is a relatively recent concept which may not be widely comprehended or accepted by the community at large, epileptic patients and their physicians, and perhaps some pathologists. Since these cases present as sudden, unexpected and often unexplained death, they will fall under the jurisdiction of the coroner, and in most circumstances require specialist forensic pathological investigation.

Like that other acronym SIDS (sudden infant death syndrome), the term SUDEP hints at a relatively stereotypical series of circumstances allied to an unascertained cause of death; but unlike SIDS (or perhaps the more controversial SADS (sudden adult death syndrome)), the field of potential causative mechanisms appears narrower and is arguably better delineated, holding the promise of effective intervention strategies.

Much research over the past few years has pointed to complex cerebral and cardiorespiratory factors, which individually or in concert may result in death during or shortly after a seizure. If the task of clinicians is to predict and intervene, the role of the forensic pathologist and coroner might best be seen as recognition and comprehensive investigation so that the true incidence (at various points in time) is documented, and effective multidisciplinary remedies implemented. A vital first step along this path is uniformity of approach, but many factors need to be addressed before this pathological nirvana is attained, some of which may be subject to considerable regional and situational constraints:

- A full appreciation and documentation of the circumstances surrounding the death including a comprehensive medical and medication history, and details of death scene examination by a

knowledgeable investigator (including position and attitude of body, details of scene disturbance, witness statements etc). Also required are further enquiries when the Police Report is inadequate, ready and timely access to medical records when necessary, consultation with clinicians if ECG or EEG available, and consideration and investigation of possible epilepsy in the unascertained autopsy.

- A full and thorough autopsy examination including recording stigmata suggestive of epilepsy (e.g. tuberous sclerosis, gum hypertrophy, unusual scalp or facial scars), asphyxial signs, and factors that may indicate a recent seizure (oral injuries, urinary or faecal incontinence, collapse injuries etc).
- Consideration given to examination of the cardiac conduction system.
- Consideration given to retention of the brain for formal neuropathological examination and alternate strategies for enhancing brain examination when permission for retention is denied.
- Full toxicological analysis, (including antiepileptic medications and vitreous biochemistry).
- Uniformity of approach in formulation of cause of death (rationalisation of the terms Epilepsy, SUDEP, Unascertained, Sudden Adult Death Syndrome, Suggestive of (or Probable) Epilepsy, Seizure, Status Epilepticus).
- Adopting a rational and consistent approach to certification when significant co-pathology exists.
- Implementing mechanisms for accurate retrieval of data and dissemination of information to families, physicians, and interested parties.
- Developing lines of communication with epilepsy bereavement services and epileptologists.

**Noel W.F. Woodford & Matthew Lynch**  
**Victorian Institute of Forensic Medicine, Australia**



# Guidance on SUDEP: clinical practice

In his 2001 report, the Chief Medical Officer of England recommended that an action plan be developed by the Government to improve epilepsy services and address the findings of the National Sentinel Clinical Audit of Epilepsy-Related Deaths (Hanna 2002). In 2003 the Government published the first action plan on epilepsy and this included the proposed publication of a clinical guideline for the diagnosis, management and treatment of epilepsy.

In England and Wales the body responsible for the development of evidence-based clinical guidelines is the National Institute for Health and Clinical Excellence (NICE). The guidelines were to address how care should be improved for children and adults with epilepsy, including areas in primary and secondary care where improvements in epilepsy services could reduce the risks of seizure-related deaths.

A development group was convened consisting of experts nominated by a wide range of organisations. The group included nine medical experts nominated by the Association of British Neurologists, Society of British Neurological Surgeons, Royal College of Physicians, Royal College of General Practitioners, Royal College of Paediatrics and Child Health, Royal College of Nursing, Neonatal and Paediatric and Child Health, and four patient representatives nominated by the Joint Epilepsy Council, Epilepsy Action, National Society for Epilepsy, and Epilepsy Bereaved. The group identified key clinical questions and reviewed the evidence identified by a methodology team based at the Clinical Governance Research and Development Unit at the Department of Health Sciences, University of Leicester. This review led to recommendations for clinical practice. Other experts were involved as co-opted members and there was widespread consultation with all stakeholders at each draft of the guidelines.

The clinical guidelines offer recommendations on diagnosis, classification, investigations, treatment, information, and support. Key priorities include

timely assessment by a specialist within two weeks of a suspected first seizure, a consulting style that enables a partnership between patients and clinicians about management decisions, the need for a comprehensive care plan, individualised medication, and a regular structured review. All of these recommendations reflect the findings of the audit. The importance of the need for information to reduce the risk of SUDEP is a core theme. An example of the importance of information provision about SUDEP is found in the women and pregnancy section where the guideline recommends that women considering stopping their medication should be specifically warned about SUDEP.

The guidelines also emphasise why preventing seizures is important to reduce the risk of epilepsy-related death. The 'Epilepsy – Be Aware' card has recently been published by the government. This card has essential information on epilepsy, helpline details, and a leaflet setting out the importance of annual review. Both the card and the leaflet include information about SUDEP. Research showed that this was valued by patients.

Tailored information on the individual's risk of SUDEP should be part of the counselling checklist for people with epilepsy and their families and/or carers taking account of the small but definite risk of SUDEP. The guidelines recognise that there may be factors that increase the risk of SUDEP. These include poor seizure control, having convulsive or nocturnal seizures, having a learning disability, being a young adult male, not taking treatment as prescribed or having abrupt or frequent changes to medication.

The guidelines also recognise particular issues relating to young people and the learning disabled. Both groups are at increased risk of SUDEP. Lifestyle issues and the importance of taking medication are particularly important issues to discuss with young people. Health professionals should be aware of the higher risks of mortality for people with learning

disabilities and epilepsy and discuss these with individuals, their families and/or carers. SUDEP is also an essential part of a risk assessment of people with learning disability.

The time at which information about SUDEP should be given is after confirmation of the diagnosis, and tailored to the individual. The discussion is best made during a consultation where there is a partnership between clinician and patient. It is important that essential information on how to recognise a seizure, first aid measures, and the importance of reporting further attacks, should be given after the first suspected seizure.

A series of guidelines recommending advising health professionals to contact families and/or carers to offer their condolences, invite them to discuss the death, and offer referral to bereavement counselling and a SUDEP support group after a bereavement, was the result of research carried out with bereaved families.

For further information there are quick reference guides for health care professionals:

the diagnosis and management of the epilepsies in children

[www.nice.org.uk/pdf/cg020childrenquickrefguide.pdf](http://www.nice.org.uk/pdf/cg020childrenquickrefguide.pdf)

the diagnosis and management of the epilepsies in adults

[www.nice.org.uk/pdf/cg020adultsquickrefguide.pdf](http://www.nice.org.uk/pdf/cg020adultsquickrefguide.pdf)

information for patients.

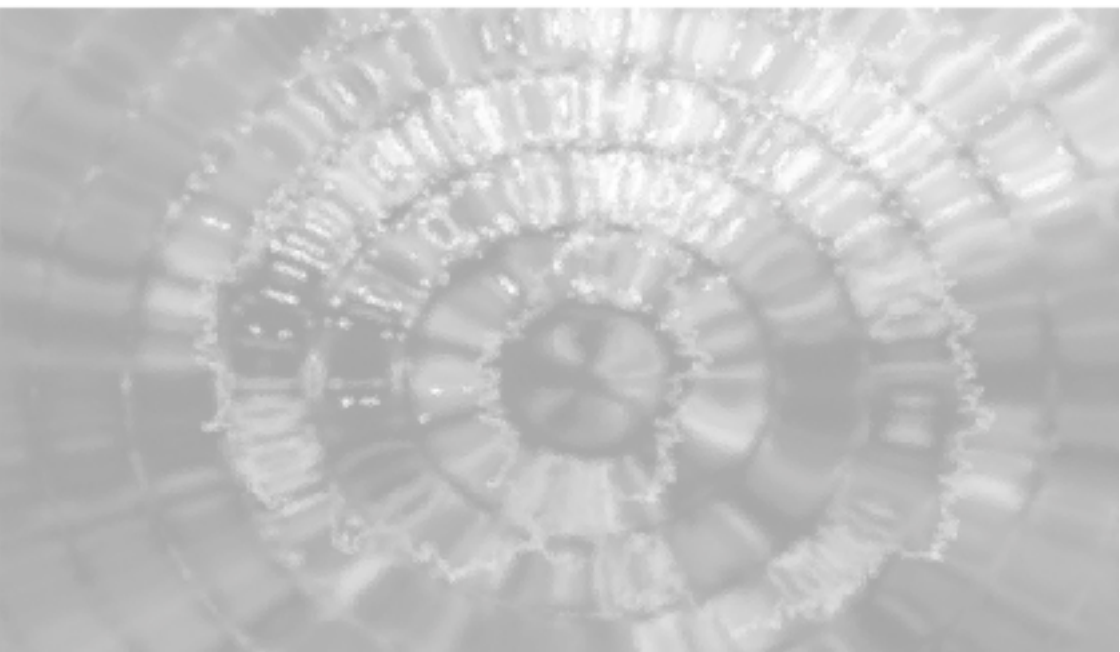
[www.nice.org.uk/pdf/cg020publicinfoenglish.pdf](http://www.nice.org.uk/pdf/cg020publicinfoenglish.pdf)

***Henry Smithson, GP North Yorkshire, UK  
Chair Epilepsy Guidelines Development Group***

# Part 3.

**Part**

*facing the uncertainties*



# DAVID



My cousin threw her arms around my neck. 'David's died,' she was repeating. It didn't register. She sobbed into my shoulder. What was she saying? 'David's died.' The words formed a sentence with meaning. What? It must be a joke. Who would joke about something like that? No one, I realised. Sickened, I pushed her away in horror and disbelief and started choking out the word, 'No, no, no....'.

On that terrible day in 2003, my brother's housemate arrived home to find David dead in the shower. David was just 30 – and he was my closest friend.

As David had a history of epilepsy, my parents and I imagined he had fallen during a seizure and hit his head, drowning in the running water. We had no idea that epilepsy can kill directly. David's autopsy found no obvious cause of death. It was something called SUDEP, the pathologist said. Something we'd never heard of before, something that kills without leaving a trace.

I've since discovered that David, though unique in so many ways, was typical of someone who dies from SUDEP. He was a young, fit and healthy man with epilepsy. He took medication to control his tonic clonic seizures, but sometimes after a late night he'd forget to take it. My parents and I had seen him have a handful of seizures over the years, in bed or as soon as he got up, and we thought they occurred only when he missed a tablet or was extremely over-tired. It now appears David may have been having more seizures than anyone knew. He didn't remember the ones we witnessed, and it's likely more took place in bed. His friends have since mentioned either seeing seizures occurring or noticing suspicious bruises. David swore others to secrecy, both because of the stigma associated with epilepsy and his reluctance to modify his fun-filled and friend-filled lifestyle. He worked long hours, travelling between states, and he studied hard and socialised harder.

I know now what David's doctor had never told him – that the risk of SUDEP is considered low for people whose epilepsy is well controlled. Preventing seizures, by complying with medication or getting enough rest, for example, may reduce the risk. I wish David had been given this knowledge.

And so my wonderful friend, my smart, entertaining, charismatic brother with his wide grin and infectious enthusiasm, was given no choice about modifying his behaviour, and we'll never know if that choice may have saved his life.

*sister*

# Supporting the bereaved

Death can change everything – priorities, perceptions, abilities, view of the world, view of ourselves, relationships and so on. Sudden death brings with it the added dimensions of being unexpected, untimely and sometimes traumatic. The shock of the death can also be exacerbated because the family had not been told of any risk – or even told there was no risk!

*“I think the ignorance of not ever thinking that it could result in death is the biggest shock”* Bereaved relative (Kennelly & Riesel 2002)

In addition, with sudden deaths the bereaved are thrust into an unfamiliar world of investigation into the death. This can have a considerable impact on the bereaved particularly when the body is taken away and they are unable to see and spend time with the deceased. At best unhelpful, this situation can also be detrimental.

So, it is not surprising that those who contact the support team of Epilepsy Bereaved feel their world has fallen apart and is, perhaps, frighteningly out of control. Everyone's reaction is different, as is their way of grieving. However to begin with people generally want information and answers to their questions – what is SUDEP? Why weren't they told about SUDEP? How could this happen? Could they have saved their loved one? Why did resuscitation not work? They may also want information regarding the legal process, the post mortem, the coroner, the inquest, and their lawful rights. We can explain legal procedures and requirements since families can feel too daunted and upset to ask questions from the authorities.

Research commissioned by Epilepsy Bereaved from the College of Health with bereaved relatives (Kennelly & Riesel 2002) reveals the emotional impact on the family ranging from shock and devastation, to guilt, anger, difficulty accepting the death, and loneliness. Time and again, as the family support manager, I have been told how helpful it has been for people to

discover they are not on their own. Others have died from epilepsy and so there are people out there who have also experienced the unthinkable. This helps to lessen their sense of isolation.

For some people it is very important to talk about what has happened and the effect on them. They want, and need, to express the strong emotions they are feeling particularly to someone who had not been personally involved in any way prior to the death.

Calls to our contact line or emails to the charity from bereaved relatives are managed by myself as family support manager. Family support volunteers are also involved in our work. These volunteers are at least two years beyond their own experience of bereavement and are trained in listening and befriending skills. For newly bereaved people talking to someone from the family support team regularly over a period of time helps them adjust to the huge changes in their lives. Knowing that the listener really does have an understanding of their experience can reassure them that they are grieving rather than disintegrating or becoming mad. It also indirectly gives hope that they, too, can have a future.

After receiving information some bereaved people want to grieve by doing rather than talking so we believe in developing the charity's work to mirror the needs of those in contact with us. The charity produces two magazines a year which include their writings, poems and other contributions. People can also be directed towards focused activity within the Education and Awareness section of Epilepsy Bereaved. They are offered a range of opportunities such as running an information table or joining our speakers team.

Each year we organise several support group meetings on Saturdays in different parts of the country. This gives our members a chance to meet with others from their area and beyond, who have had similar experiences. These occasions are structured to include plenty of informal time, around refreshments, when those attending can meet and chat with each other. It

is not uncommon for people, especially first-timers, to arrive saying they need to leave early but then to stay the whole time. This shows the value they have found in meeting together. Some want to talk to many different people while others prefer to say very little. All approaches are respected, and we in the family support team do our best to enable everyone to benefit as much as possible. Interaction and contribution are also key features of the more structured part of the day, as is flexibility regarding the programme and its contents.

Every three years Epilepsy Bereaved holds an inclusive memorial service. This is another occasion for meeting together for remembrance of our loved ones, celebration of their lives and recognition of their deaths.

Within the family support team we are very well aware of our limited resources. But, rather than being daunted, we are eager to do what we can to help others bereaved by epilepsy.

***Patricia Johnston***

***Family Support Manager, Epilepsy Bereaved, UK***



# Responding to community need

The SUDEP phenomenon has been known to exist for many years, but only in the past two or three decades have neurologists in the United States acknowledged it as a common cause of death in association with epilepsy.

In the USA the educational effort about SUDEP for patients and families has been minimal. Reluctance to discuss the possibility of SUDEP when a seizure disorder is diagnosed seems to be based upon the presumption that such information would be too stressful or too difficult for the patient and family to handle. This attitude has been manifested both by medical professionals and lay organisations that support persons with epilepsy. The fear that such information may have a negative impact is not borne out by the responses of patients and families when presented with the facts.

Indeed, there seems to be some change in the wind regarding the desire to know more about SUDEP. Recently, because of requests for information from persons with epilepsy and their families, a first ever regional symposium about SUDEP was presented through the auspices of the Epilepsy Foundation of Southeastern Pennsylvania. Evaluations from the more than 100 attendees indicated that they were grateful to have been presented, for the first time, with in-depth information about SUDEP. It seemed that having this information was far more helpful than not knowing. Responses to this symposium indicate that patients and their families seem more comfortable discussing SUDEP than are the medical professionals.

The most frustrating aspect of SUDEP is our lack of knowledge about why it occurs and how it may be prevented. While there is data indicating that optimal seizure control lowers the probability of occurrence, it does not remove the chance entirely. The only intervention that is associated with an abolition of risk is that of complete cure of seizures consequent to temporal lobe surgery. The implication of this observation is that having any seizures, no matter how infrequent, is still associated with some risk of SUDEP.

The association of SUDEP with sleep has raised the question of whether monitoring of respiratory function during sleep allows for intervention by care-givers to prevent a fatal apnoea. Nonetheless, we still have a large group at risk of fatal cardiac arrhythmias for which we do not have any preventive measures.

Above and beyond the need for more scientific investigation into mechanism and prevention, we also need to determine the prevalence of SUDEP. A recent survey of medical examiners and coroners in the United States found a reluctance to use the diagnosis of SUDEP even when post mortem examination finds no other cause of death. Inappropriate diagnoses such as seizure related death, status epilepticus, or respiratory failure may be used instead. Consequently the accurate prevalence of this disorder is underestimated when compiling statistics about causes of death in epilepsy.

Many more investigators are involved in SUDEP related research than there were even a few years ago. We can be hopeful that some answers to the mystery of this disorder will be forthcoming.

***Paul L Schraeder, Professor of Neurology,  
Drexel University College of Medicine, Philadelphia, USA***

# Managing fear

I must say I am surprised at the extent of controversy regarding whether or not physicians should discuss SUDEP with patients and families. Fear of dying from seizures is nearly universal among patients and families. Most are reluctant to speak of it openly. Patients and families explain they don't ask their physicians because they are afraid their worst fears might be confirmed. These fears are substantial. In our original UCLA study (Mittan 1986), we found approximately two-thirds of patients were afraid they could die with their next seizure and nearly three-fourths were afraid seizures would cause further brain damage.

For 22 years I have presented the Seizures & Epilepsy Education (S.E.E.) program. This has given me the opportunity to speak with nearly 30,000 patients and families with epilepsy in Australia, Canada, New Zealand, and the U.S. I have found patients and families are almost universally afraid of death from seizures. It makes sense – even non-convulsive seizures are frightening to people. So far when I have asked parents, all but one thought that their child was going to die when they first witnessed the child's seizures. The one exception was an epilepsy nurse specialist whose daughter started having absence seizures.

When these inevitable patient and family fears are not discussed, they are left unchecked. These fears can, and often do, run rampant to the serious ruin of quality of life. Fear is the force behind developmentally disabling overprotection and overcontrol of the person with epilepsy. Fear is the force leaving people afraid to be alone and afraid to go out by themselves because of seizures. Fear shrinks life to the house and social contact to the immediate family for far too many.

Rather than alarming families, discussing causes of death in epilepsy gives them a more realistic appreciation of the risk – which is often much to their relief! The S.E.E. program has taught patients and families about SUDEP, status epilepticus, and fatal accidents in epilepsy, including relative risk and

circumstances for each. A controlled outcome study (Helgeson et al. 1990) and a recent study by Shore et al. not yet published showed **significantly reduced fear** as a result – and equally important, significantly improved compliance.

During every S.E.E. program I poll the audience to find out how many have discontinued their medications on their own and have gone into status epilepticus. Consistently 10-15% will raise their hands. They protest they were ‘never warned’ of the danger. Nearly all were angry with their physician about it. In fact, they undoubtedly were warned with ‘you should never stop taking your medications!’

However, telling people **what** to do is rarely effective in changing behavior. It is essential to tell people **why** to do it. Every prescription patients receive is accompanied with some version of ‘take this exactly as directed.’ Patients hear this so often it stops being meaningful. After all, how often have they failed to take all of their antibiotics or other medication and nothing bad happened? Why should it be any different with seizure medications? However, if the patient knew they risked status and possibly death by stopping their medication – that would get their attention. But to do this, the physician has to talk about status, SUDEP, and their lethal potential.

The benefits of talking about SUDEP, status epilepticus, and other risks in epilepsy not only fulfills patients’ and families’ right to know, but can significantly contribute to reducing fear. It may save a life. Rather than threatening the emotional wellbeing of patients and families (who already live with fear of death), the discussion of SUDEP offers a therapeutic opportunity. It is a chance to significantly improve quality of life and reduce harm from seizures. The methods used in disclosing this information can strongly influence medical and psychosocial outcomes.

**Robert J Mittan, Ph.D.**  
**Seizures & Epilepsy Education (S.E.E.)**

# Accessing information

In 1996 a study of the information on epilepsy given to newly diagnosed patients (Preston 1997) discovered that rarely, if ever, was the risk of SUDEP mentioned.

In 2005, in the UK, all the major epilepsy charities are now prepared to talk about the topic; some have their own literature, others use information produced by Epilepsy Bereaved. The most commonly used leaflet is 'Epilepsy – Be safe, reduce risks' which is a leaflet written by all the epilepsy organisations in the UK and Ireland under the umbrella of the Joint Epilepsy Council. The idea that all the epilepsy charities in the UK would band together to produce literature on such a taboo topic would have been unimaginable in 1996.

The biggest change in the last ten years has been the growth of the internet. A SUDEP search produces 13700 mentions, more than 20 pages.

With a few clicks of the mouse one can browse through research papers from all over the world, reports from conferences, Epilepsy Bereaved's specialist SUDEP site, guidelines from the medical profession, chatrooms, and the broad spectrum of information presented by epilepsy charities, treatment centres and consumer pages such as the 'Crazy Meds Guide to SUDEP'. It is important to remember that although web-based information is now relatively easy and cheap to access, it is not always correct.

A bookshop search uncovers very few publications about epilepsy. Those that are on sale have been slow to reflect the current SUDEP knowledge available and some still do not mention SUDEP at all. A list of recommended titles is included in Epilepsy Bereaved's booklet *'Epilepsy and the Young Adult'*. The first edition of this booklet published in 1996 was the only booklet written at that time which covered sudden death.

Most physicians, consultants, and specialist epilepsy nurses now agree that it is better to cover the slightly increased risk of a sudden death in

epilepsy in the same way as they would with asthma or diabetes. Patients, or their carers, are entitled to know the facts about their condition so that they can make informed decisions. Epilepsy Bereaved in cooperation with the Royal College of Nursing has produced a facts sheet for doctors – SUDEP Aware in Primary Care – to help them do this. Literature is not always the most suitable way to cover the subject. Often a doctor or nurse, talking through the risks and putting them into perspective, is a more adaptable way of approaching a difficult topic with a new patient.

Since the National Sentinel Clinical Audit of Epilepsy-Related Deaths (Hanna 2002) confirmed that there are about 1000 deaths a year in the UK as a result of epilepsy, of which about 500 will be classified as SUDEP, it is no longer possible for the epilepsy community to ignore the issue. New national guidelines on epilepsy in England and Wales 2004 now include SUDEP as essential information.

Much information about SUDEP is now readily available from the medical profession and voluntary bodies through books, leaflets and, most of all, the internet. Links to the literature discussed in this article are found at [www.sudep.org/publications1a.asp](http://www.sudep.org/publications1a.asp)

Epilepsy Bereaved, the leading charity formed in 1995 to support and inform families bereaved through epilepsy, now hears from families all over the world within weeks of a death. Many of us who have lost family members through SUDEP have achieved one of our main ambitions; to ensure that, when a death occurs to others, they have been forewarned, understand that it has happened before, and know where to turn for support and information.

**Jennifer Preston**  
***Epilepsy Bereaved , UK***

# Empowering the global community

Epilepsy.com is an online resource provided by The Epilepsy Project. Our mission is to inform and empower two groups of patients and their families: those facing newly diagnosed epilepsy, and those struggling with epilepsy that has resisted treatment. Approximately 120,000 people visit epilepsy.com each month and read over 500,000 pages of information.

As editor-in-chief, I oversee all the content on epilepsy.com. Believing that knowledge is empowering, we strive to present information about all the medical and psychosocial aspects of epilepsy. No topic is off-limits, including SUDEP. 2,000 to 3,000 people read this page each month.

In addition to content on epilepsy.com, we have an active Community Forum, where over 4,000 members communicate with one another, ask questions and share personal insights about their experiences with epilepsy.

SUDEP is a common topic discussed on the Community Forum. Family members and friends express their fear that the person with epilepsy will die from a seizure, or have severe brain damage, and are particularly concerned when during a seizure their friend stops breathing and turns blue. While most participants know that death from seizures rarely occurs, and that when it does it generally is associated with severe and uncontrolled seizures, some people are clearly misinformed. One person said that a neurologist had assured him that no one has ever died from a seizure, but that continuous seizures could cause enough heart damage to cause a heart attack. Another said that most neurologists 'play down' SUDEP. Yet another said 'The doctors and nurse educators do not talk about SUDEP. I mentioned it to the nurse after reading it online and she said it is very rare and not to worry. In all her 20 years of experience, she had only one patient die of SUDEP. She was interested to hear that it is being talked about on the web and that maybe they need to consider it as part of their patient education'. One person said, 'One of my problems, I realise after researching epilepsy on epilepsy.com, is that my doctor did

not do his job of educating me about my condition. He never explained how or why my medication would work and why I should take it regularly. If I had known how it worked, then I probably would have taken it more often. If he had educated me about SUDEP or had referred me to epilepsy groups, things may be different.'

Several participants in the Community Forum have been touched personally by SUDEP. They search for answers and understanding. A wife lost her husband. 'I was never told of the risk that my husband might die from a seizure. He had instructed me NEVER to call 911 (he found it humiliating and unhelpful). 'It's not going to kill me', he said. My husband died of SUDEP at the age of 40.' A mother lost her 18-year-old daughter:

'SUDEP was something that I was totally unaware of. I called to wake her up one morning only to find her dead. She suffered from poorly controlled seizures and would have 2 to 9 a month. I know that losing a child is the most difficult event that one can experience. I have good days and bad ones. I am slowly healing from the shock of this. I think about her all the time. The autopsy showed that she did not aspirate nor suffocate. No abnormal findings whatsoever in her organs. I am getting better at wondering if there was something else that I could have done, or missed, to prevent this. I was never told that she was at high risk of sudden death. I found this out after she passed. The clinic that we went to had told me that it was actually better that she had seizures at night. I did ask the neurologist why he never informed me that she was at high risk of sudden death and he responded by asking me if I thought that this was something that they should be telling people. I do and I don't. I am thankful that I did not know. I would have sheltered her and would have been paranoid. But then on the other hand I believe that I should have known about the possibility. I just feel that there needs to be more research on this SUDEP and those who are at high risk should be told. Families should be informed about the possibilities.'

I think that says it all. We will continue to add new information to [epilepsy.com](http://epilepsy.com) about SUDEP as it becomes available.

**Steven C Schachter, Professor of Neurology  
Harvard Medical School, Boston, Massachusetts, USA**



# PETER

Peter had his first epileptic seizure at the age of 14. At the time he was quite ill and we hoped the cause of the seizure was just his high temperature. However, this became the start of regular medical treatment for epilepsy. At no stage were we told that the likelihood of an early death was increased with epilepsy.

Peter was an extremely handsome and charismatic young man, but he had a maturity, which really staggered me. There were times when I wondered, who was raising whom. Being a stepfather can be a difficult role because you really have only limited authority. My relationship with Peter was wonderful. I can never remember raising my voice or having any confrontation with him over any issue. Peter's mother Mani and I both loved him dearly and although he rarely asked for anything we loved indulging him when we could.

All players, including Peter himself, have to accept some responsibility in the mismanagement of his epilepsy. Peter absolutely hated being an epileptic. Basically it was rarely mentioned and, if it was, Peter would not participate or cut the topic short. His attitude lulled Mani and myself into a false sense of security. He was fitting regularly but would never tell us. He always had an aura or warning of about 30 seconds, which gave him enough time to get off by himself. He even hid his seizures from partner Tam, who was a nurse. With the combination of no apparent concern from the medical profession and Peter's attitude to his epilepsy, it was not hard to let the guard down. Even today when we talk to some doctors they show utter surprise that we lost a son to epilepsy. Peter's doctor at the time was stunned by Peter's death.

On reflection, there were many aspects of the handling of Peter's death that we were not happy with. I tried to manage everything and made most of the decisions in an attempt to be a help to Mani. At the time I thought it was the best way to go. We were all shocked and under pressure.

The night Peter died, two detectives attended our house. Their attitude was one of disrespect and it came to light in the following days that Peter's employer – a television station – was contacted before us and told that Peter had taken his life. Even though Peter was a gorgeous young man his house could be very

untidy. I understand that when the police first went into his room and saw the mess with empty pill packets their first impression would have been suicide. They told us that he had taken his life but we suspected immediately that there had been a complication with epilepsy.

Peter's mother Mani is a Buddhist and the Buddhist belief is that the body must remain untouched for three days after death. There was no consideration or advice sought on how to treat Peter's body. Peter was taken straight to the morgue where an autopsy was performed the next day. We were not allowed to see his body until it was presented to us by the funeral director, on the Friday morning of his funeral. If we had made a fuss I am sure we could have seen his body earlier, but my brother who is a surgeon advised that it may be distressing for Mani to view Peter as his condition was poor.



While there were many things that were not to our liking in this whole episode we have taken the view that we were dealing with our son's death and no matter what transpired, nothing would give us back our son. If everything had run 'smoothly' I doubt it would have made us feel better. It is of more importance and relevance to us that we were not aware that an early death could be a consequence of Peter's epilepsy. We had accepted epilepsy as Peter's lot in life, not knowing what this could mean.

***mother & stepfather***

# Communicating risk

Very often, how a message is given is more important than the content of the message itself. How many times have you been upset with someone, not for what they said, but how they said it? The same is true when talking about SUDEP. How it is discussed often has a greater impact on the result than hearing of SUDEP itself.

Let's say a man falls off a ferry into the ocean. His life is at risk. He knows it and the ferry captain knows it. If the ferry captain shouts to the man 'Swim or you might drown!' the man is likely to become alarmed and thrash more violently out of fear he might die.

If instead the captain said, 'This happens sometimes. I'm going to tell you what you can do to keep yourself afloat. You don't need to drown when you can do things to prevent it. First, take off your shoes, jacket, and heavy clothing because those will weigh you down. Next, lie on your back and try to float on the water. Fighting against the water will only tire you out. I have stopped the boat. Just paddle gently to it. Take your time. That way you will reach the boat without spending yourself and getting into trouble.'

Telling persons with epilepsy and their family members about SUDEP is similar to the wise ferry captain coaching the passenger. The captain does not avoid discussing death – the risk is obvious to everyone. What the captain does is reassuring and useful. He focuses his message upon providing the passenger with the *practical skills* the passenger needs to have the best opportunity to preserve his life.

We have advantage over the captain regarding SUDEP. The crisis has not occurred yet, so the conversation can (and must) begin with specific positive steps persons with epilepsy and their families can take to improve their overall outcomes. These would include explaining how medications work, their behavior in the bloodstream, therapeutic ranges, and the challenges to be faced in maintaining proper blood levels day in and day out. These include talking about first aid, about how lifestyle habits can

improve the chance of seizure control, and the importance of identifying and avoiding seizure triggers. These include the unambiguous goal of good seizure control, with a clear plan for further diagnostic workups and/or treatment changes if current efforts are not successful. These include educating the person about medication side-effects and how to recognise toxicity so these can be reported – and especially so these do not cause poor compliance.

Once patients and families possess the knowledge and skills they need to help protect life, then the physician is in the ideal position to introduce SUDEP as constructive therapy. SUDEP provides the physician with a compelling opportunity to illustrate why proper medical self-management skills are so valuable to the person and family. While these skills are designed to prevent seizures, they also afford important protections against more rare and serious complications in epilepsy, including SUDEP and status. The take home message, ‘Practising these skills daily can reduce your risk of harm from epilepsy. That puts your future in your control.’

So what does this mean for real world medical practices? First, patient and families can handle the discussion of SUDEP and other epilepsy risks when presented properly. Second, the discussion of SUDEP must be preceded by a boatload of patient and family education that provides the knowledge and practical skills needed. This understanding allows them to cope medically *and psychologically* with the knowledge of SUDEP. Third, knowing epilepsy carries risk is what cements patient and family skills into daily practice and insures better therapeutic outcomes. Finally, the time required to teach every family is not practical for the physician. Specially trained support personnel, such as nurses, health educators, and epilepsy association staff are the key to providing this care. Add them to your practice.

**Robert J Mittan, Ph.D.**  
***Seizures & Epilepsy Education (S.E.E.)***

**Catalina Rofloc Mittan, Former Executive Director,**  
***Los Angeles County Epilepsy Society***

# Telling children and adolescents?

Children with epilepsy have an increased risk of death but this is largely due to the underlying neurological disorder. In contrast, SUDEP is very rare in children (1-2 per 10,000 patient years) (Camfield & Camfield 2005); neurologically normal children are not at increased risk of death compared to their peers. Of course, these figures are little comfort to parents, many of whom are terrified by SUDEP.

There is no good evidence to guide prevention of SUDEP. Close supervision has been suggested, but in practice this should be combined with training in respiratory stimulation or even in respiratory support (Langan, Nashef & Sander 2000). However, children, especially adolescents, strive for independence and so intrusive supervision for otherwise healthy children is impracticable and mostly undesirable.

Despite the lack of preventative measures, many clinicians report that bereaved relatives frequently express anger that SUDEP had not been discussed with them. However, we do not know if relatives of patients who have not died of SUDEP feel the same.

Disclosure of SUDEP information to patients has been recently highlighted in medico-legal cases and by epilepsy management guidelines. The UK National Institute of Clinical Excellence guideline (Stokes et al. 2004) suggests: 'Information on SUDEP should be included in literature on epilepsy to show why preventing seizures is important. Tailored information on the individual's relative risk of SUDEP should be part of the counselling checklist for people with epilepsy and their families and/or carers.' However, it is unclear how this should best be implemented, and whether an individual at low risk benefits by being so informed.

In considering possible negligence claims, Beran (2004) considered the paramount issue to be whether advising a patient of SUDEP would overcome a 'material risk' inherent in the treatment of their illness. The uncertainty surrounding mechanisms and effectiveness of potential prevention

options precludes sound, evidence-based judgements about specified interventions. Thus, an informed patient and his/her family are aware of the potential risk of SUDEP but have no certain ways to prevent it.

‘Paternalism’ is nowadays frowned upon, and patient autonomy applauded; many clinicians opt for full disclosure. The English requirement to copy clinical letters to patients epitomises this new approach. Beran however, argues that this ignores the ‘right not to know’; unsought knowledge may cause patient and/or family distress, and even prompt negligence claims. Many patients, including children and adolescents fear dying and many erroneously believe that their risk of death is very high; here a detailed SUDEP discussion may actually be reassuring.

So, should we tell children, adolescents and their families about SUDEP? We suggest an individual case-by-case approach, where some form of valued judgement is inevitable. Those actively seeking information (children, adolescents or parents) should be informed in a frank and reassuring way, highlighting the low risk. We do not feel that patients and families should be bombarded with unwelcome information at diagnosis. The decision to discuss SUDEP should be regularly reviewed and documented. Written and website information should be available for those who seek it.

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# MATTHEW

The eldest of three children, Matthew, and his brother were always healthy but our daughter was diagnosed with asthma by the age of three and there were many times we sat through the night with her as she struggled to breathe. We were very aware that children and adults could die from asthma and that attacks could be sudden and fatal. Despite this knowledge and anxiety we did what most parents do and we managed her illness as best we could. We learned about asthma and she had regular check-ups. She never needed to go to hospital although it was very close at times. She leads a very active life and does almost everything she wants to do, due to knowledge and good management of her illness.

Matthew was diagnosed with epilepsy when he was 21. He had had some turns from age 18 but it was not clear then that it was epilepsy. When diagnosed he was referred to a specialist and we joined the local epilepsy association to gain more information. His doctor believed Matthew did not need medication initially and could better control the seizures by managing his lifestyle. This was to be reviewed and Matthew did modify his lifestyle to a degree. We read about epilepsy and the fear always with us was that he might have a seizure while driving a car, or injure himself during a seizure. SUDEP was not mentioned in the information we received.

At the time Matthew died he was still managing the triggers for his seizures without medication. To our knowledge his seizures had not increased – however he was 26 and living his own life in another city and it is possible he did not tell us. Like many young men he also disliked going to doctors.

The shock of Matthew's death was overwhelming. We were so unprepared. We spoke with his doctor who could not remember discussing this with Matthew. His view was that it could raise people's anxiety unnecessarily. However he said he would have answered any question Matthew might have asked. How can you get information if you do not know the question to ask? Matthew was an intelligent adult and very capable of making good decisions about his health. We will never know whether he had all the information he needed to make fully informed choices about managing his lifestyle or taking medication. It may not have prevented his death but as parents we would have felt he knew all that was necessary.

Another difficulty is that epilepsy deaths are not discussed openly – it seems to be a taboo subject. There appears to be more SUDEP information available now but there is still a reluctance to discuss it in medical circles. Since Matthew's death we have spoken with other bereaved families and their stories echo ours. This aspect is almost a denial of our tragedy and compounds the trauma and grief. Being heard and understood is such a basic human need when people are suffering.

***mother***

# Reflecting on my clinical experience

Over 15 years I have lost many patients to SUDEP. In the old days of long waiting lists people would sometimes die whilst waiting for scans or inpatient monitoring prior to surgery. But SUDEP occurs in many situations. There were patients I had seen perhaps only once after a single seizure and there were patients I hadn't seen for a long time, who had been, as far as I knew, quite well. On average, 6-10 patients of mine have died from this every year.

It is difficult to describe the feeling that you have as a neurologist taking care of someone when this happens. First, you are conscious of what an awful event it is for those closely involved, but there is no doubt that you feel a lot of guilt and responsibility. This is particularly the case if the person had persistent seizures no matter what treatment was tried. It might even be harder though when the person had seemed well controlled.

Sometimes SUDEP occurred where I had given strong warnings that it was possible yet people hadn't complied with medications or lifestyle advice. However, because it has sometimes happened 'out of the blue' in patients who had been taking good care of things, I am less convinced that it does a lot of good to make patients feel responsible for this. Bereavement is even more difficult for a family to deal with when they think that if they had pushed their spouse or child a little harder to behave that bit better it would have saved them. I'm not sure this is true.

I try to contact all the families after hearing of such a death. Once I would hear from the Coroner first but fortunately this is less common now because of greater awareness of SUDEP. Police or ambulance paramedics often ring me from the scene and I have even spoken to families at that time but it is a harrowing experience and not one where I think I provided much benefit.

Because of the way these deaths have occurred, I have become less dogmatic in explaining to people that they are really in control of



preventing this. Good seizure control is an important element but there is so much we don't know about this condition that it is very hard to provide specific advice. Certainly, I alert people to the possibility of SUDEP and I generally try to bring it up at the time of first diagnosis. I explain that not treating asthma or diabetes can have serious consequences and the same applies to epilepsy. Most people can grasp that. Put in these terms people react to this information very well. It is much harder for people who have lived with epilepsy for a very long time and not heard of SUDEP, to suddenly be confronted with it. That is a difficult situation and one that generates a lot of anger. Nevertheless, it is critical for people to understand that this is a possible complication of epilepsy while keeping in mind that it is still a relatively rare occurrence. Once again, the comparison with asthma is a good one. People who have very well controlled asthma can have attacks that are fatal, even those who take good care of their condition.

I don't think SUDEP has changed the way I manage seizures. The aim is always to try and get complete control of convulsions and that remains the case. One of the limiting aspects of epilepsy is the fact that it is so random. Seizures can't be predicted and it is this unpredictability, which causes most of the disability. SUDEP is much the same. It is an unpredictable development which, whilst relatively rare, can occur at any time in the course of illness and sometimes even in those whose seizures appear to be very well controlled. This causes much anxiety; the combination of an unpredictable event with such devastating consequences. I think that speaking with families who have lived through this is one of the hardest things I've ever done. The tragedy of the situation is compounded in that we know so little about it and so little research is undertaken.

**Mark Cook**

***Victorian Epilepsy Centre, St Vincent's Hospital, Melbourne, Australia***

# Educating health professionals

The epilepsy community is striving to change the public discourse about seizures and draw attention to epilepsy as a health problem that can yield serious and devastating consequences. Two years ago, the Epilepsy Foundation, the American Epilepsy Society (AES), the National Centre of Epilepsy Centres, the Centres for Disease Control and Prevention, and the Chronic Disease Directors sponsored a conference, *Living Well with Epilepsy II*, to craft a comprehensive public health strategy for epilepsy in the United States. Recommendations highlighted the need for greater research and understanding of epilepsy-related mortality, including sudden unexpected death in epilepsy. In particular, recommendations called for identification of risk factors for mortality using incident cohorts, increasing basic science research to understand the pathophysiology of SUDEP and other causes of death, facilitating research by creating databases of autopsy findings, and encouraging the use of brain bank resources.

Conference participants also recognised the lack of knowledge about SUDEP. This lack of knowledge may stem from, and in turn lead to, a serious lack of communication between patients, families and providers about this problem. The epilepsy and public health communities were challenged to change this, calling for increased educational efforts among all audiences and the development of effective interventions and support systems for families who have lost a loved one with seizures.

The *Living Well with Epilepsy II* Conference highlighted critical gaps in what is known, what is needed, and what is talked about. Unfortunately, these gaps remain and can be seen in the level of concern and questions raised by patients and families, the limited number of educational materials or programs, and the extent of research in this area. The Epilepsy Foundation website ([www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)) reflects public concerns about epilepsy – a large number of people are talking publicly about SUDEP in online community groups, story boards that honor loved ones

who have died from seizures, and in general educational articles. The level of discussion was surprisingly passionate, with people searching for answers from anyone who could help. Consumer website information identifies some risks of seizures, but tools to help patients and families assess their risks are still lacking. These concerns are repeated in many clinical practices across the country as families of people who have died from SUDEP question why they were not forewarned of this risk.

On professional websites, the discussions are much quieter. The American Association of Neuroscience Nurses' website has limited content addressing epilepsy, and nothing that addresses SUDEP. A review of the professional journal contents over the past three years reveals a similar lack of attention. This lack of information could pertain to the fact that this is not an epilepsy-specific organisation and SUDEP may not be perceived as a critical educational need for their members. It could also mean that nurses are not comfortable discussing this area or do not have the expertise to address it.

To examine this facet further, the website of the American Epilepsy Society was examined. What SUDEP information existed was unfortunately limited and not readily available. For example, archived abstracts for 2000-2003 yielded only 23 addressing SUDEP in some way, yet over 100 on mortality in general. There were no nursing abstracts addressing care or support of patients and families coping with death from epilepsy. Excellent articles exploring the scope and known risk factors of SUDEP were found in the AES journal, *Epilepsy Currents*, but SUDEP was not included in the educational program for medical residents and nurses. Additionally, SUDEP has not been a topic of a major plenary in recent years. Educational teleconferences offered to AES members and non-members (including nurses, social workers, psychologists, or pharmacologists) have not addressed SUDEP or mortality. These findings were surprising and suggest that we are not educating our colleagues about one of the main concerns for people with epilepsy.

Despite the questions raised by people with epilepsy and their families, some health care professionals question whether they should tell people about SUDEP for fear of worrying them needlessly. Professionals struggle with how to address these safety and mortality risks while balancing concerns of overprotection. Educational efforts also suffer from not knowing what preventive strategies, if any, should be stressed.

This brief perspective on SUDEP focused on the gaps in research, education, and communication. To eliminate these gaps, nurses and other caregivers who are on the ‘front line’ must be given education and resources to address patient and family needs appropriately. Nursing and other behavioral science researchers must also develop research agendas that will examine their role in death and epilepsy, and identify strategies for risk assessment and prevention, health promotion and communication, and coping.

***Patricia Osborne Shafer***

***Epilepsy Nurse Specialist, Beth Israel Deaconess Medical Centre  
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***Joan K Austin***

***Distinguished Professor, Indiana University School of Nursing  
Indianapolis, Indiana***

# Living with the risks

I had uncontrolled seizures for many years never realising that people could die from a seizure. Being diagnosed as a child I wasn't told about the risks of sleep deprivation or high alcohol intake so during my early adulthood years I was doing both, not knowing about the possible consequences. I had frequent seizures but I never considered this to be a serious condition – just something I had to accept.

My seizures were never controlled by medication and there were times that I felt like coming off the 3 or 4 different drugs I was taking; they didn't seem to help much, but something held me back. I was eventually offered epilepsy surgery and in preparing for the operation I was informed about the risks – including death. This was the first time I had ever thought of that possibility. I considered the risk, but it did not stop me going ahead.

The surgery brought me into contact with different doctors and epilepsy counsellors and for the first time I began to learn about epilepsy. Learning about my condition gave me a sense of confidence and positive self-esteem. Some of the things I discovered about epilepsy and its treatment were not easy to hear, and when a young man I knew through the surgery program subsequently died as the result of a seizure, the issue of death really hit home. However, I don't live in fear of death. Now I know about epilepsy I make choices to take care of myself. I strongly believe people have the right to know about all aspects of their condition.

Now, working as an epilepsy counsellor, I often speak with people who are newly diagnosed. For many, the decision to take medication is a huge one. If they are not aware of the dangers of seizures as well as the side-effects of medication I do not feel that their decisions are truly informed. Informing patients does not mean simply labelling their condition and giving them a list of risks. They need a broad base of information so they can put the risks into context. The information needs to be clear and people must feel comfortable to ask all their questions without feeling foolish. This takes time and understanding.

**Maree Kearton, Client Services Counsellor  
Epilepsy Foundation of Victoria, Australia**

# Considering medico-legal issues

SUDEP is essentially an unavoidable complication of epilepsy. It is not experienced as a consequence of something which the doctor has, or has not, done. A recent audit of a single clinic's experience of SUDEP identified the most susceptible individuals as young males with focal epilepsy treated with polypharmacy (Beran et al. 2004). In this particular study there was no relationship between SUDEP and left or right handedness, use of alcohol nor deterioration of epilepsy at the time of death. Despite these findings the very next case of SUDEP, encountered within this practice, was that of a healthy young female with primary generalised seizures treated with monotherapy.

The reason for the above background information is to reinforce the notion that there cannot be a material risk, which is the doctor's unequivocal responsibility to divulge within the common law legal system. The Australian case of *Rogers v Whitaker* cast in stone the doctor's responsibility to discuss material risks with patients so as to protect them with the capacity of informed consent to propose treatments. It follows that the doctor cannot be considered negligent for failure to discuss SUDEP with a patient who has not asked questions relevant to it, as there are no material risks involved.

What is also apparent from the above discussion of a single practice audit is that the definition of propensity to SUDEP is not an absolute domain. While the audit reinforced the popular conception of what constitutes the higher risk population, the very next case defied all these accepted standards. To have advised this young lady that she was not at risk of SUDEP may have been deemed both irresponsible and potentially negligent in the light of her subsequent demise.

Should a patient ask pertinent questions, relevant to SUDEP, then the situation is quite different. The doctor is the accepted expert and thus, if asked questions, has both a duty of care and an ethical responsibility, to

provide truthful answers to the best of his/her ability. If incapable of providing adequate answers, the doctor has a responsibility to either refer the patient to a better informed specialist or to an appropriate source of information.

Where the patient has not asked any questions regarding SUDEP, and there is no material obligation to discuss issues pertinent to SUDEP, then there emerges a question of the patient's unassailable right not to be advised about it. To discuss a condition for which there is no definable remedy, and where such discussion may evoke fear and impair quality of life for both the patient and his/her relatives, there may be raised questions of negligence. As the doctor cannot adequately protect against SUDEP, it is argued that the doctor has no obligation to discuss the condition, unless such explanation is sought by the patient. To discuss it without consent from the patient may significantly destroy quality of life and may be grounds for litigation against that doctor.

The material discussed thus far has not been subjected to the adversarial debate within the courts. It merely reflects conjecture up until such time as the opinions expressed have been tested by the judiciary. The purpose of this discussion is to air the competing views within the legal debate rather than to provide absolute answers.

The final issue, when considering legal questions relating to SUDEP, focuses upon the doctor's obvious duty of care to all patients under his/her management. The doctor has an obligation to provide optimal care to patients and to ensure that he/she is capable of offering a standard of care expected from similarly qualified professionals. The level of what constitutes such care was based upon the standards provided by a body of doctors, considered to be the peers of the doctor in question, as was determined by the *Bolam Principle*. This meant that the doctor could base his/her behaviour on that expected from similarly qualified colleagues.

This standard of care was questioned subsequent to *Rogers v Whitaker* and it was held that it was the role of the courts to define what constituted an acceptable standard of care.

With an explosion of litigation and the perilous state of one of the medical defence organisations (medical indemnity insurer) there was a concerted effort to revisit tort law and to reinstate the concept of the *Bolam Principle*. Again this will require court decision to fully define what is the current state of practice but what is apparent is that doctors will have to practice defensive medicine and will need to respect the duty of care owed to their patients. In other words, one cannot divorce legal considerations of SUDEP from the broader issues of legal expectation in the treatment of epilepsy as a whole.

**Roy G Beran**

**Professor, School of Medicine, Griffith University**

**Director, Strategic Health Evaluators**

**Neurologist, Liverpool Hospital, Australia**



# DIANNE & COLETTE



Our sister Dianne suffered from severe epilepsy for most of her life. Her seizures were unpredictable, and never fully controlled by medication. Despite this, Dianne lived a full life as a daughter, sister, mother, community activist and friend. Despite being reassured by her doctors that epilepsy in itself was not life threatening, Dianne died in her sleep suddenly and unexpectedly in March 1989 aged 32. Our grief and loss were incalculable and remain so to this day. Only one person kept us going through the devastation of Dianne's death — Colette, Dianne's only daughter, then aged 8 and the much adored centre of our family.



In 1991, Colette began to suffer from seizures. Given Dianne's death, we were terrified that we could lose her. However, that terror receded when we were told that she had a benign seizure condition unlike her mother's epilepsy, that the seizures would stop as she grew up, and that her condition was not sufficiently serious to require continued hospital supervision. Colette suffered only 4-6 seizures a year, always on awakening. She took a small amount of medication prescribed by her GP, and her seizures caused her little inconvenience. She was a strong, healthy and happy young girl. Yet in April 1998, Colette died in her sleep, aged 17. It is impossible to describe the pain of losing her, a pain that will be with us forever.

Colette's death was the subject of a lengthy and complex judicial inquiry (Taylor 2002). The Inquiry concluded that Colette's death might have been avoided had she received a better standard of medical care and had we been advised of the risks of SUDEP and of precautions to minimise that risk. One of the most difficult things for us to deal with was the realisation that the risks of Colette's condition were known by the medical profession, and yet despite raising the issue of epilepsy death explicitly with Colette's doctors, we were never told of those risks. Colette's doctors held all of the power in terms of providing (or not providing) information. Yet we bore all of the loss.

We hope the lessons learned from the investigation into her death will minimise the possibility of other families suffering the terrible loss of a loved one. Colette and Dianne have inspired many people to make great efforts to protect the lives of others with epilepsy and we are, as we have always been, immensely proud of them.

***sisters & aunts***

# Determining the right to know

The law on medical negligence in the UK relies heavily on the Bolam test whereby a doctor is not negligent (i.e. does not breach the legal standard of care) where their practice is supported by a reasonable body of similar professionals. The test has been applied to the provision of information to patients as well as in diagnosis and treatment. Further, following the Bolitho case, any practice must also be justifiable on a logical basis and doctors must have considered the risks and benefits of competing options. Logical justification of any medical practice must reflect any advances in medical knowledge rather than a residual adherence to out-of-date ideas. Thus, the Court may test the medical evidence offered by parties in litigation in order to reach its own conclusions. It may consider not only the magnitude of risk, but also the seriousness of the consequences, the ease by which the risk might be avoided, the resource implications of such avoidance, and the risk of alternative interventions.

Regarding SUDEP, while a small number of medical practitioners appear to oppose the provision of any information on risk, there is a sizeable body of practitioners who believe the contrary. Whether that small number who oppose the provision of information can now be regarded as a reasonable body of opinion is debateable and would be a matter of evidence before the court in a damages claim for medical negligence. The court would be entitled to consider the available knowledge base on SUDEP and in particular on the nature of risk. In the UK, the finding of the National Sentinel Clinical Audit of Epilepsy-Related Death (Hanna 2002) that SUDEP is causally related to continuing seizures (of a variety of types) may constitute strong evidence that SUDEP is potentially preventable insofar as continuing seizures are often amenable to intervention. In addition, there is an extant literature on possible risk categories, precautions and interventions, which also suggests the possibility of precautions and interventions to avoid SUDEP. The court would also consider the potential seriousness of the consequences of not informing a patient of risk which, in the case of SUDEP, is likely to be an influential factor.

In addition, any failure by doctors to provide information on the risks of epilepsy death may be incompatible with human rights protections. Existing rights to life and to family life protections, as well as prohibitions on degrading treatment (such as treatment without informed consent), are likely to impact on any assessment of the appropriateness of medical practice. Such a failure is clearly incompatible with existing clinical guidelines on the management of epilepsy such as the NICE guidelines in England and Wales (2004) and the SIGN guidelines in Scotland (2003), both of which categorise information on SUDEP as an essential element of information provision. The increasing number and importance of clinical guidelines assist the Court in assessing what amounts to a reasonable standard of care.

Given that there has been only one judicial determination in the UK relating to SUDEP, it is prudent to consider the approach taken by the court in that case to the issue of information provision. The determination issued by Sheriff Taylor in 2002 in the Fatal Accident Inquiry into the death of 17 year old Colette Findlay provides clear guidance for doctors on this matter (Taylor 2002). The court accepted evidence that SUDEP was a real risk for individuals whose seizures were not fully controlled. The determination acknowledged that precautions can be taken to minimise this risk. These precautions include controlling the seizures, altering sleeping arrangements, and using alarms. Providing such information was viewed as a reasonable precaution to prevent death. Consequently, Sheriff Taylor determined that in the vast majority of cases patients and/or their families should be told about the risk of SUDEP.

Given this determination, doctors would be well advised in almost every circumstance to advise patients and their families about risk and give information on possible precautions. Indeed, it is arguable that the case for providing information on risk has been strengthened since this court heard its evidence by the findings of the National Sentinel Clinical Audit of Epilepsy-Related Deaths (Hanna 2002).

It is worth stressing the distinction between legal and medical definitions of proof – civil courts will assess evidence on a balance of probabilities rather than scientific certainty. The court will assess whether on a balance of probabilities there was a departure from the standard of reasonable care and whether a death would have been avoided. In the absence of information on risk, individuals and their families lose the chance to take potentially preventative measures. As Sheriff Taylor (2002) noted:

“The risks of sudden death in epilepsy should have been explained to them. There should have been a discussion as to how Colette’s condition might be managed. Issues such as apnoea alarms to detect any cessation of breathing, sleeping in the company of another adult and other similar measures should have been discussed. I accept that there are pros and cons about taking such measures, but there ought to have been an informed discussion. If such measures were not to be taken, then it should have been a deliberate, conscious decision as opposed to a decision by default”.

It is sometimes argued that a doctor’s duty of care requires open and frank discussion of SUDEP with patients who seek information. However, to rely on patients seeking information on risk is an illogical (if commonly held) position – it requires that patients know about risk in order to raise the issue. While some individuals wish to know very little information about risk, they should be offered information and its decline recorded, albeit that opportunity must be provided to revisit the issue where their wishes change. Additional speculation on this matter might look to the potential liability for harm to carers who suffer the shock and trauma of losing a loved one to SUDEP.

In any event, the strongest argument for the provision of information on the risk of SUDEP may well be a moral one in terms of rights to information or one based on good medical practice in empowering patients to deal with risk. Doctors should, however, be mindful of the real possibility of legal liability.

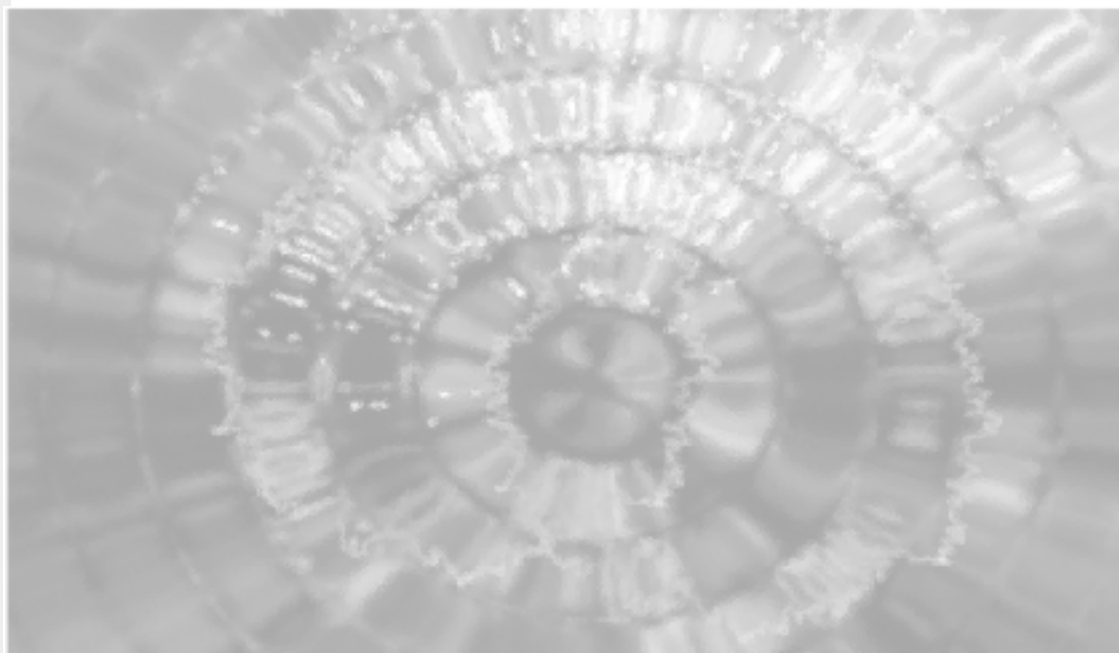
**Robert Carr**

***Solicitor-Advocate at Anderson Strathern and a Law Society of Scotland Accredited Specialist in Medical Negligence and Personal Injury Litigation.***



# Part 4.

*facing the future*



## AUSTRALIA

Australian epilepsy organisations began to face the issue of SUDEP around nine years ago. Initially the most pressing need was to provide support for bereaved people seeking answers as to why a death had occurred. The unexpected loss of a young person is tragic for any family however, with SUDEP, families are devastated when they discover that epilepsy can cause death in this way. Many are angry that they didn't know about SUDEP, and often blame themselves for not having sought out that knowledge. They wonder if the death could have been prevented and these emotions extend beyond the family to friends and colleagues, rippling out in waves through the community, compounding the grief. Epilepsy Australia counsellors offer whatever information and assistance is needed, for example providing information about SUDEP or helping families to understand post mortem reports. Support is given also by volunteers, who themselves have experienced SUDEP in their family. Bereaved families are carefully matched to this peer support as requested. As the network of bereaved families has expanded memorial services have been held in Melbourne with subsequent services held in other states.

The discussion of SUDEP has been promoted throughout the epilepsy community. A SUDEP session was coordinated for an Australian epilepsy conference in 1998 and brochures produced including an information kit distributed at the 23rd International Epilepsy Congress (1999). In conjunction with the release of the UK audit report (Hanna 2002) a media campaign was initiated to attract both public and government attention to epilepsy. It has been encouraging to see the effect of the audit on UK epilepsy management policy and we have always looked to the positive outcomes for epilepsy services generally in Australia, which might arise from an informed discussion of SUDEP by all stakeholders.

Australian data on epilepsy related deaths is inadequate and we have worked closely with the Victorian Institute of Forensic Medicine, not only to improve family support at the time of the death, but also to highlight the need for a uniform approach to the identification and

certification of epilepsy related deaths. In 2004 this work resulted in a joint SUDEP presentation to the Australasian pathology conference.

At times we have been criticised for raising issues which might cause fear to patients. Certainly SUDEP can be confronting, but the topic is now out in the open around the world. We can't ignore it. Health care services expect patients to be active participants in their own health care decisions and this requires patients to be informed. We have a responsibility to ensure that SUDEP information is clear and accessible. Rather than ignoring the topic of death we present it as part of a comprehensive discussion on epilepsy and risk.

There would appear to be positive outcomes that could be achieved by open and honest discussion of SUDEP. For example, consider Sudden Infant Death Syndrome (SIDS). It is not easy to tell parents that babies can die suddenly and unexpectedly. However, the SIDS campaign in Australia has led to a staggering reduction in child deaths. Raising public awareness educated parents about research findings, while attracting more the \$15 million dollars to further that research. It is possible that there are more SUDEP deaths in Australia now than SIDS deaths, but very few dollars have been spent on SUDEP research in this country.

One interesting aspect of SIDS research is that the reduction of deaths has come about through the identification and management of risk factors although causative mechanisms remain elusive. With this in mind, and because we have several families that have experienced both SIDS and SUDEP, we have sought to facilitate joint research with SIDS researchers. To date we have been unsuccessful.

Looking back over ten years, progress with SUDEP issues has been positive but limited. Looking forward, much still remains to be done in the areas of research, education, and prevention.



In Canada, the incidence of SUDEP has not been evaluated. Epilepsy Canada reported that the incidence of SUDEP was lower than the one for asthma, a condition with much less taboo than epilepsy. The incidence was higher than for Sudden Infant Death Syndrome, a condition that gets much more media attention and special research initiatives than epilepsy. However, the awareness of SUDEP has increased with recent Canadian publications over the past 3 years.

In a recent review Tellez-Zenteno, Ronquillo & Wiebe (2005) reviewed the incidence and risk factors of SUDEP in the literature, and the risk factors appear to be similar worldwide. In studies using non-SUDEP deaths as controls the most consistent risk factors were a seizure preceding death, and subtherapeutic antiepileptic drug levels. In studies that used persons living with epilepsy as controls the main risk factors for SUDEP were youth, high seizure frequency, high number of antiepileptic drugs and long duration of epilepsy. A 10-year paediatric review in Ontario by Donner, Smith & Snead (2001) revealed that the risk factors observed in adults might not apply to children. Low serum levels of anticonvulsants and polytherapy did not appear to be risk factors in their population.

An earlier Epilepsy Canada publication had led to a surprisingly severe reaction from both patients and physicians. Most reactions were negative but for different reasons. Some individuals, mainly patients, were surprised by the fact they did not know about the risk of sudden death associated with epilepsy. While on the other side, both patients and physicians believed that overstating this risk might even further negatively modify the attitude of individuals and insurance companies towards people with epilepsy. However, this helped our group and others realise that we need to discuss this with patients, especially those at risk. We believe that knowledge empowers individuals increasing their chance to live a full life.

Our local epilepsy organisation (Epilepsie Montreal Metropolitain) has not discussed the issue over the past 10 years in our annual information meeting. Again, I believe the possible negative reaction of patients and families has made this a difficult issue to tackle. In future years, better

knowledge of the worldwide incidence of the condition, including in Canada, could make it much easier to discuss this topic.

Au Canada, la fréquence de MSISE (Mort Subite Inexpliquée Secondaire à l'Épilepsie) n'a jamais été évaluée. Épilepsie Canada rapporte que l'incidence de MSISE est cependant inférieure à celle de la mortalité reliée à l'asthme, une condition porteuse de beaucoup moins de tabou que l'épilepsie. Mais son incidence est supérieure à celle de la Mort Subite du Nourrisson, une condition beaucoup plus médiatisée et subventionnée que l'épilepsie (Lumina, Automne 2004). Cependant, une prise de conscience s'est effectuée au cours des 3 dernières années avec des publications canadiennes sur la MSISE.

Une revue récente de la littérature (Tellez-Zenteno, Ronquillo & Wiebe 2005), suggère que l'incidence et les facteurs de risque pour la MSISE sont identiques partout dans le monde. Les études comparant son incidence à celle des morts non subites montrent que une crise récente et des niveaux sous thérapeutiques d'anticonvulsivants sont les principaux facteurs de risque. Quand on compare à tous les patients souffrant d'épilepsie, les facteurs de risque sont le jeune âge, une forte fréquence de crises, la polythérapie et la durée prolongée de l'épilepsie. Cependant, une étude rétrospective sur 10 ans en Ontario (Donner, Smith & Snead 2001) montre que les facteurs de risques ne sont pas nécessairement les mêmes que chez l'adulte. En effet, les faibles niveaux d'anticonvulsivants et la polythérapie n'apparaissent pas comme des facteurs de risque chez l'enfant.

Discuter de MSISE peut entraîner de chauds débats. Une ancienne publication d'Épilepsie Canada avait provoqué une vague surprenante de réactions de la part des patients et médecins. La plupart des réactions étaient négatives mais pour des raisons distinctes. Un premier groupe, composé surtout de patients, était surpris de ne pas avoir été informé de

cette condition. Le second groupe, composé de patients et médecins, nous indiquait qu'il n'était pas nécessaire de publiciser cette condition rare et qui risque d'influencer négativement l'attitude des gens et des compagnies d'assurance envers les personnes atteintes d'épilepsie. Cependant, notre équipe et d'autres à travers le Canada ont reconnu le besoin de discuter du syndrome avec les patients, au moins ceux à risque. Nous croyons que le savoir est un avantage pour chacun et permet aux individus et à leur famille de pleinement profiter de la vie.

Notre organisation locale (Epilepsie Montreal Metropolitain) n'a pas abordé le sujet de façon officielle au cours de 10 dernières années à notre journée annuelle d'information. Encore une fois, l'impact négatif du sujet sur les patients et leur famille en font un sujet difficile d'aborder en groupe. Dans le futur, nous croyons qu'en informant mieux les patients et leur famille individuellement sur l'incidence de la MSISE, pourrait faciliter une discussion ouverte sur le sujet.

***Lionel Carmant, President, Canadian League Against Epilepsy***

## CHILE

It is known that the mortality in epilepsy is two or three times higher than in the general population, but in Chile we do not have studies about it. This situation gets more difficult due to the lack of precision in the death certificates and the refusal of many relatives to permit autopsies, thus we are unable to determine the cause of death. Throughout the different regions of our country, there are places in which there are not reports of mortality by epilepsy, denoting that this is a concept that is not used uniformly by all the professionals or general doctors.

As the above background demonstrates, it has been a major difficulty to diagnose SUDEP, since the first barrier is to have an agreement regarding its definition. The current definition is 'the abrupt, unexpected death in

patients with epilepsy, with or without witnesses, non traumatic and in absence of suffocation, with or without evidence of crisis and with exclusion of a documented epileptic state, in which the autopsy does not reveal a cause of death from a toxicological or anatomical origin' (Nashef 1997). If we also want to add the three levels of certainty: a) definitive SUDEP: considers the full definition b) probable SUDEP: an autopsy has not been performed c) possible SUDEP: other possible causes of death, but death by epilepsy cannot be ruled out. These levels allow us to check and establish the facts in a more orderly fashion, but in general, this has not been done.

In Chile, reports of SUDEP were presented in the First Latin American Epilepsy Congress in 2000, held in Santiago. Devilat et al. describe in four years, seven children with epilepsy who died in an epilepsy centre, with regular controls, from a total population of 862 patients. Four children qualified as SUDEP, that is 0.46% of the cohort. One definite, two probable and one possible. In none of them, the death certificate makes any reference to death by epilepsy. All the patients were very poor, and with the exception of one family, they all received psychosocial support, revealing they did not know about the risk of sudden death in epilepsy.

The League Against Epilepsy, in its educational program, has been considering this subject with an increasing interest. It has also been considered at the Latin American regional events, but we are aware that there is plenty of work to be done about it, as it is requested by the families. It is necessary that the health team, the patients and the families of people with epilepsy know the risk factors (gravity of the seizure, the type of seizure and the type of epileptic syndrome, neurological compromise, use of antiepileptic drugs, nocturnal seizures, age and others). On the other hand, it is convenient to continue researching for the mechanisms of its pathogeny and the anatomopathological findings, in order to be able to take preventive measures. The role of education in SUDEP is very important, to raise awareness of the risks, frequency and causes, and in that way to give support to the families and the community of the individual with SUDEP.

Se sabe, que en epilepsia la mortalidad es dos a tres veces superior que en la población general, pero en Chile no tenemos estudios al respecto. Esto se ve dificultado por la falta de precisión en los certificados de defunción y la negación de realizar autopsias por muchos familiares, con lo que no podemos precisar la causa del fallecimiento. Es así que a lo largo de las diferentes regiones de nuestro país, hay lugares que no se reporta mortalidad por epilepsia, denotando que no es un concepto que se maneje uniformemente en todos los profesionales o médicos generales. Con los antecedentes previos, mayor dificultad ha sido el diagnosticar la MUERTE SÚBITA POR EPILEPSIA (MUSEP), ya que la primera barrera ha sido el ponerse de acuerdo con su definición, siendo actualmente “la muerte brusca, inesperada, en pacientes con epilepsia, con o sin testigos, no traumática y en ausencia de sofocación, con o sin evidencias de crisis y con exclusión de estado epiléptico documentado, en el que la autopsia no revela una causa de muerte de origen toxicológico o anatómico”. Si además quisiéramos agregar los tres niveles de certeza: a) MUSEP definitiva: considera la definición completa. b) MUSEP probable: a la definición le falta la autopsia. c) MUSEP posible: son posibles otras causas de muerte, pero no puede excluirse la por epilepsia. Estos niveles contribuyen a que constatemos y consignemos los hechos de forma más ordenada, pero en general no se ha hecho.

En Chile, reportes de MUSEP, podemos encontrar dentro de los trabajos presentados al Primer Congreso Latinoamericano de Epilepsia, el año 2000, realizado en Santiago de Chile. Devilat y col., describen en 4 años, 7 niños con epilepsia que mueren a un centro de epilepsia, con controles regulares, de una población total de 862 pacientes. Cuatro niños se calificaron como MUSEP, es decir un 0.46 % de la casuística. Uno definitivo, dos probables y una posible. En ninguno de ellos el certificado de defunción hizo alusión a muerte por epilepsia. Todos eran pacientes de muy escasos recursos y excepto una familia, todas recibieron apoyo psicosocial, manifestando que nada sabían del riesgo de muerte por epilepsia.

La Liga Chilena contra la Epilepsia, dentro de su programa educativo, ha considerado con creciente interés este tema como también en los eventos regionales Latinoamericanos, pero estamos conscientes que aún falta mucho trabajo al respecto, tal como los familiares nos lo solicitan.

Es preciso que el equipo de salud, los pacientes y los familiares de individuos con epilepsia, sepamos los factores de riesgo (gravedad de las crisis, tipo de crisis y tipo de síndrome epiléptico, compromiso neurológico, uso de medicamentos antiepilépticos, crisis nocturnas, edad y otros). Por otra parte se hace conveniente seguir investigando los mecanismos de su patogenia y los hallazgos anatomopatológicos, para poder tomar medidas de prevención. Es importantísimo la educación en MUSEP, tanto por saber los riesgos, frecuencia, causas y así poder brindar un apoyo a la familia y al entorno del individuo que presenta una MUSEP.

**Tomás Mesa, MD. Chile, Child Neurologist**  
***Past President of the Chilean League Against Epilepsy***  
***Pediatrics Department of the Catholic University of Chile***

**Chile** has an estimated population of 15.5 million inhabitants. Approximately, 65% of the people receive their medical coverage from the government and the majority are covered for their entire medical needs and medicines. We can always find things that can be improved and we've been involved in a health reform in the last couple of years. Our health indexes show a mortality rate of 5.3/1000 inhabitants and an infant mortality rate of 8.3/1000 live births. The most important causes of death are circulatory, cancer and trauma. All of these, place us near the demographic indexes of developed countries and present us new challenges to improve them.

In terms of epilepsy, a National Plan for rational management was developed and is being used since last year. The Plan defines uniform criteria and actions to be taken at public primary and secondary level.

This plan ensures treatment with phenobarbital, phenytoin, carbamazepine and valproic acid for all patients. It also establishes frequency of blood testing, EEG, neuroimaging and referral criteria to neurologists. SUDEP has not been included in these guidelines as a specific point and so far it has not been considered a priority for this national plan.

Reducing mortality is an important aim of epilepsy management as it is 2-3 times higher than in the general population. SUDEP accounts for approximately 2% of deaths. This has been the subject of several publications, but so far there's nothing definitive regarding its aetiology, management or prevention. Whether concomitant diseases are risk factors for SUDEP is unknown. In general terms SUDEP patients have been found to be of a younger age and they are commonly found dead in bed with evidence of having had a seizure. Studies on SUDEP are difficult to conduct and interpret because it is relatively uncommon and a large number of cases are needed to achieve clinical significance.

SUDEP is an issue that hasn't been addressed in a specific way in our Epilepsy Program and its approach depends on each physician. It has been a growing concern for neurologists as reports appear in literature and the risk of malpractice suites is more frequent. Last year it was discussed in our yearly National Epilepsy Meeting and it is still a thing that needs to be solved in terms of management and interaction with patients. In general, Chilean doctors are aware of the problem and should discuss in more detail, matters such as suicide, accidents, injuries and SUDEP. Some centres in Santiago, Chile's capital, keep records and study their mortality cases according to local guidelines. Their families are instructed to contact their physician as soon as possible if the patient dies, in order to ensure appropriate study of the case. Unfortunately, sometimes this is done too late and in about half of the cases SUDEP has been suspected but not confirmed. So far there is no accurate registry of the problem and probably we would need a national survey in order to establish the magnitude of the problem, to describe the characteristics of

our affected population, and to settle common guidelines that may benefit our patients and reduce the problem. The next Latin American Epilepsy Congress that will be held in Guatemala during 2006 will include as one of the main topics 'Death Prevention in Epilepsy'. This initiative may be a strong support to start national protocols in Latin-American countries about SUDEP.

In summary, SUDEP is a challenge and there is no official policy about it. There are only isolated initiatives and we need to work on common protocols to ensure adequate registry of the cases and to establish some guidelines that could reduce SUDEP cases.

***Carlos Acevedo & Keryma Acevedo, Paediatric Neurologists  
Clínica Alemana, Santiago, Chile.***

## CHINA

According to the reports of the World Health Organisation, there are around 50 million people with epilepsy (PWE) in the world, including 40 million patients in the developing countries. Of these people, 60-90% do not receive medical treatment or regular treatment. There are around 9 million PWE in China, including 6 million people with active epilepsy. Moreover, there is an addition of 0.4 million new cases each year in the nation. A survey suggests that nearly 65% of these patients do not receive appropriate medical treatment. Furthermore, due to the lack of relevant knowledge and under the influence of traditional custom or superstitious ideas, many PWE not only suffer from the condition, but also endure social pressure. They receive unfair treatment or even discrimination in respect of employment, education and marriage. Therefore, epilepsy is not only a disease, but also an issue of public health and a social problem.

Death caused by epilepsy is a major concern of epileptologists, public health workers, and PWE's families. Unfortunately in most countries



epilepsy is not listed in “cause of death” statistics as an independent disease. Deaths of persons with epilepsy are almost always registered as caused by the underlying disease or other cause, such as ‘accident’. So, mortality of epilepsy usually does not have a valid statistical basis. Reports from China showed mortality for epilepsy was 7.9/100,000/yr in urban area and 6.9/100,000/yr in rural area (WHO 2004).

Research and data on SUDEP, the cause of which remains poorly understood, are very rare in China. From 1994 to 2004, only three papers on this topic were published, and two of them were literature review. Wang XF and colleagues (2004) analyzed the clinical and pathological information of seven SUDEP cases. They found all the seven cases had oedema of brain and lung. Some of the patients had a reduction of neurones and an increase of gliocytes. No neoplasms or injuries to the brain were found. All seven died when they had general tonic clonic seizures; two in sleep. Four had agitation or fright before death.

One hundred and twenty epileptic patients who had been under an extended test for ‘Community Control of Epilepsy’ in the late 1980’s in two provinces in China were followed up five years after the test. Thirteen had died during the five years. The mortality rate of this group was 2.2% per year and around 3.4 times higher than the rate in general population. Among the thirteen deceased, two (15.4%) might be categorized as SUDEP. This might be the only epidemiological information for SUDEP in China (Wang et al. 1993).

The China Association Against Epilepsy (CAAE) has just been established in the People’s Republic of China. CAAE is a nationwide professional and social organisation. The establishment of CAAE is of great significance for promoting scientific and normative treatment of the 9 million PWE in the country, rectifying the social discrimination and prejudice against them, and safeguarding their lawful rights and interests.

CAAE aims to promote improved medical treatment and scientific research

and education on epilepsy, and to enhance international cooperation through participation in relevant international organisations on behalf of the Chinese epilepsy community. It is a milestone in the development of prevention and control of epilepsy in China. We also expect to focus more attention on SUDEP in China in the future under the coordination of CAAE.

*Shichuo Li, China Association Against Epilepsy  
Yongqing Zhao, Epilepsy Centre, Beijing Tiantan Hospital*

## CUBA

Despite the fact that some articles and books have been published in Cuba dealing with Sudden Death, only three articles relate it to epilepsy (González Pal S et al. 1982, 2004, 2005). These articles include patients suffering from chronic psychosis and epilepsy hospitalized in a psychiatric hospital. In these patients, the following is observed:

- The average age at the time of death of patients suffering from epilepsy was 51.84, which is 25 years less than the average life expectancy of the population in the country.
- SUDEP was present in 8.96% of the patients suffering from epilepsy that died in the Psychiatric Hospital from 1979 to 2004.
- The people that died due to SUDEP were 43.33 years old as an average, which is almost 10 years less than the remaining patients suffering from epilepsy and 32 years less than the life expectancy of the rest of the population in the country.

In postgraduate courses on epilepsy for doctors, SUDEP is a topic that must be discussed by students. In Cuba both radio programs and published newspapers for the general public have dealt with SUDEP. Doctors and other professionals who deal with patients suffering from epilepsy, and are familiar with SUDEP, consider it necessary to discuss this issue. But

the topic is not dealt with in a similar way by all health staff (both doctors and paramedics). Therefore, as health professionals that work with patients with epilepsy, we aim to disseminate information regarding SUDEP in order to raise the general knowledge of the public and of other professionals on this issue.

**Salvador González Pal & Erick González Delgado**  
**Cuban League Against Epilepsy**

## GERMANY

At the Deutsche Epilepsievereinigung we are concerned about causing unwanted fear of SUDEP in our members. Currently we have no official policy but we are planning to discuss very, very carefully how we can adequately react when this question arises, as well as considering the necessity of possible publications of SUDEP in our magazine, and the possibility of organising a workshop on SUDEP. At present, if families raise the question of SUDEP, we try to connect them with other concerned people by placing an informative article in our magazine *einfälle* asking for contacts to exchange experiences. We also ask neurologists to try and give explanations about SUDEP and to talk about their patient experiences.

Our advice of possible prevention is, or may be:

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

**Robert Bauer**  
**Deutsche Epilepsievereinigung e. V.**

Autonomic symptoms frequently occur during epileptic seizures, not as a reaction to motor manifestations, but by activation of central autonomic networks. Among the autonomic symptoms (cardiovascular, respiratory, gastrointestinal, cutaneous, papillary, genital, sexual, and urinary) cardiorespiratory arrest and ictal syncope can lead to serious complications such as sudden unexplained death (SUDEP). In children autonomic symptoms are the most common manifestation in Panayiotopoulos syndrome (81%)(Panayiotopoulos 2004) and temporal lobe epilepsy.

As a child neurologist with a special interest in epilepsy I see a large number of children and their parents. I am faced with numerous questions relating to the fears the parents have regarding the possibility of losing their child from an epileptic seizure. These fears are proportional to previous seizure experience and are increased by the outdoors activities of their children, nocturnal seizures, and irregular parental working hours resulting in inadequate care. Even though children with epilepsy have an increased risk of death, SUDEP is very rare. In the majority of children mortality is due to the underlying neurological disorder, not the seizures. All parents and children who are able to read are supplied with written information explaining epilepsy facts, care, the treatment of an acute seizure (rectal diazepam), and early identification of an epileptic event, particularly during sleep (alarms).

In treatment, care must be taken to avoid misdiagnosing cardiac dysfunction as epilepsy. Special attention is required for those children with medically resistant epilepsy, polypharmacy, and long lasting autonomic status.

Although SUDEP is discussed among professionals in different meetings, the issue is rarely discussed with the parents except with those seeking the information. Conversely, disclosure, in the absence of the patient seeking the information, may causally adversely affect quality of life of the family and the child by increasing overprotection and anxiety levels.

This can in turn lead to behavioral problems, low self-esteem, poor self-image, long lasting dependency, and a negative personality.

The office of the Greek association is hosted within the quarters of the neurology department, adjacent to a very large epilepsy clinic where discussions with all those caring for these patients take place daily. Undue fears are not provoked unless questions are specifically asked and detailed professional answers are given based on medical facts.

Knowledge about SUDEP remains limited. However, understanding the pathophysiology of the autonomic symptoms may help us to understand the mechanisms underlying SUDEP.

***Athanasios Covanis***  
***Head Neurology Department***  
***The Childrens Hospital 'Agia Sophia' Greece***  
***President, The Greek Association Against Epilepsy***

Very little attention is given to SUDEP in India. SUDEP is a relatively new topic of discussion and, more importantly, a rare condition (according to community studies).

The Indian Epilepsy Association is basically concerned with social aspects of epilepsy, emphasising the regularity of medication, and clearing the misconceptions, myths, fears, and stigma attached to epilepsy. When this is the prime concern the rare occurrence of SUDEP is kept in the background. The people with well controlled epilepsy and their relatives are more worried and distressed because of the societal attitudes. Hence our aim is on making life more comfortable by talking about the positive aspects. Sometimes SUDEP may be mentioned just to emphasise that such a thing can happen in uncontrolled epilepsy with irregular medication.

Epileptologists, neurologists, and occasionally paediatricians or others do discuss SUDEP during scientific meetings. Sometimes patients or the carers raise this issue, particularly the internet savvy group who access the information.

It is important to know the prevalence and incidence of SUDEP. It should be pursued and discussed by the medical fraternity. However when it comes to discussion with people who have epilepsy and their carers, I feel that we have to weigh the pros and cons, as the discussion of such an entity may affect quality of life in some people. Perhaps this need not be raised in people with well controlled seizures. However, in patients with poorly controlled seizures, irregular medication, or polytherapy – this entity should be discussed emphasising that poor seizure control is a contributory factor for SUDEP.

***H.V. Srinivas,  
Consultant Neurologist Sagar Apollo Hospital, Bangalore, India  
Secretary General, Indian Epilepsy Association***

When Epilepsy Bereaved (EB) started to make an impact upon the epilepsy world Brainwave was trying to come to terms with the deaths of several students from its training programme who had died in similar circumstances. EB brought the answer to the question of how they had died and this knowledge energised the organisation into action on SUDEP. This knowledge and suggested action plan were not universally accepted throughout the organisation and the first battle was to gain acceptance of the need for action. The first steps decided on were as follows:

- A major article on SUDEP in Epilepsy News (Brainwave's newsletter)
- Dissemination of the facts about SUDEP to Brainwave's students
- Advocating the use of safety pillows for all people with epilepsy
- Training for all staff in providing information on SUDEP and supporting bereaved families
- Building up of a database of bereaved families

Publishing the SUDEP article proved a seminal point in the development of Brainwave's initial strategy. Many members responded to it in varying ways, many of them negative and angry, despite great care having been taken writing the article. Nonetheless, it opened the debate on epilepsy death, providing the platform to put the other steps in place.

In May 1999, Brainwave got direct access to the Minister for Health for the first time and SUDEP was one of only four topics raised with him. It was next decided to hold a cross-border seminar on epilepsy deaths, combining with Epilepsy Bereaved and Epilepsy Action, Northern Ireland. The meeting was a success drawing families from all over Ireland. However, the Brainwave staff found it hugely draining emotionally.

In 2000 a meeting was held in Dublin for Brainwave bereaved families. This was a successful but small meeting. By this time, the JEC was at an advanced stage of preparations for the National Sentinel Clinical Audit of Epilepsy-Related Deaths (Hanna 2002) in the UK with Epilepsy Bereaved leading the project for the JEC.

The publication of the audit, in time for National Epilepsy Week (NEW) in May 2002, brought the issue of SUDEP and other epilepsy deaths to major prominence in the UK. Brainwave made SUDEP the focus of NEW with events held all around the country. Additional training in SUDEP information, advice, and support was arranged for the charity's staff prior to NEW. In Dublin, the major event was a special 'Call to Action' (on epilepsy deaths) press event. A number of prominent politicians and a good gathering of press ensured some very good publicity. The keynote speaker at this event was a young Irish neurologist working in the UK, Dr Yvonne Langan, who has done some groundbreaking research into SUDEP.

The audit findings, particularly those in relation to information for families, seizure control, and access to specialist, care led to Brainwave refining its strategy in relation to the whole area of epilepsy deaths. The following additional aims were added to the strategy:

- To step up the campaign to increase the numbers of neurologists and neurophysiologists in Ireland
- To have a major Irish research project similar to the audit
- To campaign for Community Epilepsy Specialist Nurses
- To inform key professionals such as GPs and Teachers about SUDEP

Brainwave has had success in all these areas but they are all works in progress. Earlier this year another cross border SUDEP seminar was held and now Brainwave has decided to consider regional meetings. In addition, the concept of joint working with our two partners in the cross border events is being explored.

Since Brainwave first took action on SUDEP prevention, one further death (one too many) of a student attending our courses has taken place in the past six years. This compares very favourably to the earlier experiences but does not make us complacent and, until a cause and cure for SUDEP is found, demands our on-going attention.

***Mike Glynn***  
***Ireland***



# JOHN

John developed epilepsy at the age of 11 years. He had many attacks, suffering injuries and burns. We live in rural Kenya where epilepsy is highly stigmatised. We faced a lot of rejection from our neighbours, and before long, word spread like fire. Soon John was thrown out of school because the parents of other children were threatening to remove their children from the school as they 'knew' the disease was contagious.



I took John to the nearest health centre, which is twenty kilometres away. The health worker treated him as a case of malaria. There was no relief and the seizures were now occurring daily and we were desperate and disillusioned. Friends advised us to seek the help of a witchdoctor as this was not a normal disease. We tried a witchdoctor, herbalist, and offerings, and when there was no improvement we gave up and just prayed to God to spare our son.

Then a friend told us about Kenya Association for the Welfare of Epileptics (KAWE). After he was started on treatment, and we were counselled, the seizures gradually reduced to a point where he could stay up to three months seizure free. He was able to go back to school and later enrolled in a Motor Vehicle Mechanical Course. Life was almost normal for our son: he had a job he loved and seizures once in 2-3

months. He started saving money to build his own small house. He later took some time off from work to start building the house.

Two weeks into the project, and on this particular day, he woke up early, jovial and enthusiastic, and ready for work. After lunch, he took his medication and complained of feeling a bit tired, and had a headache. He decided to take a nap on the sofa opposite me.

He never woke up again! Never! He was only 19. After the shock and disbelief, this has left me with so many unanswered questions. The last time he had a seizure was a week earlier, it was short and he had fully recovered, happy, busy and enjoying life as never before. He had no other history of another medical problem. What could have gone wrong?

Before he was put on medication, when we could watch him helplessly having one seizure after another, we knew his chance of living was slim, but why? how? when everything was going on so well for our son!

***mother***

Epilepsy is still highly stigmatised in Kenya and many communities believe it is due to witchcraft or curses, that it is contagious, and that anyone who touches the patient or his excreta will acquire the disease themselves. Therefore, the patient and the family are very unpopular and isolated. Many people do not believe in modern medicine and therefore will foremost seek help from a witchdoctor, a herbalist, offerings, and prayers. They only seek modern medicine when sometimes it's too late. The common belief is that once a person develops epilepsy the disease will eventually kill him, and so it doesn't come as a major surprise to many when the victim dies from SUDEP.

SUDEP is a condition that occurs more often than it's talked about here in Kenya. From reports gathered at one of our epilepsy clinics (Karen clinic) that has 600 registered patients coming on a regular basis, we have lost 15 patients whom we suspect to be victims of SUDEP in the last 16 years. These could be even more, as the relatives do not report on the deaths.

It is very difficult to get a true picture of epilepsy in this country. Hospital data on epilepsy is not prioritised but still lumped together in a column as 'other conditions'. It is even worse for SUDEP as no information is available. Most deaths occurring in the community are not routinely certified hence the causes of death are not known. Post mortem investigations are not routinely carried out so this makes it very difficult to ascertain the relationship between the deaths and epilepsy. Most relatives of patients who have epilepsy find it very difficult to talk about it as even now epilepsy is still shrouded in stigma. It is even worse when a death has occurred. Up to now KAWA has not raised the issue of SUDEP as we are still struggling to have epilepsy recognised as a priority in the National Health Agenda.

***Charles Gachenia Woiye, Medical Manager, KAWA***  
***Anne Gathoni, Community Development Officer, KAWA***

Epilepsy is a major public health problem for Niger and there are many obstacles to the well-being of people with the disease. The population is poorly informed about epilepsy and there are strong negative attitudes to both the condition and those who have it. There is also a lack of trained staff, inadequate facilities, and no epilepsy policies.

Fear, lack of sympathy, stigma, and social discrimination, push the people with epilepsy to be 'hidden in the shadows'. In Niger epilepsy is associated with weakness, possession by a bad spirit, and to a belief that epilepsy is contagious. Children have difficulties with schooling because of rejection by their classmates and even by some teachers. Deaths from epilepsy do occur in Niger although it is difficult to know the extent of the problem.

Following WHO advice, a National League Against Epilepsy has been created in Niger. The League works in partnership with other Niger health organisations and is coordinating a pilot project for travelling medical visits to fight epilepsy.

Travelling medical teams visit communities, sending word ahead using town criers. The teams include a psychiatrist, a neurologist, a psychologist, a nurse, and a welfare officer. The team provides public information about epilepsy, the effect of the condition on life, the risks of injury and death, crisis management, treatment, diagnosis and treatment of newly presenting cases and cases identified earlier by local health workers, training of doctors, nurses and social workers from the intervention area, phenobarbitone medication, and treatment guidelines for the local community. The results have been so good that the league hopes to generalise this experience to a wider area with the assistance of international organisations and funding bodies.

***D. Douma Maiga, Psychiatre assistant: Centre psychothérapeutique "les oliviers" Route de Noisy, France  
President, National League Against Epilepsy of Niger***

***A. Alzouma, Psychologue at National Hospital of Niamey-Niger  
General Secretary, National League Against Epilepsy of Niger.***

Twenty-six neurologists and fifteen paediatricians in Pakistan were contacted by telephone or email and asked to comment about SUDEP.

Of the neurologists interviewed, 22/26 were trained in Pakistan. Only 13/26 knew about SUDEP and only 6 had seen a case. None of the neurologists raised SUDEP in the discussion of epilepsy management in Pakistan, nor observed any other doctor raising it. Their patients never asked about it. In one case a relative of a patient whose death was classified as SUDEP had raised this issue, but that relative was living outside Pakistan in a developed country. Although most of the doctors never discussed this issue with the patients, one neurologist included SUDEP in the discussion if any patient asked about the death related to epileptic seizures.

All the paediatricians interviewed trained in Pakistan. Of those interviewed 13/15 didn't know about SUDEP. However, two paediatricians had seen a case. None of the paediatricians had discussed the issue with the patients nor had any of their patients asked the question. The doctors did not raise the issue in the discussion of epilepsy management in Pakistan and never saw any other doctor raising it.

Since March 2001, the Comprehensive Epilepsy Control Program of Pakistan (CECP) has conducted 25 free Epilepsy Camps for counseling of patients (n= >2500), 13 Epilepsy School Awareness Workshops for schoolteachers (n=529), 1 Awareness Workshop for Lady Health Workers (n=101), 10 Epilepsy CMEs with interactive sessions for family physicians (n= >500) and 1 Epilepsy CME for final-year medical students (n= >250). No one in the audience ever asked about SUDEP. It should be noted that the objectives of CECP do not include raising the SUDEP issue.

Considering cultural background in Pakistan death is an area which is not talked about (although life after death is believed and talked about). In fact if death is mentioned to a patient or a relative it may be considered as a bad omen. Hence, information on this subject has a lot of inherent

problems. Moreover, the emergency health services are not well developed in this country and any discussion pertaining to an emergency may be perceived as a frightening discussion.

However, the sudden death of a patient may raise medico-legal issues therefore, it is advisable to discuss SUDEP at least with the relatives but with reassurance that it is rare and many doctors never see it.

It is concluded that in Pakistan 50% of the interviewed neurologists, most of the paediatricians, and all of their patients are not aware of SUDEP. Those doctors who know it do not raise the issue in scientific discussion. It is very difficult to discuss the issue with the patient or relatives but it should at least be discussed with the relatives.

**Syed Wasim Akhtar**

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## ROMANIA

SUDEP is not really an issue in Romania; unfortunately not because it does not exist, but because people don't want it to be an issue. Those who are aware of this phenomenon do not want to bring up the matter and those who should be aware of it, in order to take all the possible precautions, are not.

As far as we know, both GPs and neurologists, are reluctant to discuss the matter with their patients. The main reason is that they find it difficult to raise this rather sombre prospect. Another reason may be that in Romania epilepsy is quite frequently associated with mental retardation and other debilitating illnesses. SUDEP can be very difficult to explain in such cases. As for the patients themselves, it is difficult to say if they would be interested in knowing about SUDEP. We have observed that people with epilepsy in Romania sometimes lack even the most basic

information about the disorder. We have also observed that many people with epilepsy do not understand why it would be important for them to know about their own disorder. So it may be fair to say that we should first make people aware of the importance of knowing their own disorder, before they can be interested in knowing about SUDEP.

Until the year 2003, we ourselves were not aware of the existence of such a phenomenon. It was only then that we ‘discovered’ it, accidentally, while doing some research on the internet. It was 2004 when we first learned that in other countries a lot of attention is devoted to this phenomenon and especially to preventing it. Ever since we have been trying to identify such cases in Romania and we have been trying to discover what is the best way to make this a public issue without causing panic amongst the people with epilepsy. We have also been spending a lot of time trying to get funding in order to initiate an awareness campaign regarding SUDEP; and we are still trying. Although we have not been able to make this a public issue, we have been able to inform some of our members about SUDEP.

Our organisation has made a conscious decision to include a SUDEP awareness campaign in a much broader awareness campaign. People with epilepsy in Romania have to be taught the importance of knowing and controlling one’s own disorder, before they can understand the complexity of the SUDEP phenomenon. This is something that we have been working on for the past months and this is one of our most important future directions.

***Gelu Stanculescu***

***President, National Association of People with Epilepsy in Romania***

Epilepsy Scotland is committed to raising awareness of SUDEP with the public, politicians, policy makers and the media. We have secured a high profile as the lead non-government organisation in both the Scottish Parliament's Cross-Party Group (CPG) on Epilepsy and in the development of Managed Clinical Networks (MCNs) on epilepsy.

The National Sentinel Clinical Audit of Epilepsy-Related Death (Hanna 2002) and the findings from the Findlay Fatal Accident Inquiry (Taylor 2002) were made widely available throughout the NHS in Scotland by the Deputy Chief Medical Officer. The number of epilepsy-related deaths recorded annually in Scotland increased after the 2002 audit.

As a result of the inquiry findings, Epilepsy Scotland continues to be involved in training on epilepsy for GPs and nurses. To ensure that this agenda has political support, Jane Hanna, Director of Epilepsy Bereaved and Patricia Findlay, who lost two relatives through SUDEP, gave a presentation to the CPG on epilepsy about the audit. Following on further from this, in August 2002, Members of the Scottish Parliament from the CPG on Epilepsy were invited to write to their own Health Boards to ask how the findings of this audit would be implemented. We also urged the Health Minister to keep this on his agenda. Epilepsy Scotland continues to have an active working relationship with the Health Minister's office.

In terms of input into ongoing practice development there are four MCNs for epilepsy across Scotland. Epilepsy Scotland ensures that information about SUDEP is included as part of their agenda in order to improve clinical practice in the management of epilepsy.

We participated in a debate at the 2004 International League Against Epilepsy Congress about 'when is it best to discuss SUDEP with people who have epilepsy?' Clinicians from across the UK decided this should happen during a subsequent appointment, in partnership with an epilepsy

specialist nurse. However, patient information routinely given at first consultation generally includes information about SUDEP. Understandably, this is not an easy topic for people with epilepsy or their families and needs sensitive handling.

National guidance (SIGN 70 2003) advises that information on SUDEP is part of the essential package of information recommended for people with epilepsy. SIGN 70 stresses that clinicians ensure people understand the information given to them and that it is reinforced over time.

SUDEP is specifically mentioned in Epilepsy Scotland's information literature and this is available on our website, as is Sheriff Taylor's ruling on the fatal accident inquiry. SUDEP was included in the 'Epilepsy–A Case Of Neglect' briefing we gave to the Health and Community Care Committee regarding our petition for uniform care and services across Scotland. It was also included in our 'Epilepsy–What's Your Attitude' briefing for Scottish Parliament Members.

In summary, SUDEP has been given an increasing amount of attention in Scotland over the past three or four years, doctors and patients have become more aware of the issue and discussion now takes place more routinely. Epilepsy Scotland continues to raise this significant issue with senior health professionals and politicians.

***Susan Douglas Scott***  
***CEO, Epilepsy Scotland***



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# Websites – SUDEP links

## **Epilepsy Australia: SUDEP**

<http://www.sudep.org.au>

## **Epilepsy Bereaved**

[www.sudep.org](http://www.sudep.org)

## **Epilepsy Action UK**

<http://www.epilepsy.org.uk/info/sudep.html>

## **The Epilepsy Association of Calgary**

<http://www.epilepsycalgary.com/sudden.html>

## **Epilepsy Canada**

[http://www.epilepsy.ca/scans/FALL\\_04\\_AN.pdf](http://www.epilepsy.ca/scans/FALL_04_AN.pdf)

<http://www.epilepsy.ca/eng/mainSet.html>

## **epilepsy.com**

[www.epilepsy.com](http://www.epilepsy.com)

## **Epilepsy Denmark/ Dansk Epilepsiforening**

<http://www.epilepsiforeningen.dk/artikler/sudep.htm>

## **Epilepsy Foundation**

<http://www.epilepsyfoundation.org/epilepsyusa/silent.cfm>

## **Epilepsie Nabestaanden**

<http://www.epilepsienukanhetbeter.nl/site/omgaanmetepilepsie/doelgroepen/sudep.htm>

## **Epilepsy Newfoundland & Labrador**

<http://www.nfld.net/epilepsy/laesudep.htm>

## **Epilepsy New Zealand**

<http://www.epilepsy.org.nz/news.cfm?fullarticle=40>

## **Epilepsy Ontario**

<http://www.epilepsyontario.org/>

## **Epilepsy Research Foundation, London**

<http://www.erf.org.uk/info/SUDEP.htm>

## **Epilepsy Toronto**

<http://epilepsytoronto.org/sudep.html>

## **International Bureau for Epilepsy (IBE)**

<http://www.ibe-epilepsy.org/>

## **IBE: Commission for Risks and Insurability**

[http://www.ibe-epilepsy.org/about\\_comm\\_det.asp?ID=14](http://www.ibe-epilepsy.org/about_comm_det.asp?ID=14)

## **International League Against Epilepsy**

<http://www.epilepsy.org/>

## **Japanese Epilepsy Network - Jepnet**

<http://www.synapse.ne.jp/jepnet/>

(Type SUDEP in search engine)

## **Joint Epilepsy Council UK**

<http://www.jointepilepsycouncil.org.uk/>

## **Karolinska Institutet**

<http://diss.kib.ki.se/2002/91-7349-123-3/>

## **Liga Chilena Contra la Epilepsia**

<http://www.ligaepilepsia.cl>

## **The National Society for Epilepsy UK**

<http://www.e-epilepsy.org.uk>

<http://www.epilepsynse.org.uk/>

## **Seizures and Epilepsy Education (SEE)**

<http://www.theseeprogram.com/>

## **World Health Organisation**

<http://www.who.dk/>



## *Notes*

## *Return to Bennetts Lane*

My sister Celene came to jazz music later in life. Like her enjoyment of fine wines, music, too, was an acquired taste. For Cec it was the lyrics and words of the pieces that drew her in, for me it has always been the melodies and harmonies.

The last jazz concert my sister saw was at Bennetts Lane Jazz Club in Melbourne. She was so excited that she had found a greater understanding of what I did and she felt strongly that she was also now a part of this new world. Celene was the most supportive and loving big sister a brother could ever be blessed with.

Entrée is the culmination of my life as a musician up unto this point. The pieces were written over a long period of time – from my university years to my time living and working abroad.

Forever remembered in my music, I dedicate the album to Cec.

The CD launch at Bennetts Lane in July of 2005 was a bitter sweet triumph. It was made easier by knowing \$5 from every CD sold will be donated to further research into SUDEP.

To purchase a CD or find out more information on the project please visit [www.markharris.com.au](http://www.markharris.com.au)



**This publication raises some difficult and painful questions, but also begins to provide some answers in a way that will make it an invaluable asset to many, both people with epilepsy and those supporting people with epilepsy ...**

– Ann Jacoby, *Chair, 3<sup>rd</sup> International Commission on Epilepsy Risks and Insurability*

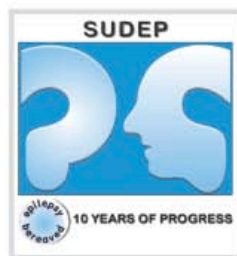
For many years it has been known that people with epilepsy can die suddenly and unexpectedly a phenomenon now known by the term SUDEP.

Over the last ten years SUDEP has become more widely discussed within the medical profession and beyond. This community conversation was promoted by Epilepsy Bereaved and is gaining momentum around the world. An internet search produces over 13,000 SUDEP references to journal articles, forums, and information posted by epilepsy organisations or health-related sites. As researchers continue to seek the elusive cause, families affected by SUDEP reach out to others to share information and experience.

Written for anyone with an interest in epilepsy, Sudden Unexpected Death in Epilepsy – a global conversation, draws together considered observations on the many issues surrounding SUDEP providing the reader with a snapshot of SUDEP as it is understood in 2005.

Epilepsy Australia and Epilepsy Bereaved are pleased to launch this publication at the 26<sup>th</sup> International Epilepsy Congress, Paris 2005.

Editors Denise Chapman, Brendon Moss, Rosemary Panelli and Russell Pollard (Epilepsy Australia) have worked for many years as epilepsy advocates.



*proudly supported by Pegasus Printing*

ISBN 0-9758011-0-4

