

## PAPER

## Sudden unexpected death in epilepsy (SUDEP): don't ask, don't tell?

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**Background:** The National Institute for Clinical Excellence in the UK has issued guidelines stating all individuals with epilepsy be given information about sudden unexpected death in epilepsy (SUDEP).

**Methods:** We conducted a survey of current practice among UK neurologists, using a questionnaire sent to all practising neurologists in the UK listed on the Association of British Neurologists database, asking under what circumstances they told patients about SUDEP.

**Results:** Of the validated respondents, 5% discussed SUDEP with all patients, 26% with a majority, 61% with a few, and 7.5% with none. The commonest reasons for SUDEP to be discussed were the patient asking about it and the neurologist counselling people with known risk factors for SUDEP.

**Conclusions:** The variation we found, although not necessarily in tune with the guidelines, reflects the variation in patients' need for knowledge about their condition.

Sudden unexpected death in epilepsy (SUDEP) accounts for between 500 and 1000 deaths per year.<sup>1</sup> Studies have identified possible risk factors but no mechanism for the phenomenon has been elucidated.<sup>2</sup> Despite evidence that uncontrolled seizures predispose to SUDEP, there are case reports of individuals dying during their second seizure.<sup>3</sup>

The recently published National Institute for Clinical Excellence (NICE) guidelines states "individuals with epilepsy and their families/and or carers should be given and have access to information on SUDEP".<sup>4</sup> Part of the impetus for this recommendation comes from patient advocacy groups, some of whom represent the relatives of deceased patients. This recommendation has led to discussion within the neurology community, with some arguing that, as there is no known way of predicting or preventing SUDEP, a blanket policy of telling all patients will only cause anxiety for no purpose.

The views of the majority of people with epilepsy on whether and how they are informed about SUDEP have not been systematically studied. Below we present the results of a survey of the current practice of the membership of the Association of British Neurologists.

## METHODS

We sent a questionnaire to all practising neurologists in the UK listed on the Association of British Neurologists database,<sup>5</sup> asking under what circumstances they told patients about SUDEP. The questionnaire also asked respondents to record patient reactions to the information. This qualitative data were assigned into three "reaction" groups under "positive", "equanimity", and "negative".

## RESULTS

## Quantitative data

In total, 738 questionnaires were posted, of which 387 were returned. Of these, 288 were completed by consultant neurologists. As there are approximately 350 consultants in the UK,<sup>5</sup> this represents 82% of the consultant body and 74% of all respondents. In addition, 63 specialist registrars (SpRs) responded, approximately 19% of trainees. The remainder

comprised associate specialists, consultants in other specialties who run epilepsy clinics, and specialist nurses. Those who had attained consultant status (that is, were in possession of Central Consultants and Specialists Committee membership or equivalent) were included in the consultant neurologist group for analysis, making a total of 301. The rest, including associate specialists, were added to the SpR group, making a total of 82. The four responses from nurse specialists were excluded. Of the respondents, 120 (31%) stated a special interest in epilepsy.

Only 18 (4.7%) of respondents discussed SUDEP with all of their patients (table 1). The  $\chi^2$  analyses of the data are shown in table 2. Half the respondents discussed SUDEP in only one clinical scenario others were prompted by a number of different patient circumstances (table 3).

\*Number who did not reply to question.

Year of qualification (date of MB, ChB or equivalent), had no effect on whether the neurologist discussed SUDEP or not, and there was no difference in responses between registrars and consultants (table 1). Knowing about SUDEP was not thought by 47% of respondents to have any effect on patients' quality of life. A third of respondents thought information about SUDEP caused anxiety. Most respondents (80%)

**Table 1** Analysis of response from medical personnel

	n	%
Discuss SUDEP with all patients	18	4.7
Discuss with majority of patients	99	25.6
Discuss with very few of my patients	237	61.2
Discuss with none of my patients	29	7.5
Total no. of respondents	383	100
Missing data*	4	

\*Four responses not analysed.

**Abbreviations:** NICE, National Institute for Clinical Excellence; SIGN, Scottish Intercollegiate Guidelines Network; SpR, specialist registrar; SUDEP, sudden unexpected death in epilepsy

**Table 2**  $\chi^2$  analysis of differences in practise between those neurologists with a special interest in epilepsy versus those without, and of differences in patient reactions as recorded by neurologists who tell the majority of patients about SUDEP versus those who tell the minority of patients

	A*	B†
Interest category		
Special interest in epilepsy	49	69
No special interest in epilepsy	68	196
Total	117	264
	$\chi^2=0.002$	
Patient reactions		
Positive	8	7
Equanimity	70	101
Negative	18	71
Total	96	179
	$\chi^2=0.001$	

\*I tell all or the majority of my patients about SUDEP; †I tell some, few or none of my patients about SUDEP.

thought patients did not understand the relative risks of SUDEP compared with smoking 20 cigarettes per day or the risk of developing lung or breast cancer. Interestingly, a majority reported they did not think informing patients about SUDEP improved drug compliance or to avoidance of risk factors for SUDEP.

Respondents who stated a special interest in epilepsy were significantly more likely to tell patients about SUDEP. Doctors who discussed SUDEP with all or the majority of their patients were significantly less likely to report negative reactions from patients than those who did not (table 1).

**Qualitative responses**

Respondents were asked to record their experiences/opinions and suggestions about practise in this area (tables 4 and 5)

**Table 4** Responses to the question "If you do discuss SUDEP with your patients when do you do so?"

- Variable, sometimes spontaneously and always if asked
- When asked and when I think it is appropriate, although it is always a subjective assessment
- If refuses treatment
- If not compliant with treatment
- To help patients decide they should go on treatment
- If there are problems with adherence to treatment that are putting the patient at increased risk
- If patient is considering the option of no treatment
- Riot act for non-compliance
- Those patients with frequent attacks who decline drug therapy
- If the patient asks generally what the risks of epilepsy are
- Since I qualified in 1969, none of my patients have died of SUDEP. I see children and adolescents with special educational needs. None of them or their parents has ever asked about SUDEP
- I discuss that epilepsy is dangerous and death can result. I do not state that if they have it they are at risk of death immediately and at any time
- If another member of the family/friend has been a victim of SUDEP
- Difficult to say, but when it feels appropriate—that is, patient led

There were 299 respondents who wrote comments in the "how do patients react?" question box, of which 275 could be assigned to the "positively", "with equanimity", and "negatively" groups. The remainder were comments that could not be assigned, for example "difficult to tell".

**DISCUSSION**

As 82% of consultant neurologists in the UK replied to our survey, we have obtained a representative picture of how neurologists practise in this area. Other specialties in the UK such as psychiatry and medicine for the elderly also care for people with epilepsy, and practice may be different in those fields.

**Table 3** Reasons for discussing SUDEP

	(Only) if patient asks	Spontaneously at time of diagnosis	When initiating AED therapy	Spontaneously at subsequent appointment	Only in patients with recognised risk factors	n	%
No. of respondents who discussed SUDEP in one or more clinical scenario							
✓		✓	✓	✓	✓	60	15.7
✓		✓	✓	✓	✓	42	10.9
✓		✓	✓	✓	✓	17	4.4
✓		✓	✓	✓	✓	15	3.9
✓		✓	✓	✓	✓	10	2.6
✓		✓	✓	✓	✓	10	2.6
✓		✓	✓	✓	✓	4	1.0
✓		✓	✓	✓	✓	4	1.0
✓		✓	✓	✓	✓	4	1.0
✓		✓	✓	✓	✓	3	0.8
✓		✓	✓	✓	✓	3	0.8
✓		✓	✓	✓	✓	2	0.5
✓		✓	✓	✓	✓	2	0.5
✓		✓	✓	✓	✓	1	0.3
✓		✓	✓	✓	✓	1	0.3
Total	—	—	—	—	—	178	46.4
No. of respondents who discussed SUDEP in only one of the scenarios							
✓		✓				62	16.2
✓			✓			42	10.9
✓				✓		20	5.2
✓					✓	13	3.3
✓					✓	46	12.0
No response*	—	—	—	—	—	22	6.7
Total	—	—	—	—	—	183	47.7

**Table 5** Responses to the question "How do patients react?"

- Most take it in their stride
- Generally not surprised, take it well
- Some are alarmed, most accept possibility with equanimity
- Quite calm (surprisingly)
- Makes no difference in majority of patients
- They understand epilepsy carries a risk of death and injury, some are terrified
- Matter of fact, pragmatic
- Reassured that it does seem overall rare
- Makes no difference in the majority of patients
- They react in a positive way and welcome being told all of the facts. They view it as important information they should be aware of
- No problems, however patients are selected. I suspect I might encounter problems if I did this on a routine basis. It is important to consider psychological morbidity versus very questionable benefit in morbidity in providing information
- Terrified
- Fearfully
- Anxious
- Astonishment
- Anxiety and resentment
- Surprised
- In my limited experience I can distinctly recall one young woman with epilepsy well controlled on monotherapy who was extremely distressed and resentful that SUDEP was discussed during her first consultation
- Acute distress – two patients never returned again!
- Young men who have never been ill, have had a first seizure, and then think they are going to die have catastrophic psychological reactions to SUDEP info. Most patients are fine about the info although it is not infrequent that they say "I really don't want to know about that"

Our study suggests that the majority of neurologists in the UK are not following the NICE guidelines. It does not necessarily mean that patients are ignorant of SUDEP. There are many sources of information now available, most notably patient groups and the internet, but it implies that many neurologists do not feel this information is something all patients need to know.

Neurologists with a special interest in epilepsy were statistically more likely to discuss SUDEP with patients. This may reflect familiarity with NICE or the Scottish Intercollegiate Guidelines Network (SIGN), the influence of patient advocacy groups, or a patient population that is more likely to ask about SUDEP. These neurologists were also significantly less likely to report negative reactions. This might be explained by a practice effect, with those neurologists who frequently discuss SUDEP being more at ease with the topic, or patients who have already heard about the phenomenon being prepared for the information. Neurologists who only discussed SUDEP in a minority of cases were significantly more likely to report negative reactions. Emotive terms such as "terrified", "acute distress", and "catastrophic" were used. Such reactions may have served to inhibit these doctors from frequent discussion of SUDEP because of a wish not to cause distress or as a way of protecting their own emotional state.

Practitioners were equally divided between those who only discussed SUDEP in one of the clinical scenarios put to them and those who did so in more than one clinical situation. The commonest single scenario was if the patient asked about SUDEP (16%). Those who discussed SUDEP in more than one clinical scenario were prompted most often by the patient asking or a patient having risk factors for SUDEP (16%). It would appear that many neurologists were led by their patients' request for information.

NICE gives no guidance on how, when, and by whom information on SUDEP should be imparted. If patients are to be told they could die because of epilepsy, then it would be

useful to put that risk in context. There is a striking lack in NICE/SIGN and the literature of league tables of relative risks to enable patients to see what their chances of succumbing to SUDEP are compared with a fatal road traffic accident, myocardial infarct, or common cancers. One recent paper has produced estimated years of lost life expectancy in a table format. A man aged 20 years with idiopathic epilepsy has, according to the authors, a 9 month reduction in life expectancy.<sup>6</sup> Some would question what use this information would be to a patient. Another study concluded that as the main risk factors for SUDEP, such as male sex, need for polypharmacy, and having a localisation epilepsy are impossible to modify, information on SUDEP should be targeted at this group.<sup>7</sup>

Medical opinion leaders and patient advocates maintain people must be given as much information as possible, and that guidelines will cover all medical contingencies. This stance denies the patient the right not to know,<sup>8,9</sup> and undermines the physician's ability to treat patients as individuals. One in depth examination of the information needs of patients with Parkinson's disease<sup>9</sup> identified three equally sized patient groups: "seekers", who needed information and found ignorance unbearable; "weavers", who incorporated information into their lives at their pace, often ignoring much of it; and "avoiders", who found more than the minimum of information a threat to their overall sense of wellbeing. A broadly similar pattern is seen in cancer patients, with patients differing markedly in the quantity and type of information they want, and a small but significant number stating they do not want to be told they have an incurable or terminal illness.<sup>10,11</sup>

The variation in neurologists' practice in respect of SUDEP, although out of tune with the current vogue for medicine by guidelines, reflects what every doctor knows: that patients differ vastly in their need for information. To our knowledge, there have been no studies of the impact of telling patients about SUDEP. In the whole SUDEP debate, the voice of the individual patient has been absent. Perhaps when such studies are undertaken, we will discover that Ruth Pinder's conclusions about Parkinson's disease patients hold true for other neurological conditions:

"knowledge of what the clinical facts mean is not always the priceless resource other writers suggest. Sometimes it is too threatening".<sup>9</sup>

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## NEUROLOGICAL PICTURE .....

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### Focal splenial hyperintensity in epilepsy

A 13 year old boy presented with complex partial epilepsy of 10 years duration with a seizure frequency of 1–2 per month and one recent episode of secondary generalisation. Clinical and video EEG localisation was towards the right parieto-temporo-occipital region. Brain MRI scan done 5 years previously was reported as normal. He was on treatment with carbamazepine with no clinical evidence for drug toxicity. MR imaging showed a focal hyperintensity of the splenium of corpus callosum on T2 weighted sequences with evidence of cytotoxic oedema on diffusion weighted imaging (fig 2C, D). Various mechanisms have been proposed for this rare, transient MR finding in epilepsy, including drug toxicity, vasogenic oedema, and vitamin deficiency.<sup>1</sup> However, cytotoxic oedema due to excitotoxicity appears to be the more likely cause as demonstrated by diffusion imaging.<sup>2</sup>

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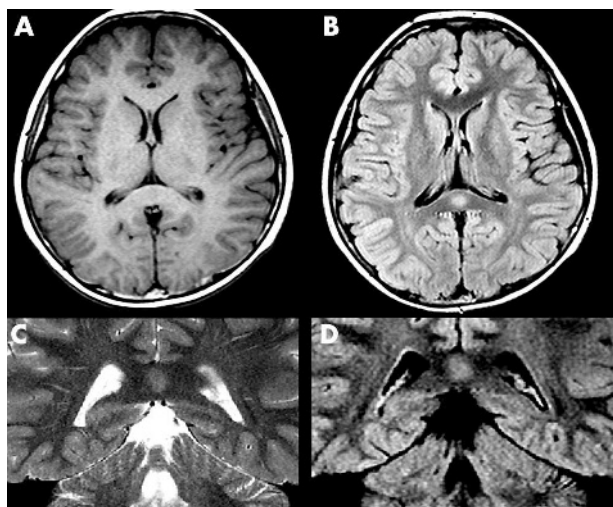
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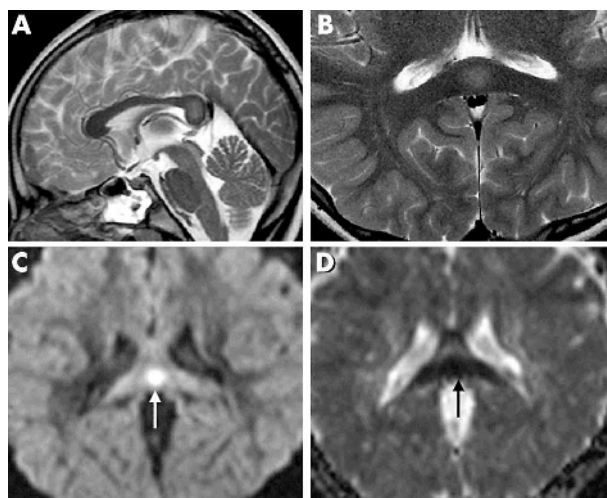
Competing interests: none declared

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**Figure 1** (A) T1 weighted axial SE; (B) T2 weighted axial FLAIR; (C) Coronal T2 fast SE; (D) Coronal FLAIR. Note the well defined focal hyperintensity in the splenium of corpus callosum on T2 weighted images, which is hardly visible on T1.



**Figure 2** Sagittal FSE (A) and high resolution axial (B) T2 weighted images demonstrate the hyperintense signal through the centre of the splenium. On the axial diffusion weighted image the lesion appears hyperintense (C) and the corresponding ADC map shows hypointensity (D) (arrow) suggesting cytotoxic oedema as the cause of T2 hyperintensity.