



Epilepsy –  
death in the  
shadows

**Sudden Death  
and Epilepsy**  
The Views and  
Experiences of  
Bereaved Relatives  
and Carers



# Sudden Death and Epilepsy The Views and Experiences of Bereaved Relatives and Carers

## Report 2002: Summary

*A qualitative study conducted in parallel  
with the National Sentinel Clinical Audit  
of Epilepsy-Related Death*

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## INTRODUCTION

Epilepsy, meaning a tendency to have recurrent seizures, is the most common serious neurological condition. At any one time between 1 in 140 and 1 in 200 people in the UK (at least 300,000 people) are being treated for epilepsy.<sup>1,2</sup> People with epilepsy have a risk of premature death that is 2-3 times higher than in the general population.<sup>3</sup> Most premature deaths among people with epilepsy are directly related to the epilepsy itself.

Every year in the UK about 1000 people die because of epilepsy, and most of these deaths are associated with seizures. Sudden unexpected death in epilepsy (SUDEP) is the principal cause of seizure-related death in people with chronic epilepsy and has been estimated to account for about 500 deaths each year. SUDEP is the sudden, unexpected, witnessed or unwitnessed, non-traumatic and non-drowning death in patients with epilepsy, with or without evidence for a seizure, and excluding documented *status epilepticus*, in which post-mortem examination does not reveal toxicological or anatomical cause for death.<sup>4</sup>

This is a summary of a College of Health project, commissioned by Epilepsy Bereaved, to investigate the views and experiences of carers prior to, and as bereaved relatives following, an epilepsy-related death. The study was undertaken in parallel with the National Sentinel Clinical Audit of Epilepsy-Related Death<sup>5</sup> and both reports are available from the Epilepsy Bereaved website at [www.sudep.org](http://www.sudep.org). The National Sentinel Clinical Audit of Epilepsy-Related Death was the result of a call for a confidential enquiry into epilepsy-related deaths. It was a multi-disciplinary project managed and led by Epilepsy Bereaved and funded by the National Institute for Clinical Excellence (for England and Wales), the Scottish Executive and the Northern Ireland Department of Health, Social Services and Public Safety. The aim was to establish whether deficiencies in the standard of clinical management, or in the overall healthcare package, could have contributed to the deaths. Two key areas were reviewed

- investigations into the deaths (pathology)
- general practice and hospital-based care.

The audit reported findings that

- 57% of patients experienced deficiencies in care
- 42% of deaths were potentially avoidable
- 13% of deaths were adequately investigated
- 1% of patients had recorded discussion of risk that seizures could be fatal.

The audit report follows five government reports over a 50-year period which have drawn attention to the neglect of epilepsy.<sup>6</sup>

The aim of this project was to review health services and services for the investigation of death from relatives' and carers' perspectives to highlight issues that they themselves had identified as important in order to make recommendations on how the needs of people with epilepsy and their carers before and after death can be met in the future.



## METHODOLOGY

The research was designed to ask the questions that bereaved relatives and carers had themselves defined as important. The study design therefore employed qualitative methods to collect data on bereaved relatives. Qualitative methods are appropriate for exploring participants' views, ideas and experiences as they allow people to express themselves and draw conclusions in their own words.<sup>7</sup>

The research consisted of two stages, with each stage informing the next

- 1 Six focus groups were held throughout the UK to identify issues that bereaved relatives and carers considered important between March and September 1999
- 2 Seventy-eight semi-structured interviews with bereaved relatives administered by trained interviewers over the telephone to explore important issues in further detail were carried out between March 2000 and July 2001.

Participants were recruited from among the bereaved relatives who contacted Epilepsy Bereaved during the audit period. Relatives were invited to participate in the project by Epilepsy Bereaved staff only if they had previously expressed an interest in doing so when contacting the charity for support and information.





## KEY FINDINGS

### 1 Characteristics of the family

#### *The person who died*

Of the people who died from epilepsy, 50 were male and 28 were female. Their ages ranged from 2 to 82, with the median age 31.

Nearly all bereaved relatives and carers (n = 75) described the ethnic origin of the person who died from epilepsy as 'white'. Two relatives described the ethnic origin of the person who died from epilepsy as 'Asian' and one as 'black'.

Almost three-quarters of the people who died from epilepsy (n = 58) were living with their family. Seven were living with friends and seven were living by themselves. Five were living in residential care, while one relative did not answer the question.

#### *Study participants*

Fifty-three participants were parents of the person with epilepsy; over half (n = 40) were parents of an adult and 13 were parents of a child under 16; 16 were spouses or partners of the deceased; four were adult children of parents with epilepsy; three were siblings and two did not describe their relationship to the person concerned.

Relatives provided the person with epilepsy with a high level of care, support and assistance. For example, 56 out of 78 participants said that they had provided general care and support, while 55 had attended medical appointments with the patient; 53 had provided first aid after a seizure; 46 had made medical appointments on their behalf; and 37 had kept records of seizures.

### 2 History and description of seizures

The people who died from epilepsy had experienced differing histories of seizures. Forty-four had their first seizure more than 10 years previously, 20 between one and 10 years previously, and 11 less than one year previously. Two had had no previous seizures, and one relative did not answer the question.

Relatives and carers found it difficult to describe a 'typical' seizure for the person with epilepsy. Some relatives and carers had never seen them have a seizure due to their short (known) history, while others said that they had experienced different types of seizures, ranging from absences (when they appeared to day-dream) to tonic-clonic seizures (when they fell to the ground and had convulsions).

Many relatives reported that the frequency of seizures varied, making it difficult to detect any pattern. Participants most frequently reported the deceased as experiencing clusters of absences or seizures with seizure-free periods in between.

A few participants said that there were certain times when the epilepsy sufferer was more likely to have a seizure

- either early morning on waking, or around bedtime
- when their medication was changed
- for female patients, the week before menstruation
- when they were tired or stressed.

### 3 Diagnosis and treatment

Seventy-two out of the 78 people who died from epilepsy had been to the doctor about their symptoms, where they had undergone medical tests for epilepsy. Fifty-nine of these were diagnosed with epilepsy and put on anticonvulsant medication, while 11 were not, and two were unknown.

In a few cases, relatives said that the tests showed nothing and that epilepsy was not formally diagnosed. In a number of paediatric cases, parents reported being told that their child would grow out of the seizures and that it was not serious. In one case, the GP refused to put the diagnosis of epilepsy on the patient's records as he said that having a diagnosis of epilepsy would affect his life, although he did prescribe anticonvulsant medication.

Most participants reported that the person with epilepsy was monitored by both their GP and a hospital specialist, while some said that they saw only their GP. A few participants pointed out that even when the patient was referred to a consultant, they were not always referred to an epilepsy specialist. Ten relatives said that they were given information on the expertise of medical professionals involved in the epilepsy sufferer's care.

*'We would have wanted to know that the paediatrician that L was seeing was not a [epilepsy] specialist and had advice to go somewhere else.'* (PARENT OF A CHILD)

Monitoring and review of patients varied greatly. Some relatives said that the person with epilepsy had regular check-ups with their GP or consultant once or twice a year; others said that there was no systematic monitoring – they only saw their GP when they had a problem – while two did not visit their doctor due to fears about losing their driving licence or employment.

Many relatives (n = 35) expressed concerns about the lack of tests, checks, follow-up and monitoring of the patient, including prescribed medication levels and side-effects.

*'I didn't know W had stopped taking his medication until after he died... the last medication they'd given him was well over a year before... and I really do think if they thought he was epileptic, they should have kept a check on him and made sure he was on medication.'* (PARENT OF AN ADULT)

*'They never called him up. I thought this is what GPs are for... they deal with smear tests and with diabetic people, why are epileptic people different?'* (SIBLING)

Twenty-two relatives said that they had expressed their concerns prior to the death, mainly to the GP or hospital doctor. Ten of these reported positive responses to their concerns, saying that they had been listened to by the involved medical professional, and that recommendations for further action were made. Six relatives reported negative responses, including having their concerns dismissed and being given an answer that was too technical to understand.

#### 4 The role of carers

Recognition of the participant's role as carer by medical professionals varied greatly. Some participants said that health professionals actively included them in their role as carer to the person with epilepsy. However, other relatives said that medical professionals were not interested in the support they provided, nor were they interested in the information they kept on the patient.

*'I did [keep records of seizures] for quite some time, but then nobody seemed interested in the records so I stopped writing them down.'* (PARTNER)

One participant spoke for many other bereaved relatives when they pointed out that medical professionals were **not** interested in supporting them as carers of a person with epilepsy.

*'In my experience they haven't given the carers a considerate thought at all.'* (PARENT OF AN ADULT)

#### 5 Information before death

Few relatives were provided with information about epilepsy following the diagnosis, and prior to the death, of the patient. For example, over half of the participants said that they had **not** been given information on

- the risks of seizures (n = 61)
- ways of preventing seizures (n = 55)
- first aid or safety measures (n = 55)
- epilepsy helplines (n = 52)
- signs and symptoms (n = 51)
- medication tests and investigations (n = 50)
- available medications (n = 49)
- support/ self-help groups (n = 49)
- what epilepsy is (n = 44)

Eight out of the 72 people diagnosed with epilepsy were offered access to a specialist epilepsy nurse, clinic or counsellor for further information, advice and support.

Many relatives expressed concerns about the lack of information and advice on epilepsy from medical professionals. Thirty-seven relatives said that they were either 'unsatisfied' or 'very unsatisfied' with the level of information provided on epilepsy prior to the patient's death. They felt that more information would have enabled them to provide better care and support.

*'Medical advice... it was no advice really. It was just a case of 'take the tablets or not take them'... they didn't really listen to what I had to say... it was a load of gobbledegook, you know, it went very technical, something I didn't understand.'*

(PARENT OF AN ADULT)

*'If anyone said to me what was the one thing I'd like to change in our family, it would be that my dad had more information, and to come to terms with it because he would have had a choice to talk to people, to see people, or just to read up on it and learn a bit more about the ways of avoiding it...'* (CHILD)

## **6 Participants' attitudes towards the provision of information on sudden death**

Out of 57 relatives questioned, only two said that they were provided with information on the risks of sudden death prior to their bereavement. The majority of participants (n = 68) felt that information on sudden death should be provided to the person with epilepsy and their family or carers either on or soon after diagnosis. Relatives felt that they needed this information so that they could provide support before death, and at the same time it would make sudden death less of a shock.

*'If you have asthma or diabetes you are told, if you've got cancer you are told, if you've got anything life-threatening you are told, and epilepsy you're not.'* (PARENT OF AN ADULT)

Participants had differing views on how information on sudden death should be provided. Suggestions included providing the information either verbally during consultations, in written information leaflets, or a combination of both. They stressed that information on risks needs to be provided in a way that does not unduly frighten the patient and their family.

*'There should be some form of... group where people can go and families can go and be taught how to do the recovery position, clear the airways and given some support while the person's alive and then... people can be made aware of it [sudden death].'*

(PARENT OF AN ADULT)

## **7 Circumstances of death**

Participants reported many different circumstances and events in the lives of the people with epilepsy in the three months prior to death, such as good or bad health, increase or reduction in seizures, positive and negative life events, change or no change in medication.

Many relatives said that the deceased had been alone (n = 33) at the time of death. Of these, 13 said that the death had occurred at night with the deceased found either face down in the bed (n = 11) or half in and half out of bed (n = 2).

*'We were away from home, we all went for a friend's 50th birthday party and stayed in a hotel... X stayed to about 11pm... then went up on her own... she was watching television... X was on her own for about three... hours. [Her sister] went into the room first and saw that something was wrong. X was looking blue and had been sick. The TV was still on and she was half on the bed, her head over the mattress to the side. Her sister came to call us... we called the ambulance.'* (PARENT OF A CHILD)

Other relatives said that someone had been present at the time of death. In three cases relatives reported that the person had been experiencing almost continuous seizures until death.

## 8 Contact with health professionals after death

Thirty-eight relatives said that health professionals involved in the patient's care had not contacted them after their death, while thirty-three said that they had, and seven did not answer the question.

Participants reported a mixture of both positive and negative experiences when describing the contact that they had with the patient's GP and hospital doctor in charge. Positive experiences included being offered condolences, support and information from the GP or hospital doctor, either through personal visits or letters and bereavement counselling.

*'They were fantastic with us right the way through, they spoke to us all the time and kept us up-to-date. They did say should we want to go back at any time and discuss anything with them, they'd be more than happy to do that. We never felt strong enough to take that offer up, but the offer was certainly there.'*  
(PARENT OF AN ADULT)

Negative experiences included delayed contact by the GP or consultant because they had not been informed of their patient's death; defensive behaviour due to fears of accusations of negligence; relatives having to request contact with the health professional in charge; and, in one case, being refused their request for an appointment.

*'I went up to see my GP, which was A's GP and she didn't know A died on the Saturday and I went to see her on the Tuesday, but she didn't know anything about it, so I had to tell her...'*  
(PARENT OF A CHILD)

*'I actually wrote to him [Y's specialist]... and I just wanted an appointment to see him for five or ten minutes just to try and explain to me, you know. And he just wrote a letter back saying he was very sorry and did I know that sudden death could occur.'*  
(PARENT OF AN ADULT)

## 9 Investigation of death

Fifty-two of the epilepsy-related deaths were investigated by post-mortem, 16 by inquest, and seven by GP or hospital certification, while in three cases the methods of investigation were not specified.

The five most frequent causes of death registered on the death certificate were

- epilepsy (n = 25)
- sudden unexpected death in epilepsy (n = 11)
- epileptic fit (n = 11)
- *status epilepticus* (n = 7)
- epilepsy and cardiac condition or arrest (n = 6).

Over three-quarters of participants (n = 54) said that it took less than 14 days to receive the cause of death. Eighteen participants said that it took between 14 days and six months, while one respondent said that it took longer than six months. Four did not answer the question.

## 10 Information provision after death

Few bereaved relatives were provided with information about the process of investigating epilepsy-related deaths. For example, many participants said that they had **not** been provided with information on

- how sudden deaths are investigated (n = 46)
- what investigations would be carried out (n = 44)
- how long the process would take (n = 39)
- the role of the Coroner and the Coroner's Office (n = 37)
- the findings of the post-mortem report (n = 32).

Half of the participants (n = 39) said that they had faced difficulties in receiving information, including not being offered information automatically and having to request it, being refused their requests for information, having to pay for a copy of the patient's medical records or the post-mortem report, receiving an inadequate level of information, long waits for information, and difficulties getting through to the Coroner's Office.

*'I have had little contact with the Coroner's Office. I didn't even know I was entitled to the pathologist's report. I got that through checking some information and then requested it from the Coroner's Office. I think that everybody is very forthcoming with sympathy and not so forthcoming with information.'* (PARTNER)

However, a number (n = 12) said that they had not faced any difficulties in receiving information and that they were kept well informed throughout the whole process.

*'The Coroner's Office was excellent. I would give them top marks because the Coroner's Officer was very good. She was very sympathetic. She did everything she was supposed to. She let me know what was going on.'* (PARENT OF AN ADULT)

## 11 Relatives' and carers' views of investigations into the death

Half of the participants (n = 39) said that they did not have any concerns about either the way the investigation was handled or the way they were treated, although almost one third of participants (n = 22) said that they did, while seventeen participants did not answer the question.

The main concerns that participants said that they had had with the investigation were

- insensitive or indifferent treatment by public officials; not being treated as relatives who had recently experienced a bereavement
- lack of information about the investigation, including organ removal
- the length of time the investigation took.

*'I saw him (the deceased) that afternoon because we put up such a stink. I had to see him... and that's what I found hard, that you don't have any rights, so they just take over and... he's my husband, that bothered me a lot – everyone else takes over.'*

(PARTNER)

*'I did find the 'phone call from the Coroner's Office rather abrupt... I was taken aback about the brain being removed for tests. Obviously it had to be, but then I was told not to worry because I could always have another funeral for the brain. [It] isn't the sort of thing you want to be hearing... it didn't seem very sensitive... I felt it could have been handled better.'*

(PARENT OF AN ADULT)

## 12 Self-help groups

Almost three-quarters of participants (n = 58) said that they had been in contact with a self-help group at some point throughout their experience. Most participants were in contact with Epilepsy Bereaved (n = 55) and that they had first come into contact with a group following the death of a relative. Few relatives (n = 6) had been in contact with a support group prior to the death of the person with epilepsy.

Of those participants (n = 17) that were not in contact with a support group, fifteen said that they would have wanted to be.

Ways that bereaved relatives said the support group had helped them included the provision of useful information on epilepsy and sudden death; the opportunity to talk to someone who had undergone similar experiences and reassurance that they were not alone.

*'[Epilepsy Bereaved gave] information in aiding me to get reports from hospitals and guidance and help that sort of thing... it actually resolved a lot of the problems I was facing.'* (PARTNER)

### 13 Impact of the death on the family

Seventeen participants described how the death had affected their families. Their emotions ranged from shock and devastation to guilt, anger, difficulty accepting what had happened, and loneliness.

*'Just total devastation for the whole family, as you can understand. I mean my daughter's not only lost a brother, she's lost me and my husband as well, because we'll never be the same people. There aren't any words when you lose a child, it's the worst scenario, and he was just a super strapping lad, it's so hard to believe... and obviously the strain on the marriage is just, well it's horrible really.'* (PARENT OF AN ADULT)

*'It still affects me. I still feel very bitter about it and I also feel very guilty about it... people say I shouldn't do... What I'm saying is that if I'd known more I could have prevented it, I believe, or extended it.'* (PARENT OF AN ADULT)

*'I think the ignorance of not ever thinking that it [epilepsy] could result in death is the biggest shock, and sudden death, not knowing. The shock is devastating.'* (PARENT OF AN ADULT)

### 14 Follow-up of other family members with epilepsy

Some families (n = 16) reported that there were other members with epilepsy in their family. A quarter of these (n = 4) said that they had been offered follow-up appointments with health professionals to review the other family member's case after the death.



## CONCLUSION

The study was based on six focus groups and 78 semi-structured interviews held across the UK with a wide range of bereaved relatives. Focus groups and semi-structured interviews are qualitative methods intended to provide insight into participants' experiences as carers of people with epilepsy and as bereaved relatives after death. Their purpose is to make suggestions for improving health care and investigation of death services, rather than to be statistically representative of the total population.

The findings show that the care and treatment of people with epilepsy is something of a lottery, provided in different care settings and ways, with varying degrees of quality. The same services and quality of services should be available equitably to all, and from these services individual packages of care should be designed in conjunction with the patient's needs. There were many examples of individual good practice from medical professionals and personnel investigating the death which should be learnt from and built on through wider dissemination and sharing.

Participants prioritised information, communication, involvement and support as key aspects of care both before and after the death of the person with epilepsy. They said that prior to the person's death, a lack of these things had affected medical care and treatment decisions, their behaviour as carers and, perhaps, even the final outcome. After death, on the other hand, families identified access to information, communication and support as having been helpful in supporting them.

More effective case management of people with epilepsy would be facilitated by improved information and communication between patients, carers and health professionals as well as greater follow-up and review of people with epilepsy. Suggestions for improving service delivery include

- the involvement of patients and carers in the daily management of epilepsy
- access to specialist management
- the provision of written and verbal information
- access to a named health professional for information and support
- access to self-help and advocacy groups
- the use of an enhanced system of care where a named individual is responsible for checking on the patient.

The findings show that there is a need for better information and communications systems for bereaved relatives following an epilepsy-related death. Access to medical professionals in charge of the patient's case is important for bereaved relatives to enable them to make sense of what has happened and help them come to terms with the death.

Personnel investigating the death, and medical professionals, need to remember that they are dealing with people who have been recently bereaved and should treat them sensitively. Staff should adopt a proactive approach to keeping relatives informed about the process: what their rights are, what support groups they can join, and what is happening at any particular time, especially with regard to issues such as system delays and organ removal.

To conclude, bereaved relatives are understandably shocked by the death of a family member with epilepsy. Before the death they often feel excluded, and afterwards abandoned, by medical professionals and people investigating the death. They want epilepsy services to be patient and carer centred, and would like to be actively informed, included and involved in the planning and provision of the patient's care and treatment and in the process of investigation into death. Relatives and carers are a valuable resource, and many epilepsy services have a long way to go before they recognise their role and utilise them to help make improvements in medical care and treatment. As one bereaved relative said:

*'I'm left with the overall feeling in another two hundred years time they [health services] won't be any further forward... they won't be able to stop it happening.'* (PARENT OF AN ADULT)



## RECOMMENDATIONS

- 1** Where a patient has a seizure, but has not yet been diagnosed with epilepsy, the patient and their carer should be offered essential information, including how to recognise seizures, first aid and the importance of reporting any further seizures.
- 2** On diagnosis of epilepsy, health professionals should offer written and verbal information automatically to patients and their carers or families on
  - epilepsy as a medical condition
  - risks and preventive measures
  - what to do during and after a seizure
  - first aid and resuscitation
  - medication and side-effects
  - support groups
  - local epilepsy services.
- 3** Any person who is acting as a carer should be identified and offered information and support. The role of a carer in the shared management of epilepsy should also be recognised, in accordance with the wishes of the patient. The carer's role should also be recognised when the patient does not have legal competence, for example, because they are a child or learning-disabled and therefore may not be able to give a view.
- 4** Following diagnosis, the person with epilepsy and their carer should be followed up and referred to a specialist epilepsy nurse and support group for further information and help.
- 5** An enhanced system of care management is needed for epilepsy as a chronic medical condition, based on the 'three Rs' – registration, recall and review – covering
  - medical tests and investigations
  - referral to a consultant specialising in epilepsy
  - continuing access to a specialist for all patients still having seizures after initial treatment
  - referral to other services such as a specialist epilepsy nurse
  - referral to an epilepsy support group
  - information and counselling checklist (of essential discussion items)
  - carers' involvement and role
  - regular monitoring and checks for effective case management.
- 6** Patients with epilepsy and their carers should have a greater involvement in their medical care and treatment.

- 7** Patients, relatives, carers and health professionals should work together to manage the patient's epilepsy, building up a picture of the patterns of seizures to identify any warning signs and times when the patient is most at risk and in need of additional help and support.
- 8** An epilepsy management plan should be agreed by the team of professionals involved, in partnership with the person with epilepsy and their carer (where appropriate). The patient and carer should have a copy of the plan which should include access to a named person in the health professional team who will respond to any queries or concerns.
- 9** The risk of SUDEP should be an essential part of the risk management of epilepsy, and these risks should be addressed in decision-making and information provision. Written information on SUDEP should be included in literature on epilepsy to show why preventing seizures is important, while tailored information on SUDEP should also be part of the counselling checklist for people with epilepsy and their carers. Individual discussions between health professionals, people with epilepsy and their carers (where appropriate) should take account of the risk of SUDEP. Patients and carers need information in order to make informed choices about the treatment plan and also to decide how much detail they would like on the different topics in the counselling checklist.
- 10** National guidance on the investigation of epilepsy deaths should be drawn up in consultation with bereaved relatives, and cover
  - information on rights and regular reporting processes
  - support
  - communication.
- 11** Information on the process of investigating a sudden death, relatives' rights and potential outcomes should be automatically provided by a dedicated responsible person.
- 12** A dedicated office should provide tailored information on the investigation of a particular death, and be responsible for informing the patient's GP.
- 13** The GP of the person who has died should inform any other health professionals involved in the management of the patient's condition of their death, and agree on who would be the appropriate individual to make initial contact with the bereaved family.
- 14** Health professionals should contact the family to offer their condolences, invite them to meet to discuss the death, and offer a referral to Epilepsy Bereaved.
- 15** Health professionals and staff involved in the investigation of the death should be trained in how to deal with bereaved relatives following a sudden death, including how to communicate sensitively with them.
- 16** A local support network should be created for families affected by a sudden death, including their local surgery, health visitors and support groups.
- 17** A health promotion campaign is recommended, targeting the general public's awareness and understanding of epilepsy, while aiming to reduce its stigma.

- 18** A National Research Strategy should be created, to include a continued national review of epilepsy deaths and additional medical and social research into epilepsy and sudden death.
- 19** Voluntary sector support for people with epilepsy and for families affected by epilepsy deaths should be reviewed to ensure that appropriate services are accessible.

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