

## **Knowledge and Attitudes among Neurologists about Sudden Death in Epilepsy**

Thank you for taking the time to complete this brief survey. We begin with the following vignette:

*A 45 year old woman was found dead in bed in the morning by her family. She had a history of epilepsy since childhood. She had partial seizures with secondary generalization, occurring once every 2-3 months, despite treatment with 2 medications. She was awaiting an evaluation for epilepsy surgery when she died.*

Sudden death is nearly 24 times more likely in people with epilepsy. Many deaths are unexpected and unexplained. Sudden Unexplained Death in Epilepsy (SUDEP) refers to the sudden unexpected death of a person with epilepsy (defined as >1 unprovoked seizure), with or without evidence of a recent seizure and excluding documented status epilepticus and trauma. Autopsy does not demonstrate a structural or anatomical cause of death.

This one-time survey of neurologists seeks to increase awareness of SUDEP, identify gaps in knowledge, and help plan for educational materials for patients and families.

## Information about the provider

*Please provide a little information about yourself.*

### 1 You are a: \*

Please choose **all** that apply:

- Adult Neurologist
- Child Neurologist
- Additional training in epilepsy
- Additional training in neurophysiology
- Academic Practice
- Private Practice

### 2 How many years have you been in independent practice? \*

Please choose **only one** of the following:

- 0-5
- 5-10
- 10-15
- >15

### 3 In a typical year, how many patients do you follow with epilepsy? \*

Please choose **only one** of the following:

- None
- 1-10
- 11-20
- 21-50
- 51-100
- >100

## SUDEP experience

The following questions relate to your experience with SUDEP.

### 4 Which clinical factors do you think put people with epilepsy at risk for SUDEP?

Please choose **all** that apply:

- Treatment with 3 or more antiepileptic drugs (AEDs)
- Lack of AED therapy
- Sleeping with two or more pillows
- Electrocardiogram showing QTc at upper limit of normal
- Recent generalized tonic-clonic seizures
- Nocturnal complex partial seizures
- Childhood onset epilepsy

### 5 SUDEP is defined as:

**Definite:** sudden, unexpected, witnessed or unwitnessed, non-traumatic, and non-drowning death in patients with epilepsy with or without evidence for a seizure in which autopsy does not reveal a structural or toxicological cause for death. This excludes death from status epilepticus.

**Probable:** sudden, unexpected death occurring under benign circumstances where no competing cause of death is known but no autopsy was performed.

**In the past 24 months, have any patients for whom you are the primary neurologist experienced definite or probable SUDEP? \***

**Only answer this question if you follow patients with epilepsy:**

- Yes
- No (skip to question 8)

**6 How many in adult patients (>18 years of age)? \_\_\_\_\_**

**7 How many in children (<18 years of age)? \_\_\_\_\_**

## SUDEP Discussion Experience

The following questions pertain to your experience discussing SUDEP with patients and their caregivers:

### 8 How often do you discuss SUDEP with people with epilepsy and/or their caregivers? \*

**Only answer this question if you follow patients with epilepsy.**

Please choose **only one** of the following:

- All of the time (>90%)
- Most of the time (50-90%)
- Sometimes (10-49%)
- Rarely (1-9%)
- Never (0%) (skip to question 16)

### 9 When do you discuss SUDEP with people with epilepsy and/or their caregivers? \*

Please choose **all** that apply:

- If a patient asks
- At the time of diagnosis
- When initiating AED therapy
- Spontaneously during a follow-up appointment
- When I consider a patient to be at high risk
- Other: \_\_\_\_\_

**10 Which clinical factors lead you to discuss SUDEP with patients and/or their caregivers? \***

Please choose **all** that apply:

- Intractable seizures
- Tonic-clonic seizures
- Symptomatic epilepsy
- Surgical candidates
- Poor compliance with AED therapy
- Patient lifestyle factors (*circle all that apply*: drinking alcohol/recreational drug use/living alone/smoking tobacco/ poor fitness status/ other: \_\_\_\_\_)
- Other: \_\_\_\_\_

**11 Does the age of the patient influence your decision to discuss SUDEP? \***

Please choose **only one** of the following:

- Yes
- No (skip to question 13)

**12 At what patient age do you discuss SUDEP with persons with epilepsy and/or their caregivers? \***

Please choose **all** that apply:

- 0-8 years
- 9-16 years
- 17-21 years
- 22-54 years
- >55 years

**13 Who in your practice discusses SUDEP with patients and/or their caregivers? \***

Please choose **all** that apply:

- Yourself
- Nurse
- Counselor
- Other:

**14 When you discuss SUDEP with people with epilepsy and/or their caregivers, they typically respond with (please rank the top 3 responses in order of frequency): \***

Please rank your **top three responses**:

- relief
- appreciation
- indifference
- distress
- anxiety
- depression
- other (answer question 15)

**15 Please list other reactions here:**

Please write your answer here: \_\_\_\_\_

**16 When you do not discuss SUDEP with people with epilepsy and/or their caregivers, it is because: \***

Please choose **all** that apply:

- Patient is at minimal or now risk
- The information could affect my patient's quality of life or mood
- The patient lacks an adequate support network
- There is insufficient information about SUDEP
- I do not have sufficient time to discuss SUDEP during an office visit
- Information is available through other sources
- SUDEP is so rare and the risks of discussion outweigh the potential benefits
- There is no proven way to prevent SUDEP
- I do not know enough about SUDEP
- Other:

**17 Will knowledge of SUDEP improve antiepileptic drug compliance in people with epilepsy?**

Please choose **only one** of the following:

- Yes
- No

**18 What tools would you employ in supporting your patients with epilepsy and/or their caregivers around the issue of SUDEP?**

Please choose **all** that apply:

- brochures/pamphlets
- websites
- training sessions/webinars
- newsletters with the latest research in SUDEP
- support groups for families
- guide for health care professionals about the medico-legal issues surrounding the discussion of SUDEP
- none
- other: \_\_\_\_\_

**19 May we contact you for more information?**

- Yes
- No



## Contact Information

**20 Name:**

**21 Address:**

**22 E-mail address:**

**23 Phone:**

Thank you for taking the time to complete this survey.

Some risk factors that have been associated with increased SUDEP risk in epidemiological studies include:

- Frequent generalized tonic-clonic seizures
- Long epilepsy duration
- Childhood onset epilepsy
- Symptomatic etiology
- Intelligence quotient < 70
- Lack of AED use or subtherapeutic AED levels
- Polytherapy (>3 AEDs)

For more information on SUDEP, please visit:

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

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