

SUDEP Registry in EpiNet

Please note; some of this information is collected already on other forms. This is the case for information displayed here in brackets)

1) Demographic Data

- (Age) *(recorded on demographics page)*
- (Gender) *(recorded on demographics page)*
- (Age of seizure onset) *(recorded on Overview page)*
 - (duration of epilepsy) *(Calculated from info on Overview page)*
- (Aetiology) *(recorded on Aetiology form)*
- (Epilepsy Syndrome) *(recorded on Epilepsy Syndromes form)*

2) Method of notification

- 2a) How did you (i.e. the patient's epilepsy health providers) find out about the patient's death?
 - Notification by family
 - Notification by GP
 - Notification by coroner
 - Notification by epilepsy support worker
 - Other (Specify)

3) Circumstances of Death

- 3a) Date of Death
- *(Age at death calculated by system)*
- (3b) Was the death witnessed? Y / N / U
 - If Yes to Q3b:*
 - Time of death
 - 3c) Was a seizure witnessed? Y / N / U
 - Give details regarding circumstances of death (Free text box)
 - If No to Q 3b: (Was the death witnessed?)*
 - 3d) When was the patient found (Specify time)
 - 3e) What were the circumstances in which the patient was found?
 - In bed (Give details)
 - Other (Give details)
 - 3f) When was the patient last known to be alive? (Give details)
 - 3f1) Is there an estimate of when the patient died? Y / N
 - *If Yes to 3f1) Provide details*
 - 3g) What was the patient's position when found?
 - Prone (lying on stomach)
 - Supine (lying on back)
 - Lying on right side
 - Lying on left side

- Other (Specify - Free text box)
- Unknown / Not recorded

- 3h) Was there evidence of a seizure at the time the patient was found?
 - Lateral tongue biting
 - Other oro-lingual trauma
 - Urinary incontinence
 - Faecal incontinence
 - Injury strongly suggestive of seizure eg posterior fracture dislocation of shoulder (Specify- Free text box)
 - Other (Specify- Free text box)

If found in bed (i.e. Question 3i to be asked only if option 'Bed' was chosen for Question 3e);

- 3i) Was the patient alone in bed without anyone else in the room when it is thought he/she died ? Y / N / U
 - *If No to Q 3i:*
 - 3j) Was there another person at least 10 years of age with normal intelligence with the patient? Y / N / U
 - Provide Details (Free text box)

Question 3k to be asked regardless of response to Q 3e)

- 3k) (Any response to Q3i) Was there nocturnal supervision or other nocturnal precautions, such as the use of a remote listening device? Y / N / U
 - *If Yes to Q3k:* Provide details

4) Coroner's Involvement

- 4a) Did the patient have an autopsy?
- *If Yes to 4a)*
 - Please upload a de-identified copy of the autopsy report (if possible)
- 4d) What was recorded on the death certificate as the cause of death?- (Free text box)
- 4e) Please list antecedent or other significant conditions thought to have contributed to death. (Free text box)
- 4f) Did the coroner adjudicate regarding the cause of death Y / N / U
 - *If Yes to 4f:*
 - 4g) What was the coroner's verdict? (Give details - Free text box)

4.5) Epilepsy Management

4.5a) Was the patient under specialist follow up for their epilepsy? Y / N / U

If Yes to 4.5a:

- Neurologist
- Paediatric Neurologist
- Paediatrician
- Physician with special interest in epilepsy
- Other (Specify)

4.5b) How long prior to death was the patient last seen by a specialist? (months)

Include Unknown option

4.5c) How long prior to death was the patient last seen by a general practitioner / family health care physician? (months)

Include Unknown option

5) Risk Factors – Seizure types

- (Seizure types) *(Recorded on Seizure form)*
 - (Seizure frequency) *(Recorded on Seizure form)*
 - 5b) When was the previous known seizure of this type prior to death?
- 5c) Was the patient known to have tonic-clonic seizures? Y / N / U
 - *(if 'Yes' to 5c)* When was the previous known tonic-clonic seizure prior to death?
 - *(if 'Yes' to 5c)* How many tonic-clonic seizures had the patient had in the preceding 12 months? *(number or text field)*
- 5f) Was the patient known to have seizures from sleep? Y / N / U
 - *If Yes to 5f:* Did the patient have tonic-clonic seizures from sleep? Y / N / U

6) Risk Factors - AEDs

- 6a) Was the patient ever treated with an AED? Y / N / U
- *If Yes to Q6a):*
 - (Current AEDs) *(recorded on Treatment page)*
 - (Previous AEDs used) *(recorded on Treatment page)*
 - 6d) Did the patient change their AED regimen in the last 3 months Y / N / U
 - *If Yes to Q 6d:* "Please record this change on the treatment form"
 - 6e) Had the patient collected AEDs in the last 3 months Y / N / U
 - AED levels
 - 6f) Did the patient have AED blood levels in the 12 months before death? Y / N / U
 - *If yes to 6f:* Were any levels sub-therapeutic? Y / N / U
 - (Give details - Free text box)
 - 6h) Is there any other reason to believe the patient had not been taking anti-epileptic drugs (AEDs) as prescribed at the time of death? Y / N / U
 - *If Yes to 6h)* (Give details - Free text box)
 - 6i) Were drug levels assessed after death?
 - AEDs
 - Therapeutic
 - Sub-therapeutic
 - Uncertain whether therapeutic
 - (Give details- Free text box)
- 6k) Is there any reason to suspect an overdose of medication contributed to the patient's death? Y / N / U
 - *If Yes to Q 6k:* (Give details- Free text box)

7) Risk Factors - General

- 7a) Is there evidence that the patient used alcohol to excess? Y / N / U
 - (If Yes to 7a; Give Details- Free text box)
- 7b) Was the usual alcohol intake known? Y / N / U
 - If Yes to Q 7b:
 - Number of standard drinks (units of alcohol) per week
- 7d) Was there evidence the patient had drunk alcohol within 24 hours of death? Y / N / U
 - If Yes to 7d:
 - (Give Details- Free text box)
- 7f) Is there evidence that the patient used other recreational drugs in the 6 months prior to death? Y / N / U
 - (If Yes to Q 7f, (Give details- Free text box)
 - 7f1) Were any recreational drugs detected at post mortem Y / N / U
 - (If Yes to Q7f1): (Give details- Free text box)
- 7h) Did the patient have any seizure-related injuries in the previous year? Y / N / U
 - (If Yes to Q 7h: Give details- Free text box)
- 7j) Did the patient have any Intellectual disability? Y / N / U (recorded on Other Important Info page)
 - If Yes to Q 7j: Nature of disability (Give details- Free text box)
- 7l) Did the patient have other health issues which may have contributed to his/her death?
 - Known cardiac disease (Give details- Free text box)
 - Known respiratory disease (Give details- Free text box)
 - Mental health disorders (Give details- Free text box)
 - Other health issue which may have contributed to death (Give details- Free text box)
 - No other health issue which may have contributed to death
- 7m) (If female) Was the patient pregnant? Y / N / U
 - If yes to Q 7m: Was there any reason to think the patient had discontinued her AEDs? Y / N / U
 - (Give details- Free text box)
- 7o) Was the patient taking Psychotropic drugs (medication) at the time of death?
 - Treatment for depression (Specify- Free text box)
 - Anxiolytic drugs (Specify- Free text box)
 - Antipsychotic drugs (Specify- Free text box)
 - Other (Specify- Free text box)
- 7p) Did the patient have a structural lesion on MRI? Y / N / U
 - If Yes to 7p: Please record details on the Investigations form, if this has not already been done.
- Genetic factors
 - 7r) Does the patient have DNA stored for possible future analysis? Y / N / U
- 7s) Is there a family history of sudden death or cardiac arrhythmia? Y / N / U
 - If Yes to Q7s: Please give details (Free text box)

- 7t) Has anyone else in the family suffered from SUDEP?
 - *If Yes to Q 7t:* Please give details (Free text box)
- 7u) Had the patient ever had an EEG? Y / N / U
 - *If Yes to 7u:* Please record details on the Investigations form if this has not already been done.
- 7v) Had the patient had seizures recorded with Video EEG? Y / N / U
 - *If Yes to 7v:* 7w) Did the EEG show postictal EEG suppression? Y / N / U
 - *If Yes to Q 7w:* How long did the suppression last?
 - (Give Details - Free text box)
 - 7x) Were there any cardiac abnormalities during or after a seizure? Y / N / U
 - *If Yes to Q 7x:*
 - bradycardia, (Give Details- Free text box)
 - asystole, (Give Details- Free text box)
 - arrhythmia (Give Details- Free text box)
 - other (Give Details- Free text box)
 - 7y) Were there any respiratory abnormalities during or after a seizure? Y / N / U
 - *If Yes to 7y:*
 - 7z) Was there cyanosis noted during or after a seizure? Y / N / U
 - 7aa) Was respiratory depression or apnoea noted during or after a seizure? Y / N / U
 - (Give Details- Free text box)
 - *If Yes to 7v:* Please load anonymised report (if possible).
 - *If Yes to 7v: 7ab)* Are you willing to be contacted for further details? Y / N (*If Yes to 7ab:* Please provide contact details- Free text box)
- 7ac) Had the patient ever had an ECG showing any of the following features?
 - Prolonged QT interval (Give Details- Free text box)
 - Atrial Fibrillation (Give Details- Free text box)
 - Ventricular arrhythmia (Give Details- Free text box)
 - Other significant abnormality (Please specify- Free text box)

Family Follow up

- Has the family of the deceased person been contacted by the local support services? (eg IBE field worker, SUDEP action etc) Y / N / U
 - Comments box
- Has the family of the deceased person been offered contact with Epilepsy Health care provider team? Y / N / U
 - Comments box

Conclusion

With regard to all the information you have, what do you think the correct diagnosis is:

- Definite SUDEP
- Definite SUDEP plus
- Probable SUDEP
- Probable SUDEP plus
- Possible SUDEP
- Not SUDEP
- Unclassified

Definitions to be displayed

1. Definite SUDEP
 - i. Sudden, unexpected, witnessed or unwitnessed, non-traumatic, and non-drowning death that occurs in benign circumstances in an individual with epilepsy, with or without evidence for a seizure, and excludes documented status epilepticus, in which post-mortem examination does not reveal a cause of death
2. Definite SUDEP plus
 - i. Death satisfying criteria for definite SUDEP, if a concomitant condition other than epilepsy is identified before or after death, if the death might have been due to the combined effect of both conditions, and if autopsy or direct observations or recording of the terminal event did not prove the concomitant condition to be the cause of death
3. Probable SUDEP
 - i. Same definition as definite SUDEP but without autopsy.
4. Probable SUDEP plus
 - i. Same definition as Definite SUPED plus, but without an autopsy
5. Possible SUDEP
 - i. A competing cause of death is present
6. Not SUDEP
7. Unclassified