

# Beyond the Basics Specialized Knowledge for Nursing Staff and Paramedics on Sudden Unexpected Death in Epilepsy (SUDEP)

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## ABSTRACT

Sudden Unexpected Death in Epilepsy (SUDEP) is the greatest cause of death in epileptic patients; however, it is little recognized by healthcare workers. This review paper attempts to fill the knowledge gap for nursing staff and paramedics by providing specific insights that go beyond the basics. The publication emphasizes the pathophysiological mechanisms, risk factors, and preventive interventions linked with SUDEP by summarizing current research and clinical recommendations. Continuous monitoring, patient education, and the execution of tailored therapies in clinical settings are all given special priority. Furthermore, the review highlights the significance of effective communication and coordinated care among multidisciplinary teams in improving patient safety. Practical advice for identifying and managing high-risk patients is presented, along with an examination of the psychological effects of SUDEP on patients and their families. Finally, the purpose of this study is to provide nursing staff and paramedics with the important knowledge and abilities required to reduce the risk of SUDEP, hence improving patient outcomes and encouraging a proactive approach to epilepsy management.

**Keywords:** Sudden Unexpected Death in Epilepsy (SUDEP), Epilepsy, Seizure, Nursing Staff, Paramedics, Patient Education.

## INTRODUCTION

The issue of sudden unexpected death in epilepsy (SUDEP) has garnered significant attention over the past 20 years, not only from patient advocacy groups but also from medical professionals who treat epileptic patients. Even though

Epilepsy is a difficult condition, it is especially distressing when a person with the condition passes away abruptly and unexpectedly. Sudden Unexpected Death in Epilepsy (SUDEP) is the name given to this enigmatic occurrence [1]. The mechanism of epilepsy-related sudden death is uncertain. Sudden Unexpected Death in Epilepsy (SUDEP) is the most frequent cause of death among the leading causes of epilepsy-related deaths, which also include status epilepticus and accidents [2]. Developing plans to pinpoint high-risk individuals and enhance PWE management is necessary to lower premature mortality, specifically SUDEP. In recent years, there has been a rise in awareness of SUDEP, leading to a better understanding of its significance in epilepsy-related death [3]. For nurses and paramedics who care for people with epilepsy, it is crucial to go beyond the basics and understand more about SUDEP. Nurses and paramedics are on the front lines of patient care, and knowing SUDEP is critical to providing better treatment to patients who have epilepsy.

## METHODS

A systematic review of data on Sudden Unexpected Death in Epilepsy was undertaken by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) criteria. The research team searched PubMed, Medline, Scopus, and Google Scholar for publications published between January 2000 and March 2024 using keywords including "SUDEP," "epilepsy," "nursing," "paramedics," "risk factors," and "preventative strategies." Reference lists from pertinent articles were also searched for further manuscripts. Full-text English language research published in peer-reviewed journals was chosen. Each study's data covered pathophysiological mechanisms, risk factors, monitoring measures, patient education, nurse and paramedic responsibilities, and multidisciplinary care options.

## RESULTS

The initial search returned 500 studies, 25 of which qualified for inclusion, published between January 2000 and March 2024. The papers chosen were primarily observational, retrospective reviews, or uncontrolled case series, with varied degrees of evidence quality.

The review's goal is to identify clinical pathways for SUDEP prevention and management, describe the responsibilities of continuous monitoring and patient education, highlight the contributions of nursing staff and paramedics, and emphasize the value of multidisciplinary care in lowering SUDEP risk.

## DEFINITIONS

When a person with epilepsy passes away suddenly and mysteriously without a known reason, either through an autopsy or a medical inquiry, the term Sudden Unexpected Death in Epilepsy (SUDEP) is used to describe this situation. People with epilepsy frequently experience this condition, particularly those who have uncontrollable or controlled seizures.

Sudden Unexpected Death in Epilepsy (SUDEP) was defined in 2012 by researchers and neurologist Dr. Samden Lhatoo and colleagues. SUDEP, with or without seizure evidence, is defined by Nashef as the unexpected, abrupt, non-traumatic, non-drowning death that happens in a benign setting in an epileptic individual. Documented status epilepticus, in which a post-mortem examination fails to reveal a toxicological or structural cause of death, is not included in this definition [4].

The particular conditions accompanying an epileptic person's unexpected death are highlighted in Annegers' criteria for identifying Sudden Unexpected Death in Epilepsy (SUDEP) [5]. These standards are intended to differentiate SUDEP situations in epileptic patients from other causes of death [6]. Let us delve into each criterion:

### 1. Epilepsy Diagnosis:

- The individual must have been diagnosed with epilepsy, characterized by the presence of recurrent unprovoked seizures.

### 2. Unexpected Death in a Reasonable State of Health:

- The victim experienced an unexpected death while being in a reasonable state of health. This criterion implies that the death was not anticipated due to any known illness or deteriorating health condition.

### 3. Sudden Death in Minutes:

- The death occurred suddenly, typically within a short timeframe of minutes. This underscores the abrupt nature of the event.

### 4. Occurrence During Normal Activities and Benign Circumstances:

- The death took place during normal activities, such as being in or around bed, at home, or work. The circumstances surrounding the death are considered

benign, meaning there is no apparent external cause or dangerous environment.

#### 5. Absence of Obvious Medical Cause:

- An obvious medical cause of death was not found upon post-mortem examination. This criterion helps rule out other identifiable reasons for the sudden death.

#### 6. Not Directly Caused by Seizure or Status Epilepticus:

- Seizures or status epilepticus did not directly cause the death. This criterion distinguishes SUDEP from deaths that are directly related to a seizure or persistent seizure activity.

These criteria collectively provide a comprehensive framework for identifying and categorizing cases as SUDEP. They consider both the clinical history of epilepsy and the circumstances surrounding the unexpected death, while also excluding cases where a direct link to a seizure or other identifiable medical cause is present.

### INCIDENCE OF SUDEP

Based on variables like age, gender, type of epilepsy, and general health, there can be variations in the occurrence of Sudden Unexpected Death in Epilepsy (SUDEP). Unfortunately, several variables, such as underreporting, discrepancies in diagnostic criteria, and changes in study groups, make it difficult to pinpoint an exact incidence rate.

The identification of Sudden Unexpected Death in Epilepsy (SUDEP) cases involves various approaches, and most reports fall into one of the following categories:

#### 1. Medical Examiner or Coroner Records:

- SUDEP cases are identified through autopsy records of the Medical Examiner or Coroner in a specific geographic area. The number of confirmed SUDEP cases is then related to patient years based on an assumed prevalence of epilepsy in the region served by the Medical Examiner.

#### 2. Registry of Antiepileptic Drug (AED) Prescriptions:

- SUDEP cases are identified by reviewing deaths in a population of presumed cases with epilepsy, identified through registries of antiepileptic drug (AED) prescriptions. This approach links cases to individuals receiving medication for epilepsy.

#### 3. Hospital or Pharmaceutical Registries:

- SUDEP cases are identified by reviewing deaths among epilepsy patients from hospital registries or pharmaceutical company registries. These registries may include patients participating in clinical trials of new AEDs or therapeutic devices.

#### 4. Hospital, Clinic, or Referral Center Cohorts:

- SUDEP cases are identified by reviewing deaths among cohorts of epilepsy patients attending hospitals, epilepsy clinics, or referral centres. This approach focuses on specific healthcare settings where epilepsy patients receive medical care.

#### 5. Community-Based Cohorts:

- SUDEP instances are found in community-based cohorts of epilepsy incidence cases, either prospectively or retrospectively. This method entails researching community demographics to determine the prevalence of SUDEP among people who have recently received an epilepsy diagnosis.

These different methodologies allow researchers to gather data on SUDEP incidence and risk factors, providing a more comprehensive understanding of this phenomenon.

The mortality rates within the overall epilepsy population are approximately 2.5 times higher than those in the general population. Among the various causes of death related to epilepsy, Sudden Unexpected Death in Epilepsy (SUDEP) is considered the most common. According to a population-based study in the USA, SUDEP, although rare in the epilepsy population, surpasses the expected rate of sudden death in the general population by nearly 24 times. The incidence of SUDEP in this study was reported as 0.35 per 1,000 person-years [7].

It's important to note that the incidence rates of SUDEP can vary significantly based on the study cohort and design. In unselected cohorts, the incidence ranges from 0.09 to 0.35 per 1,000 person-years, while in general epilepsy populations, it can be higher, ranging from 0.9 to 2.3 per 1,000 person-years [8].

For individuals with refractory epilepsy (seizures not well controlled by medication), the mortality rates are still higher than in the general population, and the incidence of SUDEP may be even higher, ranging from 1.1 to 5.9 per 1,000 person-

years(9). In the context of epilepsy surgery, for candidates or patients who continue to experience seizures after surgery, the incidence rate of SUDEP varies from 6.3 to 9.3 per 1,000 person-years [10].

These findings highlight the significant impact of epilepsy on mortality rates and underscore the need for proactive measures in identifying and managing the risk factors associated with SUDEP, particularly in individuals with refractory epilepsy and those who have undergone epilepsy surgery.

## RISK FACTORS

The complex phenomenon known as Sudden Unexpected Death in Epilepsy (SUDEP) has multiple risk factors recognised, despite the fact the exact reasons are not entirely understood. Though they are linked to an elevated risk, it's crucial to remember that the existence of these risk factors does not ensure that SUDEP will happen. The clinical traits of epileptic patients who are particularly at risk for SUDEP have been the subject of several investigations. Most of this research on risk factors had inadequate controls.

One significant risk factor is the frequency and severity of seizures. Individuals experiencing a higher frequency of seizures, especially generalized tonic-clonic seizures, face an elevated risk of SUDEP. Medication non-adherence is another critical factor; failure to adhere to prescribed antiepileptic medications can lead to uncontrolled seizures, increasing the risk of SUDEP [11].

Early age of onset of epilepsy is associated with a higher risk, and the longer a person has had epilepsy, the greater the susceptibility to SUDEP. Respiratory dysfunction during seizures, including episodes of apnea, has been identified as a potential contributing factor, emphasizing the importance of monitoring breathing patterns during and after seizures [12].

Postictal Generalized EEG Suppression (PGES) on electroencephalogram (EEG) recordings after a seizure is linked to an increased risk of SUDEP. Nocturnal seizures, occurring during sleep, may contribute to a higher risk, possibly due to delayed detection [13].

## SUDEP Pathophysiology

The pathophysiology of Sudden Unexpected Death in Epilepsy (SUDEP) is not fully understood, and it remains a complex and multifactorial phenomenon. Researchers are actively studying various aspects to uncover the mechanisms underlying SUDEP.

Research on both humans and animals has shown evidence that SUDEP is associated with a compromised central nervous system that regulates arousal, heart rate, and breathing. It makes sense to hypothesise that the brainstem plays a role in the pathophysiology of SUDEP because it is basically in charge of all these activities [14]. Some evidence suggests that brainstem dysfunction is linked to the cardiorespiratory stoppage seen in experimental models of SUDEP. Seizures, particularly the generalised tonic-clonic form, set off a chain of events that disrupt the delicate balance of autonomic nervous system (ANS) function. ANS dysregulation during seizures causes unpredictable heart rate, blood pressure, and respiratory fluctuations, producing a setting suitable for cardiorespiratory dysfunction. Respiratory impairment, including hypoventilation and postictal apnea, appears as a critical component. The inability to breathe during the postictal period causes hypoxia and hypercapnia, putting stress on the cardiovascular and respiratory systems. Seizures also cause cardiac arrhythmias, which interrupt the regular rhythm of the heart and compromise blood circulation. The participation of the central autonomic network, a complex web of brain areas that govern autonomic activities, is important to SUDEP pathogenesis [5]. The disruption of coordination between the respiratory and cardiovascular responses during seizures is partly caused by dysregulation in this network.

SUDEP is also more likely to occur during postictal generalized EEG suppression (PGES), the seizure recovery process. PGES is a time of cerebral inactivity that affects the autonomic nervous system and arousal processes [15]. One important aspect that prolongs changes in heart rate and respiratory function is the reduced ability to quickly return to baseline physiological states postictally. The longer vulnerability window highlights the intricate pathophysiology of SUDEP. Individual and genetic variables contribute to the mystery by altering vulnerability to cardiorespiratory dysfunction during seizures. As researchers delve into the intricate mechanisms, there is optimism that unravelling the mystery of SUDEP would pave the way for tailored therapies and methods aimed at minimising the risk associated with cardiorespiratory failure in patients with epilepsy. Jansen et al.'s 2019 study, which was published in *The Journal of Neuroscience*, offers fresh perspectives on the possible mechanisms that underlie SUDEP. The scientists employed a transgenic mouse model (Cacna1a<sup>S218L</sup> mice) that carries a homozygous S218L missense mutation, which has been proposed as an SUDEP model and results in gain of function of voltage-gated Ca<sub>v</sub>2.1 Ca<sup>2+</sup> channels and increased risk for spontaneous fatal seizures. The primary

discovery of Jansen et al. (2019) was that medullary spreading depolarization (SD) is the source of cardiorespiratory failure associated with spontaneous brainstem seizures in *Cacna1aS218L* mice. Both lethal and nonlethal spontaneous seizures were shown in *Cacna1aS218L* mice [16]. It is important to highlight that SUDEP is most likely the result of numerous factors interacting, and the postulated mechanisms are not mutually exclusive. SUDEP research is constantly evolving, and ongoing studies attempt to increase our understanding of the pathophysiology to develop preventive methods and therapies.

## Diagnosis

SUDEP diagnosis is difficult due to a lack of reliable biomarkers or unambiguous criteria. Typically, physicians depend on a thorough examination of the patient's medical history, seizure frequency, and any relevant contributory variables. Examination findings supporting a diagnosis of SUDEP include a prone position, as well as signs of recent seizures, including oral trauma, ecchymoses, conjunctival haemorrhage, or lacerations to protruding areas of the head or limbs. Post-mortem tests, such as autopsies and neuropathological analyses, are frequently performed to rule out other probable reasons for death. Seizure frequency and severity, the occurrence of nocturnal seizures, and insufficient seizure control with medicines are all risk factors for SUDEP. However, the precise mechanisms that cause SUDEP are unknown. These findings are non-specific but may support the diagnosis of a recent seizure [17].

## TREATMENT

### 1. Number of ASMs

The primary approach to reducing the risk of SUDEP involves optimizing epilepsy management, given its close correlation with inadequate seizure control, effective treatment seems to be essential in lowering the incidence of SUDEP. However, there is a chance that ASMs could theoretically have the opposite impact, such as effects on the heart that are direct or indirect [18]. Tennis et al. found that the incidence of SUDEP increased with the amount of ASMs the patient was prescribed in their AED-prescription research. Be aware that the number of ASMs in this study does not always indicate exposure at the time of death; rather, it shows the history of prescription. A large number of ASMs in this study could simply be a sign of a chronic seizure disease, which would indicate severe epilepsy. Even after adjusting for seizure frequency, taking three ASMs

was associated with an RR for SUDEP of 8 (2.3-28) when compared to mono-therapy [19].

### 2. Specific ASMs

A few studies have attempted to investigate the possibility of a relationship between particular AEDs and a higher frequency of SUDEP. Timmings' study is the only one that indicates such a correlation. It is based on an assessment of a Welsh epilepsy clinic. Timmings discovered that the 14 SUDEP patients utilised carbamazepine far more frequently than the clinic's regular epileptic patients. However, no efforts were taken to account for additional confounding risk variables, such as age, duration of epilepsy, polytherapy, or frequency of seizures [20]. There was no difference in the incidence of SUDEP between carbamazepine and phenytoin monotherapy, according to the Swedish case-control research. Nonetheless, the therapeutic medication monitoring data of the 171 controls and the 57 cases were examined in further detail. Even after adjusting for seizure frequency, carbamazepine plasma levels above 40  $\mu\text{mol/L}$  at the last visit were linked in this analysis to an elevated risk. Patients receiving polytherapy were shown to be particularly at risk when their plasma concentrations were high. A comparable correlation with phenytoin was not discovered [21].

### 3. Changes in dose or treatment

Lip and Brodie discovered that a change in dose or therapy was associated with death in 5 of 12 cases, and frequent dose changes were also recognised as a risk factor in the Swedish study [22]. This information underscores the complexity of managing epilepsy and suggests that alterations in treatment regimens may have implications for patient safety.

## Enhancing SUDEP Care: Specific Knowledge for Nurses and Paramedics

The crucial role of nurses and paramedics in delivering optimal care to people with epilepsy, particularly in the context of Sudden Unexpected Death in Epilepsy (SUDEP), needs specialised knowledge beyond epilepsy management principles. With roughly 50 million people suffering from epilepsy worldwide, the unique issues connected with SUDEP highlight the necessity for healthcare practitioners to have specific insights and skills [4].

Recognising warning signs is fundamental to nurses' specialised expertise. Comprehensive training helps them detect subtle behavioural changes and physiological



markers that may precede a catastrophic seizure, allowing them to intervene before it becomes too late. Nurses play an important role in patient education, emphasising the significance of drug adherence. It is critical to communicate clearly about the hazards of SUDEP and preventive measures, which necessitates a careful balance between transmitting information and ensuring patient comprehension.

As first responders in an emergency, paramedics must be well-versed in urgent response methods. Their ability to keep patients safe during seizures is critical in avoiding complications that could lead to SUDEP. Furthermore, paramedics armed with cutting-edge equipment can record and send pertinent data during and after a seizure incident. These real-time data assists neurologists in fine-tuning treatment strategies and comprehending potential SUDEP risk variables [11].

Both nurses and paramedics require ongoing training and skill development. A high standard of care is ensured by being up to date on the newest research findings, treatment guidelines, and technological innovations. In SUDEP talks, nurses must foster sensitivity by addressing concerns and helpfully

delivering facts.

Monitoring and documenting are critical components of nurses' and paramedics' jobs. Regular monitoring of epileptic patients, along with detailed documentation of seizure incidence, medication changes, and any adverse events, adds to a full patient profile. This information is useful in fine-tuning care regimens and identifying probable seizure triggers.

Encouragement of supportive communities is a comprehensive method that both nurses and paramedics can use. Connecting people with epilepsy to communities or services that provide emotional support, shared experiences, and empowerment helps patients' overall well-being.

Epilepsy first aid is a crucial skill for nurses and paramedics, as they are often the first responders during seizure emergencies. Prompt and appropriate intervention can significantly impact patient outcomes. Below are essential steps for nurses and paramedics to effectively manage and provide care during and after a seizure [23]:

Step	Action
<b>1. Ensure Safety</b>	Prioritize safety for both the patient and yourself. Remove any nearby objects that could cause harm and create a clear space. If the patient is in a hazardous location, carefully move them to a safer area.
<b>2. Time of the Seizure</b>	Note the start time of the seizure. Seizures lasting longer than 5 minutes or multiple seizures in a row require immediate medical attention.
<b>3. Protect the Head</b>	Place the patient on their side to help keep the airway clear and prevent aspiration. Gently cushion their head to minimize the risk of head injury.
<b>4. Do Not Restrain</b>	Avoid restraining the patient's movements. Allow the seizure to run its course to prevent injury and increased anxiety.
<b>5. Clear the Airways</b>	If possible, turn the patient onto their side to aid breathing and prevent saliva or vomit from obstructing the airway. After the seizure, help maintain a clear airway.
<b>6. Do Not Insert Objects</b>	Never put anything into the patient's mouth during a seizure to avoid injury to the teeth, jaw, or airway.
<b>7. Monitor Breathing</b>	Keep a close eye on the patient's breathing. If breathing stops or becomes irregular, initiate CPR, administering rescue breaths and chest compressions as needed.
<b>8. Time the Postictal Phase</b>	Note the duration of the postictal phase (the period after the seizure). Some patients may need additional time to recover consciousness and orientation.
<b>9. Reassure and Comfort</b>	Provide reassurance and comfort after the seizure. Create a calm and supportive environment to aid in recovery.
<b>10. Seek Medical Attention</b>	Seek emergency medical attention if it is the patient's first seizure, lasts longer than 5 minutes, is followed by another seizure, if the patient is injured, or if breathing difficulties persist.
<b>11. Document the Seizure</b>	Document details of the seizure, including duration, characteristics, and observations. This information is valuable for medical records and future care planning.
<b>12. Provide Post-Seizure Care</b>	Assess the patient for injuries and address immediate needs after the seizure. Check blood sugar levels in diabetic patients, as low blood sugar can trigger seizures.
<b>13. Educate and Support</b>	Educate the patient and caregivers about epilepsy management, triggers, and medication adherence. Offer support and answer any questions.
<b>14. Ensure Follow-up Care</b>	Coordinate with the patient's healthcare team for appropriate follow-up care. Adjustments to medications or further evaluations may be necessary.

By following these steps, nurses and paramedics can provide effective epilepsy first aid, ensuring the safety and well-being of individuals experiencing seizures. Training and ongoing education in epilepsy management are essential for healthcare professionals to confidently handle diverse situations and contribute to improved patient outcomes.

## DISCUSSION

Raising awareness about Sudden Unexpected Death in Epilepsy (SUDEP) is a collaborative effort involving healthcare professionals, advocacy groups, and the public. Nurses and paramedics, who are on the front lines of patient care, are critical in distributing information and promoting understanding about the hazards associated with epilepsy.

Nurses have a unique chance to engage in continuing conversations with patients and their families as main carers. Their role in promoting awareness entails giving accurate and easily accessible information regarding SUDEP, emphasising preventative measures, and refuting myths [24]. Developing a trustworthy connection with patients enables nurses to address concerns and offer the necessary support in dealing with the emotional burden of SUDEP awareness.

Paramedics, who are frequently the first responders in emergencies, help raise awareness by presenting clear and succinct information in real time. Their duty entails not just handling emergency medical requirements, but also advising patients on follow-up care, treatment plans, and the significance of getting medical help as soon as possible. Continuous monitoring, particularly during sleep, is crucial because many SUDEP cases occur at night. Implementing technologies such as seizure detection devices and adhering to medication regimens are key preventative approaches. During an emergency, effective communication can have a major impact on patient knowledge and proactive management of SUDEP risks.

Finally, specialised knowledge for nurses and paramedics in SUDEP care goes beyond the basics. It entails a comprehensive set of skills and knowledge that enable healthcare practitioners to manage the unique issues provided by epilepsy. Nurses and paramedics become essential partners in the search to reduce the hazards associated with SUDEP by recognising warning indicators, adopting fast response protocols, educating patients, promoting collaboration, integrating technology, and being sensitive in talks. Ongoing training and ongoing development are critical in ensuring that healthcare personnel are well-equipped to navigate the expanding terrain of epilepsy care, offering the highest level of support and safety to those living with epilepsy globally.

## CONCLUSION

Epilepsy is far from a benign disorder, as the recent medical and public debates, publications, and nice guidelines on SUDEP provide a timely reminder. The most prevalent cause of epilepsy-related death, SUDEP, is a diverse illness for which specific risk factors for each individual are still largely unknown as well as the underlying mechanisms are still unknown. specialised knowledge for nurses and paramedics is crucial in addressing the unique challenges presented by SUDEP. By fostering awareness, enhancing care, and advancing research, healthcare professionals play a pivotal role in minimizing the risks associated with SUDEP and improving the overall well-being of those living with epilepsy globally.

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