

Learning from Prevention of Future Death Reports in Epilepsy

Stirling J, Donovan, B, Hanna J
SUDEP Action

INTRODUCTION

- At least 21 epilepsy-related deaths occur each week in the UK and young adults have the highest relative risk of epilepsy-related death, particularly from SUDEP. Up to 80% of deaths in young adults are thought to be preventable through improved epilepsy care. Prevention of Future Deaths (PFD) reports offer clear insights into failures in epilepsy care that increase risk but represent only the tip of the iceberg. Nevertheless, they are a red-flag for the true scale of preventable harm.
- Coroners have a duty to report where deaths could be prevented, but the process is shaped by structural inequalities. NHS Trusts are routinely legally represented, while, due to cost, bereaved families rarely are. This imbalance affects the evidence heard and learning captured.
- SUDEP Action's free, family centred casework service helps address this gap, ensuring over 70 families a year are supported through complex investigations and inquests.

RESULTS

Documents reviewed

- Notes from SUDEP Action's free casework service (60 cases)
- Six Prevention of Future Deaths Reports since 2024
 - David Compton
 - Amber Walker
 - Paul Nash
 - Charlie Marriage
 - Andrew Ewin-Ripp
 - John Fisher
- Clive Treacey's Independent Review

Failure to discuss risk with patients and poor discharge information

Patients were often uninformed and unaware of their own degree of risk and of what they could do To proactively mitigate this risk.

Delays in accessing medications

Delays in being able to access medications risked deterioration in seizure-control and increase in risk of SUDEP.

KEY THEMES

Appointment delays and cancellations

Patients were often not provided with timely interventions and responses to changes in the presentation of their epilepsy.

Inadequate epilepsy risk management

Patients were made vulnerable by failures to identify, monitor and respond to risks over an extended period of time, increasing risk of serious harm.

METHODS

A retrospective qualitative analysis was conducted complimentary sources of information around learning from epilepsy-related deaths.

Materials were reviewed to identify recurring patterns and factors implicated in the deaths being discussed. Relevant factors were independently drawn out from reports and compared across the reports by two researchers.

Overarching themes were developed and refined based on independent reviews.



Amber Walker



Andrew Ewin-Ripp



David Compton



Clive Treacey



Charlie Marriage

CONCLUSION

Findings of this study echo concerns that have been being voiced for over two decades. Key issues around person-centred communication of risk, access to medications and epilepsy support, and systematic learning from deaths, can be traced back to the Prevent21 "Time to Listen" consensus.

Despite evidence from past leading to present, many issues continue to be left unaddressed, causing preventable risks to persist and putting people with epilepsy at risk of harm and potential premature mortality.

Furthermore, learning from deaths is still hampered by inconsistent use of Royal College of Pathologists guidelines and misattributed causes of death. The Hillsborough inspired Public Authority Accountability Bill would transform the PFD system by introducing a statutory duty of candour for public bodies and funded legal support for families at inquest.