The Epilepsy Deaths Register

We should be doing more for families who experience an epilepsy associated death

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About the Epilepsy Death Register (EDR)

The Epilepsy Deaths Register (EDR) intends to make every epilepsy death count. The EDR was developed and supported to collect details on factors and events surrounding deaths in epilepsy. The register aims for better understanding of any contributors to the risk of death and works to reduce common factors.

Families wait many months for an inquest to report and yet – even after this wait – are often left with inadequate answers.

We need to continue to accurately learn on the risks contributing to epilepsy death but recognizing the effect of these deaths on families.

The EDR provides a different perspective that complements population sources that may be incomplete and not fully encapsulate important background circumstances.

We also sought to determine from which service information after death was provided and to assess if there was opportunity to feedback and the ability of support to discuss issues and the timing of this.

The Epilepsy Deaths Register is owned and operated by SUDEP Action. The Epilepsy Deaths Register is endorsed by government, but in the UK there are no major bodies that fund registers or their infrastructure.

Important research questions that the EDR may contribute in finding answers to are:

- How important are social factors and life-style factors
- Why is SUDEP less common in children than adults
- What proportion are in less severe epilepsy
- IS SUDEP associated to particular drug or non-drug treatments / is it due to sub-optimal care
- Does communication of risk reduce risk-taking behaviours
- Are seizure detection devices and alarms protective / Is night-time surveillance protective
- What triggering mechanisms are effective in targeting people at risk
- What interventions can support clinical, patient, carer decision-making and risk management
- What is the impact on the family? / How can services for families be improved

References

1. Chen S et al. Under-reporting of sudden unexpected death in epilepsy
Epileptic Disorders 2018
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4. Nashof L, Leach JP. SUDEP, the aftermath: supporting the bereaved Practical Neurolgy 2017