Seminar in Epileptology

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Sudden unexpected death in epilepsy (SUDEP): what every neurologist should know

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Aims

- To empower general neurologists to provide informed person-centred advice on Sudden Unexpected Death in Epilepsy (SUDEP) to people with epilepsy to help keep them safe.
- To provide ‘fingertip’ information to the practicing neurologist with regards to identifying and communicating risks for SUDEP.

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Methods

- Past and present evidence is consolidated in order to inform readers about SUDEP.
- The epidemiology, diagnostic classification, pathophysiology, risk factors, and influence of co-morbidity are described.
- The positives and negatives of discussing SUDEP with the person with epilepsy are highlighted.

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Outputs

- Confirms the need to discuss SUDEP with people with epilepsy early during the course of a person's seizure management.
- Suggests practical templates, structures, and tools to discuss what is perceived a difficult conversation in a person centred manner.
- Suggests practical measures for managing the risk in partnership with the patient.

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Brief facts on SUDEP

Definition

SUDEP is defined as sudden, unexpected, non-traumatic, non-drowning death in an individual with epilepsy, witnessed or unwitnessed, in which post-mortem examination does not reveal an anatomical or toxicological cause of death.

Causes

It is likely that there is no single explanation for all deaths, and different mechanisms may be involved. The vast majority of SUDEPs occur in the aftermath of a generalised tonic-clonic seizure. Witnessed recorded SUDEP cases involve postictal cardio-respiratory dysfunction with failure of arousal. The most important risk factor is a history of generalised tonic-clonic seizures.

Incidence

The risk of sudden unexpected deaths has been estimated to be 24 times higher in young persons with epilepsy than in the general population of the same age.

SUDEP incidence is estimated at 1 per 10,000 patient-years in newly diagnosed epilepsy in community-based studies and 1-2 per 1,000 patient-years in cross-sectional studies of patients with chronic epilepsy. A higher incidence, of 2-10 cases of SUDEP per 1,000 patient-years, is reported in studies of patients with treatment-resistant epilepsy.

The incidence in children is estimated to be lower than in other age groups; approximately 0.2 per 1,000 patient-years.

Key points when discussing SUDEP with your patient

Direct SUDEP risk factors	Potential indirect factors which may affect seizure control
Generalised tonic-clonic seizures >2/year	
Nocturnal seizures and lack of surveillance	Excessive use of alcohol (other substances).
Early age at epilepsy onset, i.e. before the age of 16	Non-adherence with AEDs.
Treatment resistance defined as absence of 5-year terminal remission.	Sleep deprivation and irregular sleep pattern.
Long duration of epilepsy of over 15 years	Prescribed drug changes likely to result in worsening or loss of seizure control.

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Positive reasons and concerns when discussing SUDEP

Discussing SUDEP: positive reasons	Discussing SUDEP: concerns
The patient's right to know about his/her condition.	This might dismay and distress patients.
In circumstances of low risk, discussion may ease patient fear and anxiety.	Increased patient fear and anxiety resulting in a move from leading a 'normal life' to a 'risk averse' life.
Supports patient empowerment and identifies key areas for patients to focus and work on.	Might lead to a false sense of security in those at a lower risk.
Encourages epilepsy self-management and effective collaboration during treatment between clinician and patient. The aim is to prevent seizures and minimise risk of SUDEP.	Cultural and ethnic differences in attitudes need to be considered.
Supports a relationship of trust between clinician and patient.	Based on cultural and ethnic issues, this could be seen as the professional abdicating responsibility.
Guidelines recommend SUDEP discussion as part of comprehensive care.	
Structured discussion provides evidence of quality of patient care and sense of direction of treatment management.	
Following guideline recommendations reduces clinician and corporate risk in case of an adverse outcome.	