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Optimising Early Care in Epilepsy: Psychological Health, Treatment Alignment, and SUDEP Counselling

A guide to clinician awareness, knowledge, and medication preferences in seizure management and outcomes

Epilepsy affects 50 million people worldwide and is one of the most common neurological disorders[1]

Compared to the general population, all-cause mortality rates are higher in people with epilepsy (PWE)[1]

Chronic epilepsy is characterised by neuropsychological comorbidities[2]

- Impaired memory and attention
- Impaired language and executive function
- Mood and anxiety disorders

Patients with newly diagnosed epilepsy also exhibit high cognitive and psychological dysfunction[2]

- Worse cognitive performance
  - Verbal and working memory
  - Executive functions
- Increased depression and anxiety

Factors influencing neuropsychological function[2]

- Stress from diagnosis of epilepsy
- Recurrent seizures
- Antiseizure medications (ASMs)
- Polytherapy with multiple ASMs

Telehealth screening is a useful tool to assess mental health and thinking skills[2]

- Cost-effective
- Accessible to all patients
- Promotes early identification and intervention

↓

Reduced seizure recurrence

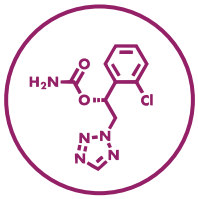
Telehealth identifies the prevalence of deficits immediately after the first seizure*, indicating underlying brain disturbance rather than the effects of secondary risk factors

*Prior to diagnosis, ASM treatment, and recurrent seizures

Newer third-generation ASMs have demonstrated good efficacy[1]

- Lacosamide
- Eslicarbazepine
- Perampanel
- Brivaracetam
- Cenobamate

→ Reduce frequency of focal seizures



Cenobamate therapy[1]: 18.4%–36.3% of seizure freedom for a consecutive ≥12-month duration

New ASMs increase therapy adherence and improve outcomes by reducing adverse effect burden[3]

Despite the emergence of newer and effective ASMs, their inclusion in first-line therapy remains limited[1]

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Common barriers to use and optimisation of newer ASMs[1]

Treatment complacency

Both clinicians and patients hesitate to try new ASMs

Patients

- Fear of increase in seizures
- Fear of side effects
- Underreporting of seizures, delaying regimen adjustments

Clinicians

- Respond to patients' fear with reluctance to change treatment
- Short office visits impede communication

Inadequate trial of new adjunctive therapies

Clinicians often select ASMs with:

- Fewer drug interactions
- Easier add-on
- Suboptimal efficacy

Premature termination of a new ASM upon the appearance of adverse events (AEs)

- Avoidance of an effective drug
- Inaccurate diagnosis of drug-resistant epilepsy

Pitfalls of rational polytherapy

Patients achieving seizure freedom decline with the addition of each ASM[1]

Points to consider while selecting concomitant ASMs

- Mechanism of action (MOA)
- AEs
- Pharmacokinetic interactions
- Need for dose titration
- Excessive ASM drug load over time

ASMs with similar or different MOA need to be evaluated for AE profile and safety

Sodium channel blockers with similar MOA cannot be combined

Carbamazepine, oxcarbazepine, and eslicarbazepine

Increased neurotoxicity

Sodium channel blockers with different MOA can be combined

Lacosamide and cenobamate with other sodium channel blockers

Role of depressive symptoms on ASM adverse effects[3]

- Depressive disorder was found to influence the perception of side effects that are caused by ASMs
- Treating depression might increase the tolerability of ASMs by reducing side effect perception

Restricting the use of newer drugs[1]

- First-line therapy remains limited to generic ASMs
- Treatment guidelines, including newer ASMs as a first-line approach are needed

Updated and detailed expert consensus recommendations, backed by safety and efficacy data from clinical trials, will inform and guide decision-making

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Matching therapeutic goals is the first step towards selecting the appropriate ASM[4]

Discrete choice experiment surveys that identify patient and clinician preferences revealed divergent treatment goal importance

Attributed preferences for ASM monotherapy

Clinician	Patients
1 Efficacy preventing seizures	1 Efficacy preventing seizures
2 Limited personality changes	2 Avoids cognitive issues and "trouble thinking clearly"
3 Avoids cognitive issues and "trouble thinking clearly"	3 Limited personality changes

Aligning clinical decisions with patient preferences is essential for a more holistic approach of shared decision-making and patient-centred treatment

Open communication between the clinician and patient is essential for management of ASM and associated comorbidities like sudden unexpected death in epilepsy (SUDEP)

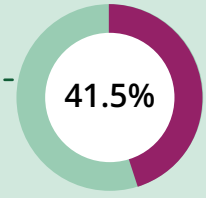
- SUDEP is the leading cause of death in adults and children with epilepsy[5]
- 20 times higher incidence than in the general population[5]
- Higher among patients with frequent generalised or focal to bilateral tonic–clonic seizures (TCS)[5]

Potentially modifiable risk factors of SUDEP[6]

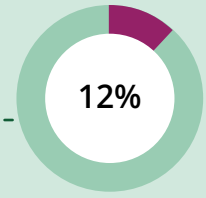
- Treatment optimisation to reduce seizure frequency, particularly TCS
- Nocturnal surveillance
- Medication compliance
- Epilepsy action plans
- Awareness and communication

- Clinical practice guidelines require clinicians to discuss SUDEP with PWE and their caregivers[5]
- Patients and caregivers want to be informed about SUDEP in person by their neurologist at the time of diagnosis[5]

In a 2022 global survey[5]:



Neurologists discussed SUDEP rarely with 1%–9% of PWE



Neurologists discussed SUDEP often with 50%–90% of PWE

Despite guideline recommendations, many paediatric and adult neurologists do not routinely inform PWE about SUDEP or inform only a subset of patients considered at high risk[5]

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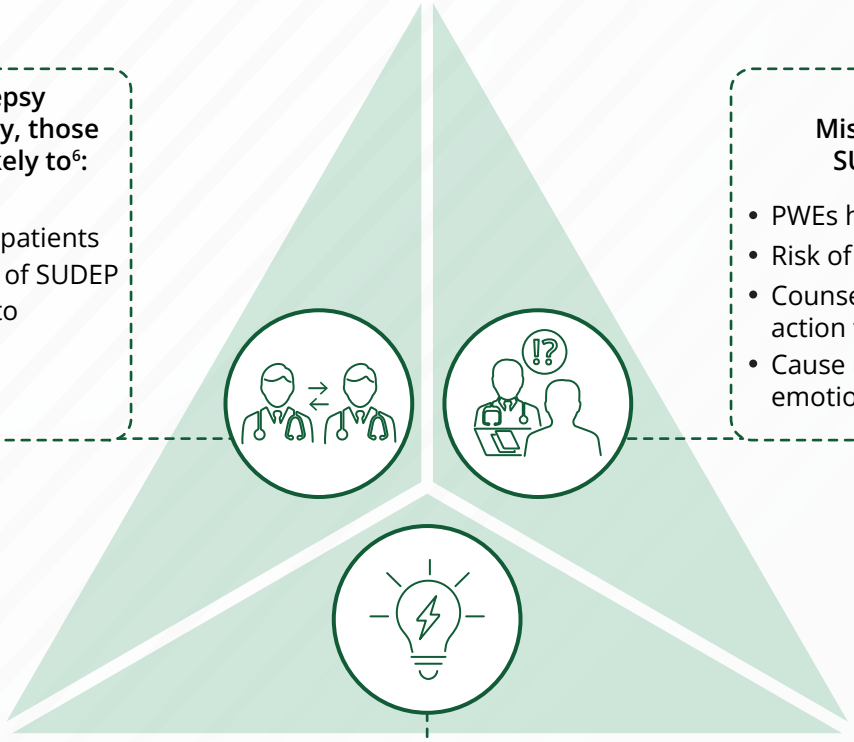
Compared to epilepsy professionals in Norway, those in the UK are more likely to[6]:

- Discuss SUDEP with all patients
- Emphasise importance of SUDEP
- Have access and refer to bereavement support

Misconceptions about SUDEP counselling[5]

- PWEs have a "right not to know"
- Risk of SUDEP is rare
- Counselling may not motivate action to reduce SUDEP risk
- Cause unnecessary anxiety and emotional difficulties



Importance of SUDEP counselling[5]

- Patients have a "right to know"
- Avoid misinformation from alternative sources
- Enhance epilepsy care and self-management
- SUDEP risk reduction
- Educate and empower patients

Improved clinician training and education needed to enhance knowledge and understanding of SUDEP counselling among healthcare providers, caregivers, and patients

Key messages

- **Early identification of psychological dysfunction in PWE will aid timely intervention, reducing the risk of seizure recurrence**
- **Clinicians need to continuously reassess and optimise ASM treatment, and tailor the treatment to achieve the best outcomes for their patients**
- **Clinician education is necessary to overcome current hesitation, avoidance, and subjectivity in initiating SUDEP-related conversations**

References:

1. Rosenfeld, W. E. (2025). Epilepsy medication management: addressing common treatment barriers to adopting cenobamate and other new antiseizure medications. *Epilepsia, 66*(S1), 38–48.
2. Pugh, R., Vaughan, D. N., Jackson, G. D., Ponsford, J., & Tailby, C. (2024). Cognitive and psychological dysfunction is present after a first seizure, prior to epilepsy diagnosis and treatment at a first seizure clinic. *Epilepsia Open, 9*(2), 717–726.
3. Panholzer, J., Hauser, A., Thamm, N., Gröppel, G., Yazdi-Zorn, K., & von Oertzen, T. J. (2024). Impact of depressive symptoms on adverse effects in people with epilepsy on antiseizure medication therapy. *Epilepsia Open, 9*(3), 1067–1075.
4. Rosenow, F., Winter, Y., Leunikava, I., Brunnert, M., Joeres, L., Sutphin, J., ... & Brandt, C. (2021). Relative importance of clinical outcomes and safety risks of antiseizure medication monotherapy for patients and physicians: discrete choice experiment eliciting preferences in real-world study "VOTE." *Epilepsia, 63*(2), 451–462.
5. Whitney, R., Jones, K. C., Sharma, S., & RamachandranNair, R. (2023). SUDEP counseling: Where do we stand? *Epilepsia, 64*(6), 1424–1431.
6. Watkins, L., Henning, O., Bassett, P., Ashby, S., Tromans, S., & Shankar, R. (2024). Epilepsy professionals' views on sudden unexpected death in epilepsy counselling: a tale of two countries. *European Journal of Neurology, 31*(9).

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The Brain Health Knowledge Hub is supported by Angelini Pharma