EPILEPSY ACTION

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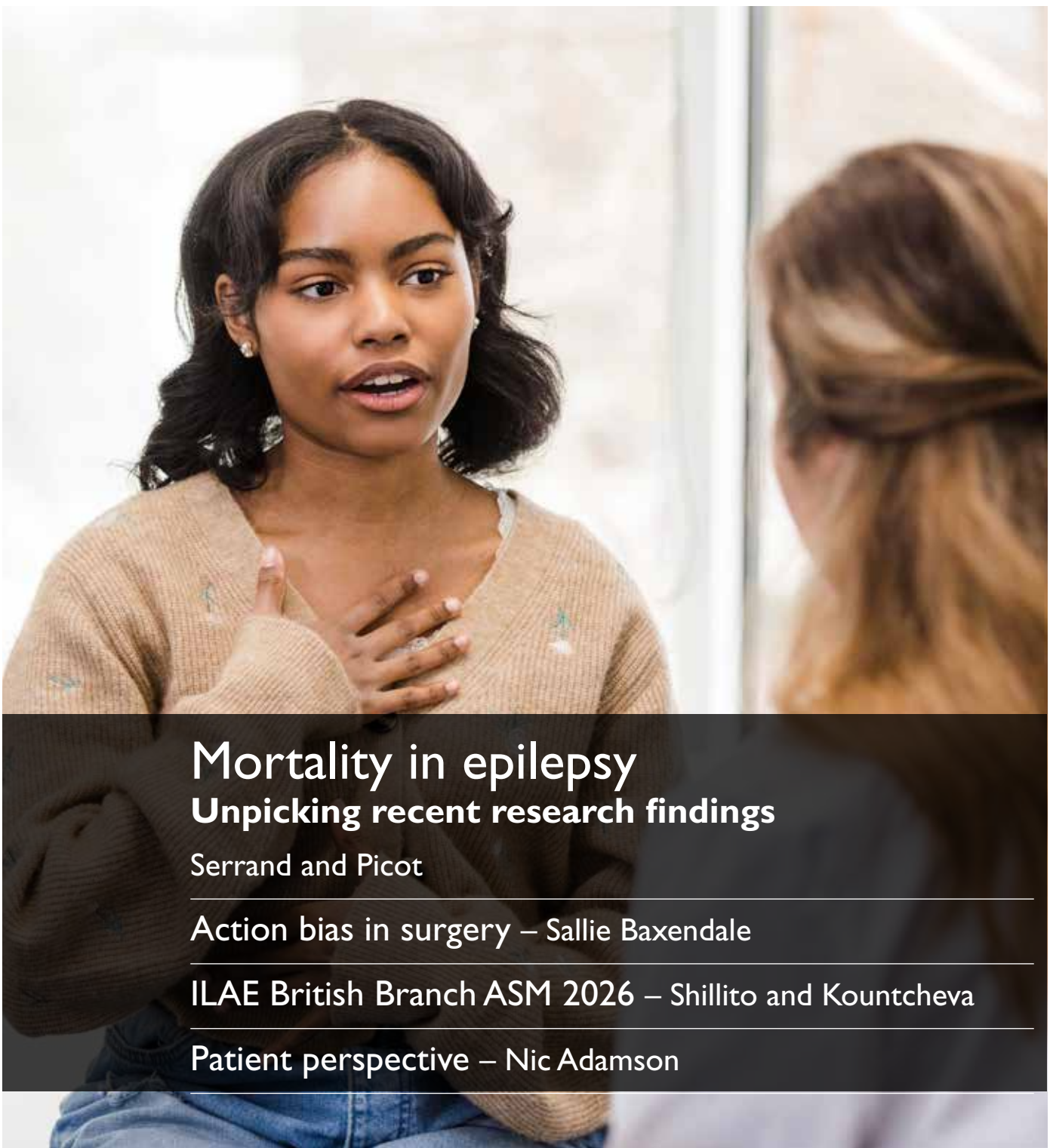


Mortality in epilepsy

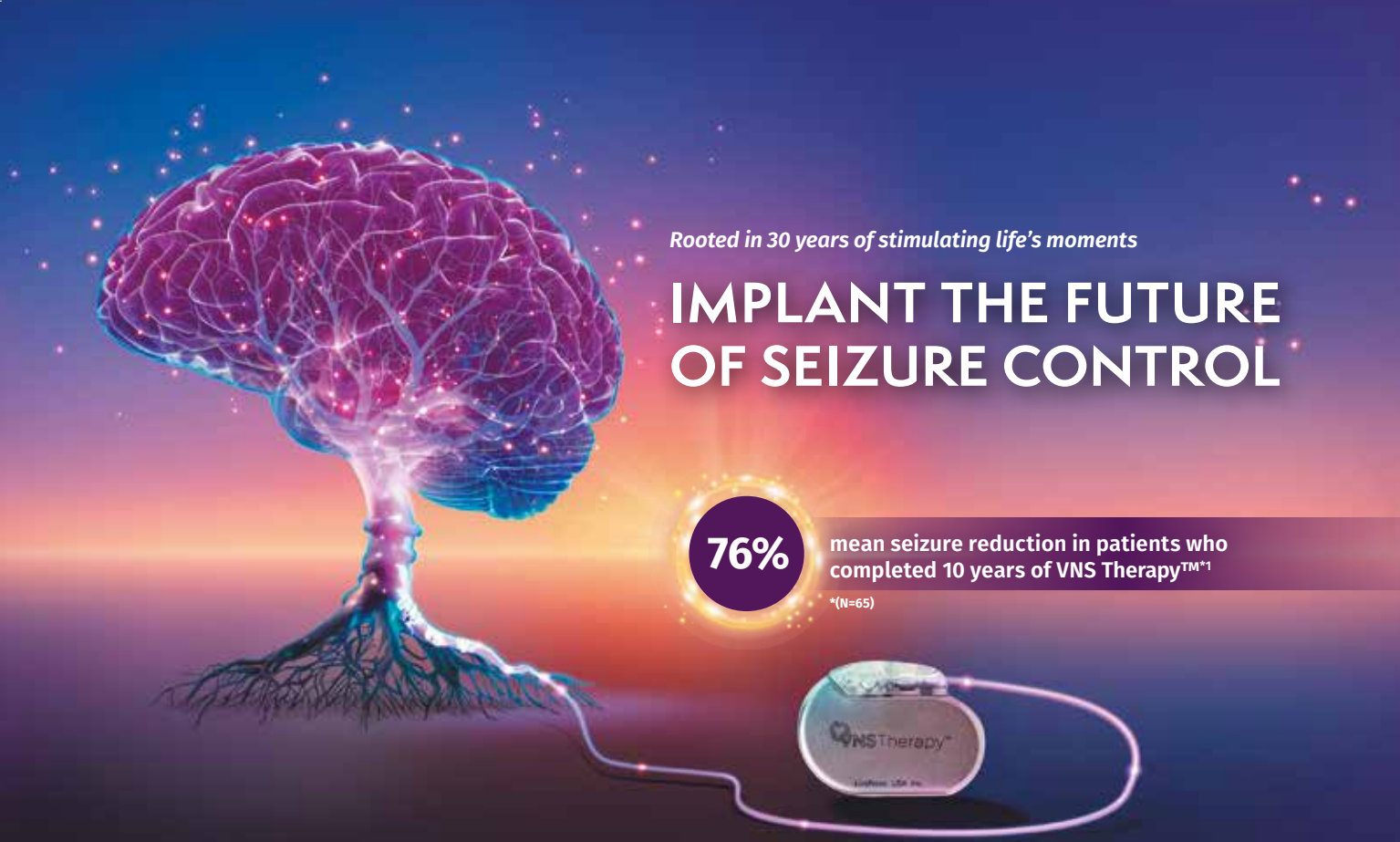
Unpicking recent research findings

Serrand and Picot

Action bias in surgery – Sallie Baxendale

ILAE British Branch ASM 2026 – Shillito and Kountcheva

Patient perspective – Nic Adamson



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1. Elliot RE, et al. Epilepsy Behav. 2011;20(3):478–83. **2.** Data on file. CORE-VNS Clinical Study Report, LivaNova, USA, June 2025. **3.** Data on file, LivaNova USA, Inc., Houston, TX. 2025. **4.** VNS Therapy™ System Physician's Manual (OUS), December 2023, LivaNova, Houston, TX. **5.** Ben-Menachem E. J Clin Neurophysiol. 2001;18(5):415–8.

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Maybe it's a bit late to say Happy New year to readers, but at the time of writing the days are already longer and so maybe it's timely that I welcome our readers to the Spring edition of Epilepsy Professional.

This edition has a focus on decision making in patients with refractory epilepsy, trying to do no harm and in light of this an interesting patient perspective and some highlights from the autumn conference in Bournemouth.

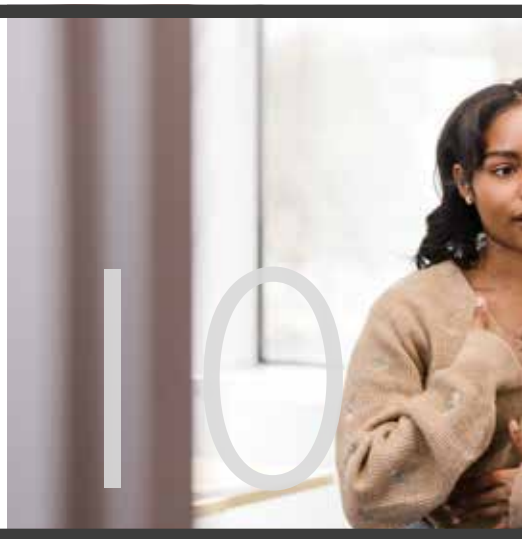
It's always a challenge of how to approach the patient with epilepsy who has been on multiple antiseizure medications; do we always insist on trying the latest new ASM? Do we suggest drug trials or do we explore surgical options? Prof Sallie Baxendale looks the biases we and patients hold onto when we continue to use seemingly ineffective or harmful treatments and challenges us to carefully consider the real individual and population benefits of certain treatments especially epilepsy surgery. I recall a senior colleague once challenging me that sometimes the hardest thing is to do nothing, rather than pursue an intervention that seemingly because it's an intervention creates the illusion that doing something is better than doing nothing?

Dr Serrand and Dr Picot from Nimes and Montpellier share their research from a nationwide French cohort which focused on adolescents and adults aged 12-60 years between 2009 and 2019, with data on nearly 620,00 people with epilepsy. The main headline from this research which will inform our practice is the clear increased mortality in young adults with epilepsy aged between 20-40, who were six to seven times more likely to die than their peers without epilepsy. However, the real striking result was the finding that women in this age cohort between 20 and 40 years had up to 11 times higher risk of death compared to women in the general population. This of course raises many research questions and should focus our attention in clinical practice. It also poses the question of reduced valproate prescribing in women and are we seeing this play out?

And finally in case you weren't able to attend due to other commitments, or did attend, but missed a session, or had a snooze Tom Shillito and Kami Kountcheva provide some helpful highlights on the ILAE Conference in Bournemouth from late September 2025. Some personal headlines I took home included the increasing emerging evidence around dissociative seizures; that up to 30% do not have a cause, that they in themselves are not harmful although the overall mortality rates in people with functional seizures is slightly higher than the general population. Marcus Reuber also provided some helpful practical tips, a few dos and don'ts on how to manage an acute dissociative seizure which I for one will try to put into practice as I move into 2026.

Ann Johnston
Consultant neurologist
Chief medical adviser
Epilepsy Professional

contents



18

ILAE British Branch ASM 2025

Shillito and Kountcheva

Tom Shillito and Kami Kountcheva from Epilepsy Action share an update on a few of the sessions from the ILAE British Branch Annual Scientific Meeting, discussing epilepsy and dementia, functional dissociative seizures and seizures during sleep

If variety is the spice of life, then this issue is the spice rack of champions, as we bring you four different but equally interesting articles to make you think on lots of different elements of healthcare for epilepsy patients.

Dr Serrand and Dr Picot kick things off this issue by delving in to their research into mortality and epilepsy and exploring some of the more unexpected findings, such as a disproportionately heightened death rate among 20-40-year-old women (page 10).

Next up, Prof Baxendale helps us toe the line between action and inaction when it comes to the best outcomes for our patients and helps us understand why patients may persist with ineffective or even harmful treatments (page 14).

For anyone who couldn't make it to the ILAE British Branch ASM last year, look no further than our round-up of some of the sessions at the meeting on page 18. You'll find more on where we are at with seizure detection devices, best practice when it comes to supporting people with functional dissociative seizures, updates on epilepsy and dementia and presentations around sleep seizures.

Last but not least, I really recommend reading Nic Adamson's diary from her experience having stereo EEG. Stepping in the shoes of patients and seeing things from their perspective is invaluable in better understanding their experience and how best to support them. Nic has been very keen to try anything that will help reduce the focal seizures that have disrupted much of her life, but even so, her much awaited SEEG was a time of ups and downs.

I hope this issue provides some varied, well spiced food for thought. Enjoy!

Kami Kountcheva
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People with learning disabilities die significantly younger from epilepsy causes, study finds

Gaps in services and poor-quality care are causing adults with learning disabilities and epilepsy to die significantly younger from epilepsy related causes, than those who died from non-epilepsy related causes, according to new research.

The paper published in the Journal of Neurology, Neurosurgery and Psychiatry in December, included 9,756 deaths in people with intellectual disability and epilepsy from the English Learning from Lives and Deaths programme between 2016 and 2021.

Researchers Prof Rohit Shankar and colleagues found that epilepsy was the main cause of death in 1,584 (16.2%) people. They found that people in this group died significantly younger, at an average age of 56 years. This compared to 62 years in those who died from non-epilepsy related deaths causes.

Across both groups, those with moderate-to-profound intellectual disability and those of African or Asian ethnicity were at higher risk of death.

The researchers found that risk factors included poor quality of care, gaps in services and lack of annual health checks. Meanwhile, interventions like psychiatry and speech language therapy were found to reduce this risk.

Prof Shankar, MBE, lead researcher, professor of neuropsychiatry at the University of Plymouth and director of the Cornwall Intellectual Disability Equitable Research (CIDER) unit, said: "Our study shows that among people who also have an intellectual disability, [epilepsy] poses a greater threat of them dying younger with those from ethnic minorities living in the UK being even more at risk.

"What is arguably even more shocking is that there are strategies including psychiatric support to speech and language therapy out there to help people.

"It is wholly unacceptable that these are not routinely and systematically used in a proactive manner everywhere in England, particularly when we're talking about people who are extremely vulnerable and often have difficulties in communicating their needs or concerns. It is a situation that urgently needs addressing."

About one in five people with a learning disability also have epilepsy (around 22 in every 100). More severe learning disabilities are linked to a higher risk of also having epilepsy. People with learning disabilities are also known to have a shorter life expectancy than the general population.

Services for people with learning disabilities and epilepsy have been under question, with the Clive Treacey Safety Checklist, developed to help health organisations meet care and safety standards for people with epilepsy and learning disabilities, discussed in Parliament last month.

This checklist was developed when Clive Treacey died aged 47 following "multiple system-wide failures in delivering his care and treatment" had placed him at "higher risk of sudden death".

Clive's sister, Elaine Clarke, said: "It's deeply shocking to see that there are so many people with a learning disability who, just like my brother Clive, continue to die avoidable deaths because they do not receive the epilepsy care and treatment that they should.


Clive Treacey

"If these terrible statistics belonged to almost any other part of society there would be public outrage – but the harsh reality is that people like my brother Clive, are not valued or prioritised."

Alison Fuller, director of health improvement and influencing at Epilepsy Action, added: "This research lays bare the shocking inequalities faced by people with epilepsy and a learning disability. It clearly shows that they are dying far too young and acts as a stark reminder that this group remains among the most at-risk group in our health system.

"Even more concerning is the finding that people from African and Asian backgrounds face an even greater risk of dying prematurely, exposing deep-rooted and persistent inequalities.

"These are preventable deaths! With annual health checks, access to the right professionals and truly joined up person centred care plans, lives can be saved, but too often support is either inconsistent or unavailable."

Epilepsy Action has also developed a guidance on services for people with a learning disability − Step Together − and easy read epilepsy information, helpful for people with a learning disability.

By Kami Kountcheva

Medication dosing strategy for pregnant women – study

New research means doctors can use evidence-based dosing strategies for epilepsy medications in pregnant and postpartum women with epilepsy.

Research published in Neurology in January 2026 analysed dosing changes made in pregnant and postpartum women in the US between 2012-2016.

Dr Page Pennell and her colleagues used data from the Maternal Outcomes and Neurodevelopmental Effects of Antiepileptic Drugs (MONEAD).

She said: "Our goal was to generate practical evidence that empowers clinicians everywhere – from rural hospitals to urban subspecialty centres – to provide the best possible care for women with epilepsy during pregnancy.

"These strategies are based on real-world data from hundreds of successful pregnancies and can be applied in the clinic immediately."

The findings are especially important, as the MBRRACE report into maternal deaths, published in 2025, showed that epilepsy and stroke were among the top five leading causes of maternal death between 2021-23.

The Neurology study included a total of 299 women aged 14-45. It looked at their medication doses and seizures in pregnancy and six weeks after giving birth.

Around two thirds of epilepsy medications (67.8%) were increased during pregnancy. Just under half of medications (47.9%) were decreased again after the women had given birth.

Lamotrigine doses taken by the women were increased in pregnancy in nearly nine in 10 cases, (87.7%), to close to double the original dose they were taking at conception (191%), on average. By six weeks after birth, most of them (70.5%) had had their dose reduced to just over what it was originally (116% on average).

For those taking levetiracetam, more than half (56%) had their dose increased in pregnancy, reaching, on average, 177% of their original dose. By six weeks postpartum, around a third (34.4) had had their dose reduced to around 136% of the original.

The researchers concluded that these medication management strategies are why previous MONEAD studies showed no difference in seizure control between the pregnant and not pregnant groups. They added that "these findings can be useful for the management of pregnant women with epilepsy".

Tom Shillito, health improvement and research manager at Epilepsy Action, said: "This research highlights how important it is to carefully manage epilepsy during pregnancy. Changes in the body can affect how medications work, so regular monitoring and adjustments can play a vital role in keeping women safe during pregnancy.

"We have been working with midwives, obstetricians and epilepsy specialist nurses, as well as people with epilepsy, to develop guidance to support healthcare professionals in providing the best possible care for pregnant women with epilepsy. This includes guidance on monitoring anti-seizure medicines during pregnancy and in the weeks after birth, when needs can change again.".

By Kami Kountcheva

Football training

Chelsea FC has become the first top-flight club to take part in dedicated epilepsy first aid training delivered by national charity Epilepsy Action, setting a new standard for safety and inclusion in the Premier League.

Epilepsy Action carried out the landmark sessions at Stamford Bridge, equipping staff with the confidence and practical skills to recognise seizures and respond quickly and appropriately both on match days and behind the scenes.

By Lisa Greer

Discrimination at work

People with epilepsy dealing with discrimination at work will be able to use Epilepsy Action's new service in partnership with law firm Slater and Gordon.

Those experiencing problems at work to do with their epilepsy will have the opportunity to access independent legal support by calling the Epilepsy Action helpline.

This new service partners with law firm Slater and Gordon to provide specialist solicitors that can offer legal advice for those in need of additional employment support.

Mum unaware of sudden unexpected death in epilepsy until after daughter's death, inquest hears

A Dorset mum of a 22-year-old woman who died of sudden unexpected death in epilepsy (SUDEP) said in an inquest in October last year that she only became aware of SUDEP after her daughter's death.

Amber Grace Walker, who had epilepsy and attention deficit hyperactivity disorder (ADHD), died on 19 April 2023. She had a consultation with a neurologist the month before her death.

During the consultation on 8 March 2023, Amber had said no to an increase in her dose of topiramate, one of the epilepsy medications she had been prescribed. Her risk of SUDEP, and the potential that a higher dose of medication may have reduced it, was not discussed then.

Amber's mum, Amanda Walker, had attended all of Amber's appointments with her and told the inquest that SUDEP had not been discussed at any neurology appointments.

This is despite Amber having an "increased risk" of SUDEP "given her uncontrolled generalised tonic-clonic seizures that she experienced at night" (sleep seizures), the coroner's 'prevention of future deaths report' stated.

In August 2022, Amber had had a cluster of seizures, leading to a trip to the hospital, where she'd had another seizure. In November 2022, she spoke to an epilepsy specialist nurse.

In the month before her neurologist consultation, Amber had had another two seizures.

Coroner Brendan Allen outlined his concerns with the case in the report, published on 21 October, to be sent to the Secretary of State for Health and Social Care. He said:

"Doctors can be reluctant to discuss SUDEP with patients and/or presume it is a discussion that has been had at previous appointments with colleagues that does not need repeating.

"Discussions about SUDEP ensure that patients are aware of the general risks of SUDEP, the risks that are specific to the patient and the measures that can be taken to mitigate the risk."

Another concern was that "SUDEP is not covered in the medical training of doctors, despite it being the leading cause of death in patients with a diagnosis of epilepsy.

"It is not only neurologists that will encounter patients with epilepsy where a discussion regarding SUDEP may be required, as demonstrated by Amber's experience."

Alison Fuller, director of health, improvement and influencing at Epilepsy Action said: "We express our deepest sympathies to Amber's family and everyone who loved her, who had their daughter taken away by this cruel condition. We welcome the Coroner's report and strongly support the recommendation that the Department of Health and Social Care must take further action to prevent deaths from SUDEP.

"As highlighted in this case, SUDEP is the leading cause of premature death among people with epilepsy, yet far too many families tell us they were never made aware of it. It is especially worrying that Amber, who was experiencing uncontrolled sleep seizures – a known risk factor for SUDEP – was not given information about the condition or the measures that can be put in place to sometimes help reduce risk.

"Every person with epilepsy deserves clear, sensitive conversations about SUDEP so they and their loved ones can make informed choices and feel supported and safe. We support the urgent calls for a consistent national approach to ensure these conversations happen routinely in epilepsy care, backed by targeted training for healthcare professionals and available guidance to empower and support both patients and their families."

The coroner highlighted the use of tools, such as the SUDEP Checklist from SUDEP Action to help facilitate conversations between doctors and patients with epilepsy.

He called for urgent action from the Health Secretary to prevent future deaths.

By Kami Kountcheva

Budget misses mark on valproate

The Chancellor of the Exchequer Rachel Reeves announced more spending on schools, playgrounds and the NHS in her Autumn 2025 budget update in November last year, but Epilepsy Action says this was another missed opportunity to offer redress to people affected by the valproate health scandal.

Acknowledging the Office for Budget Responsibility's (OBR) gaffe in publishing its budget assessment early, the chancellor announced effective tax increases across income, national insurance, property and council tax, and a cap on pension contribution through salary sacrifice.

While measures to help with the cost of living were welcomed by Epilepsy Action, the organisation said it is disappointed that the 20,000 children harmed by the sodium valproate scandal, many of whom are living with physical, learning and mental health problems, are still waiting for support they need.

Alison Fuller, Epilepsy Action director of health improvement & influencing, said: "The Chancellor acknowledged the infected blood scandal in her budget speech, saying she is exempting all payments from the scheme from inheritance tax. So we were really disappointed to see the government miss an opportunity to address another major scandal in providing support to the many thousands of children harmed by valproate.

Some epilepsy medicines still facing supply chain issues

The government has said it is still aware of shortages affecting two epilepsy medications, but that "most issues" with medication supplies have been resolved.

In a reply to a written parliamentary question from Labour MP Tanmanjeet Singh Dhesi on 9 September, health minister Zubir Ahmed said the government was aware of continued shortages of topiramate tablets of 25mg, 50mg, 100mg and 200mg, and phenobarbital tablets of 15mg from some manufacturers.

He explained: "Resupply from the affected manufacturers is yet to be confirmed but stock remains available from alternative manufacturers to meet patient demand, and we have issued management guidance to the National Health Service."

He added: "The department is working hard with industry to help resolve intermittent supply issues with some epilepsy medications.

"As a result of ongoing activity and intensive work, including asking manufacturers to expedite deliveries, most issues have been resolved."

The seriousness of the situation has been compounded by the deaths of David Crompton and Charlie Marriage, both resulting from a lack of access to epilepsy medications.

Epilepsy Action is continuing to urge the government to "ensure an open and transparent supply chain".

By Kami Kountcheva

Patients stranded at Hywel Dda

Epilepsy patients with learning disabilities have been left stranded by the Hywel Dda University Health Board in Wales after its dedicated service ended in June 2021, the Public Services Ombudsman for Wales has found.

In a Public Interest report published in October last year, the ombudsman found that the health board did not review patients' needs in a timely manner and did not put "adequate alternative provision" in place for them.

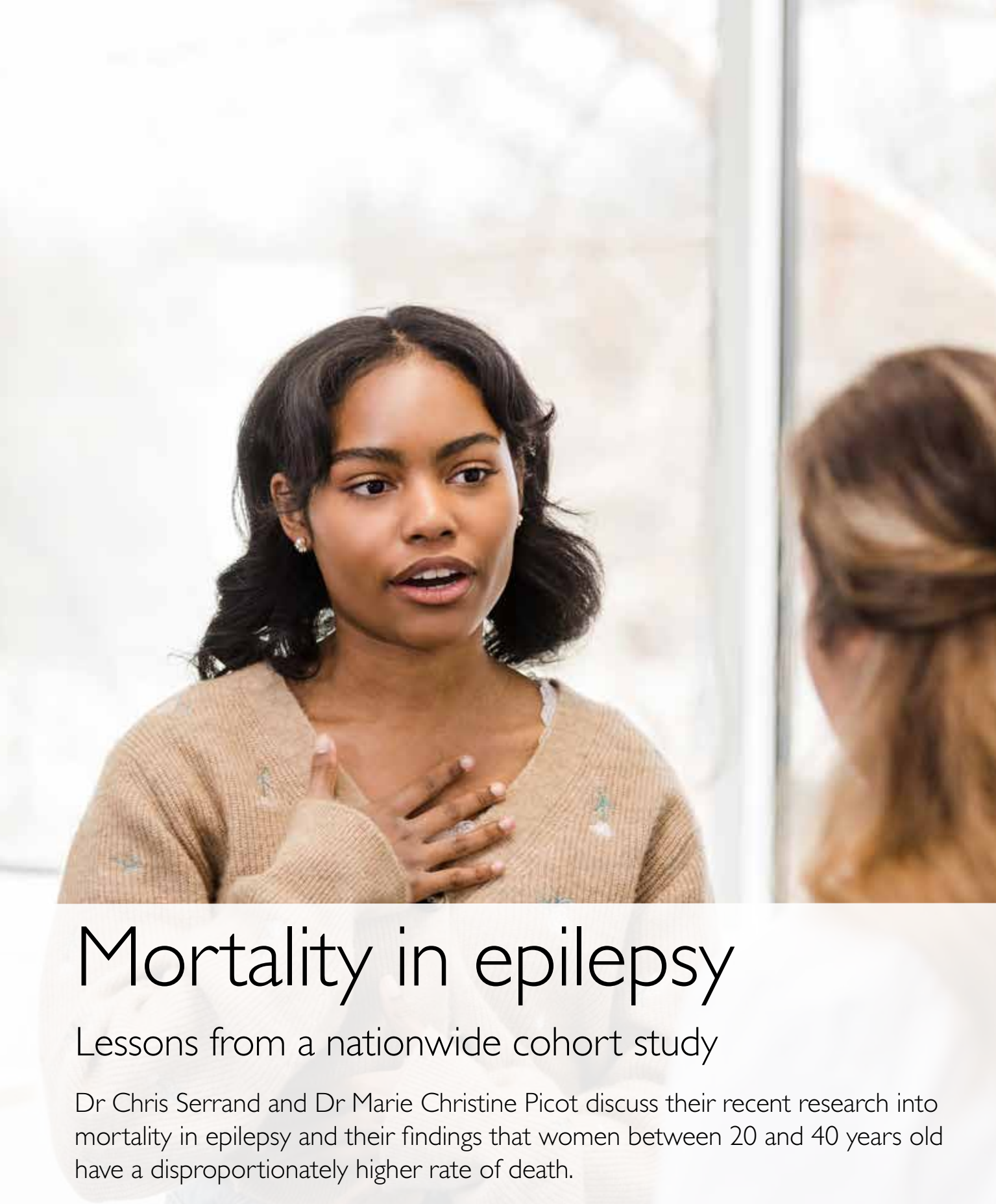
The report said the lack of service and poor communication have placed significant pressure on carers and healthcare staff.

The ombudsman launched the investigation after a complaint was made on behalf of seven parents who'd had adult children using the service. The families said the health board did not arrange ongoing care for their children after the service ended and had no clear plans in place to support patients with epilepsy and learning disabilities.

They added that many of these patients have multiple complex needs and are at a higher risk of sudden unexpected death in epilepsy (SUDEP).

Public Services Ombudsman for Wales, Michelle Morris, said: "The lack of service provision, poor communication, and slow response to complaints has caused significant distress to the seven complainants.

"This represents a serious injustice to patients and their families, and I am mindful that others may be experiencing similar failings. The Health Board must now take urgent action to ensure these vulnerable patients and their carers receive the care and support they need."



Mortality in epilepsy

Lessons from a nationwide cohort study

Dr Chris Serrand and Dr Marie Christine Picot discuss their recent research into mortality in epilepsy and their findings that women between 20 and 40 years old have a disproportionately higher rate of death.

Epilepsy remains one of the most common chronic neurological conditions, yet its impact on life expectancy is often underestimated. Recent large-scale research provides new insights into how epilepsy affects mortality, who is most at risk, and what this means for neurologists and other healthcare professionals involved in patient care. It also provides a valuable case example of how population-based research can shed light on patterns of prevalence, incidence, and treatment in epilepsy, and highlight the importance of epidemiological data.

Why mortality matters in epilepsy

Beyond seizures themselves, people with epilepsy face a significantly higher risk of premature death. Across studies, their mortality risk is two to three times higher than in the general population [Nevalainen et al, 2014; Thurman et al, 2017], with life expectancy shortened by 8–10 years on average [Dreier et al, 2023]. In some cases, particularly when psychiatric comorbidities are present, this gap can reach 16 years. These deaths occur for many reasons. Some are directly related to seizures, such as sudden unexpected death in epilepsy (SUDEP), status epilepticus, or accidents during seizures. Others are indirectly linked, such as aspiration pneumonia, injuries, or the adverse effects of anti-seizure medication (ASM). Psychiatric comorbidities, including depression and suicide, also contribute significantly. For clinicians, this raises two pressing questions: how can we better quantify the excess mortality in epilepsy, and how can we intervene to reduce preventable deaths?

Women had a higher rate of excess mortality than men, even though men generally had more deaths in absolute terms

Answers from a nationwide cohort study

We set out to answer these questions using the 'Système National des Données de Santé' (SNDS) [Tuppin et al, 2017]. This administrative database covers the entire French population and includes combined information from hospitalisation records, medication dispensations, and mortality data. It offers an unprecedented opportunity to track healthcare use and outcomes over time. Here, we focused on adolescents and adults aged 12-60 years with evidence of epilepsy, between 2009 and 2019. This resulted in a cohort of nearly 620,000 people with epilepsy.

What did the study find?

By 2019, epilepsy prevalence in France was estimated at 11.7 per 1,000 persons, slightly higher than previous national estimates. Participants were followed for a median of 8.5 years, providing robust long-term data. Overall, people with epilepsy had a mortality rate of 9.6 deaths per 1,000 patient-years, more than three times higher than the

general population. Women had a higher relative excess mortality than men, even though men generally had more deaths in absolute terms.

The highest excess mortality was observed among young adults. Between ages 20 and 40, people with epilepsy were six to seven times more likely to die than their peers without epilepsy. Strikingly, young women were disproportionately affected: women aged 20-40 had up to 11 times higher risk of death compared with women in the general population, while men of the same age had around a sixfold increase. This finding challenges the traditional expectation that men face higher mortality risks than women. In the general population, young men have death rates about twice as high as women. But among people with epilepsy, the male–female gap narrows considerably, meaning that the relative disadvantage for women with epilepsy is much greater.

When looking at epilepsy-related deaths (status epilepticus, aspiration, drowning, falls, or unexplained sudden death), this accounted for around 10% of all deaths. And while SUDEP could not be clearly explored in such administrative database, approximation of possible SUDEP cases, using available ICD-10 codes, found an incidence of 0.5–1 per 1,000 person-years, somewhat lower than in previous clinical studies but consistent with the limitations of administrative coding.

What does this mean for clinical practice?

1. **Mortality risk must be part of the conversation**
   Neurologists and epilepsy specialists are often focused on seizure control and medication management. But this study reminds us that mortality risk is a central part of the epilepsy burden. Discussing risks openly with patients and families – while also stressing that some deaths are preventable – can empower them to make informed decisions.
2. **Special vigilance for women of childbearing age**
   The finding of particularly high excess mortality in women aged 20-40 should alert clinicians to the unique challenges faced by this group. This could be explained in part by suboptimal treatment due to concerns about ASM teratogenicity in pregnancy, poorer seizure control linked to under-treatment, but also risk associated with hormonal changes. This could also simply highlight a lesser resilience to overall risk of death in women with epilepsy compared to the general population. In any case, neurologists should balance teratogenic concerns with the risks of uncontrolled epilepsy, ensuring shared decision-making and close monitoring.

Women aged 20-40 had up to 11 times higher risk of death compared with women in the general population

3. **Psychiatric comorbidities cannot be ignored**
   The study also highlights the excess risk of suicide, especially in younger women. This reinforces the need for routine screening for depression and anxiety, collaboration with mental health professionals, and proactive management of psychiatric symptoms. Integrating mental

health care into epilepsy services seems more relevant than ever.

What does this mean for future research?

While this study [Serrand et al, 2025] provides some of the most comprehensive national data to date, it also raises new questions. The increase of risk in women needs to be explored and understood. Why do women face such high relative mortality in young adulthood? What role do pregnancy, hormonal influences, and treatment restrictions play [Eadie, 2021; Fu et al, 2024]? A question especially arises regarding certain ASMs used instead of valproate. Could different drugs be linked to change in the mortality profile? Future work should combine big data approaches with clinical registries to explore these questions.

Conclusion

This study confirms what many clinicians suspect: people with epilepsy face a markedly higher risk of premature death, with mortality rates around three times those of the general population. What is new, and particularly striking, is the magnitude of excess mortality in young women, who lose much of the natural survival advantage usually seen in women of the same age. Work is still needed to refine our understanding of epilepsy-related deaths, particularly SUDEP, and explore how treatment strategies may influence outcomes, to ultimately bridge the survival gap between patients with epilepsy and the general population.

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Further reading

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Action bias in surgery

Operating on seizures or soothing our nerves?

Prof Sallie Baxendale discusses the reasons why patients and clinicians might persist with treatments that are not only ineffective but even harmful – and how to tackle this issue.

Throughout history, people have repeatedly endured, and fiercely defended, treatments that make their condition worse. Bloodletting, mercury treatments and other notorious practices reveal a recurring but puzzling pattern in medicine: people rarely abandon a treatment because it is ineffective or even harmful. They only abandon it when something better comes along. Understanding why patients and clinicians persist with treatments that offer limited benefit, or even potential harm, is essential for improving clinical decision-making and safeguarding patient outcomes. This article examines some of the common psychological mechanisms that perpetuate ineffective and harmful treatments and reflects on how these dynamics may shape contemporary approaches to managing treatment-resistant epilepsy.

Why do patients persist with ineffective or harmful treatments?

It is tempting to view people who continue ineffective treatments as lacking in insight or being misinformed. But the motivations behind these decisions are a fundamental part of the human psyche and rooted in well-described psychological phenomena.

1. **Fear of inaction**
   Living with an uncontrolled condition creates understandable anxiety and helplessness. Doing nothing can feel intolerable. Taking action provides a sense of agency, even if the action is unlikely to lead to improvement. In this context, 'try anything' becomes a coping strategy, not necessarily a rational medical decision.
2. **Effort justification**
   In their quest to 'try anything', people often invest considerable time, emotional energy and hope in pursuing a new treatment. This can lead to effort justification – a type of cognitive dissonance in which individuals convince themselves that a treatment must be doing good simply because it has been a long road to obtain it. In chronic and difficult conditions like drug-resistant epilepsy, the desire for a treatment to be effective can eclipse the absence of objective evidence of efficacy. While the cold hard numbers representing seizure frequency might not change, people may convince themselves that the duration, recovery time or overall subjective experience of the seizure might be a bit better. Horrible side effects and even an exacerbation of symptoms may paradoxically be interpreted as a sign that the treatment is 'doing something'. This is often combined with the erroneous belief that things must get worse before they get better, reinforcing continued engagement with a treatment that really isn't helping.
3. **Trust in authority**
   Patients often persist with ineffective, or even harmful treatments because they place significant trust in medical authority. When a doctor recommends a treatment, frames it as the best available option, or expresses confidence in its potential, patients tend to internalise that optimism. This trust can override their own doubts or negative experiences. Additionally, many patients feel uncomfortable challenging or disappointing their doctor. The power imbalance in clinical settings, combined with the

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Sallie Baxendale

patient, can make it difficult for them to voice concerns or discontinue a treatment. As a result, they may persist long after it is clear that a treatment is ineffective, simply because they believe the doctor knows best, or worry about appearing ungrateful, difficult or noncompliant.

Why do clinicians continue offering ineffective treatments?

Patients' biases are only part of the story. clinicians' own assumptions and optimism also play a critical role in perpetuating ineffective or harmful treatments.

1. **Authority bias and tradition**
   Established practices carry significant momentum. If a treatment is part of 'how things are done' within a specialty or institution, clinicians may continue to recommend it without reassessing the evidence. In addition, the authority of mentors, senior colleagues, or institutional culture exerts a powerful influence in perpetuating practice.
2. **Confirmation bias**
   Clinicians often recall rare success stories more vividly than the many non-responders who were never expected to benefit in the first place. This can create a distorted perception of efficacy. When the clinical picture is ambiguous, clinicians may interpret borderline findings as supportive of their recommended treatment pathway.
3. **Action bias**
   Action bias often comes into play in clinical situations where the patient's situation is desperate and other clinical options have been exhausted. As a patient's seizures worsen and their life become increasingly impacted, clinicians feel increasing pressure to intervene, often with an unspoken belief that an imperfect treatment is better than none.

Action bias and the illusion of a 'lifesaving' intervention in epilepsy surgery

Clinicians, patients and their families understandably feel an urgency to do something when seizures are frequent, profoundly disabling and life-threatening. The spectre of sudden unexpected death in epilepsy (SUDEP) can make surgery appear a reasonable option, even in a 'bad' surgical candidate. When surgery is framed as 'lifesaving', the multidisciplinary team begins to view it less as an elective procedure and more as an intervention justified by clinical urgency, shifting the usual risk-benefit calculus. However, when viewed through absolute risk reduction (ARR) and numbers needed to treat (NNT), the 'lifesaving' rationale for surgery for these candidates is not always supported by the evidence.

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A central issue is the mismatch between group-level statistics and individual-level benefit. At the population level, epilepsy surgery is unquestionably effective in reducing

mortality: postoperative mortality rates fall dramatically in those who become seizure free, with all-cause mortality dropping from 11.33/1000 person years to 2.5/1000 person years and SUDEP rates falling by more than 80% [Baxendale et al, 2025]. However, these group averages conceal significant variability in individual probabilities of achieving seizure freedom, and important differences in postoperative mortality for those who continue to experience seizures.

With a 20% chance of seizure freedom following surgery, 178 person years of treatment are needed to prevent one all-cause death, and 264 person years to prevent one case of SUDEP. Even at a 50% chance of postoperative seizure freedom, 146 and 243 person years are needed respectively [Baxendale et al, 2025]. These figures reflect a fundamental truth that action bias obscures: most individuals undergoing surgery, particularly poor candidates, will not personally experience a mortality benefit, even though the group-level statistics look encouraging.

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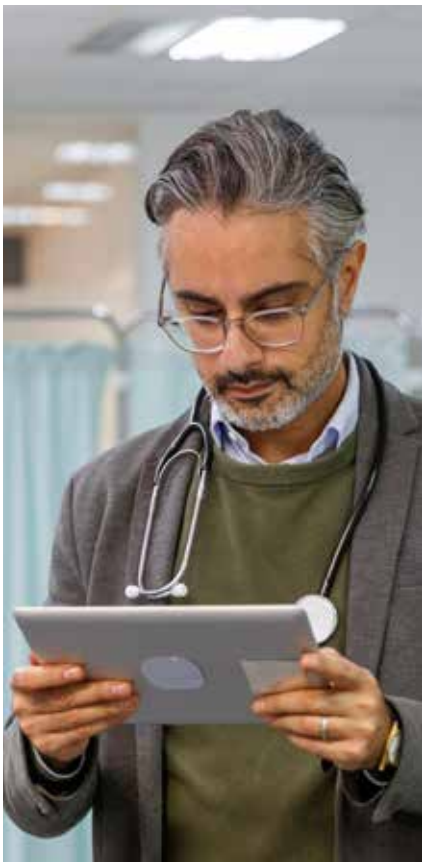
In the context of a significant overall postoperative reduction in seizures, mortality may actually increase in patients who continue to have two or more generalised tonic-clonic seizures (GTCS) per year. Sperling et al report an all-cause mortality of 15/1000 person years in patients who continued to have >2 GTCS per year after surgery [2016]. Compared with the weighted average of 11.3/1000 person years in unoperated patients, this suggests that surgery may increase mortality in those with persistent GTCS despite reduced overall seizure frequency. The number needed to treat may tip into a number needed to harm in this group.

For the individual patient, the relevant question is not "Does surgery reduce mortality in the population?", but rather: "Given this patient's probability of seizure freedom and expected postoperative seizure pattern, what is the likely impact on their mortality risk and quality of life?"

Ultimately, countering action bias requires a disciplined adherence to probabilistic reasoning and person-specific risk assessment. Patients and clinicians must be supported to navigate the emotional weight of life-threatening epilepsy without defaulting to the intuitive but often misleading belief that surgery is inherently 'lifesaving'. By grounding decisions in transparent NNT and ARR estimates, distinguishing population-level benefit from individual likelihood of harm or improvement, and openly acknowledging when surgery cannot meaningfully alter a patient's mortality risk, the multidisciplinary team can promote choices that are informed rather than reactive. This reframing does not diminish the value of epilepsy surgery, but rather aligns its use with realistic expectations, ensuring that intervention is pursued for the right reasons – and not as a reflexive response to fear, urgency or the illusion that doing something is always better than doing nothing.



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Further reading

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ILAE British Branch ASM 2025

A round up of some key sessions from the congress

Tom Shillito, health improvement and research manager at Epilepsy Action and Kami Kountcheva, editor at Epilepsy Action, share an update on a few of the sessions from the ILAE British Branch Annual Scientific Meeting, discussing epilepsy and dementia, functional dissociative seizures and seizures during sleep.

The International League Against Epilepsy (ILAE) held its British Branch Annual Scientific Meeting in Bournemouth in September 2025, bringing together researchers, health professionals, organisations and industry leaders to share learnings, ideas and innovations.

We share a few highlights from the congress.

ILAE British Branch President Dr Rhys Thomas welcomed attendees before opening the floor to the speakers in session one, discussing epilepsy and dementia.

Dr John Baker from Guy's and St Thomas' NHS Foundation Trust, presented on epilepsy and memory. Dr Baker explained that memory can be affected by epilepsy in different ways, including by the seizures themselves, by the underlying cause of epilepsy, by epilepsy medications, and by the psychosocial effects of the condition.

Epilepsy is linked to structural changes in the brain, such as changes to the hippocampus volume, which can impact memory, he explained. As well as that, some of the causes of epilepsy, such as damage, infection and genetic causes, can also cause problems with memory. Dr Baker said one of the aspects that has the biggest impact on memory is polytherapy, but that monotherapy can also impact memory. Levetiracetam appears to show the least impact on memory. He added that cenobamate is also showing promise, but more research is needed.

In terms of management, Dr Baker said getting patients to see a neuropsychologist can help them to understand and treat memory problems. He said it's important to make it clear to patients that memory problems may not go away and are a part of epilepsy, but they can be managed. Optimising treatment is an important step in reducing memory problems, as well as ensuring early referral for surgery for suitable candidates.

Next, Prof Matthias Koepp from University College London (UCL) spoke about epilepsy and neurodegeneration. He said the link between epilepsy and dementia is complicated and can be that one condition causes the other or that they both have a common cause.

He explained that dementia affects the blood brain barrier, meaning it can affect the way that anti-seizure medication can be taken up by the brain. He also added that people with epilepsy have more loss of cells in the brain than people without epilepsy, which could be why epilepsy and dementia are linked.

Still on the subject of medication, Prof Arjune Sen from the University of Oxford's Centre for Global Epilepsy went on to share more about trials of anti-dementia medications in epilepsy and new opportunities that may be on the horizon. He shared that some research has suggested that levetiracetam can help with some elements of dementia, such as executive function and spatial memory in Alzheimer's disease, but there hasn't been evidence to show dementia treatments having a beneficial effect on epilepsy.

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Functional (dissociative) seizures

Dr Mahinda Yogarajah from UCL kicked off the second session discussing functional (dissociative) seizures, by discussing advancing diagnosis methods with novel neurobiology markers in functional versus epileptic seizures. He said about 30% of functional seizure cases don't have a cause, and a third of the seizures aren't motor.

He said the experience is a person's consciousness separating from their body or alternatively being too in their body and noticing too much of what the body is doing. The experience could also be both of these things at the same time, he explained. Patients often feel better emotionally after a functional (dissociative) seizure than before it.

Next Dr Krishna Chinthapalli from UCL spoke about morbidity and mortality from functional (dissociative) seizures, sharing that there has only been one documented death because of functional (dissociative) seizures. However, he explained that around 80% of people who experience functional (dissociative) seizures have prolonged seizures, and 25% of them end up in ICU because of them.

Dr Chinthapalli also added that around 8% of status epilepticus is misdiagnosed and is actually functional (dissociative) seizures, with many people ending up with unnecessary interventions, such as intubations, due to the misdiagnosis.

People with these types of seizures are often prescribed antidepressants and opioid painkillers.

He added that the mortality rate in people with functional (dissociative) seizures is slightly higher than in the general population, but the reason is not well understood. He suggested it could be due to suicide, drug use or medications, comorbidities or lower socioeconomic class.

Dr Chinthapalli suggested making sure to manage any chronic pain, reduce the number of medications where possible, openly discuss suicidal ideation and helping patients feel like their challenges are recognised.

Finally, Prof Markus Reuber presented on managing patients with functional (dissociative) seizures. He started by reiterating that it's important for health professionals to understand functional (dissociative) seizures.

He explained that more than half of patients with these types of seizures will have a recollection of either a part of or their whole seizure, or be able to respond during it, however, they often won't tell their doctor unless they trust them. It's key to have the trust of your patients, so must be cautious not to give the impression you are accusing them of faking their seizures.

Prof Reuber added that if a patient has a functional (dissociative) seizure, it's important not to hurry the process, as it will resolve in time. While epileptic seizures can cause damage if they continue too long, functional (dissociative) seizures won't lead to extra damage, if the person is not in danger of injury. He said not to administer benzodiazepines, as they won't help or stop the seizure.

He advised that doctors speak to the patient, and ask their consent to refer them to psychiatry, even though many continue to be looked after in neurology.

Prof Reuber shared his Dos and Don'ts:

Do:

- **C**hange the environment. Make the patient safe and reduce onlookers.
- **A**ddress the patient by name and tell them what's happening.
- **R**eassure the person and onlookers that the functional dissociative seizure won't harm them and will stop.
- **E**ncourage the patient to focus

on breathing or on one body part to help them regain control of their body

Don't:

- Hurry. If the seizure gets worse, step back and wait.

He recapped that after a functional (dissociative) seizure, doctors should reassure the patient that you believe that their seizure is real and you know they're not faking it, name the condition clearly and be honest with the diagnosis. They should put together a seizure action plan and follow-up with the patient and refer them to psychology if they want this.

Mini reading list

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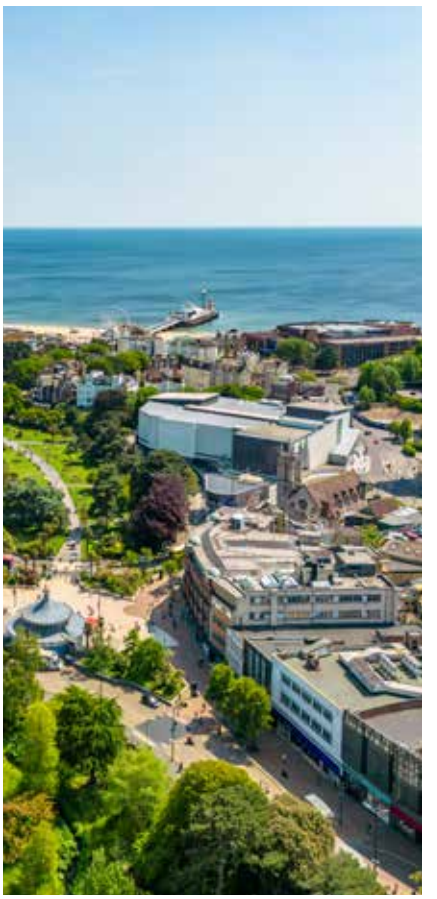
Seizures detection devices

Finally, Prof Hannah Cock from St George's University Hospitals NHS Trust spoke about seizure alerts and alarms. She shared a summary of some devices and their sensitivity. She said there are a lot of false alarms with these devices, which are usually false positives (alarms reporting a seizure has occurred when it has not). Current research suggests these devices don't help particularly with people's quality of life and it is unclear whether they're helping to protect people from sudden unexpected death in epilepsy (SUDEP).

There are also a number of issues with these devices from a patient's perspective, Prof Cock shared. Their cost could be prohibitive, ranging from several hundred to thousands of pounds. Wearing a visible medical device can make people feel more conspicuous, and may lead to experiencing more stigma. It can feel intrusive for people to be monitored or have people checking in on them all the time. From a safety perspective, alerts and alarms are only really helpful if there is someone nearby who can quickly respond to an alarm.

Other challenges include battery life durability, reliable wifi access, and lack of integration with the healthcare systems. She advised that if health professionals are recommending these devices they should be honest and clear that data is a bit mixed about their usefulness, and while it could be reassuring it's not clear if they helps with things like SUDEP. It is also important to be clear that these devices are for people who are generally unsupervised but have someone nearby who can quickly check on them if needed.



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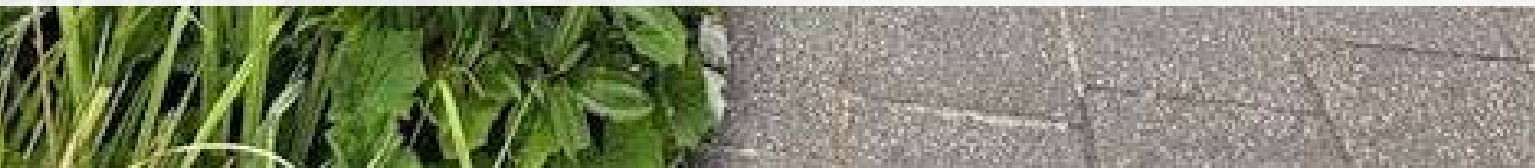
SEEG diaries

What it's like from the hospital bed

Epilepsy Action trustee Nic Adamson shares her diary from her recent stereo EEG detailing her experience from a patient point of view



Nic Adamson, Epilepsy Action trustee and former NHS employee, had a stereo EEG in 2025. She worked in Manchester Children's Hospital as strategy director until her focal seizures became too many and their aftermath too difficult for Nic to manage. She decided to leave her beloved job, and a few years later had to give up work completely, which, although difficult, opened the door for her to pursue the option of brain surgery.

The first step was an SEEG to try to locate the focus of her seizures. From starting the process, Nic's surgery was postponed three times, leaving her waiting and uncertain when and if this would happen for the best part of six months.

She shares her honest experience of this much anticipated but also long and tiring experience.

Thursday, 26 June

Today's the day! Went to surgical admissions reception. At 06:45 there was a long queue to check in. We were sent to the waiting area. At this point my husband Jay had to leave as relatives couldn't stay.

I had checks and met the anaesthetist. Had a surgeon go through consent, bloods, blood pressure. Then changed into hospital gown and stockings. Was asked to keep belongings including dressing gown in a bag and walk to theatre with blanket over shoulders.

I was allowed to keep on own underwear as I had worn a bra that wasn't underwired.

In theatre, I was given oxygen and felt woozy, cannula took a few attempts to get in (I agreed to let a lovely 4th year medical student do it) then I was off to sleep.

Don't recall much of first night or recovery area other than there being lots of frequent checks and feeling sick a lot.

Friday, 27 June

I had a urinary catheter in place which wasn't removed until this morning. Once removed, I was allowed to get washed and changed into own pjs and then porter was booked to take me to the acute neurology unit (ANU)… but that was a long wait! In the end Jay arrived, found a wheelchair and took me instead. I felt a bit unsteady but had no pain.

On ANU, the 13 wires from my brain were attached to a machine with a bag (quite heavy) to carry over shoulder all the time.

I'd planned to reduce sleep as tiredness is often a trigger for me, but my body had other ideas, and I couldn't stay awake all afternoon after six hours under general anaesthetic yesterday!

We decided to reduce epilepsy medication from day one as they take a while to get out of my system. My last seizures were a couple of days before the sEEG operation.

By 10pm I was ready for bed.

Saturday, 28 June

Was woken at 5am by staff changing water jug, then nurse did observations at 6am. (This was same every day of stay).

I felt as you would imagine sleeping with a big uncomfortable 'blanket' around my head.

I feel a bit nauseous and tired still. Hospital food is not nice, so not eating much.

Getting dressed and washed, even though showers aren't possible, made me feel a bit more human. I'm on camera 24/7 but there's an en-suite toilet and sink which is private, although if in there more than two minutes, someone comes to ask if you are okay.

No seizures yet, which is annoying, but apparently there is some activity showing in hippocampus area of brain.

Sunday, 29 June
Another night of lots of sleep and no seizures. Very frustrating. I just want to sleep all the time. Guess the general anaesthetic took its toll.

Managed to pass the time but a very, very long day. Feel like I've been here a long time and really miss my family and home.

Monday, 30 June
Managed to stay awake until midnight and pretty sure I had focal seizures overnight. Waiting to find out from staff if it's shown anything in the data.

Been told six seizures captured so far – great news!

Stimulation mapping this afternoon has shown some areas of interest on left hippocampus and a bit on right (from what I could understand!) All seizures have been from left.

At one point, one of wires caused a brief popping type shock sensation – not painful, but unpleasant. They promised me I didn't need to worry about it.

I'm asked to take some clonazepam tonight to calm down seizure activity. A relief, as it's been a tough 24 hours and I was getting anxious about sleeping and having big tonic-clonic seizures.

Tuesday, 1 July
It's very hot here today. Been 29°C with four clinicians in my room all afternoon. The bandages are like wearing blankets on your head. Hot!

Think I've got to about 10 seizures in the last 24 hours. The trigger sensations session today was at higher frequency, so triggered a focal seizure and took me about seven minutes to be fully able to talk, so they gave me some IV medication.

At home, I'd cuddle up on the sofa, take my meds and get hugs from family. Here it feels far more clinical. Staff are very kind, but I feel like an experiment. Able to take half a clonazepam again tonight so hopefully that will allow some sleep.

Wednesday, 2 July
No seizures overnight and slept well. Such a relief!

Feel anxious and fragile, as I did yesterday, but perhaps not quite so unmanageable. Jay is visiting today, he's managed to get a day off work. Can't wait for a hug!

Another few hours of stimulation testing. By end of session was told they've captured about 12 seizures. Lots of epilepsy activity in left hippocampus! Jay was with me for first half of stimulation and bought lunch for me too.

Thursday, 3 July
Today's memory testing involved being given words or shapes to recall. They stimulated different bits of brain either when remembering or trying to recall the word or images.

Finding it tough. Felt emotional and tired and miss my family so much. Just want to be home but I know I've got to tough this out for a few more days. They've lots of data, but they ideally want some tonic-clonic seizures to see how they spread.
Nurse has promised me there will be someone watching me tonight and ready with rescue meds if I need them.

Friday, 4 July
Despite getting stressed, staying up until after midnight and having no epilepsy meds, I had ZERO seizures last night on five or so hours' sleep. Very frustrating!

Can't be bothered getting dressed today (for first time). Just going to stay in PJs.

Continued feeling very emotional all day and then late afternoon had what I think is a focal seizure where my face twitches. Feel very tired but

like my emotions are reset. Often feel better after those ones.

Saturday, 5 July
Very tired, and fragile and headachy this morning. Couple of seizures this morning.

This afternoon was wonderful with a family game of scrabble and home cooked food brought in for me too. A lovely afternoon that has really helped me.

Consultant popped in to see me and explained that all my focal seizures are originating from the left hippocampus. They are going to explore if laser surgery rather than ressective could be a less risky treatment for me.

Sunday, 6 July
Bandages have slipped backwards over the week, but now getting to point where two screws securing a wire are almost exposed from underneath and are getting sore. Will have to see if someone can fix it.

Times like this, I think being autistic makes the unclear plan to fix things more stressful. Also been promised a plan (yesterday evening) to restart medication this evening but still nobody knows whether I need to build the dose back up or just go straight back into normal dose.

Update: Extra padding has been taped over top of bandages to protect things. Nurse doing medicine round this evening said I'll go back to my usual medication dose.

Monday, 7 July
Restarting meds is helping with seizures. Feeling very positive about how it's all gone. Counting the minutes until I'm home tomorrow. Also can't wait to have the wires out – the itching is driving me mad!

I'm packed for home! Not seeing the sky (windows are tinted) for nearly two weeks, or being able to leave this one room, has been tough. But, worth it.

Tuesday, 8 July
Woke early, about 5:30am, nervous and excited about the day ahead.

Around 8:30 the team arrived and initially did more stimulation of different areas to get a 'before' picture. Then they undertook the radiothermal ablation procedure, in which parts of left hippocampus were temporarily disrupted using a high electric charge. Wanting to see how it disrupts seizures over next couple of months. All I felt was a very loud pop that made me jump.

Later that afternoon, I was taken to theatre to be put to sleep whilst the wires were removed.

After waking up in the recovery area I was taken back to the ward where I was able to eat my dinner and then Jay arrived and drove me home.

I was on morphine from post theatre, so when that wore off, I needed some paracetamol at bedtime.

I was told not to wash hair or allow it to get wet, not to touch it at all, for the first week home.

Today
The ablation treatment temporarily stopped my seizures – for nine weeks! But now I'm back to about four a week. This helped confirm the seizure onset location was the left hippocampus.

Due to it being in the dominant side of my brain, though, surgery isn't an option for me. But I have been referred to the Walton Centre in Liverpool to discuss laser interstitial thermal therapy (LITT).

However, the temporary ablation also caused me to be very emotional and not feel like myself in the first few weeks, so I need to understand what side effects the LITT treatment might have and decide if it's right for me.

Markus Reuber

Highlights

Top picks from *Seizure*

Editor of the journal *Seizure*, Professor Markus Reuber highlights his key papers from the latest editions

While many people with epilepsy may still not have been made aware of the risk of Sudden Unexpected Death in Epilepsy (SUDEP) [Watkins et al, 2024], the fact that epilepsy is associated with an increased risk of premature death should be well-known to all clinicians involved in the care of people experiencing epileptic seizures. Indeed, an umbrella review of mortality linked to epilepsy reported median standardised mortality ratios (SMR) across all people with the condition of 2.2-3.4, with higher rates in African studies (median SMR 5.4), studies focusing on children (median 7.5) and on "epilepsy-related causes" including alcohol, drowning, pneumonia, and suicide (median SMR 3.8). While there is conflicting information about the relative frequency of more immediately seizure-related causes of death across the age range, it is clear that, together with drowning and status epilepticus, SUDEP features in the list of the five most common causes [Mbizvo et al, 2019], and that it is the leading cause of epilepsy-related mortality in young people with epilepsy [Kløvgaard et al, 2022].

Sudden Infant Death Syndrome (SIDS), a scenario defined as death in a seemingly healthy infant younger than one year of age whose death remains unexplained after a thorough case investigation including a complete autopsy, review of medical and clinical history, and death scene investigation, is a scenario which is so often discussed in the general media that the concept is well-recognised beyond the professional healthcare community [Duncan and Byard, 2018]. In contrast, the topic of Sudden Unexpected Death (SUD) in older children, adolescents and adults across the age has received considerably less attention.

My editor's choice from volume 131 of Seizure is a study by Marie Kroman Palsøe at al. which used the Danish National Patient Registry to identify a large group of individuals above the age of one whose deaths had been classified as SUD and which compares the circumstances of death in those with and without epilepsy [Palsøe et al, 2025]. The study drew on the recorded demographic and circumstantial information, data capturing comorbidities, autopsy findings, postmortem toxicology, and prescriptions. The first important finding of the study, that 18% of the 477 SUDs reports they found occurred in individuals with epilepsy, highlights the prominence of epilepsy as a factor when death occurs unexpectedly. Compared with SUDs without epilepsy, SUDEP was more frequently unwitnessed (93 % vs. 75 %, $p < 0.001$), had occurred in those living on their own (56 % vs. 42 %, $p = 0.018$), and those with psychiatric comorbidities (36 % vs. 19 %, $p < 0.001$). In contrast, subdiagnostic structural cardiac pathology was found less often in those with epilepsy (7.1 % vs. 22 %, $p = 0.002$). Individuals classified as having died of SUDEP were more likely to have been prescribed proarrhythmic drugs (88 % vs. 29 %, $p < 0.001$) compared to SUDs without epilepsy (most of these drugs were antiseizure medications).

The appropriate management of epilepsy cannot be limited to the control of seizures

While the phenomenon that SUDEP is more common in those living and sleeping alone has been described previously [Sveinsson et al, 2018; Lamberts et al, 2012], this study highlights a number of factors which potentially contribute to the risk of SUDEP and which may be amenable to modification, such as improvements in mental health treatment for patients with epilepsy, minimisation of pro-arrhythmogenic antiseizure medication or the use of seizure-detection and patient alerting devices.

Managing comorbidities

The appropriate management of epilepsy cannot be limited to the control of seizures — epilepsy interacts in complex ways with a range of comorbidities which make important contributions to the disability and distress attributable to the seizure disorder, and which also contribute to the elevated risk of premature death associated with it. My

editor's choice from volume 132 of Seizure is a study by Faught et al. describing the range of comorbidities of epilepsy in a cohort of 78,714 patients first receiving treatment for epilepsy with an antiseizure medication and a subgroup of 64,031 patients eventually receiving a third antiseizure medication (and therefore likely to have refractory epilepsy) [Faught et al, 2025].

The fact that a new diagnosis of epilepsy is associated with an increased risk of premature death has been confirmed in several studies. For example, a Korean nationwide incident cohort (138,998 people with newly treated epilepsy, mean follow-up ~4.8 years) found a standardised mortality ratio (SMR) of 2.25 (95% CI 2.22–2.28) compared to the general population. The risk was elevated even among those on monotherapy (SMR 1.56) and was increased by a factor of five (SMR 4.93) in polytherapy (≥ 4 antiseizure medications) [Moon et al, 2023]. Especially in older patients the increased mortality observed after a first diagnosis of epilepsy is affected strongly by comorbidities. In a study of US Medicare recipients aged 65 or above, the hazard of death increased with number of different comorbidities (per 1-point increase: AHR 1.27, 95% CI 1.26-1.27) [Blank et al, 2021]. The authors of a Danish cohort study estimated that people with epilepsy lose on average 8–12 years of life compared to the general population – but that they are likely to lose 13-16 of life if they have epilepsy and psychiatric comorbidity [Dreier et al, 2023].

The study by Faught et al. adds to our understanding of the interaction of epilepsy and comorbidities by comparing cohorts of patients whose seizures were controlled on the chosen first or third ASM and those whose seizures were not controlled. The commonest comorbidities in all subgroups included mental health disorders, hypertension and metabolic disorders (high cholesterol or obesity). The risk of developing a new comorbidity was generally higher in uncontrolled than controlled epilepsy. This either suggests that uncontrolled seizures contribute to the risk of developing these conditions or that the comorbidities are a marker of more severe or refractory epilepsy.

History of Lennox-Gastaut syndrome

The history of medicine is not one of continuous objective progress. Alongside the path of discovery of new scientific facts and methods runs a parallel track of interpretation, definition and classification. These two paths are closely related and usually head in the same direction, but they are not the same. My editor's choice from volume 133 of Seizure is a paper by Philippe Gélisse et al. [2025], which traces back both tracks in relation to Lennox-Gastaut Syndrome (LGS), a developmental epileptic encephalopathy which is a particularly good example of how a historical interaction of methods, facts and interpretations have shaped current thinking.

Notably the team of authors of this fascinating account of the development of the concept of LGS includes one of the individuals involved in its initial characterisation in 1966: the recently deceased Charlotte Dravet [Gastaut et al, 1966]. Of course, LGS was as little "discovered" as America or the source of Nile. The phenotype of this syndrome typically presenting below eight years of life with multiple seizure types (especially tonic seizures), diffuse slow spike-wave and paroxysmal generalised fast activity in the EEG and cognitive impairment (not always evident at onset) is likely to be as old as mankind.

Indeed, some characteristic features were described by Tissot in 1772 and Gowers in 1885 [Tissot, 1772; Gowers, 1885]. However, the recognition of LGS as a diagnostic entity required the invention of machines capable of capturing EEG activity (by Berger in 1929) [Berger, 1929] as well as the description of the typical slow spike-wave EEG pattern by Gibbs (in 1939) [Gibbs et al, 1939], and the observation that multiple seizure types (especially tonic seizures), EEG patterns and intellectual disability are often associated in an age dependent fashion. This "discovery" was first made by Lennox and Davis (in 1950) [Lennox and Davis, 1950] and subsequently by Gastaut et al. (in 1966) [Gastaut et al, 1966]. The bundling of features and nosology of LGS, most recently as a developmental epileptic encephalopathy, very much involved the second track described above. Given that LGS is a syndrome with many different aetiologies and a broad range of clinical outcome, it sits awkwardly in the current aetiology-oriented classification of the epilepsies. As such, the latest definition of the syndrome may not be the last. Especially in view of how our thinking about this disorder may develop in the future, it is important that those involved in debates about this syndrome are aware of its past.

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Support services

At Epilepsy Action we offer a wide range of supportive services for people living with epilepsy, designed to complement clinical care and help patients feel informed, connected and supported. Our services include:

- **Helpline** – providing trusted information, advice and emotional support via telephone, webchat and email.
- **1:1 peer-to-peer support** – a befriending service offering a regular weekly chat with a trained volunteer by phone or video call.
- **Peer-to-peer support groups** – virtual and in-person opportunities for people to connect, share lived experience and feel less alone.
- **Accredited information** – reliable, up-to-date epilepsy information available through our website.
- **Patient Support Programme (PSP)** – delivered in partnership with Angelini, where a trained adviser provides personalised wellbeing and medication support.

Our services can make a real difference to patients' confidence, wellbeing and self-management. Below is a case study from one of our Patient Support Programme users, demonstrating the positive impact this support can have.

If you have patients who may benefit from additional support alongside their clinical care, please feel free to share our details with them or refer them directly using this form Support for you form - Epilepsy Action

Case Study: How the Patient Support Programme Helped Caroline Feel Confident About Medication Change

Caroline (name changed to protect identity), 56, has lived with drug-resistant epilepsy since childhood. She experiences focal seizures that occur in clusters several times a month. Recently, her neurologist recommended trying a new medication. Although hopeful, Caroline was worried about the potential impact of any changes—particularly the risk of increased seizures or side effects that could affect her ability to continue working full-time. Taking time off sick simply wasn't an option she could afford.

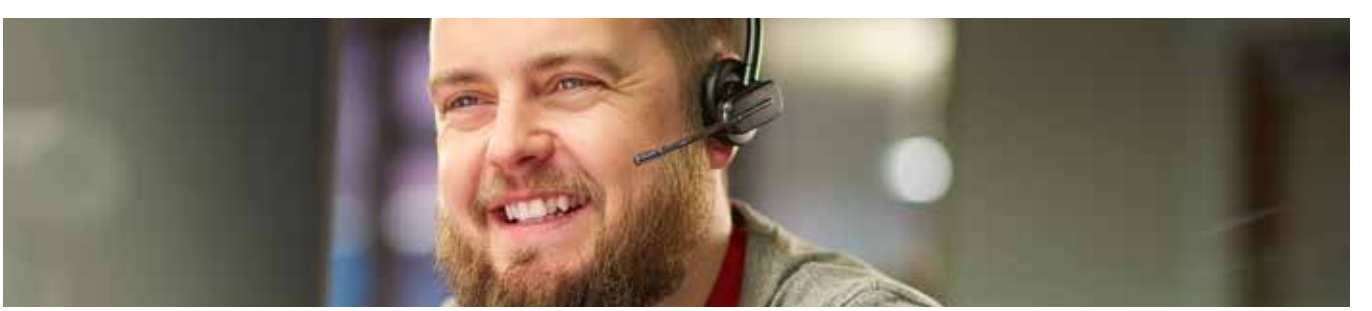
At a time when contacting her Epilepsy Specialist Nurse had become more difficult, Caroline decided to reach out to Epilepsy Action, whose support she had valued in the past. She spoke with an adviser about her concerns and the uncertainty she felt about starting a new treatment.

The adviser explained that she was eligible to join the Patient Support Programme (PSP), a partnership project with Angelini, which would give her access to personalised, ongoing support throughout the medication transition. Knowing she would have someone to talk to during the challenging titration period—someone who understood epilepsy and could offer reassurance, practical guidance, and reliable information—made Caroline feel far more confident about taking the next step.

Through the PSP, Caroline gained:

- A dedicated listening ear whenever she needed to talk things through
- Clear, trustworthy information about her medication and what to expect
- Regular check-ins and personalised support during titration
- Increased confidence in managing her epilepsy while continuing to work

With this consistent support, Caroline felt empowered, reassured, and better equipped to move forward with her treatment plan. The Patient Support Programme helped her navigate a difficult period safely—while maintaining her quality of life and independence. Caroline said: "I would 100% recommend this service to others, I was supported to manage side effects and other concerns. Thanks for your help, guidance and support."



Armour

Clinical medicine is not a battle, and we do not need to protect ourselves before turning the computer on, making a fresh cup of coffee and trying to find a pen that works. However, there are a number of jargon phrases that we use as a bit of a shielf – and that makes a lot of sense.

Have you ever seen that politicians when they are in office are cold, heartless, insufferable and inscrutable? And yet when they step down, and appear on 'Have I Got News for You', that these very same buffoons are gregarious, gracious, witty and wise? I have worked with a few neurology colleagues like that.

When shared patients grumble about their consultation style, you find yourself sympathising with the patient, more often than not, but trying also not to throw your friend under the metaphorical bus. You may break the unwritten 'professional code' and share something with them. When your words of consolation are "But he is an excellent ballroom dancer", or "No one can belt out Journey's 'Don't Stop Believing' with more gusto…" then you've probably lost the argument before you begin.

These colleagues are said to be 'wearing a mask' – they have a different public persona. This is sometimes beneficial – particularly when your personal traits mean that you may need to compensate for something, such as your youthful looks. Or you want to keep something of yourself back and present a blank canvas. This is certainly preferable to the gossipy clinical sharer who risks oversharing as they burden patients with their woes.

The second combat wearable is 'armour'. The more of this psychological protective layer one is draped in, the less likely you are to be emotionally wounded at work. Or so in lies the theory. I feel this is a two-edged sword – mail and plate armour is cumbersome, and the helms limit your vision.

The less of you that patients see, the less emotionally open you are, the less you will receive in turn. Up until recently, I felt that I was wearing a very light armour at work, the very minimum necessary – sometimes a hardly-there, barely-decent saphenous veil of psychological covering. However, events last year let me know that this was not the case at all.

In the summer, my family went back to Australia to visit very close friends and as we were going to an Aussie Rules game, my friend (my age,

i.e. young) had a collapse. He is tall, thin, in perfect health – but he tumbled and stumbled, trying to keep his feet for seconds until he ended up in a puddle, without blacking out.

Reminding myself that super-specialists get painted in to a corner where they can only make two diagnoses (this is Wilson's disease vs this is not Wilson's disease), I nonetheless told him confidently this was not a seizure – but he needed to get promptly seen (and shouldn't be driving). His pacemaker was sited a week later after a 16-second pause was spotted on telemetry. All was well. But the story did not end there.

I realised I was more emotional and invested in this than in any typical first seizure story – and therefore could estimate the weght of the daily armour that I must be wearing at work

The hyper-efficient (insurance funded) Aussie healthcare system kicked in, and no cause was found at all for his ticker trouble. My chum WhatsApp-ed me one day asking whether his cardiologist was barking up the right tree, as he wanted my mate to see a neurologist.

Initially I was non-plussed by this, but my friend said that ever since the collapses, he was having brief sensory events – always the same – and now he comes to think of it, he may have had one immediately before the summer collapses. His voice would change, his face would drop, a surge of goosebumps would flush down one arm (always the same arm). The event would last 10s only – but at its peak, multiple times a day.

Reader, you know where this is going – and you're a step ahead of me. Of course, he is having focal seizures – perhaps opercular with insular spreading. The only thing I was certain of when seeing the Aussie rules tumble was wrong.

But back to the armour. When we were discussing this on FaceTime, he immediately changes to video, as one was coming. Witnessing a friend of 25 years have a seizure, (even a relatively minor one, all things considered), was much more distressing than I would have predicted. The alien way that he was controlled, taken over, changed. This articulate epicurean, this warm-hearted intellectual was briefly being contorted by out-side forces.

He sent me a video of the seizure – I couldn't bring myself to watch it. I have never watched it. He asked me what's next, how bad could this be? What should he tell his wife and girls? On the run up to Christmas, before he had his scan, I realised that I was more emotional and invested in this than in any typical first seizure story – and therefore could estimate the weight of the daily armour that I must be wearing at work.

My friend? He was given Tegretol (not my favourite drug) and went from having in excess of 20 events a week to not having any at all, almost immediately. Me? I was unsettled for weeks in a non-specific way and have spent a lot more time chatting to witnesses of seizures not just because they hold key diagnostic information, but also because they may have been traumatised by what they have seen.

I will also keep a check of my clinical armour and mindfully keep myself adorned with the requisite coverage.

Network and collaborate

Epilepsy Action's engagement coordinator, Maisie Meegan, shares upcoming events supporting learning, networking and collaboration in the epilepsy care community

I'm thrilled to share my very first contribution to Epilepsy Professional magazine. My role at Epilepsy Action is all about building strong connections with healthcare professionals to support both them and their patients. I help deliver engagement activities and host events that create opportunities for learning, networking, and collaboration across the epilepsy care community.

My role is to build strong connections with healthcare professionals and to support both them and their patients through engagement activities and events for learning, networking and collaboration

Throughout the year, I cohost a range of events designed to inform, connect and inspire. Here's what's coming up in 2026.

Epilepsy Specialist Nurse induction days
Kickstart your journey with our interactive six-hour virtual webinar, led by industry experts and Epilepsy Action specialists. Expect practical insights, real-world advice, and the chance to connect with nurses nationwide. It's the perfect way to build confidence and knowledge for your role!

Dates:
- 6 February
- 24 April
- 27 May
- 4 August
- 20 October
- 4 December

Epilepsy Specialist Nurse refresher sessions
Already an experienced ESN or completed our induction? This half-day session is designed to refresh your knowledge, sharpen your clinical expertise and keep you up to date with the latest best practices. Learn from other expert nurses and leave feeling inspired and ready to make an impact!

Dates:
- 11 February
- 30 October

Professionals Network
Join our virtual networking event bringing together professionals from primary and secondary care. We'll share knowledge, tackle challenges and explore new ways to improve outcomes for people living with epilepsy. It's all about collaboration and innovation! I'm always looking out for guest speakers for this event, so if this is of interest, please email mmeegan@epilepsy.org.uk.

Dates:
- 6 March
- 31 July
- 8 September
- 1 December

Student education events
Know someone who's thinking about a career as an Epilepsy Specialist Nurse? Our two-part series is the perfect starting point!

Dates:
- *Part 1:The basics of epilepsy*
  - 3 March
  - 27 October
- *Part 2:The role of the ESN*
  - 11 March
  - 6 November

I'm passionate about creating spaces where professionals can learn, share experiences and feel supported in their vital roles. If you'd like to get involved in any of these events or book a meeting to find out more about the support available at Epilepsy Action, I'd love to hear from you!

Contact me: **mmeegan@epilepsy.org.uk**

Together, we can create a world without limits for people with epilepsy.

Dates for the diary

Dates and events may be subject to change – please check on the relevant websites.

2026

22-25 April
EPIPED Course: Treatment Strategies in Pediatric Epilepsies
Girona, Spain
epiped-course.com

3-6 May
18th Eilat Conference on New Antiepileptic Drugs and Devices
Madrid, Spain
bit.ly/3Wq6dcc

16-17 May
20th Specialist Epilepsy Teaching Weekend
Birmingham, UK
ilae.org/congresses/20th-specialist-epilepsy-teaching-weekend

5-9 September
16th European Epilepsy Congress
Athens, Greece
ilae.org/eec2026

30 March-2 April
8th ILAE School on EEG in the First Year of Life
Cambridge, UK
ilae.org/congresses/8th-ilae-school-on-eeg-in-the-first-year-of-life

10-13 September
16th International Summer School for Neuropathology and Epilepsy Surgery
Erlangen, Germany
ilae.org/files/dmfile/ines-2026-flyer-r2.pdf

2027

28 August-1 September
37th International Epilepsy Congress
Amsterdam, Netherlands
ilae.org/congresses/37th-international-epilepsy-congress

Next issues:

Eric Kyeremaa

Exploring the complex problem of medication shortages for people with epilepsy

Prof Heather Angus-Leppan

Prof Angus-Leppan discusses the things people with epilepsy want to know but don't get the answers to

If you are interested in submitting a research paper for inclusion in *Epilepsy Professional,* please contact the Editor:

kkountcheva@epilepsy.org.uk

Epilepsy Professional's advisory panel

EPILEPSY ACTION

We need more experts to join our forces!

Our health information needs professional feedback to continue to be PIF tick accredited.

If you can lend your professional skills to review information on an occasional basis, send an email to **health@epilepsy.org.uk** with the area you specialise in.

This is a great opportunity for your CPD portfolio as well as making a huge difference to people affected by epilepsy.

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