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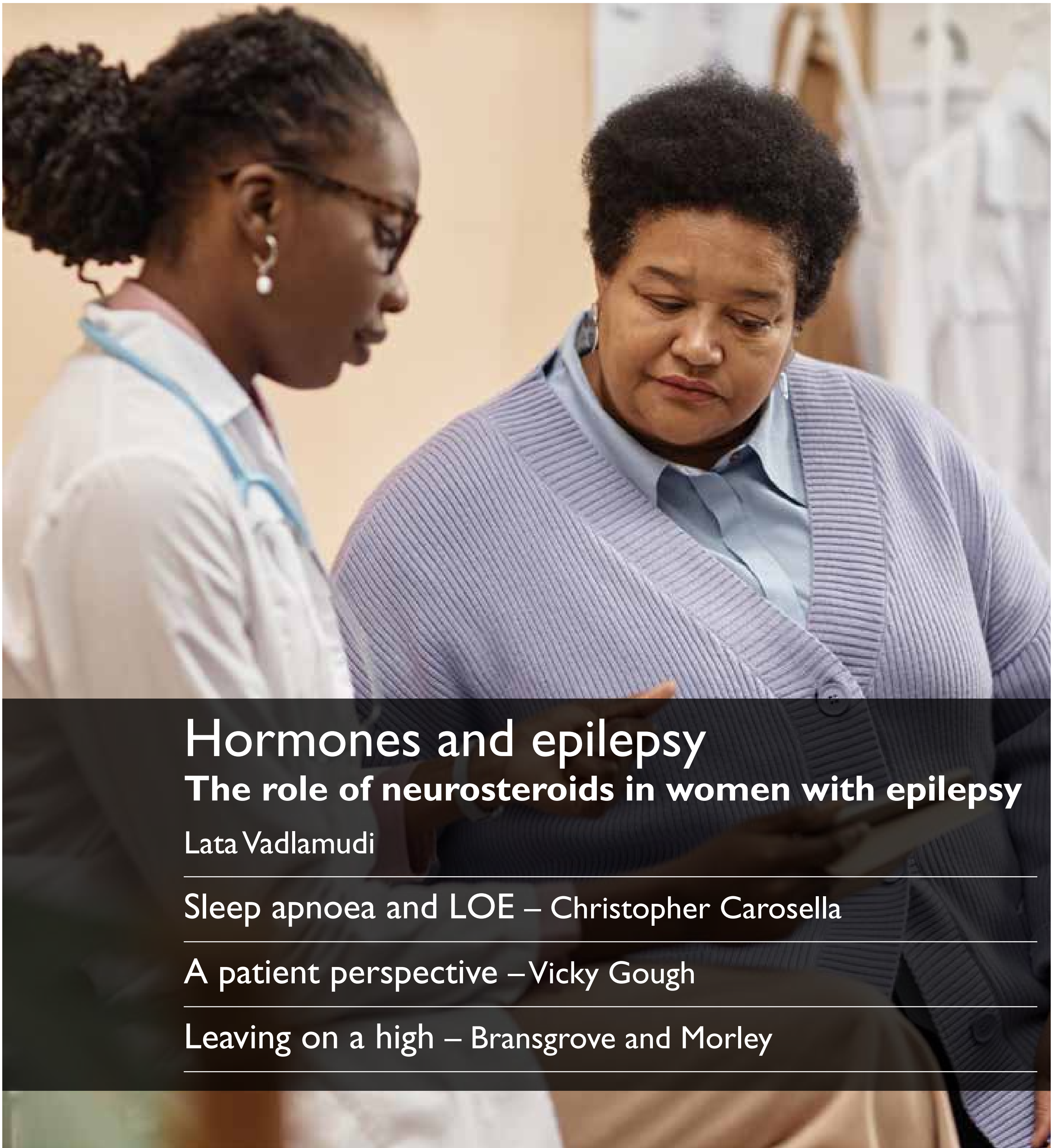


Hormones and epilepsy

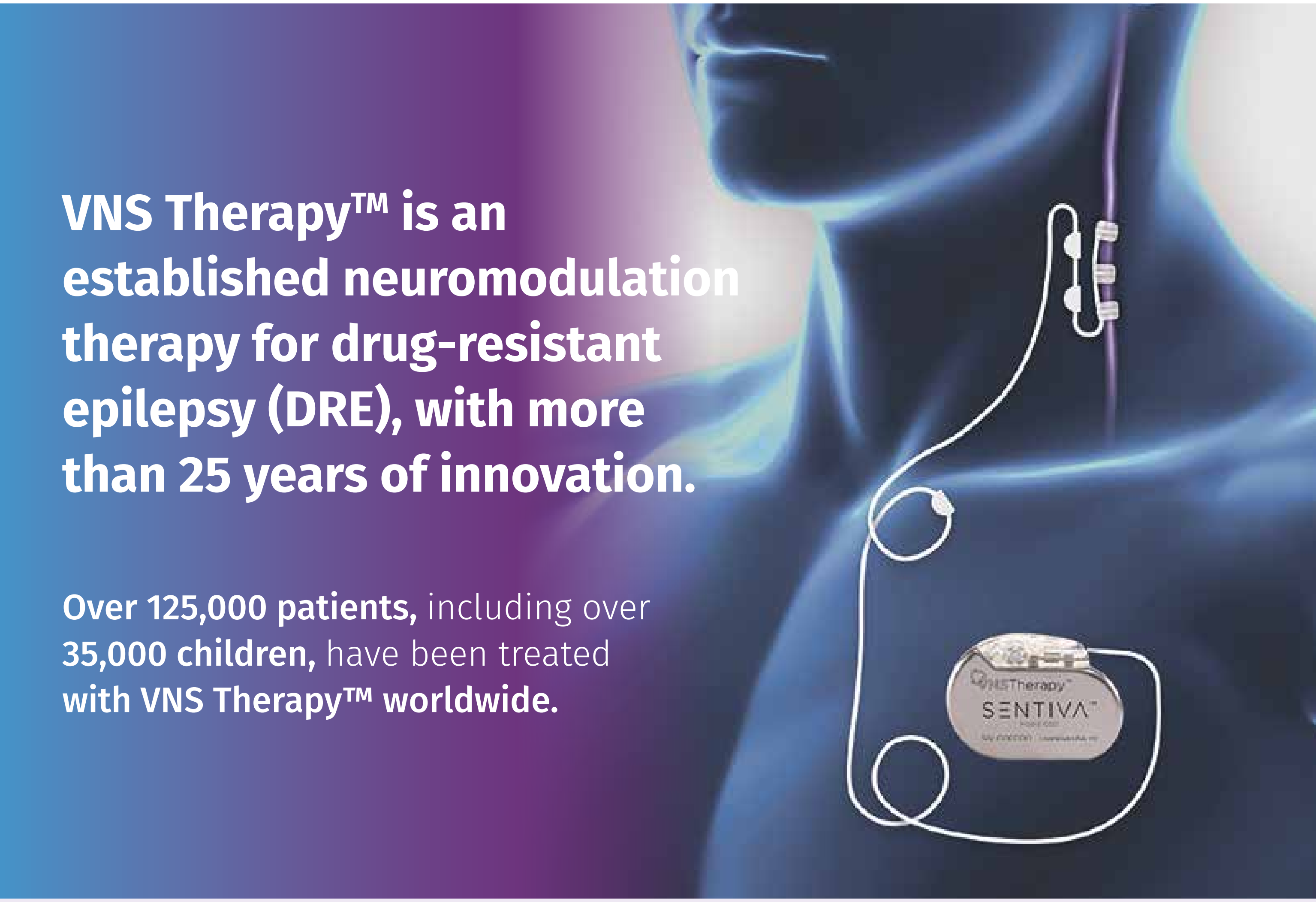
The role of neurosteroids in women with epilepsy

Lata Vadlamudi

Sleep apnoea and LOE – Christopher Carosella

A patient perspective – Vicky Gough

Leaving on a high – Bransgrove and Morley


VNS Therapy
SENTIVA

As I write and introduce you to our autumn edition of Epilepsy Professional, we are ensconced in election fever, European football bliss or doldrums, a rather wet Wimbledon and the Tour de France on the gravel stages. Time rolls on and, no doubt, when you read this edition of Epilepsy Professional, the summer will have passed. I hope by then at least some of us will have seen some brighter, sunnier days and will be refreshed for the autumn ahead.

In this edition, I want to highlight and draw your attention to a few articles. Firstly, Christopher Carosella discusses the interesting interaction between sleep apnoea and late-onset epilepsy. This is something I've encountered in my clinic in the last few months and wondered whether they are separate entities or if there is a link. His research outlines how people whose oxygen saturation fell to less than 80% during sleep were at a three-times higher risk of developing late-onset epilepsy and that those who actually had a diagnosis of sleep apnoea were twice as likely to develop late-onset epilepsy. Along with his own research, he assesses the literature on this, outlines a rationale for treatment of sleep problems and presses home the importance of discussing sleep with our patients.

Prof Lata Vadlamudi explores the interaction of neurosteroid hormones in women with epilepsy. A few highlights are presented herein from her mini review, published fully in the journal Frontiers in Global Women's Health. A seemingly rather complex relationship exists with neurosteroids and brain connectivity which is constantly changing throughout life. She outlines the role of progesterone as a modulator of neuronal excitability via GABA-A receptors and proposes that this should be explored through prospective studies, something which her group is currently recruiting to. I thought this was fascinating and it feels novel to see research into women and epilepsy beyond the pregnancy or fertile years.

Vicky Gough gives a very personal perspective on her path to a diagnosis with epilepsy. I was struck how we often invest resources and staff into those with established disease and maybe forget the vulnerability of a newly diagnosed patient. This was a timely reminder that those at the start of the journey need as much support too.

And finally, what a joy it was to read about the careers of epilepsy specialist nurses Juliet Bransgrove and Kim Morley. Both have worked tirelessly for epilepsy and have demonstrated their vast range of transferrable skills across the NHS, private sector, research domains and charities. I encourage you to be inspired and to read their career highs and future hopes ahead of their retirement.

Ann Johnston
Consultant neurologist
Executive medical adviser
Epilepsy Professional

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A patient perspective

Vicky Gough

Vicky Gough describes her experience trying to get her epilepsy diagnosed and trying to get support for post-traumatic stress disorder

It's been especially rewarding to kick off my first issue back from maternity leave with a topic that doesn't see enough discussion, in my view – neurosteroids and epilepsy. Catamenial epilepsy has been around since the existence of epilepsy and women, and yet we still know so little about how changes in neurosteroids throughout women's lifetimes affect their epilepsy. I'm thrilled that A/Prof Lata Vadlamudi spoke to me to share her insights and expertise on this important topic. You can read more on page 10.

Another important aspect of care that may need a little more attention and consideration is sleep. Dr Christopher Carosella tells us about his research into the potential link between sleep apnoea and nocturnal hypoxia and late-onset epilepsy. Understanding this link could, one day, help to stop epilepsy from developing in people with sleep apnoea. More on page 16.

We also bid a very fond farewell to two extremely influential epilepsy specialist nurses, who are retiring this summer. Juliet Bransgrove and Kim Morley have done a tremendous amount for patients with epilepsy, for Epilepsy Action and the whole epilepsy community. You can read more about their career highlights and hopes for the future on page 22.

Last but not least, we're giving you a patient experience from Vicky, describing trying to access epilepsy and mental health services. You see patients every day, but understanding more about their experiences, motivations and what they may not be telling you might be helpful in delivering the best care we can.

I hope you enjoy this issue!

Kami Kountcheva
Editor

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Topiramate use in pregnancy: MHRA tightens safety guidelines

Topiramate should not be prescribed to women of childbearing potential without a pregnancy prevention plan, the Medicines and Healthcare products Regulatory Agency (MHRA) has announced..

The MHRA updated its safety guidelines for the use of the medicine topiramate (brand names Topamax and Topiragen) on 20 June 2024. Topiramate is used to treat epilepsy and migraines.

Previous MHRA guidelines from May 2022 said that before being prescribed topiramate, women should be fully informed of the risks during pregnancy, and in epilepsy, alternative options should be considered first.

The new guidelines state that topiramate should not be given to "women of childbearing potential unless the conditions of a Pregnancy Prevention Programme are fulfilled".

They continue to stress that women must be made aware of the risks of topiramate and now need to sign the Risk Awareness Form.

The update follows a review conducted by the MHRA, which found that "the use of topiramate during pregnancy is associated with significant harm to the unborn child".

The MHRA said the medicine could lead to birth defects and low birth weight. It said that it could also increase the risk of intellectual disability, autistic spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD) in children.

Advice from the MHRA says that women should always use effective birth control while taking topiramate and four weeks after stopping the medicine. Topiramate can change how effective some hormonal types of birth control are, so the MHRA advises women to speak to their GPs or specialists about effective contraception.

The MHRA said women with epilepsy taking topiramate, who are thinking about having a baby or think they might be pregnant should continue to take their epilepsy medicine and make an urgent appointment with their GP or epilepsy team.

Stopping an epilepsy medicine could lead to seizures restarting or becoming more frequent or more severe.

The latest NHS England statistics show that in September 2023, the number of females aged under 55 years old who were prescribed topiramate was just over 30,000.

Alison Fuller, director of health improvement and influencing at Epilepsy Action, said: "Information is always key.

"From some of our previous research, we know not enough women were being fully informed about the risks some anti-seizure medications pose to pregnancy. The inclusion of topiramate in the Pregnancy Prevention Programme should at least ensure that these conversations are happening.

"Clinicians need the right support to make sure that the change in rules is effectively communicated to affected patients, and that they can make informed decisions about their care.

"While these new rules coming into effect may be concerning for some people, it's important no one stops taking medication without speaking to their specialist.

"We understand that these new measures could potentially reduce medication options for women of child-bearing age. Also, we know that neurology staffing levels are extremely low in the UK, and new referrals could increase the already critical waiting times.

"We will monitor the roll-out closely and keep sharing any new information with our supporters as any developments occur."

Laser therapy rolled out on the NHS

Laser beam therapy for patients with focal epilepsy has been made available in England on the NHS.

The NHS rolled out Laser Interstitial Thermal Therapy (LITT) at King's College Hospital in London and The Walton Centre in Liverpool as specialist national hubs in June.

The surgery was first announced in the UK in October 2022.

The fibre optic laser therapy targets the part of the brain causing seizures without the need for invasive surgery.

The treatment requires a small probe (1.5mm-wide) to be placed into the skull with a fibre optic laser at the tip of it. This destroys the epilepsy-causing brain tissue from the inside by heating it.

The minimal surgery means the wound heals quickly, allowing patients to go home the next day (within 24-48 hours) and has a low risk of infection or side effects.

To be eligible for the treatment, patients need to have focal epilepsy with a specific cause, and may not be eligible for any other treatment such as anti-seizure medications, VNS therapy or a different form of surgery.

Epilepsy Action's health improvement and research manager Tom Shillito, and a volunteer for the charity, were involved in choosing which epilepsy centres would offer the surgery – ensuring the patient voice was heard in the decision-making process.

Epilepsy Action deputy chief executive, Rebekah Smith, said: "This new therapy is an exciting ray of hope for people with focal epilepsy whose lives are being impacted by the harsh reality of uncontrolled seizures."

Epilepsy Action secures grant to expand helpline service

Epilepsy Action has secured unrestricted grant funding from Angelini Pharma UK-I Ltd to improve its award-winning helpline service.

Having the busiest helpline service in the UK for people with epilepsy, the new funding will allow Epilepsy Action to support more specialist enquiries and trial new communication technologies to expand its reach and improve accessibility.

The Epilepsy Action Helpline deals with over 11,000 enquiries a year through calls, emails, messages, and chats. But with 630,000 people with epilepsy in the UK and over 1 million visits to the charity's website every year, the charity says there are many more people out there who need help.

In the first six months of 2024, the helpline saw a 42% increase in enquiries around medication compared to the same time period in 2023. The new services will focus on improved information on medication and mental health support.

The announcement of the grant support for the next 12 months coincides with the launch of Epilepsy Action's first ever national campaign and new brand, all part of the charity's 2030 vision to create a world without limits for people with epilepsy.

Rebekah Smith, Deputy CEO at Epilepsy Action said: "We are thrilled that we have the opportunity to expand this vital service for people with epilepsy. It's very exciting that Angelini are providing this grant to help us deliver a critical element of our 2030 strategy to create a world without limits for people with epilepsy.

"The first phase of this work will enable us to provide a much more effective service for the growing number of people contacting us with mental health issues and queries around medication. We will look at how to expand this to other specialisms in the future, and how we can support healthcare professionals by providing more first stage support."

Stuart Mulheron, general manager at Angelini Pharma UK-I Ltd, said: "We are delighted to support Epilepsy Action with this grant and make a difference for people with epilepsy. Angelini Pharma UK-I Ltd provides grants and donations to support initiatives that enhance patient care or benefit the NHS in accordance with the Association of British Pharmaceutical Industry Code of Practice."

Epilepsy12 audit report – children's epilepsy services still need improvement

More than three in five children (61.1%) with epilepsy aged five and above don't have an individual healthcare plan (IHP) for school, according to the new Epilepsy12 report by the Royal College of Paediatrics and Child Health (RCPCH).

Epilepsy12 is a regular audit of children's epilepsy services in England and Wales. The latest report is the fifth audit round and covers the first year of epilepsy services that children received between 1 December 2021 and 30 November 2022.

The report found that the number of children with epilepsy with an IHP for school hasn't improved much over since the first round of audits.

While some children may not need an IHP for school, Epilepsy Action says it's a good idea to have one if a child's epilepsy could affect them at school.

One in five children (20.2%) didn't have a care plan in place in the first year after assessment for epilepsy. Also, one in ten trusts (9%) still don't do routine care plans, the audit has found.

Nearly four in five children (77.6%) weren't asked about their mental health. This is despite the NHS quoting that more than a third (37%) of children and young people with epilepsy have a mental health condition. This is the case in around one in 10 children (9%) in the general population.

Almost two in five children (38.5%) who needed mental health support hadn't received it, the audit found.

However, the audit also saw an increase in Health Boards and Trusts routinely screening for mental health disorders, up from 20% in 2022 to 30% in 2023.

Alison Fuller, director of Health improvement and influencing at Epilepsy Action, said: "The findings from this year's Epilepsy12 report highlight there are still many areas of care needing urgent improvement.

"It's concerning to see more than three in five children not having an individual healthcare plan in school, and that mental wellbeing isn't being reviewed for nearly four in five of them.

"It's vital children with epilepsy have the support they need at school, where they spend the majority of their time, and for their mental health. We know how much epilepsy can impact mental wellbeing, so it's crucial healthcare professionals have the capacity to give the correct support in this area."

A big part of the Epilepsy12 report focused on the timeliness of children receiving healthcare services. Only half of children were seen within two weeks, which is the best practice guidance time frame.

Epilepsy specialist nurse (ESN) input has increased from seven in 10 children (69%) receiving this care in the first round of audits to eight in 10 (80.7%) in the fifth round. However, this still leaves one in five children (19.3%) who didn't see an ESN in the first year.

As well as that, only half of children who needed an MRI got one, and more than two thirds (62.7%) of children eligible for a surgery referral received one in the first year.

Another finding is that around a third of children's families (33.7%) hadn't been told about sudden unexpected death in epilepsy (SUDEP), which is now compulsory for clinicians to discuss.

The report also showed that deprivation continues to have an impact on care, with people living in less deprived areas seeing lower waiting times and better care.

The audit report found that only three girls aged 12 or over were taking valproate out of a total of 2212 children overall.

Fuller added: "Overall, the report shows improvement in some aspects of care for young people with epilepsy, but there is still much work to be done."

Epilepsy Action calls for disability employment data breakdown

Epilepsy Action is calling on the Department for Work and Pensions (DWP) and the Office for National Statistics (ONS) to publish an up-to-date breakdown of disability employment data.

In May, the ONS published its 'Labour market overview, UK: May 2024'. It shows a reduced rate of employment in 16-64-year-olds between January and March 2024 (74.5%) compared to a year ago. It shows unemployment rates have also risen (4.3%).

The overall rates of unemployment in disabled people aged 16-64 in the UK have increased since last year, too, the data show (360 or 3.6% in 2023; 460 or 4.5% in 2024).

However, there hasn't been a breakdown of employment statistics by disability since 2022.

In previous years, these data have shown that epilepsy has some of the lowest rates of employment (42% in 2022) and highest rates of economic inactivity in the UK.

Daniel Jennings, Epilepsy Action's senior policy and campaigns manager, said: "It's disappointing to see the latest unemployment figures.

"People with epilepsy struggle to find, and stay in work, but with the lack of data from the ONS, we are in the dark about the true picture of the situation. So, we don't know if people with epilepsy are doing better or worse than before."

Climate change harms epilepsy and mental health, study finds

Climate change can worsen neurological conditions like epilepsy, and mental health conditions, says a new study from University College London.

In a Point of View article in the journal The Lancet Neurology, study author Prof Sanjay Sisodiya and colleagues investigated 332 pieces of research from 1968-2023 looking at climate change and various health conditions. These included neurological conditions, such as epilepsy, dementia and stroke, and psychological conditions.

Prof Sisodiya said climate events affecting brain health included hot and cold temperature extremes that people are not used to, and big unseasonal temperature changes throughout the day. As well as these, pollution was also found to affect brain conditions.

"Nighttime temperatures may be particularly important, as higher temperatures through the night can disrupt sleep. Poor sleep is known to aggravate a number of brain conditions," he added.

The research found that in epilepsy, events like infections, temperature extremes and impaired sleep can worsen seizures. The researchers said there is a "pressing need" for more research.

Epilepsy Action awarded for tackling stigma

Epilepsy Action and Be Broadcast have won two PRCA Dare Awards for their joint work in National Epilepsy Week 2023 to tackle public seizure stigma.

The companies were given the Best Use of Data and Analytics Award and the Purpose Award in the North West at the awards ceremony on 12 June 2024 in Manchester.

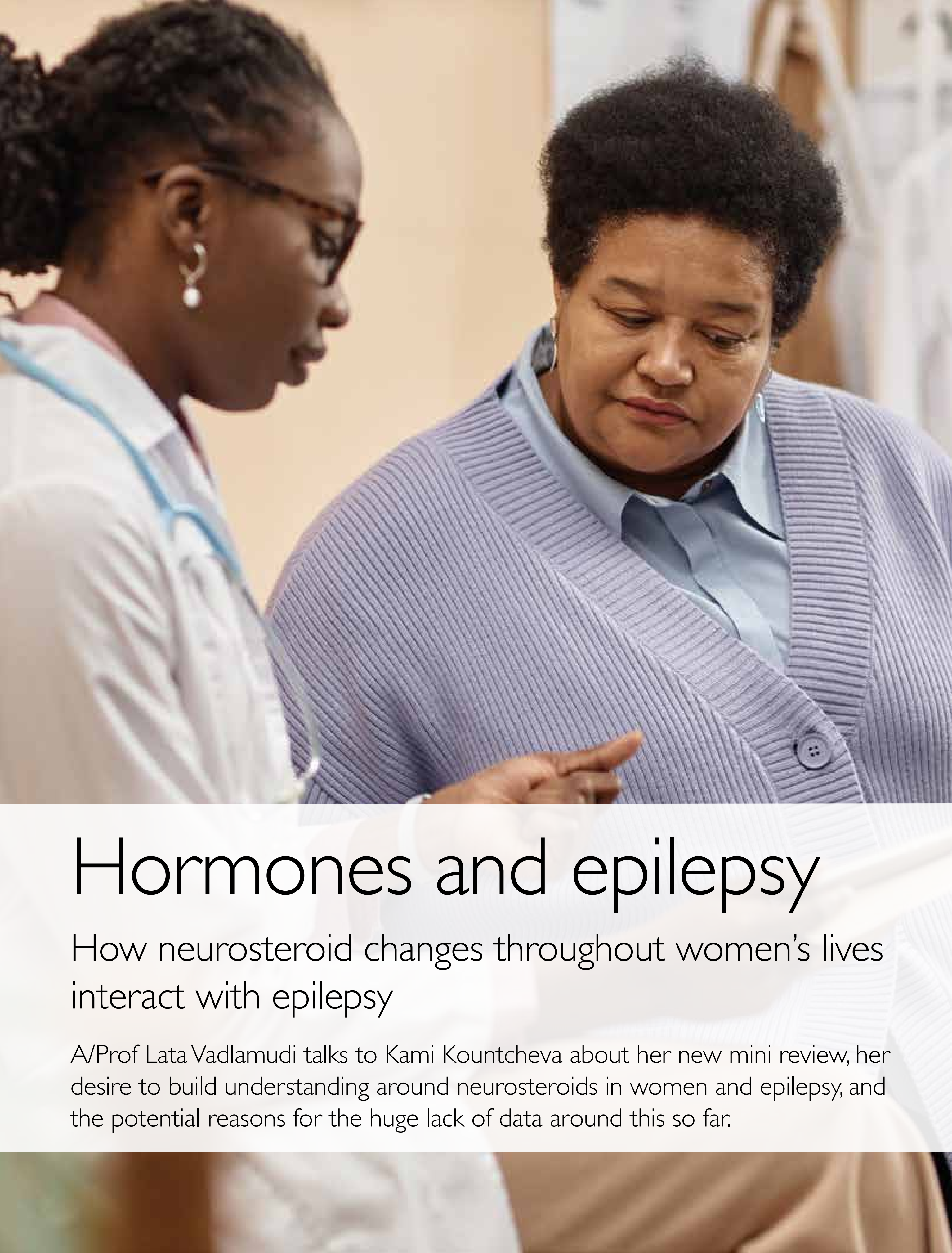
Epilepsy Action was nominated for work in 2023 for its CARE (first aid for tonic clonic seizures) campaign.

O2 removes flashing ad

O2 has removed a Priority advert featuring flashing lights, after viewers raised concerns over its safety for people with photosensitive epilepsy.

Epilepsy Action commended the phone company for going "above what is expected".

While O2 confirmed the ad had passed the Harding Test, the company said it decided to remove the advert "out of an abundance of caution".



Hormones and epilepsy

How neurosteroid changes throughout women's lives interact with epilepsy

A/Prof Lata Vadlamudi talks to Kami Kountcheva about her new mini review, her desire to build understanding around neurosteroids in women and epilepsy, and the potential reasons for the huge lack of data around this so far.

Progesterone has an important role in modulating neuronal excitability in women with epilepsy. Women with epilepsy are susceptible to changes in neurosteroids throughout their lives, a new mini review, published in the journal Frontiers in Global Women's Health, has found.

The review, by Lata Vadlamudi, Daniel Paul Ashley and P. Emanuela Voinescu [2024] suggested that changes in sex hormones and their metabolites are "intrinsically intertwined with seizure susceptibility".

This mini review looked at the role of neurosteroids, trials of exogenous neurosteroids and future research directions.

Epilepsy Professional spoke to paper author and associate professor Lata Vadlamudi. She is a senior staff specialist in Neurology at the Royal Brisbane and Women's Hospital, Australia; epileptologist within their Comprehensive Epilepsy Program; Metro North Clinician Research Fellow; and Brain, Neurology and Mental Health theme lead at the University of Queensland Centre for Clinical Research, Australia.

Epilepsy Professional: Why is epilepsy different in men and women?

Lata Vadlamudi: There are two contributing factors. The main factor is neurosteroids, which are steroids that act on the brain regardless of their site of synthesis in the body (either distant or local brain synthesis). The other potential reason is that connectivity is slightly different between males and females within and between the cerebral hemispheres.

In women, particularly from puberty onwards, there are cyclical fluctuations of neurosteroids every month. In pregnancy there are elevations of neurosteroids, followed by perimenopausal periods where the neurosteroids are quite erratic, and then in menopause where they are low. We know that neurosteroids are modulators of the GABA-A receptors, which act on inhibitory neurotransmission in the brain. The more you read about it, the more complicated it gets.

EP: When in a woman's life might neurosteroid changes affect epilepsy?

LV: In the condition protocadherin-19 in female epilepsy (PCDH19-FE), which is a very severe form of epilepsy, causing infantile seizures and cognitive impairment with long-term behavioural and management problems, seizure onset and offset coincide with changes in neurosteroid levels. Seizures commence around six months of age, once neurosteroids derived from their mother are longer present. Seizures then tend to decrease when they start puberty, with the rise in neurosteroids. This demonstrates that there are changes in seizures linked to neurosteroid levels.

Lata Vadlamudi

> **I think we probably underreport catamenial epilepsy, as I don't think we ask about this link as much as we could**

In puberty, catamenial epilepsy is a clear example. There are three different patterns: seizures can increase around menstruation (C1), around ovulation (C2) and with anovulary cycles from mid-cycle to menstruation (C3). C1 is the most common pattern, where women have more seizures around their periods. Up to 52% of women can have catamenial epilepsy [Voinescu et al, 2023]. I think we probably underreport catamenial epilepsy, as I don't think we ask about this link as much as we could. Unless we ask women to monitor their menstrual cycles in conjunction with their seizures, they may not be aware and may be underreporting this association as well.

Next in the life course can be pregnancy when women have high levels of progesterone and oestrogen. A study by Voinescu et al [2021] looked at allopregnanolone, a derivative of progesterone, and found that women who had a lower blood level of allopregnanolone, had more seizures. This once again supports the hypothesis that progesterone is protective.

Next is perimenopause. There is little research in this topic. Research by Harden et al [1999] involved a questionnaire of 42 women and they observed that women who have had a history of catamenial epilepsy tended to have more seizures during perimenopause. That's probably because their seizures have always varied on a cyclical basis, so it makes sense that they will get worse once neurosteroid levels become more erratic.

And, finally, we move to menopause. We know that women with epilepsy have a higher risk of premature ovarian failure and we know women who have had poorly controlled seizures have earlier menopause. So, we know that epilepsy affects menopause. There's very little data on women with epilepsy and the impacts of menopause, with only a small number of women completing patient questionnaires. So, we have an enormous gap in the understanding of the landscape.

EP: Do neurosteroids protect or cause seizures?

LV: We know that oestrogens tend to be proconvulsive and progesterones generally tend to be anticonvulsant. Some progesterones can also have some proconvulsive effects as well. So, it's critical to consider the type of progesterone.

There's a balance between oestrogen and progesterone and when this balance changes, for example just prior to your menstrual period, or mid-cycle, the change in that balance is potentially what's driving the change in seizure burden.

EP: What can clinicians do to support women with neurosteroid changes that affect their epilepsy?

LV: We undertook a survey of 130 women in Australia regarding perimenopause and menopause, and 74% had concerns going through menopause with epilepsy. So, I think the first thing we need to do is better educate and provide more resources for women with epilepsy. So, part of empowerment of women is the knowledge that there is a role that neurosteroid changes play in their epilepsy.

When it comes to treatment, progesterone seems to make sense, so why don't we give progesterone?

There was a landmark study by Herzog et al [2012] which gave progesterone to women for the second two weeks of their cycle and this randomised trial showed no effect compared to placebo. But when they reviewed the data further, and separated women into the different groups with catamenial epilepsy (C1, C2 and C3). They found that the C1 group who had a more severe symptoms were the most likely to respond. So, part of the reason why the study showed no effect was probably because progesterone was used on all patterns of catamenial epilepsy, and not selected for the group that was most likely to benefit. As previously mentioned, the type of progesterone is an important consideration as well. We need to be doing more studies looking at other derivatives of progesterone, such as allopregnanolone.

There is just a huge lack of research both at the clinical and the basic science level. Why are some people more prone to catamenial epilepsy than others?

The other question is that of menopause hormonal therapy (MHT). Is it safe in women with epilepsy? Perimenopausal symptoms, such as mood changes, lack of sleep, hot flushes can also aggravate seizures. There is only one small study of 21 patients from Harden et al [1999], which was ceased due to the Women's Health Initiative raising safety concerns with MHT. The study used prempro, and the findings suggested an increase in seizures with the use of MHT. But once again, numbers were very small and we don't know, for example, if an oestrogen patch would have a different effect? These are the unanswered questions, and we can have a difficult time advising women on what to do. It's about getting it right for each particular patient and weighing up the risk versus benefits of treatment options.

EP: Why is there such a big knowledge gap in this area for women with epilepsy?

LV: To date there has not been a longitudinal study of women with epilepsy, in particular in later life. We are commencing a prospective project of women with epilepsy from 40 years of age. Throughout my career, focus has been on the treatment of women with epilepsy during their pregnancies and then we have tended not to focus on the impact of neurosteroids beyond that. But their lives go on, and they go on to their 40s, 50s, 60s and beyond.

The other thing is that we don't look at anti-seizure medication (ASM) levels in menopausal women and we know that, for instance, lamotrigine − a very commonly used ASM − interacts with oestrogen and the blood levels can go up as oestrogen levels go down in menopause. But we don't routinely check blood levels.

But why haven't we focused on it? Clearly women have always had cyclical changes until menopause, and it certainly makes intuitive sense. Herzog's landmark progesterone trial demonstrated the strong interest in this topic, but then the Cochrane review stated there was moderate to low certainty evidence of no treatment difference between placebo and progesterone in catamenial epilepsy. What we need to do is to keep refining this important research.

And maybe it's also because menopause is now a topic of growing research interest and we're realising that it has an impact on many chronic diseases, such as epilepsy.

Further reading

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Voinescu PE, Kelly M, French JA, Harden C, Davis A, Lau C, et al. Catamenial epilepsy occurrence and patterns in a mixed population of women with epilepsy. *Epilepsia*. (2023) 64:e194–9. doi: 10.1111/epi.17718

There is just a huge lack of research both at the clinical and basic science levels. Why are some people more prone to catamenial epilepsy than others? Is this related to changes in their GABA-A receptor expression or sensitivity? Is there a gene predisposition?

EP: So, we don't have the research to underpin some of these healthcare decisions?
LV: We would like to develop some practice guidelines for clinicians and consumer resources for women with epilepsy.

We've just commenced a prospective study here for women with epilepsy in later life at the Royal Brisbane and Women's Hospital, and we'll start looking at women from 40 years of age. We chose 40 because we wanted to really capture that perimenopausal window. Of course, some of them are still going to be of childbearing potential, but we also know that epilepsy itself has a higher risk of premature ovarian failure and want to look at this aspect. We will be completing surveys on quality of life, epilepsy, bones and hormones.

EP: How much should women with epilepsy be monitored in light of all the neurosteroid changes throughout life?
LV: As women go through different stages in their life, we probably don't consider the impact of neurosteroids on their epilepsy as much as we could.

Conversations on bone health should start early. If someone's been on ASMs since early childhood, they probably never developed optimal bone mass, so we need to start the conversations early about the importance of exercise and bone health.

And we have to also be cognisant of the fact that we are talking about women, but they're people 'assigned female at birth'. We may have people 'assigned male at birth' who are now female and using hormonal treatments. We have to be conscious that these hormones can also impact their epilepsy. For our project, we are including anyone who is female, even if they're not assigned female at birth, because they may well be on hormonal supplements.

EP: Where does research need to focus in the future?
LV: We would like to look at the landscape and understand the characteristics of women with epilepsy. Then we want to be able to look at more targeted interventions, such as hormonal treatment.

In conjunction with this, we are very keen to understand at a basic science level the effects of neurosteroids in epilepsy. We are very keen to understand the GABA-A receptor's role, and why some women with epilepsy are more prone to seizures than others. A potential genetic cause also needs consideration. Perhaps one day, there will be a biomarker that we know makes a woman with epilepsy more susceptible, and we could recommend specific treatment.

If we can better understand what's driving the complex interplay between epilepsy and neurosteroids, there's more scope for more targeted treatments in the future.

A/Prof Lata Vadlamudi
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Epilepsy manifesto

Epilepsy Action is calling on the government to address key issues for people with epilepsy

Ahead of the general election, which took place on 4 July 2024, Epilepsy Action put together a manifesto of key issues affecting people with epilepsy in the UK. The organisation is urging the new government to address these issues.

The manifesto was split into three topics – work and benefits, justice, and health and social care. Epilepsy Action is fighting to have fair treatment and justice for the most vulnerable people with epilepsy, and to ensure that people with epilepsy are empowered to access work and benefits and be able to live independently. The organisation is already writing to new cabinet ministers Liz Kendall, Secretary of State for Work and Pensions and James Timpson, Minister of State for Prisons, Parole and Probation, to canvass their support to achieve these goals.

Another big area of work is around the healthcare sector, with the organisation wanting to see epilepsy become a priority within health and social care, and for the shortage of neurologists and epilepsy specialist nurses (ESNs) to be addressed.

In previous years, epilepsy has not been a priority when it comes to government investment into research. In 2018, the previous government invested £82.5 million into dementia research, with a patient population of 850,000, equating to £97 per person. Only £12.8 million was invested into epilepsy research for a population of 600,000 (at the time), equating to £21 per person.

Adding to the pressures is the fact that the UK has one of the worst ratios of neurologists to patients. There are 1.1 equivalent neurologists per 100,000 people in the UK, whereas France and Germany had one consultant for 25,000 people or fewer [Nitkunan et al, 2020]. There are currently two ESNs to every 500,000 people in England, seven short of the NICE guidelines [RCP, 2011].

Alongside all of this, the mental health impact on people living with epilepsy is prevalent. A report from Epilepsy Action [2024] found that 85% of people with epilepsy reported having experienced anxiety, and 70% depression. Of responders, 69% said epilepsy had limited their independence and 50% reported feeling lonely or isolated. Nearly two thirds (64%) of responders said they waited up to six months for support.

Epilepsy Action wrote to Secretary of State for Health and Social Care, Wes Streeting, asking him to "step up and advocate" for people with epilepsy.

The letter said: "The Labour manifesto made a commitment to reduce health inequalities. Epilepsy care across the UK is plagued by such inequalities. Epilepsy prevalence and incidence are strongly associated with deprivation [Wigglesworth et al, 2023], with increasing rates of epilepsy in deprived areas as well as poorer outcomes for people with epilepsy in those areas.

"We ask for urgent investment in epilepsy and wider neurological services to reduce waiting times in line with NICE guidelines, additionally for you to recruit and develop a more sustainable work force.

"We require that Integrated Care Boards and Integrated Care systems ensure mental health safety is a requirement when planning transitions, services and associated pathways, with mental health assessments and referrals to be regular and appropriate.

"Alongside the Neurological Alliance, we are calling for a national Neuro Taskforce. This will strengthen the voice of people with epilepsy."

The new government has already ordered an independent investigation into the state of the NHS, to be led by Prof Lord Darzi. This is intended to provide a "raw and honest assessment" of the issues facing the NHS and will help inform the government's 10-year plan to "radically reform" the NHS.

Epilepsy Action will continue to advocate for people with epilepsy and campaign to ensure epilepsy and neurology services are properly funded and fit for purpose.

For more information, visit *epilepsy.org.uk/manifesto*

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Sleep apnoea and LOE

Night time hypoxia and late-onset epilepsy

Dr Christopher Carosella discusses the link between sleep apnoea and late-onset epilepsy in his study, future research directions and the importance of treating sleep problems in patients

Sleep apnoea and low oxygen levels during sleep (nocturnal hypoxia) are linked to late-onset epilepsy (LOE), according to a US study.

The researchers studied the relationship between sleep problems and LOE, building on previous small studies. The team used sleep characteristics data on more than 1,300 participants from the Sleep Heart Health Study. They also used Medicare claims to find those who developed LOE.

The results showed that people whose oxygen saturation fell below 80% during sleep were at a three-times greater risk of developing LOE. Participants who subsequently reported a diagnosis of sleep apnoea between 2011-13 were twice as likely to develop LOE.

The researchers said these risk factors were independent of other comorbidities, such as high blood pressure. The study was published in September 2023 in the journal Sleep.

Dr Christopher Carosella, assistant professor of Neurology at Johns Hopkins University, led the study. He spoke to Epilepsy Professional about what it means for clinicians treating patients with epilepsy.

"I trained as an epileptologist and greatly enjoyed my time working with people with epilepsy. However, I frequently felt my patients were underserved for their sleep needs and that my training was inadequate to truly help. With that in mind, I began my research career, looking at the ways in which sleep and epilepsy interact. Eventually, I realised that to truly learn more, I would need formal training, so I left my position to complete a sleep fellowship. Since that time I have tried to continue my work in this area.

"I came to this particular project knowing that epilepsy and sleep are well known to have a strongly intertwined and bidirectional relationship. In particular, the risk of sleep apnoea is significantly higher in people with epilepsy. While attending a talk at my institution from a more senior epilepsy physician, Dr Emily Johnson, who studies late onset epilepsy, I asked whether sleep apnoea was known to be among the risk factors for LOE development. She said she was not aware that it had ever been studied, and some discussions and literature reviews later, we devised this study.

"Sleep apnoea is well known to cause numerous downstream problems involving multiple organ systems, lungs, heart and cardiovascular system, brain and so on. Further, sleep apnoea has demonstrated a bidirectional relationship with seizures and epilepsy. Patients with epilepsy have a higher prevalence of sleep apnoea compared to the general population, and studies have demonstrated that treatment of sleep apnoea in persons with epilepsy may reduce seizure frequency [Lin et al, 2017]. However, exactly how sleep apnoea interacts with epilepsy, especially regarding risk for LOE, is not yet fully understood.

"We were surprised to learn that while sleep apnoea, in general, appeared to be a risk factor for development of late-onset epilepsy in our study [Carosella et al, 2024], the severity of sleep apnoea, as measured by apnoea hypoxia index (AHI), did not correlate with an increased risk of LOE. However, overnight hypoxia in this population was associated with increased risk, and on post-hoc analysis, there was an increased risk of LOE with worsening nocturnal hypoxia.

"Based on these results, we now hypothesise that recurrent nightly hypoxia, especially when severe, may, over time, contribute to the development of LOE. The positive counter to this idea is that since LOE occurs, definitionally, later in life, there may be time for clinicians to evaluate and treat potential risk factors, such as obstructive sleep apnoea (OSA) or nocturnal hypoxia. Research already exists, showing that sleep apnoea is common in patients with epilepsy and that treatment of OSA in patients with a diagnosis of epilepsy may significantly improve seizure frequency. However, this study may be an indicator that OSA and hypoxia may be a reversible driver of epilepsy development, though much more research would be needed to confirm this hypothesis. Discovering a reversible cause of epilepsy is an aspirational goal for any epilepsy researchers or clinicians.

We not hypothesise that recurrent nightly hypoxia, especially when severe, may, over time, contribute to the development of LOE


Christopher Carosella

"While our research, by its nature, cannot determine timing or even necessarily a causal link between sleep apnoea and the development of LOE, we do still feel that the data supports close evaluation and treatment of both conditions. My clinical opinion is that anyone experiencing sleep apnoea symptoms should speak to their doctors and be evaluated if appropriate. I also strongly believe that in persons with epilepsy, it is never too late to be evaluated for sleep apnoea and to get sleep apnoea treated if it is diagnosed. There is strong evidence that the treatment of sleep apnoea in people may help reduce seizure burden, and treatment of sleep apnoea has a number of other health benefits as well, not least of which is better sleep and waking up more refreshed and with more energy.

"Just like all healthcare professionals, clinicians who treat

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people with epilepsy have a lot on their plate and often, very reasonably, focus on a patient's seizure burden. I hope that research such as this helps direct epilepsy clinicians to take sleep and sleep complaints seriously, not only because it will help patients feel subjectively better, but because it may have serious seizure implications as well. I think that we, as a medical community, are starting to wake up (pun intended) to the importance of sleep in overall health and we as a community will need to get better at screening for sleep conditions.

"LOE is a relatively newly defined subcategory of epilepsy and much remains to be known and understood. We know that while this study demonstrated a relationship between sleep apnoea, nocturnal hypoxia and development of LOE, it is only one study and not without flaws. Further research will be needed to confirm this finding, and if it does, to understand the mechanisms behind how it may lead to LOE and, ultimately, whether these risk factors can be mitigated to prevent development or lower the risk of LOE. Further, we hope this study will encourage clinicians who care for people with epilepsy to take sleep very seriously and to evaluate and treat sleep disorders.

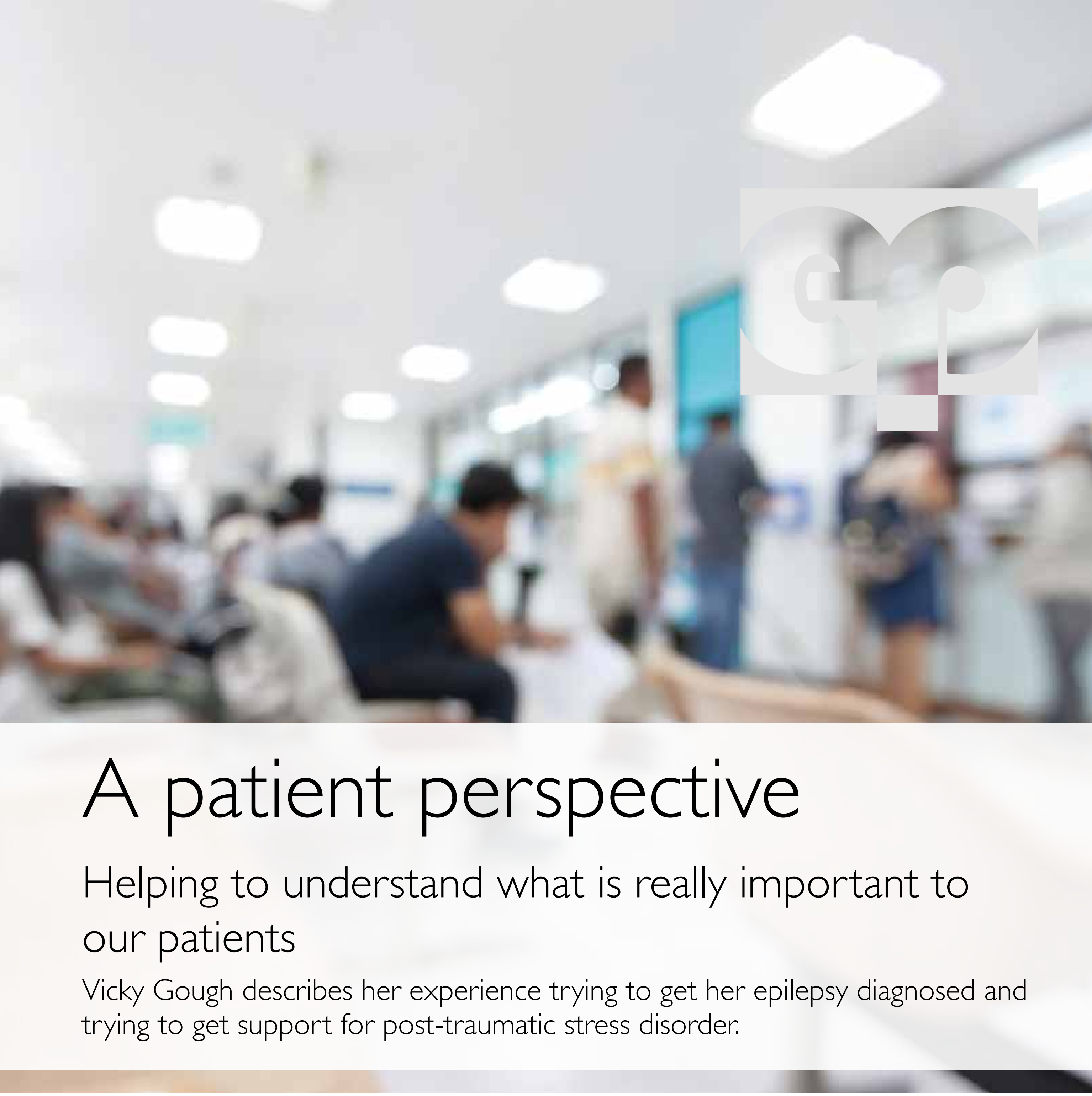
"When it comes to other neurological diseases associated with sleep apnoea, I think in this population, the strongest and maybe most important risk is with memory and development of dementia, particularly Alzheimer's dementia. Again, the mechanism for how sleep apnoea and dementia are associated is not well understood, but there is a strong link, and clinicians who study memory disorders have recently been at the forefront of advocating for the evaluation and treatment of sleep apnoea in this population.

"While I am not an expert in this area, researchers have looked at how sleep disruption and OSA can contribute to memory impairment, mild cognitive impairment (MCI) and dementia, especially Alzheimer's dementia and vascular dementia [Andrade et al, 2018]. To the best of my knowledge, no causal link could be established from the research that was done, but the evidence still shows a strong association between these diseases. Further, there is some preliminary evidence that treatment of OSA when present in patients with both OSA and MCI, may slow the progression of the MCI. Again, I will stress that these seem to be links and further research is definitely needed, but the evidence is strong enough that it has made it into various practice guidelines [American Academy of Sleep Medicine].

We hope this study will encourage clinicians who care for people with epilepsy to take sleep very seriously and to evaluate and treat sleep disorders

"While I think that those who treat epilepsy can lag behind in the area of properly addressing sleep concerns in patients, hopefully research such as ours will encourage the community to advocate for similar treatment."

Dr Christopher Carosella
Director of the Clinical Neurophysiology Laboratory
Kennedy Krieger Institute
Assistant professor of neurology
Johns Hopkins School of Medicine



A patient perspective

Helping to understand what is really important to our patients

Vicky Gough describes her experience trying to get her epilepsy diagnosed and trying to get support for post-traumatic stress disorder.

It is well understood that epilepsy brings with it a higher likelihood of mental health conditions. According to research, about 20% of people with epilepsy have anxiety [Rauh et al, 2022] but Mental Health UK says in the general population, around 1 in 10 have anxiety [Mental Health UK, 2019].

In depression, a bidirectional relationship has been widely recognised. In people with epilepsy, around a third have depression, which is nearly three times as much as the general population.

While less well explored and understood, studies have also suggested that people with epilepsy also have a higher prevalence of post-traumatic stress disorder (PTSD) [Soncin et al, 2021].

For National Epilepsy Week 2024, Epilepsy Action carried out a survey of 1,660 people with epilepsy. Of the responders, 87% said their mental health was affected. Half said they feel lonely or isolated and 69% said their epilepsy limited their independence.

Fifty nine percent of people said they were afraid of having seizures in front of others, and 31% of people said they had had suicidal thoughts.

This is a prevalent problem for people with epilepsy, but mental health services, and neurology services themselves, can be overstretched and difficult for people to access.

Vicky Gough, 49, was diagnosed with epilepsy at Christmas 2022. Her diagnosis followed an incident where she had a seizure while riding her bike on the road. She fell and injured her leg, needing stitches and months of physiotherapy.

Vicky said she was a prolific cyclist, owning three bikes. But after her seizure, she was left with epilepsy and PTSD, and she hasn't been able to get back on her bike. Vicky shares her experiences.

"The PTSD affects my life a lot. I have vivid dreams and flashbacks of when I was injured and being in the ambulance and A&E. When I see cyclists, I think they're going to fall off and get injured and I feel quite anxious and panicky.

"The lack of sleep from having bad dreams and feeling restless affects my epilepsy, as I don't function very well during the day if I have a bad night's sleep. I feel quite irritable and unsteady and this, in turn, affects my days and any plans need to be reconsidered. It definitely affects my ability to concentrate at work.

"Although both conditions affect me greatly, I feel the epilepsy is worse, as it's the concern of having no control over my body if another seizure should occur and of being vulnerable.

"When I had my first seizure in December 2022, when I was discharged, the hospital asked my GP to refer me to neurology. The referral was made to neurology at Worcestershire Acute Hospitals NHS Trust as this trust is within the catchment area for where I live.

"When I had my second seizure, which was again in December 2022, when I was discharged, Russell's Hall Hospital made another referral to neurology. This was to Dudley Group of Hospitals. Therefore, I was on the waiting lists of two hospital trusts.

"I started telephoning both hospitals at the early part of 2023 to find out where I was on the waiting list and who could offer me the earliest appointment. I recall being told my appointment would take place towards the end of the year due to severe backlogs.

"I couldn't stand the thought of being kept in limbo after everything that had happened and not knowing what was wrong with me. I was scared to go out of the house in case I had another seizure and I started to suffer with severe anxiety.

"My partner mentioned a few times about us looking to fund neurology privately as there was no way of telling how long it would be before I got an appointment with the NHS, let alone a diagnosis, and we were both extremely concerned. I didn't want to go down the private route because of the cost but to us there was no other option.

"For my PTSD, I had a telephone appointment with the NHS in June for an assessment about my mental health and to find out if they can assist. The team agreed that high intensity one-to-one therapy is the way forward for me, focusing on PTSD. But I am now on a waiting list, which is around 16 months, so I'll receive some information for coping mechanisms in the meantime. I feel I have no choice but to pay privately for this now too.

"I've had a couple of calls from the nurse practitioner at my GP surgery when I was prescribed sertraline after explaining how low I felt and how much my life had changed. But mostly, I feel as though I've been left to get on with things myself.

"Whenever I've contacted my GP about epilepsy related symptoms, they've said I need to discuss them with my neurologist, which is pushing me further towards privatisation as whenever I need to see him, there is a charge.

"I asked my GP specifically for a psychiatry referral, but she said it would be psychology and didn't think I could get psychiatry with the NHS.

"I'd like to see more in the way of support, especially for newly diagnosed patients. It has been, and still is, an extremely difficult time for me and having little contact from healthcare professionals makes the situation so much worse. I needed reassurance and support, especially in the early days instead of being left to make assumptions with little knowledge."

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Leaving on a high

Happy retirement to two influential ESNs

Epilepsy specialist nurse Juliet Bransgrove and epilepsy specialist midwife/nurse practitioner Kim Morley share some of their career highs and future hopes ahead of retiring this year.

Juliet Bransgrove
Epilepsy specialist nurse

Juliet started her career in 1984 at Broadland School of Nursing and has worked in several neurological conditions, including MS and Parkinson's disease, before becoming an epilepsy specialist nurse (ESN) and working to increase the number of ESN roles around the country.

Juliet recalled some of her favourite and proudest moments of her career.

"I trained in Norwich, 40 years ago, and ended my career back in Norfolk. "My nursing journey has been varied, eventful, exciting and fulfilling. My first qualified staff nurse job was at Oldchurch Hospital in Romford, Essex, on a neurosurgical ward. This was where my passion for neurology began and continued throughout my nursing career.

"I then moved on to the Royal London Hospital where I became a ward sister on a neurology and neurosurgical ward. It was the best time of ward nursing. I implemented team and named nursing. I took all the bed numbers off as it irritated me that patients were called by their bed number, or by their condition or what surgery they were having. Staff soon learned to call patients by their names, with a location on the ward. I don't think I was all that popular with the porters!

"Next stop was a two-year stint working at a local hospice in Chelmsford, Essex, while I had my two sons. I found this extremely rewarding, being able to give patients a good death. The care was second to none. My amusing memories were singing hymns on the landing and my first experience of working with women going through the menopause. I could not understand all the fanning with drug charts and borrowing each other's reading glasses to check the controlled drugs. Fast forward 20 years and I soon understood what it was all about!

"The Royal London had a young demographic of nurses, dealing with hangovers and relationship dramas. So, I often chuckled to myself singing hymns on the landing, thinking: 'If they could only see me now!'

"I was then head-hunted for my first specialist nurse post in multiple sclerosis at Colchester General Hospital in Essex. It was quite a transition from episodic inpatient care to working autonomously with a long-term caseload. I was not ready for the 'specialist' part of my job title and kept it a silent 'S' for a while.

"I really enjoyed working as part of a neurology rehabilitation team and setting up joint clinics with the allied health professionals. I worked with the service to create a generic rehab assistant role, they were an invaluable part of the team, pulling all disciplines together to achieve inter-disciplinary working.

It took a while to get the new ESN induction off the ground, simply because back in 2010 there were not many new posts being commissioned

"A new position as brain injury and motor neurone disease case manager came up. I saw that as a new challenge and was successful in getting the post. My biggest achievement was transferring a young man who had a brain stem infarction and who was ventilated from Stoke Mandeville Hospital to a local nursing home. This taught me a lot about communication and organisational skills.

"Then another specialist nurse role in the neurology rehabilitation team came up, this time in Parkinson's disease. I soon learned that the transferrable skills cross over quite nicely from one condition to another. I undertook the second Non-Medical Prescribing course in the country in 2004. I enjoyed the amount of autonomy it gave me in making prescribing decisions I felt competent and confident in.

"My team members would say: 'You've only got epilepsy to go', and I would say: 'That's way too complicated for me!' Little did I know that that role would turn out to be my favourite!

"Before that, though, I had time out of the NHS as I went on secondment to GlaxoSmithKline to a non-promotional role, providing service development for Parkinson's specialist nurses across the UK. I ended up staying for nine years instead of nine months. I ran a service called Healthy Alliance in partnership with Parkinson's UK, to deliver national conferences, a new nurse induction course and all sorts of other projects and resources. This taught me a lot about project management.

"My next step was to set up the same in epilepsy, an Epilepsy Alliance in partnership with Epilepsy Action. This was my introduction to the world of epilepsy, and I never looked back.

"It took a while to get the new ESN induction off the ground, simply because back in 2010 there were not many new posts being commissioned. It felt as if epilepsy was the Cinderella of neurological conditions, especially when it came to the number of ESNs. "We delivered two new ESN inductions a year based at Epilepsy Action's head office in Leeds. Year on year, this has gradually increased to four a year, all being delivered via Teams since the pandemic. This shows the steady growth in new ESN posts commissioned across paediatric and adult services. I also ran conferences and regional workshops, as well as helping design the first edition of the Professional Portfolio and ESN competencies in partnership with ESNA.


Juliet and her son Jack

"I was then successful in getting a job as a 'Sapphire epilepsy nurse consultant for epilepsy commissioning'. It was in this job that I became bilingual in clinical and commissioning speak. I toured the country speaking and presenting about epilepsy services and how to write business cases. I worked at York Clinical Commissioning Group (CCG) for two years, facilitating pathways and generating data to support service improvement across epilepsy and neurology.

"I also designed an epilepsy commissioning toolkit with Epilepsy Action. I never could imagine creating something like that in a clinical role. I worked across Epilepsy Action and Epilepsy Society representing both organisations.

"The ESN induction and regional workshops went from strength to strength. I got to know practically all the train networks across the UK. I also gained a distinction for my postgraduate certificate in the epilepsies at London South Bank University. It's amazing how you learn to study in later life. If only I'd applied that level of dedication to studying for my O and A levels!

"I worked with the Neurological Alliance designing the RightCare toolkit, and went to the NICE head office in Manchester to present the Epilepsy Commissioning Toolkit to them. Sitting in their prestigious offices, I thought: 'How did I get here?', a feeling common to me throughout my career.

"Then, an ESN post was advertised in Norfolk and my personal life also took me to Norfolk. It was one of my most tense and nerve-racking interviews, as I had been out of clinical practice for several years. I was thrilled to be offered the job. My manager at the time said: 'Good luck, there's no money in it', and I thought: 'Well, we'll see about that!' Within a month, I was in the neurology department at meeting with neurologists Dr Jeffrey Cochius and Dr Ekkehart Staufenberg, and commissioners, looking at neurology services across Norfolk.

"One commissioner, who later became a friend, asked the room: 'What's the one thing you'd like to see'. I gathered courage and said: 'More community ESNs'. We then met over coffee and chocolate digestives and wrote business cases. Every CCG at the time said: 'This is a no-brainer' and post by post was filled with the wonderful team we have today.

"The highlight and most rewarding part of my career has been consolidating my skills of business case writing and ESN experience to successfully to grow the ESN service within Norfolk Community Health and Care NHS Trust.

"I also feel immensely proud of writing the buccal midazolam Competency checklist with two esteemed ESNs Caryn Jory and Sally-Ann Remnant. This has made a huge difference to carers being able to deliver the emergency support for their patients. I'm proud of numerous research projects, working with ESNA editing buccal midazolam guidelines and nominating the Norwich Epilepsy Action group as volunteer group of the year.

"And I'm especially proud of watching the ESN team I work with now: June Greenway, Debbie Davey, Esther Cockram and Mellissa Oxborough, go from strength to strength. Seeing them implement efficient and effective delivery of care and instigate patient-led follow-up before it became a national acronym (PIFU), is the best a manager or 'boss lady', as they affectionately refer to me, could ever want.

"I'm proud of being able to leave the team knowing they will flourish without me."

Kim Morley
Epilepsy specialist midwife/nurse practitioner

Kim Morley started her career as a staff nurse at Joyce Green Hospital in Kent, working in infectious diseases. She then trained as a midwife at Princess Anne Hospital in Southampton and worked in Australia and the UK, building up her midwifery experience. In 2007, Kim established the Sapphire Community Epilepsy Specialist Nursing Service for adults in Southampton, and has since been working at the Hampshire Hospitals NHS Foundation Trust as an advanced clinical practitioner for maternity in epilepsy.

Kim recalled some of her proudest and most memorable moments throughout her career.

"I loved being a registered nurse. I then qualified as a registered midwife, working in the UK and abroad and gaining experience in the Australian outback that changed my life. I still treasure the memories of every single baby I have had the privilege of delivering. Being part of such a special moment in people's lives was, in itself, a highlight.

"Developing my skills in high-risk, complex pregnancies was equally rewarding and the impact of meticulous care provision was life-changing for many of those families.

"One day, I came across a family outside of work, bereaved from SUDEP of their loved one whose child had cranial facial anomalies, and this completely changed my career path. I felt both outcomes were potentially preventable.

"This started my interest in epilepsy and anti-seizure medicines (ASMs) and I joined Epilepsy Action. I read up about epilepsy and joined the national foetal anticonvulsant syndrome support group. I contacted researchers and geneticists studying the effects of ASMs and knew I had to raise patient and professional awareness. With no resources, I started a maternity pre-conception and pregnancy epilepsy service. This was the 'birth' of the first epilepsy specialist midwife in the UK.

"I have run this for 24 years for Hampshire Hospitals and formally Winchester and Eastleigh Healthcare Trust. I became our first and only midwife non-medical prescriber. During this time, I also established a Sapphire Community Epilepsy Specialist Service for Southampton for seven years and a secondary care epilepsy specialist nursing service for Hampshire Hospitals for four years.

"I am immensely proud of all three services. My highlights from this time were when my input completely transformed someone's life or that of their family, or when I prevented a new life being harmed.

"During my journey, I have met thousands of people with epilepsy and built up professional relationships with their care providers and epilepsy support networks. This includes the charities that are passionate about improving lives for people with epilepsy. I have cherished and gained experience from each one of these encounters, and I think of the epilepsy community as my other family. This extremely large family is flourishing so it is time for me to step back and treasure these memories and wish them all the best.

I came across a family outside of work, bereaved from SUDEP of their loved one whose child had cranial facial anomalies, and this completely changed my career path

"One of the proudest moments in my career was winning the Dr Hart Memorial Award for medical nursing. I'm also really proud of becoming a midwifery sister, when two years previously I was told I would never walk again. Other career highlights include: being the RCM National and Regional winner of the Mum's Midwife of the Year award in 2016, attending my graduation ceremony for a master's degree in advanced clinical practice in 2019 and presenting the neurology chapter for the organisation MBRRACE-UK in October 2023.


Kim

"The best part of being an epilepsy specialist nurse has been providing a personalised approach to care. The role is extensive and includes meticulous history taking, risk assessment and the provision of evidence-based information and education to help patients make wise choices and optimise their safety. This can include, for instance, advice about lifestyle, family planning, education, occupation, travelling and hobbies.

"Also, when you specialise in prescribing and deprescribing ASMs, you are able to improve lives through either action, but not without supporting people through this, often lengthy, titration process. Providing support to patients and their loved ones enables ESNs to build up trusted professional relationships and advocate on their behalf. I am immensely proud of all my patients, students, colleagues and other ESNs and the amazing things that many of them have achieved, no matter how small.

"From when I started to now, there is greater national and

Further reading

Epilepsy Action primary care commissioning book: *epilepsyaction-primary-care-commissioning-book.pdf*
RightCare Progressive Neurological Conditions toolkit: *www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2019/08/progressive-neuro-toolkit.pdf*
MBRRACE-UK: *www.npeu.ox.ac.uk/mbrrace-uk*
UK Epilepsy and Pregnancy Register: *www.epilepsyandpregnancy.co.uk*
Women with epilepsy: *www.womenwithepilepsy.co.uk/*
@epilepsymidwife

international awareness of the teratogenicity of ASMs. The research was not acknowledged in the early days because of it being underpowered or prospective, like the UK Epilepsy and Pregnancy Register. Knowing that this register is now up and running again and looking at the long-term effects of many of the ASMs during pregnancy fills me with great hope.

“From starting up my service, I was aware of the harms that drugs like valproate could cause, and lectured extensively about it. Those with children affected by ASMs in the womb triumphed in making their voices heard, but it took many years. Doing this journey with many of those families, I have witnessed tenacity and stoicism. Listening to the patients’ narrative and them feeling believed is essential in all care provision. This is improving in epilepsy care but because of service provision being fragmented or under-resourced in many areas, there is still a long way to go.

“Prescribing is a different landscape now, particularly for the generalised epilepsies. I have been conducting the valproate annual risk assessments since 2016, and supporting women coming off valproate before pregnancy for the decade before 2016. The epilepsy care I provide is very similar in pregnancy, but it is now better supported by the research evidence.

“From when I started out, SUDEP was rarely discussed in epilepsy care in pregnancy, but thanks to the charities, the bereaved families and MBRRACE-UK awareness, risk conversations have been integrated into care provision.

“During my career journey, I have helped pass on all these developments to Epilepsy Action through helping write the pregnancy and caring for babies' booklets and obstetric resource packs. I am grateful it continues to link to my website and maternity epilepsy toolkit, which will be updated next month.

“In the future, I hope that every woman with epilepsy has the opportunity to have expert pre-pregnancy counselling from diagnosis or teenage years before becoming pregnant. I hope that, through genomics, all medicines can be personalised with subsequent minimal risk of teratogenicity during pregnancy.

“It is always my aim to have a healthy mum and a healthy baby at the end of pregnancy and the postnatal year. I wish this for all women with epilepsy and this will not happen unless epilepsy services in pregnancy are properly funded and suitably staffed.

“I will continue to volunteer for MBRRACE-UK and in the coming years, and I hope to see a reduction in the pregnancy-related epilepsy deaths.

“In my retirement, I want to spend more time with my family and friends and enjoy my garden and my roses. I do intend to continue my work with the MHRA on the valproate committee until there is resolution and adequate tools in place reflecting emerging research. I shall also continue reviewing morbidities and mortalities and chapter group writing for MBRRACE-UK. I intend to update my website and start writing a professional book and continue to pursue my interests in epilepsy and functional neurological disorder through teaching nationally and internationally in low- and middle-income countries.”

Both Juliet and Kim have been a huge support to Epilepsy Action’s work and helped to make the lives of people with epilepsy immeasurably better. We would like to say thank you very much for the years of support and wish you a very happy retirement.

Highlights

Top picks from *Seizure*

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

Charles Darwin's principal work "The Origin of Species" (1859) is one of the key milestones along the route towards our discovery of human development and the relationship between humans and other living organisms. This book was undoubtedly a great scientific step forward. But, it also gave rise to some deeply problematic ideas: one being the pseudoscience of 'eugenics', i.e. the cleansing of humanity through the suppression of procreation of individuals thought to have inherited diseases and other unwanted traits. This was first proposed by Darwin's half-cousin Sir Francis Galton in his book "Hereditary Genius" in 1869. Epilepsy was among the diseases targeted by the eugenicists who turned Galton's ideas into laws intended to stop people with epilepsy from passing on their 'bad genes'. The forced sterilisation and euthanasia programme instituted in Germany in the 1940s represented the zenith of eugenic policies in action, but the last legal remnants of these ideas were only removed quite recently. For instance, in 1956 seventeen US states still prohibited people with epilepsy from marrying; the last US state only abolished this legal restriction in 1980. In the UK, a law forbidding people with epilepsy to get married was only repealed in 1970 [Anonymous, 2003].

The fact that eugenic regulations have been removed from statute books over the last decades may provide reassurance that the erroneous ideas which underpinned them are on the wane. However, they are still likely to contribute to the stigma associated with epilepsy and could easily be rekindled by reference to ever growing number of genetic risk factors for epilepsy [Zhang et al, 2023].

In this context, my editor's choice from volume 117 of Seizure, is a meta-analysis by Paolo Pierrino Mazzone et al [2024]. It provides its readers with urgently needed high quality information about the actual size of the risk of epilepsy and other neuropsychiatric or developmental disorders conferred by a maternal epilepsy diagnosis – with or without the additional factor of antiseizure medication (ASMs). Not unexpectedly, a maternal diagnosis of epilepsy increases the odds of a child being diagnosed with autistic spectrum disorder (ASD, odds ratio 1.67), attention-deficit/hyperactivity disorder (ADHD, odds ratio 1.59) or special educational needs (odds ratio 2.6). The relative risks continue to be elevated in women with epilepsy who did not take ASMs in pregnancy. However, the absolute risks of these pregnancy outcomes are low: a diagnosis of ASD was only made in 1.4%, one of ADHD in 4.9%, childhood epilepsy in 2.6% and intellectual disability in 0.9% of all children. These figures are based on unselected cohorts of mothers with a broad range of epilepsies, and the risk of having a baby with one of the listed outcomes is likely to be much higher or lower in particular circumstances. However, at a population level the size of these risks clearly demonstrates the fallacy of the eugenic policies of the past.

> **While pregnancy may be complicated by epilepsy, it has also been identified as a 'golden opportunity' for women with the condition to have their diagnosis and treatment reviewed**

Optimising pregnancy care
Medical students who visit my outpatient clinic are often amazed (or perhaps better: stunned) when they realise how much their understanding of what epilepsy is differs from the real-life challenges patients with this condition face. While talk about seizures or ASMs certainly features in most encounters, other issues are often much more pressing. Patients may not have had a seizure for nine months but still be unable to find work because they are not allowed to drive. Others are worried about going out on their own in case they have a seizure in public. Patients may seek help with symptoms of depression because their family doctor was concerned about antidepressants

lowering the seizure threshold. Women may want advice on contraceptive methods which do not interact with their epilepsy or ASMs.

Apart from realising that seizures, while only taking up a tiny proportion of a person's lifetime, have profound effects on many other aspects of life, the students learn that epilepsy does not only affect patients themselves but also their families and social circles.

Both of these features of epilepsy – that it is about more than the core symptoms of the condition itself and that it also affects people close to the person with epilepsy – are particularly relevant in pregnancy. Pregnancy may be a 'natural' phenomenon in the life cycle of mammals but, for good reasons, it has become heavily medicalised. In developed countries, pregnant women have to navigate a system of medical and maternity care which can become quite complex when they have a medical condition. While pregnancy may be complicated by epilepsy [Shahla and Aytan, 2024], it has also been identified as a 'golden opportunity' for women with the condition to have their diagnosis and treatment reviewed and optimised [Leach et al, 2017]. However, for this process to work, women have to know how to access advice, clinicians have to be aware of the evidence they should impart, and service providers in different specialities or organisations have to communicate and collaborate with each other.

My editor's choice from volume 118 of Seizure, a systematic review by Anna Hughes et al [2024] provides insights about how pregnancy care can be optimised. Of the five themes, only one is a facilitator: several of the 16 original publications which contributed to the review identified high levels of practitioner motivation to improve services. Four themes identified hurdles: while knowledge about the management of epilepsy in pregnancy is generally quite good, practitioners may struggle to apply this knowledge in individual circumstances. Communication of knowledge can be difficult, especially when patients have intellectual difficulties. The necessities of sharing the care between epilepsy and obstetric specialists create challenges of interaction. And – last but not least – clinicians have little time, and resources (including guidelines) may be lacking. Alternatively different sets of guidelines may conflict with each other.

Readers motivated to tackle the challenges and make the best of the 'golden opportunity to improve pregnancy outcomes and also the epilepsy management of women beyond pregnancy are referred to a multispeciality paper previously published in Seizure. It makes specific suggestions for patients with epilepsy, obstetricians and midwifes, neurologists and specialist epilepsy nurses, pharmacists, emergency department physicians, primary care providers and epilepsy service commissioners [Leach et al, 2017].

Psychological intervention for FDS

The last three decades have witnessed a steadily accelerating interest in what the International League Against Epilepsy (ILAE) may soon call functional/dissociative seizures (FDS, the forward slash in this label suggests that the terms 'functional' or 'dissociative' may also be used on their own). It is likely that this interest was initially sparked by the fact that better access to video-EEG (and learning from video-EEG studies) had increased the confidence of clinicians to distinguish FDS disorders more clearly from epilepsy [Reuber and Elger, 2003]. As patient cohorts grew, studies described predisposing, precipitating and perpetuating psychological, social and biographical factors characterised the aetiology of FDS with increasing confidence and granularity [Brown and Reuber, 2016a].

Although this research demonstrated that there was aetiological heterogeneity [Hingray et al, 2022], FDS have come to be understood as an involuntary response akin to a conditioned reflex [Brown and Reuber, 2016b], typically manifesting in the context of abnormal emotion processing [Williams et al, 2018]. This understanding of FDS provides a clear rationale for psychological therapies, and an impressive number of psychological treatment studies have now been published. However, while most experts consider them as the treatment of choice, many patients with FDS (even in high income countries) still cannot access such interventions [Hingray et al, 2018]. One important reason for the lack of access is that healthcare commissioners still need to be persuaded that such therapies are effective.

My editor's choice from volume 119 of Seizure, a systematic review and meta-analysis of seizure frequency and severity outcomes of psychological treatments for FDS by Chris Gaskell et al [2024] may help with this. This research follows on from previous work by the same group demonstrating improvements in non-seizure outcomes associated with psychological interventions for FDS [Gaskell et al, 2023]. The current meta-analysis of 44 studies involving 1,300 patients arrived at a pooled estimate for seizure freedom at the end of treatment of 40% and a pooled rate for ≥50% improvement in seizure frequency of 66%. Improvements were not lost during follow-up. At group level, the pooled seizure frequency improvement achieved a moderate effect size (d = 0.53). FDS frequency reduced by a median of 6.5 seizures per month.

This systematic review and meta-analysis also identified weaknesses of the research examining the effectiveness of psychological treatments in patients with FDS. Over three quarters of studies were deemed to be at high or medium risk of bias (mainly due to small study size and the inclusion of unblinded observational studies). This means that there is more work to do.

However, the most impressive study contributing to the findings by Gaskell et al (the CODES trial involving the randomisation of 368 patients) [Goldstein et al, 2020] had a low risk of bias. Patients in the psychological intervention group in this trial did significantly better than patients only receiving standardised medical care in 9 of 17 outcomes (and worse in none). Combined with this, the paper by Gaskell et al will hopefully ensure that more patients with FDS come another step closer to gaining access to treatments which can help them.

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Research update

Epilepsy Action health improvement and research manager, Tom Shillito shares updates from Epilepsy Action's research work

It's been an exciting few months for the Excellence Collective! We've been engaging with lots of people from across the epilepsy community, and have seen a big increase in people signing up to become members. Now we've become such busy hub of epilepsy activity, we'll be holding our first Excellence Collective meetings very soon. This will kick off our programme of engagement events for members- more details will be announced very soon!

If you'd like to be part of the Excellence Collective, you can sign up for free at epilepsy.org.uk/ExCo. Members get access to:

- Our information warehouse, including our repository of epilepsy statistics and facts, our examples of best practice, our toolkits, and our guidelines and supporting documents for healthcare professionals and commissioners
- Regular updates from across the Collective, covering both the projects we are running within Epilpesy Action and the work that our members are carrying out across the country
- Access to our network of health and social care professionals, researchers, policymakers and people affected by epilepsy
- Members are also eligible to apply for our new quality improvement bursaries!

Quality Improvement Bursaries

As part of the Excellence Collective, we have reviewed how we can work in partnership with healthcare professionals to make a difference for people affected by epilepsy. One of the best ways we can do this is by making quality improvement easier for the people delivering healthcare. For this reason, we are launching our Excellence Collective bursaries this summer.

We are looking for healthcare quality improvement projects which will improve the experiences people with epilepsy have within the NHS. We are interested in projects which can be tested within one service, and the findings shared across the country as an example of best practice. This will allow your work to have an even bigger impact on the lives of people with epilepsy.

These bursaries will award up to £5000, which can be used to reimburse staff time or support data analysis. To qualify you must:

- Be a member of the Excellence Collective and a nurse or professional member of Epilepsy Action
- Propose a project which will

improve an aspect of care for people affected by epilepsy
- Create a detailed project plan and budget
- Be willing to dedicate time to test the idea in a structured way and formally report your methods, results and outcomes
- Your findings must be able to be shared and applied by other healthcare professionals across the UK

If you would like to find out more about the bursaries, including how to apply, please join the Excellence Collective and contact researchadmin@epilepsy.org.uk

Hearing Patient's Voices

Sodium Valproate

We have heard from Excellence Collective members that clinicians and service managers are eager to hear from women with lived experience of being prescribed sodium valproate. They would like to understand their experiences to inform how the new prescribing measures will be implemented locally. We have had many requests over the past few months for volunteers who could speak to professionals to help guide them on this topic. It has been challenging to find women living in each region with this experience, as there are very few women still being prescribed valproate, and even fewer who are comfortable sharing their experiences.

To make it easier for professionals to hear from women with this experience, we will be hosting an online sodium valproate patient voice event on Wednesday 21st August at 2pm. This event is an opportunity for professionals to meet a panel of women who are taking sodium valproate currently, or have taken it in the past. We will be asking our volunteers to share their experiences and to tell us how they would want the new valproate measures to be implemented. There will be a Q&A session where you can ask questions specific to your trust/system. We will also have some talks from neurologists and nurses on how they have included the patient voice in their planning. If you would like to join this event, or submit a question to the panel, please join the Excellence Collective and visit [link]. If you're not able to attend live, the recording will be made available for Excellence Collective members.

Lived Experience Volunteers

It is vital to listen to the voices of people affected by epilepsy, to make sure all of the work we do is relevant and helpful to them. Everyone within the epilepsy community wants to tackle the problems that people with epilepsy face, and the best way to do that is to speak to them, hear what barriers they face and understand how they would like things to change.

To support our members in doing this, we will soon be expanding our group of lived experience volunteers. We currently have 80 volunteers who are trained to give feedback on research and healthcare quality improvement projects, as well as taking part in focus groups and consultations for a range of healthcare topics. We will be opening recruitment to even more volunteers in the summer, to enable us to support even more consultation projects.

If you would like to find out what people living with epilepsy and their carers would like, what barriers they face and what they have found useful in their healthcare journey, please get in touch. We can also support patient and public involvement in research projects, from promoting surveys to running patient advisory panels. For more information, join the Excellence Collective and contact researchadmin@epilepsy.org.uk

Loose change: unintended consequences

We have a new Labour government that campaigned under the slogan “Change”. It is worth sparing a momentary thought for the apocryphal words attributed to the Marquess of Salisbury, when approached by an assistant about the need for change: “Change? Change? Aren't things bad enough as they are?”

Without wanting to resort to cynicism or pessimism, even the best-intentioned interventions have the potential to blow up in your face. Continuing on the political theme, the unintended consequence of right-wing Reform gaining so much popular support in the general election has to be to hand the UK a centre-left government.

Unintended consequences? Fairy stories abound with the trope of wishes that rebound on the wisher. And myth godfather Midas (holding a golden fountain pen) could write a book on them. Max Boyce, the Welsh Rugby-obsessed folk singer ends ‘Divine Intervention’ (1976) with a small prayer from an English rugby fan watching his team play Wales. (For this, reader, you will need to know that orthopaedic surgeon and rugby player Mr JPR Williams never lost a rugby game against England.) It goes: “And he asked, ‘Oh Lord please let us see a try, we are losing I can tell. Oh Lord let us see a try, something absolutely twiffic.’ And then JPR scored again and God said, ‘You should have been specific’.”

One of the theories behind piloting major policy is to ensure that people are not using the new guidelines (for example) to game the system, or that the innovation does not unintentionally discriminate against a certain patient group. So, what to do when change is predicated upon new data and the concern is that to drag your feet on brining in the new change may comprise a safety issue?

But we have crossed the Rubicon, and we are through the looking glass now with regards to the level of risk to a developing foetus that we must communicate to women and men of child-baring potential. Currently there are false equivalents drawn between the risks if women take valproate (sizable and underpinned by robust research data) versus when men take the drug (less of an impact, and a flimsier clinical and mechanistic research foundation). I presume that any future drug that carries that ballpark-risk will need to be communicated via an annual form. But why are we not consenting women and men who take drugs of unknown risk on an annual basis? What about cumulative non-drug risks? Do we need to speak to women every year if they’ve had a child with a prior malformation, and they are heavy drinkers, for example? The unintended consequences of the valproate paperwork-exercises include: diverting the limited resource of clinical time towards a cohort of well, working-aged adults and away from people with active epilepsy; the creation of a new standard of what level of research evidence creates policy; and I do fear that this is another turn-off for future epileptologists. Doctors and nurses in training want to be healing the sick, not counselling the well.

Within the NHS, which is financially threadbare, any new edict that comes without budgetary support, or even an implementation plan, is set up to fail. It would be akin to coming home one day and telling your spouse that ‘we must now send our kids to private school’, but there is no bursary or savings left for this. There would have to be cuts to other parts of the household budget, and you’d need to know how to cope with childcare in the longer school holidays. It’s one thing to say ‘this must happen’, but it is, at best, unrealistic. George RR Martin’s Game of Thrones says: “Words are wind”. Manic Street Preachers in Despair to Where insist that: “Words are never enough. Just cheap tarnished glitter”. I do trust that the super UK epilepsy community can step up and do what’s right for their patients. But if words are cheap, you can buy them with loose change.

Dates for the diary

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

20-27 July
6th ILAE School on Advanced EEG and Epilepsy
Dianalund, Denmark
bit.ly/3xqeGSp

7-11 September
15th European Epilepsy Congress
Rome, Italy
bit.ly/45p17Pg

15-20 September
10th Eilat International Educational Course: Pharmacological Treatment of Epilepsy
Limassol, Cyprus
www.eilatedu.com

19-22 September
14th International Summer School for Neuropathology and Epilepsy Surgery
Erlangen, Germany
bit.ly/3UCYOWp

23 September
ILAE British Branch Annual Scientific Meeting, Liverpool, UK
bit.ly/3Gjx8gO

2025

2-4 April
International Congress on Structural Epilepsy & Symptomatic Seizures 2025
Gothenburg, Sweden
bit.ly/3X8FlOt

30 August-3 September
36th International Epilepsy Congress
Lisbon, Portugal
bit.ly/3uz1ARq

2026

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

Next issues:

Prof Rohit Shankar

Prof Shankar speaks to Epilepsy Professional about how to discuss SUDEP with patients and why sometimes conversations aren't happening

Castañeda and Ultanir

Marisol Castaneda and Dr Sila Ultanir describe new therapeutic targets for CDKL5 deficiency disorder

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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