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Epilepsy Today

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The community shares what absence seizures feel like p22

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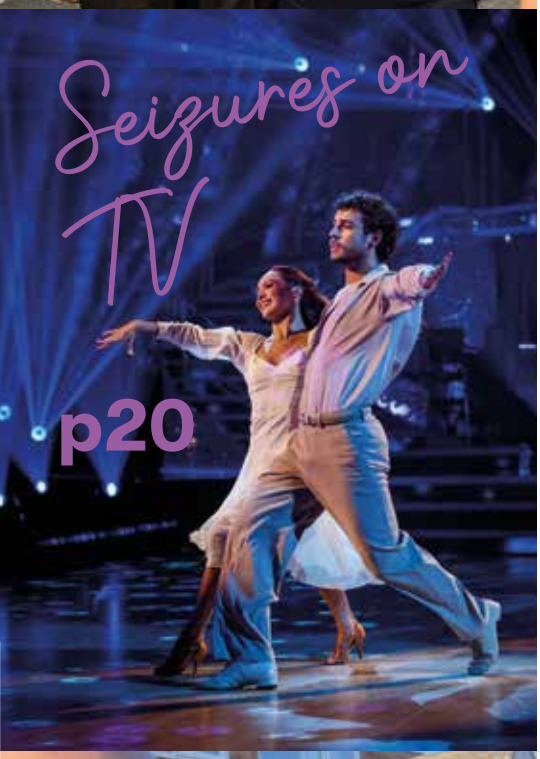

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Community

There's something powerful about a community. A sense of belonging and togetherness, support and safety. Being surrounded by people who you can rely on, and who can rely on you. This issue, we are launching our new community (page 10), and many of the stories reflect why this is something we all need.

No one exemplifies this better than our cover stars, Charlotte and Allie. When Charlotte had a tonic-clonic seizure in a Sheffield shopping centre causing a severe injury to her head, Allie found her and protected her head, very likely saving Charlotte's life (read more on page 12).

When you're not sure what you're experiencing, community holds answers, whether you're wondering about absence seizures (page 22) or you're a health professional learning from your peers' research (page 24).

You can also read about recent epilepsy representation on TV (page 20), how Aidan broke a rowing record (page 18), how two teens showed bravery and knowledge on flights to support their parents (page 26) and what turned Jez's decades-long streak of seizures around to see him back behind the wheel (page 28).

Thank you for being part of our community!

I hope you enjoy this issue!

Kami Kountcheva
Editor

Good news

At Epilepsy Action, we want to celebrate the good things in our community. If you want to be featured, email kkountcheva@epilepsy.org.uk

Hospitality company receives training to support employees with epilepsy

Epilepsy Action has helped UK hospitality company BaxterStorey train up 24 of its mangers as Epilepsy Champions through epilepsy awareness training.

The company is aiming to train up at least another 12 managers in early 2026, saying it hopes this will encourage more of their employees to open up about their epilepsy so they can receive the support they need.

Jo Gater is a chef manager at BaxterStorey and has had epilepsy since early childhood. She has experienced stigma around her epilepsy and has even been turned away from jobs because of it.

While she says she "takes pride in keeping up with the pace" of what she calls a "high-, fast-paced environment", knowing that her health and safety is properly considered is really important to her.

Jo said: "I've been in workplaces where health and safety support wasn't properly in place. I challenged it, because anything can happen to anyone, epilepsy or not. People aren't always born with it, and workplaces need to be prepared."

Following BaxterStorey introducing Epilepsy Champions, Jo said: "It makes a huge difference to know you can talk openly, without judgement. Epilepsy can be overwhelming, but when your company recognises that and offers support, it helps you keep going."

The training from Epilepsy Action includes first-aid information, as well as how epilepsy affects daily life and people in the workplace. Epilepsy Champions receive unique training that enables them to support their colleagues with epilepsy.

Simon Privett, learning and training lead at Epilepsy Action said: "At Epilepsy Action, we believe that people with epilepsy should be supported to live a life without limits – and that includes in the workplace.

"With employment rates for people with epilepsy still worryingly low, it's inspiring to see BaxterStorey taking such a proactive and meaningful approach.

"From the moment they reached out to us, it was clear that BaxterStorey was committed to developing a robust training programme to upskill their teams, empower their managers, and establish Epilepsy Champions to provide dedicated support for colleagues with epilepsy.

"Being in the workplace can be extremely daunting for people with epilepsy, especially if adequate adjustments and training are not in place.

"An Epilepsy Action survey (2023) revealed that 60% of respondents with epilepsy had faced some form of discrimination or unfair treatment in the workplace, and 42% of employers admitted they would be inclined not to hire someone with epilepsy because of the potential challenges.

"These statistics are shocking, but, unfortunately, we do hear many anecdotal stories from our supporters highlighting that this is still a big concern.

"This partnership is a strong example of how organisations can lead the way in creating inclusive workplaces where people with epilepsy are supported to thrive."

Lyndsey Oliver, head of equity, diversity and inclusion at BaxterStorey, said: "We're proud to be leading the way for the hospitality industry with our partnership with Epilepsy Action.

"Our people are the heart of our business, and creating an environment where everyone feels seen and supported is non-negotiable.

"Our 24 Epilepsy Champions will play a vital role in helping us embed inclusivity into our everyday culture."

You can find out more about Epilepsy Action's training and e-learning courses on the Epilepsy Action website.

Sacked after a seizure – new service helps fight back

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.

According to the latest government data, only 33% of people with epilepsy are in employment. This is the second lowest employment rate of any disabled group in the UK.

Previous research from Epilepsy Action has shown that one in three people with epilepsy have been bullied at work and six in 10 say they have faced discrimination because of their condition.

Almost half of employers taking part in the research admitted they would be reluctant to recruit someone with epilepsy.

Epilepsy Action and Slater and Gordon will also work with employers to raise awareness, improve understanding of reasonable workplace adjustments and promote inclusive practices.

Louise (name changed for confidentiality) has faced problems at work because of her epilepsy. After moving to the UK to build a new life and career, the 34-year-old was offered her first teaching role after completing a master's degree in education.

But just weeks later, she was sacked after having a seizure at work, and told she should have declared her epilepsy on her job application.

Louise said: "I didn't mention my epilepsy because I was scared I wouldn't be given a chance, as that has always been how things have gone for me in the past.

"Losing my job was devastating and it still affects me now. You try to move on, but it knocks your confidence and makes you question your worth."

Louise said she could have really benefitted from something like the new service from Epilepsy Action.

"I think this partnership is such a brilliant idea. Having that kind of support would have made a huge difference to me at the time – just knowing someone understood and could stand up for me.

"I'd hate for anyone else to go through what I did and it's reassuring to know that now people have somewhere to turn for help and hope."

To find out more about the service, contact the Epilepsy Action Helpline at **epilepsy.org.uk/support-for-you** or by calling 0808 800 5050.

Epilepsy news

People with learning disabilities die significantly younger from epilepsy

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

Kami Kountcheva

receive the epilepsy care and treatment that they should.

"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.

"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.

"The evidence is clear the NHS must act urgently to deliver proactive, coordinated, equitable care, so that everyone with epilepsy and a learning disability has the chance to live a longer, healthier life."

Epilepsy Action has also developed a guidance to describe what good quality integrated services for people with a learning disability should look like, Step Together. The organisation also has easy read epilepsy information, helpful for people with a learning disability or those whose first language isn't English.

People from ethnic minorities lack access to epilepsy care

People belonging to ethnic minorities are lacking access to epilepsy care, according to a new study from Manchester, published in Seizure journal.

The researchers studied 1,609 adults attending Manchester Centre for Clinical Neurosciences between 2020 and 2024.

They found that people from Asian, Black and Mixed backgrounds were underrepresented in the clinic compared to census data.

Asian people make up 13.6% of the demographic of Greater Manchester but only made up 6.4% of the demographic of the adults attending the clinic.

Similarly, Black and Mixed-race people make up 4% and 3% of the Greater Manchester population respectively, but only 1.4% and 1.7% of the patients attending the clinic.

Researchers Natasha Carmichael and the team concluded that disparities in access to treatment was a predominant issue, as people from ethnic minorities had similar outcomes to the White population once they were receiving specialist care.

Ms Carmichael explained that cultural, practical and system-level issues could be barriers to access to care for these communities. She said: "Although our study didn't look directly at why some people have more difficulty accessing care than others, previous research suggests there are several likely reasons.

"Previous studies suggest that perceptions of epilepsy, stigma, and differing health beliefs within some ethnic minority communities can influence help-seeking behaviours and engagement with healthcare services.

"Language barriers, employment constraints, transport difficulties, and other logistical challenges associated with attending appointments may disproportionately affect underrepresented ethnic minority groups.

"In our dataset, most people from ethnic minority backgrounds lived in the most deprived areas. Previous research shows that people living in deprivation often face greater challenges with work and transport, such as unsociable working hours or reliance on unreliable public transport, which can make attending healthcare appointments more difficult.

"How people are referred between services, unconscious bias, and differences in how well healthcare providers engage with and reach out to local communities are also issues to address."

Ms Carmichael said the research found that "the majority of patients attending the epilepsy clinic came from the most deprived areas, highlighting that epilepsy disproportionately affects socioeconomically deprived populations.

"We also observed that most patients from ethnic minority backgrounds in our study lived in more deprived areas,

indicating that deprivation and ethnicity were closely linked within our cohort.

"However, the number of individuals from ethnic minority groups was too small to robustly assess whether deprivation contributed to their underrepresentation or modified outcomes differently within these groups."

Previous research has also confirmed that socioeconomic deprivation is linked to incidence of epilepsy. A study by Dr Kathryn Bush in 2024 found that there was greater risk of epilepsy incidence in high- and medium-deprivation groups, compared to low.

The team also proposed pathways to help reduce this inequality in epilepsy service access among ethnic minorities, including destigmatising epilepsy, cultural awareness for professionals and support for socioeconomically deprived communities.

Kami Kountcheva

Football training

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

The landmark training session was carried out at Stamford Bridge by Epilepsy Action, equipping staff with the confidence and practical skills to recognise seizures and respond quickly.

Lifelong Chelsea supporter Tracy Brown said this is "genuinely transformative".

Lisa Greer

Knowledge into practice

A man from Atlanta, US, said he was "taken aback by the timing" after seeing someone have a seizure in an airport in November last year, the day after receiving epilepsy training.

Jeff Delong, senior director of strategic partnerships at Worldpay, had a chance to put the training into practice when a woman started having a tonic-clonic seizure near security. He was prepared to help and felt "reassured" as he could tell the woman was okay.

Kami Kountcheva

Research finds strategy for adjusting medication doses in pregnancy

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.

A previous MBRRACE report from 2023, showed that deaths from sudden unexpected death in epilepsy (SUDEP) in mothers with epilepsy had doubled between 2013-15 and 2019-2021.

Epilepsy Action says there is a higher risk of death during pregnancy or 12 months after giving birth in people with epilepsy compared to those without. 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."

The Traitors contestant recovers from "terrifying" seizure

Kami Kountcheva

Former contestant on The Traitors, Charlotte Chilton, has had an "absolutely terrifying" seizure following brain surgery over the festive period, it is reported.

Charlotte, who featured on the hit BBC series' second season, has a condition called trigeminal neuralgia (TN), in which people can experience sudden, severe pain in areas of the face including the jaw, teeth or gums.

Charlotte posted a picture on her Instagram on 14 December in a hospital gown, sharing that she had been rushed to A&E following "a huge attack".

While recovering at home, reports say she had a seizure and collapsed. It is believed the seizure was caused by medication she was taking.

Wes Streeting commits to respond on valproate redress before next election

Health Secretary Wes Streeting has said he will respond to the Hughes Report's redress recommendations for families affected by the valproate scandal before the next general election.

Speaking to ITV on Thursday 12 February, the Health Secretary acknowledged how long families have been waiting for support, calling the criticisms a "fair and understandable challenge".

He said: "I am working actively with colleagues right across government to make sure that we respond to the Hughes Report in a way that's fair to the victims of this scandal.

"Given how long families have campaigned, I can well understand why they are critical, having waited so long, and I've got to take that criticism on the chin.

"I'm sorry to families that they have been waiting this long. I'm asking people to bear with me, but we will get there."

However, Epilepsy Action said families need "more than warm words".

Alison Fuller, director of health improvement and influencing at Epilepsy Action, said: "For families affected by sodium valproate this is a matter of urgency given the reality they live with every single day.

"Many have waited years while raising children with complex needs, still hoping for the recognition and support they were promised.

"So, while it is encouraging to hear the Health Secretary, Wes Streeting, stating that he will respond to the Hughes Report, families need more than warm words, they need clarity, a timetable and a clear route to delivery.

"Every acknowledgement understandably raises hope, but when detail doesn't follow that hope quickly turns back to uncertainty and further despair.

"What matters now is not another statement but action – turning this promise into something tangible, fair and transparent and delivered without further delay."

The government's response follows a debate in Parliament on Wednesday 11 February about the Hughes Report, with MPs urging for more clarity and commitment.

MP for Chelmsford Marie Goldman called the response from the government on the issue so far "rubbish, useless and uncaring".

Epilepsy Action is due to hold a roundtable in March with MPs and Peers to speak about redress for those harmed by sodium valproate.

The roundtable will bring together MPs, patient groups and the Patient Safety Commissioner to discuss a way forward and press the government for a timeline, ensuring patient groups are part of the conversation.

Med shortages hit epilepsy harder

More than seven in 10 people with epilepsy in the UK experienced difficulty getting their prescribed epilepsy medication in the past year, according to a new study published in the journal Pharmacy.

Researchers Eric Kyeremaa and colleagues set out to explore the impact of anti-seizure medication (ASMs) shortages on people with epilepsy and their caregivers.

Eric said: "We knew this was important because people with epilepsy were increasingly reporting shortages of their epilepsy medications through epilepsy charity helplines.

"These reports showed a real worry within the community, so it was felt to be essential to carry out a survey to understand how widespread the problem was and what impact it might have on people with epilepsy and their caregivers."

An online survey was distributed between January and April 2024. There were 1,312 responses from people with epilepsy and their carers.

Shortages were most commonly reported for carbamazepine (92.6%), clobazam (82.6%) and topiramate (81.5%), but also included sodium valproate (60.8%), lamotrigine (65.2%), levetiracetam (62.8%), zonisamide (74.0%), lacosamide (71.0%) and brivaracetam (70.5%).

Two in five people (40.4%) reported stress, anxiety or both caused by the medication shortages.

The study authors added: "Normally, about one in five people report problems getting their medicines in a typical year. But for families affected by epilepsy, this figure was reported by respondents to be much higher with one in three experiencing problems.

"This shows that shortages may be hitting people with epilepsy harder than others."

The authors said problems could also be down to the local supply chain and said the NHS should develop ways to minimise disruption to the supply chain.

Kami Kountcheva

Supporter engagement manager Crispin Northey shares the launch of our new community

We're thrilled to officially launch our new community of support to all our members.

Last year, thousands of you took part in our membership review through surveys and focus groups. What you told us was powerful. You made it clear that being part of Epilepsy Action has never been about perks or discounts. It's about purpose. It's about belonging to something that matters.

You told us you value the free services we provide, the change we drive, and the supportive community that surrounds you. One member summed it up perfectly: **"It's not about benefits. It's about having someone on your side. You don't feel like you're the only one anymore."**

That insight shaped a major decision. We are going to open up our membership and make it more inclusive, welcoming our incredible regular givers and volunteers into the heart of the community.

Over the past few months, we've been calling members to explain the change: that your payments will no longer be an annual subscription, but continue as a regular donation powering a world without limits for people with epilepsy.

The response has been extraordinary. The vast majority of members have embraced the change, and almost a third chose to switch to monthly giving and increase their support. Many of you also agreed to receive Epilepsy Today by email to help us reduce costs and strengthen our long-term sustainability goal.

If we weren't able to reach you, please don't worry. We'll be in touch again around what would have been your renewal date to make sure you have all the information you need and the opportunity to decide what's right for you.

Epilepsy can be isolating, life-changing and invisible to others, yet overwhelming for those living with it. That's why Epilepsy Action exists: not just as a charity, but as a lifeline, a trusted voice, and a place where people truly understand.

One survey responder told us that being part of this community gave them **"something to hold on to when I felt completely lost. Epilepsy Action were there when no one else was. I joined because I wanted to give something back."**

Another said: **"Sometimes all it takes is someone asking how you are. If my donation means someone else gets the help I got, that's enough."**

This new community of support is a movement that sustains vital services like our free helpline, Talk & Support, peer groups, and 1:1 Peer Support check-ins that help people feel less alone.

And giving is just one way to stand with us. Many members are volunteer champions, sharing their time, voice and lived experience to make a difference. Whether you support people locally, join our Action Team or become a community fundraising champion, there's a place for you to lead, inspire and connect.

As one member put it: **"I want to be seen as someone who's helping, not just consuming. Even when I don't need them now, I keep the connection. I'm still part of it."**

We're also working with trusted partners to build some discounts and offers for members of our community. So watch this space.

Thank you. You've shown us that, for you, this is more than giving. It's belonging. It's standing up. It's showing up for others and for yourself.

Whether you give, volunteer or advocate, you are helping build a world without limits for people with epilepsy. You're helping someone feel seen, supported and safe.

Thank you for being part of this extraordinary community.

N.B. If you were unable to take our call and would also like to adjust the amount or frequency you give then please call our team on 0113 2108810.

Thank *you*

Peer support officer Cathryn Hampshire extends our gratitude to retiring longstanding volunteer Caroline Brown.

This spring, we extend our sincere thanks to Caroline Brown as she retires from her volunteering role with Epilepsy Action. Caroline founded the Aberystwyth support group in 2009 alongside two other mother and daughter families living with epilepsy in the local area, officially joining Epilepsy Action as a Coffee and Chat volunteer later that year.

Caroline's passion for epilepsy support has always been clear. In 2014, she became an ambassador and campaign leader in Hywel Dda, advocating for the introduction of epilepsy specialist nurses. She was recognised as an accredited volunteer, providing information and delivering presentations to schools and many organisations.

A true ambassador for epilepsy awareness, Caroline has been a steady, caring presence within the Aberystwyth group and across Wales ever since.

Her kindness, reliability and commitment have helped create a welcoming space for people affected by epilepsy. Caroline's contribution has made a real difference, and her impact will continue to be felt.

Wales manager Janet Paterson said: "I've had the privilege of knowing and working with Caroline since I first joined in September 2016, and she has been a constant source of support, kindness, and encouragement, not just to me, but to so many of our volunteers. Her dedication has made such a difference over the years."

We're also delighted that her daughter, Christina, remains a strong lead contact for the group, continuing the family's dedication to supporting the local community.

We are deeply grateful for everything Caroline has given and wish her a happy and fulfilling retirement.

Guide our *future*

Become a part of the Board of Trustees

Over the coming months, we will be appointing up to four new trustees to be part of our Board and lead the strategic direction of Epilepsy Action over the next few years. This is a voluntary role with the responsibility for making sure that the charity meets its strategic aims and objectives and provides the governance and oversight set out by the Charity Commission.

This is a really exciting time to join our Board. Our income has reached record levels and in September, when this role would start, we will review the first three years of our strategic plan, how far we have come and what the next three years will look like for the charity.

We will be advertising the roles, with more information about skills and experience, from the end of March. If you are interested in finding out more about being a trustee, or would be interested in supporting the recruitment process and appointments panel, then please email **exec@epilepsy.org.uk** and we will send you further details when they are ready.

If you are passionate about improving the lives of people living with epilepsy, if you want to help us support families and carers of people living with epilepsy, and if you are determined to change public perception and make epilepsy a condition where people can live their lives to the full without limits, you can do all that by joining us as a trustee.

We are an enthusiastic, friendly bunch of people who just want to make the world a better place for people with epilepsy. So, reach out to us and have a chat. We would love to hear from you!

Jane Riley, Chair of the Board


Charlotte and Allie

How to save a *life*

When Charlotte had a life-threatening seizure, fate brough Allie to her rescue. Words by Kami Kountcheva.

"I started feeling unwell, so I went to the toilet to have a minute breather. The next thing I know, I'm in A&E."

Charlotte Hoggard was diagnosed with epilepsy at 15 years old. Now, eight years later, while her seizures were mostly at bay, the 23-year-old found herself in Sheffield's Meadowhall shopping centre, just days before Christmas, in a pool of blood and at the mercy of passers-by.

"Epilepsy affected my life at first," Charlotte said. "It was all really sudden. I'd been having déjà vu episodes. My mum's a nurse, so she knew that I had epilepsy before the doctors did.

"I ended up having a tonic-clonic seizure, and we'd gone to a neurologist, but they didn't diagnose me initially. It took a second time [having a tonic-clonic seizure], about two months later, and then I got diagnosed.

"I got put on 25mg of lamotrigine and then it was gradually increased. And then I kind of got over it. It didn't really affect me – I was on my medication and my seizures were well controlled. But then they crept up again."

Charlotte's seizures were mostly controlled, apart from the occasional absence seizure. So, she had no inkling that December, when she headed to Meadowhall to her temp job selling Moonshine at a kiosk, how that day would pan out.

After leaving the kiosk to head to the toilets, Charlotte had a tonic-clonic seizure, falling and hitting her head on the steel reinforced base of a marble pillar in the shopping centre.

Fate

"The weird thing is, we weren't even supposed to be going in the direction where I actually found Charlotte," explained Allie Blackshaw, the woman who would end up likely saving Charlotte's life.

Allie, 25, had been out shopping with her baby boy and her brother that day, and she believes fate took her towards Charlotte that day.

"My brother wanted to go straight home and I said 'no, let's go down the Lanes', and as soon as I went down there, I just found her laid on the floor having a seizure.

"There was a massive pool of blood from her, obviously where she'd banged her head, and I just jumped into care mode."

Allie explained that she had works as a support worker for Mencap and has worked in the care sector since she was 18. She said in her job, she sees a lot of people who have epilepsy and she said she often has epilepsy first aid training, so it wasn't new to her.

"But I've never seen such a bad seizure like I have with Charlotte from her fracturing her skull.

"I grabbed my baby's blanket and put it under her head to stem the bleeding. I started timing the seizure because I know how important it is to time it in case it goes past five minutes.

"When she was having the seizure, somebody was actually trying to restrain her. I had to tell them they shouldn't do that, and that we should let her have the seizure as long as we're protecting her head.

"After her seizure another passer-by and I put her in the recovery position, and another lady called an ambulance."

Allie found Charlotte's medical information and emergency contacts on her smartwatch, which she could share with the paramedics, and called her parents, Sam and Graham. She gathered all of Charlotte's belongings and waited with her until the paramedics arrived to take Charlotte to A&E.

Some of the shops nearby ended up sending staff home that day because of

the shock of what they had seen happen to Charlotte.

"The man who helped out was in tears and had to be taken away," Allie explained. "He was really shaking. It's very frightening – Charlotte went very blue and she had froth coming out of the mouth. At one point I started checking her breathing and her pulse. I was shaking as well, I think it was all the adrenaline.

"I'm not surprised people who aren't used to seeing that had to go home. It can be traumatising."

Recovery

Charlotte found herself in A&E. "I wasn't aware at the time," she explained. "One minute I'm in Meadowhall, the next minute there's blood coming from somewhere and I don't even know what happened."

Charlotte had had neurosurgery for her injury. The neurosurgeons told Charlotte's mum Sam that if Allie hadn't had been there to protect her head from further injury during the seizure, Charlotte could have sustained serious brain damage or possibly died.

Charlotte is recovering really well from her injury and surgery. She said: "To be fair, to say I had a skull fracture, it's actually been alright. I was a bit dizzy at first, but I got discharged from hospital four days after my surgery – they only kept me in for my antibiotics.

"I struggled getting up and down stairs, and my hair was matted for a week before they took my stitches out, which was hard. But apart from that, the recovery has been pretty linear.

"The only thing that upset me was deferring my course. I was supposed to start an Occupational Therapy master's in January, and I deferred it by a year. That was a very emotional day. I'm doing a lot better physically – taking baby steps – and I've been going out in public when it's quiet, but I just felt the course start date was a bit too soon."

And this was not the first time epilepsy had thrown a curve ball in Charlotte's life.

"I was actually learning to drive," she said. "I'd been seizure free for a year, and I had a test booked in April. But I had a seizure at work and got sent home and I had to call the DVLA and let them know, and I had to cancel the test.

"I cut up my provisional licence and I sent it in. It's frustrating because I have to do my theory test again. At least if I'd passed, I wouldn't have to do that again."

But despite the challenges, Charlotte doesn't let epilepsy stand in the way of what she wants to do. She works, she's attended university and she took part in Camp America, spending nine weeks in the US working at a special needs camp.

"It was so tiring!" she recalls. "I'm surprised I didn't have an episode out there because I was going to bed at midnight after being on duty and waking up at seven."

What if?

While very proud of Charlotte's independence, Sam explained that she and Graham still worry about her.

"From that point of view, we've let her go," Sam said. "We've had to, what can you do? You can't wrap people up in cotton wool for the rest of their lives.

"And she has led a very independent life. She's been living with her boyfriend in Doncaster recently, and she was looking forward to starting her master's degree in Sheffield and was going to be living independently there. So, this has all been a big set back for her and scary for us.

"It makes you realise, you never know what's around the corner. This is a big emotional thing for me. I'm always there – yes, professionally as a nurse – but also when we go on holiday or wherever, there's always some disaster that befalls somebody, and I'm always there to help them.

"And, on this occasion, Allie was there for us. Allie has told us that no one there really knew what to do, there was just a lot of panic. But she was there.

"The neurosurgeons who looked after Charlotte said if she hadn't have had that head protection, she could have died.

"Hitting the steel reinforcement on the pillar, her skull smashed into tiny pieces like fragments of broken glass. Allie protecting her head was key in saving her life.

"You can hear the emotional toll more in me, because Charlotte is so resilient and so brave. I'm so proud of the way she's recovered, but we're still left thinking 'What if?'

"It was also really important that Allie knew to look for Charlotte's emergency information on her watch. She knew if she had it on her phone, which she had left at the kiosk, that it would be mirrored on her watch.

"That gave me the ability to get in the car and get to my daughter when she was in that state. I felt like that would have been robbed from me if I couldn't have been there with her.

"Allie is a superhero and a guardian angel to our family."

Allie added: "I didn't realise the extent of what I'd done until Sam explained it to me. It's like it was fate because I wasn't even supposed to go down the Lanes that day."

Charlotte

Charlotte needed surgery for her injuries

Sam

Me, my *health* and AI

A dive into the role of AI in epilepsy health and how to ensure you can trust what you read online. Words by Kami Kountcheva.

Technology is always fast evolving. I remember a time when a phone that's not tethered to a nearby wall was a thing of distant sci-fi future. Now most people not only have a phone in their pocket wherever they go, but it's also a camera, a camcorder, an organiser, an alarm clock, a music player, a wallet, a computer and a navigation system.

Recently, one big technological advancement that has been in the news is AI – artificial intelligence. That means powerful computers crunching hundreds or thousands or millions of data and becoming informed by them to, say, recognise your face, spot fraud on your bank account or correct your spelling in text messages.

Last year, AI platforms were introduced on a mass scale to everyone by names such as ChatGPT, Gemini, Claude and Copilot among others. Each one has different specialisms, some designed to create content, others to do research, automate tasks or develop software.

You might have seen the AI Overview on Google, offering summaries of your Google searches. You might have used ChatGPT to get more insights or support with work, or you might have asked it to make a funny image.

However, while powerful and useful, AI is not quite there yet. It has the potential for errors – delivered with confidence as facts – and misuse. So, it is more important than ever to follow up any summaries by visiting reputable, trusted sources of information. Or, better yet, go directly there.

For your epilepsy queries and concerns, the Epilepsy Action website offers trusted, accredited information based on research and put together with the support of experts. We are accredited by the Patient Information Forum, which runs the only quality mark for print and digital health information in the UK – the PIF TICK.

This means Epilepsy Action has gone through a rigorous editorial process to ensure our information is evidence-based, medically accurate and easily accessible. We are here to answer your questions and offer information you can trust.

The issues

When it comes to the likes of AI Overview, while it can summarise webpages and offer a quick and seemingly thorough and

well-researched response, it's important to know that it is not always accurate.

Google's AI Overview itself reports inaccuracies in more than half of cases, with misleading information or what's been coined AI hallucinations, where information is made up but presented as fact. This is especially vital to keep in mind around healthcare.

We've long been advised not to turn to 'Dr Google' for our symptoms for fear of accessing inaccurate or even dangerous information from different websites. With AI Overview collecting information to sum up for us from sources we don't – and can't – always follow to check, it's even more important advice.

A recent article in the Guardian exposed many instances in which not only wrong, but dangerous information was delivered by AI Overview, offering advice on medical issues that could have put people with those health conditions at risk.

Research by the University of Oxford also found that using AI chatbots for medical advice can be dangerous. The researchers found that large language models (like ChatGPT) would give a mix of correct and incorrect information to patients, which they wouldn't be able to tell apart.

GP and study author Rebecca Payne told the BBC: "Patients need to be aware that asking a large language model about their symptoms can be dangerous, giving wrong diagnoses and failing to recognise when urgent help is needed."

The benefits

Having said all of that, AI has so much potential to be a powerful and helpful tool in a lot of different ways – not least of all in epilepsy treatment. It could help locate where a seizure starts from. Or figure out the likelihood of a seizure happening based on your own body's reactions or over a timeframe. Or estimate what the outcome of different treatments might be for you.

Last year, King's College London scientists developed an AI-powered tool that could recognise nearly two thirds of brain abnormalities that human radiologists miss. This year, researchers from Glasgow Caledonian University in Scotland developed an AI-powered headset that can predict epileptic seizures before they occur. These are among many other pieces of research looking at how AI can support epilepsy care. There is still a long way to go, as these studies are relatively small, but AI holds a lot of hope for the future.

AI algorithms have long supported systems for things we use every day – from Google Maps and autocorrect, to search engines and digital assistants. When used well, they could have real potential to improve healthcare provision and research in the future.

In the meantime, our trusted information and helpline is always here to rely on when you have questions and concerns. You can help spread the word and ensure more people have access to safe, correct epilepsy information by sharing and recommending the Epilepsy Action website within your networks.

Consultant radiologist reviewing a scan and AI report

Purple day

Purple Day, the global awareness day for epilepsy, is just around the corner and with it comes an opportunity to shine a spotlight on epilepsy – everything from how common it is and how different it can be for different people, to the wider effects of the condition and how to help during seizures. While over the years many myths have been dispelled, there is still a long way to go, according to a new poll by Epilepsy Action.

Almost eight in 10 people in the UK, of the poll of 2,000 UK adults, underestimate how many people are diagnosed with epilepsy each day, with more than half (52%) believing that fewer than 30 people are diagnosed with the condition each day. In reality, that number is 79 people.

More than half of people believe epilepsy only affects people during seizures but also nearly half of Brits admitted they have little or no understanding about epilepsy.

Many people in the epilepsy community share their story or some information about the condition, while others hold fundraisers to help support Epilepsy Action and get the word out about the condition that way.

Twelve-year-old Maddison marked last year's Purple Day by doing a presentation about epilepsy in front of her whole school. There were activities throughout the day which helped her raise £1,424 for Epilepsy Action.

This year, Ed is hiking to fundraise for his daughter Lyla, covering the Surrey three peaks and a little extra to take his distance to 26.2 miles – the length of a marathon.

Last Purple Day, Jessica asked her Brownies Leader if she could hold a Purple Day at Brownies, with lots of activities like quizzes, dressing up and a bake sale. She wants to hold another Purple Day at school and share out a factsheet about epilepsy she's created.

On March 26th, keep an eye on our website (epilepsy.org.uk) and social media (just search for Epilepsy Action) for all the latest Purple Day activities – and like and share to spread the word!

You can still grab a digital Purple Day pack for your own fundraiser at **epilepsy.org.uk/purple**

A year of *impact*

See the impact you helped us create this year in numbers and directly from people

Over the past 12 months, we've continued to support thousands of people affected by epilepsy, offering vital services, expert advice and a community where no one faces their epilepsy journey alone.

Whether through a friendly chat on our helpline, sharing their experience in a support group or accessing advice that gave them confidence in managing live with epilepsy, every bit of support ha helped people feel understood, connected and less alone. And none of this happened by accident – **it happened because of you**.

Whether you've donated, volunteered, attended an event or shared our vision you've made a lasting difference for people living with epilepsy.

On behalf of everyone we support, thank you for helping create a world without limits.

ONE-TO-ONE SUPPORT

355 people

received one-to-one support from a trained volunteer

HI.

HELPLINE

10,165 enquiries

supported with compassion and care by our award-winning helpline team

"Being part of a community that listens, educates, and uplifts has made a real difference to me."

EPILEPSY SERVICES

92%

of the people supported rated our services as good or excellent

"Getting in touch with Epilepsy Action really did save my life"

"Being part of this community has really improved my quality of life."

PEER SUPPORT GROUPS

2,191 visits

to our in person and online support groups

COUNSELLING

224 people

supported through professional one-to-one counselling

VOLUNTEERS

461 volunteers

contributed 4,434 hours of support, reaching 85,032 people! The equivalent of 620 working days.

£££££

FUNDING

£5.2 million raised to make this all possible!

Aidan and Olympic gold medalist Lauren Henry

Record rower

After being told he wouldn't achieve anything because of his epilepsy, Aidan Leverage went on to break a championship record at the British Rowing Indoor Championship. Words by Emily Stanley and Kami Kountcheva

A rower living with epilepsy has broken the championship record for the Open Indoor Adaptive Rowing (IAR)7 2,000m event at the British Rowing Indoor Championships (BRIC) on Saturday 5 December.

Aidan Leverage, 20, from Leicester, took on the challenge in Birmingham this year in support of Epilepsy Action, achieving a time of 6:36.9 in the category for people with physical, sensory or learning impairments.

He also competed in his age group,

"Lots of doctors said I wouldn't achieve anything. I was told I would struggle academically and that I may not do anything in sport as I'd struggle there too. I've rejected those ideas."

coming seventh the under 23 category with a time of 6:48.2. So far, he has raised more than £1,000 for Epilepsy Action.

Aidan was diagnosed with epilepsy at the age of four, facing uncontrolled seizures with no known cause of triggers. He chose to support Epilepsy Action as this was the organisation his parents turned to when he was first diagnosed with the condition.

He said: "When I look back, I can't even imagine how stressful it was for my parents, worrying about me, not knowing when my next seizure would be.

"That's why my parents have always turned to Epilepsy Action for help when they felt completely lost.

"I want to be living proof for parents out there that it does get better."

Olympic gold medallist and world champion British rower Lauren Henry, who comes from the same small town as Aidan, was among those cheering him on.

Ahead of the race, she said: "I want to wish Aidan all the very best for his incredible challenge at BRIC this year. He's overcome some huge obstacles and continues to inspire everyone with his resilience and determination. I'm sure he'll have a fantastic day at BRIC and absolutely smash it!".

"I feel unstoppable"

Aidan was hospitalised around 14 times due to tonic-clonic seizures, and he has lost lots of his childhood memory due to his epilepsy.

He tried many different medications and eventually found a treatment that has controlled his epilepsy for the past few years.

Aidan explained: "I found my childhood with epilepsy quite difficult. I faced a lot of stigma, I was excluded from activities as a child, and was known as the 'weird kid with epilepsy'. Some parents were even scared their child would 'catch it' and so I was left out of things.

"I was really into my rugby and football when I was a kid. My parents have told me that sometimes I would simply stop and stare, mid-game, and other parents would shout at me from the sidelines. What they didn't understand was that I was having a seizure. Eventually, for my own safety as well as others, I had to stop my rugby and football.

"Now I have finally found a medication that works, I feel unstoppable. I started rowing after being introduced to the sport by my dad. I joined Leicester Rowing Club who were amazing with my epilepsy. They were very caring and cautious of my condition.

"Although I am seizure free, my medications still have tough side effects. I can be very tired and experience mood swings – getting up at five or six am to be on the water can be difficult!

"I am now rowing for Anglia Ruskin University, where I'm studying. Being a rower with a disability can be hard at times, but I want to show people that there is nothing that should stop you from pushing yourself. My message isn't going to people with epilepsy, it's to everyone.

"Lots of doctors said I wouldn't achieve anything. I was told I would struggle academically and that I may not do anything in sport as I'd struggle there too. I was told it would be best to find an easy sport for me.

"I've rejected those ideas. I've chosen to be a high achiever and not be held back by what some doctor is going to tell me."

"Empowered to live their lives"

Rebekah Smith, chief executive at Epilepsy Action, said: "Aidan's resilience and determination are extraordinary, and we are confident he will inspire many others, with and without epilepsy, to push themselves.

"The 2000 metre individual race is one of the toughest in rowing, so Aidan completing it twice in one day is truly remarkable.

"Representation of people with epilepsy in sport is so important. Whilst precautions should always be taken, epilepsy should never be a barrier to participation.

"It's heartbreaking to hear of the exclusion Aidan faced as a child, which is why it is so important that the public understand epilepsy and the types of seizures.

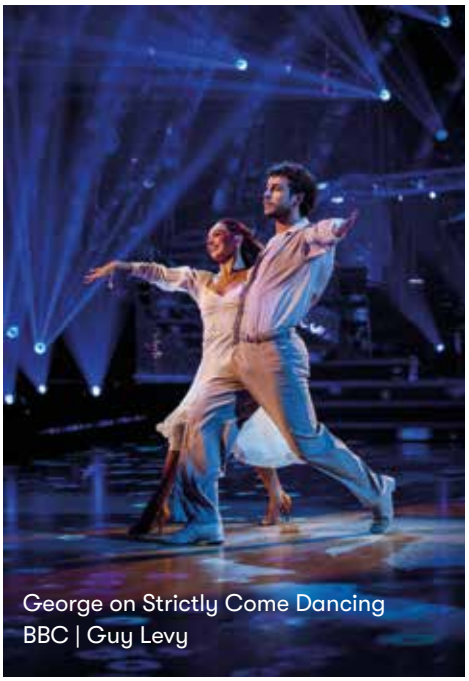
"By 2030, Epilepsy Action hope to see a 'World Without Limits' for people with epilepsy – we want everyone with the condition to feel empowered to live their lives to the fullest.

"Aidan is a powerful example of the incredible resilience so many people with epilepsy show, and how overcoming these challenges can sometimes help people to go further in life."

Aidan broke the IAR7 2,000m championship record at BRIC


Aidan and paralympian Benjamin Pritchard

Epilepsy on TV


George on Strictly Come Dancing
BBC | Guy Levy

This winter, epilepsy has seen a fair amount of limelight on TV – we share six appearances that are key for representation

Words by Kami Kountcheva

Epilepsy representation on TV has been precious little over the years. And when there has been a nod or a mention, it's often misrepresented, or it's been a flash in the pan, forgotten by the next episode.

Representation is hugely important. People need to see themselves, see people like them and see their own experiences mirrored in order to feel seen and connected, to relate to the programme and to build confidence. And showing epilepsy is invaluable in helping develop public awareness, understanding and empathy about the experiences of 630,000 people in the UK.

So, imagine our delight to see a winter brimming with representation of epilepsy, seizures and people with the condition starting in late 2025 and still continuing now into 2026 – from famous faces with the condition, to new and resurrected storylines and tributes on one of the biggest shows in the rundown to Christmas.

Here are six recent TV appearances helping bring a little more understanding to living rooms across the UK.

Martin Kemp on I'm A Celebrity... Get Me Out Of Here!

Sunday, 16 November 2025 saw the return of ITV's I'm A Celebrity... Get Me Out Of Here. Alongside an exciting line-up including Heart Radio DJ Kelly Brook, 45, TV personality Jack Osbourne, 39, and presenter and former footballer Alex Scott, 41, 64-year-old Spandau Ballet star and DJ Martin Kemp also swapped everyday life for the famous Australian jungle.

As well as being a global music icon, one of Martin's strengths is his openness about his health. He has previously spoken about having two brain tumours diagnosed and undergoing surgery and radiotherapy to remove them. He has also shared that he lives with epilepsy, which he controls with medication and also dyslexia, affecting his reading.

Martin appeared on Morning Live a few years ago with Epilepsy Action story champion Murray Goulder, both speaking about their own experiences with epilepsy and discussing groundbreaking new technology.

Between being showered in bugs, crawling through offal and eating and drinking unspeakable things, Martin's participation also brought about conversation about epilepsy on social media and an example for the show's nine million viewers of the strength and resilience of someone with epilepsy.


Maisie on Taskmaster
Channel 4


Marin on I'm A Celebrity | ITV

Maisie Adam on Taskmaster

Comedian Maisie Adam has been going from strength to strength since winning the contest So You Think You're Funny at the Edinburgh Fringe Festival in 2017. Since then, she's been on tour, appeared on a number of TV quiz, panel and competition shows, and has hosted several podcasts.

One of her most recent gigs was joining the 20th series of Taskmaster alongside actors and comedians Ania Magliano, Phil Ellis, Reece Shearsmith and Sanjeev Bhaskar, coming out victorious after a previously unseen three-way tiebreaker for the series (you can stream the series on Channel 4).

Maisie has previously spoken about being diagnosed with juvenile myoclonic epilepsy (JME) at the age of 14. She wrote

a comedy show called Vague, in which she spoke about growing up, drawing on the nostalgia of that time as well as navigating epilepsy.

In an interview with Epilepsy Today in 2018, Maisie said: "Picking out material for the show felt quite good actually. I knew that I had all the stories there. And when I first started talking to my friends about it, I naturally made a joke about it.

"Also, I think my audiences have become more aware about epilepsy. Things like that there's not just one type, that it's not all 'strobe-lights-and-foaming-at-the-mouth', it's different for each person."

Watching Maisie on the popular Channel 4 show over a number of weeks brings a lot of hope and representation.

George Clark on Strictly Come Dancing

Strictly Come Dancing contestant George Clarke, 25, spoke out about his mum's health on week eight of the show, sharing that she's been diagnosed with encephalitis since he was 16, and more recently she'd also been diagnosed with cancer.

The social media star and podcaster dedicated his rumba number, danced to Keane's song Somewhere Only We Know with partner Alexis Warr, 25, to his mum, Nicky, who he called "the most selfless person".

In his pre-dance VT, George shared how at 16, just before heading out with his dad for hockey practice, his dad had checked up on his mum to find her having a seizure. She was later diagnosed with encephalitis.

George said: "Encephalitis is something that, I had no idea what it was. And most people who do know what it is, it's because it's affected them in a horrible way."

George described encephalitis as a brain inflammation and, according to the NHS, some people make a full recovery, but "many" don't and have to life with long-term problems, including memory loss, seizures, problems with brain functions like attention and concentration, or persistent tiredness.

According to the organisation Encephalitis International, people who have had encephalitis are around 16 times more likely to develop epilepsy than the general population.

George reached the final, with several mentions of his rumba over the next weeks, bringing continuous light to a largely poorly understood condition.

CorrieDale

As 2026 began, the epilepsy representation continued, moving from reality TV and competition shows to fictional drama.

The hotly anticipated crossover between two of the nation's favourite soaps, Coronation Street and Emmerdale, was action packed with injuries, explosions, arrests and pursuits in the dark forest, as well as a big health reveal following a vehicle pile-up.

Shona (Julia Goulding) and David (Jack P Shepherd) were part of the multi vehicle pile-up as passengers on a minibus. At the hospital, Shona's waters break and she goes into premature labour in the waiting room, leaving David running to look for help. As he returns, he drops to the floor and has a tonic-clonic seizure, with medical staff coming to his aid and protecting his head, leaving Shona is horrified by the events.

The episode highlighted how high levels of stress can be a seizure trigger for some people, even in someone with relatively well controlled epilepsy. The following day, David decides to drive to the hospital to see Shona, and she challenges him on the choice to get behind the wheel, highlighting a key challenge for many people with epilepsy.

After the Flood

ITV aired the second season of its police drama After the Flood in January featuring a character with epilepsy at the centre of detective constable Jo Marshall's investigation.

When two bodies turn up on the Moors, Jo's (Sophie Rundle) investigation unravels personal conflicts in Waterside, the truth behind the contamination of the river and the culprit behind it all.

Todd Drake (Jason Walsh) was one of the victims found on the Moors. We find out he has epilepsy from his medical ID band when his body is discovered. It is later revealed he had a seizure while breaking into a chemical plant to look for evidence of a leak with his activist group.

Todd's epilepsy provides key clues for Jo to uncover the cause of death of the two bodies on the Moors and follow the trail to the villain behind the piece.

EastEnders

BBC One's flagship soap EastEnders introduced a brand-new epilepsy storyline in February, with Davinder 'Nugget' Gulati (Juhaim Rasul Choudhury) developing the condition after being assaulted.

Nugget starts 'spacing out' during his driving lessons and ends up having a tonic-clonic seizure in the stopped car as his parents argue outside. He undergoes tests and is diagnosed with epilepsy, shown to clearly be struggling to accept what this means and how it might change his life.

A few episodes later, we see Nugget forget to take his medication and have another seizure. There is a showdown at the pharmacy when Nugget and his dad Ravi (Aaron Thiara) try to pick up his medication but find it's not in stock.

This ongoing storyline weaves realistic epilepsy experiences in with the dramatic storylines we've come to love from the nation's soaps, exploring many different facets of life with epilepsy.

For more on these and emerging stories, visit **epilepsy.org.uk/news**.

Corriedale | ITV


After the Flood | ITV


EastEnders' Nugget
BBC | Jack Barnes | Kieron McCarron

Am I having absences?

The epilepsy community tells all about what absence seizures feel like and we look at some recent research about absence seizures. Words by Kami Kountcheva

Seizures are often misinterpreted. Depending on the type of seizure, people are often assumed to be drunk or on drugs, or just behaving strangely. Absence seizures are some of the most commonly missed and mistaken seizures, often confused for daydreaming because of their brief nature and lack of obvious characteristics.

However, they're real seizures, and they can be debilitating and confusing for people having them. We share some descriptions from people with epilepsy about what they feel like, and a little bit of recent research about them.

What can happen when you have an absence seizure?

Some common elements of absence seizures that the community shared, include:

- Blackness/pause/'power cut'
- Small movements
- Feel like you can't speak or can't hear or understand what's happening around
- Feel stuck
- Feel blood draining away from head
- Confusion at losing chunks of time or missing parts of conversations
- Anxiety, fear, guilt after the seizures

How did people describe their seizures?

People with epilepsy used a whole host of analogies to try to explain what it feels like when you've missed a chunk of time, which highlight the frustration and disorientation these seizures can cause.

- It's like I time travelled
- When you press 'skip forward' on a TV show
- Feels like a time jump
- I'm stuck
- I've paused
- A time jump
- A paralysis
- Like a CD skip
- A brain freeze
- A light bulb going on and off
- A power cut
- A computer that suddenly freezes
- As if someone presses the reset button on the brain
- Like a finger snap
- A daydream that you can't shake yourself out of

A supporter took to Instagram to share their experiences: "They feel surreal. Sometimes I can hear people talking and see everything moving around me."

Another said: "It might have only been 10 seconds you miss, but it's very disorientating and takes you a minute to realise what's happened and catch up."

Another service user said: "I can be part way through a conversation and then I've missed part of it. Then I've forgotten where I am completely for a few seconds after. Or it feels like my body stops working and it's just still. While my mind is still aware and conscious of what is going on."

In another Instagram comment, another supporter added: "Sometimes I know I'm having a seizure, but I can't stop it or hear you. Also, [I feel] very guilty. Although it's not my fault, I feel bad I'm ignoring people."

A Facebook user explained: "Mine feels like my blood has been replaced by ice water that has drained quickly from my head to my feet. It's like I know I'm there, but I'm not."

Another person described it as "blackness", adding: "My eyelids flutter and I stare into space. I had them on

the way to school and would have no recollection of how I got there. I would have to cross a busy road and get on the bus. The amount of time I must have missed from lessons must be ridiculous."

Describing the after-effects, another supporter said: "I'm left with uncontrollable feelings of confusion, fear and anxiety for hours. I've learnt to be strong and carry on regardless at work and at home, not showing the impact my seizures have, but I do admit that it can feel very tiring and lonely."

Another added: "Mine can erase my memory. I can't speak and I will stop mid-conversation. Most of the time when alone I wouldn't know if I had one – but small things like picking up that the time has suddenly changed, the cooking pot has boiled over or the TV programme I've been watching has ended, tend to show me I have had them. But apart from that, they can go unnoticed."

A parent shared: "My little girl has them. When at school, she will ask to go to the toilet, leave the room, then 10 minutes later they will find her wandering. She is lost and has no idea what she's doing. It's as if someone presses a reset button on her brain and she has to re-establish where she is and what she's trying to do."

What recent research says

There is more information on the Epilepsy Action website around absence seizures and seizure first aid for this type of seizure. Here, we share some recent research into absence seizures from 2025.

Researchers have been looking at improving the detection of absence seizures. In a paper in Clinical Neurophysiology, a team from the Netherlands developed a computer program, which can detect absence seizures in real time.

They tested their tool on 22 24-hour recordings of EEGs of children with absence seizures. The tool was able to identify more than 95% of seizures and could almost always detect the seizures in less than two seconds. The researchers said this has the potential to be useful in future research of these seizures.

Another study from France, published in Biomedical Signal Processing and Control, looked at how well an AI-based algorithm could detect absence seizure onset early to allow for an intervention. Using the EEGs of 117 people, the algorithm (adapted to use fewer electrodes to potentially work in a wearable device) was shown to detect seizures more than 80% of the time in around half a second.

Machine learning also featured in a Belgian study in Epilepsia which investigated a device to detect absence seizures in adults. The device was designed to be used at home for 12-24-hour periods and its results could be used by clinicians to guide medical treatment.

The study tested the device on 19 adults, with 79% of them having no further absences after the last measurement. including more than half of the people who had been diagnosed with refractory epilepsy.

The results also showed that one 24-hour period was not enough to say a person was seizure free, and that at least two consecutive 24-hour recordings. This also helped reduce review time by the neurologists, but the researchers acknowledged that it was a small study and should be considered as preliminary.

A review in Epilepsia Open explored brain circuits involved in absence seizures, looking at more areas in the brain than most studies have previously. The researchers explained that understanding how these brain networks interact with each other could lead to better treatments being developed in the future.

In Clinical Neurology and Neurosurgery, a team from Italy analysed cases of early-onset absence seizures and their outcomes. The researchers reaffirmed that typical absence seizures, normally starting between the ages of four and 10 years old, are a sign of likely childhood absence epilepsy (CAE).

Children with early-onset absence epilepsy, usually starting before the age of four, tend to have good outcomes with epilepsy medication, while those with atypical absence seizures with extra elements suggest a more severe epilepsy condition, the study explained.

An evaluation of 23 children with absence seizures starting before the age of four, showed that those with atypical absences often had a genetic cause and were more likely to have medicine-resistant epilepsy. Genetic tests can help to identify what genes are involved, and help to tailor treatment for the individual, such as the ketogenic diet. In contrast, those with early onset typical absence seizures achieved seizure freedom, the paper concluded.

Finally, a paper in the journal Children analysed lifestyle challenges for children with epilepsy. It looked into physical activity levels in children with absence seizures and those without epilepsy. Children with absence seizures appeared to have lower levels of physical activity, although this wasn't statistically significant.

The research also found that children with absence seizures were more likely to have traits of anxiety and depression.

The researchers concluded that children with absence seizures already face barriers in being able to take part in physical activity, and mental health problems could be adding to that. They said it's important to develop physical activity programmes for children with neurological conditions.

What's *new?*

A round up of some key sessions from the ILAE British Branch meeting 2025. Words Tom Shillito and Kami Kountcheva

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 meeting, focusing on epilepsy and dementia, functional (dissociative) seizures and seizure detection devices.

Epilepsy and dementia

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 effects of the condition on mental health.

Epilepsy is linked to changes in the brain structures, such as the hippocampus, 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 people needing multiple epilepsy medications, but that even taking just one medication 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 people need to see a neuropsychologist to help them to understand and treat memory problems. He said it's important to understand that memory problems may not go away and are a part of epilepsy, but they can be managed. Getting the best treatment possible is an important step in reducing memory problems, as well as early referral for surgery for people who could benefit from it.

Next, Prof Matthias Koepp from University College London (UCL) spoke about epilepsy and neurodegeneration, the decline of neurons and their function. 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 can affect the way that epilepsy 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 problem solving and managing everyday tasks, as well as some types of memory in Alzheimer's disease. However, he added there hasn't been evidence to show dementia treatments having a beneficial effect on epilepsy.

Functional (dissociative) seizures

Dr Mahinda Yogarajah from UCL kicked off the second session on functional (dissociative) seizures, by discussing advancing diagnosis methods. 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. He added that people often feel better emotionally after a functional (dissociative) seizure than before it.

Next Dr Krishna Chinthapalli from UCL spoke about the impact of functional (dissociative) seizures on people's health, 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 intensive care 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 medical treatments or procedures due to the misdiagnosis.

People with these types of seizures are often prescribed antidepressants and specific 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, associated health problems or lower income.

Dr Chinthapalli said doctors should help people manage long-term pain, reduce the number of medications people take where possible and openly discuss suicide and people's worries and challenges.

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

He explained that more than half of people with these types of seizures will be able to remember either a part of or their whole seizure, or be able to respond during it, but they often worry about telling their doctor unless they trust them.

Prof Reuber added that if a person 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 rescue medications for epilepsy won't help or stop the seizure.

He advised doctors to ask a person's consent to refer them to psychiatry for treatment, even though many continue to be looked after in neurology.

> **"People often feel better emotionally after a functional (dissociative) seizure than before it"**

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 how well they detect seizures. 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 too high for people to be able to afford, ranging from several hundred to thousands of pounds. Wearing a visible medical device can make people feel like their condition is more obvious and may make them concerned about stigma. It can also 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 length, reliable wifi access, and lack of links between these devices and 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 help with things like SUDEP. It is also important to be clear that these devices are for people who are generally living independently but have someone nearby who can quickly check on them if needed.

Amazing allies

Partners, parents, children and doctors – we celebrate lots of recent Star Awards winners who have been real allies to someone with epilepsy. Words by Emily Stanley

Last August's Epilepsy Star Award went to David from Manchester, for his unwavering support of his wife Lauren, who lives with epilepsy.

Lauren nominated David for being her 'rock' and says that she couldn't be where she is today without him. Lauren also praised David for his efforts to raise awareness for epilepsy as a condition, from talking to his family, to starting conversations with people in public.

Lauren said: "David and I have been together for nine years and have been married for six. I didn't have epilepsy when I met David, and it came as a big shock to both of us as it appeared from nowhere.

"There aren't really words to describe the support David has shown me throughout this journey. I understand that this condition can break up families and can be difficult to navigate in a relationship. David has to live with the 'what if she has a seizure' ,'what if she falls', 'what if I'm not there', all the time and it takes over his life. Epilepsy doesn't just affect the person, but everyone around them.

"He sits and talks to me while I have a bath, he checks on me when I've gone upstairs to get dressed, he makes sure I've taken my medication. When I do come round from a seizure, nine times out of ten his is the first face I see – seeing his face makes me know I'm safe.

"There's times he's been scared, he's

Lauren and David

cried, he's felt lost... Yet he still manages to work full time, spend time with the kids, taking them to cricket matches and dance performances, driving me around. Most importantly, he still carries a beautiful smile on his face and has such a positive outlook on life.

"David is more than just an amazing husband – he is an advocate. He educates other people about epilepsy. He tells them what to do if I have a seizure, explains about the aftermath after one and ensures people are aware of seizure first-aid. He speaks to everyone from his 85-year-old nan, to his 11-year-old son, to colleagues, to friends or even people in the pub!"

Debbie

Last September's Epilepsy Star Award was awarded to Debbie Cockayne from Norfolk, for the unwavering support she has given her daughter, Holly, throughout her journey with epilepsy. Debbie not only supports her daughter with epilepsy, but also her own mum, Margaret. She was nominated by Holly, who says her mum is the reason she's got through her epilepsy diagnosis.

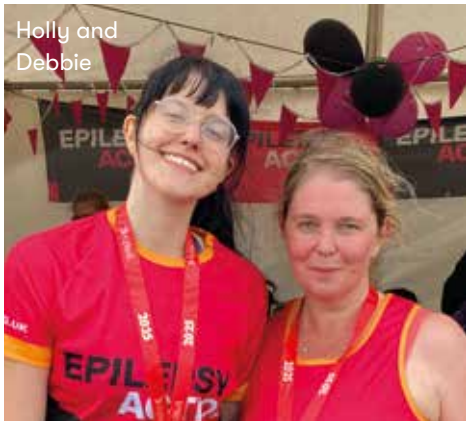
"I had my first seizure in November 2023, when I was 22. My mum drove five hours north to come see me.

"After I had a second seizure, I received my epilepsy diagnosis in May 2024. This was two weeks after a break-up, so not great timing! Luckily, I was at home at the time, so my mum was able to support me. She reached out to my local neurology/ epilepsy team who went through the diagnosis with me.

"My mum has been there for me when I've had seizures, and knew exactly what to do. She made sure I was safe and reassured me as I came round. Whenever I get down about things, she's always there to cheer me up.

"It's not just me she's supported – she's also been there for my grandma throughout her epilepsy journey. My grandma, Margaret, has had epilepsy for 50 years, and my mum does exactly what she does for me – she helps her with neurologist appointments and ensures she's taking her medication.

"As well as looking after us both, she is an incredible advocate for people with epilepsy. She is constantly advocating for greater awareness about epilepsy and seizure first-aid. She shares what she


Holly and Debbie

has learned with colleagues, friends and other families.

"Mum, I could never thank you enough for everything you've done and continue to do for me. I don't think I could've gotten through everything we've been through the past few years without you – I love you times infinity."

Max and Faith

October 2025's Epilepsy Star Award was a very special double award. Max, 15 and Faith, 14, have both been recognised for their above-and-beyond care of their loved ones with epilepsy. Max supports his dad John, whilst Faith has three generations of family with epilepsy – her mum, grandmother and great-grandmother.

Incredibly, both teens have given their parents seizure first aid on aeroplanes when no one else could help.

Max's dad, John, nominated Max because of his exceptional bravery during that flight. "Max and I were travelling to Geneva. I don't like flying in general and on this particular flight we were sat separately.

"During the flight, Max (13 at the time) recognised the sound I make when I am having a seizure. Immediately, he came to find me.

"The lady in the chair next to me was French and didn't understand what was going on or try to help the situation. Max, despite being only 13, had to take control. He asked the lady to move and gave instructions to the cabin crew, who were unfamiliar with epilepsy or seizure first-aid. Of course, this was really disappointing to hear afterwards.

"After a seizure, I feel exhausted and disoriented. Max had to ask for a wheelchair for me – the airline staff did push me through the airport and fast-tracked us to baggage claim, but we were left wait in the arrival hall for our luggage with everyone else. I am so thankful that Max was there to take care of me.

"Max – thank you. In times of emergency I know I can rely on you. You are always strong, calm, and organised. You take control and lead the show, directing people with what they need to do such as calling a first aider or ambulance. At 13, you should have been supported by others, not left on your own on an airplane to support and care for me. I trust you and know you will always be there to help me, when I need it."

Fourteen-year-old Faith also had to help her mum when she had a seizure on a flight. Faith was nominated by her grandmother Barbara, who says she is an incredible advocate for people with epilepsy and passionate about raising awareness of the condition.

Barbara said: "Epilepsy is in three generations of our family, including myself (Barbara), Faith's mother, Kate, and her great-grandmother. I've had epilepsy since I was 10 and it was much worse when I had children – I had an average of six tonic-clonic seizures a month. Kate had to look after me a lot despite being in primary school. Kate also has epilepsy, and so my granddaughter Faith is experiencing a similar amount of responsibility.

"At the age of 14, Faith recently gave a talk to her school on a topic of her choice. I was so proud that she chose epilepsy. She researched the topic and wrote about it – she outlined statistics of how many people have epilepsy and spoke about the many different types of epilepsy. She also talked about the prejudice and difficulties.

"Faith also spoke about her experience of her mum having a seizure on a plane. When this happened, Faith was shocked by the cabin crew's lack of knowledge about what to do if someone had a seizure.

"Faith recalls how when Kate was unconscious the cabin crew did know what to do, but when she started to come round, and was in a trance-like state, this went out the window. The staff took Kate out of her seat, put her on the floor and gave her oxygen, which she didn't need. They kept talking to her when she was confused. Amazingly, Faith took charge and told the airline staff to just leave Kate to come round slowly, and not make a fuss.

"I am incredibly proud of Faith."

Charlotte

November's Epilepsy Star award winner was Professor Charlotte Lawthom, for the exceptional care she provides her patients as a consultant neurologist. Charlotte was nominated by her colleague, Sian, who says Charlotte's passion has inspired her to go the extra mile in her own work too.

"Charlotte is extremely passionate about the care she provides to patients and has inspired me ever since the first day of working with her.

"As well as her clinical duties, Charlotte also goes the extra mile and helps patients outside of work. She signposts them to other services, provides them with information leaflets, as well as spending time outside of work discussing patients with other healthcare professionals to support their care. She ensures all factors are considered in her patients care, including mood, sleep, work schedule and stressful life events.

"Charlotte is passionate about research and published widely on epilepsy topics including SUDEP, medication safety and patient-reported outcomes and she regularly speaks on improving quality of life for people with epilepsy and intellectual disabilities."

Read Allie's story on page 12 for another recent winner.


Max and Faith


Prof Charlotte Lawthom

Driverless *decades*

Jez learned to drive at 19, but at 22, a diagnosis of epilepsy put him in the passenger seat for the foreseeable future. Words by Kami Kountcheva

"I began taking driving lessons in around 1986 with my brother Jonathan in my father's 1977 Lada," Jez Orbell, 57, recalled.

"The following year I began proper lessons in a Peugeot 205 and passed my driving test at the first time of asking in October 1987.

"After passing, I remember asking Jonathan if I could go out for a drive on my own, just two days later, and, to my surprise, he said yes. He said, 'You've passed, why would it be a problem?' Being out on my own I felt automatically calmer and a sense of freedom.

"Over the two years or so that I drove, I travelled all around the UK, from the South Coast to see friends who had gone to college, to Liverpool to see football matches, and also to make spur of the moment trips like to Scarborough in Yorkshire, simply because I could and there was no reason not to.

"It was that spontaneity that I would come to miss the most."

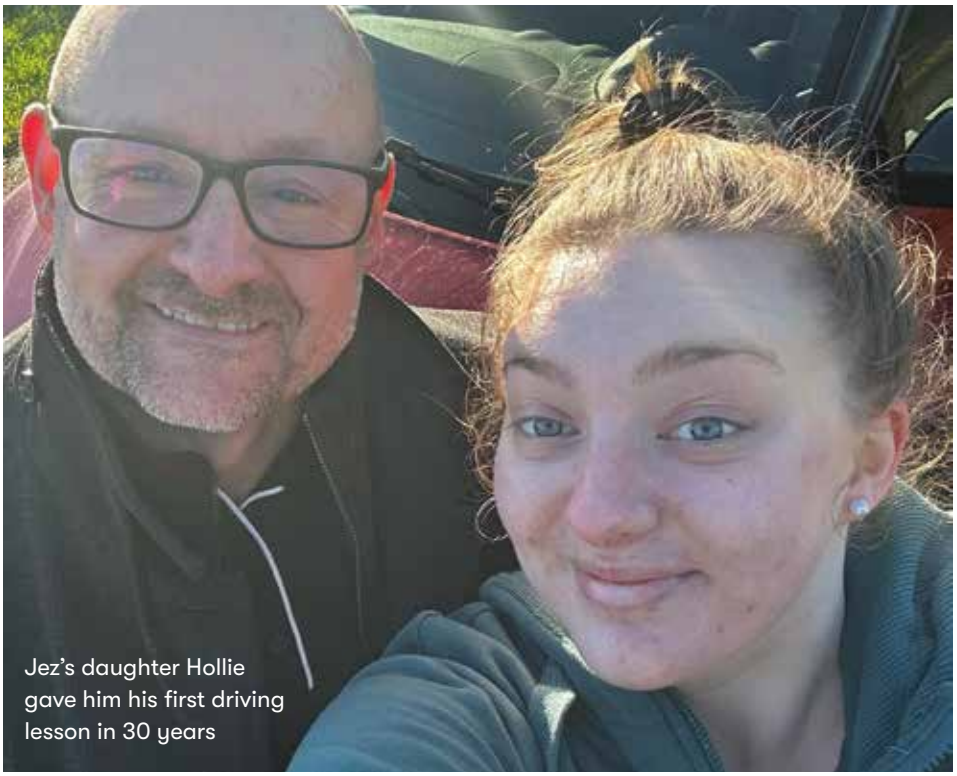
Thirty years of seizures

Jez was diagnosed with epilepsy in February 1991, shortly after turning 22. Towards the end of the previous year, he'd experienced a number of 'mini blackouts' – "like being part of a film and two seconds of footage had been cut out", that he later realised were absence seizures. A colleague at Thomas Cook, where Jez was working at the time, noticed and advised him to go to the doctor.

But Jez reckons his epilepsy went unchecked for years, as he recalls odd events, but thought they were down to tiredness or lack of concentration. "I just told myself that I needed to 'pull myself together'."

Once he had his diagnosis, Jez went on

> I remember going to about four months without an absence and then having one and bursting into tears in the office, knowing I was back to square one



Jez's daughter Hollie gave him his first driving lesson in 30 years

a journey to find medication that would help with his seizures – but to no avail. He was initially prescribed carbamazepine alongside tegretol at too high doses, which gave him double vision. "It appears that in the 90s, my diagnosis was incorrectly treated."

He continued: "The problem was that none of the medications seemed to make much difference. I do remember getting to about four months without an absence and then having one and bursting into tears in the office, knowing I was back to square one. At the time, it hadn't occurred to me I wouldn't drive again. To me, it was only a matter of time before I got my licence back but the longer it went on the more doubts I had.

"I didn't go that long without a seizure for another 30 years. The biggest issue in those early days was that my medication was chopped and changed and doses increased and there was a time where it felt worse to be taking any medication because it was making my head spin with terrible double vision."

Ups and downs with medication

Over the years, Jez felt that the inability to drive meant work prospects were turned down and opportunities missed for his family.

"By the late 90s when it seemed that no medication was working, I did begin to lose faith that I would drive again.

"I didn't help myself in some ways because I became lax with taking medication because there was no discernible difference. I certainly don't condone that approach but after a decade you can understand why someone would lose confidence.

"That said, it didn't stop me challenging myself in other ways. I took part in four London Marathons between 1995 and 1999. I did the London Duathlon in 2007 so I always tried to remain active.

"There was a spell in the late 2000s where I didn't take medication at all. I spoke to my consultant and said I didn't see the point of putting chemicals into my body if it was making no difference. That felt noble at the time but in hindsight it was also like giving up.

"One positive was seeing the same epilepsy specialist nurse - it was good to have someone who understood my situation without having to explain myself each time.

"As you get older, form relationships and have children, new challenges arise. I am a father of three and, for a time, my first wife didn't drive, so we had to travel by bus, which made holidays difficult. I do feel a tinge of guilt at some of the things they may have missed out on.

"By 2013 my first marriage had broken down. In time I met someone new and we married in 2017. In those intervening years, we spoke about my epilepsy and wondered if there was a new medication or if treatments had changed, so I went back to the neurology clinic to try again.

"It took a while and, like before, we tinkered with different forms of medication at different doses, but it felt much more reassuring. I was given time and understanding. I felt more listened to and hopeful that the seizures could be controlled, but I wasn't seriously considering the possibility of driving at this stage.Just having an appointment which wasn't rushed made me feel more understood which hadn't really happened before.

Running marathons in the 90s

"Then, following a review in 2023, something changed. In what was one of the most challenging and stressful times in my career a new medication called ethosuximide, coupled with my levetiracetam which I'd been taking since 2014, just seemed to work. There was renewed hope."

Jez and his eldest daughter Hannah

Jez's children bought him a ticket to drive around Silverstone

> **"You can have even the mildest symptoms and it can impact your life in a major way"**

Back behind the wheel

Jez continued: "Four months became five, and then six and seven. When the day arrived that meant I was 12 months seizure free in September 2024, I couldn't quite believe it. I reapplied to the DVLA.

"Friday 27 December 2024 was the day when I knew I could drive again.

"I had been cleaning the bathroom and hadn't even heard the postman. My wife Clare had noticed there was a letter from Wales. Before opening it, I felt the edges of something the size of a credit card, so I knew what was coming. And there it was: a driving licence. I'm not ashamed to say that I cried because I never thought the day would come.

"On my 56th birthday three days later, my daughter Hollie was able to give me a refresher driving lesson in her car. We arranged an hour's insurance cover and drove around the back roads of Peterborough, where I live.

"That 60 minutes will live with me forever. The kindness, the trust, the belief, the empathy and love between father and daughter is impossible to explain.

"The life experiences we have in 34 years are extraordinary and it was like being taken back in time. It was a little overwhelming, but also it was like riding a bike – it felt natural to be behind the wheel again."

It took Jez a little while to build up to to buying a new car. At the end of January, he bought a Kia Picanto and took a few refresher lessons from an instructor, covering all bases, from country roads and icy conditions to traffic lights and pedestrian crossings.

Jez realised that getting back behind the wheel hasn't been as straightforward as it could first appear. "Speaking today as a driver, I am effectively at the 'life default' level as someone with a car. It has made me 'normal' but, given my back story, that is not the case.

"It needs to be understood that I have to do things at my own pace and not be rushed or pressurised unnecessarily. A different set of rules apply. I know I am safe to drive but I occasionally have to explain to passengers that I need to be allowed to concentrate. By having those conversations makes it easier. Most of the time I drive alone anyway."

Choice, independence, self-worth and freedom

In the first instance, driving has cut Jez's commute to work to Grantham in half. Last Christmas, Jez marked the first anniversary of being able to drive with a trip to Silverstone racing course – a gift from all three of his children, which he found "extremely touching". It was extra special for him, as his father had worked in Formula 1 in the 1950s.

Alongside the convenience of having a car, Jez is pleased to be able to "contribute and take the pressure off" others.

"Jobs that probably only took 10-15 minutes each were totally impractical for me before.

"This is about so much more than just driving. It's about choice, independence, self-worth and freedom.

"You can have even the mildest symptoms, and it can impact your life in a major way. Loss of confidence and opportunities. Mental health issues and the knock-on effect with other members of the family too. Those with even more severe forms of the condition have a constant battle and we need understanding and funds to aid vital research.

"Since getting my licence back I have come into contact with so many people with so many different forms of epilepsy and their stories are so often heartbreaking and inspiring.

"The community is a powerful force for good and epilepsy charities are making huge inroads in raising awareness. At the end of the day, it is about the people, and their strength and bravery in adversity has blown me away."

The difference a year makes

After decades without being able to drive, and almost losing hope that he ever would again, the last four years held significant markers towards getting back behind the wheel.

- **January 25th 2023** – 24 days short of 32 years since my official diagnosis of epilepsy and when I drove a car for the last time. No inkling that would ever change. Why would it?
- **January 25th 2024** – four months since my last absence seizure following a change in medication at the beginning of the previous year. The longest spell absence-free I'd ever had.
- **January 25th 2025** – the day after I picked up my first ever car aged 56 I parked it in the same spot as I parked my dad's old car I used to drive outside the bedsit I lived at in 1991. A full circle moment.
- **January 25th 2026** – I drive 100 miles North with my wife to see our 10th month old Grandson in Yorkshire. He was born on Purple Day in 2025.

Epilepsy support for you

For many people, living with epilepsy can feel isolating and misunderstood. But you're not alone. There are so many others navigating similar experiences – whether they're living with epilepsy themselves or caring for someone who is.

At Epilepsy Action, we're here to support you and help you connect with others who truly understand. We offer a range of free, confidential services designed to make a difference:

- **Helpline**: Speak with our trained advisers who are ready to listen and help you explore possible options and solutions.
- **Befriending**: Have a friendly weekly chat with a volunteer who understands.
- **Groups**: Join others affected by epilepsy through virtual or in-person groups to share stories, experiences, and support.
- **Counselling**: Available in Wales, offering professional support to anyone affected by epilepsy.
- **Family Support**: Tailored support for families and carers in South Wales and Northern Ireland, including practical help and opportunities to connect.

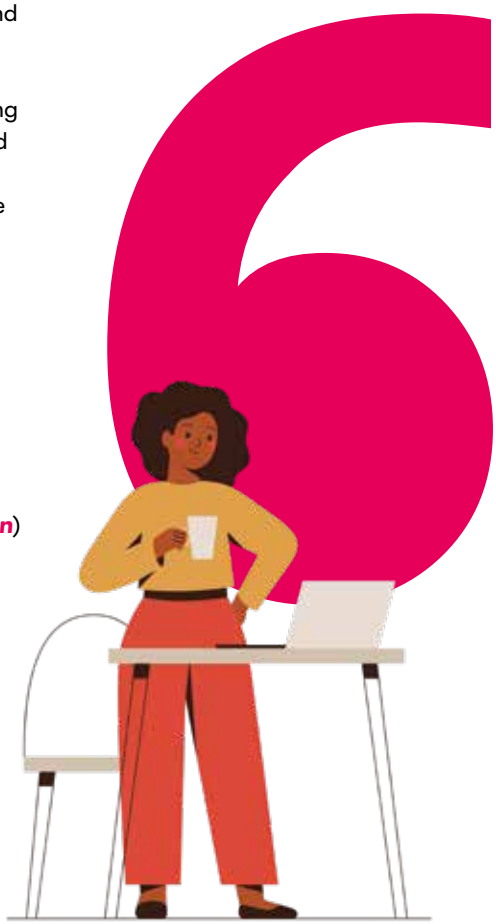
We're here to listen, support, and bring people together – because no one should feel alone on this journey.

For more information call our Helpline on 0808 800 5050 or visit ***epilepsy.org.uk/support-for-you***

You can also find us on:

- HealthUnlocked (***healthunlocked.com/epilepsyaction***)
- Discord, (***bit.ly/3vHLOkT***)
- Facebook (***facebook.com/epilepsyaction***)
- X (formerly Twitter) (***@epilepsyaction***)
- Instagram (***bit.ly/3zSKMVM***)

"We're here to listen, support and bring people together"



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- **Website –** high quality information about all things epilepsy
- **Epilepsy awareness courses**

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