

# Epilepsy

Today

‘Writing helps me claw back control’

AUTHOR ADAM CONNORS  
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Epilepsy manifesto  
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New brand unveiled  
PAGE 12

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Lucy talks pots, crafts and epilepsy **p14**

Meet our Virtual 10k champions **p16**

**EPILEPSY  
ACTION**

# Medication alone isn't the answer for 1 in 3 people with epilepsy.



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## Summer fun

**For anyone wondering what to do with the last week or two of the summer holidays, this is the Epilepsy Today issue for you.**

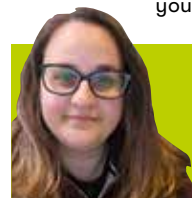
For the prolific readers among you, Adam Connors has written a new novel, in which central character Kyle discovers that his seizures take him to another world called the Stillness. Adam shares more about his epilepsy and his inspirations on page 24.

If spending time outside in the garden is more your thing, on page 14 Lucy shows off some of her beautiful painted pots, which will bring an extra sprinkling of joy to any garden. Lucy has epilepsy and started her business when she was home-bound while being weaned off her medicine.

If you are more of a theatre goer, Angelika describes writing and starring in her new play The Unicorn in Captivity on page 22, which features a central character with epilepsy. She hopes the play will be picked up for another run soon.

You can also read about some of Epilepsy Action's upcoming events, including Doodle Day (page 29) and the Auction of Promises (page 13). Or, if you'd just like a feel-good story, you can read about Star Awards winner Sienna on page 28.

Thank you, as always, for your steadfast support of our work, and thank you for reading.



**Kami Kountcheva**  
Editor

At Epilepsy Action, we want to celebrate the good things in our members' lives. If you want to be featured, email [kkountcheva@epilepsy.org.uk](mailto:kkountcheva@epilepsy.org.uk)

## Debut author nominated for awards

**A**uthor, Emma-Louise James, whose debut novel, *Jo's Hidden Secrets*, features a character struggling with her epilepsy, has been nominated for awards at the West Country Women Awards and the Mental Health Awards.

The West Country Women awards celebrate outstanding women in the area, while the Mental Health Awards champion successful interventions and inspirational people.

James said: "It was a lovely surprise to be nominated for these awards for my book and fundraising. I hope to raise a lot of epilepsy awareness whenever I can, as it is so important to me."

*Jo's Hidden Secrets* tells the story of Jo, who develops epilepsy after an accident causes her to hit her head. She deals with a host of problems alongside her epilepsy, including mental illness, eating disorders and domestic abuse. Jo's journey leads her to discover where she can find help and support.

James said: "I wrote the book because I wanted to talk about how my epilepsy started and how it affected my life and my family's life too. I wanted to share all the challenges I faced in my life and the obstacles I've had with my epilepsy, such as struggling in school, being unable to drive and losing jobs."

The author explained that she has

struggled with mental health issues and other health conditions, as well as epilepsy, and said she had "hit rock bottom" before she was considered for surgery.

She added: "I want my book to help readers know they are not alone and what wonderful charities are out there for them to get support. All the charities I've had help from are listed in my book."

James also met Bargain Hunt presenter and antiques expert Charlie Ross, sharing information about epilepsy and about her book. She was also given a grant to attend an epilepsy charity event in the US because of her fundraising.

*Jo's Hidden Secrets* is available to purchase now: [amzn.to/4d9HJK8](https://amzn.to/4d9HJK8)

## Epilepsy Action launches first TV first-aid campaign

**Epilepsy Action launched its first TV campaign, airing 28 June-26 July 2024. The ad featured Epilepsy Action's first aid video on what to do if someone has a tonic-clonic seizure.**

The CARE video was first shared on YouTube and social media in May 2023 as part of the organisation's first aid campaign. Epilepsy Action adapted this for TV to raise wider public awareness of epilepsy and tonic-clonic seizure first aid.

The ad featured on several channels, including More 4, Brit Asia TV, Quest Red, W, Sky Nature, Sky Arts 1 and Alibi.

A national poster campaign also

went live from the beginning of July, with posters popping up around UK high streets, also sharing the tonic-clonic seizure first-aid information.

Epilepsy Action director of communications and digital, Jon Eaton, said: "When we launched the first aid campaign last year, so many of you told us you wanted to see it on TV. So, we listened, and we're really excited to have this opportunity to raise so much more awareness of first aid for tonic-clonic seizures."

You can text CARE to 70800 to donate £5 and get your seizure first aid card.



# Epilepsy Action secures grant to expand award-winning helpline

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

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

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

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

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

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

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

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

Stuart Mulheron, general manager at Angelini Pharma UK-I Ltd, said: "We are delighted to support Epilepsy Action with this grant and make a



difference for people with epilepsy. Angelini Pharma UK-I Ltd provides grants and donations to support initiatives that enhance patient care or benefit the NHS in accordance with the Association of British Pharmaceutical Industry Code of Practice."

The Epilepsy Action Helpline won Helpline of the Year at the Helpline Awards in 2023. Advice and information officer, Diane Wallace, was awarded the Lifetime Service Award for her 30 years of dedicated service, and advice team leader, David Thornton, also received a runner-up award for Mentor of the Year.

## Epilepsy Action receives comms award

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

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

The PRCA Dare Awards celebrate "the very best PR and communications professionals" across the UK.

Epilepsy Action was nominated for work in 2023 for its CARE campaign, which offered a simple acronym to help the public know how to help someone having a tonic-clonic seizure.

The work involved conducting research into the experiences of people with epilepsy and using the results to inform

and educate members of the public about epilepsy and seizure first aid.

The research found that more than 50% of people with epilepsy in the UK have avoided public spaces due to fear and stigma. Nearly half (47%) said they had wrongly been accused of being drunk or on drugs.

People also reported having been robbed or physically abused while having a seizure in public.

The Epilepsy Action and Be Broadcast teams got the message out in more than 1,000 pieces of media coverage, including online stories, broadcast and print.

The CARE campaign video had more than 550,000 views across social media and 21 MPs wore Epilepsy Action badges in parliament supporting National Epilepsy Week 2023.



# Epilepsy news

## GP collective action: NHS urges patients to continue to seek GP care

**T**he NHS is urging the public to still come forward for care at their GP services as usual during the GP collective action in England, which began on 1 August.

GP practices will still be open from 8am to 6:30pm, the NHS said, but the action will cause disruption to some services. The NHS said it is “vital” that people still attend their appointments unless told otherwise by their GP.

People affected by the GP collective action can seek urgent medical help by calling 111. In a medical emergency, call 999.

In a ballot by the British Medical Association, 98.3% of GPs voted in favour of collective action to oppose the new GP contract, announced by the last government. This only agreed to a 1.9% funding increase for 2024-25.

The England general practitioners committee (GPCE) has called GP

practice finances “precarious”. It said it is “greatly concerned” that practices may have to close before the new government can intervene.

The collective action, which will continue for an indefinite period of time, is not a strike, the GPCE has said, as services will remain open and contracts won’t be breached.

Instead, GPs will choose actions to take from a list of 10, which are not in breach of contract. They include limiting the number of patients a doctor can see a day to 25 and stopping any voluntary work that GPs are doing.

Dr Amanda Doyle, NHS national director for primary care and community services, said: “GPs and their teams are the bedrock of the NHS, and we recognise they are working really hard and dealing with record demand. On behalf of patients, the NHS has a duty to plan for collective action, and we will continue



to work with [the] government to find a resolution and end collective action.

“Our message to the public remains the same – they should continue to come forward for care during this collective action, as GP practices will remain open.”

People with epilepsy affected by the collective action can get advice and support from the Epilepsy Action Helpline at 0808 800 5050. For advice on medicine, people can also speak to their pharmacist.

## Cat Deeley apologises after seizure joke on TV

**This Morning presenter Cat Deeley apologised on the show on 18 June 2024, after being called out by charities and people with epilepsy for “careless use of language” on the show on 17 June 2024.**

Deeley made the initial comment as the show returned from a commercial break. Introducing the next segment, Deeley started dancing to the music playing, and after Shephard quipped: “You alright?”, she replied: “Yeah, I’m fine. Just having a seizure. Welcome back.”

On the show on 18 June 2024, Deeley said: “I just wanted to apologise to anyone who was offended yesterday

when I made a light-hearted comment about my dancing style.

“It really wasn’t supposed to cause any upset to anybody, but I can see why that might have been the case, so I do apologise, I’m very sorry.”

Jon Eaton, Epilepsy Action director of communications and digital engagement said: “We appreciate Cat Deeley’s apology. That said, it would be even better if epilepsy wasn’t at the top of the list when it came to light-hearted remarks. Epilepsy is a serious condition.

“We need high-profile people to help bring epilepsy to light and make it more visible, not make the stigma worse.”



## Woman died after seizure in A&E waiting room - inquest

**A** woman died days after a seizure caused “significant, irreversible” brain damage while she waited in A&E, an inquest has heard.

Inga Rublite, 39, was found unconscious and appearing to be having a seizure under her coat in the Queen’s Medical Centre (QMC) in Nottingham on 20 January 2024.

Staff discovered her “tucked behind a door” and “seemingly asleep” under her coat.

The inquest was told that there were “missed opportunities” to check on the mother of two, during the eight hours that she waited in the crowded A&E waiting room.

On 19 January, Ms Rublite had called 111 after getting a sudden headache, neck pain and blurry vision. She had described it as feeling like she was “hit by a brick”. She was advised by a clinician on the phone to go to hospital.

She arrived at 10:30pm and staff called out three times for her in A&E and called her mobile phone. She wasn’t found until 7am the next day.

Nottinghamshire coroner Elizabeth Didcock said: “There were three opportunities for the headache to be recognised as something more dangerous than it was thought to be.”

Emergency department matron, Luke Derby, said that it was “reasonable” that staff would have walked past the place

where Ms Rublite was sat, but would not have been “physically seen” by the person calling for her.

Mr Derby also said it was “not unusual” to see people with coats over their heads, especially at night. He said the chairs have now been moved so people can’t sit where they can’t be seen from the navigator’s desk.

Ms Didcock said: “I’m aware from the investigation report that there was significant crowding and additional numbers of people.”

A&E consultant at the QMC, Dr Robert Jamieson, said: “As soon as you start to put all these targets in and look at the number of staff to do it, it becomes unachievable.

“There was an opportunity missed to see how she was, how the pain was and how she appeared, but that didn’t happen.

“Unfortunately, Inga was sat there, and she was missed.

“We have talked about lots of options and the investigation has talked about lots of options in terms of checking who’s in the area and managing the space.”

The inquest continues.

**“There was an opportunity missed to see how she was, how the pain was and how she appeared, but that didn’t happen”**

## English long-distance runner provisionally diagnosed with epilepsy

**Gold medal-winning English athlete Jessica Warner-Judd has been provisionally diagnosed with focal epilepsy after having two seizures during the 2024 European Championships in Rome.**

The mid- and long-distance runner had a seizure during the women’s 10,000m final on 11 June 2024, and had to drop out with 600m to go.

Warner-Judd posted on X: “From getting the bus to the warm up track, I can’t explain it – something felt off! I don’t

remember much about the race apart from around 3k in, my head felt incredibly tight but I stubbornly persevered.

“With 600m to go, I suffered a seizure, and when taken to the medical centre I suffered a further seizure and so was sedated and taken to hospital where I spent the night.

“It has been an incredibly tough couple of months and has culminated in me being provisionally diagnosed with focal epilepsy.

“I’m not sure what the future holds.”

She received an outpouring of support on social media, including from Wales 400m hurdler Dai Greene and British sprinter Beth Dobbin, who also have epilepsy.

In 2019, Warner-Judd won a gold medal for the 5,000m in the 2019 World University Games – the Summer Universiade – in Naples, Italy.

In her post on X, she said: “I’m not sure what my year will look like, but I’m eager not to let this stop me and be back running soon”.

# Epilepsy12 – children’s epilepsy services still need improvement

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

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

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

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

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

## Mental health

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

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

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

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

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

“It’s vital children with epilepsy have



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

## Timeliness of care

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

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

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

**“It’s concerning to see more than three in five children not having an individual healthcare plan in school”**

## Other important findings

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

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

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

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



# Guidelines tightened on topiramate in pregnancy

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

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

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

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

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

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

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

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

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

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

## Reduced medication options for women

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

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

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

“Clinicians need the right support to make sure that the change in rules is

effectively communicated to affected patients, and that they can make informed decisions about their care.

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

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

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

## “No information and no idea”

Epilepsy Action, Young Epilepsy and Epilepsy Society surveyed more than 1,200 women and girls with epilepsy in 2022 about epilepsy medicines in pregnancy. The survey showed that more than a quarter of respondents taking topiramate (28%) didn’t know about the risks of the medicine in pregnancy.

One responder taking topiramate said: “I had no idea any of these medications could be harmful.”

Another commented: “When I was first diagnosed, I was 20. I had no information and no idea about epilepsy and pregnancy. I think part of the reason I haven’t had children is because I was afraid of the effects of my tablets on a baby.”

Some responders had already been through pregnancy. One said: “It was mentioned when I was first diagnosed that some medications wouldn’t be suitable if I wanted a child, but my neurologist didn’t tell me which ones would put my baby at risk. I was on topiramate and carbamazepine when my child was born seven years ago (I didn’t know I was pregnant until I was in labour) and I had to be checked over. Luckily my child is okay, however, he’s on the waiting list to be screened for autism and ADHD.”

Another responder shared her experience, saying: “I’ve successfully had two safe pregnancies and healthy children with advice from my neurologist and epilepsy nurse.”

The MHRA is urging anyone taking topiramate to use the Yellow Card Scheme to report any side effects of their treatment.



# New device for drug-resistant focal epilepsy available on NHS

**A** 'brain pacemaker' aiming to reduce seizures in people with drug-resistant focal epilepsy is now available on the NHS.

The device is called EASEE (Epicranial Application of Stimulation Electrodes for Epilepsy) and is developed by medical technology company Precisis.

EASEE is placed just under the scalp over the epileptic focus, where seizures start. It sends high-frequency pulses every two seconds to disrupt emerging seizures. It also has direct current-like phases every day for 20 minutes, designed to "regulate over-excitabile brain areas in the long term to prevent seizures".

Research by Andreas Schulze-Bonhage

and colleagues from Germany and Belgium looked at how effective and well tolerated the device was. The research was carried out on 33 people. It found that four in five people (81%) who started the treatment continued using the device for the two years of the research.

In the first year, seizures reduced for two fifths of people (41.4%). After two years, seizures reduced for around two thirds (65.4%).

The median number of seizures reduced from 12 a month to eight a month after one year and five a month after two years. This means a 33% reduction after one year and a 68% reduction after two.

The researchers concluded that the



device is "effective and well tolerated".

CEO of Precisis, Dr Angela Liedler, said: "Drug-refractory patients wait, on average, 22 years before they are offered further treatment options. With EASEE, the treatment spectrum is expanded in the early phases of the disease, meaning patients are able to access effective treatment earlier in their lives.

"EASEE is minimally invasive compared to other non-pharmacological treatment methods, and it is available for epilepsy patients over the age of 18 years."



## HELLO BRAIN! exhibition brings research to life

**HELLO BRAIN! is a free exhibition at the Francis Crick Institute, exploring the brain and how it works.**

Open from 2 March until 7 December, the exhibition spans the beginning of neuroscience to recent discoveries and technological progress. It explores key themes, including sleep, pregnancy, old age and perception.

The exhibition is aiming to highlight research into advancing our understanding of the brain, carried out at the Francis Crick Institute.

The labs featured in the exhibition work on growing neurons, creating 3D brain maps and understanding why animals and humans act in different ways. As well as that, it explores damage to the brain and how the brain creates thoughts.

HELLO BRAIN! brings this research to life through features, including 3D-printed brains, knitted neurons and floating curtains.

Andreas Schaefer is group

leader of the Sensory Circuits and Neurotechnology Laboratory at the Crick, and senior advisor for HELLO BRAIN!. He said: "The brain is probably the most complex object in the known universe, and it's ever-changing throughout our lives.

"One of the biggest challenges in neuroscience is understanding the connectome: how billions of cells are connected with each other and communicate to produce behaviour which makes us uniquely human.

"Labs at the Crick, including my own, are working at the forefront of neuroscience, aiming to uncover the secrets of the brain, from what happens at different life stages to the impact of disease and injury.

"The HELLO BRAIN! exhibition offers visitors the chance to marvel at what we know, and contemplate what's still left to discover."

Holly Cave, Curator of HELLO BRAIN!, said: "Visitors can peek into the fascinating conversations and lab tours

I've had with Crick scientists, getting as close as possible to the cutting-edge neuroscience research happening above their heads.

"From working with mums in the local community to find out how parenthood has changed them, to learning how the brains of mice, crocodiles, goldfish, and other animals have evolved to suit their needs, this has been such an exciting exhibition to curate."

The exhibition is located in the Manby Gallery on the ground floor of the Francis Crick Institute. It takes around 30 minutes to go through and is designed for people aged 12 and over (with books and toys for younger children also available). Access resources are available, including large print, Braille and Easy Read materials, and British Sign Language and Audio Described tours.

People can also book bespoke visits to the exhibition, including an introduction from the gallery host. For more information about bespoke tours, contact [exhibitions@crick.ac.uk](mailto:exhibitions@crick.ac.uk).



NOW AVAILABLE IN THE UK

# MAKING LIFE EASIER

FOR PATIENTS WITH DRUG-RESISTANT FOCAL EPILEPSIES

„I have had focal epilepsy since I was 12 years old, with many seizures a month and no relief from medication.

Following my motto #nevergiveup, I decided to have the EASEE® system implanted when I was 18 years old.

Since then, my life has changed significantly for the better and I have been seizure free for over three years.

I have even been able to get my driving licence.“

*Ibrahim Soyudogan, an epilepsy patient, who is seizure free thanks to EASEE®*

Watch Ibrahim's impressive story here:



Scan QR-Code  
[easee.precisis.de/en/case-ibrahim](https://easee.precisis.de/en/case-ibrahim)

68%

After two years of using the EASEE® system, patients experienced a median seizure reduction of 68%.

“Long-term outcome of epicranial Focal Cortex Stimulation with the EASEE® system in pharmacoresistant focal epilepsy”, Schulze-Bonhage et al. 2024

- **Invisible from the outside:** Minimally invasive implant inserted under the scalp without touching the brain
- **Innovative electrode design:** Allows targeted stimulation of affected brain areas
- **Not perceptible:** EASEE®-System works discreetly, allowing full freedom of movement
- **Individually adaptable:** Individually customised stimulation parameters for optimal therapy settings for each patient



# EPILEPSY ACTION

## Brand *new*

Epilepsy Action has had a much-needed refresh to help it achieve its lofty goals. Epilepsy Action's director of communications and digital engagement, Jon Eaton, talks us through the new look.

**In June 2024, we launched the new Epilepsy Action brand. The new logo represents the interruption that epilepsy brings to people's lives, while the strapline speaks to our role in removing limits: 'Epilepsy says stop. We say go!'**

Jon Eaton, director of communications and digital engagement, who led on the project, explains:

"We had a good question from a service user after the brand launch in June.

"Why has Epilepsy Action made a big investment in its brand after nearly 25 years?"

"The answer lies in what our new strategy is trying to achieve. Last year, when we surveyed over 5,000 people, we received a really clear message – tell the general public what epilepsy is really like.

"Our supporters are right. People with no connection to epilepsy don't know what

it is really like. Epilepsy isn't seen in order to be comparable to health conditions like cancer, Parkinson's disease or motor-neurone disease. Because epilepsy is not visible and understood in society, there are a lot of limits on people with epilepsy.

"Our job is to remove these limits so that as many people as possible can live a full life with epilepsy: have great jobs, fantastic holidays and brilliant relationships. In short, we want to challenge conventions on epilepsy and create an inspiring future.

"When reviewing our brand, we felt that it did not look inspirational. Increasingly in a digital world, our old logo looked very 'stuck on'. Compared to other charities, it looked very dated. The previous rectangular brand also became too inflexible for the new spaces and media we wanted to expand into.

"To break into public consciousness,

**“To break into public consciousness, we need to say what is different about epilepsy”**

we need to say what is different about epilepsy compared to other health conditions. We concluded that no other large-scale illnesses are as unpredictable as epilepsy. You can be fine one day and completely thrown off course the next. Some people achieve seizure control, and some don't. That's why interrupted words and pictures appear in our brand. We wanted to show that reality of a hidden disability. Most people probably walk past many people with epilepsy every day and have no idea that their lives are subject to unexpected disruption.

"We are here for people throughout their journey with epilepsy, from those early days when everything feels very scary, to crossing the finish line at the London Marathon. To show this full spectrum of emotions we wanted a flexible brand. This is what we have built.

"We are super proud to have done that and launch a national TV campaign straight away. We really believe this is a brand worthy of putting in front of six million people to make them take notice.

"The feedback we have had has been overwhelmingly positive, but whatever your feedback in the months ahead, please get in touch.

"We want our service user voice to shine through in all of our communications."



# Auction of promises

This Autumn, bid to win some one-of-a-kind prizes and support people with epilepsy

**W**e are so excited to be launching this new and exciting fundraising auction this Autumn!

From Monday 28th October to Sunday 3rd November, you can bid on a selection of one-of-a-kind prizes which include:

- A fully signed cast program from The Duke of York Theatre's production of Romeo & Juliet (2024), starring Tom Holland (Spider-Man), Francesca Amewudah-Rivers (Sex Education) & Freema Agyeman (Doctor Who).
- The opportunity to chat 1-2-1 with Eurovision 2023 contestant TEYA (Austria's Who The Hell is Edgar?) via

Zoom, where she will write the chorus of a pop song specifically for you.

- Props & Memorabilia, owned and used by Just May and Le Fil on BBC's RuPaul's Drag Race UK.
- Custom Artwork in the Style of the Rainbow Magic book series, by the original illustrator Georgie Ripper.

Keep your eyes on Epilepsy Action's social media channels for more information about where you can bid, and the other exciting prizes that will be up for grabs!





# Pots by Lucy

Lucy shares how her epilepsy, the pandemic and a creative birthday present blossomed into her crafting and pot painting business.

**E**ighteen-year-old Lucy Davis is someone who makes the best of things. For example, Lucy takes the ordinary, humble plant pot and makes it into something fun and bright and joyful.

And another example is the launch of her businesses: Pots by Lucy and Lucy's Crafty Creations. She started these in

2020, when the global pandemic left her, and the rest of us, at home, anxious and isolated. At the time, Lucy was also being weaned off her epilepsy medicine by her doctor, so she wasn't allowed "to go anywhere or do anything, in case anything happened", which left her feeling even more alone.

For fun, Lucy likes to turn her hand

**“I couldn't go out with friends and I always had to be supervised by an adult who knew what to do if I had a seizure”**

to many different forms of creative pursuits, from digital art, product design and painting, to working with resin and jewellery making. Making the best of a challenging situation, Lucy decided to use her time to turn her hobby into something more.

“It all started in 2020, when I painted an old plant pot from my garden for my grandma for her birthday. My mum then shared it on Facebook. A large number of her followers began asking if I could paint



them some pots; I had made £400 before the end of summer.

“This was when I decided I wanted to carry this on and make it a business. I set up my Facebook and Instagram pages not long after, where I could share all my work (I also make greetings cards).”

Lucy says she likes to do crafting for fun – from digital art, product design and painting to working with resin and jewellery making.

### A lot of limitations

Despite getting to the point where she could be weaned off her epilepsy medicine, things haven't always been so smooth for Lucy. She was first diagnosed with epilepsy in 2016 when she was 11.

“I'd just started high school and seemed to be getting these ‘episodes’. I went to the doctors and they referred me to a paediatrician. I was sent for an MRI and an EEG, which was said to be to ‘rule out’ epilepsy. But, in this case, that’s not what happened.

“I was then diagnosed with epilepsy. I had a lot of absence seizures at the start and was prescribed lamotrigine. I did also go on to have a few tonic-clonic seizures a while after my diagnosis.

“Going into high school and meeting new friends is already hard enough but with epilepsy, it seemed to be a lot harder. I couldn't go out with friends, and I always had to be supervised by an adult who knew what to do if I had a seizure.

“There have been a lot of limitations, but these have helped me become the person I am today. Throughout school, there were things I couldn't do, such as rugby. I loved sport at the time, but due to it being a contact sport, I had to sit it out. That's just one example.

“It was quite isolating and annoying at the time, but I knew it was for my own safety. Through school my memory was affected a little bit, as I could have gone to school and had absence seizures and been there all day but not remember a thing after. When it came to exams, I was kept in a separate room where I could be monitored.

“I was lucky enough to participate in and complete my Bronze Duke of Edinburgh Award, as a school staff member was trained in my emergency medication.”

Lucy's seizures began to lessen over time, and by 2020, she had been two years seizure free. Her specialist had suggested weaning her off her medicine,



and with the pandemic, it was “the perfect time to start the process”.

### The one that started it all

Lucy explained she has been seizure free since 2018 and is no longer taking any medicine, so she has been signed off as ‘in remission’.

She added: “There are still times even now, where I stop myself from doing things in case something was to happen, but this is just me being cautious.

“I am a twin and seeing my sister grow up and go out with her friends and get that independence a teenager needs was quite difficult. But on the other side, I had all the attention on me, so my sister and older brother didn't have as much of the attention they probably needed. It was hard not just on me but my family. You never want to see anyone go through something like that.”

Having come through to the other side, Lucy credits a lot of her current situation to her life experiences. She works full time, and on evenings and weekends runs her businesses, which are doing really well. She's also just bought her first home.

“At this current point, I sell a range of greetings cards, painted plant pots, trinket dishes, crystals, knitwear and much more.

“I look back and think, if I had never had epilepsy, I probably wouldn't be the person I am today and maybe wouldn't have started my business or kept it going.

“I now attend markets monthly and have a website with items available for purchase. My favourite pots have got to be the Heinz Ketchup pot and the UP themed pot.

“Or the one that started it all, the yellow and red flowers on the black background.”

**You can find Lucy on Facebook ([facebook.com/potsbylucy](https://facebook.com/potsbylucy)), Instagram ([instagram.com/potsbylucy](https://instagram.com/potsbylucy) and [instagram.com/lucyscraftycreations](https://instagram.com/lucyscraftycreations)) and TikTok (@[lucyscraftycreations](https://tiktok.com/@lucyscraftycreations)), and you can peruse her products on her shop ([lucyscraftycreations22.myshopify.com](https://lucyscraftycreations22.myshopify.com)).**

**Lucy has arranged an exclusive 20% discount on her products with the code: Epilepsy**



Scan code to browse Lucy's shop



# Meet the runners



**Name:** David  
**Team name:** David and Isabel  
**Longest ever run (or walk):** 10k  
**Best moment of the 10K:** Knowing we'd completed it  
**Hardest bit:** When the rain started  
**First thing you did after the 10k:** We had a sit down and reflected on how it went, and had a cup of tea  
**Favourite running song:** Anything with a good beat  
**Favourite place to run/walk:** Parks or the countryside which is 10 minutes from where we live  
**Reason for signing up:** My daughter has epilepsy and I wanted to give something back  
**Connection to epilepsy:** My daughter was diagnosed with epilepsy in 2023

With so many events in the calendar designed to raise vital funds while also raising your daily step count, we meet some of our virtual 10k challengers and find out what motivates them

**T**aking on a fundraising challenge to support people with epilepsy is simply a win-win.

Challenging yourself to run a certain distance, or walk a certain number of steps is empowering, rewarding and let's face it, a boost to our health and wellbeing. And, on those rainier days, it's also character-building.

Knowing that you're doing it all for a great cause as well is the icing on the cake.

This year's Virtual 10k took place in May

over National Epilepsy Week. Participants from across the globe laced up their trainers and completed their 10k to earn themselves a shiny medal and raise money for epilepsy. For most participants, epilepsy is close to their heart.

David, 53, and Isabel, 10, from Didcot, Oxfordshire, did their 10k on the Sunday of National Epilepsy Week.

David said: "Isabel was around eight when the seizures started, and it took a while to recognise they were not daydreams. We got a diagnosis in 2023.

"Accepting the diagnosis and understanding how we can support Isabel has been one of the hardest parts.

"Isabel has been very positive and my wife and I have made sure her life remains the same, with some small adjustments.



**Name:** Katy  
**Team name:** The Three Degrees

**Longest ever run (or walk):** 10k run

**Best moment of the 10K:** Seeing the ducklings at the Tarn

**Hardest bit:** Finding the energy to keep going!

**First thing you did after the 10k:** Ate my lunch!

**Favourite place to run/walk:** In the countryside

**Reason for signing up:** To support people affected by epilepsy

**Connection to epilepsy:** Working for Epilepsy Action



**Name:** Harvinder  
**Team name:** The Three Degrees

**Longest ever run (or walk):** Half marathon walk and 5k run (but many years ago!)

**Best moment of the 10K:** Being out in the fresh air, watching the swans and ducks

**Hardest bit:** Starting the walk in the rain

**First thing you did after the 10k:** Have a coffee

**Favourite place to run/walk:** Roundhay Park

**Reason for signing up:** To make a difference to people with epilepsy

**Connection to epilepsy:** My uncle had epilepsy, and I also have a cousin with epilepsy



**Name:** Maxine - Max, Maxi or my favourite, Auntie Max

**Team name:** The Three Degrees

**Longest ever run (or walk):** 10k

**Best moment of the 10K:** Loved the training, which gave us a chance to meet up outside of work. We put the world to right discussed what's for tea, weekend activities, Netflix, family, friends, and we took pictures of the scenery and wildlife.

**Hardest bit:** Blisters during training

**First thing you did after the 10k:** Had a coffee

**Favourite place to run/walk:** Yeadon Tarn and Roundhay Park

**Reason for signing up:** I like a bit of a challenge and I like to get involved

**Connection to epilepsy:** I have a cousin with epilepsy



There isn't a reason to let this stop her from leading a nearly normal life.

"Our family has helped us pull through the difficult times. Isabel's hospital consultant has been amazing. And Isabel's attitude has been incredible. She presented to her whole class about her epilepsy and how it's impacted her.

"It felt right to raise money and give something back."

### The Three Degrees

For other participants, working with people with epilepsy every day is a motivator to take part in these challenges. And getting to spend time with your friends is a welcome bonus!

Katy has worked for Epilepsy Action for two years.

She said: "It felt great knowing that I was one of hundreds of people running and walking to raise awareness and improve the lives of people affected by epilepsy."

Alongside her were her two friends and colleagues at Epilepsy Action, Harvinder and Maxine. Harvinder has been working at Epilepsy Action for 13 years, and Maxine for 29.

Harvinder said: "I am so proud of being a part of a fabulous team of people that

work continuously to support and improve the lives of people affected by epilepsy."

Maxine added: "I'm always proud to say where I work. Epilepsy Action does some incredible work raising awareness and making life easier for people with epilepsy.

"I think working for a charity, I can't expect everyone else to raise awareness or funds if I don't. So I've helped out at many of our events: Bradford 10k a few times, last year I walked in the Pride march, I've been at the Reindeer Stampede, I've done previous walks, handed out flyers in the centre of Leeds advertising our events, and taken part in lots of bag packing at M&S Guiseley."

**To take part in one of our events, visit [epilepsy.org.uk/fundraise](http://epilepsy.org.uk/fundraise)**



**Scan the QR code to see future walking and running fundraising events**



# Epilepsy

Ahead of the 4 July general election, Epilepsy Action put together its manifesto sharing key asks from the new government on important issues for people with epilepsy.

*manifesto*



**W**ith the new government firmly in place, at Epilepsy Action, we wasted no time in getting in touch with key ministers to share key issues facing people with epilepsy and what improvements we want to see for people with epilepsy. The three key areas are health and social care, justice, and work and benefits.

With the new government firmly in place, at Epilepsy Action, we wasted no time in getting in touch with key ministers to share key issues facing people with epilepsy and what improvements we want to see for people with epilepsy. The three key areas are health and social care, justice, and work and benefits.

We have called on the new government to act on improving numbers of epilepsy specialist nurses and neurologists, putting together a sodium valproate compensation scheme and closing the disability employment and pay gap.

We wrote to Secretary of State for Health and Social Care, Wes Streeting, stressing that epilepsy has not been a priority for government investment into research in the past. We also explained that the ratio of neurologists to patients in the UK is one of the lowest in Europe, and that the number of ESNs is much lower than best practice guidelines suggest.

We have asked the Health Secretary

for increased investment into epilepsy services, more neurologist and ESN posts to be created and a Neuro Taskforce to be put together.

We also wrote to James Timpson, Minister of State for Prisons, Parole and Probation to campaign for justice for people with epilepsy.

We called for a compensation scheme for families affected by the sodium valproate scandal, and for mandatory epilepsy training for police officers and prison staff. This is because the level of epilepsy in prisons is twice that of the general population.

#### **Work and benefits**

A letter has also been sent to Liz Kendall, Secretary of State for Work and Pensions, highlighting changes needed around work and benefits for people with epilepsy.

At 42%, people with epilepsy have one of the lowest employment levels among disabled people, according to data from the Office for National Statistics. Those who are in employment are paid 12% less than non-disabled peers.

A 2024 survey by Epilepsy Action showed that 60% of responders with epilepsy faced discrimination at work, while 42% of employers said they would avoid hiring someone with epilepsy.

We are now asking the government for mandatory reporting of the disability

# “ It is time to take action to tackle these issues

employment pay gap and skilled job coaches to help people with hidden disabilities find work. We want the government to ensure the Equality Act is fit for purpose and to introduce a minimum fine for any employer discriminating against disabled employees.

The letter also outlines challenges people with epilepsy face in applying for personal independence payments (PIP). The PIP assessment system needs updating to take into account the needs of a fluctuating condition and the higher costs of living with a disability.

#### **Take action**

Daniel Jennings, senior policy and campaigns officer at Epilepsy Action, said: “Before the general election, we set out clear priority areas that need to change to help us create a world without limits for people with epilepsy. Now we have our new government in place, it is time to take action to tackle those issues across healthcare, justice and employment and welfare to make real change.

“For too long, people with epilepsy have been overlooked in so many areas of life – from lack of prioritising neurology services to having to fight to find and stay in employment. Please help us to achieve long-lasting and impactful change by contacting your MP to stand up and fight for these issues so people affected by the condition can live the life they deserve.”

You can support the asks in the Epilepsy Action manifesto by writing to your MP. Visit [epilepsy.org.uk/manifesto](https://epilepsy.org.uk/manifesto)



Epilepsy Action is calling for more epilepsy specialist nurse posts



Scan the code to read the full manifesto



# Research update



New studies shed light on SUDEP communication and the use of progesterone to reduce seizures in women.

**A** new study in the *European Journal of Neurology* has set out to compare clinicians' views on discussing sudden unexpected death in epilepsy (SUDEP) in patients in the UK and Norway.

The researchers used a survey and received 197 responses from the UK and 112 responses from Norway. The responses showed that clinicians in the UK are more likely to have had experienced SUDEP in a patient and were more likely to discuss it.

International guidelines strongly advocate for the discussion of SUDEP with patients, but there is still hesitation, avoidance and subjectivity in clinicians about speaking about this topic, the researchers concluded.

Professor Rohit Shankar, study author and consultant in adult developmental neuropsychiatry at the Cornwall Partnership Foundation NHS Trust said: "Every single guideline makes it mandatory – not even good practice, but mandatory – that we should be talking about SUDEP.

"What we identified in our study is that in the UK, awareness of SUDEP has become part of the culture. So

that was the positive thing. The UK is way ahead in terms of developing guidelines. It was at the forefront of early research into SUDEP, and charities have also played a significant role. We are still research oriented in this area and we are leading on it.

"There is no debate about why we should talk about SUDEP in the UK. That flies against the grain and against best practice. That battle has been won, which is a good thing."

Rohit added that other reasons why the UK is ahead in terms of discussing SUDEP include the presence of epilepsy specialist nurses, who are much closer to the patients and help with that communication, and the health system, which encourages patients to be more knowledgeable about their condition.

He continued: "The worrying thing for the UK is that there was a subjective inclination for clinicians to decide risk and speak about SUDEP only to people they consider 'high risk'.

"But how do we know who is high risk? There is no barometer for that."

Rohit explained that if clinicians are judging risk on seizure frequency alone,

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

they could be missing psychological and social factors which could have an impact on the person and change the risk level.

"When we talk about SUDEP, we communicate the risk and we hope that people will change their habits and lifestyle to mitigate that risk or continue their good habits."

Rohit explained that there is a "significant gap" between UK and Norwegian attitudes to SUDEP. Clinicians in Norway, to a larger degree than the UK, did not feel like SUDEP needs to be communicated. He said: "In Norway, some of the old arguments that this might upset patients were used. And, of course, it might, but that's the job we've signed up to."

In both countries, other factors



contributing to a lack of communication about SUDEP included problems with time and resources.

The comparison in this study was between two “economically developed” countries, but Rohit explained that there are even more challenges with economically developing countries. He explained that through previous research, he and his colleagues realised that “SUDEP is a very economically developed country concept”. He said that a lack of resources means that developing countries may not be able to carry out procedures to identify cause of death and may not have the systems to record it. In other countries, aspects like religious practices mean that cause of death isn’t always able to be identified, so SUDEP is less well understood.

When it comes to next steps, according to Rohit, it’s important for clinicians to take the time to explain SUDEP, and also to repeat the messages at appointments, as his research has shown that people can tend to forget what they’ve been told.

He said that to help break down the idea of trying to gauge risk, it would be beneficial for clinicians to speak about their experiences with SUDEP with each other and foster that peer-to-peer learning.

The next research focus Rohit and his group will be on the attitudes of clinicians in other European countries, including Denmark, Sweden, Finland, Spain and Italy.

You can read the full research at: [bit.ly/4ftq6qh](https://bit.ly/4ftq6qh)

For more information about SUDEP, visit: [epilepsy.org.uk/info/sudep-sudden-unexpected-death-in-epilepsy](https://epilepsy.org.uk/info/sudep-sudden-unexpected-death-in-epilepsy)

### Hormones and seizures

A new mini review in the journal *Frontiers in Global Women’s Health* has suggested that the hormone progesterone may have an important role to play in helping to reduce seizures in women.

The research says that changes in the levels of different hormones throughout women’s lives are “intricately intertwined with seizure susceptibility and affect epilepsy during the life course of women”.

Study author and epileptologist in Brisbane, Australia, Lata Vadlamudi explained: “In women, particularly from puberty onwards, there are cyclical fluctuations of neurosteroids (hormones) every month.”

She said that there are hormone

increases during pregnancy, erratic changes in hormones during perimenopause and then low levels of hormones in menopause. She said these can all have an effect on seizure activity.

Lata explained that catamenial epilepsy (where seizures increase in line with a woman’s menstrual cycle) is a clear example of the link between hormones and seizures. She said that there are three different patterns – seizures increasing either around menstruation, around ovulation or from mid-cycle to menstruation.

She remarked: “The most common pattern is where people have more seizures around their periods. Up to 52% of women can have catamenial epilepsy. I think we probably underreport it, as I don’t think we ask about this link as much as we could.”

Studies in pregnant women showed that low levels of a product of the hormone progesterone, called allopregnanolone, was linked to a higher frequency of seizures. “This once again supports the hypothesis that progesterone is protective,” Lata explained.

Moving on to perimenopause and menopause, Lata said there is little research into these groups. She said that a questionnaire of 42 women suggested that those who had a history of catamenial epilepsy tended to have more seizures during perimenopause. She added that we also know women who have had poorly controlled seizures can go through menopause earlier, but she stressed that “we have an enormous gap in the understanding of the landscape”.

Among the things we don’t yet understand are which specific types of epilepsy would benefit from progesterone most. Studies suggest it could be best for people with catamenial epilepsy who have

severe seizures around their period.

More research is also needed around menopause hormonal therapy (MHT) and whether this affects seizures. However, Lata added: “Perimenopausal symptoms, such as mood changes, lack of sleep and hot flushes can also aggravate seizures.”

Only one small study of 21 patients has looked into this and the findings suggested an increase in seizures with MHT. “But once again, numbers were very small and we don’t know, for example, if an oestrogen patch would have a different effect,” Lata concluded.

To challenge this lack of understanding Lata and her colleagues are working to produce resources for women with epilepsy to help educate and empower them on this issue. They are also working to develop practice guidelines to help clinicians support women with epilepsy and tailor the care to the individual.

Lata said: “As women go through different stages in their life, we probably don’t consider the impact of neurosteroids (hormones) on their epilepsy as much as we could.

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

“And we have to also be cognisant of the fact that we are talking about women, but they’re people ‘assigned female at birth’. We may have people ‘assigned male at birth’ who are now female and using hormonal treatments. We have to be conscious that these hormones can also impact their epilepsy.”

You can read the full research at: [bit.ly/4fxvYPb](https://bit.ly/4fxvYPb)





# The unicorn in captivity

Writer and actor Angelika May describes the inspiration behind her new play featuring epilepsy, why she chose to explore the subject and how the team went about portraying the condition.

**“T**he play is called *The Unicorn in Captivity*,” says 24-year-old Angelika May. “The unicorn is symbolic, representing the idea of love. Its captivity serves as a metaphor for being in a vulnerable position where you have a lot of love for someone and they take advantage of that.”

Angelika was born and raised in

Bradford, West Yorkshire, but after moving to London to study acting at Goldsmiths University, has lived there ever since. Over the last seven years Angelika graduated from drama school, completed a master’s degree in drama, and been working as an actor. But she says she’s had “a million different part-time jobs to sustain that”.

“I work at a vintage shop, and I teach special educational needs students,

usually with ASD, kind of one-to-one support work.

“I love being at the school. There’s a specific facility that is just for special educational needs students and I love working there. All the kids are so amazing!”

Outside of this, Angelika is also “in the music scene” in London, writing for *Dazed* magazine and other publications and frequenting post-punk and alternative music gigs. “And I play the trumpet and the guitar quite badly myself,” she says.

But working as an actor in London is not quite the glitz and glamour it might sound, and even though she is represented by an agency, Angelika says it’s really difficult to find work. “So I started writing to create work for myself and then found my voice through writing, which has been a really great journey.”

*The Unicorn in Captivity* is Angelika’s first play as a writer and centres around a relationship between F and M. F is a fine

arts student in her final year of university and M is a photographer who is at the peak of his career. While F struggles with her health and a new diagnosis of epilepsy, M's relationship with her starts to become exploitative.

### Misrepresented on television

The play features some of Angelika's own experiences, having been diagnosed with chronic vertigo and vestibular migraines. She had a really challenging time getting support and the right care from the NHS.

"I've been chronically ill for around four years, and I've had one neurology appointment and one MRI in that time.

"I've been diagnosed with chronic vertigo for now, but I think there's still room to explore. I'm waiting for an EEG, that's the next thing I'm going to be pushing for at my next neurology appointment.

"The problem with the diagnosis that I have at the moment is that it's not being treated as its own illness. They treat vertigo as a symptom of an underlying condition. But when you don't have an underlying condition [diagnosed], it makes it really difficult to know what's wrong.

"It's so hard when you're explaining neurological conditions, because they can't see what's wrong with you. And, especially as a woman, I think that a lot of the time our pain and concerns can either be misdiagnosed or they're ignored.

"My best friend Celia has epilepsy. She's had it since she was a teenager, but she was diagnosed with depression first. She had her first seizure at a festival, so that didn't help, because doctors thought she'd just taken something and was having a bad reaction to it.

"She was misdiagnosed and ignored for years and finally got a diagnosis of epilepsy when she was 17. She's 24 now. But she spent years trying to obtain a diagnosis, having multiple EEGs at hospital, having EEGs at home and having to have 24-hour care from her parents.

"When I met Celia, we bonded over our mutual chronic illnesses."

Angelika found crossovers with her symptoms and Celia's focal seizures, and the care that they both received from the NHS and from friends and family.

Angelika explains that she decided to include epilepsy over vertigo in the play for a few reasons. One is that she's not sure she's at the end of her diagnosis journey. "Vertigo seemed like an odd choice to use, even though it affects my life daily. I still don't know how to describe it myself.



Angelika (left) and Celia

People think: 'Oh vertigo, are you afraid of heights?' And I think no, I just feel awful 24 hours a day."

But another reason for choosing to include epilepsy was that speaking to Celia, Angelika realised how little she had known about epilepsy. "I had never had such a close relationship with someone with epilepsy, and when she was explaining it to me, I was so shocked at how misinformed I had been about epilepsy, and the misconceptions I'd already had about it.

"Most people probably know someone who is living with epilepsy, but they don't really understand the implications it has on their life or how they deal with it on a day-to-day basis.

"Celia has always been adamant that epilepsy is really misrepresented on television and it's also underrepresented. It's always tonic-clonic seizures and it never is about the everyday side of epilepsy. So, I was trying to create some noise around it and make people more aware."

### Purple lighting

As well as writing the play, Angelika is also playing F. She says representing epilepsy and seizures in a respectful and sensitive way is a priority for her and the director, Mayra Stergiou.

Angelika explains: "It's been really interesting working with the director. I think the biggest thing for us was how we're staging the seizures stylistically. So, during the play, F has focal seizures, which are indicated with purple lighting. The purple lighting is then dopped in throughout the play when she's having auras.

"It's been really interesting to work with movement, because we don't want



to portray the seizures like they've been done typically on TV. I think there's a different way to go about it. I understand that I'm coming from a perspective of privilege, where I haven't ever experienced a tonic-clonic seizure and I don't want to act something I don't really have experience in, because I don't want to be disrespectful.

"We're working with movement that suggest holding tension in different parts of the body that make it look like the body is experiencing something but the mind is somewhere else."

Being Angelika's inspiration for part of the play, Celia watched a work-in-progress performance. "I was so nervous," Angelika recalls, "and when the lights came up at the end, we embraced and it was incredibly emotional. I think she felt really seen."

The Unicorn in Captivity premiered in July 2024.





# A kind of superpower

What if the place we go during a seizure isn't just darkness and quiet, but a whole different world entirely? Author Adam Connors tells us about his new novel, *Find Me After*, which explores that very idea.

“I was in my 30s when I stepped out of a restaurant saying I needed a breath of fresh air and my partner found me unconscious in the street a few minutes later”

**A**dam Connors is the author of novels for teens, including his latest book, *Find Me After*, which was inspired by his own experience of epilepsy. A. Connors started his career as a physicist, building part of the Large Hadron

Collider in CERN. He has also sold encyclopaedias in Chicago, worked for an investment bank, taught physics in Sudan, fitted emergency Wi-Fi in the refugee camps in Greece, and now works as an engineering manager in the Google Research team.



Scan the code for more info on Adam's books

## Can you tell me a little bit about your epilepsy?

I had my first seizure in my grandad's house when I was nine. One minute I was brushing my teeth in front of the mirror, the next I was being carried outside. From the direction of travel, I knew that Grandad had carried me first into the living room and then (in a panic I suppose) changed his mind and decided to carry me outside instead.

I remember the event with surreal clarity, but I only have vague memories of the medical appointments that came afterwards. It was a big drama, but in the end, it was misdiagnosed as "vasovagal syncope" (fainting) and life went back to normal.

I lost consciousness a bunch of times after that, but we thought we knew what it was, so we never went back to the doctor. I remember feeling quite a lot of shame then, like I was weak for being 'a fainter', or I was attention seeking. I was an awkward child anyway, and this just made it worse.

I get prodromal symptoms, so I usually get an hour or so of warning that a seizure is going to come on. That meant I got really good at having my seizures in secret. It's a terrible idea, by the way, and not to be recommended, but I didn't know that at the time and I just felt there was less fuss that way. I really don't like being the centre of attention, and having a seizure in public doesn't play well with that.

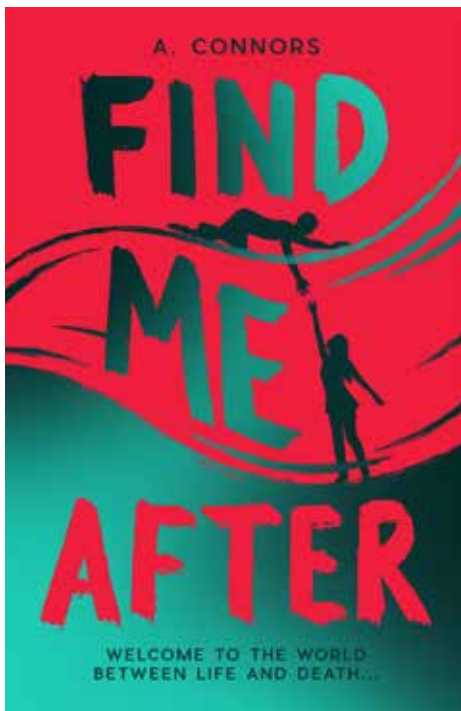
I was in my 30s when I stepped out of a restaurant saying I needed a breath of fresh air and my partner found me unconscious in the street a few minutes later. That finally triggered another round of visits to the doctor, a diagnosis, and medication.

## How did your experiences inform this book?

Not that long ago, I was on holiday with my family, and I suddenly found myself on the floor — alone, at night, in a strange room, in a strange house, with not very much memory of how I got there. For a few moments it felt like I'd just been born, but I had a single thought in my mind: oh no, not again.

I often have that thought after a seizure, it acts like a seed and sort of pulls all the other memories back with it. There's a familiarity to it, a kind of checklist as my brain reboots itself.

I wrote most of the first chapter that



night, lying in bed, my brain still fizzing. It felt very natural to start the book with my character waking up from a seizure, feeling the disorientation, the heaviness, the fear and confusion.

As my main character, Kyle, puts it: Coming back from a seizure makes you feel a special kind of rubbish. Hot and cold at the same time; my throat tastes like burnt pennies; my eyes feel like somebody took them out and put them in the wrong way around.

I started playing that forward and I got to thinking: what if I'm not where I think I am? What if I'm not all the way back?

## Can you tell me a bit more about the 'Stillness'?

The Stillness is the world where my main characters find themselves. It's kind of like this world, except the only people there are people who are caught in a similar state to Kyle: either having a seizure, or in a coma, or at the point of death.

I didn't want to write a story that was set in some kind of supernatural 'afterlife' or 'purgatory'. I don't believe in those things, and there's so many books and films set in the afterlife that it would be hard not to write something that felt quite clichéd.

My day-job is as an AI researcher in Google DeepMind, so neuroscience is kind of adjacent to what I know, and I work with a lot of people who studied neuroscience. I started reading articles and papers and plugging my colleagues for information. One article in particular



caught my attention. It was called: A Lucid Death: Sparks of Consciousness Detected in Dying Brains. It describes a piece of research where they measured brain activity in patients at the point of death, and they found that some brains spark into life in the last moments, a last spasm of gamma wave activity in the parietal lobes, the so-called 'hot zone' of the neural correlates of consciousness.

That account still sends shivers down my spine. Brain activity in those moments is hundreds of times higher than activity in a normally functioning brain and so perception of time could be different, and those few minutes could contain anything: worlds and worlds and worlds.

That idea gave me the core idea — and the confidence — to create the world of the Stillness in a way that felt plausible to me.

Later in the book, Kyle encounters a team of scientists who are studying the Stillness. I didn't start out with that as part of the plan, but when I stumbled across the idea, I really fell in love with it. Not only is Kyle trying to understand the world of the Stillness in order to exert some kind of control over it, but so is science.

In terms of how it looks, I really wanted to capture the disorientation and fraught energy of a seizure. As Kyle describes it: The view stretches over the surrounding area and it looks ... wrong. Insubstantial. Hazy. A lazy artist's impression of a town that trembles like a reflection on the surface of a soap bubble, threatening to shatter at any moment. The buildings feel flimsy and unconvincing: detailed

in places, blurry and indistinct in others. The colours leach into the murky distance. This is the half-done underside of the world. The steel and girders behind the facade, the tangled threads behind the embroidery.

**Does your main character, Kyle, share a lot of similarities with you?**

Yeah. I think when you're writing a book you always look for ways to relate to the characters, often by making them an amalgam of several people you know.

Find Me After felt pretty personal. Kyle is growing up in a small town in the Midlands where he feels trapped by both his upbringing and his epilepsy, and perversely he blames himself for both. All of that's pretty close to my own formative years.

Some of Kyle's experiences are lifted directly from my own – the awkwardness of losing consciousness in a church; the weary familiarity of getting picked on; the checklist after a seizure. Kyle's love of science as a way of trying to regain control of a chaotic world is very central to my own way of seeing things.

The main difference is that Kyle is a bit more self-aware than I was. He knows he's trapped; I didn't see it until after I left.

**Why did you decide to write this book? And why for a teen readership?**

We all deal with things in different ways but I like to make up stories because they're a way of finding the cool or the funny in otherwise rubbish situations.

Losing consciousness is rubbish, being afraid of losing consciousness is rubbish, the way it feels when you come back is rubbish... For reasons I don't fully understand, I often come back from a seizure screaming, which is pretty rubbish for everyone.

But if you can turn that around and say: wow, what was I escaping from that was making me scream so much? Suddenly there's a whole bunch of intriguing questions that as a writer (or a reader) you get to think about instead. It's much more fun to dwell on that than just on the rubbish bits.

The thing I hate most about losing consciousness is the loss of control. As I say in the book: it's a bit like going out and leaving your front door open. Except it's not your front door, it's you. So, I made it possible for people with epilepsy to come and go from the Stillness in a way that other people can't. That makes epilepsy a kind of superpower, and so by writing a story about that it gives me a way to claw back some control from a condition that I associate mostly with an absence of control.

Why teens and young adults? Mainly because I think they're a whole lot more interesting than adults. My eldest son is 16, and I see firsthand how intense his mental landscape is. You're figuring out so many things, trying out so many things, both about yourself and your identity, and about the world as well.

My book talks a lot about consciousness and reality, and it weaves

in a bunch of science and a fair amount of philosophy as well. If I manage to introduce one idea or plant one seed that takes somebody in a direction they wouldn't otherwise have discovered, that would be pretty cool.

**What do you hope readers will take away from the book?**

I grew up with the idea that I was just 'a fainter' and even after my diagnosis the idea was so ingrained that I was in denial I had epilepsy for a long time. Writing the book forced me, for the first time, to read a bit more about other people's experiences, and I was really surprised by how recognisable they were. Things I'd thought of as just something I did, or something I experienced, turned out to be familiar to other people as well.

That was weirdly validating.

The issue, I think, is that epilepsy isn't just one thing, there's a whole range of symptoms. When people think about epilepsy, they think about the classic tonic-clonic seizure. But for someone with epilepsy it's more about the before and after, and any other neurological effects that unfortunately come with it – you're not there for the actual seizure. It's easy to feel like you're alone in those other experiences, and for me (and I suspect others) that comes with a whole bunch of feelings of shame and isolation.

I'm lucky in that my epilepsy doesn't affect my daily life all that much (except that I can't drive until next March, again!). But if there's one thing for people to take away it's that epilepsy isn't your fault, it's not a sign of weakness, it's not attention seeking. Our bodies do what our bodies do, and we do our best to live around them, but we're not responsible for them doing stupid things sometimes.

**Find Me After by A. Connors is out now.**  
[aconnors.com](http://aconnors.com)  
[adam@aconnors.com](mailto:adam@aconnors.com)

“ Kyle's love of science as a way of trying to regain control of a chaotic world is very central to my own way of seeing things ”



Adam and his family





# Thinking of *you*

Epilepsy Action held its Memory Walk in July to remember loved ones lost.

**O**n Saturday 6 July 2024, hundreds of Epilepsy Action supporters participated in our Memory Walk all across the country, walking to remember everyone who we have loved and lost – with many choosing to walk their 10k route in a place of significance to their loved one.

Ian, a long-term Epilepsy Action supporter, lost his daughter Carla to epilepsy. He said:

“Raising money for Epilepsy Action is hugely important to us, as the charity helped our daughter Carla so much. She used the Epilepsy Action Helpline a lot, particularly at university. They provided great practical advice.

“Fundraising also helps us to manage our grief at losing Carla at the young age of 27. It keeps memories of Carla alive.”

Many Epilepsy Action staff members also joined the walk, taking the opportunity to chat and share stories of

loved ones in the sunshine, bringing along little ones in pushchairs and flanked by four-legged friends.

Harvinder Chaggar, in memory and supporter legacy engagement officer at Epilepsy Action, said: “Our supporters that took part have been getting in touch to share their experiences – it’s all been really positive. Roxy was walking in memory of her cousin. She said: ‘My son completed his walk yesterday, he set out for the 10k but ended up doing 12.23k in total and ended up with very tired three-year-old legs, but he has raised £1,220 so far, which he is super proud of’.”



**To join in future fundraising events, visit [epilepsy.org.uk/fundraising](https://epilepsy.org.uk/fundraising) or scan the code**

# Brave Sienna

Sienna has scooped April's Star Award for her bravery in the face of scary hospital visits and missing out on sleepovers and playdates  
Words by Rebecca Lock



**S**even-year-old Sienna Jones has been given this month's Epilepsy Star award for always being 'so brave'. She was diagnosed with epilepsy last summer but doesn't let it stop her from doing all the things she still loves, like trampolining with her friends, swimming and musical theatre. She was nominated by her mum, Sophia, who shares their story.

"Sienna was perfectly happy and healthy until one morning in August of last year when she had several episodes where she said she didn't feel well. She'd then come to me for a hug and go all pale and vacant; her skin was clammy, and her heart would beat so fast.

"It was so worrying as a parent for this to keep happening and it was impacting everything we were doing. It became a regular thing, and the episodes would happen over and over again. It could happen anywhere – at home, at the supermarket, while playing in the park or at a restaurant. Sometimes she'd go on and resume her normal activities but sometimes she'd be sick or have to lie down and sleep.

"I called the GP and got an appointment but unfortunately I was left disappointed as it wasn't taken seriously, so I went back the next day for a second opinion. This GP was very thorough and told me he thought Sienna was having

seizures. He referred us to paediatrics and we were lucky to get an appointment the week after.

"Two days before our appointment with paediatrics, Sienna had one of these episodes while at the park with friends. However this time, she fell to the floor unconscious which was very scary.

"Sienna's consultant was absolutely amazing and explained that she thought it was epilepsy, but unfortunately there was a long wait on the NHS for an EEG. We decided to go private which thankfully meant Sienna was given a diagnosis very quickly – it was around two or three weeks from the first seizure to her actually starting medication.

"Sienna also has prolonged seizures so has buccal midazolam prescribed as an emergency medicine which we have to carry everywhere. Her medication has definitely reduced her seizures, but it's had a real impact on her mood and emotions. Her memory is quite bad and she gets easily confused.

"Although we don't know of any trigger for Sienna's seizures, she does have auras so she knows when it's going to happen which helps massively as sometimes if she has a bad seizure, she does just drop to the ground.

"We've now started another medication and are weaning her off the other one in hope that this improves things for her. She's recently had another EEG and have





now been referred to Great Ormond Street Hospital.

For Sienna's family, one of the biggest challenges has been coming to terms with and learning more about epilepsy. Sophia said:

"The biggest challenge we've faced as a family has been adjusting to the diagnosis and actually coming to terms with it. It's a hard process at first, especially when it's your child. Talking as a family and being open with Sienna has definitely helped us.

"I wish more people understood that not all epilepsy diagnoses are the same. I was so uneducated about epilepsy before Sienna's diagnosis, but dealing with it every day and doing training has really opened my eyes. There are many different types of seizures, and these seizures affect people in different ways."

Sophia nominated Sienna for this award to give her some recognition. Sometimes Sienna has to miss out on sleepover and playdates but always 'gets on with it' and makes her family so proud.

"I decided to nominate Sienna because, like all children with epilepsy, she doesn't deserve to go through this. She struggles everyday but never feels sorry for herself.

She always gets on with it and she makes us proud. Although she absolutely hates the hospital visits, she's always so brave and does her best to overcome the fear she feels," said Sophia.

"It means so much for Sienna to win this award. We are so proud of her, and this award shows her that she is amazing just the way she is."

Sienna is very 'happy' and 'proud' to be named Epilepsy Action's Star of the Month. Accepting the award, she said:

"It makes me feel happy, proud, and very special. I can't wait to tell my teachers Mrs Thompson and Miss Raymond, and all my friends.

"I love my friends and family. My favourite animals are doggies. I've just started musical theatre and swimming and really enjoy it. I love playing on the trampoline with my big brother Kai and playing with my friends at school.



To read more awards winners' stories like this, visit [epilepsy.org.uk/star-awards](https://epilepsy.org.uk/star-awards)

**“ I wish more people understood that not all epilepsy diagnoses are the same ”**

# Don't forget

# Doodle Day



Doodle Day returns on **27 September**, and you can bid on your favourite artworks between **20-29 September**



Scan the code or visit [epilepsy.org.uk/auction](https://epilepsy.org.uk/auction) to place your bids



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# Council of management

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## May 14

**The Council of Management met at New Anstey House on 14 May with six members attending by remote video connection.**

This was the last Council meeting before the Council elections take place at the Annual General Meeting on 18 June. Members used this opportunity to express thanks to Jayne Burton and Avril Coelho who are not seeking re-election to the Council. Jayne has served on Council for 12 years and previously served for two years between 2006 and 2008. Avril has served on Council from 2021. Both were warmly thanked for their dedication and commitment to Council and to the work of the charity.

During the meeting the Council made the following decisions.

- Council received and approved the annual reports of each of its Committees.
- The terms of reference of every Committee were reviewed, slightly amended and approved. All Committees were confirmed to continue for a further 12 months.
- The terms of reference of the Council's advisory panels were also reviewed and slightly amended and the panels were confirmed to continue.
- Council member Ian Walker was elected to be Council's safeguarding lead.
- Reports were received and considered on the charity's financial performance and position; the progress being made with implementing the new strategy, the work being carried out on the constitution and governance review and the work being done to review and refresh the charity's branding.

The next meeting of the Council of Management will be on 16 July 2024.

## July 18

**The Council of Management met at New Anstey House on 16 July. This was the first meeting of the Council after the Association's Annual General Meeting held in June. Members were pleased to welcome two new colleagues who were elected this year – Nicola Adamson and Sally Taylor.**

Jane Riley was elected as the Chair of Council. Nicholas Hutton was elected as the Vice Chair of Council, after Peter Clough had decided to step down. Katie Stevens was elected as the Association's Honorary Treasurer.

The following people were elected to the Corporate Governance committee: Cameron Hill, Diane Hockley, Sarah Lawson, Tom McLaughlan and Ian Walker. June Massey was appointed to the casual vacancy on the committee.

The following people were elected to the Finance and Strategic Policy committee: Deirdre Black, Joanne Greer, Cameron Hill, Diane Hockley and Tom McLaughlan. Jane Riley, Nicholas Hutton and Katie Stevens are all ex-officio members of the committee as Officers of Council.

Annual reports were received from Council's EDI champion and its champion for research. Katie Stevens was re-appointed as Council's EDI champion for the next 12 months. Peter Clough was re-appointed as Council's champion for research. Members noted the significant steps being taken to show improvement in both of these areas.

Dr John Craig and Sarah McCann were re-appointed as members of the charity's Northern Ireland National Advisory Council.

Policies on activities involving deliberate head injury, sponsorship and the charity's investment policy and procedure were reviewed and refreshed.

In other business, Council reviewed and were content with the charity's financial position and progress being made against this year's revenue budget and business plan. It also completed its quarterly review of the top ten risks on the corporate risk register and reviewed the quarterly safeguarding report.

The next meeting of the Council is scheduled to be held on 8 October 2024.



# Annual General Meeting 18 June 2024

## Ballot Results

### A. Election of Members of the Council of Management

	Votes received	Percentage share	Outcome
Nicola Adamson	246	18.28	Elected
Robert (Nicholas) Hutton	207	15.38	Elected
Joanne Greer	189	14.04	Elected
Sally Taylor	183	13.60	Elected
June Massey	171	12.70	Elected
Nicholas Bennett	138	10.25	Not elected
Chris Phillips	112	8.32	Not elected
Glen Gains	100	7.43	Not elected
<b>Total</b>	<b>1,346</b>	<b>100</b>	

	Number	Percentage
Electorate	7,030	100
Valid proxies returned	319	4.54
Invalid proxies returned	17	0.24
Total response	336	4.78

### B. Confirmation of election of Baroness Ford as President

Votes Yes to confirm	Percentage Yes to confirm	Votes No	Percentage No
309	95.37%	15	4.63%

	Number	Percentage
Electorate	7,030	100
Valid proxies returned	324	4.61
Invalid proxies returned	12	0.17
Total response returned	336	4.78

### C. Result of Resolution 1

Resolution 1	Number for	Percentage for	Number against	Percentage against
To appoint Saffrey LLP as auditors	315	98.13	6	1.87

	Number	Percentage
Electorate	7,030	100
Valid proxies returned	321	4.57
Invalid proxies returned	15	0.
Total response returned	336	4.78

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Epilepsy Action is the working name of British Epilepsy Association, a registered charity (No. 234343) and a company limited by guarantee (No. 797997) in England and Wales. All income generated by Epilepsy Today funds the association's work.

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# Epilepsy Action is here for you



helpline

Epilepsy can be very confusing. Our **Helpline team** are ready to answer any questions you might have on the phone, via live chat or email.



counselling

Counselling can be really helpful when things get tough – we're ready to help in Wales and Northern Ireland. Our professional **Counselling team** can provide the support you need online or over the phone.



talk and support

If you want to talk to other people about life with epilepsy, you're welcome to come to one of our **Talk and support** groups to meet and share your experiences either on line or face-to-face.



family support

Epilepsy doesn't just affect the person with the diagnosis – that's why our **Family support** service is there for family members and carers.



befriending

Not everyone's ready for a group, though – one-to-one support through **Befriending** might be better for you. We'll connect you to a volunteer who will offer you a friendly listening ear either on the phone or online.



[epilepsy.org.uk/support](https://epilepsy.org.uk/support)

“Epilepsy Action has made such a big difference in my life... they have helped me learn to live with my condition”

**Epilepsy Action Helpline: freephone 0808 800 5050**  
**email [helpline@epilepsy.org.uk](mailto:helpline@epilepsy.org.uk) [epilepsy.org.uk](https://epilepsy.org.uk)**

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