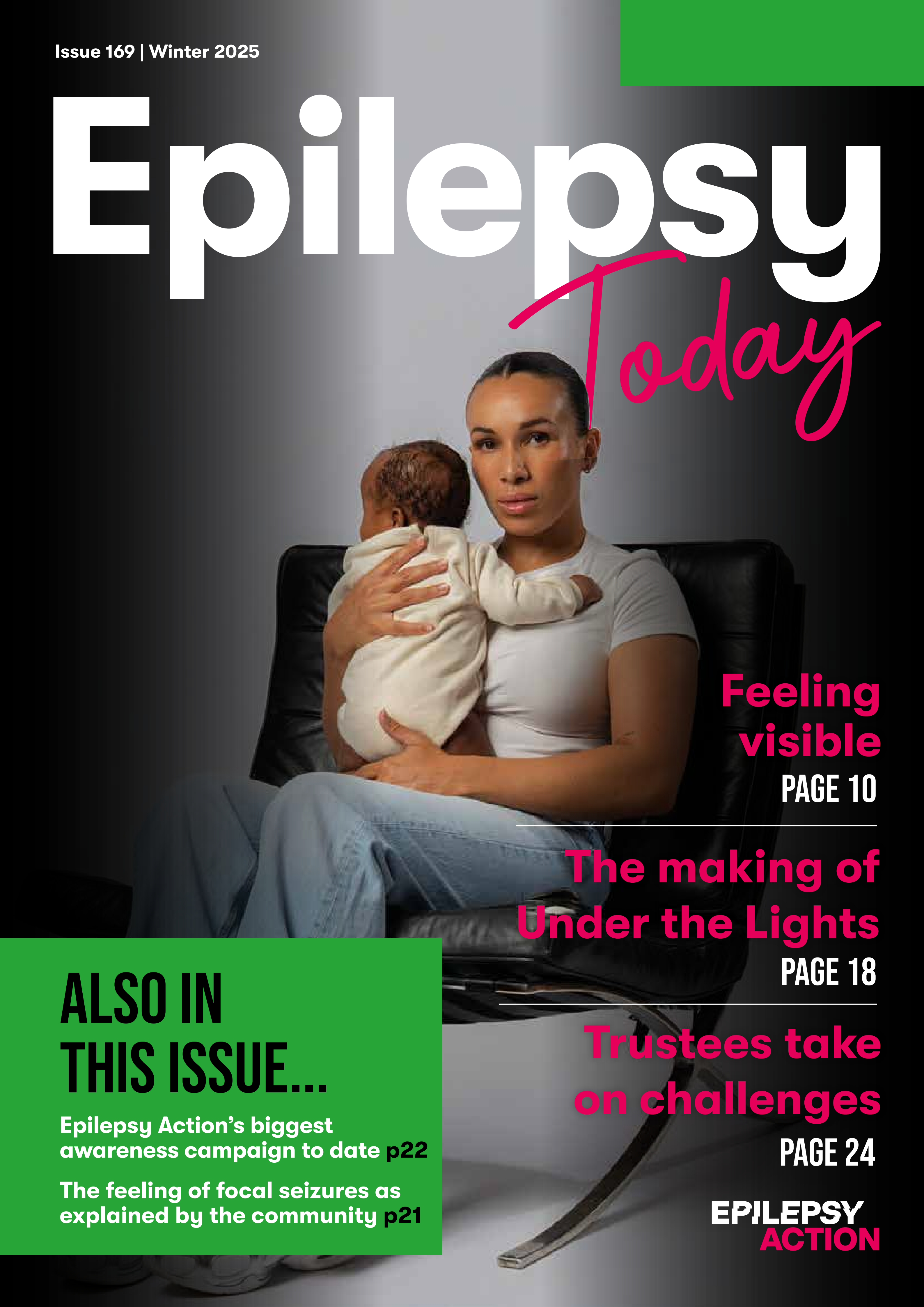
Issue 169 | Winter 2025

Epilepsy Today



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EPILEPSY ACTION

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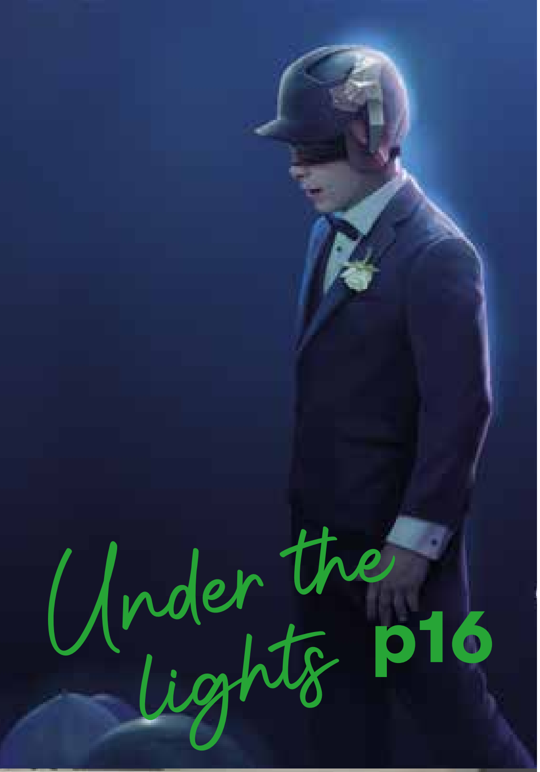

Connecting

Welcome to the winter issue of Epilepsy Today magazine!

Our trustees have been busy! Many of them have taken on daring challenges in order to fundraise to mark Epilepsy Action's 75th anniversary, and those who couldn't have sponsored and supported their colleagues. As a festive treat, find out what challenges they took on and how much they raised on page 24. Meanwhile, another of our trustees, Nic, underwent stereo EEG earlier in the year and kept a diary, sharing every step of the experience (page 18).

There's a real air of connection in this issue. On page 12 you can read about how Katie and Sharon reached out for Epilepsy Action's Befriending service to talk through their struggles with epilepsy. Glen has written in to share her unusual epilepsy and ask our Epilepsy Today community to share, too, if anyone can relate to her symptoms (page 14). On page 16, Miles describes how he wanted to make his epilepsy challenges worthwhile by writing and directing a film about epilepsy, trying to connect the world with the experience of the condition.

Also, don't miss our biggest epilepsy awareness campaign yet (page 22) and find out how you can support people through the often tricky festive period (page 10).

Happy holidays!

Kami Kountcheva
Editor

Good news

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

Epilepsy Action produces new book for young children

By Ayesha Hamid

Epilepsy Action has teamed up with Young Epilepsy to produce a new book, "Izzy and Joe's Camping Adventure", aimed at four-to-eight-year-olds who live with the condition.

The book, developed with input from children and families, aims to help children come to terms with their epilepsy and feel more confident, more connected and less alone.

The book was released in September as part of a three-year project to develop resources for children with epilepsy aged four to 12.

The book is now available in the UK and is free to order as a digital or printed version from the Epilepsy Action and Young Epilepsy websites.

Sharing feedback, parents said their children can see themselves in the story. In the words of one parent: "It's so nice to read stories that can relate to my child and her condition – finally!"

Another reader said: "I like that the focus isn't on the seizure primarily but that it is a part of the story." A third parent added: "I think it describes epilepsy in a way that informs children without making them scared."

The two charities worked with an agency, an external illustrator and an author to produce the book. They also consulted with 10 different epilepsy, education and child development specialists. More than 20 families helped shape the story through interviews and play sessions, and 12 children took part in co-creation workshops. Children with epilepsy fed into the story, in particular what the struggles, challenges and solutions could be with their condition.

Emily Mossman, health information and research officer at Epilepsy Action, said: "The aim of this project was to create something that would help children in the ways they needed, identified by them. We didn't want to make assumptions, so we involved children and families with epilepsy from the very beginning.

"It's been inspirational to hear from so many young people and how passionate everyone is to help other children with epilepsy."

There are more than 11,000 children aged between four and eight who are living with epilepsy in the UK. The organisations say there are limited resources for this group at present.

You can download order the book at: **bit.ly/43cYktk**

Epilepsy Action among YouGov's top 200 charities

Epilepsy Action has been featured in the YouGov Most Popular Charities and Organisations for the third quarter of 2025.

The organisation climbed to the 150th spot from 162nd in quarter two, published in July, when it first featured on this list. This is the first time an epilepsy charity has featured on the YouGov most popular 200 charities list.

YouGov is an online research data and analytics organisation which uses surveys and polls to share insights on public opinion of brands, media and politics.

Jon Eaton, director of communications and digital engagement at Epilepsy Action, said: "Getting into the top 200 shows that your brand, services and messaging are cutting through into the public consciousness.

"This year was the first time we have ever been on this list. No epilepsy charity has ever made the top 200 before. We are now at position 150!"

Split by different generations, Epilepsy Action's position is on the rise among them all, nearing the top 100 for Millennials, at 103.

Doodle Day auction raises £26,000

The Epilepsy Action Doodle Day auction closed on 5 October, with 302 artworks raising more than £26,000 over the 10 days.

The artwork donated by Sir Ian McKellen this year raised £3,000 alone. He said: "I'm delighted to lend my hand — quite literally — to National Doodle Day this year.

"My little Gandalf sketch joins countless others in raising vital funds for Epilepsy Action, whose work makes such a difference to so many lives. It's a joy to be involved, and I hope these doodles bring both smiles and support where it's needed most."

Michael King, Doodle Day Lead at Epilepsy Action, said: "I want to thank everyone who created a doodle for us, or who bid on or bought a doodle. Every single penny goes towards helping Epilepsy Action provide their services that really can be life changing."

Alongside Sir Ian, illustrators Ralph Steadman and R.W. Alley and actors Freema Agyeman and Dame Joanna Lumley contributed some of the highest-selling artworks at this year's auction, together coming to more than £6,000.

With more than four million people viewing the eBay auction during its 10-day period, this has been the charity's most popular National Doodle Day to date.

Lord Hastings award winners announced

The founder of Purple Day, the global epilepsy awareness day, Cassidy Megan, and former chair of the board of trustees and stalwart supporter, Richard Chapman, will receive Epilepsy Action's Lord Hastings Award in December this year.

The Lord Hastings Award is Epilepsy Action's most prestigious award, recognising outstanding contribution to improving the lives of people with epilepsy.

This is the first time that a national and international winner has been picked.

Richard said: "I was really surprised to get a letter about the Lord Hastings Award. It came right out of the blue. I never thought for a minute that I would be a contender for the award, let alone a recipient.

"When you look back at the list of previous winners, there are some really high-profile names. You don't volunteer in the expectation of recognition or reward for what you do. But it is really nice when something like this happens and it feels gratifying that others felt my efforts were worthy of such a special accolade."

The award was named after Lord Hastings, a former president of Epilepsy Action – a position he held for 28 years. In that time he raised issues around epilepsy at the House of Lords, he fronted and led appeals and campaigns, and he served on research committees.

Lord Hastings was the first recipient of the award named after him, given to him in 1990.

Epilepsy news

Valproate has "minimal" effect on male fertility

Sodium valproate has a "minimal" effect on male fertility, according to large-scale, international research by the University of Liverpool and funded by the Epilepsy Research Institute UK, published in Nature Communications.

The Medicines and Healthcare Regulatory Agency (MHRA) last year released a guideline advising men taking sodium valproate and any female partners to use contraception to prevent unplanned pregnancies.

The MHRA warned of a "potential small increased risk" of neurodevelopmental disorders in children born to fathers taking the medication.

Earlier this year, the MHRA confirmed that any new prescriptions of valproate for men under the age of 55 will need to be independently signed off by two specialists. This doesn't affect men currently prescribed valproate or men over the age of 55.

The new research covered 19 countries and more than 200 healthcare organisations. It compared almost 92,000 men with epilepsy or bipolar disorder who had taken sodium valproate with 536,000 men with the same conditions who had not taken the medication.

They found that differences in infertility diagnoses, sperm counts and testicular atrophy (shrinkage of the testicles) were less than 1% between the two groups. Hormone levels in men taking valproate were also found to be within normal ranges.

Dr Gashirai Mbizvo, NIHR academic clinical lecturer and deputy director for Epilepsy Research at the Liverpool Interdisciplinary Neuroscience Centre, who carried out the research, said: "In the largest study of its kind, we found little evidence that valproate impairs male fertility over and above the epilepsy or bipolar disorder themselves or other antiseizure medications – all of which can impair male fertility.

"These results are significant because fear of fertility side effects specifically attributed to valproate can lead men to discontinue the medication, risking uncontrolled seizures, mental health deterioration, hospitalisation, or death in extreme cases.

"It is important to consider the wider picture of what else may be causing infertility. For example, epilepsy, in and of itself, can affect fertility rates, which are two-thirds lower in men with epilepsy than without."

Alison Fuller, director of health improvement and influencing at Epilepsy Action, said: "Many men have expressed their concerns about the impact of sodium valproate on their fertility, and our helpline team receives inquiries relating to this issue.

"We hope that this study provides reassurance for men prescribed this medication, but we know that current MHRA guidance still means that doctors are required to warn patients about the risks of potential infertility.

"This is concerning, as incorrectly telling male patients that they may not be able to have children could prompt them to stop taking their medication, which puts them in danger."

MHRA report shows falling valproate prescriptions

Prescriptions of sodium valproate in England are continuing to drop since April 2018 in all patients, according to new information from the Medicines and Healthcare products Regulatory Agency (MHRA) published on 23 September.

According to the new report, the overall proportion of women and girls prescribed sodium valproate fell by 56% between 2018 and 2024. New prescriptions in those aged 16-44 years old fell by 77%.

Just under a third (29%) of women and girls in that age group, who were prescribed valproate for epilepsy before May 2018, switched to lamotrigine or levetiracetam without then switching back to valproate.

This fall reflects the changing guidelines from the MHRA since 2018 in the prescription of sodium valproate in women, as it is known to cause risks to unborn babies if taken during pregnancy.

During the same timeframe, the overall proportion of males prescribed sodium valproate fell by 14%. However, new prescriptions in males aged 16-44 fell by 78%, with a lot of this (63% drop in new prescriptions) happening after the introduction of new safety measures in November 2023.

A fifth of men aged 16-44 switched to lamotrigine or levetiracetam from valproate.

Study finds link between gabapentin and dementia

A new study from the journal Regional Anaesthesia & Pain Medicine has revealed a link between the medication gabapentin and the risk of dementia and reduced learning and thinking skills (cognitive decline).

Gabapentin can be prescribed for epilepsy and nerve pain in the UK.

The study investigated the use of gabapentin in 26,416 people with chronic back pain in the US between 2004 and 2024.

The researchers, Nafis Eghrari and colleagues, found that there was a higher rate of dementia in people with six or more prescriptions of gabapentin. This group also had a higher rate of problems with thinking skills (mild cognitive impairment).

In adults aged 18-64, the risk of dementia doubled. The risk also increased with more prescriptions of gabapentin.

The researchers acknowledge that since their study is observational and retrospective, they can't confirm cause and effect and they couldn't account for some variables, like dose or length of use. However, they suggest that doctors should monitor learning and thinking skills in people taking gabapentin.

The full study is available at: **bit.ly/4oa9Kqk**

If you are worried about your medication, please speak to your epilepsy specialist, epilepsy nurse or GP. Don't stop taking your medication without speaking to your health professional first. You can also speak to the Epilepsy Action Helpline at 0808 800 5050 or epilepsy.org.uk/helpline if you have any questions.

COVID booster autumn 2025 targets "highest risk"

Those eligible for the autumn 2025 and spring 2026 COVID booster vaccines include people aged over 75, those aged six months to 74 years who have a weakened immune system and those who live in care homes for older adults.

The eligibility criteria does not automatically include people with epilepsy, unless they also fall in one of these categories.

Eligibility for those aged over six months old is described in the Joint Committee on Vaccination and Immunisation's (JCVD) Green Book, in the 'immunosuppression' section of tables 3 and 4.

People who will turn 75 before 31 January 2026 are also eligible.

The UK Health Security Agency said the JCVD is moving towards "targeted vaccination of those at highest risk of serious disease".

Government responds on supply issues

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

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

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

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

Help us create the ultimate tech guide

Epilepsy Action is working on creating an Epilepsy Technology Guide, aiming to offer clear descriptions and reviews of alarms, monitors, apps and wearables from the community.

The organisation is asking for anyone who has used any tech for their epilepsy, or a loved one's, to share their experiences at **bit.ly/4hm8fmi**.

Krishan Srinivasa, health improvement coordinator at Epilepsy Action, explained: "We know that finding the right devices and apps to help manage your epilepsy can be overwhelming.

"We would like to bring all of that information into one place, with reviews and easy-to-understand descriptions of all the different options.

"Your feedback will help us identify what works and what doesn't. It will also help other people with epilepsy make the right choices when they are deciding which devices and apps to use."

Gemma Atkinson speaks out about daughter Mia's epilepsy

Actress and podcaster Gemma Atkinson has shared that her six-year-old daughter Mia has had treatment for epilepsy.

Speaking on Women's Health magazine's podcast, Just as Well, on 29 September, Gemma revealed that around 18 months ago Mia started having absence seizures.

She spoke about the ketogenic diet and shared that it has been very effective for Mia, saying her seizures have "got so much better a year in".

Gemma said: "My daughter is under treatment for epilepsy. She has absence seizures. Obviously when I was told that, I was like: 'right, I need to research, research, research.'

"I went down a rabbit hole, and [discovered] the keto diet was designed for patients with epilepsy. The improvement we have had… in the last six months, she's had none."

The subject came up in an interview for the podcast with actor Davinia Taylor.

Gemma later shared in a story on Instagram that Mia is "now absolutely fine" and "thriving".

She added: "18 months ago, it was a scary time and to any other families who have been through or are currently going through similar, I truly understand how you feel. There is light at the end of the tunnel though."

She urged others in her situation to "stay positive", adding that children can grow out of these seizures, like Mia has.

Gemma, 40, appeared on the TV series Strictly Come Dancing in 2017, where she met her partner Gorka Márquez, 35. The pair have two children, Mia and Thiago, two.

Sarah Wasserman, CC BY 2.0, via Wikimedia Commons

Patients at Hywel Dda left stranded

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

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

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

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

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

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

"Carers have described feeling abandoned and unsupported, unsure who to contact for advice or assistance, while having to navigate a lengthy complaints process with no clear outcome.

"The role of a carer is already demanding, and the sudden removal of a key support system has only added to their stress. This represents a serious injustice to patients and their families, and I am mindful that others may be experiencing similar failings.

"The Health Board must now take urgent action to ensure these vulnerable patients and their carers receive the care and support they need."

Epilepsy Action Wales Manager Jan Paterson called on the health board to implement the ombudsman's recommendations. She said: "The Ombudsman findings are shocking but sadly unsurprising and highlight the devastating impact the service closure at Hywel Dda is continuing to have on people with epilepsy and learning disabilities.

"This is an already vulnerable group of patients who are more likely to have severe uncontrolled epilepsy, which can place them at higher risk of death. There are 54,000 patients with learning disabilities in Wales and 1 in 5 will go on to develop epilepsy. This means it's even more essential their care is totally holistic and joined up with epilepsy and LD services.

"The board has recruited a learning disability nurse but she is not specialised in epilepsy, so these patients are falling between the cracks in the system and not receiving the basic level of care they need.

"The issues around the closure of the learning disabilities service at Hywel Dda are just part of a much wider health crisis facing people in Wales, with many services underfunded and under-resourced."

Charli XCX criticised for excessive strobing in new film trailer


Harald Krichel | Wikimedia Commons

Singer Charli XCX has faced a spate of complaints over the strobing light in the new online trailer she posted on social media for her upcoming film, The Moment.

The 58 second video, posted on 9 October, is a promotion for the film, due to be released in 2026, and features flashing images throughout. It carries a small warning towards the bottom, visible for the first four seconds, warning viewers with photosensitive epilepsy that the content “could cause seizures”.

Online users took to X to raise their concerns, having not seen the warning or finding it too small and quick to be effective. Many commented that they have epilepsy or that they’ve had a seizure.

One user wrote: “This goes on the ‘for you’ page and autoplays, barely any countdown and you cannot see the epilepsy warning because it’s hidden unless expanded, and even then it’s behind the caption.”

Another said: “So there was no warning on this and I just had a seizure, love do something pls,” while another commented: “I’ve never had a seizure but sometimes when videos like this come up I silently brace myself in case today is my day.”

Jon Eaton, director of communications and digital engagement at Epilepsy Action, said: “Charli XCX’s new trailer includes excessive flashing visuals with barely any warning making it dangerous for people with photosensitive epilepsy.

“The warning is tiny, hard to read and disappears too quickly to give viewers a chance to avoid the strobing. This could easily trigger a seizure for someone with epilepsy. With the title of her trailer front and centre, it’s clear that Charli has chosen her brand over her audience’s safety.

“Whilst the Harding test is only mandatory for TV advertising, this advert is an example as to why it should be for online content too.

“For people with photosensitive epilepsy this volume of strobing is incredibly likely to cause a seizure. We are reaching out to Charli XCX’s agent to ask for this content to be removed. It is not inclusive and downplays the issues of a condition which kills over 1,000 people every year.”

This is not the first time Charli XCX has received backlash for using flashing lights. In a surprise performance in Times Square in November 2024, she used strobing black-and-white text to announce her show with no seizure warning.

The Moment, set to feature Kylie Jenner, will explore fame and industry pressure in a rising pop star.

Epilepsy Action patron Duchess of Kent dies at 92


Carfax2 | Wikimedia Commons

Katharine, the Duchess of Kent, died aged 92 on 4 September.

The Duchess was a patron of Epilepsy Action for 33 years, among her involvement with other organisations including Samaritans and UNICEF.

Buckingham Palace made the announcement noting all the Duchess’ work and saying she had a “lifelong devotion to all the organisations with which she was associated.”

Jane Riley, Chair of the Board of Trustees of Epilepsy Action, said: “We were very saddened to learn of the death of the Duchess of Kent who has been a patron of Epilepsy Action since 1992.

“As we celebrate our 75th anniversary and look back on the incredible achievements of our valued patrons, we would like to express our sincere gratitude for all the support the Duchess gave to the charity over the past 33 years.

“We particularly extend our thanks for the legacy she left in building a fairer world for people with epilepsy and our thoughts are with her family at this very sad time.”

Epilepsy Action trustees Katie Stevens and Richard Chapman attended the Duchess’ Requiem Mass on 16 September.

Katie said: “It was an absolute privilege to be a part of history and to attend the Duchess of Kent’s Requiem Mass. It was humbling to see the volume of representatives attending from many, many charities.

“She will be sorely missed by us all for her contributions to the charity and her clear commitment to our cause.”

The duchess was born in Yorkshire in 1933. She was famous for being the first member of the royal family in 300 years to convert to Catholicism, which she did in 1994.

She was also often seen at Wimbledon presenting the trophies and speaking to the finalists.

Her other charity work focused on music, children, cancer charities.

NO ONE SHOULD FEEL INVISIBLE THIS CHRISTMAS

For many, Christmas is painted as the season of joy, bright lights, bustling shops, family traditions, and gatherings with friends. But for people living with epilepsy, the festive season often carries a quieter, more complex reality.

Behind the sparkle lies an invisible checklist.

As Marnie explains, “Christmas is an exciting time and there’s lots to think about, but people with epilepsy have an extra list. Have I taken my medication? Will I get enough sleep? Do they know what to do if I have a seizure?”

These are the kinds of thoughts that don’t disappear just because it’s December.

For James, who is facing his first Christmas since being diagnosed, that invisible list feels overwhelming.

“I need to think differently this year about how I celebrate,” he says. For him, the season will be about reflection and acceptance—working out new ways to join in while keeping himself safe.

Others know the feeling all too well. Andy remembers the time a seizure struck on New Year’s Eve. “It completely wiped the day from my memory. I don’t even remember it happening,” he says. What should have been a day of celebration became, in his words, a “deleted Christmas.” The anxiety of not knowing whether it might happen again leaves him feeling as though epilepsy is always lurking in the background of the festivities.

For some, the hardest part isn’t just the seizures themselves, but how they affect those around them. Murray loves Christmas, yet admits he often feels guilty. “I know my seizures can change the mood of the day,” he says. “Sometimes I feel like I’ve ruined Christmas for everyone.” Anita recalls the embarrassment of a seizure at a family party that left her feeling exposed and disoriented: “I just wanted to disappear. I didn’t want anyone to see me like that.”

These emotions - guilt, anxiety, shame - can be particularly heavy at a time of year when everyone else seems to be celebrating. Molly captures it in simple words: “I think Christmas is a difficult period when I see everyone celebrating, and I can’t in the same way.”

Yet among these difficult feelings are also glimmers of resilience. Yasmin remembers a Christmas Eve when she had a seizure that “slowed everything down.” At the time it was frustrating, but looking back she has chosen to focus on what the season still brings. “Now I try to find gratitude and relief where I can, even if things don’t go perfectly,” she says.

This balance—between the fear of missing out and the determination to still find meaning, is something many people with epilepsy will recognise. The festive season can amplify feelings of isolation, but it can also highlight the importance of kindness, understanding, and small moments of connection.

As Marnie puts it: “I don’t want to be seen as just ‘the girl with epilepsy.’ Yes, I have epilepsy, but I’m so much more than that.” It’s a reminder that people are never defined solely by their condition, and that the greatest gift at Christmas is to be seen fully for who you are.

Yasmin's seizure on Christmas eve “slowed everything down”

At Epilepsy Action, we know that while epilepsy doesn’t take a holiday, neither does community. We are glad to announce that this year, new wellbeing resources will be there this Christmas for anyone who feels overwhelmed, anxious, or alone. Because no one should feel invisible at a time that’s meant to bring people together.

> ## “ My seizures can change the mood on the day

For James, Andy, Marnie, Yasmin, Murray, Anita, and Molly, the festive season may not always be straightforward, but their stories remind us that hope, resilience, and connection are still possible. And perhaps that’s the real meaning of Christmas: making sure that everyone, whatever challenges they face, has a place at the table.

Anita said: “Epilepsy Action has provided a platform that reassures me that I am not alone in my journey with epilepsy. Knowing that there is an organization dedicated to raising awareness, advocating for people with epilepsy, and providing resources has been encouraging.

“Through Epilepsy Action, I have been able to access helpful information about seizure management, workplace rights, and ways to navigate daily life with epilepsy. Seeing the stories of others who have shared their experiences has also been inspiring, reminding me that epilepsy does not define who I am or what I can achieve.”

Anita’s experience is exactly how we want all who come into contact with Epilepsy Action to feel. We believe the Christmas Wellbeing Package we’ve designed will be vital to hundreds of people living with epilepsy this festive season.

Each pack costs £35 and will include a wellbeing programme, a wellbeing puzzle book and access to our award-winning helpline at a time when it is needed the most.

We’re asking our readers to help us support as many people as possible this Christmas and across the Winter season.

How many packages can we supply? Our aim is to get to at least 500.

How many will you buy? How many people will you help?

Visit epilepsy.org.uk/Christmas to respond to this urgent appeal.

Katie and George

Someone who *gets it*

Sharon and Katie tried out Epilepsy Action's Befriending service and never looked back.

Words by Kami Kountcheva.

Feeling seen, heard and understood is an incredibly powerful thing in all aspects of life. Sharing with the friend who's also been through a break-up. Unloading to the colleague who's also overwhelmed with the workload. Venting with the parent who's also struggling with the mental load.

Having that instant understanding is validating. It's a relief.

And it is exponentially more so for people struggling with the challenges of a condition famous for being invisible, unspoken about and often fundamentally misunderstood. You know the one I'm talking about.

But Epilepsy Action's Befriending service is here to provide that feeling of validation. You are matched up with a trained volunteer and have weekly phone calls for 12 weeks, free to talk through all your epilepsy troubles.

It aims to give people "direction, hope and confidence" and help you "feel better about epilepsy in under 90 days". And the proof is in the pudding – everyone of the

300 people who have used the service has rated it 'good' or 'excellent'.

If you're umming and aahing about whether to give it a go, you have nothing to lose. And like Sharon and Katie, you have a whole lot to gain.

A lightning strike

Sharon, 51, from Skegness has had epilepsy almost all her life, after getting struck by lightning as a child.

"I was about eight or nine," she explained. "I was riding a bicycle. I had stopped for a minute and put my foot on the ground. A bolt of lightning hit the roof of a house. As it diverted off the roof, I took my foot off the ground to push off on the pedal and it hit me.

"It turned the handlebars of my bicycle around and I went over the top of the bicycle and hit the floor. I went unconscious for a few seconds.

"I was in my cul-de-sac, and everybody told me there had been this massive scream. I had a blue line going all the way around my body. All I remember basically is feeling this horrible, itchy feeling going through my body.

"A few days later is when my seizures started and they found out from then that I was photosensitive."

Sharon's experienced tonic-clonic seizures as long as she's known. She's suffered with damage to her long-term and short-term memory, and has faced discrimination and problems with work and friendships through her life due to her condition.

Over the years, she learned to live with her condition, and even getting polarised, mirrored sunglasses to help reduce the effect of lights.

In 2016, she explained that her epilepsy changed again. She started to hear during seizures and after a hospital stay, she found out she also has focal seizures. As time went by, she started to be aware during most of her seizures.

She explained: "As an example, one time I was sat on a chair [during a seizure]. I knew I was falling off the chair, but I couldn't stop myself because I had no control of my body. I could feel my face being pulled. You can feel yourself jolting, you can feel everything, you've just got no control. I had trouble breathing during the seizure as well, and I felt my throat being pulled inwards.

"It scared the living daylights out of me. That's why I phoned Epilepsy Action."

Sharon was referred for the Befriending service. She added: "I decided to use the Befriending service because I just wanted to speak to somebody. It was nice to actually speak to somebody that had the same experience with the same epilepsy.

"The person I spoke to was brilliant. He was lovely to speak to and he made me feel better in myself. He'd cheer me up, he was brilliant, he really did help me a lot.

"He did help me understand a bit more about what was happening. But I did it more because I was scared. He gave me a bit more confidence. The days went by so quickly, I didn't even realise how long we'd been speaking. It flew by."

Invaluable experience

Four-year-old George loves the outdoors – cycling, riding his motorbike, fishing – along with the colour red, crafts and getting messy. He is also a wonderful big brother to his baby brother.

George was diagnosed with epilepsy a year ago after starting to have tonic-clonic seizures. His mum Katie, 33, from Cheshire, explained that his epilepsy changed with time, when he began also having tonic and atonic seizures.

"The drop attacks (atonic seizures) were particularly bad as they were so aggressive and violent. The main injury he had was that he knocked his four front teeth at the top out during a drop attack. We couldn't eat at the dinner table for months as he would constantly split his head or chin open."

Recently, after trialling several medications, George has gone from 20-50 seizures a day to over a month seizure free. Katie said: "I didn't realise how much of my little boy I'd lost to epilepsy until we got seizure control."

Katie struggled with George's diagnosis, feeling guilt and anxiety. "I feel like George's epilepsy is all my fault and I am just absolutely helpless. I feel angry that it has been my perfect little boy that has been diagnosed with epilepsy, and so sad for him. Why did it have to be my sweet, beautiful boy?"

Signing up for the Befriending service, Katie wanted to speak to another parent whose child also had myoclonic seizures. "The drop attacks are so awful and so quick, and unless your child has them you just cannot understand the aggressiveness of them.

"I was matched with a gentleman whose daughter has a really similar seizure profile to George. It has been a really emotional but really helpful process and we would feel so incredibly alone if it wasn't for my match. Knowing that there is another child like George out there and that there is support and hope and some form of normal family life has just made me feel so much better.

"I would absolutely recommend the Befriending service to others. It's someone to talk through all your feelings and hopes and fears with, that has all the experience of epilepsy and knows all the jargon and will help you as much as they can.

"My experience with the befriending service has been invaluable and my befriender has been so wonderful, I can't thank him enough."

Find out more at: **epilepsy.org.uk/befriending**

Sharon

Mystery seizures

Glen shares a letter to the editor, reflecting on living with monthly seizures, her research and gaining resilience at 80. Words by Glen Clerk.

Joining Epilepsy Action this summer immediately heightened my awareness of the immense communication advantages of the highly informative Epilepsy Today magazine. As someone who has lived with epilepsy for the past 10 years, I have found it invaluable to be able to read at my own pace (especially now that glaucoma restricts my sight making things more difficult). The magazine has also helped me discover new ways of connecting with others — not only through reading, but also by reaching out by telephone and other means.

So access to this ‘living’ document has brought me up to date with many of the issues, problems, case studies, medical advances, and research currently being encountered in this challenging area of specialist medicine.

My epilepsy

I am now nearing my eighties, but many years ago, in the 1970s, I worked in further education with 15–19-year-old students. Here, I spent many hours as a first response carer for suffers. In those days, it was thought that the largest proportion of epilepsy sufferers were young people. Today, we know that the largest percentage of suffers are older people. This raises many important questions for ongoing research. For example, how was this information historically recorded? Are people like me today now living longer with epilepsy than before?

Personally, I have no family history of epilepsy. I rarely suffer from headaches, and x-rays have shown no abnormalities. My local neurology department prescribed Zonisamide twice daily. The unusual thing is that I only experience one seizure a month.

Through working with a medical researcher in Switzerland, I have learned that pre-menstrual women can suffer monthly seizures, a condition known as catamenial epilepsy. Yet my seizures do not fit neatly into that category, and, frustratingly, medical professionals do not appear familiar with my situation.

I am post-menstrual, having had a complete hysterectomy at 38, along with a hormone implant. This I was told would only last a year, and my GP assured me it would no longer be active now. However, my own attempts to research the details of this implant from my medical records have been unsuccessful.

I also learned from the medical researcher that the body depletes of Thiamine (Vitamin B1) after a month if not replaced by diet. This can cause neurological issues. So, I had it tested but it showed negative.

My own research suggests that my seizures may be triggered by a hormonal link of some kind, though that may not be the full story. So, it is well worth asking whether others out there may have had similar experiences. Establishing connections with people who share these symptoms could help drive forward more positive and relevant research and attract funding.

My usual symptoms

For me, what usually happens is that once a month I wake up or remain unconscious, having had one of several possible ‘seizure presentations’. These can include shaking, unconsciousness in a trance-like state, sometimes what they used to call petit mal, now known as an absence seizure, excluding mouth frothing or difficulty speaking. I am told that I sometimes present with a slight temperature as well.

Occasionally this results in a hospital visit, but more often I simply recover at home, utterly exhausted. I count myself fortunate to have the support of my husband, who worries for me and helps us plan our lives accordingly.

One small but important tip I would like to share is the Message in a Bottle service — a container kept in your fridge that holds essential written medical information. A matching sticker on the inside of your front door alerts ambulance staff to its presence.

> “ My seizures don’t fit neatly into a category

This free service is available across the UK, and more information can be found at **lionsmessageinabottle.co.uk**. I obtained my information from a local charity with a telephone call for a new form when needed to update information from Lions Club.

Build understanding

Finally, if anyone else has experiences of monthly seizures or experiences a situation similar to mine, I would urge you to share your story with the editor of this magazine. Together, we can build a greater understanding.

Catamenial epilepsy

Catamenial epilepsy is defined as a pattern of seizures that worsen at certain times of the menstrual cycle. It’s thought this might be because of changes in the levels of the hormones oestrogen and progesterone during the monthly cycle.

Catamenial epilepsy can happen with focal and generalised epilepsies. Recent studies suggests that catamenial epilepsy could affect around 4 in 10 women with epilepsy.

Recent research has also shown that it is still possible to have catamenial epilepsy if you don’t release an egg (ovulate).

There aren’t any tests that can confirm catamenial epilepsy and it can be difficult to diagnose.

If you think you may have catamenial epilepsy, keep a diary of your monthly cycle and seizures for three months. This will help you to see if there is a pattern.

Seizures associated with catamenial epilepsy may be difficult to control with your usual epilepsy medicines. If your doctor thinks you have catamenial epilepsy, they might prescribe an extra medicine for you to take.

There is more information at: **bit.ly/46S6V7e**

Under the Lights

Miles Levin’s new feature film, Under the Lights, hopes to bring epilepsy to the masses through film, building empathy and starting conversations

> “If you are able to make your struggles useful to one other person, it starts to make the struggle worthwhile”

“Movies can do something that a seminar or a pamphlet or an educational article can’t do. They can be something that an average person seeks out on their own volition,” explained Miles Levin, writer and director of the film, Under the Lights.

Under the Lights started out life as a short film, about a boy who goes to his school prom, knowing it would trigger a seizure, just to feel ‘normal’ for a night.

Miles, who has epilepsy himself, wrote the nine-minute short film in 2017 and shot it in 2018. Since then, it has received the Jefferson Award in the US for public service, and has had more than 100,000 views online. People have got in touch with Miles to tell him the difference this film has made – telling him its role in helping them express how they feel and in making meaningful change in their lives.

Miles has now turned the short film into a feature-length movie, aiming to help connect even more people to the experience of epilepsy.

“Build the loudspeaker”

Miles believes in the power of films to help connect the public to a message, to grow empathy and to “start a worldwide conversation”.

He explained: “What I noticed going wrong in the epilepsy community is that when we talk about awareness and we beg and we plead about stigma, we are always talking to our own. And it’s this echo chamber.

“If we wait for an unacquainted audience to just start showing up, out of sheer curiosity, to our galas and our walks, we’re not going to get anywhere.

“Those sorts of events are wonderful for solidarity, they’re wonderful for fundraising, and they’re deeply necessary, but they’re not awareness events in the way that public-facing media is.

“A movie can reach more people in a year than, I feel, most organisations can do in a decade. And that’s not a competition. My aim is to make something that those organisations can use, so that they are heard and their reach is compounded.

“Basically, I wanted to build the loudspeaker for other people, who are doing great work, to be more effective.”

“A responsibility”

The full feature film, Under the Lights, goes into more depth around Sam’s life and his dynamic with other people.

"I always knew I wanted to do the full-length movie, but it went from being a personal goal of something that I want to do, to being a responsibility.

"The short film covers the general universal truths about what it's like to feel when you have a silent struggle, and position it in such a way that the average unacquainted person feels similarly. Everyone knows what it feels like to be left out, alone and misunderstood.

"But the feature goes the extra mile. The feature goes into the caregiver experience. What's it like to be mum in this situation? Because Mum's story is untold. What's it like to be the person who really wants to be a friend but doesn't know where to start, and is probably going to do the wrong thing at some point? What's it like to be afraid to talk about something and open yourself up to the potential backfire of that vulnerability?

"Epilepsy is so much more nuanced than what we saw in the bathroom in the short film. And I also wanted to give credit to people who mean well, and say we're all capable of mis-stepping and saying the wrong thing or doing the wrong thing. We're all flawed, at the end of the day."

"A coming-of-age moment"

Through his experiences with his own epilepsy, Miles is acutely aware of what life feels like with epilepsy, outside of seizures, and has fed this into the movie.

He said: "Epilepsy is just about seizures. For most of us, the seizures are the part that we're not around for. So, for many, epilepsy is the experience between seizures. The seizures are the punctuation in the narrative. So, I wanted to take the time to express those things, those little nuances that together have tremendous weight."

In the short film, Miles wrote in a key moment for Sam that he can't pass up even if it threatens to worsen his seizures – going to prom. This desire to take part in regular things alongside everyone else is something he drew from his own experience growing up.

He said: "The thing that I craved desperately as a teenager was a coming-of-age moment. I wanted that transition from childhood to adulthood, which was impossible when you're not hanging out with your friends, you're in doctors' offices.

"What do you do after school? I get an MRI. That's the experience.

"I had enrichment, but I wasn't developing in the same way that other people did.

"I remember a distinct moment – I was the graduation speaker, and I was the one who didn't go to college. And I remember this distinct moment where everyone threw their hats in the air, and I just held on to mine, because I wasn't going anywhere.

"It was really important for me to go to prom. I had to do every single thing that felt to me like it was a rite of passage, even if it wasn't going to let me out.

"My friends sometimes got criticised for being stupid kids, or doing stupid things, but I didn't have the right to mess up. Simultaneously, I wasn't a child and I wasn't an adult, but I really wasn't allowed to be either."

Writing, directing and watching the performances based on some of Miles' most vulnerable moments, such as a scene where Sam has dislocated his shoulder, hasn't been easy. He remembers "sobbing" through some of the scenes.

"The shoulder stuff was really tough for me, because it's the most pain I've ever experienced in my life and it would be a weekly thing, where I'd need anaesthesia to put it back for many years.

"That's something that I shiver when I think about. It was really hard to put that on screen."

"Ask them to know us"

The feature-length film stars an exciting cast, including Pearce Joza (Zombies 2, Lab Rats), Tanzyn Crawford (Servant, Tiny Beautiful Things), Lake Bell (In a World, Man Up), Randall Park (WandaVision, Fresh Off the Boat) and Nick Offerman (Parks and Recreation, The Last of Us) in a supporting role. Miles is hoping the film will give the public a new perspective on epilepsy.

He says: "Here's the secret sauce to life – if you are able to make your struggles useful to one other person, it starts to make the struggle worthwhile.

"If you can talk about it, you must. And it's not just a responsibility to others, it's to yourself, because it liberates you, and you find tremendous meaning in your struggle, even if it's over, by making someone else feel seen, who's not able to talk about it.

"What I found with the short film, and certainly what will happen with the feature, is that people who are unacquainted with epilepsy tend to watch, and they go: 'Oh, I know someone with epilepsy.' They think about epilepsy through a lens that they haven't before.

"Most of the people sending in fan art of the project, they don't have epilepsy! It's not the epilepsy community. It's people who are curious and they want to be part of something that's bigger than themselves, and it welcomes them into the fold.

"So, that's what I hope happens, is basically we pass the torch onto people who don't know us and ask them to know us."

To get updates about the full feature film you can subscribe at **underthelightsfilm.com/contact**.


Nic arriving for her SEEG treatment


After surgery, 13 wires were attached to Nic's brain

SEEG *diaries*

> “I felt as you would imagine, sleeping with a big, uncomfortable ‘blanket’ around my head”

Epilepsy Action trustee Nic Adamson shares her diary from her recent stereo EEG.

Nic shared her story in the Spring issue of Epilepsy Today, talking about how uncontrolled focal seizures have affected her life, work and safety. She recently had a stereoEEG done to see if a precise area where her seizures start from can be found. Here is her account of the experience of an SEEG.

Thursday, 26 June

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

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

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

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

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

Friday, 27 June

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

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

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

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

By 10pm I was ready for bed.

Saturday, 28 June

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

I felt as you would imagine sleeping with a big uncomfortable 'blanket' around my head. I feel a bit nauseous and tired still. Hospital food is not nice, so not eating much.

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

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

Sunday, 29 June

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

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

Monday, 30 June

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

Been told six seizures captured so far – great news!

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

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

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

Tuesday, 1 July

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

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

At home, I'd cuddle up on the sofa, take my meds and get hugs from family. Here it feels far more clinical. Staff are very kind, but I feel like an experiment.

Able to take half a clonazepam again tonight so hopefully that will allow some sleep.

Wednesday, 2 July

No seizures overnight and slept well. Such a relief!

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

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

Thursday, 3 July

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

Finding it tough. Felt emotional and tired and miss my family so much. Just want to be home but I know I've got to tough this out for a few more days. They've lots of data, but they ideally want some tonic-clonic seizures to see how they spread.

Nurse has promised me there will be someone watching me tonight and ready with rescue meds if I need them.

Friday, 4 July

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

Can't be bothered getting dressed

Feeling knocked out after six hours under general anaesthetic

Family game of scrabble

> **“Times like this, I think being autistic makes the unclear plan to fix things more stressful”**

today (for first time). Just going to stay in PJs.

Continued feeling very emotional all day and then late afternoon had what I think is a focal seizure where my face twitches. Feel very tired but like my emotions are reset. Often feel better after those ones.

Saturday, 5 July

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

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

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

Sunday, 6 July

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

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

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

Monday, 7 July

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

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

Tuesday, 8 July

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

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

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

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

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

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

Today

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

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

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

Nic and husband Jay

Focal seizures

How you describe your focal seizures and recent research round-up.

Words by Kami Kountcheva

Focal seizures are often under-portrayed in the media and often misunderstood by onlookers and bystanders, despite being the most common type of seizure. They can look and feel very different from person to person, and the aftereffects of a focal seizure can also vary.

We share some recent research and your real-life experiences of what focal seizures feel like.

What people said

Everyone experiences focal seizures differently. For some they are short, for some they're longer. Some people have more 'typical' characteristics, while others have more unusual ones. The way people feel during a focal seizure can also differ.

We asked you on our social media to share how your focal seizures feel. You shared openly your experiences – thank you! – and there were a few more common elements:

- A feeling of déjà vu
- Stomach flipping, like being on a rollercoaster
- A feeling of anxiety
- Feeling hot
- Confusion after the seizure
- Lost control of speech
- Everything slowing down
- Headache

However, everyone's description showed how unique this experience is to each person.

One person said: "I get an odd sensation in my lips which often spreads to my tongue and teeth/gums. No one apart from my other half knows I'm having them, but they're so intense to me!"

Another added: "Focal seizures are just as real and just as scary [as tonic-clonics]. My focal seizures would involve lip smacking/chewing, hand rubbing, smacking my legs, rocking backwards and forwards and pulling at my clothes.

"After the seizure my speech can be affected for a while and I am normally very confused."

An Instagram user explained: "My body heat goes supernova. I can't really talk or respond. It's like I'm watching myself from behind myself."

Another shared: "Before I was diagnosed, I used to hear the white rabbit from Alice in Wonderland during [focal seizures], but my meds have stopped that. I feel like I'm not real but still aware at the same time, and can sometimes speak clearly while I'm in it, but most times it's difficult to speak. I remember everything from the seizure, too."

Another person said: "I get a weird smell – always the same – and sometimes hear my mum's voice coming out of my mouth. Lasts about a minute, followed by feeling groggy."

Over on Facebook, a responder described their focal seizures saying: "Focal dancing lights, like the trace of sparklers that lasts up to 10 or 15 minutes and lead into a headache."

Another added: "I feel like I'm 'not real' and am not sure if what I'm seeing is actually happening or if I'm watching a film or a programme from the outside looking in.

"I sometimes claw at my arms – I think that might be me trying to see if I AM real!"

A third explained: "I have focal seizures which always start with a really powerful sense of déjà vu, which lasts for a couple of minutes, followed by a strange feeling in my head, like a wave pulsing through it. I feel very dazed and confused afterwards and get a monster headache and feel very tired."

What recent research says

A quick glance at recent research highlights an unmet need in this group. Focal seizures affect around 61% of people with epilepsy, according to a 2022 multinational review paper. But there is still a lot to learn and understand about how best to treat these, especially in people with medicine-resistant epilepsy.

Some newer medications, such as cenobamate, perampanel, brivaracetam and lacosamide, have shown effectiveness for focal seizures. However, they can have significant side effects in some people, with researchers stressing that doctors need to be mindful of those when choosing which to prescribe to an individual.

Cenobamate, as one of the most recent medications, has been the subject of many of the more recent studies. They suggest that it offers more effectiveness for people with medicine-resistant focal seizures than other medications, and is no more likely to cause side effects than alternative medications.

Researchers agree that more treatment options are needed for this group, as well as more research into focal seizures.

There is more information about focal seizures and first aid at **epilepsy.org.uk/focal**.

COULD I COUNT ON *you?*

Epilepsy Action's biggest awareness campaign to date. Words by Kami Kountcheva.

“Somebody helped me that day. I don’t know who they were, but that simple act meant so much to me!”

Andy Deighton, 54, from Harrogate, knows firsthand how crucial the support of others can be when you live with epilepsy.

Andy has had epilepsy since the age of 16. For him, it’s something “constantly in the background”. He has tonic-clonic seizures, which he says are unpredictable. They could be at bay for long periods of time, or they could be more frequent and disrupt his life.

Keeping fit and staying active is important for Andy, helping him boost his wellbeing and mental health. But it was during one of his runs that he found himself in need of help.

“I was on a training run in Leeds. It was a run from the outskirts into the city centre. I had a seizure and smashed my head open.

“The person who found me probably thought I’d been stabbed or mugged, because, unfortunately, I had a big gash in the back of my head where I landed.

“The next thing I remember is waking up in the hospital. So, for want of a better word, the period between running and coming round was deleted.

“A paramedic told me that someone had left their coat under my head to protect it while I was having the seizure.”

The campaign

This moment left a huge impression on Andy. A stranger had helped him when he was having a seizure and at his most vulnerable. But unfortunately, this isn’t the case for everyone.

More than half of UK people wouldn’t know what to do if they saw someone having a seizure, according to a survey of 2,000 people by Epilepsy Action. This is despite the fact that this simple knowledge could help prevent people coming to harm and even save their life.

This statistic underpins Epilepsy Action’s new campaign, Could I Count on You, launched last week, encouraging people to become more familiar with seizure first aid and become an ally to people with epilepsy.

The survey revealed a lack of knowledge and confidence among the UK public around seizures and the steps to take if you see one in public.

While 54% of respondents felt they wouldn’t know what to do if they saw someone having a seizure, 37% said they would only recognise a seizure if they saw someone convulsing (like during a tonic-clonic seizure).

Only 2% said they would consider that someone walking into a busy road could be having a seizure. More people said they would assume attempted suicide (13%) or drug or alcohol abuse (4%).

Also, 9% said their instinct would be to hold the person down and 22% said they would put something in the person’s mouth. This could cause harm to them and the person having a seizure.

Nearly a quarter of people admitted they would probably panic or freeze under the pressure, and two in five (39%) said they worried they might make the situation worse.

Willing to help

While Andy has had people step in and help when he’s needed them to, he’s also experienced people in ‘flight mode’.

He said: “I was on holiday one year with my wife – we’d been at the seaside and just got some fish and chips to eat at the seafront. I had a seizure and yet no-one came to help us that day. People just walked by as if I was drunk or on drugs, completely ignoring us.

“It was hard, not just for me but for my wife too, knowing that some people just weren’t willing to help.”

For many people with epilepsy, help from strangers isn’t just a kindness, but could be lifesaving. In a survey of nearly 900 people with epilepsy, half of people (51%) said they are likely to seriously hurt themselves during a seizure if no one stepped in to help.

Just over half of people (53%) said they thought it was unlikely that a member of the public would help them during a seizure, but nearly half (47%) said they would feel ‘very reassured’ knowing the public was more aware.

Murray Goulder, 45 from Crawley, has had a stranger save his life. Murray lives with absence seizures, meaning during these episodes, he can walk without any awareness of what he is doing or where he is going. During one absence seizure, he almost walked onto a train track.

Speaking about the experience, he said: “The worst situation was coming home from work one day – I was in Farringdon station. I remember walking down the stairs, then being told I had dropped my bag and walked towards the platform. The gent that stopped me, got me on the next train and went 45 mins in the wrong direction to hand me over to the local station team to get me safely out of the station and home.”

The good in people

Like Murray, Andy has seen the best in people when he’s really needed help, and fervently looks for and believes in the good in people. “I think the media likes to portray a world, at the moment, where everyone is unpleasant. They’re selfish, they get out their phones and film you… Maybe I’m naïve, but I don’t believe that.

“I’ve always helped other people. I recently helped an old lady to cross the road. She just looked a bit lost and was about to step out into the traffic. So, I went to walk across the road with her. Simple as that.

“And I think most people would do the same. If you think of a shopping centre, for example, with 100 people there, I’d like to think that at least one of those 100 people would help me. I know that, because I’ve experienced it.”

The ‘Could I Count on You’ campaign has been the largest ever national campaign Epilepsy Action has done, reaching 10 million people across the UK through posters, billboards and podcast adverts, as well as 1 million people online. We are thrilled to have reached so many people with this vital message and shedding much needed light on epilepsy.

WALK, RUN, SOAR, *Leap*

Epilepsy Action's trustees taking on brave, daring and testing fundraisers.

Words by Kami Kountcheva.

Cameron

Cameron gained 8,200m of elevation during his challenge

How do you celebrate a 75th? Going out for a nice meal? Balloons? Definitely cake.

But Epilepsy Action's trustees have taken things a bit further. And a bit higher. And a bit more adrenaline-fuelled. Have a look and the lengths (and heights!) they have gone to to fundraise and mark Epilepsy Action's big anniversary.

Trekking with Cameron

Trustee Cameron Hill undertook a mammoth walking challenge around the Lake District over the summer, walking for eight consecutive days and raising over £500 for Epilepsy Action. Over that time, he:

- Covered 126 miles on foot – "about the distance from [Epilepsy Action HQ] New Anstey House to Scotland, Buckinghamshire or the Cotswolds."
- Took 246,000 steps
- Gained 8,200m of elevation – "comparable to some of the highest mountain peaks on earth in the Himalayas, though I experienced more bogs and sheep than snow and ice."
- 46 fell summits and 33 mountains – "including England's 1st, 3rd, 4th, 5th, 6th, 7th and 8th highest peaks."

Cameron walked the southern half of the Ullswater Way, the full Helvellyn range and Scafell Pike, among many others.

He said: "My highlights included the incredible views around Ullswater and from the summits of Helvellyn, Skidddaw and Blencathra; an excellent curry pasty at Aira Force tea room; spotting some beautiful highland cows just outside Ambleside; trying not to get hit in the face by low branches on top of the open-top 78 bus through the Borrowdale Valley and along Derwent Water; and stumbling upon the highest bake sale in England at the summit of Scafell Pike, where I bought and briskly devoured a very welcome flapjack, enjoying 360 degree views of nothing but dense clouds, loose rocks and tired walkers taking a rest.

"It's been an exhausting but deeply

Jane flew at a speed of 120-140mph

Jane strapped to the bi-plane for her wing walk

“I’m so glad to have helped in a small way”

rewarding experience – sore legs and all – and it’s been a privilege to support Epilepsy Action not only as a trustee, but also as someone who now understands the strategic value of Kendal Mint Cake and squashed bananas.”

Wing-walking with Jane

Chair of the Board of Trustees, Jane Riley strapped herself to a plane and took to the skies to fundraise and support people with epilepsy.

In September, Jane did a wing walk, which she described as being “strapped onto the wings of a bi-plane and fly 500ft into the air at around 120-140mph for around 10 minutes”, and raising nearly £1,000 alongside her friend Kevin.

She explained: “I wanted to do something a bit different for our 75th anniversary and something that would raise a few eyebrows! I’ve always been a little nervous of heights and with it being my 60th birthday year, I thought it time I stepped up and conquered a few fears!

“Take-off was amazing – 0-120mph in around five seconds! Up there, the wind speed is tough against your face and body.

“When I came down, I felt truly uplifted and energised. The views were amazing and to see my family and supporters on the ground welcoming me back was emotional. My son Matthew, who has had epilepsy for over 20 years, and my husband were with me. My friend and one of Matthew’s support workers, Kevin, also took part and helped us raise funds for Epilepsy Action. In fact, Kevin was the main driving force and twisted my arm to take part.

“I’m so glad to have helped in a small way to raise awareness of this most amazing, supportive charity.”

Skydiving with Katie

Also looking to challenge and overcome a fear of heights was Katie Stevens, honorary treasurer of the Board of Trustees. She elected to do a skydive in aid of Epilepsy Action, raising over £3,000.

Katie said: “The main reason I wanted to do it is the fact that, due to my epilepsy, I haven’t been able to even contemplate skydiving for many years, so how could I say no to the chance?

“Beforehand, I was excited, nervous and full of adrenaline. But I did feel sad for my colleague, who was also planning to skydive with me, but was unable to take part due to his recent seizures.

“The skydive was amazing! It is difficult to explain how it feels to jump out of a plane and to be hurtling down at 120mph. I could hardly get my breath, but the scenery was stunning, so I soon lost my nerves and felt simply elated by the experience. My favourite part was when I pointed out to my instructor an aeroplane that was flying below us – quite something to see!

“My wonderful husband greeted me with many Epilepsy Action balloons when I landed.

“I feel really proud that I overcame my fear and I also feel really humbled by the many, many kind contributions that family, friends, colleagues and even strangers have donated over the last few weeks.

“It means the world to me to fundraise for Epilepsy Action. I wouldn’t be in such a happy place now if it wasn’t for the support I received from Epilepsy Action during the most difficult years I faced. To think the money we have raised will help others is just wonderful.

Jane and Matthew

“Whilst raising funds for the skydive, I was blown away by the volume of individuals who contacted me to share their or their family’s experience of epilepsy. It impacts all too many so the more we can do to support Epilepsy Action, the better.”

Running with Sally

Sally Taylor, another of our trustees, ran the Hampton Court Palace 10k with three of her friends, looking to challenge herself and “do something meaningful for a cause close to my heart”.

She said: “One of our family members has epilepsy, so I've seen the impact it can have – but also the strength, resilience and courage that goes with it.

“Taking part in this run feels like a way to turn that personal connection into something positive, raising awareness and funds to help others affected by epilepsy.

“Epilepsy Action means so much to me and my family. The charity provides support, information and understanding for people living with epilepsy and


Katie did a skydive for her fundraiser


The initial free fall was at 120mph

their loved ones. They help make life with epilepsy less isolating and more manageable while making a real difference in improving care and awareness.

“Being a trustee has given me a deeper appreciation of just how vital that work is and I’m proud to play even a small part in helping to continue it.

“My husband, our twin girls and our dog, Bingo, met us afterwards. I felt emotional, proud and so grateful – not only for the support from my family and friends on the day, but also for everyone who donated and believed in the cause.”

Sally raised a fantastic £2,300.

Rebekah Smith, chief executive at Epilepsy Action said: “We’re amazed by all the incredible challenges our trustees have taken on and couldn’t be prouder of their determination to fundraise and mark Epilepsy Action’s 75th birthday. No-one has taken an ‘easy route’ either – from wing-walks and skydives to extreme hikes, they’ve all pushed themselves to take on something challenging and out of their comfort zone, and there is more to come over the next few months.

“Our trustees are an integral part of Epilepsy Action, keeping us on track and pushing us to achieve our ‘World Without Limits’ strategy. They have so much passion and care for the charity which they’ve demonstrated through their 75th celebrations challenges.

“Epilepsy Action has achieved so much over the past 75 years, and the trustees have been a real driving force behind this. The current trustees have recognised the need for change and growth and are doing everything they can to make sure we succeed. I am so grateful for the significant amount of time and effort they put into Epilepsy Action.”

You can support the trustees at **bit.ly/49k9Rej**

Special support

A special mention goes out to a few extra trustees who are also helping mark the 75th anniversary.

Tom McLaughlan was set to skydive with Katie, but, unfortunately, he ended up unable to take part. His doctor raised concerns around the fact that his last two seizures have resulted in status epilepticus. He raised more than £1,300, which is an incredible feat and boost to the charity. The trustees who weren’t able to take on their own challenges sponsored the trustees who were, helping to reach and surpass their fundraising goals.

June Massey has created the beautiful Lord Hastings Award, which this year will be recognising a national and international winner. Set to receive the award in December are Richard Chapman, former trustee, chair and stalwart supporter of Epilepsy Action, and Cassidy Megan, founder and creator of global epilepsy awareness day Purple Day. More on this on page 5. We are very grateful to June for creating something so fitting for one of Epilepsy Action’s most prestigious awards.

Last but not least, Sarah Lawson is taking the new Epilepsy Action brand around the world with her as she embarks on a travelling adventure in May 2026. We look forward to seeing how far and wide they go.


Sally ran 10k for her fundraiser


Medal at the finish

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Doodlers digest

Epilepsy Action is launching its 12-page monthly puzzle book

Doodlers Digest is a 12-page monthly puzzle book, which is full of activities all centred around mindfulness and taking some time out to focus on your mental wellbeing. These activities will feature things such as puzzles, colouring pages, drawing prompts and much more!

With 87% of people telling us in a survey that epilepsy has affected their mental health, we've decided to create a an exciting resource to help combat that.

To subscribe to the first edition of Doodlers Digest, head over to **crowdfunder.co.uk/p/ea-doodlersdigest**, and make your first donation today! We'll send out your first edition, and all the information you need to keep your subscription active.

Doodlers Digest is usually available for £10 per month, but as a limited edition offer for Epilepsy Today readers, you can claim your first edition for a £5 donation via the link!

We've shared a little taster of the puzzle book below!

31% SAID THEY HAD SUICIDAL THOUGHTS RELATED TO THEIR EPILEPSY*

*AS PART OF OUR 1,246 MENTAL HEALTH SURVEY

CLUES

1. R.W. Alley is best-known for illustrating which fictional bear, created by Michael Bond?
2. The surname of the actress Olivia C_____, who wore the royal crown, not born to it, but favoured by it.
3. Sir Ian McKellen's character who had a stick in hand, whispering wisdom in Middle-earth.
4. An agent of chaos and a protector, Tom Hardy's role in The Dark Knight Rises.
5. Alice Oseman is the author and illustrator of which best-selling young adult graphic novel series?
6. Freema Agyeman played the companion to which universe-travelling character.
7. The Scottish morning presenter that greets the a nation on television, Lorraine K____.
8. The first name of this Absolutely Fabulous film and TV star, ______ Lumley.
9. Una Healy was a member of this band, named after a day of the week.
10. First name of the illustrator A___ Scheffler, who is best-known for bringing to life Julia Donaldson's characters such as The Gruffalo and Pip & Posy?

Crossword answers 1. Paddington **2.** Colman **3.** Gandalf **4.** Bane **5.** Heartstopper **6.** DoctorWho **7.** Kelly **8.** Joanna **9.** TheSaturdays **10.** Axel

Amazing mum

Jack's mum Rachel has been given an Epilepsy Action Star Award for her unwavering support. Words by Emily Stanley

July's Epilepsy Star Award has gone to Rachel Murphy for her above-and-beyond care for her son, Jack. Nineteen-year-old Jack nominated his mum for her unwavering support of him, during his journey with epilepsy. Jack says his mum advocated for him during his diagnosis, pushed for better treatment plans when they weren't working, and has never missed a single call from him when he was away at university, even at 2am. Jack tells their story below:

"I was a 'normal' 18-year-old, enjoying their first year of university. I'd gone to Bournemouth University, to study Networks and Cyber Security. I was having an amazing time, enjoying the nightlife, friendships and the independence of being away from home. Then, suddenly, I had my first seizure in March of this year.

"I was given a very early diagnosis in May, and had a series of unpredictable seizures throughout May, June and July. It came as a huge shock to me.

"Suddenly my world got smaller. My body wasn't behaving the way it used to. My independence fell more by the day. My friends didn't want to go out with me because they were scared I'd have a seizure.

"But through all of this, my mum was there for me. She never missed a beat."

"Whilst I'm at university, mum is based back at home in Birmingham. Despite being 150 miles away, it felt like she was next to me every second.


Rachel and Jack

"She'd answer my calls at 2am when I couldn't sleep from side effects. She chased up consultants for answers and called wards I was in when I couldn't advocate for myself. She'd be on the phone to the ward before I'd even come round from a seizure.

"I'm autistic, so I can struggle to advocate for myself sometimes, especially in unfavourable situations. She helps me to find the right words to explain how I am feeling, and she always truly understands what I mean. She is my voice when I've lost mine.

"She helped me get the diagnosis I needed, questioned treatment plans when they didn't feel quite right, pushed for my safety when I couldn't, and asked questions no parent should ever have to ask.

"Most of all, she believed me, at a time I felt incredibly unheard.

"She did all of this whilst keeping our home running – she was still working, parenting my other four siblings. I know she's worrying endlessly about me but she never lets it show.

"I'm currently back home and her support is still unwavering. She runs to me when I drop, rides in the ambulance with me, sits by my hospital bed, and asks all the hard questions when I can't speak.

"She never freezes – she acts. She's made every call, chased every answer, calmed every panic, and never once made me feel like I'm too much.

"She's never treated this condition as something I'm facing. She's taking it on with me.

"Over the last few weeks, with the help of Epilepsy Action, I've learnt a lot about epilepsy and that acceptance is a huge key to freedom.

"I've attended a New to Epilepsy Talk & Support group, and this has been so helpful. I felt so alone, but the group allowed me to express my emotions to people who have been through it before, and they answered the questions that healthcare professionals can't answer.

"The helpline was also really useful for when I wanted to ask a question that was on my mind, but I didn't want to put pressure on the NHS.

"It's still an ongoing journey for me, but it's one I wouldn't have been able to do without her. Her strength gave me mine.

"If anyone deserves to be recognised as an Epilepsy Star, it's her. She hasn't just supported me, she carried me, when no one else did."

Upon accepting her award, Rachel said: "I don't feel I deserve it because I'm doing what any parent would! When situations change, you change with your child. Whether they're 19 days, months, or years old, that never changes."

Board of trustees

9th September

At the Annual General Meeting (AGM), 95% of members approved the new Articles of Association, demonstrating strong support for the governance decisions made over the past year. This milestone reflects both confidence in the charity's direction and an exciting step toward a more agile and effective organisation.

7th October

1. **Annual General Meeting**

The minutes from the approved; to be published with ballot results.

Confirmation received of new Articles from Charity Commission and Companies House.

Trustees to complete eligibility declarations and register on One Gov.

Jane Riley to survey trustees on preferred term lengths.

2. **Bye-Law Amendment**

Bye-Law 5 updated to allow honorary role holders to attend Board meetings as observers with Chair/CEO approval.

3. **Investment Management**

Re-tender process to begin at the end of 2025.

4. **2026 Budget Planning**

2026 revenue budget preparation guidance approved.

5. **Patron Succession**

CEO to contact Royal Office for guidance following Duchess of Kent's passing; further discussion at next meeting.

6. **Lord Hastings Award**

Awards to Richard Chapman and Megan Cassidy confirmed; presentations in progress.

7. **Corporate Partnerships**

Presentation by Philippa Cartwright scheduled for next meeting on partnerships and the launch of a new membership scheme.

8. **Governance Review**

NCVO-led review of governance progress to take place in the New Year.

9. **DEI Report**

Diversity, equity, and inclusion (DEI) paper to be included in December Board papers.

10. **Communications Update**

Jon Eaton presented on digital engagement, outlining successes and challenges.

11. **AI and Governance**

Senior Leadership Team to refine and return with AI governance and risk proposals based on Cameron Hill's report.

12. **Risk Register**

Updates approved; CEO to assess and report on AI-related risks.

13. **2026 Meeting Schedule**

Board meetings reduced to four hybrid sessions in 2026, plus one in-person training day.

Committees to confirm their own meeting dates.

In 2026, more detailed board meeting reports will be shared online rather than through Epilepsy Today.

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.

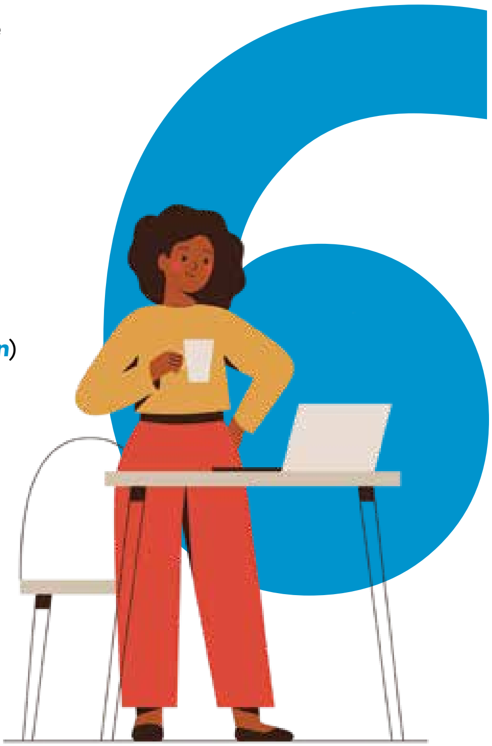
We're here to listen, support, and bring people together – because no one should feel alone on this journey.

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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- **Talk and Support Groups –** online & in-person
- **Befriending –** online or phone
- **Counselling –** Wales
- **Family support –** NI & Wales
- **Website –** high quality information about all things epilepsy
- **Epilepsy awareness courses**

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