

Epilepsy

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Writer Clair shares what inspired her new book **p18**

Olivia Colman doodles for National Doodle Day **p22**



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A summer of stories

I'm so excited to be back making your epilepsy magazine, and we're starting off with an issue full of stories. They're the stories of people learning to live with their epilepsy, those of people with the condition achieving amazing feats, and those from storytellers making epilepsy accessible, understandable and even whimsical.

Our cover star this issue is Andy, who talks about how he worried about being a burden on his family when he was diagnosed with epilepsy. His mental health plummeted, but when he found Epilepsy Action, everything started to improve. Read more on page 12.

Also sharing truly remarkable experiences are Vicky and Sophie. Vicky developed suspected post-traumatic stress disorder after falling from her bike during a seizure (p20). Meanwhile, Sophie ran this year's London Marathon, but a year previously she was in a coma following a seizure (p14).

Book fans might enjoy reading about Clair and Marielle, two authors bringing epilepsy into children's literature. Clair has written a book called Benji and the Birds, where the main female character, Bella, has epilepsy (p18). Marielle is bringing neurons to life in a six-book series on neurodiversity for 3-5-year-olds, starting with epilepsy (p24).

For a quick pick-me-up, don't miss our good news stories (p4), browse our National Doodle Day doodles that will soon be available for auction (p22) or read about our latest Epilepsy Action Star Awards winner (p28). I hope you have a wonderful summer!



Kami Kountcheva
Editor

Purple Day pooch named Super Trooper

Epilepsy Action's Purple Day pooch received his name – Super Trooper – on the global awareness day.

Zach, 5, chose the name Super Trooper and received his cuddly dog toy shortly after Purple Day.

Zach's mum and dad started calling Zach 'Super Trooper' to encourage him to take his epilepsy medicine – but now, with the help of a few chocolate buttons, he takes it no problem.

Anna, Zach's mum, began to notice his epilepsy symptoms last year.

She said: "Zach (now 5) was under investigation for epilepsy for around a year or so after we noticed unusual jerking movements. They were particularly prevalent while falling asleep but then presented during the day resulting in injuries such as hitting his head on the

sink while washing his hands, falling off his bike and hitting his head on the dining table while eating a meal. This was my main concern at first.

"Then we noticed he would often lose control of his bladder straight after one of these jerks. Other symptoms became more noticeable such as extreme tiredness."

To get a diagnosis for these symptoms, Zach's neurologists asked Anna to video his seizures and they gave him an EEG. But a few months after, his symptoms completely vanished.

"After a second normal EEG he was discharged with a view that he had grown out of whatever it was," says Anna. "But, about three weeks after being discharged, in July 2023, completely out of the blue, I walked into him post seizure. He was literally grey in colour, there was

vomit everywhere, he had wet himself and was unresponsive, although breathing.

"After being blue lighted to hospital, he had a further seizure in the night and another in hospital the next morning. A prolonged EEG strongly showed focal epilepsy in the frontal lobe and we were told there and then. His seizures were not what I had thought epileptic seizures could be like. It was as if he had been locked in his own body. Having to film it for the specialists to see was especially traumatic for myself and his dad but we knew it was important."

Zach was given clobazam as an emergency medicine and he began to recover.

"After the effects of the seizures and the clobazam wore off, he was back to his old self," says Anna, "although he has many small jerks throughout the day.

"Having to adjust to long-term medication has been hard. Zach has issues with food and we have struggled to even get him to take Calpol. Luckily, he has seemed to realise the importance of his epilepsy medicine and has been super brave, even after we had to switch medication.

"We refer to him as 'Super Trooper' when he takes his medicine and now he takes it with no issues (as long as he gets a chocolate button!)"

Anna adds: "We are so proud of how Zach has overcome his fear of taking medication and his entire attitude to his condition."



Zach and Super Trooper

Man becomes first 'book' on epilepsy at Human Library



Murray Goulder has been 'published' as a book on epilepsy by the Human Library.

The Human Library is an international organisation, originally set up in Denmark in 2000, that hosts events in which participants can pose questions to topic experts, also known as 'books'.

All of the library's human books are volunteers with personal experience of their topic, and the books represent "a stigmatised group in society".

The learning platform wants to create "a safe space for dialogue, where topics

are discussed openly between our human books and their readers".

The organisation says it is a place where "difficult questions are expected, appreciated and answered".

The idea is that it allows students, teachers and others to access conversations with people they might not meet in normal life.

Goulder is the first 'book' on epilepsy that the Human Library has published. He has already been 'read' by people from the US, Australia, Glasgow and London.

He said: "I'll introduce myself, say that my book is epilepsy, and I'll do a blurb – so I say: 'I started seeing ghosts when I was 15', and give them an example of what I see. 'Two years later I was in a car and that's when I found out I needed to get help, because I put my foot down on the accelerator and I didn't even know I'd done it'. I give a few more examples about hurting myself; times I've almost gone off a train platform; and then I open it up to questions.

"They ask about how it has affected your work life: 'Did people shun you at any point?'; how people reacted in public; what do you do to try to promote it and let people know you've got it?', so I tell them stuff like that. I talk about Epilepsy Action.

"Every reading is different," he says. "Your intro is the same, but you never know what you're going to get asked.

"I've had an in-person one that I did in London – West London Zone, which is an organisation that gives young people opportunities in the area. So, it was talking to community workers. I was surprised with the amount of things they asked: 'Where is the most embarrassing place you've had a seizure?', one asked."

Topics can include gender, mental health and even witchcraft. "There are all sorts of things. Religion. One I saw online was 'black police officer' in the states. It's any topic that you have experience of."

To find out more about the Human Library project, go to: humanlibrary.org

Virtual 10k supporters raise £18k

Participants in Epilepsy Action's Virtual 10k race, which took part during National Epilepsy Week (20-26 May), have raised £18,000 to support people with epilepsy.

More than a hundred runners and walkers across the world, including the UK, Germany and the US, signed up for the race, raising vital funds and awareness of the condition.

Participants included team The Three Degrees, comprising Epilepsy Action staff members Harvinder, Maxine and Katy.

They said: "We aren't runners, just three friends who wanted to get involved, so we walked our 10k. It was great being out in the fresh air, walking by the lake, watching the swans, ducks and moorhens looking after their babies. Walking as a team gave us plenty of time for a

catch-up, kept us motivated, and raised lots of awareness for Epilepsy Action."

Tamaa Tetlow did her 10k on the sunny Monday of National Epilepsy Week. She said: "The best bit about my walk was the lovely stroll through the Forest of Dean. I like to think the money I raised will go to support people like my son with epilepsy."

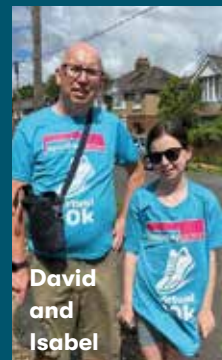
David Dancer and his daughter Isabel did their walk on the Sunday. He said it had been a "great walk, but we both need to sit down now."



The Three Degrees



Tamaa



David and Isabel

He added: "With Isabel having been diagnosed at the end of last year, if what we have raised can make a difference and help others, then it's all worthwhile."

Due to the popularity of the event, Epilepsy Action has extended the Virtual 10k for the next few months. To sign up, email virtual@epilepsy.org.uk.

Epilepsy news

O2 praised after removing flashing lights advert

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

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

O2 said it decided to remove the advert “out of an abundance of caution”.

The Only on Priority advert, offering access to exclusive gigs and ticket presales, included flashing lights from the start. It appeared on TV and social media.

O2 confirmed that the advert had passed the Harding Test, used by Ofcom to check that video footage is safe for people with photosensitive epilepsy.

However, social media users said they were still worried it could trigger seizures in those with photosensitive epilepsy.

People reported paying to watch Channel 4 ad-free to avoid the advert or having family members rush in front of the TV to block their view of it.

One Facebook user said: “Apparently it passed all the tests it needed to, but wow, certainly not great that’s for sure”. Another said: “In my opinion, why even take the risk.”

Epilepsy Action contacted O2 to share concerns over the safety of the strobe lights and the stress it was still causing people with photosensitive epilepsy.

O2 said: “The advert passed the PSE test and was cleared by Clearcast, but we always listen carefully to any concerns raised by customers or anybody viewing our content. Out of an abundance of caution, we have taken the decision to remove the advert.”

Jon Eaton, director of Communications and Digital Engagement at Epilepsy Action, said: “It is great to see a large advertiser like O2 going above what is expected when it comes to photosensitive epilepsy.

“They rightly pointed out that their advert was cleared by Ofcom, which uses the Harding Test to clear TV Adverts.



“However, we heard from many people who were scared by this advert. One person told us that they had paid for a premium YouTube account to avoid adverts. Another person had decided to hold a cushion at all times when watching TV to block their view if the advert came on.

“With this feedback, O2 has done the responsible thing and taken the advert down.

“Interestingly, thresholds for photosensitivity are higher in Japan due to an issue in the late 1990s. We would encourage Ofcom to consider whether a new threshold is needed in the UK now that we are in a fully digital age.”

Latest epilepsy medication shortages

Epilepsy Action is aware of the following epilepsy medicine shortages:

Epistatus

Epilepsy Action are aware that Epistatus (midazolam) 2.5mg/0.25ml and 5mg/0.5ml oromucosal solution pre-filled oral syringes made by Veriton Pharma are currently out of stock with no confirmed return date.

Phenobarbital

Also currently out of stock with no

confirmed return date is phenobarbital 15mg tablets made by Accord.

Lamotrigine

Accord's lamotrigine 25mg, 50mg, 100mg and 200mg tablets are also out of stock. The company estimates that they will return in August 2024.

Carbamazepine

Crescent's carbamazepine 100mg and 200mg tablets are out of stock, with an estimated return date of mid-June 2024.

Medicine shortages becoming ‘new normal’, says Nuffield Trust report

Medicine shortages are becoming “shockingly” commonplace according to a report from the Nuffield Trust.

It said the past two years had seen “constantly elevated medicines shortages” and a “frequent disruption to crucial products”, which worsened in 2023, becoming a “new normal”.

Epilepsy medicines including Tegretol (carbamazepine) and Lamictal (lamotrigine) were among the medicines consistently affected by shortages.

The report, titled ‘The future for health after Brexit’, said this had placed a “significant burden on pharmacists and affected the medicines available to patients”.

The Nuffield Trust is an independent health think tank. It said the shortages reflect “significant problems in the global medicine market”, and that while Brexit was not to blame it had “contributed to difficulties by lowering the value of sterling and removing the UK from EU supply chains”.

It added that the English NHS had increased medicine prices to deal with supply problems, which cost the taxpayer £220 million more in just one year.

Reacting to the report, Epilepsy Action deputy chief executive Rebekah Smith said: “Epilepsy medication availability has been a fluctuating issue for years, but it has definitely reached a precarious point more recently.

“Most people with epilepsy rely on medication to control their seizures, and very often finding the right one, or the right combination, is a tough journey. Medication is the first step to getting some degree of stability, and the potential of this stability being taken away is devastating.

“We have heard of many people struggling to find the right medication over the past few months, and the stress surrounding running out or having to take a substitute has been overwhelming. It could mean more seizures, or having a seizure after being seizure-free for years, which could have a massive knock-on effect on other aspects of a person’s life, such as their ability to drive, or



their job. But at its worst this can be life threatening.

“People with epilepsy and other conditions affected shouldn’t have to worry about whether their symptoms are going to worsen for factors totally out of their control. Our Helpline team has listened to the worries and struggles of a record number of people since the start of this year. They deserve to know why this is happening, and when it’s going to get solved.”

Smith called on the government to review the medicine supply chain so that people with epilepsy could be confident about getting their medications.

She added: “The Department of Health and Social Care needs to ensure a robust review of all the processes and procedures to ensure an open and transparent supply chain, so that people with epilepsy do not have to worry about not being able to get their medication.”

The Nuffield report also made a number of recommendations to the government. It called for:

- Better anticipation of medicine shortages
- More openness about shortages in line with other European countries
- A plan for the EU’s stockpiling and medicine transfer schemes.

Nuffield Trust’s Brexit programme lead Mark Dayan said: “The rise in shortages of vital medicines from rare to commonplace has been a shocking development that few would have expected a decade ago.

“More and more patients across the UK are experiencing a pharmacist

“The rise in shortages of vital medicines from rare to commonplace has been a shocking development that few would have expected a decade ago”

telling them that their medication is not available, it may not be available soon, and it may not be available anywhere nearby. This is also creating a great deal of extra work for both GPs and pharmacists.

“We know many of the problems are global and relate to fragile chains of imports from Asia, squeezed by Covid-19 shutdowns, inflation and global instability. Officials in the UK have put in place a much more sophisticated system to monitor and respond, and used extra payments to try to keep products flowing. But exiting the EU has left the UK with several additional problems – products no longer flow as smoothly across the borders with the EU, and in the long term our struggles to approve as many medicines might mean we have fewer alternatives available.”



Scan the QR code to find drugwatch online or call our Helpline on 0808 800 5050 if you are concerned

People with epilepsy must keep access to PIP, says Epilepsy Action

Epilepsy Action is opposing proposed changes to Personal Independent Payments (PIP) announced in early May by the UK government.

The Department for Work and Pensions announced a consultation into the benefit, saying it would move from a fixed cash benefit system towards tailored support.

However, Epilepsy Action said a further crackdown on disability benefits, especially with the proposed criteria, will only make it harder for people with epilepsy to access PIP.

It is urging people with epilepsy to make their voices heard, as being refused PIP could affect access to further benefits such as the enhanced disability premium, council tax relief, housing benefit deductions and others.

As part of the proposed reforms, the government has launched the 'Modernising Support Green Paper', which it says will "explore how our welfare system could be redesigned to ensure people with disabilities and long-

term health conditions get the support they need to achieve the best outcomes, with an approach that focuses support on those with the greatest needs and extra costs".

But campaigners are fearful that any reforms could make it even harder for disabled people to access the financial support they need.

Daniel Jennings, Epilepsy Action's senior policy and campaigns manager, said: "The proposed changes to PIP payments are very concerning.

"There is no such thing as a mild mental health issue and to suggest as such is massively insulting. We know that many people with epilepsy experience depression and anxiety, which can have a severe impact on their daily lives, on top of the impact their epilepsy has."

In a statement on Monday (29 April, 2024), Work and Pensions secretary Mel Stride said: "We're making the biggest welfare reforms in a generation – protecting those most in need while supporting thousands into work as we



modernise our benefit system to reflect the changing health landscape.

"A decade on from the introduction of PIP, this Green Paper opens the next chapter of reform, enhancing the support for people with health conditions and disabilities while ensuring the system is fair to the taxpayer."



Epilepsy Action will be responding to the consultation. To let the government know your views, scan the QR code

Epilepsy Action only epilepsy charity with PIF Tick accreditation for information

Epilepsy Action has been awarded PIF TICK accreditation for a further year.

The certification recognises that the health information on Epilepsy Action's website is high-quality, evidence-based, understandable, jargon-free and up-to-date.

The website first achieved the accreditation in 2021, just one year after the scheme was established.

Epilepsy Action is the only epilepsy charity to have the accreditation for its information.

Epilepsy Action's health information lead Hannah Beckitt said the certification is important because it shows healthcare professionals can be confident when signposting their patients to Epilepsy Action.

She said: "The PIF TICK process has been invaluable in making Epilepsy Action what it is: a trusted source of information covering all aspects of someone's life that epilepsy can affect.

"It can be hard to find reliable information on the internet, but the little green PIF TICK ensures healthcare professionals and people with epilepsy know they can rely on us.

"This is very much a collaborative effort. Without the help and feedback from people with

lived experience and experts, we would not be able to reach the standards outlined by PIF."

If you are interested in being involved or want to find out more information, please email health@epilepsy.org.uk.



Morrisons loses appeal over death of employee with epilepsy

Morrisons has lost its appeal to overturn convictions for health and safety failures, following the death of its employee Matthew Gunn.

Matthew, 27, had epilepsy. He fell from a staircase during a seizure at the Morrisons store in which he worked. Matthew died 12 days later as a result of head injuries.

He worked at the WM Morrisons store in Tewkesbury, Gloucestershire, and died in September 2014.

Epilepsy Action has contacted Morrisons to offer first aid training as a result of Matthew's death.

Morrisons was fined £3.5 million in March last year after it was convicted of three health and safety offences. It also admitted a fourth charge.

At hearing on Wednesday 22 May at Gloucester Crown Court, the company's lawyer said the health and safety laws had been incorrectly interpreted at trial.

Three judges, Lord Justice William Davis, Mrs Justice Cheema-Grubb and Judge Dennis Watson KC, dismissed the appeal bid, stating that steps "could have been taken" to mitigate the risks.

Lord Justice Davis said: "We accept that the staircase did not present a risk for almost all members of staff at the store.

"In our judgment that is not the point. It created a material risk to the health and safety of Matthew Gunn."

Matthew, who worked as a shelf replenisher, regularly used the staircase to access his locker on the first floor of the shop, where he stored his belongings in line with company policy.

He never regained consciousness after his fall on September 25, 2014, and died on October 7.

Three and half months before his death, Matthew's mother, Sue Goellner, had warned Morrisons managers of the risk to her son due to his frequent seizures.

The company was convicted in February 2023 of failing to ensure the health, safety and welfare of employees and failing to carry out a suitable and sufficient risk assessment.

Sue, who attended Wednesday's hearing via a video link, said her son's death had "left a massive hole in my heart" and she had lost her job as a result



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and her marriage had ended.

Richard Atkins KC, representing Tewkesbury Borough Council, which brought the prosecution, said Morrisons was aware of the nature of Matthew's epilepsy and had records of him falling on stairs previously.

He also told the court that while Matthew's locker was initially on the ground floor of the store, it was later moved upstairs without a risk assessment being carried out.

Richard Matthews KC, for Morrisons, described the case as "tragic" but said a "control measure to forbid Matthew from using the stairs" was not an option.

He told the court that the stairs were a safe "means of access" and a lift was also available.

He said: "No one can or should suggest that every staircase, fixed staircase, in a workplace, with a lift, has to have a rule that epileptics who may have a severe epileptic seizure are not permitted to use it."

He added: "If this court finds that as a matter of law, which it would have to do, a fixed permanent staircase used as a means of access amounted to that person a material risk to their health and safety, that has enormous ramifications."

Refusing the appeal bid, Lord Justice Davis said: "There was ample evidence that the conduct of the company exposed Matthew to a real risk.

"The event that led to Matthew's death was one that had been feared by his mother, his colleagues and the company's occupational health officer.

"All these fears were made known to the company."

Epilepsy Action deputy chief executive Rebekah Smith said: "We were extremely saddened to hear about Matthew Gunn's death, who passed away after having a seizure at his place of work.

"What was even more distressing, was finding out that his death could have been prevented.

"Epilepsy is different for everyone, and so are the risks it poses, in the workplace and in every day life. But all people with epilepsy deserve the right to be able to work safely without worrying if appropriate risk assessments have taken place.

"Employers need to do better to protect their employees with epilepsy. This always starts with better awareness. We have reached out to Morrison's to start a conversation about this. We hope they'll listen."

Fighting

During National Epilepsy Week, Epilepsy Action focused on working to end the public's fear around epilepsy and seizures

Fears



During National Epilepsy Week 2024 (May 20-26), we called on the public to move past their fears surrounding epilepsy. We asked people, instead, to learn about the condition and find out how they could help.

A new report by Epilepsy Action, released for National Epilepsy Week, has found that a lot of the public are still “fearful” of epilepsy and seizures. The charity says this fear could leave people with epilepsy in “total isolation”.

The data showed that 87% of people with epilepsy reported having mental health issues linked to their condition. Almost a third (29%) said they have faced negative attitudes towards their condition, which affected their mental health.

Meanwhile, a quarter of people in the UK (23%) said they would be scared to be in a room with someone with epilepsy “in case they had a seizure”. A further 24% said this would make them “uncomfortable”.

Almost one in five (18%) people admitted they would be likely to walk past if they saw a person having a seizure. One in 10 (10%) said their first reaction to seeing someone having a seizure would be to laugh.

Fear and public stigma further impact the mental wellbeing of people with epilepsy, which is already affected by their diagnosis and the disruption it brings to their lives.

An epilepsy diagnosis can affect people’s work or education opportunities, their ability to drive, and independence. A huge 69% of people with the condition said the biggest impact on their mental health is caused by a lack of independence.

Not just this, but exactly half of respondents with epilepsy report feelings of isolation, which shows how feeling misunderstood can push people with epilepsy to loneliness. In some cases, people even withdraw from society.

Fear can be the immediate reaction of someone who isn’t prepared to deal with a seizure, or has no knowledge of epilepsy. Epilepsy Action’s data confirm this, with two fifths (43%) admitting they don’t know much about the condition.

Rebekah Smith, deputy chief executive at Epilepsy Action, said: “Fear is an understandable human reaction to something out of our comfort zone. But that doesn’t mean we shouldn’t challenge that fear.

“ Make people with epilepsy feel that they’re not ‘something to be scared of’

“When it comes to epilepsy, we want the public to understand that the fear they may feel around the condition, or the prospect of seeing a seizure, has very real consequences for people who have it.

“They already face major changes in their life after diagnosis. They have to adjust to a lifelong condition that can affect their work opportunities, their ability to drive and their independence.

“All of these aspects already impact their mental wellbeing, often making them feel lonely, misunderstood and anxious. But feeling as though people are ‘scared’ to be in a room with them ‘in case’ they have a seizure can push people with epilepsy into total isolation.

“People with epilepsy have told us the most important thing we can do to help them feel less alone and improve their mental health is change the attitudes of the public. Get them to learn about epilepsy, and how they can help.

“This is why, in National Epilepsy Week, we asked the public to take a small step towards people with epilepsy: look past that initial barrier, and learn what they could do to help instead – to make people with epilepsy feel that they’re not ‘something to be scared of’.”

For more information about mental health and epilepsy, or if you want to direct someone to information about epilepsy, seizures or first aid, visit epilepsy.org.uk/scared.



Scan the QR code to read the National Epilepsy Week report

The week’s highlights

BBC Radio 5 Live presenter Steve Crossman and Epilepsy Action deputy chief executive Rebekah Smith were on BBC Breakfast raising awareness about the impact of epilepsy on mental health. They were also joined by Professor Tony Marson, consultant neurologist from The Walton Centre in Liverpool. On the airwaves



Radio fans were in luck for the week, as life with epilepsy and its challenges were discussed across a whole host of radio stations. Rebekah and a number of our story champions were interviewed on local BBC Radio stations including London, Leeds, Manchester and Sheffield.

Step by step

A huge number of you laced up your trainers and took to the great outdoors to take part in our Virtual 10k, donning your Epilepsy Action T-shirts and raising vital funds and awareness of the condition. More on this on page 5.

Andy’s story

We also shared Andy’s story. Andy spoke about how his epilepsy affected his mental health and his family. Read his full story overleaf.





Andy

I was *lost*

Andy's mental health plummeted after he was diagnosed with epilepsy, but Epilepsy Action was there to offer the help and support he really needed

Andy's life was going really well, he was enjoying his job, spent lots of time with his wife and children and was running every day.

Until everything stopped.

Andy experienced the same life-changing moment many other people have felt when they have their first seizure.

He awoke to find a team of paramedics in his bedroom. He was terrified, worried

that something had happened to one of his children. But it was Andy, he'd had a seizure in the night.

From then on, life changed forever. Andy stopped exercising after this, he couldn't get his head around what it all meant. Andy was like so many of the 29,000 diagnosed with epilepsy every year: without answers.

Then, Andy had another seizure. This time in the playground when he was

waiting to pick up his eight-year-old son, Reeve.

Andy was unable to talk. Eventually, he and his wife came home. He was in the living room when he noticed his father-in-law staring at him. Next thing he knew, he was being helped up the stairs.

He'd hit his head on the worktop following a serious tonic-clonic seizure but he had no idea what had just happened.

After several months of tests, Andy was

diagnosed with epilepsy, he was given some medication and sent home. That was it, no advice, no referrals. Nothing.

He was left scared, confused and without support – something that is sadly all too common within the epilepsy community. Andy, like so many others, had no resources, no real knowledge, and no idea what epilepsy would mean for his future and his family's.

Like so many others living with epilepsy, Andy's mental health started to decline. He was another one of the 87% who say epilepsy has affected their mental health.

Then Andy became one of the 50% who felt lonely or isolated due to the toll epilepsy was taking. His independence was taken away, and he was fearful.

Andy says: "I was kind of lost, and afraid, I didn't know what epilepsy meant. "It was a lot of unknown, I didn't know what to expect."

Andy didn't want to talk about it, he worried he'd become a burden.

He adds: "It's probably just the way I'm wired. I never really talked about mental health as there's always that stigma especially around men. You're just expected to get on with it.

"I read someone else's story of how they found it useful talking to others about their experience of living with epilepsy.

"So, that night, I broke down with my wife, and told her how I was feeling, why I'd been quiet. I felt like a burden and had to rely on someone, which took away my independence."

Luckily, Andy reached out to Epilepsy Action, where he discovered he was not alone. He joined a Talk and Support group and found a new community.

Andy says: "I was unsure about attending the Talk and Support groups. I'm not really a talker and I think that comes from my upbringing.

"I booked myself onto one and started attending some calls. I was surprised



Andy and son Reeve

at how common it was, people being diagnosed and then let go with no support.

"I didn't want to put my camera on, I wasn't even sure I was going to talk. Listening to stories from other people really helped. I attended more of them, then started to fully engage."

Andy is now doing a lot better, he has found the new normal. He and his family understand what epilepsy means and it's no longer in control of his life.

This was only possible because of the support Andy received. It was lucky that Epilepsy Action found him.

But Andy is just one person, out of the 630,000 living with epilepsy in the UK right now. There are many more people in his position. They've just been diagnosed, they're scared, confused, with no support.

They've just been given some life-changing news and they're on their own. No one deserves that. With Epilepsy Action's help, they don't have to feel this way.

Epilepsy Action's Talk and Support groups help so many people impacted by epilepsy, but it's not enough.

That's why it's time to act now, and help find others like Andy. Every donation given to Epilepsy Action means more Talk and Support groups, more calls answered by the helpline, more befrienders to offer one-to-one support.

It means more people are found, and more people are saved. It's time to help the 29,000 people who will be diagnosed this year and get them to the new normal, like Andy.

If every one of our faithful members were able to give at least £10 to this urgent appeal, then Epilepsy Action would be able to take those critical funds and



Andy and his family

“ I felt like a burden and had to rely on someone

help so many more like Andy! Will you do that today and help others like Andy?

"Now I'm in a much better place because of the support and I feel I can provide that support to others too," Andy says.

"Epilepsy Action has helped me hugely. My understanding of epilepsy and my mental health has improved as I've gone through this journey with them.

"Anybody thinking of donating money for any reason, I think it's a charity well worth considering.

"Thank you Epilepsy Action for being there for me, you've helped me and my family so much."

To find out how you can donate and support people like Andy, visit [finding-andy-member-appeal.raiselysite.com](https://www.epilepsy.org.uk/finding-andy-member-appeal)





Immense sense of pride

Sophie ran the London Marathon in April this year in under four hours – an achievement made even more impressive by the situation she found herself in only a year before...

“I was out for a run and I remember feeling a bit odd, and then I woke up with a stranger calling an ambulance,” recalls 30-year-old Sophie Morgan.

“I had badly cut the back of my head and so I needed quite a few stitches.

“Exactly a week after that, I had another seizure while I was alone, and I was found unconscious, unable to breathe and ingesting vomit.”

Sophie is one of the 53,000 runners who completed this year’s London Marathon in

April. But only a year earlier, she was in a very serious condition.

“Technically, the first tonic-clonic seizure I ever had was when I was 17 and on a school trip in London”, she explains.

“I can remember walking into a hotel lobby and suddenly feeling a bit odd. The next thing I knew, I was in an ambulance.

“I remember aching for days after because of how my muscles had tensed up.”

At the time, doctors told Sophie this was probably just a one-off. But in March last year, her seizures returned and left her

unconscious and struggling to breathe.

“The paramedics were very concerned about my ability to breathe unassisted, and so when I got to A&E, I was put in an induced coma.

“This was in part because I was a 6 on the Glasgow Coma Scale, which meant my consciousness was extremely impaired. But also, the vomit had gone into my lungs and the doctors needed to scrape it out.”

Sophie was brought out of the coma the next day. “I can only describe my last memory as a ‘curtains closed’ moment. I went from functioning normally to

complete darkness, to suddenly waking up in intensive care.

“I was absolutely terrified about what had happened.”

A complete shock

Even though this had been “a complete shock” to Sophie, this wasn’t her first run-in with epilepsy. Her sister Steph had been diagnosed with the condition years ago, when Sophie was really young.

“I only remember being told what to do if she had a seizure. I remember her struggling for a number of years to get on the right medication and she never quite got to the one-year mark before having a seizure again.”

Luckily now Steph has been seizure-free for “a long time”, which Sophie calls “a blessing” and “a mental load off my parents”.

“She can now drive, which gives her so much freedom to ferry around my nephew to various hobbies.”

Despite Steph having the condition, Sophie said she never thought she might also have epilepsy.

“It definitely took a long time to process, as I’ve had to readjust to quite a new life. My medication makes me incredibly tired, so I have to prioritise sleep and not over-commit to social plans.

“I found adjusting back to normal life hard. I spent quite a while feeling very scared of something happening to me while I was alone.”

While Steph and Sophie were dealing with seizures, a scary new diagnosis and trying to find the right treatment, Epilepsy Action was a source of support.

“The charity provides a wealth of information, which has been so helpful for me to use to communicate what epilepsy means for me and how it affects my life.

“When I was diagnosed, I discovered that I’d been having absence seizures for a while, but had always thought they were just funny episodes possibly caused by sugar lows or being tired.

“It was incredibly hard to describe what they felt like, and I found Epilepsy Action’s

information really helpful. It conveyed exactly what I experienced.

“In those early days, it also helped put all the practical support in place in case I had another seizure. Things like getting a fall monitor and having a key safe so that anyone could access my flat in an emergency.”

The most popular event on the planet

Sophie now lives in South-East London. Despite retaining “a strong West Yorkshire accent and mindset”, and enjoying chatting to reticent Londoners when out and about, one thing she prefers to do alone is run.

“I’m definitely not a ‘social runner’ – I enjoy stepping out on a solo run with my headphones in, so that I can forget about the world for a bit.

“I was an absolute couch potato up to the age of about 19. But then, I found that running gave me the opportunity to find some headspace that I struggle to get in other areas of life.

“When I’ve finished a run, I feel like I’ve worked things out that I otherwise wouldn’t have.”

Sophie ran the marathon in an impressive 3:54 hours, raising more than £2,500 for Epilepsy Action. Thinking back to the atmosphere of this world-famous event, she said: “It’s hard to put into words what running the London Marathon is like. They call it the most popular event on the planet for good reason.

“At the start line, there was a real buzz of nervous energy as we waited to set off. Once you get further into the marathon, and the grind gets harder, it is entirely true that the crowds are what gets you through.

“The cheers from strangers, the music blaring out of speakers, the offers of orange segments – the kindness and motivation from people you’ve never met is something really special to experience.

“From mile 20 onwards, I was just

ticking off each mile to mentally get myself through it. So, when I saw the finish line, it almost came as a bit of a surprise. It wasn’t until a beaming volunteer put the medal around my neck that it really felt real.

“It’s a very overwhelming experience to work so hard for something for so many months and then for it to be over, so it took quite a while to sink in.”

But for Sophie’s mum, Lorraine, it took no time at all to appreciate her immense accomplishment, made all the more impressive remembering where she was in March 2023.

“A year ago she was in an induced coma after [a] massive seizure,” she wrote in a post on X. “Smashed it in 3hrs 54 mins.”

Sophie added: “I’ve relived that finish line moment many times in my head now, and just feel an immense sense of pride at the achievement and all the money I raised for Epilepsy Action.”

You can support Sophie at justgiving.com/page/sophie-morgan-1700924301408

A team of 55 runners took part in the London Marathon for Epilepsy Action this year, raising over £111,500. If you are feeling inspired to take part in the London Marathon, Epilepsy Action has a limited number of charity places available and are currently taking applications. Scan the QR code or visit: epilepsy.org.uk/londonmarathon



Scan the QR code to apply for the London Marathon

“I spent quite a while feeling very scared of something happening to me while I was alone”



Sophie with her sister Steph and nephew Leo



What's new?



We share some recent advances in epilepsy research

New research has focused on climate change, novel epilepsy surgery techniques and links between sleep problems and late-onset epilepsy. Find out more below.



Laser therapy to be rolled out in England from June

Laser beam therapy for patients with focal epilepsy will be made available in England on the NHS from June.

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

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

The fibre optic laser therapy targets the

part of the brain causing seizures without the need for invasive surgery.

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

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

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

Epilepsy Action's health improvement and research manager Tom Shillito, and

a volunteer for the charity, were involved in choosing which epilepsy centres would offer the surgery – ensuring the patient voice was heard in the decision-making process.

Laura Diable, 39, from Birkenhead, was one of the first patients with epilepsy to have LITT at The Walton Centre.

She said: "Since having the procedure nearly a year ago, I've not had one seizure. It's made a huge difference to my quality of life.

"Before, the seizures were incapacitating me, leaving black spots in my memory. Thanks to LITT I've been able to get on with my life and worry less about my epilepsy – I can't thank the team at The Walton Centre enough."

Epilepsy Action deputy chief executive Rebekah Smith spoke to BBC Radio 4 about the surgery (from 18 minutes in), which she described as a "massive alternative to open brain surgery".

In a statement, Smith said: "This new therapy is an exciting ray of hope for people with focal epilepsy whose lives are being impacted by the harsh reality of uncontrolled seizures.

"Research shows that 7 in 10 people respond well to conventional epilepsy medication, which means many continue to face challenges in all areas of life, from education to employment. We also know that many people have tried several epilepsy medications without success, with no other alternative treatments likely to control their seizures."





Sleep apnoea linked to late-onset epilepsy

Sleep apnoea and low oxygen levels during sleep are linked to late-onset epilepsy, says a US study.

The researchers wanted to understand the relationship between sleep problems and late-onset epilepsy, building on previous small studies.

The team used sleep characteristics data on over 1,300 participants from the Sleep Heart Health Study. They also used Medicare claims to find those who developed late-onset epilepsy.

The results showed that people whose oxygen saturation fell below 80% during sleep were at a three-times greater risk of developing late-onset epilepsy. Normal oxygen saturation levels in humans should be between 96-100%.

Participants who subsequently reported a diagnosis of sleep apnoea between 2011-13 were also at a two-times higher risk of developing late-onset epilepsy.

The researchers said that these risk factors were independent of other comorbidities, like high blood pressure.

Dr Christopher Carosella, assistant professor of Neurology at Johns Hopkins University, led the study. He said finding a reversible cause for epilepsy is an “aspirational goal for epilepsy researchers or clinicians”.

The study was published in September 2023 in the journal Sleep.



Neurological conditions leading cause of illness

The number of people living with, and dying from, neurological conditions has increased globally by 18% in the last 30 years,



according to research published in The Lancet Neurology.

The research included conditions such as epilepsy, stroke, dementia, migraines and nervous system cancers.

According to the study, in 2021 3.4 billion people worldwide had a neurological condition – the leading cause of illness worldwide.

The paper, titled: Global, regional, and national burden of disorders affecting the nervous system, 1990–2021: a systematic analysis for the Global Burden of Disease Study 2021, was published on March 14, 2024.

The authors concluded that effective prevention, treatment and rehabilitation strategies for neurological disorders were needed.

The study’s lead author, Dr Jaimie Steinmetz, from the Institute for Health Metrics and Evaluation (a global health research organisation based at the University of Washington in Seattle), told PA News: “We hope that our findings can help policymakers more comprehensively understand the impact of neurological conditions on both adults and children to inform more targeted interventions in individual countries, as well as guide ongoing awareness and advocacy efforts around the world.”

According to The Neurological Alliance, one in six people in the UK lives with a neurological condition.

Epilepsy Action’s deputy chief executive Rebekah Smith said: “These findings highlight the urgent need for epilepsy and other neurological conditions to be prioritised by government and the department of health and social care.

“All too often we have seen that epilepsy has been left behind, as seen when neither epilepsy, nor other neurological conditions, were included in the government’s Major Conditions Strategy.”

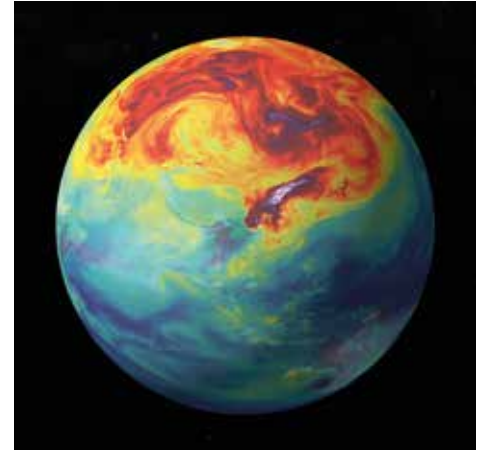
Epilepsy Action is a member of The Neurological Alliance, which is a coalition of more than 90 organisations that support people with these conditions.



Climate change harms epilepsy and mental health

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

In a Point of View article in the journal The Lancet Neurology, study author Prof



Sanjay Sisodiya and colleagues said that human-caused climate change is affecting people’s health worldwide.

The study investigated 332 pieces of research from 1968-2023 looking at climate change and various health conditions. These included neurological conditions, such as epilepsy, dementia and stroke, and psychological conditions, including depression, anxiety and schizophrenia.

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

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

The research found that in epilepsy, events like infections, temperature extremes and impaired sleep can worsen seizures.

Temperature extremes and fluctuations also worsened mental health conditions, alongside extreme weather events like storms, flooding or wildfires.

Other conditions mentioned in the research include meningitis, multiple sclerosis and migraines.

The study authors said that data were sparse and often too broad to draw any further conclusions. They added that there is “a pressing need” for more research.



To keep up to date with the latest research news, scan the QR code



Benji and the birds

Photo by Emilu Blodgett

Clair Chapwell shares how an online writing group, started during lockdown, and her lived epilepsy experiences led to her new novel, *Benji and the Birds*. Words by Grace Wood.

Author, theatre maker and actor Clair Chapwell didn't want to write about her epilepsy, but then a mentor asked her outright: 'Why aren't you writing about epilepsy?'

"I said: 'I don't want to do that.' And she said: 'Why?'," says Clair.

"She said: 'There's a whole book about epilepsy.' And I said: 'Well, no. I don't want to write it.' I was very anxious about it and I couldn't figure it out."

Clair was diagnosed with epilepsy aged 14. At the time her parents told her to keep it a secret.

"When I went to university my father said: 'If anyone finds out they'll kick you out,' which was ridiculous and not true," she says. "I never told anyone, but I never thought of myself as different."

Eventually epilepsy found its way into Clair's book for children age 9-12.

"Bella is the main girl character," she says. "And I thought: 'Well maybe I'll just try.'"

In the novel Bella has epilepsy and there are descriptions of her seizures and the impact they have had on her life and independence.

"I thought: 'I'll give Bella an overprotective mother.' Who will only let Bella do anything if the mother is with her or if her sister is with her, which makes her think she can't do very much – even though her epilepsy is not very bad.

"So, during the course of the adventure story, set in Suffolk, she's pretty much trapped in this tree house that her grandfather built. And it's got an open side to it, and the birds fly in – because she

loves birds. She says: 'I trust birds more than people' and then she meets Benji [the male lead] and she gets involved in the adventure, and she gets more and more confident."

During the story, Bella's confidence grows and her fears subside.

"She just gets so brave through the course of the book," says Clair. "You watch her, and you're on her side. I've had kids read it, and I say: 'If I did another book, who would you want that one to be about?' And they say 'Bella' – every single one! By the end of the books, she really grows up. She is so bright and brave and strong. And she's got a real flair with birds. They come to her and she's good with them. So, that's the story of Bella in *Benji and the Birds*."

Benji and the Birds came about during the Covid lockdowns. Clair had worked in theatre all her life – writing shows with teenagers and older people. She started the feminist theatre company Spare Tyre in the 1970s and wrote theatre and songs about self-image and weight. *Benji and the Birds* was the first time she had written prose.

"When Covid happened, obviously no theatre was happening," says Clair. "So,

I was asked to facilitate a writing group on Zoom. I invited actors, singers, friends and the group is still going four years later. Every week I give them a theme and ask them to write a page.

“I also write a page. Sometimes I think: ‘I really like this character.’ That’s how I started writing about Benji and Bella. They appeared in one of my stories. I thought, ‘I like them. I like to hear more about these kids.’ So, I just started writing their stories.”

Inevitably, Clair’s own epilepsy experiences led into her writing of Bella. While her parents were not so strict, and she never ‘felt different’, it did affect her early teenage years.

“I was 14, watching TV, when I had my first seizure,” she says.

“But, like so many people, you don’t really know what’s happening – you just wake up with a headache. My sister and I were in bunkbeds and she said to me afterwards: ‘Don’t ever do that again’. I had no idea what she was talking about. I went to the doctor the next day with my grandmother and my mother, and I was still out of it, and they were talking away, and I had no idea what they were saying.

“At the time, in the 1960s, they gave me an EEG – they were horrible things because the needles went in and then you had all crusty bits on your head for days and you couldn’t really comb your hair. They kept trying random pills and they made me very sleepy. The medication has got much better. Then nothing happened for a while.

“When I was about 16, I had another seizure. I went away to university and I had loads because I was being a bit crazy – because that’s what you do. Then I moved over here [the UK] from the states and



I got even crazier. I had lots of seizures but I sort of lived with it. I decided there were so many things I couldn’t do for a living – I would get sacked from most jobs – and because it was a really good time for political theatre, I started a women’s theatre company.

“I never got sacked for having epilepsy there. I ended up doing work like that. I performed for a while – started writing songs, started writing plays. I’ve had a really lucky life.”

Clair says epilepsy probably led to her unconventional life. Her parents were teachers and her sister became one too. She suspects that had she not had seizures, she would also have been a teacher.

“That was the natural place for me. And when I’ve done teaching and run workshops, I’m very comfortable. I thought: ‘I’ll never be a teacher because it will be too pressurised and I’ll have seizures, so there’s no point in even trying.’

“Because it was the 1970s, and you could get cheap or free housing and also there was quite a lot of money around for creative work. I was really lucky.”

More recently, now that she’s “quite ancient”, Clair has begun attending Epilepsy Action’s Talk and Support groups in North London.

“There’s a place near me in North Finchley and they are just great.

“The thing is about epilepsy, there are so many different shades – you don’t know what it looks like.

“If you’re sitting in a group of breast cancer survivors, you have a lot of: ‘What did you take? Did you have chemo? Did you have radiotherapy? Did you have to have a mastectomy? Who was your specialist?’ So you know, exactly. If you have epilepsy... I walked into the room with these people, and we were nothing like each other.

“They told their stories and I was in shock. I was astonished at the kind of things people said. One woman said: ‘I have a little card, and when I get auras I sit down with my card in front of me saying: I’m not collecting, I’m just possibly having a seizure so don’t worry.’

“People with epilepsy are so brave. It’s not like heart disease and cancer. Those are high-profile conditions and somehow socially acceptable; everyone knows people who are affected. Epilepsy is a weird one, it’s not visible so people don’t support you in the same way. People are frightened of it, don’t get it, don’t want



Photo by Emily Blodgett

to know about it and it’s hard for us to explain what’s going on for us.

“Going to the Finchley session has been wonderful. I’ve heard stories there that have made me want to cry for the people involved – the things parents have done to them, society has done to them, jobs they’ve lost, and people who have shouted at them. And the lack of understanding and the lack of knowledge is tragic.”

Bella, Benji and Clair are doing their part to fight the stigma that affected Clair and the other members of her Talk and Support group. The book goes into detail about seizures, the after effects and how they don’t have to mean an end to adventures.

At one point in the story, Bella has a series of absence seizures and Benji doesn’t know what to do. Bella also experiences tonic-clonics during the book. During one absence seizure, rather than being alienated by her friends, they gather around her – much like Clair’s experience of the Talk and Support group.

“Bella has a seizure and then everybody in the friendship group gets around her,” says Clair, “which is what penguins do. When one of the penguins is ill they get around each other, giving support.”

Benji and the Birds is a novel for nine to 12 year olds. Clair is hoping to see it published soon. But it’s hard. “Apparently only 1 out of 6000 authors can get an agent,” says Clair. “A lot of them are saying they’re looking for ‘underrepresented communities’, but who’s underrepresented if not the epilepsy community?”

For more information, email: cchapwell@gmail.com



Breath of fresh air

Vicky took a chance on Epilepsy Action's Befriending scheme when she was really struggling, and found understanding and information

“I love cycling,” Vicky says. “I’ve still got a bike in the office and I used to go along the canal at lunchtime. I live in beautiful countryside here, and it was a lovely way to keep fit.”

Vicky, 49, lives in Bromsgrove in Worcestershire with her partner Mark, their dog Boycie, and Mark's daughter Amelie, who stays over every other weekend. Despite their beautiful surroundings, one

of Vicky's favourite pastimes has suddenly become a big source of anxiety.

Last May, she had a seizure while out cycling. “I had just come off the main road, and I felt a bit odd. I remember thinking ‘I’ve got to get off my bike’ and then I can’t remember anything else.

“I fell off my bike and split my leg open. It required stitches and months of physiotherapy.”

Before this happened, Vicky was a

very keen cyclist – to the point that she owned three bikes. “One’s at work and I’ve got two bikes at home as well.” But this accident left her with a diagnosis of epilepsy and possible post-traumatic stress disorder (PTSD), bringing an abrupt stop to her hobby.

“I have flashbacks and I can’t go back on my bike because I’m petrified. When I see a cyclist turn, I get really anxious.

“My partner said a few weeks ago: ‘Shall we sell these bikes?’ because I don’t even want to look at them. I just can’t envisage going out cycling again. It just turns my stomach thinking about it.

“When I saw my neurologist last, he said he thinks that there could be some PTSD. So, I’m waiting now to be referred to psychology.”

A recent diagnosis

Vicky works as a legal manager in a law firm. Her first two seizures happened Christmas 2022, while she was on her lunch break at work. During her first seizure, she banged her head, and during her second, she split her head open. “I had to have it stapled.” Her last tonic-clonic seizure happened just over a year ago.

Thinking back over the last year-and-a-half, Vicky says: “It’s been a bit of a horrible time really.” She has navigated tonic-clonic seizures, injuries, a diagnosis of epilepsy, medication side effects (“really bad stomach upset, feeling dizzy and sickness”) and a possible mental health condition, all of which have taken their toll.

“I was only diagnosed last April, so it’s quite a recent diagnosis really,” she explains. “Since then, my life has just turned upside down.

“I sold my car. I had to surrender my driving licence. I don’t go on isolated walks anymore. I wouldn’t go on my own, I’d be too scared. I used to love walking along the canal. But I wouldn’t do that now because I just feel quite anxious about it all, being on my own in an isolated area where something could happen.”

Hard to accept

Faced with long wait times, Vicky has paid to see a neurologist privately, and expects she might have to do the same to see a psychologist for her PTSD. She says she didn’t know anything about epilepsy when she was diagnosed, to the point where she thought it must be a mistake.

“When my neurologist said: ‘You’ve got epilepsy’, I said: ‘Sorry?’

“I think I was just shocked. I said: ‘I think I need a test to determine that’, and he just said: ‘No, you don’t. You’ve had two major seizures in public places, we’ve got evidence. This is the diagnosis.’”

Along with her recent tonic-clonic seizures, Vicky had a history of other neurological problems, such as temporary sight loss, disorientation and headaches for a number of years. All of this also helped to inform the diagnosis.

“When Mark and I came out of the room, I said: ‘I think he’s definitely got this wrong.’”

“Ironically, I work in medical negligence, and I keep thinking he’s misdiagnosed me.

“But I look back at his card, at his correspondence, and he did set out everything in detail as to why he’s come to this conclusion. And I have confidence in him, but I just keep thinking: ‘Have you got it wrong?’ And that’s me not being able to accept it. And, to be honest, I don’t think I’ve still really accepted it yet.”

Not on my own

Having a hard time coming to terms with her epilepsy is one challenge that Vicky is facing. But along with that has come a feeling of isolation. With all of this going on, her GP sent her in the direction of Epilepsy Action.

“My GP sent me a link to Epilepsy Action, because I was really struggling, and said: ‘You might want to get in touch because they can offer you things that we can’t.’”

“I looked into it, I saw that there was the befriending service and I thought: ‘I’ll give it a go and just see what happens.’”

Vicky was paired up with a volunteer called Gary.

“At first I was very cautious and unsure about it because I was in a bit of a negative frame of mind.

“After the first session, I thought it was quite nice to have a chat with somebody who is in the same situation.

“I was getting along with him and I was thinking that it was quite nice, being able to talk to him. Especially because he was having weekly seizures, and I thought, ‘I don’t feel so isolated now, after speaking to him and hearing his story.’”

“I was thinking, ‘I don’t feel like I’m on my own with this now’.”

Unfortunately, Gary had to withdraw for his own health reasons. Vicky was then paired with Peter. Feeling apprehensive about the change in volunteers at first, Vicky said that Peter had been like a



“breath of fresh air”. She described both as “totally different people” but considered it serendipitous that she got the opportunity to meet and speak to both. “I got a lot from both of them in different ways,” she said.

Continuing the befriending service with Peter, Vicky said: “We didn’t always talk about the condition, but most of the conversation related back to it, but in a way that didn’t feel pressurised.

“Peter was brilliant and he really listened. I could tell, because we could be talking for a while about my weekend or something, and he would always relate it something we talked about before.”

After finishing her befriending sessions, Vicky said she is much more aware of the resources available to her and her husband Mark. Mark has been looking into groups for carers, and Vicky has got a Disabled Persons Railcard. And, importantly, she has been able to start breaking down the feeling of isolation.

“Before I had a befriender, I didn’t know anybody at all with this condition. I remember my partner saying to me: ‘I wish you would get engaged in this process, because I just can’t share in some of your thoughts, and I don’t know where to go with it myself. I don’t understand where you’re coming from with some of this stuff.’”

“Just to listen to Gary and Peter’s stories made me think: ‘Well, you know what? I’m not on my own here.’”

“Since I had conversations with them, I’ve made my neighbours aware of my condition. I thought, if I have another accident, people need to know.”

Befriending service

You can find out more about befriending and register your interest in the service

“After the first session, I thought it was quite nice to have a chat with somebody who is in the same situation”

by visiting the Epilepsy Action website: epilepsy.org.uk/befriending

The service involves a weekly 30-minute call with a befriending volunteer for three months, providing a friendly listening ear and helping you build confidence and social connections.

If you’re feeling a bit nervous – you’re not alone. “I was a bit reluctant at first,” Vicky says, “and I thought, ‘this probably won’t be for me’, but I’m really glad I did it. Go into it without any expectations, but just try the journey, and you’ll be glad you started it.”

Vicky’s experience has helped her to continue to come to terms with her epilepsy. While she isn’t ready to get back on her bike, she is still managing to enjoy the great outdoors.

“I love walking with my dog, Boycie. I spend a lot of time with the dog. Because I’m home quite a lot, we completely redid the garden – I love the garden.”



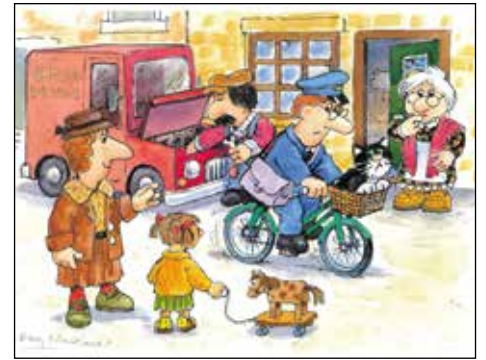
To find out more about taking part in the befriending service or becoming a befriender, visit epilepsy.org.uk/befriending or scan the QR code



Olivia Colman



Joe Lycett



Ray Mutimer



Axel Scheffler



Gabriella LaBucci



Actor Paddy Holland

Going once,
going twice...

Your favourite celebrities have been putting pen to paper for National Doodle Day 2024. This September, we will auction off original artwork from the likes of actor Olivia Colman and comedian Joe Lycett.

Friday 27th September sees the return of National Doodle Day – Epilepsy Action’s annual fundraising auction, filled with hundreds of original artworks from all your favourite artists, illustrators and celebrities! This year, we will be celebrating the 20th anniversary of this campaign – and YOU can help make this our best ever!

We have already had pieces from the likes of Academy Award winner Olivia Colman, Dame Joanna Lumley and Heartstopper author & illustrator Alice Oseman that will be available to bid on between Friday 20th – Sunday 29th September on eBay.

Eurovision runner-up Sam Ryder, Traitors favourite Diane Carson and TV and theatre actor Anton Lesser (Game of Thrones) are also among this year’s

fantastic doodlers, alongside a host of brilliant children’s book illustrators.

Singer-songwriter Teya, who is best known for representing Austria at the Eurovision Song Contest 2023 in Liverpool, is excited to be doodling again this year after her Edgar Allan Poe-inspired piece became one of the highest selling items in last year’s auction. She said: "My brother and friend both got diagnosed with epilepsy a couple of years ago. It’s a scary thing to go through for everybody involved. That’s why I am incredibly grateful that there is a platform that spreads awareness and raises funds for epilepsy. When National Doodle Day reached out it was a no-brainer for me. I am very honored to be a small part of it this year."

Make sure to follow NationalDoodleDay on Instagram, to keep up to date with



Joanna Lumley



Illustrator Andy Catling



Sam Ryder



Alice Oseman



David Bradley



It's Just L



Traitors star Diane Carson

all the exciting announcements we'll be making, and to see the latest artworks that will be included in the auction this September.

If you're an artist or illustrator that would like to create an artwork for this year's auction, we would love that! Send us an email with your best postal address to doodle@epilepsy.org.uk, and we can get a pack sent out to you.

Get your school doodling!

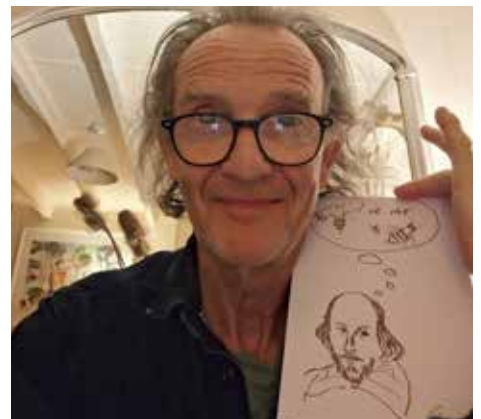
That this year we want to get students all across the country raising awareness for epilepsy while getting creative for this

year's National Doodle Day!

Whether you're wanting to hold your own National Doodle Day auction, or have something super fun and creative in mind, if you want to get your school, college or university involved with all the fun this year, make sure to email Michael at doodle@epilepsy.org.uk for more information.



Scan the QR code to follow National Doodle Day on Instagram for all the latest doodles!



Anton Lesser



Enzo *explains*

Children's author Marielle is using her experience of epilepsy to bring neurons to life in her new book. Words by Grace Wood

“The way I see neurons is that they know what you're going to do before you do,” says children's author Marielle Bayliss.

“So the minute I touch a hot radiator there will be a little first sensory neuron that's going to send a message to my brain and go: ‘Oh, that's hot.’ And then my brain is going to send another neuron

back, probably an interneuron. He's going to go back to the first sensory neuron and say: ‘Yeah, no, that's going to hurt. We need to move our finger away from the heat.’ So, to me, these neurons are like, in my head, they're like the reporters, they're on the beat.”

Marielle writes children's books. Her first book, *Frog's Bog*, was about doorstep nature. But this project, *The Neurons on Epilepsy*, is part of a six-book series covering neurodiversity for 3-5 year olds. The first in the series, *The Neurons on Epilepsy*, is about what happens in our brains to make them different.

“It started off as Enzo explains epilepsy. It's kind of morphed into something else now,” she says.

The Neurons on Epilepsy is a series of books about neuro-divergencies, starting with epilepsy, but also including topics such as autism. At the moment Marielle has written about Enzo, a neuron inside a brain, explaining epilepsy.

“I saw Enzo as this neuron that's almost like electricity,” she says.

Although it's for children, and will feature illustrations and jokes, "The Neurons on Epilepsy is definitely factual," says Marielle.

"But, I hope, with a dose of whimsy in there," she adds. "The neurons themselves are entertaining and there's going to be lots of different characters who will focus on different things – hopefully funny and engaging for children.

"So, before you scratch your bum, guess what? They know you're going to be scratching your bum. I loved the idea that perhaps they loved gossip, that they had to be at the front, that they had serious FOMO. So in my head, all these neurons, they're just waiting for the next story. They can't wait to spread the news. They're fun, they're involved, they can't keep their noses out."

When Marielle was diagnosed with epilepsy aged 15 she had no idea what it was. And neither, really, did her parents.

"Even before my first book came out, I knew I wanted to write something about epilepsy from my own experience," she says. "I was diagnosed at age 15, and back then – that's a good 32 years ago now – I was literally given a really dry pamphlet. That was it.

"I didn't research. I didn't look into it. And then as I got older, I thought: 'I want to write about this and I want to make it engaging, and I want it to be fun for kids. I don't want it to just be dry.' That's when I started to research it. And, honestly, it was when I was in my early 40s that I discovered all this stuff that I didn't know."

Marielle's research "opened up the whole neurodiverse universe" she says. And, in her 40s, she began to understand more about the condition she'd had nearly her whole life.

"And the more research I did and the more I discovered, it just seemed to me that there was so much to talk about within epilepsy," she says.

"It's been great discovering all about neurons and the central nervous system. It's just this bizarre, amazing universe going on inside of us. I find it fascinating.

"So when I'm overwhelmed, when I'm tired. You know, it's the same with neurons, we're following on from what's happening to them. I found it fascinating and I love research. I'm a bit of a geek – give me any subject and I love to research it.

Marielle's research into her own condition became the inspiration for *The Neurons on Epilepsy*.

"That's when the idea of the neurons having their own characters and the reader being told the story through the point of view of a neuron came about, rather than an adult or somebody telling them. I wanted it to be: it's part of you, it's a part of your system."

Her experience of seizures left her with many questions: what is happening to me? How do I explain to my friends? To my teachers? To my parents? If a trip to the local library had been able to answer some of those questions, life would have been easier for the family and Marielle might have had an earlier diagnosis.

"It took a few years to get diagnosed. I think I was about 11-12 when I first started having absences," she says. "But I didn't know how to communicate it. I didn't know how to say: 'This really weird thing happened. I was sat on a wall and my friend was there. And then the next second she'd somehow time leapt and she was over there.' I remember that was the first time it happened. I didn't understand what had happened.

"How do you explain? I thought I'd just seen time travel or something. I did not know what had happened at all. I remember in my exams as well, weird auras and things. And I just didn't know.

"To be able to read something that might explain an aura or an absent seizure, it definitely would have helped. I had not come into contact with that at all and neither had my friends, and my parents definitely didn't know anything about that."

It was when Marielle began having tonic-clonic seizures that her parents became concerned.

"In the end, I remember talking to my mum. I was having really vivid dreams where I was getting up at night and there was all sorts going on. That went on for a while, and then it wasn't until my parents were there when I had a tonic-clonic seizure.

"It wasn't until I was about 15 that we started going to the doctor and then everything started to make sense. But honestly, nobody used the words epilepsy. Nobody. I think my parents just thought I had a very vivid imagination."

As life progressed, Marielle's epilepsy took a back seat. With medication she had her seizures under control. Aged 18, she went to drama school and then began a career as an actress.

"Theatre was my first love, but I always wrote," she says. "I would write and then I would have all this work that was just sitting there. I always assumed the first time I showed someone something

“I was diagnosed at age 15, and back then - that's a good 32 years ago now - I was literally given a really dry pamphlet That was it.”



it would be a play because I worked in theatre and I did write plays but never showed anyone.”

Then, aged 41 – with one young daughter already – she became pregnant with twins.

“I couldn’t go back to work because childcare for twins is just phenomenal and I just thought: ‘What do I want to do?’ And I just applied myself.”

Frog’s Bog was Marielle’s first children’s book. It came from a simple writing exercise and a passion for doorstep nature.

“I sent that to publishers when I was 43 and then when I turned 45 I had my first book published,” she says.

“I’ve loved it and I’ve never looked back. Honestly the amount of lovely writers, illustrators, people in the publishing world that are so open and lovely. It’s just been really refreshing.”

It wasn’t just Marielle’s career that changed with motherhood. Her first pregnancy aged 34 affected her epilepsy and now, in her 40s with three children, she’s beginning to feel the effects of further hormonal shifts.

“I think it was in my mid-20s – obviously with medical advice – that I gradually came off the medication. I was fine as long as I got plenty of rest, no stress. And then, when I was pregnant with my eldest daughter I had a tonic-clonic seizure during the labour, which was not good. After I had my daughter, I went back on the medication.

“It’s been a funny one for me because it sort of seemed to have come and gone in my life. Now I’ve come off medication again to have children later on in life. And again, we did it all with medical advice.

“But now that I’m 46, and there are hormonal changes again, I think at some point I’ll probably be going back on the medication because I can feel the shift again. It’s kind of interesting for me that I didn’t just go on medication and stay. I’ve come through these waves where I’ve needed it and then when I haven’t.”

It’s a story many women with epilepsy will relate to. But the experience is different for everyone. It’s for this



reason, Marielle says, that it’s important epilepsy stories are told by people with first-hand experience of the condition.

“It must be so difficult for someone who doesn’t have epilepsy to write about it,” she says.

“Yeah, they could explain what happens, but I don’t know how authentic it would be. And I think that’s what publishers, perhaps, I hope, are looking for now. They’re looking for a more authentic experience of these things.

“I understand lots of people want to write about it and we should be discussing it. But it needs to come from writers and illustrators who have the conditions, rather than people telling them what these conditions are. And I think publishers are starting to realise that now. They’re opening the door for more authentic experiences and voices rather than well-meaning people telling other people about it. Yes, people are open to the idea of neurodiversity but epilepsy is very niche. And that’s been the difference.”

While working on *The Neurons on Epilepsy*, Marielle has also been working on a sequel to *Frog’s Bog: Frog in a Fog*.

“It was really nice to write two completely different books,” she says. “It’s almost like having a break.

“We’ve got *Frog in a Fog* coming out in September. We’re literally at the stage now where I’ve kind of done all my bits and I get to step back a bit.

“When you do one thing and then you work on something else, it’s fun as well.”

The next step for *The Neurons on Epilepsy* is to bring the characters to life through illustrations.

The illustrator, Kellyanne Thorne, is pulling together

some images of Enzo and his friends.

“It’s been a really fun process,” says Marielle, “because I basically got to tell Kelly about the characters and then she went away, because who knows what a neuron looks like?”

“You can look up these very technical images online, but I didn’t know if she was going to come back and make them look like animals or people. Were they going to look like little humans? But she’s really cleverly looked at each type: so an interneuron looks a bit different than a first sensory neuron, there’s these wonderful spiral ganglion neurons and they deal with sound and they’re all really long limbed. So you instantly thinking: ‘OK, they deal with sound. They’re long limbed, maybe they’re always dancing!’

“So she has taken inspiration from what they look like. And then she’s gone another level. I think it’s been really fun for her.”

It was Kelly who encouraged Marielle to develop *The Neurons on Epilepsy* beyond epilepsy into autism and other neurological conditions.

“Number two will be autism because Kelly’s son has autism,” she says. “And we’ve started doing lots of research on that as well. So she’s done a lot of research and that’s going to be our next stage when we do the next set of books. So it’s a passion project for me. It’s most definitely a passion project for her as well.”

Marielle’s whole family have got involved with the books, with her eldest daughter getting involved in the creative process behind the illustrations, and her twins also giving their feedback – “kids are so honest. You get away with nothing with kids” – but ultimately it’s for the next little Marielle with epilepsy. So that when she goes to her local library, a friendly spiral ganglion or interneuron can answer her questions and remove the fear of the unknown.

The Neurons on Epilepsy (working title) is due for publication in February 2025.



Smartwatch apps that can detect seizure type movements and falls, raise alarms, and provide help and support to keep users safe



Reliance Technology Care Solutions is proud to be partnering with My Medic Watch to provide innovative smartwatch apps that can detect movement associated with seizures and general falls. Users can set up key contacts who are notified when the smartwatch detects an incident or when the user raises the alarm themselves. If a contact does not respond, then support is only seconds away with our 24/7/365 in-house monitoring centre and we can escalate all alarms through the emergency services if required.*

My Medic Watch 

Download now – Search for My Medic Watch



*Reliance Technology Care Solutions monitoring service and website is coming soon

Did you know that another way of supporting Epilepsy Action is to leave a gift in your will?

Even 1% left would make a huge difference to people's lives.

For more information visit epilepsy.org.uk/legacy



Epilepsy Action Lottery

Play today for £1!

Our weekly lottery gives you the chance to win £25,000 while supporting the work we do to help everyone impacted by epilepsy. As well as the chance to win big, 50p of every £1 allows us to continue our vital work.

There is a 1 in 63 chance of winning a prize.
Entries cost just £1 and are drawn every Friday.

For more information and to play go to epilepsy.org.uk/lottery or call Jenny on 0113 210 8822.

Players must be 18 years or over. The promoter of this Unity Lottery is Epilepsy Action, New Anstey House, Gate Way Drive, Yeadon, Leeds, LS19 7XY. Epilepsy Action's weekly lottery is managed by Unity Lottery (Sterling Management Centre Ltd) and regulated in Great Britain by The Gambling Commission under account number 5195.

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Forever grateful

Thomas has received the March Epilepsy Star award, nominated by his partner Katie for being her “life saver”. Words by Rebecca Lock

Thomas Daws has been given this month’s Epilepsy Star award. He was nominated by his partner Katie, who discovered she had epilepsy after going into hospital about an ear infection. Katie’s epilepsy journey has had many ups and downs – including relearning how to speak – but Thomas’ ongoing support has made “a world of difference”. Katie shares their story.

“I was diagnosed with temporal lobe focal epilepsy in the summer of 2016. This came a few months after an MRI scan for an ear infection revealed I had an atrioventricular malformation (AVM) in my left temporal lobe. The diagnosis came as a bit of a surprise, and it was a huge learning curve. I’d only ever heard of tonic-clonic seizures and I didn’t even know focal seizures were a thing, despite having them on a daily basis.

“My seizures involve me experiencing déjà vu before spacing out and experiencing hallucinations, where I think I can see things but can never recall what they are. I often also have right hand and head tremors with them.

“Since my diagnosis, it has been quite a journey. It started with trialling what felt like dozens of different anti-seizure medicines, which sadly didn’t work in my favour. The next step led to a year of tests, both medical and intelligence, to determine whether I could undergo brain surgery to have the AVM removed.



Unfortunately, the AVM was found to be partially based in my hippocampus, so brain surgery went out the window. The only option left to me was Gamma Knife radiosurgery (GKR) in Sheffield.

“I finally underwent GKR in September 2022, primarily to remove the greater risk of stroke that AVMs bring, but also with the hope that it may reduce my seizures. Currently, the AVM has decreased in size, and all is seemingly improving. I’ve gone from having around three to four seizures a day at diagnosis in 2016, and at least two per week prior to GKR, to having no seizures in the last two months!”

Katie’s epilepsy diagnosis impacted her “whole way of life” and her study and career plans were all affected.

“The moment I had my diagnosis, my whole way of life and plans for the future changed. I was due to go to university to study veterinary medicine but was declined entry on disclosure of my epilepsy diagnosis. Finding my dream career still continues to be a challenge, with the inability to drive hindering most opportunities for me. After a few years of solo travelling, and later obtaining a master’s degree in biological sciences, I have pushed on into the world of work. I have brilliant support from my colleagues who encourage me in all aspects of my current role as a data consultant, which makes it all worth it.

“Tom and I met through online dating (thank you Bumble) toward the end of

2019 and had our first date in Stratford-upon-Avon where we talked for hours on end. I believe I had it on my profile that I had epilepsy because, by this point, I was quite open about my diagnosis and had come to terms with it, so would quite happily discuss it with anyone who asked. Then, thanks to COVID-19, I moved in with Tom on 26 March 2020 (Purple Day!) and never left!

“Every day I can count on Tom to make me laugh, be a shoulder to cry on, be someone to talk to about everything going on, big or small, practice karate (which Tom introduced me to) or just sit in silence while we enjoy a good movie or TV show. He is always checking in on me. Even when he is at work I get: ‘How are you doing today?’ messages. Additionally, on days where I am not doing so well - whether from having a seizure or being absolutely conked out by medication fatigue - he asks me what I’d like for lunch or dinner before heading to the kitchen to put it together for me.

“Since having Tom in my life, his support has made a world of difference. He has been by my side through so many appointments, my GKR treatment and has helped me view my epilepsy diagnosis in a different light: not as a negative entity but as something I can live an amazing life with. He constantly reminds me that while there are some limitations, there are no boundaries, so if I want to achieve something, such as my degree, I can.

“With all the challenges I have faced - whether it be constant fatigue, memory loss, social anxiety or seizure anxiety to name a few - I have always made sure to surround myself with those I love. Family, friends, my partner Tom, and our rescue greyhound, have all supported me on my journey, and are there for me when I am struggling, because they all know how to reassure me. I have also found solace in basic breathing techniques and journaling, which I learnt from many hours of therapy, to help centre myself and reduce any heavy stresses.”

In August 2023, Katie began to have more seizures and, later that year discovered she had a swelling of the brain.

“I unexpectedly started to experience more seizures and daily migraines. This continued through to October, despite going to A&E multiple times with Tom to query it and instead being turned away and told to increase my medicine dosage and take time off work. On 7 October 2023 we had just returned from walking

our dog and my head felt as though it was on fire. It later progressed into a seizure that I didn’t come around from. Instead of calling the emergency services, who would take me to the local hospital, Tom carried my unresponsive body into his car and drove me straight to the hospital where my neurologist is based. He stayed by my bedside while they ran all the necessary tests and found the culprit behind all that had been going on over the last few months: an acute cerebral oedema (a swelling of the brain).

“After being discharged, my family looked after me and Tom worked close to home to ensure he could get to me should I worsen. The incident also left me unable to talk due to trauma and he, alongside NHS speech therapists and my family, helped me relearn to speak. Tom also ensured I was taking my huge list of new medication. He cooked wonderful meals to make sure I was eating well, drove me everywhere for appointments, and cared for our dog and cat.

“On top of all of this, Tom was coming toward the end of the second year of his radiography apprenticeship, so not only did he juggle multiple assignments and tests but he also took on the care of me - something I will forever be grateful for.”

In her thanks to Tom, who she is now engaged to, Katie said: “Thank you for being my best friend, partner and life saver. You have always been there for me and what you went through for me at the end of last year just shows how incredible of a person you are. I am one lucky girl and I love you to the stars and beyond.”

Accepting the award, Tom said: “It was a lovely surprise to be told I’d won this

award. I wasn’t aware I’d been nominated and I think it’s a wonderful way to share our story. I’ve been enjoying reading previous winners’ entries since learning about the award.

“Working in radiology in a hospital, I had come across patients with epilepsy, but even so my knowledge of what it’s like to live with epilepsy was very limited. Since meeting Katie I have learnt so much about her condition and what living with epilepsy means to her. I’ve learnt about the different medications she has been on, all the side effects that come with those, and that even after many years her condition can change quickly and needs to be adapted to.

“I am always so proud of Katie. She is a constant inspiration to me. When going through some of the scariest moments medically, such as when she lost her voice after a large seizure, Katie always stayed positive and could keep a smile on her face. Katie and others living with epilepsy are the real stars in my opinion.”



For more information about the Star Awards, or to nominate someone, visit epilepsy.org.uk/stars

“I am always so proud of Katie. She is a constant inspiration to me”



Council of management

At a meeting of the Council of Management held on 9 April, the following decisions were made.

- Approval of the 2023 trustees' report and 2023 year end accounts.
- Approval of the 2023 Audit Findings Report and agreement to sign the Auditor's letter of representation.
- Approval of a resolution to nominate Baroness Ford for re-election as President of the Association at the Annual General Meeting on 18 June 2024.
- Approval of a resolution to nominate Saffery LLP as auditor to the Association at the Annual General Meeting on 18 June 2024.
- Approval of a resolution to close the register of Association members from 19 May to 18 June 2024 for the duration of the Council elections.
- Appointment of Rachel Rankmore as a member of the charity's National Advisory Council for Wales.
- Approval of a new more regular reporting system to Council on EDI.
- Approval of the Fundraising Delivery and Monitoring Plan 2024.
- Approval of a role description for a Council safeguarding lead.
- Completion of the quarterly review of the corporate risk register.
- Received and noted a report from the Officers of Council on the 2024 Council members' personal appraisal.
- Decision to hold a Council members' away day on 7 October 2024.

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.

Shaping the charity's future together

If Epilepsy Action's recent Let's Talk about Mental Health survey showed us one thing, it is that the charity is needed now more than ever. With more than 600,000 people currently living with epilepsy and a further 29,000 people being diagnosed with the condition every year, the task of supporting those in need is huge. That is why we have gone bigger and bolder with our new strategy **A World Without Limits for People with Epilepsy** so we can reach more and more people, like Andy (who you can read about earlier in this edition). Our

ambitions below were informed by you, our members, on what to focus our efforts on.

- **By 2030 everyone in the UK who has epilepsy will be able to say that life has improved because of the things we are achieving together.**
- **By 2030 everyone in the UK will understand what epilepsy is and how they can support people who live with epilepsy.**
- **By 2030 we will be fully inclusive in who we are and who we support.**

With costs rising for us to achieve these ambitions, we need to increase our income. That is why our membership fees will be increasing slightly from £24 to £27 or from £12 to £15 for reduced rate members. Our professional memberships will also increase to £72. All members will have direct confirmation of this when their renewals approach.

We continue to thank you for your support, and we look forward to sharing the impact we're collectively having on people's lives in future editions.

Epilepsy support for you

For some of us, epilepsy can be an isolating condition which can make us feel lonely and misunderstood. But there are actually many people in the UK and around the world with the condition. One of Epilepsy Action's roles is bringing people together to share their knowledge and experiences and talk to others going through similar situations.

Join one of our virtual groups

We know many of you take comfort from connecting with others affected by epilepsy. We have face-to-face group meetings as well as online meetings using video calls instead (technical support is available). If this is of interest, you can find out more at epilepsy.org.uk/virtual-groups or by calling 0113 210 8800.

If you previously went to a local support group, they may also be offering a chance to get together online. You can find out if this applies to the group you attended by emailing Iso@epilepsy.org.uk or calling 0113 210 8899.

Online resources

There are many ways to be part of Epilepsy Action's online epilepsy community. You can find us on:

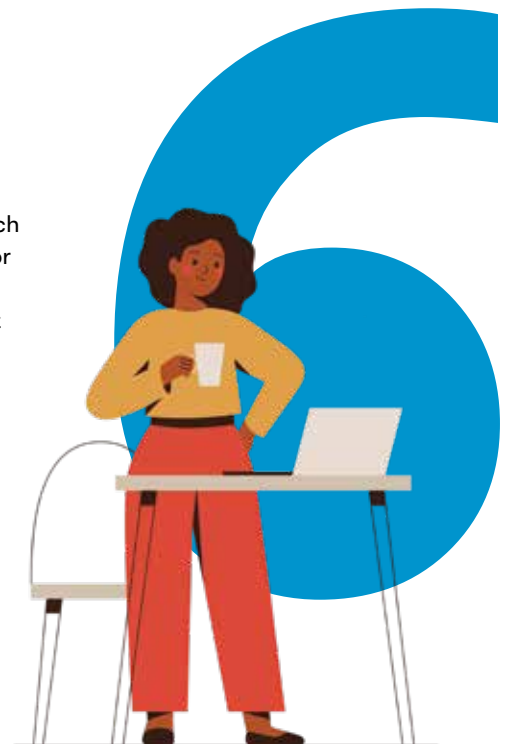
- HealthUnlocked (healthunlocked.com/epilepsyaction)
- Discord, (bit.ly/3vHLOkT)
- Facebook (facebook.com/epilepsyaction)
- Twitter ([@epilepsyaction](https://twitter.com/epilepsyaction))
- Instagram (bit.ly/3zSKMVM)

There are also a number of websites which can help people find pen pals, such as penpalworld.com, or ablehere.com for people with disabilities and conditions. Bear in mind that these websites are not part of or run by Epilepsy Action.

“One of Epilepsy Action's roles is bringing people together to share their knowledge and experiences”



For more information scan the QR code



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Epilepsy Action has revised its privacy statement (September 2022) to better reflect its activities and use of data. Please go to epilepsy.org.uk/about/our-privacy-statement to access it.



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

“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 epilepsy.org.uk

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