

# Epilepsy

Today

Research updates

PAGE 16

Help for Holly

PAGE 18

Doodle Day

PAGE 22

## ALSO IN THIS ISSUE...

Runners raise thousands  
at Bradford 10k **p4**

HSBC and Zoom develop  
safety feature **p6**

Grandfather wins  
Epilepsy Star Award **p26**



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Doodle Day  
p22



## Inside

### Good news

**4** Bradford 10k, HSBC and Zoom develop safety feature, football team fundraises

### Around the UK

**7** Updates from groups and events in England, Wales and Northern Ireland

### News

**8** Specialist staff shortage, Epilepsy12 update, father develops safety harness, Welsh Senedd debates healthcare

### What are we up to?

**13** Updates from Epilepsy Action

### Epilepsy Week

**14** Public first aid campaign launched

### Research news

**16** CBD study in Argentina, stem cell research, algae coatings developed for brain implants in Glasgow

### Obituaries

**27** Remembering nurse Ena Bingham and volunteer Pauline Spencer

### Gavin and the Laas

**28** Gavin Sillar talks about the song he wrote to cope with his diagnosis

### Drug update

**29** Professor Martin Brodie looks at the drug Cenobamate

### Council news

**30** Minutes and election results from the Council of Management

Meet Holly  
p18



My Journal  
p24



Star Awards  
p26



## A fresh start

Welcome to your new look Epilepsy Today magazine.

For many people, the end of the summer leads to a season of opportunities but also responsibilities: the end of holidays means back to school and back to work. But, with beginnings come chances to get to know new people (like our cover star Holly who was paired up with volunteer Lisha in our Befriending scheme, p18), develop fresh ideas (such as those discovered by scientists and researchers, p16), and experience new hobbies (perhaps doodling, like our Doodle Day donators on p22). We hope autumn will bring chances to start something different.

As you can see, we've given the magazine a spruce. You will notice there are some extra features – such as QR codes, which you can scan with your phone to read more online – and a greater focus on what your membership fees are paying for with our community pages. If you have any notes on our new design or ideas for content you would like to see in future, please drop me an email at [gwood@epilepsy.org.uk](mailto:gwood@epilepsy.org.uk).

And on a personal note, keen-eyed readers may have spotted a new face at the end of this column. Our usual editor Kami has started a new project of her own: a baby! And so for the next year I will be covering her and trying to keep you informed and entertained.



Grace Wood  
Editor

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

## On your marks: Bradford 10k 2023

**O**n May 28, almost 1,000 people took to the streets of Bradford for the annual Epilepsy Action 10k.

At 9am, 996 people set off from the iconic City Park, raising more than £42,000 for Epilepsy Action.

Epilepsy Action's director of health improvement and influencing Alison Fuller said: "It filled me with pride and joy to see the first runner come through. The sea of faces was fabulous, with each person having a story to tell about how epilepsy has impacted their lives."

Among the runners was Holly Wild, pictured right. The 2023 Bradford 10k was Holly's first race, but it was not her first experience of the event. In previous years she has volunteered with St John Ambulance.

She said: "I've been thinking about running it for a few years but I was scared of making a fool of myself and being too slow. But then I thought, what have I got to lose? And I get to raise awareness and money for a cause that has impacted my life."

Now 20, Holly was diagnosed with epilepsy at 17 but believes she may have been having seizures since she was six.

"I started having 'fainting spells' and was told I was 'daydreaming' when I was six years old. I was referred to a cardiologist but nothing showed up on the tests," she said.

"When I first had a tonic-clonic seizure, I was sent to hospital and had EEGs and an MRI done. It was then that I was diagnosed with epilepsy after years of

thinking I was fainting and daydreaming with no physiological reason."

Bradford 10k race director Louise McCormick said: "We're so grateful for Holly's support of the Epilepsy Action Bradford 10k in the past and it's fantastic that she took part in this year's race."

The Bradford run began in 2008, and since then the event has raised more than £600,000 for the charity, with more than 17,000 runners crossing the finish line.

Another of the runners on the day was Anna Warrington, who was running for her daughter Sophia.

Anna said: "I started running a number of years ago and I did the Couch to 5k with my local running club. I progressed from 5k and completed the Bradford 10k in 2019. The atmosphere at the finish line was great and it was even better to know I did it for Epilepsy Action. I've hardly run in the last year, but I was determined to complete the 10k again this year."

Six-year-old Sophia had her first seizure when she was just five weeks old.

"She was asleep in the front room and I was in the kitchen when I heard an odd cry," said Anna.

"When I went to check on her, she looked pale and something didn't seem right, but I wasn't sure what it was. I now know that she'd already had the tonic part of a seizure. We took her to hospital but we were discharged shortly after.

"The following day, Sophia was in the sling on my front and suddenly went totally solid and held her breath. I thought she was choking and was going to die. We went back to the hospital and this time



Holly Wild at  
Bradford 10k

she was admitted. Things soon escalated and the seizures came thick and fast."

Anna says Sophia is making good progress and makes her proud each day.

"Her determination to do and achieve new things is admirable. Watching Sophia progress makes me want to be the strongest person I can be for her," Anna said.

The funds raised from Bradford 10k allow Epilepsy Action to support people with epilepsy, such as Holly and Sophia, as well as parents such as Anna.

Epilepsy Action would like to thank everyone who took part, thanks to you we are able to keep vital services and support available to people who are impacted by epilepsy.

# Volunteers' Awards announced

**As part of celebrations for Volunteers' Week 2023, which ran from June 1-7, Epilepsy Action announced the winners of its volunteer awards.**

Epilepsy Action's volunteer programme manager Kathryn Hughes said: "We celebrated our amazing volunteers who have a massive impact on enabling people to live better with epilepsy. Every one of them makes a difference and we are thankful for all their contributions."

This year the award winners included Kerry-Ann Smith, who won the Volunteer Superstar award. Kerry-Ann leads the Lowestoft Talk and Support Group, she is a befriender and has recently joined the Action Team. Kerry-Ann won the award for her enthusiasm, positivity and commitment to her volunteering. This year she stepped up to provide cover for an additional Talk and Support group and was one of the first volunteers to join the Befriending scheme.

Kerry-Ann said: "If anyone asks me about volunteering, I tell them how much of an amazing experience it is to be able to support others."

The New Starter awards were given to Chris Palmer-Nash and Natasha Miles.

Chris is a befriending volunteer and Natasha is helping to set up a Talk and Support group in Liverpool, which she will be running alongside another volunteer. Chris and Natasha completed their volunteer training and have shown positivity and enthusiasm.

The Digital Champion award went to Bec Shaw. Bec has embraced technology, helping her to not only run the Truro Talk and Support Group, but also one of our virtual Talk and Support groups.

The Positive Participant winners were Lisha Howen (see p16) and Daniel Bedeau. Kathryn said "Lisha and Dan's positivity has shone brightly in their volunteering. Both Lisha and Dan are always keen to be as involved as possible and have taken part in various events and volunteering roles, from attending our Let's Talk About Epilepsy events, to Befriending and supporting our runners at this year's London Marathon."

Louise Kirkup and Maureen Roy won the Resilient Rebounder awards. Both Louise and Maureen have overcome challenges in their volunteering or personal lives. Kathryn said they were resilient and remained positive,



**Bec Shaw**

**Dan Bedeau**

always asking whenever they needed support.

Maureen said: "Volunteering has been so rewarding for me. I always enjoy meeting people and listening to their stories."

Kathryn said: "We appreciate all our volunteers regardless of what role they have or how much time they have to give. We are doing more to ensure we recognise their contributions all year round. We would love more people to join us."



**For more about volunteering go to: [www.epilepsy.org.uk/volunteer](http://www.epilepsy.org.uk/volunteer) or scan the QR code**

## Football team raise hundreds following manager's seizure

**When Jonathan Buckley had a seizure on June 3 he didn't expect the reaction he received from his football team, Ashby Sands.**

Jonathan was diagnosed with epilepsy 16 years ago. Since then, he's only had five tonic-clonic seizures, but as he was walking his dog one Saturday morning, he had his sixth.

"I left my house to walk my dog at 5.30am and then I collapsed. I started walking to my mum and dad's house thinking I lived there. I've not lived there for 20 years! I managed to get home and my wife, who's a nurse, took me down to A&E," said Jonathan.

At the hospital he had a CT scan and thankfully everything was all right, but he had injured his eye and face. The next few days were a blur – but two weeks later he had one of the most memorable days of his life.

Jonathan is the manager of Ashby Sands football club, which is for men who have been affected by baby loss.

"Everyone in the Sands squad has been through a child or baby loss so we come together as a group of lads to talk about baby loss.

"They know I'm a member of Epilepsy Action, I've known a couple of players in our team all my life. We had

a game at the weekend and we were all planning to meet at half nine, but when I arrived they were all there in Epilepsy Action T-shirts waiting for me. They had ordered 20 T-shirts unknown to me.

"They made me captain even though I didn't play because I'm past that age now! So, I went down and kicked off the game."

The team also held a raffle and together they raised £735 for Epilepsy Action.

"I've been in floods of tears all day of what they have done for me," said Jonathan.

*Continues on p12*

# HSBC and Zoom develop epilepsy safety feature

**Z**oom and HSBC have developed an accessibility feature that stops users from viewing potentially seizure-triggering content.

The feature became available earlier this month and has been launched globally. All users can now go into their settings and select 'Dim Screen Share Video'.

Employee Joanne Austin raised concerns with HSBC during the pandemic following an increased use of Zoom.

She said there were two instances when colleagues shared content that included flashing patterns over Zoom and she narrowly avoided having seizures.

Joanne was first diagnosed with epilepsy 22 years ago. She has spent her career working for banks, and for the past six years she has worked for HSBC where she is compliance assurance manager.

She said: "I often have to protect myself from digital technologies that can trigger my epilepsy. During the pandemic, you had to use digital video communications such as Zoom, Microsoft Teams or Google Meet to do your job. Everyone was doing quizzes via Zoom to introduce some fun into all the seriousness of what was happening.

"On one of these calls a colleague shared a game that had moving pictures. That's one of my triggers. Out of nowhere,

that set me off – unlike the auras or a funny taste in the mouth that others have to warn them, I don't get any warning. The wrong moving images come up on the screen and I end up on the floor."

Although Joanne doesn't have photosensitive epilepsy, she finds repeating image patterns can be a trigger – especially if she is tired or unwell.

"In the past, I've thought: 'This is my condition – I've got to get on with it'. But then a month or so later I was asked to review some marketing and the patterns in that work set me off too."

Luckily, Joanne's husband was able to turn off the screen before a seizure began. She decided something had to be done, fearing there might be other people suffering in silence.

"Even in disability and accessibility circles, people with epilepsy tend to get forgotten. I thought: 'This isn't just me now – we need to sort this.' I am aware that, as I have clusters and have previously been in status epilepticus with my seizures, not taking action could put me or someone else in hospital or worse."

HSBC's accessibility team got to work.

"They immediately jumped into action to prevent these things happening again. They got settings changed in my browser to turn off images automatically on websites. They gave me software to work around my condition. They reviewed all

the HSBC screen savers and got rid of all those that could trigger seizures and migraines," said Joanne.

Then HSBC contacted Zoom to see what it could do. The two companies developed a safety mechanism to recognise flashing images, which are turned off and the screen is dimmed. HSBC's accessibility team tested the function to make sure it would work at home and in the office.

Joanne said: "Zoom is now accessible and safe for others with epilepsy. I'm so proud that me and my employer had a hand in making this happen. By speaking up for change that benefits all."

**"Zoom is now accessible and safe for others with epilepsy"**  
Joanne Austin



*Continued from p11*

"I've been playing football with the team for two years. We look after each other. We've got support groups for anybody who needs to talk about any issues or wants to confide."

Jonathan, who lives in Derbyshire, said it had been an emotional few weeks since his seizure, but that his friends, football team and work colleagues at the NHS have been great. He described his team's support as "absolutely staggering".

We're also pleased to say Ashby Sands won the game 3-2!

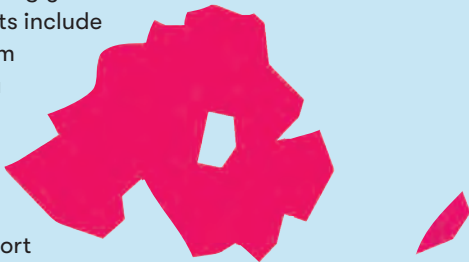


# What's happening *where* you are?

Members are integral to Epilepsy Action's work across the UK and Northern Ireland. Here we round up how you can get involved

## Northern Ireland

Epilepsy Action Northern Ireland celebrated National Carer's Week in June with a wellbeing session focusing on relaxation, mindfulness and meditation techniques. There was also a men and epilepsy wellbeing programme and events for families. At the southern area family fun event the sun shone, with one attendee saying: "Everyone involved had a lovely day, as a family we are very thankful and grateful for everything you have done." Future events include the Antrim Fun Farm Family event and a Living Well with epilepsy support programme in August. There are also Talk and Support groups in Fermanagh and Belfast as well as online.



## North of England

In the North of England there are Talk and Support groups in Leeds, Huddersfield, Sheffield, Tyneside, Teesside, Wigan and a North of England virtual group. In September runners will be taking part in the Great North Run to raise money for Epilepsy Action and earlier in the year runners took part in the Bradford 10k (more on p10). We are also looking for Talk and Support volunteers for the York group.

## Midlands

There are Talk and Support groups in Coventry, Leicester, Stoke on Trent and a Central England virtual group. In Ashby Sands, a local football team raised money for Epilepsy Action in support of their manager who had a seizure (more on p11).

## Wales

In Wales, Epilepsy Action hosted a family fun day at Welsh Mountain Zoo in Colwyn Bay. The event was for children with epilepsy aged up to 16 and their families. It was a great opportunity for parents and guardians to meet and share experiences with other parents and Epilepsy Specialist Nurses. The day included watching sea lions being fed, circus activities and a birds of prey display. One mother said: "Days like these make you realise you're not alone." Upcoming events with Epilepsy Action Cymru include Talk and Support groups in Aberystwyth, Caernarfon, Pembrokeshire and Swansea, as well as the virtual online group.

## South of England

Our group attendees in Exeter enjoyed taking part in a quiz at their meeting this month. At one of our face to face groups in the South of England, many people said that attending the meeting was the best thing in their lives. They explained that the people in the group understood the worries and difficulties of living with epilepsy, in a way that others couldn't.



To get involved  
go to: [epilepsy.org.uk](http://epilepsy.org.uk)  
or scan the QR code



# Epilepsy news

## Specialist staff shortage a ‘crisis’

**T**here is a significant lack of epilepsy specialists in the UK, a report by Epilepsy Action has found. Meanwhile the government’s latest NHS plan failed to mention epilepsy or neurology.

Epilepsy Action’s prevalence and incidence report described the situation as a “neurology workforce crisis”. It found there was one neurologist to every 868 people with epilepsy in the UK, and one epilepsy specialist nurse to every 1,397 people with epilepsy in the UK.

There are 721 full-time neurology consultants and 448 epilepsy specialist nurses (ESNs) in the UK, and 626,000 people with epilepsy.

There are currently 110,000 vacancies across the NHS. The government’s long-term workforce plan for the NHS (published June 30, 2023) failed to mention neurology and epilepsy or increasing pay for current staff.

Epilepsy Action’s director of health improvement and influencing Alison Fuller said: “It’s really concerning to see the low number of available healthcare professionals specialising in epilepsy across the UK. This is even more significant when there are areas across the country with a high incidence and prevalence of epilepsy but limited workforce resources.

“This disparity makes it harder to manage and support patients in line with NICE guidance. For example, anyone with a suspected first seizure should be seen by a specialist within two weeks, but with the workforce stretched so thin, it’s often not possible to stay within this target.”

The epilepsy prevalence and incidence report said there were 79 new epilepsy



diagnoses made each day, with 1 in every 107 people having epilepsy.

The research came from S Wigglesworth’s 2023 paper: ‘The incidence and prevalence of epilepsy in the United Kingdom 2013–2018: A retrospective cohort study of UK primary care data’, which is the most recent research conducted regarding epilepsy prevalence and incidence in the UK.

The research is based on GP electronic health record data, which was collected between January 1, 2013, and December 31, 2018, and is based on the electronic health records of 14 million patients, representing about 20% of the population.

The figures are particularly high in Northern Ireland, where there are only five epilepsy specialist neurologists and 14 epilepsy specialist nurses (ESNs), with a resulting ratio of one ESN to every 1,947 people with epilepsy.

Meanwhile, in Wales there are approximately 32,000 people with epilepsy and 22.5 ESNs and 12 epilepsy specialist neurologists. That’s one epilepsy specialist neurologist to every 2,996 people with epilepsy and one ESN to every 1,598 people with epilepsy.

In England, the highest concentration of neurologists was found in London, where the prevalence and incidence of epilepsy is lowest. The report says the opposite is also true – that the lowest concentration of neurologists is found in the North East, where the incidence and prevalence of epilepsy is highest.

Fuller said: “Way too often, people with epilepsy are faced with huge barriers in accessing routine care, because there simply are not enough professionals available. This situation can have serious consequences for patients: reduced quality of life, unplanned hospital admissions, even a higher risk of SUDEP (Sudden Unexpected Death in Epilepsy).

“Despite this massive shortage, the government is once again not taking epilepsy, or even neurology, into consideration within its strategy to address the current workforce issues.

“There is no mention of increasing staff pay, which is disappointing, as it has been a big issue for workforce retention. We will continue to call for neurology services to be awarded the staffing and funding they need, so that people with epilepsy can get the care they deserve now.”



# Children's care improved but inconsistent – Epilepsy12

**Epilepsy care for children has improved but remains inconsistent, according to the latest Epilepsy12 report.**

The study of paediatric epilepsy care showed wide regional variations, with the most deprived areas having the highest prevalence and incidence of epilepsy.

## According to the report:

- 99% of diagnoses among children were accurate.
- 91% of children received input from a paediatrician with expertise in the first year since diagnosis – an improvement of 2%. But only 21% were seen within two weeks of referral.
- 77% received input from an epilepsy specialist nurse – an improvement of 1%.
- 70% underwent an ECG.
- 79% had comprehensive care plans.
- 37% had individual healthcare plans in schools.

However, the percentage of children who received input from tertiary care providers, were referred for epilepsy surgery or had an MRI, decreased.

Director of health improvement and influencing Alison Fuller said: "It's fantastic to see a positive trend in many aspects

of epilepsy care for children and young people. However, the figures are also showing massive regional differences in provision, meaning there is still more to be done to achieve the right level of quality of care across the UK."

Established in 2009, the 'National Clinical Audit of Seizures and Epilepsies for Children and Young People (Epilepsy12)' focuses on holistic and equitable care, care in education and improvements in care. This is its fourth auditing round.

Fuller added: "It's vital that children with epilepsy have the support they need at school. While it's certainly positive that the number of pupils with epilepsy having a School Individual Healthcare Plan has increased, only two in five have one currently, when all of them should."

While epilepsy and mental health are commonly linked, the report said 80% were not being screened for mental health conditions and more than a third of trusts did not have referral pathways for depression, anxiety or mood disorders.

The report also showed an increase in the number of girls aged nine or over taking sodium valproate, which has been linked to risks in pregnancy, but only 86% had those risks explained to them.

No trusts reported speaking to 100% of children about Sudden Unexpected Death in Epilepsy (SUDEP). Overall, 56% of children or families had been warned about the risk of SUDEP.

The report echoed findings by Epilepsy Action (among others) earlier this year that the most deprived areas of the UK have the highest prevalence and incidence of epilepsy. In England and Wales, 28% of children and young people with epilepsy were living in the most deprived areas.

## The report recommends that:

- All children and young people with epilepsy should be supported holistically from a network of professionals.
- They should have appropriate access to care irrespective of age, sex, ethnicity, social deprivation status, learning disability, autism or geography.
- Health services should explore with education services ways to improve the number of children having effective ongoing health care plans.
- Coordinated reviews should be carried out to identify barriers, establish enablers and implement improvement plans for areas requiring improvement.

## Wearable brain scanner developed at Nottingham University

**A wearable brain scanner that can measure brain function while the patient is moving has been developed at the University of Nottingham.**

It is believed the scanner will improve epilepsy diagnosis, especially for children.

The first wearable brain scanner was developed in 2018, but researchers have now demonstrated that the system can be used while the patient is moving.

Epilepsy Action's health improvement and research manager Tom Shillito said: "This is an exciting advancement with the potential to improve epilepsy testing for many patients. MEG scans can be used in addition to EEG tests to obtain more detailed data about a patient's epilepsy, which can result in better treatment."

The technology uses optically pumped magnetometers (OPM) to measure magnetic fields in the brain – a technique called magnetoencephalography (MEG).

The 3D-printed helmet is lightweight, meaning the scan is more comfortable.

Patients can currently access MEG scans through the NHS, but the testing process doesn't allow them to stand or walk around. Cerca Magnetics is the commercial company that produces and sells the scanners. It is working towards gaining clinical approval.

Young Epilepsy's Health and Research Centre installed the first scanner in the UK. It believes the technology can be used for earlier epilepsy diagnosis, interventions and treatments for patients.



# NI patients missing ‘vital information’

**W**aiting list communication for patients in Northern Ireland is “incomplete, difficult to access and leaves them without vital information to manage and make decisions about their health,” a report from the Public Ombudsman has said.

Northern Ireland’s Public Ombudsman, Margaret Kelly, released the findings from her investigation into healthcare waiting list communications in June, stating that 88% of those on healthcare waiting lists feel forgotten.

In Northern Ireland 1 in 83 people have epilepsy. Epilepsy Action has heard from people who have been told they face a wait of four to five years for an

appointment. In this time they are often given little information.

The Ombudsman’s investigation, which draws evidence from trusts, the Department of Health, surveys to GPs and the public, found that significant and repeat failures amounted to “systematic maladministration”.

Such information included whether patients were on a waiting list, whether their cases were deemed as routine, urgent or red flag, expected wait times and who to contact if their circumstances changed.

This is despite guidance such as the Integrated Elective Access Protocol (IEAP), which contains directions on expected patient communication.

## Report recommendations

The report made a number of recommendations to improve the waiting list system, including:

- Revising the IEAP to include clear instructions on expected patient communication; accepted reasons for departures from guidance; and monitoring compliance.
  - A standard acknowledgement letter used by all health trusts. This should give patients information on clinical urgency, general wait times, what to expect and who to contact for further information.
  - An update for patients waiting more than six months.
  - An area on every trusts’ websites that contains waiting list information.
- Kelly also said she would continue to engage with the department and the trusts over the next 12 months to ensure progress is made with the implementation of the recommendations.

## View from Epilepsy Action

We welcome the Ombudsman’s recommendations and are calling for the Department of Health to ensure progress is made. It is vital that patients are given accurate information about when they will be seen by a neurologist.

We will continue to monitor the level of communication people with epilepsy experience while on waiting lists.



For more information visit: [bit.ly/3pX9xhs](https://bit.ly/3pX9xhs) or scan the QR code

# Health dept to miss wait list targets

**Northern Ireland’s Department of Health will not be able to meet its waiting list targets due to a lack of recurrent funding, it has said.**

It said even if the department received “new recurrent investment” it would not be possible to meet the targets, because

“the deficit between demand and capacity has been going on for too long and the waiting list backlog has been exacerbated by the impact of Covid”.

Northern Ireland has the longest waiting times for neurology appointments in the UK. It also has the highest prevalence of epilepsy in the UK.

The department’s objectives were set in 2021 and are supposed to be met by March 2026. They include:

- No one should wait more than 52 weeks for a first outpatient appointment and inpatient/day case treatment; or 26 weeks for a diagnostics appointment.

- The gap between demand and capacity for elective care will have been eradicated.

It said both targets were dependant on sustained funding.

Epilepsy Action policy and campaigns officer Jack Morgan said: “Urgent action needs to be taken to address waiting times. We are again repeating our call for political parties to break the current stalemate, restore power sharing and work together to address the problems facing people with epilepsy.”

The Elective Care Framework is a five-year plan to clear the backlog of patients awaiting hospital treatment and close the gap between capacity and demand.

# Family make safety aid from car harness

**A** father in Northern Ireland is raising awareness of a harness he developed to support his daughter who had drop falls (atonic seizures) as part of her epilepsy.

Dermod Ryder developed the harness from a car belt, and with support from Rik Fradgley of White Knight Wellbeing – an organisation that makes specialist equipment for disabled people – they created something Dermod’s daughter Katie could wear all day without injury.

Katie was born with a chromosomal abnormality, which led to her having autism and epilepsy. She would regularly have drop seizures that caused her injuries. Katie died in January 2021 following an epileptic seizure in her sleep.

Before Dermod developed the harness, Katie wore a helmet, which the family said caused concussion, rode forward, gave her black eyes and grazed her scalp.

Dermod said: “It started with a physio who gave us a handling belt, but it didn’t work well enough – so I had a brain wave.

“The harness we came up with was absolutely perfect. She never had contact with the ground once she started using it.”

He added: “We used to put it on her in the morning and she would wear it most of the day. If we were going out in the winter we took one of her coats and we cut a hole in the back, you stuck your hand in and held the harness at the back.”

But it wasn’t just the physical safety of the harness that improved Katie’s life. It also improved her confidence and wellbeing.

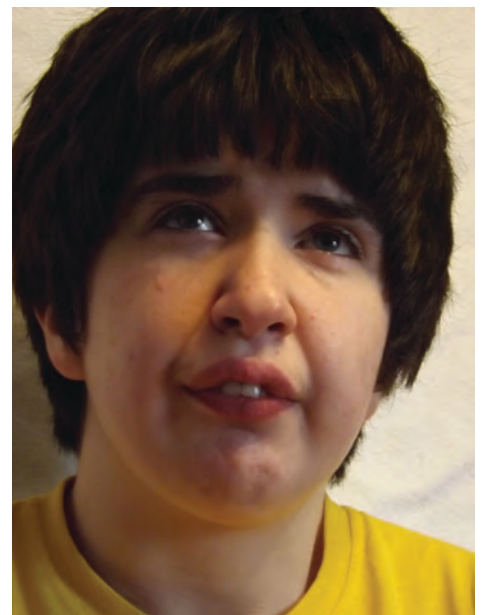
Dermod said: “When Katie wore the helmet her head was down and wasn’t enthusiastic, but a neighbour of ours said to me: ‘It’s the difference in her I notice. You used to walk her, and she would be hesitant, and her head would be down and not too keen. But now, head up, shoulders back and leading the way.’

“She was much happier with it. Our Katie was quite determined in her own way. If she didn’t like something she’d let you know. But she stood there every morning while I put it on and had a great time in it.”

Dermod said the harness had been used by carers of varying strengths.

“Savannah, Katie’s carer, was 5ft nothing. Some think: ‘Oh, it’s okay for Dermod he’s 6ft 4 and built like a brick dunny, we couldn’t possibly handle it.’

**“The harness we came up with was absolutely perfect. She never had contact with the ground once she started using it”**



But Savannah could and she was 5ft nothing,” he said.

Sarah McCann, who is an Epilepsy Action Northern Ireland council member, was Katie’s epilepsy specialist nurse, and worked with her for about 10 years. She said the harness was an improvement for Katie and the family.

“It definitely provided Katie with the support and stability she needed. And it actually changed her, there was more independence for her. She was able to get up and walk about safely,” she said.

Sarah said occupational health had tried a number of devices to support Katie, but nothing worked as well as the harness.

“We had to draw up protocols to do with the harness so that we could put it into the adult centre. In order for staff to be able to use it, we needed these protocols and procedures on how to use the harness to keep her safe,” she said.

Even after Katie died the trust continued to use the harness.

Sarah said: “In the nursing home that Katie was in [for respite] they have been using it for the last 18 months.”

Now, Sarah and Dermod would like to see other families benefit from safety aids.

Dermod said: “It was Sarah who opened my mind that it could have applications for other conditions, because all I did was make it for Katie. Katie’s legacy is to put it out there as best we can.”

Sarah added: “A team is going to be looking at all the research behind this harness. We would love for all the families that felt they could benefit from this to know that something was there for them.”



# Welsh Senedd debates ‘inadequate’ epilepsy care

**T**he Welsh Senedd has been urged to reduce waiting times for epilepsy services and improve staffing levels.

Luke Fletcher, member of the Senedd for South Wales West, brought the motion to the Senedd and it was passed without opposition.

Seven members of the Senedd spoke in favour of Luke Fletcher’s motion. They highlighted the lack of epilepsy specialist nurses across Wales, the difficulties people with epilepsy face accessing treatment due to under-resourcing and waiting times, and the prevalence of epilepsy in Wales.

The debated motions were:

- To support measures to reduce current waiting times for patients and service users accessing epilepsy services.
- To support health professionals in Wales, by ensuring the levels of staffing across the health boards of Wales are appropriately resourced to achieve and maintain sustainability, patient safety and quality of service.

Fletcher said: “In Cwm Taf Morgannwg University Health Board, it is estimated that five epilepsy specialist nurses are needed. There are currently zero. In Swansea Bay University Health Board, it is estimated that 11 are needed. There are, in actual fact, only four.”

He added: “I’d like to thank Epilepsy Action Cymru for consistently raising the concerns of those who live with epilepsy with myself and with other members.”

The motion was backed by members including Tom Giffard member for South Wales West, Mike Hedges, member for Swansea East, and Delyth Jewell, member for South Wales East and deputy leader of Plaid Cymru.

Giffard said: “NICE suggests that waiting times for routine epilepsy appointments should take no longer than a fortnight, but the reality is that not one health board in Wales is meeting that target.”

He added: “We’re spending just £21 per person on epilepsy research, compared to £97 for dementia and £234 for Parkinson’s disease.”



Jewell said: “It’s a sad reality that, in 2023, the provision of care for people living with epilepsy is inadequate.”

In response to the motion, health minister Eluned Morgan outlined some of the work the Welsh government had been doing, but also acknowledged the financial pressures the NHS is under.

She said: “I’ve noted the recommendation from this report of a ratio of 300 patients to one epilepsy specialist nurse, which would equate to a requirement for another 95 whole-time equivalent epilepsy specialist nurses in Wales. I’ve got to tell you we are in a time of financial difficulty.”

She added: “We know that the NHS is facing multiple challenges, and I don’t underestimate these. We’ve set out clear aims within the neurological conditions quality statement.

“It’s now the responsibility of the health boards to plan and deliver their services accordingly.”

Hedges spoke about his experience of epilepsy. He said: “Until my mother had a brain tumour, I had no personal experience of epilepsy. Her brain tumour led to epilepsy and it came as a shock to our family and to her.

“When it’s actually somebody who you know and love going through it, it brings it home. It certainly brought the problem of epilepsy into focus for me.”

**“It’s a sad reality that, in 2023, the provision of care for people living with epilepsy is inadequate”**

Closing the debate, Fletcher asked for a meeting with the Welsh health minister, which she agreed to. He said: “It’s welcome very much to hear the government will continue supporting epilepsy services.

“I would welcome the opportunity to meet with the minister after this debate. I appreciate that this is a really complex field of medicine, and the difficulty she will have in conveying everything in the time that she has in the chamber.”

Epilepsy Action’s senior policy and campaigns manager Daniel Jennings and Wales manager Jan Paterson were on the steps of the Welsh Senedd before the debate. They spoke to members about the motion and issues around epilepsy care.

The motion was based on Epilepsy Action’s Epilepsy Service in Wales report.



**For more information on the report go to: [bit.ly/47beR1p](https://bit.ly/47beR1p) or scan the QR code**



# What are *we* up to?

Your support helps us carry out so much vital work. Here are just some of the ways you've been helping us make a difference

**Epilepsy Action's aim is to improve the lives of people living with epilepsy – and that happens in a lot of different ways. We are here to support through our helpline, Talk and Support groups and other services. We are also here to campaign for a better, fairer world for people with epilepsy. Here are some of the things we've been up to:**



## Live Chat service

Epilepsy Action's Live Chat service, recently piloted by the helpline team, has become a permanent

offering following a successful launch last Autumn.

During the pilot, 96.4% of respondents said they were happy with the advice and information they received.

The Live Chat service dealt with more than 1,500 chat enquiries in the first half of 2023 – a 12% increase in enquiries dealt with compared to the same period in 2022.

One anonymous user said: "I was surprised how quickly someone responded to my message. The agent was very helpful and understood my situation, was empathetic and did well helping me with advice and sharing some knowledge I never knew about. I have left the chat wiser and more positive."

Another said: "Wow what a service. It's all new territory for us with our daughter having just been diagnosed and I can't thank you enough for a fast, user-friendly, knowledgeable service that provides the information and support needed."

A survey of users found 76% felt more informed after speaking to Epilepsy Action and 70.5% felt empowered to act following the conversation.

Survey respondents gave the service an average 4.6 out of 5-star rating. The rating improved over the course of the pilot, from 4.3 in December to more than 4.9 in March.

Commenting on success of the pilot, Epilepsy Action's advice and service improvement manager Tom Beddow said the next steps for developing the project included training all helpline staff on Live Chat and trialling offering it at the weekend.

Tom said: "Our helpline team at Epilepsy Action is here to support as many people as possible by offering a service that meets the wide-ranging needs of people affected by epilepsy. The increase in the number of enquiries we received during the trial period of the new helpline shows there is a clear demand for this service and we're delighted that this new offering has helped us to reach more people who need our support."

"The tool allows us to respond to people quickly and efficiently while

delivering high-quality advice, information and empathetic support to those who need it most. We're pleased that following such a successful pilot, the helpline team will continue to deliver and further develop this important service."



## Social media

On Instagram, Epilepsy Action's series of Lunchtime Lives returned with topics including being a parent with epilepsy, which included a chat with Millwall football commentator Karl Bates.

On Twitter, entries are streaming in for Doodle Day (see pages 22-23), and we celebrated the NHS's 75th birthday and Volunteers' Week (see page 10).

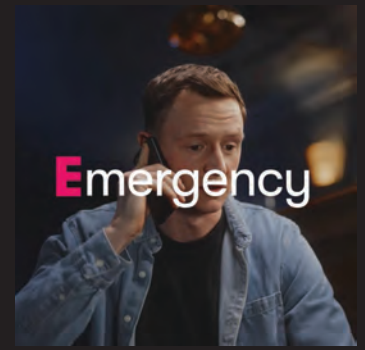
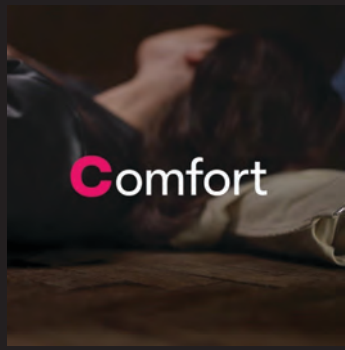
Elsewhere on social media, we provided tips for coping with the hot weather and staying safe at music festivals with epilepsy. We also chose an Epilepsy Star Award winner – featured on page 26.



## Surveys

We want to help people with epilepsy find and stay in fulfilling employment. As part of that, we want to hear

from people with epilepsy about their experiences of work. You can scan the QR code here to see our survey and share your thoughts.



# Take *CARE*

National Epilepsy Week 2023 took place at the end of May. Epilepsy Action took the opportunity to launch a new first aid campaign. We went behind the scenes to find out more

**D**uring National Epilepsy Week 2023, from May 22 to May 28, Epilepsy Action launched a new first aid campaign.

Using the acronym CARE: Comfort, Action, Reassure and Emergency, the campaign informed people how to support someone having a tonic-clonic seizure.

The video features two people at a bar, when one of them begins to have a seizure. It was shown on BBC Breakfast, ITV and heard on radio stations from Scotland to Cornwall, as well as featured in The Mirror and local newspapers across the UK.

Epilepsy Action deputy chief executive Rebekah Smith appeared on BBC Breakfast, alongside epilepsy story champions Imogen Cauthery, Simon Breeds and Morgan Forrington to discuss the campaign.

So far, the video has had a reach of 1.2 billion and fantastic feedback, with Twitter users saying they now felt confident about epilepsy first aid.

More than 100 people downloaded a poster for their school or workplace.

According to an Epilepsy Action survey, 36% of people in the UK wouldn't know what to do if they saw someone having a seizure in front of them. Meanwhile, almost half (47%) of people with epilepsy reported being accused of being drunk or on drugs.

Simon Breeds from East Sussex has had multiple seizures in public, but one instance stands out in his memory. He was out on a run through countryside when he started having an "aura".

**31% of people would feel uncomfortable being in a room with someone with epilepsy in case they have a seizure**

"I knew I only had two more miles to run before I reached home. I had to make a decision: to carry on running or stop and knock on a nearby door to ask for help. I made the decision to go for it, but I then started feeling like the world was closing down on me. My running stride became a walk, I felt dizzy and started having tunnel vision. For some reason, I still believed I would make it home. I tried to stay focused and breathe slowly," Simon says.

He had multiple tonic-clonic seizures in the middle of the field. Luckily, a farmer and a dog walker found him and called for help.

"I woke up with paramedics over me. I was freezing," he says.

The strangers' quick thinking could have saved Simon's life.

The CARE video provides members of the public with lifesaving first aid knowledge, as 31% of people in the UK say they would feel uncomfortable about being in a room with someone with epilepsy in case they have a seizure.

More than half (54%) of people with epilepsy report avoiding public spaces due to worries about having a seizure, as well as missing out on social events.

Jacqui Kiltie from Scotland, says she has felt stigmatised, and that people often assume she is intoxicated when she has a seizure in public.

“I have been videoed, had things stolen, ignored and been accused of substance abuse, to name a few. This has caused me to be cautious about going out, and I feel like I can’t do any of the things that I once enjoyed and that most take for granted.”

Data from the Epilepsy Action survey shows many have been subject to misconceptions and stigma when they have had a seizure in public; 23% have been laughed at, while 5% have even been filmed.

Epilepsy Action hopes the campaign will educate the public and make life easier for people such as Jacqui and Simon.



To watch the CARE video go to: [www.youtube.com/watch?v=MgpkYo1jNWw](https://www.youtube.com/watch?v=MgpkYo1jNWw) or scan the QR code



Above: the YouTube video for the CARE campaign.

Below: Rebekah Smith and Imogen Cauthery on BBC Breakfast



## How was it made?

**Epilepsy Action members told us they wanted the public to be better informed about epilepsy. A video was agreed as the best method, because it is the most powerful and popular form of communication online.**

“You can get across lots of information in a short period,” says project manager Josh Booth. “We already had a video covering seizure first aid, but we felt it was time for a new one.”

Firstly, the team agreed what essential information needed to be included in the campaign.

“There is a lot people can do to help someone having a tonic-clonic seizure, but some of it won’t always be necessary, and we were wary of overloading people with information. We wanted it to be accurate and helpful, but also accessible and not intimidating – we wanted people to come away thinking: ‘Yeah, I can do that!’”

“We then consulted people who have tonic-clonic seizures, to see what they felt was important. The big theme was reassurance. People said when coming around from a seizure the last thing they want to see or hear is a big panic or crowd around them. They would much rather find one or two people helping them, reassuring them that they’re okay, and keeping everyone else calm,” says Josh.

Once the team had all the information, it worked with video agency On the Ark to come up with a way to make all this information memorable.

A few acronyms were suggested, but CARE stood out, says Josh. “It covered all the essential information, including the reassurance that people with epilepsy wanted, and felt proportionate and empowering.”

The team agreed the video needed to be in a real-life situation, so they decided to set it in a bar.

“We saw this as an opportunity to tackle some of the misconceptions about epilepsy. While drinking alcohol isn’t advised for some people, for many others, there’s no reason they couldn’t go to a bar and enjoy a night out like anyone else,” says Josh.

Seizures can happen anywhere and everywhere, which can include some awkward places, but the important thing is about helping that person.

Josh adds: “We are really pleased with the outcome and we are even more pleased to see the fantastic response it has received among our community and beyond. We’re delighted that this video has made people feel empowered and informed to help someone having a seizure, and we have already heard a couple of stories of the steps being put into action. We’ll definitely make more, so watch this space!”

# What's new?



We share some recent advances in epilepsy research

**R**esearchers across the globe have been working on various treatments for epilepsy, we cover a few of the big updates and look at how they might improve medications in the future.



### Chat GPT

Could Chat GPT improve care for people with epilepsy? You may have seen articles about Chat GPT writing emails for people, searching the internet for complex problems or even writing poems, but could it have a use in healthcare?

Chat GPT is an online artificial intelligence programme that is trained to follow instructions and have human-like conversations. It is commonly used to assist with tasks such as composing emails, essays and writing code.

In March, Christian M Bosselmann wrote an editorial for the International League Against Epilepsy's *Epilepsia* journal titled: 'Are AI language models such as ChatGPT ready to improve the care of individuals with epilepsy?'

He said similar software models had been used to analyse medical records and identify patterns. This information can be used to assist with treatment options and identify people who may need surgery. The programmes can also be used to provide information to patients.

Bosselmann and researchers tested Chat GPT with some questions. They

asked it about epilepsy medication and side effects. It was able to provide good information and a seizure action plan when asked. However, when the researchers complicated the questions by adding details such as the patient having "evidence of right temporal lobe seizure onset" it was unable to give correct information.

Bosselmann concluded there may be potential for Chat GPT and similar programmes to be used in healthcare, but they needed to be more thoroughly tested.



**For more information:**  
[bit.ly/ChatGPTstudy](https://bit.ly/ChatGPTstudy)



### Stem cell research

Two people with epilepsy who received a newly developed stem-cell therapy have seen a more than 90% reduction in seizure frequency.

The research was presented at the annual meeting of the International Society for Stem Cell Research (ISSCR) in Boston, USA.

The therapy is designed for people with drug-resistant mesial temporal lobe epilepsy. The first patient is now one-year post treatment, and the second patient is seven-months post-treatment. Both patients reported an improvement in memory and no serious side effects.

The stem cell treatment is called NRTX-1001 and is derived from human stem

cells. Neurona is the company behind the research.

Both patients had a history of significant monthly seizures that were not controlled by anti-seizure medications. One patient had a nine-year history of seizures and averaged 14 seizures per month in the six months prior to treatment.

There is potential that these therapies may not only reduce seizure frequency but also have a positive impact on memory and possibly fewer side effects for some patients than other available treatments. This is an area of research that may have a significant impact on epilepsy treatment in the coming years.



**For more information:**  
[bit.ly/StemCellStudy](https://bit.ly/StemCellStudy)



### CBD study in Argentina

Researchers in Argentina have found a "significant improvement" in the quality of life of focal epilepsy patients who received CBD as an additional treatment.

Cannabidiol (CBD) is an active ingredient in cannabis that does not cause a high and is not addictive. There is currently one cannabis-based medicine approved for treating epilepsy in the UK, called Epidyolex. However, it is only prescribed to patients with Dravet syndrome, Lennox-Gastaut syndrome or tuberous sclerosis complex.



Of the 44 patients who completed the Argentinean trial, 5% were seizure-free, 32% reduced more than 80% of their seizures and 87% reduced their monthly seizures by half. Only 11% presented a decrease of less than half.

The Buenos Aires-based team studied 55 patients between 18 and 60 years old with a diagnosis of drug-resistant focal epilepsy. 11 patients abandoned the trials.

The team said the treatment was “effective, safe, well tolerated and associated with a significant improvement in quality of life”.

Epilepsy Action’s senior policy and campaigns manager Daniel Jennings said: “We welcome the findings of this research, which backs up what we have heard from the families of many people who have used medicinal cannabis to improve their quality of life.

“It is vitally important that we get more such research here in the UK that would give doctors the confidence to prescribe medicines that could make a huge difference for so many people.”

The study was reported in the journal *Epilepsy & Behavior*.



**For more information:**  
[bit.ly/CBDstudyArgentina](https://bit.ly/CBDstudyArgentina)



### Brain implants

Bioengineers at the University of Glasgow have produced a paper on flexible brain implants that could help regulate temporal lobe epilepsy.

The research focused on dissolvable coatings that could help safely guide implants into a patient’s brain. The probes send electrical impulses to targeted areas of the brain.

Deep brain stimulation (DBS) is already used to treat epilepsy but its use is current very limited. DBS treatments require special arrangements due to the limited quality of the current evidence.

Currently, DBS probes are made from silicon, which can cause scarring in the brain because it is stiff compared to the soft tissue of the brain.

The research was presented in the *Advanced Nanobiomed Research* journal. The lead author of the article, Maria Cerezo-Sanchez, from Glasgow’s James Watt School of Engineering, said: “The tests show some really promising results.

“It’s an exciting step forward, and we’re continuing to explore the potential of these materials.”

The team looked at four kinds of coating made from biological materials: sucrose, maltose, silk fibroin and alginate (which comes from algae).

The alginate-covered probes performed well but the silk fibroin performed best. The silk fibroin coating was tested in samples of lambs’ brains and rat brains.

More research is needed before the devices can be used in humans.



**For more information:**  
[bit.ly/BrainImplantStudy](https://bit.ly/BrainImplantStudy)



### Constipation

A research review in the journal *Seizure* has reported that irritable bowel syndrome is five times more frequent in people with epilepsy.

The review said constipation was reported in more than a third of people with epilepsy – a higher rate than among the public.

It suggested one of the causes was the side effects of anti-seizure medications (ASMs) and anti-depressants. Many people with epilepsy are also on medication for mental health issues.

Constipation is the third most common side effect of ASMs. The researchers said that among children with epilepsy, constipation was the second most common additional condition.

The researchers suggested the relationship between the gut and brain may play a role in understanding why constipation was more common in people with epilepsy.

They concluded it was important to educate patients about constipation as a potential side effect of ASMs and that further research was needed to understand why this might be. It added there was currently no mention of constipation or changing bowel habits in National Institute for Health and Care Excellence guidance for epilepsy and patients needed more information.



**For more information:**  
[bit.ly/PooMattersStudy](https://bit.ly/PooMattersStudy)



# A helping

When Holly was diagnosed with epilepsy she felt lost and alone. Earlier this year she reached out to Epilepsy Action's Befriending scheme and was matched with volunteer Lisha. Jaimie Kay explains how the project has changed both their lives

hand



**S**ometimes, people can be left in such a dark place with their epilepsy, they need focused one-to-one support. That's why, earlier this year, we launched our Befriending service.

The service pairs a volunteer with a person living with epilepsy and they have one-to-one weekly virtual or phone sessions to get advice and support.

One of those people is Holly. They were at their lowest ebb when they became aware of the Befriending service. They had no other support and faced severe isolation and loneliness.

"I felt alone and never left my room," says Holly.

Holly was matched with Lisha as they had similar interests and it was hoped that they would form a connection.

"Lisha made me feel like I wasn't alone anymore," added Holly. "I felt as though

I could open up to her about pretty much anything. Having the sessions with Lisha has inspired me to put myself out there a lot more. She has lowered my anxiety and given me confidence within myself."

#### **Holly's story**

Holly was diagnosed with epilepsy after their first seizure aged 13. The diagnosis brought issues with their social life, education and home life.

"One day I was sat on my computer, my mum left the room for 10 seconds, the next minute I was on the floor with my mouth pouring out with blood.

"I was scared because I had no idea what epilepsy was. When I asked the nurse, she just said: 'You're going to be having seizures.' So, I had to go home and do my own research."

For Holly, even reaching a diagnosis was a battle.

"It was very tough because they kicked me out of high school for 10 months and they refused to provide me with any work. I knew I was going to fail all my exams at that point.

"All my friends left me because they didn't want to deal with my seizures. So, I felt alone quite a lot. I just never left my room. I only left my room when I had to.

Like many of those who reach out to Epilepsy Action for support, Holly was left wondering and then they found the Befriending service.

"When I heard about the Befriending service I decided to sign myself up, because at that point I really didn't have anyone supporting me apart from family. I thought to myself: 'Maybe I can talk to someone who might actually understand what it's like.' And then I got matched with Lisha.

"I was very nervous at first, but as the sessions went by it just felt natural. I struggle with trusting people and, I'm not sure how, but Lisha gained my trust very quickly. Lisha made me feel like I wasn't alone anymore. I felt like I could open up to her about pretty much everything.

Since the sessions finished, Holly has got a job and applied for college, with a hope to go on to become a computer scientist.

More people every day are in need of vital support. One of the 72 people diagnosed with epilepsy every day could face isolation if they do not get the help they need, it's only through people such as Lisha that we are able to provide these services.

For just the price of a cup of a coffee (or two) per month, you can help people on the way to a better life, and make their life with epilepsy as fair as anyone's.



You can watch Holly tell their story on the Epilepsy Action website here: [bit.ly/44XfVD](https://bit.ly/44XfVD)

**66**  
**Lisha made me feel like I wasn't alone**



**Holly at home in Belper**

## Lisha's story

Following her diagnosis, Lisha signed up to volunteer with Epilepsy Action. Like Holly, Lisha received very little in terms of answers.

"I was diagnosed about six and a half years ago, completely out of the blue and it derailed my life," says Lisha.

"It's quite a scary condition to have because it's not just the seizures, it's also the anxiety you get from it – being worried about going outside or being on your own, worried about going to sleep in case you have a seizure in your sleep. There's so much more to epilepsy than meets the eye.

"I struggled quite a lot, and I still do, with anxiety and other issues, but I managed to make epilepsy work for me. Originally, I went to university and was studying marketing, but after a few months I realised it wasn't working for me, and that, on top of the anxiety of living on my own, made me leave.

"But to my amazing luck, I actually managed to get a job working remotely, which meant I could work from home and live with my parents so I was safe. Now, I work in social media."

Lisha began following people who have epilepsy on social media and through this discovered Epilepsy Action.

"That's kind of why I'm here right now volunteering. I want to volunteer and I want to give back to my community because epilepsy is an invisible disability unless you see somebody having the seizure."

Getting her seizures under control with medication and overcoming her anxiety were two of the reasons Lisha decided to start giving back.

"I'm now well enough in myself to be able to support others who may not be. Three years ago I would have loved to have been the person receiving support through the Befriending scheme from Epilepsy Action, and while I can't go back in time, I can support other people and help them get through it."

Lisha adds: "It's amazing to see how much Holly has grown and how much they've got that self-worth back and confidence."

Lisha could not be more enthusiastic about volunteering and what working with Holly has taught her.

She says: "I cannot stress enough how amazing it is being a befriender for Epilepsy Action.



Lisha on call to Holly

You get to learn so much about different people from all walks of life who are living with epilepsy. And yes, you're helping them but you're also learning yourself. It's such an amazing feeling when you finish a session knowing: 'Wow, I've really helped a person.'

"So if you're considering it, just do it. You've got nothing to lose."

Epilepsy Action has been inundated with requests for befrienders from people struggling with their epilepsy. Being a Befriender like Lisha is a medium-term commitment, with an even longer-lasting impact. We hope to help as many people like Holly as possible who are in need of

answers, which is why, if you can, we would love you to support befriendees as the service continues to grow.

These half hour calls can make all the difference in a person's life. No one should have to face epilepsy alone.



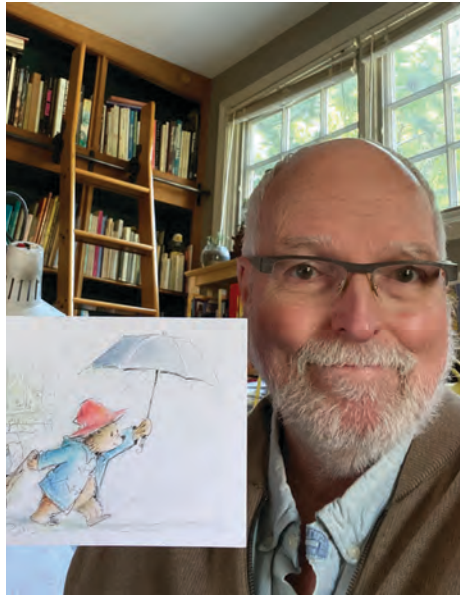
**You can find out more about the Befriending service, our other support services and our volunteering roles on the Epilepsy Action website ([www.epilepsy.org.uk/summer-appeal-2023](http://www.epilepsy.org.uk/summer-appeal-2023)) or by scanning the QR code.**

**66**  
**It's amazing  
to see how  
much Holly  
has grown**





The Traitors star Maddy Smedley



Paddington illustrator RW Alley



Heartstopper author Alice Oseman

# Let's get bidding

National Doodle Day is back for 2023 – this year with contributions from doodlers such as actor Maddy Smedley, illustrator RW Alley and author Alice Oseman



**Epilepsy Action will once again be holding a three-day auction of work from artists including Grayson Perry, West End superstar Carrie Hope Fletcher and The Beano's first female artist Laura Howell.**

Each year, Epilepsy Action asks artists, illustrators and celebrities to pick up their pens, pencils or paints, and create an original artwork to sell.

This year's fundraising auction will run from September 15-17.

The popular event, which began in 2004, has previously included artworks from celebrities such as Ian McKellen, Axel Scheffler, Tom Hardy, Joe Lycett and Geri Halliwell, and raised more than £250,000 for Epilepsy Action.

Last year was the most successful year to date, generating £15,378.21 from 307 doodles – and Epilepsy Action is hoping to make this year even bigger.

### Celebrity doodlers

Actor Miriam Margolyes has donated a signed self-portrait, as has drag queen River Medway and star of RuPaul's

**“Everyone can draw. And doodling is drawing. If you can doodle, you can draw”**

Drag Race Anita Wig'it has submitted a portrait of their Carmen Miranda show.

Una Healy from girl band The Saturdays has doodled a music-inspired piece and John McCrea, a Northern Irish comic book artist, has donated several Star Wars drawings.

In her 16th National Doodle Day, Joanna Lumley has created a signed Absolutely Fabulous-style sketch. Meanwhile, Eurovision entrant Teya, who sang 'Who the Hell is Edgar' for Austria, has drawn Edgar Allan Poe. BAFTA-winning animation director Rich Webber, who is behind the Shaun the Sheep series, is taking part for the tenth year in a row.

Doodling extraordinaire and illustrator of the Horrible Histories books, Martin Brown, sketched three doodles



Postman Pat illustrator Ray Mutimer



Joanna Lumley



Carrie Hope Fletcher



Anita Wiglit

for last year's auction. He said: "My mum has epilepsy. She started having seizures when she was in her 60s but it took a distressingly long time to get the diagnosis. Epilepsy can be quite unlike what we think epilepsy is. So, any way to spread awareness of everything that epilepsy is – and isn't – is okay by me.

"I'm a great believer in the idea that everyone can draw. And doodling is drawing. If you can doodle, you can draw. Who cares if your drawing doesn't look 'right'? Drawings can be realistic, but they don't have to be. In fact, maybe drawing can be quite unlike what we think drawing is. So go on, have a doodle, have a draw."

### Mini doodlers

Epilepsy Action is also inviting school children into the National Doodle Day family this year, with schools organising their own art exhibitions for children to take part in.

So, if you're interested in buying any of these pieces, set your calendars and don't miss the opportunity to own a unique and original artwork.

You can keep up to date with the latest doodles featured in the auction, by following Epilepsy Action's Doodle Day account on Instagram at @NationalDoodleDay.



John McCrea



Grayson Perry



Billy Childish



Dave Windett



To request a pack or for more information, go to [www.epilepsy.org.uk/doodleday](http://www.epilepsy.org.uk/doodleday)

# My Journal

## Adventure across the Channel

Photos by  
Alex Thomas

Travelling can be scary for photographer **Alex Thomas**, but his epilepsy has not stopped him from being a “go-getter”

**A**lex Thomas is a photographer, he was diagnosed with epilepsy in 2021. Travelling can make him feel stressed about having seizures in unknown places, but in May this year he went to France with his friend Clare. He explains why he undertook the adventure.

“Is it too late to turn back?” I ask as the ferry begins to pull away from the harbour. I’m not keen on large open water or large ships, so why am I on a ferry to France? Why did I suggest this trip? Why did I think it was a good idea?

Since my epilepsy diagnosis I’ve pushed myself to do more. Even though I was a go-getter before the condition struck, epilepsy has offered me another reason to get on with things. Life is short enough as it is.

My diagnosis came in 2021 and, during Covid, my first seizure happened in a

basement at my then job. I’ve long since left that job, and now I’m back doing what I love, being a photographer.

So here I am, on a ferry in the English Channel, on my way to France, being a go-getter. The purpose of this short trip is to show myself that I can do the things that frighten me.

For some, being on a ferry on a lovely warm spring day would be a great way to spend a few hours – for me, not so much. I have asked my friend Clare for company, and I’m pretty sure she knows more French than I do.

Stress can act as a trigger for seizures. De-stressing your life is a difficult task in and of itself. How are you meant to know all the stressful points? And then, how are you meant to apply or limit them in your life? I’m still learning this process, so, if you’ve had any success, please send me answers on a postcard!



### Bonjour France

We got to the lovely town of Dieppe in Northern France in one piece. I had completed the first major obstacle – crossing the channel. This trip had no agenda, it was all about getting there. Our first few hours were spent admiring the architecture and things that were different from home. We lucked out with the weather, there was hardly a cloud in sight and it was an easy-to-handle temperature. It was perfect.

This was the furthest from home I had been while living with epilepsy, and that was on my mind while we explored.





“I won’t allow epilepsy to take the adventure out of my life”

I thought: “What if I have a seizure here?” Not having a good grasp of your surroundings after a seizure is difficult enough when you speak the language of those trying to help, it’s totally different when the people around you are speaking another language. But, I kept this worry at the back of my mind, or at least I tried.

We got to the hotel, a pleasant just-out-of-town place. We remarked more than once that being out of town was a better choice than being in the middle of the bustling Dieppe streets. The town was hosting motorbikes and fast cars in their hundreds on the day we arrived.

### Rouen

Remember the no agenda part? Well, in the spirit of adventure, on day two we decided to visit the city of Rouen – a historic city on the banks of the Seine in the north of France, just 45 minutes away. But first, French pastries!

Rouen was bustling compared to Dieppe, a vastly different place in every sense. As the day went on, my fears and worries of a seizure reemerged. I’ve become used to these feelings and my usual way of coping is to be present with everything that arrives. Being rational and calm goes a long way. I take deep breaths, ground myself and feel my pulse in my wrist. Everything plays a small part in keeping me from peddling the fear cycle.

Our trip quickly came to an end. We decided not to overstretch ourselves and went back to Dieppe in good time, because being in a rush always panics me and that starts to fill up the stress tank. We ended our trip with a celebratory ice cream and the French seagulls were much more polite than the British ones!

### Au revoir France

The ferry again, but, this time I was looking forward to it. While the trip over



from England was smooth sailing, the trip back had more movement, but it was nothing a well-prepared travel-sickness-prone person couldn’t manage.

When we face our fears, we often come away thinking: “Why did I make such a big deal out of that?” and that’s the perfect way to summarise the ferry. I don’t want to shout it too loudly, but I’m looking forward to my next journey on a ferry.

Epilepsy has not diminished my

go-getter-ness, it has only amplified it. I’ve had to adapt and change course a few times, but I won’t allow epilepsy to take the adventure out of my life.



For more of Alex’s photography go to: [www.alexthomascreative.com](http://www.alexthomascreative.com) or scan the QR code.

To share your journal, email [gwood@epilepsy.org.uk](mailto:gwood@epilepsy.org.uk)

# Hero Granddad

Growing up, granddads are often our heroes, but not many win awards for their heroic deeds. Georgia Davies decided her granddad deserved recognition. Words by **Rebecca Lock**

**A**lan Davies, or 'G-Pa', from Telford, Shropshire, has won an Epilepsy Star award, recognising his unwavering support, care and encouragement of his granddaughter who has epilepsy.

Alan has supported Georgia in every step of her journey, from being at every neurology appointment to encouraging her to pursue medical research into epilepsy when she went back to university after her diagnosis.

Georgia nominated him to thank him for his incredible encouragement.

She said: "He has always been there to share the emotional burden of my epilepsy. Without him I would be struggling with my mental health, I wouldn't have been able to carry on at university and he has given me the confidence to do further medical research. I don't think I will ever be able to put the impact he has had on my life into words, but I'll try my best."

Accepting the award, Alan said: "My granddaughter is worth all the hassle. I know my help, support and understanding is appreciated."

Georgia was 18 when she had her first seizure. She was living six hours from home, studying Marine Biology at university. She had to interrupt her studies after her second seizure, but thanks to the support of her family, she moved back home and pursued a Biochemistry degree.



"After my second seizure, I made the difficult decision to move back. For the next year I felt hopeless. I had to give up everything I worked for. I stopped scuba training, I stopped going out, my mental health was worse than it had ever been. I watched all my friends achieve so much while I felt stagnant," Georgia said.

The diagnosis and medication process was difficult for Georgia. In the second year of her Biochemistry degree, she was taken off medication due to her seizures being attributed to a mental health issue, and her condition worsened. In this time, she had more than 70 seizures in three months. Throughout the process, G-Pa was always there for her.

"He drove me to and from university every day when I was unable to take public transport. He's been with me to all my neurology and epileptologist

appointments. But most of all he's been there when things got too much. He rushes over day or night if I have a seizure or feel ill. I fell down the stairs during a seizure once and he was there in three minutes" Georgia said.

After being referred to an epileptologist, Georgia gained better seizure control, and in her third year of university she decided she wanted to pursue medical research in neurological conditions after completing her degree.

"I don't want anyone to go through the pain of watching a family member with epilepsy, and while I know that's not possible, I hope to ease some of the burden. My granddad has always engaged in research, reading articles I send him and finding a way to understand my condition. When I need somewhere to go, his door is always open. He always has snacks and vegan ice cream too!

"He'd never admit to how much he worries but I know and appreciate it all the same. I want to thank him for all the help and support he has provided, his kindness, compassion and care has made all the difference in my life.

"Thank you for being an ally, friend and amazing grandfather, I couldn't have made it without you. I love you."



To nominate someone for an Epilepsy Star Award go to: [epilepsy.org.uk/star-awards](https://epilepsy.org.uk/star-awards)

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# Obituaries

## Ena Bingham

**W**e were saddened to hear of the passing of Ena Bingham on May 5, retired epilepsy specialist nurse, former Epilepsy Action council member and unparalleled champion of people with epilepsy in Northern Ireland.

Born on November 17, 1945, Ena became a nurse at the Royal Victoria Hospital, Belfast.

Some will remember her as the 'red' or senior sister on the neurology ward, which she ran with military precision. The staff were always well turned out, the ward immaculate, yet always the patients came first – woe betide any medical student or junior doctor who dared to sit down on a bed to talk to a patient.

At the height of her career, Ena became the first ever epilepsy specialist nurse in Northern Ireland – a post so different from her previous position that some initially wondered if she could adapt to it.

One need not have worried. Ena quickly became a model to others and made a huge difference to many thousands of lives directly or indirectly affected by epilepsy in Northern Ireland.

She was committed to helping people, through volunteering with Epilepsy Action for more than 25 years, running local support groups, and giving talks and presentations to raise epilepsy awareness.

She was an advocate for all those with epilepsy and their families (yet still found time to keep the doctors on their toes).

Ena served on Epilepsy Action's Council of Management between 2007 and 2013 and on Epilepsy Action's Northern Ireland advisory council from the beginning of 2010 until 2021. She was awarded an MBE for services to epilepsy in 2012.

Ena made an immense contribution to epilepsy services and her legacy will be the motivation, dedication and enthusiasm she demonstrated throughout



her life, which she has undoubtedly passed on to the many others who now follow her lead and continue her work.

She will be greatly missed.

**Dr Jim Morrow**

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## Pauline Spencer

**It was with great sadness that we received news of the death of Pauline Spencer, chairman of Epilepsy Action's Huddersfield branch, on May 2.**

Pauline supported Epilepsy Action for more than 40 years. She became involved with the charity's work when her son Daniel was diagnosed with epilepsy.

At the time, Daniel was having several seizures a week and struggling to find medication. From attending the group, Pauline was put in touch with a consultant neurologist and found support for her son.

She became a committee member of Huddersfield's Talk and Support group and was elected chairman.

During her time leading the group she persuaded the then Huddersfield Hospital Trust (now Calderdale and Huddersfield NHS Foundation Trust) to appoint a consultant neurologist.

The group raised £12,000, in less than a year, to appoint a Sapphire Nurse at the Huddersfield Royal Infirmary. It also donated £1,000 towards the cost of appointing a nurse in Halifax. Since then, 40 nurses have been sponsored to study for an Epilepsy diploma.

As part of her support for the group, Pauline became an accredited volunteer, attending training sessions at Epilepsy Action's head office and speaking to many local groups.

**“We shall miss her so much and all the group will remember her enthusiasm and care for us all”**

About 20 years ago, Pauline attended a conference in Sheffield at which a consultant neurosurgeon explained the operation he undertook to help people with epilepsy who had not found medicine to control their seizures.

This led to her son undergoing the operation and he has since been able to attend adult education courses at Huddersfield University.

Pauline was diagnosed with cancer and after several years of treatment she passed away at Kirkwood Hospice in Huddersfield.

General secretary of the Huddersfield group Joan Gorton said: “We shall miss her so much and all the group will remember her enthusiasm and care for us all.”

**Joan and Tony Gorton**



“The song helped me to come to terms with living with epilepsy”

# Musical healing

Playing music has been a theme throughout Gavin Sillar’s life, so when he was diagnosed with epilepsy, he wrote a song about it. Words by **Rebecca Lock**

**M**usic has been a lifelong passion for Gavin Sillars. He had his first seizure in January 2022 and was later diagnosed with epilepsy. With his band, Gavin and the Laas, he released a song about it called *Julius Seizure*, which has been played on BBC Radio Leicester.

He says: “In January 2022, I had a tonic-clonic seizure at work. It was my first one and I hadn’t shown any previous signs of problems, but the doctors found I had acute hypophosphatemia [a low level of phosphate in the blood], which they suggested could have caused the seizure.

I had a series of tests, MRI, CT, EEG and ECG scans, and I started a course of B12 injections.”

Gavin’s life changed dramatically. “Nutrition and exercise became a bigger part of my day and we looked at stress and tiredness as possible triggers. I was then free from seizures for 15 months until sadly, in March 2023, I had a second tonic-clonic seizure. I was referred to a neurologist and was diagnosed with epilepsy and put on a course of Levetiracetam,” he says.

The biggest challenge for Gavin was losing his driving licence.

“You realise how reliant on driving you

become for work and social gatherings. I love driving. I passed when I was 17 and to have that taken away aged 38 was pretty devastating. My wife is now my chauffeur and she’s been so supportive and understanding of my condition and what that means for our family, including our eight-month-old daughter. I also started a course of anti-depressants to stop my mood from dipping. I keep reminding myself that it’s only temporary and I’ve started to enjoy walking more.”

Playing with his band has helped Gavin through his epilepsy diagnosis and helps him manage the anxiety he faces.

He says: “Music has always played a huge part in my life as I was in bands throughout high school and college. I write and record my own songs – I love the freedom of creativity. For me, music constantly evolves. You hear something new, or you learn a new lick on the guitar, and it can be really rewarding. It helps me to zone out and have a little break where all of life’s stresses just leave you.”

Music has allowed Gavin to face his feelings in a safe, creative environment.

“I was so overwhelmed with the whole epilepsy thing and I had all these feelings that I needed to write down – really personal thoughts that I knew would make me feel quite vulnerable. I spoke to family and friends and decided that writing a song about epilepsy would be a good coping mechanism for me, especially if I could keep it upbeat and quite raw.

“The song helped me to come to terms with living with epilepsy. It’s a reflection on the time immediately after the seizures in hospital when I was frightened and in a state of total confusion. I spoke to my brother on the phone and the first thing he said was: ‘Alright Julius Seizure’. We laughed a lot and it helped me get through a tough time, so it became the title of this track.”



Listen to Gavin’s song here: [www.youtube.com/watch?v=mL1-XHJT3DO](https://www.youtube.com/watch?v=mL1-XHJT3DO) or scan the QR code

# Medical update

## Cenobamate



Professor Martin Brodie looks at the various anti-seizure medicines prescribed for epilepsy. This quarter he talks about Cenobamate

**C**enobamate (CNB) has recently been approved across Europe and elsewhere in the world as an add-on treatment for those 18 years and above with focal seizures.

CNB acts on GABA ions and sodium channels in the brain. This method seems unique among anti-seizure medicines. CNB is taken once daily. The starting dose is 12.5mg per day with gradual titration to a recommended target dose of 200mg or more if necessary based on how the person responds. Some people will benefit from higher doses assuming they don't experience intolerable side-effects.

During the clinical trials programme, CNB appeared to demonstrate particularly high efficacy compared with other newer anti-seizure medicines.

The most common side effects with CNB include somnolence (drowsiness), dizziness, tiredness and headaches, which is similar to many other anti-seizure medicines. Other problems can include double vision, poor balance, confusion, nausea, vomiting and diarrhoea. Drug rashes can occur, as can fever and liver damage. CNB's excellent efficacy appears to be offset by an increased risk of poor tolerability at high dosages. No important drug interactions have been documented to date with anti-seizure and other medicines.

**“Hopefully CNB can be used for drug-resistant epilepsy”**

CNB has only recently become generally available, and so it is too early to judge its long-term efficacy. In addition, it is less tolerable in people already on high doses of other anti-seizure drugs, particularly those that also have effects on sodium channels, such as lamotrigine and lacosamide.

Additionally, the everyday use of CNB may increase the metabolism of the hormones in the oral contraceptive pill, potentially reducing its efficacy. Current advice, therefore, is that women taking CNB should not rely on this method of contraception. CNB is not recommended at this early stage for women of childbearing age who are not taking any form of contraception until its long-term safety has been confirmed.

The drug should not be prescribed in pregnancy. There are, however, very rare cases where it might be decided that it is appropriate. Its effects on fertility are unknown.

Overall, CNB looks like a promisingly effective medicine for the adjunctive treatment of focal seizures, but it is still at an early stage of development. Concerns need to be allayed regarding its long-term safety, particularly at high doses in people with previously refractory seizures. Hopefully, its excellent efficacy and acceptable tolerability will be confirmed over time, allowing CNB to be used for drug-resistant epilepsy.

**Always follow your doctor's instructions for taking your medicine. If you are experiencing any problems with your epilepsy medicine, it's important that you don't stop taking it without discussing it with your GP or specialist. Suddenly stopping your epilepsy medicine could cause you to have more, or more severe, seizures.**

# Council of Management

## May 16

**The Council of Management met at New Anstey House with four members attending by remote video.**

This was the last council meeting before the elections at the annual general meeting on 13 June. Members expressed thanks to Mike Harnor and Gavin Barlow who were not seeking re-election. Gavin has served for 12 years and previously ran the Sapphire Nurse programme. Mike served for 38 years, including periods as chair and vice chair, and is council's longest serving member having been first elected in 1985. Both will be missed.

**Council made the following decisions:**

- An investment in IT systems and infrastructure was approved.
- Council received and approved the committees annual reports.
- The terms of reference of every committee were reviewed, amended and approved. All committees were confirmed to continue for a further 12 months.
- Mubarak Ahmed and Fathiya Bahdon were appointed as members of the Ethnic Communities Advisory Panel.

## July 18

**The Council of Management met at New Anstey House. This was the first meeting of the council after the association's annual general meeting held in June (results right). Members were pleased to welcome two new colleagues who were elected this year – Deirdre Black and Cameron Hill.**

Jane Riley was elected as chair. Peter Clough was elected as vice chair. Nicholas Hutton was elected as the association's honorary treasurer. The following people were elected to the Corporate Governance Committee: Jayne Burton, Richard Chapman, Diane Hockley, Sarah Lawson, Tom McLaughlan and Ian Walker. Avril Coelho and Richard Chapman were appointed to the Staff Appeals Panel.

The following people were elected to the Finance and Strategic Policy Committee: Richard Chapman, Joanne Greer, Diane Hockley, June Massey and Tom McLaughlan. Jane Riley, Peter Clough and Nicholas Hutton are all ex-officio members of the committee as officers of council.

Annual reports were received from council's EDI champion and research champion. Katie Stevens was reappointed EDI champion for the next 12 months. Peter Clough was reappointed champion for research. Abi Babatunde was appointed as the latest member of the Ethnic Communities Advisory Panel and five members of the charity's Research Advisory Panel were reappointed for a 12-month period.

Council reviewed and were content with the charity's financial position and progress with this year's business plan. It completed its quarterly review of the top 10 risks on the corporate risk register. Council also approved a bye-law and recommendations that will facilitate online attendance at the 2024 AGM.

### Annual general meeting June 13 2023: Ballot results

	Number	%
Electorate:	7,780	100
Valid proxies returned:	237	3.05
Invalid proxies returned	7	0.09
Total proxies returned	244	3.14
Members voting at AGM	0	0
Total response	244	3.14

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

	Votes	%	Outcome
Ian Walker	203	18.68	Elected
Richard Chapman	196	18.03	Elected
Cameron Hill	178	16.38	Elected
Deirdre Black	160	14.72	Elected
Sarah Lawson	124	11.41	Elected
Jim Berrington	114	10.49	Not elected
Christopher Bruce	112	10.30	Not elected
	1087	100	

### B. Confirmation of appointment of vice presidents

	Votes Yes	% Yes	Votes No	% No
Karen Armstrong	192	86.49	30	13.51
Paul Maynard MP	196	86.73	30	13.27
Prof. Ray Tallis	203	90.63	21	9.38

### C. Result of resolution 1: To reappoint auditors RSM UK Audit LLP

Number for	% for	Number against	% against
207	94.95	94.95	94.95

**The next meeting of the council is scheduled to be held on 3 October 2023.**

# Epilepsy support for you

**F**or 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](https://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](mailto:Iso@epilepsy.org.uk) or calling **0113 210 8899**.

## Online resources

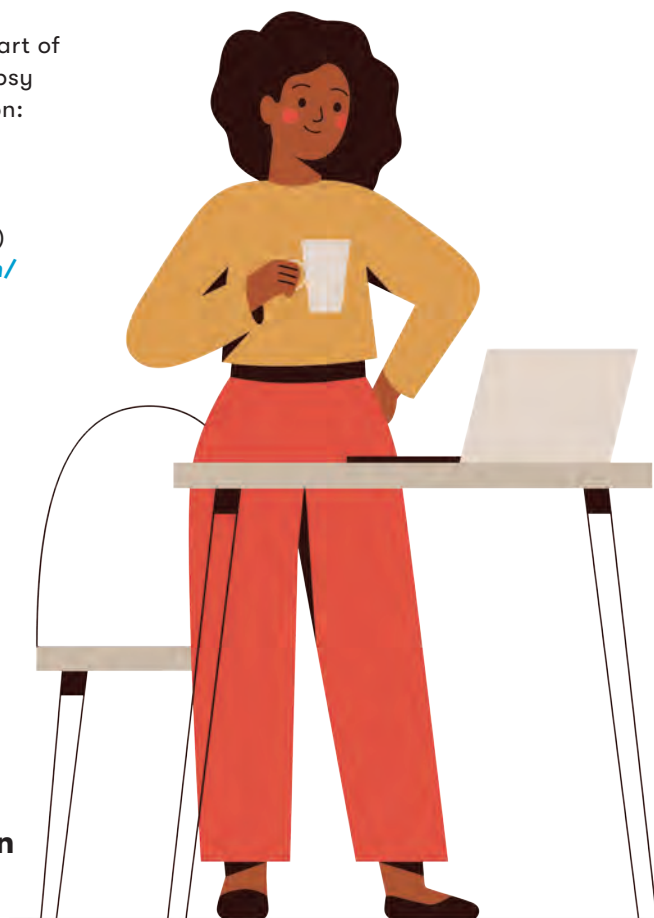
There are many ways to be part of Epilepsy Action's online epilepsy community. You can find us on:

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

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



**For more information scan the QR code**



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