

## A new lease of life

At her lowest ebb,  
Amanda made a  
life-changing call



Also in this issue

- brothers win the first **Epilepsy Stars** award
- diagnosing and understanding **mixed seizure disorders**
- dispelling myths and sharing your key words on epilepsy for **Purple Day**



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# editor's letter

Welcome to the June 2023 issue of *Epilepsy Today*.

As we head firmly forward into the year, towards the warm glow of the summer months, we've already had some exciting events in the epilepsy community calendar.

One of these is presenting the first new Epilepsy Stars award to its first recipients, Sam and Ollie, who have been model big brothers to their little sister Charlotte who has epilepsy. While the condition has pulled the focus away from the boys, their mum Jaimee says they have shown "compassion and resilience" throughout. Read their story on page 9. Congratulations, Sam and Ollie!

Another big event was Purple Day 2023. This year, we wanted to bust some frustrating, and sometimes dangerous, myths to mark the global awareness-raising day. More on this, and some of the words people with epilepsy most associate with their epilepsy, on page 16.

For those thirsty for research and information, we have some great reads for you this issue. On page 14, we explore the challenges of living with both epileptic and dissociative seizures. Their causes and treatments are very different, but the seizures can be very easily mistaken for one other. We summarise recent medical papers looking at differentiating the seizures, and diagnosing and treating people with both conditions.

Meanwhile, on page 24, we share three very exciting pieces of recent research. We talk about repurposing an old cancer medicine to treat epilepsy – which may stop not only seizures, but epilepsy itself from developing. We also share a study showing that a blood test could become a quick and easy way to help diagnose epilepsy, and we summarise research looking at the potential to administer rescue medication using just a nasal spray. There is a lot to be excited about here.

And finally, we have our heart-warming real-life stories. You can read about Amanda's struggles getting to grips with her epilepsy diagnosis and how a call to Epilepsy Action changed everything for her (page 10). On page 20, you can read Tolly's story. After his friend Charlie died due to his epilepsy, Tolly took on a project they had both started, wanting to raise awareness of the hidden effects of the condition. You can also read a story by Anne, a retired secondary school teacher with two grandsons who have epilepsy (page 26).

We hope you enjoy this issue!

Kami Kountcheva  
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**Grandmother to two boys with epilepsy, Anne shares her thoughts and experiences**

## New valproate prescription rules called "a risk" by coalition of epilepsy organisations

New prescription rules around sodium valproate, announced in December 2022, have been called "out of proportion" by a coalition of epilepsy charities.

The organisations, including Epilepsy Action, the International League Against Epilepsy (ILAE) and SUDEP Action, are calling for the Medicines and Healthcare products Regulatory Agency (MHRA) to pause its decision.

Last year, the MHRA announced that no one under the age of 55 years should be prescribed sodium valproate unless two epilepsy specialists independently agree it's the only suitable medicine. The new rules include boys and men for the first time.

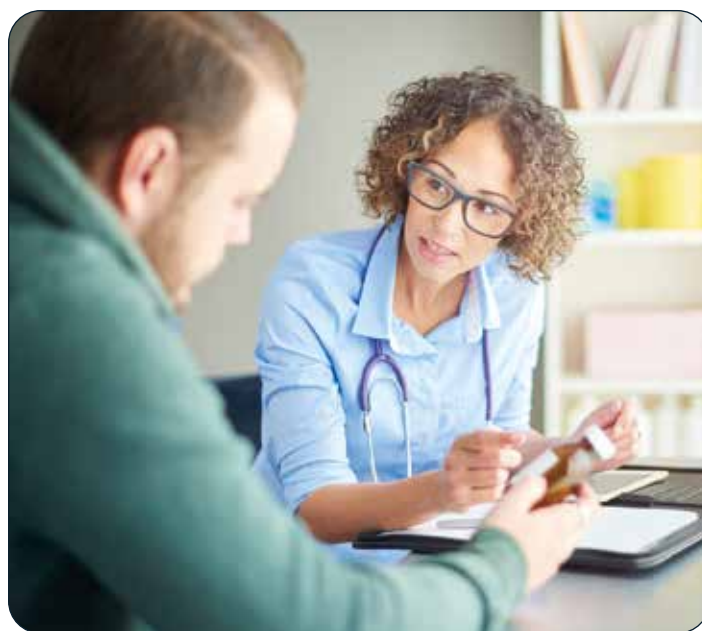
In a public statement, the coalition said: "This is a dramatic shift in practice and risk for people with epilepsy without regard to each person's situation and life choices and totally out of proportion to the risks to patient safety."

The group has also written to the Health Secretary Steve Barclay, sharing their concerns over the decision.

The MHRA previously tightened the rules around prescribing sodium valproate in 2018. These said that girls and women should not be prescribed sodium valproate unless a pregnancy prevention programme is in place.

The rules were intended to ensure women and girls to be fully informed of the risks of taking sodium valproate, and the need to avoid becoming pregnant while taking the medicine. Safety reviews have shown that the medicine can cause developmental disorders and birth defects in babies exposed to it in the womb.

With the newly announced rules from the MHRA, the coalition said there has been no consultation around this change. The organisations added that they have also not been given access to the safety review results from



the Commission of Human Medicines, on which the MHRA based its decision.

In their open letter, the organisations warn that for 10% of people with generalised epilepsies, sodium valproate is the "first line of defence against visits to A&E and the risk of SUDEP (sudden unexpected death in epilepsy)".

They also stress that the new rules will increase pressure across the NHS when there are already general and epilepsy-specific workforce shortages.

There is more on sodium valproate ([epilepsy.org.uk/sodiumvalproate](https://www.epilepsy.org.uk/sodiumvalproate)) and the coalition letter ([bit.ly/40jCJew](https://www.epilepsy.org.uk/40jCJew)) on the Epilepsy Action website.

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## Further delays on Teva's zonisamide capsules stocks



Teva, who manufacture the epilepsy medicine zonisamide, have said that all strengths of their zonisamide capsules are now out of stock until the beginning of July 2023.

This is the second recent report of delays to Teva's zonisamide stocks. Previously,

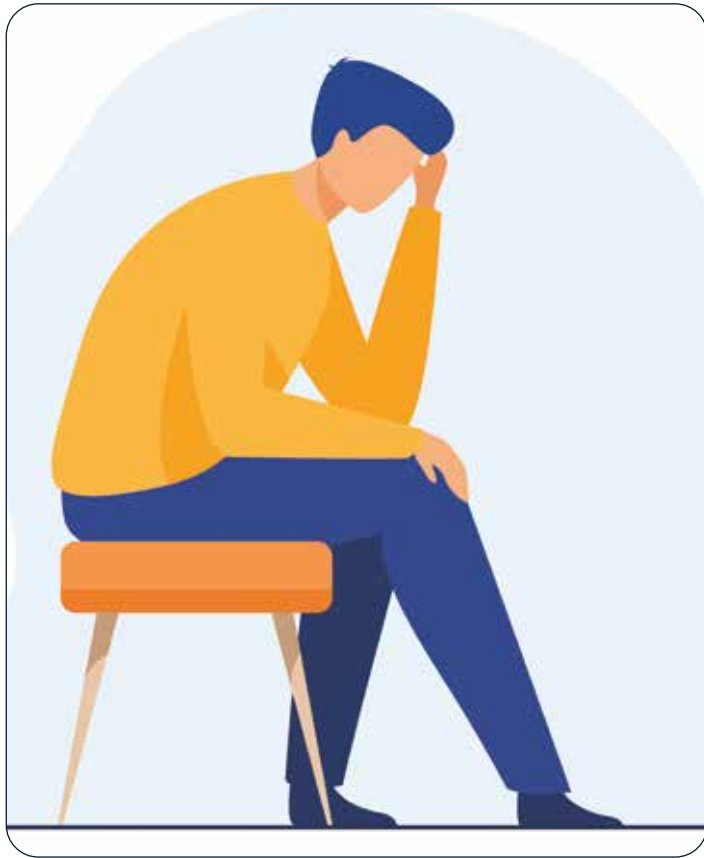
the company told Epilepsy Action that their 100mg capsules would be out of stock until February 2023, and their 25mg capsules would be out of stock until April 2023.

People taking Teva's zonisamide capsules may be offered a different version

of the medicine by their pharmacist or doctor.

Epilepsy Action has information about switching between different versions of epilepsy medicines ([bit.ly/3LcCC0e](https://www.epilepsy.org.uk/3LcCC0e)). Anyone worried should speak to their pharmacist or GP.

## High rate of economic inactivity in epilepsy



According to the Office for National Statistics (ONS), more than half of people with epilepsy of working age in the UK are economically inactive. This term refers to people who are not currently in employment and are not looking for work.

The ONS figure shows that 53.1% of people with epilepsy were economically inactive in the year from July 2020 and June 2021. This is a reduction from around two thirds (65.2%) at the beginning of 2020 (January-June).

However, this is still among the highest rates of economic inactivity among disabled people, behind conditions like autism, severe learning disabilities and mental health conditions. In 2021, across England, Scotland and Wales,

22% of working age people in the general population were economically inactive – less than half that of people with epilepsy.

Reports suggest that the reason for the high levels of economic inactivity is “long-term sickness and pressure on the NHS”.

Paul Fawcett, 44, from Northumberland has had to give up work because of his uncontrolled epilepsy.

Paul said he has lost two jobs because of his epilepsy. His first job was in advertising and required a lot of driving. When Paul had to hand in his licence, he felt unsupported by his employer.

“I was told not long after that that I was being made redundant,” Paul said. “They

had to make cuts and I was the only member of staff to lose their job. A few weeks later, they had employed someone else to do my job.”

Paul’s second job was in the prison service. He had disclosed his epilepsy during his interview and had got the job, but following a seizure, he started to feel pushed out. He was eventually told there was no position in the prison for him and was offered a position in Durham.

“How was I going to get to Durham for 7am if I couldn’t drive? Unfortunately, [since then] I haven’t been able to work as my epilepsy has got a lot worse. I have daily seizures.

“I read about faster access to treatment for people with epilepsy [to help to] possibly get employment or stay in a job. I’ve been waiting around two or three years now to go into hospital for a week for video monitoring, but with the current situation with the strikes, think I may have to wait a bit longer.

“My wife Michelle is my carer. She’s amazing and has seen me in all sorts of states.”

Michelle has also had to give up her full-time job as a mediator to look after Paul. She said: “I wake up in the morning thinking ‘Is he dead?’ At night, I pray I can hear him snoring so I know he’s alive. People don’t understand the responsibility I feel to keep him alive.”

Daniel Jennings, senior policy and campaigns officer at Epilepsy Action, said: “Long-term health conditions can have a huge impact on people’s

ability to work, as we know that’s often the case for people with epilepsy. We know of many instances in which an epilepsy diagnosis has meant having to leave a job, massively reducing hours or changing career paths completely, and that is never easy.

“Not only are people with epilepsy more than twice as likely to be economically inactive compared to the working age population overall, but the delays they’re now facing in the Access to Work scheme are making it even harder for them to access and stay in jobs.

“New reports now suggesting the sharp increase in economic inactivity is more likely to be driven by people waiting for treatment, as well as by individuals who permanently live in poorer health, show there is a clear need to re-evaluate and address the causes.

“The NHS struggling to cope with demand may be further delaying or preventing people with a condition from being in work, including those who are waiting to be treated for operations, as well as those who need ways to manage a long-term condition like epilepsy.

“Better and faster access to treatment could mean more people, including those with epilepsy, may be able to re-enter or stay in the workforce.”

Epilepsy Action has more information on employment ([bit.ly/3LbSxft](https://bit.ly/3LbSxft)) and the Access to Work scheme ([epilepsy.org.uk/benefits](https://epilepsy.org.uk/benefits)).

## Northern Ireland epilepsy numbers "highly concerning"

Epilepsy numbers in Northern Ireland have been called "highly concerning" by Epilepsy Action following recently published UK epilepsy prevalence and incidence figures.

A UK research team published findings on the prevalence (number of people) and incidence (number of new cases) of epilepsy in the UK's different nations in *Seizure* journal in January this year ([bit.ly/3Lau7Tf](https://bit.ly/3Lau7Tf)). The total number of people with epilepsy in the UK has increased to around 633,000 from 600,000 between 2011 when the last review took

place and 2018. But the proportion of people who have epilepsy in the whole population of the UK has dropped slightly in that time.

However, the research also looked at England, Scotland, Wales and Northern Ireland separately. The findings showed higher rates of prevalence and incidence of epilepsy in Scotland, Wales and Northern Ireland compared to England and the UK overall. It also showed that the prevalence of epilepsy has increased in Wales and Northern Ireland when compared to the previous 2011 review.

Epilepsy Action has expressed particular concern about the numbers in Northern Ireland, especially considering the political situation at the moment.

In Northern Ireland, one in 83 people has epilepsy. This is the highest prevalence among

the UK nations and compares to one in every 107 people in the UK overall. It is also an increase from the prevalence in Northern Ireland in 2011, which was one in 90 people. The number of new cases in Northern Ireland is just over 45 in every 100,000 people a year. This is higher than the UK overall, which is just over 42 new cases in 100,000 people a year.

Carla Smyth, Northern Ireland manager at Epilepsy Action, said: "These new figures around the prevalence of epilepsy in Northern Ireland are hugely concerning and highlight a significant difference between Northern Ireland and the rest of the UK.

"This situation is further exacerbated by the fact that waiting times for neurology appointments in Northern Ireland are the highest in the UK. We have heard from some people who have

been told they face a wait of over four years for an appointment.

"We urgently need all political parties in Northern Ireland to get back round the table, break the current stalemate, restore power-sharing and work together to address the vast problems facing people with neurological conditions like epilepsy."

The research also found that epilepsy levels were a third higher in poorer areas compared to wealthier areas around the UK. This link has been seen before, with Public Health England figures from 2001-2014 showing a three-times higher risk of epilepsy-related deaths in people living in poorer areas compared to wealthier areas.

The *Seizure* paper authors said this link between epilepsy numbers and poorer areas needs more research.



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## Researchers uncover one way CBD stops seizures

A new US study, published in the journal *Neuron*, found that CBD affects a particular molecule in the body that's involved in brain signalling.

In November 2018, it became legal to prescribe CBD in the UK. Since then, one CBD medicine – Epidyolex – has been legalised for use in epilepsy in the UK.

The National Institute for Health and Care Excellence

(NICE) also recently approved CBD for use in people with tuberous sclerosis complex.

Until recently, the way CBD works to help control seizures hasn't been well understood.

The new study, by Evan Rosenberg and colleagues, found that CBD blocks a molecule called LPI (lysophosphatidylinositol).

LPI has been found to strengthen nerve signals

in the hippocampus of the brain, which could lead to seizures. The study has also suggested, for the first time, that LPI weakens signals that stop seizures.

This may explain why CBD blocking this molecule helps to reduce seizures.

The authors said this research adds to our understanding of the way seizures start and can offer another route for new treatment development.

The full study is available at [bit.ly/4IG6ZBE](https://bit.ly/4IG6ZBE).





## Better communication needed about epilepsy medicine risks in pregnancy



More than half of UK women with epilepsy under the age of 24 are not aware of the risks of some epilepsy medicines in pregnancy, a new survey by three epilepsy charities has found.

Epilepsy Action, Epilepsy Society and Young Epilepsy conducted a survey of over 1,200 women and girls with epilepsy across the UK in November and December 2022, to gauge awareness around the risks of some epilepsy medicines if taken in pregnancy.

The Epilepsy Medication in Pregnancy survey showed that 53% of women under 24 years old were not aware of potential risks of taking some epilepsy medicines, such as topiramate, carbamazepine, phenobarbital, phenytoin or pregabalin, in pregnancy.

These medicines, alongside sodium valproate, can increase the risk of babies being born with physical birth abnormalities if taken during pregnancy.

Nearly two fifths (39%) of under 24-year-olds said they

were not satisfied with the information they received about these risks.

Overall, a third (33%) of women taking these medicines were not aware of the risks they carry in pregnancy.

The survey did show that awareness around the risks of taking sodium valproate in pregnancy is improving, with only 9% of responders unaware. However, the level of awareness was different between age groups, with a fifth (20%) of over 45-year-olds unaware of the risks, compared to just 2% of 25-44-year-olds.

The charities say the overall results show that communication around epilepsy medicines and pregnancy must be improved.

Over a third of the responders (36%) said the information they received about the risks from their medicines was not adequate, including one in responders (17%) who said they weren't at all satisfied.

Alison Fuller, director of Health Improvement and

Influencing at Epilepsy Action, said: "While it is encouraging that there has been an increase in the proportion of people who are aware of the risks of valproate medicines, it is very concerning that a significant number of women and girls were unaware of the risks of other epilepsy medicines.

"We have received multiple testimonies from women with epilepsy saying no discussions were ever held with them about the risks of taking certain medications while pregnant, some of which were really upsetting.

"Our report on the survey results outlines recommendations for key stakeholders on how to address safety by communicating the risks of these medications, and ensure that the historic mistakes made with sodium valproate are not repeated.

"These include a national review of pre-conception counselling services to

ensure that all women and girls with epilepsy are provided with the right information, at the right time and by the right healthcare professional.

"We will actively be pursuing and monitoring their implementation.

"We would also encourage all women and girls affected to raise this issue with their MPs, asking them to support our call for a national commitment to fund research on the effects of taking ASMs on pregnancy."

The charities are calling for better communication and more information from healthcare professionals, and more research in the area.

It is vital that anyone taking epilepsy medications does not suddenly stop taking them as doing so could cause breakthrough seizures which could be harmful. The charities encourage anyone with any concerns to talk directly to their doctor about their treatment options.





# Brilliant big brothers

**The first of Epilepsy Action's Epilepsy Stars awards celebrates two brothers for outstanding empathy for their little sister.**

*Words by Rebecca Lock.*

Getting a diagnosis of epilepsy can be an extremely challenging time, fraught with questions, worries and uncertainties. And when a child is diagnosed with the condition, it can turn things upside down for the whole family.

Despite this, two brothers from Northfield, Birmingham, Sam, 10, and Ollie, nine, have shown incredible understanding and support when their little sister Charlotte was diagnosed with epilepsy.

Charlotte was diagnosed with infantile spasms (also known as West syndrome) when she was only a year old.

Mum Jaimee explained: "Charlotte was born in 2016, five weeks early, by emergency C-section. She struggled to feed from the start and was diagnosed with neonatal sepsis. After being given antibiotics for two weeks, she was allowed home and we thought all was well.

"Fast forward to January 2017, when we took Charlotte to A&E and Birmingham Children's Hospital after we noticed she was making some strange movements. Our worst fears were confirmed later that day.

"We were seen by a neurologist who looked at a video of Charlotte [making these movements] and diagnosed her with infantile spasms. In that moment, our lives turned upside down."

The following day, Charlotte had an EEG scan, which showed hypsarrhythmia, a disorganised pattern

of electrical brain activity. She also had an MRI scan, which showed that Charlotte had suffered a stroke.

"Charlotte was immediately started on medication which left our previously happy and smiley child sleeping most of the day. After a month in and out of hospital, Charlotte was taken off this medication and thankfully the seizures stayed away."

Charlotte started having physiotherapy and occupational therapy, as her left side was left paralysed by the damage to her brain.

In 2020, at the height of lockdown, the family faced new challenges when Charlotte began having focal seizures. She has three or four of these a week, leaving her completely exhausted. Charlotte is also dealing with physical disabilities from her stroke, as well as hemiplegic cerebral palsy, a vision impairment and learning difficulties.

Jaimee has been amazed at the way Sam and Ollie have adapted and show their support for their younger sister. She said: "Our family life revolves around Charlotte's care and abilities which often leads to plans changing at short notice. Sam and Ollie always accept this graciously despite the disappointment it can cause.

"During all this time, Sam and Ollie have remained by Charlotte's side. Ollie often sets up his own 'physio school' to encourage Charlotte to complete her physio activities, which he practices alongside her. They've also raised

hundreds of pounds for various epilepsy and children's brain injury charities."

Sam and Ollie are the first winners of the Epilepsy Star awards for their inspiring support of their little sister.

Ollie said: "I'm happy and proud to be the first winner of an Epilepsy Star award. I love helping Charlotte – she is the best sister!"

Sam added: "I'm proud to receive an Epilepsy Star."

Jaimee added: "We're so immensely proud of the boys and would like them to know that we love them and are in awe of the compassion and resilience they show. Often the impact on siblings is not appreciated when a child is given such a devastating diagnosis. It really does affect the whole family and we're grateful to Epilepsy Action for recognising our wonderful boys and giving them this Epilepsy Star award."

To nominate an unsung hero for an Epilepsy Star award, visit: [epilepsy.org.uk/star-awards](https://epilepsy.org.uk/star-awards)



Charlotte, Sam and Ollie



# More than just a call

**When epilepsy suddenly starts to introduce injuries, unpredictability and memory problems to your life, it can be overwhelming. But a phone call can transform everything, just like it did for Amanda.**

*Words by Crispin Northey and Giada Origlia.*

Many might remember the moment they were first diagnosed with epilepsy. For many, it came with feelings of loneliness, isolation and fear. It can be a heart-wrenching and emotional time.

But the Epilepsy Action freephone helpline is here for everyone – both newly diagnosed and already living with epilepsy – to help navigate the difficult times and find the support that they need. Our brilliant helpline team is working hard to answer every call they can. But currently, they are only able to answer three out of every four calls.

Only generous donations from people like you help us to answer that fourth call. But as well as that, it can help us expand our other services, from Talk and Support groups and e-learning online courses to our new one-to-one Befriending service.

And one person who knows, first hand, how much of an impact that first phone call can have is Amanda.

Amanda, from Wallsend, had her first known seizure in lockdown. It changed her life completely.

“It was the day before my son’s 11th birthday. As normal, I went to the bathroom to clean my teeth. That’s all I remember.

“I woke up again. I was in bed and there were two strange men in the bedroom. My husband and my son were in the hallway. It was heart-breaking, because I couldn’t recognise my son at first. I was absolutely petrified,” she said.

The ‘strange men’ were ambulance drivers and Amanda was taken to

It was heart-breaking, because **I couldn't recognise my son at first.** It was absolutely terrifying

hospital. There, she was given a brain scan and doctors could see she had been experiencing seizures.

“I then found out that I had epilepsy and it was a really, really difficult time for me.”

Prior to her first seizure, Amanda had just been promoted at work, and received training to be a paraplanner, helping people with their mortgages. After she



started having seizures and was diagnosed with epilepsy, however, she started struggling with her memory, which had a major impact on her job.

“When I went back to work, I couldn’t remember any of the training or what the job involved. I found it really hard to be there. My memory hadn’t returned and new learning took a lot longer than it had previously. My life changed had changed so much. One day I was being promoted, and the next I had to stop my job and give up my driving licence. I was frustrated and embarrassed.”

I didn't have a clue what I was asking for. I just knew I needed help

After a few months, Amanda had another seizure. This time she was on the treadmill in her garage.

“Everything was going really well and then the next thing I knew, I was on the floor and there was just blood all over. It was awful. At that point, I decided I needed to try and get some more help and that’s when I contacted Epilepsy Action.

“The [helpline advisor] was just absolutely brilliant, she was just so welcoming and friendly. I didn’t have a clue what I was asking for, I just knew that I needed help. She really listened and I felt that she really understood what was going on. I rang a couple of times and I always got the help and advice that I needed and it really reassured me.”

Amanda found out she could download action plans and care plans from the Epilepsy Action website ([epilepsy.org.uk/careplan](https://www.epilepsy.org.uk/careplan)) and they were a real help to her.

“When I look back, I can just see how scared I was, but also how I wanted to try and get back to a point where I could live a more normal life. I only could do

that by following the care plan from Epilepsy Action.”

Due to her condition, Amanda had to give up her job as a paraplanner, but she found out about the Disability Confident Scheme through Epilepsy Action, which led to her getting a two-day-a-week admin job with the NHS.

“It was amazing. It gives you guidance and help to prepare for a role, and when I was successful and I got the job, I took the [Epilepsy Action] employer toolkit in with me. Everybody knew what to do if there was an emergency. If it wasn’t for that toolkit, I think I would have been really scared to go into work.”

Amanda now also runs her small business alongside this.

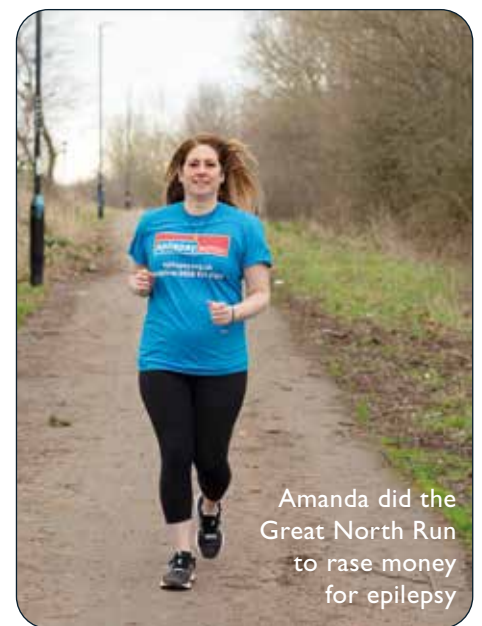
“It’s one of my biggest achievements. At the beginning of this journey, I never thought my learning skills would come back, but they have!

“I am now a fully qualified holistic therapist. Personally, I feel epilepsy took me down the path to receive holistic therapies, so much so that I wanted to share this with other people. It really puts a smile on my face, and I may not be doing it now, had I not had my seizures,” said Amanda.

Amanda also attended an Epilepsy Action Talk and Support group.

“I am so glad I attended those sessions. I had felt so alone and scared, even though I had so many friends and family around me offering help. No-one understood what was going on in my head. So it was good to share with a group who did get it. I’m in a better place now and the future looks a lot brighter!”

You can donate by visiting [epilepsy.org.uk](https://www.epilepsy.org.uk) **Amanda** or calling us on 0113 210 8851.



Amanda did the Great North Run to raise money for epilepsy



Amanda called Epilepsy Action for help and felt listened to and understood





## Wales weather presenter stars in epilepsy documentary

A new documentary has aired on the channel S4C, raising awareness of epilepsy to Welsh-speaking TV audiences.

The programme, *Drych: Alex Humphreys: Epilepsi a Fi*, aired on Sunday 16 April and featured weather presenter Alex Humphreys sharing her epilepsy story and speaking to other people about their experiences.

The documentary explored the subject of epilepsy and also scientific discoveries in the field.

Alex has avoided speaking or thinking too much about the condition over the years, but she still remembers what it was like being diagnosed.

“I've had a lot of time to come to accept it. I remember asking the doctor if the condition was going to disappear, if it was going to get better. They said it would be possible in a few years, but now I know I'll have it forever.

“I had my first seizure when I was 17 years old, and at the time I was staying at my grandparents' house. I remember

feeling like I had a cramp in my leg, which woke me up. The feeling continued to get stronger and stronger to the point where my body felt like it was breaking. It was as if I could feel myself screaming but I couldn't hear myself, which was strange. I'll never forget that, and I don't talk about it a lot.”

Alex said that she doesn't know much about epilepsy, but she's reached the point where she's eager to learn more. She said she feels that much of the ignorance surrounding the subject exists because it's not widely discussed – partly due to the taboo associated with it.

“I don't hear people talking about epilepsy in the same way they talk about other [conditions] like diabetes, asthma or Parkinson's. Unfortunately, I think the ignorance about epilepsy still exists because we don't talk about it enough. It's like we don't want to acknowledge that we have the condition, and I'm just as guilty as everyone else.”

Jan Paterson, Wales manager at Epilepsy Action, said: “This programme will highlight why it's important to talk about epilepsy, especially with the stigma there is around the condition.

“Alex has gained a good insight into her epilepsy and how she felt growing up struggling with the diagnosis and having to rethink her career. Alex now feels she is ready to talk and learn about her journey, most of all why it's important to talk about epilepsy to break down barriers around the condition.

“I had the pleasure of working with Hall of Mirrors on this documentary from the start, I was able to be the link between clinicians and patients, where they were happy to participate.”

You can watch the documentary on BBC iPlayer at [bbc.in/3KDnva](https://www.bbc.com/iplayer/epilepsy-action) and subtitles can be switched on for non-Welsh speaking viewers.



Alex, Katie (who took part in the documentary) and Jan

## Running and raising



Harry

Harry Clarke, from Newtownabbey, is raising money and awareness of epilepsy after being diagnosed with the condition.

The 22-year-old is committed to raising money for Epilepsy Action Northern Ireland, after his parents got a lot of information from the Epilepsy Action website when he was first diagnosed at 17.

Harry has mostly tonic-clonic seizures. He has faced many struggles with his epilepsy, including cluster seizures, having to delay applying for his drivers licence and dealing with misconceptions.

“Sometimes I can foam at the mouth, which can be associated with taking drugs. It’s sad to think that’s the impression someone had,” he said.

With no family history of epilepsy in his family, Harry said he didn’t know much about the condition before he was diagnosed. “It’s been five years since my first seizure, so I am pretty clued in now about epilepsy, as there is a lot of information out there,” he explained.

He is now on epilepsy medicines and has been seizure free for nearly three years.

Harry has fundraised for Epilepsy Action Northern Ireland for a few years, particularly enjoying running events. He started with a 10K run a few years ago, and has raised around £500, which has gone towards providing free services for people with epilepsy in Northern Ireland.

Harry is hoping to raise more money for epilepsy at the Run the Runways in Newtownards in May this year.

## Twelve-year-old earns bravery award

A twelve-year-old girl has been given an award for her bravery after calling an ambulance when her dad had a seizure.

Lily-Alice Foster, from Nottinghamshire, received the Laverick Award from the East Midlands Ambulance Service (EMAS) in April 2023.

Lily had been staying with her dad, Lawrance, 34, at her grandparents’ house in December 2022, when she found him in the midst of a seizure on the sofa. She was alone in the house with him, as her grandparents had gone out. Lily said she hadn’t seen her dad have a seizure before, but she realised what was happening and called 999.

The call handler at EMAS, Christopher Turk, said at first she had been very upset but called her “brilliant throughout”.

With his guidance, Lily had been able to find the address of the house by looking for letters, and had unlocked the doors, ready for the ambulance crew.

Lawrance’s epilepsy had started following a head injury in November 2021, which had left him in a coma for a few months. He had had a metal plate

fitted inside his head. His seizures started around a month after leaving hospital.

Lawrence explained he gets warning signs that a seizure is coming on. He felt these signs and laid down on the couch waiting for the seizure.


He said: “I was devastated that Lily was on her own with me at the time, as she had never witnessed me have a seizure before that day, but I am so proud of her at the same time for how she handled the situation.”

The ambulance crew who arrived at the house commended Lily for having put her dad in the recovery position after his seizure, ensuring his airway was clear.

The award recognises children and young adults who have gone above and beyond to help another person.



Lily-Alice receiving her award from the ambulance crew



Blood tests could help tell epilepsy from dissociative seizures

# Mixed seizure disorders

**Diagnosing epilepsy can be hard enough, but for some people, there might be more than one condition contributing to their seizures.**

Words by Kami Kountcheva.

One of the most frustrating things for people can be trying lots of different epilepsy medicines and finding they aren't working for their seizures. For many people, it could be that their particular form of epilepsy is drug-resistant and their neurologist has to find an effective combination of epilepsy medicines, or another option, such as surgery or vagus nerve stimulation (VNS).

But for some, there could be a different seizure disorder that is at play.

It exists under a few different names. Some people call it dissociative seizures. Others will have heard of non-epileptic attack disorder (NEAD), psychogenic non-epileptic seizures (PNES), or functional seizures.

This is a different seizure disorder from epilepsy. Like epileptic seizures, dissociative seizures involve uncontrolled movements, sensations or behaviours. But

unlike epilepsy, these are not caused by abnormal electrical activity in the brain.

Instead, health professionals think they are a physical reaction to distressing triggers, like sensations, thoughts, emotions or difficult situations. A study from 2023 from the journal *Epilepsia* reported that people who have dissociative seizures tend to report a background of childhood trauma more often than people with epilepsy. This could include things like emotional or physical abuse or neglect in their past.

Around one in five people who go into hospital for seizures are diagnosed with dissociative seizures. However, these can sometimes be misdiagnosed as epilepsy, meaning people might be needlessly taking epilepsy medicines for years before getting the correct diagnosis. A 2020 study from Italy said that between four and five in 20 people who go in for video EEG monitoring for drug-resistant epilepsy are

later found to actually have non-epileptic events. They said the majority of these are dissociative seizures.

According to the International League Against Epilepsy (ILAE), on average, it can take between 7-10 years for a case of misdiagnosed epilepsy to be correctly diagnosed as dissociative seizures.

But things become even more complicated for those people who have both conditions.

## Link between epilepsy and dissociative seizures

A 2015 review in the journal *Epilepsy & Behavior* estimated that the number of people with dissociative seizures is between 2 and 33 in every 100,000 people. The authors said this makes it a "significant neuropsychiatric condition". They found that the number of new cases of dissociative seizures were somewhere between one and five people in every 100,000. However, the study authors stress that there are still not enough data around how common dissociative seizures are, and that the studies that currently exist might not be giving a clear enough picture.

According to another study, published in 2021 in the journal *Acta Epileptologica*, people with epilepsy have a higher risk of developing dissociative seizures than people without epilepsy. Also, around 1-3 in 10 people with dissociative seizures will also have epilepsy.

The study authors called a combination of epilepsy and dissociative seizures a "particular diagnostic challenge".



### Diagnosing dissociative seizures

At the moment, specialists will sometimes be able to identify dissociative seizures from the way they appear. The 2021 study shared some features of seizures that might inform specialist that the seizure is dissociative, which include longer-lasting seizures, changes in the severity of the condition and crying during seizures. Certain movements, such as pelvic thrusts, the body or head moving side-to-side and closed eyes and mouth could also suggest that a seizure is dissociative. After a dissociative seizure, people might also be less likely to feel confused and more likely to remember the seizure experience.

Other ways clinicians may identify dissociative seizures in someone with (or without) epilepsy is if they are not responding to epilepsy medicines, if they have frequent trips to hospital or if they are developing new seizure types.

The study authors added that home videos of a person's seizures can be helpful, and if a doctor suspects dissociative seizures, they may want to do a video EEG.

Some research has even looked at whether wearable technology could be used instead of video EEG to distinguish between dissociative and epileptic seizures. The researchers explained that while video EEG is an important way to identify dissociative seizures, it can take a lot of resource, it can't be done over long periods of time, and it may not always be available.

The device in their study, published in *Epilepsia Open* in 2019, uses movement data to sense seizures and a programme identifies whether it is epileptic or dissociative. While the device sometimes picked up seizures when there weren't any happening, overall, it appeared to diagnose seizures with the same effectiveness as epilepsy specialists looking at video EEG. However, more and bigger studies are needed to confirm the findings.

### New research to help with diagnosis

As well as this, there are some other exciting new studies which are also working towards making diagnosis of dissociative seizures and epilepsy easier.

A study in *Seizure* journal from 2022 set out to find out if the level of the hormone prolactin in the blood could help differentiate between dissociative seizures and epilepsy.

The group reported that the level of prolactin was significantly higher in the blood after a convulsive epileptic seizure than a convulsive dissociative seizure or a convulsive faint. The authors found that the presence of a 'normal' level of prolactin in the blood could be used to identify convulsive dissociative seizures. They added that it could also be useful to identify non-convulsive dissociative seizures, but that the numbers were too few in their study to draw a firm conclusion.

Another study, published in *Heliyon* in 2023, also looked at the possibility of using a blood test to identify epilepsy and dissociative seizures. The researchers found that the level of a protein in the blood, called IL-6, was higher in people with frontal or temporal lobe epilepsy. It was also elevated in people with both temporal lobe epilepsy and dissociative seizures, but was not increased in people who just had dissociative seizures. The researchers are now looking to repeat their research in a broader group of people, hoping to confirm their findings. There is more on this study on page 24.

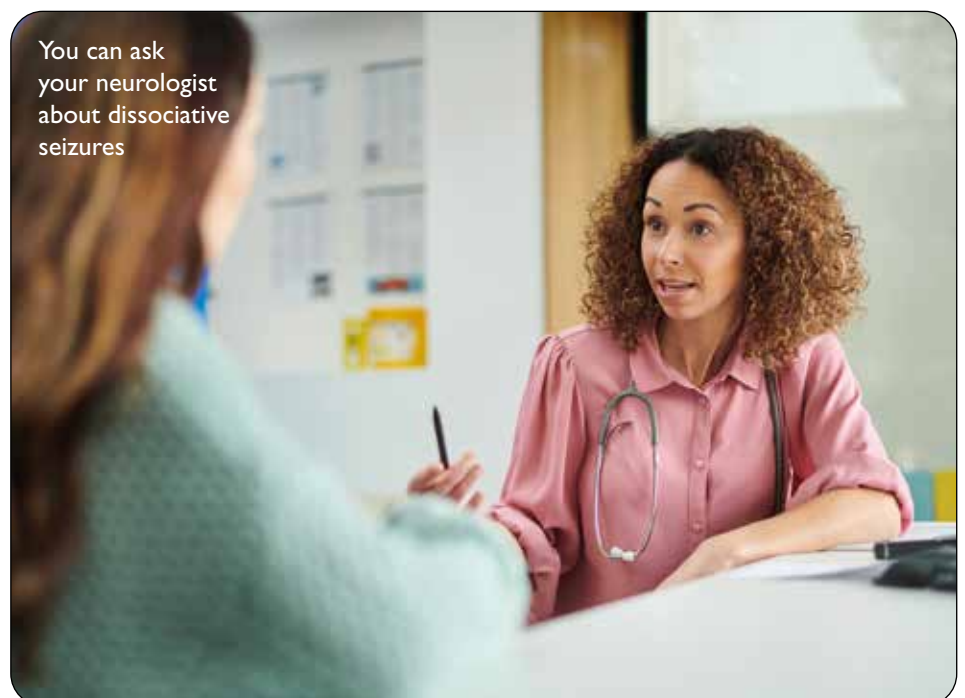
### Treating dissociative seizures

The way dissociative seizures are treated is with psychological therapy, also called talking therapy. This could be cognitive behavioural therapy or counselling. These can help people understand if there are any triggers for their seizures, and teach techniques to help manage them.

Epilepsy medicines will not work for dissociative seizures. People with both conditions may continue to take their epilepsy medicines as well as having talking therapy. For people who may have been misdiagnosed with epilepsy but are found to have dissociative seizures, their doctor will help them to safely reduce and stop the epilepsy medicines.

It can be really difficult for a person to know if they may have epilepsy, dissociative seizures, or both. Especially when epilepsy medicines aren't working well or at all for their seizures. But knowing about dissociative seizures means that you can ask your neurologist about them if you have any questions or concerns about your diagnosis, and it could help unravel the situation.

There is much more information about dissociative seizures, first aid and places to find more support on the Epilepsy Action website: [epilepsy.org.uk/dissociative-seizures](https://www.epilepsy.org.uk/dissociative-seizures).



You can ask your neurologist about dissociative seizures



# Armed with knowledge

**Myths and misconceptions can have very real consequences for people with epilepsy. This Purple Day, we set out to bust myths and we amplify the voices of people with epilepsy.**

*Words by Giada Origlia.*

The epilepsy community celebrated Purple Day on 26 March 2023. Fifteen years since the first Purple Day was held, this event is still incredibly important for epilepsy.

Despite being one of the most common neurological conditions, epilepsy is still very much misunderstood among people who don't have a connection to it. Awareness is slowly rising, but there is still a lot that people with epilepsy wish was just simply common knowledge. And not only that, but there is a lot that is believed out there, which needs to be debunked.

Purple Day gives people the epilepsy the occasion, motivation and encouragement to share their experiences – and with every story, more and more people understand epilepsy better.

It's a daily activity for us at Epilepsy Action to share factual and correct information about epilepsy. But Purple Day also gives us a great opportunity to really get the message out there.

### **The three most common myths**

Marking this year, we investigated public attitudes towards epilepsy and asked people affected by the condition to share their feelings and experiences. Over 2,000 Epilepsy Action supporters took part in the survey. We wanted to encourage an open and honest conversation about the condition and bust some myths in the process.

The new survey findings showed that nearly nine in 10 people (89%) believed at least one myth about epilepsy. Almost three in five people (58%) also admitted not knowing much about epilepsy.

As part of Purple Day, we debunked the three most commonly-believed myths about epilepsy. And we bet they won't surprise you.

#### **1. Flashing lights are the biggest seizure trigger for people with epilepsy**

According to the survey, this was



the most widely-accepted myth, with over half of people (53%) believing it. It feels like everyone with epilepsy will have heard this one at one time or another. But, in reality, flashing lights can be trigger for people with photosensitive epilepsy, who make up just 3% of people with epilepsy. And not all people who are photosensitive will be affected by flashing lights, as seizure triggers can vary from person to person.

**2. If you see someone having a seizure, you should call an ambulance straight away**

Over a third of people in the survey (36%) believed this myth. While this might be understandable if someone isn't sure what is happening when someone is having a seizure, it's an important one to shed light on. This is actually not necessary in most cases, unless a seizure goes on for longer than five minutes, the person has one seizure after another without recovering in between, they have difficulty breathing after the seizure has stopped or they have seriously injured themselves. A lot of people don't want to make unnecessary trips to A&E, and it saves an already strained NHS time and resources.

**3. If you see someone having a seizure, you should restrain them to prevent them from getting hurt**

Almost one in three people (32%) believed this to be the case, but it could actually be dangerous. It can affect a person's airways, and cause injury and distress.

**“Always the weird kid”**

Meanwhile, the answers from people with epilepsy themselves showed that almost four in five respondents (79%) believe they are treated differently because of their condition. Two in five (40%) said the lack of public understanding is one of the biggest challenges.

The responses from the public did seem to reflect this as well. Almost a

third (31%) of respondents said they would be uncomfortable about dating or being in a relationship with someone if they knew they had epilepsy. Just over a quarter (27%) said they would be unsure about employing someone with the condition.

When asked to define their condition with just one word, people with epilepsy most commonly described it as “unpredictable”, “frustrating”, “misunderstood” and “challenging”.

Twenty five-year-old Amy, from Swindon, said she would describe her epilepsy as “lonely”. Amy was diagnosed with epilepsy as a small child, initially with absence seizures, which later developed into tonic-clonic seizures.

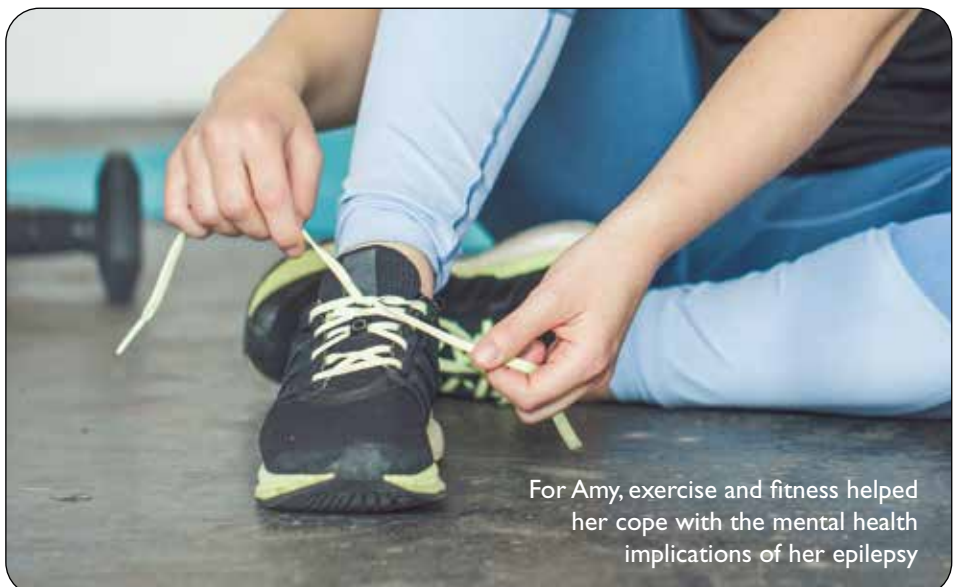
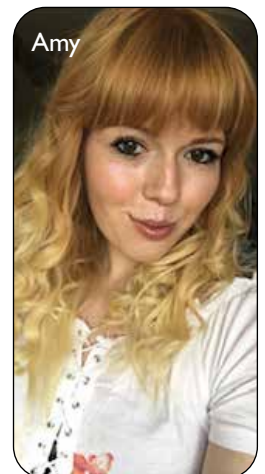
“Epilepsy has had a major impact on my life. I was diagnosed when I was just one and a half, and in my childhood, I remember feeling so alone. I was always the weird kid who was staring, or daydreaming,” she said.

Amy said she has endured stigma around her condition all her life, from society, employers and even friends. Because of this, she is passionate about educating the wider public and raising awareness about the condition.

“I feel there just isn't enough education out there. I want people to know epilepsy isn't just seizures. It's constant hospital appointments, constant medication changes, fear of not waking up the next day, side effects of medications, relationship issues. And, most of all, it's judgement from people who don't understand it.”

Epilepsy can cause serious mental health consequences to those affected by it. For Amy, it was depression and anxiety. But she found exercise and fitness were a powerful way for her to cope with the mental health implications of the condition, and is now on a journey to become a personal trainer.

“When I was 18, my specialist told me something that has inspired me and stuck with me ever since. His words were: ‘You can either let epilepsy take over your life, or you can beat it.’ This is when my personal training journey started. I



For Amy, exercise and fitness helped her cope with the mental health implications of her epilepsy





Emma

told myself: 'I'm doing this for me. If I fight these seizures every day, I can definitely do this.' The best thing I ever did was turn my pain into power," she said.

### **"I can never predict which one I'll get"**

For Emma, 32, from Essex, the word would be "unpredictable". Emma was initially diagnosed with the condition at six years old. As a teenager, she discovered she had a rare, drug-resistant form of epilepsy called Dravet syndrome.

"I have two types of seizure, absence and tonic-clonic, and I can never predict which one I'll get. I also don't get any warning for my seizures, which has meant I have sometimes had one in dangerous places, like train platforms, zebra crossings and swimming pools," said Emma.

Because of her epilepsy, Emma has faced barriers in both education and employment, often due to a lack of understanding of the condition.

"School was not a happy time in my life. By year 11, I was having seizures so often that I kept missing school, and I was also

struggling with medication side effects, which impacted my GCSE results.

"While I was at college, my mental health declined even more. I was determined to be 'normal', and behaved as if epilepsy didn't exist. I drank a lot. I went out a lot. And I also reached my lowest point mentally."

And work was just as challenging for Emma at first. She was put on disciplinarys because of the number of seizures she was having, despite this being totally out of her control. She was also being avoided by her colleagues out of fear she would have a seizure in front of them. But despite the challenges she faced, Emma is now thriving in her personal and professional life.

"I am very proud of myself. Despite my challenges within school and previous workplaces, I have completed a Business Administration course, which I would consider my biggest achievement so far. I have worked my way up to an Executive Assistant role within a charity. I love what I do."

### **"Beyond the health implications"**

Rebekah Smith, deputy chief executive at Epilepsy Action, said: "Despite it affecting over 630,000 people in the UK, epilepsy is still not talked about enough. And when it is, it's often reduced to stereotypes.

"But the reality is much more complex and varied. While it's understandable not everyone will know everything about epilepsy, we need to take steps to talk about it openly, and we need to break down the stigma that still surrounds it.

"Misconceptions have very real consequences for people with epilepsy, that go beyond the health implications of it. We hear multiple testimonies from people who have been treated differently because of their condition, whether this was at work, at school or in relationships.

"While this doesn't always come from a place of discrimination, it does contribute to the stigma, to making people feel like they don't belong, or that they're viewed negatively because of something they can't help."

This Purple Day, we aimed to help tear down these barriers by asking members of the public to listen to the experiences of people with epilepsy and to take a step to learn a little bit more about it.

If you are finding yourself in need of more support and information, we are here to help. You can call the Epilepsy Action helpline on freephone 0808 800 5050, or you can email [helpline@epilepsy.org.uk](mailto:helpline@epilepsy.org.uk).

You can also find helpful information on our website – [epilepsy.org.uk](http://epilepsy.org.uk). It's also a great place to direct anyone who is open to better understand epilepsy, as there is a wealth of information about different seizures and lifestyle challenges.

Until the next Purple Day, we will continue to work to bring epilepsy into the spotlight, and help make sure people with epilepsy feel safe and understood.

# What are we up to?

Words by Kami Kountcheva.

Our aim at Epilepsy Action is to improve the lives of those living with epilepsy. And that comes in a lot of different ways. We are here to support those who are in the thick of it with their epilepsy, through our helpline, Talk and Support groups and support schemes. We are here to make things fairer for people with epilepsy, through things like campaigning for better benefits. We are here to make everyday life better for people, by making epilepsy, in all its shapes and sizes, better understood.

Supporting the organisation feeds into all of these different aspects of our work – and more. And it's really great to be able to see it happen and see how far your support goes. We will always do our best to keep you up to date through the magazine, but here we share a few other key places where you can keep an eye on our work in between.

## Keeping epilepsy on the agenda

A good understanding of epilepsy among the general public is a big thing. On the smallest level, it means people don't always have to explain their condition and what it means to someone new. But more than that, it can mean that a person is safe when they have a seizure in public, because people will know how to help. And it can mean more fairness, if, for example, benefits assessors have a better understanding of how epilepsy affects people's lives outside of seizures.



We are talking about epilepsy every day – from the fun and the good news, to the hard-hitting and tough stories. You can see daily updates on Twitter, and keep abreast of epilepsy stories and our work, such as our campaigning around the cost of living.

## A chance to connect

Helping people forge connections with others in the same situation is another huge part of our work. We hold a number of face-to-face and virtual Talk and Support groups to help people meet and interact with others ([bit.ly/40IzOg0](https://bit.ly/40IzOg0)). But for those that are not feeling especially comfortable sharing their story yet, we also host live conversations on Instagram. We've had some fantastic guests and have covered some really important topics, from helpline questions to love and relationships and losing someone to epilepsy.



It's great to be able to see how far your support goes to help us carry out vital work. Here's where you can see more

## Events, stories and help for you

For those of us who prefer longer-form content, you can find some fantastic personal stories, raising awareness of life with epilepsy, on our Facebook page. It's also a great place to see work we're doing, from our Let's Talk About Epilepsy events, to appeals, new services around the UK, campaigns and even our awards!



## Inform in short form

If you want short, punchy video bulletins with helpful information, more from our campaigns, and maybe even some purple tutus, the place to be is TikTok. Well worth having a look!





epilepsy  
feature



WEAR MONICA'S STORY:





# More than seizures

**Tolly started a project with his friend Charlie to try to show how much more than seizures epilepsy is. When his friend Charlie died, Tolly continued with the project, aiming to bring more light to this misunderstood condition**

*Words by Tolly Robinson.*

#MoreThanSeizures was a project that I was supposed to do with my friend Charlie.

He invited me to work with him on visualising his epilepsy in a photography project and asked me to video him when he next had a seizure.

I refused.

As his close friend, I wasn't going to get my camera out when I should be keeping him safe from harm.

When asked why he was asking this of me, he explained that everyone else saw his epilepsy at its most public - when he collapsed due to his seizures.

Everyone, that is, aside from him.

He had tonic-clonic seizures and was therefore unconscious during these periods. I witnessed Charlie have many seizures during our friendship. I remember them being quite scary to someone who had never seen one.

However, as our friendship grew, Charlie told me how I could help - to protect him from harm, call the ambulance if they

went on for too long and be reassuring when he came round. Although simple and minimal, the agency this gave me afforded me a much needed toolkit to deal with his seizures. Once I knew what to do, the panic I felt disappeared.

However, the calm manner with which Charlie's friends, family and I dealt with his seizures was often in direct contrast with the responses of others when his seizures took place in public.

Strangely and frustratingly, it is these 'public' seizures that stick in my mind the most. I would love to see a world where seizures were met in the same caring way that his were when they occurred in private.

For Charlie, having epilepsy meant being in a state of near-constant vigilance – choosing to stand on carpet rather than concrete, or avoiding escalators so that if he were to have a seizure, he would minimise the possible damage.

At this point I had known him for the best part of a decade. Yet I had never realised the way he navigated the world was completely different to me.

He invited me to get involved in a photography project that looked at making this visible to people who didn't have the condition. He showed me a post he had made on Epilepsy Action's forum that invited other people that



Monica's head begins to pound if she spins around too much.



Derrick says his epilepsy has made him more understanding and compassionate

The first person I met was Monica. She has had epilepsy since she was 17. Thanks to a particularly nasty seizure on a flight of stairs, her condition broke her back and gave her a bleed on the brain. It also, understandably, left her with a severe wariness of steps, and the camera that I gave to her came back with numerous images of them.

Epilepsy seeps into her everyday life though, controlling how she cooks (lots of timers so as to stay away from the hob as much as possible) and even, how she plays with her children.

“It’s that vibration, that shock inside my head... Which sucks for me, but also the boys, because I can’t be that fun, spin-them-around kind of mum.”

The condition has not beaten her though, and has, in fact, pushed her on to get her dream job as a children's epilepsy specialist nurse.

Some of the other photos I got back were quite mysterious. Samantha for example sent back quite a few empty frames.

She was pregnant when she received the camera and at that time, her morning sickness was preventing her from leaving the house, so she couldn’t get the images she wanted.

had epilepsy to share these elements of their lives. The large number of replies underlined just how prevalent this was for them.

Charlie died suddenly due to his epilepsy in 2021.

We never got round to achieving the project together. Yet, in his passing I decided to continue it.

As someone who doesn’t have epilepsy, my first question was whether I could, without Charlie’s help, approach the

subject. Ultimately, I decided I could, provided I work closely with people who have the condition.

Thanks to the wonderfully generous spirit of the people pictured here, and who continue to agree to be part of the project, I am pleased to say that MoreThanSeizures is able to exist.

As you will see, each person was given a camera and asked to take photos of ways in which epilepsy impacts their life. The results I get back are remarkably varied.

But, when coupled with her epilepsy, the morning sickness provided another issue. Samantha's condition had been well controlled by medication for a number of years. However, her inability to keep things down was putting this in jeopardy. For the first time in a long time, the chance of another seizure was becoming more likely.

These blank images took on, for me at least, a new meaning – one of the unknown.

Other people approached the project in a more abstract way, sometimes managing to look at their condition in a positive way.

Derrick, a railway worker and vlogger, for example, sent me a picture of an ugly street. When talking about this image he said: "Don't get me wrong, it's not pleasing to have epilepsy, but at the same time I feel like it's made me become so much more compassionate, so much more understanding and just so much better a person. So even though something might look not aesthetically pleasing, doesn't mean that we should judge it."

The project has proved to me that people's experiences of living with epilepsy are very varied. I was naively worried at the outset that the project would become too 'samey'. However, I was staggered by the breadth of

experiences and perspectives that people sent me - epilepsy seemed to mean something different to each person. That is not to say that they are not certain commonalities however. One of the strongest themes that came through from all participants was the gratitude that participants felt towards their friends and family.

These similarities and differences came out at one point in the project. In some of the videos I made, I gave participants other people's negatives to look at. There were some images that the participant

recognised instantly. Other photos, however, remained an enigma despite the shared experience of epilepsy.

I want more people to understand the condition – both in its severity and its complexities. Charlie wanted to let people know that epilepsy was more than just seizures. If this project does this in any way, I will be happy.

These are just a few people from the project, which is continually expanding. If you would like to find out more, find us on Instagram as [@morethanseizures](https://www.instagram.com/morethanseizures)







# What's new?

**We share some very cool and exciting recent advances in epilepsy research.**

*Words by Kami Kountcheva.*

Watching Sci-Fi films can sometimes feel a bit like a bit of a glimpse into the future we want to see. Not necessarily the space wars and the aliens and trying to grow potatoes on Mars, but definitely the technology.

We've seen it lots of times before. Our protagonist is injured. She lies down in a pod, a laser scans her from head to toe and a computer has instantly and accurately diagnosed everything that's going on. She punches a few instructions into a translucent air keyboard that has appeared before her, and a few robot arms come out of the pod and expertly start to fix all her ailments.

It sounds pretty good, doesn't it? And if we can think it up, maybe some of our brightest minds will try to figure out a way to make it happen.

But until then, we're taking baby steps in the right direction. And baby steps can feel like giant, zero-gravity moon leaps with the difference they could make. Maybe not a Sci-Fi pod, but how about a blood test to diagnose epilepsy? Or a pill that might stop epilepsy from developing?

We share some very exciting new advances in medicine that might soon change medical care for people with epilepsy.

## **A new hope**

An old cancer medicine is providing hope for people with epilepsy, as scientists from

the University of Melbourne in Australia believe it could stop epilepsy in its tracks.

The medicine, known as sodium selenate, has been around for over 10 years as cancer treatment, but recent studies have shown it could hold potential for epilepsy treatment.

In 2016, a group of researchers from Australia looked at the ability of sodium selenate to treat epilepsy in animal models. The group looked at models of epilepsy, status epilepticus and post-traumatic epilepsy.

The study authors, Shi-Jie Liu and colleagues, believed that, in epilepsy, a protein in the brain called phosphatase 2A would become reduced and this would increase the amount of another protein called tau. Tau has long been associated with causing damage to brain cells in disorders such as Alzheimer's and dementia.

In their study, published in the journal *Brain*, the researchers treated the different forms of epilepsy with sodium selenate. They found that this medicine increased the amount of phosphatase 2A and reduced tau and its effects. They said that continuous treatment with sodium selenate lessened the progression of epilepsy (known as epileptogenesis) and other problems caused by the epilepsy, and this continued even after the medicine was stopped.

Another study from this year looked at the effect of sodium selenate on animal models of temporal lobe epilepsy (TLE). The researchers, Pablo Miguel Casillas-Espinosa and colleagues, explained that there have been some reports that this medicine could stop TLE from developing in the first place, but we can't yet tell ahead of time if TLE might develop.

In their study, they investigated animals who already had TLE, and again found that sodium selenate had a "disease-modifying effect" on the condition, including improving learning and memory problems linked to the epilepsy.

All of that sounds really promising. And the particularly exciting part is that this medicine isn't only treating seizures. It

appears to be reversing the worsening of the epilepsy itself, and other linked conditions, in the studies done on epilepsy so far.

Now, the team in Australia will carry out clinical trials on humans, starting in October, to see if the effects of this medicine are similar in people. They have been given a Medical Research Future Fund of \$3 million for this research.

Lucy Vivash is one of the researchers, who will lead the clinical trials. She told the Herald Sun: "Right now, the data we have is showing that a proportion of the animals in the preclinical study stopped having seizures altogether, with the remainder having fewer, less severe seizures.

"We suspect reducing the amount of the toxic forms of tau can alleviate symptoms of disease and prevent ongoing symptoms. It may be curative."

The studies on sodium selenate are available online at: [bit.ly/3KxYNh2](https://bit.ly/3KxYNh2) and [bit.ly/3UgsO8b](https://bit.ly/3UgsO8b).

### Answers in the blood

Diagnosis in epilepsy can be tricky. For some people, it can be fairly quick. But for others it can take a long time and numerous tests to get there. But a research team from Lund University in Sweden may have found a faster and easier way to know if a person has epilepsy.

Matilda Ahl and colleagues published their research in *Heliyon* in March, in which they found that there are higher rates of a protein called IL-6 in the blood in people with epilepsy.

The researchers investigated 56 people with epilepsy, split into four groups: those with temporal lobe epilepsy (TLE), frontal lobe epilepsy (FLE), psychogenic non-epileptic seizures (PNES), and combined TLE and PNES.

The scientists confirmed patients' seizures using video EEG and knew if they were taking blood samples before or after seizures.

The study found that levels of IL-6 in the blood were higher in people with FLE and TLE, including in the group of people who

had both TLE and PNES, compared to people without epilepsy or PNES. After a seizure, the levels of the protein increased even more in people with TLE, but not in people with FLE.

The results also showed that the IL-6 levels were not increased in people with PNES.

Marie Taylor, part of the research team, said that investigating whether someone has epilepsy or PNES takes a lot of resource. She said: "It may require the patient to be admitted to hospital for several days with constant video and EEG surveillance, with medical staff on hand around the clock. It is hard on the patient that it takes time to reach a diagnosis."

The researchers said the next step is to repeat the research in a broader group of people, including both adults and children.

The full research is available on the Heliyon website at [bit.ly/41IAT2C](https://bit.ly/41IAT2C).

### Hooray for spray

Rescue medication can be tricky to administer. It could require an IV or may need to be given rectally. These options can be challenging and inconvenient. But other options have been developed, which can make it simpler, including buccal midazolam, given in a person's cheek, and a midazolam nasal spray.

Recently, a meta-analysis, a study which looks at a number of different independent

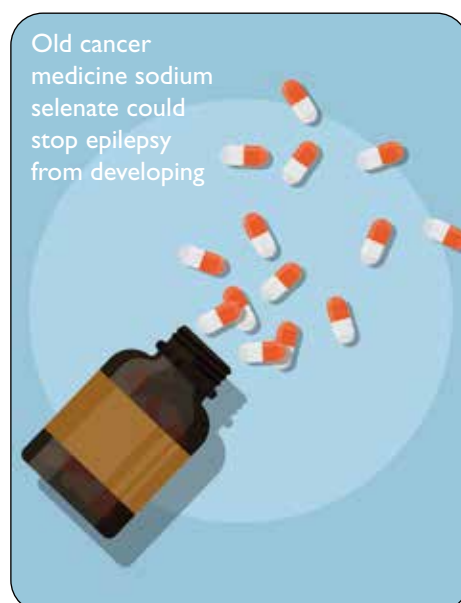
studies, has concluded that midazolam nasal spray is safe and effective in managing cluster seizures. These are seizures that happen quickly one after the other.

Published in *Cureus*, the meta-analysis included three studies that met the criteria set by the researchers, Niraj Niraj and colleagues.

The meta-analysis found that 5mg of midazolam nasal spray was as safe as receiving a dummy medicine. The researchers also found that after receiving the nasal spray, people were either seizure free for six hours or more, or the seizure stopped within 10 minutes and the person remained seizure free for between 10 minutes and six hours.

The researchers called the nasal spray effective in treating cluster seizures, and found it to be well tolerated, with its use being considered "relatively safe". The meta-analysis is available at: [bit.ly/3KcEK67](https://bit.ly/3KcEK67).

These feats of research are really exciting and have the potential to speed up and vastly improve epilepsy treatment for many people. Research is constantly pushing to improve care in epilepsy, but progress can take a long time and a lot of money and trials. That's what makes visible advances like this all the more exciting and builds our hopes for the future.



# My journal



Retired school teacher Anne explains how epilepsy has affected two of her grandsons, what she believes is needed in schools and why she wrote a children's book about epilepsy



Joe and Anne

My husband William and I have 13 grandchildren – with another expected in August! Our eldest is Joseph, or Joe, who is 16 years old this year. He has uncontrolled epilepsy, having had seizures since the age of five years old.

In January 2021, Toby was born. He has Sturge Weber syndrome, a rare neurological and skin disorder which appears at birth, associated with a port wine stain on the face. This condition also leaves him periodically vulnerable to seizures.

## Joe

Joe is a bright, happy and sensitive young man who tries hard in school. He enjoys cooking, football and ten pin bowling – just a few of his favourite activities.

I'll never, ever forget the first time Joe had a seizure and the worry and anguish it caused us. He was at home with his family when he started his convulsions. Not knowing why this was happening, Joe was rushed into hospital in an ambulance. He stayed there for several days because the seizures didn't stop.

His father called us, as we were on holiday, and explained what had happened. Needless to say, we were in close communication with his parents, eager to know why this was happening.

On returning, we went to visit Joe, who had been through several tests and was looking very poorly. The seizures stopped and the doctors thought it had occurred due to a high temperature caused by an infection. However, that was not the end of the seizures because, from then on, they never stopped.



The consultant at Alder Hey Children's Hospital in Liverpool told us Joe was "in for a hard time" – that's something that I have never forgotten, because he was right.

When Joe was first diagnosed, it was the start of a learning curve for him and the rest of the family. He was aware of the seizures after they happened, and called them his 'poorly times'. However, he has always remained strong and determined.

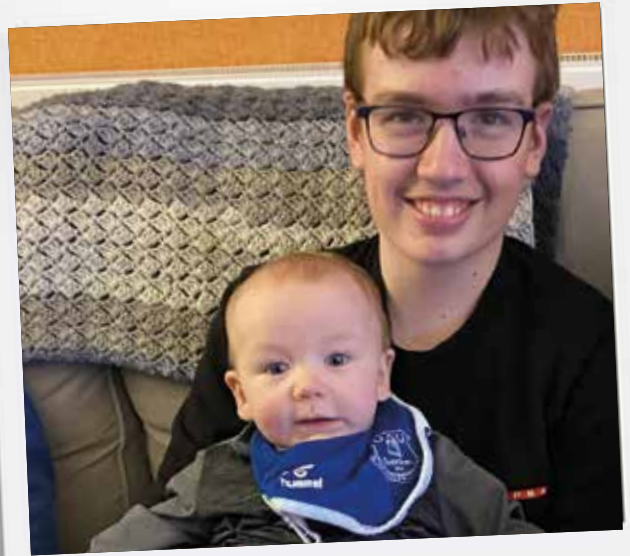
Joe has tried 12 different medications, including CBD oil, which wasn't prescribed. He has had seizures for over 10 years. Initially, he was having them every other day. This pattern has changed frequently over the 10 years, and, on some occasions, he has had spells of four or five weeks without having a seizure.

*The consultant at Alder Hey Children's Hospital in Liverpool told us Joe was "in for a hard time" – that's something that I have never forgotten, because he was right*

Now, he takes Briviact and lamotrigine, and he tends to have seizures in monthly clusters, with them concentrated over



*Anne with Joe and his brothers*



*Joe with his baby brother*

three to four days. These seizures can make Joe feel very tired, which means he has a lot of time away from school.

Sadly, his primary school was not open to accommodating Joe's needs when he was first diagnosed, as it affected the staffing levels at school because he needed full time assistance. I can remember his parents having to battle their way through for him to be granted a 'statement' so he could have the support he needed.

*Sadly, they forgot that Joe was a young child who wanted to be treated the same as the others and not to be singled out as different*

They addressed his needs for safety, but sadly forgot that Joe was a young child who wanted to be treated the same as the others and not to be singled out as different. He found this hard, as did his parents and we as grandparents.

### *Toby*

For Toby, things are a little bit different. Toby is a curious child who enjoys lots of company, especially with his cousins, and playing with his toys.

# epilepsy experience



*Toby loves playing with his cousins and his toys*

For Toby, he's had a hard time from birth and his parents have to be extra vigilant because he is so young. He is now two years old and he has already had to have a few hospital visits when he has had prolonged seizures caused by infections.

His diagnosis included the possibility of him having seizures so his family was informed of what to expect and what to do should this occur. However, no one is ever truly prepared to see a child have a seizure, as it feels like time stands still.

Toby's first seizure occurred very early on in his life, and he was taken to hospital with an overnight stay as a precaution. His seizures are not tonic-clonic, they are more likely to be absences.

At present, Toby is responding well to his medication (phenobarbital). However, he is only young, and, as we have learned, the pattern and frequency of seizures can change.

## *More information in schools*

For us as grandparents, it has been difficult to watch the boys have these challenges. Seizures can be very distressing to see, especially when children are having them. However, there is no time to lose control of your emotions when someone needs help. You have to be prepared to help in any way you can and know the correct procedure during and following a seizure. We have seen Joe have numerous seizures and each one is as distressing as the first time we witnessed one.

Before the boys were diagnosed, we knew very little about epilepsy. I am a retired teacher of children with special needs at secondary school, but there was no special training on how to deal with epilepsy in school.

I have tried very hard to implement training for teachers in first aid, specifically to assist anyone having a seizure in school. I come from a family of teachers and also know lots of teachers in the local area. My husband is also a retired secondary school teacher. However, no one in the teaching profession that I have met has ever been given the opportunity to learn more about what to do should someone have a seizure.

Witnessing a seizure can be upsetting and children may find this traumatic when they see it happening in class, especially when they do not have any prior knowledge of what is happening. Therefore, this lack of information about epilepsy can only cause more problems for those who have it.

*No one is ever truly prepared to see a child have a seizure – it feels like time stands still*

We all also need to raise awareness of hidden disabilities so that they don't create more problems beside the condition itself which can be harrowing. We have a key for a disabled



*Anne believes schools need seizure first aid training*

toilet in a supermarket for Joe, so that we can keep an eye on him. Once, when he came out of the toilet, the person behind me was disgusted because a perfectly 'normal-looking' young man had been given access to it.

*This may sound a little simplistic, but if we can fly to the moon or create robots to think and talk, why can't we develop a cure for epilepsy?*

Joe now attends a special school and enjoys his time there. He's offered extra curricular activities periodically, where he chooses an activity he enjoys doing. On a few occasions, his choice has been turned down. This is not because he isn't capable of the challenge, but because confidence in dealing with Joe's condition is low and it is easier to assign him to an activity which is closer to school should he have a seizure.

This is very upsetting for Joe, as he is nearly 16 years old now and he is aware of the real reason for not being allowed to attend the activity of his choice, despite being told something else.

### *Help to understand*

I wrote a book inspired by my grandsons, called Secret Warrior, to try to help other children understand more about epilepsy. I specifically aimed it at lower secondary school-aged children. I did this not only to provide information about what a seizure feels like, using Joe's own words, but also to teach children a little about empathy. I wanted to help explain how Joe feels, the effect it has on him socially and how it has, at times, made him feel excluded from situations, especially in free time.

The book is short and succinct enough to be distributed to pupils and provide either a discussion session or written exercise about epilepsy. The teacher can also ask the children to role play the situation, which would reinforce the correct procedure and the first aid required, such as demonstrating the recovery position, timing the seizure and not crowding the person.

When I first retired, it was also my intention to open a charity shop from which I could donate the takings to epilepsy charities. I found this almost impossible. There are numerous charities addressing the needs of people with the condition, but there are very few epilepsy charity shops



to help raise funds and awareness. And charity shops are becoming very popular!

In my opinion, more awareness needs to be raised. With this, more money would be donated to finding a cure, especially for children like Joe and Toby who have their whole life ahead of them. In a perfect world, I would love to see a cure for all types of epilepsy to benefit families with this diagnosis, which causes a lot of suffering, stress and anxiety.

This may sound a little simplistic, but if we can fly to the moon or create robots to think and talk, why can't we develop a cure for epilepsy?

Anyone interested in the book, Secret Warrior, please email [yozer1537@gmail.com](mailto:yozer1537@gmail.com).

There is more information on education and epilepsy, including school support, education laws and support for special educational needs, on the Epilepsy Action website at: [epilepsy.org.uk/education](http://epilepsy.org.uk/education).



# Medical files

Every issue, Professor Martin Brodie looks briefly at the various anti-seizure medicines for people with epilepsy. This time round, he talks about acetazolamide, primidone, rufinamide and stiripentol.

I have now covered 19 epilepsy medicines over the past four years or so. In this penultimate piece, I will discuss four rarely prescribed epilepsy medicines in brief, focusing particularly on when they might be prescribed and any side effects.

## Acetazolamide

Acetazolamide is an older epilepsy medicine that is used for glaucoma, an eye disorder, as well as for epilepsy. Acetazolamide can be prescribed for focal as well as generalised seizures as an add-on treatment. It can cause a lot of side effects, which include nausea,



Professor  
Martin  
Brodie



vomiting, diarrhoea, poor appetite, weight loss, headache, dizziness, tiredness, depression and kidney stones. Because of these potential issues, acetazolamide is rarely prescribed these days.

## Primidone

Primidone is broken down in the liver to phenobarbital and another similar substance. It can be broadly effective for a wide range of seizures, except generalised absences. Primidone can also cause a lot of side effects, particularly sedation and dizziness. It can also reduce the level of folate in people, which can cause anaemia over time. It is rarely prescribed nowadays, although some people have been taking this medicine for many years with benefit. However, primidone has largely been replaced by other, newer epilepsy medicines, as well as phenobarbital.

## Rufinamide

Rufinamide is licensed as add-on treatment for seizures associated with Lennox-Gastaut syndrome in children aged four years and above. Particular benefit has been demonstrated in reducing 'drop attacks'. Rufinamide can also be effective for drug-resistant focal seizures whether or not they turn

into tonic-clonic seizures, but it is not licensed for this because its side effects were not well tolerated by participants in clinical trials. The most common side effects with rufinamide include headache, dizziness, fatigue, tiredness, anxiety, insomnia, weight gain, nausea and vomiting. Like some of the other older medicines, such as phenobarbital, phenytoin and carbamazepine, rufinamide makes hormonal contraceptives, such as the pill, break down faster and reduces its amount in the blood. This can stop them working properly to prevent pregnancy, meaning that other forms of contraception are advised if you're taking rufinamide.

## Stiripentol

Stiripentol has been licensed in many countries for the treatment of severe myoclonic epilepsy in infancy (Dravet's syndrome). It is usually combined with clobazam and valproate. The most frequently reported side effects with stiripentol include drowsiness, dizziness, poor appetite, weight loss, nausea, abdominal pain and, occasionally, slowing of mental function. Stiripentol has particular benefit against tonic-clonic seizures in infants, children and adults diagnosed with Dravet syndrome.

**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 7 February and 4 April

At a meeting of the Council of Management held at New Anstey House on 7 February, the following outcomes and decisions were made.

- Five people were appointed to a new panel set up to advise the charity on matters relating to young people and epilepsy.
- Five other people were appointed to another new panel set up to advise the charity on matters relating to epilepsy and different ethnic communities.
- Reports were received on progress with the charity's review of its strategy. Additional meetings of Council were agreed for later in the year to give Council members sufficient time to reflect on the results of consultations.
- Council's Finance and Strategic Policy Committee was tasked with reviewing the charity's corporate risk policy, procedure and risk register and to report back with any recommendations for improvement.
- Council's Corporate Governance Committee was tasked with reflecting on the two new advisory panels to ensure they have been soundly established.
- Council heard details of the new Epilepsy Stars award programme that will launch in March.

At a meeting of the Council of Management on 4 April 2023, the following decisions were made.



- Approval of the Fundraising delivery and monitoring plan for 2023.
- Council received and approved the 2022 Trustees' annual report and year end accounts.
- The 2022 Year End Audit Findings Report was received and noted.
- Council agreed to sign the Letter of representation to RSM UK Audit LLP
- Council approved a resolution for presentation at the AGM to re-appoint RSM Audit UK LLP as auditors.
- The register of Association members will be closed from 14 May to 13 June inclusive.
- Rez Rogers was appointed as a member of the Ethnic Communities advisory panel.
- Council members Sarah Lawson and Tom McLaughlan were appointed as members of Council's Staff Appeals Panel.
- Ten members of the Association's Scientific Awards Panel were re-appointed for a 12 month period.
- The quarterly review of the top 10 risks to the charity was completed.

The next meeting of the Council of Management will be on 16 May 2023.

### 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. The traditional face-to-face group meetings just aren't possible right now, so the local services team have set up 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://discord.com/invite/3vHLOkT)), Facebook ([facebook.com/epilepsyaction](https://facebook.com/epilepsyaction)), Twitter ([@epilepsyaction](https://twitter.com/epilepsyaction)) and 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.

# Do you need to talk?



**Our FREE UK helpline offers confidential advice to anyone affected by epilepsy.**



Call: **0808 800 5050** (Monday-Friday 8:30am to 5pm, Saturday 10am to 4pm)



Email: **helpline@epilepsy.org.uk**



Live chat: **epilepsy.org.uk** (Monday-Friday 10am to 4pm)