

# Epilepsy

*Today*

**Rare  
epilepsy  
in film**

**PAGE 12**

**Out of  
the dark**

**PAGE 10**

**Get to know  
Variety D**

**PAGE 16**

## **ALSO IN THIS ISSUE...**

**What people with epilepsy say  
about VNS therapy p18**

**How our built environment can  
impact seizures p20**

**EPILEPSY  
ACTION**

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



After at least 2 anti-seizure medications fail to control seizures, alternative treatment options like VNS Therapy™ should be considered.



VNS Therapy™ is a **safe** and **effective** treatment used alongside medication for people with drug-resistant epilepsy (DRE).



It's designed to reduce the **frequency of seizures** in people with drug-resistant epilepsy.



It can also **shorten seizures**, reduce the **intensity of seizures** and **improve recovery** after seizures.



Scan to learn more about DRE

The VNS Therapy System is indicated for use as an adjunctive therapy in reducing the frequency of seizures in patients whose epileptic disorder is dominated by partial seizures (with or without secondary generalization) or generalized seizures that are refractory to seizure medications.

The most common side effects with VNS Therapy are hoarseness, shortness of breath, sore throat and coughing. These side effects generally only occur during stimulation and usually decrease over time. The most common side effect of the surgical procedure is infection.

For important safety information, visit [www.vnstherapy.co.uk/safety-information](http://www.vnstherapy.co.uk/safety-information)

LivanoVA Belgium NV  
Ikaroslaan 83  
1930 Zaventem  
Belgique  
Tel: +32.2.720.95.93  
Fax: +32.2.720.60.53

[www.VNSTherapy.co.uk](http://www.VNSTherapy.co.uk)

LivanoVA USA, Inc.  
100 Cyberonics Boulevard  
Houston, Texas 77058, USA  
Tel: +1.800.332.1375  
Fax: +1.281.218.9332

[www.livanova.com](http://www.livanova.com)



Lyla's story  
p10



Med access  
p22



Bringing  
laughs  
p16

## Inside

### Good news

**4** New standards for maternity services and EastEnders features epilepsy storyline

### News

**6** Medicine shortages could worsen, appeal lodged against phrase 'verbal epilepsy' and PIP assessments cause 'anxiety'

### Missing memories

**15** Awareness of losing memories in epilepsy this National Epilepsy Week

### VNS therapy

**18** The epilepsy community shares their experiences with VNS therapy

### Build inclusivity

**20** Jessie shares how her lived experience of epilepsy informed her research

### What's new?

**27** Round-up of recent epilepsy research

### Soaking up the atmosphere

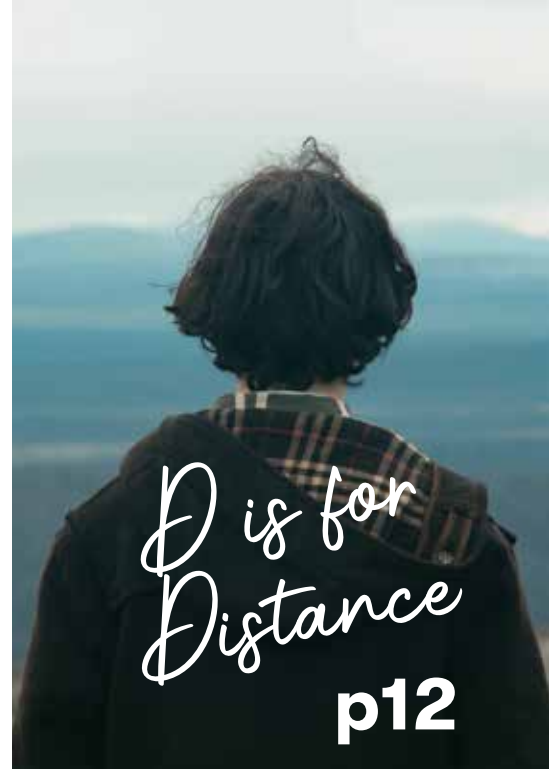
**26** Four Epilepsy Action London Marathon runners describe the experience

### Star awards

**28** We shine a light on two more Star Award winners

### Spread the word

**30** Five great ways that Epilepsy Action and the community raised awareness of epilepsy this Purple Day



D is for  
Distance  
p12

## Spice of life

**Putting this issue together started with an interview with comedian Variety D (page 16). She proudly represents diversity in all different ways (hence her stage name), from her background to disability. And as the other stories came together, 'variety' continued to be the word to describe this issue's features.**

From a documentary film about a rare form of epilepsy that left a family at wit's end (page 12), to a researcher exploring how buildings and spaces we create affect seizures in people with epilepsy (page 20), it's a real mixed bag of treats and there is something for everyone.

Read more about how Ed and Robyn were left blindsided by their daughter's first seizure and epilepsy diagnosis (page 10) and Alan's advice about staying persistent with your pharmacist if you experience problems getting your medication (page 22).

You can also find out more about how some of our runners found the atmosphere of the London Marathon (page 26), read more about our National Epilepsy Week campaign about missing memories (page 15) and what the epilepsy community's experience has been with VNS devices (page 18).

I hope you find the stories interesting and inspiring and have a wonderful summer.



**Kami  
Kountcheva**  
Editor

## NHS sets new clinical standards in maternity services to “significantly reduce” maternal deaths

**T**he NHS has set new clinical standards for maternity services across England to “significantly reduce” the number of deaths of women during or after pregnancy.

As part of these new clinical standards, due to be fully rolled out by March 2027, women with epilepsy will be able to access local specialist teams to help manage their epilepsy during pregnancy.

Women will also be offered a tailored seizure control plan with access to medications that are safer for use in pregnancy, the NHS said.

This initiative is targeting five areas identified by the MBRRACE-UK reports as the leading causes of maternal deaths, one of which was epilepsy.

Other areas that the new standards will target include earlier assessments for blood clots in deep veins, routine mental health assessments, and more timely specialist care around significant blood loss after birth.

These clinical standards are part of the NHS's maternal care bundle, a collaborative effort between clinicians, families and partner organisations, including charities.

Epilepsy Action has been working to improve safety and experiences for pregnant people with epilepsy through its Maternity Project.

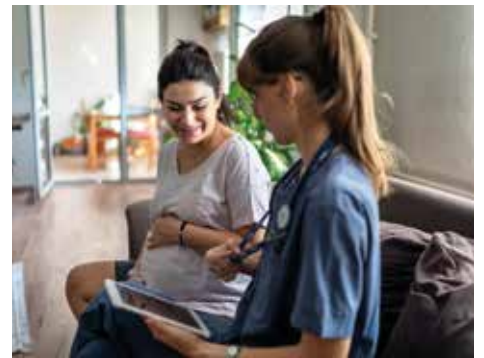
The organisation has collaborated with the maternity and midwifery team covering the North West of England to

identify problems people with epilepsy face in pregnancy, and create solutions.

The organisation has put together clinical guidance which explains how to keep someone safe before, during and after pregnancy, as well as a benchmarking tool. These resources have been used by all maternity hospitals in the North West and South East of England, and are currently being rolled out in other areas of the UK.

Alison Fuller, director of health improvement and influencing at Epilepsy Action, said: “It’s really positive and encouraging to see the NHS has put epilepsy front and centre in the new clinical standards for maternity services. We know women with the condition face significantly higher risks in pregnancy and so the new measures should give them the specialised care they deserve and ultimately reduce maternal deaths.

“However, this is only one part of the picture and we need to ensure that maternity care is not just integrated locally but also that is represented nationally. There is currently no representation of epilepsy in the new Maternity and Neonatal Taskforce, announced by the Secretary of State for Health and Social Care Wes Streeting. We have written to the Minister to seek his reassurances on this so we can bring our expertise in improving maternity outcomes for women and their babies at a national level.”



The NHS explained that between 2022 and 2024, there were 252 maternal deaths, down only slightly from 257 maternal deaths between 2021 and 2023.

According to the health organisation, research shows that improvements in care could have changed the outcome in almost half of the deaths between 2021 and 2023.

Chief midwifery officer for England, Kate Brintworth, said the measures will ensure “no stone is left unturned” for the one in five women who have medical issues during pregnancy.

She said: “Every death during or after pregnancy is a tragedy especially when differences in care may have changed the outcome.

“We still see symptoms of serious medical problems being missed, especially for Black and Asian women.

“By setting out these clinical standards and holding hospitals to account we can significantly reduce avoidable deaths and prevent future tragedies.”

# EastEnders storyline highlights elements of life with epilepsy



Photo: BBC | Jack Barnes | Kieron McCarron

**Long-running BBC soap EastEnders has been highlighting elements of living with epilepsy in its recent epilepsy storyline featuring Davinder (Nugget) Gulati, played by Juhaim Rasul Choudhury.**

Earlier in the year, the soap introduced the condition in Nugget's character after he was assaulted by an unknown assailant, showing him experiencing different types of seizures for the first time and going through the diagnosis process.

In April, the soap explored themes around filming seizures and sharing them online without consent, bullying and someone having seizures as a passenger in a moving car.

In the month, saw Nugget confront Will Mitchell (Freddie Phillips) over filming him having a seizure in the chicken shop and sharing the footage.

A few weeks previous, we had seen Nugget having a seizure while waiting in line at McKlunky's takeaway. He received exemplary first-aid care from his friend Denzel Danes (Jaden Ladega), who cushioned his head, helped protect his dignity when he lost bladder control, called his dad Ravi (Aaron Thiara) and walked home with Nugget after he recovered from his seizure.

In this scene, we see Will Mitchell with the group of teens, making a mysterious appearance despite supposedly being on holiday – an inconsistency that wasn't lost on viewers. He takes out his phone and starts filming Nugget having the seizure.

Nugget found out that this video of him

having a seizure was posted online by an anonymous account, leaving him furious. His sister Avani (Aaliyah James) calls it an "invasion of privacy".

Nugget challenged Will in the market, saying it was him who took the video, and he and Ravi went to discuss it in the café with Will and his parents Billy (Perry Fenwick) and Honey (Emma Barton).

Will confessed taking the video, thinking Nugget was pulling a prank and not realising it was a seizure until afterwards. While he said he didn't post the video online, he admits sharing it with another friend who did.

Later, Nugget faced a spate of nasty comments about his epilepsy from the bully who had posted the video online – Will's friend Jacob. He mocked Nugget for convulsing and losing bladder control, calling him "a joke". Nugget walked away and Avani defended him.

Experiencing deteriorating mental health problems, Ravi locks himself and his family in their home to protect them from harm. When Nugget discovers a bruise on his mum Priya's (Sophie Khan Levy) arm, he confronts his dad. This leads to the revelation that Ravi was the person who attacked Nugget during a hallucination. Nugget is hurt and angered hearing this, telling his dad that he feels terrified and humiliated about his condition.

After the shocking revelation, Priya comes up with a plan to free the family from their hostage-like situation. She convinces Ravi they need to leave Walford, and the family embark on an

## What to do if passenger has a seizure

1. If someone has a seizure follow our seizure first aid advice. For tonic-clonic seizures, follow our CARE guidance. For other types of seizure first-aid, you can find more information on the Epilepsy Action website.
2. Stay calm – it's easier said than done, but it really is so important to stay calm and continue focussing on the road to keep you and your passengers safe.
3. Stop the car when safe to do so – as soon as you find a safe area, you'll need to pull over. Turn off the engine and put on the hazard lights to alert other drivers if you need to.
4. Don't move them – the person doesn't need to be moved unless it is too dangerous to leave them where they are. You can leave the seatbelt fastened if it helps stabilise their movements.
5. After the seizure it will be difficult to put them in the recovery position so monitor their recovery and help to make them as comfortable as possible being mindful of the individual and the situation.
6. Depending on where you have stopped, you may need to move your car to a safer spot or alert emergency services about your car.

escape mission, stealing a car from Lauren's car-lot.

The family almost arrive at the hospital, but Ravi notices Priya's plan. As he demands the car be stopped, Nugget, as a car passenger, has a seizure, causing Priya to turn around to check on him and crash the car.

Nugget's story continues on BBC One at 7:30pm Monday-Thursday.

# Epilepsy news

## Man unable to get his epilepsy medication dies after seizure

**A 58-year-old man from Bedfordshire died after not being able to get urgent access to his epilepsy medication, an inquest has concluded.**

Paul Nash had been diagnosed with epilepsy in 2014, following “significant brain injury” from encephalitis. He had been prescribed carbamazepine and had not had a seizure since 2016, according to the coroner’s report.

According to the report, Paul had not requested all of his prescriptions in September 2025. His full prescription was requested on 20 October, and on 21 October, he informed the charity Headway, in Luton, that he had taken the last of his medication that morning.

The charity had contacted his GP to ask for an urgent prescription, but this was not ready to pick up the next day.

Paul was found dead on 23 October 2025, with “evidence at the scene” suggesting that he had had a seizure in the night.

Although he inquest said the reasons for the seizure were unclear, it concluded that he had “died following an epileptic seizure after running out of his epilepsy medication which meant he had missed three doses”.

Senior coroner Emma Whitting raised concerns with the GP surgery, saying that despite Headway contacting them and stressing that an urgent prescription is needed, this information wasn’t passed on to the GP and the prescription was not prioritised.

The other concern was for Health Secretary Wes Streeting, highlighting that Paul Nash’s consultant neurologist

had said that “epilepsy patients across the country currently experience difficulties in obtaining sufficient quantities of medication to ensure optimum seizure control.”

Research published in 2025 in the journal *Pharmacy* found that more than seven in 10 people with epilepsy in the UK experienced difficulty getting their epilepsy medication in the past year.

More than nine in 10 people reported shortages for the medication carbamazepine. The medications for which shortages were most commonly reported were carbamazepine, clobazam and topiramate.

The researchers explained that their findings showed that the shortages appeared to be hitting people with epilepsy harder than others. They added that problems appeared to be with the local supply chain and not just manufacturers.

Health improvement and research manager at Epilepsy Action Tom Shillito stressed that the consequences of someone being left without their usual medication can be very serious.

Medication shortages became more commonplace in the last five years.



A 2024 report from the Nuffield Trust said “constantly elevated medicine shortages” and disruptions were becoming “a new normal”.

Alan Brown, 80, from York, was diagnosed with epilepsy three years ago. When he experienced problems accessing his medication from his pharmacy recently, he was pleased to have a Charlie card to help explain the situation to his pharmacist.

“I showed this Charlie Card and indicated to the pharmacy that they had some responsibility to do something.”

The pharmacy managed to find a different formulation of Alan’s medications and he was able to collect them that day.

You can read more about Alan’s story on page 22.

# Medication access could worsen in England

**P**roblems with medication access could get worse again in England, according to recent news reports.

Issues accessing medication became widespread in 2024, when they were called ‘the new normal’ by the Nuffield Trust.

People with epilepsy are one of the groups particularly affected by these shortages, as many are on long-term medication. Changes or disruptions to their prescribed medication can result in worsened or breakthrough seizures, which, in some instances, can be life-threatening.

There have been multiple reports over the last two years of people failing to access their medications from pharmacies and experiencing fatal seizures.

News reports say the Iran war is disrupting global supplies, and rising prices and a convoluted system around funding medicines in England is causing additional pressures.

Epilepsy Action has been calling for a review of the supply chain, highlighting that problems with it place people with

epilepsy at “risk of sudden, sometimes fatal seizures”.

In a letter to MPs last year, Epilepsy Action, Epilepsy Society and SUDEP Action wrote: “If action is not taken to properly understand the crisis we face and explore potential solutions, it will worsen. A review into the shortage of vital medications is urgently needed.”

In October last year, the government said that “most issues” with medication supplies had been resolved, but recent research found that this issue was still widespread in the last year.



## Tips to avoid running out

- Try to **get your prescription earlier** so if there is a problem you can try a different pharmacy or ask them to contact a different wholesaler. Independent pharmacies are more likely to be able to do this.
- Use our **Don't Sub My Drug** guide (available on our website) for more top tips and advice on discussing options with your pharmacist.
- You can also **request a Charlie card from SUDEP Action** which allows you to request a minimum emergency supply from any chemist if you find yourself without your regular medication.
- If you have any concerns and have been experiencing any issues getting your medication, **get in touch with our Epilepsy Action helpline**.

# Eligible people need a valid medical exemption certificate to claim free NHS prescriptions

**The NHSBSA is reminding people who are claiming free NHS prescriptions for a qualifying long-term medical condition to check that they have a valid medical exemption certificate.**

People with certain conditions, including ‘epilepsy which needs continuous anticonvulsive therapy’, are entitled to a medical exemption certificate, which they can use to claim free NHS prescriptions.

Around 156,000 people with epilepsy who qualify currently hold an active certificate, the NHSBSA says. Certificates

are valid for five years and can be applied for or renewed through a GP or doctor.

The NHSBSA will send a renewal reminder before a person’s medical exemption certificate expires to help them renew in time.

The NHSBSA says it’s each individual’s responsibility to ensure their certificate is valid when claiming free NHS prescriptions. Those who claim without a certificate in place could receive a penalty charge notice of up to £100.

In 2025, around 50,000 penalty charge notices were issued where people had

ticked medical exemption certificate but did not have a valid one, according to the organisation. In around 40% of these cases, people had a condition which entitled them to a certificate but didn’t have one in place.

The full list of qualifying medical conditions is available on the NHSBSA website.

People can also use the NHS eligibility checker to see if they’re entitled to other help with NHS health costs.

Epilepsy Action has more information around this and other benefits.

# Appeal lodged after regulator rejects complaint over phrase ‘verbal epilepsy’

**A complaint made by Epilepsy Action about the use of the phrase “verbal epilepsy” in an article by The Spectator has not been upheld by the Independent Press Standards Organisation (IPSO), the regulator for the UK digital and print news industry.**

On 18 March, Epilepsy Action made a complaint to IPSO about an article published by The Spectator titled “PMQs was ruined by Starmer’s verbal epilepsy”.

The organisation argued that this language was in breach of Clause 12 of the Editors’ Code of Practice, which states that “press must avoid prejudicial or pejorative reference to an individual’s physical or mental illness or disability”.

Epilepsy Action said the language “reduces a complex medical condition to a punchline”, adding that it is not relevant

to the story and encourages stigma and outdated stereotypes about epilepsy.

“This creates a hostile environment for the millions of people in the UK affected by epilepsy,” the organisation wrote.

The rejection of the complaint from IPSO was on the grounds that Clause 12 is designed to protect specific individuals mentioned by the press from discrimination based on certain characteristics, including illness or disability.

A spokesperson for IPSO said because the word wasn’t referencing Sir Keir Starmer’s own illness or disability, “it criticised his performance at Prime Minister’s Questions, not his protected characteristic”.

Epilepsy Action has appealed for a review of the decision to reject the

complaint. The organisation said: “To describe poor performance in PMQs as ‘verbal epilepsy’ pushes a narrative that epilepsy means poor performance. It doesn’t.

“It is a medical condition that many people live with successfully. It is also a condition that limits lots of lives, with 42% of employers telling us they would not employ or promote people with epilepsy, even though they know it is wrong.”

Epilepsy Action continued: “But why should people with epilepsy continue to be the punchline to jokes when so many other protected characteristics now sit firmly in our public consciousness as a place not to poke fun?

“Why is ‘verbal epilepsy’ permissible? The reality is that it is not.”

The appeal the decision has been passed on to the Complaints Committee.

## Mum of four makes London Marathon comeback after seizure

**A mother of four with epilepsy who was taken to hospital during the London Marathon after experiencing a seizure returned hours later to complete the race in support of Epilepsy Action.**

Kayla Cooper – known as Cooper – from Seattle in the United States, had travelled to the UK to take part in the iconic event in aid of Epilepsy Action, raising more than £2,400 for a cause close to her heart after being diagnosed with the condition at the age of 16.

Having trained for 20 weeks, and completed hundreds of training sessions, this was the 31-year-old’s first marathon.

After a difficult journey to the start and rising temperatures, Cooper began experiencing symptoms early in the race, including visual disturbances and dizziness.

By the time she reached the halfway point near Tower Bridge, she was assessed by medical teams, where she experienced

a focal seizure and was taken by ambulance to hospital.

Following medical checks and after around two and a half hours recovering, Cooper decided to return to the course – determined to finish the marathon.

Rejoining the race as crowds thinned, she continued the remaining miles largely without the usual race-day atmosphere.

In the final stretch, her husband ran alongside her in sandals, supporting her through the last kilometres to the finish line. She crossed the line in 9 hours, 13 minutes and 14 seconds.

Cooper said: “I had a big cry because



I felt like I’d let a lot of people down. But I knew my six-year-old daughter was so excited and really wanted me to get the medal. That’s what got me through.”

# PIP assessments leave claimants with “anxiety”

**P**eople with epilepsy report “anxiety” over the Personal Independence Payments (PIP) assessment process, while awaiting the findings from the Timms Review this autumn.

The review into PIP, due to be carried out by Sir Stephen Timms alongside two other co-chairs and an appointed committee of 12 disability experts, is looking to ensure PIP is “fair and fit for the future”.

The inclusion of the steering committee has been welcomed by disability charities, but they warn that the review “cannot become about making cuts”.

Epilepsy Action is calling for the review to focus “on fixing the real challenges people face with the current system”.

Daniel Jennings, public affairs coordinator at the charity, said: “What matters most is making PIP fairer and more supportive and not putting up more barriers for people that need support to live well.”

Recent news has also uncovered huge turnover in health professionals acting as assessors for claimants of PIP and Universal Credit.

According to a study by the DWP, around half (52%) of the assessors left the role over the year in 2021. The study also found that around “40% of new recruits also leave during the training period”.

Health professionals cited feeling “de-skilled”, “despised” and being “a cog in the machine doing bureaucratic work.”

One health and disability benefit assessor (HDA) is quoted in the study, saying: “We all got in healthcare for altruistic reasons and that maybe isn’t the case in this job...”

With the Timms Review on the horizon, and a continuing narrative from the government that the benefits bill needs to be cut, people requiring PIP are still facing assessments that they say leave them “dismissed” and “disheartened”.

Murray Goulder, 46, from Crawley, who has epilepsy, shared his worries in a post on Facebook. He said: “I find myself once again preparing for my DWP assessment, scheduled for tomorrow at 9am.

“Despite knowing I shouldn’t feel this way, I can’t shake the overwhelming anxiety that has me feeling like I’m about to face a daunting challenge.

“Over the past 30 years, I have meticulously gathered and submitted extensive documentation to support my case. I have followed the advice of my doctors and nurses, exploring every avenue they suggested.

“I have to build myself up to the day. It’s not comfortable.”

“On the day, a good friend came with me. My appointment was massively delayed, and I was due to work later that day.

“This was probably the worst assessment I’ve had to date.

“I had a new piece of further medical evidence from my neurologist clarifying my requirements and risks, and a video of a seizure captured on my doorbell



that showed the type of injury I could experience. The lady assessing me didn’t pay attention to either.

“My friend said she thought the experience was intense and intimidating if you’re on your own. She also found the interview style quite cold and felt like people shouldn’t be made to wait weeks to find out the result of it.”

“It ended up that my PIP was downgraded. I don’t trust the system after so many rejections. I predicted that my PIP would be stopped again and I’d have to start the slow challenge again. I missed continuing my PIP by 2 points.

“I’ve had to go to tribunal for PIP twice – and won my claim both times. I’ve now got to apply for mandatory reconsideration – again – and I predict it will go to tribunal. It’s just frustrating.

“What is labelled as a ‘benefit’ is, in truth, a necessity. I bear the costs of things like travel, including to and from work, non-prescription medication for daily headaches from my epilepsy and more expensive life and travel insurance because of my epilepsy. PIP is not ‘bonus’ money – it’s not a perk.”

# Carers to children with epilepsy have poorer mental health

**A new study has added to evidence that UK carers to children with epilepsy experience high levels of stress, anxiety and depression.**

UK researchers set out to find out what the quality of life is like for carers to children with epilepsy, both physically and mentally.

Study author Sasha Coates and colleagues investigated quality of life, sleep, mental health and resilience in a group of 127 caregivers – almost all of whom were female.

Nearly three quarters (73%) of people reported high levels of sleep problems. More than two-thirds of people reported

stress (68%) and depression (67%), and 61% reported high levels of anxiety. While physical health-related quality of life was in line with the general population, people’s mental health was especially affected by having more sleep difficulties, lower resilience and if the person’s child themselves had a lower quality of life.



# Coming out of the dark

When Ed's daughter Lyla was diagnosed with epilepsy, life became dark for the whole family, but support from Epilepsy Action brought information and hope. Words by Ed Parvoux

**W**e have always been an outdoorsy and adventurous family. Lyla was just eight in 2022 when we climbed Snowdon as a family. Our kids have always been what we call "free range children" and enjoyed outdoor activities like hiking, geocaching and even shotgun shooting. The kids were always our little adventurers.

Sadly, her first seizure changed all that. It was horrible. People often have first aid training, and you learn about what a seizure might look like, but nothing can prepare you for what actually happens. Even more so when it happens to your own child. I had never seen a seizure first hand and the experience was very traumatic and will stick with me forever.

At the time, I thought Lyla was dying and there was nothing I could do to stop it.

It was very dark in the first days, weeks and months. It didn't feel like the rug was pulled out from under us, **it felt like the whole floor disappeared and we were falling into the abyss.**

**Lyla became this fragile thing that needed constantly watching,** she couldn't be left alone for even a moment and I became her shadow. I didn't sleep properly for weeks initially, every time she moved in bed or made a sound at night,

## “I thought Lyla was dying and there was nothing I could do to stop it”

I would get up and check on her through fear of SUDEP.

I worried about her being on the stairs, crossing the road, having a bath. Her whole routine changed overnight and became this regimented ritual which unfortunately seems to have stuck, and we are desperately trying to undo the OCD she created in Lyla. We all went from happy-go-lucky, outgoing individuals, to a family that now lives with PTSD, anxiety, OCD. Unfortunately, Robyn, Lyla's mum, really suffered and was quite unwell with her mental health for quite a while. Robyn lost a lot of weight and found that her bed was her safe sanctuary and that was where she would go after seizures or when she felt anxious.

Lyla was so brave throughout the whole thing and although we didn't get the diagnosis until after her fourth seizure, we knew after the second one what was going on. The team at the NHS specialist clinic at QE Hospital in Woolwich were fantastic. Lyla was naturally nervous of the MRI machine, but we were able to play her favourite music at the time, Ellie Dixon, through the headphones, and I stayed with her throughout. She was and has been incredibly brave and stoic since day one.

The first year was a very difficult time for all of us. We were all trying to process what was happening and the emotions that go with that in our own way. As parents we were on high alert, just waiting for the next seizure to come and at the same time, trying not to neglect Lyla's older sister, who was struggling with this too in her own way.

It was a minefield of emotions. We had to be cautious with Lyla's activities and watched her like a hawk. She would tell you herself just how many times I've called her and asked: "you ok?" Changes were made at school for Lyla whilst her seizures were uncontrolled, and it was the little things that had the most affect. She couldn't be alone, so if she needed the toilet during the school day, she had to be accompanied by friends and wasn't able to lock the door. She couldn't go swimming

with the class unless I was there as the pool staff weren't trained to get her out of the water if she had a seizure whilst swimming. We have spoken about it since, and Lyla recalls it was a very difficult time for her even though she was supported. Lyla wasn't allowed to ride her bike or, as she has photosensitivity epilepsy, go to the cinema, watch certain programmes on the telly, play certain video games. The list goes on.

### Strobe lights became our family's enemy number one.

I felt angry and a lack of control of the situation. I was angry that this happened to my little girl and for no reason. She was healthy and happy, and we made sure that both the kids had a healthy upbringing. Lyla had no reason for this to happen to her, and yet it still did. I still wrestle with the WHY even today. Robyn and I feared for what Lyla's life might be like in future and what she would potentially miss out on.

Robyn called Epilepsy Action's helpline and that was a big help to us and a huge confidence booster to her. I found Epilepsy Action's website extremely helpful and informative. The stories of people who had been affected and helped gave us a lot of hope.

Lyla's school were great. They created a care plan for her implemented all the changes discreetly. They also allowed me to come into school and give an assembly about epilepsy what to do if Lyla or anyone had a seizure school. She had a close group of friends who were very supportive and that really helped. Moving up to secondary school was a bit harder as she didn't want to be seen as different so none of the students have been told except her closest friends. The school and staff are of course fully aware

and have measures in place, but Lyla has been seizure free since joining the school.

We are in a better place than we were two years ago. Lyla's seizures are well managed has had no seizures for over two years. Life is almost back to 'normal'. It will never be what it was before, that's just the nature of experience, but we are getting close to where we were before the first seizure. We have just come back from a long weekend where Lyla rode her bike and went swimming and did all the things she wasn't able to do two years ago. We still have to check what films she can watch and things like concerts and shows are pretty much a no-go as they often use strobe lighting effects.

Epilepsy Action have been a big help to us. To anyone who has supported the charity I'd like to say thank you and for anyone who could still give more, then please do, as none of their services would be possible without that income. I also think the more donations that come, the better the awareness of the public will be on this condition.

To donate, visit [epilepsy.org.uk/lyla](http://epilepsy.org.uk/lyla).



Ed and Robyn on a family hike



Louis  
Petit

A new documentary film explores a rare and life-threatening form of epilepsy, medical bureaucracy, the impact on memory and the salvation of art. Words by Kami Kountcheva.

**“As it was, Louis nearly died coming off phenytoin, going into status 10 times in 10 months”**

**“You can hear my voice asking if he could hear me, if he was there.”**

These are some of the words that Emma Matthews would end up saying many multitudes of times over the course of five years, after her son Louis suddenly developed a rare and life-threatening form of epilepsy at the age of 12. She’s calling him back from one of the many seizures he would experience over this time.

These seizures, alongside artworks, old family videos and early cinema clips form the family’s new documentary film, *D is for Distance*. Both of Louis’ parents, Emma and Christopher Petit, are filmmakers and

they decided to document their family’s journey with epilepsy, battling medical bureaucracy, managing brutal medication side effects and trying everything to give their boy his life back.

#### **Harm and medication side effects**

“Louis had his first seizure when he was 12, after a normal, healthy childhood,” Emma explained. “I was 54 and knew nothing about epilepsy. I had seen one seizure in my life when I was 21. I was waiting for a tube when an elderly woman sitting next to me fell sideways onto my lap, convulsing and frothing at the mouth. It was rush hour and the platform was crowded, but everyone turned away. I

called out more than once before anyone came to help.”

Many years later, epilepsy re-entered the family’s life with Louis’ diagnosis, but none of them could have known the uphill battle that was ahead.

Louis’ focal seizures were initially misdiagnosed as functional (dissociative) seizures, until an EEG revealed epileptic activity during them. The family were initially told that Louis couldn’t have both generalised and focal seizures, only to have it confirmed months later that he did, in fact, have both.

“Louis suffered terrible cognitive impairment from all the different drugs they tried him on,” Emma continued.

“None of them worked. In fact, they did the opposite: they exacerbated his seizures and caused new seizure types. His seizures would cluster and he’d often need emergency hospital admissions for treatment to stop clusters or status epilepticus.

“His neurologist said they were struggling to know what medication to give him. They’d had to withdraw lacosamide because while on it, Louis was incapable of remembering anything three minutes after being told, and he was still having seizures. At the time, he was also taking Keppra (levetiracetam) and clobazam. He went into status epilepticus for the first time coming off lacosamide.”

After doing extensive research of her own, Emma began to suspect that Louis’ epilepsy medication was actually causing him harm.

“I was starting to wonder whether the types of epilepsy medications known as ‘sodium channel blockers’ were, in fact, making him worse. I’d read that this type of drug can cause cognitive impairment as well as paradoxical seizures in rare cases.

“The following week, Louis went into status epilepticus again and we were told that he had to start on phenytoin. This is another sodium channel blocker, and I begged them not to. The hospital said he would not be discharged unless he was already taking it.

“As it was, Louis nearly died coming off phenytoin, going into status 10 times in 10 months, and needed to spend three months in a residential clinic in the Netherlands to withdraw it.”

Emma sought a second opinion from another neurologist, who said it was possible that the medication was making Louis’ epilepsy worse, saying this could be a ‘clue’ to its underlying cause.

### “We had to try everything”

Great Ormond Street Hospital, where Louis was being treated, had said Louis would not be able to have epilepsy surgery and suggested a VNS implant may help, but would be unlikely to control his seizures. He would have to remain on epilepsy medication as well, all of which was affecting Louis’ cognition and seizures.

Before going down this road, Emma decided to pursue one last option she’d heard about.

She explained: “In 2018, I heard Hannah Deacon on the radio talking about her son, Alfie, and I started to wonder whether medical cannabis might help Louis. I

managed to contact Professor Mike Barnes, who worked with Hannah, and he put me in touch with her.

“Hannah was the first mother I’d spoken to who knew what it was like to have a child with severe drug-resistant epilepsy. Hannah was always there for me – she had a deep understanding about epilepsy from her own experiences, and her empathy was phenomenal. After getting cannabis medication legalised, Hannah could have stopped and enjoyed time with her family, but she couldn’t accept that her son was well when other children were suffering. Hannah suggested I wrote to the Erasmus in Rotterdam to see if they could treat Louis.”

Feeling like “we had to try everything before accepting that he would never be well again”, Emma took Louis to Rotterdam in the Netherlands to try the medication Bedrolite. This is a cannabis-based medicine which contains a small amount of tetrahydrocannabinol (THC) and is not licensed in the UK.

The family spent two years withdrawing the medication that had been making Louis’ condition worse, dealing with withdrawal seizure clusters and hallucinations, and starting him on Bedrolite.

Testing revealed that Louis had a rare genetic epilepsy, which explained his sensitivity to medication changes and the strong adverse reactions to certain types of medications.

Louis’ seizures became controlled on Bedrolite in the Netherlands, but when the family returned to London in 2022, the NHS refused to fund the medication for Louis, saying it can only be prescribed for ‘clinically exceptional cases’.

Emma said: “The Trust looking after

“When Louis wrote to ask for an alternative treatment, he received a letter discharging him from the Trust. He was told never to contact them again”

Louis applied to NHS England for funding for his Bedrolite, saying withdrawing it would risk brain damage or death.

“NHS England told them that they had removed unlicensed cannabinoids from their commissioning lists and his case was never reviewed. A few months after that, his neurologist suddenly changed her mind about prescribing it, citing unknown safety concerns.

“When Louis wrote to ask for an alternative treatment, he received a letter discharging him from the Trust, stating that the family’s only focus was on them prescribing an unlicensed medication. He was told never to contact them again.

“We felt completely let down by the NHS, both before we went to the Netherlands and after we returned. Louis can only stay well if we could afford a private prescription for medical cannabis.

“He has been on Bedrolite for eight years with no adverse reactions, so safety isn’t an issue. His current neurologist wants to prescribe it and says Louis is



Photo: Shweta Shukla BFI London Film Festival

Louis, Emma and Christopher at the London Film Festival



The idea for D is for Distance came from a 10-minute video for a crowdfunding campaign for Louis' medication

clinically exceptional, and that the panel's criteria are wrong. Louis does not have drug-resistant epilepsy anymore – he has been seizure free for over five years. The problem is the only drug which controls his seizures is Bedrolite.”

#### “A shadow of myself”

The idea for D is for Distance actually started when the family returned to the UK. Feeling let down by the NHS, they started a crowdfunding campaign to help pay for Louis' Bedrolite. They filmed a 10-minute film called “Louis' Story”, which really resonated with other parents.

This expanded into the full-length documentary film, which explores Louis' story, the challenges with the health system, the way his memory was impacted and how his art was a constant release throughout even the most challenging times.

Both Louis and Emma struggle to watch back the scenes showing Louis' seizures underscored by the sound of Emma's words: “Can you hear me? Are you there?”

Louis explained these were “triggering to say the least”, but that with time, the film has pushed him to “face certain parts of my trauma I'd been unaware of”.

Meanwhile, Emma said that she has been “living in frozen time” since Louis' seizures started. Now she feels “ambushed” by thumbnails from seizure videos she took to show his doctors, “often with an expression of excruciating pain on his face”, but before Louis' seizures were controlled, she felt similarly “ambushed by happy photos of life before epilepsy”.

Explaining what this time was like for him, Louis said: “My life became a vicious hallucination that robbed me of my teens.

“Epilepsy moved my family abroad in the hope of getting proper medical

treatment. It took my Dutch doctors the best part of two years to sort me out. It prevented me from getting a secondary education. In these years, I lived closer to death than life.

“Over some of that time, I stopped processing information and found talking a struggle. I spent three weeks in hospital seizing all night as soon as I fell asleep. I couldn't eat and vomited after my seizures. My weight dropped to 45kg, and I was too weak to walk and needed a feeding tube.

“The Dutch doctors said I was their most complex epilepsy case at the time, but they never gave up on me.

“My memory is incredibly fractured because of the drugs and seizures and most of my memories of that time are more bound to dreams and hallucinations.

“While suffering seizures, I had to stop many of the things I loved. The one attachment to the life I lived before was painting. The compulsion to make art salvaged something.

“A painting of mine that has always stayed with me is a work called TRIAGE (below), made when I started working with aluminium in 2023. It depicts three shadow figures in a bedroom.

“On top of it being a massive breakthrough piece, opening my practice to what it is now, it is also incredibly personal, with the shadow figures originally being a hallucination I frequently had, then evolving into becoming symbolic of the state I was in – a shadow of myself – before

evolving into something beyond epilepsy, as simply a presence in absence, the weight of losing someone in your life or growing apart, and that absence being a rather large presence in your life.

“Slowly the figures have developed from a frightening hallucination into a lonely friend. I think that also begins to symbolise an acceptance of my epilepsy.”

#### “Heal, grow and move forward”

Despite everything, Louis wants the film to be viewed as being “about hope, not as an excuse for pity”. He says it showcases how to “heal, grow and move forward”.

Meanwhile, Emma wants the film to be a poetic interpretation bringing awareness, championing the importance of art and showcasing “how a mother will sacrifice everything for her child”.

“I also hope our film can give people hope,” she added. “Maybe there will be changes in the NHS which will help more families to try medical cannabis. It can be lifechanging if it does work. There are no other options for these children, and it will save the NHS millions. This is not a ‘difficult choice’.”

The film is dedicated to Hannah Deacon, who campaigned for better access to medical cannabis until she died last year. She is a co-founder of the organisation Medcan Family Foundation.

Emma said: “I miss her every day. It's thanks to her that Louis is well now. We need more people like Hannah in the world.”

You can hear Emma share more about the film and her experiences on Woman's Hour at [bbc.co.uk/programmes/m002tbt3](http://bbc.co.uk/programmes/m002tbt3).

**D is for Distance will be available to stream on BFI Player from 11 May at [player.bfi.org.uk](http://player.bfi.org.uk)**





# Missing memories

Losing precious memories of once-in-a-lifetime moments is an often unseen side of epilepsy. Words by Lisa Greer.

**M**any people with epilepsy experience memory problems – either from their condition itself or from their epilepsy medication. There are times when this is inconvenient and frustrating, like having to rely on alarms to remember medication or wondering where you left your keys.

But at times, epilepsy can rob people of some of the most important, meaningful and precious moments of their lives – weddings, holidays or the birth of their children. This can be a heart-breaking side of the condition that often goes unseen or misunderstood.

Amy-Jane Foster from Hampshire, who was diagnosed with epilepsy aged 11, has no clear recollection of the day her son Joe was born.

“I’ve been told what happened, but I don’t remember it,” she said. “There are just flashes – my waters breaking, bits of labour... then nothing.”

Joe was born early and was taken away for urgent care. Shortly after, Amy aged 45 had a severe tonic-clonic seizure and was in and out of hospital for nine weeks.

It was only later that the full extent of what had been lost became clear.

“After my second brain operation, I realised two years of memory had just disappeared. I had lost the first two years of my son’s life!”

While not everyone with epilepsy experiences memory loss on this scale, many people say it is a daily reality.

From missed conversations to forgotten plans, it’s often the small, everyday moments that quietly slip away – with some people being labelled as “forgetful” or “unreliable” for something beyond their control.

Others describe relying on reminders, routines and support from those around them just to stay on track each day.

In a recent Epilepsy Action poll, responses from the community show just how common and disruptive memory problems can be for people with epilepsy.

Nearly nine in ten people say they rely on reminders at least some of the time, while more than eight in ten say they have been misjudged as ‘forgetful or unreliable’.

Around seven in ten say epilepsy affects their everyday memories and for some the

impact goes even further with one in five saying it has affected major life moments.

Amy-Jane hopes speaking out will help people better understand what living with epilepsy can be like.

“Memory problems are part of epilepsy for many of us. It doesn’t mean we are lazy or not trying – we just need a bit more understanding.”

Jon Eaton, director of communications and digital engagement for Epilepsy Action said: “Every year, we hear from thousands of people suddenly isolated by a condition that can rob them of consciousness at a moment’s notice. Alone, they struggle to regain control, while missing the key memories that make them who they are.

“This National Epilepsy Week we are asking people to imagine what that feels like.”





# Making people *laugh*

Comedian Variety D represents all things diversity, and she shares the highs and lows that come with that. Words by Kami Kountcheva

**A** quick Google search for comedian Variety D, also known as Dominique Davis, will tell you straight away that she is “the first black, female, British, disabled comedian” of her era. And the truth is that she wears all her points of diversity like a badge of honour. Within her comedy and the rest of her work, she is powerful and proud in her representation of ethnicity and disability.

“Variety – it represents my heritage,” she explained. “I’m a mix of Jamaican, British Guyanese and Cockney. It also represents the audiences that I connect with.”

Variety, 35, calls herself a “proud born South Londoner”. She’s the eldest of her

siblings and has four brothers. And Variety has a strong sense of family – she lives around the corner from her mother’s house and took her to an event at The House of Lords a few years back, invited by Small Business Britain.

But she has always been close with her extended family too, proud to be in the footsteps of her uncle Paul Murphy, who was an actor in *Bugsy Malone* in 1976 and then became a producer on Channel 4 show, *291 Club*.

#### **A career in comedy**

It was her uncle who first sparked her interest in comedy. He introduced her to comedians, such as Felix Dexter, that she would end up looking up to as mentors.

“I first started with the urban circuit consistently, even though I was age 16,” Variety explained. “I went through ‘the other doors’ of the Comedy Café, which is a mainstream sort of level.

“I didn’t know at the time. I didn’t really care. I had bunked off school (me and William Shakespeare don’t get along!)”

Variety had snuck in to watch amateur comedy, but being “bored and loud”, she was soon approached by the compere of the club and challenged to have a go herself. She got up and performed a set off the cuff. The compere was impressed, saying she was “hilarious” and had potential.

Soon after, Variety reconciled with William Shakespeare, and redid her

English Literature, getting “a lovely letter C”. She later went on to study at Middlesex University, continuing with her comedy alongside.

It was in her first year at university that Variety first saw how the comedy industry could turn cold at the sight of epilepsy.

“I had a seizure one time in Wales, about 15-30 minutes before I got on stage. They put me on first and I remember the compere saying to me: ‘You alright, yeah? You were walking up and down funny. Do you want to go back home?’”

“I was like: ‘Listen, home? I live in Croydon. This isn’t even Camberwell or Clapham. We’re in Cardiff! You better give me that microphone, give me my emergency medication (I used to have gabapentin) and give me a few moments and then I’m ready’.

“My head was hurting, I had to take some breaths, and then I could hear the compere introducing me. I just got out there and I told the audience what happened, and I just took the mick out of myself.

“It was a wonderful performance and one person from the show said afterwards: ‘My son has epilepsy, but I couldn’t bring him because he’s photosensitive’ and she asked me about my epilepsy.

“I did give big thanks to the comedians and the crew backstage, but the promoters at the time didn’t book me back. Looking back, I think it was fear, because they’re thinking what if I have a seizure on the stage? Would they get in trouble?”

### **Epilepsy and other conditions**

Variety’s epilepsy began when she was a baby. She has experienced tonic-clonic seizures, focal seizures and absence seizures at points throughout her life. She now takes brivaracetam and levetiracetam, but can still sometimes have seizures, especially around stress or excitement.

“On top of that, I’m also visually impaired,” she added. “So that’s the cherry on top. My vision’s got worse and worse and it’s due to – after having a seizure – vigorously rubbing my eyes. It’s a habitual pattern after a seizure and your cornea gets thinner and thinner. If you don’t sort it out as soon as possible, you could end up blind. But now I wear strong, hard contacts.”

The diagnosis process, as well as trying to get her epilepsy under control, she describes as “I’ve been a lab rat!”

“Because, remember, in the early 90s,

society didn’t really know about epilepsy and different types of seizures,” she explained. “They thought it was just the one where you fall on the floor or the one where you react to flashy pictures.

“Mine isn’t like that, I can’t say when it’s going to happen. It’s stress related sometimes. Also, as a female with PCOS (polycystic ovary syndrome) since the age of 16, I have very heavy periods, where you start to lack iron and then – an absence seizure.

“My periods aren’t regular because of the PCOS, but when I’m doing gigs and it’s the time of the month, I’ve got to be really careful, take my tablets before the gig, make sure I have something to eat. And then I still have the excitement of making people laugh.”

In 2020, during lockdown, Variety’s health took a turn, as she ended up having a stroke and having surgery to remove some scar tissue from her brain. Following that, she underwent physiotherapy to learn to walk and talk again, spending five weeks in hospital.

### **TV and radio**

When she returned home, a few months after her brain surgery, Variety got a spot as the ‘Hot Goss Girl’ on BBC Radio London with comedian Judi Love.

Variety estimates she’s been on TV “one and a half times”. Once was on the ITV show ‘Sorry I Didn’t Know’ in 2022. The other was as an extra in the BBC Two programme ‘Then Barbara Met Alan’, about the founders of the disability activism group DAN (Disabled People’s Direct Action Network). She and her brother were part of the protest scenes, which she said she found “emotional”, thinking back to the Brixton Riot in the early 1980s, a clash between young black people and the Metropolitan Police in Brixton over racial discrimination, which her family members had been a part of.

Her very real connection with all the parts that make her unique is something she still holds closely as she gets on stage to do the job she loves.

“I’m not scared. A lot of my community is scared to talk about disabilities. I want to make light of it and put a reflection on society. I want to give people food for thought whilst they’re laughing.

“It’s the real things I talk about. And a lot of people can relate to it, if not for themselves, then for other people that they know – loved ones, neighbours or whoever.

And that’s what I like most. It makes me be remembered from that gig to the next.”

Despite getting the occasional critic, Variety is still determined to raise awareness of different issues – “but in an artistic, avant-garde way,” she quips.

### **Open more doors**

Performing today, some things haven’t changed. Her performances are still daring and real – and still improvised. “I don’t write down my stuff,” she said. “My agent says to me – and a lot of comics from before me – they say that I should learn to write stuff and remember it. I like challenges, but that challenge is so hard! It’s like a big boss challenge.”

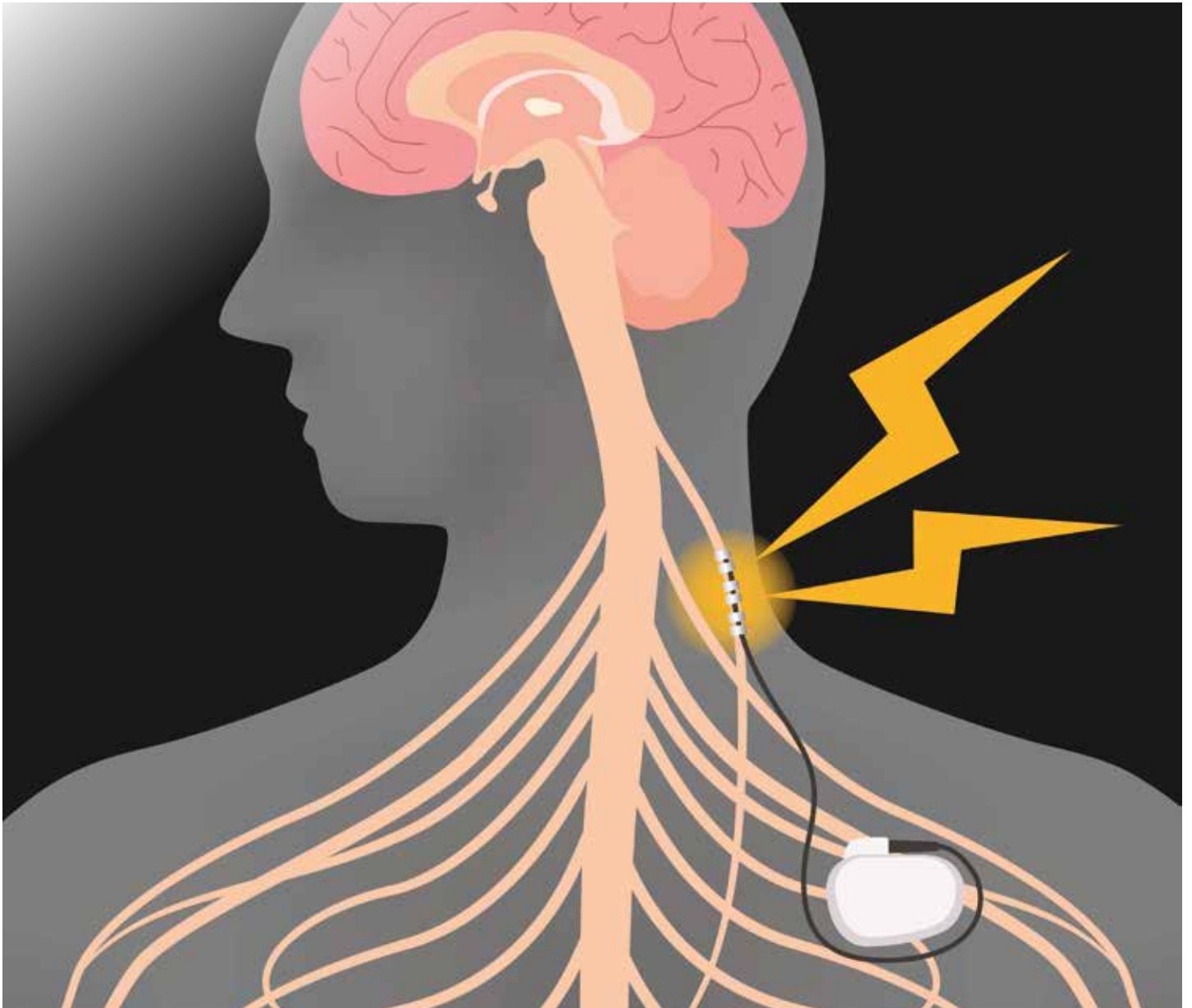
But one thing that Variety hopes has changed is the attitudes towards disability in the urban circuit. “One of my goals this year is to get back into the black British circuit and see how things have changed and if they’ve opened up to disabled comics.”

Having experienced firsthand how challenging it can be competing for space in the comedy arena when you represent different aspects of diversity (“It’s like Game of Thrones!”), Variety is keen to try to create space for more people from her communities.

“It’s a lonely mountain. But I just want to open more doors for people from my heritage.”

Her best piece of advice for comedians looking to follow in her footsteps? “Make sure you stand with a purpose, because no one can take that from you. And you will have fans that you didn’t even expect.”





# VNS

## therapy

Epilepsy Action's community share their and their loved ones' experiences with vagus nerve stimulation (VNS). Words by Kami Kountcheva.

**V**agus nerve stimulation (VNS) is a treatment offered to people with epilepsy whose seizures are medication resistant and don't respond to two or more epilepsy medications, and for whom brain surgery is not possible.

This treatment involves having a small device called a generator implanted under the skin on a person's chest and connected to their vagus nerve with a small wire under the skin. This is done through a one-to-two-hour operation under general anaesthetic.

The generator sends impulses to the vagus nerve either at regular intervals, or if it senses an increase in heart rate, which could be an indication of a seizure. There is also a hand-held magnet which the person can sweep over the generator if they

## “Research as much as you can, discuss with doctors and take your time with healing”

sense a seizure coming on, to send an electrical pulse.

The role of a VNS device is to reduce the number or severity of seizures. It may reduce recovery time and improve quality of life in some people, but Epilepsy Action stresses that it is not a cure and may not work for everyone.

Each person should be advised by their specialist or epilepsy specialist nurse about whether this treatment could benefit them. There is more information about what VNS is and what's involved with this treatment on the Epilepsy Action website.

We asked on social media for people who have had the device to share their experiences and thoughts about VNS.

### Does it work?

Many people shared how effective they are finding the VNS, and it's clear from the answers that this varies from person to person.

One responder said: “Best thing we ever did for our daughter. Using the magnet can stop a seizure instantly and her seizures are less and recovery is better.”

Another said: “I've had my VNS for around 18 months now. It was uncomfortable at the beginning when I had it turned on, but it subsided after a few weeks. It has vastly reduced my seizures and when I do have one, the recovery is so much faster. It has altered my voice and I take longer to eat and swallow, but again, I'm getting used to it and I'm waiting for some treatment to hopefully improve it. I've just started coming off one of my two medications, which was my main goal. It's made a difference psychologically too. I feel safer and I know it's there to help pull me out of a seizure if I have a bad one. Overall, great!”

A third responder said: “My epilepsy is caused by an autoimmune condition, and I had tried pretty much all the medicine out there. We eventually found a combination that did not have too many side effects and reduced the seizures, but they were still coming and I got permanent brain damage. My epileptologist suggested a VNS. Nothing to lose.

“It has been nearly a year and it is working really well! It's important for people to understand it is not a cure but a management system and, so far, it has helped me manage my seizures. They start but I can stop them from progressing into full tonic-clonic. So, if you have not found a chemical solution or management system, it's worth trying!”

Another added: “My surgery went well, I was back to work within 11 days, although I could've taken less time off. It healed well and I got used to the weight of the implant fairly quickly. When it was turned on, I could barely feel it, and it's been difficult following the programme as I've struggled to breathe and continue running at the level I was at. However my nurses have been amazing, I've continued running whenever I can!

“I had not got many other options left as I had drug resistant absences but this has given me a 90% seizure reduction, it's changed my life! Always do your own research and work with doctors but it's not a harsh surgery to endure (in my opinion), especially against brain surgeries or other major operations! I'm so glad I went for it!”

Whilst many people reported seeing improvements with the VNS, this was not everyone's experience.

One person said: “My son has one and no positive outcomes as of yet. It can take over two years to have any effect though, so bear that in mind – it is not a quick fix!”

Another added: “My daughter had a VNS implanted in Oct 24, and it is switched on at a specific pattern, but we are still waiting for its effectiveness. Sometimes the seizures get under control by swiping the magnet over but most of the time it seems to be ineffective. It takes time to be adjusted from patient to patient.”

### Delays in getting the VNS fitted

Some responders commented on how long it can take to have one fitted. One said: “My son is going to be having one fitted. Unfortunately, the procedure has been cancelled four times so far...”

Another simply added: “I am still waiting for mine.”

### Battery life and waiting for replacements

Where waiting for operations is concerned, having the VNS initially fitted is not the only time delay people said they have been experiencing. The battery on the VNS can run down and need replacing as well.

A social media user said: “I would say it

has certainly improved my epilepsy since having it fitted. The only problems I have had is waiting so long to get my battery replacement, as there are only around four or five hospitals in the UK that do the replacement. Hope soon my hospital in Plymouth will be able to start doing the replacement, after writing to my MP to try and get things moving.”

Another person said: “This is going to be my third battery. I went to the hospital yesterday for my VNS appointment, they scanned it and it was showing 0.08%. We were shocked! When I went there six months ago, they said the battery will still last one and a half years.”

### Challenges, obstacles and things it won't do

Whether successful or not, the VNS device may still come with side effects which people should be aware of, as one responder told us. “I have had mine for around 11 years now. Getting used to changes in your voice takes a bit of time, as does care taken during exercise as any raise in heart rate will set it off. It can cause snoring if it's on at night and battery need replacing every five years. It takes getting used to but isn't painful.”

Another responder cautioned: “Southmead Hospital, Bristol, will not give you an MRI if you have it. So, if you have physio problems and live in Bristol, I don't recommend it.”

A third identified that it wouldn't solve their biggest concerns. They said: “This has been offered to my adult son, but when I asked about him having a seizure and him falling hitting his head what would it do. They couldn't answer. He has had quite a few seizures resulting in head injuries. That's mainly our concerns. He has seizures regularly and medication helps but VNS doesn't stop his injuries from happening.”

Ultimately, it can be effective and make a big difference to many, but it very much depends on each person's epilepsy and situation. One responder gave some great advice to anyone trying to decide if VNS is for them. They said: “Research as much as you can, discuss with doctors, if you know someone that's had it talking to them may help (although we're all different so take that into account!), take your time with healing. Always tell the doctors and nurses how you are doing when the machine is switched on!”

Read more about VNS on the Epilepsy Action website.



Jessie in the  
Pink City,  
Jaipur, India

Jessie Buckle knows first-hand how climate and built environments can affect her own epilepsy, and through her PhD, she wants to make building standards better geared for people with the condition. Words by Kami Kountcheva.

**“I was travelling in India with my best friend Ashleigh for a friend’s wedding and a cluster of seizures took place. This had been the longest period of time I’d been seizure free for.**

“The only defining alteration was the environment which I was in – the architectural environment and the climate.”

Jessie Buckle, 30, from Brighton and Hove is in the middle of a PhD, looking at how the built environment and climate impact on seizures and epilepsy. Her interest in this area was first sparked when she herself was diagnosed with generalised epilepsy at the age of 19.

“My diagnosis followed an eight-month

trip travelling around Asia, Indonesia and Australia before I started university,” Jessie recalled. “The diagnosis came just before I was about to start my architectural degree, so I transitioned from this really independent, stubborn 19-year-old, to suddenly my world getting so much smaller.”

Jessie has tonic-clonic seizures and absence seizures, which she says can be sporadic and are not fully controlled. However, Jessie does everything she can to look after herself and reduce the chance of seizures. “I try to keep my body as healthy as possible as kind of a mitigation strategy.” For her, all of this helps to reduce the impact of her seizures,

which she calls “quite violent”, often leading to injuries.

Jessie lives with her boyfriend Alex and their dog Buddy. Harboring a real love for keeping active, Jessie is often walking her dog on the beach in the sunshine, going to yoga or spending time in the gym. “I love being outside, so I try to get outside as much as I can.”

#### **An uninclusive world**

Getting diagnosed at 19 was difficult, Jessie says, feeling acutely aware of how elements like losing her driving licence affected her independence at an age when it’s all she wanted. It even affected her decision about which university she applied to, choosing to stay closer to family and friends.

The diagnosis process itself, while straightforward, left Jessie with a lot of unknowns. “We are very lucky to have the NHS, but things are a bit slower. I was very lucky that, actually, mine was fairly straightforward, but during and after the diagnosis, it was very much medicalised language. It wasn’t explained in layman’s terms how much my life was going to change. You’re given the medication and you’re just left to figure things out.

“There wasn’t support, other than medical appointments, and through the research that I’m doing, I’m realising that, actually, that’s only 30 minutes of your day every few months. It’s not a reflection on what the daily reality of living with epilepsy is like and how it impacts loved ones.

“I’m 11 years down the line and I feel like I’m at a point now where I’m starting to understand my condition, but that’s years of figuring things out, research, noting things down, creating a seizure diary and really sort of mapping what my epilepsy looks like.”

Part of getting to know her condition over the years has been experiencing the outside world as someone with epilepsy. She explained: “Going to university, it became very real how uninclusive the world was and that I had to learn to navigate a world which isn’t designed for neurodivergence or neurological conditions.

“In university, for example, you expect to have an element of autonomy and independence. However, with epilepsy, you can’t do that to an extent. Academia and the workplace follow a very regimented structure, whether it’s deadlines or the workday that’s 9-5. And epilepsy doesn’t follow that structure. It’s fluid and spontaneous. That’s one of the things I struggled with, because epilepsy can interrupt that structure at any time without warning.

“I would imagine it’s the same with other invisible conditions. One day I’d be at uni, the next day I’d have a seizure and be out for a couple of weeks because of a head injury or a broken nose. Once I return, I appear bright, shiny and new – but that is not the case. You could see that people couldn’t quite get their head around that.”

### Advocate for epilepsy friendly policies

All of these experiences made Jessie aware of how challenging daily life with epilepsy and seizures can be for someone. Through her medication and her own strategies to avoid triggers, she ended up getting her seizures under control for the longest period since her diagnosis, even getting her driving licence back. But on her trip to India, she found herself at square one again. Her breakthrough seizures whilst being in a new place, sparked the idea in her of researching how climate and the built environment impact on epilepsy and seizures.

She started a master’s degree looking into this, feeling determined that factors we can control can have an impact on her seizures. She quickly realised this was a PhD and could not be captured in a 10,000-word thesis, which she is now doing in architectural design at the Bartlett at University College London.

“We know from studies that health concerns are being exacerbated by climate change,” she explained. “Research into how environments can trigger seizures – both climate and architectural – is crucial at this moment.

“It can be a mixture of things. For example, really high temperatures can lead to things like dehydration and electrolyte imbalances which can be triggers for seizures. Hot environments can lead to poor sleep quality – and we know sleep deprivation can be a huge trigger for people with epilepsy. Air quality could be another factor.

“Architecture and design have a real opportunity to modify some of these impacts from the climate. One of the things which often gets missed is transitions between spaces. In India, for example, it was 50 degrees outside, but then you walked into a highly air-conditioned airport, and the body becomes exposed to a drastic temperature drop, which could trigger seizures for some.

“When designing buildings, we can introduce natural elements. Natural materials such as wood, or more muted colours can make you feel calm. Introducing more plants, curved furniture or things that mimic natural environments can naturally reduce stress on the nervous system.

“We know lighting is the most well-known trigger despite affecting a very small percentage of people. Introducing adjustable lighting and lighting which does not flicker can give people back some autonomy. Avoiding patterns like striped effects or repetitive geometric patterns can help, as these can be overwhelming and overstimulating. Very reflective materials can cause glare and be a trigger too.

“There are lots of different things that can be implemented into your space, whether it’s at home or within public spaces that can really help.”

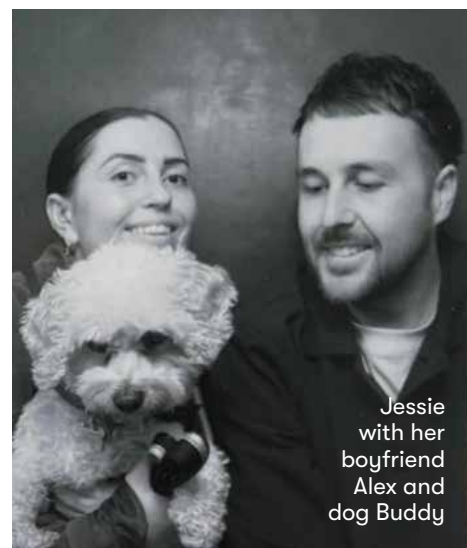
As she continues with her research, Jessie wants to demonstrate that these effects of uninclusive architectural design exist, raise more awareness around this and influence building standards to factor in more elements that can make spaces more inclusive of epilepsy and other conditions. As part of her research, she is collecting data from people with epilepsy and people who support someone with epilepsy.

“Brene Brown calls it ‘data with soul’, which I absolutely love, because people with lived experience are prioritised and included within the conversation. This is why the PhD exists in the first place – to deliver the data that we can use to advocate for epilepsy friendly spaces, policies and built environment standards. It exists to present the lived reality of epilepsy – the entire reality – directly from the voices of people with epilepsy.”

Jessie is collecting lived experience stories from people with epilepsy and their support networks for her work. If you would like to share more, email: [jessica.buckle.21@ucl.ac.uk](mailto:jessica.buckle.21@ucl.ac.uk)



Cannula after a seizure at a Mumbai airport



Jessie with her boyfriend Alex and dog Buddy

Alan Brown  
with his  
Charlie card



# Stand your ground

When Alan's pharmacy failed to help him get his medication, he challenged them with the help of his Charlie card. Words by Kami Kountcheva.

**“Some people are a bit nervous about doing this, but you have to kind of stand your ground, or you could be in real trouble,” advises Alan Brown.**

You may have seen in the news recently that access to medication is “set to get worse”, as medication prices surge globally and due to a convoluted funding system in the UK creating delays.

For people with epilepsy, this can be particularly concerning. We've seen sobering cases in the news, including that of Paul Nash, David Crompton and Charlie Marriage, where they've been unable to access their anti-seizure medications through their pharmacies and died following a seizure.

A recent study highlighted that seven in 10 people with epilepsy in the UK have experienced difficulty getting their

prescribed epilepsy medication in the past year. At best, this is a nuisance and at worst, it's life-threatening.

This is why Alan, 80, thinks people should be a little bit more persistent with their pharmacies when they run into problems accessing their medication.

“It's important to understand that pharmacies do have some responsibility in this area. I'm afraid you may find yourself simply having to challenge them on this.”

Alan lives in Haxby in York with his wife. He has three children and seven grandchildren, who are spread across the world from York to Switzerland to Japan.

Now a retired Senior Civil Service worker, Alan was diagnosed with epilepsy unexpectedly in his late 70s.

“It was about three years ago. I simply had a tonic-clonic seizure out of the blue with no history of this whatsoever. I ended up being carted off to A&E, where I spent three days on a trolley in a corridor in the hospital. It was really grim.

“I had a number of tests done and the upshot of it all was that I have something called a dermoid cyst in my head.

“This is a kind of tumour, but usually it’s benign and something you have all your life – you’re born with it. But often you wouldn’t even know you had one. But for reasons nobody understands, it decided to lodge in my brain and get bigger. Going back to the beginning, it may have started its life on my head the size of a pinhead, but it has grown over these last 80 years and it’s inoperable. It can’t be removed because of where it is.

“This caused two things – one, this epilepsy, and the other, a side effect of epilepsy probably, it’s had a very serious effect on me remembering things from the past. I mean, I don’t forget where I’ve been today and I don’t forget how to turn the TV on, but if you’re talking about my past life, most of that in my memory just doesn’t exist anymore.”

Alan was initially assessed by a non-specialist doctor and prescribed levetiracetam for his seizures at quite a high dose of 1,750mg a day. He ended up having two more seizures which were “less severe” than the first one.

“When I did get to see a consultant neurologist, he said: ‘Had I seen you before you were prescribed levetiracetam, I wouldn’t have prescribed that at all. I would have prescribed lamotrigine.’ Which is a cheery thought!”

Alan was told by his neurologist that now that he’d been prescribed levetiracetam, he would have to continue to take that alongside the lamotrigine, but at a reduced dose.

“So, one slightly unhappy thing about all of this is that had I seen a consultant neurologist to begin with, I’d have never been on the levetiracetam at all, I’d have been just on lamotrigine. I ended up taking two very powerful medications twice a day when I could have perhaps only had one powerful medication twice a day.”

Having two instead of potentially only one medication, makes medication shortages more likely to affect Alan, as he experienced a few months back.

“In my suburb of York, there’s my GP practice on the one side of the road and on the other side of the road is the pharmacy which interacts with the health centre. I order my prescriptions online, they get authorised, the authorisation goes to the pharmacy, after a while I get a text message and a code for the machine outside the pharmacy to get my medication.

“It’s always worked fine and I don’t have any issues about that. But coming to the thing that I don’t think is very satisfactory. A few months ago, I could see online through the NHS app that the surgery had authorised my repeat medications, but hadn’t received a text message. So, I rang up the pharmacy to say I can see that these have been authorised but I haven’t heard from you that they’re ready to collect.

“I was told that I’ve not been contacted because one of the is simply not available. But they had the rest of it.

“Two things – why haven’t you told me one of them is not available and why not at least give me the rest?”

Alan was told on the phone by the pharmacy that it wasn’t their job to let people know they’d run out of certain drugs and therefore his prescription would not be fulfilled.

He then walked over to the pharmacy to challenge what they were saying and argue his case. He showed them his Charlie card.

The Charlie card outlines that people have a right to request an emergency supply of their regular epilepsy medications from any pharmacy under the Human Medicines Regulations 2012. It is available at [sudep.org/charlie-card](http://sudep.org/charlie-card)

When they still “wouldn’t budge on this”, Alan asked to speak to the senior pharmacist and insisted that the pharmacy had some responsibility to help.

“I spoke to the senior pharmacist and she initially said it’s not their job to go hunting around for medications they don’t have. I said: ‘I’m sorry but I think actually you do have a responsibility.’ She went away and looked this up on the NHS website and came back rather shamefaced and said they actually should be doing something about it.”

It turned out they had Alan’s lamotrigine in a different form and he was able to

collect his medication that day. This was an option for Alan, but this isn’t the case for all people and all medications. Find out more about switching between different brands and formulations of medications on the Epilepsy Action website. You can download a leaflet that summarises key information.

Having experienced this, Alan was happy to have a Charlie card, which he found helpful as “something to stick under their nose” if the pharmacy were refusing to help.

“What was particularly unsatisfactory, leaving aside the denying they had any responsibility, was the idea that I would never have found out my prescription wasn’t available unless I had asked, but they knew they couldn’t fulfil it.

“I don’t think I’m particularly hard to deal with, but there’s a lot of other people who might have just gone away and they wouldn’t have pushed it.”

Aside from encouraging people to stand their ground and know that pharmacies have a responsibility to help, Alan’s advice is to “get one of these Charlie cards straight away.”

## What can you do?

- Try to **get your prescription earlier** so if there is a problem you can try a different pharmacy or ask them to contact a different wholesaler. Independent pharmacies are more likely to be able to do this.
- Use the Epilepsy Action **Don’t Sub My Drug guide** for more top tips and advice on discussing options with your pharmacist.
- You can **request a Charlie card from SUDEP Action** which allows you to request a minimum emergency supply from any chemist if you find yourself without your regular medication.
- If you have any concerns and have been experiencing any issues getting your medication, **get in touch with the Epilepsy Action helpline** – call 0808 800 5050 or email [helpline@epilepsy.org.uk](mailto:helpline@epilepsy.org.uk)

# What's new?



We share some recent advances in epilepsy research

## **A** n “encouraging” new medication, zorevunersen, appears safe and effective as a treatment for Dravet syndrome according to a new study in *The New England Journal of Medicine*.

A total of 81 children from the UK and the US aged 2-18 years entered the study and received one, two or three doses of zorevunersen over a three-month period.

Of these, 75 children went on into an extension study, continuing to have 45mg of the medication every four months for 20 months.

On average, the number of convulsive seizures in the children reduced by between 59% and 91%.

In this early trial, the researchers could see improvement in the children’s health, quality of life and adaptive behaviour.

Epilepsy Action’s health improvement and research manager, Tom Shillito, said: “This is an encouraging early result particularly given the urgent need for better treatments for children with Dravet syndrome.”

Dravet syndrome affects around one in 15,000 children. It tends to be difficult to treat, as seizures in this condition often don’t respond very well to current epilepsy medicines, the organisation says.

Zorevunersen was delivered through a lumbar puncture to combat the underlying cause of Dravet syndrome. The condition is often caused by a faulty SCN1A gene which means that there is too little of

a particular protein produced which helps nerve cells to work properly. The medication helps to increase production of this protein.

The study authors Dr Linda Laux and colleagues found that in their research, the medication’s side effects were mild or moderate.

They conclude that the medication has the potential to be disease-modifying, meaning it doesn’t just treat the symptoms, but can reduce the progression of the condition, and warrants more research and development.

One family who took part in the trial said the effects of the medication have “completely changed our lives”.

Freddie Truelove from Huddersfield went from 12 seizures a night to one or two short seizures every few nights. His mum, Lauren, said: “We now have a life we didn’t ever think was possible and, most importantly, it’s a life that Freddie can enjoy.”

Consultant paediatric neurologist and study author Helen Cross said: “I regularly see patients with hard-to-treat genetic epilepsies with impacts that go beyond seizures and it’s heartbreaking when treatment options are limited.

“This new treatment could help children with Dravet syndrome lead much healthier and happier lives.

“Overall, our findings showed that zorevunersen is safe to use and well tolerated by most patients and supports

further evaluation in the ongoing phase three study.”

Tom Shillito added: “We regularly receive enquiries to our helpline from affected families and know just how challenging and heart-breaking it can be caring for a child with Dravet syndrome.

“The study suggests this targeted approach could make a meaningful difference and give families greater options in treatment and more positive outcomes for their child. We look forward to seeing further research on this drug and similar drugs.”

Find out more about Dravet syndrome on the Epilepsy Action website.

## **ADHD risk in epilepsy**

Children with epilepsy whose seizures begin earlier in life, have neurodevelopmental challenges or need more epilepsy medications have a higher risk of having ADHD, according to a new study.

Attention Deficit/Hyperactivity Disorder (ADHD) is a condition where the brain works differently to most people, according to the NHS.

The research by Guang Ni and Dong Meng in the journal *Epilepsy & Behavior* was a meta-analysis of 12 studies looking at epilepsy and ADHD in children.

The authors wrote that ADHD is the most common neuropsychiatric condition in children with epilepsy. They said ADHD is estimated to affect almost one third

of children with epilepsy in the largest study in their analysis, but the researchers explained that it is still underdiagnosed in this group.

This could be due to similarity in the symptoms of the conditions, the complexity of the diagnoses or because of a lack of “standardised screening protocols”, they explained.

Children with both conditions can have worse seizure outcomes and quality of life, and more struggles with their healthcare and schooling.

The research looked at different diagnostic tools, finding that one called the SDQ-Hyperactivity scale was the most accurate in diagnosing ADHD in children with epilepsy.

The researchers said that as well as earlier seizure onset, higher number of epilepsy medications needed and neurodevelopmental challenges, the male sex and additional medical conditions were also risk factors for ADHD in children with epilepsy.

The researchers conclude: “Children with poorly controlled seizures, early onset epilepsy and those receiving polytherapy warrant heightened screening vigilance.

“Implementation of systematic ADHD screening targeting high-risk subgroups may substantially improve early identification and intervention outcomes.”

### New genetic discovery

A new genetic condition discovered by researchers in Manchester is offering answers and hope for the future to some children with drug-resistant seizures and developmental delays.

The researchers have called the condition ‘recessive RNU2-2-related neurodevelopmental disorder’ which is caused by a faulty RNU gene. The RNU genes are a group of small non-coding genes, which recent research from Manchester has suggested are important

in how the brain develops and works.

The condition causes drug-resistant epilepsy and developmental delays in children, often starting before the child turns one year old.

Study lead Dr Adam Jackson explained that the researchers estimate around 1 in 100 people could be a carrier of the faulty gene without knowing, meaning millions of people worldwide could be carriers.

They explained that if two parents are both carriers of the faulty gene, there is a one in four chance that their child could be affected by the condition.

“We estimate roughly 1 in 40,000 people may be living with this condition, making it one of the most common neurodevelopmental disorders currently known,” Dr Jackson said.

“Our discovery brings hope for many patients and families who have been searching for answers and is already having a positive impact around the world.”

Dr Jackson added: “What makes this discovery even more remarkable is that RNU2-2 is extremely small in comparison to other genes. Unlike most other genes, RNU2-2 does not even make a protein. We were astonished to discover how changes in this tiny gene can have such profound effects in so many individuals.”

Professor Siddharth Banka, study lead and clinical director of the Manchester Rare Conditions Centre (MRCC), explained that this shines a light on areas of human DNA “sometimes dismissed as ‘junk DNA’” and their importance in health.

He added: “Looking to the future, this discovery paves the way to help unlock life-changing treatments for the recessive RNU2-2-related neurodevelopmental disorder.”

The team studied changes in hundreds of the RNU genes using data from the 100,000 Genomes Project by Genomics England.

The research was carried out by the National Institute for Health and Care Research (NIHR) Manchester Biomedical Research Centre (BRC).

The research has already made a difference to more than 80 children around the world. One family based in Sydney, Australia, said being able to have the diagnosis for their daughter Ava is “incredibly meaningful” to them, giving her “a place in the medical world” and feeling “closer to the starting point of finding a cure or treatment”.

Tom Shillito, health improvement and research manager, Epilepsy Action said: “For families facing rare and severe epilepsy, the impact is felt every day from unpredictable seizures to challenges with communication, learning and independence.

“Research into the RNU2-2 gene is an important and promising step in helping us better understand what’s driving these conditions. It is still early days but progress like this brings hope for improved support and future treatments.”

## Key info on ADHD

- ADHD is a condition affecting how a person's brain works
- It affects a person's ability to pay attention and control impulses, and causes them to have high energy levels
- In children, it can look like forgetfulness, being easily distracted, fidgeting or having a lot of energy
- Symptoms usually start before the age of 12
- To help with ADHD, the NHS recommends making time for exercise, regular sleep and meals, and avoiding food or drink that makes symptoms worse
- A school educational needs coordinator (SENCO) can help put support in place at school
- A GP could help rule out other conditions and recommend support
- ADHD specialists can prescribe medications that could help with symptoms

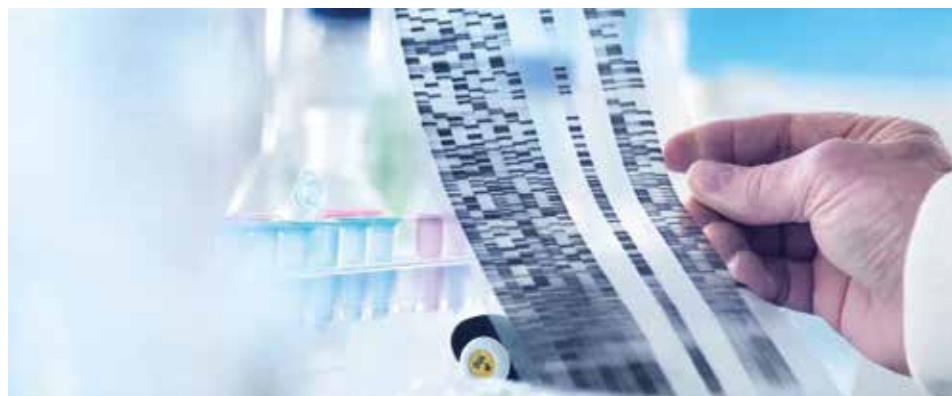




Photo: Harris Tomlinson-Spence

# Soaking up the atmosphere

Epilepsy Action’s runners raised thousands for people with epilepsy – four of them share what it felt like to be there.

**I**t has been said that experiencing a seizure can feel like running a marathon. So, for our Epilepsy Action runners – all 114 of them – it makes the iconic London Marathon even more poignant and meaningful. The fastest of our runners, Lloyd Mellens, finished the race in under three hours, while Kayla Cooper, who had a seizure midway through and was taken to hospital to be checked over, still managed to return to complete her marathon.

Whether running for themselves, for



Daisy

Photo: Harris Tomlinson-Spence

friends and loved ones, or for a community they see and admire, the Epilepsy Action runners took on the gargantuan challenge of 26.2 miles across London with determination and gusto and helped raise more than £251,000 for Epilepsy Action. All their hard work will help pay for vital services like our helpline, counselling and 1:1 peer support, as well as helping us campaign, raise awareness and educate the public about the condition.

But as well as the strong will to support a cause close to their hearts, taking on the London Marathon brings other rewards of its own – namely an atmosphere unlike anything else.

Four of our runners share their experience from the day.

## **Daisy – “truly unforgettable”**

Daisy ran the marathon in memory of her brother Tom, who had epilepsy since the age of 10, and passed away following a sleep seizure at the age of 29. Daisy says she finds a lot of inspiration from Tom’s strength, spirit and outlook on life.

On the day, Daisy was bowled over by the support. “The atmosphere that day was unlike anything I had ever experienced, it felt almost surreal. The support from the crowd was

overwhelming, with charity cheer points lifting spirits all along the route. Seeing my friends and family there meant so much, but watching my children witness their mum achieve something so incredible truly made it unforgettable.

“Hearing people shout your name throughout the course gives you this powerful sense that you’re part of something extraordinary. That you’re taking on a challenge that really matters.

“Crossing the finish line was an overwhelming moment of ‘I actually did that!’ I had just run an entire marathon, something I chose to take on and truly enjoy every step of the way. I smiled the whole course, soaked it all in and in that final moment, it all came together. The feeling was unlike anything I’ve ever experienced, pure elation and pride and all for a charity so very close to my heart.

“With heavy legs, a medal round my neck and a huge smile on my face, I hobbled over to the Epilepsy Action meeting point in St James’s Park. The team welcomed me warmly and handed me a well-earned glass of Prosecco. As I stood there taking it all in, I was treated to a leg massage, which felt incredible after the run.

“Not long after, I was reunited with my

husband, children, and family. Sharing that moment with them after everything made it all feel even more special. It was truly unforgettable.

### **Bex – “felt like running in a big hug”**

Bex was diagnosed with epilepsy two years ago. Her last seizure was whilst waiting for a train with her husband Richard and twin girls Florence and Elizabeth. Bex says she wishes she could have shielded them from that experience, but is incredibly proud of them for having learned what to do if it happens again. She went out to show them – and herself – that she can live the same life and be even stronger.

“It’s hard to put into words what the atmosphere was like. But the biggest thing is how supportive everyone was – in particular the other runners. It didn’t matter if you were a first timer or a regular marathon runner, everyone was kind and helpful. It felt like running in a big hug!

“Crossing the finish line was a bit bizarre, as at every other running event I have done (10ks and half marathons) there are crowds at the end and it is so loud. At London Marathon, you cross the line and it is pretty chilled! It gives you the chance to take it all in and reflect on your huge achievement! Saying that it doesn’t seem real!

“The first thing I did when I finished was I took my running trainers off and drank a bottle of chocolate milk! Heaven!

“Then I headed to the Epilepsy Action meeting point. I got an amazing reception and finally got to meet the team. My family then also came to find me there.”

### **Rachel – “have I actually managed to do that?”**

Rachel’s uncle Jeremy was diagnosed with epilepsy as a young child in the 1970s, but lost his life to seizures at the age of 23. Rachel now works as a children’s epilepsy clinical nurse specialist. She uses Epilepsy Action’s resources and directs many of the families she looks after to the Epilepsy Action information.

“The atmosphere on the day was just one big party! Insane! People talk about it being wonderful, but you can’t comprehend how wonderful, and how much you need it! People shouting your name, playing music, offering you sweets, water (not just the water station, random people too), pints – so much.

“It was honestly such a hard day, and I am fairly sure I wouldn’t have got around without the incredible crowds. The way



Bex with daughters Florence and Elizabeth



Rachel with husband Kingsley and friend Georgina

I’ve explained it to people so far, is I just wanted it to be over, while also never wanting it to end. And the crowds and atmosphere were the sole reason I didn’t want that pain to end!

“I’m not even sure how to describe crossing the finish line. ‘Oh thank goodness I’ve finished. Wait what? No, I’ll go back and enjoy it a bit more first!’ Just an absolute sense of ‘Wow, have I actually just managed to do that?’ I remember also thinking about what finishing meant, for me personally but also the money I’d been able to fundraise, and the combination of those just filling me with pride.

“Job number one after I finished was to hobble to get my medal! Then I called my mum because she was unwell and couldn’t make it. She also did London 19 years before me! Then I limped around to the Epilepsy Action tent and had a lovely Prosecco, and an ice-cold cola from my husband. I then sat for a while with my amazing supporters, because I couldn’t stand up again for a bit!”

### **Mia-Rose – “exhausted but completely buzzing”**

Mia-Rose ran the London Marathon in memory of her sister Lily who died at just eight weeks. She said Lily was “a piece of my world” and through running the marathon, she wanted to “turn that grief into something that could still do good”. The crowds and support on the day meant a lot to Mia-Rose.

“The atmosphere was incredible. The crowds were continuously buzzing and cheering me on the whole way round. Even in moments when I slowed down and felt like giving up, someone always seemed to shout my name or give a pat on the back, which really gave me that extra push to keep going.



Mia-Rose at the pub after finishing the marathon

“Crossing the finish line felt like such a huge wave of relief as well as pride after everything my body had been through. But also, it was really emotional. All the months of training, the early mornings, the long runs, and the sacrifices suddenly felt worth it in that one moment. It’s hard to describe – you’re exhausted, but at the same time completely buzzing. As soon as I crossed, I found myself already thinking about doing it all over again, which probably says everything about how special the experience was.

“After finishing, we headed straight to a pub to celebrate properly. And after being so disciplined for eight months with really watching what I ate and changing my diet slightly, I finally treated myself to a cheeky McDonald’s – which honestly tasted even better knowing I’d earned it. It was the perfect way to round off such a massive day.”

**You can read more about Daisy, Bex, Rachel and Mia-Rose on the Epilepsy Action news site.**

# Strength and care

Read more about how Hope shows strength through challenges and the way Chapel Hill Primary School staff support Amelia.  
Words by Emily Stanley

**The December 2025 Epilepsy Star award went to 12-year-old Hope Lowery, from Cardiff, for her incredible bravery and resilience in living with epilepsy. Hope has lived with epilepsy for four years and was nominated by her Mum, Kelsey, who says Hope has never let epilepsy get in the way of her life**

After a complex childhood, Hope was diagnosed with epilepsy in 2021. Since then, Hope has also had numerous other diagnoses, such as ADHD, a language disorder and non-epileptic seizures, which her mum says she has taken in her stride.

“Hope suffered from febrile convulsions since she was six months old. Doctors told us they would only last until she was around six, but as a parent I knew something wasn’t right. I was adamant that she had epilepsy, as I had seizures in my childhood before growing out of them, and it runs in the family too.

“In the autumn of 2021, I demanded that Hope had the relevant tests done, as she was still having seizures. The doctors agreed and Hope had an EEG – this revealed that she had left temporal lobe epilepsy, and she was started on medication in the December. Hope struggled to find a medication that worked for her, and I had to demand that she was switched to others, due to bad reactions to the initial medications she was put on.

“I felt like we were finally getting



somewhere, but two years later, Hope started having non-epileptic seizures. We found out that these can be triggered by her environment. At the time, her primary school was a major trigger due to excitement, stress – anything really. Eventually, I made the decision to take her out of her last year of primary school and home schooled her until high school.

“In this year, Hope was also diagnosed with a language disorder, and her epilepsy is now determined to be drug resistant generalised epilepsy. Because of these additional diagnoses, I felt Hope needed to be in a special needs high

school. I fought for her to get a place in one, and in January 2025 we were able to achieve this.

“Hope is now absolutely thriving. Her teachers are able to support her with her epilepsy, seizures and additional learning needs. She has joined the football team, been on school trips – most importantly I can see her spark has come back.

“Hope absolutely loves dancing and she has danced since she was four years old. She is a part of her local dance team. When she’s dancing, I see her eyes light up, and they really do.

“Despite everything she’s been through, Hope has never let it faze her. She inspires me to just get up and get on with things. Even after a seizure, she’ll just get herself up and get on with whatever she was doing.

“Hope is also very lucky to have an amazing healthcare team behind her, as well as the support of her amazing younger brother, Kayden.

“I am so proud to call Hope my daughter – as a single mum of two children it’s difficult to have a child with such complex needs but as a family we will overcome anything life throws our way. We will not ever let epilepsy define who we are – epilepsy is a part of Hope and always will be, so we can either hold a grudge against it or just accept it.

“Hope would like to thank Epilepsy Action for even considering her for

this award, and she wishes there was more awareness for epilepsy and non-epileptic seizures. She wants people to know that not all seizures are epileptic, and that it's okay to be different. She wishes epilepsy was spoken about more in school, as not many children know about hidden disabilities.

"To Hope, you make me proud every day and I will always be there right by your side. No matter what life throws at us, your brother and I will always protect you. Keep shining."

### Chapel Hill Primary School

February 2026's Epilepsy Star Award went to Chapel Hill Primary School in Basildon. The school has shown outstanding support for one of their pupils, Amelia, who lives with epilepsy. Amelia's mum, Kelli, nominated the school, describing how they have shown exceptional care, understanding and dedication for Amelia.

Kelli tells Amelia's story and why she wanted the school to receive an Epilepsy Star award below.

"Amelia was diagnosed with epilepsy at just six months old. When she was three, she underwent TOP disconnection surgery at Great Ormond Street Hospital.

"Sadly, her seizures returned when she was five. After a period of stability, her epilepsy became uncontrolled again in October last year. She is now trialling different medications and has been placed back on an epilepsy surgery pathway.

"This has been an incredibly difficult time for Amelia and our family.

"Amelia faces a number of challenges in school at the moment due to significant changes in her epilepsy and treatment. She is currently adapting to major medication adjustments, ongoing seizures, and the difficult side effects that come with both. These side effects – including tiredness, headaches and general fatigue – make it much harder for her to manage the demands of a school day.

"She also has frequent hospital appointments, which interrupt her routine and add to the strain she's already experiencing. To help support her health, Amelia attends school on a reduced timetable, which can be challenging academically and socially as she works hard to keep up while still prioritising her wellbeing.

"In addition to this, Amelia is visually impaired as a result of a previous epilepsy surgery. This brings its own

daily challenges in the classroom – navigating the school environment, accessing learning materials, and managing visual fatigue all require extra care and support.

"Throughout this difficult time, every member of the Chapel Hill team has shown exceptional care, understanding and dedication. From the receptionist who greets Amelia each morning with a smile and shares important information with her teacher, to her wonderful teaching assistant who keeps her laughing and helps her safely navigate the school day. Her class teacher knows exactly how to lift her spirits during difficult moments and connects with her through her interests, such as Pokémon.

"Amelia is always included in all activities and school events – her PE and English teachers work closely with our family to ensure she can still take part safely. We've used Epilepsy Action's toolkits to assist the school.

"The SENCo is always available, offering constant support and reassurance, and never makes us feel that any question or concern is too small. She does an incredible job of keeping all staff informed of Amelia's changing needs, which can sometimes vary week by week.

"The whole team has gone above and beyond to support Amelia and our family, helping her to feel safe, valued, and included despite the challenges she faces. What stands out most is that this isn't down to just one person – the whole staff team is fully aware of her needs, confident in how to support her,

and consistently go above and beyond to make sure she is safe and included.

"The way the staff share information so quickly and effectively is incredibly reassuring. It means everyone who interacts with Amelia understands her needs and how best to respond to them. As parents of a child with epilepsy, trusting others with your child's wellbeing can be daunting, but Chapel Hill has given us genuine peace of mind. We always feel Amelia is safe, understood, and cared for, and that level of confidence is truly rare and invaluable.

"We are incredibly grateful for everything they do, and they truly deserve to be recognised for their outstanding support.

"We are incredibly thankful to Mrs Burke, Mrs Goodgame, Mr Nawaz-Stevens, Mrs Cox, Mr Summerfield and all staff at Chapel Hill that make a difference to Amelia. Supporting her in the way that you do, makes an invaluable difference to us as a family who are facing some challenging periods with her health. Thank you for all that you do."

Speaking about her teachers at school, Amelia said: "My teachers at school really look after me when I have a hard day. I love that Mrs Goodgame can always make me laugh and spends time with me in the playground when I don't feel well. I always feel safe at school."

Upon accepting their award, Chapel Hill Primary School said "We are immensely proud to accept the Epilepsy Star Award following our nomination by the parent of one of our pupils.

"Amelia exemplifies the importance of resilience, positivity and persistence. She is a true role model within our school, and we are honoured to celebrate this recognition alongside her and her family."

Kelli says epilepsy awareness is vital in schools and hopes other places of education are inspired by Chapel Hill's inclusivity.

"When schools are truly aware and informed, they're able to support the whole child, not just their condition. That understanding helps ensure a child feels safe, included, and understood throughout their school day. Awareness also empowers staff to respond confidently and appropriately, which gives parents like us real peace of mind. It makes a huge difference to a child's wellbeing, confidence, and ability to thrive in education."



Amelia and her teachers



Chloe and Ellie raising awareness at the rugby

# Spread the word

Read about five great ways in which Epilepsy Action and our amazing community helped to spread the word about epilepsy this Purple Day.

**O**n 26 March, we marked Purple Day, the global epilepsy awareness day, trying to raise the profile of the condition and bring more knowledge and awareness to the public.

Survey results from Epilepsy Action demonstrated that this is still sorely needed. Of around 2,000 people surveyed, 81% did not recognise that epilepsy is common and could affect anyone. Just under half (47%) admitted they didn't know anything about epilepsy and just under two fifths of people (39%) said they think epilepsy only affects someone during a seizure.

This means that we still have work to do to get more people knowing about epilepsy and spreading the word about it. Our efforts this Purple Day took us on the airwaves, on the news, in print and on social media. We share five cool ways our community helped to spread the word about epilepsy.

## 1. Epilepsy in the news

News outlets around the country, including BBC News and Metro, featured epilepsy – from sharing key information about epilepsy and seizures to our story champions sharing their lives experience of what having epilepsy is really like. Robert shared more about the misconceptions he faces and why epilepsy awareness is so important to him in BBC East Midlands Today's Lunchtime News.

Our seizure first aid information – CARE – also featured as a full-page advert in The Guardian newspaper on Purple Day itself.

## 2. Awareness on the airwaves

Epilepsy Action's brilliant story champions shared more about living with epilepsy across multiple radio stations, including Heart, Capital and BBC Radio.

We spoke to Bradford Community Radio's sister station, Radio 119, run by adults with learning disabilities, and featured on the Strategic Health Check podcast talking all things epilepsy. President of the International League Against Epilepsy, Dr Rhys Thomas, was also interviewed across a number of different stations, sharing more about epilepsy and encouraging people to head to the Epilepsy Action website for more high-quality information.

## 3. Celebrity support

UK actor Freema Agyeman – the Doctor's companion Martha Jones in Dr Who and Dr Helen Sharpe in New Amsterdam – shared a post from Epilepsy Action Doodle Day wishing everyone a happy Purple Day with her 744,000 followers.

## 4. See it on the big screen

Cinemas around

the UK held special Purple Day screenings of new documentary style film 'D is for Distance' ahead of it coming out in cinemas in early April. The film features Louis Petit and his family navigating Louis' rare and life-threatening form of epilepsy juxtaposed with early cinema footage. Read more about the film and the family behind it on page 12.

## 5. Community

One of the best things to see on the day was members of our community spreading awareness in their local areas. Among them were community champion Ruth and one of our 1:1 peer support volunteers Tarynn, who hosted a stand full of resources and information at Kirkstall Forge in Leeds. Elsewhere, community champion Chloe and 1:1 peer support volunteer Ellie attended the Castleford Tigers VS Bradford Bulls rugby match, also hosting a stand of information and resources and engaging people to share the work of the charity.

A big thank you to everyone who helped to spread more awareness about epilepsy on Purple Day and beyond – collectively every voice helps amplify the message and make life easier for people with epilepsy.



# Epilepsy support for you

**F**or many people, living with epilepsy can feel isolating and misunderstood. But you're not alone. There are so many others navigating similar experiences – whether they're living with epilepsy themselves or caring for someone who is.

At Epilepsy Action, we're here to support you and help you connect with others who truly understand. We offer a range of free, confidential services designed to make a difference:

- **Helpline:** Speak with our trained advisers who are ready to listen and help you explore possible options and solutions.
- **Medications support** - help if you are struggling with side effects or changing medications.
- **Wellbeing support** - support with how to live well with epilepsy if you are finding life a bit tough.
- **1:1 Peer Support:** Have a friendly weekly chat with a volunteer who understands.
- **Groups:** Join others affected by epilepsy through virtual or in-person

groups to share stories, experiences, and support.

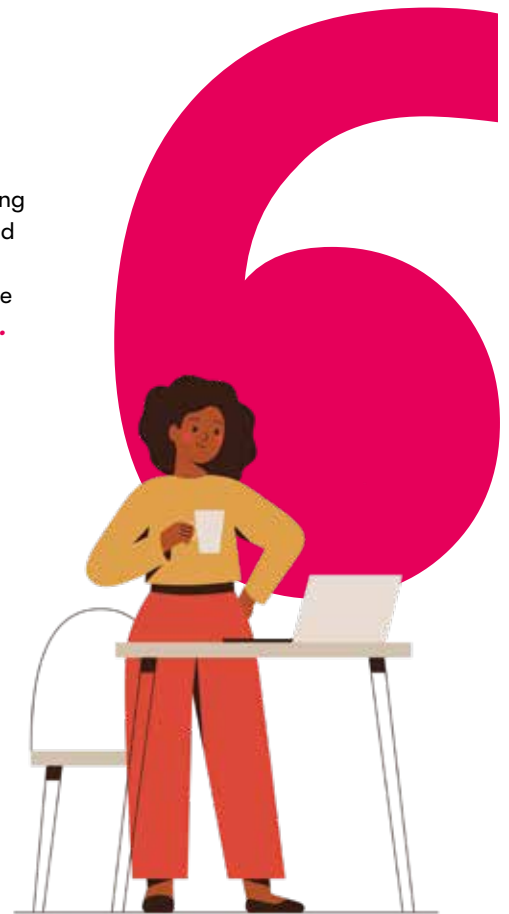
- **Family Support:** Tailored support for families and carers in South Wales, including practical help and opportunities to connect. We're here to listen, support, and bring people together – because no one should feel alone on this journey.

For more information call our Helpline on 0808 800 5050 or visit [epilepsy.org.uk/support-for-you](https://www.epilepsy.org.uk/support-for-you)

You can also 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))
- TikTok ([@epilepsyaction](https://@epilepsyaction))
- Instagram ([bit.ly/3zSKMVM](https://bit.ly/3zSKMVM))

**“We're here to listen, support and bring people together”**



Editor

**Kami Kountcheva**

[kkountcheva@epilepsy.org.uk](mailto:kkountcheva@epilepsy.org.uk)

Publisher

**Epilepsy Action** [epilepsy@epilepsy.org.uk](mailto:epilepsy@epilepsy.org.uk)

New Anstey House, Gate Way Drive, Yeadon,  
Leeds LS19 7XY, UK

Tel: 0113 210 8800 Fax: 0113 391 0300

Freephone Epilepsy Action Helpline:

0808 800 5050

[www.epilepsy.org.uk](http://www.epilepsy.org.uk)

Every reasonable effort has been taken to ensure the accuracy of the content, but no responsibility can be taken for any error or omission. The opinions of contributors do not necessarily reflect the views of the charity, nor does the inclusion of an item constitute

a recommendation. Epilepsy Today is available on subscription to non-members – £20 a year to UK residents and £45 to non-UK residents.

Please send all letters, articles and so on to the Editor. We are unable to acknowledge receipt of materials, due to cost. We cannot offer payment to authors.

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

©2026 Epilepsy Action ISSN 0958 496X

All models are used for illustrative purposes only.

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

# **EPILEPSY SAYS STOP. WE SAY GO.**

## **Support for you:**

- **Helpline** – phone, webchat or email
- **Medications Support**
- **Wellbeing Support**
- **Talk and Support Groups** – online & in-person
- **1:1 Peer Support** – online or phone
- **Family support** – Wales
- **Website** – high quality information about all things epilepsy
- **Epilepsy awareness courses**



**scan for more**

Registered charity in England and Wales (No. 234343)

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



**0808 800 5050**