

# Epilepsy

Today

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## Welcome

January is often a time of fresh starts, whether that be welcoming in the new year, setting resolutions or looking forward to more sunshine and longer days. In this edition of Epilepsy Today we introduce readers to our new strategy – not just a refresh for 2024, but for the next six years. As part of that we need you, and you can find out more about how to get involved on pages 14-15.

If health resolutions are your thing, our fundraising team have created a challenge calendar on pages 12-13, which lists all the activities available in 2024. And, on pages 28-29, Instagram star That Keto Guy explains how he starting the ketogenic diet changed his life. If your resolutions involve supporting others, we have volunteering roles to suit a range of people on page 18.

To look forward, it's also key to reflect. And, on page 16, you will find our impact report where we look back on everything you achieved with us in 2023. Meanwhile on pages 24-27 you will spot some familiar faces in our round up of the Epilepsy Star awards so far.

Whether your January involves looking forward, looking back or just getting your head down and through the winter months – we hope you find something to help you in this issue. Happy New Year!



**Grace Wood**  
Editor

## Brain wave study shows potential new treatments

**S**low brain waves may reduce the impact of seizures and could provide potential avenues for future therapies, according to a group of researchers at University College London (UCL).

The academics found that people with epilepsy have slow brain waves – which are usually seen during sleep – while they are awake.

The study, titled 'Wake slow waves in focal human epilepsy impact network activity and cognition', was featured in the journal *Nature Communications* last month. Speaking to Epilepsy Action, lead author Dr Laurent Sheybani explained the results of the work.



"During sleep, slow waves of nerve cell activity decrease the excitability that has accumulated during the day, allowing the brain to reset, ready for the next day.

"We found that these slow waves, which usually occur only during sleep, also occur during wakefulness in people with epilepsy," he said.

The team made the discovery by analysing the EEGs of 25 patients with focal epilepsy who were undergoing assessment for surgery at the National Hospital for Neurology and Neurosurgery in London.

Dr Sheybani added: "These slow waves slowed people's reaction times but did not affect how accurately people did on memory tasks. This contrasts with epileptic activity, which affected memory performance.

"We propose that enhancing these slow waves could open up avenues for future therapies in epilepsy for both reducing seizures and improving memory performance."

## Epilepsy Action launches quality mark for employers

**The Epilepsy Action Mark of Quality, for employers who have been trained to support staff with epilepsy, was launched in November.**

The 'Mark of Quality' shows that employers create a safe environment and know how to support people with epilepsy.

Research from Epilepsy Action shows that about 40% of working-age people living with epilepsy are in work. To improve this, the charity says employers need to have better knowledge to support employees living with epilepsy.

Epilepsy Action's training modules aimed at businesses cover three levels. The basic level is called Epilepsy Aware, the next step up is titled Epilepsy Confident and the final level, Epilepsy Positive, represents the highest standard.

Each level reflects the training undertaken, with Epilepsy Aware covering basic epilepsy knowledge for staff. Epilepsy Confident includes information for line managers on how to support staff

living with the condition. Epilepsy Positive is earned by undertaking a masterclass for human resources and equality diversity and inclusion specialists. This level covers the legal implications, including the Health and Safety at Work Act, the Equality Act, and how to ensure staff are supported with reasonable adjustments, care plans, personal emergency evacuation plans and more.

The purpose of the Epilepsy Action Mark of Quality is to help employers look after staff and build confidence and trust with people who have epilepsy. These people often have the necessary knowledge and skills but are overlooked because of stigma.

# Disability-safe panto performances launched

**A** pantomime in South London is catering for the needs of children with epilepsy and other disabilities by providing sensory-sensitive performances.

Peter Pan at Wandsworth Civic Suite was created by theatre company Hurricane Productions and organised by the not-for-profit organisation Enable.

The relaxed performances for children with disabilities include a number of special considerations:

- A chill-out room for audience members who need a bit of quiet time before and during the performance.
- Reduced lighting and special effects.
- Free tickets for carers.

- Familiarisation visits, which are opportunities for audience members to check the auditorium to make sure it will be safe before the show.

Enable works with councils, charities and other organisations to deliver health, leisure and community services across South London.

The sensory-sensitive performances were inspired by members of the local community who asked for these to be provided after last year's show.

Enable's senior PR and communications manager Lorna Dorrell said the charity was looking to scale up the events next year if people in the community wanted more. She said: "We're always willing to do more and learn more."

The show catered to children aged 3-11. Marketing manager Jake Leonard said they had chosen Peter Pan because it was a classic British story.

"Last year we chose Dick Whittington," he said. "But this year we wanted to go for something with more magic to it."

Other considerations include that house lights are kept on; there are no rapid lighting changes or sudden loud noises; there is lower audience capacity to allow for space in the auditorium and there is a relaxed attitude to walking around during the show.

These were also opportunities to meet the cast to "close the circle of understanding for people who have difficulties with flexibility of imagination".

# Railway ticket office closures halted

**Proposals to close railway ticket offices have been scrapped following a campaign against the closures from charities and organisations including Epilepsy Action.**

More than 70 groups representing disabled people and allies wrote a letter of objection to the government.

Epilepsy Action senior policy and campaigns manager Daniel Jennings said: "While we're certainly pleased to see ticket office closure plans will not be going ahead, this decision only comes after weeks of pushback that wouldn't have been necessary if accessibility was taken into account from the start.

"We have strongly opposed the measures since their announcement,

alongside many other organisations representing disabled people and allies. Ticket offices are essential for people with a disability. This is especially true for people with epilepsy who often rely on public transport due to not being able to drive.

"Ticket office closures would have compromised the safety of disabled people travelling on the rail network, so knowing they won't go ahead is a huge victory for everyone who supported the campaign. However, we're hoping accessibility needs will be taken into consideration from the start as an integral factor for any future measures."

Transport for All, the umbrella group behind the campaign, said it was a

victory for campaigners but described the decision as "bittersweet".

Speaking in November, campaigns manager Katie Pennick said: "This represents the best possible outcome – but it's not a step forward, instead we have resisted things getting worse. While we are proud of the incredible tenacity of disabled people and our community for securing this major campaign victory, the outcome is bittersweet. The disastrous and discriminatory proposals should never have been put forward."

According to the BBC, the government's transport secretary Mark Harper said it had asked train operators to withdraw the proposals because they failed to meet passenger standards.

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# Epilepsy news

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## Sodium valproate restrictions begin

**New restrictions for sodium valproate are to come into effect from January 31, 2024.**

The changes, announced by the MHRA last year, affect men and boys for the first time.

Sodium valproate is an anti-seizure medication, also known as: Epilim, Episenta, Epival, Dyzantil or Depakin

The MHRA is a government body that regulates the safety of medicines and medical devices.

The restrictions mean no one under the age of 55 will be newly prescribed sodium valproate unless two specialists agree there is no other effective or tolerated treatment, or unless there are “compelling reasons that the reproductive risks do not apply”.

The update means all women who could become pregnant and girls who are currently taking valproate will be reviewed at their next annual specialist appointment, and will require a second opinion to continue taking the medicine. This will be done using an Annual Risk Acknowledgement Form, which will also be introduced for men in 2024.

According to the MHRA, about one in nine babies born to mothers taking valproate will have birth defects and about 30-40 of 100 will have learning difficulties. The MHRA has also said that there is a risk of reduced fertility in men and boys taking valproate.

There have been restrictions around valproate for women under 55 since 2018 when the MHRA introduced the Pregnancy Prevention Programme.

Epilepsy Action understands that for 10% of people with generalised epilepsies, valproate is the first-line defence against hospitalisation and the risk of sudden unexpected death in epilepsy (SUDEP).

Epilepsy Action chief executive Philip Lee said: “Throughout 2023, we have raised our concerns around the new policies as part of a group of epilepsy charities and organisations. The new regulations represent a dramatic shift in clinical practice, and the group expressed concerns when it came to their impact on patient safety and workability for healthcare professionals.

“The group gave the MHRA constructive feedback on proposed patient materials,

as well as the development and implementation of the policy. These changes were necessary so that patients and families could be empowered with all the insight they needed to make informed choices about their treatment.

“With the new policy being rolled out from the end of January 2024, we hope that all healthcare providers will be given the time to safely implement it at a time when these systems face unprecedented waiting times, resource limitations and access issues.

“Epilepsy Action will remain engaged with the MHRA and others on this issue for as long as we feel we can have a positive benefit for people with epilepsy and the wider epilepsy community. We will continue to be alongside people and families and seek accountability and learning as needed. We will also continue to call for openness of evidence, positive opportunities for engagement and balanced messaging, so that people can make properly informed choices.”

**Do not to stop taking your epilepsy medicine without talking to your doctor first.**

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## Epilepsy Action wins Helpline of the Year

**Epilepsy Action won Helpline of the Year at the Helplines Partnership Awards in 2023.**

Advice and information officer, Diane Wallace, was awarded the Lifetime Service Award for her 30 years of dedicated service. In her time with the charity, she has answered more than 100,000 enquiries.

Advice team leader, David Thornton, also received a runner-up award for Mentor of the Year, in recognition of the

guidance and support he provides to the helpline team and wider organisation.

The Helpline Awards recognise the exceptional work done by individuals and teams across the helpline sector. The ceremony was held on 2 November at Birmingham Crowne Plaza Hotel.

The awards are organised by Helplines Partnership, the membership body for organisations that provide information, support or advice via phone, email, text or online.

# Church describes epilepsy as ‘spiritual problem’

**A** leader of a church in the UK has described epilepsy as a “spiritual problem”, an investigation by BBC Panorama has claimed.

While being filmed undercover by Panorama, Bishop James Marques said: “We know that epilepsy is a medical condition but in the Bible the Lord Jesus casts out an evil spirit that was causing epilepsy. So we can understand that epilepsy in reality is a spiritual problem that has a physical, visible manifestation. But it’s a spiritual problem.”

The preacher is part of the Universal Church of the Kingdom of God (UCKG).

UCKG is an international Evangelical Christian denomination with headquarters in Brazil.

The Panorama investigation visited a UCKG youth group service in Brixton, south London, and a service in Croydon, south London. The church has more than 30 branches in the UK.

According to the Panorama programme, the church leaders believe mental health problems and other conditions can be caused by demons. The leaders would then pray ‘strong

prayers’ for people with depression and other illnesses. In a statement to the BBC, UCKG said “strong prayers” are never “promoted as a replacement for medical or professional help”.

In response to Bishop Marques comments about epilepsy, Dr Joe Aldred, a Pentecostal bishop – not affiliated with UCKG – said: “For a minister today to insist that something like epilepsy is demonic is exceedingly misleading, inappropriate and not a message for the times in which we live.”

Responding to a post about the programme on Twitter, one user said they had experienced something similar to “cure” their epilepsy.

“I experienced this in the 1980s. I’ve had holy water sprinkled on me, as part of casting out the evil spirit that lurked within. Ten years ago, I was advised that a pastor could cure me. It’s sad that such backward thinking still exists.”

Epilepsy Action deputy chief executive Rebekah Smith said: “We’re appalled by the practices at the Universal Church of the Kingdom of God uncovered by last night’s BBC Panorama report, particularly concerning people with epilepsy.



“The use of so-called ‘strong prayers’ as a treatment for epilepsy, which UCKG misleadingly labels as a ‘spiritual problem’, is not just scientifically baseless but also potentially harmful.

“This investigation is a stark reminder of why there’s an urgent need for greater education, understanding and advocacy concerning epilepsy. Portraying epilepsy as a condition that requires spiritual intervention is a dangerous representation, akin to conversion therapy tactics, which can have devastating psychological and physical effects.”

**To read more and watch the Panorama investigation: [www.epilepsy.org.uk/church-leader-describes-epilepsy-as-spiritual-problem](http://www.epilepsy.org.uk/church-leader-describes-epilepsy-as-spiritual-problem)**

## 75% of carers struggling with mental health

**More than three quarters of carers are struggling with their mental health, according to a report from Carers UK.**

The charity is calling for the government to develop a National Carers Strategy, make caring a protected characteristic and invest an additional £1.5 billion in carers’ breaks.

The recommendations follow Carers UK’s annual report into health, which found that more than three quarters of carers feel stressed or anxious, half feel depressed, and half feel lonely.

More than a quarter said their mental health was bad or very bad. Of those, 39% said they were not receiving any support with their mental health and 73% were continuing to care even though they felt they were at breaking point.

Epilepsy Action is backing the recommendations. Director of health improvement and influencing Alison Fuller said: “Caring for someone with epilepsy can involve a multitude of responsibilities, varying from person to person, and while it can be hugely rewarding, being a carer can also be demanding.

“It is essential that moving forward, carers are better supported based on their individual needs and they have access to the services they need to improve health and wellbeing. We welcome the recommendations made by Carers UK, calling on the government, the NHS, and local and voluntary organisations to implement better

systems and invest in additional funding to support our carers.”

Across the UK, 5.7 million people are carers. Of those, 80% are female, and 29% have a disability of their own. 16% also have childcare responsibilities.

A 2021 ONS census for England and Wales found there had been an increase in the proportion of people caring for more hours.

Fuller added: “This study from Carers UK highlights that an alarming number of carers are struggling with their mental and physical health, and it is concerning to see this figure has risen significantly in the last year. Carers play an essential role in keeping families together, often working long, unpaid hours to look after their loved ones. It is unacceptable that so many of these people, who dedicate their time to caring for others, are falling through the cracks, unable to access the support they need.”

# Autumn budget 2023: welfare reforms announced

**T**he government has announced reforms to welfare for disabled people and those who are out of work.

As part of the autumn budget, announced in November 2023, chancellor Jeremy Hunt said he wanted to reduce “workless households” through a new “Back to Work” plan.

The Back to Work plan seeks to help around one million people with long-term health conditions, disabilities, or long-term unemployment to look for and stay in work by expanding the treatment and employment support available.

However, it also introduces stricter benefit sanctions for people who can work but refuse to engage with their Jobcentre or decline work offered to them, including stopping people’s benefits if they don’t do enough to look for a job in six months.

Many people with epilepsy currently qualify for welfare benefits.

Hunt also announced that Universal Credit and other benefits would increase from next April by 6.7% in line with

September 2023’s inflation rate.

Hunt said: “Today’s measures reward effort and work.”

The autumn budget also included measures on tackling inflation, public sector spending and increases to the state pension and national living wage.

Earlier in November, MPs told Sky News and Times Radio that disabled people should look for work they can do from home.

Chief secretary to the Treasury Laura Trott said: “There is a duty on citizens if they are able to go out to work they should. Those who can work and contribute should contribute.”

Epilepsy Action’s senior policy and campaign officer Daniel Jennings said: “We know that only 42% of people with epilepsy are in employment so we welcome efforts to get more people with disabilities and long-term health conditions into work.

“However, the way to do this is to provide tailored support for specific conditions to address the barriers to



employment faced by people with disabilities, and not by pursuing harsher and harsher punishments for people already struggling on benefits during a cost-of-living crisis.

“While overall benefits are increasing, which is certainly a positive, people are going to be facing much tougher requirements for entitlement.

“These measures only cause people more stress, which is a seizure trigger for many people with epilepsy and is not the way to support people into work.”

Jennings added: “In addition to more tailored employment support, we also need to see a change in the attitudes of employers, as we know that far too many don’t treat people with epilepsy fairly.”

## Cost-of-living payments cut from disability benefits

**Cost-of-living payments for people on disability benefits have been dropped by the government this winter.**

A £150 cost-of-living payment was given between 20 June 2023 and 4 July 2023 to people in receipt of certain disability benefits, including personal independence payment (PIP), but will not be given out this autumn.

However, a cost of living payment of £301, for those on low incomes, was paid out in October 2023.

People with epilepsy, and other disabilities, may have received the £301 cost-of-living payment if they receive benefits other than PIP.

Research from the charity Scope claims that extra living costs for disabled people add up to £583 a month on average.

Last year, a survey by Epilepsy Action suggested that 58% of people with epilepsy are worried about being able to afford bills, including the cost of running important medical equipment such as seizure alarms and monitors.

Epilepsy Action’s senior policy and campaigns manager Daniel Jennings said: “Even before the cost-of-living crisis began, living with a disability added up to an extra £583 each month. Excluding those on PIP from the next round of cost-of-living payments will make disabled people more financially vulnerable.

**“Even before the cost-of-living crisis began, living with a disability added up to an extra £583 each month”**

“In autumn 2023, almost 3 in 5 people with epilepsy were worried about being able to afford their bills, including the cost of running equipment such as vital seizure alarms and monitors, and 2 in 5 were experiencing more seizures due to stress about managing rising costs.

“This decision does not take into account the needs of people with epilepsy and other disabilities and it is worrying that disabled people are not being given the financial support they deserve as we enter into winter.”

A spokesman from the government’s department of work and pensions said: “Disabled people on low incomes in receipt of qualifying means-tested benefits during the relevant eligibility windows will be eligible for the means-tested cost-of-living payments.

“The £150 payment was on top of these cost-of-living payments, with disabled people who wouldn’t qualify for the means-tested support, but who are in receipt of disability support, also receiving the payment.”



# Survey: 42% wouldn't hire employees with epilepsy

**A** survey from Epilepsy Action has found 42% of UK managers wouldn't hire someone with epilepsy to save their company challenges, even though they know this is discrimination.

The Make Things Work campaign heard from managers and people with epilepsy who have faced workplace discrimination. The charity called for an urgent change in attitudes towards people with epilepsy at work. It said a higher minimum compensation for employment discrimination was needed.

A petition calling on the government to strengthen employment law and ensure employers are properly punished for discriminating against disabled people reached 1,500 signatures.

According to the survey, 60% of people with epilepsy said they had experienced unequal treatment or discrimination at work because of their condition. More than a third (36%) had heard a colleague, or their employer, make a derogatory comment about their epilepsy, and 33% had been bullied because of it.

Epilepsy Action deputy chief executive Rebekah Smith said: "In 2024, it's simply unacceptable for so many people with epilepsy to still face unequal treatment and discrimination at work. What's even more concerning is seeing how widespread the misunderstanding of the condition seems to be among managers and employers."

The survey included 1,420 people with epilepsy and 500 UK employers and managers.

When Sam, 35, from Kent, had a seizure at work, a group of managers stood laughing instead of helping.

Over the years, Sam has had other seizures at work, and on occasion has had to take time off to recover.

He said: "When I returned, I was faced with disciplinary actions for taking time off, even though they knew about my health condition. I was threatened with being sacked if it carried on. I felt as though I had to apologise."

Over the past three years, Sam's



seizures worsened and he is currently waiting for an appointment to trial new medication.

He said: "Trying to apply for Universal Credit and Personal Independence Payments (PIP) was a nightmare. I felt as though they looked down on me, as though I was lying. Like I can work, but just don't want to."

Sam is hoping to return to work when his seizures are under control. In the meantime, he wants to share his experience to raise awareness and educate people.

Holly, from Paisley, Scotland, has juvenile myoclonic epilepsy. During one of her first jobs, aged 19, her manager said to her: "Don't have a seizure in front of me, I wouldn't know what to do!"

Holly added: "More recently, while working for a company remotely, I was told I still needed to go into the office 'to impress the director', despite it being a time when my medication and seizures weren't stable.

"At the time, I was being weaned off my medication, and I was unable to legally drive. My consultant epileptologist wrote a letter to my company requesting I be able to continue working from home, but I was still told I needed to go into the office three days a week. It was a 90-minute commute on public transport, which made me very tired. And all of my seizures are triggered by a lack of sleep."

Holly says that more needs to be done to educate people about epilepsy in the workplace.

"I want employers and colleagues to know more," she said. "Epilepsy is actually very common, and there are lots of different types of seizures. It is

hard having epilepsy. It can fluctuate, it certainly has for me.

## Response to the campaign

The Make Things Work campaign, to improve work prospects for people with epilepsy, was broadcast across the UK, with thousands signing a petition to government.

Deputy chief executive Rebekah Smith appeared on radio stations from BBC Radio Scotland to Greatest Hits Radio and Sky News Radio.

The campaign was the top evening story on ITV News Wales, with Korri James from Cardiff telling the channel that during one job she would be punished for having seizures.

She said: "Every time I had to phone in sick for a seizure, they would punish me, I would have warning after warning, no matter how many times I brought up the discrimination act."

Epilepsy Action's Wales Manager Janet Paterson spoke to BBC Radio Cymru and BBC Radio Wales.

Elsewhere, story champion Tracy spoke to City Talk FM Liverpool about working with epilepsy.

Tracy explained how she had applied for a job and was honest about her epilepsy in the interview, and was told this would be okay. She left the job she was in at the time to move on, but three days prior to starting the new position, she was told she didn't pass security clearance. She says was told later that it was not because she had epilepsy, but because she had seizures.

The charity estimates the campaign's media coverage reached around 334 million people.



# What's new in research?

In Autumn 2023, neurologists, academics and other epilepsy professionals met at the International League Against Epilepsy's British Branch meeting to discuss their latest research. **Tom Shillito** reports

**T**he International League Against Epilepsy's British Branch held its Annual Scientific Meeting in Gateshead in Autumn 2023.

There was a packed agenda of talks and events over three days, hosted in the Glasshouse overlooking the Tyne. Here are some of the highlights.

### Driving regulations

Dr Paul Cooper, a neurologist and chair of the DVLA medical panel for neurological disorders, gave an update on the driving regulations around epilepsy.

People with epilepsy were first banned from driving in the 1930s. This ban remained in place until the 1970s, when driving regulations started to come into place that allowed for people with epilepsy to drive under certain conditions. Currently, people with epilepsy are

allowed to drive if they have been seizure free for a year, or if their seizures don't affect their consciousness.


While the DVLA manages driving licences, the laws that decide who can and can't drive are created by the UK government, and can only be changed by parliament. This means it can be very difficult to make changes to those laws, even when we learn something new about epilepsy or discover a new treatment. There is also a difference in the way those laws define epilepsy, and how it's defined by doctors and medical professionals.

In driving law, you are considered to have epilepsy if you've had two or more seizures that were more than 24 hours apart within a five-year period. In medicine, epilepsy can be defined as having two seizures more than 24 hours apart over any period of time, or having

the probability of seizures, or having a diagnosis of an epilepsy disorder. This mismatch between the definitions and the misunderstandings that can occur from it, can make it difficult for people with epilepsy and their doctors to understand what is needed to get a driving licence, and when driving needs to be stopped. The DVLA receives more than 3,000 medical forms a day, and there can be long waiting times to hear from the

**“Many of the delays are due to the DVLA waiting for responses from doctors”**

DVLA when you submit a form or ask for advice. Dr Cooper's advice was to always contact the organisation by email, and to make sure that you and your doctors are providing any information you're asked for as quickly as possible. Many of the delays are due to the DVLA waiting for responses from doctors, so it is a good idea to keep in regular contact with your doctor when the DVLA may need information from them.

 For more details about the driving regulations, visit [www.epilepsy.org.uk/driving](http://www.epilepsy.org.uk/driving).

### Juvenile myoclonic epilepsy

Prof Arjune Sen from the University of Oxford gave some updated findings about juvenile myoclonic epilepsy (JME) and the differences between men and women who have this condition.

JME affects about one in ten people with epilepsy. It usually begins when someone is a teenager or young adult, and it affects slightly more women than men. Everyone with JME experiences seizures that cause sudden jerks in the limbs, called myoclonic jerks. People with JME may also experience absence seizures (where they 'switch off' and look like they are daydreaming) and tonic-clonic seizures (where they stiffen, lose consciousness, fall to the ground and jerk).


This research aimed to find out what different features might be helpful to look for when predicting how helpful a course of treatment might be. It looked at a large amount of data gathered from both men and women with JME, including what their seizure triggers were and whether they'd been able to become seizure free using anti-seizure medications (ASMs).



The research found that for men with JME, the only factor that could predict whether they might have drug-resistant epilepsy (meaning their seizures couldn't be stopped by taking ASMs) is whether they had absence seizures. Men who had absence seizures were more likely to have drug-resistant epilepsy.

For women, the picture was more complicated. Women with JME were more likely to have drug-resistant epilepsy if their seizures began before they were 12. Similarly to men, women who experienced absence seizures were also more likely to have drug-resistant epilepsy than those who didn't. Among the women who had absence seizures, those who did not have photosensitive epilepsy were more likely to have drug-resistant epilepsy than those who did. Women with JME who didn't have absence seizures were more likely to have drug-resistant epilepsy if their seizures were triggered by stress, sleep deprivation, their menstrual cycle and concentration. Photosensitivity also played a role – if their seizures were triggered by one of those things, and they did not have photosensitive epilepsy, they were even more likely to have drug-resistant epilepsy.

This research does not mean that every woman with JME who has absence seizures will not be able to control her seizures with medication. Neither does it mean that every man with JME who doesn't have absence seizures will be able to become seizure free. Each person's epilepsy is different, and this research can only give us some clues as to what is more likely in a group of people with JME.

 To read the paper scan the QR code or go to: <https://bit.ly/48eLR8Q>

### Transient epileptic amnesia

Professor Chris Butler from Imperial College London gave an overview of transient epileptic amnesia. This is a rare but very recognisable condition that can affect people with temporal lobe epilepsy. People who experience this will have short (usually 15-30 minute, but sometimes longer) periods when they can't remember anything from that day or the previous few days. This often happens just after they wake up. During this period they can't form new memories, and may ask the same question many times as they can't remember the answer. They are usually able to remember who they are and who their family is, and can communicate and




## “JME affects about one in ten people with epilepsy”

move around as normal. Once this period is over, their memories from the last few days will return.

Alongside these short episodes of amnesia, people who experience this may also feel more emotional in general, and cry more easily. They may also experience other memory problems. It is common for them to experience accelerated long-term forgetting, which means their memories fade much more quickly than usual, particularly memories of events. They also very commonly experience autobiographical amnesia, which is where they lose memories of events from their past (such as holidays and weddings). These are symptoms that are easily missed in normal testing.

More than two thirds of people who have transient epileptic amnesia are men, and it usually starts when they reach their 60s. Episodes generally happen roughly once a month. People who experience transient epileptic amnesia are not any more likely to develop dementia, hypertension or have a stroke.

Transient epileptic amnesia can be treated using the same ASMs usually used in any type of epilepsy. People who experience transient epileptic amnesia can usually become seizure-free using ASMs. One study found that 98% of people with transient epileptic amnesia had their seizures either become less frequent or stop completely by using medication.

 To read the paper scan the QR code or go to: <https://bit.ly/3uNfuPV>

# Running resolution?

If getting fit is your New Year's resolution this January, take on one of our Epilepsy Action challenge events. Here you can see what's coming up throughout the year

**A** great way to start the New Year is to sign up to one of our challenge events and raise money to help people affected by epilepsy. We have everything from marathons to skydiving, and our fundraising events team will support you every step of the way.

## April

**London Landmarks Half Marathon (7th)**  
**Brighton Marathon (7th)**



**You can get 50% off your entry fee for selected events until January 30th. Enter the code NY24 at [www.epilepsy.org.uk/running](http://www.epilepsy.org.uk/running)**

\* Discount does not apply to Virtual 10k, trekking and cycling events.



## May

**Leeds Half Marathon (12th)**  
**Hackney Half Marathon (19th)**  
**Epilepsy Action Virtual 10k (20th-26th May)**

## July

**Jump in July skydive (15th-21st)**  
**National Three Peaks (26th-29th)**



**London to Paris Cycle (5th-9th)**



# Virtual 10km

In 2024, Epilepsy Action will be hosting a Virtual 10k, open to anyone, anywhere.

The 2024 Epilepsy Action Virtual 10k is your event. Run, jog, walk or dance the 6.2 miles at your own pace, from anywhere in the world, on a day of your choosing during National Epilepsy Week (20-26 May 2024) to earn yourself a shiny medal and a place on our leaderboard. There is also the option to purchase an official technical T-shirt, which will be posted to you ahead of the race.

**You can also expect some special prizes, which we will share more information about soon. Sign up today at [www.epilepsy.org.uk/virtual10k](http://www.epilepsy.org.uk/virtual10k).**



# August

Mount Snowdon at Night Trek (3rd-4th)



# September



National Three Peaks (6th-8th)  
Great North Run (8th)

# October

Cardiff Half Marathon (6th)  
Royal Parks Half Marathon (13th)  
Dublin Marathon (27th)  
Sahara Desert Trek (30 Oct-4 Nov)





Epilepsy Action – in partner with its members, volunteers and community – has developed a new strategy for 2024-30. Here we talk you through that strategy and how you can be involved.

**E**pilepsy Action has been fighting to improve the lives of people with epilepsy for more than 70 years, and we've delivered some life-changing support in that time. But post-pandemic, and with growing challenges in both healthcare and society more generally, we know that we need to be more ambitious, and bolder, in what we do. Our goals as a charity are not significantly changing, but the scale needed to achieve them is, and this is at the heart of our 2024-2030 strategy.

We need to extend our reach, support new communities and become a more inclusive organisation.

We know that epilepsy has no boundaries in the people it affects, so we need to be more effective in reaching into new communities and empowering people with epilepsy to live their best lives. This will mean thinking big and ensuring epilepsy is as much in the public consciousness as other major health conditions. It will also mean that we as a charity need to think about new ways to deliver our ambitions, which includes working with others for maximum impact.

Through our Let's Talk About Epilepsy campaign, 5,000 of you told us what you really think about epilepsy. Your answers were frank, honest and not always easy to read, but every single one of them was

As part of the survey, we asked you to sum up epilepsy in one word. This is what you told us.

Nearly 40% of your responses spoke about how epilepsy limits the life of the person affected, through either its practical impact or the fear and anxiety it brings.



important. This is the biggest and most open response we've ever had to questions about life with epilepsy and that is what this strategy is built on.

Creating this strategy was a team effort and we are so grateful to the people who contributed their thoughts to developing it. We cannot deliver this without your help, so please join us in building a world without limits for people with epilepsy.

## Our big three ambitions

**By 2030 everyone in the UK who has epilepsy will be able to say that life has improved because of the things we are achieving together.** People with epilepsy tell us they feel isolated, stigmatised and discriminated against. They tell us there is a lack of understanding about the wider effects of the condition beyond seizures, such as the life-changing restrictions on

driving, employment and education. But lots of people tell us that life with epilepsy can be a positive one. People with epilepsy have so much to contribute, in so many ways. We promise that we will help you by understanding the individual journey you are on, supporting and empowering you every step of the way.

**By 2030 everyone in the UK will understand what epilepsy is and how they can support people who live with epilepsy.** People affected by epilepsy tell us this is the number one thing we can deliver: ensuring that people who have no contact with epilepsy in their lives understand what the condition is. This can have so many positive impacts on their wellbeing, sense of belonging and opportunities. We will do everything we can to create a positive attitude to epilepsy so that people are proud, not afraid, to talk about the condition they live with.

**By 2030 we will be fully inclusive in who we are and who we support.** There is no point delivering our first two aims if we are only reaching certain communities. We understand that communities come in many shapes and sizes and that some are more definable than others. But we also know that there are some communities that we are not currently reaching, and they are often the most at risk in terms of isolation, discrimination and social barriers. We need to demonstrate that everything about our organisation, culture and ways of working defines us as an inclusive charity; if we are unable to do that, we will never achieve inclusivity in our strategy.

“We need to demonstrate that everything about our organisation, culture and ways of working defines us as an inclusive charity”

## Spread the word

We cannot deliver any of this without the support of our volunteers, as they are crucial in our ambition to reach more people. We understand the commitment involved in volunteering and will look at more informal delivery models so more people are able to get involved.

We know meeting our ambitions is a team effort and we will develop tools that enable anyone connected with epilepsy to get actively involved in raising public support.

None of our ambitions will be achievable without a significant growth in income. We want to be a charity with an £8-10 million turnover by 2030. We have a new income strategy, but we know it can only be achieved by increasing awareness of epilepsy, and through that, the number of people who support us.

## How can you help?

**Volunteer:** We're going to need people who are able to give up a little bit of time to make a massive difference.

**Fundraising:** We're going to need people who can take on big challenges to help raise big funds.

**Spread the word:** We're going to need people who can speak openly and honestly about epilepsy, to help spread the word.

**Donate:** And we're going to need people who believe in our vision to contribute to making it happen.

**For more information:**  
[www.epilepsy.org.uk/without-limits](http://www.epilepsy.org.uk/without-limits)



# What did we achieve in 2023?

Epilepsy Action's supporter engagement manager **Crispin Northey** looks back on 2023, and the impact you made for people with epilepsy by supporting Epilepsy Action

**A**s we welcome in the new year, it brings us immense joy and pride to reflect on 2023 and review the incredible journey we have taken together. The unwavering support and dedication of our members was at the heart of Epilepsy Action's success, making it a year in which we took significant steps in our mission to support everyone affected by epilepsy.

In 2023, Epilepsy Action took substantial strides in educating communities about seizure recognition and first aid. By providing comprehensive training programmes, we equipped individuals, caregivers and educators with the tools needed to respond effectively during a seizure. Your support in spreading this critical knowledge has undoubtedly



saved lives, empowering communities to be proactive and supportive.

An example of this was our CARE video, which outlined how to help someone having a seizure (Comfort, Action, Reassure, Emergency). The CARE video was watched on social media 558,738 times in its first month and we were delighted that it achieved wide coverage in the media, including a slot on BBC Breakfast during National Epilepsy Week.

The idea was not only to inform, but to break down barriers, reduce stigma and create an inclusive environment for people living with epilepsy. This work expanded into workplaces, including the English Football League and Heathrow Airport.

Our commitment to advancing epilepsy research and advocating for improved healthcare continued throughout the year. Epilepsy Action played a pivotal role in developing the Step Together toolkit, which assesses NHS care for people with a learning disability and epilepsy. We were grateful to all the healthcare professionals who worked with us on this and delighted that the project was a finalist for a Health Service Journal (HSJ) award.

We also continued to work alongside Epilepsy Specialist Nurses across the country as we ran our in-demand induction days, which this year will be increased with a view to clearing our waiting lists. Our relationship with the Epilepsy Specialist Nurses Association (ESNA) has also grown, with some exciting news to come later in 2024.

During our Let's Talk About Epilepsy events, your voices came across loud and clear and this was echoed through



our advocacy efforts, influencing policy changes to improve quality of life for people with epilepsy. These included the debate in the Welsh Senedd on our Epilepsy Services in Wales report, and our Make Things Work employment campaign, which found that 60% of people with epilepsy have been discriminated against at work. Together, we are creating a future where epilepsy is better understood and treated appropriately.

We are also proud to be a founding member of the Epilepsy Research Institute UK, which launched in October with the mission to "radically advance research into the causes, prevention and treatment of epilepsy and its associated conditions".

Recognising the importance of a strong support system, Epilepsy Action dedicated resources to strengthen and expand our support networks including our popular Talk and Support groups, providing a safe space for individuals and their families to share experiences and belong. These have created a powerful network of compassion and understanding.

Our incredible Helpline and Webchat Service continued to give the very best



advice to more than 10,000 people – winning the Helpline of the Year award in November.

Our helpline assists people such as Rhys, who, at his lowest, called 111, which referred him to Epilepsy Action.

Rhys said: “I got a lot of help from Epilepsy Action, which I’m so grateful for. Speaking to the helpline made me feel I wasn’t alone. They really understood my situation. I felt like I could breathe and met people who had been through similar experiences. Getting in touch with Epilepsy Action really did save my life.”

We were also delighted that so many people signed up to our Befriending Service, which matches people with epilepsy with a friendly volunteer either online or via the phone. One such person was Holly, who was paired with volunteer

Lisha. Holly said: “Lisha made me feel like I wasn’t alone anymore. I felt like I could open up to her about anything. Having the sessions with Lisha has really inspired me to put myself out there a lot more. She has lowered my anxiety and given me confidence within myself.”

In response to the ever-evolving digital landscape, Epilepsy Action embraced innovative technologies to improve accessibility. Your feedback played a crucial role as we revamped our digital

“Getting in touch with Epilepsy Action really did save my life”

platforms to provide valuable resources, support and information in more accessible formats.

As we celebrate these achievements, we would like to acknowledge each and every member of the Epilepsy Action family, including our amazing members. Your commitment to supporting us financially, including responding to our appeals, has been instrumental in making 2023 a year to remember. As we look towards the future, let us continue our journey with renewed energy, knowing that together we can make an even greater impact on the lives of those affected by epilepsy.

Thank you for being an integral part of Epilepsy Action’s success in 2023. Here’s to a future filled with hope, understanding and continued progress.

# Your voice, your mission, your community

**We are so grateful for our members. As a member-led organisation, Epilepsy Action has built a new long-term strategy, and our members are at the heart of it. We have also been looking at how we can go the extra mile for our members in the future.**

## Your voice

We want to hear from you. Your opinion matters and that is why you’ll always have opportunities to tell us what you’re thinking, to help us make the most informed decisions. We can’t create a world without limits for people with epilepsy without you.

Nominate and vote: you are in a special position to decide who sits on our Council of Management (trustees). If you would like to nominate or be nominated, we will remind you to do so in the next edition of Epilepsy Today.

We also have a new system to make it easier for you to vote. Everyone will be sent an email in May with a unique link to a secure website and from there you can read about the candidates and make your selection.

## Your mission

Membership with Epilepsy Action is more than just a subscription. As we break down barriers and improve understanding, our members are invited to become a part of the journey. Together, we can make a lasting impact on the lives of people with epilepsy.

Members have the opportunity to participate in campaigns, raise awareness about epilepsy-related issues and push for change. This can either be through a formal volunteering role or on an ad-hoc basis.

The support of our members is essential as we continue to help people on that journey from their first seizure to their new normal. Through our services, people know they’re not isolated or alone. These include:

- Advice from our expert helpline and information from our webpages.
- Talk and Support groups, where people can find others who have been through similar experiences.
- One-to-one support through our Befriending and Counselling services. We can only make these services free with your help.

To support us financially:

- Giving your membership to us monthly by direct debit helps us budget better.
- If you are able to give more money each month, that will help us reach more people.
- Read our fundraising appeals and consider what you can give.
- Consider leaving a legacy gift.

Together, we can break down stigmas, promote inclusivity, drive policy changes and support those who have been recently diagnosed.

## Your community

Whether you are a parent caring for a child with epilepsy, a teenager navigating the challenges of adolescence or an adult managing seizures, we have a place for you.

Living with epilepsy can feel isolating, but membership with Epilepsy Action offers an community where you can share experiences and offer support.

So, hopefully, you now appreciate just how important your membership will be in the years to come. We are looking forward to creating a world without limits for people with epilepsy, together.

# New year new start: try volunteering

**K**ickstart 2024 with a new challenge and positive change. Join our supportive and thriving volunteer community and see how much volunteering can benefit you. You can make a difference to people's lives while learning new skills and improving your own wellbeing.

In our recent volunteer survey, 83% said volunteering with Epilepsy Action had given them a sense of personal achievement and more than half said it had improved their confidence.

Research volunteer Jade said: "Volunteering helps me feel like I am part of something. It gives me confidence and knowledge."

According to the survey, 96% of volunteers are satisfied in their role.

Volunteering doesn't just benefit others, it can help you to learn new skills, meet

new people and improve your wellbeing. Many of our volunteers said volunteering helped them to feel more confident and gives them a sense of achievement.

Talk and Support Group volunteer Bec said: "I have gained so much confidence, I used to get so anxious talking to a group of people, but now I'm leading face-to-face and virtual groups. I believe in myself and my capabilities."

We have roles to suit a range of people: from supporting people on a one-to-one basis, group support, campaign support and ah-hoc bits through our Action Team through to

helping raise awareness online and in your local community. We've got something that can fit around all interests, schedules and availabilities.

Volunteer Mark assists with Talk and Support groups, the Action Team, Research, Facebook Challenges and Health Information. He says: "Volunteering gives me an increased feeling of self-worth and empowerment."

As well as the benefits to your own mental health and wellbeing, Epilepsy Action will be here to support you through your volunteering journey to make sure you have everything you need to shine in your role.

**“ Volunteering helps me feel like I am part of something ”**



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

## Meet volunteer befriender Claire

**Claire began working with Epilepsy Action when she signed up for our Befriending service. Now, she volunteers to give back.**

Since childhood I've had to deal with limitations associated with my epilepsy, which has made it harder for me to learn and participate in various everyday activities. Despite having to deal with these, I have always strived to do as much as anybody else.

However, since attending Epilepsy Action's Talk and Support groups, I have become more confident interacting with others.

I contacted the Befriending service, which offered one-to-one virtual

meetings, and I thoroughly enjoyed the volunteer's company. They inspired me to become a volunteer befriender myself.

Listening to and exchanging shared experiences of having epilepsy comforted the person I was paired with and made them feel that someone actually understood how they felt and they were no longer suffering in silence.

It has been a very rewarding experience and given me a sense of direction and purpose, which I had spent years searching for. Being more empathetic and supportive towards others made me feel better about myself.



# Reassurance and immediate assistance 24/7, when you need it most



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

Download now – Search for My Medic Watch



\*Reliance Technology Care monitoring service and website will be live mid January 2024

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

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

For more information visit  
[epilepsy.org.uk/legacy](http://epilepsy.org.uk/legacy)



## Epilepsy Action Lottery

Play today for £1!

**Our weekly lottery gives you the chance to win £25,000 while supporting the vital work we do to help everyone impacted by epilepsy.**

As well as the chance to win big, 50p of every £1 allows us to continue our vital work in helping people living with epilepsy. It costs just £1 per entry then you submit your details and we will send you your lucky numbers.

Visit the Epilepsy Action website to find out more and sign up to play. [bit.ly/EpilepsyLottery](https://bit.ly/EpilepsyLottery)

A minimum of 50% of the total lottery proceeds are spent on supporting the work carried out by Epilepsy Action. 18.4% is spent on prizes and 31.6% is spent on the running and administration of the lottery.

GambleAware



# Sisters

*Interrupted*

Sisters Chelsea and Tamsin Leyland both have epilepsy, but their lives have taken very different paths. A new film about them explains more...

**“Most kids blow out the candles and wish for a truck or a new doll, but my wish was always: ‘I want Tamsin to be better.’”**

Chelsea Leyland, a DJ and model who now lives in New York, was diagnosed with juvenile myoclonic epilepsy aged 13. Tamsin, her sister, started having seizures as a baby and also has autism. She lives at a residential epilepsy clinic in the UK.

In November 2023 a documentary about their story was selected for the Raindance Film Festival and shown at London’s Soho Curzon cinema. It is directed by Caroline Sharp and produced by Sophie Daniels.

“Seeing someone you love suffer is the worst thing in the world,” says Chelsea. “I have gone through a long journey and had to do a lot of healing and therapy around the guilt of being healthy and able to live a normal life.

“I will always fight for Tamsin,” she adds. “She loves to laugh. She loves to be

the centre of attention. It’s a different day every day with Tamsin. Some days are not so good and others are amazing.”

While medication keeps Tamsin alive and reduces her symptoms, she continues to have seizures and has tried multiple anti-seizure medications. This has meant managing the various side effects that come with them.

“Tamsin can have up to 70 of these types of seizures [tonic-clonics] a day,” says Chelsea.

“I’ve had less than 10 tonic-clonic seizures. So, to put things into perspective, my epilepsy is very mild compared to hers. We haven’t found a solution that truly stops Tamsin’s seizures. She’s always being taken off drugs and trying new ones.”

But Chelsea’s journey has taken a different path. As a teenager she began to experience symptoms. In the mornings, her hands would open and jerk. It was especially bad if she had disrupted sleep – but she was repeatedly told by the school doctor that it was just stress.

**“Seeing someone you love suffer is the worst thing in the world”**

“I kept going to my GP, explaining my symptoms. It took about three visits before it was suggested that I go to see a neurologist,” she says.

“Within 10 minutes of telling my story he said: ‘You’ve got juvenile myoclonic epilepsy’.

“Lamictal was the first drug I was put on,” she says. “There was a bit of a honeymoon period when it worked and then it started to tail off. Then my neurologist suggested that we introduce another drug, so we introduced Kepra and I really suffered from side effects, but it was a frustrating situation because it was also the more effective drug.

“And, then, at 28 – eight years ago – I was introduced to cannabinoids.”

#### Medical cannabis

Chelsea moved to New York aged 19. And, because she lives in the US, she has relatively easy access to medicinal cannabis. But it wasn’t as straightforward as having it prescribed.

She says: “I was probably making decisions that were irresponsible and I started using cannabis in conjunction with lamotrigine. Almost instantaneously I felt a difference. It wasn’t that I felt high or that I got some effect from it. I felt a tremendous difference cognitively. I always describe it as Humpty Dumpty being put back together. It was like I was being plugged into a power source.”

Chelsea began by using CBD full spectrum. This kind of medicine contains all the compounds of the cannabis plant – including CBD (which is legal in the UK), THC (the compound that produces a ‘high’), terpenes (which produce the smell)



and flavonoids (a chemical compound found in many plants and vegetables).

“There was a feeling of wholeness in my brain. It didn’t feel so fragmented. I could finish thoughts. My concentration was better. And it was exciting,” she says.

“I remember going to Ibiza on holiday and being able to watch the sunrise. I hadn’t been able to watch the sunrise ever. The first three weeks to a month that I started using it, I was sleeping 12 hours a night. It was like my body was getting rest that it had been deprived off for so long.”

Chelsea believes medical cannabis could also help Tamsin. But Tamsin is in the UK, where, although medical cannabis was legalized in 2018, there is only one medicine, called Epidyolex, available to people with epilepsy.

At the moment, Epidyolex is only recommended as a treatment on the NHS for people with Dravet syndrome, Lennox-Gastaut syndrome or Tuberous sclerosis complex. These are rare forms of epilepsy that usually appear in childhood. Fewer than five people in the UK have a prescription through the NHS.

“I feel proud to be English because we have a public healthcare system,” says Chelsea. “But, as we all know, there are many cracks in the system and the care I am getting here in America versus Tamsin in the UK is wildly different.”

While Chelsea acknowledges she is privileged to be able to pay for healthcare in America, the family are frustrated about how the two sisters have been treated when it comes to medication.



Tamsin and Chelsea

“I’m not saying that this is going to be the right medicine for Tamsin,” says Chelsea, “but it’s worth us trying.”

#### Making the film

Six years ago, Chelsea and her friend Caroline began to make a film about her campaign for medical cannabis and life with Tamsin. Together, with producer Sophie, they have made an hour-long film about Chelsea and Tamsin’s fight for equal treatment.

Caroline and Chelsea met at a music festival through mutual friends. Caroline had been studying neuroscience and moved into filmmaking. While at the festival, Chelsea had a seizure – and that’s where the project began.

Caroline says: “I thought: ‘Poor Chelsea, she shouldn’t be alone.’ So I went over to see if she was okay and we started talking. Chelsea was telling me what it felt like to have epilepsy and I was telling her what I knew from a neuroscience perspective. We realised that, through a series of conversations, it was really important to make something.”

“There’s two elements to our film that really matter to us,” she says. “Number one, and the most important one, is that it’s so important to have exposure to the diversity that we see of people’s lived experiences.

“The other side of things, of course, is the legislative landscape around cannabis,” she adds. “We’ve been trying to push for reform on that for a long time.

“We’ve crossed one regulatory hurdle but we haven’t actually seen it trickle down,” she adds.

#### Creative accessibility

The team were aware that making a film about epilepsy might mean people with the condition would struggle to enjoy it. For Caroline, that meant it needed to be



Caroline, Sophie and Chelsea while making the film

inclusive – she felt they couldn't make something that might exclude people.

“Creatively there was something kind of different we decided to do around photosensitivity,” she says. “We wanted to have more abstract breaks where you would feel emotionally involved.”

While only about 3% of people with epilepsy are photosensitive, even some people who aren't can find flickering lights uncomfortable if not triggering. Chelsea says she is light sensitive. In fact, it was her first symptom.

## 66 Tamsin felt like a movie star

“I remember sitting in the back of the car, the light coming through the trees, and as it flickered across my eyelids I would feel really funny,” she says.

It's an effect that runs through the film – and a theme that Caroline wanted to pick up on while keeping the audience safe. They decided a blanket warning at the beginning of the film wasn't right. Though it might be safe, it was exclusionary. And so, while you're watching the film, a beep and a screen with 'Epilepsy Warning' written across it occur before sections with strobes or flashing lights.

Caroline says: “We realised we could use the fourth wall to interrupt the audience's experience of watching the film by forcing them to feel the interruptions of everyday life for people with epilepsy.

“Every time we have to warn someone that this could be potentially triggering we interrupt everyone's experience.”

The film is made up of interviews with

Chelsea, cannabis campaigners and footage from Chelsea and Tamsin's real lives – including home video footage of them as children, interviews with their father Rex and even a section where Tamsin has a series of “small seizures” at her care home in Sussex. It's moving and powerful. And while all the team say it was a difficult and emotional process, it also brought them joy.

“Tamsin loved it,” says Chelsea. “She felt like a movie star. She made us laugh so much. It was also really cathartic to me to bring in friends to my quite sacred world with Tamsin because I hadn't really done much of that.”

She adds: “It was a very big change to go from something that was really behind closed doors to then making a documentary project about it.”

Caroline says: “It was a very healing and cathartic process for all. Chelsea is so amazing at communicating her story and so magnetic.”

### The film's future

While working together as friends as well as colleagues wasn't an easy process for the team, it has made their work unique. It gave Caroline access to the Leyland family that would otherwise not have been possible. And it's not just their hope that Tamsin will be able to try medical cannabis that has inspired them, they want to raise more awareness about epilepsy – and it what it means for other people.

“Let's talk about this condition that has been hidden for so many years. Let's put it on the map,” says Chelsea. “It affects so many people, why is it so stigmatised?”

“If I had seen one cool person speaking about it and had that moment of: ‘I'm not alone' or ‘I can live a normal life', rather than feeling like I was facing so many challenges and I was going to be limited, that would have been helpful,” she says.

In the short term, the aim is for more people to see the film.

“The most imminent aim,” says producer Sophie, “is to get it on to a UK broadcaster and have as many people see it locally as possible. And then greater distribution. We'll start with the UK, but, we think the film has a global reach.”

**For more about Sisters Interrupted go to: [www.instagram.com/sistersinterruptedmovie/](https://www.instagram.com/sistersinterruptedmovie/)**  
**For more about cannabis medicines: [www.epilepsy.org.uk/cannabis](https://www.epilepsy.org.uk/cannabis)**



Chelsea at a cannabis farm in California

# Stars of 2023

From a hero Grandad to a life-saving toddler, we look back on our Star awards winners from the last year. Words by **Rebecca Lock**



## March

**In March, our first Epilepsy Star award went to brothers Sam and Ollie who went above and beyond to support their sister Charlotte, who was diagnosed with epilepsy aged one year old.**

Sam and Ollie were nominated by their mum Jaimee.

In January 2017, Charlotte was taken to A&E at Birmingham Children's Hospital after Jaimee noticed she was making some strange movements.

Jaimee said: "Our worst fears were confirmed later that day. We were seen by a neurologist who looked at the video of Charlotte and diagnosed her with infantile spasms. In that moment our lives were turned upside down.

"The next day, Charlotte had an EEG and MRI, which showed hypsarrhythmia and that she'd suffered a stroke in the centre of her brain. Charlotte was immediately started on medication which left our previously happy and smiley child sleeping most of the day."

The family's life revolves around Charlotte's care, which can often lead to plans changing at short notice. Sam and Ollie always accept this graciously despite the disappointment it can cause.

Jaimee said: "We're so immensely proud of the boys and would like them to know that we love them and are in awe of the compassion and resilience. Often the

impact on siblings is not appreciated when a child is given a devastating diagnosis. It really does affect the whole family and we're grateful to Epilepsy Action for recognising our wonderful boys."



## April

**In April, four-year-old Daisy Scott won a Star award for her incredible**



**bravery and quick thinking. Daisy, from Hertfordshire, was nominated by her dad, Kevin, after she used the family's Alexa to alert him that her mum Michelle was having a seizure.**

Kevin said: "In an emergency, Daisy knows to ask Alexa to 'call Daddy' and it will connect to my mobile so I can talk to her directly. Once, when I was at work, Daisy called me through Alexa and I could tell Michelle wasn't well from what Daisy told me. She was so calm and explained that Mummy was on the floor and shaking. Daisy went to unlock the front door calmly and waited for Grandpa.

"Another time, after our second child, Rosie, had been born, I was with Michelle when she was having a seizure and Daisy made sure to stay with her sister. She rocked Rosie in her basket and looked after her so that she didn't get upset."

Michelle and Kevin want more people to understand the effect epilepsy has on the family. They said: "The more people know about life with epilepsy, the better families will be able to cope. We've bought some children's books to help explain the condition to Daisy, so she knows what to look out for."

Michelle and Kevin are immensely proud of Daisy. Kevin said: "She never runs away from situations, which even a lot of adults would have, and always stays with Mummy and Rosie until there is someone to help. She has saved Mummy's life on more than one occasion."



**May**  
**In May, Rich and Mike Stevens took part in an Ironman challenge after Rich's son was diagnosed with Lennox-Gastaut syndrome – winning them that month's Star award.**

Lennox-Gastaut Syndrome is a rare and severe form of epilepsy that involves lots of different seizure types. Ralph primarily has atonic and tonic seizures, which see him fall to the floor and injure himself.

Rich and his brother Mike wanted to follow suit and take on their own warrior challenge. Rich said: "The ironman is a 1.9km swim, followed by a 90km bike ride and a 21km run. We wanted to do something that was super tough and something that felt impossible at the time of starting. Neither me nor Mike could swim properly or had ever even sat on a road bike eight months ago."

Accepting the award, Rich added: "Receiving this recognition is an extra boost in morale and motivation for me and Mike. Our family has had such a tough year and so we all really appreciate the positivity and support."



**June**  
**A 'hero granddad' was awarded June's Epilepsy Star award.**

Alan Davies, or "G-Pa", from Shropshire, has supported his granddaughter Georgia in every step of her epilepsy journey, from being with her at every neurology appointment to encouraging her to pursue research into epilepsy when she managed to go back to university after her diagnosis.

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

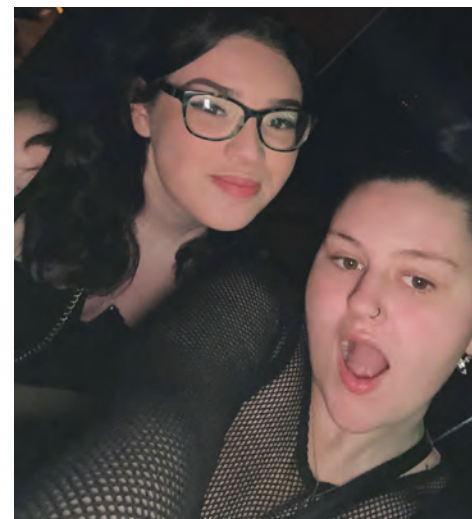
**“Our family has had such a tough year and so we all really appreciate the positivity and support”**

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

Throughout the process, G-Pa was always there for her.

She said: "Of all the people in my life, my grandfather has supported me the most. He drove me to and from university every day when I was unable to take public transport. He's been with me to all my neurology and epileptologist appointments, with video evidence to show them, which is important in getting an epilepsy diagnosis. But most of all he's been there when things got too much.

Alan said: "My granddaughter is worth all the hassle. I know my help, support and understanding is appreciated and I thank Epilepsy Action for their recognition."



**July**  
**Charlie Gardiner, a paramedic student from Worcestershire was given the Epilepsy Star award in July, for "inspiring and motivating" her best friend Ellie Weston.**

Charlie nominated Ellie for being by her side throughout her epilepsy journey. They met on their first day of university and have been inseparable ever since.

Charlie was studying to become a paramedic when she was diagnosed with epilepsy. She said: "I had my first seizure in July 2022 when I was in hospital with suspected appendicitis. At the time, I was scared, terrified even. I didn't understand what had happened and why it had happened to me. I had to withdraw from university after my second seizure. I was absolutely devastated. All I've ever wanted to do was be a paramedic. It was a difficult time, but the university and my course mates have been nothing but supportive, especially my best friend Ellie."

Accepting the award, Ellie said: "I didn't expect Charlie to nominate me, let alone actually win the award. I knew a little about epilepsy before, but I have learnt a lot more about the condition from Charlie."



### August

**In August, Katie Davies from Caernarfon received the Star award for her awareness raising.**

Katie was diagnosed with epilepsy in 2008 following an inflammation on the brain, which is known as encephalitis, and has lived with the condition since.

She explains what living with the condition is like: "Recently, I've been

## “ Jennifer is an inspiration to people with epilepsy. Nothing stops this inspirational woman ”

having absence seizures where I repeat words and can't remember anything. I'm left feeling confused and drained after I have a seizure but there are lots of other daily challenges that come with epilepsy. I struggle with memory loss and sometimes need to be reminded of things because of this."

Epilepsy Action Cymru has played an important role in Katie's epilepsy journey and have been there to help her open up about her condition.

Working alongside Epilepsy Action, Katie shared her experiences in a documentary called 'Epilepsi a Fi' for S4C. She said: "Awareness is everything for me and it's important for me to be a voice for people with this invisible condition. If anyone is feeling unsure or nervous about talking about their epilepsy, just think that raising awareness can make a huge difference. Epilepsy can affect anyone and not everyone who has epilepsy is born with it."



### September

**Jennifer Constant from Southampton was given September's Epilepsy Star award. You may remember her from the last edition of Epilepsy Today. Jennifer had her first seizure while scuba diving.**

"While diving, my husband Terry witnessed something he will never forget,"

she said. "He looked left and right and couldn't see me. I'd disappeared. He looked behind and another dive buddy with bright, wide eyes pointed downwards. It was me floating down into the darkness, having a seizure and falling.

"The dive master caught me and we ascended to the top with no other considerations but to get me to the surface. I was unconscious. My wetsuit had to be cut off and I was resuscitated. Everyone thought this was it, but it wasn't my time to die."

For Jennifer, this seizure was the first of many. Since being diagnosed with epilepsy, Jennifer has gone on to set up three successful businesses and has explored more of the world with her family. In 2010, she set up a wedding celebrant business.

Jennifer's husband, Terry, nominated her. He said: "Jennifer is a true inspiration to people with epilepsy. Literally nothing stops this inspirational woman."



### October

**In October, nine-year-old Nathan Swift from Wigan received the Star award. He stayed "calm and collected" when his brother, Joseph, 13, had a seizure.**

Nathan and Joseph's mum, Wendy, said: "Recently, Joseph had an unexpected tonic-clonic seizure. He was in his room, and when I found him, he was trapped between a wall and the radiator. His head was banging against the wall and his arm was trapped. Nathan calmly followed my instructions to get rescue medication from my bag. He then brought me the landline phone and my mobile, and helped me call 999.

"Without Nathan assisting me, I would've had to leave Joseph, and in

## “ Raising awareness can make a huge difference ”

that time the injuries could've become really severe. Nathan's calm and collected composure saved the day. He was a superhero."

Joseph had his first seizures when he was eight months old. He was diagnosed with epilepsy when he was two years old. He is now 13.

Wendy said: "Nathan is an amazing brother and son. He also joined me, Joseph and dad in the Walk 50 Miles in February challenge. He walked with us in all kinds of weather to help us with our fundraising challenge. In the end, we raised £845 and he's very proud of this."



#### November

**Joanne Griffiths was given the Epilepsy Star award for her campaigning work in November, and for being an incredible source of support to her son Ben, 14, who has epilepsy.**

Joanne was nominated by her husband and mum. Paul said: "I nominated Joanne because I wanted to publicly thank her for all she's done. Without her, Ben probably wouldn't still be alive."

Ben was diagnosed with epilepsy at six months old due to brain damage at birth.

He has tried multiple medicines as well as the ketogenic diet, and was evaluated twice for possible surgical treatments, but his seizures remained severely uncontrolled.

Joanne said: "On a good day, Ben would have 80 seizures a day. And at its worst, the seizures would go well into the hundreds.

"In 2014, we learnt about cannabis oil and I looked into how it could be used for epilepsy. We were able to buy CBD oils alone, which helped Ben's cerebral palsy and mobility, but it did not help to control his seizures. Then in early 2018, we had the opportunity to try a whole-plant medical grade cannabis product from Canada. Ben's seizures reduced to just six a day. He was brighter and started to enjoy life.

"Fighting for a medically complex child is so hard in the UK. It feels like every need Ben has is a challenge and a battle, but the biggest battle has been the fight for medicinal cannabis. First, the fight was for it to be legal to prescribe cannabis for epilepsy. Then, we had to find a UK-prescribing doctor, navigate the complexities of government and NHS stakeholders.

"All of this has taken us out of our comfort zone, but we've continued the fight."

Receiving the award, Joanne said: "I feel deeply honoured and grateful to be recognised as a Star winner. The support from my family means the world to me."



#### December

**Our final Star Award of the year went to Emma Harvey, a student services coordinator at a school in Somerset.**

**“Knowing school was a safe place helped my family to feel less anxious about me going”**

One of Emma's students Freya, and her mum Anna, nominated Emma because they wanted to recognise her for helping to make school a safer and more comfortable space.

Freya is 13 years old and had her first seizure earlier this year. She said: "Ms Harvey has helped me by explaining to some of my friends what they can do if I happen to have a seizure in school. Although I was worried about some of my friends knowing about my epilepsy, knowing that they knew how to help made me feel a lot safer and more comfortable going to school, especially when I was not on medication.

"Ms Harvey always takes the time to listen to me, and she offers me a safe space if I just need some time to feel better as I suffer a little bit with nausea and headaches from my medication. Ms Harvey has always been quick to come and find me whenever I've had a seizure in school to make sure everything she told me would happen did happen."

Freya added: "One thing I would like to say to Ms Harvey is a big thank you for supporting me, understanding my epilepsy and putting up with my mum's distressed rants. Knowing school was a safe place helped my family to feel less anxious about me going."

Receiving the Epilepsy Star award, Emma said: "I am delighted that I have been selected to win this month's Epilepsy Star award. When I received the email from Freya's family informing me of their nominations, I was so moved by their thoughtfulness. I have supported many students with medical conditions to ensure they have safe access to an education, and both student and their families feel confident with them attending school, knowing they're looked after."

**“I feel deeply honoured and grateful. The support from my family means the world to me”**



**For more about Epilepsy Star Awards, or to nominate someone, visit [www.epilepsy.org.uk/stars](http://www.epilepsy.org.uk/stars)**

# How keto changed my life



That Keto Guy (also known as Ryan Tindall) explains how trying the ketogenic diet changed his life

**In March 2020, Ryan Tindall had tried his sixth anti-seizure medication and his consultant had said the next option was surgery.**

“I sat down with my wife and said: ‘I don’t have to do it because there’s lots of risk. All I’ve committed to is going for the testing that comes with it,’” says Ryan.

But Ryan and his wife were concerned about the possible after-effects of surgery.

“My wife said: ‘I really don’t want you to have the surgery. Look at you, you can hardly say that you’ve done everything to try to manage your seizures.’ And by that, she meant you haven’t tried the ketogenic diet.”

Ryan’s wife had read about the

ketogenic diet online. And, though the literature they had found suggested it was mainly for children, the couple decided to give it a go.

“It might not work but that’s the same with all meds – they might not work, you’re trying it,’” says Ryan.

At the beginning of his journey, Ryan met with a new doctor.

“I had some money set aside,” he says. “It was the beginning of Covid, so I went: ‘Do you know what, I’ll spend some money on a very good nutritionist.’ We did all of that online, but the doctor helped me get my bloods tested, he sent me off to somewhere in Harley Street and they collected eight vials and tested for

## Ryan’s tips

- Keep it simple, don’t overcomplicate it.
- Start looking at Instagram – go right the way back. Instead of looking at what other people are eating now, go back to day one on their account.
- ‘I’m starting out, what can I eat?’ Think about what you can’t eat: because if you realise what you can’t eat, it make it pretty obvious what you can.

everything. They did my salivas to test my gut health as well and urine, and I then came back with his findings of where I was low and what I needed.”

From there Ryan decided to try the ketogenic diet.

The ketogenic diet is a specialist medical diet that is very high in fats and lower in carbohydrates and proteins than a typical diet. Everyone reacts to the ketogenic diet differently and it should not be tried without medical supervision.

For Ryan, it hasn't reduced his seizures, but it has made them less aggressive. “My seizures are less strong,” he adds. “I tend to have more temporal lobe seizures now than I used to have. I used to have more generalised tonic-clonics (GTC).”

Ryan decided to document his journey on Instagram where is he known as That Keto Guy. At the start of the process he documented every meal, he says. But now he's more selective.

“Go back to the bottom of my page and you will see how I started it. I used to post a lot more food than I do now. My postings then were just as a food channel. That's all it was. I was just telling people what I was eating and how I was getting on with that food. So, every single meal of the day was posted. If I look at those meals, they were so simple – they were really basic.”

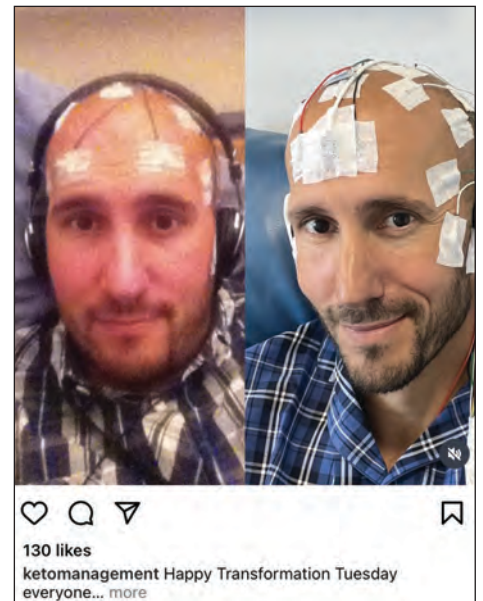
Now, he's not only developed his cooking skills, he has begun a fitness journey to go with the changes to his diet.

It was the South Downs trail half marathon that started his running journey. “It's a lot harder than I thought it would be,” he says. “Now, it is a nice training run – back then it was hell.”

In the last three and half years he's completed four trail half marathons, six marathons and a 102km ultra marathon. As part of this journey he's raised more than £6,000 for charity – but it's also improved the management of his epilepsy.

“Being fitter and physically stronger, my recovering time for a GTC is within 24 hours – it used to be 48 or 72. My body would ache for up to a week. They can be still pretty extreme but they're a lot less frequent and a lot less severe

**“I'm quite strict in what I eat. I think that's the only way keto can last”**



than they were,” says Ryan.

While it's been a positive journey, moving towards the ketogenic diet wasn't easy to begin with, and Ryan and his family have had to accept that his eating is different to the rest of the family.

“I'm still quite strict now in what I eat,” he says. “I think that's the only way keto can last. The thing that I hear all the time is keto is too hard. The reality is it isn't. You don't need huge amounts of the substitutes, you just need to start separating foods in your house. You just need to go to your cupboards and throw everything away.

“There's going to be boundaries. Your children won't be doing keto, your husband or wife or your partner most probably won't be doing keto. It is just going to be you at times – so, sometimes having that

online community can be helpful but also having your own sections, like a cupboard for only your food.”

But Ryan has found that the world is increasingly embracing the ketogenic diet. There's no need to fear eating out, for example. He says: “It can be a bit dull sometimes. But even somewhere like Pizza Express – my kids love it, it's our birthday-type celebratory place to go – they do a great salad. You can ask for things. I've got far more used to asking in restaurants. I don't think I've ever had someone say no.”



Follow Ryan on Instagram at: @ketomanagement. For more about the ketogenic diet: [www.epilepsy.org.uk/ketogenic](http://www.epilepsy.org.uk/ketogenic)

# Epilepsy Action is here for you



helpline

Epilepsy can be very confusing. Our **Helpline team** are ready to answer any questions you might have on the phone, via live chat or email.



counselling

Counselling can be really helpful when things get tough – we're ready to help in Wales and Northern Ireland. Our professional **Counselling** team can provide the support you need online or over the phone.



talk and support

If you want to talk to other people about life with epilepsy, you're welcome to come to one of our **Talk and support** groups to meet and share your experiences either on line or face-to-face.



family support  
Northern Ireland

Epilepsy doesn't just affect the person with the diagnosis – that's why our **Family support** service is there for family members and carers in Northern Ireland.



befriending

Not everyone's ready for a group, though – one-to-one support through **Befriending** might be better for you. We'll connect you to a volunteer who will offer you a friendly listening ear either on the phone or online.



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

“Epilepsy Action has made such a big difference in my life... they have helped me learn to live with my condition”

**Epilepsy Action Helpline: freephone 0808 800 5050**  
**email [helpline@epilepsy.org.uk](mailto:helpline@epilepsy.org.uk) [epilepsy.org.uk](https://epilepsy.org.uk)**

Registered charity in England and Wales (No. 234343)

# Council of management

**A**t a meeting of the Council of Management held by remote video conference on 5 December, the following decisions were made.

- A revenue budget and business plan for the charity were approved for 2024.
- Council reviewed, updated and renewed its scheme of delegation. This is the record of how the council delegates authority on some matters to the chief executive to make decisions and manage day to day operational issues.

- It reviewed the charity's corporate risk register and ensured adequate measures are in place to manage those risks.
- A new joint membership scheme to run with the Epilepsy Nurses Association (ESNA) was approved.
- It was decided to close the following association advisory panels at the end of 2023 because their functions are now provided by alternative means. The panels to close are the Health and Clinical Advisory Panel, the Scientific Awards Panel, the Women's Advisory Panel and the Research Advisory Panel.

- Council has begun framing the remit of a comprehensive constitutional and governance review as part of the charity's new strategic plan.
- Council noted the retirement of Judith Davies, PA and executive assistant, at the end of the year and thanked her for her 20 years of service to the charity and for supporting the council and its members so well throughout that time.

**The next meeting of the Council of Management will be on 6 February 2024.**

## Epilepsy support for you

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

**Join one of our virtual groups**

We have face-to-face group meetings as

well as online meetings using video calls instead (technical support is available). If this is of interest, you can find out more at [epilepsy.org.uk/virtual-groups](https://epilepsy.org.uk/virtual-groups) or by calling **0113 210 8800**.

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

### Online resources

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

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



**For more information scan the QR code**



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



**epilepsy** *action*

**Will  
you  
push  
the  
purple  
button?**



**Purple Day  
26 March 2024**

Join thousands of others pushing the purple button this March, to turn the word purple, raise money and help make a difference for people living with epilepsy.

Sign up for your free fundraising pack today!  
[epilepsy.org.uk/purple](https://epilepsy.org.uk/purple) or call 0113 210 8851



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