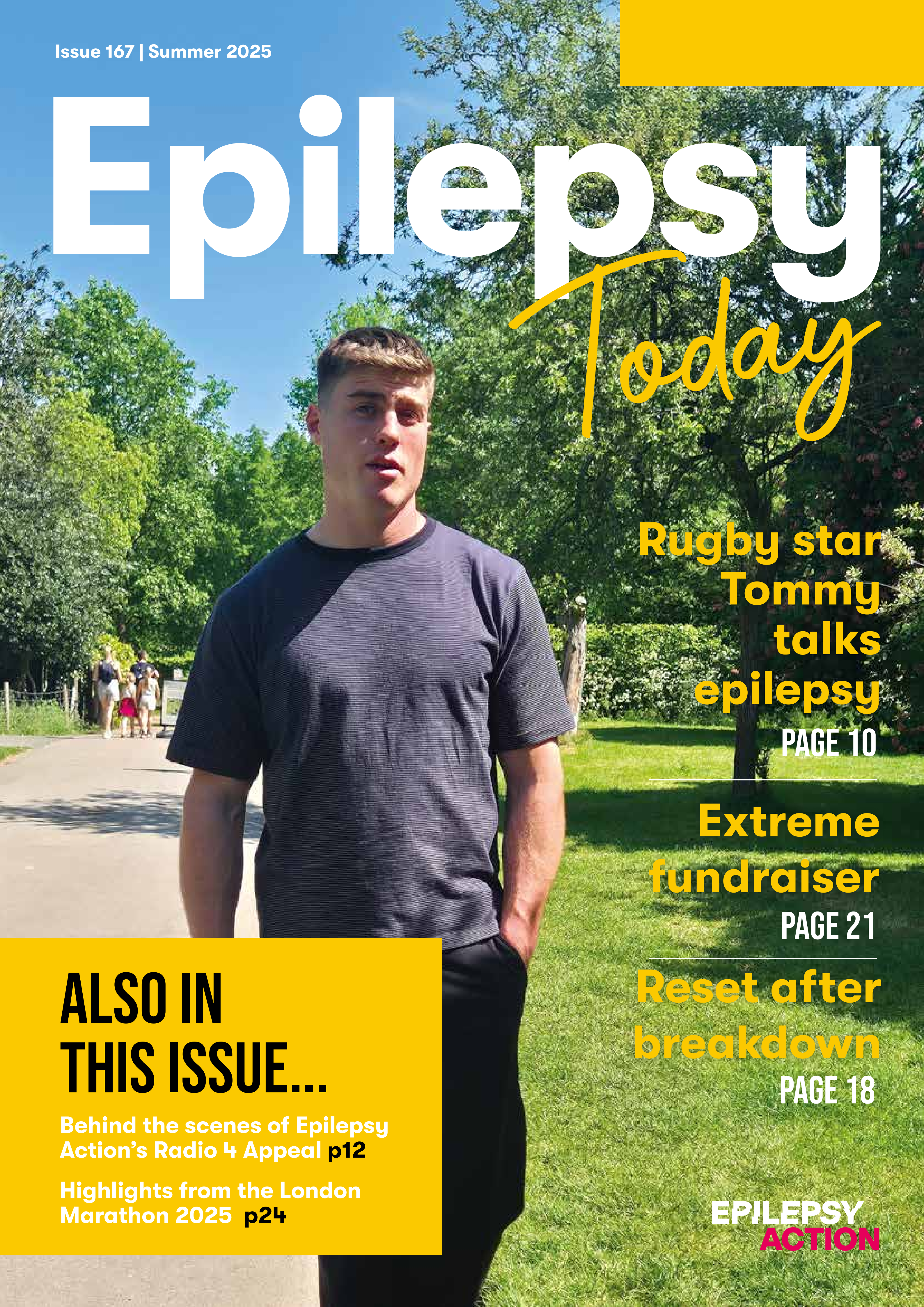
Issue 167 | Summer 2025

Epilepsy Today



Rugby star Tommy talks epilepsy

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EPILEPSY ACTION

VNS Therapy™

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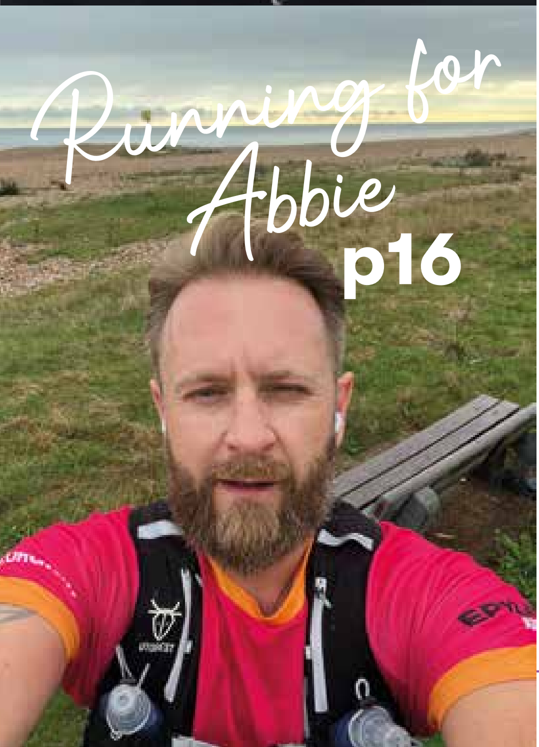

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Story special

Welcome to the Summer issue of Epilepsy Today! This edition is a story special, full to the brim with different tales from people with epilepsy, fundraisers, supporters and our very own Epilepsy Action staff sharing the behind the scenes of their work.

Our cover star is England rugby superstar Tommy Freeman, who has shared his story on page 10 of growing up with epilepsy and worrying that he wouldn’t be able to go on to do what he loves – play rugby. Spoiler alert! He did get there, and now he wants to give back. He is appealing for donations to help support others who are newly diagnosed and at the start of their journey with epilepsy. Tommy also presented Epilepsy Action’s Radio 4 Appeal (peek behind the scenes on page 12).

On page 16, you can find out why Barry ran exactly 27 half-marathons in memory of his sister Abbie, and on page 18, David shares how a breakdown helped to reset his life.

For anyone who likes an adrenaline boost, Emma's story on page 21 might give you the motivation to do a fundraiser like hers. And don’t miss our Star Awards winners’ heartwarming stories on page 28.

I hope you enjoy this issue. I love reading stories and I know their power in helping us feel connected. If you want to share yours, email **kkountcheva@epilepsy.org.uk**.

We wish you a lovely summer!

Kami Kountcheva
Editor

Good news

At Epilepsy Action, we want to celebrate the good things in our members' lives. If you want to be featured, email kkountcheva@epilepsy.org.uk

Police officers help 8-month-old baby during seizure

Greater Manchester Police officers, PC Harry Moore and PC Alexandra Higginson came to the aid of a family when their eight-month-old baby was having a seizure.

Police arrived at an address in the Gorton area after getting reports of a "concern for welfare", Greater Manchester Police reported.

The baby's father ran to the officers as they entered the street, PC Moore recalled. He said the baby was unconscious and breathing irregularly.

PC Moore started performing CPR on the baby and giving recovery breaths, while PC Higginson supported the family and delivered information over the radio.

When the paramedics arrived, the baby was taken into the ambulance. He was crying, so his breathing had recovered.

PC Moore said: "I told the father, who was just outside the ambulance at the time – he was so relieved and gave me a hug. This is a moment I will never forget."

PC Moore said this was a team effort and praised the support of PC Higginson.

Two boys see "life-changing" benefit from pioneering drug trial

Two children from Sheffield Children's Hopital, who took part in "pioneering" research on a new medication for Dravet syndrome, have seen "life-changing" results

Freddie and Albie, both aged seven, have Dravet syndrome, and took part in the UK trial for the medication zorevunersen.

This was a phase 2 trial, in which 19 children aged 2-17 years took part from across four centres: Sheffield Children's Hospital, The Royal Hospital for Children, Great Ormond Street Hospital for Children and Evelina Children's Hospital. This aimed to investigate how safe and easy-to-tolerate the medication is.

The results of this study are due to be published in a medical journal around the beginning of 2026, and a phase 3 study is intended to begin in the summer of 2025, looking at effectiveness, as well as again assessing safety and tolerability.

However, Freddie's mum Lauren and Albie's mum, also called Lauren, both have found that there has been a profound improvement in the seizure frequency and severity in the boys since starting the trial. Freddie started taking the medication in 2021 and went from more than a dozen seizures in the night to one or two brief seizures, lasting only seconds, every three to five days. Albie took part in the trial in 2022. His seizures have reduced dramatically as well since starting. Both boys' mums say their life has changed.

Epilepsy Action to feature on Radio 4 Appeal

Epilepsy Action is due to feature on BBC Radio 4's Radio 4 Appeal on 25 May this year. The Radio 4 Appeal is a weekly programme which champions the work of a charity and appeals for donations on their behalf.

Epilepsy Action's appeal will be made by professional rugby union player Tommy Freeman, who has epilepsy himself.

Tommy went to Broadcasting House in London with members of the Epilepsy Action team in April to record the appeal.

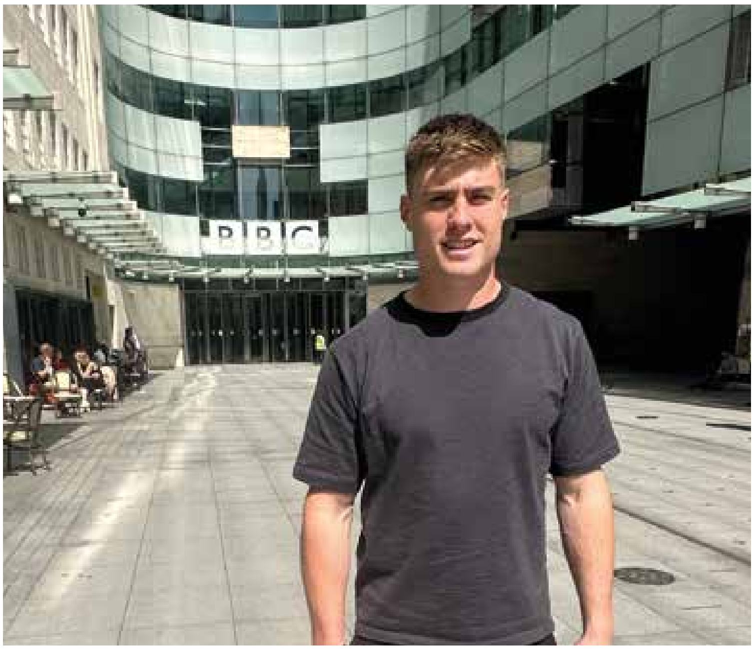
He shared his own experiences with epilepsy and why he wants people to support Epilepsy Action.

You can read more about the behind-the-scenes of the recording of the Epilepsy Action Radio 4 Appeal on page 12.

You can also read more about Tommy's story on page 10.

The 24-year-old is famous for playing full back for premiership rugby club Northampton Saints. He also plays rugby for the England team.

This year, Tommy became the first England player to score a try in all five games of a single Six Nations Championship.



London Marathon runners raise £100k for Epilepsy Action

Epilepsy Action runners have raised £108,000 for charity at the London Marathon this year, which took place on Sunday, 27 April.

This year's iconic race saw a record-breaking 56,725 participants crossing the finish line, including 53 runners doing the race in support of Epilepsy Action.

Runners took to the 26.2-mile race during temperatures reaching as high as 22 degrees on the day. Sebastian Sawe crossed the finish line first, while Tigst Assefa set a new women's only world record of 2:15:50.

Some of Epilepsy Action's runners took part in the race in support of loved ones with epilepsy, others ran in memory, and some runners had epilepsy themselves.

You can read more about the event and the atmosphere on the day on page 24.

Epilepsy news

People with epilepsy can't be "left in limbo" in plans to abolish NHS England

Sir Keir Starmer announced in March that he will abolish NHS England to bring the NHS into "democratic control".

In an address at British consumer goods company Reckitt, the prime minister said there is too much regulation. He said he wants to "cut bureaucracy across the state" and "shift money to the frontline".

He said management of the NHS should be "at the heart of the government, where it belongs".

He added: "I don't see why decisions about £200bn of taxpayer money, on something as fundamental to our security as the NHS, should be taken my arms-length body NHS England.

"I can't, in all honesty, explain to the British people why they should spend their money on two layers of bureaucracy [NHS England and the Department of Health and Social Care (DHSC)].

"That money could and should be spent on nurses, doctors, operations, GP appointments."

However, organisations like Epilepsy Action are concerned over the practicalities of the restructure and warn that people with conditions like epilepsy can't be "left in limbo" while it is carried out.

NHS England was established in 2013, to function as an arm's-length body responsible for delivering safe and high-quality care, supporting NHS staff and deliver value for money.

Photo by Lauren Hurley | No 10 Downing Street

The government plans to bring in NHS England's work into the DHSC, which Health Secretary Wes Streeting said, in an address to Parliament following the prime minister's announcement, would take around two years.

He said hundreds of thousands that would be saved a year will flow down to frontline workers, help cut waiting times and deliver better care.

A transformation period of bringing NHS England into the DHSC began immediately.

Sir James Mackey will take over as Transition CEO of NHS England, and Dr Penny Dash will take up position as chair. Mackey paid tribute to the work of NHS England, including managing the COVID pandemic and delivering a successful vaccination campaign.

He added: "But we now need to bring NHS England and DHSC together so we can deliver the biggest bang for our buck for patients, as we look to implement the three big shifts – analogue to digital, sickness to prevention and hospital to community – and build an NHS fit for the future."

While streamlining of processes and more money into the NHS has been welcomed, organisations are concerned over the significant job losses that will result (reportedly 9,000+) and how the practicalities will be managed. They are calling into question how programmes, services and records run by NHS England will be handled as part of this move.

Tom Shillito, health improvement and research manager at Epilepsy Action, said: "There is no doubt the announcement of NHS England being abolished came as quite a shock for many.

"While we need to see how the reform will work in practice, it raises concerns about what it will mean for areas previously managed by NHS England and the impact this could have on the care of people with epilepsy.

"Such a massive restructure poses the risk of slowing down quality improvement work, when it was starting to gain momentum. Shifting more power to local commissioners could make the current service postcode lottery even worse. With epilepsy often being low on the priority list at best, and completely forgotten at worst, this is clearly worrying.

"There could be some potential for process improvement, but it's unclear if we will able to see much progress in the short-term. But there are 80 new people being diagnosed with epilepsy every day. They can't be left in limbo in the meantime."

The prime minister said this will not be a return to austerity, but made it clear that more "tough choices" will be made.

Benefit cuts to PIP "damaging" for people with disabilities

People will need to score at least four points in a category to qualify for daily living personal independence payments (PIP) support, Work and Pensions Secretary Liz Kendall announced in March.

Speaking in Parliament, Liz Kendall announced the government's plans for "significant reform" to the welfare system and save £5 billion by 2029/30.

The planned changes mean people will need to score at least four points in any category in order to qualify for the daily living component of PIP. This will not affect the mobility component.

Disability charities have widely criticised the decision which will effectively tighten the eligibility for PIP, saying it is "immoral" and "devastating", and warning that it will push disabled people into poverty.

Epilepsy Action warned that cutting the benefit that helps disabled people manage daily life is "damaging" and counterproductive for getting people into work.

In the announcement, Liz Kendall added that there are no plans to means test or freeze PIP (which would essentially cut the benefit by not increasing it with inflation).

She said the government will launch a review of the assessment for PIP in consultation with disabled people, the organisations that represent them and other experts.

Alison Fuller, director of Health Improvement and Influencing at Epilepsy Action, said: "If the government wants to get more people with disabilities into work, this just isn't the way to do it.

"For people with epilepsy, it's hard enough to get PIP as it is. We've heard too many stories over the years of people feeling really alienated by the process, and having to 'prove' they actually have a disability. Being made to feel 'they're not disabled enough'.

"And the assessment is one of the most difficult parts. We have said time and time again that this should change. But not in this way. We think that more weight should be given to the views of the individual's healthcare professionals about the impact of their health condition, not what the assessor says. Now, it sounds like people are going to have to fight even more to achieve a higher score when being assessed.

"Also, PIP is paid to help people with a disability offset the extra costs of living with the condition. Claimants don't have to be out of work to receive it. The rhetoric that cutting disability benefits is going to help more people into work is just damaging. Plus, lots of people with epilepsy need PIP precisely to manage all aspects of life, which includes getting to work."

Photo Parliament TV

Surveys conducted by Epilepsy Action have shown that people with epilepsy face a number of pressing challenges when it comes to employment. Of employers, 42% admitted that they would be inclined not to hire someone with epilepsy to save their company potential challenges, even though they know this is discrimination.

Among surveys of people with epilepsy, 40% said their employers refused to provide reasonable adjustments, 60% said they'd faced discrimination at work because of their epilepsy and 28% had been given disciplinaries because of seizures.

Alison Fuller continued: "Epilepsy has the second-highest disability pay gap, at 26.9%. People with epilepsy still get discriminated against when trying to find or stay in a job. Too many employers are not willing to give people with epilepsy reasonable adjustments – 40% of people with epilepsy have told us this is the case. These are the issues to address.

"People shouldn't be punished for having a condition, or being made to feel like their quality of life can be sacrificed to make 'savings'. For people with epilepsy, anxiety and stress are major seizure triggers. This could potentially make this worse for so many people, not knowing if their independence, the very thing this benefit should be supporting, could be stripped away.

"We will respond to the consultation, and urge everyone who could be affected to do the same, as well as sharing the issue with their MP."

Alongside changes to PIP, Liz Kendall announced that the work capability assessment for the health-related part of universal credit will be scrapped and incorporated into the PIP assessment.

People aged under 22 years won't be able to claim the health-related "top up" of Universal Credit, given to people if their health condition or disability limits their ability to work. This saving will help fund "high-quality, tailored and personalised support" to help them get into work, Kendall said.

Universal Credit claimants will see an increase higher than inflation of £7, but the health elements rates for people already claiming will freeze, and will be halved for new claimants.

The government will introduce a new benefit called 'Unemployment Insurance', which will be "time-limited" and intends to provide "stronger income protection during periods of unemployment for those with a recent work record".

There will also be a right to try, which will protect disabled claimants' entitlement to benefits if they try to get into work but it doesn't turn into long-term employment.

ILAE updates how seizures are classified

The International League Against Epilepsy (ILAE) has updated the way it classifies epileptic seizures in a new paper published in the journal Epilepsia.

The new classifications include four classes and 21 different seizure types. This will help clinicians better understand the type of seizure a person is having and what treatment might be the most appropriate.

However, Epilepsy Action says people can still use the language they're most comfortable with, even though they may hear doctors and nurses using these updated terms.

The updated classification puts seizures into one of four groups: focal, generalised, unknown (whether it's focal or generalised) and unclassified.

Seizures in the focal or unknown groups are then also classified by whether the person loses consciousness (impaired) or doesn't (preserved) during the seizure.

Focal seizures start in one part of the brain, and generalised seizures start in multiple parts of the brain. Focal seizures may begin in one part and then start to spread as the seizure continues, but these are still classified as focal seizures.

The generalised seizure group will include absence seizures, generalised tonic-clonic seizures and other generalised seizures, which will now include negative myoclonus as seizures. Negative myoclonus is where the muscles stop tensing for a brief moment, and the person briefly loses muscular tone.

Seizures can then be further classified using visible signs and movements.

Tom Shillito, health improvement and research manager at Epilepsy Action said: "Everyone's epilepsy is so different and it can be challenging for medical professionals to describe different seizure types in a way that's understandable. We welcome the new seizure classifications from the ILAE – we believe they're now easier to understand and are more in line with how people with epilepsy and their healthcare professionals tend to describe the more observable signs about their seizures.

"However, this won't change the way people describe different seizure types more broadly, such as tonic-clonic, absence or myoclonic seizures. While they will help clinicians to explain a patient's condition more clearly, people with epilepsy should still be able to use the language they prefer and that this should be honoured by their doctor."

Study authors Sandor Beniczky and colleagues concluded that the updates to seizure classification have been made to "establish a common language for all healthcare professionals involved in epilepsy care, from resource-limited areas to highly specialised centres, and to provide accessible terms for patients and caregivers."

The update work was done by a working group comprising 37 members from all ILAE regions, and additional experts. The full article is available online on the Epilepsia website.

Heart problems in drug resistant epilepsy – study

A new study has found that drug-resistant epilepsy in children and adolescents could increase the risk of heart problems.

Researchers from Thailand investigated change in heart rate variability (HRV) in 54 children and adolescents aged between six and 20 years old. In general, higher rates of HRV mean that a person's heart can adapt well to different changes in their environment, for example beating faster during exercise or slower during relaxation. Lower HRV could be a sign of health problems.

Of the 54 children, 27 were in the epilepsy group and were diagnosed with drug resistant epilepsy. The results of the study found that the children and young people with drug-resistant epilepsy had lower HRV measures. Lead study author Chinnuwat Sanguansermesri and his colleagues warned that this may make this group more likely to have heart-related health problems.

“Fundamentally unfair” system leaves 144,000 carers in overpayment debts

An open letter by Carers UK, signed by 108 campaign groups and charities, including Epilepsy Action, is calling out “fundamentally unfair” government rules leaving thousands of carers with debts of up to £20,000.

Around 144,000 carers are facing outstanding repayments due to what have been called “cliff-edge” rules limiting how much carers can earn from part-time jobs while also being able to claim Carer’s Allowance benefit.

Of these, 9,000 carers are unpaid and trying to juggle working and caring at the same time.

People with epilepsy may need a carer if their seizures are frequent and uncontrolled. Additionally, epilepsy can come with other conditions, such as mental health problems, autism and learning disabilities, which could make it even more likely a person may need support from a carer.

An independent review into the overpayment debts carers are facing, announced in October 2024, is being led by Liz Sayce OBE.

The letter to the Secretary of State for Work and Pensions, Liz Kendall, is urging the government to “halt the creation of new Carer’s Allowance overpayment debts until the independent review has concluded and its recommendations are implemented”.

According to Carers UK, Carer’s Allowance of 81.90 a week can be claimed if you spend at least 35 hours a week caring for someone. But you can only earn £151 a week to claim this benefit, and earning even £1 more means you have to pay back your weekly carer’s allowance in full.

This could mean that people earning £1 more than the £151 limit, would have an extra gain of as little as £52 a year, but be forced to repay £4,258.80.

A Guardian investigation has found that carers have racked up thousands of pounds of debt because of how strict the rules are and because the Department for Work and Pensions (DWP) didn’t promptly notify carers of overpayments.

The letter added: “This cliff edge often forces carers to choose between poverty and debt. Many already struggle financially and these debts impact entire households, including children and disabled family members.

“Carers make an invaluable contribution to society. We want the system to reflect their worth, rather than leaving them in debt for trying to balance paid work and unpaid care.”

Epilepsy open access service in Wales reopens

The Aneurin Bevan University Health Board’s (ABUHB) epilepsy open access service in Newport, Wales, has reopened after an unexpected closure in November last year.

The service closed without notice around mid-November, and Epilepsy Action understood this was due to staffing problems and sick leave.

The open access service was set up to offer timely support, specialist care and ongoing management for people with epilepsy.

The service has now resumed with improved staffing in the health board. People from the area have called the helpline service “excellent” and something that patients are “reliant” on.

Epilepsy Action Wales manager, Janet Paterson, said: “It’s certainly positive news to hear the service is back up and running. As many people with epilepsy in the area rely on it, it’s absolutely crucial that any future fluctuations are communicated in a timely and complete manner. Patients need to be fully aware of the options available to them. We’re hoping this will be taken on board in the future, should there be any more changes to service provision.”

Epilepsy affects around 36,000 people in Wales, with around 1,500 new diagnoses each year. ABUHB provides specialised epilepsy services and the use of open access for people across Wales, with 6,700 people with epilepsy living in the ABUHB area.

“I want to give back”

Tommy

England’s rugby superstar Tommy Freeman shares how epilepsy threatened his favourite hobby and future career, and why he wants people to support Epilepsy Action

> “Having a seizure was probably the hardest thing I have ever experienced, it was so difficult and I had lots of emotions flying around. Seeing your parents upset and looking to them for help, that was hard”

England rugby star Tommy Freeman fell in love with the sport at the age of seven. As a young boy it was all he wanted to do, playing professional rugby was his dream.

Tommy achieved his dream, most recently representing England at the Six Nations Tournament, scoring a number of tries along the way.

But it wasn’t an easy journey to get to where he is today. Tommy had to overcome a lot and faced a lot of uncertainty. He didn’t know what the future would hold, or if he even had one.

One day when he was in school reading out loud in class, all of a sudden he just stopped. He was halfway through a sentence and he couldn’t continue.

Tommy said: “That was the wake up call for me to know that something wasn’t right, I felt like I wasn’t in control.”

He had no idea what was happening, his parents didn’t know what was happening. Initially it was thought that Tommy might have been daydreaming but, after being in and out of hospital, eventually the doctors confirmed he had been having absence seizures.

He said: "As soon as I heard the word epilepsy, it was kind of like, no, it can't be. No one wants to be diagnosed with something that's incurable.

"It was a little bit embarrassing.

"When I went to see the doctors and they said it was daydreaming, my mum stepped in and said: 'this has gone far enough', and we went to get a scan. That's when they noticed I was having around 30 seizures.

"It was my mum who accepted what it was and was determined to get me the right answers."

Despite this, Tommy was able to carry on. Slowly, it seemed as if he had grown out of these seizures and life returned to normal.

However, just after signing for Northampton Saints Rugby Club at age 19, he had a full tonic-clonic seizure.

This was the moment when Tommy thought "Can I carry on playing rugby?"

He said: "I had a full-on seizure. You can't breathe. My mum was lying next to me, my dad was there. They said my lips went blue.

"I woke up what felt to me like 30 seconds later, but it had been a few minutes, and I was taken by ambulance to hospital.

"Immediately I was put on the tablets I was on as a kid, then I was referred to a neurologist who did an EEG.

"I was having all these tests to make sure it was clear what it was, then they changed my medication as the tablets weren't working, all this took about six months."

Even though his journey to a diagnosis was quicker than some, he said: "It felt much longer than six months, it felt like a decade."

All this was a really scary time for Tommy. He said the uncertainty was unsettling, and all he wanted was to go back to being a regular kid.

He added: "I think it was more of the unknown that was scary, not knowing if there was a cure. I just wanted to carry on being a kid, I was so active and, as long as I was outside with my mates and chucking the ball around, I was pretty happy."

When he was first diagnosed with epilepsy, the first thing that came into his head was: "What does it all mean for me?"

He said: "Having a seizure was probably the hardest thing I have ever experienced, it was so difficult and I had lots of emotions flying around.

"Seeing your parents upset and looking to them for help, that was hard."

As someone who knew exactly what they wanted to do, Tommy said it was a real fear of his that he might not be able to play the sport he loves.

"It was a pretty dark and lonely place," he added.

After that tonic-clonic seizure, he immediately lost a lot of his independence. He wasn't able to drive or even go to the shops alone, he had to rely on other people to help.

"I felt really isolated," Tommy said.

He was afraid to do simple daily tasks on his own, he said this made him wonder how he would have to adapt.

He said: "You want to do things on your own and you kind of have to think twice about it.

"Even just having a bath and knowing you're on your own, you kind of want someone around you. It's that slight change in mindset where you need to prioritise things."

Thankfully, Tommy had family and friends around to support him, and his journey to a diagnosis and control of epilepsy was probably a little bit easier than other people have experienced. He now feels he is more in control of his epilepsy.

However, he says the worry never goes away.

"I still worry about will I have another seizure? That does go through my head quite a lot to be honest.

"Those thoughts happen when I'm alone, if I'm swimming for example, for a split second those thoughts pop into my mind.

"I might get a funny feeling in my chest or head, then you can go into panic mode, and they worry me a lot.

"But I do try to get those thoughts in and out pretty quickly so I can carry on doing whatever I am doing."

With Tommy still on his journey with epilepsy, he now wants to help others who are facing that uncertainty and share some of the ways he was able to overcome the condition and continue his dream.

He said: "I would say to anyone recently diagnosed, find out as much as you can. You want to get it under control as quickly as possible and understand what your approach will be.

"As soon as you do that, that's when you can start looking to carry on doing what you love."

Tommy is using his platform to inspire other young people like him who are maybe concerned about their epilepsy holding them back.

"Since the diagnosis, I have been trying to get on with my life, but now I have a platform, I want to give back and support charities like Epilepsy Action who are helping people who are newly diagnosed."

He's advocating for more people to get in touch with Epilepsy Action.

He said: "I think Epilepsy Action is a brilliant charity, anyone considering donating to Epilepsy Action, please do.

"They offer helplines, Talk and Support groups and loads of online information.

"Don't hesitate to pick up the phone to those guys, because they will do a lot for you."

Now that you have read Tommy's inspiring story, we wanted to ask you to consider continuing your generous support by donating to Epilepsy Action.

With more donations from people like you, we can help more people achieve their dreams and get them to a new normal like Tommy.

If you would like to donate, please visit epilepsy.org.uk/tommy or fill out the form in the enclosed appeal letter.

Tommy wants to use his platform to help others

Tommy in the recording studio for the Epilepsy Action BBC Radio 4 Appeal

Recording for *radio*

Epilepsy Action's Jayme, Crispin and Jaimie met with rugby superstar Tommy Freeman to record our BBC Radio 4 Appeal. Jayme and Crispin share the behind-the-scenes.

> **❝ It was just a really positive, exciting day and I really enjoyed meeting Tommy. I think his attitude is really great ❞**

Crispin: We are so grateful to England rugby legend Tommy Freeman for travelling to London on his day off – and one of the hottest days of the year so far – to present our BBC Radio4 Appeal.

We met Tommy and his agent in the lobby of Broadcasting House near Oxford Circus. There we were met by a BBC Radio 4 producer, who, once we had shown our IDs, had passes printed our and had put our bags through scanners, led us past the famous BBC Newsroom and up a lift to the sixth floor.

Jayme: Walking past the big news area on the way to the recording studios was really exciting. You could see all the screens were popping off.

When we got to the studio, we met the producer and executive producer, who were really nice and friendly. They got Tommy sat in the booth ready to record. I think he

The producers helped Tommy with the script

At Broadcasting House in London

L to R: Jaimie, Crispin, Tommy and Jayme

Tommy filmed content with Epilepsy Action's Jaimie, Crispin and Jayme

was quite nervous, because up until the day, he had thought the appeal was going to be broadcast live, so he relaxed a lot when he realised it was pre-recorded.

Crispin: Tommy recorded his story, sharing his own struggles with epilepsy and why he thought Epilepsy Action was the charity Radio 4 listeners should be supporting. Tommy was a natural and really impressed the producers who were very supportive with their hints and tips.

Jayme: After that, I got to go into the little studio with Tommy to create what's called an audio boom. It's like a minute-long promo recording that they use for marketing. That was probably my favourite part of the day. We had a lot of laughs at that point, and it really helped to break the ice even more and for Tommy to feel more relaxed.

Tommy asked a lot about us as a charity and our services and what we do, and even said that he would have benefitted about knowing about our helpline earlier. And that just solidified the value of what we were doing on the day and why we work so hard to get the message about epilepsy out there.

Crispin: Afterwards, we were shown downstairs and appeared onto Portland Street. We'd preplanned to do some filming with Tommy at nearby Regent's Park and were very fortunate it was a beautiful, sunny day.

Jayme: We got some really great behind-the-scenes content for our social media (find us on Facebook, Instagram, LinkedIn, X and TikTok).

Crispin: Tommy was very generous with his time and answered both very tough and some more light-hearted questions around his experience of living with epilepsy.

One thing that really stuck out to me was how passionate he is that people truly understand the condition and that the stigma is broken down.

Jayme: It was just a really positive, exciting day, and I really enjoyed meeting Tommy. I think his attitude is really great. He recognises that everyone's condition and situation is different, but he really believes in not letting it hold you back from the things that you really want to do.

Crispin: Thank you, once again, to Tommy, and we're hopeful Radio 4 listeners will really respond to his story and give generously to the appeal. We know that every penny will be used well to create a world without limits for people with epilepsy.

Jayme: You can catch the BBC Radio 4 Epilepsy Action appeal on the 25th of May.


Rebekah (left) and Jane

Making more of *membership*

As we celebrate our 75th anniversary as a charity, Jane Riley, chair of the Board of Trustees and Rebekah Smith, chief executive, discuss the recent governance review and the changes this is leading to in the charity

Why did we need to carry out a governance review?

Rebekah: When we created our new strategy, one of the first things we said we would do was to make sure that our governance was fit to deliver our ambitious plans. We chose the National Council for Voluntary Organisations (NCVO), as they have worked with hundreds of charities to make sure their governance is fit for purpose.

What were some of the findings of the review?

Jane: It was an extensive review, carried out over several months, and, ultimately, we were offered a detailed report with 32 separate recommendations to consider. The message that came over loud and clear was that we were using some old and tired practices that do not now reflect current best practice in charity governance. It immediately became clear that we needed to look at new ways of

> “In the recent membership survey, 90% of respondents said that they were most interested in engaging with the charity in more informal ways. They wanted to be involved in groups, such as online communities, where two-way conversations could take place”

Talk to us

Want to ask more questions about the changes you will be asked to vote on in September? These will be presented in full in the next edition of Epilepsy Today, but in the meantime, you can send any questions you might have direct to our CEO, Rebekah, at **rsmith@epilepsy.org.uk** or join Jane and Rebekah for a Q&A session on **Wednesday 25th June** by signing up to the event here: bit.ly/44UGaOE

appointing trustees, who could provide the charity with the skills it required, combined with shared values and lived experience of epilepsy.

The NCVO also highlighted more practical issues, such as having no limits on how many times a person could stand and remain as a trustee, and that 16 trustees was a high number for the type of charity we are. Their recommendation of a board size of 8-12, and time limits on trustee appointments, will be two of the changes included in the new constitution that we will be asking members to vote on in September. Many of the issues pointed to ensuring we develop a more inclusive and diverse board, and that is hugely important to me.

What did the review find around our current membership model?

Rebekah: When all the trustees began looking at the recommendations of the review, they all agreed it gave us a really great opportunity to look at our membership model. I personally found it really confusing when I first came to Epilepsy Action four years ago that 80% of our volunteers – people who give up many hours of their time to help us deliver our services – weren't recognised as members. On top of that, I'd come from 10 years working in Students' Unions, where elections and voting were central to everything that we did. So, seeing that less than 4% of our membership were voting to appoint the trustees meant that what looked like an inclusive and democratic way of appointing a board had actually become exclusive, as was highlighted by the review.

Jane: Yes, I completely agree. It was so disappointing to see that after investing in new digital methods of voting in 2024 we still only managed a 4% turn out – that's just 300 people from a 7,500-person membership – and interestingly that was the highest election turn out we had ever achieved. So, this became a central discussion for us as trustees.

What kinds of changes are being considered to membership?

Jane: We established a dedicated working group to look in much more detail at how we can create a wider reaching, more inclusive membership that can still offer our members a voice in appointing our trustees. And this is what we will be asking people to vote on in September. We will also ask people to consider and then vote for an appointed trustee board, rather than an elected trustee board. Of course, the charity would continue to provide a range of opportunities for members to be part of the recruitment and appointment process if they chose to.

Rebekah: This also gives us a fantastic opportunity to create a membership product that is open to all, which we haven't been able to do in the past because of the way membership is written into our legal documents. We will be talking in the next issue of Epilepsy Today about what that new membership scheme could look like if the Resolution is passed.

What are you hoping to achieve with the changes?

Rebekah: We've already had feedback from over 900 members and non-members about what they would like to see as part of the membership scheme, and there is work continuing to understand the practicalities of how a new scheme would work, which you may well hear about over the next three months. What we already know is that we want it to be open to as many people as possible, especially our volunteers and regular supporters, and create something much more flexible and inclusive. We want everyone who supports Epilepsy Action to feel like they are a valued part of our community, rather than divide people by the way they choose to support us.

Jane: A more inclusive membership will also help us with another area that came through the governance review, which was about being more transparent and providing improved communications about our governance to everyone who is engaging with us. By creating a new form of membership, we can also change the focus from a formal Annual General Meeting (AGM) that very few people attend, to an open event that talks about the achievements and challenges of the charity and gives everyone an opportunity to ask questions of both me and the Senior Leadership Team. That will be a new and valuable addition to our communications, however we will still keep some of the core elements, such as the ever-popular Epilepsy Today, and continue to develop our informal methods of communications, such as our social media channels.

It's a really exciting time for the charity. We are offering more support services than ever before and are celebrating significant success through partnership working. As a board of trustees, we know we have to make sure our governance can keep pace with all the ambitions we have, and we are really excited to see where the charity can go with the continuing support from our community.

Barry with his mum and wife Naomi after running his 27th half-marathon

27 half-marathons

Barry ran 27 half-marathons and raised over £22,000 for Epilepsy Action in memory of his sister Abbie. Written by Emily Stanley

Barry Ahearn, 44, completed his monumental challenge of running twenty-seven half-marathons in memory of his sister, Abbie, in March. Abbie passed away in 2023 after she went into cardiac arrest during an epileptic seizure. She had only been diagnosed with the condition six weeks earlier. Barry decided to raise funds for Epilepsy Action to ensure his sister's memory lives on.

Barry said: "Abbie was kind compassionate, attentive and loyal. She was so much fun to be around, always making jokes and playing pranks. She brightened any room she walked into with her smile and is sorely missed by everyone who knew and loved her."

"She had her first seizure in early 2023, and of course went to the hospital to get checked out. They checked her heart with an ECG, but ultimately she was sent home. In July, she had another seizure, and at the end of this month, she was diagnosed with epilepsy. It was only six weeks later that we lost Abbie.

"Abbie had a seizure which was so severe it sent her into cardiac arrest. Despite the best efforts of the paramedics, doctors, nurses, Abbie passed away three days later. She was only three months away from her 30th birthday.

"Losing my sister has been the worst experience of my life. Every day since losing Abbie I have been in emotional pain. So I

Barry ran a half-marathon around meaningful places to Abbie, including the hospital she was born in, the house they grew up in, her primary and secondary schools and her local pub

> **“Losing my sister has been the worst experience of my life. Every day since losing Abbie I have been in emotional pain. So I thought, why not turn that into physical.”**

thought, why not turn that into physical. That’s why I decided to do this challenge.

“I want her passing to mean something, to help make a difference, not only by raising money to go towards research, but also to raise awareness of how serious this condition is.

“I chose to do 27 half-marathons because this represents the amount of time Abbie’s brain was without oxygen, whilst paramedics tried to revive her.”

Around 1,000 people die from epilepsy-related causes each year, which is about three people every day. Barry wanted to take on this challenge to make sure that Abbie is not just ‘one of the three’.

Barry continued: “Over the past year, I have completed 27 half-marathons including London Bridges, Carsington Water and even at my local park where I had to run up and down the path 55 times to reach 21km! Some have been at organised events, others have been solo runs. In that time, I’ve been joined by friends and family who’ve ran with me and helped to raise funds.

“It’s of course been tough at times. Physically, the runs obviously took a toll on my legs. Although this was mainly because I was attempting to fit my runs in around my busy social schedule. Runs eight to fifteen were done within nine weeks, but five had to be done within twelve days as I had to finish before a weekend wedding!

“The solo runs were the toughest emotionally, as it can be hard to stay focussed and motivated, and of course sometimes I was thinking about Abbie, which adds to the emotions. Luckily, I have had such amazing support from my friends and family throughout the events I have run, no matter the weather. Seeing my family, best friends and their kids cheering me on with banners has been very special.

“Of course, my biggest supporter is my wife, Naomi. She has been at every running event, cheering me on, videoing me, organising other spectators and has even run parts of them with me, including the full final half-marathon.

“On the final run at the Battersea Park Half I was joined by 40 other runners to support me, and around 150 people were there to spectate and cheer us on. It was a day of completely mixed emotions, but I am so happy with how it went. The support received was incredible and I am so proud of the entire team who took part. There were tears before, during and after and I know that they really pushed themselves to complete the run.

“I am extremely proud of my wife for taking part and I even had the privilege of being able to rejoin the race and cross the finish line with her. It was a very special moment.

“When I set myself this challenge, I hoped to raise awareness about epilepsy, along with some money to support Epilepsy Action. Whilst it’s not possible to measure the impact that this has had or will have, whether it’ll save at least one life, I think the chances are now slightly higher, having done this. The story has been spread much further than I could have hoped for and having raised nearly £22,000 across the team, I can only consider this a success.”

Epilepsy Action Director of Fundraising, Philippa Cartwright, says “All of us at the charity are in complete awe of Barry’s incredible fundraiser. His determination and resilience is so inspiring and the money raised in Abbie’s memory will help so many people with epilepsy.

“Barry and his friends have raised almost £22,000 for Epilepsy Action, which will go towards supporting our amazing services including Talk & Support groups, one-to-one befriending, and our helpline. Just £108 can recruit and train a new befriending volunteer, and £768 can fund the helpline for an entire day, showing the difference Barry’s donations will make.

“Epilepsy Action would like to say a big thank you to Barry, his friends and supporters for this incredible effort, and we are sure his sister Abbie would be so proud.”

David

A life *reset*

David's life has seen a lot of challenges, but a breakdown a few years ago has given him a chance to learn to live again. Written by Kami Kountcheva

David had a breakdown on November 30th 2022, at the age of 59, when he cried for the first time in his adult life, letting out years of suppressed pain that had built up over a lifetime of difficult moments; the death of his mum from cancer when he was 17, the breakdown of his marriage, being diagnosed with a brain tumour and developing epilepsy.

Throughout much of his life, David kept his grief on the inside, feeling that he did not have the security of a financially settled homelife to "allow himself to break." And as a young man, growing up in the 60s and 70s in Chester in an area which, in an interview with the Guardian, he calls "a tough place", he felt he had to learn how to survive.

But David was to go on to experience a number of difficult moments in his life, bottling up more and more and one of these challenges was around his health.

Developing epilepsy

In 2020, David began receiving radiotherapy for a tumour he had been diagnosed with the previous year. "I had no experience of epilepsy until the first week of radiotherapy in September 2020, when I suffered two sleep tonic-clonic seizures, waking up on both mornings at around 11:30am having bitten my tongue and urinated in my bed.

"After these first two seizures, I seemed to settle into a pattern of one seizure every month and that carried on for six months. But the seizures changed."

While receiving treatment for his tumour, David continued to get on with things, like he'd done his whole life. "I had 30 sessions of radiotherapy in 2020 and managed to carry on working, in many respects aided by the COVID 19 pandemic and lockdown, which meant working from home became the norm.

"At the time, I was working as a coach mentor to unemployed people setting up in business for themselves. I spent much of my adult life working in coaching and mentoring, business development, training and consultancy roles, including specialising in behaviour and motivation."

However, in 2022, the effects of inflammation caused by radiotherapy forced David to stop working. Over time, his epilepsy changed as well, leaving him to experience and deal with different seizures.

He explained: "My seizures have gone through phases. The first two were tonic-clonic seizures and after that, they became passing-out episodes, but without the tongue biting or wetting myself. On two occasions, I woke up on the floor."

David recounts these events in his book, saying he would wake up on the floor with no recollection of what had happened, once next to his computer while he'd been working, and once having broken his living room – thankfully safety glass – table that he'd been walking past.

"Then, after six months, they stopped. The medication seemed to be working and I enjoyed a sustained period without a seizure. But my other symptoms post radiotherapy worsened.

"Then, in late 2023, thinking I didn't need the medication anymore, I stopped taking it. In January 2024, the seizures started again. I had one whilst assembling a wardrobe, broke three ribs and suffered a severe black eye. Then, a month or so later, I woke up having bitten my tongue in my sleep.

"In April 2024, I had my last seizure – and my first one in public. I had an absence seizure in the supermarket whilst doing my weekly food shop. It took an hour before I came out of it and found myself in an ambulance outside the main entrance, having been guided there by the manager of the store."

The perfect storm

David explained that he "got on with life as best as he could" around his epilepsy, like he'd always done throughout his life. When his seizures started again, he decided to ask his doctor about Keppra, having read about the medication, which he is now taking for his epilepsy.

David says developing epilepsy after a string of difficult and stressful events in his life was "like the perfect storm".

He said: "My wife and I were together for 30 years and I was very sad to lose my marriage, but I didn't grieve because I didn't know how to grieve. Grieving was not part of my life, I just got on with things and kept myself positive and busy.

"My wife told me in 2012 she wanted to separate and that meant I had time to mentally prepare to be on my own when it happened.

"From 2014, for five years, things were pretty much 'normal'. I got on with my new life in a new place (I moved to Warrington when we separated). I was socialising, working, dating, travelling. Doing things that were every day for me. Then, slowly but steadily, my life closed in. First the tumour, then lockdown, then becoming too unwell to work.

> "I was very sad to lose my marriage, but I didn't grieve because I didn't know how to grieve. Grieving was not part of my life, I just got on with things and kept myself positive and busy"

David had a seizure in January 2024, waking up with three broken ribs and a black eye

Burns on the face from radiotherapy

> **“In many respects, I am learning to live again and it feels very much like the beginning of the third stage of my life”**

“All of this finally led to the situation where I had to face the trauma that was bottled up inside me. Including the new trauma of epilepsy.”

David’s life completely changed again in a new way, he explains, when his tumour was diagnosed and he began radiotherapy treatment. He had had “an active life” before, going to sporting and social events and travelling, but he says he now lives “quietly”.

“I walk for exercise, I read, occasionally I visit an art gallery or meet an old friend for a bit of lunch. Since October 2023, I go to church. I no longer drive, so I take public transport for longer journeys and walk for anything local, such as shopping.”

Raised vein in the head reacting to the radiotherapy

David added that symptoms of the inflammation from his radiotherapy have been ramping up until a year ago.

He explained: “As the effects of radiotherapy slowly build up, the treated area becomes inflamed and numb. Over time, you lose feeling and movement in the treated area. It sort of becomes deadened. For example, the treated area of my forehead lost its wrinkles and my eyebrow and eyelid lost some movement, so my eye didn’t close as it normally would. As this inflammation slowly dies back, literally a few years later, the movement and feeling comes back and with it comes the feeling you had lost and you can feel the pain the inflammation leaves behind. It is as though the area has been in shock.

“It is much better to have that movement back, but the pain it brings with it, needs to be managed.”

David has pain in his head, behind his ear and his eyebrow. His hearing in that ear is also affected, as is the focus of his eye.

Fortunately, recently, the symptoms have started to steadily improve, leaving him to figure out how active he can become again.

“What I find five years later is that, so long as I live within myself, get plenty of rest and look after myself in terms of sleep and diet, these symptoms are less intrusive. They become more ‘background’ issues but are always there waiting to flare up in the wrong circumstances. The single-sided deafness, tinnitus and the pain are always there but are manageable. And, of course, my seizures are showing signs of being under control.”

The down and the up

David explained that keeping all his feelings bottled in through everything he had gone through affected his mental health. “I could feel the suppressed grief I had in me bubbling up,” he said.

When the pandemic caused a national lockdown, and David had to give up his job, he had time to himself to reflect. “Finally, the circumstances I needed to allow me to ‘breakdown’ safely were in place. I had the thinking time and my life was stable. And the breakdown happened.”

David was admitted to hospital in 2022, with his mental health having hit breaking point. In his book, he writes what was said in his hospital admission notes – “Working diagnosis: acute delusional disorder secondary to chronic anxiety and depression.”

David writes that during his breakdown, he believed he had died. He was able to speak frankly with his sisters about their mum’s death and cry with them, and be able to face all the other difficult moments he’d been keeping at arm’s length.

“Over my lifetime, I have become quite skilled at managing difficulty, so my focus to this point was to just get on with things and make the best of it.

Following his breakdown, David feels like he’s had a ‘reset’ and is now able to cry freely and be a lot more in touch with how he’s feeling.

“In many respects, I am learning to live again and it feels very much like the beginning of the third stage of my life. I am starting again and having to learn how to do it.

“Learning to be ‘emotionally normal’ makes me more rounded, more grown up and mature as a person, and it illustrates how our capacity to grow carries on right through life. When the time and circumstances allow, personal growth kicks in.”

You can find out more about David's story and his book on his website: www.daves-story.co.uk

A fundraiser with a *difference*

Fundraising can take many different shapes and forms – and Emma chose something a little more high-octane than the average. Written by Kami Kountcheva

> “It’s so lovely. It looks so magical and bright. It’s quite peaceful looking above the clouds.”

The first surprise for Emma is seeing the plane gather pace towards her. It takes off directly above her head and over the building as she’s walking in with the rest of her team.

It’s 8am on a November morning. It’s cloudy and chilly, but it’s dry.

Job number one is getting registered and watching the safety briefing. Then, getting kitted out. Emma is wearing leggings and sportswear and is presented with a jumpsuit, which she dons happily. She likes a jumpsuit anyway, it’s comfortable. The instructor triple-checks her harness straps on her request – they’re definitely tight enough, he reassures her.

The atmosphere is jittery and jovial – a cocktail of nervous energy, pent-up excitement and the smell of fresh americanos from the café.

In the weeks leading up to today, Emma’s nerves had been building. She had been keeping calm by doing extensive research – from the practical, like having her hair in braids, to the more theoretical, like what could go wrong. Turns out, not much, really!

Now, on the day, she is pretty much just excited. All the instructors seem very relaxed – they do this eight times a day.

Emma goes outside to watch the planes for a while and does sporadic jumps to let some energy out as she waits for her turn. She is called in to practise her landing with her instructor. You need to lift your legs quite high, they tell her.

Other groups, along with their friends and family are sitting at the café with snacks and pastries waiting for their turn and chatting animatedly.

The instructors are keeping a weather eye on the clouds – if they can see the top of the mountain in the distance, the group is good to go.

The group huddle together and the instructors fist-bump Emma and her group. It’s time!

The plane takes off with Emma and her instructor and the rest of her team. That includes her colleague Philippa, Channel 4’s First Dates waiter David Marc, who she met earlier today, and their instructors.

They’re all facing the back of the plane and looking out to see the ground getting smaller, until it’s covered with an expanse of white, cotton-ball clouds.

They’re about to skydive from 15,000ft to raise money for Epilepsy Action. Emma and Philippa know firsthand how far every penny goes, as members of the fundraising team. So, with that in mind, they set out to take on a challenge to help raise even more money for people with epilepsy.

About three-quarters of the way up, Emma’s instructor clips the two of them together. He attempts to have a little joke with her about the clips, but is swiftly – and playfully – reprimanded by mum-of-two Philippa. “Don’t do that to her,” she tells him.

Emma is feeling a bit sick with the build-up of nerves now, and gripping on to her harness. She looks over to Philippa and is met with an excited grin. She’s been

> “Hanging over the edge, because it happens so suddenly, my brain is like white noise. It’s empty and at the same time every single thought is in my mind.”

> “When you’re falling, it feels like falling, but when you’re paragliding, it actually feels like flying. It’s not the same as when you’re on a plane, it’s just you. It’s incredible – it feels like you’re the only person in the world above the clouds.”

itching to get her goggles on in case her instructor forgets them, but he doesn’t. He also reminds her to scream if she’s finding it hard to breathe. It’s noted.

Emma is first to jump. Within about 20 seconds, and without much thinking time, the doors slide open, helmets and goggles are on and she is sat on the edge, feet tucked underneath the plane. She’s leaning back, head pressed against her instructor’s chest, giving him the room to see over her.

The crystal blue sky fills her vision and the whirring white noise of the wind blocks out any other sound. Her instructor will communicate with taps and gestures from now on.

And then, they’re out. A tumble. A summersault. Tap-tap. That’s the sign to put your arms out. Emma stretches her arms out. She and her instructor are now freefalling at 120mph.

The feeling is unlike anything else. It feels like falling into nothing, but also into something. Something’s putting pressure on your body. It’s exhilarating and Emma is beaming. Or at least she thinks she is, she can’t feel her face at all.

Her instructor spins them around. She gets a 360o view of the endless stretch of fluffy clouds below, like a duvet ready to embrace them. It doesn’t look to Emma at all like they’re hurtling at 120mph towards the ground.

About halfway through the fall, she remembers what her instructor told her. She starts to scream, letting out all the energy and excitement, and getting in big gulps of air. After 60 seconds of falling, the instructor opens up the parachute.

The second surprise for Emma is how much she would love the feeling of gliding through the air once the parachute opened. As she and her instructor glide into the cloud, a cool mist hitting their faces, he can’t resist one last prank. He spins them around and around in the cloud, to the sound of Emma’s screams, until they emerge from underneath.

Emma thinks she could spend an hour in this lovely, suspended state, looking out over the world. She briefly wonders what would happen if she collides with a bird up here, but that doesn’t happen. Five minutes feel like they pass in a flash, and her instructor is now preparing to land.

She’s meant to lift her legs up by the handles on her knees and land sat down, but the instructor says, “stand up”, and she lands on her feet. Before she’s noticed, he’s unclipped himself and her skydive is done.

She watches Philippa and David descend one after the other, heart still racing at the thought of what she’d just done. She heads back into the building for something to eat, anticipating the “adrenaline dump” they told her could happen a little while after her skydive.

She starts to plan her next skydive – somewhere with a view, she reckons.

If you want a piece of the action, why not Jump in July? you can sign up for a skydive at epilepsy.org.uk/skydive to support people with epilepsy

> “When we broke through the clouds, and I could see everything below, I think that was the happiest I was the whole time. I just felt really joyful.”

Over the finish line

With more than 56,000 runners crossing the finish line of the London Marathon 2025 on Sunday 27 April, Emily Stanley tells us her experience going down for the first time to support the Epilepsy Action team. As told to Kami Kountcheva

I was kind of apprehensive going down. Not in a bad way – I was really excited – but I'd never been before and I didn't know what to expect.

I got the train from Leeds and got to Kings Cross at about 11. I'd come down with all the football fans, but when we arrived, the tube was quite quiet. I got to Embankment, and when I came out of the station, it was full of people. I thought, "I'm here!" I could hear all the cheering as I was coming out.

It was quite early still, so before heading to the end of the race, where I was going to be waiting for people finishing, I thought I'd watch some of the runners. I was somewhere near the end, it must have been around the last few miles, and I could just see what an effort this was for them. It was so hot on the day, the sun was shining right down on them and they all just looked exhausted.

As I walked over to the finish line, I could see runners with their medals already, and my first thought was, "Wow, that's fast!" They must have done it in around three hours. I started to see people with their families, some people were on their own, people wrapped up in the foil blankets. I thought people looked really relaxed for having just done something so huge as to run a marathon.

I found the Epilepsy Action station, and I thought it looked amazing with all the flags and the table set up, and the two massage tables. If I was a runner, I'd have been delighted. When I got there, spirits were really high. The team were tracking our runners, and we could see some of them were near the finish.

As people started arriving, there was a real mix. Some people were quite tired, some people were really happy. One guy that came over was in really great spirits. His wife and two little girls arrived and he made use of the massage tables, and I got to ask him some questions about the race. (He said it was hard.)

As more people crossed the finish line and came to us, I met lots more runners, friends and families, and everyone was so lovely. We had prosecco and juice for everyone, and also some goody bags with snacks.

The first thing most people said when they got to us was "it's so hot" or "it was so hard". Most people were relieved to be at the finish line and see their friends and family. But one person stuck out to me, because he came over and just said: "Hi, how are you guys, are you okay?" And I just thought, "You've just ran a marathon! Are you okay?" I thought, "He's just done that enormous challenge and is still thinking of other people."

Among the people I spoke to, a couple of people had epilepsy, so I thought it was even more impressive that they've put their bodies through such a challenge when they've also got the condition. And there was a couple of people running for relatives who have epilepsy and a few running in memory.

But everyone was mainly running because they really liked Epilepsy Action, and they were all really grateful and wanted to fundraise for us. There was a real mix of people but all lovely and brilliant.

I think what left the biggest impression on me was just the spirit of the place. You can't be there and not be happy. Something else that struck me was that every person I met, every person walking past or at the stands, they've all just achieved probably one of the biggest things in their life. Every time I saw someone with a medal, I just thought, "They've done it! Everything they've worked for", and it's just so impressive.

It sounds cliché, but there were all kinds of people. All different shapes and sizes, men, women, young people, old people – everyone. And it doesn't matter who you are or where you came from, all they needed was running shoes and they all committed to training, and they all turned up and they all did it!

I loved seeing people meet up with their loved ones at the finish line. One guy was saying to his wife, who had epilepsy, "I did it for you!", which really stuck with me. And one girl had ran a lot of the race with another girl, and they found each other at the end and gave each other a massive hug and said, "We did it!", which was also so lovely to see.

A lot of people were saying how the WhatApp group that Epilepsy Action set up for the runners had created this lovely community and it had been a massive part of helping them get through it as well.

The day was so special, and I got to meet lots of different people and hear lots of different stories, so it was amazing to be there. We had 53 runners for Epilepsy Action and they helped to raise £108,000 – a brilliant achievement!

If you're a keen runner and want to fundraise for Epilepsy Action, you can apply for a place with us for the London Marathon 2026 now at **epilepsy.org.uk/londonmarathon**.

What's new?

We share some recent advances in epilepsy research from Epilepsy Action's Seizure journal

The Seizure journal paper summaries were written by Fay Dawes. Fay is an Epilepsy Action volunteer. She is now retired and became a volunteer two years ago. Fay lives in Kent and really enjoys hosting Talk and Support groups and being part of the Befriending Team

Outcomes in adult-onset generalised epilepsy

A team of specialists from the Department of Neurology at Beaumont Hospital in Dublin recently carried out research into idiopathic generalised epilepsies (IGE). These are seizures that start for no known reason, usually in childhood or adolescence. Sometimes, but more rarely, this can also happen in adults (18 years and older in the study).

They wanted to study how the condition develops over time when it starts in adulthood.

Their research was based on a group of 425 patients. For 55 of these, seizures had started when they were over 18, and out of those 55, six had experienced their first seizure when they were aged 30 or over. Most of these initial seizures had been generalised tonic-clonic seizures with only 11 diagnosed with focal seizures. More than 60 % of people developed epilepsy with generalised tonic-clonic seizures alone. The most frequent medications prescribed were lamotrigine, levetiracetam and valproate.

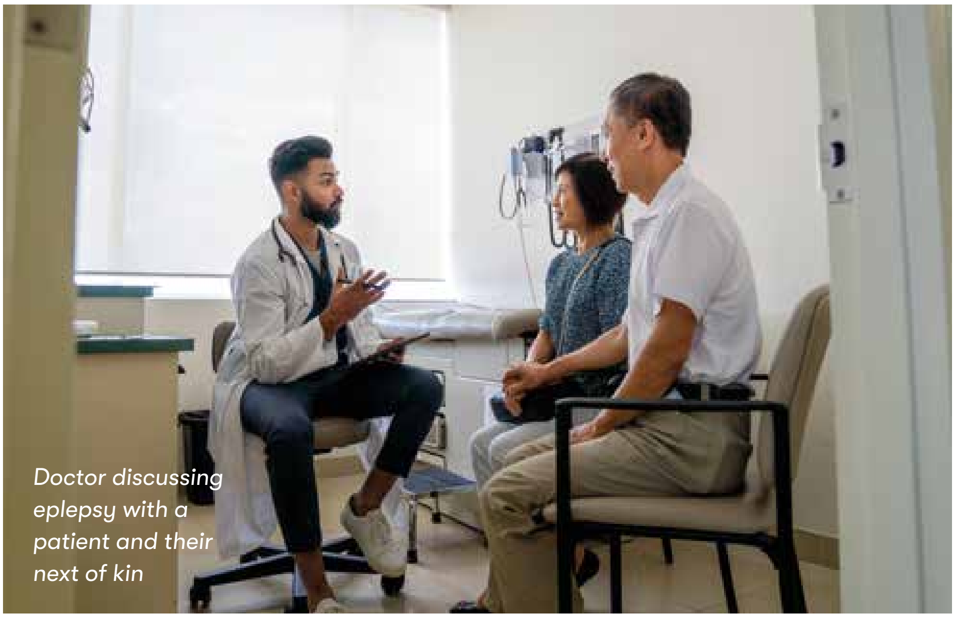
When the patients were reviewed, over 70% had been seizure free for over 12 months, including those with absence and myoclonic seizures. Eight (14.5%) had developed drug-resistant epilepsy and required more than two types of medication.

The significant findings from the study suggest that most adults whose seizures start when they are over 18 become seizure-free with medication, although there is a high probability that the seizures will recur if they stop taking the medication. This includes focal, absence and myoclonic seizures as well as tonic clonic seizures. A small number of adults may develop drug-resistant epilepsy and need more than one type of medication.

You can find the paper at: bit.ly/3YOgGP5

Ketogenic diets for epilepsy

In February 2025, a group of researchers



Doctor discussing eplepsy with a patient and their next of kin

> **“This should be a wake-up call for healthcare professionals working with this patient group”**

in Iran, made up of food nutritionists and medical scientists, undertook a review of 38 previous research papers into the effectiveness of ketogenic diets in reducing epileptic seizures.

Diet therapies for epilepsy, including the ketogenic diets, have been used as a treatment for both children and adults. The objective of this review was to look at the evidence around how safe, effective and easy to follow the different kinds of ketogenic diet are, especially in people with drug-resistant epilepsy.

Their findings showed that the Classic Ketogenic Diet can show “significant benefits” in reducing the frequency of seizures. The Modified Atkins Diet and the Medium-Chain Triglyceride Ketogenic Diet were also found to be effective and people were more able to adapt to these. The study also found that the Low Glycaemic Index Diet was a possible option, particularly for the treatment of children, although it may not be as effective. The researchers concluded that further research is needed to refine these dietary approaches and investigate their long-term impact.

You can find the paper at:
bit.ly/4ddj8VH

Call for better information

In February 2025, a group of specialists from the University of Oslo and Oslo University Hospital published their research into the information available to the next of kin of those with epilepsy. They concluded that information about the nature of the condition is a prerequisite for next of kin being able to give the best possible care to people with epilepsy.

The study looked at the amount of information available to Norwegians to support their close relatives with epilepsy, both in terms of caring for them and in knowing where to go for extra support. They also proposed that a lack of information about epilepsy in next of kin had a negative impact on helping to manage the condition, their use of support from the healthcare system and attitudes in others around them.

A questionnaire was posted on the homepage of the Norwegian Epilepsy Association for five months. Out of the 231 people that responded, almost 90% said more information was needed, both on general topics around epilepsy and specific information on aspects like seizure management and sudden death in epilepsy. A high proportion of these said they had not been able to obtain information on specific issues and that this lack of information caused a lot of emotional distress.

The study authors found that the next of kin of people with epilepsy whose seizures were well controlled were the least happy with the information they had been given. The research found that they were not sufficiently informed around managing seizures, seizure-related injuries, concentration and memory. They were also less well informed on mental health aspects that can come with epilepsy, like anxiety and depression.

The study concluded: “This should be a wake-up call for healthcare professionals working with this patient group”.

You can find the paper at:
bit.ly/449MmSK

The ketogenic diet can be effective for people with epilepsy

Epilepsy stars

We celebrate an amazing dad, a supportive school and a brilliant workplace with our Epilepsy Star Awards. Words by Emily Stanley

February's Epilepsy Star award winner is Joshua Granelli, who has continually fundraised and raised awareness for epilepsy since his step-son was diagnosed with the condition. Joshua has currently completed five runs for Epilepsy Action, including the London Marathon, London Landmarks and Cardiff Half. He is now due to complete The Ironman in September this year in aid of Epilepsy Action. Joshua was nominated by his partner Ceri, who says he hasn't stopped since her son's diagnosis and shows no signs of slowing down:

"My son, Ioan, developed epilepsy three years ago when he was only 14. At the time, we didn't know much about epilepsy, and so we turned to Epilepsy Action to help us with support and advice. Josh decided that he wanted to give back and ensure other families can get the support they need, whilst also raising awareness of the condition.

"Three years ago Josh couldn't run – now he doesn't stop! His next big event is the iconic Wales Ironman. This includes a 2.4mile swim, 112mile bike ride and ends with a 26.2mile full marathon. It will be the biggest physically enduring challenge that Josh has done.

"Our lives were turned upside down by Ioan's epilepsy diagnosis. As parents, you never get used to seeing your child have a seizure. Josh is always there for me during these times – he stays calm and holds me, whilst being there for my son. I don't know what I'd do without him.


Josh Granelli

"Epilepsy Action helped provide resources and helped upskill us both to be able to feel confident in supporting Ioan. We've also seen how the charity has helped others too. Like many conditions, epilepsy can come with a stigma attached, and we know this needs to be broken down. That's why Josh wants to play his part in raising awareness and funds for the charity, so they can keep breaking these barriers and supporting other families.

"Josh and I met in 2016, when we were helping to set up a new nursing team for adults with mental health issues and learning disabilities in the community. Josh completed his nurse training last year and is now a registered learning disabilities nurse in the Cardiff community. One of his main roles now is to work with adults and their families who have learning disabilities and epilepsy.

"Aside from his fundraising, awareness efforts and giving back to the community as a nurse, he is also an amazing partner and dad. His patience, willpower and motivation are off the scale. His determination to keep going and continue supporting the people he loves and works with is inspirational.

"He is our hero."

Caring, genuine and supportive staff

March's Epilepsy Star Award has been given to the year 10 teachers at Tanfield School, in Durham. The school was nominated by Katy Parkin, who says her teachers have supported her throughout her journey with epilepsy, from her very first seizure in year 7. Katy's mum, Sharon Bowes, helped her with the nomination, and says she is forever grateful for everything the teachers have done for her daughter.

"Katy had her first seizure on her very first day of secondary school. My heart absolutely dropped to my stomach when I got that call. Since that day, the school has given us full support and understanding.

"Katy is now in year 10 and still suffering from seizures. Katy has had full support from the school throughout these years, especially from her year manager, Mrs Farrell. They help her with school work, talk to her about any of her worries, sorting a routine for her, never leaving her out of anything and never treating her any different to any other student.

"At the beginning of Katy's epilepsy journey, every few weeks she would have a seizure at the same time of around 3pm. I was always informed straight away by the school, and they always took brilliant care of her; made sure she didn't hurt herself, made her comfortable, stayed by her side.

"Katy's initial EEG came back with no abnormalities, so we were asked to keep a diary of dates of seizures, and record them if possible. They mainly happened at school, so they got cctv footage of the seizures for us.

"It was a scary time, and Katy was finding it hard to do her day-to-day things, such as seeing friends and going places because of the 'what if's in the back of her mind. She eventually started making excuses to stay home. Her dad and I were understanding, as we felt exactly the same.

"A couple years later, we got a sleep deprived EEG, her blood pressure monitored for 24 hours, and the school cctv, which enabled us to get a diagnosis of epilepsy. The epilepsy nurses were fantastic and we were able to sort a healthcare plan with the school. Katy was a shell of herself at this time, but we always stayed positive.

"Unfortunately, Katy was still having seizures, even after being put on the highest dosage of medication. We were told she did not in fact have epilepsy, and was to be slowly taken off her medication, and to see a psychologist. Katy's dad and I were determined to help Katy, as we knew this wasn't just 'in her head'. We kept logging the dates of her seizures, and school always tried getting videos for us. It was heart-breaking to see our daughter not able to leave the house.


Tanfield School teachers

"After a few more hospital trips, and another EEG, we have been told again it is epilepsy. Katy is starting on a different medication.

"We met with the school to discuss attendance and a way to ease Katy back into lessons. They were absolutely brilliant and offered her a reduced timetable with people around her who she feels comfortable around.

"We are forever grateful for everything they have done for us. I couldn't ask for a more caring, genuine, supportive group of teaching staff than who Katy has around her. 'Thank you' never seems enough, so hopefully this is a special kind of thank you to Mrs Farrell, and all of the year 10 teaching staff."

A judgement-free workplace

April's Epilepsy Star Award is awarded to a workplace that have gone an extra mile for their colleague with epilepsy. Trad UK Hire & Sales Leeds were nominated by Rosie who says they have provided her with support, care and a judgement-free workplace since she started working there five years ago. Rosie says her team are the only colleagues she has had that genuinely care about her, and tells us why she wanted to give them this award:

"When I began working, as someone with epilepsy, I was so nervous about getting the support I need. I didn't really know what to expect.

"I started working at Trad UK five years ago in an admin role. From the beginning, they never judged me in any way, and were happy to support me into the role, even with my epilepsy.

"The team has made so many adjustments for me and they always check I'm doing okay. If I need extra breaks, or a bit of time away from the computer, they are happy to do this. If I am feeling unwell or just want to talk to someone regarding my epilepsy, they are always there for me.

"I have an Epilepsy Action plan I keep on my desk, so if I do have a seizure they know what to do, and also have my contact details for next of kin. They know what the signs are if I'm about to have a seizure, and if I'm looking unwell they'll check if I've taken my medication.

"I have had quite a few seizures at work, and some have caused injuries. On one occasion, I had a seizure which led to me falling into a cupboard. I had to have many stitches in my face, broke my nose and stayed in hospital for a few days. During this time, the management team called me every day to see how I was and told me to only return to work when I was ready.

Trad UK Hire & Sales

"A few months ago, I had a seizure in the gym which caused really bad anxiety, and I wouldn't leave the house unless I was with my partner who also supports me a lot. Due to this, work made a plan for me. They gave me time to rest and get my head round things. Then they provided me with a laptop so I could do work at home.

"When I started feeling better, the management team didn't ask me to come back into the office straight away. They gently eased me in, starting with two days in the office, then three and so on. They kept checking I was okay and that I wasn't too stressed, or work getting on top of me. They have also put a system in place so I am not alone in a room for a long period of time.

"It feels amazing knowing I don't have to hide my condition. They don't get annoyed if I need something explaining a little further, or if I re-ask the same questions.

"No doubt due to all of their support over the past few years, I have now been promoted to senior admin. I felt so happy that someone believed in me and has actually given me a chance. This means a lot to me, and I couldn't have done it without their support.

"I would like to say a big thank you to everyone at Trad UK Leeds, but especially to Michael McLoughlin and Stewart Quinn who have always been there to help me and given me support when needed. Epilepsy is not an easy condition to live with, but having you guys there when I need it is amazing."

You can nominate someone for an Epilepsy Action Epilepsy Star Award at epilepsy.org.uk/stars

Board of trustees

Board meeting 8 April
Key discussions included the next actions in response to the NCVO Governance Review. It was agreed that a Corporate Governance Committee would consider the constitutional recommendations that would go to the membership to vote on in September before discussion at the Board.

The new CEO report included updates on: developing the new strategic plan for the Epilepsy Research Institute, ongoing partnership work with Angelini Pharma and the Neurological Alliance, recent media coverage with ITV over prescription shortages leading to the death of a Leeds man and meeting MP Fabian Hamilton.

Two amendments to the scheme of delegation were accepted: the Standing Committee will approve senior leadership changes as well as oversee the CEO role, and policy reviews and responsibilities will be referenced on the risk register. Financially, overall income was behind budget by £43,000 at the end of February, mainly due to delays in receiving legacies. Expenditure was £691,000, 23.6% below budget, primarily due to payroll savings from vacancies and phasing of event expenditure. Cashflow stood at £810,000, with general fund reserves within the criteria set at six months.

A discussion about the importance of the charity’s policy work took place, emphasising the need for a proactive policy position. It was suggested that the charity invest time in identifying key stakeholders and building relationships, and create thought leadership documents and research setting out the charity's solutions.

An update on the 2025 Strategic Roadmap was presented, showing progress against targets set and the key work to be delivered this year. There was a focus on our Health Improvement and Influencing work and various projects were discussed, including the maternity safety and learning disabilities projects.

The Board discussed changes to the current articles of association, addressing key questions about quorum, AGMs, lived experience, minimum age and terms of office. The annual review of the corporate risk register was highlighted and the proposed changes to the board appraisal process were presented, now to be referred to as trustee personal reviews. The Fundraising Delivery Monitoring Plan for 2025 was approved and Tom McLaughlan was appointed as the Trustee Safeguarding Lead.

The meeting finished with some reflections from the Chair on the staff away day and the positive experience of attending.

The next meeting will take place on Tuesday 13 May at 10.00am.

Epilepsy support for you

For 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.
- **Befriending**: 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.
- **Counselling**: Available in Wales, offering professional support to anyone affected by epilepsy.
- **Family Support**: Tailored support for families and carers in South Wales and Northern Ireland, including practical help and opportunities to connect.

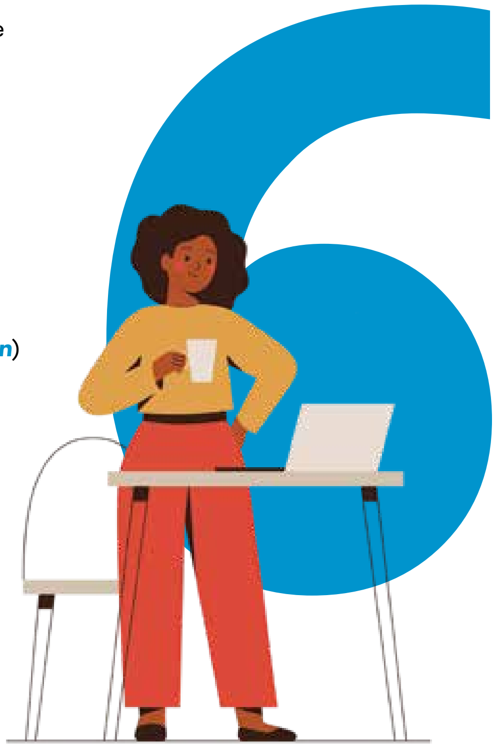
We're here to listen, support, and bring people together – because no one should feel alone on this journey.

For more information call our Helpline on 0808 800 5050 or visit ***epilepsy.org.uk/support-for-you***

You can also find us on:

- HealthUnlocked (***healthunlocked.com/epilepsyaction***)
- Discord, (***bit.ly/3vHLOkT***)
- Facebook (***facebook.com/epilepsyaction***)
- X (formerly Twitter) (***@epilepsyaction***)
- Instagram (***bit.ly/3zSKMVM***)

> **"We're here to listen, support and bring people together"**



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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.

ISSN 0958 496X

EPILEPSY
ACTION

EPILEPSY SAYS STOP.
WE SAY GO.

Support for You:

- **Helpline –** phone, webchat or email
- **Talk and Support Groups –** online & in-person
- **Befriending –** online or phone
- **Counselling –** Wales
- **Family support –** NI & Wales
- **Website –** high quality information about all things epilepsy
- **Epilepsy awareness courses**

epilepsy.org.uk/support

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