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Love and hope

Welcome to the Winter issue of Epilepsy Today. In this edition, we tackle some serious and difficult topics, which need more awareness. But we also share stories of hope, support, love and joy.

One of the most difficult subjects to talk about is sudden unexpected death in epilepsy (SUDEP). It's rare, affecting one in 1,000 people with epilepsy, but knowing about it is vital, as there are risk factors associated with it – and things we can do to reduce them. On page 18, Joanne shares why talking is so crucial and you can find more information on managing the risks. On page 20, Jo Scott's husband Craig and mum Caren pay tribute to Jo's life and continue in her footsteps, raising awareness of epilepsy.

Our cover star this issue is Chloe. She tells us how epilepsy left her afraid and feeling like her life was stolen from her. But when she found Epilepsy Action, she began to find courage and acceptance. More on page 10.

Also, don't miss Will's return to sailing after epilepsy threatened to end his favourite activity (p 26), Martin's excitement for the Bradford 10k race in 2025 (p 24) and the heart-warming stories of two of our Star Awards winners (p 28). Last but not least, don't forget to check out our Christmas shop and stock up early on the essentials! (p 5)

Finally, thank you for your stalwart support this year and I hope you have a wonderful festive season.


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

First Dates waiter David Marc to skydive for epilepsy

Channel 4's First Dates waiter David Marc is taking part in a 15,000ft skydive to raise money for Epilepsy Action. He is set to skydive at Lancaster Airfield in November.

Alongside his part in the popular dating show, David works with children with Special Educational Needs and Disabilities (SEND). He said he has seen the challenges some of these children face with epilepsy.

David said: "I have seen first-hand the difficulties that come with a diagnosis of epilepsy. I also have a close friend who has struggled a lot living with epilepsy and so it's a cause extremely close to my heart. Epilepsy is not spoken of enough and I am determined to help spread the message.

"I'm feeling nervous but incredibly excited to be jumping from 15,000 feet! Raising money for Epilepsy Action makes it more meaningful, and the thought of supporting this important charity really motivates me. It feels incredible to combine the thrill of the dive with making a positive impact."

David announced his skydive on 17 September on Instagram, saying: "Your support and encouragement would mean the world to me as I take this giant leap for a great cause!

"I'll see you in the sky!"

David will be skydiving alongside two Epilepsy Action members of staff, Emma George, trust fundraising officer, and Philippa Cartwright, director of fundraising.

Emma said: "I've worked at Epilepsy Action for three years and feel really lucky to see the difference we make to people affected by epilepsy every day. I'm so excited to skydive for this fantastic cause alongside Philippa and David – I don't feel nervous yet but I'm sure it will hit me on the day!"

Epilepsy Action shortlisted at Royal College of Midwifery Awards

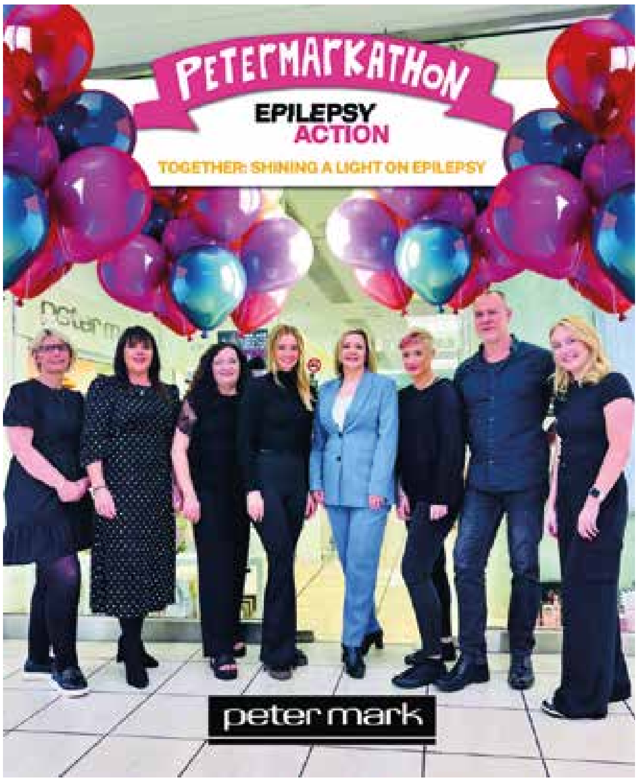
Epilepsy Action was shortlisted for a Royal College of Midwifery (RCM) Award for Partnership Working alongside the NHS North West Midwifery Team.

Members of the organisation attended the event on 18 October 2024 at the Brewery London.

Leah Norton, engagement and project coordinator at Epilepsy Action, said being shortlisted is "huge recognition" for the work of the partnership, which "highlights the impact third sector can have."

She added: "Whilst we didn't win this year, I am so incredibly proud of the whole team for our nomination!"

Epilepsy Action named hairdressing chain’s charity of the year



Irish hairdressing chain Peter Mark has chosen Epilepsy Action NI as its charity of the year. The salon’s annual ‘Petermarkathon’ has donated all funds raised to the charity, to support people with epilepsy across Northern Ireland. The event ran from 23-31 October 2024.

The ‘Petermarkathon’ has been running for the last 12 years and has raised over €800,000 for various charities. The annual event involves a variety of different fundraising activities that take place across Peter Mark salons.

There were five salons in Northern Ireland taking part in fundraising and raising awareness for Epilepsy Action. Each parlour created its own unique way of raising money. Customers were treated to pyjama parties, fancy dress, raffles, games and many other fun-filled events.

Epilepsy affects 23,000 people in Northern Ireland, meaning one in 83 people are diagnosed every day. Northern Ireland has the highest prevalence of epilepsy in the UK and ROI. The funds raised through the ‘Petermarkathon’ will help to support the services that Epilepsy Action Northern Ireland provides.

CEO, Peter Mark, said: “We are delighted to support Epilepsy Action as our Charity of the Year for our salons in Northern Ireland.”

He highlighted the importance of “raising awareness of this wonderful cause” over the week of the event.

Carla Smyth, Epilepsy Action Northern Ireland manager, said: “We are absolutely thrilled that Peter Mark has selected us as their Charity of the Year. Epilepsy Action NI is the only charity in Northern Ireland dedicated to providing front-line services for those affected by epilepsy, and the funds raised will contribute towards the amazing services the charity provides.

“The event will not only help us to raise much-needed funds but it also allows us to raise awareness about such a challenging condition. It’s important that we take the time to talk about epilepsy and how it affects people.”

You can find more information about the ‘Petermarkathon’ at epilepsy.org.uk/petermarkathon.

Browse our online Christmas shop now!

With Christmas just a couple of months away, there’s no better time to browse the Epilepsy Action Christmas shop and get set up with your essentials early.

There is a whole host of Christmas cards and e-cards, as well as gift wrap, labels, tags, advent calendars, Christmas crackers and lots more!

With every purchase, you will also be supporting the essential work of Epilepsy Action – two gifts in one!

Visit the shop at: charitycardshop.com/epilepsyaction or scan the QR code

Epilepsy news

Cannabis medicine trials for refractory epilepsy to start in 2025

Two national NHS clinical trials will investigate the safety and effectiveness of cannabidiol (CBD) and tetrahydrocannabinol (THC) in adults and children with treatment-resistant epilepsy.

Prof Finbar O'Callaghan and Prof Helen Cross from University College London (UCL) and Great Ormond Street Hospitals (GOSH) will co-lead the trials, which are due to start in 2025.

The trials will randomly assign CBD, CBD with a small amount of THC or placebo to a total of 500 adults and children with medicine-resistant (refractory) early-onset and genetic generalised epilepsies for 24 weeks. People will be recruited into the trial from NHS sites around the UK. The trial will use formulations by the company Ananda Developments, known as MRX2 (CBD) and MRX2T (CBD+THC).

The researchers want to investigate whether these medicines are safe and effective in reducing number and severity of seizures, and how they affect learning, sleep, behaviour, quality of life, stress and anxiety.

Ananda Developments said: "These will be the world's first double blind randomised controlled trials to investigate the use of CBD and THC together for epilepsy, and the first to evaluate the medicines in children and adults who have a broad range of difficult-to-treat epilepsies."

If successful, the results of the trials may support applications to the Medicines and Healthcare Products Regulatory Agency (MHRA) and other regulatory bodies for approval for use in refractory epilepsy.

At the moment, the CBD medicine Epidyolex is licensed and recommended for use on the NHS for people with Dravet syndrome and Lennox-Gastaut .

Currently, the National Institute for Health and Care Excellence (NICE) has not recommended this medicine for severe and treatment-resistant epilepsies. The institute says more high-quality evidence is needed on safety and effectiveness of CBD and CBD in combination with THC for severe treatment-resistant epilepsy.

Rebekah Smith, deputy chief executive at Epilepsy Action, said: "It's encouraging to see these long-anticipated trials for medicinal cannabis finally taking place. The NHS has had a cannabidiol product available since 2018, but there have been very few prescriptions, and it has only been approved for two rare forms of epilepsy.

"The need for more research on the effectiveness and safety of both the CBD and THC elements of cannabis is much needed, and announcing this research is a source of hope for many families.

"We are eager to understand how these clinical trials could advance the way we treat epilepsy, and while we recognise that this will take time, we will continue to inform and educate people about their options and support them in ways to access this and other forms of medication."

Matt Hughes, co-founder and director of Medcan Family Foundation, said: "We are pleased to hear that the long-anticipated trials proposed by GOSH and UCL in 2019 will commence next year.

"Research is a much-needed step in expanding access to CBD medicines for the treatment of drug-resistant epilepsy. The trials bring renewed hope for children and families affected by uncontrolled seizures.

"A trial including THC is also crucial for addressing the questions posed by NICE.

"However, it's important to recognise that these trials do not include second generation, advanced cannabinoid medicines; the variety that is used by most families seeing significant and sustained improvements in seizure control and which have been shown through real-world data and observational trials to be the most effective.

"For those for whom CBD and THC alone are not effective, and for those already privately prescribed advanced cannabinoid medicines, we continue to urge government support in creating a pathway for the licensing of these more advanced medications."

There is more information on the Epilepsy Action website: **epilepsy.org.uk/info/treatment/medical-cannabis-based-treatment**

Employment Rights Bill overlooks disability

Labour's Employment Rights Bill has "missed the opportunity" to support disabled people with finding and staying in work, says Epilepsy Action.

The bill, published on 10 October 2024, promises to end unfair employment practices, boost economic growth and "make work pay". However, Epilepsy Action said it is "disappointing" that the bill doesn't mention any specific measures around disability employment.

The measures proposed by the bill include making flexible working the norm where practical and strengthening statutory sick pay.

It also discusses providing basic rights from day one, including protection against unfair dismissal and parental and bereavement leave, stronger dismissal protections for pregnant women and new mothers, and ending zero hours contracts and unscrupulous practices.

Daniel Jennings, senior policy and campaigns officer at Epilepsy Action, said: "While some of the measures announced in the Employment Rights Bill are very welcome, it is disappointing that the government has missed the opportunity to address the wider issues that many disabled people face in finding and staying in work.

"The employment rate for people with disabilities remains around 54%, compared to 82% of non-disabled people, and yet no specific measures to support disabled people into work were announced as part of the bill.

"For people with epilepsy, the employment rate is even lower, at 42%, and so it is clear that specific measures are needed to address this gap. We have previously called for reforms to Access to Work, to provide support for people while they are looking for work, and more robust action against employers that refuse to implement reasonable adjustments. This bill would have been the perfect opportunity to implement such measures as well as others we have suggested."

Research from the Trade Union Congress (TUC) showed that, on average, people with epilepsy are paid around 11% less than non-disabled workers.

The disability employment gap, the difference in the employment rate of disabled people and people who are not disabled, has also remained at around 30% since 2010.

In a recent survey by Epilepsy Action, 60% of respondents who had epilepsy said that they have faced discrimination at work due to their condition. People have reported misconceptions and misunderstandings in work or while job hunting, which they say have affected their opportunities and wellbeing.

Meanwhile, in another survey, 42% of employers 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.

A separate draft bill is expected to discuss legislation to end pay discrimination, including mandatory reporting on ethnicity and disability pay gap for large employers.

Jennings added: "The government needs to urgently review the employment support available for disabled people to ensure that people are not marginalised when it comes to employment opportunities."

What do you think about the new Employment Rights Bill? Get in touch with your thoughts and employment experiences by emailing campaigns@epilepsy.org.uk

Seizure detection

UNEEG Medical has launched a smaller than before, wireless seizure detection device, called EpiSight, in Europe.

The device is implanted just under the skin on the scalp during a 20 minute procedure. It records brain activity 24/7 while the person lives their daily life and can stay in place for up to 15 months. It includes an app and sends data directly to a person's clinician. Speak to your doctor to see if you could be eligible for this device.

Folding electrodes

Tiny folding implants, inspired by the Japanese art of origami, could make epilepsy surgery safer and improve diagnosis, UK researchers say.

In a new study, the University of Oxford-led research team said that the 32 electrodes, embedded in a flat rectangular silicone wafer, can fit through a 6mm surgical hole. They hope this technology will make diagnosis safer and more efficient, and will help cut down recovery time andreduce risk of infection.

Winter fuel allowance

The UK government has brought in changes to winter fuel payments, meaning only people getting means-tested support, such as pension credit, will be able to get it.

The plans have been criticised by MPs and charities like Age UK, saying it will "leave millions of struggling pensioners without money they rely on".

Have you been affected by the changes to winter fuel payments? Write to let us know at **campaigns@epilepsy.org.uk**

Darzi report highlights 'critical state' of NHS

The NHS is in a "critical state, but the vital signs are strong", according to the Darzi report into the state of the UK's health service, published in September.

The Independent Investigation of the National Health Service in England report was commissioned by the Secretary of State for Health and Social Care, Wes Streeting earlier this year.

Conducted by Professor Ara Darzi, the investigation has concluded that the NHS is "in serious trouble".

In a response to the report, Prime Minister Kier Starmer said that the public have a right to be angry. He added that the NHS is broken, but not beaten.

He announced three "big shifts" are planned over the next 10 years to improve the state of the NHS. They include investing more in community care rather than hospitals.

However, Epilepsy Action has stressed that historically, neurology services have been "severely underfunded".

The Darzi report highlighted a number of issues. It referenced 'ballooning' wait times, health inequalities in areas like maternity care, and an A&E in an "awful state" which could be contributing to an additional 14,000 deaths a year.

The investigation found that people are struggling to see GPs and waiting lists for community care and mental health services are "surging". Meanwhile, the health of the nation has deteriorated, the report added.

The report found that the NHS is "starved of capital", is still feeling the effects of the pandemic and the austerity of the 2010s.

Prof Darzi also concluded that the patient voice is not loud enough, with patients' concerns not being heard or acted upon.

Despite all of this, Prof Darzi said the "vital signs are strong".

He said: "The NHS has extraordinary depth of clinical talent, and our clinicians are widely admired for their skill and the strength of their clinical reasoning.

"Our staff in roles at every level are bound by a deep and abiding belief in NHS values and there is a shared passion and determination to make the NHS better for our patients. They are the beating heart of the NHS.

"It is not a question… of whether we can afford the NHS. Rather, we cannot afford not to have the NHS, so it is imperative that we turn the situation around."

The government's three 'big shifts' programme to lead to the major recovery of the NHS include moving from hospital to community care, becoming more digital and focusing more on preventing sickness rather than treating it.

Epilepsy Action is campaigning for epilepsy to be prioritised within health and social care. The organisation says the UK has one of the worst ratios of neurologists to patients among high income countries.

There are 1.1 full-time-equivalent neurologists per 100,000 people in England. Both France and Germany have one consultant for every 25,000 people or fewer.

Also, guidelines recommend that there should be nine epilepsy specialist nurses per 500,000 people. But in England there are two per 500,000.

Alison Fuller, director of Health Improvement and Influencing at Epilepsy Action, said: "The findings from the Darzi report are disappointing but not surprising. It's a harsh truth that the NHS has faced major challenges since way before the pandemic.

"We welcome aspects of the government's vision such as getting more people with long-term conditions into work, and empowering community care. At the same time, we still think there is investment needed into hospitals when it comes to specialist workforces, and it's concerning to hear this doesn't seem to be a part of the 10-year plan.

"Our country's neurology services have historically been severely underfunded. There just hasn't been enough resource. Lack of access to specialists has a major impact on people with a long-term condition like epilepsy, who are already faced with a life-changing diagnosis and need all the support they can get.

"There are huge regional disparities in the numbers of specialists available in our country, and even the better-served areas are not keeping up with the rest of Europe.

"We know there are major NHS-related issues that need addressing, including improving A&E waiting times and investing in digital technologies. But we were hoping for more support for people with long-term conditions.

"As a member of the Neurological Alliance, we have supported calls for a Neuro Taskforce to address the common problems faced by people affected by neurological conditions and make their voices heard.

"The lack of mental wellbeing support, delays to treatment and care, and a lack of information and support at diagnosis. These are still major issues. They are still very real for people with epilepsy. And they still need resources to be addressed."

What have been your experiences with NHS services? What do you think of the report and the government's plans? Get in touch at: campaigns@epilepsy.org.uk

Men taking valproate advised to use contraception – MHRA

Men taking the medicine sodium valproate are advised to use effective contraception by the Medicines and Healthcare Products Regulatory Agency (MHRA) in a release published in September in the UK.

The MHRA advises that men taking sodium valproate use condoms and ask female partners to use contraception to prevent an unplanned pregnancy.

This is because taking the medicine may cause a "potential small increased risk" of neurodevelopmental disorders in children born to fathers taking sodium valproate.

Sodium valproate is an epilepsy medicine which people may know by its brand names: Epilim, Episenta, Epival, Dyzantil or Depakin.

The MHRA says no one should stop taking valproate without advice from their specialist, so doing so could worsen their seizures.

However, it advises that health professionals should discuss the risks with men taking the medicine at their next epilepsy appointment, as well as available options.

The new advice also encourages patients to attend their routine appointments to discuss their treatment plans and ask any questions.

The organisation says men shouldn't donate sperm while taking sodium valproate and three months after stopping the medicine.

For anyone not currently taking sodium valproate, but wanting to have it prescribed, the restrictions brought in in January 2024 will apply.

These say that no one under the age of 55 will be 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 new guidance is precautionary and is based on a study from a few Scandinavian countries. This research found that around five in 100 children whose fathers were taking sodium valproate at conception had a developmental disorder, compared to around three in 100 children born to fathers who were taking lamotrigine or levetiracetam.

The MHRA said that "this study does not prove that valproate use in men increased the risk of problems in children". However, it said that it is "an important safety issue", which needs "precautionary" action.

Alison Fuller, director of health improvement and influencing at Epilepsy Action, said: "When the MHRA introduced regulations for new sodium valproate prescriptions in January 2024, we raised concerns about adding additional restrictions to a potentially effective medication.

"We know there are around 65,000 boys and men currently on sodium valproate in the UK. The measures are precautionary, meaning they will not require two signatories to stay on their medication. That said, they will still need to have an in-depth conversation with a healthcare professional. We think healthcare professional capacity is still going to be a real issue.

"We are concerned people with epilepsy will feel confused at best, and very worried about what this means for their treatment at worst."

For more advice and information, you can call our Helpline at 0808 800 5050.

Centre for Global Epilepsy opens

The University of Oxford is launching the Centre for Global Epilepsy to address the global epilepsy challenges.

Led by consultant neurologist and professor of Global Epilepsy at the University of Oxford, Arjune Sen, the new centre will drive advancements in epilepsy research, diagnosis, treatment and care by linking expertise from high-income settings to lower-resource areas.

Research by Simon Wigglesworth and colleagues showed that even within the UK, there is a higher prevalence and incidence of epilepsy in more deprived areas, compared with more affluent areas.

The centre will act as a global epilepsy hub, linking research institutions with epilepsy clinics across the world, and facilitate "bidirectional knowledge transfer". It will also aim to inspire clinicians and trainees to help transform global epilepsy care.

Prof Sen said: "The need for epilepsy research and improved care is crucial. Most people in lower-income countries are currently undiagnosed, or incorrectly diagnosed, lack access to treatment, and face severe stigma.

"Through its holistic approach to sustainable global partnerships, and commitment to empowering local stakeholders, the Centre for Global Epilepsy has the potential to transform the lives of millions affected by this neurological disorder, especially those who happen to be born in less well-resourced settings."

The establishment of the new centre is part of the University of Oxford's commitment to "addressing global mind-brain health challenges and promoting equitable access to quality healthcare worldwide". It will be based at the university's Wolfson College.

Life was *stolen*

Chloe faced a near-death experience and spent 10 years in the dark about her epilepsy, but Epilepsy Action's resources helped her find acceptance

> **"I can stand in the bus stop next to someone now and I can talk about epilepsy, and I don't feel like I have five heads"**

That first seizure changes everything. A person's life can be moving along as normal then suddenly, it stops. For so many people in the UK, it's not just that moment – the impact of that first seizure has a lasting effect.

For Chloe, an Epilepsy Action member, it took 10 years for her to get a diagnosis and even longer to be able to come to terms with living with epilepsy. She had her life taken away, she faced discrimination; epilepsy took over.

This is her story.

Scan the code or visit epilepsy.org.uk/christmas-appeal to give an extra Christmas gift this year

Chloe Whelan was living the dream – working at the BBC, mixing with high-profile actors, her life was going great.

However, at the age of 21, all of this stopped.

Chloe was sat having a meal with her friends and all of a sudden, she became very unwell. Chloe started to display symptoms similar to meningitis and she was rushed to hospital where doctors noticed a bleed on her brain.

Chloe spent hours in hospital, then started having seizures due to the bleed on her brain.

She almost passed away in the night.

For the next 10 years, Chloe was in and out of hospital having various procedures and tests done. Everything seemed to be going okay again. She went travelling to Australia and Thailand, became a teacher in 2007 and then met her husband.

Chloe said: "I went out clubbing, I drove, I was never medicated, there was nothing, no suggestion that I needed to live carefully."

Then, in 2011, Chloe awoke to 'two green men' in her room. Chloe had suffered a massive seizure in the night and an ambulance had to be called. The men were paramedics.

After this, Chloe tried to get on with life again. She got married, had her daughter in 2012 and then, the day after her daughter's baptism, she went for a routine angiogram. Again, everything changed.

During the routine procedure, Chloe noticed the doctors went quiet, then they started chatting and that's when a neurosurgeon told Chloe that she was very sick and couldn't go home.

Following the surgery done years earlier for her brain bleed, doctors discovered radionecrosis, this meant Chloe's brain tissue needed removing to save her life. Her seizures were caused by post-surgery scarring.

Her whole life changed, only now she fully understood why.

She said: "Radionecrosis is a condition many now suffer with, attempts to heal us cause serious harm, having seizures as a result of this is shattering."

When asked how she felt after being told she had epilepsy, Chloe said:

"I felt my previous life was just snatched away, I was told 'you're not going to do that now' it felt like everything was stolen from me.

"I remember being terrified. It's that fear, the fear of the medication, fear of going out on my own, being unable to drive. What if I collapsed? Can I be a real mum to my baby? It was lots of little things."

Chloe was afraid. She was worried that her life would never be the same again. She faced difficulty coming to terms with her diagnosis, she was no longer able to drive, her medication was causing unsettling visions – it was a massive adjustment.

Chloe also struggled with employment. She felt that her epilepsy pushed her out of a job and she found that it always held her back.

She said: "I've had to leave because of the way I've been treated. It has driven me out of where I have been."

Like so many living with epilepsy, Chloe didn't know where to turn. She hadn't received much signposting from medical staff and she felt at a bit of a loss.

"Then I joined Epilepsy Action," Chloe said.

"It was through Epilepsy Today that I was able to find out information about the different medications available.

"I asked questions, started making suggestions myself when I went to hospital."

Chloe said the information she found through Epilepsy Action was "invaluable", and she was able to understand her condition better.

Chloe also attended some of Epilepsy Action's Talk and Support groups and it was on these calls that she realised that there were other people like her. People living with epilepsy. People struggling to come to terms with what it all meant.

She added: "I went a couple of times, and it was really, quite an emotive experience, you very quickly realise there's so many different people, with a range of experiences.

"It's incredibly moving and empowering."

By being an Epilepsy Action member and attending the Talk and Support groups, Chloe felt more able to ask questions and get those answers she always deserved; she didn't let her epilepsy hold her back. Now Chloe is advocating that everyone asks those question and reaches out to the epilepsy community and stands up for their condition.

Chloe said: "It's about not being afraid to ask questions. You're not told about things in hospital, you're not given the information you need. I don't really know why, but there's a lack of signposting."

Now, Chloe says she feels much more accepting of her diagnosis, she's able to see herself as Chloe again and says she is "okay" with epilepsy being a part of her.

She added: "It's okay to be upset, it's okay to be angry about it, you can use that positively and talk about it.

"I can stand in the bus stop next to someone now and I can talk about it, and I don't feel like I have five heads.

"I think I am starting to find acceptance, and not be so afraid."

Like so many others, Chloe was left without answers, not knowing what her future might be like after a diagnosis of epilepsy.

Thankfully, through Epilepsy Action's membership community, Chloe was able to find acceptance, she was able to ask those questions and find other people who were also on that journey.

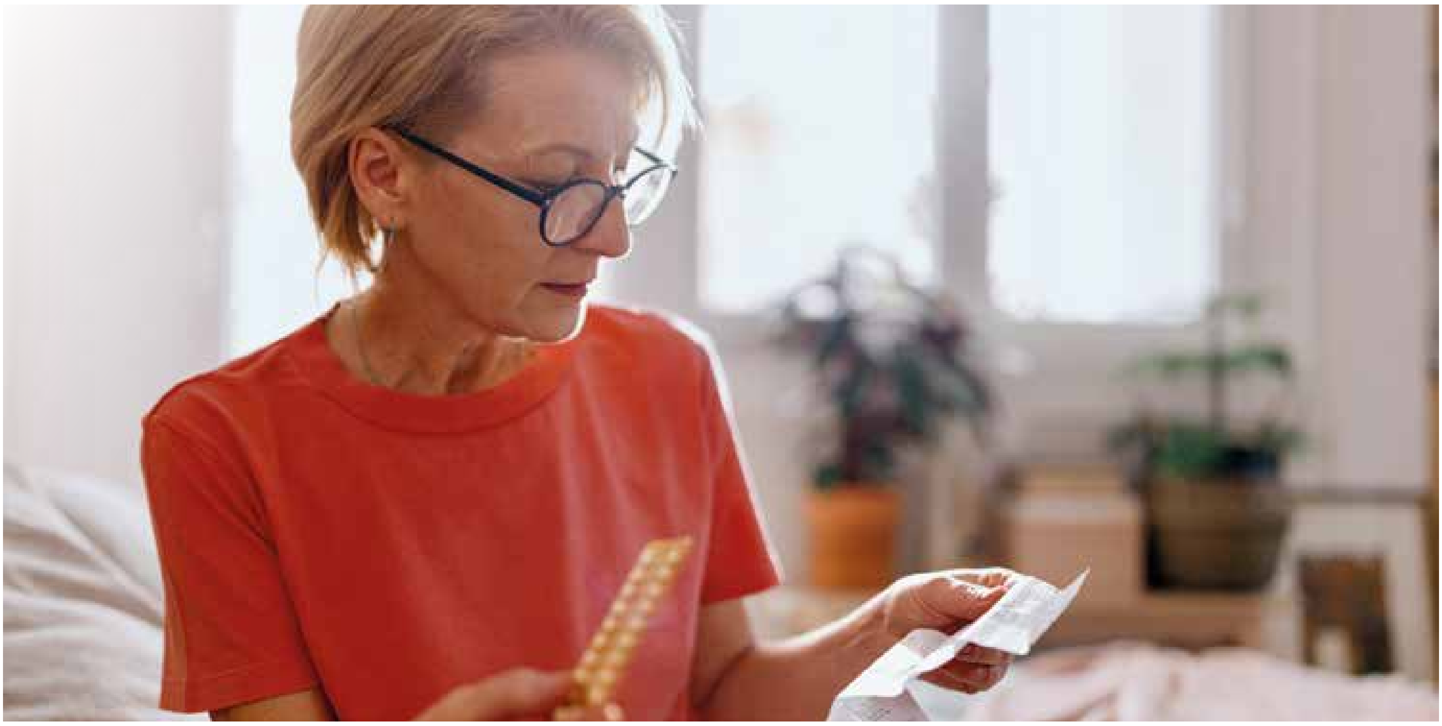
She doesn't let her past hold her back from the future.

We need to reach everyone like Chloe now more than ever. We need to bring them into the epilepsy community but we need your help to do this.

Please, if you can, give an extra gift this Christmas to ensure someone newly diagnosed today doesn't have to wait 10 years before they get the support they need, to find acceptance and feel less afraid.

Visit epilepsy.org.uk/christmas-appeal


Chloe and her daughter



Menopause unmasked

Menopause specialist Sian Rees answers some of the questions we've heard from people with epilepsy

Scan the QR code for more information or visit bit.ly/3UniexD

Around half the population will experience menopause at some point in their lives. It can often cause symptoms like hot flushes and brain fog, as well as affecting mood and mental health. For women with epilepsy, it can also affect seizures.

While we need more research on menopause, including how it interacts with conditions like epilepsy, menopause specialist Sian Rees says there is a lot that we can do to manage the impact of perimenopause (when you have symptoms of menopause but your periods have not stopped) and menopause.

As well as being a menopause specialist, Sian is a nurse, with previous experience as an epilepsy specialist nurse (ESN). She answers some key questions around menopause and epilepsy.

What questions do people often ask you in your practice?

People have a lot of questions about whether they can take hormone replacement therapy (HRT), and what the risks are of taking it or not taking it.

I also get a lot of questions around seizures – will menopause affect them, why has seizure frequency changed and how can I tell which symptoms are

Sian Rees

related to epilepsy and which are related to menopause.

Who might have their epilepsy affected by menopause?

Any female assigned at birth with epilepsy going through the menopause could have a change in seizure frequency. Seizure frequency can be affected in women with catamenial epilepsy (where seizures are linked to the menstrual cycle), as it is affected by their hormones. During the perimenopause, hormones fluctuate and this can change the seizure frequency.

Women who don't have catamenial epilepsy could also be affected, as symptoms such as night sweats, tiredness due to disturbed sleep, anxiety and low mood could affect seizure control, as these are common seizure triggers.

Also, women who have frequent seizures may start the perimenopause earlier than average.

What tips do you have to help people feel empowered to speak to their doctor about epilepsy and menopause?

My best tip would be to do research around perimenopause and menopause beforehand. There is a wealth of information on the Epilepsy Action and Balance websites. Completing and taking a copy of the Menopause Symptom Questionnaire can be very helpful.

Also, it can help to be aware of the National Institute for Health and Care Excellence (NICE) guidelines regarding menopause and shared decision making (when a person and their health professional work together to make decisions about treatment and care). Going armed with resources can make a big difference.

Many women attend multiple healthcare appointments before receiving adequate menopause treatment. But for women with epilepsy, the situation is more complex – the majority of GPs are not menopause specialists, and often refer patients with perimenopause/menopause and epilepsy to neurology, who in turn are also not menopause specialists.

By having robust information/guidelines, people will hopefully feel more confident to have a discussion with their GP.

What treatment options are there?

Woman reading a prescription that came with medicine pills for hormone replacement therapyHRT remains the first-line treatment for menopause symptoms. Non-hormonal prescription medication options include antidepressants, gabapentin or pregabalin, clonidine and oxybutynin, which can help to decrease hot flushes and night sweats. However, they do come with their own side effects, which can limit their use. Also, some of these are anti-seizure medications (ASMs), which may not be suitable for some women with epilepsy, as they may interact with other ASMs or affect their seizure control.

Cognitive behavioural therapy (CBT) is recommended in the 2015 NICE menopause guidance for menopause-related low mood. The new updated guidelines have not been published yet.

Some women may opt to try herbal medicines – there is a very small amount of evidence that St John's Wort or black cohosh may improve hot flushes and night sweats, however quality and potency may vary, and these may interact with medications. It is not recommended for people with epilepsy as it can interact with ASMs and affect seizure control.

There is a lot that women can do to help manage the impact of perimenopause and menopause, including eating healthily, avoiding too much alcohol and caffeine, staying active, managing stress levels, sleeping well and regularly doing enjoyable things. These measures are also very important for people with epilepsy to minimise triggers and their effect on seizure control.

What do you think needs to change in order to improve our understanding about epilepsy and menopause?

We still need to raise more awareness, even though this has improved greatly over the last few years.

More research is definitely needed, as the majority of studies have been done on the older, synthetic HRT, rather than the safer, transdermal/body identical HRT.

We also need compulsory training for GPs on menopause in general. Many GPs are working with outdated knowledge, so training would hopefully give them more confidence prescribing HRT for women with epilepsy.

More publicity is also needed on the Women's Health Initiative study, which was stopped in 2002 because of claims HRT caused breast cancer, which turned out to be flawed and incorrect. The media coverage around this has had a huge knock-on effect on women's health and HRT use.

ESNs are also in a difficult position, as many women go to them for advice regarding their epilepsy and menopause. I feel it is crucial for them to have conversations with their patients and to arm them with the resources and knowledge to empower them to discuss their concerns and wishes with their GP.

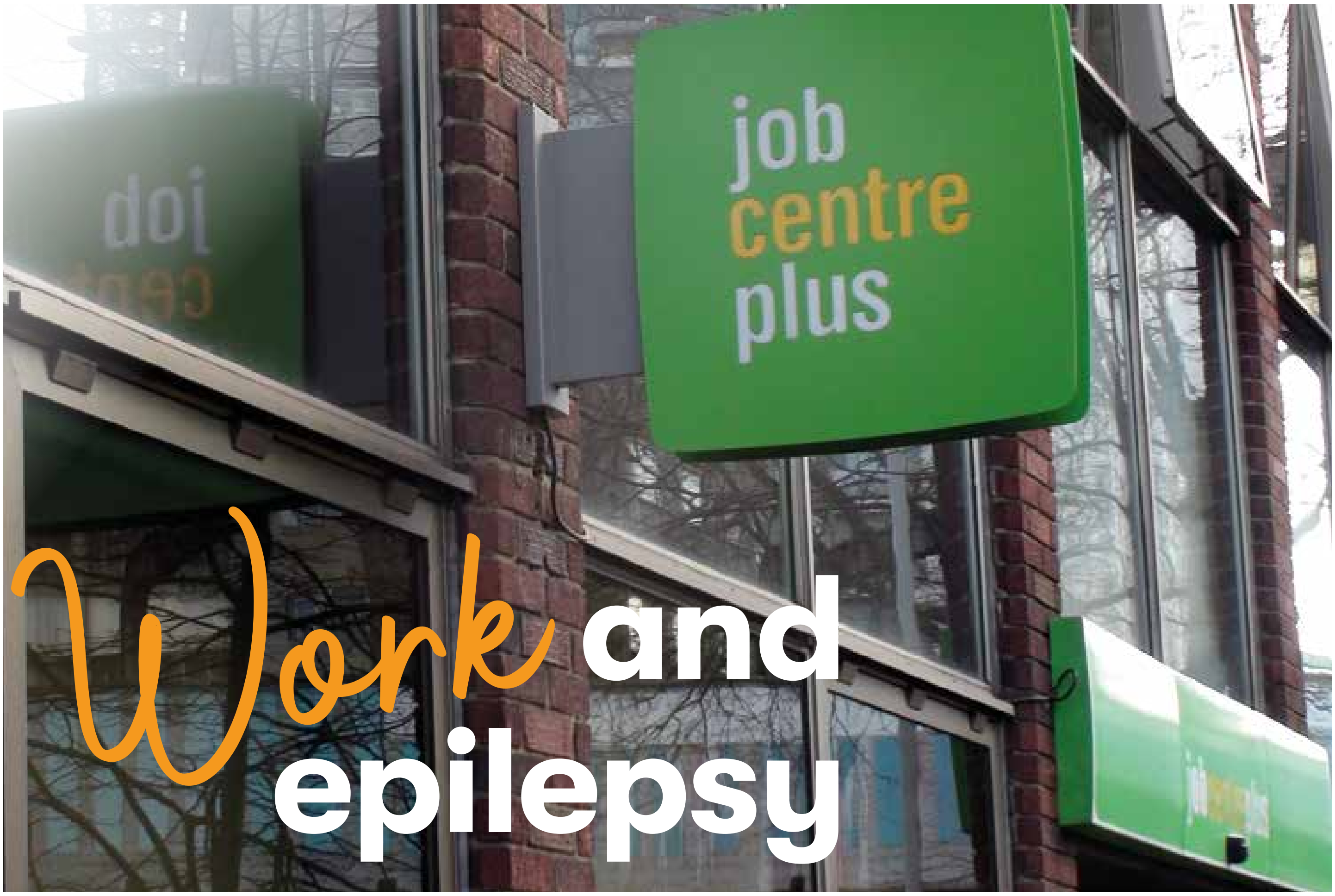
Can you tell me a bit more about your work in helping to set up the menopause support groups with Epilepsy Action?

Epilepsy Action set up an online Talk and Support menopause group, and invited me to be a part of in June 2023. I was there for advice and to provide patients with information about the perimenopause and menopause, and treatment. It was very informative for me to listen to everyone's journey, as they varied so much. Some were very positive some not so.

It surprised me how many of the women I spoke to had a change in their seizure frequency during this time. It reinforced how difficult it can be to differentiate between menopause and epilepsy symptoms, as they can be the same.

Tracking symptoms can be helpful at this time to see if there are any changes in frequency of symptoms or if new ones start.

It was also clear from attending this group how important it is to empower women with epilepsy to have the confidence to have a discussion with their GP at what can be a very difficult time.



Work and epilepsy

Murray, Beverley and Chloe share their experiences navigating the world of work while having epilepsy

Earlier this year, news stories suggested that people who are out of work were to blame for the spate of riots across the country. They said people out of work are 'lazy' and 'idle' and that's led to the recent unrest.

Many people with epilepsy can find themselves in this 'out of work' group. But they are far from idle, far from lazy and far from enjoying the situation they're in.

Here's just a few stories from people with epilepsy about work life when you also have epilepsy.

'Some people have thought roles aren't for me without any knowledge of my potential'

"I'm offended by the recent comments," Murray Goulder says. He's referring to statements made in the media in August about people who are out of work. Murray has epilepsy, a hidden condition, but one which can present challenges to everyday life. Epilepsy is so varied, that the situation will be different for everyone.

For people with epilepsy, it's often not a choice about whether to work or not. In some cases, the condition is too severe for people to work. In other cases, employer biases or misunderstanding around the condition can stand in the way.

Murray says: "I've had misconceptions and misunderstandings at work around epilepsy. Some colleagues in the past have considered epilepsy to be all about tonic-clonic seizures, to the point of being worried to work with me.

"Some people have thought certain roles aren't suitable for me without any knowledge of my potential.

"I have worked full time for 28 years, up to 63 hours a week. It's disgusting [to suggest if people are out of work, they're lazy or idle] and attitudes need to change."

'I was told no employer would consider me'

Beverley has a talent for art and wanted to pursue it as a job. But epilepsy caused problems along the way – from seizures during exams to having to go into teaching to earn a living, which she couldn't do with her seizures. Epilepsy made surviving as an artist almost impossible, requiring driving, the use of tools and chemicals or an initial influx of money to start up a career.

Facing this reality, Beverly remained far from idle, and began thinking of retraining.

She explains: "I stepped back and tried to work whilst considering which degree would be best. After 10 years of interviews for everything from toilet cleaner (chemicals too dangerous) to civil service, it was the Jobcentre who told me that I had to be 'realistic' and accept that no employer would consider me. Unemployment rates were already high, and the initial disability discrimination laws only helped people already in work, not people entering the job market, I was told.

"By the time I was 30, 'ageism' was a big topic, where anyone who'd studied after raising a child, for example, found it difficult to get a job unless they were very highly skilled.

"Voluntary work wasn't permitted then, because the attitude was that if you could volunteer you could work – employers' attitudes weren't considered.

"What still hurts now is that other people (including the Department for Work and Pensions) assume that if I do voluntary work I can get a paid job."

'I had a brain haemorrhage at 22 and was immediately let go'

Chloe always wanted to be an actress. She found school difficult but studied hard in drama and secured a degree course in London.

She says: "I secured roles in small student pieces, did jobs for the BBC, had a role in a tribute act and signed to a record label as part of a duo. We had just began promoting our track when I fell ill.

"I had a brain haemorrhage when I was 22 and was immediately let go from the tribute act, the record label and my rental accommodation, and I had to move home.

"I've been offered jobs that I couldn't take because they included travel that was too risky if I had a seizure. One was to work in London and Paris with fashion houses, models and high-profile clients."

Chloe now works as a teacher working with young people who are not engaging with education. But even having found another job she loves, Chloe still faces discrimination because of her epilepsy.

"I love the constantly changing environment, and I enjoy helping young people.

"I have had many comments made about my ability to work with my condition. I've heard colleagues talking about me amongst themselves. I've had a member of staff tell me: 'You shouldn't be alone with children'.

"I was also told by a head of school how disappointed they were that I 'had not disclosed' my condition with them sooner. I have always disclosed my epilepsy when starting a new job. On this occasion, it was a failing by HR to inform the school over a month before my start date.

"Staff won't sit near me in the staff room or meetings, and it can be so isolating.

"It's not just what people say either. I have had responsibilities taken away, such as taking children to the toilet or helping to change and feed them, I've been told that parents feel their children are unsafe in my care, despite parents who I see daily never expressing any concerns to me.

"I have even been suspended from a post after having a seizure. This happened in front of staff, after hours. One teacher said they were going to administer my Buccolam, which I have never had. This would have been so dangerous, especially without staff training. Luckily, I regained consciousness in time.

"There is little support in the workplace for me, and management often have no knowledge of epilepsy and put no effort into offering first aid training for other staff. I am several months into a new post at school, and this lack of training still exists. There continues to be both indirect and direct discrimination in the workplace and a fear of this neurological condition."

You can read more on Chloe's story on page 10.

Full of dreams and aspirations

People with epilepsy can have a really hard time trying to find, secure, and keep a job. The condition is so varied and so misunderstood, that people often face poor attitudes and misconceptions.

A recent post on the Epilepsy Action members' Facebook group showed that this group of people is full of dreams and aspirations. People wanted to become drivers, teachers, firefighters and fighter pilots, dreaming of joining the armed forces or going into nursing. Many have to work extra hard to achieve these dreams, and many don't get to realise them at all because of their condition.

Many people with epilepsy have to go above and beyond just to get their foot in the door. They deserve better support and understanding to help them get into work and thrive there, not to be blamed for the country's problems.

If you identify with Murray, Beverley and Chloe's stories, you are not alone.

There is more information on work and epilepsy at epilepsy.org.uk/living/work or you can simply scan the QR code

30%

The disability employment gap since 2010, according to the office of national statistics (ONS)

42%

The number of UK managers who wouldn't hire someone with epilepsy to save their company challenges, even though they know this is discrimination

60%

The number of people who report that they've been discriminated against at work

42%

The number of working-age people with epilepsy who are in employment

Behind the *helpline*

Scan for more information on contacting the helpline

Epilepsy Action's award-winning helpline is a keystone resource for people with epilepsy. But what's it like being part of the team? Helpline team leader David Thornton tells us more about the last year.

> **“It was so lovely to speak to someone who listened and understood”**

What a year it's been! In November 2023 we won the Helpline of the Year award, and since then, we've answered more than 10,000 of your questions. We're glad to have been able to help, and I'm really thankful to our staff and supporters for making it possible for us to have been there.

So, what's it like working on the Epilepsy Action Helpline? No day is the same. That isn't surprising, with epilepsy being such a wide-ranging condition. While many of you have contacted us about your medicine or work, for example, some have also asked about some less common topics – things like thunderstorms, Ironman challenges and Mozart. Common or unusual, all of your questions are important to us. We don't always have all the answers, but we do our best to help support and empower you with some information and options.

Besides the questions we hear again and again, sometimes a new issue will bring on a surge of new queries. As an example, the start of 2024 was challenging for many people with epilepsy, mainly because of widespread medicine shortages. We saw a more than 300% increase in enquiries about this compared to the year before, which was deeply concerning. While this has now settled somewhat, we know that getting your medicine remains a worry for many and we will continue to raise this with manufacturers and policymakers.

Our role is also more than information and advice. We're also a gateway into our other support services, such as our one-to-one Befriending service and our Talk and Support groups. While we love to try and get you options and solutions, we know that having ongoing support from us and from others affected by epilepsy can be invaluable.

We also have some exciting times ahead of us. You may have seen that we have secured funding to expand the helpline. We felt that with 630,000 people with epilepsy in the UK, and more than a million visits to our website every year, we needed to do more.

So, this exciting grant means that we can keep doing what we love to do while also expanding our offer.

Our live chat pilot has been very successful, and this funding will help us improve and continue this way to contact us. We will also look to welcome more staff to our team. This will help us to answer more of your questions and give us more resources to support people with more in-depth information.

We will provide a much more effective service for the growing number of people contacting us with mental health issues and queries around medication. We will look at how to expand this to other specialist topics in the future, and how we can support healthcare professionals by providing more first-stage support.

We're working hard behind the scenes to deliver this exciting expansion, but day to day, we are still here for you. Whether you are a person with epilepsy, a carer, friend or family member, a professional, or just someone who wants to know more about epilepsy – if you have any questions, we'd love to hear from you.

You can contact us on our freephone number **0808 800 5050**. Our helpline is open Monday to Friday, 8:30am to 5pm and Saturdays 10am to 4pm.

You can also complete our webform at any time, email helpline@epilepsy.org.uk, or chat with us on our website Monday to Saturday, 10am to 4pm.

Throughout the year, you have told us the impact our service has had, and we're very thankful for your kind words. Your wonderful feedback reminds us of the important work we are doing together with the epilepsy community. Whether it is being able to get your usual medicine, the confidence to challenge a decision, feeling more independent, or just knowing there's someone who will listen, it's brilliant to be able to help and empower people to change their lives for the better.

"It was so lovely to speak to someone who listened and understood, I really needed that."

We're really glad we've been here for you this past 12 months – and for the past 30 years that the helpline has existed. And we aren't going anywhere.

Meet the team

So, how do we run an epilepsy helpline? It takes a special blend of ingredients: a heap of empathy, a dollop of listening, a splash of epilepsy knowledge, and dash of personality. It's all baked into every member of the helpline team! Here's a bit more about the people on the other end of the line.

Diane

Diane is a fountain of epilepsy knowledge and has helped so many people on the helpline, which was recognised with a Lifetime Achievement Award from the Helplines Partnership.

Most rewarding moment – A young actor got a part in a high profile show, but was then turned away when they said they had epilepsy. I helped the production team understand about epilepsy, which led them to reverse the decision.

Favourite biscuit – Jam BN biscuits

Jess

Jess has made such a positive impact for people who were unfortunately really struggling this year. Jess is keen to support others, whether that's through the helpline or going out to Talk and Support groups to speak about all things epilepsy.

Most rewarding part of the role – Helping people overcome the challenges that epilepsy presents and finding solutions and options to help improve their day-to-day life.

Favourite TV show – The Walking Dead

Julie

Julie has been a champion for all things medicine shortages at such a crucial time. She's tirelessly got answers for people affected and supported the team with this.

Most rewarding part of the role – Ending a call knowing that you've had a positive impact, however small. That makes it all worthwhile.

Favourite film – Best in Show

Mags

Mags has not only been on hand to answer your questions, but has also been involved with researching and producing our accredited online epilepsy information.

Most rewarding part of the role – Being able to listen to people and link them to support and information they weren't aware of. We've a great team and if I'm stuck for answers to questions there's usually one of us that can help to find an answer.

Favourite TV show – Rebus (anything detective drama really!)

Rosie

You may have seen Rosie answering your questions live over on Instagram. In between providing support and information, Rosie is always looking for ways we can talk with other organisations to support and empower people more.

Most rewarding part of the role – Working with people who care so much about improving the lives of people affected by epilepsy.

Favourite TV show – The IT Crowd

David

Here I am! Epilepsy is close to my heart, as my wife lives with the condition. This inspired me to change career path, and I haven't looked back since. I enjoy leading a wonderful helpline team and was proud to be runner up helpline mentor of the year 2023 at the Helplines Partnership awards.

Most rewarding moment – Having a service user tell me that after the calling the helpline, they felt back in control for the first time since their first seizure. They felt listened to, and ready to get back their independence – starting with getting their driving licence back after now meeting the driving rules.

Favourite biscuit – Chocolate Digestive


David (right) with ex colleague Tom

We need to *talk*

Joanne Doody's son Peter died from sudden unexpected death in epilepsy (SUDEP) in May 2019 at the age of 21. Joanne shares why SUDEP awareness is so important

Peter was our first born, big brother to Harry and loved deeply by many. He was someone who transcended individual friendship groups throughout school. Peter was so fondly thought of because of his kind nature that he fitted in everywhere.

He was caring, thoughtful, sensitive and funny, and he wanted to make life better for others whenever he could.

Peter was also a talented musician and music producer, and there wasn't much he didn't know about technology! He had a wonderful enquiring mind.

It is engraved on his headstone that he was too beautiful for this earth, and he truly was. We have always preferred to say, however, "Peter is", not "was". We believe fervently that Peter still exists but not in the way we long for.

Peter was 17 years old when he was diagnosed with front temporal lobe epilepsy and died when he was just 21. Aside from the limiting support we were able to give during those four years, he received minimal support elsewhere.

Stop SUDEP silence

The first time we became aware of sudden unexpected death in epilepsy (SUDEP) was when we were informed of his cause of death. At no point while Peter was alive did any of the clinicians involved in Peter's epilepsy care mention SUDEP or provide us with any SUDEP literature.

In a recent film I made with the aim to stop the SUDEP silence, I refer to and acknowledge a considered unconscious bias around this. Would I really have wanted to know about SUDEP when Peter was alive? The answer is unequivocally yes.

Of course, we would have been fearful and anxious as would have Peter, but, ultimately, we would have been empowered to help keep him safe. Any feelings of anxiety we may have felt at the time pale into insignificance compared to the trauma and finality of losing Peter forever.

> **“If we had known about SUDEP from the start, we all would have understood the seriousness of his condition”**

If we had known about SUDEP from the start, we all would have understood the seriousness of his condition. We believe it

Peter with his mum Joanne, dad Andrew and brother Harry

would have made a significant impact on medication adherence, for one.

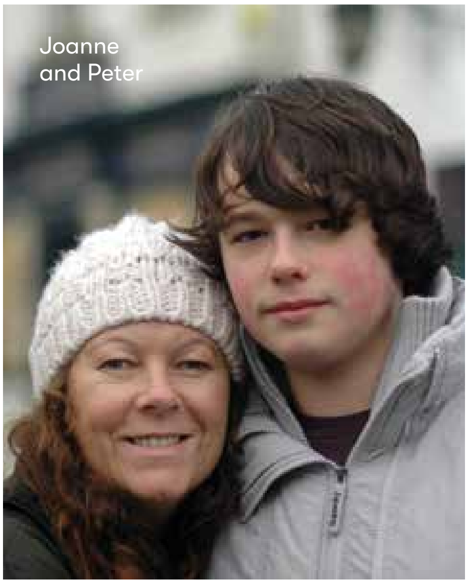
It would have also enabled us, as a family, to take safeguarding measures knowing about SUDEP and the risks associated with sleep seizures. We would have made adaptations to his sleeping arrangements and used a seizure detection device and an anti-suffocation pillow.

We would have also had a far better understanding of Peter's vulnerability whilst being away from home at university.

'You matter'

What we would like to see happen in the future around SUDEP communication is for people living with epilepsy to be informed about SUDEP in clear terms. To not avoid using the word SUDEP, and what that means, by only talking about generic 'risk'.

We are often asked how clinicians should deliver the SUDEP conversation. First and foremost, SUDEP just simply needs to be spoken.



Joanne and Peter

Similarly to discussions oncologists and cardiologists have with their patients, the informing of SUDEP will be extremely difficult and challenging, however this information must be given. There is no easy way, it is as simple as that. It just takes courage, kindness and time.

My personal opinion is that people living with epilepsy are among the most courageous. I can't even begin to imagine how it must be to manage this complex neurological condition.

From personal experience being Peter's mum, and in the work I have done these past five years running the epilepsy charity, the Peter Doody Foundation, I feel that people living with epilepsy are not getting the optimal care and support they should.

These past two years I have been making a film titled 'Stop SUDEP Silence' which was released on the 8th of July this year on what would have been Peter's 27th birthday. The film includes accounts of parents who have lost a child to SUDEP, parents of children living with epilepsy, clinicians and someone living with epilepsy.

People don't like talking about SUDEP. But we have to.

You matter, unbelievably so.

Such a 'mum' thing to say I know, but do take your medication as prescribed. Ask your clinicians about SUDEP and the risk factors. Ensure you are given information relating to seizure detection devices and safeguarding aids. Understanding fully about your diagnosis and SUDEP can be empowering. It will help keep you safe.

For more information about the Peter Doody Foundation, visit peterdoodyfoundation.org.

Managing the risks

Am I at risk of SUDEP?

Epilepsy Action's information says: SUDEP is rare, affecting around 1 in every 1,000 adults with epilepsy each year. This figure is for people with epilepsy in general. Your individual level of risk will depend on what type of seizures you have and how well-controlled they are. No one can say exactly who will be affected by SUDEP, but research has shown there are some things that can put you at a higher risk.

Risk factors of SUDEP

The risk factors for SUDEP include:

- Tonic-clonic seizures
- Sleep seizures
- Missing doses of seizure medicines
- Alcohol or drug dependency
- Living alone

What can I do to reduce the risk of SUDEP?

- Take your seizure medicines every day as prescribed – speak to your doctor if you have any concerns with your medicines, such as side effects.
- Try to avoid situations that could trigger your seizures, such as lack of sleep, drinking too much alcohol and stress.
- If your seizures are not fully controlled, ask to be referred to an epilepsy specialist for a review of your epilepsy.
- Keep a seizure diary to help you track what is happening.
- Think about sleeping and living arrangements – having someone there could help if you have a seizure. If you live alone, a safety check plan could help.
- Consider alarms and monitors, safety pillows and sleeping on your back.

For more info, visit: epilepsy.org.uk/info/sudep-sudden-unexpected-death-in-epilepsy

Craig and Jo with their son John

A life full of love

Jo Scott lived life to the fullest, championing openness and awareness of epilepsy. Her mum Caren and husband Craig share Jo's story and how they're continuing in her footsteps.

Jo Scott had a lot of loves in her life – music, teaching, raising epilepsy awareness – but the greatest one, and one that made her happiest was her family.

"Jo was always smiling. She was a gentle, kind young lady with so much love to give," her mum, Caren, says.

She was the youngest of three children, and spending time with her siblings, grandparents, nieces and nephews was the "best of times".

"But above all," she says, "she loved her husband Craig and her now three-year-old son John."

To Craig, Jo was the "centre of our little family".

He continues: "A brilliant mum, she was patient, loving, caring and unselfish. She always thought of everyone else before herself and was loved by everyone who knew her.

"Having a child was everything Jo ever wanted, and the love she had for our son John was endless. The bond they had was special and she was never happier than when the three of us were all together."

The family loved to go on weekends away, especially to the seaside. "Jo was not in any way 'high maintenance' and a weekend at the seaside with fish and chips and a whippy ice cream was perfect for her," says Craig. "She loved the sea and paddling with John was always a highlight."

Jo also attended church and put her musical passion and talents into it, becoming head of music. When John came along, she gave this up in order to be able to attend church with him.

Lived life to the full

Jo had her first seizure in 2000, while she was still at school. She was diagnosed with photosensitive epilepsy, and later developed juvenile myoclonic epilepsy. There wasn't much awareness of epilepsy at her school, as they hadn't recognised Jo's first seizure as one, but the family soon figured out what had happened when a friend of Jo's described what she had seen.

While it can make things challenging and complicated, Caren said Jo never let her epilepsy hold her back. "She lived life to the full, as much as she could.

"Whilst at secondary school, she went on three trips abroad with the music department and one with the history department. She was a Girl Guide and a Young Leader, and she went camping often.

"She also swam regularly, passing all her grades and continuing to take her life saving awards. This is why she was always so keen that John should learn to swim, and she first took him at six weeks old."

Jo also travelled by herself at 16 to visit her cousin in London, and after her A Levels, she also went to Spain for a week with a friend.

"All of these trips could be anxious times for the family," Caren adds, "but we would never let on or try to stop her living her life to the full."

Jo went to university, with a view to becoming a music teacher. There, she became involved with HCPT, a charity offering holidays to Lourdes in the south of France for disabled and disadvantaged people. She went to Lourdes three times with the group, taking disabled and vulnerable children for a week away each time.

"She could see the benefit first hand that it had on these young people, and she found the whole experience both cathartic and rewarding," Caren said. It became a life goal for Jo to work with children with additional needs.


Craig and Jo's wedding


Jo and John

A lifelong dream

While Jo had a positive attitude to life with epilepsy, she did experience ignorance around the condition in her life. On one occasion, she had to defer her start at her final teaching practice by a day after having a seizure. Her mentor "did not want to understand, and made life very difficult for Jo, and she could not complete the placement" Caren remembers. Luckily, after this, she started a new placement, where she had "the most rewarding time".

While Jo had a teaching job that became stressful and "toxic", one of her traits that Craig describes was being "relentlessly stubborn, though she termed it 'strong-willed'. When she set her mind to something, she was tenacious and hard-working."

One of the things she set her mind to was teaching music, and teaching children with special educational needs. "She always championed disability and working with children who were often misunderstood or just needed love no matter how difficult the situation suited Jo's patient nature and ability for unconditional love," Craig explained.

Despite previous challenges with work, Jo realised this lifelong dream shortly after John was born. And, while there, Jo did a tremendous amount to spread more awareness and education about epilepsy.

Caren says: "During National Epilepsy Week 2023, she asked if she could do some work around epilepsy with the students to raise awareness. They watched a video from Epilepsy Action, talked about seizures, created posters and discussed what they would do if Jo had a seizure.

"As there were only six students in the class, they were all given a job. Throughout that day, she would suddenly say: "Miss is having a seizure". She would get on the floor and the students would leap into action.


John's birth

"They would practice moving furniture, making sure she was safe, putting her in the recovery position once the 'seizure' had ended, and calling for help.

"They were all really sensible and one can only hope that this is something that will stay with them, the knowledge of what to do and not to be frightened to help."

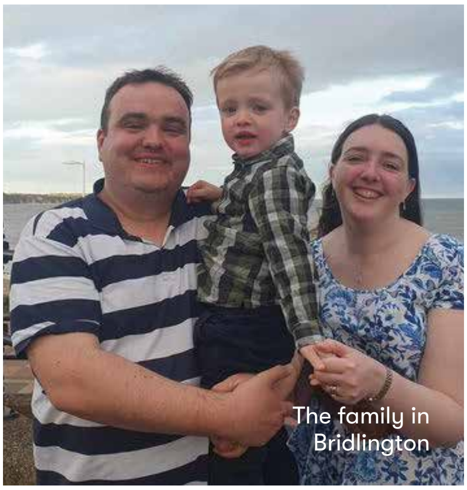
This had been such a success that Jo was invited to undertake some activities with the whole school. Craig says this was a "highlight of Jo's professional career".

Caren adds: "Elements Academy were a breath of fresh air in the way that they saw beyond epilepsy to Jo, the person, and Jo, the teacher with so much to give her students. We can never thank them enough for fulfilling her dream."

Jo's legacy

Jo died in May this year from what her family believe was sudden unexpected


Jo was always open about her epilepsy


The family in Bridlington

death in epilepsy (SUDEP). It came out of the blue and brought the family's life "crashing down", Caren says.

Stress and tiredness had been triggers for Jo's seizures. When she first met Craig in 2015, her seizures were one every six months, but over time, circumstances meant that they became more frequent and lasted longer.

The stress from her previous job, and changing epilepsy medication when she became pregnant meant her seizures worsened. While the new medication made her feel less tired and gave her a better quality of life, it did not improve her seizures. On top of that, COVID had made contact with her neurologist increasingly difficult, Craig says. At their most frequent, her seizures were happening every six or seven weeks.

"Jo was always bullish about the reduced side effects of her medication dosage as worth the risk of seizures, but whether more input from professionals might have shifted that balance we will simply never know.


One of Jo's biggest dreams was to be a mum

"Jo was always very conscious of the fact that seizure frequency and medication side effects was a balance that involved an element of risk, and this, as her husband, was always difficult to accept. Jo's seizures were always a worry, but she knew herself how ill and tired higher medication doses made her, and her seizures were just something, to an extent, we had to live with.

"Jo was always very aware that dealing with her seizures was something that I generally had to do ("well I'm out of it" was her usual response!) but it was part of who she was. I knew Jo had epilepsy before we met for the first time and, while learning how to deal with seizures and post seizure care was at times a very steep learning curve, it was just part of our lives.

"We had mitigations in place to manage caring for John as a baby (things like Jo never doing bath time alone, and changing nappies being done on the floor). As such, Jo was able to be a 'normal' mum. The worry about seizures was ever present, but, as with so much in our lives, it was a case of mitigating and balancing risk."

When Jo passed away, she had been putting John to bed in the evening. "Our wonderful son simply stayed with her until Jo's mum arrived," Craig says. Caren adds that John was not distressed by this at all, and simply said: "Mummy is sleeping."

Craig continues: "Jo usually sorted John on a morning due to my shift pattern, but, unusually, that morning we had done so as a family. We hugged together as a three before they left for their taxi."

Jo was an active supporter of Epilepsy Action. She would answer questions, complete questionnaires and join discussions on social media. Jo and Craig took part in an Epilepsy Action survey about pregnancy when they were expecting John, and she campaigned to her local MP for more epilepsy specialist nurses. She took part in as many fundraising activities as she could.

During National Epilepsy Week this year, five days after Jo's funeral, the whole family took a trip to Bridlington that they had pre-planned – something they did often, and Jo loved to do. While there, the family decided to do the Epilepsy Action Virtual 10k, "to give us focus". They aimed to raise £1,000 but ended up raising £5,290 – an amount they're confident Jo would have been "blown away" by.

Jo's whole family has been taking part in fundraising events and sharing Jo's story to continue her incredible work raising awareness and spreading knowledge about epilepsy.

Craig wants to see more research into epilepsy to prevent others from going through what Jo's family are going through.

He says: "Life without Jo is impossible to describe. I am now a husband without a wife and my son is a boy without his mummy. We are coping the best we can with the support of friends and family, but life has become unrecognisable in so many ways. Our wonderful boy is Jo's legacy, and we are all immensely proud of him.

"The more research and understanding that can be secured about epilepsy and how to treat it more effectively, the better."

Caren's message, through all of this, is ultimately beautifully life-affirming. She says: "We could have wrapped Jo up in cotton wool for the last 24 years, had someone with her at all times, watched her constantly. But who would that have helped? Certainly not Jo, she would have hated that.

"She lived a full life, albeit with a few minor adjustments. She fulfilled her dreams, reached her goals, she just wasn't able to live the dream for very long.

"Live your life, reach for the stars, fulfil your dreams and raise awareness along the way."

For more information on SUDEP risks and how to reduce them see page 19.

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Take on the *challenge*

With Bradford 2025 sign-ups open, Martin Sellors tells us how he discovered running nearly 10 years ago and how wanting to challenge himself led him to the Bradford 10k

> **“I do find both physical and mental benefit from the exercise, as well as getting to meet and socialise with other runners”**

Martin, 66, has lived in Bradford all his life. He has been married to his wife, Andrea, for 32 years and up until July 2021, he worked as a Management Accountant for Vantage Motor Group based in North Yorkshire. Martin likes going to live music gigs (“mainly Indie music”), motor sport and real ale. As well as this, he also discovered an enjoyment for running by taking a punt on a 5k parkrun, and he has never looked back.

He says: “I was never really interested in sport or running at school, but it was a friend who ran parkrun that got me into running. It was back in March 2015 that I went to Lister Park in Bradford for my first parkrun, and what I enjoyed was the inclusivity and the friendly welcome at the event.

“I have now participated, both running and volunteering at more than 370 parkrun events at different locations in the UK, the Netherlands and South Africa. I now look forward to my Saturday morning ‘5k fix’.

“After running 5k distance for two years, I thought I would look for another challenge and saw the 2017 Epilepsy Action Bradford 10k advertised. It was with apprehension that I entered, as I had doubts about whether I could manage the distance, but was pleased to not only complete the distance, but also in a time of under one hour. I found the event extremely well organised on closed roads and with plenty of support. It was well marshalled and there was the bonus of a medal and T-shirt. Since then, I have participated in the event six times. I ran the event in March 2019, looking for a sub-one hour time, and was gutted when I saw my result was 01:00:01!

“I ran the 2022 and 2023 Bradford Epilepsy Action 10k races and also the 2024 Virtual 10k, so I have a collection of all the T-shirts and medals.

"I didn't have epilepsy myself when I first signed up. However, in December 2020, I was rushed to York Hospital following a cerebral venous thrombosis (a blood clot in the brain) whilst driving to work. There, I was diagnosed with epilepsy, having symptomatic complex partial (now called focal impaired awareness seizures) and secondary generalised (spreading to both sides of the brain) seizures.

"Prior to this I had been in good health generally, so all this came as a bolt out of the blue! Thanks to the quick actions of my work colleagues in contacting the ambulance service, and to the treatment I received at York Hospital for four days as an in-patient, I am lucky that the outcome was not worse.

"I took early retirement due to ill health in July 2021, as I had to surrender my driving licence for 12 months and also wanted to be free from the stress and pressure of work, especially around the time of the pandemic. I was prescribed levetiracetam and have annual medical checks. I am pleased to say that I have not had any seizures since.

"I now do voluntary finance work for BackCare charity and as a Group Treasurer for Guide Dogs. I am also signed up as a volunteer for the Bradford City of Culture 2025, all of which keeps me mentally active.

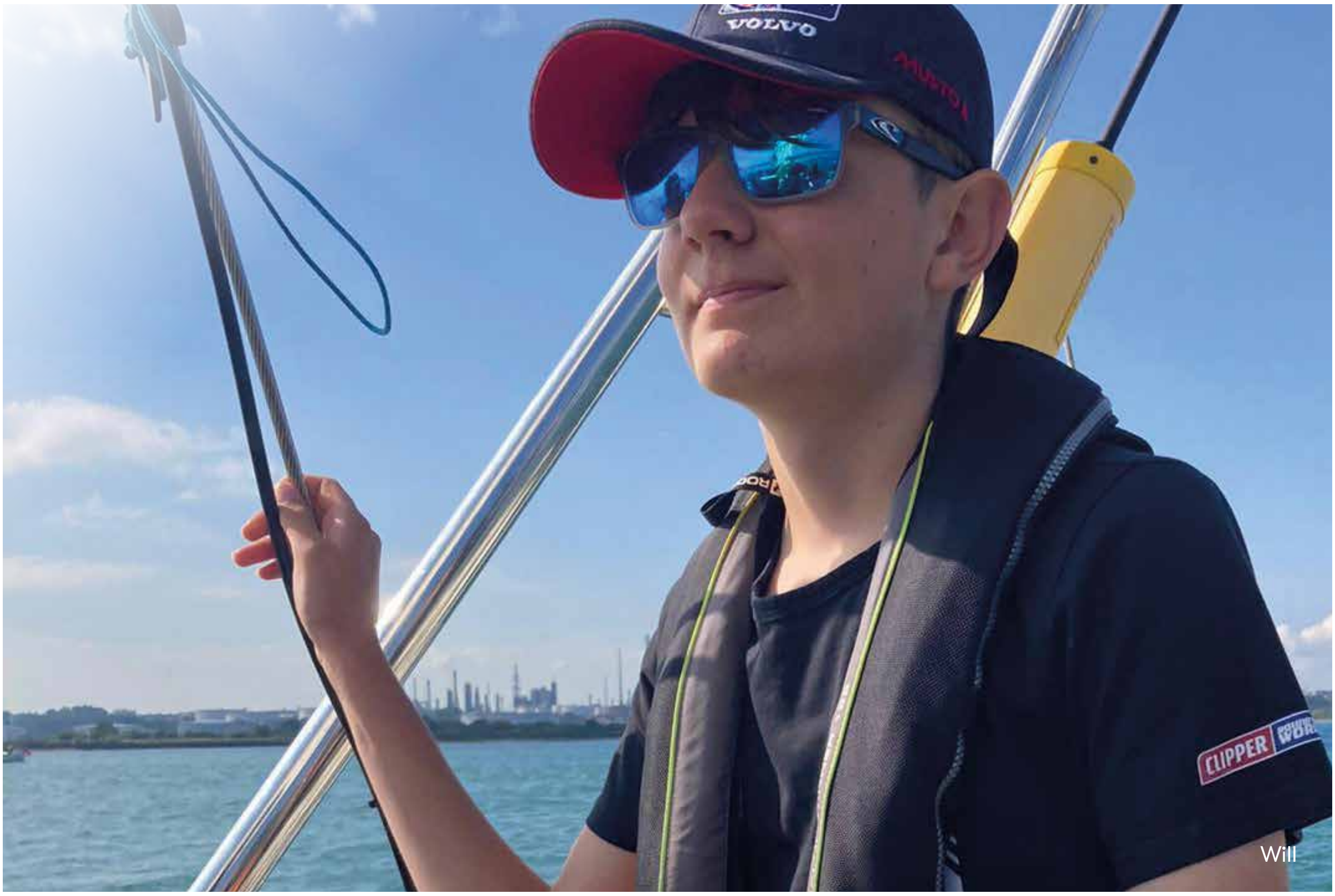
"I joined Queensbury Running Club in 2022 and, since joining, have run other 10k races. This year I ran my first half marathon, the Great North Run, raising funds for the Stroke Association. I find that although I am not a fast runner, I do find both physical and mental benefit from the exercise, as well as getting to meet and socialise with other runners. There is also the benefit to charities, such as Epilepsy Action, BackCare etc, in raising essential funds.

"When I saw that entries for the Bradford 10k 2025 were open, I signed up immediately. I am excited for this in June. Hopefully it'll be nice weather in the year that Bradford is City of Culture, and also the 75th anniversary year of Epilepsy Action."

The Bradford 10k is a race for all running abilities, whether you're looking to smash your existing PB, or have a go at the 6.2-mile distance for the first time ever. All are welcome!

You can sign up now by visiting epilepsy.org.uk/Bradford or scanning the QR code

Martin got into running through trying out parkrun


Will

A sense of *freedom*

Will's passion for sailing ended up in jeopardy when he was diagnosed with epilepsy. But he was determined to change his fate

Eighteen-year-old Will lives in Bournemouth, Dorset, with his mum, Cherie, and his dad, Dan. Adventuring is in the heart and soul of the family. They all love to travel and get out on the water. Will is part of the scouts and attended the World Scout Jamboree in South Korea in 2023. When he's not out on the water sailing, he's travelling abroad "to watch the America's Cup (the oldest international sailing competition) in Barcelona," Cherie says. "He's a massive fan!"

Will started sailing through an RYA 'Push the Boat Out' event, aiming to get people to try out sailing and windsurfing. "None of my family sailed, but I loved it and quickly got hooked," Will explains. "Sailing feels like all my worries vanish and I am in complete control. I love the feeling, even in rubbish weather. It's a real sense of freedom."

And then everything changed.

'Couldn't see past my diagnosis'

Aged 12, Will got a bleed on his brain. This caused a brain injury that led to him developing epilepsy. Suddenly, life felt "dark, really dark", Will says.

"It felt like everything I knew in life was over and people couldn't see past my diagnosis. I was miserable."

This was a difficult time for Will's whole family. For Cherie, it was "terrifying".

She adds: "I had no idea how to manage and not only was I dealing with the medical side of his diagnosis, his mental health spiralled as well. It was incredibly hard, but things slowly got better with the support of Will's epilepsy specialist nurse (ESN) – she's amazing!"

The family's world had "turned upside down", Cherie explains, with a lot of change and a new norm to get used to. And one of the most difficult parts was getting Will back to the activity he loved.

She says: "People had not really heard of epileptic sailors and were, understandably, risk averse at first. It took a lot of persuading, but he's now the example that's changed the narrative. Epilepsy should not be a barrier."

Will adds: "When I was first diagnosed, no one would agree to me sailing. There wasn't much history of epileptic sailors, and everyone was really fussy.

"I had to really fight to get back on the water, but once I did, people started to see my ability – and past my disability – and I was determined to compete and prove that you are more than your diagnosis. It took some changes and additional equipment to keep everyone safe."

'Feeling safe and supported'

The RYA's Sailability programme offers information for disabled people wanting to get out on the water and helps sailing clubs to support these activities.

Sailability manager Joff McGill says: "The RYA's Sailability programme is all about people feeling safe and supported on the water so that they can enjoy all the benefits it has to offer, from being more active, to connecting with others.

"We are a thriving community committed to creating a level playing field and an environment where everyone feels welcome, safe and enjoys their time sailing.

"Epilepsy is different for every person and so, for those looking to start sailing, it all begins with having a really good conversation between you and the people involved at your local sailing organisations.

"We know about sailing and what this will involve, whereas you know about the support you need. Between us, we can come up with a plan for you to pursue your sailing goals, but the key is working out what is right for you."

This is exactly what Will did. "At first there were a lot of challenges! People were very anti my return and there were lots of conversations between sailing clubs, medics, my ESN Kat (she's a legend!) and the RYA. But people soon came round and, as long as I followed the strict rules, I was able to go out on the water."

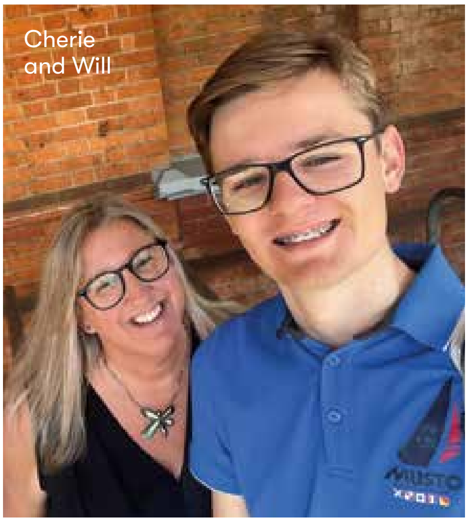
Cherie added: "We started with a risk assessment and some planning discussions with the sailing club. It was important that we all agreed how to keep him safe, and Will agreed how to keep himself safe.

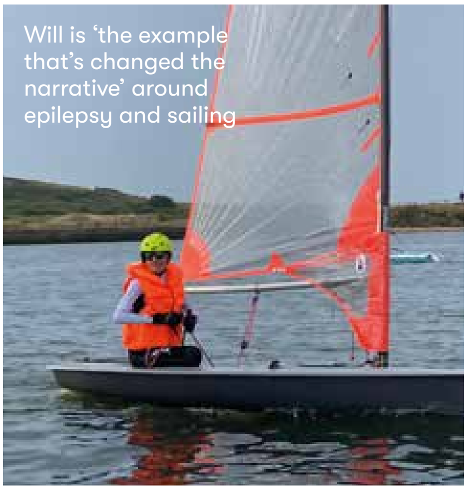
"He wears a helmet on the water (but that's good practice regardless) and he also has a life jacket instead of a buoyancy aid. In the case of a seizure on the water, if he fell in, the life jacket automatically flips him onto his back and cradles his head.

"His sail has a small indicator on it so the safety boat can keep a close eye and get to him quickly if needed."

While Will says these things made him look different from his peers, his attitude to that was: "why fit in when you can stand out!"


Will was diagnosed with epilepsy at 12


Cherie and Will


Will is 'the example that's changed the narrative' around epilepsy and sailing

'Like coming home'

After what Will calls a "rough couple of years" of trying different epilepsy medicines, he got offered brain surgery at Great Ormond Street. This was successful and he has been seizure free for nearly three years now.

For Will, sailing is not just a hobby, it's a huge part of his life. He says: "A few months after my diagnosis, I got a special dispensation to still compete in the World Championships, so my family drove me and my boat to Sweden. Despite feeling rubbish, I competed. I was determined not to be 'poor Will'.

"Since then, I have sailed both with Sailability and in mainstream competitions. I was RYA Youth Sailor of the Year and, thanks to Tall Ships Youth Trust, I have had the opportunity to sail some amazing boats, learn some new skills and even become their youth ambassador. They embraced my diagnosis and showed me it was about my ability rather than my disability.

"A real highlight for me now, though, is giving back. I love teaching others to sail and I have been lucky enough to support both mainstream and Sailability events. I am now a Senior Instructor, Powerboat Instructor and I have my Day Skipper qualification. I'm now at university and part of the sailing team. It's a great privilege to be able to empower others to enjoy the water whatever their circumstance."

Being able to see Will getting back to what he loves has been "life-affirming", Cherie says. "He was in a very dark place after his diagnosis and the freedom of being back on the water has made a really positive turn. I am so very proud of his determination and resilience and I'm a happy mum, watching him do what he loves."

Will adds: "It's like coming home. I'd recommend it to anyone. There are ways around the diagnosis and, as long as you work with the sailing club or organisation, with a few adaptations, you should be good to go. If not, send them to me!"

There is more information on epilepsy and sport, exercise and leisure activities at **epilepsy.org.uk/living/daily-life/sports-and-leisure**.

You can find places on the water near you online at **find.rya.org.uk** including venues part of the Sailability programme by filtering the service to Sailability centre.

Brill big sister

Ruby is the winner of the September Epilepsy Star award for being a 'calming presence' in tough moments for her brother, Leo.

Words: Emily Stanley

Nine-year-old Ruby has won September's Epilepsy Star Award. Ruby is an amazing big sister to her six-year-old brother Leo, who has several disabilities and was diagnosed with epilepsy last year. She supports her brother, who has autism, on a daily basis and always puts him before herself. Ruby's dad Josh, shares her story:

"Ruby has always been caring, loving and puts everyone before herself. I think this has come from having a brother with special needs. Every day, she plays a crucial role in his life, offering support and understanding to help him. She uses a calm and soothing voice that helps calm him. She is patient, assists him and is able to read his cues when he wants something or needs help; she knows when he's feeling overwhelmed or anxious and can help him regulate.

"Her depth of understanding allows her to communicate with him in ways that transcend words, using gestures, expressions and even sounds that resonate with him. She is a calming presence in moments when he struggles. She often holds his hand or gives him a reassuring hug, helping him feel secure. Leo feels so safe with Ruby, he often becomes upset when she leaves him so Ruby is always wary of what she is doing and if Leo is going to be okay when she is not there.

"If Leo has a seizure, Ruby knows exactly what to do. Her job is to time the seizure and get shoes for everyone to be able to get Leo the right medical help he needs."


Ruby


Ruby, Josh and Leo

Josh continued: "I am incredibly proud of Ruby for winning the star award. She demonstrates a level of maturity and understanding beyond her years. She not only engages with him in meaningful ways but also knows how to respond during difficult moments, particularly when he has seizures. This award is a testament to her kindness and dedication, and it highlights the amazing bond they share. I couldn't be happier to celebrate her accomplishments and the positive impact she has on her brother's life."

Ruby was nominated by Josh's friend Charlotte. She wanted Ruby to be recognised for the incredible daily support she provides Leo.

She said: "Ruby is amazing at supporting Leo. She adapts how she plays with him, protects him and even sacrifices partaking in certain activities that other children her age may take part in, because of her younger brother's disabilities.

"To Ruby: the unyielding support, the adaptions and the sacrifices you have made for Leo are incredible. Nevertheless, we recognise Leo's conditions' impact on your life and never feel as though you are unable to take some time out to take care of yourself. As someone with epilepsy, I know you are just as affected by Leo's conditions as Leo, just in a different way."

Little life-saver

Gwen was given the July Epilepsy Star award for her 'incredible' understanding of epilepsy and support of her mum, Imogen.

Words: Emily Stanley

Nine year-old Gwen Harries has been given an Epilepsy Star award being an "incredible" support to mum Imogen, who has epilepsy. Imogen says Gwen "saved her life when she was having a seizure" and has an "incredible" understanding of epilepsy for her age.

Imogen was diagnosed with epilepsy in 2020. The day she had her first seizure, she was due to meet a friend. Then everything changed. She tells her and her family's story.

"I still get overwhelmed with emotion when I think about my epilepsy journey. I was found on the landing having a seizure. It came out of nowhere. From there, I had clusters of seizures until I was diagnosed with epilepsy in 2020." says Imogen.

Imogen has both absence seizures and tonic-clonic seizures. Despite being just nine years old, Gwen has been an incredible source of support and help for her mum. When Imogen had a seizure at home, Gwen knew exactly what to do. She stayed calm and called 999.

Not just this, but when Imogen happened to have a seizure at her school, Gwen was better prepared to deal with it than most of the adults around her.

"Gwen is one incredible girl. For her age, her understanding of epilepsy is incredible." Imogen says.

"Gwen saved my life when I happened to have a seizure at home with her. She called 999, she was calm in that situation. When the officer came, they had to get through the window as the door was on a chain. Apparently, Gwen told them: 'Be careful! Don't break my mum's blinds!', but she was really calm. She put our dog in the kitchen to give them space.

"I also had a seizure at her school recently. The teachers were taken aback at how calm she was, and how well she dealt with it. She knew she had to phone her father, time the seizures and count how many seizures I had.

Imogen says her diagnosis didn't just change her life, but her family's, too. But they worked together to put measures into place for all of them, and are now stronger for it.

"I was very concerned about Gwen and her brother Reuben, how they would cope with seeing me having a seizure" she explains.


Imogen and Gwen

"But my partner and I sat down with them, we were honest with them both. We explained what epilepsy was, how I would tell them if I was about to have a seizure or what to do if I wasn't aware I was going to have one."

Imogen taught them the basics of tonic-clonic seizure first aid, and how to help her in case she had one.

"I told them what a seizure would look like. If they happened to see one, taught them to move anything that could hurt me, not to try and put anything in my mouth and to just talk to me. They know to call 999 if they're by themselves or if it's longer than five minutes, and to get in touch with their dad as soon as they can."

Coming to terms with her diagnosis was a tough journey for Imogen. She says she still struggles with some aspects, especially with her memory and with the anxiety of not knowing when a seizure is going to happen. She says the Epilepsy Action counselling service was a massive help in her journey.

"I didn't realise how much I was trying to be strong, until I wasn't myself mentally.

"I had counselling with Epilepsy Action, and now I know I can say 'I don't need to be strong every day, and, most of all, I can't control the uncontrollable'," says Imogen.

Imogen says they are "incredibly lucky" to have Gwen in their lives.

"Gwen has so much kindness in her heart and would help anyone. Gwen, I am so proud of all you have achieved in the nine years you have walked this Earth. I'm looking forward to when you get your double decker bus, and we all go on adventures together. I love you to infinity."

Accepting her award, Gwen said: "It feels absolutely awesome! It doesn't feel real at all! I want to pat myself on the back. It feels epic!"

To read more awards winners' stories like this, visit epilepsy.org.uk/star-awards

What's *new?*

We share some recent advances in epilepsy research

This issue's research news is pretty wild – quite literally. We share two studies, in which scientists have investigated animal venom and the possible therapeutic potential of parts of that venom for conditions like epilepsy.

While some of this research is still in its infancy, the potential to harness mother nature's tried and tested substances is fascinating and exciting.

In the first study we round up, spiders might hold the key – in the shape of a particular protein in their venom – to creating new epilepsy medicines for some of the rarer forms of the condition. Meanwhile, a Mexican marine animal, similar to a centipede, may offer hope for further new epilepsy treatments.

Spider venom: precision potential

Experts at the University of Queensland, Australia, have developed medicine based on spider venom which could help treat some forms of genetic epilepsy.

Professor Glenn King from the university's Institute for Molecular Bioscience developed the medicine using molecules called 'peptides' from the venom of the K'gari funnel web spider.

Prof Kind said: "We believe these venom peptides can be very precise, personalised drugs for specific epilepsy patients."

The researchers are using a synthetic brain 'organoid' the size of a lentil to test the medicine. These are produced by Professor Ernst Wolvetang from the Australian Institute for Bioengineering and Nanotechnology using stem cell technology.

Prof Wolvetang said the venom-derived treatment has "proven efficacy" for some types of genetic epilepsy which are "in dire need" of better medicines.

He said that testing new treatments is challenging for ethical, practical and commercial reasons. The organoids are an ideal way to speed up the process, he added.

Prof Wolvetang said these lab-produced organoids help to develop treatments that are more precise and tailored.

Testing the medicine on synthetic organs is also helping to build the case for their use in future testing, Prof Wolvetang added.

Prof King and associate professor Nathan Palpant have already developed a medicine to treat heart disease and stroke from the same spider venom, which is currently being tested.

Prof King will be speaking at Epilepsy Queensland Thinking Outside the Box | 14th Epilepsy Symposium on 15 October.

Remipede venom: new hope

Venom from a marine animal living in underwater caves in Mexico could hold potential for new epilepsy treatments, according to scientists in Germany.

Researchers from Goethe University Frankfurt have studied the marine remipede's venom and its effects on channels in the brain.

The marine remipede, similar to a centipede, uses a neurotoxin to paralyse its prey. One protein in the venom, called xibalbine, can affect potassium channels in the brain and reduce electrical activity.

The researchers, Pinheiro-Junior and colleagues, say this is an important characteristic when it comes to developing medicines for epilepsy. The protein also has the potential to treat chronic pain.

However, the scientists said other components of the remipede's venom have the potential to stop crucial functions of heart cells.

Remipede venom could be used to create new epilepsy treatments

Image by Ivanenko VN, Antonenko EA, Gelfand MS, Yager J, Ferrari FD. 2016. via Wikimedia Commons

The researchers said their paper is "an important cornerstone for future studies to untangle the origin and function of these enigmatic proteins".

Venom from land animal, such as snakes, spiders and scorpions, has been previously studied, but the paper authors said this is the only crustacean for which the venom has been described.

However, they stressed that the remipede's habitat is under thread with the construction of the Tren Maya intercity railroad.

"Our study highlights the importance of protecting biodiversity, not only for its ecological significance, but also for potential substances that could be of crucial importance to us humans," said co-author Dr von Reumont.

For all the latest epilepsy research news and more, visit epilepsy.org.uk/news/category/research or scan the QR code

Epilepsy support for you

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

Join one of our virtual groups

We know many of you take comfort from connecting with others affected by epilepsy. 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*** 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 ***lso@epilepsy.org.uk*** or calling **0113 210 8899**.

Online resources

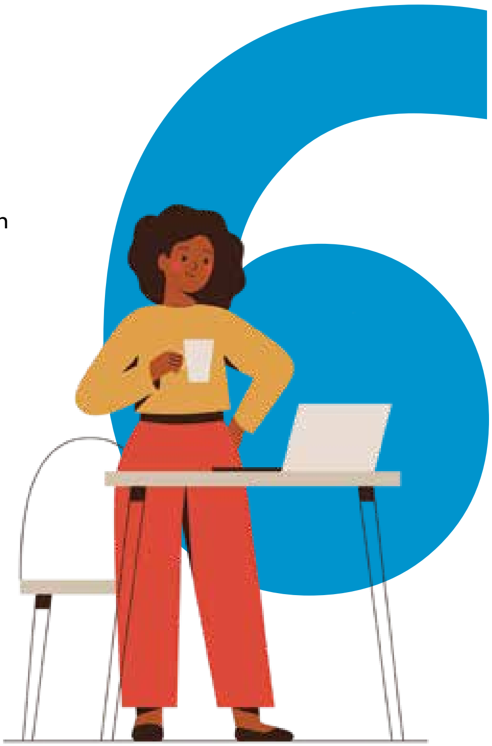
There are many ways to be part of Epilepsy Action's online epilepsy community. You can find us on:

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

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

> **"One of Epilepsy Action's roles is bringing people together to share their knowledge and experiences"**

For more information scan the QR code



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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.
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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

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