

## Invisible force

Mark battles  
agoraphobia and  
depression with a little  
help from his loved ones



Also in this issue

- join the Jog 30 Miles in June Facebook **challenge**
- a look back at another fantastic **Purple Day**
- the difficulties and bright spots of life with **complex medical needs**



# editor's letter

Welcome to the June 2022 issue of *Epilepsy Today*.

The summer rays are peering through the window blinds as I type. It's a sure signal that it's the time of year to get outside and soak in the sun. Those of you who have been out doing the Epilepsy Action Facebook challenges in February, or out fundraising for Purple Day in March, have shown iron will, getting outside even in blustering winds and sideways rain (and surprise snow!) But now is really the ideal time to take on one of the Facebook challenges – as even the weather itself is beckoning us outside. On page 16, you can read the stories of Josh and Scott, both of whom have taken on these kinds of challenges before, and you can find out how you can join the Jog 30 Miles in June Facebook challenge coming up soon.

And speaking of Purple Day, you have once again shown us your boundlessly generous spirit, doing sponsored walks, litter pick-ups, piano playing and more to raise vital funds for people living with epilepsy. Many of you also shared your moving and inspiring stories about how you have felt left in the dark by epilepsy. To everyone who took part in Purple Day in any way – thank you! You can read our round-up on page 18.

Its impact on our mental health is certainly one way epilepsy can cast a shadow over our lives. On page 8, you'll find a summary of some research from 2021 around mental health and epilepsy, and you can read Mark's story – you remember Mark from the cover? His epilepsy left him depressed and nervous to go outside, but his wife, dad and friends have been a pillar of strength.

On page 12, photographer Caoimhe shares her epilepsy journey in a series of photos she calls 'From the inside out', picturing the hospital she spent so much time in for appointments when she was younger. In another lovely story, Jan tells us about the joys of spending time with her son James, who has epilepsy and other complex needs. She shares the challenges he has experienced through his life, and recalls one of the happiest Christmases their family has had. Why was it the happiest? Have a look on page 26 and find out.

Finally, Epilepsy Action's chief executive Phil Lee pays tribute to two people who have played a huge part in the organisation over the years – Tony Gorton and Angie Broadhead.

I hope you enjoy this issue and find some joy in our wonderful community.

Kami Kountcheva  
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## Blood levels of some epilepsy medicines lower during pregnancy

The amount of some epilepsy medicines in the blood drops in women during pregnancy, according to a new study in *JAMA Neurology*.

The Maternal Outcomes and Neurodevelopmental Effects of Antiepileptic Drugs (MONEAD) study, by Page Pennell and her colleagues, investigated the pregnancy-associated changes in several epilepsy medicines. These were lamotrigine, levetiracetam, lacosamide, oxcarbazepine, zonisamide, carbamazepine and topiramate.

Reduced levels of epilepsy medicines in the blood during pregnancy can lead to more frequent or severe seizures which could be harmful to the woman and baby.

The research included 430 participants – 326 pregnant

women with epilepsy (the study group) and 104 women with epilepsy who were not pregnant for comparison (known as controls) – aged 14-45 years. The pregnant women were at less than 20 weeks of pregnancy when the study started. The study group was monitored for nine months after giving birth, with a similar timeframe used for the control group.

In the study group, blood tests were done four times during pregnancy and three times after the women had given birth. Seven blood tests were also done in the control group over 18 months.

Amounts of epilepsy medicines in the blood were compared during and after pregnancy in the study group, and between the study and control groups.



When comparing the blood levels during and after pregnancy in the pregnant women group, levels of many of the epilepsy medicines were significantly reduced during pregnancy. Lamotrigine levels decreased by over a half (56.1%) and levetiracetam by over a third (36.8%). Oxcarbazepine reduced by around a third (32.6%), as did zonisamide (29.8%), and lacosamide levels dropped

by two-fifths (39.9%). The authors say that monitoring of medicine levels in the blood should start early in pregnancy, and that increasing the doses of some epilepsy medicines may be needed throughout pregnancy.

There is more information about epilepsy, medicines and pregnancy on the Epilepsy Action website at [epilepsy.org.uk/medicines-pregnancy](http://epilepsy.org.uk/medicines-pregnancy)

## Lower heart rate variability could be risk factor for SUDEP

Heart rate variability (HRV) could help assess risk of sudden unexpected death in epilepsy (SUDEP) in people with epilepsy, according to a new Portuguese study in the journal *Epilepsy Research*.

Researchers Maria Teresa Faria and colleagues explained that people with epilepsy, especially treatment-resistant epilepsy, have lower HRV. They said this reduced variability is a risk factor for sudden death in other diseases.

The researchers included 23 people, aged between

16 and 55 years, who have generalised tonic-clonic seizures in the research, as these types of seizure are known to be a risk factor for SUDEP. They measured HRV every five minutes, and looked at results during daytime, during night time and before and after a tonic-clonic seizure. The data were compared with values from people without epilepsy.

About a third (30%) had heart disease risk factors, such as smoking and high blood pressure, but none had had heart disease previously.

The team found that HRV was significantly lower in the period after a seizure had occurred. They also found that HRV was generally lower in the people in the study than people without epilepsy.

However, there were no significant differences in HRV between other measured factors, such as between daytime and night time. There was also no significant difference in HRV between seizures starting in the temporal lobe or elsewhere, and whether or not there was

a heart-related risk factor or not.

The team concluded that their research confirms a heart-related risk factor in people with treatment-resistant epilepsy, and they said this may play a part in some SUDEP cases. They said that identifying these kinds of heart-related problems can be a marker for a higher risk of SUDEP.

There is more information about SUDEP on the Epilepsy Action website at [epilepsy.org.uk/SUDEP](http://epilepsy.org.uk/SUDEP).

## Epilepsy organisations call for uninterrupted epilepsy supplies for Ukraine

Global epilepsy organisations, including the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) are calling for uninterrupted epilepsy aid for Ukraine.

Around 250,000 people in Ukraine have epilepsy, but epilepsy medicine supplies are running low, according to the ILAE. People with epilepsy also need regular contact with healthcare professionals for often related conditions, such as depression, anxiety and dementia.

Following the start of the conflict in Ukraine, the ILAE and IBE put out a statement urging for continued supplies and support for people living with epilepsy in Ukraine.

The statement said: "ILAE and IBE are concerned about the impact of the current situation in Ukraine on the

availability of treatment and access to care for people with epilepsy in the region.

"We also know that an increase in seizures and epilepsy is likely as a result of conflict-related injuries, infectious disease outbreaks and a rise in premature and complex births.

"ILAE and IBE call on authorities and humanitarian responders to ensure uninterrupted supplies of critical and life-saving anti-seizure medicines.

"ILAE and IBE urge all to respect the neutrality and sanctity of medical personnel and health facilities during this conflict."

The ILAE has set out seven key actions and is creating a task force to fulfil them. The actions include assessing medical and supply needs,



working with pharmaceutical companies and organisations to help provide ongoing supplies, and developing prescription changes guidelines for affected countries. The organisation will also offer translations of key phrases, fundraise for communication systems like mobile phones, develop support and referral networks and advocate for free treatment with all governments.

The European Reference Networks is another group, made up of 24 organisations

working to support people in Ukraine who need support for rare or very rare diseases. This includes EpiCARE, focusing on help for those with rare and complex epilepsies.

Epilepsy Action has written to the UK government to call for provision of urgent epilepsy supplies to Ukraine.

Anyone wishing to help can visit Project Hope at [bit.ly/39gPoKv](https://bit.ly/39gPoKv), supporting healthcare workers in areas of crisis.

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## Post-traumatic epilepsy linked to poorer quality of life

Post-traumatic epilepsy, occurring after brain injury, is linked to a lower quality of life than non-traumatic epilepsies, according to a US study in the journal *Neurology*.

Dr Gugger and his colleagues carried out a survey of 529 people who went through the events of 9/11, many of whom had experienced traumatic brain injury. The respondents were split into four groups: epilepsy controlled with medicines (249), hard-to-treat (known as drug resistant)

epilepsy (124), post-traumatic epilepsy (86) and hard-to-treat post-traumatic epilepsy (70).

The study authors found that hard-to-treat epilepsy was more common in people with post-traumatic epilepsy than with non-traumatic epilepsy. People with post-traumatic epilepsy and hard-to-treat post-traumatic epilepsy had significantly more additional health conditions alongside their epilepsy than the groups with non-traumatic epilepsy. The

poorest quality of life scores were reported by people with both post-traumatic and hard-to-treat epilepsy.

The researchers concluded that people with post-traumatic epilepsy are especially vulnerable to having other health conditions linked to their epilepsy and their traumatic brain injury. They said this "at-risk group" should be the focus of future studies looking into factors linked with poorer health and

finding treatments that could stop epilepsy from developing, following a traumatic brain injury.



## Cenobamate safe and effective in children, study finds



The new epilepsy medicine, cenobamate, has been found to be safe and effective in children with hard-to-treat focal-onset epilepsy, in line with study findings in adults with epilepsy. This is according to a piece of research from the US by Dr Robin Varughese and colleagues, published in the journal *Epilepsy & Behavior*.

The team set out to assess how safe and effective cenobamate is as an add-on treatment in children with hard-to-treat focal-onset seizures. They said this medicine is useful in adults but this has not yet been confirmed for children.

The study included 21 children, aged around 16 years old, on average. Cenobamate was introduced and the dose slowly increased as needed or up to a maximum of 400mg a day. On average, children weighing over 50kg needed around 200mg a day. In children weighing under 50kg, the average dose was 4mg a day for each kilo they weighed. The average reduction in seizure frequency was over half. Around three in five children (62.5%) had their seizures reduce by at least half. In over half of the children, seizures reduced by three-quarters, similar to the seizure

reduction in adults. Just under one in five children (19%) became seizure free.

Of the 21 children, nine (42.8%) had side effects from cenobamate, which were usually problems with their balance or speech (ataxia) in about a quarter (23.8%) or sleepiness (sedation) in about one in 10 (9.5%). Three children dropped out of the study because of the side effects.

The researchers concluded that their findings show that cenobamate has similar effectiveness and safety in children as it does in adults, making it effective, safe and well-tolerated even at the maximum doses a day. However, larger studies are needed to confirm their results.

At the moment, cenobamate is only approved for use in adults. Doctors can only prescribe it for children on an unlicensed (off-label) basis. This means the doctor has to take individual responsibility for prescribing it. They will only do so if they are satisfied there is enough evidence it's safe and effective, and that there are no approved medicines that would work instead.

## Epilepsy could be a risk factor for Parkinson's disease, study suggests

Epilepsy and hearing loss are among some of the risk factors for developing Parkinson's disease later in life, according to a new study in *JAMA Neurology*.

Dr Christina Simonet and colleagues aimed to investigate common risk factors for Parkinson's disease and how early these can occur before a Parkinson's disease diagnosis is made. The research wanted to focus on an ethnically diverse group of people from less affluent backgrounds.

The study used the electronic health records from GP practices in East London of over a million people between 1990 and 2018. They compared people with Parkinson's disease stated in their medical record to those without. People with neurological diseases that get worse with time, such as dementia and multiple sclerosis (MS), were not included in the study.

The researchers found that people with Parkinson's disease tended to be older and more often male, compared to the group without. Loss of hearing and epilepsy were found to be risk factors for Parkinson's disease, which haven't been well reported before.

According to the NHS website, Parkinson's disease is thought to affect around one in every 500 people. The researchers found that people with epilepsy are 2.5 times more likely to be diagnosed with Parkinson's disease than the general population. This means for every 500 people with epilepsy, two or three people will go on to have a diagnosis of Parkinson's disease.

Consultant neurologist at the Royal Victoria Infirmary in Newcastle, Dr Rhys Thomas, said: "This is not the first time that epilepsy has been suggested to be a risk factor for Parkinson's disease, but the size of the study makes this finding potentially important.

"There could be a few different reasons for this increased risk of being diagnosed with Parkinson's disease in people with epilepsy. If you are already seeing a neurologist for something else, and you do have early signs of Parkinson's disease, you are more likely to have it diagnosed correctly. Also, some epilepsy medicines can cause a tremor, which could be misdiagnosed as Parkinson's disease (what is called parkinsonism) or it could prompt a doctor to investigate for Parkinson's disease.

"Epilepsy is a term for a number of diseases, and some of them may be more likely to increase the risk of Parkinson's disease than others, specifically vascular disease."

Other risk factors included tremors, seen up to 10 years before the diagnosis of Parkinson's disease, and memory problems, present up to five years before. Links were also found with high blood pressure, low blood pressure, constipation, depression and type 2 diabetes.



## Epilepsy Action NI secures grants for counselling service and to support carers

National charity Epilepsy Action will expand its counselling service for people with epilepsy in Northern Ireland, after securing a £200,000 grant from the Department of Health Northern Ireland.

The grant is an award from NI Department of Health's Mental Health Support Fund, which was set up to help charities to provide mental health support in the communities.

People with epilepsy are twice as likely to have depression than people without, and suicide rates can be twice as high in people with epilepsy than people without.

Currently, the counselling service includes free online and telephone counselling for adults with epilepsy, or parents or carers to someone with the condition, who are based in NI. Online counselling is done on the video conferencing application Zoom, and instructions are provided at registration.

The counselling sessions take place once a week, for 6-8 weeks, and each session lasts 50 minutes. They are delivered through qualified volunteer counsellors. To register, you can fill in the enquiry form on the Epilepsy Action website.

With the grant, Epilepsy Action Northern Ireland will be able to expand its counselling services. It will also offer online therapy groups covering issues like new diagnosis, independence and change to relationships, as well as resilience sessions teaching self-help techniques. The funding will also help the organisation develop training materials and resources for counsellors.

Carla Smyth, Northern Ireland manager at Epilepsy Action, said: "We know how much epilepsy can have such a wide-reaching impact on people's lives and talking to someone can make a huge difference."

There is more information about the counselling service



at [epilepsy.org.uk/involved/branches/nireland](https://www.epilepsy.org.uk/involved/branches/nireland)

Epilepsy Action Northern Ireland has also secured funding of approximately £60,000 for a part time family support officer in Northern Ireland.

The funding from the Department of Health (DoH) will be for two years and will go towards the project aiming to support around 2,300 carers to people with epilepsy.

Epilepsy Action explains that there are a number of

problems with provision of epilepsy care in Northern Ireland at the moment. They include the longest waiting times for services in the UK at the moment and a "severe lack" of neurologists and epilepsy specialist nurses (ESNs).

The new role and the project funded by the DoH will support carers through activities like information events, raising awareness, working with healthcare professionals and working to reduce social isolation.

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## WHO sets out action plan on epilepsy 2022-31

World Health Organization sets out action plan on epilepsy and other neurological disorders for 2022-31

The World Health Organization (WHO) has put together a draft 'Intersectoral global action plan on epilepsy and other neurological disorders' for the 10-year period 2022-31.

The goal of the action plan, shared in January 2022, is to

reduce the stigma, impact and burden of neurological disabilities, including epilepsy. It also aims to reduce related deaths, linked conditions and associated disabilities. At the same time, the WHO is looking to strengthen prevention, treatment and care for these conditions through the action plan.

The action plan aims to make neurological conditions a

higher priority in government policies and promote financial and social protection benefits. It further seeks to help to make sure people get effective and timely diagnoses, treatment and care, as well as include strategies for raising awareness, supporting prevention and fostering research in neurological conditions.

The plan is looking to encourage people-centred

care, evidence based policy and involvement of people with neurological conditions and their carers in healthcare.

The draft plan follows a request from the World Health Assembly in November 2020 for the WHO to address challenges and gaps in care and services for people with epilepsy worldwide. It was developed with input from member states.



# An invisible force

**Epilepsy and mental health often go hand in hand. We look at what some recent research shows and hear from Mark, who has had a very difficult time with epilepsy, depression and agoraphobia, but finds support from a few key people in his life**

On the whole, our physical health is often under the spotlight. We all see adverts encouraging us to get our five-a-day and walk our daily 10,000 steps. We see big campaigns helping us recognise early signs of diseases and get help early, or to go for our routine check ups. If we stop and think, the importance of our physical health is everywhere.

But mental health is often much more in the shadows. It has historically not got the attention that our physical health has, and even though this tide is starting to turn, there is still a lot more work to be done.

Mental health conditions like depression and anxiety are well known for being fairly common in the general population. About one in six people in the UK will

have depression. In England, one in six people report having anxiety or a similar mental health problem in any given week. And if these conditions are not common enough already, people with epilepsy are twice as likely to have depression (one in three people) and at a higher risk than the general population of having anxiety.

It's incredibly important to take mental health seriously too. Depression and anxiety can have a huge effect on someone's life. They can put a strain on friendships and relationships with others, affect livelihoods or social lives, and in very bad cases, cause people to have suicidal thoughts. We wouldn't walk around with toothache and not get it treated, and we wouldn't ignore a pain in our body and not get it checked

out. So why would we accept and deal with mental health problems on our own, especially when it can have such a profound effect on our lives?

But it's not something that's only down to us. Mental health in epilepsy has not been on the radar enough in scientific studies, and there are many aspects we don't understand well enough yet. This is something that is slowly changing too. We summarise a few studies from the last year.

## Diagnosing depression

One of the things about anxiety and depression is that it can sometimes be difficult to know that we're experiencing it. For one thing, we can all have low mood or feel anxious from time to time, without it being a serious problem. But when this anxiety or low mood continues for a long time, that's when it can turn into a bigger issue. But it's something that can creep up on you, which can make it difficult to recognise.

And it's not just challenging for us to tell. Despite how common depression and anxiety are in epilepsy, they are still often underdiagnosed. An Australian study from 2021 by Dr Amelia Scott and colleagues, published in *Epilepsy & Behavior*, found that from 106 people with epilepsy attending a hospital appointment, about a third of people with symptoms of depression didn't have a diagnosis. The rate was even higher for anxiety, with two-thirds of people with symptoms not having a diagnosis.



Another study by Dr Tan and colleagues, published in *Epilepsy Research*, also from last year, found that nearly one in 10 people with epilepsy (9.3%) attending a hospital in Malaysia did not have their depression diagnosed. This study wanted to look at risk factors for having epilepsy and undiagnosed depression. The researchers found that risk factors were having a lower income level, having generalised seizures and having temporal lobe epilepsy.

Also looking at risk factors was another *Epilepsy & Behavior* study published in May by Dr Rachel Batchelor and Dr Michelle Taylor. They wanted to find out if people's coping strategies and level of support from friends and family could help them determine who might be more at risk of mental health problems, such as anxiety, depression and suicidal thoughts. The researchers studied 144 young people with epilepsy using an online survey. They found that over a third of the group showed signs of suicidal thoughts or behaviour. More than three-quarters of the young people had signs of anxiety and depression, but only about a third had formal diagnoses for anxiety or depression.

The study authors found that coping through ignoring or avoiding problems was linked to having symptoms of mental health conditions. Other coping strategies the study looked at were problem-focused coping and meaning-focused coping. Problem-focused coping involved people dealing with a problem by planning and looking for information, and meaning-focused coping is finding meaning in a situation through beliefs or looking for possible positive sides. Both of these coping methods were linked with reduced symptoms of mental health problems. Having support from family and friends was also linked to reduced mental health problems.

The authors concluded that there should be more screening for mental health problems and risk factors, and teaching better coping strategies could be beneficial in epilepsy services.

While the amount of underdiagnosis of anxiety and depression in epilepsy appears to vary, better understanding of what puts people with epilepsy more at risk of

developing these conditions is key. It can mean earlier and more effective treatment. This appears to be something that the scientific community is already working towards, but more work is still needed.

### Tricky treatment

For those people who are diagnosed with a mental health condition as well as their epilepsy, there is also the question of treatment. Epilepsy has a two-way relationship with depression, where if

"I was struggling to come to terms with my condition. I was very frustrated and short-tempered and not pleasant to be around."

you have epilepsy, you are more likely to develop depression, but also if you have depression, you are more likely to develop epilepsy. The close link between these two conditions means that there is a balance to be struck with medicines for each of them.

Some epilepsy medicines can worsen symptoms of depression, and some antidepressants can affect seizures. If you are experiencing symptoms of depression, your epilepsy specialist might be able to adjust your medicine or dose to help reduce these. Other treatment options your doctor may recommend include talking therapy and antidepressants to help.

The relationship between epilepsy and depression was discussed in a piece of research by Dr Singh and Prof Goel, published last year in *Neurochemical Research*. The researchers explained that two types of antidepressants – selective serotonin reuptake inhibitors (SSRIs) and selective serotonin and norepinephrine reuptake inhibitors (SNRIs) – are usually the first choice for people with depression and epilepsy. They are considered safe in epilepsy, but the study authors say that there is still not enough evidence. They added that they also might not work for some people. The researchers suggested that perhaps looking at the common cause of epilepsy and depression should be a focus for research going forward, and may lead to new treatment options.

While there are some studies on the topic, more research is needed around the use of different antidepressants in epilepsy. A *Cochrane* review by Dr Melissa Maguire

Epilepsy specialists can adjust your epilepsy medicine dose or prescribe antidepressants if you are experiencing symptoms of depression



Research shows that clear pathways and procedures should be put in place to support mental healthcare in epilepsy



and colleagues from last year looked at the research available on antidepressants and therapies for people with depression and epilepsy. They wanted to see how effective and safe the different treatments were. Each of the studies the group looked at showed some level of reduction in depression with the different treatments, however the researchers found that the results varied a lot. They were hard to compare to one another because of the different structures of each study, and there wasn't enough evidence to make meaningful conclusions. They said studies need to be carried out for longer and include more people with depression and epilepsy to be able to better understand the effects of the antidepressants. However, they added that none of the treatments in the studies seemed to worsen seizures, even though they weren't able to compare different treatments with one another.

### What's next?

The importance of tackling this issue is not lost on researchers and healthcare professionals and more research and work is underway. The International League Against Epilepsy (ILAE) has set up a Psychology Task Force with the goal to improve global mental healthcare for people with epilepsy. Dr Milena Gandy and colleagues from the Task Force carried

out some research to look at the current experiences and practices of epilepsy specialists, as well as barriers and unmet needs around addressing depression. The findings have informed the way the Task Force will carry out its work.

The researchers sent an online survey to members of the ILAE networks. Members from around 67 countries took part and around 80% of responders were neurologists or epilepsy specialists. Around two-thirds of the responders came from high income countries.

The findings showed that less than half of the specialists who responded felt they had the resources they needed to manage depression and anxiety in people with epilepsy. It wasn't clear to the responders whose responsibility it was to screen for and treat mental health problems in epilepsy, and many said a barrier to offering care was also a lack of time. People were referred to mental health specialists about half the time, but around a third of people said they used 'watchful waiting', which is no longer considered to be good practice.

The respondents said a lack of trained specialists and a lack of defined pathways and procedures for managing mental

health in people with epilepsy was a barrier for them. The researchers concluded that future work should focus on creating these clear pathways and procedures and adding mental health specialists into epilepsy settings.

On a personal level, we can all support ourselves and each other by looking out for signs of mental health problems. Low mood for long periods of time could be a sign of depression, as well as feeling guilty, sleeping more or less than normal and losing interest in the things you enjoy. With anxiety, you might feel worried all the time, or feel tired and irritable. You might also have fast or irregular heartbeats, sweating, trembling, dizziness or stomach problems.

If you or a loved one has symptoms like these, or feels like life is too much, it's important to speak to your doctor or seek help. You don't have to live with these conditions and there are steps that you and your doctors can take to help to improve your wellbeing and quality of life.

### More information

**Epilepsy Action**  
[epilepsy.org.uk/depression](https://www.epilepsy.org.uk/depression)  
0808 800 5050

**NHS website**  
[nhs.uk](https://www.nhs.uk)

**Mind**  
[mind.org.uk](https://www.mind.org.uk)  
0300 123 3393

**Rethink Mental Illness**  
[rethink.org](https://www.rethink.org)  
0300 5000 927

**Anxiety UK**  
[anxietyuk.org.uk](https://www.anxietyuk.org.uk)  
03444 775 774

**Samaritans**  
[samaritans.org](https://www.samaritans.org)  
116123

**Saneline**  
[sane.org.uk](https://www.sane.org.uk)  
0300 304 7000

### Mark's story

"My epilepsy was diagnosed in March 2017 after a serious, unexplained car crash in November 2016 and then an incident at home in January 2017. I predominantly have absence and focal impaired awareness seizures, but I also have the odd atonic. I also have non-epileptic seizures as well.

"Before the car crash, I worked full time as a freelance IT and management consultant and was a volunteer with AbilityNet. Most of the time, I worked from home – I had an office in the garage – and had become aware of losing time in the day. But as no one was there to observe, I just put it down to getting older. My wife, Julia, would also complain that I was ignoring her, but that could have also been selective deafness. After the crash, I suffered with post-traumatic stress disorder (PTSD). I couldn't work out what had caused me to crash the car, but I was thankful no one else was involved.

"During the incident in January, my wife was awoken at 5am by me falling through the stair banister. She was very shocked, scared and apparently slapped me in the face a couple of times to try and wake me up because I was unresponsive, before dialling 999. When the paramedics arrived, they wanted to know why I was naked. She said she didn't know what they needed to see – they said 'not that'. And this was the beginning of the neurological investigations resulting in my diagnosis.

"Immediately after my diagnosis, I felt safest either in bed or sat on the sofa. I'd had two near-death experiences and did not want to risk another. I resigned from AbilityNet and reduced my hours at work, only dealing with urgent or essential tasks. In the two months it took to diagnose my epilepsy, I had imagined all sorts of alternatives – brain tumour, multiple sclerosis (MS) (which my mother had), Parkinson's disease. I'd got to the point where I was relieved to hear that it was 'only' epilepsy.

"My elation at the diagnosis was short-lived, and depression kicked in. For three years my temper shortened significantly and I struggled to accept my new normal. My wife struggled to understand what was

down to my epilepsy, to my non-epileptic seizures or my diagnosis.

"The last two years have been better, but while my seizures are more under control now, an incident will just set me back. There is still an invisible force stopping me stepping outside the front door unless I'm with someone I trust. When COVID took hold and we had to isolate, while others struggled, I said I had been training for this for the last three years.

"Daily, I have fatigue, poor concentration and memory loss. I resist planning things in advance because I don't want to let people down if I'm not fit to do the planned activity. I've never got back to full time work but I did try to do some volunteering with both my wife's allotment association and The Ramblers. But as of April last year, I stopped working and the only voluntary work I do now is managing a couple of non-profit websites, which I can deal with on my terms.

"I have grieved for my old life and still struggle at times to accept my life now. I wouldn't have been able to do it without a few key people. One is Julia. She has battled her own mental health issues and has found it difficult over the last five years at times. We had a particularly difficult year in 2019, as I was struggling to come to terms with my condition and how it had changed my life. I was very frustrated and short-tempered and not pleasant to be around. We recently celebrated 27 years together.

"Another person is my closest friend of 30 years, James. While for the last 15 years he has lived outside of the UK, he is always there for support and when things have been very bad for me, he has made time to come and visit. He is now back living in the UK and we are planning to complete Wainwright's Coast to Coast walk in 2023. After I had a seizure while we were walking in the Lake District



Mark

last year, he suggested rather than have a medical bracelet I should just tattoo it on my bald head!

"My father Keith is another hugely important figure in my life. He is 79 and was diagnosed with epilepsy at 76 years old. I now know who to blame! In December 2017, we lost my mother. They were living in Penrith at the time but since then, he has moved to Derby. He is now only half a mile away and walks 3-8 miles a day – weather permitting! When my agoraphobia (a fear of being in situations where escape might be difficult or help might not be available) is at its worst, he will walk to mine and then we will walk together.

"The last indispensable person in my life is my therapist, Michael. I started seeing him in August 2019 when I was at my lowest. He has made a big impact on my life. My non-epileptic seizures have reduced considerably. Two of the biggest changes he encouraged was journaling and allowing myself to have a nap in the afternoon. He was the first person to make me aware that the two biggest emotions that I was experiencing were shame and guilt.

"I am very fortunate to have these four people in my life, in addition to other good friends from my wife's allotment community and The Ramblers, of which both dad and I are members. I also have a great mother-in-law who also lives within half a mile. The online epilepsy community is a great support too."



A journey back in time

# From the inside out

**Photographer  
Caoimhe  
Clements  
shares her  
epilepsy journey  
in photos**

“I bought my first camera when I was 18, and I never looked back,” said Caoimhe Clements. She is a photographer from Kilkeel in Northern Ireland, and has had epilepsy since she was just a few weeks old. Among her photography projects is ‘From the inside out’, which takes the audience on her journey of having epilepsy. The photos have been taken at the Royal Belfast Hospital for Sick Children where Caoimhe went for appointments when she was growing up.

Caoimhe shares the photographs she has taken so far as part of this series and describes what it was like having epilepsy as a teenager, what her seizures feel like and pushing beyond perceived limits.



“I have focal aware seizures, where I am conscious during the seizure. It basically means I’m fully alert as to what is going on and I will remember everything that happened in the aftermath.

“I was diagnosed as a baby, so I don’t remember the early appointments. My parents sadly had to experience the anxiety of those early ones.

“When I experience a seizure, my heart starts racing, I get very scared, I sometimes have a headache and I end up completely exhausted. I will also feel like ‘why did I let this happen!’ which is very silly to think because it’s out of my control. I hate not being in control of my own body.

“Growing up, going through my teenage years, I absolutely hated going to these appointments. I remember having so much anxiety and frustration. On a personal level, I kept thinking to myself ‘why do I have this?’ and ‘why can’t I just be normal?’ The experience of going to these doctor visits was frustrating because I had to speak about this, when I didn’t want to.”

“Epilepsy definitely impacts by mental wellbeing. I can’t control my anxiety or seizures, but I can do things to help prevent serious anxiety or seizures from happening. I make sure I get enough sleep, I eat healthy and I enjoy yoga, cooking and reading. These are just some ways I cope.

“The biggest challenge of having epilepsy is the limits that can come with it. But I refuse to let that stop me from reaching my goals and aims in life. Now, in adult life, I don’t feel limited in terms of things I want to do and the things I already have achieved.

“I ended up taking a gap year and deferring the start of my Master’s course from September 2021 to September 2022. I was really upset at the start because I felt like my plans had been ruined. That was a challenge, but now I see that gap year as a chance to breathe, slow down and focus on myself.”

“I have met people who have epilepsy as well, but their story was completely different and harder than my story. I feel it’s important to realise that. I never wanted people to feel sorry for me because I had epilepsy.

“Epilepsy has inspired me. A 20-year-old me realised epilepsy was a part of me, and it changed my mindset. I wanted to learn more about epilepsy and that journey has been so interesting so far. I’m now about to turn 24 in June.”

A measure of blood pressure



The room I remember



# epilepsy feature

“I take Keppra (levetiracetam). I had a four-year seizure gap between 2017-21, which was amazing. I could focus on university, studying Photography with Video, and not worry about seizures.

“Due to COVID-19, my final year of university was online and I ended up having emotional exhaustion. I found things difficult and ended up having two seizures as a result – one in February and one in December last year.”

“We need to create awareness around epilepsy. When I speak to others who have been impacted by epilepsy so much worse than me, I automatically feel I am responsible to do something about it.

“Going back to the Royal Belfast Hospital after years was such a surreal feeling. During one of my photoshoots there, I took my best friend with me, who continues to support me no matter what.

“It was hard being around the ages of 12-15 years old and attending these appointments, feeling like I wasn't the smartest in school and I wouldn't do anything in life. I felt like people expected that I couldn't be successful – go to university, get to exhibit my work all over the UK and Ireland or get accepted onto my Master's course – which I'm about to start in a few months.”

[@caimhetakesphotos](#)



The element of prevention



The cycle repeats

# Administration of buccal midazolam online course

Epilepsy Action offers specialist online training in using the emergency medicine buccal midazolam.

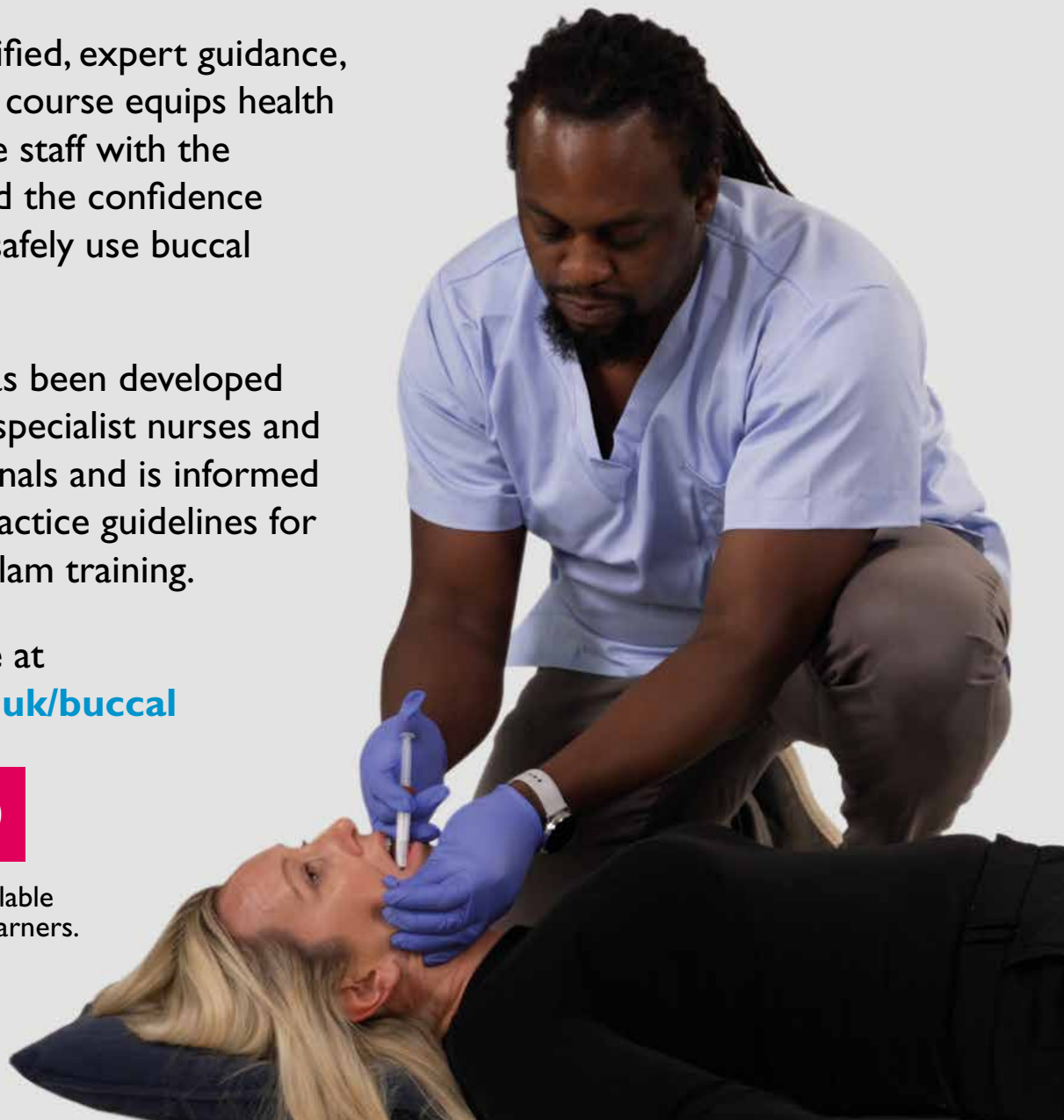
Based on qualified, expert guidance, this accessible course equips health and social care staff with the knowledge and the confidence they need to safely use buccal midazolam.

The course has been developed with epilepsy specialist nurses and care professionals and is informed by the best practice guidelines for buccal midazolam training.

Find out more at  
[epilepsy.org.uk/buccal](https://epilepsy.org.uk/buccal)

**COST £20**

Bulk discounts available for five or more learners.



Get in touch: [helpline@epilepsy.org.uk](mailto:helpline@epilepsy.org.uk)

Registered charity in England and Wales (No. 234343)

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Josh with his son Arthur

# Stepping to it

**The Epilepsy Action walking, running and step challenges have inspired the nation to get their trainers on, get outside, and, on some occasions, break through personal barriers, all to help people living with epilepsy**

Since the lockdowns of 2020 and 2021, it's felt like the humble walk has had a resurgence. Not that it ever went away, exactly. Many of us 'go for a nice walk' after a meal, or on a long weekend, admiring views we don't often get to see and breathing in fresh outdoor air. But during those difficult times in the pandemic, many people felt like their foray outside was a little moment of peace and escape from the challenges of day-to-day life. Our daily walk became something to really look forward to, take in and be in the moment for, come rain or shine.

As spring is in full bloom, it's even nicer to head outside and spend time in the great outdoors. And many of you have, all for a brilliant cause. Over the last couple of years, we have had so many of you take on step challenges, pushing yourselves

to traverse miles in just a few weeks – walking or running – to raise money for people with epilepsy. This generosity and commitment to getting outside day after day has meant that we can be here for more people with epilepsy, be that answering helpline calls, holding Talk and Support groups or fighting for change for the better.

Most people taking on these challenges have a connection to epilepsy, and are motivated by their loved ones with the condition, or by showing their epilepsy is no barrier. And many have had very inspiring stories to tell.

Josh Crosby, 30, from Ashton-under-Lyne, took on the previous challenge – 50 miles in February – this year to raise money and awareness for epilepsy. Josh was diagnosed with epilepsy six years ago and his seizures have turned out hard-to-control.

*"I've had seizures in public places and now I have panic attacks when leaving the house. I have to rely on my family a lot when I'm unable to do daily tasks"*

"Epilepsy has affected my life massively," he said. "I have tonic and absence seizures and struggle to control them. I'm unable to work, as the injuries I suffered became a health and safety issue. Epilepsy has also affected my mental health, and sometimes I can't leave the house. I've had seizures in public places and now I have panic attacks when leaving the house. I have to rely on my family a lot when I'm unable to do daily tasks."

Struggling to get out of the house made Josh's 50-mile goal even more momentous. He managed to do 25 miles in eight-and-a-half hours in a single day, together with his friend Gareth.





Josh and his friend Gareth

Getting out for this challenge was really important for Josh. He explained: "Epilepsy Action have helped me understand and learn how to live with epilepsy. They have a community of people who understand the struggles we all go through and have experts there ready to listen and give advice."

"I want to raise awareness of epilepsy and help other people. It can be a really difficult time when your condition changes your life and how you live it. My biggest supporters are my family and friends and my little boy Arthur, who really keeps me smiling."

*"In mid-July, I achieved 350,000 steps and decided to keep on going. I'm so proud of myself. It makes me feel more alive, just breathing in that air and making every step count."*

Last year, in July, we also held the 350,000 steps in July, where again, people from all across the UK got their trainers on and took to the great outdoors. One of those people was Scott Woodhouse, from Castleford.

"I was first diagnosed when I was 14 years old," Scott said. "It was a typical family Christmas and we were celebrating. All I can remember is the dog barking and sniffing around me, and then I was having a seizure. I was very emotional afterwards – I couldn't keep the tears back. I felt so alone, but my family and support groups picked me up."

"As a teenager, I struggled with my mental health and had to seek counselling. I felt like people were watching and talking about me, making fun of how I walked or talked. I had to hide behind blinds and was diagnosed with agoraphobia. I couldn't go to school from year 9 onwards and had home tutoring. I couldn't see friends or speak to them and sometimes what made it worse is they made fun of me. It still upsets me to this day."

"I didn't do well in exams but I went to Wakefield College and came out with good A Levels. The seizures continued and in my final year I had to work from home. I couldn't see anyone or interact with them. I always had to be home on time, especially to study."

"I have an amazing family who have always been there for me throughout the toughest of times with my epilepsy. They've been my saviour and my rock. I love them all very much."

Scott's agoraphobia, a type of anxiety where a person fears situations where they might feel trapped, helpless or embarrassed, has meant the July challenge was a real achievement for him.

"The pandemic has been awful. My epilepsy has played up so much, especially the absence seizures, sometimes on a daily basis. But this challenge I've made my own. I am very passionate about it and doing this fundraiser has made me more self-aware. In mid-July, I achieved 350,000 steps and decided to keep on going. I'm so proud of myself, to have taken on this challenge to raise money, improve people's lives and spread awareness. It makes me feel more alive, just breathing in that air and making every step count. I will never let epilepsy beat me."

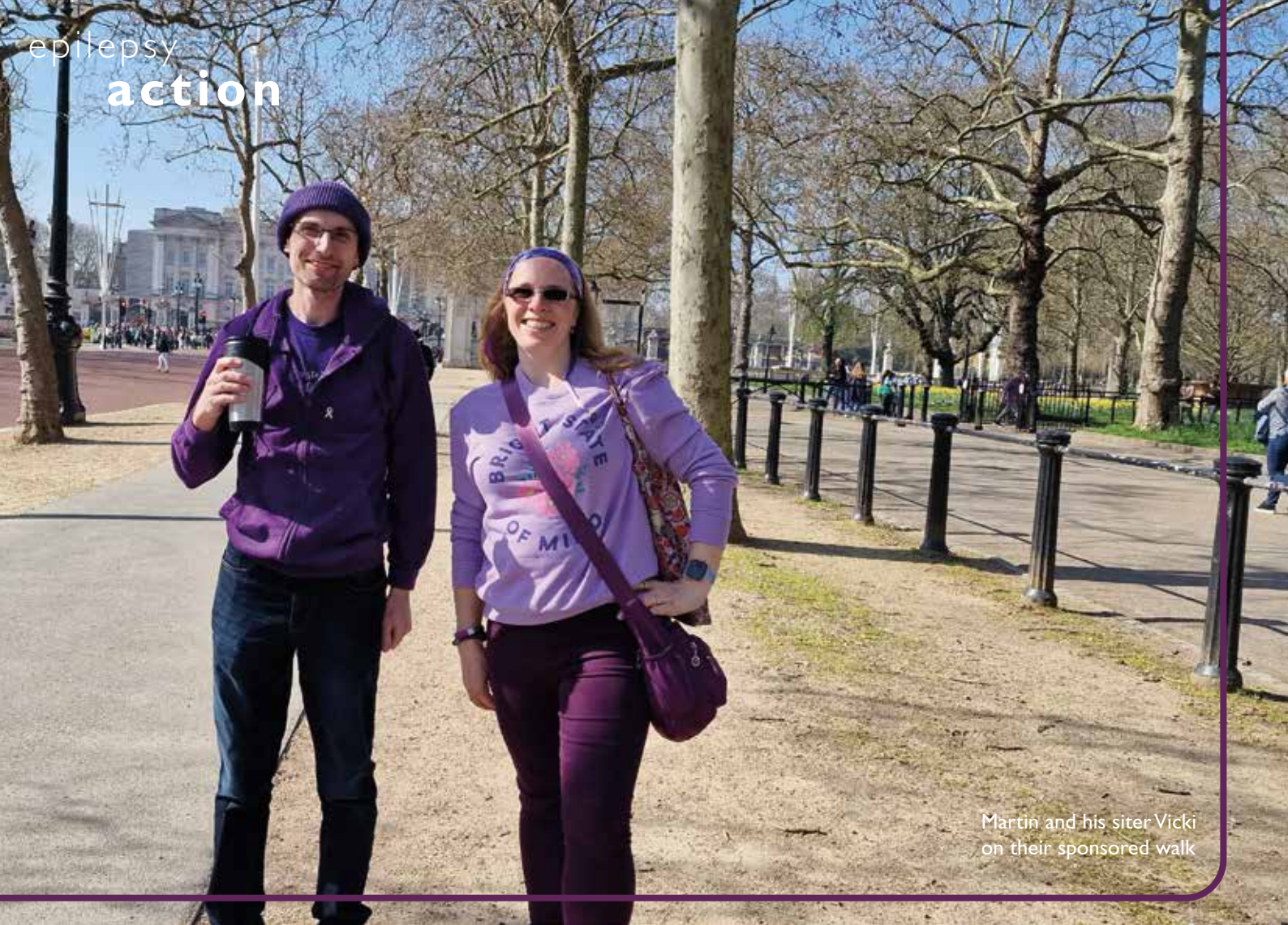
Those taking on the challenges in February this year have raised a phenomenal £415,000 for people with epilepsy and to raise awareness of the condition.

If you are getting itchy feet with the sunnier weather out there, you can sign up for Epilepsy Action's 'Jog 30 Miles in June' Facebook challenge. Registration will be open all throughout May. Everyone who signs up will receive an Epilepsy Action T-shirt and challenge pack. You can decide how you want to complete your 30 miles – you could jog a mile a day or do a longer distance a few times a week. The Jog 30 Miles in June Facebook group is a great place to meet the other challengers and cheer each other on throughout the month.

For more information on how to take on the June Facebook challenge, email [fbchallenge@epilepsy.org.uk](mailto:fbchallenge@epilepsy.org.uk).



Scott



Martin and his sister Vicki on their sponsored walk

# You have us

**This Purple Day, we shone the spotlight on the dark moments around epilepsy – from the shadow cast by the diagnosis, to things like memory loss and mental health challenges – and reminded you that we are here when you need us**

Purple Day is a big day in the epilepsy calendar. Many people celebrate with activities to raise awareness, show solidarity and fundraise to support those living with epilepsy – from bake sales and sponsored walks to sponsored piano playing, balloon guesses and lashings of purple hair dye. Martin was diagnosed with epilepsy at 10 years old. He and his sister Vicki did a 10-mile sponsored walk around London on Purple Day. Charlotte, who

was diagnosed with epilepsy at the age of 12, decided to do a sponsored litter pick for Purple Day, to help people and wildlife in one stroke. These are just three of so many fantastic events and activities you did to take part this year.

As always, you went above and beyond to show your support and raise vital funds. Your time and generosity helped raise £35,000 to date for people with epilepsy – a fantastic effort that means we can be here for more people affected by epilepsy. We can't say thank you enough!

It's always a hectic time ahead of Purple Day at Epilepsy Action too. Fundraising packs, activities, planning interviews, writing



Charlotte did a sponsored litter pick up

up stories – it’s all go. It’s one of our biggest opportunities to help bring epilepsy out of the shadows and gain support and understanding for people living with the condition. This year, we wanted to help people get a sense of what it’s like to get the diagnosis in the first place – the questions, the uncertainties, the misconceptions and everything in between. We unveiled our new minute-long video, capturing the feelings and thoughts of how everyday life can suddenly change completely after a diagnosis of epilepsy. If you haven’t seen it already, head to [epilepsy.org.uk/purple](https://www.epilepsy.org.uk/purple) to watch it. If you’ve struggled to explain what it feels like to be diagnosed with epilepsy to others, sharing this video with them might help.

*"It's okay to have those dark times, it's okay to cry, it's okay to feel all these emotions at once. But it's also okay to talk about these emotions and it's okay to make light of whatever is bringing you down"*

Alongside the video, we shared lots of your stories of epilepsy. It can’t be overstated how much difference your stories make, not just on Purple Day, but throughout the year. They’re incredibly emotive and really help others to understand what it’s actually like living with epilepsy – not just the seizures they see. They are also incredibly powerful in helping everyone else in our community feel less isolated and like they’re not the only one going through it.

**“It’s okay to have those dark days”**

One of the people sharing their honest experiences this year was Cassidy Megan, the woman who created Purple Day in 2008 when she was eight years old. Thinking she was the only one with epilepsy and no one else understood what it was like, she wanted a day when everyone with epilepsy could see they are not alone. Little did she know that it would spread worldwide and do a tremendous amount of good for people with epilepsy.

She joined Epilepsy Action’s Chantal Spittles, PR manager, and Simon Privett, volunteer coordinator, for an interview on Purple Day on Instagram Live (you can find this video online too, on our Instagram @epilepsyaction).

As a champion for openness right from the start of Purple Day, she explained that it can be an understated strength.

“Talking about epilepsy and owning your epilepsy is almost empowering, because you have this health condition that used to be labelled as a disadvantage, but you’re saying ‘yes, I’m owning that and I can still do all these things’”

Like many of us, Cassidy has experienced different misconceptions throughout different areas of her life, but her goal is to increase awareness of epilepsy in schools, as well as of the mental health side. She said: “People don’t always understand that it’s not just the seizures, it’s the tiredness, it’s the memory

loss, it’s the confusion, it’s that after seizures you’re sore, it’s the last minute cancellations, it’s the mental health toll it can take on you, it’s that it plays on your family and friends. It’s not just the seizure, it’s everything that comes along with it as a side effect.

“I’d love to see epilepsy talked about as a mandatory class in the school curriculum, because it’s [one of the] most common neurological disorders. But people don’t realise how common it is. I’d also love to increase [awareness] of the mental health toll epilepsy can take on you. I went through a depression, I wrote a suicide note... it’s draining. But again, people only see the seizures.”

Having been through such challenging times in her life, Cassidy offered some of her family’s coping strategies and words of encouragement for anyone else feeling that way: “A saying that we’ve come up with in our house is that it’s okay to have those dark times, it’s okay to cry, it’s okay to feel all these emotions at once. But it’s also okay to talk about those emotions and it’s okay to make light of whatever is bringing you down, because if you make light of it in an appropriate way, it makes it less daunting and less draining. And talking about it, you realise that, much like epilepsy in general, there’s so many other people who get it.



Cassidy Megan,  
founder of Purple Day



“It doesn’t always go away, you always have down times, but being open about it and talking about it with the community, with people you trust, makes a world of difference.

“When having these down days, they’re all okay to have, but you can’t stay there, you can’t live there. Have your moment, have your day, but the next day, when you wake up in the morning, tell yourself ‘I made it another day, I can do it again. I’m that strong and that powerful in myself that I’ve made it this far, and I can make it further.’ Because you have that support system, you have the community, you have the [organisations], you have your family and friends. You have some kind of support system, no matter what. I know some people unfortunately don’t have family with them or struggle making friends. If that is you, you still have a support system, because you have us here, you have a whole world of epilepsy communities and even though we’re all strangers, we’re all family. If you’re in the dark, reach out to anyone in the epilepsy community and it will help shift you out of that dark spot.”

**“It feels like the first 20 years of my life are like a film”**

Jo is 50, lives in Bradford, and has had epilepsy since around the age of 22. She has tonic-clonic, atonic and focal seizures, and has them in the daytime and during sleep.

“As far as I know, my first seizure was around a week after the sudden loss of a close friend called Joe, who died in a tragic accident. He was only 20 and this was a huge shock for us all.”



Doctors told Jo they thought the shock of losing her friend had caused her seizures. She started keeping diaries of her seizures from then on.

Jo added that she was told “nothing at all really” about the way epilepsy might impact her day-to-day life. She said her mum was the one who managed to get more information as she was “used to extracting information from GPs and consultants”.

Among the many things about epilepsy Jo wasn’t told about were the possible harmful effects of Epilim – also known as sodium valproate – if taken during pregnancy. This medicine is an important epilepsy treatment, which may be the most effective to control seizures in some people. However, if taken in pregnancy, it can cause physical and developmental problems in babies.

*Jo woke up from a seizure in a strange room. A woman she didn't recognise was sitting next to her. She introduced herself as her mum, Carol.*

“I was prescribed Epilim as my first medication. Like most women at the time, I wasn't told anything about these risks at all. I found out after I'd become pregnant, but I was on a different medicine by then. Luckily, my daughter Meg was born with none of the problems that some epilepsy medicines can cause.

“Also, there was no information at the beginning about the long-term effects of other medicines such as my current one, carbamazepine. This can cause bone problems, such as

osteoporosis, after using it for a long time. When I became aware of this, I asked for blood tests to check my vitamin D levels. The results were low, so I take vitamin D daily and my levels are normal now.”

But, for Jo, one of the most significant effects of epilepsy emerged at the age of 24.

One day, Jo woke up from a seizure in a strange room. A woman she didn't recognise was sitting next to her. She introduced herself as her mum, Carol. Downstairs, two more unfamiliar faces told her that they are her stepdad Charlie and her brother Sam. Jo didn't recognise the house she was in or even her own name on a college folder in her bedroom.

Jo's mum took her to the doctor, who said that he expected this was a short-term side effect of her epilepsy medicines. Weeks and months went past, but Jo's memories were gone.

“A few years ago I had a look through my photos and diaries again with my best friend Nikki. We've been best mates since our early teens and still are to this day. She confirmed people we knew and places we went.

*"It feels like the first 20 or so years of my life are like a film I've watched many times and know the scenes well, but it doesn't feel like that person is the person I've known since then."*

“To explain it simply, it feels like the first 20 or so years of my life are like a film I've watched many times and know the scenes well, but it doesn't feel like that person is the person I've known since then. I just have to trust and believe what I've been told. Photos, videos and letters prove things to be correct, but this doesn't feel like it was my own childhood or young adulthood.”

Jo explains that her memory is still not good to this day – a common problem for many people with epilepsy – but she has developed coping strategies. “I have my own systems for running our business – I use reminders, the notes app on my phone, and I take lots of photos and videos of various things. I ensure that I keep these files in named folders and they are backed up.

“To this day, I still get told about things that happened when I was younger. I have incredible support from my husband, daughter and close friends - I wouldn't cope without this.”

Jo was asked to come to the filming of the video and take part. She shared some glimpses from behind the curtain, including the feelings it brought to her. “We'd already had a few retakes before I heard the pre-recorded audio for the first time,” she said. “It was quite emotional to hear this the first few times – I actually felt goosebumps. The way it was produced was really powerful.”

### “Hold tight to each other”

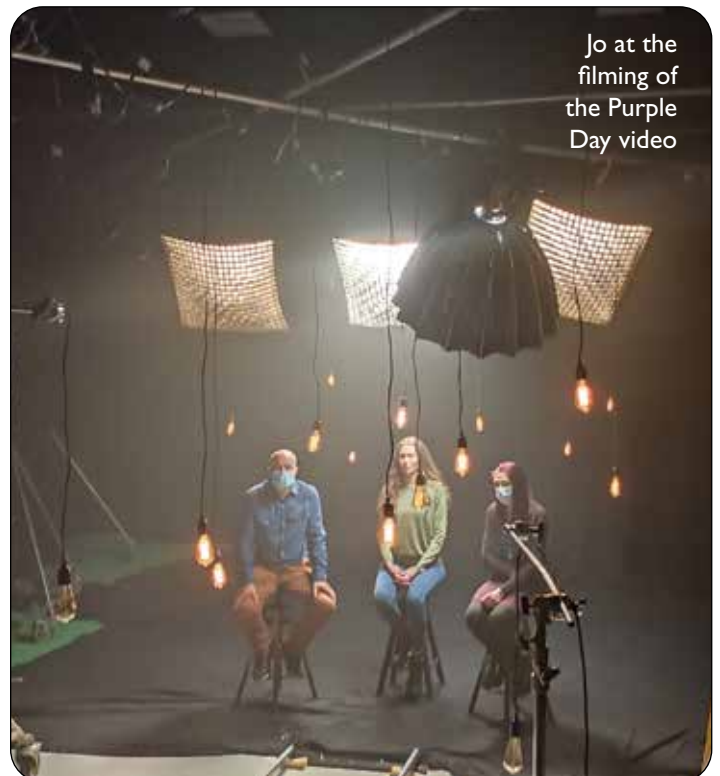
Hayley, 30, from Staffordshire, has had epilepsy almost all her life. Her parents describe what it was like to have their baby daughter diagnosed with epilepsy.

Hayley was nine months old when her seizures started, recalled her dad. “It started with a twitch, the slightest of tremors in her hand, barely perceptible. The twitching became more pronounced and moved to the left side of her

*"I felt relieved to have a diagnosis, but frustrated that she had to suffer for months before any treatment started. I also felt sad that I couldn't make it better for my child, and guilty."*

face and into her left arm. Hayley and I were very lucky as her mum was – and still is – an excellent nurse. As we moved through the NHS, we had a rock who could explain the things I didn't understand and who was always by her side no matter what.”

It was a mix of emotions hearing that Hayley had epilepsy, her mum said. “I felt relieved to have a diagnosis, but frustrated that she had to suffer for months before any treatment started. I also felt sad that I couldn't make it better for my child, and guilty – was it something I had done during the pregnancy?”



Jo at the filming of the Purple Day video

Hayley



Hayley's mum said: "One thing I'd tell another parent is to keep fighting for your child to get a specialist neurologist. Ask questions no matter how silly they may seem. Take every opportunity to raise the profile of epilepsy."

"Take all the positives you can when they are well and hold tight to each other when they are not," her dad added.

Hayley wouldn't remember those early times, having been so young, but epilepsy left a huge impression on her life since then, too. She said: "I couldn't have been prepared for what epilepsy would mean for me growing up. It ruined the dreams I created and wanted for myself and that isn't something I was ok with.

"I have been bullied, beaten, abused, discriminated against and made to feel like I'm less of a person and that I don't matter all because of a condition. But these experiences have made me strong and brave and knowledgeable enough to help others.

"My mum and dad were my everything and I owe them my life many times over as without them I wouldn't be here today. They were my strength when I was too young to have any, they always encouraged me to fight when I was too weak to and they always loved me no matter how bad things got. My brother and sister didn't always understand why I was poorly but they always knew how to reach me and they both knew if they saw me smile that things would be ok.

"I was angry as well. Angry that local medics were so thoughtless. They stood at the bottom of her cot, watching her have these seizures, saying it was 'fascinating' and talking about Jacksonian seizures. Terrified doesn't begin to explain how I felt.

"How did we manage? It was trial and error, many different drug changes, many hospital admissions and a childhood lost."

While the immediate family understood what was happening to Hayley, this wasn't the case for everyone else. Hayley's dad explained: "Most of our relatives were unaware of exactly what Hayley went through. They saw very little of her seizures, they just knew she was just off to hospital. It all changed with her first grand mal [now known as tonic-clonic] seizure when she was 16 at a family gathering. That frightened a lot of people that day, myself included."

And it wasn't just members of the family. "There was ignorance from many," Hayley's mum said. "One person said 'you wouldn't think she wasn't normal'. We were told, after a particularly worrying admission, when she went into non-convulsive status epilepticus, that if she had died it 'would have been God's will'. Hayley was bullied by children and teachers, and abused by strangers when she has had seizures in the street, as people wrongly assume she is drunk or on drugs."

Hayley's parents had a difficult time watching their daughter have seizures and fighting to get her diagnosis and to make people understand more about epilepsy. Their experiences are shared by families all around the world.

*"My mum and dad were my everything. They were my strength when I was too young to have any, they always encouraged me to fight when I was too weak to and they always loved me no matter how bad things got."*

"The key thing is to remember you have epilepsy, it doesn't have you. Feel what you need to, listen to your head and heart and speak up if something doesn't feel right. You are special, you are valid and having epilepsy can't diminish that."

For more information on Purple Day, visit [epilepsy.org.uk/purple](https://epilepsy.org.uk/purple)

You can also find more information about issues raised in this article on the Epilepsy Action website, including:

epilepsy medicines and pregnancy – [epilepsy.org.uk/medicines-pregnancy](https://epilepsy.org.uk/medicines-pregnancy)

bone health – [epilepsy.org.uk/bone-health](https://epilepsy.org.uk/bone-health)

mental health – [epilepsy.org.uk/depression](https://epilepsy.org.uk/depression)

memory – [epilepsy.org.uk/memory](https://epilepsy.org.uk/memory)

diagnosis – [epilepsy.org.uk/info/diagnosis](https://epilepsy.org.uk/info/diagnosis)

# Medical files

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

## Clonazepam

Clonazepam was first used by being given directly in the vein for status epilepticus in the late 1960s. Shortly after, it was also shown to be effective when taken by mouth as a tablet for a wide range of seizure types. It works in a similar way to other medicines in the family of benzodiazepines, such as diazepam (Valium) and clobazam (Frisium). Clonazepam is usually prescribed as an add-on medicine for generalised seizures, including absence, myoclonic and atonic seizures. It is also effective against focal and tonic-clonic seizures. Adults should be



initially prescribed a dose of 0.5-1 mg of clonazepam, going up every two weeks as needed. In children, 0.5mg is the usual starting dose. Increases up to 4-8mg daily can be effective and well-tolerated in all age groups.

Drowsiness, tiredness, headaches, sleepiness and dizziness are the most common side effects with clonazepam. Mild or moderate dizziness, which may come and go, can occur in two-fifths of people (40%). However, these may improve with time. Behavioural changes are common in teenagers, including hyperactivity, irritability, anxiety and aggression. Other possible problems include poor concentration, restlessness, confusion and forgetfulness (amnesia). Treatment with clonazepam can also cause or worsen symptoms of depression. Sexual problems are unusual but potentially important complications.

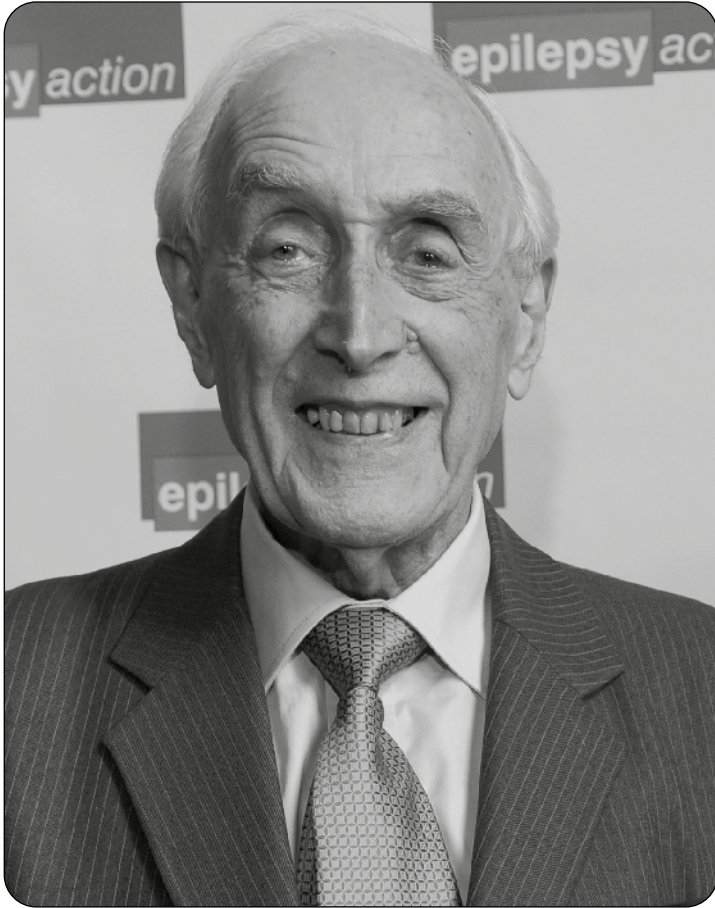
Clonazepam doesn't usually interact with other drugs, but its levels in the blood can be reduced by some types of epilepsy medicines, such as carbamazepine, which can reduce its effectiveness. The Medicines and Healthcare Products Regulatory Agency (MHRA) reviewed the safety of epilepsy medicines in pregnancy. The MHRA found there were not enough data to make any conclusions about the safety of some epilepsy medicines, including clonazepam.

Overall, clonazepam is an easy-to-use, broad spectrum, usually add-on medicine, which is effective for a range of seizure types and epilepsies. Its one big drawback is the risk of it having a sedative effect, but this will not be the case for everybody. Tolerance to clonazepam's therapeutic effect and side effects can sometimes occur in children and adults at higher doses.



Professor  
Martin  
Brodie

**Always follow your doctor's instructions for taking your medicine. If you are experiencing any problems with your epilepsy medicine, it's important that you don't stop taking it without discussing it with your GP or specialist. Suddenly stopping your epilepsy medicine could cause you to have more, or more severe, seizures.**



# Tribute to Tony Gorton

Tony Gorton died in October 2021. Epilepsy Action's chief executive, Philip Lee, pays tribute to Tony's life and legacy, including his work with the Epilepsy Action Huddersfield Group, campaigning for better medical and social care and tremendous fundraising

It was with great sadness that we learned of the death on 3 October 2021, at the age of 91, of Mr Frank Anthony (Tony) Gorton.

Tony was a stalwart supporter of Epilepsy Action and the charity's Huddersfield Group for more than 40 years. He served as a trustee of the charity on the Council of Management between 1981 and 1985. But it was his voluntary work with his local Epilepsy Action Huddersfield Group that really stands out. With his wife Joan, Tony was one of the founders of the Group and he remained an active and inspirational member of it until poor health limited his involvement in recent years.

Tony operated as a trained accredited volunteer, raising awareness about epilepsy in his local community. This was never more effective than when he was campaigning for improvements to local epilepsy services. He was

tireless in his efforts to advocate for people with epilepsy in Huddersfield and the wider Kirklees and Calderdale areas, always promoting the need for better medical and social care.

He served as a lay member on numerous local committees and groups with many notable successes. Working with the Board of Directors of the Huddersfield Hospital Trust, he was instrumental in securing the appointment of a consultant neurologist. The establishment of a Sapphire Nurse (epilepsy specialist nurse) at the Calderdale (Halifax) Royal Hospital and another one in Huddersfield were direct consequences of the work put in by Tony and the Group. In fact, it was the Group, led by Tony, that raised the money to appoint the Huddersfield nurse. In addition to this, the Group sponsored 36 nurses and allied staff in Kirklees to go on distance learning courses at Leeds Metropolitan and Edinburgh Napier Universities.

Tony was a tremendous fundraiser. He once estimated that over the years he had raised more than £80,000 for Epilepsy Action's work nationally. To this impressive sum should be added all the money Tony helped to raise for the Huddersfield Group locally.

Tony's contributions were recognised by several awards over the years. In 1996 the Huddersfield Group was Epilepsy Action's Branch of the Year. Tony himself received an Epilepsy Action branch member of the year award and in 2017 (with his wife Joan) he received the Epilepsy Action Hilary Figg Award for long and outstanding service to the charity.

Tony will be long remembered by everyone who knew him for his dedication and commitment to helping people with epilepsy. Our thoughts and good wishes go to his wife Joan, daughter Sarah and his wider family.





# Tribute to Angie Broadhead

Angie Broadhead died this year at the age of 82. Philip Lee, chief executive at Epilepsy Action, remembers her work with the organisation, her continued support for people with epilepsy after her retirement, and her enthusiasm and goodwill

It was with great sadness that we received the news of the recent death of Angie Broadhead at the age of 82. Our thoughts and sympathies go to her family, especially her husband Peter.

Angie worked for British Epilepsy Association (Epilepsy Action) for nine years between 1992 and 2001. She originally joined the charity as a fundraising development manager working on charitable trusts and legacies. In 1996 she was appointed as Development Director and her responsibilities were expanded to include all fundraising, membership, local groups and branches and

local volunteers. In 1998 Angie was appointed as Operations Director with responsibility for all operational activity across the charity. It was in this role that Angie led the critical project over 18 months to relocate the charity's head office from Anstey House in Leeds to its present location at New Anstey House in Yeadon. It was to her immense credit that this transformative move was accomplished so smoothly.

Angie officially retired from Epilepsy Action in July 2001 but continued to work for the charity on an ad hoc basis for a further year, administering legacy cases. She

remained a member of the charity for the rest of her life, keeping in touch with former colleagues and following and supporting the development of the charity.

All those who worked with Angie, or who came into contact with her, will remember her as larger than life, full of enthusiasm and goodwill and always encouraging and supporting those around her. She was deeply committed to the cause of the charity and through her work she was able to make a significant difference to improving the lives of so many people affected by epilepsy.

# My journal



*Jan's son James has had epilepsy and other complex medical needs since he was very young. She shares some of the challenges, and some of the bright moments from the last 40 years*



When James was a baby, we thought he was a very thoughtful soul. He would stare and appeared to be thinking, though we did try waving a hand in front of his eyes and noticed they didn't flicker. We had no previous experience or other babies to compare him with, so we just thought he was thinking. Of course, we now know he was having absence seizures.

At five years old, when out with a friend, the mother of the other child told me James had suddenly fallen backwards from a standing position for no reason at all. We then noticed that he was doing that quite often – he also fell forward a lot. James was born with a condition where his feet were turned in and under, and even though he had been discharged by his specialist years ago, we thought he fell more due to a weakness in his legs.

I shared some of these odd things with the paediatrician at his pre-school medical review. Other odd things for an apparently

very bright boy were that there were things his sister, two years younger than him, could do that he couldn't. She could jump on a trampoline without falling over, which James couldn't do. She could cut with scissors, he couldn't.

*I remember the room full of people all looking at the scans, pointing to things on the images and murmuring*

We were sent for a barrage of tests, including an EEG. I remember this and the CT scan, and the room full of people all looking at the scans. They were pointing to things on the images and murmuring.

I felt sick. I could only think he had a tumour, as I didn't realise the various things he had could be down to epilepsy. So, when the consultant looked at me with such care in his eyes, and told me James had epilepsy, I simply said "Oh, thank God!" I had no idea then that James' epilepsy was so complex. I just thought it couldn't be too bad because he wasn't having tonic-clonic seizures.

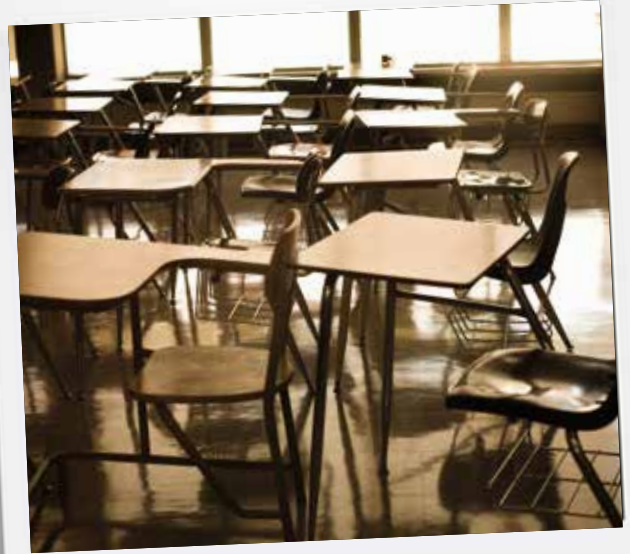
*James started having focal seizures and was hardly ever out of his absences, but the consultant seemed to think I was overreacting*

His diagnosis was Lennox-Gastaut syndrome. This syndrome, back then, carried a dreadful prognosis. We had the same consultant for two years until he retired, and, ever caring, he said we would be needing a lot of support over the years. He referred James to the local consultant paediatrician. Our first meeting with him was sobering. He said he didn't know anything at all about this type of epilepsy, and would we go away for a month and he would read up on it. That's when I started reading up on it too!

When we returned, he continued to say "I don't know this type of epilepsy" but also added "my hunch is it will be a minor irritation"! Within a year, James had started having focal seizures



*James was diagnosed with Lennox-Gastaut syndrome*



*School was difficult for James as he was often bullied*

and he was hardly ever out of his absences, but the consultant seemed to think I was overreacting.

James was also having a terrible time at his mainstream school, because none of the teachers recognised his seizures, so he was frequently punished, kept in from playtimes to finish work he couldn't focus on, and mocked by a teacher (and the children followed) for being slow getting changed for PE. But James had difficulty with things like buttons, laces and focusing on the task in hand.

Eventually I researched for a specialist who could help with Lennox-Gastaut syndrome, and had James referred to the Park Hospital in Oxford. He was in there for two months and they found he had been in a non-convulsive status epilepticus (a prolonged seizure during which a person can still perform some simple tasks). His dose of sodium valproate wasn't high enough to help with his seizures. And he needed time out from all the bullying at school!

*James was also having a terrible time at his mainstream school because none of the teachers recognised his seizures*

The two months in hospital allowed the doctors to get his medicine to the right dose, but his seizures have never been controlled. Over the years, he has had myoclonic seizures,



*At 18 months old, James could solve a Rubik's cube*

frequent absences, tonic seizures, where he would go rigid and fall, or atonic seizures, where he would fall like a sack of potatoes. The tonic-clonic seizures escalated throughout his teens, and we tried various medicines to get him a better quality of life.

Around the time of his hospital stay was also when he stopped learning. He has never managed maths beyond the level of a six-year-old. His reading age went down too, which was very high before the nine months of relentless absences. After that, his learning difficulties set in and were recognised by doctors, and he moved to St Elizabeth's School, a specialist centre for children with complex epilepsies. It was a great move for James, though painful to have to succumb to. He was 11 when he went there, and they were great throughout. By then, he was really

*Along with his epilepsy and learning difficulties, James was also diagnosed with autism at 25*

anxious about social settings, but St Elizabeth's gave him a sense of normality as all the children had epilepsy.

Along with his epilepsy and learning difficulties, James has many medical complexities. He was diagnosed with autism at 25, which explained a lot about how he struggled over the years.

There were signs when he was really young. He was a bright baby, counting the stairs at 14 months. It was the days of the

Rubik's cube, and we had one that neither I or my partner could do, but we found it completed one day. We asked each other to see if either of us had suddenly managed it – then twiddled it around and left it again on the coffee table. James, 18 months old at this point, toddled by, picked it up, completed it in a couple of minutes and toddled off! We thought we were blessed with a very bright boy and I remember thinking there would be nothing I wouldn't do to ensure he had the best chances to fulfil his potential. Only much later did we realise that infants that young do not repeatedly do things like these.

These days, James is better able to articulate when he doesn't understand something. I have never given up on trying to teach him social skills, and he is a loving, empathetic and compassionate man, always has been. But his social empathy is lacking due to the autism. His anxiety rises to panic levels if

*I have never given up trying to teach him social skills, and he is a loving, empathetic and compassionate man, always has been*

any suggestion is made of someone else taking him to medical appointments apart from me.

This is in part because when we have tried having support staff take him, in the interest of independence, they have put him in a room with a doctor, and he has had no idea what the doctor has said or done, or what any of it means. So, he panics. If he has a seizure at the time, he won't remember anything that's been



*James had a VNS first fitted in 2005*

said. But unless people really tune into what epilepsy is like after a seizure, they leave James completely lost. This is why he insists that I attend everything with him. Any changes to routine are still very difficult for him.

James also has diabetes, high cholesterol, an underactive thyroid, problems with his stomach and complex physical disabilities, due

*James is now living in a small care home with lovely staff, but I do all his hospital trips with him and oversee and manage his medical complexities*

mainly to the falls from his seizures. James is now living in a small care home with lovely staff, but I do all his hospital trips with him and oversee and manage his medical complexities. So many of them have developed and I am the only person who has an overview of it all.

By the time James was 28, he was averaging 100 tonic-clonic seizures a month, along with all the other seizures, and he spent a huge amount of his life sleeping off the seizures. The consultant told us we couldn't expect any further improvements because we had tried so many combinations of medicines, and that we had to accept this was to be his life. It was at that point I remembered having seen a documentary about some research into vagus nerve stimulation (VNS).



*In a month, James could have around 100 tonic-clonics*



*James had his first conscious Christmas lunch five years ago*

I managed to get James referred to the Royal London Hospital, where there was a research programme with VNS. After all the tests, James was accepted and had his first VNS fitted in May 2005. The research meant that there had to be no changes to medicines in the first two years, but within six months James' seizures were so out of control again that he needed another opportunity. This came in the form of a new medicine called zonisamide, and so he had to drop out of the research. While

*The VNS didn't appear to reduce the frequency or severity of James' seizures, but the magnet was a revelation*

the VNS didn't appear to reduce the frequency or severity of James' seizures, having the magnet to use when he was having a seizure was a revelation for us. It meant as soon as he began having a seizure, we could sweep the magnet over the device and he would get a bigger and longer electrical impulse, and it would sometimes interrupt the seizure. It felt like we could do something, instead of just watching the time in case we had to use rescue medicine.

James' seizures are currently still daily, but we have had good control of the tonic-clonics for about four years. His new cocktail of medicines combined with his latest VNS (this one has autostim, which means it automatically activates when it senses a seizure) mean he is less at risk. But the frequency of tonic and atonic seizures, and other falls, as well as spending much of the daytime sleeping due to his clusters of brief seizures, all mean that his life is still affected by his epilepsy.



*The creations James has made at his weekly pottery class*

About five years ago we had our first Christmas that James was conscious during Christmas lunch. Since then, he has had seizures before, but has been conscious during Christmas lunch again, which has been amazing. Every other year, until he was 40, he would be so excited that he would have a seizure. The whole family would move the table and my younger grandsons would get him a cushion and blanket, and he would sleep on the floor with us while we ate. We were used to it. He often had seizures during meals – just generally often had

*We sing together in the car, we watch funny videos on YouTube and we laugh about daft things*

seizures – but we made him comfortable and carried on. Occasionally a great wave of grief would come over me, but I wouldn't let him or the rest of the family see that. So the first Christmas, when he was with us for the whole meal, was very special.

James is a bright man. He's creative and enjoys arts and crafts, which I have always encouraged. We find if he is focused on an activity, he is less likely to have a seizure. He loves going to college weekly to do pottery, and he makes beautiful things. He is accompanied by staff from the home, and a learning assistant in the class, so he gets to be with mainstream adults.

Any time with me also makes James happy. He has always wanted to live at home with me, and that has always been a source of sadness for me, as I can't manage alone with all his needs. So, we sing together in the car, we watch funny videos he has found on YouTube and we just laugh about daft things. I take him to the theatre or on holiday – or I did, before lockdown – and he is just happy to be there with me.

James found the lockdowns extremely upsetting, as his routine of spending every other weekend at home and holidays at home, was gone. I organised family zoom sessions every week when no visiting was allowed, and I speak to him every day anyway. Also, he did get more mum time than most, because he had so many hospital appointments and procedures, which I was taking him to and from. I also stayed in hospital with him when he had his VNS replaced. I supplied him with lots of art materials, and we also did two mosaic family sessions online, with a lovely teacher. But it was very difficult for him, especially with the rules changing all the time.

I feel blessed to have such a loving, compassionate and stoic son. He is the bravest person I know – he lives with chronic pain but rarely complains about that. He has the capacity for joy despite all the challenges in his life. He is the person who winds me up the most, but also the person I laugh with the most. He is extraordinary.

### *James said...*

"My mum is thoughtful, loving and caring. We laugh, we watch funny shows, go to the theatre, sing together in the car. She is my rock."



*James says Jan is his rock*

## Council of Management 12 April 2022

At a meeting of the Council of Management held by remote video conference on 12 April, the following decisions were made.

- Approval of the Fundraising delivery and monitoring plan for 2022.
- Council received and approved the 2021 Trustees' annual report and year end accounts.
- The 2021 Year End Audit Findings Report was received and noted.
- Council agreed to sign the Letter of representation to RSM UK Audit LLP
- Joanne Greer, Kerry Watkinson and Gillian Dourish were appointed as new members of the National Advisory Council for Northern Ireland.
- Dr Abigail Swift was appointed as a new member of the National Advisory Council for Wales.
- Beryl Sharlot was appointed as a Vice President of the Association subject to confirmation by the members of the Association at the Annual General Meeting (AGM).
- Council approved a resolution for presentation at the AGM to re-appoint RSM Audit UK LLP as auditors.
- The register of Association members will be closed from 15 May to 14 June inclusive.
- Council approved draft terms of reference for two new advisory panels – the Ethnic Communities advisory panel and



- the 16-30 advisory panel.
- Council also approved revised terms of reference for the Register of Advisors.
- The quarterly review of top 10 risks was completed.

The next meeting of the Council of Management will be on 10 May 2022.

### Epilepsy support for you

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

#### Join one of our virtual groups

We know many of you take comfort from connecting with others affected by epilepsy. The traditional face-to-face group meetings just aren't possible right now, so the local services team have set up online meetings using video calls instead (technical support is available). If this is of interest, you can find out more at [epilepsy.org.uk/virtual-groups](https://www.epilepsy.org.uk/virtual-groups) or by calling **0113 210 8800**.

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

#### Online resources

Epilepsy Action also has an online space where people can meet others with epilepsy and exchange stories and information about their condition. This is called forum4e and can be found at [forum.epilepsy.org.uk](https://forum.epilepsy.org.uk). You can also find us on social media.

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

If you are living  
with uncontrolled  
seizures,  
**you are  
not alone.**

1 in 3 people with  
epilepsy have  
the kind that is  
resistant to  
anti-epileptic  
drugs.<sup>1</sup>

## Take the next steps.

Talk to your Neurologist or Epilepsy Nurse about other options  
beyond medication.

To learn more about Drug-Resistant Epilepsy (DRE) and  
alternative treatment options such as VNS Therapy®, visit  
**[www.vnstherapy.co.uk/learn-more/what-is-dre](https://www.vnstherapy.co.uk/learn-more/what-is-dre)**

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[www.vnstherapy.co.uk](https://www.vnstherapy.co.uk)

#### INTENDED USE / INDICATIONS:

Epilepsy (Non-US)—The VNS Therapy System is indicated for use as an adjunctive therapy in reducing the frequency of seizures in patients whose epileptic disorder is dominated by partial seizures (with or without secondary generalization) or generalized seizures that are refractory to seizure medications. AspireSR® and SenTiva™ feature an Automatic Stimulation Mode which is intended for patients who experience seizures that are associated with cardiac rhythm increases known as ictal tachycardia.

The most commonly reported side effects are hoarseness, sore throat, shortness of breath and coughing.

Visit <https://vnstherapy.co.uk/safety-information> to view important safety information.

1. Brodie MJ. Epilepsia 2013; 54 (Suppl. S2): 5-8.