epilepsy action

epilepsytoday

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A family battle

Laila's mum Saima describes sleepless nights, family strains and looking for the positives after her daughter was diagnosed with epilepsy

Also in this issue

- three years on, families are still fighting for access to **medical cannabis**
- we round up some sessions from the latest **ILAE British meeting**
- Epilepsy Action welfare campaign challenges flawed **PIP system**

editor's letter

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

Happy 2022! Let's hope this year is a bit less turbulent than the couple before! I think we all deserve it. However, if the last couple of years have taught us anything, change happens whether we want it to or not, and – credit where credit's due – we have all got quite good at dealing with it and adapting pretty quickly.

And not all change is bad! Two of our articles this issue look at changes that we actually really want to see. On page 8, three years after the law changed to allow these to be prescribed on the NHS, we revisit the situation with cannabis-based medicines. After three years, things have not moved very far forward, and families are still struggling to access the medicines they so urgently need. Meanwhile, on page 22, you can read more about the experiences of people with epilepsy applying for Personal Independence Payments. It is clear that the system is failing people with epilepsy, and Epilepsy Action is campaigning for an overhaul of the system to make it fairer.

This issue, we also bring you an update from the latest British Branch International League Against Epilepsy (ILAE) conference. As well as some really interesting insights about brain stimulation techniques, and the challenges for people with absence seizures, there is a really useful roundup of wearable technology devices from Prof Mark Richardson. He looks at the three devices with the best evidence around effectiveness and shares the pros and cons of each.

Alongside all of that, we have some powerful stories from Saima (page 19) and Rob (page 26). Saima's daughter Laila – this issue's cover star – has been diagnosed with epilepsy, and this has had a profound effect on her whole family. Saima describes the dark cloud that uncontrolled seizures cast over her, Laila's fear of having a seizure, especially in public, and the effect on her marriage and her other daughters. Rob describes non-convulsive status epilepticus and shares his memories of traversing the streets of Sheffield during this type of seizure, in a confused state and drifting in and out of consciousness.

Finally, on page 16, we say a big thank you for all of your support in 2021. Without you, we can't do any of the work we do at Epilepsy Action. From taking on challenges and fundraising, to giving us your input and feedback, you make it possible for us to be there for others with epilepsy. At the risk of repeating myself – thank you!

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Rob occasionally experiences prolonged non-convulsive seizures, while also seemingly going about his day. He shares what these seizures are like for him

Epilepsy medicine cenobamate recommended for use on the NHS

The National Institute for health and Care Excellence (NICE) has recommended the use of cenobamate for treating focal onset seizure in adults with hard-to-treat epilepsy on the NHS.

NICE has recommended its use when at least two other epilepsy medicines have not worked. Cenobamate is only recommended as an add-on treatment, after at least one other add-on medicine has not worked. NICE also says that treatment with this medicine should be started by a specialised epilepsy service (tertiary care).

The recommendation is based on evidence from two medical trials, showing the effectiveness of cenobamate. The larger of the two trials showed that cenobamate reduced focal seizures by at least half in nearly two-thirds (65.2%) of people taking the largest dose in the study (400mg). This is compared to a similar reduction in just a quarter of people (25.5%) in the group taking a dummy medicine (placebo). The most commonly seen side-effects with cenobamate were sleepiness, dizziness and tiredness.

Daniel Jennings, senior policy and campaigns officer at Epilepsy Action, said: "We are very pleased that NICE has recommended cenobamate for use in treating people with focal onset seizures, particularly as a treatment for people whose seizures are currently uncontrolled. Epilepsy Action was involved with NICE's appraisal process on cenobamate and supported proposals to recommend this treatment.

"We know that with the right treatment the number of people whose seizures are controlled could increase significantly. Many people with uncontrolled and hard-to-treat epilepsy have tried a large number of medications without success. We welcome any new treatments that could offer people with epilepsy a better quality of life."

NICE's recommendation means cenobamate will be available on the NHS in England, Wales and Northern Ireland. Scotland is expected to publish its own decision about cenobamate early in 2022.

There is more information at: ***bit.ly/3nTQUXp***

Epilepsy Action 'trusted information creator'

Epilepsy Action has gained a Patient Information Forum (PIF) TICK. It certifies the organisation as a 'trusted information creator'.

This is the UK's only quality mark for print and online health information. To gain the accreditation, Epilepsy Action underwent an assessment to show its information met 10 key criteria.

The PIF TICK means PIF was satisfied that Epilepsy Action's information is evidence-based, understandable, jargon-free, up-to-date and produced to the best possible standard.

The PIF TICK was launched in May 2020. In June 2021, the organisation also launched a website to help people find trusted health information and spot false health information.

PIF TICK manager Dan Willis said: "We are thrilled to welcome Epilepsy Action to our ever-growing community of accredited PIF TICK members. Accurate, accessible, evidence-based information is key to increasing patient empowerment and improving health outcomes."

Previously, Epilepsy Action's advice and information had received the Information Standard logo from a scheme run by NHS England, until the scheme ended in 2019.

For more information about the PIF TICK, visit the PIF website at ***piftick.org.uk***.

Trusted
Information
Creator
Patient Information Forum

No worse seizures or side-effects in people with epilepsy after COVID-19 vaccine, studies find

There is no evidence of worsening seizures after the COVID-19 vaccine. This is according to two recent studies, one from China by Lu and colleagues, published in *Epilepsia*, and another from Germany by von Wrede and colleagues, published in *Epilepsy & Behavior*.

The Chinese study aimed to understand the COVID-19 vaccine uptake among people with epilepsy and investigate associated side-effects in this group.

The study included 491 people with epilepsy, 217 people with other neurological conditions and 273 without neurological conditions, all matched for age and sex. Of those with epilepsy, 42% had had their first COVID-19 vaccine at the time of the study. This was compared to 84% of people with other neurological conditions and 93% of people without neurological conditions.

The researchers found that among those people with epilepsy who were not vaccinated, more than half (59.6%) were willing to have the vaccine. However, around half were concerned about possible side-effects (53.5%) and just under half (47%) were worried about losing seizure control.

Despite these worries, the researchers found that the occurrence of side-effects was similar between those with epilepsy and those with no neurological conditions. Nineteen people with epilepsy reported an increase in seizure frequency (4%). However, the study authors explain that there is no way to say what the cause was, and suggest it may have just been a natural fluctuation. They also explained that around a third of those who reported an increase in seizure frequency had also stopped or reduced their epilepsy medicines.

The authors explained that there was no evidence of worsening seizures because of the vaccine, and yet the uptake of the vaccine among people with epilepsy was less than half of that of people without epilepsy. They added that measures should be put in place to increase the uptake of the COVID-19 vaccine among people with epilepsy.

Most people in the study had inactivated vaccines, which are the ones available in China, and are different to the ones available in the UK. However, the study from Germany looked at tolerance and side-effects from the COVID-19 vaccines that are available in the UK.

This study included 54 people with epilepsy who had received their first vaccine. The vaccine was well or very well tolerated by two-thirds of people, and one third reported general vaccine side-effects, such as headache, fatigue, fever and shivering. However, only two people (4%) reported epilepsy-related side-effects. In one person it was an increase in seizure frequency the day following the vaccine and in the other it was a new seizure type experienced. The researchers in this study also said it is not clear whether this is vaccination-related or just a natural fluctuation in seizures.

The study authors concluded that the data suggests that the COVID-19 vaccine "is safe and well tolerated, particularly with regard to epilepsy-related adverse effects".

There is more information about epilepsy and COVID-19 at ***epilepsy.org.uk/COVID-19***.

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"Chronically flawed" PIP system

New research by Epilepsy Action shows over two-thirds of people with epilepsy have been left 'unsatisfied or very unsatisfied' with the Personal Independence Payment (PIP) process.

This government benefit is designed to support people living with a long-term health condition or disability with the added costs of care.

But Epilepsy Action says the system is "failing people with epilepsy".

Concerns from respondents ranged from lack of understanding of the condition to inaccurate records of people's answers.

Epilepsy Action is calling for a complete overhaul of the system to make it fairer for people with epilepsy. Read more on this story on page 22.

Attendance and inclusion at school

Children with epilepsy and their parents feel that they are less included in playground activities than children without epilepsy, a new study, published in the journal *Seizure*, suggests.

The study aimed to better understand whether children with epilepsy, their parents and school staff feel these children are included and able to participate at school.

The research, carried out by researchers from Young Epilepsy and Great Ormond Street Hospital, included 68 families and 56 staff members. Staff in mainstream schools were found to be more worried about attendance for children with epilepsy than staff in special schools. Two-fifths (41%) of parents said their child was currently or had experienced difficulties attending school. While most staff and parents agreed that the children with epilepsy were included in classroom activities as much as children without epilepsy, this wasn't the case for playground activities. Parents were significantly less likely than staff members to feel their child was included in playground activities. Parents were also more confident in their child's inclusion at school at special schools compared with mainstream schools.

Parents worried that children may be excluded from activities at school due to staff decisions, the child's own choice or exclusion by other children, the research showed. Almost two-thirds (64%) of children felt restricted in their activities at school due to their epilepsy and over half (56%) of parents agreed.

Parents and children with epilepsy reported bullying at school, but most did not put this down to their epilepsy. Parents were more likely than school staff to agree that their child was being bullied because of their epilepsy or another reason. Parents were also more likely to feel this way if their child went to mainstream school compared with special school.

Study authors Emma Johnson and her colleagues stressed that attendance problems for children with epilepsy can lead to academic, social and emotional difficulties. The researchers suggest that issues with taking part, bullying and friendships may be down to other health conditions rather than their epilepsy itself. They concluded that we need to better understand the effect of epilepsy on school life in order to improve attendance and reduce bullying.

The full study is available on the Seizure journal website at ***bit.ly/3tJgJNz***.

Epilepsy diagnosis after one seizure

Epilepsy resulting from certain causes could be diagnosed after one seizure. This is according to a new *Epilepsy & Behavior* study.

Dr Salvador Vergara-López and colleagues aimed to assess what causes of epilepsy could allow for a diagnosis to be made after only one unprovoked seizure.

The International League Against Epilepsy (ILAE) says that if a person has at least two unprovoked seizures more than 24 hours apart, this can be classified as epilepsy. However, it also says that one unprovoked seizure could also be diagnosed as epilepsy, if there is more than a 60% chance that there will be a second unprovoked seizure within the next 10 years.

The study authors said that the second definition is challenging, as the risk of a second seizure is different depending on the cause of epilepsy. They explained that it is difficult to find the risks among the studies that have been done so far.

The researchers reviewed the studies done to date on this topic, and found only two that were relevant. These studies concluded that there was more than 60% chance of a second seizure to occur within eight years in epilepsy with some causes. They included stroke, traumatic brain injury, cavernous or arteriovenous malformations (problems with the blood vessels in the brain) and infections of the brain.

The researchers concluded that for this group of potential causes, epilepsy could be diagnosed after only one seizure. However, they warned that the strength of the evidence is low and more studies are needed in the future.

The full study is available on the *Epilepsy & Behavior* website at ***bit.ly/3GR5w1k***.

Ketogenic diet could reduce sleep problems

The ketogenic diet could help reduce sleep anxiety in children with hard-to-treat epilepsy, a new Turkish study, published in *Epilepsy & Behavior*, has found.

It is known that sleep problems are common in children with hard to treat epilepsy. The research by Dr Aycan Ünalp and colleagues aimed to find out what effect the ketogenic diet would have on the sleep quality of children with epilepsy and their mothers.

Fourteen children were included in the research. Their families were asked to complete questionnaires before starting treatment with the ketogenic diet, and after three months of treatment.

After three months of treatment, half of the participants (seven) reported improvement in quality of sleep, a third (five) reported worse sleep quality, and two people saw no change.

Even though sleep scores improved for both children with epilepsy and their mothers, the findings were not statistically significant. However, after the third month of following the ketogenic diet, a significant decrease in sleep anxiety was found in the children.

The research found that seizures stopped in half of the children (seven) and in most of the rest (six), seizures were more than halved. About two thirds (71%) of the children whose sleep quality improved also became seizure free on the ketogenic diet. The researchers explained this indicates that poor seizure control is linked to sleep problems.

The researchers acknowledged that the study had limitations, the most important of which was the small number of children involved. They said a large-scale study with a longer study period is needed.

The study is available on the Epilepsy & Behavior website at ***bit.ly/33YOaRC***.

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New epilepsy management pathway launched in Wales

The 'All Wales Adult First Seizure and Epilepsy Management Pathway' was launched at the Senedd in Cardiff on 8 December 2021.

MS Jack Sargeant launched the pathway to an audience including consultant neurologists and epilepsy specialist nurses (ESNs).

The clinical pathway was developed by the Epilepsy Task and Finish Group and the Neurological Conditions Implementation Group in September 2020 to help structure and navigate care for people with epilepsy. The groups comprise clinicians and charity representatives, including from Epilepsy Action.

The pathway is a system designed to improve access to epilepsy services in Wales, and reduce variation of services across the country. It will also serve to improve experiences and outcomes for people with epilepsy, as well as promote and support self care and independence, and improve mental health and wellbeing.

The new pathway is also aiming to increase public awareness of epilepsy, and help to make more efficient use of resources available in Wales. It was developed for use by GPs and in emergency departments, for people with epilepsy diagnoses as well as those who are first starting to have seizures.

The launch of the epilepsy pathway follows recent news that there is a lack of ESNs in Wales as a whole, and the ones in post are not evenly spread across the country.

More information about the pathway is available at: ***bit.ly/3FHnt0F.***

We cannot be back here again

November 2021 marked three years since the prescription of cannabis-based medicines was legalised in the UK. However, families are still struggling to get the treatment they urgently need

In November 2018, cannabis-based medicines were legalised for prescription in the UK. This followed the high-profile case of Billy Caldwell, who ended up in hospital after his cannabis-based medicine was confiscated at Heathrow Airport.

This led the Home Secretary at the time, Sajid Javid, to launch a review into cannabis-based medicines. The review resulted in the legalisation of the prescription of cannabis-based medicines in the UK.

However, the guidance around prescription of these types of medicines was called "extremely restrictive" by Epilepsy Action, and has meant that now, three years on, families are still struggling to get the medicine they need.

Since 2018, only one cannabis-based medicine has been licensed for use in the UK – Epidyolex. This is a cannabidiol (CBD) product, based on only one part of the cannabis plant, and is effective for some people. However, some people with severe, treatment-resistant epilepsy, have found they respond better to different cannabis-based medicines that contain tetrahydrocannabinol (THC) as well as CBD. THC is the part of the cannabis plant linked to the feeling of a "high", and these medicines are not currently licensed for use in the UK. Although doctors can legally prescribe them, prescriptions for these medicines on the NHS are extremely rare.

Daniel Jennings, senior policy and campaigns officer at Epilepsy Action, said: "Three years ago, the government changed the law, but in that time, there's been only one cannabis-based medicine licensed for epilepsy in the UK. A lack of research is the real problem. There have been no trials on other cannabis-based medicinal products in that time, so clinicians just don't have that evidence base they need to feel confident prescribing these products on the NHS."

This has resulted in many families resorting to funding private prescriptions for the medicines they need, which could be costing them thousands of pounds a month.

> **There have been no trials on other cannabis-based medicinal products** in the last three years

Trying to address the lack of research in the area, a recent study published in the *British Medical Journal Paediatrics Open* reported findings from 10 children with medicine-resistant epilepsy taking whole-plant cannabis medicines. Whole-plant means that the medicines contain components from the whole cannabis plant, including THC.

The National Institute for Health and Care Excellence (NICE) has recently increased the use of data in the development and evaluation of their guidance. This includes 'real world' data and relevant data even if it's not collected in a traditional clinical trial format.

> We cannot be back here again in three years **having the same conversations, seeing more and more families suffer**

The *BMJ* study, by authors Rayyan Zafar and colleagues, presents the cases of 10 children with hard-to-treat epilepsy and the effect that taking a whole-plant cannabis medicine has had on them. The children had all tried other epilepsy medicines before, including Epidyolex in some cases. The whole-plant cannabis medicines and doses were different for each child, depending on each case, and were prescribed by the children's doctors.

The research concluded that seizure frequency reduced by 86% with no significant side-effects. The researchers found that the number of other epilepsy medicines the children were taking could be reduced from an average of seven to one after being treated with their cannabis-based medicine.

The study also acknowledged the cost of sourcing these medicines outside of the NHS, saying that it was on average £874 a month.

The researchers acknowledged the limitations of their study, including a small number of participants and not being a rigorous clinical trial. However, they said that despite this, this study shows that whole-plant medical cannabis could be well tolerated and effective for reducing seizure frequency in children with medicine-resistant epilepsies. They added that this research shows the value in further studies looking at whole-plant cannabis-based medicines.

Speaking on LBC in November 2021, Chantal Spittles, Epilepsy Action PR and media manager, shared the organisation's message to current Health Secretary Sajid Javid: "Three years has gone on too long. We cannot be back here again in three years, having the same conversations, seeing more and more families suffer, and at a huge financial and emotional cost.

"Ultimately, epilepsy is life-threatening. It's hard enough to have relatively controlled epilepsy, let alone vicious and relentless seizures every day. These families need to be given back the hope that they thought they had back in 2018. Things need to change – and they can change – but they need that backing."

Many families from the organisation End Our Pain, which fights for better access to these medicines in the UK, shared their stories on the anniversary of the change in law around medical cannabis, urging the government to do more.

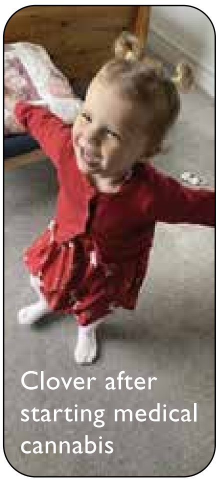
Clover

Clover, two, from Somerset, was diagnosed with Aicardi syndrome and infantile spasms at three months old. Clover's mum, Emily, said:

"The only drug that controlled her seizures was industrial levels of steroids. They made her so poorly that she suffered from adrenal insufficiency [a hormonal disorder] for over a year after stopping them.

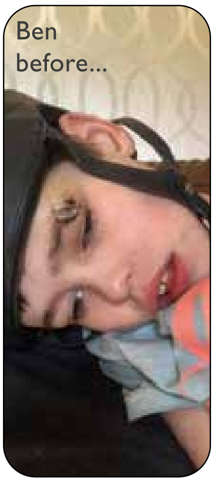
"Clover previously had over 30 clusters of seizures a week (50+ seizure per cluster), sometimes lasting hours at a time. Since starting Bedrolite and Bedica [cannabis-based medicines not licensed in the UK], she is mostly seizure free, but will have 1-5 seizures every week, all within a 24-

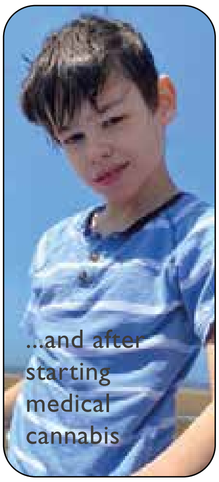

Clover


Clover after starting medical cannabis


Eddie


Helen


Ben before...

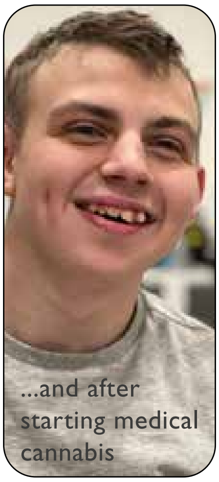

...and after starting medical cannabis


Alfie


Fallon before...


...and after starting medical cannabis


Bailey before...


...and after starting medical cannabis

hour period. She now has one seizure every eight or nine days, and the seizures she does have are so mild.

After being told initially that she would never walk or talk or function on her own, cannabis [medicine] has enabled her to live a life as a normal, happy little girl, free of the horrendous side-effects that come with a cocktail of medications."

Eddie

Six-year-old Eddie, from Chester, has a condition called COL4a2, or Gould syndrome. It can result in cerebral palsy, medicine-resistant epilepsy, global developmental delay and problems with vision (cerebral visual impairment). Eddie's mum Ilmarie said: "Our hopes have been raised and dashed so many times over the last few years. I just want to be able to enjoy time with my son Eddie knowing he has a safe and secure prescription for the only medication that has ever really helped him."

> After 20 years of no quality of life and trying every medication available, **Fallon has had her best life over the past three years and six months taking canabis medication**

Helen

Helen, 50, from Liverpool, was diagnosed with epilepsy at 21 and has not been able to control her seizures with other medicines. Her sister Margi explains: "My sister Helen has gone from having around 70 seizures a month to just 30 after taking whole-plant medicinal cannabis. It's costing me over £2,500 a month to just fund her private prescription. This can't continue. Three years on and we're still waiting. Now's the time for action."

Alfie

Ten-year-old Alfie has a severe form of epilepsy and would previously have up to 150 seizures a week. But his life turned around after he started taking cannabis-based medicines for his epilepsy. Alfie's mum, Hannah, has been fighting to make prescriptions for cannabis-based medicines available and accessible on the NHS for years. She said: "My son Alfie got the first NHS prescription for cannabis-based medicine in 2018. Since then, his life is now full of joy. Why is it acceptable for just a few children to get an NHS prescription for cannabis-based medicine containing CBD and THC and no one else?"

Fallon

Fallon's mum Elaine has seen a drastic change in her daughter's life. Fallon was diagnosed with Lennox-Gastaut syndrome at four years old. She is now 28, and after being prescribed cannabis oil containing CBD and THC four years ago, she has gone from having 200 seizures a month to having less than 20. Fallon no longer needs her wheelchair and the family, from Waltham Abbey, have seen such a change in her that they have enrolled her onto basic courses for reading and maths. Elaine said: "After 20 years of no quality of life and trying every medication available, Fallon has had her best life over the past three years [and] six months of taking cannabis medication. I urge the government to give her the observational trials they had promised."

Ben

Ben was having hundreds of seizures a day despite taking multiple epilepsy medicines and a CBD only cannabis-based medicine. His mum Joanne said he didn't have a quality of life, having daily injuries from seizures and a lot of side-effects from all the medicines. However, she says taking whole-plant cannabis medicines has transformed his life. "He is 95-100% seizure free with no hospital admissions due to seizures. He is now able to learn and progress, some days seizure free, for the first time in his life!

"I urge the NHS to fund prescriptions for families. No help exists for those already taking prescribed medical cannabis. Our GPs want to help but are blocked as no individual funding request (IFR)/clinical commissioning group (CCG) policy exists for our son's medication."

Bailey

Bailey could have hundreds of daily seizures and when he was hospitalised in 2016, his parents Rachel and Craig were told he may not wake up as the Bailey that they know, if at all, and there were no medicines left to try. That's when they decided to try cannabis-based medicines.

They said: "From having hundreds of seizures a day, Bailey is now living his best life since taking cannabis-based medicines. He's doing everything from talking, bowling, arts and crafts, to cycling.

"Bailey will be accessing his own home with 24-hour care and be able to start a life filled with all the things he has missed out on over the last 18 years. Laughter and the biggest, most infectious smile have returned to his life, and we know the decision we've made will always be the right one. We will never give up on the life that Bailey deserves.

"We urge the UK government to take action – we don't have the luxury of time."

Murray

Murray spent over 240 days in hospital between January 2018 and April 2019 because of his epilepsy. Murray's mum Karen said between 2018 and 2019, he could have up to 600 seizures a day despite taking four epilepsy medicines. From March, Murray started taking a cannabis-based medicine containing a small amount of THC and things have improved for him. Karen said: "We need a policy change to allow our GPs to continue writing our children's prescriptions."

Teagan

Twelve-year-old Teagan, from Kent, has Lennox-Gastaut syndrome and a rare chromosomal disorder, which left her having up to 300 seizures a day. Her mum Emma said: "Three years ago the government changed the law, but in that time, there's been only one cannabis-based medicine licensed for epilepsy in the UK. There's something that will keep my daughter alive but I have to find £2,000 every month to do that."

Oliver

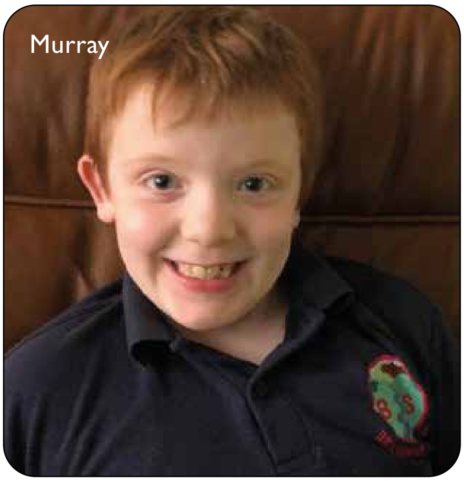
When Oliver was born, there was no indication of epilepsy – he was "healthy and happy". But just after turning two, Oliver had his first seizure, and since then he's had multiple seizures daily. But since trying a cannabis-based medicine, the whole family's lives have changed. His mum Michelle said: "Oliver tried drug after failed drug and his seizures were relentless and getting progressively worse. With each added drug came a whole host of side-effects that were so damaging to Oliver and his quality of life. Once we'd tried seven epilepsy medicines and a failed diet, we pursued medical cannabis. Within a few months of taking this medicine, his seizure burden went from hundreds everyday to 30-40 a day, which was really dramatic. And this was with no added side-effects. We successfully weaned off all other epilepsy medicines with no increase in seizures and the release from only being on a cannabis-based medicine was like a fog had lifted. We had Oliver back.

"Oliver underwent neurosurgery in the summer to try and reduce his drop attacks that were causing injuries. This surgery was successful and his recovery was good. He was left with only a few daily seizures that were less severe. With Oliver being so well and finally gaining weight we increased his CBD dose and within a few weeks Oliver had his first seizure-free day since his epilepsy started in 2018. This has been life changing for the whole family. With the regular relief from seizures that medical cannabis has brought, Oliver is able to learn, have fun, laugh and run around. It's been wonderful."

The situation is far from perfect, but organisations like Epilepsy Action and End Our Pain are putting pressure on the government to deliver on promises made three years ago. Whole plant cannabis-based medicines are anecdotally showing to be promising for hard-to-treat epilepsy, and more research is needed to make these medicines more accessible.

There is more information on cannabis-based medicines in epilepsy and the campaigns around making this more widely available at ***epilepsy.org.uk/medicalcannabis*** and ***epilepsy.org.uk/cannabis***

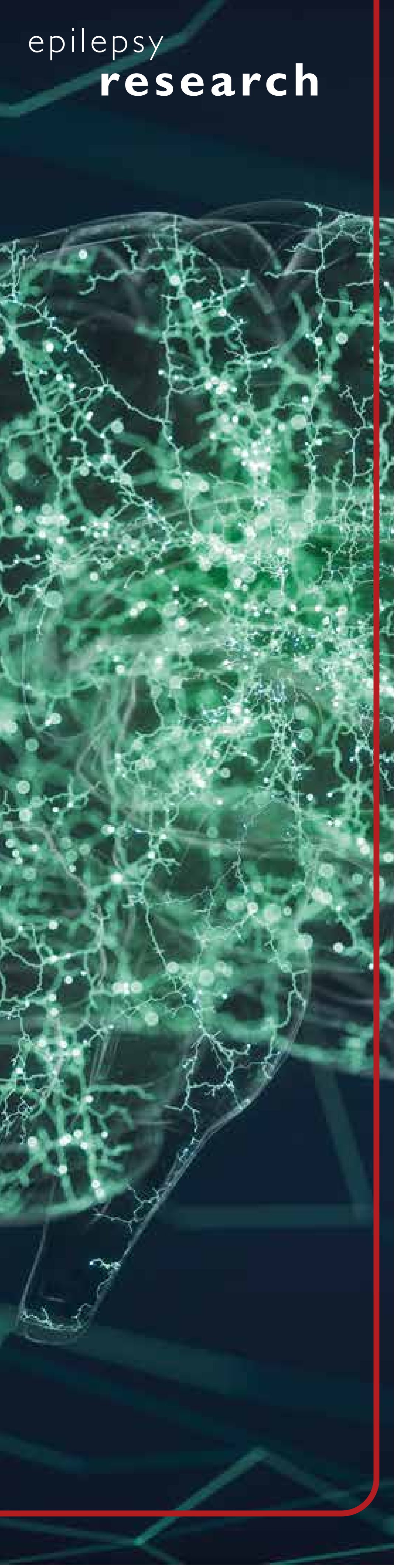
> With the regular relief from seizures that medical cannabis has brought, **Oliver is able to learn, have fun, laugh and run around – it's been wonderful**


Murray


Oliver


Teagan before...


...and after starting medical cannabis



Science advances

Kami Kountcheva shares some research highlights on wearable technology, brain stimulation and absence seizures from the 2021 International League Against Epilepsy's (ILAE) British Branch Annual Scientific Meeting

Attending scientific meetings is always an exciting prospect for me. It's really encouraging to hear all the work that is going on behind the scenes and find out more about research advances around the many aspects of epilepsy that people with the condition face every day.

Last year, I (virtually) attended the ILAE British Branch Annual Scientific Meeting (September 23-24), bringing together researchers and healthcare professionals from around the UK and beyond to share epilepsy knowledge.

There were many presentations, spanning topics like sleep and epilepsy, wearable technologies, brain stimulation and brain imaging. There is a lot of interesting work and research going on to help better understand the experiences of people with epilepsy and tackle the challenges epilepsy brings. Below we share some highlights from the meeting, including thoughts on the best seizure detection technology available at the moment, use and effectiveness of brain stimulation to control seizures, and treating absence seizures.

Wearable technology

Professor Mark Richardson, vice dean of neuroscience at King's College London presented on wearable technologies in epilepsy. He started off by saying that there are two important blind spots in epilepsy management – a lack of accurate and reliable information about seizure occurrence, and a lack of accurate and reliable information about how well people stick to their medicine programme.

To assess the effectiveness of medical devices, Prof Richardson looked at ones with medical approval for use in seizure detection, or ones with evidence of effectiveness.

The available devices can detect a number of different features, such as heart rate and movement. But for most cases, these devices are used to detect generalised tonic-clonic seizures. Prof Richardson stressed that there is not a device on the market or with evidence of being effective for focal onset seizures at the moment.

Prof Richardson selected three main devices to focus on which had good published evidence – the Empatica Embrace, the Brain Sentinel SPEAC System and the Livassured NightWatch.

The Empatica Embrace has been approved by the Food and Drug Agency (FDA) in the USA and has a CE mark certification for use in Europe. It measures movement, as well as the skin's electrical signals and temperature. Events detected show up on a phone app that can alert someone if the device detects a seizure. An early paper on this device involved 69 people in a hospital epilepsy monitoring unit. In this study, when adjusted to offer good sensitivity, the device could detect 52 of 55 tonic-clonic seizures, but there were also 50 false alarms. The time between the event happening and the device raising the alarm was fairly long, up to two-and-a-half minutes in some instances. Prof Richardson estimated that for every 100 true seizure detections, people in this group would have had 95 false alarms and five missed seizures.

Prof Richardson said that these were not the data used by the FDA to approve the device. The FDA data are unpublished but available on the FDA website. The FDA requires the device set-up to offer 100% detection rate, so it was adjusted to increase the sensitivity. This meant that it detected all the seizures in the study (40), but the false alarm rate was 117. Prof Richardson said that this meant for every 100 true seizure detections, there were nearly 300 false alarms. He added that the price of better sensitivity to seizures is a very high rate of false alarms.

The SPEAC device also has FDA approval and a CE mark. This device measures electrical activity in groups of muscles – known as surface electromyography or sEMG. Published data suggest the device detected 35 out of 46 tonic-clonic seizures, but with 970 false alarms. This means that for every 100 true seizure detections, there would be 2,766 false alarms, Prof Richardson estimated. In the study, the researchers analysed a subgroup of people who had "placed the device correctly", and got 100% seizure detection, but still a very high false alarm rate. Prof Richardson posed that it might not be an ideal device for use in the real world if it's difficult to place correctly.

The NightWatch is an upper arm band for detecting tonic-clonic seizures during rest or sleep. It works through motion detection and measuring heart rate changes. It has been tested in a real world setting of 34 adults with intellectual disability in a long-term care centre. The device correctly detected 696 out of 809 seizures with 59 false alarms. This meant for every 100 true detections, there were eight false alarms and 14 missed seizures.

Prof Richardson said that comparing devices isn't always straightforward because the devices are a combination of the technology and also the way it is programmed. However, he said in all the devices, there is a trade-off between sensitivity and false-alarm rate. He added that in his opinion the Empatica Embrace or the NightWatch are the best options available at the moment, as the SPEAC device had too high a false alarm rate.

Prof Richardson also touched on wearable EEG devices. He said that among people with epilepsy, devices stuck to the head or worn as an arm band were not considered as acceptable for long-term use. However, new technology called subcutaneous EEG, which does not require an operation to be fitted, is now undergoing trials. These devices collect really good data and provide opportunities for tracking EEG over very long periods of time, Prof Richardson said.

In the future, people may be using wearable technologies and have data on their mobile phones, and there may be a way to use this data to forecast seizure risk for individuals in the future.

Neurostimulation

The keynote presentation was delivered by Prof Michael Sperling, professor of Neurology at Thomas Jefferson University in the US, on neurostimulation in epilepsy. This is the use of electrical stimulation in the brain to try to reduce seizure frequency and severity. This is through techniques like deep brain stimulation (DBS), responsive neurostimulation (RNS) and vagus nerve stimulation (VNS).

Prof Sperling explained that a number of areas of the brain have been suggested as candidates for neurostimulation. His talk focussed on approved techniques – DBS, RNS and VNS. He explained that all of these are usually done with a view to reduce the effect of seizures, rather than expecting them to stop them completely, and that these options are offered to people who are not suitable for traditional brain surgery.

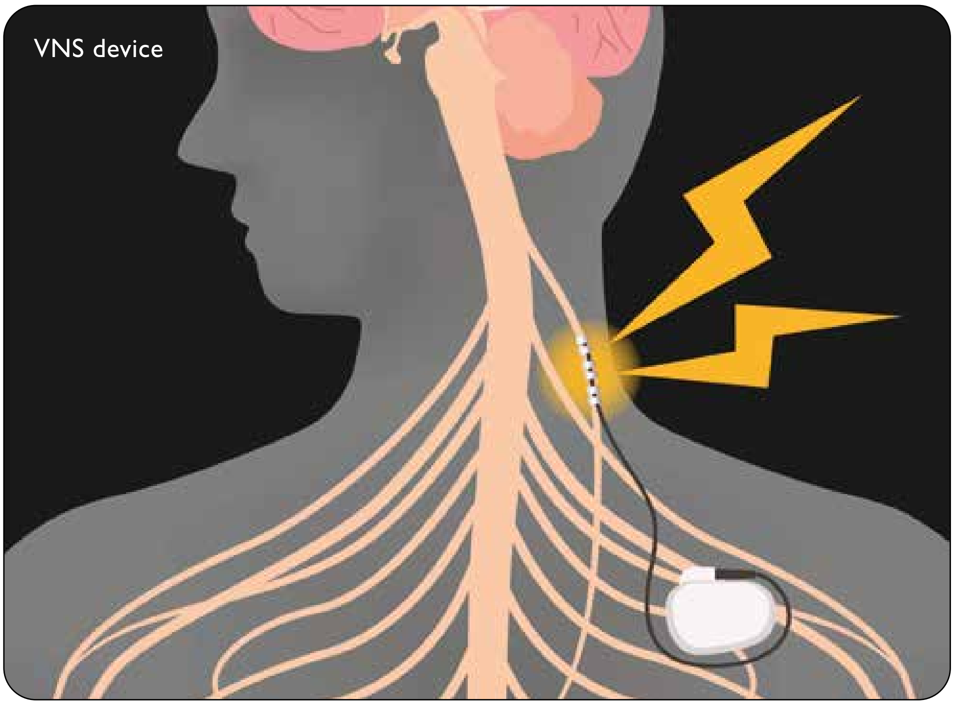
VNS

For VNS, a device is fitted under the skin in the chest and sends impulses to the brain through the vagus nerve in the neck. Prof Sperling explained that this is an established method and has been approved for over 20 years. It is set up to send regular impulses to the brain and can also be programmed to respond when a person's heart rate reaches over 100 beats a minute – known as tachycardia. Both variations also allow the person or a carer to trigger VNS stimulation by hand with a special magnet.

Prof Sperling explained that evidence shows VNS reduces seizures by around half, and it works better after a year of use than it does in the first couple of months, whether or not a person changes their epilepsy medicine. However, seizure freedom occurs in less than one in ten people, and most of these people end up having seizures again further down the line, he added.

Data on automatic stimulation based on heart rate going above 100 beats a minute suggest that catching a seizure early and triggering the device has a


Prof Richardson focused on three wearable seizure detection devices – Empatica Embrace, SPEAC System and the NightWatch



better chance of stopping the seizure before it spreads, Prof Sperling said. However, there are not enough data on this to be sure. However, increasing the sensitivity can mean more false positive detections and more stimulation from the device in the day.

There are some possible side-effects with this device, Prof Sperling highlighted. Areas of the neck could be injured, and it can affect a person's voice, especially people who talk a lot as part of their day, such as teachers. It can make sleep apnoea worse in people with this condition. Sleep apnoea is a sleep disorder where breathing repeatedly stops and starts during sleep. Prof Sperling pointed out that the LivaNova VNS can be programmed to switch off for a while before bedtime to help with this, but this needs to be adjusted in the clinic for clocks changing twice a year. VNS is also not suitable in people with certain conditions, such as severe mental health conditions, severe heart diseases and breathing problems, such as asthma.

Prof Sperling also noted that some data suggest that VNS reduces the risk of sudden unexpected death in epilepsy (SUDEP). At two-years follow-up, one study found that this was at a rate considerably lower than would be expected for people with medicine-resistant epilepsy. But there was no proof to say this was due to the VNS. Other studies have also hinted at this effect, but there is a lack of data generally, and more studies are needed. Prof Sperling said possible reasons are that VNS reduces the number of seizures, that it reduces inflammation or that it increases heart rate variability.

RNS

Next, Prof Sperling discussed RNS. RNS is a neurostimulation method which is most suitable for people with focal seizures starting from one or two known places in the brain, but in whom epilepsy surgery is not an option. It involves two electrodes and a small plate being fitted under the skull and contacts for the electrode placed in the place where seizures start. The device detects a specific electrical signal from these areas of the brain and delivers a brief electrical impulse.

Prof Sperling explained that trial evidence shows that long-term treatment with RNS for medicine-resistant focal seizures works by preventing seizures from occurring rather than stopping them once they've started. Trials show improved quality of life with this treatment, and many patients have their seizures reduce by more than half. Around two-thirds of people (60-70%) responded to this kind of treatment, regardless of where in the brain their seizures started.

The risk of SUDEP also appeared reduced with this treatment in people with medicine-resistant seizures, according to some data, Prof Sperling noted.

DBS

DBS is another technique where electrodes are inserted into the brain to deliver electrical impulses to try to reduce seizure number and severity. Prof Sperling explained that this method reduces seizures by two-fifths (40%) in the short term, but there is a higher risk of infection than with other techniques, like VNS. However, in the longer term, after around seven years, DBS can be 70-80% effective.

Prof Sperling again highlighted that the risk of SUDEP was lower than would be expected in people with medicine-resistant epilepsy with this type of treatment too.

Prof Sperling warned that evidence is limited and randomised controlled trials are lacking, so while all three techniques show a lot of promise, more trials are needed. Controlled randomised trials would also be important to confirm the effects of neurostimulation on SUDEP.

Absence seizures

One of the sessions of the meeting was dedicated to absence seizures and their management. Prof Matthew Walker kicked the presentations off, discussing the mechanisms of absence seizures. He explained that absences occur when there is a certain pattern of electrical waves on the surface of the brain. Depending on how much of the surface of the brain is affected, the normal function of the surface areas of the brain could be hampered, leading to loss of consciousness.

The nature of the way absence seizures happen means that some epilepsy medicines, including vigabatrin and tiagabine, can make them worse, because of where they work, Prof Walker explained. He added that absence seizures are not characterised by excessive electrical activity in the brain, like others are, but by the way they stop and start electrical activity on the surface of the brain.

Epilepsies with absence seizures

Dr Britta Wandschneider, consultant neurologist at Barts Health NHS Trust in the UK, presented next on the epilepsies which typically involve absence seizures. She described a typical absence seizure as coming on suddenly, involving a loss of consciousness, becoming still, staring, eyes drifting upwards and flickering eyelids. This could last from two to over 20 seconds. Dr Wandschneider added that nine in 10 of these seizures are caused by rapid or deep breathing known as hyperventilation.

She said absences can be simple, with a brief loss of awareness, or more complex with repetitive movements, loss of consciousness and jerks. She added this can make them hard to distinguish from focal impaired awareness seizures.

Typically, childhood absence epilepsy (CAE), juvenile absence epilepsy (JAE) and juvenile myoclonic epilepsy (JME) are epilepsy syndromes that involve absence seizures. Dr Wandschneider said that often, good seizure control can be achieved with these conditions, but about one in five will continue to have seizures.

Dr Wandschneider said people with these syndromes may have more trouble than others with things like employment, educational achievement and quality of life. In some people with these syndromes, there can also be some learning disability or their cognitive abilities, such as their thinking, learning and remembering, can be affected. She also noted that studies point to a genetic element to these conditions.

These absence syndromes can really affect quality of life for people, Dr Wandschneider said. They can sometimes be overlooked by healthcare professionals, but need to be addressed.

Treating childhood absence seizures

Finally, Dr Andrea Whitney, consultant paediatric neurologist at Southampton Children's Hospital, delivered the last presentation of the session, on treatment for absence seizures in children. Dr Whitney explained that among medicines that could be prescribed, lamotrigine turned out to be less effective than other options including ethosuximide and sodium valproate. In terms of effectiveness, ethosuximide and valproate were both fairly equally effective. However, sodium valproate is known to cause problems in babies if used during pregnancy, often making ethosuximide the better choice.

Evidence showed that between these two medicines, there was around a two-thirds chance of having a breakthrough seizure while taking sodium valproate Dr Whitney said. This was only one third in people taking ethosuximide. She added that this was linked to stopping the medicine, in some cases, whereas with sodium valproate, it happened when people were still taking their medicine.

Dr Whitney added that with ethosuximide, evidence suggested that seizures stopped in around three in four children after five years on the medicine and five years after it was withdrawn. This was lower in children taking sodium valproate, at just over one third (39%). Dr Whitney proposed that this could suggest that ethosuximide may actually treat the underlying epilepsy, rather than just treating the seizures. However, more research needs to be done into this.

Dr Whitney suggested that the order of medicines to try should be ethosuximide, then valproate, then lamotrigine, and then a combination. However, she highlighted that the way to treat female patients may well be different, with the risks around sodium valproate. She suggested offering lamotrigine and levetiracetam before trying sodium valproate, but for those who still have seizures, a discussion has to be had with the family about the balance of risk of prescribing sodium valproate. She added that discussing risks needs to be supportive, sensible and pragmatic, and that families need the information to make an informed choice.

Epilepsy meetings and conferences are always really interesting to be a part of. It's a chance to take a peek at the exciting projects, new research and advances in understanding that are going on in laboratories and research offices around the country and beyond. The next ILAE British Branch meeting is due to be held in Cardiff in October. I'm looking forward to finding out what this year will bring.

More information

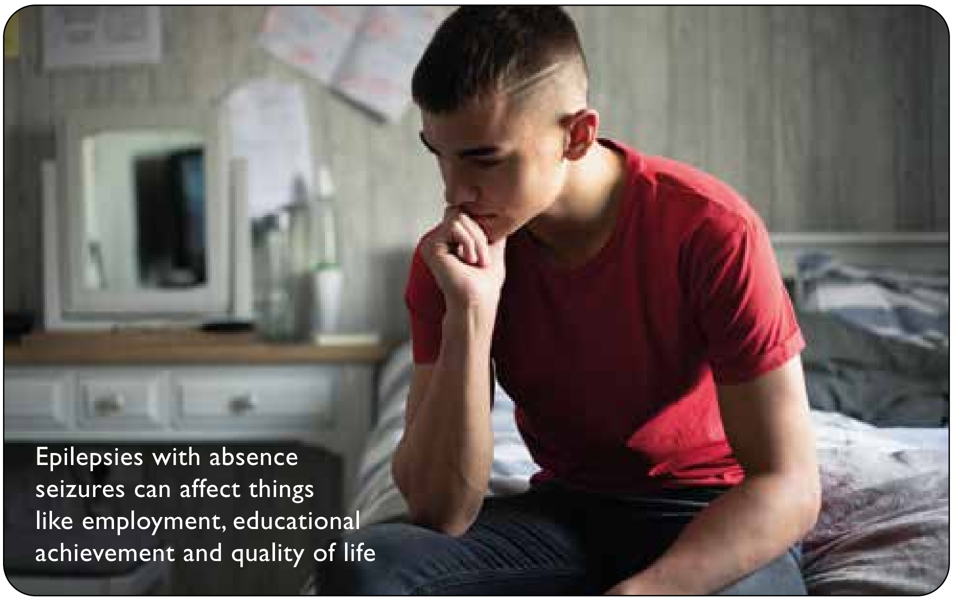
There is more information on the topics of the article on the Epilepsy Action website.

Wearable devices – ***epilepsy.org.uk/alarms***

VNS – ***epilepsy.org.uk/VNS***

DBS – ***bit.ly/3AqPEAa***

Absence seizure – ***epilepsy.org.uk/absenceseizures***



Epilepsies with absence seizures can affect things like employment, educational achievement and quality of life

5 amazing things
you did in 2021

Your support is the fuel driving every resource, event and campaign that we have at Epilepsy Action. Here are five huge ways in which you directed and supported our work and the impact that it has

1 You took on challenges

Last year started much like most of 2020 was spent – in lockdown, with restrictions and with COVID-19 very much casting a shadow over all our plans and hopes for the year. But despite all of that, last year you took on extra challenges to support others with epilepsy, be it walking, running or giving up your vices. Your tenacity and excitement for these events was unmistakeable. In February, you ran 50 miles in your droves. Come rain or shine, you donned your running shoes and you jogged up and down the country during the coldest and dreariest month of the year.

In March, you gave up your favourite things to raise money. Some closed the cupboard doors on crisps, biscuits and chocolate for a whole 31 days, others cut caffeine and alcohol out of their diets, some said no to meat and bread. Some people even gave up being sedentary and took on extra walking for the month.

In May, for National Epilepsy Week, you stepped up again, walking 50,000 steps in seven days. Through all of these challenges, you pulled epilepsy out of the shadows, and you helped raise in excess of £300,000 at the same time!

> *Epilepsy Action was so important to Lisa, and still is. I know there's still so much work to be done, awareness to be raised and lives we can save*

The challenges didn't end there. The London Marathon took place in October last year, and many of you tested yourselves physically and mentally yet again to raise money and awareness for people with Epilepsy. Patrick ran the marathon in memory of two family members who died because of their epilepsy – his aunt Mary and his partner's sister in law Lisa. He said: "Epilepsy Action was so important to Lisa, and still is. I know there is still so much work to be done, awareness to be raised and lives we can save. Donating £20 a month and running the marathon is me doing my bit to help."

Anne ran the virtual London Marathon too, in memory of her sister Brigid, who had epilepsy for 23 years and died after having a seizure in the bath. She said: "Losing Brigid was very hard for me because we were very close. She coped with this debilitating condition bravely. I was thinking of Brigid every step of the way, hoping she was looking down on me in my endeavours in her memory. I was very pleased to have done the London Marathon for Epilepsy Action, such a very important and personal charity."

2 You shared your views

For last year's Purple Day, we asked you what was the one thing you would like people to know about epilepsy. You shared your thoughts with us, with one in five people saying they wished people knew more about the different seizure types. People also wanted more awareness of the fact that not all seizures are triggered by flashing lights and that epilepsy is a fluctuating condition, with better and worse periods.

> *It's been amazing to work with the Epilepsy Action team. I have never felt this heard or appreciated when it comes to speaking about my condition, and it has been such a cathartic experience*

But overwhelmingly, more than half of you said that the one thing you wanted people to understand that epilepsy is about more than seizures.

Your views and experiences with epilepsy are incredibly important, as they informed all the Purple Day work we did. It allowed us to raise more awareness of the aspect of epilepsy that was your top priority, through radio, news outlets and social media. Your Purple Day support raised a brilliant £90,000 for people with epilepsy.

3 You gave us your feedback

With the way the last two years challenged all of us to adapt, we've had to change the way we work quickly and dramatically. We created a web page on the website dedicated to information around COVID-19 and epilepsy, which proved extremely important. In the first three months of last year, there were nearly 78,000 visitors to the page. The time spent on this page was equivalent to 79 days of non-stop browsing in the first 89 days of 2021. While sometimes, we can see the numbers to know something is working, other times it can be hard to know how these changes reflect on all of you, who use our services. This is why hearing back from you is invaluable.

One big change has been adapting our local groups from face-to-face to virtual, to allow you to continue to meet and connect with others in the same situation as safely as possible. It was fantastic to hear, through a survey conducted this year, that the groups were still working well for you. Of the people responding almost everyone (98%) felt that attending the virtual local groups helped them stay connected with others. Nine in 10 people (93%) felt that attending a group has helped them gain practical information and support. A similar number of people (88%) also said the groups helped them feel better about living with epilepsy. Hearing from you is the one way that we can make sure the services we deliver are working for you.

4 You campaigned with us

We have had many campaigns over the years, but your support is the thing that really brings them to life. One big campaign from last year called on the government to make the welfare system fairer for people with epilepsy, so they can access the support they really need and rely on (more on page 22).

As part of the campaign, we called on you to fill out a survey about your experiences claiming personal independence payments (PIP) and to share your stories. You answered our call – as always – with brilliant insights into your feelings about the system as it is, and the ways it is failing people with epilepsy. We have built on what you shared with us, and have been able to present these findings and concerns in government, as well as share them far and wide across national and regional TV and social media to raise awareness of the issue. Hayley, who shared her experiences as part of the campaign, said: "Thank you so much for everything surrounding the launch of this campaign. It's been amazing to work with the Epilepsy Action team. I have never felt this heard or appreciated when it comes to speaking about my condition, and it has been such a cathartic experience."

The campaign is still ongoing, and there is more information about how you can get involved on page 22.

5 You gave generously

It's only your support that makes the work we do possible – there would be no Epilepsy Action without you. Last year you rallied once again, despite lockdowns and uncertainties,

Ella


Cate

and gave your time, your energy, your expertise and your donations, to help so many others affected by epilepsy.

Every penny you raise and donate helps us be there for people at their lowest ebb, create spaces to share and grow in confidence, and fight for better support and services.

Ella, Cate and Paul's stories are just a few examples of the invaluable difference you make to so many lives.

Ella

"I called the Epilepsy Action Helpline because my seizures were so bad and it was really affecting my mental health. It even made me even doubt why I live sometimes.

"It was just so nice to talk to someone who understood! Speaking to someone on the Helpline really helped me feel like a normal person. I don't think I'd be here today without that call. Thank you for giving someone like me a chance to live seizure-free!

> *After the first meeting, I felt like a weight had been lifted off my shoulders*

"I'm very fortunate now to be able to fundraise and be part of the work this amazing organisation does.

"Epilepsy Action is genuinely such an incredible charity. If you need any info or advice on anything to do with epilepsy, they're always ready to help, over the phone, over social media and on the website."

Cate

"I took part in an online support group because my epilepsy was not under control and I felt very isolated.

"Talking to other people who were in the same boat really helped me process my epilepsy and understand I am not alone.

"After the first meeting I felt like a weight had been lifted off my shoulders. I am a lot more positive because of the groups. I can support other people now because my epilepsy is under control for the first time in about eight years. I feel less isolated and more part of a community.

"The groups have been a lifeline to me because I have depression and anxiety and it has boosted my confidence. I've got my stress under control now and have been three months seizure free!"

> *Raising awareness has had such a massive impact on our lives, especially in our community. People now know what we go through on a daily basis*

Paul

"Thank you for giving us the opportunity to raise awareness of epilepsy and how it affects the sufferer and their families.

"This has had such a massive impact on our lives, especially in our community. People now know what we go through on a daily basis. They have seen the types of seizures I suffer from.

"When I shared my story for Purple Day, I said how people had mistaken me having a seizure for being drunk or on drugs.

"Now we both feel a lot more confident out and about. Better than that, we have actually had help from members of the public when I've had seizures outside! It really does seem that people do understand better. We know we can't get through to everyone, but we are so happy with what we have achieved!"

Thank you for all your support over the last year, it really is life-changing.


Paul

Out of the dark

Coming to terms with an epilepsy diagnosis, and how much it affects your life, can be really challenging. Saima shares her experiences of her daughter Laila's epilepsy

Some of us may be able to think back to the first time we heard the word epilepsy from a doctor delivering a diagnosis. Whether it was said to us, or a loved one, it can set off a wave of emotions and questions. But for many of us, it is as the days and weeks go by that we start to slowly realise the true impact of the condition.

That first step into the unknown can feel terrifying and isolating. An epilepsy diagnosis can turn your life upside down, derail plans and dreams and make you question your or your loved ones' future prospects. It can be a truly difficult moment. Saima shares how her and her family's day-to-day life changed when her daughter Laila was diagnosed with epilepsy, and how she copes and stays strong.

Saima explained that epilepsy first came into her life around four years ago. Her eldest daughter Laila was struggling at school, and Saima was called in to discuss this. Despite being nine at the time, the school said that Laila's work was that of a much younger child and that Saima may need to take her to be checked over by a doctor.

"It was like they already knew there was something. I remember getting her eyes checked, because she was doing this daydreaming and I thought that maybe she was trying extra hard.

"And then one Saturday, we had an appointment at the hospital and Laila kept having these, what I thought were, daydreams. The doctor looked over at her and whispered to me 'I know we've not got a diagnosis yet, but I can clearly tell that you daughter's got epilepsy.' My heart sunk – that word just seemed so scary."

Over the next few weeks, Laila had some tests and her epilepsy diagnosis was confirmed. She was prescribed ethosuximide to try to control her seizures, but Saima said that the family continued to do their usual activities as a family, not letting epilepsy slow them down. However, Laila was still having up to 100 absence seizures a day.

Shortly after Laila's 11th birthday, she had her first tonic-clonic seizure. "I was upstairs, it must have been about 11 o'clock," Saima recalled. "The scream I heard... My husband screamed for me to come downstairs. That was the first time I saw Laila having a tonic-clonic seizure.

"I know that you've got to be strong, but as a mother, seeing that, it was like someone had just pulled my heart out. I couldn't help, I was just shouting her name. I can't even remember ringing the paramedics, but when they got there, I was just begging them to help her. I was saying to them: 'She's got epilepsy, but this has never happened before, I don't even know what this is.' I had so many questions. Was it something I'd done? Was I doing something wrong as a parent?"

Laila stayed in hospital overnight. Saima said that this being during lockdown as well, there was no one to help and they felt completely alone. After this, Laila was diagnosed with a juvenile epilepsy syndrome and her medicine was changed from ethosuximide to levetiracetam.

Saima with two of her three daughters, Laila and Anya

Laila is nervous about having seizures at school

Laila experienced a lot of side-effects from levetiracetam. Saima said her 13-year-old daughter is like any other 13-year-old – she enjoys watching TV and listening to music (particularly "these Korean pop bands that are around now").

"She is quite a happy girl," Saima explained, "she's always been positive and upbeat and happy-go-lucky. She has two younger sisters, seven-year-old Anya and six-month old Eleyna, and she is very caring over them. She is just overall a really good girl and she does quite well at school as well.

"But this is what Laila is like on a very good day. Because she has side-effects from her medication, her mood can go down and she becomes very depressed, crying a lot, and very angry. She can be in such an awful mood, and sometime she's so quiet that you worry as well. She can become paranoid and confused due to the medicine side-effects too. "

Laila's medicine is being changed to lamotrigine, but it's not just the side-effects making things difficult for her. She is also scared of having a seizure, and especially of having one in front of anyone else as well, which can also make her panic and feel low. Saima said this is one of the biggest struggles for her. She is embarrassed by her epilepsy and is very nervous about having a seizure at school. Laila has also given up swimming, which she used to really enjoy, finding it annoying having to be chaperoned in the water.

Saima explained that she got information about epilepsy from Laila's doctor and a specialist nurse, and sought out videos about epilepsy on YouTube. But she said this didn't prepare her for how life would change for the whole family. It didn't prepare her and Laila for how Laila would feel about her seizures, being so nervous and self-conscious that it would bring on panic. It also didn't prepare Laila for losing friends because they thought her absence seizures were standoffishness. And Saima had no idea how her own life would change too.

"Eight or nine months after the first tonic-clonic seizure, there were more seizures. After this, and seeing Laila like that, I now sleep in the same room as the girls, because I have to be on watch. I don't know if other parents did this, but I have my own bed just next to hers and I watch over her. I don't even know how much I sleep, I just keep waking up – I've got timers set – and I check up on her, because she has had a tonic-clonic seizure in her sleep before. I check up on her if she's having a bath, I walk in front of her down the stairs in case she has a seizure, so I can hold her. I'm always watching over her.

"It really feels like a family battle, dealing with this condition, not just the one person. Even her sisters are affected. Anya is only seven, but she's told her friends at school that she is scared because her sister has epilepsy and she changes. A seven-year-old shouldn't feel like that, she's constantly walking on eggshells.

"And I'm on edge too. If someone even shouts in the house, my heart just sinks, because I think 'Oh no, what's happened?' It's that constant fear. Even if they haven't had a seizure in a few weeks, other people might think that we feel fine, but for a parent, it's not like that. You're constantly on watch, you're constantly scared. My daughter is a teenager now, and growing up, and you want to give them that freedom, but it's really hard. She even asks me things like 'When am I allowed to lock the bathroom door?'

"Even just going out for a family activity, you have to check every little thing, you just can't do things as a family the way you could before. It's such a restriction on life. I wish I had read more about it beforehand. Before this, I always thought you have a seizure and you get better, but it hasn't happened like that. Until you're walking in those shoes, you can't understand the day-to-day life. It's like a black cloud over my head, and it's always there, it never goes away. I think epilepsy is a condition that's just not talked about as much as it should be."

Saima said the condition also creates a strain on her marriage, when she and her husband disagree about how to talk about Laila's epilepsy and seizures with her. It has been a challenge to accept for her family as well, who refused to believe she had epilepsy, saying Saima shouldn't be saying things like that. When Laila started to have tonic-clonic seizures, some family members asked if she had contacted a priest. Saima said that this may not be the case in all Asian communities, but in her community, she found there is still a lot of stigma around epilepsy.

> I don't even know how much I sleep, **I just keep waking up and I check on her because she has had a tonic-clonic seizure in her sleep**

However, with all the challenges, there have also been positives for Saima and Laila. As the family have navigated through what Saima called their "new reality" Laila has broadened her interests and Saima has found ways to cope and be kind to herself.

"I always tell Laila that she should be proud because her brain is so amazing, even doctors can't work it out. Epilepsy is difficult, but it's not something you should stop your life for. Since she can't do swimming, we have tried a lot of things we didn't do as much before. Laila loves reading, her bedroom is like a library, with lots of books. She likes writing as well. I bought her a few diaries and I told her to write things down – positive and negative – and look back on what she's written so she can see how far she's come. We like to go on walks as well, and she likes drawing and she loves singing and dancing, so that's something epilepsy hasn't taken away from her. Sometimes I think, if she didn't have the diagnosis, she might not be so into some of the things that she is.

"As for me, I have good days and bad days. I often think that if I'm negative, it's going to impact on her, so I try to look for the positives where I can. For example, I will tell her that we're lucky to be in this country, because if we were somewhere else, we might not have had a diagnosis or medication or support right now. But some days I'll say to my husband 'I'm going to go and get groceries, but I'll have a good cry in the car'. You need to be good to yourself as well. Sometimes I would go to my mum's house and just sit with her, or go for a walk, or go for a coffee. It's important, because if you're stressed, your child can sense that mum is feeling down."

Despite everything Laila is confidently determined that she wants to be a neurologist when she's older, finding the work neurologists do fascinating. Saima explains that she strives to find a good balance between supporting Laila's ambitions for the future and also managing her expectations if her seizures don't become controlled.

"I think of times when she's grown up and will want to leave her mum and dad's house and spread her wings and go, and that scares the life out of me. But epilepsy shouldn't have a hold of your life, you should still try to do all the things you want to do.

"I look at Laila and all three of my girls and I think life is a lottery and some people have money in their lottery, but I've got my three daughters and there's no bigger prize than that. Whatever challenges I get, I'm ready."

To mark Purple Day this year, Epilepsy Action is shining a light on this challenging time. Look out for Purple Day activities and a very special video this March. Keep an eye on ***epilepsy.org.uk/purple*** for updates and you can get a fundraising Purple Day pack at ***epilepsy.org.uk/purple-pack***.

If you have questions or difficulties with your or a loved one's epilepsy, you can contact the Epilepsy Action Helpline at 0808 800 5050 or email ***helpline@epilepsy.org.uk***. You can also find information online at ***epilepsy.org.uk/info***.

Saima says after Laila gave up swimming, she found a lot of new interests like drawing, writing and reading

Unfair welfare

A recent survey by Epilepsy Action revealed some deep-set flaws in the welfare system, leaving people with epilepsy in challenging or desperate situations

Over two-thirds (68%) of people with epilepsy have been left 'unsatisfied' or 'very unsatisfied' with their Personal Independence Payment (PIP) assessment, according to new research by Epilepsy Action.

PIP is a government benefit designed to support people living with a long-term health condition or disability with the added costs of care, including daily living and mobility.

Epilepsy Action has called the system "chronically flawed" and has said it is "failing people with epilepsy". The organisation is calling for a drastic overhaul of the PIP system, "including fairer assessments and reporting to ensure people receive the support they need".

In the survey of 700 people who have claimed PIP, four in five (82%) respondents stated that their assessor did not understand epilepsy and over three-quarters (78%) said they did not believe their medical evidence was taken into account.

Two-thirds (68%) of respondents also said their PIP assessor did not record their answers accurately, and over half (58%) said the PIP application form did not allow them to fully explain their condition.

Of the successful PIP claimants, 63% reported that the money they received was not enough to cover their extra living costs.

Unwilling to understand

Epilepsy Action has criticised the assessment process and is calling for better medical training for assessors on fluctuating and invisible disabilities like epilepsy. This is following evidence from survey respondents that assessors were "unwilling to understand their condition". Respondents said that assessors made "informal judgements" about their health based on observations unrelated to their condition.

One respondent said: "My report stated I wasn't suffering from depression because I gave her eye contact throughout the interview, even though I had evidence from the doctor stating otherwise.

"In the report, they miswrote some things and outright lied about others. They claimed I couldn't have medical issues or seizures because my nails were painted."

Another survey respondent, Hannah, said ignorance and lack of awareness of epilepsy is the biggest problem for her when applying for benefits: "I felt in PIP assessments that the evidence I provided was completely disregarded and as a result, I only get half the amount of money I qualify for. I only get the mobility aspect, but not daily living."

Another respondent, Hayley, was put off reapplying for PIP after her previous experiences. She added: "This whole process is more stressful than I care to experience as my main trigger [is] stress. How can I not be stressed at the idea of losing my home, my health and my independence and much more?"

> **My report stated I wasn't suffering from depression because I gave her eye contact** throughout the interview even though I had evidence from the doctor stating otherwise

Left out information

Vicky has sleep seizures and despite trying many different epilepsy medicines, her seizures are not fully controlled. She is not eligible for brain surgery, but had a VNS put in, which means she now has fewer tonic-clonic or focal seizures, and they've mostly changed to tonic or short clonic seizures. She also has difficulties using her right arm due to a suspected stroke when she was a baby.

"All of this can impact my life a lot," Vicky said. "It affects my memory and I can struggle with basic things such as cutting up bits of food."

While some of her struggles are linked to her stroke, Vicky's right arm is also often affected by her seizures. Vicky has little energy and is struggling to get a job, which in turn puts pressure on her husband to work and look after Vicky. Vicky's seizures also mean she can't drive, so she has to rely on friends and family for lifts, or taking taxis or public transport.

"On a scale of 1 to 10 for how stressful I found the process when applying for PIP, I would say it was a 10. The assessor was hopeless and left out a lot of information I'd told her or misquoted me about what I put in my form. For example, I told her I need my pills in blister packs from the chemist as I can't organise them myself and that I need to have reminders on my phone to take them, but even then my husband has to remind me as sometimes I don't notice the phone reminders when I'm really tired. Yet despite this, the DWP said I needed no help (so no points) for handling my medication as the assessor hadn't included any of those details in her report.

Vicky appealed the PIP decision, which meant it was looked at again by a tribunal.

"I also found it very stressful going through the tribunal which caused me to have more frequent and stronger seizures. I was initially turned down for PIP. The DWP gave me a deadline to send my appeal letter in by, but it took over three months to get the medical report from my assessor so I knew what to put in the appeal letter. So I had to guess what to write in the letter to get it in in time for the deadline. If I'd received the report on time, I could have written a more relevant appeal letter and maybe I wouldn't have had to go to court.

"My PIP has been extended until December 2024, but I hate the thought of re-applying and am worried about the cost of living going up, as I very much doubt they'll increase PIP accordingly. I want the DWP to be more organised. They shouldn't give people a deadline to appeal their case and not provide us with the documents we need to prepare for the appeal until after the deadline. I want them to employ more qualified and more professional assessors – not ones who miss out vital information from their reports."

Vicky felt that her PIP assessor left out information she gave and misquoted her

Donna said she things there is still a lot of ignorance around hidden disabilities

Ignorance around hidden disabilities

Donna had epilepsy as a toddler in the 1970s, but was only formally diagnosed as an adult at 46 years old after a prolonged tonic-clonic seizure. As well as tonic-clonics, Donna has absence and focal impaired awareness seizures. She ended up being given ill health retirement despite asking for reasonable adjustments and wanting to continue working.

Donna explained that she finds the PIP application and interviews very stressful, and the paperwork difficult. "I don't think the assessors understand that epilepsy isn't just about having seizures. I also have significant memory and word recall issues, anxiety, insomnia and migraines, all related to epilepsy. My anxiety can be so debilitating that I have almost come to a point of self-harm."

Because of Donna's conditions, she can sometimes forget simple tasks such as taking her medicine, eating or how to operate the microwave. She has trouble being left alone and struggles with socialising, worried that she would forget words or have a seizure in public.

The help Donna needs at home is usually around reminding her of things. However, she also sometimes needs help after having seizures which result in injuries.

"I have had seizures in the shower and damaged both my shoulders. I had to have surgery to repair them. We are having a new shower installed soon so my husband can more easily step in to help me if I have a seizure whilst showering. This is very expensive, so I appreciate any financial support, especially as I do not receive any additional benefits.

"It seems almost a waste of time to have to be reassessed for PIP every two years. I think there is still a lot of ignorance around hidden disabilities. Stress is a big trigger for me so it would be helpful if I didn't have to keep completing the same paperwork and be put through the same humiliating interview. On the day of my PIP assessment, I had three seizures and I will do anything in the future not to provoke seizures and this may mean that I will not re-apply.

"When I received a written copy of the assessment and what I had been awarded (I was awarded the lower level daily living allowance), a comment was made that as I was able to answer some of the questions quite comprehensively myself, then I don't need much help. It was also noted that I should be able to use a microwave and that would be enough to meet my nutritional needs. I can physically put food in and out of the microwave but quite often my husband has to instruct me as I forget which buttons to press. He tells me he often finds the milk in the dishwasher. I think there is an assumption that people with epilepsy always have just bad days or just good days with nothing in between.

"It is very upsetting that PIP assessors do not recognise that epilepsy isn't just about dropping to the floor and foaming at the mouth. So I am prepared that I will not receive PIP next time now that my seizures are more controlled. Financially, having PIP takes a huge pressure off me, especially with travel costs. My husband and I have already had discussions about my next application and the stress it will involve. We have decided that it will probably be easier to sell our current home and buy something cheaper to alleviate some of the financial pressure if I no longer receive PIP."

> A comment was made that as I was **able to answer some of the questions quite comprehensively myself, then I don't need much help**

Government's lack of understanding

Andrea has tonic-clonic seizures, usually twice a month, as well as "frequent blackouts". Her seizures leave her exhausted and their after effects continue for days.

"I sleep for the whole day afterwards and can't function at normal speed for several days after," she explained. "I have two sons, aged 17 and 9. My youngest saw me have a seizure recently which really scared him.

"I'm from a strong military background and was always brought up to be self-sufficient. Claiming benefits was not in my nature. But I've struggled to find work since March 2020. I have two kids and I was becoming housebound and my costs were, and still are, mounting up."

> **There is a woeful lack of training** and assessors are quick to dismiss the severity of the condition

Andrea explained that when she tells potential employers about her epilepsy and diabetes, they find reasons not to employ her. She has now gone into full-time education to increase her qualifications and prove that epilepsy is not a barrier. She is studying social sciences and GCSE biology with a view to doing a primary education degree.

"I receive Universal Credit. The extra £20.00 a week helped slightly in covering my monthly bills, putting fuel in my car to get kids to school and college. But with the government cutting this, I am finding myself in financial hardship. Not only am I losing the £20.00 a week, but I'm paying another £133.00 for over payments, which is leaving me with unpaid bills. But I can't get additional financial support from Universal Credit. If I ask for help, I just get fobbed off with food banks and told to manage my money better.

"I don't receive PIP, as, according to the DWP, I'm not entitled to it as I can 'function without aids' and can communicate. I did once fight for it and was successful by tribunal, but they tried to appeal the judge's decision. Then I had to fight for my backdated payments. I never renewed because the stress made me ill.

" The biggest problem claiming benefits is the government's lack of understanding of epilepsy. Until they walk in our shoes, they won't realise the true impact our health has on each and every one of us."

Harmful and concerning

Daniel Jennings, senior policy and campaigns officer at Epilepsy Action, said: "Applying for PIP is an ordeal for many people with epilepsy. Our survey clearly exposes the flaws in the assessment process, which have not improved in eight years.

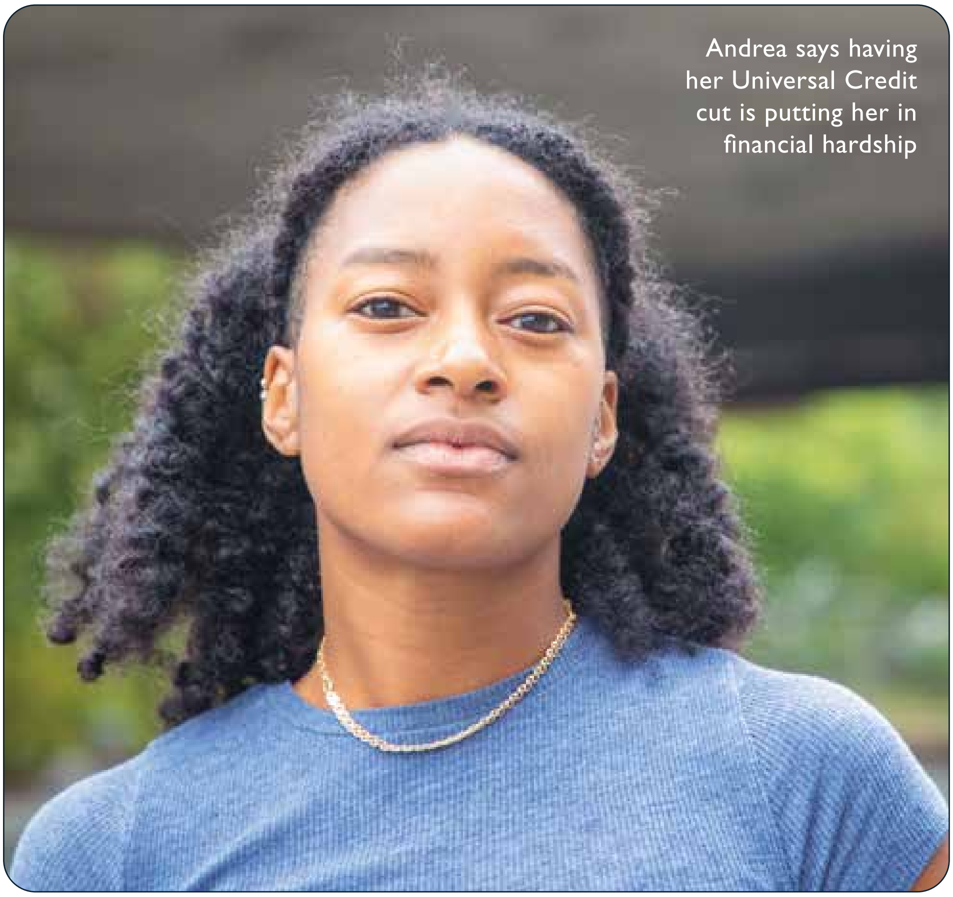
"There is a woeful lack of training and assessors are quick to dismiss the severity of the condition. They are not looking at medical evidence or considering how unpredictable epilepsy can be.

"Not only that, the snap judgements made during interview are harmful and concerning. How can anyone hope for a fair assessment when they are penalised for walking across a room, or their seizures aren't deemed 'serious' enough?

"The PIP process is confusing and full of stressful hurdles, designed to put people off appealing. At a time when people are struggling financially, we need to remove these barriers and make the system fairer and more transparent. This will help claimants with epilepsy afford the added costs that come with their condition.

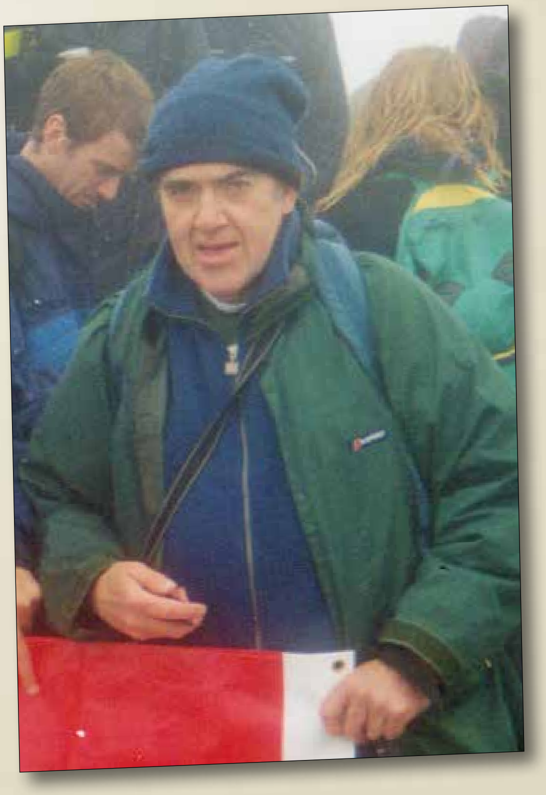
"We are calling on the DWP to provide assessors with proper training, to simplify the application process and to reform the system so it captures the reality of living with a fluctuating, often hugely debilitating, condition. We would be happy to work with the DWP and assessment providers to ensure that their 'condition insight reports' accurately reflect the full impact of epilepsy."

Epilepsy Action has made some recommendations for the government encouraging the DWP to increase the length of the PIP award, ensure assessors are trained in the condition and simplify the application process, among other things. The organisation is also asking people to write to their MP and detail their experiences with applying for PIP. There is more information about the Epilepsy Action welfare survey and campaign work and how to contact your MP at ***epilepsy.org.uk/welfare***.


Andrea says having her Universal Credit cut is putting her in financial hardship

My journal

Robert Wilks' epilepsy is such that he can occasionally experience prolonged non-convulsive seizures, while seemingly getting on with his day. He talks about what these seizures are like



"Epilepsy was first suggested for me about the age of nine, and I received treatment for this, but the seizures were so mild that it was always felt that it could be something else. I got no firm diagnosis until after the age of around 20. It was a possible temporal lobe epilepsy, and I tried all kinds of epilepsy medicine, such as phenytoin, phenobarbitone, gabapentin and many others, some more successful than others.

"When it came to seizures, you name it, I've had it, but for the most part my seizures are mainly focal. Very occasionally I had tonic-clonic seizures, and one or two developed into status epilepticus in adult life after I got married. At present, my epilepsy is quite well stabilised. I have been offered epilepsy surgery several times, but being a bit of a coward, I always maintained "if it's not that broken, why mend it?" I have, however, acted on the advice of my consultant to have a vagus nerve stimulator fitted.

"Growing up with epilepsy was a bit of a nuisance, but you learn to live with it. It manifested as bad behaviour at school. I successfully entered a grammar school, but there was a feeling from some teachers that it was probably not the right place for me at the time.

"I only passed one O level, but eventually, after working as a printer, I had a second chance. I passed six O levels in one year and got into college to train as a teacher.

When it comes to seizures, you name it, I've had it

"I first had status epilepticus around the age of 65. On one occasion, I collided with a door in the middle of the night and later on had a seizure that turned into convulsive status epilepticus. This was when I was placed on inappropriate medication. Had my wife not been there, I am convinced I would have died. But this would not be my only experience of status epilepticus, and in fact, I would come to find that it can take different forms.

"Then, about two years ago, I took part in a soup run with the church I go to. As I often do when with a small group of people, I explained that I have a fairly mild form of epilepsy which they should be aware of. I also add that I do very occasionally have a seizure that could last longer than five minutes. Little did I or the other people involved in the soup run know, that about 30 minutes after giving my usual explanation, I would actually experience such a seizure (perhaps brought on by stress, who knows?).

Non-convulsive status epilepticus can appear as confusion or unusual behaviour and I might wander off

"But this was different to the convulsive status epilepticus. Non-convulsive status epilepticus can appear as confusion or unusual behaviour and I might wander off. In some ways the medical condition can be a kind of learning curve, for 10 years ago I was not aware that this kind of seizure, known as non-convulsive status epilepticus, existed. I, along with most GPs I know, thought of status epilepticus as convulsive.

"So, I just walked off and left the church group wondering where I had gone!


Rob has done sponsored Ben Nevis climbs for Epilepsy Action


Rob wandered the streets of Sheffield during a seizure

"I can recall making sandwiches, I can remember taking things out to a car, ready to depart, as usual, for town, but just what happened after that, I have no idea. The next thing I knew, I found myself near one of Sheffield's big roundabouts, Hunter's Bar roundabout, in a very confused state. Such is the nature of epilepsy.

"I seem to recall being unable to remember which of two nearby churches I should be in – Ecclesall or St. Mark's – and that in my confused state I decided to make my way back towards St. Mark's. This involved crossing several quite busy main roads – ones that I cannot recall crossing!

I crossed several quite busy main roads – ones that I cannot recall crossing!

"I then made another mistake in my confusion, and got on a bus thinking perhaps it would take me towards my home in Bradway. No sooner had I sat down, however, my brain signalled that something was wrong so I got up thinking "no, this is not right" and got off the bus.

"Reassured, but feeling a bit dazed, I crossed the road and got on a bus that I felt more sure might help reunite me with my soup-run companions, unsure what sort of a welcome I might receive. I made my way to the old market place where I knew the team would be and was reassured when I saw the beaming face of the leader of our group. I now know she had searched the church quite thoroughly thinking she might find me having a more stationary seizure.

Rob has worked as a teacher, printer and care worker

"Thankfully I did not get the sack for going absent without leave, but, in future, I shall have to amend my description of the kind of seizures I experience. They're best summed up in the words of my wife, based on some 'interesting' experiences we've had: "he'll turn up somewhere, some time" or "if he falls down someone will pick him up".

"I rather feel my senses remained intact enough to keep me safe in this situation, but this may not be the case another time. This kind of non-convulsive status epilepticus seizure has occurred once or twice a year over the last ten years. It's 'non-convulsive', because you do not fall to the ground and shake, and 'status' because the seizure can last a long time. In such seizures, which are not as rare as I first thought, I've been told by my consultant that one can perform quite complex actions. One might be able to get dressed or buy a bus or train ticket. Alarmingly, I am also told by my consultant, that such episodes can last hours, days or even months!

"I do however feel blessed that I have been able to handle epilepsy quite well in life with the help and support of others. As one epilepsy nurse said "epilepsy has certainly never held you back in life". And this is true, as I lead a very busy life even in retirement, let alone for nearly 30 years spent in different jobs.

"I am very fortunate to be able to advocate for myself, and one of the people I credit with helping me to become assertive when necessary over the years is a past chief executive of Epilepsy Action, Alec Aspinall. I first met Alec over a cup of coffee and a cake or two (or could have been three), when I agreed to speak about my experiences to a group of teachers. He later called on me again to speak on Granada television. I kept in touch with Alec until shortly before he died, and he even gave me a donation towards one of my sponsored Ben Nevis climbs for Epilepsy Action – one of two I undertook when I was younger. He was a great man. I recall, as a former printer about to embark on a career in teaching, he wrote to see how I was getting on. I wrote back to him saying that occasionally I had cause to "bend the rules" and he wrote back saying "keep on bending the rules".

"In my time working as a care worker, I realised how misinformed some people can be about epilepsy. I decided I wanted to speak up about non-convulsive status epilepticus, as, when I first experienced the condition, I had to work it out for myself. It was an occasion, similar to my experience on the soup run. I needed to catch a bus home from a church where I help out at a lunch club for people with dementia. I got on a bus but it was heading the opposite way to where I wanted to travel. I was in a semi-conscious state, but I recognised certain buildings and knew I had to get off the bus. I somehow successfully crossed some roads, produced my bus pass and got on the right bus. I seemed to be drifting in and out of consciousness but I recognised some buildings on the way, which satisfied me that I was heading the right way home. I was attending Epilepsy Action meetings at the time, and at the next one, I asked one of the volunteers whether you might develop a less dramatic form of status epilepticus that is non convulsive. "Well, I suppose so," he said. I mentioned this to my

> I was in a semi-conscious state, but I recognised certain buildings and knew I had to get off the bus

Rob says his wife is a tower of strength in life consultant neurologist when I next saw him and he confirmed that there was such a prolonged seizure.

"My wife has been a tower of strength in life as I feel she has seen my epilepsy at its worst and regards it as part of the person she married. She was called on one day last year, when someone from a walking group spotted that something was wrong with me. She took one brief look and simply said, "yes, he's gone. Don't worry, he'll be back in a few minutes". And I was before we got much further down the path."

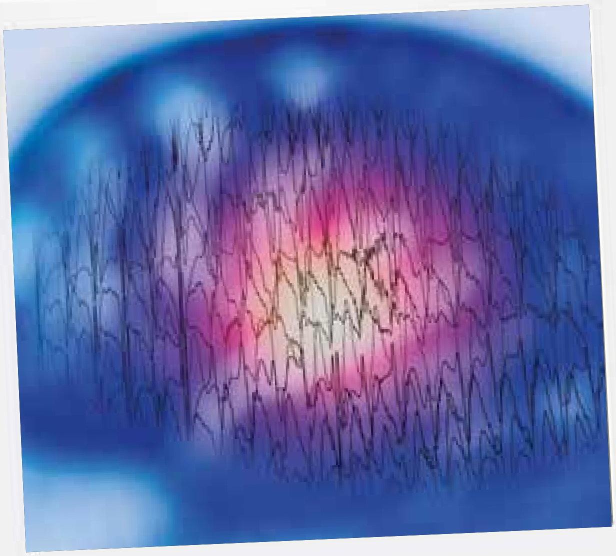
Non-convulsive status epilepticus

Most people with epilepsy have seizures that last a short time and stop by themselves. But sometimes a seizure can last too long or a series of seizures can follow one another without recovering in between, which is known as status epilepticus.

Convulsive status epilepticus is when a tonic-clonic seizure lasts longer than five minutes, or a series of tonic-clonic seizures happen one after the other without regaining consciousness in between.

However, non-convulsive status epilepticus can also happen, and can appear very different to convulsive status epilepticus. This can happen when some types of seizures, such as absences or focal impaired awareness seizures, become prolonged. A person going through this may not show obvious signs of having a seizure. They may appear confused or less responsive than usual, or have changes to their speech or behaviour for no clear reason.

Professor Markus Reuber is a professor of clinical neurology and a consultant neurologist at Sheffield Teaching Hospitals NHS Foundation Trust. He explains more about this kind of seizure:



Non-convulsive status epilepticus can last hours or even days

Simple tasks like walking are possible during these seizures

"Although the term non-convulsive status epilepticus refers to prolonged seizure activity in the brain (with a few exceptions), it is much less dangerous to the person experiencing the condition than convulsive status epilepticus.

"Convulsive status epilepticus can cause irreversible brain damage within 10-30 minutes, but non-convulsive status epilepticus may continue for hours or even days without causing permanent changes in the brain.

"It is very difficult to say how common non-convulsive status epilepticus is, because its diagnosis can require access to EEG. However, not all hospitals have access to EEG, and even those with EEG departments may not be able to offer out of hours or tests in emergency departments or on wards.

"One reason why non-convulsive status epilepticus may be missed is that it often occurs as part of some acute illnesses, such as strokes or infections.

"In the context of acute illness, especially in older people, non-convulsive status epilepticus is often missed because GPs are not sufficiently aware of it and because the effects might be quite subtle. They can include, for instance, difficulty understanding speech, following commands, confusion or drowsiness. Many people in non-convulsive status epilepticus are still able to do things like walk or feed themselves.

"The treatment of non-convulsive status epilepticus may be difficult. However, it stops again in most cases, either because the epilepsy medicines start to work or because the illness causing it has been treated or has improved."

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 gabapentin.

Gabapentin

Gabapentin (GBP) was initially licensed in the UK as an add-on treatment for focal seizures, whether or not they turn into tonic-clonic seizures, as far back as 1993. Shortly afterwards, it obtained its monotherapy license for the same seizure types. GBP is also available for children with epilepsy aged two years and above. It is widely used to treat pain from nerve damage and to prevent migraine attacks. GBP can be prescribed as capsules, tablets or in an oral solution. The starting dose in adults is low, aiming to reach 300mg three times daily over the first week. It can be increased, as necessary, to a maximum of 1200mg three times daily. For children, GBP is usually prescribed in the liquid form, with the dose depending on age and weight.

Professor Martin Brodie

Overall, GBP is usually well tolerated with side-effects being mild and sometimes temporary. The most common complaints include headache, tiredness, drowsiness, unsteadiness, dizziness, and double vision. Diarrhoea is a rare problem. Weight gain occurs in up to 5% of patients taking GBP, particularly at high doses. Serious allergic side-effects are very rare and interactions with other medicines does not usually occur with GBP. The risks of taking gabapentin during pregnancy are not yet fully understood, according to the Medicines and Healthcare products Regulatory Agency (MHRA). GBP is passed unchanged in the urine and so care must be taken when using it for people with kidney problems. Blood levels are not normally measured.

GBP is an easy to use epilepsy medicine that does not interact with other medicines. The three times daily dosing schedule can be a bit of a nuisance, as is the need to sometimes go up to quite high amounts to obtain a good response. Its role in the treatment of epilepsy and nerve-damage pain has been largely replaced in the UK by the more recently available structurally similar pregabalin. Pregabalin works in the same way in the brain and nervous system but is much easier to use.

The only bad news with GBP's use for people with epilepsy is its relatively limited effectiveness and the need for three times daily dosing. It is also sometimes sold and used recreationally, which can be dangerous. To prevent misuse, it was reclassified (along with pregabalin) as a class C drug in 2018. This makes it illegal to have without a prescription. However, it is safe to use if taken as has been prescribed by a person's epilepsy doctor.

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.

Council of Management 7 December 2021

At a meeting of the Council of Management held by remote video conference on 7 December, the following decisions were made.

- The Council noted the resignation for personal reasons of one of its members, Torie Robinson on 1 December and wished her well for the future.
- A revenue budget and business plan for the charity were approved for 2022.
- Council reviewed and renewed the charity's advisory panels covering scientific awards, research, women and health and clinical practice.
- It reviewed, updated and renewed its scheme of delegation. This is the record of how the Council delegates authority on some matters to the Chief Executive to make decisions and manage day to day operational issues.
- It reviewed the charity's corporate risk register and ensured adequate measures are in place to manage those risks.
- It reappointed William Fiennes and Professor Gus Baker as Vice Presidents of the Association when their current term of office expires at the date of the AGM in June 2022.
- It has been two years since the Council of Management last met in person in the same room. During that time all meetings have been held by video conference. If pandemic conditions allow, the Council has targeted to hold its scheduled meeting in May 2022 at New Anstey House.

The next meeting of the Council of Management will be on 12 April 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

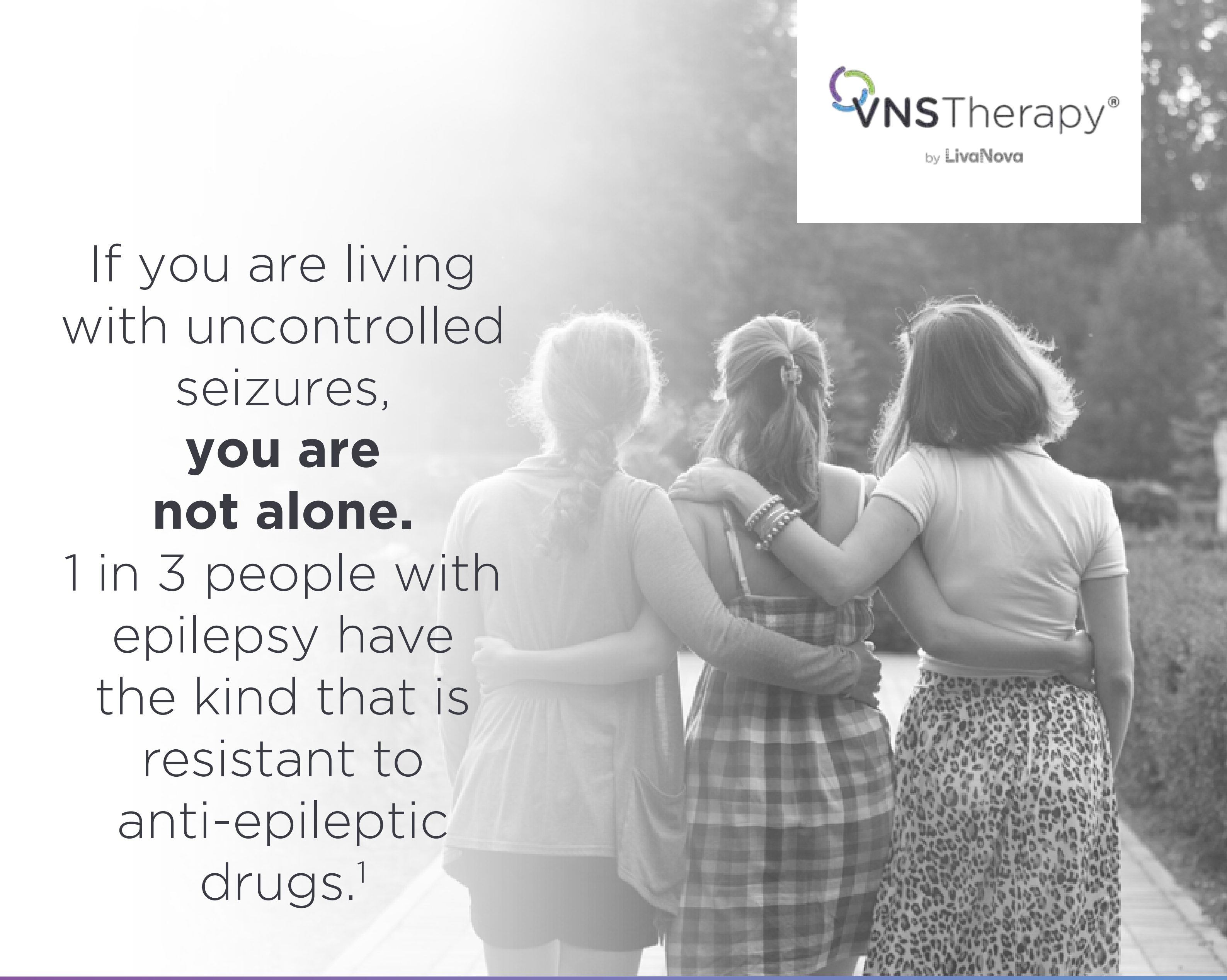
We know many of you take comfort from connecting with others affected by epilepsy. The traditional face-to-face group meetings just aren't possible right now, so the local services team have set up online meetings using video calls instead (technical support is available). If this is of interest, you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

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***. 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***, or ***ablehere.com*** for people with disabilities and conditions. Bear in mind that these websites are not part of or run by Epilepsy Action.



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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.