

Surgery at last

Steve talks deciding to have surgery, cycling 45 miles in six hours and winning a Freddie Mercury look-a-like contest

Also in this issue

- an update on the **disability employment gap**
- heart-warming tales from the winners of the **Helping Hands awards**
- raising awareness of SUDEP in memory of **Jill and Peter**



editor's letter

Welcome to the December 2021 issue of *Epilepsy Today*.

Epilepsy Action has been continuing to fight the good fight, pushing and campaigning for more to be done by the government about the disability employment gap. It has stubbornly remained at about 30% for many years, and we know that people with epilepsy are some of the worst affected. Improving the situation is hugely important for people's livelihoods, as well as for a better quality of life. You can read more about this on page 8. Another aspect affecting quality of life is access to an epilepsy specialist nurse (ESN). It is no secret that ESNs are in short supply around the country, and they are not equally distributed, leaving some areas worse off than others. One such area is that covered by the Hywel Dda University Health Board in Wales. Epilepsy Action Cymru has been campaigning for the health board to appoint another ESN there to help with the workload. On page 20, Leanne and Elaine explain why it is vital to have more ESNs in the area.

This issue we also share the stories of Jill and Peter on page 22. Both of them died from sudden unexpected death in epilepsy (SUDEP) and their families wanted to raise more awareness of the condition and the safety information around SUDEP. It is a really difficult topic to think about, but it's important to be aware of how to reduce the risk of it happening. On page 11, we also hear from Emily and Rich about their experiences at university. Looking after ourselves for possibly the first time is difficult, and managing our epilepsy can be put on the back burner. But their stories show how looking after yourself doesn't have to be difficult and will help you make the most of your university experience.

We also share a research update from the International League Against Epilepsy's (ILAE) 34th International Epilepsy Congress, which was held virtually in August. You can read our summary of some of the congress presentations on technology, diagnosis delay, managing seizures, information delivery and more on page 17.

Finally, to end on a lighter note, we have some wonderful and heart-warming stories from our Helping Hands awards winners (page 14). You can read about the stranger who helped cushion Ray's head during a seizure and called an ambulance for his injuries, and about the teacher who helped Abbie thrive at school, and feel safe and included. You can also find out more about the brothers who completed challenges in memory of their cousin Sandi, and the young man who walked 60 kilometres to raise money for people with epilepsy. On page 26, you can also read our cover star Steve's story, talking about how he has navigated difficult situations in his life, never giving up his zest for life, his love for his hobbies and his fight to reduce his seizures.

We hope you enjoy this issue and that you have a very happy holiday season.

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this issue...



4 News

This issue: establishing research priorities in epilepsy, new MEG imaging technology for children unveiled and computer models use EEG to predict response to medicine



8 Disability employment gap

Update on recent pressure on the government to better support disabled people with employment

11 A leap into the unknown

Starting university can be a shock, but Emily and Rich share how they coped with their first year



14 Spotlight the superstars

Warm your heart with the stories of some of the winners of the Helping Hands awards 2021

17 Test, learn, share, repeat

A research insight from the 34th ILAE International Epilepsy Congress held this year



20 Access to a specialist

Leanne and Elaine share their stories of why the fight for another epilepsy specialist nurse in their area in Wales is so important

22 Forever young

Two families raise awareness of SUDEP in memory of their loved ones, Jill and Peter

26 My Journal: Steven Marshall

Find out why Steven waited 45 years to have epilepsy surgery, and the difference it made once he had it

Partnership aims to establish research priorities for epilepsy



A group of epilepsy charities, clinicians, researchers and people with epilepsy have joined forces to identify which areas of epilepsy need to be prioritised for research.

The group is part of Epilepsy Research UK's (ERUK) James Lind Alliance (JLA) Priority Setting Partnership (PSP) which was launched this week. It includes Epilepsy Action, Young Epilepsy, SUDEP Action and Epilepsy Society, as well as ERUK.

The process that the JLA PSP will use will identify the most important themes around epilepsy for people with the condition and reach a top 10 of research questions for epilepsy. Researchers and funders will then devise the most meaningful research projects within those areas, aiming for them to support those who need it most.

The JLA PSP will consider causes and prevention of other related conditions,

access to health services for diagnosis, and treatments for epilepsy, drug-resistant epilepsy, side-effects and related conditions. They will also look at risk of epilepsy-related deaths, social and psychological factors, epilepsy in older people, medical education and pathways to improved medical care.

A similar JLA priority setting activity was done 12 years ago by consultant neurologist Dr Rhys Thomas, who will also lead the current group.

Dr Thomas said: "A new study is long overdue, the outcomes for which would benefit people living with epilepsy by providing the evidence of need and priorities to support research development. We know that PSPs can lead to increased funding from NIHR [National Institute for Health Research], which is so urgently needed for epilepsy, given

the shocking inequalities in research funding."

Angie Pullen, research and healthcare projects programme lead at Epilepsy Action, said: "We are really pleased to be encouraging people participation in agreeing priorities for the future of epilepsy research. Knowing directly from people with epilepsy and their loved ones about what is really important to them is key to helping us to drive forward positive change.

"When the priorities have been agreed we will be able to make the case for more research funding for epilepsy and how care can be improved for people affected by the condition."

ERUK will fund and provide the resources for the programme to establish research priorities.

Epilepsy Action Cymru calling for health board to appoint epilepsy specialist nurse

Epilepsy Action Cymru is calling on Hywel Dda University Health Board (UHB) to appoint an extra Epilepsy Specialist Nurse (ESN).

The organisation said it has heard reports of people waiting up to 18 months to see a neurologist in areas in Wales covered by the health board. Hywel Dda UHB covers Carmarthenshire, Ceredigion and Pembrokeshire, including Bronglais, Glangwili, Prince Philip and Worthybush hospitals.

There is currently one ESN working for the health board, but a proposal had been made to create a post for a second ESN, which was rejected by the health board. Epilepsy Action Cymru has urged the health board to reconsider, by writing to the chief executive of Hywel Dda UHB, Steve Moore.

ESNs are a vital part of the epilepsy healthcare team, supporting consultant neurologists and healthcare professionals to provide

advice, support and care during and between appointments, Epilepsy Action stressed. ESNs are an important point of contact for people with epilepsy, offering help with medicine, managing risks from seizures and supporting people to cope with daily life.

The letter outlines the support ESNs offer people with epilepsy, their role in relieving pressure from epilepsy services and the urgent need for another ESN in the area.

Epilepsy Action is urging members and supporters in the area to also write to the chief executive to raise their concerns about the decision not to employ a second ESN and share their experiences. The organisation has drafted a template letter which can be downloaded from the Epilepsy Action website at epilepsy.org.uk/hyweldda and sent by email or post.

The organisation is also campaigning more broadly for more ESNs in Wales.

Levetiracetam improves learning and memory in people with Alzheimer's disease and epilepsy

Levetiracetam has been found to improve cognitive functions, like learning and memory, in people diagnosed with Alzheimer's disease who also have epileptic brain activity, a study in *Journal of the American Medical Association (JAMA) Neurology* has found.

There are around 850,000 people with dementia in the UK. Alzheimer's disease is a particular type of dementia. It affects between half and three-quarters (50-75%) of people with dementia, according to the Alzheimer's Society.

According to the study, among people with Alzheimer's disease, up to around three in five (60%) have seizures or silent epileptic activity in the brain. This means that epileptic activity shows up in tests, but

there are no visible signs of a seizure in the person.

Lead study author Dr Keith Vossel called Alzheimer's disease with epileptic activity an "epileptic variant" of the disease.

The study analysed 34 people with Alzheimer's disease, of whom two-fifths (40%) had epileptic activity. People were split up into two groups, and received treatment with a dummy medicine or a low dose of levetiracetam for four weeks. This was alongside their current Alzheimer's disease treatment. Then, the groups had a four-week break and swapped over to receive the opposite treatment.

The researchers assessed people's abilities to



problem solve, reason, remember words and navigate during treatment. People treated with levetiracetam showed a tendency towards improvement in these kinds of skills. People with silent epileptic activity were seen to have a clear benefit of this medicine to their cognitive functions.

The researchers concluded that these findings showed the importance of extended neurology assessments in Alzheimer's disease patients, to identify people with epileptic activity who may benefit from levetiracetam.

The full study is available on the *JAMA Neurology* website at epilepsy.org.uk/jamasep21

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New MEG imaging technology improves accessibility to children

New technology to make magnetoencephalography (MEG) brain imaging more accessible in children has been developed by UK scientists and Young Epilepsy.

The charity unveiled the brain scanning system for children at their Neville Childhood Epilepsy Centre in Surrey at the end of September.

MEG brain scans can look at brain activity and offer very precise information about where seizures start in the brain. However, up until now, MEG imaging has been difficult

to use. It required a large and expensive machine, a specific and expensive room, and for the person being scanned to remain still.

This has made the technology difficult to access in many epilepsy centres and not suitable for use in children.

The new technology allows the MEG scanner to be worn like a helmet and for the person being scanned to move freely. The room the scan needs to take place in is also less expensive and children can bring toys and family in with them.

The improved accessibility and cost could mean a wider use of MEG imaging around things like diagnosis and surgery, and more MEG facilities could become available around the UK in the future.

Young Epilepsy says the helmet can fit the head of any child and also helps to make MEG more accessible to children with complex needs.

The technology was developed in partnership with the University of Nottingham and University College London, as well as companies Cerca

Magnetics Ltd and Megnetic Shields Ltd. It is currently being used at Young Epilepsy's research centre in Surrey.

There is more information at: epilepsy.org.uk/youngepilepsymeg



Study sheds light on why Mozart's music shows anti-seizure effect



A new *Scientific Reports* study has shed light on why some pieces of music composed by Mozart may have an anti-seizure effect in people with epilepsy.

It has previously been shown that listening to some pieces by Mozart, namely Piano Sonata in C Major (K545) and Sonata for Two Pianos in D Major (K448), can have anti-seizure properties. But earlier studies haven't been able to say why this is the case with these and not other pieces of music.

The new study from the US involved 16 people with refractory focal epilepsy whose seizures could not be fully controlled with medicine. During the study, they were monitored for epileptic brain activity outside of seizures. The participants listened to Mozart's K448 piece, as well as music genres that they liked and a piece by Wagner called Prelude to Act I of Lohengrin.

The results showed that there were reductions in epileptic activity in the brain after 30 seconds or more of the K448 piece. This reduction was found to be significant in areas of

the frontal lobe of the brain, linked to emotion. The other pieces of music did not show an anti-seizure effect.

The research authors, Dr Quon and colleagues, looked at the structure of the music and found that changes between longer musical segments in the piece were linked to this therapeutic effect. This kind of structure characterised this piece of music, but not the piece by Wagner.

The researchers theorised that this kind of musical structure has a positive emotional effect, which contributes to the therapeutic effect of the piece. However, they suggest this is a subconscious emotional response on a neurological level rather than a subjective feeling, as the same effect wasn't seen when people listened to their preferred music genres.

The authors suggest that more studies on music with similar structures should be carried out to further explore these findings and their therapeutic potential.

The study is available on the Nature website at [epilepsy.org.uk/naturesep21](https://www.nature.com/articles/s41586-021-03211-1).

Dogs can use sense of smell to predict seizure

Dogs can use their sense of smell to detect a specific odour associated with seizures, a new study from Queen's University Belfast has found.

The research, published in the journal *MDPI Animals* in July 2021, has built on anecdotal accounts from people saying their pet dogs give them warnings before a seizure happens. Until now, it was not known how they sensed an oncoming seizure.

A way of predicting seizures can make people aware of an oncoming seizure and reduce the risk of injury, provide the opportunity for medical intervention and increase a person's sense of independence.

The research, led by Dr Neil Powell, looked at how a group of 19 pet dogs reacted to seizure-related and non seizure-related odours, using a special tool called the Remote Odour Delivery Mechanism (RODM). The seizure-related odours reflected three separate phases of a seizure – before, during and after.

They analysed the reaction and behaviour of the dogs, and found that all 19 dogs showed

a change in behaviour to try to connect with their owner with the seizure-related odours, compared with the non seizure-related ones.

Dr Powell said: "Our findings clearly showed that all dogs reacted to the seizure-associated odour, whether this was through making eye contact with their owner, touching them, crying or barking.

"There is a unique, volatile smell linked to epileptic seizures, detectable by dogs, who, in turn, warn their owner a seizure is likely to occur.

"Our research was based on pet dogs with no prior training. If we can train dogs, this has the potential to make a big difference to owners who experience unpredictable seizures and should go a long way in improving not only their safety but also their quality of life."

The research looked at how dogs reacted to seizure-related odour, but did not study how the dogs would react to an actual seizure. Untrained dogs can react in different ways to seizures, and there have been reports of dogs acting in a dangerous way. It is important to be cautious.



Lower depression levels during the COVID pandemic, study from India finds



Depression levels have reduced during the COVID-19 pandemic in a group of 449 people with epilepsy, a new study from India has found.

The research, published in *Epilepsy & Behavior* journal, aimed to assess the impact of the pandemic on seizure control, depression status and medicine adherence, given that healthcare services have been disrupted.

The study evaluated 449 people with epilepsy, who had

previously been assessed for depression in New Delhi, India, over the phone. They were asked about their epilepsy medicines, seizures, depression and suicidal thoughts in the last six months.

The results showed that around one in five (19.9%) had symptoms of depression, compared to around two in five (40.1%) before the pandemic. Around one in 20 had had suicidal thoughts. Just over one in five (23.9%) reported seizures during the pandemic.

The study authors, Prof Jatinder Katyal and colleagues, found that seizures during the pandemic, increased seizure frequency, previous history of depression and changes to medicine regime were significantly linked with depression during the pandemic. Needing more than one epilepsy medicine, having seizures during the pandemic and a previous history of depression and suicidal thoughts were linked with people experiencing suicidal thoughts during the pandemic.

The researchers concluded that depression levels dropped significantly during the pandemic in their study group, despite other reports mostly finding an increase in anxiety and depression during this time. The reason for this isn't clear, but the study authors suggested that lockdown may have

provided a better support structure with things like taking medicines regularly, which may have contributed to lower depression levels. However, the researchers warned that conducting the follow-up interviews over the phone may have resulted in missed cases of depression.

The study authors called for restoring epilepsy services to pre-COVID levels, as well as putting in place continuity plans to help make this kind of care for people with epilepsy a priority.

There is more information about epilepsy and depression, including sources of support on the Epilepsy Action website at [epilepsy.org.uk/depression](https://www.epilepsy.org.uk/depression).

Read the full story on the *Epilepsy and Behavior* website at [epilepsy.org.uk/eabnov21](https://www.epilepsy.org.uk/eabnov21)

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Computer model uses EEG data to predict epilepsy medicine effectiveness

A new study from Italy has shown that a computer model using electroencephalogram (EEG) data can predict whether a person will respond to the epilepsy medicine levetiracetam.

The researchers, Pierpaolo Croce and colleagues, created a machine learning model based on data from EEG tests, which are used to record brain activity in people with epilepsy. Machine learning models are computer programs that process data

and can use that to create predictions for new data.

The group used EEG data from 23 people with temporal lobe epilepsy to test whether it can predict how well levetiracetam would work.

EEGs were done before people started to take levetiracetam and three months after starting. After two years of the study participants taking the medicine, the researchers grouped them into those who

were seizure free and those who were not seizure free.

The team found 152 features in the EEG data that could help predict whether a person's medicine would work for them or not. Their machine model showed that it could predict the effectiveness of levetiracetam in about three quarters of cases when using just data from before the medicine was started. When using data from before the medicine was taken and data from three months after starting, the model could

predict correctly in about four in five cases.

The study, published in the journal *Clinical Neurophysiology*, concluded that this shows the possibilities of machine learning models using EEG data in predicting medicine effectiveness in people with epilepsy. The researchers added that future studies should use this to try to develop a model that can match people with epilepsy to the epilepsy medicine most likely to work for them.



Disability employment gap

The government has recently come under pressure to better support disabled people in terms of gaining and staying in employment. Kami Kountcheva updates on the situation

Challenges with finding work and holding down a job are a huge concern for people with epilepsy. The disability employment gap has remained at 30% since 2013, meaning that for every three non-disabled people in employment, only two disabled people are in work. And this has not changed in at least eight years.

Research from the Office of National Statistics has found that employment rates for people with epilepsy have fallen from around four in 10 (42%) in 2008 to three in 10 (34%) in 2021. Not only that, but those people with epilepsy who are in work earn on average 11.8% less than non disabled people.

People with epilepsy have reported to Epilepsy Action that they have experienced discrimination and a lack of understanding at the application level and interview stages of the recruitment process, and even once they are in a job. This is despite the fact that many people with epilepsy can work safely with some reasonable adjustments from employers. Reasonable adjustments are changes an employer can make to aspects of a role or workplace, such as flexible or adjusted working hours, or providing specific equipment.

There are a few different reasons why people with epilepsy often face so many barriers when it comes to work.

One major obstacle is that the support the government offers to disabled people when it comes to work is often found by people with epilepsy to not be fit for purpose.

Government support

The Work and Pensions Committee, which assesses the policies of the Department for Work and Pensions

Employment rates for people with epilepsy have fallen from around four in 10 in 2008 **to three in 10 in 2021**

(DWP), held an inquiry into the disability employment gap in April this year. The inquiry heard evidence from many different organisations representing disabled people, about the different challenges people face and the effectiveness of the government support available.

Epilepsy Action was part of the inquiry and urged the government to provide

specific targeted support to help people with epilepsy find and stay in work. The organisation said disability employment gap statistics show that current support isn't working and the schemes the government currently has need to be reformed.

The current support includes Access to Work, a scheme intended to support people with the extra costs of practical support in the workplace. It also includes Disability Confident, a programme that educates employers on the benefits of recruiting disabled people.

Daniel Jennings, senior policy and campaigns officer at Epilepsy Action said these have clearly fallen short, considering the continuously high disability unemployment rates. He added: "From a 2016 YouGov survey, we know that more than one in four employees in the UK would be wary of working with a colleague who has epilepsy. We also know that a majority of the UK employers would not know how to help a co-worker having a seizure."

Mr Jennings called the current schemes supporting disabled people with employment "far too generic", adding that they don't include enough tailored support for people with epilepsy and those with other disabilities.

Epilepsy Action called for more transparency from employers about how many disabled people are in employment, as well as support offered on a more local level. The organisation also called for government schemes to be reformed in a way that is more tailored for different disabilities and is more fit for purpose.

Pressure on the DWP

On Friday 30 July, the Work and Pensions Committee released its report entitled 'Disability employment gap' shortly after the DWP's National Disability Strategy, which was published on 28 July.

The report has taken account of all the evidence provided during the inquest and all the concerns raised by organisations representing disabled people. The report has called on the DWP to readopt its previous target of halving the 30% disability employment gap. It has also

called for the DWP to introduce a target of getting an additional 1.2 million disabled people in work by 2027. The report has criticised the lack of ambition in setting a new target, saying the current target the DWP has is benefitting from a general rise in employment rather than a reduction in the disability employment gap.

MP Stephen Timms stressed that **disabled people should be involved in conversations and decision-making** around employment support

Chair of the Work and Pensions Committee, MP Stephen Timms, has agreed that a more localised, rather than centralised, approach to providing support for people is needed, that is "personalised,

flexible and effective". He also stressed that disabled people should be involved in the conversations and decision-making, in order for changes to be useful and fit for purpose. "Only then can we start to break down barriers to employment and ensure everyone has equal opportunities when it comes to work," he said.

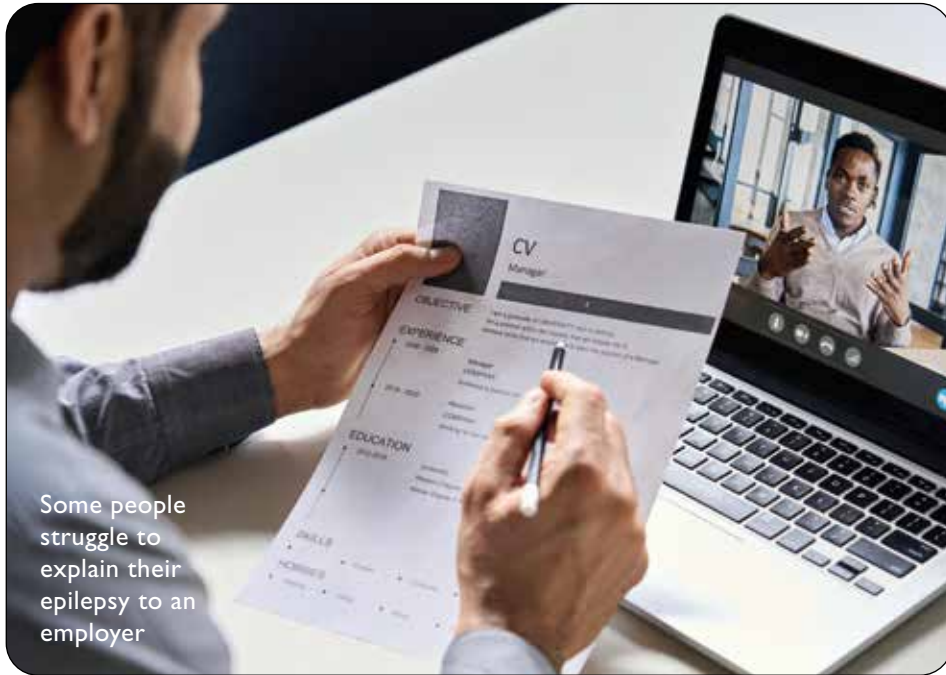
The report has echoed many of the recommendations made by Epilepsy Action, including for more transparency, better benefits systems and more targeted assessment processes. The report has suggested that employers with more than 250 employees should publish data on the proportion of workers who are disabled, and for employers who "flout the law" around reasonable adjustments to be "named and shamed". The report also stresses that disabled people should be supported to work flexibly and wherever best suits them – including at home where possible.

The Work and Pensions Committee has also agreed that various schemes and assessments need to be redesigned, including Access to Work and the

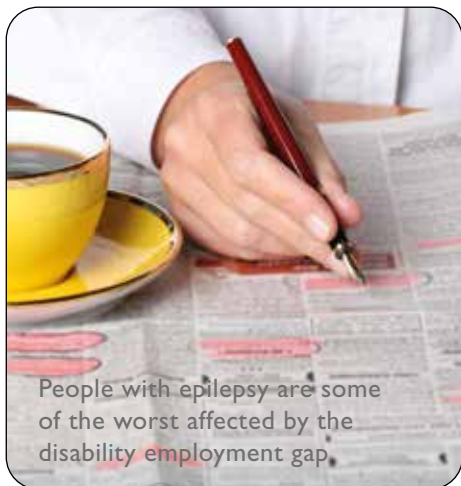
The Work and Pensions Committee has called on the government's DWP to be "bolder" in its efforts to reduce the disability employment gap



epilepsy feature



Some people struggle to explain their epilepsy to an employer



People with epilepsy are some of the worst affected by the disability employment gap.

"Epilepsy Action will continue to raise these issues with the government to **ensure that much more is done to close the disability employment gap**"

issues with the government to ensure that much more is done to close the disability employment gap, particularly for people with epilepsy."

Support for employees

While government support is essential, research from the Institute for Employment Studies on employment support for people with epilepsy has identified that people may sometimes need other support too.

Some people reported having trouble explaining their epilepsy to their employer. Sometimes people didn't fully understand their own condition, but were expected to advocate for themselves in the work arena. With misconceptions about the condition still around, some people found it difficult to broach the topic with their employers.

It can be difficult to know what to say, what the law says employers should do and what you can ask for. To try to combat some of these challenges and support people with epilepsy in work, Epilepsy Action has created the Employer toolkit (employers.epilepsy.org.uk). This aims to give organisations the confidence to better support employees with epilepsy in the workplace. There is also more information on the Epilepsy Action website around looking for work, reasonable adjustments, disclosing your condition, what the law says and more: epilepsy.org.uk/employment

Seeing change happen

Disabled people have been navigating what have been found to be clunky and time-consuming schemes for support with work for many years now. The report from the Work and Pensions Committee has put pressure on the DWP to revise these and provide better support to disabled people with employment. Epilepsy Action has helped inform a lot of the conclusions the committee has come to and will continue to also put pressure on the government to see change happen.

You can also find the full Disability employment gap report epilepsy.org.uk/parliament-employment-gap and the government's National Disability Strategy epilepsy.org.uk/gov-disability-strategy online.

Disability Confident programme. The report also mentioned the Work Capability Assessment for people applying for Employment Support Allowance. They are currently time-consuming and not fit for purpose, and need to be improved, the report suggests.

In response to the publication of the report, Mr Jennings said: "Epilepsy Action welcomes the Work and Pensions Committee's report into the disability employment gap. We know that people with epilepsy are one of the groups most severely affected. This is despite the fact that many can have successful careers and stay in work with minimal reasonable adjustments from their employers.

"We are pleased that the committee has accepted many of the recommendations

made in both our oral and written evidence to the inquiry. We agree that both Access to Work and Disability Confident need to be reformed to support people with epilepsy in securing, and staying in, their jobs.

"We also welcome the recommendation that employers should be required to publish data on the proportion of workers who are disabled, as an effective way of holding them to account and closing the disability employment gap.

"This report comes on the back of the government's National Disability Strategy which had been touted as a transformational plan for disabled people. But it lacked any detail on how this so-called transformation would actually be achieved. We will continue to raise these



A leap into the unknown

Starting university can be a shock to the system – having to do everything for yourself, study and navigate new friendships is a lot, especially with epilepsy in the mix. But Emily and Rich tell us how they made the most out of their university experiences

Starting university can be a turbulent time for everyone. Setting out on your own for potentially the first time is as nerve-racking as it is thrilling. The first few weeks are often spent finding your feet, calling home every night and becoming fast friends with everyone in your halls of residence and at your lectures. It can be quite an overwhelming time. Cooking meals, doing your own cleaning, managing money, coordinating timetables and finding your bearings is all part and parcel of the early university experience.

The environment is rife with challenges for someone with epilepsy. Late nights, close proximity to alcohol, few close

friends at the start, and lots of other priorities can all leave taking care of your health and epilepsy on the back burner. You might be finding juggling your course, social life and looking after yourself a bit challenging.

But looking after ourselves well is one of the things we need to learn to do and prioritise. Making sure not to miss meals, get enough sleep, and stay on top of our medicines and triggers can make the university experience a whole lot better and easier.

University is an incredibly exciting time. It's a very liberating moment, where we

finally get to take charge of our own lives. And the best way to make the most of it is to look after yourself and let other people in who can help.

You might be a few weeks into your university experience, or you could have finished your first term. You may well have found your footing and know what to expect, but it's always useful to hear tips from others in a similar situation. Emily and Rich have told us about how they managed their epilepsy during their first year at university.

Emily – tackle it head-on

“Starting uni was a daunting experience. I met my flatmates in a university group chat a few weeks before moving out and told them I had epilepsy. I didn't want to make a huge deal about it, but it was only fair in case I did have a seizure and they had no idea what to do. They were really grateful that I told them prior to moving into my flat because they were able to research how they could help me.

“Because of the intensity of my course, I knew that I had to keep myself organised and make sure that I got enough sleep. I have a weekly pill box so that I know that I have taken my medications. I also keep reminders on my phone when I am due to take them in case I forget.

“I used a weekly planner to write down when my lectures and seminars were, and

epilepsy feature

any other work that needed to be done. I split my work as evenly as I could to allow me to have a relatively structured week; I woke up and finished around the same time so that I had the rest of the evening free to cook and wind down.

“Whatever you study, university is difficult and it’s important to prioritise your wellbeing over everything. My medications can affect my mood, my concentration and make me tired. I use different study techniques with regular breaks, so that I don’t get too stressed and experience burnouts. I keep as organised as possible throughout the working week to minimise the amount of work on the weekends. This way, I have free time to see friends or just chill out. But, whenever I am unwell, I put my work away and take time to recover – you are more important than anything.

“My uni has been really good with my epilepsy. Soon after I accepted my place, they sent a ‘Reasonable Adjustments Plan’ that had been emailed to all tutors and lecturers to notify them of my condition and any instances where I wouldn’t attend uni. The plan included things such as any extra time that I’ve been given during

exams, and the ability to rearrange my exams in case of a hospital appointment or a seizure.

“There’s no escaping the fact that drinking culture is a huge part of uni. But, for me, it hasn’t been a huge deal. One of the great things about university is that there are so many different activities that accommodate everyone. There’s a society

There's no escaping the fact that drinking culture is a huge part of uni, **but for me, it hasn't been a huge deal**

called sober socials, a place for those who don’t drink to hang out and have fun. I really thought that the only way to make friends was to go to parties, and if I didn’t I would have a rubbish uni experience. But it’s so easy to meet like-minded people.

“I have been so lucky to meet people who have taken the time to get to know me and my condition, and make sure that I’m okay. One of them I’ll soon be moving into a student house with for second year. Being open and upfront about my epilepsy has helped a lot; I now have friends who I feel completely comfortable and safe around.

“I have had a couple of seizures while at uni. One was in the kitchen while I was cooking dinner. It only lasted about a minute, but my flatmate was there to help and calm me down after, and I called my parents for a while to talk through what had happened.

“In the past, I have struggled with anxiety and self-consciousness and they don’t go away completely. But, throughout my first year, I pushed myself just a bit at a time, and now I’m a completely different person to who I was this time last year. Even doing little things that seem easy to others, like shopping by myself and getting the train on my own. These things were out of my comfort zone but eventually they got easier. I think moving out has been a big step in all that.

“There is no denying that moving to uni is one of the biggest things you’ll ever experience, and at first it is so overwhelming. Meeting new people, getting through welcome week, settling into your accommodation – it is all very big. However, it is such a great experience. One of the biggest lessons I learned this year is to not let my condition rule my life. You can either choose to let it stop you from doing what you want to do, or tackle it head-on. It’s so important to stay conscious of your triggers, be responsible and look after yourself, but also have fun! Put



Emily



Emily found friends at uni who help when she has a seizure



yourself out there, join societies, attend events and talk to new people.

“Also, don’t try and change yourself to fit in and don’t do anything you’re not comfortable doing. Another great thing about uni is that everyone is so different, so embrace it, and don’t be afraid to be yourself.

“But most importantly, make sure that you stay on top of things and not stress yourself out too much. Make sure you have a good balance between work and your social life.”

Rich – you’re in charge

“I was diagnosed with epilepsy in my first year of uni.

“In 2016, I began having seizures as a result of encephalitis. I kept having weird turns and passing out, which I just put down to tiredness. But one month into uni, I was in Truro hospital getting an epilepsy diagnosis. It came out of nowhere.

“I was a long way from home, studying music in Cornwall at Falmouth University. My parents were devastated and I just felt so bad for them. They came down a lot to see me in those early months. My mum has given me the most amazing support.

“I was a bit down for a while just adjusting to my diagnosis. I was worried epilepsy would jeopardise my degree and my results. But I’m a positive person and I just thought I had to get on with it.

“To be honest, my main challenge at uni was dealing with other people’s reactions. Epilepsy can be pretty scary for those around you, so I was coping with their fears more than my own. But once I



Rich with his mum, who has been a big support to him

explained what it was all about, what to do when I had a seizure, they were fine. My flatmates got me to hospital loads of times, they were great.

Heat and lack of sleep tend to be my triggers – **once I was playing bass at a gig and had a tonic-clonic seizure and broke the guitar**

“My tutors were brilliant, too. When I was in hospital for two weeks, they told me not to feel any pressure or rush back to lectures. I could catch up when I was well enough. They were really supportive when I struggled to finish my course, and I was able to retake some modules. I had such a good experience at Falmouth, they couldn’t do enough for me.

“Of course, there’s the social side of uni and I wanted to be part of that. But you

have to know your limits with epilepsy. If I ever tried to overdo it, that didn’t end well for me. I just had to adapt, and I always had my music. That kept me healthy – music is so good for the brain! Heat and lack of sleep tend to be my triggers, as well as stress. Once, I was playing bass at a gig and had a tonic-clonic seizure on stage. I dropped to the floor and broke the guitar! Very rock’n’roll...

“I now work in the music industry at a record label, which I love. I’m also really keen to work with young people who have epilepsy, helping them during their education, especially in creative ways. I still have absences every day, focal seizures occasionally and the worst are tonic-clonic seizures, about once a month. I have sleep seizures, too.

“If you are off to uni, try not to worry. It’s such an exciting time of your life, and epilepsy is just an extra consideration. The beauty of it is you’re in charge. I really believe that. If you are open and comfortable talking about it, your friends will be too. When everyone is aware they’ll be understanding, and they’ll look out for you. But watch your triggers and don’t overdo it. Always put your health first.”



Spotlight

the superstars

This year's recipients of the Helping Hands awards are shining stars supporting people with epilepsy. We share a few of their heart-warming stories

For many people, it might be hard to imagine what it's like living with epilepsy. They might underestimate the gravity of having seizures when you least expect it. They might not understand the vulnerability of losing control during a seizure. Or they might not appreciate the frustration of having extra hurdles to jump and boundaries to push because of your diagnosis or someone else's misconceptions.

But some people have empathy and compassion in abundance. These are the people who are cushioning our heads when we're having a seizure, who are adjusting our working hours to help us thrive or who are learning how to give our child emergency medicine at school if they need it. These are the people doing these, and countless other things to support someone else with a challenging condition.

The fact that epilepsy was seldom spoken about in the past, and is rife with misconceptions, makes it even more important and meaningful when someone shows this much understanding and

kindness. And this is why Epilepsy Action's Helping Hands awards have recognised many of these superheroes.

But the awards also champion people with epilepsy themselves. Within the epilepsy community, you will often find some of the most fantastic stories of persistence and perseverance, joy for life, new outlooks and perspectives, and boundless generosity. The Helping Hands Awards also celebrate people with epilepsy who go above and beyond, despite their own challenges, to support others in the same situation.

The recipients of the Helping Hands Awards are a joy to read about each year. We share a few of the winners' tales.

Sarah Allriott – safe hands at school

Abbie is 14 and was diagnosed with epilepsy last year. She nominated Sarah Allriott, pastoral head of year at Bishop's Hatfield Girls' School, for the Epilepsy Action Helping Hands award.

"I was diagnosed with epilepsy in December 2020," said Abbie. "It has ruined my life and lost me my independence, but Mrs Allriott has stood by me every step of the way. She has changed my care plan over and over again and made it possible for me to feel safe in school, even if I just go in for lunch. She has supported me so much. I call her my school mum.

"Mrs Allriott meets me at the office and gives me a drink, just so I can get into school. She organised seizure first aid and emergency medicine training for the staff. When I've had a seizure, she is always the first one there to care for me and make me feel safe. She is amazing and I could



Abbie
and Mrs
Allriott

not have got through the last year without her support. I love her so much.

“Mrs Alliott, thank you for everything you have done for me, you are a real-life Miss Honey from Matilda.”

Abbie’s mum Mel said: “Mrs Alliott is a teacher, social worker and therapist all rolled into one. Abbie can go to her any time. In fact, the whole school is amazing. They couldn’t do more for Abbie. Even when she can’t get to school, they involve her in the community. They deal with her changing seizures and medications without question. As for school work, they have been brilliant. She has Google classroom and is never put on a deadline. This year they were so flexible in working around what GCSE options would suit Abbie.

“Abbie’s two older siblings also have epilepsy. But her seizures are very different and unpredictable. We’ve had delays getting her diagnosed and issues with treatment and support. Abbie has gone into status epilepticus twice recently and was so close to being intubated. She struggles with the side-effects of her medications, gets tired, slurs her words and her bones ache. We are just so lucky to have Mrs Alliott and the school as our constant source of support. It’s the place Abbie feels not only safe, but where she can feel like just a regular teenage girl.”

Accepting the Helping Hands award, Sarah Alliott said: “I feel very honoured to have received this award. For me, it recognises what can be achieved when everyone pulls together. We have a wonderfully caring, inclusive and supportive team at Bishop’s. Abbie’s mum has put her trust in us and worked with us every step of the way; it’s been a real team effort! Abbie is tremendously courageous and has



Ray with injuries from a seizure

overcome obstacle after obstacle. I have huge respect for her.”

Rossi – a stranger’s support

Rossi, 14, from Seaton, Cumbria, has been awarded an Epilepsy Action Helping Hands award for performing first aid when he saw a stranger, Ray, having a seizure in the street in June this year.

Rossi ran to help when he saw Ray, 40, having a tonic-clonic seizure, cushioning his head, making sure he was safe and calling an ambulance. He even stayed with him once the ambulance arrived. Rossi said the first aid he’d learnt at school the week before made a big difference.

“When I saw him having a seizure I just wanted to help. It was the first time I’d seen someone have a seizure but I just did what I had to do. It’s great to receive the award and it was just good to be able to help him. I’d tell anyone to take some time to learn first aid – it doesn’t take long to do but it can make all the difference.”

Rossi’s quick-thinking and bravery is the reason why he has won a Helping Hands award.

Ray, who was diagnosed with epilepsy in his early teens, had been seizure-free for 26 years but started having seizures again in 2019. He doesn’t get any warning and said all of his recent seizures have resulted in him needing hospital treatment. After the seizure where Rossi helped, Ray needed surgery to repair a fractured cheekbone.

He said: “Rossi, thank you for everything: from the first aid to ringing the ambulance



Rossi with his award

and for making sure I was ok. I will be thankful to you every day of my life for what you did. If he hadn’t stepped in that day, I’d have been lying there for much longer, confused about what had happened.

“I work at Asda and recently helped a customer who was having a seizure in store. I know it can be scary to see someone have a seizure, especially if they’ve injured themselves. It’s been difficult for me for my seizures to have returned after so long. I’m trying to get on with it, but it’s always at the back of my mind that I might have a seizure again in public. I just want people to know that there are things they can do to help, like Rossi did, that will make all the difference.”

Cameron and Fraser – family love and compassion beyond measure

Cameron and Fraser Rutherford are brothers who have raised thousands in memory of their cousin, Sandi, who died from sudden unexpected death in epilepsy (SUDEP). Their aunt, and Sandi’s mum, Shelley Stratfull nominated them for the Helping Hands award.



Sandi and Shelley



Cameron and Fraser completing the Wolf Run



"In 2019, these two amazing young men decided to take on a series of four Wolf Run challenges to raise money for Epilepsy Action. Their cousin Sandi (my daughter) had lived with juvenile myoclonic epilepsy since the age of nine. Initially, her seizures did not disrupt her life too much and we always encouraged her to live life to the full – and she did! She snorkelled off the Great Barrier Reef, she windsurfed in Fiji, she partied in Koh Samui and rode camels in Marrakech. She visited her brother in Budapest and her sister in Switzerland. Life became more difficult in later years as Sandi's seizure frequency increased. But her smile, her sense of fun and her quirky view of life endeared her to everyone she met.

"Sandi was so proud that her cousins would even think to put themselves through the Wolf Runs and fundraise for a charity dedicated to helping people like her. She was eagerly awaiting to cheer them on this summer.

"Devastatingly, our beloved Sandi passed away in her sleep in April. She was just 27. Cameron and Fraser, still reeling from shock, picked themselves up and decided that although their fundraising could no longer help Sandi, it could still help others in her name. The boys still have two more runs to complete, which will take them into 2022. To date they have raised over £6,000.

"Cam and Fray, at the most difficult time in our lives, you are demonstrating family love at its finest and compassion for others beyond measure. My heart is bursting with pride. Thank you, from the bottom of my heart."

Cameron and Fraser said. "It's only a few months ago that we lost Sandi to epilepsy. She meant so much to us and played a key part in our lives. She was brave and kind-hearted, always spreading her unique Sandi flavour. She went through so much and persevered so much with her condition. Doing the Wolf Runs in her name for Epilepsy Action will raise awareness and funds to support others, helping them to live the way Sandi wanted to live.

"We are both so appreciative of the award, but we can't take all the credit. Our family and friends have supported us and continue to be the backbone of what we set out to achieve, to drive awareness of such a great cause and in honour of our Sandi. It's not easy to convey our shared gratitude, but to be chosen for this award is a massive deal for us."

Matthew Mulhall – pushing through to help others

Matthew Mulhall, 21, from Buckinghamshire, was nominated by his mum Lisa for his fantastic fundraising during the Epilepsy Action Walk 50K challenge this year.

Matthew has had tonic and absence seizures since he was three months old and currently has up to three seizures a day. Despite these challenges, he took part in a challenge during May's National Epilepsy Week, walking 60 kilometres and raising £948 for people with epilepsy. Alongside his fundraising and super stepping efforts, he also did voluntary and college work, as well as going to football club during the awareness week.

Nominating her son, Lisa said: "Despite his many other commitments, daily seizures and other health issues, he smashed it. He did so well – there were some tough days when he struggled, but he really pushed through because he knew he was raising money to help others. He was extremely proud of himself by the end of the challenge, as are we of him. Matthew – you never let epilepsy beat you or control

your life and your dad and I absolutely admire you and your drive. Carry on being you and being amazing!"

Matthew's award certificate is now taking pride of place in the family's home as a daily reminder of his fantastic achievements. Accepting the award, Matthew said: "It was great to receive the award and really boosted my confidence to know I have made a difference. I want to do another event in the future like the Walk 50K to continue to support Epilepsy Action and other people who are affected by epilepsy."

Congratulations to all the brilliant winners. You can read the full stories of all the winners online at epilepsy.org.uk/features

And the winners are...

Cameron and Fraser Rutherford – for their strong hearts and strong legs, raising money in memory of their cousin Sandi.

Rebecca Millington – for being a fantastic flatmate.

Minworth Junior & Infant School – for helping Daisy feel safe and included at school.

Michael Robertson – for supporting his partner through thick and thin.

Sarah Alliott – for being a real-life Miss Honey from Matilda.

Matthew Mulhall – for keeping on going to complete his walking challenge despite daily seizures.

Rossi Gunson – for quick thinking, courage and kindness to a stranger.

Shine Cymru – for being the 'second family' to young adults like David who have complex needs and learning disabilities.

Currys PC World Hemel Hempstead – for showing how employers can help their workforce thrive.

Corbaley Morris – for being a caring and compassionate big brother.



Test, learn, share, repeat

The 34th ILAE International Epilepsy Congress was held virtually in August 2021. Kami Kountcheva summarises some of the exciting talks in the sessions

Scientific and medical research is a big deal for a lot of diseases and medical conditions. It fosters better knowledge and understanding, which is key for better management and support. It also creates new advancements in technology and medicine, which can mean better treatments, more options and fewer side-effects. It also helps to keep things like services and patient management in check, making sure the healthcare community is striving for the highest standards possible.

In epilepsy, research can be the start of things like higher rates of seizure freedom and better quality of life for many people. It can present gold standard practice and update previous practices to better meet the needs of people with epilepsy.

The 34th International League Against Epilepsy (ILAE) International Epilepsy Congress ((IEC) was held virtually in August 2021, covering a huge number of topics. These included telemedicine, wearable seizure prediction devices, delays in diagnosis, employment and epilepsy surgery, among many others.

A lot of very interesting and exciting talks were delivered at the meeting, offering hope and opportunity for new improvements in healthcare and technology for people with epilepsy. We share a summary of some of the presentations from the IEC.

Today's technology

With the first presentation of the Presidential Symposium, Dr Josephine Chan discussed how telemedicine can be used responsibly in epilepsy. Telemedicine is the use of technology for healthcare, for things like virtual consultations, phone calls with specialists, sharing seizure videos and more. She explained that it offers a lot of benefits, such as less travel, reduced accommodation costs, less time off work and reduced risk of infection from COVID-19, among other things. However, there are a number of challenges with it, such as the need for high-speed broadband and familiarity with electronic devices. These may disadvantage some groups, like older people, people with lower incomes and people with mental health problems.

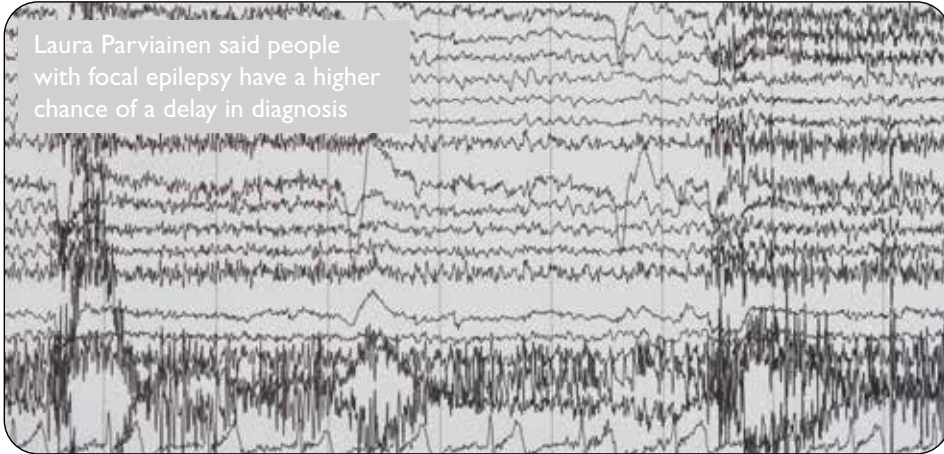
Telemedicine could also result in missed non-verbal cues and physical examinations, and patients may struggle to share due to worries about confidentiality. There is the potential for fewer medicine changes to be made through virtual consultations, for a poorer rapport between the clinician and the patient to be established and for local clinicians to be bypassed.

Dr Chan concluded that telemedicine is an acceptable alternative to traditional care at times of need, but should be used alongside, rather than instead of face-to-face clinics. She added that international standards need to be set and met around privacy and confidentiality.

In a similar vein, Prof Sameer Zuberi described one technological platform which has shown a lot of promise in Scotland, where it was created and trialed during the pandemic. This is the vCreate system, which has been used to share videos of seizures in a secure way with clinicians. This platform meets UK and EU security standards and offers an opportunity for faster referrals and more accurate diagnoses. The creators of the system are hoping to expand its use across the UK and beyond. However, Prof Zuberi explained that it relies on access to smartphones. He said half of the world's population have a smartphone, but acknowledged that this is not evenly spread across the world.

Where technology is concerned, it's hard not to mention wearable seizure prediction devices. Prof Sandor Beniczky presented on these, saying there is a big appetite for them, as they have the potential to reduce injuries resulting from tonic-clonic seizures. These kinds of seizures are also a risk factor for sudden

Laura Parviainen said people with focal epilepsy have a higher chance of a delay in diagnosis



unexpected death in epilepsy (SUDEP), so prediction devices could also play an important part in reducing this risk.

The ILAE and IFCN (International Federation of Clinical Neurophysiology) Working Group looked at evidence around the currently available and certified wearable devices, and found that studies were lacking. Among the studies that existed, they found that often, to get the best accuracy, false alarm rates increased. The group said that clinically validated wearable devices were recommended for detection of tonic-clonic seizures where significant safety concerns exist (for example, if a person doesn't share a bedroom) and if an alert would lead to quickly getting help. However, no devices are currently recommended for other types of seizures. Prof Beniczky concluded that more research is needed to improve the performance of wearable devices, especially for non-convulsive seizures, and to reduce false alarm rates.

Stopping seizures

Gaining better control over seizures is incredibly important for people with epilepsy. It reduces risks to the person and it helps to give them back some control and independence. While we know epilepsy is more than seizures, stopping them can improve many other aspects, such as driving, work and education.

The winner of the *Epilepsia Open Prize*, Laura Parviainen, presented her and her team's study around delay in diagnosis. She started off saying that previous studies suggest that somewhere between a third and a half of people (38-55%) live with undiagnosed seizures until a seizure

happens that is recognised and the epilepsy is diagnosed. She said for some people, this delay in diagnosis can be years long.

Ms Parviainen explained that this is dangerous, as it means a higher chance of things like injuries and car accidents. The study aimed to look at the impact of delay in diagnosis, involving 176 people with different or multiple seizure types. Most of them had between three and 10 seizures before diagnosis, but one in 10 people had more than 50 seizures before they were diagnosed.

The study found that having more seizures before diagnosis was linked to poorer outcomes and people with focal epilepsy had more chance of bigger delays to diagnosis. The researchers offered a few reasons why diagnosis may be delayed. They included a lack of awareness of seizure by the person themselves, no eye witnesses to seizures and not recognising subtle seizures. Other factors were denial of the symptoms or the diagnosis due to stigma or mental health problems, and challenges in accessing medical care for people in lower income areas. People with epilepsy and healthcare professionals can also miss seizures that don't involve movement.

The study authors concluded that more public and healthcare professional awareness of the diversity of symptoms of epilepsy is important.

Trying to stop seizures is always important, and epilepsy surgery is a big part in achieving that goal. Dr Maria Eriksson discussed children's epilepsy surgery at one of the surgery sessions, asking the question – have we reached a plateau in seizure freedom?

Dr Eriksson explained that over time, seizure freedom rates after surgery have remained at about 60-70%, despite advances in pre-surgery assessments, technology and surgical techniques, as well as more people being referred for surgery. She explained that there could be various reasons for this.

One is that perhaps more children are weaned off their epilepsy medicines at one year after surgery, some of whom may then start to have seizures again. Another possible reason is that more complex cases may now be accepted for surgery, with types of surgery being performed (such as disconnections) to try to reduce, rather than stop seizures. The last possibility is what Dr Eriksson called 'the ceiling effect' – that maybe there is a limit to the seizure freedom rates that can be reached with the surgical techniques and tools we have. She said alternative treatments may be needed to push seizure freedom rates higher.

Below the tip of the iceberg

As already mentioned, we know the effects of epilepsy to extend further than seizures. This is something which is gaining more and more recognition among the epilepsy healthcare community, with a view to improve the care and support for people with epilepsy. Prof Nathalie Jette discussed what is called 'patient reported outcomes', or PROs, at the Presidential Symposium of the meeting. This means treating the problems that patients report specifically, which may not be the seizures or epilepsy themselves, but something related to them. Prof Jette gave the example of depression in epilepsy as a good PRO. This is a problem that often accompanies epilepsy, and has been reported to have a bigger effect on quality of life than seizures. She said listening to PROs can help avoid assumptions made by clinicians about what is important to the person, can help improve their quality of life and can help tackle the symptoms most important to them.

Alongside this, the new president of the International Bureau for Epilepsy (IBE), Dr Francesca Sofia, championed real world evidence. This is information derived from things like electronic devices, personal devices, consumer data, social media, surveys, wearables, medical records and more. She explained that

there is a lot of data collected in real life situations that could be useful to better understand people's epilepsy experiences. However, she warned that people with epilepsy need to be brought into this, as many worry about their data being used without seeing any benefit. She added that we need to decide how to collect and analyse real world data that is reliable and unbiased. Dr Sofia concluded, saying: "We are missing crucial knowledge from individuals with epilepsy and if we combine all the information – genetic, clinical and real world – we will unlock more and better ways to support and care for people with epilepsy."

Mary Secco from Epilepsy Southwestern Ontario delivered a presentation at the session on needs and reality in patient care, on the ongoing support needs of people with epilepsy. She raised the point that seizures are often the tip of the iceberg and that it's important to make people feel safe and encouraged to seek treatment and help for other aspects of epilepsy too.

Ms Secco went on to say that people diagnosed with epilepsy will turn to the internet for answers if they are not given them at the clinic. She said this can lead to misinformation, and relying on TV and media can be inaccurate and dramatic.

Healthcare providers should give people the information they need in an understandable and personalised way. People may find it difficult to process and deal with too much information, especially around things like status epilepticus (prolonged seizures) or SUDEP, so clinicians need to take that into account. Ms Secco explained that rushed appointment times, insufficient knowledge and lack of care coordination could be why information isn't always given to people in a timely manner. She added that seizures dominate the appointment conversations and not much time is given to emotional, behavioural and social issues, such as school, driving or work. Ms Secco finished by saying community education is a good way forward, where clinics connect to organisations that can provide more information to people. The team is currently trying to establish something like this in Canada.

Dr Kette Valente also spoke at the session about thinking outside the box when treating people with epilepsy, although she said that treating seizures is rightly a top priority for clinicians and will remain so. This is because seizures increase the risk of injuries or accidental death. However, she added that the reason to also look beyond seizure control is that some parts of life may not improve with seizure control, like some physical and emotional aspects.

Dr Valente discussed mental health problems and suicide, as well as cognitive problems, financial issues and bone health, which may be impaired in people with epilepsy. She also raised sexual problems as a potential issue for some people, with a big impact on quality of life. She said that this can happen in older age, but also in teenagers, and that it is not talked about enough, especially in men.

When it comes to social issues related to epilepsy, one of the biggest things to get mentioned is employment. Ms Holy Chan presented on a recent study she and her team carried out around employment. This included 138 people with epilepsy, who received a questionnaire about themselves. The study found that in those who were unemployed, lower education levels, epilepsy not responding to medicines and mental health problems were significantly higher than in those who were employed. They found that people with higher education levels had more bargaining power at work and suggested that poorer seizure control may imply more time off

work to employers. Ms Chan concluded that job counselling services need to target and focus on the worst affected groups – people with medicine resistant epilepsy, with mental health problems and with lower education levels.

The congress shed a lot of light on work currently going on in epilepsy research, which is very encouraging to see. It felt like there was more time given to the wider scope of epilepsy, and the impact it has on life, which is important to see. We can look forward to next year's congress to see what new steps forward have been taken.

More information

There is more information on the Epilepsy Action website around many of the issues raised at the congress.

Employment – epilepsy.org.uk/employment

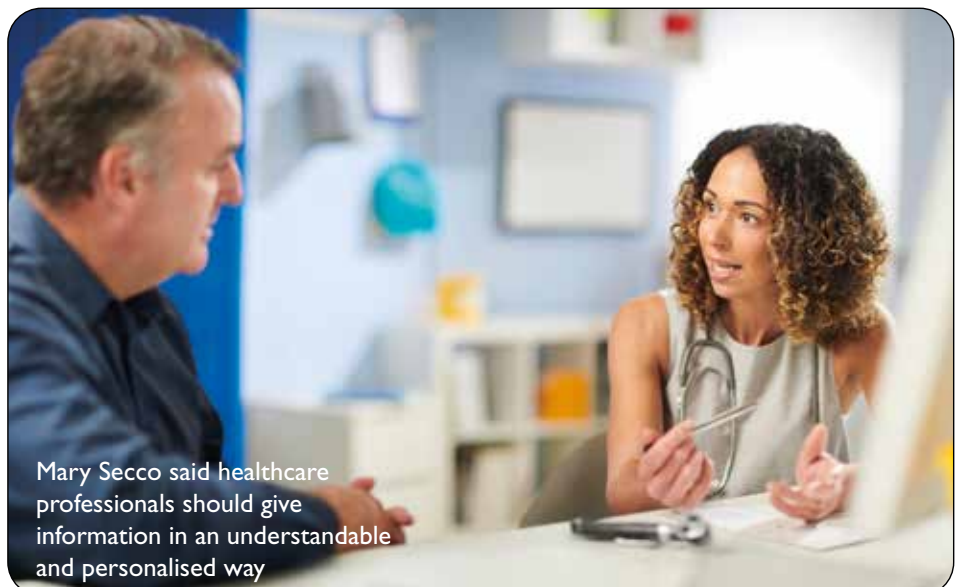
Safety – epilepsy.org.uk/safety

Sexual problems in men – epilepsy.org.uk/men

Wearable devices – epilepsy.org.uk/alarms

Surgery – epilepsy.org.uk/surgery and epilepsy.org.uk/childre surgery

SUDEP – epilepsy.org.uk/SUDEP



Mary Secco said healthcare professionals should give information in an understandable and personalised way



Leanne

Access to a specialist

Epilepsy specialist nurses offer a brilliant service, but are in very scarce supply across the country. Leanne and Elaine share their experiences with epilepsy services at the Hywel Dda University Health Board, and why they think ESNs are a vital part of the team

Most people who have come into contact with an epilepsy specialist nurse (ESN) will know exactly what a massive difference they make. For people with epilepsy, they provide care and support during and between appointments and can offer advice on medicines, side-effects, risks and daily life. Consultant neurologists will know how much load ESNs can take on, supporting an epilepsy service, and providing better and more holistic care for patients.

In short, ESNs make people's lives better and easier and are a vital part of the epilepsy healthcare team. But despite this, ESNs are in desperately short supply around the country, and the ones we do have are not spread equally across the UK. This means that there is a postcode lottery about whether a person will have access to an ESN or not, with some areas left with a significant gap in this service.

For example, research carried out by Epilepsy Action Northern Ireland last year found that one in three participants did not have access to an ESN. According to the organisation, there should be around 30 ESNs in Northern Ireland to provide adequate care to people with epilepsy, but there are currently only three ESNs in full time positions.

Recent news from Wales also shows a worrying lack of ESNs. Epilepsy Action Cymru said that there are nine ESNs for adults with epilepsy across Wales,

and 32,000 people with epilepsy in the country. This means the number of patients for each nurse is more than ten times the recommended number of 300. Epilepsy Action Cymru has specifically been calling on Hywel Dda University Health Board (UHB) to appoint an extra ESN to support people with epilepsy across Carmarthenshire, Ceredigion and Pembrokeshire. Currently there is only one ESN working across this large area (more on page 4).

Two people from Wales under the care of the Hywel Dda UHB share their experiences with ESNs, explain why they are such an imperative member of the epilepsy healthcare team, and stress the need for more ESNs in the area.

Alone, upset and unsupported

Leanne said: "In my opinion, an ESN could be the difference between life and death, especially for those people waiting to be diagnosed with epilepsy or who have just been diagnosed. There is a lot of fear when someone has seizures – you worry about when they will have one next and what they can do to avoid them. An ESN can provide vital advice on managing risks, as often you don't get all the safety aspects from a neurologist. Seizures can be deadly, so it is absolutely essential that there is a nurse who can provide services and advice when the neurologist can't, to prevent serious injury or, in extreme cases, death. They act as an important point of contact between yourself and the neurologist.

“I haven’t had the best care under Hywel Dda for my epilepsy in terms of neurologists. But the ESNs under Hywel Dda I cannot fault. There are two part time ESNs, equivalent to one full time ESN. They have been very helpful and supportive. However, during my pregnancy, one of the ESNs was also pregnant and went off on maternity leave the same time as me. This meant that after my pregnancy, I wasn’t supported much and I did have two seizures after my child was born. This left me feeling alone, upset and unsupported. A seizure is emotionally draining and exhausting. If I had had an ESN there after the birth of my daughter, I could have asked if my medicine dose would need to change immediately. I had a seizure three days after my c-section, which resulted in a trip in an ambulance to hospital and me having to leave my newborn daughter with my mother. This was very distressing in itself, as I felt upset that I couldn’t care for her. Hormones are all over the place after birth, and changes in hormone levels can contribute to seizures, which is what I think happened in my case.

“The current ESNs are doing the job for three counties and it is so obvious they need more support in their role to care for all their patients adequately. I haven’t heard from my ESN now in several months, but the last time I spoke to her, she said they were looking to employ another ESN. Obviously these plans seem to have been cancelled.

“It isn’t fair that there are inequalities between health boards and different areas. All of Wales needs to be treated the same and offer the same care. It is my understanding also that some areas have more than one full time ESN, while three counties under Hywel Dda have two part time (equivalent of one full time) ESNs. This makes it impossible to help everyone and give them the full support they need, as the ESNs are so stretched.

“I recently had a seizure, so I got in touch with the ESNs for advice. It is so frustrating and lonely when you can’t get in touch with anyone for advice, as I have faced countless times before. It is so scary too, as you don’t know what to do for the

best while you wait for proper medical advice and reassurance. It is absolutely essential that timely advice is given by an ESN to avoid more seizures and potentially serious injury or worse.

“I do find epilepsy is seriously underfunded in Wales within the health services and it needs to be taken more seriously.”

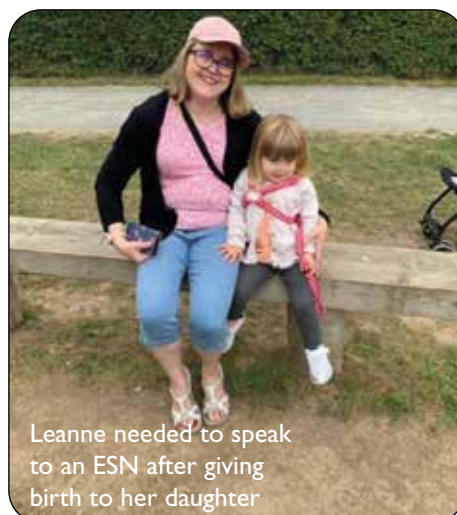
Direct access to a specialist

Elaine said: “I developed epilepsy in my late thirties and it was misdiagnosed for three or four years. Focal seizures were diagnosed as atypical migraine and then as stress related incidents. I was having seizures in my sleep and lived alone at that time, so no-one witnessed them. I was aware of how ill I felt afterwards and felt that something had gone wrong in my sleep, but didn’t know how to explain all of that.

“Eventually I was diagnosed after receiving help following one of the most severe sleep seizures I’ve had.

“There was no epilepsy consultant in the Hywel Dda UHB then (2005) and I was referred to the Heath in Cardiff. I have now been discharged from their clinic after several years seizure free. During one of my appointments there, I saw an ESN and I have also telephoned the clinic a couple of times with queries.

“Knowing that you can contact an ESN can be reassuring and it is useful to be able to have advice without having to wait for an appointment with the consultant.



Leanne needed to speak to an ESN after giving birth to her daughter

The ESN can potentially flag up any concerns to the consultant too. An ESN service can often answer your questions and also free the consultant’s time to deal with more complex cases. This can reduce waiting times while ensuring that everyone can receive advice when they feel they need it.

“I have been seizure free since 2010, but I am still on medication as the latest EEG I had in 2019 showed significant abnormalities.

“I would like to be able to review my medication – the dose and the side-effects – with an ESN but, with the overstretched services in Hywel Dda, I feel there is no-one to turn to.

“I think an ESN service is very important, as it can help people who have epilepsy receive appropriate advice, discuss medicine issues (such as side effects, effectiveness and so on) and discuss any concerns. It gives people direct access to a specialist, which is very reassuring for people who live with this challenging condition, and for their families.”



Elaine would like to be able to review her medication with an ESN



Jill

Forever young

Sudden unexpected death in epilepsy affects one in 1,000 adults and one in 4,500 children with the condition. Two families share their experiences with SUDEP to raise vital awareness in memory of their loved ones

Jill's story

told by her dad, Colin, and her mum, Sheila, and her brothers Ric and Steve

Jill's epilepsy first showed itself when she was aged nine. What started out as absences quickly moved to tonic-clonic seizures, and these continued, despite changes to her medicines, until May 2010. Jill's character played a part in that; she was a very determined person throughout her life, and she was not going to take any medicine which

gave her what she called "a head full of feathers". She always took her medicine, even though several of the ones she tried proved to be ineffective and had unpleasant side-effects, and she carried on searching for a medicine regime that would allow her to reach her academic potential. When she was 16, one consultant found it hard to understand Jill's reluctance to stay on a particular medicine, the side-effects of which, Jill believed, were ruining her life and making her a different person.

Similarly, she refused to compromise on lifestyle. She liked to party with everyone else at university and she loved the great outdoors from a very early age. She would go striding out, rosy cheeked, rucksack on her back while the rest of the family tried to catch up. She was determined to find a treatment regime which gave her the life she wanted. She frequently scared us out of our wits; we'd get phone calls saying that she had been found unconscious in the street or in a supermarket or in her flat, asking did we know her and so on. But, as a family, we never willingly gave the condition an inch in terms of limiting Jill's potential and lifestyle. In truth, she was so strong willed that she wouldn't have allowed us get in her way in any event.

Her childhood was, episodes aside, completely normal. She had learned to swim before she was five and continued swimming throughout her childhood. Later, when she visited the pool alone, we just had a discreet word with the pool manager and left her to get on with it. She was a bundle of energy and enjoyed life to the full. She had a group of close friends who knew about her epilepsy, but just accepted it as something which might happen from time to time.

She was what would these days be called an empath; she could see right through people and, at the same time, feel what other people were going through.

She was a campaigner too, something of a rebel (a family trait). She upset the hierarchy at her secondary school by appearing in the local newspaper advocating for Latin to remain a GCSE

Jill loved the great outdoors from an early age - she would **go striding out, rosy cheeked, rucksack on her back while the rest of the family tried to catch up**

option. She wore a big badge saying "Lingua Latina in Perpetuum" (Latin language forever). We were so proud!

At university, she blossomed. A first class honours degree in Geography (BSc), a distinction in her Masters degree, and later a PhD, eventually taking her to Alaska. This was a setting she loved, both the people she met there and the animal life (including encounters with grizzly bears).

She continued her post-doctoral studies at Oxford, attended Trent University Peterborough in Ontario, Canada and



finally became assistant professor at the University of Windsor in the same city. She absolutely adored her team at Windsor. They spent many hours in the wild gathering data, maintaining sensors and so on. Her research, which frequently involved international collaboration, was largely funded through grants she secured working with State and Federal Government and the Natural Sciences and Engineering Research Council of Canada.

She published many academic papers. Her main focus became water quality. It involved lots of 'ologies' – hydrology, glaciology, ecology, and a lot more. Her work involved the use of computer models calibrated to show the likely impact of climate change in the areas she was studying. On top of that, she taught undergraduates, rewriting and configuring courses to make them more meaningful to students, and mentored people doing postgraduate studies.

Our lovely Jill passed away in her sleep at her home in Windsor, Ontario, on 11 September 2021 at the age of 38. The

coroner concluded that SUDEP is the likely cause.

She was a member of Epilepsy Action, and knew it as a charity which seeks to garner support for people with epilepsy, helping them to control their seizures or even stop them completely. That's why, as a family, we wanted to do some fundraising for them.

One sad fact is that Jill felt that she had to be careful about telling people about her epilepsy. She worried that she would be denied opportunities or have unnecessary restrictions placed upon her by well-meaning but ill-informed people. The truth is that her untimely death was nothing to do with her work or her lifestyle or her approach to her medicines. It was just something which could have happened at any time, and we are so glad that she was able to live her 38 years to the full.

We always knew of the risk to her, but kept it in context. The number of cases of SUDEP are one in 1,000 people with epilepsy, which is really small. Her



epilepsy feature

last evening was a lovely dinner with her best friend Mercedes, and she was found to have passed away quietly in her sleep when she didn't turn up for an appointment on the following day.

Our younger son Steve also has epilepsy, but his story is different. His epilepsy started much later in life, when he was an adult working as a football commentator. He is fit and well and last had a seizure in

early 2018. He has had to make lifestyle changes, but his seizures have been much further apart than those Jill had. A downside of that is that it is hard to tell how effective Steve's tablets are, so dose adjustment is something of an art.

Steve was told that there was a little over 50% chance of his first seizure being a "one off", but that a case could be made for not starting medication at that stage, since a decision to take medication would be a lifetime decision.

In the event he had repeat seizures, often associated with late night/early morning working and dehydration (whether through not drinking enough water or through having a bit too much alcohol on occasion).

His worst seizure was in Brazil when he was covering the Olympic Games. He fell and hit his head hard and had to be rescued by a Canadian police officer (a Mountie!) who was on duty with the beach volleyball team. Fortunately, Steve was able to contact the police officer

later to get a very full description of what had actually happened. That detailed information was important for the process of diagnosis. There was some post traumatic stress disorder (PTSD) symptoms associated with this episode, because of the circumstances, and it affected Steve for a long time. Today, he's happy and working as a radio presenter at BBC Radio 5 Live.

Jill would have said:
"Don't accept any limitations lightly and **strive to realise your potential, whatever that may be**"

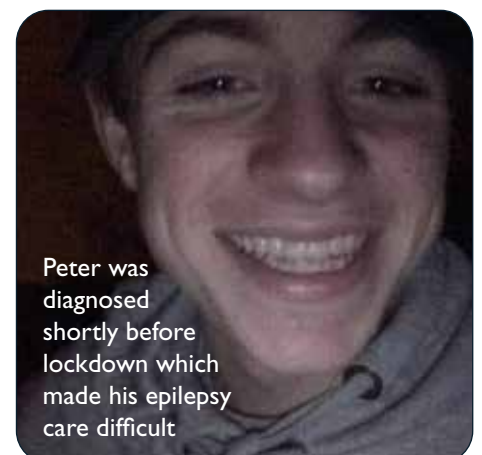
We are all currently travel-weary following a trip to Windsor to organise Jill's funeral, and to deal with all of the other details which have to be attended to when people least feel up to it. But we are very glad to have the opportunity to share some of Jill's story in the hope that it might help others in the future. She was a larger-than-life character, full of fun, who didn't suffer fools gladly (or at all, for that matter), and was unbelievably hard working and determined. She would just have said, both to people with epilepsy and their families: "Don't accept any limitation lightly and strive to realise your potential, whatever that may be".



Peter



Peter had recently become a dad



Peter was diagnosed shortly before lockdown which made his epilepsy care difficult

Peter's story

told by his aunt Margaret on behalf of his family

Our Peter was a fun-loving, outgoing, sociable wee boy, who loved life, his family and his friends. His life took a sudden turn

We didn't realise the **impact this diagnosis would have on Peter**

when he had his first seizure in December 2019. This was completely unexpected and out of the blue. It was a very worrying time for the family as a whole, as we didn't know the cause of the seizures. After spending a few days in hospital and after various tests, Peter was diagnosed with epilepsy. It was just before Christmas and he was released from hospital on Christmas Eve. We were so glad to have him home and we were also glad to have a diagnosis of something that we thought was manageable.

We didn't realise the impact this diagnosis would have on Peter. He battled on a daily basis with his seizures. Epilepsy had a big impact on his work life and his day to day living. Peter wasn't able to get his seizures under control and this was very difficult for him to deal with and accept. Like any teenager, all he wanted was to live a normal life. He wanted to work, he wanted to learn to drive but all of this was put on hold because of epilepsy. It also had a big impact on his family. Having



to watch someone have a seizure and learn the first aid needed in that instance was very scary. No one prepared us for this. A few months after Peter was diagnosed, lockdown happened. This also had a huge effect on him. It was difficult to get a doctor's appointment and everything was done over the phone, no face-to-face contact was allowed. His seizures continued to get worse. His medication kept getting increased but it wasn't having much effect. Peter's health continued to go downhill.

The day before Peter died he was sent home from the training centre, where he was training to be a joiner, as he wasn't feeling very well. A few hours after he got home he phoned his nurse, and while he was on the phone, he had a seizure. He was always left exhausted when he came out of a seizure, so he went to bed. His mum and dad checked on him at various times just to make sure he was ok. He had his dinner and he told them he still felt very tired so he went back to

bed. Peter never woke up. He died from SUDEP in the night. We had never heard of SUDEP until the morning of his death, when the doctor came out and signed his death certificate. That was the first time it was ever mentioned to us.

We have been left to deal with the trauma and shock of Peter's death and it is something that we will never get over. We miss him every second of every minute of every day. Our grief is still very raw, but as a family we want to raise awareness of epilepsy, the different types of the condition and especially of SUDEP. This is something that we never thought we would have to deal with, it isn't talked about enough. Doctors also need to make patients aware of the risks, the triggers and how the risk could be reduced. If we can help any family by sharing this, then putting our story out in the public was worthwhile.

Our Peter was a loving dad, son, brother, grandson and nephew. #forever18

Reducing the risk

SUDEP can be really worrying, but there are steps that can be taken to reduce the risk

The most effective way to reduce the risk of SUDEP is to try to reduce the number of seizures as much as possible, especially tonic-clonic seizures. Having fewer seizures also reduces the risk of death or injury from status epilepticus (prolonged seizures) or accidents.

While seizures can't always be fully controlled, taking epilepsy medicines every day, exactly as they have been prescribed by your doctor is vital. If you don't like your medicine or have side-effects, talk to your epilepsy specialist so they can make changes. It's good to find out in advance what to do if you miss a dose of your medicine or have vomiting or diarrhoea after taking it.

Avoiding situations that could trigger seizures, where possible, is also important. Common triggers include

missing a dose of epilepsy medicines, lack of sleep, stress and drinking too much alcohol.

If your seizures are not fully controlled, ask to be referred to an epilepsy specialist for a review of your epilepsy and medicines. They may be able to suggest changes to your epilepsy medicines, or other treatment options.

If you have seizures while you sleep, as well as steps to reduce seizures, you could consider different sleeping arrangements so there is someone else in the room where you sleep who could help if you have a seizure. If not, then alarms or monitors could alert someone else if you have a seizure. You could also consider sleeping on your back or getting a safety pillow, although there is limited evidence to say if these things help.

If you need more information, you can call the Epilepsy Action Helpline on 0808 800 5050 or visit the Epilepsy Action website: [epilepsy.org.uk/SUDEP](https://www.epilepsy.org.uk/SUDEP)

My journal



Steven spent 45 years living with seizures before getting epilepsy surgery, which has made a huge difference to his epilepsy, and, in all that time, his joy for life remained intact



Steven's epilepsy story started when he was just six months old. He was hospitalised with meningitis and suffered blood poisoning (septicaemia). At the age of five, Steven's seizures started, caused by the meningitis. Steven has lived his whole life with seizures.

"You name it, I've had it," he said, reflecting on the types of seizures he's experienced throughout his life. He explained he's had a variety of focal and tonic-clonic seizures, including auras, and could have up to 180 a year.

To begin with, Steven found his seizures difficult. Spending time with his friends at school or in the playground, he didn't understand what was happening to him when he would have a seizure. He found keeping up with early schoolwork wasn't always easy if he had had seizures, and due to being in and out of school a lot because of his condition.

When he moved to secondary school, where he had more independence, Steven explained that he took a different

approach. "In high school, there wasn't as much pressure. If I was given homework and I couldn't do it, I wasn't going to force myself to do it just to get better grades and to get a better job than someone else. I decided I'd rather put my health first."

"I decided I'd rather put my health first"

Steven's epilepsy has had an effect throughout his life. It has affected job hunting in the past, leading to "problems galore" with employers, and "doors closed in his face" at the mention of his epilepsy. Despite this, he was able to find jobs, working in a bakery and as a bicycle mechanic. "I really appreciated when I was given a chance. I told them about my epilepsy straight away, as it's a question of safety."

With seemingly quite unsocial hours at the bakery, Steven would start at five in the morning and work until around three in the

afternoon. He worked operating 70ft ovens. All of this could sound like a recipe for disaster for someone with epilepsy, but Steven loved his job. "I didn't find the ovens or anything being a problem. I told them about my epilepsy and they had me wearing my cycle helmet in case of a seizure. I've always been into cookery. I wasn't allowed to do metal work or wood work at school because of my condition, so I took up cookery. I love it, I do the catering at Christmas for all of us – that's sometimes 16 people!"

Steven was a candidate for epilepsy surgery, however, his mum was always worried about the risks of surgery for Steven

Steven's second career passion, working as a bicycle mechanic, was born from a lifelong love for cycling. He explains that he could cycle from his home in Leamington Spa to Oxford and back in six hours.

Steven's personal life was also affected by his epilepsy. He's had to carry his medical ID and information any time he has gone out for the evening with his friends. He's fallen and cut his head open in the past at work and while he's been out and about. "I was crossing the road one day and I had a seizure and fell and hit my head on the kerb. A doctor happened to be passing and stopped to help me that time. I find people are generally quite



Steven with his partner Cyd in Morocco

supportive and will always help me. But it is frustrating when they insist I need to go to the hospital after I've had a seizure, when I don't always. On that occasion, the person insisted I go to hospital and I was waiting in A&E for six hours. It is also frustrating when people think you're drunk. That's what lots of people always assume."

As is the case with many people, Steven tried a number of different epilepsy medicines over the years, including phenobarbitone, sodium valproate and lamotrigine. His doses were increased to as high as he could tolerate, but no medicines have ever controlled his seizures.

Steven was a candidate for epilepsy surgery, as the damaged area of his brain due to his early life illnesses could be operated on. However, Steven's mum was always worried about the risks of surgery for Steven and didn't want him to have it. Steven held off from having this treatment for years. His mum, dad and his sisters also worried about his cycling, with him having so many seizures. But Steven refused to give up this pastime which gave him so much enjoyment. "As far as I know, I've never had a seizure on my bike," he said.

Despite this, Steven got in a road accident with a van, which resulted in him spending a long time in hospital. "I was in the intensive care unit for around nine weeks. My bike helmet had split into three pieces."

Steven had time to reflect during his stay at hospital. His father had recently died and he had time to think about the future. He decided that as soon as he could, he would go in for the surgery.



Steven is a keen cyclist and cycles big distances

epilepsy experience



After surgery, Steven's seizures reduced significantly

A few years later, Steven's mum died too. Despite going through a difficult time, he decided it was time for him to plump for better seizure control. "After my mum passed away, I decided to have the surgery. I was 50 when I finally had it. No one was going to stop me now, because I was willing to take that risk. It made some big improvements to my life. It has cut my seizures in half, if not cut them to a quarter. One year I had around 160-180 seizures – all different types. This year, I've had 25 so far."

Before the surgery, Steven had a lot of side-effects from the high doses of his medicines. He experienced frequent headaches and sleeplessness. "Days would just go by sometimes when you don't know what you're doing. I had headaches and insomnia. I didn't know what was going on, but it was the medicine I was taking that was keeping me awake." But as a result of his surgery, his medicines could be reduced and he is now in a place where he has a balance he wants to keep.

"But I lost my warnings, that's been the only downside," Steven said. He used to have auras, but with the reduction in his seizures, there is now no warning that a seizure is coming on. Steven had a section the length of 1.5cm removed from his left temporal lobe.

Despite all the challenges of living a long time with uncontrolled seizures and experiencing the direct and indirect effects of epilepsy, Steven has a real zest for life. He has been with his partner Cyd for 14 years now, and has three children, Louise, Tanya and Russel, and many grandchildren. Steven recently moved out of the flat he was living in, with the help of his sister. He now lives in a house with a garden – something which was really important to him, so his grandchildren can play. He

explained that while things with his epilepsy can sometimes be difficult for his family, they are very understanding.

He is a big music fan and has played drums since school, from around the age of 12 or 13. "That's what I took out all my frustrations on. Mum and dad wouldn't get me drums at home because they were too expensive. But when I was older, I bought some and I have a £2,500 kit. I still play to this day. I play to entertain people and I've played for three decades in a hotel near where I used to live. When I was 15 or 16, I was doing all the discos there."

With so much love for music, one of Steven's favourite bands is Queen and he even won a look-a-like contest of Freddie Mercury. He's also quite artistic, with art being a favourite subject of his at school, and he helped design a friend's wedding invitations.

"I was 50 when I finally had the surgery. No one was going to stop me now, because I was willing to take that risk"

Steven's love of life has prevailed over the many years he lived with uncontrolled seizures and the challenges this has brought along the way. Now, at 58, he is surrounded by his family and is able to do many of the things he enjoys – including mending his grandchildren's bikes for them.



Steven once won a Freddie Mercury look-a-like contest

Epilepsy surgery

Steven's family was worried about him having surgery - but it is a carefully considered treatment option for people with epilepsy. We share some more information on epilepsy surgery

Epilepsy surgery is a treatment option for some people whose seizures don't improve with two or more epilepsy medicines, and who have a type of epilepsy that can be helped with surgery. Epilepsy surgery can reduce the number and severity of seizures, and it can stop them completely in some people.

There are different types of epilepsy surgery which can be performed depending on the case. Some involve removing a small section of the brain that is causing the seizures. These include temporal lobectomy, extra-temporal resection, lesionectomy, in all of which damaged sections from different brain areas are removed, and hemispherectomy, where the outer layer of one half of the brain is removed. Other types of surgery cut the connections between different parts of the brain to prevent seizures from spreading. They include corpus callostomy, where the connections between the two sides of the brain are cut, and multiple subpial transection, where the nerve fibres in the outer layer of the brain are cut.

Over several months, potential candidates for surgery will undergo a number of tests to identify the area that needs to be operated on and other areas that may be affected by surgery. These tests may include EEG and video telemetry, and invasive EEG telemetry, where electrodes are placed directly onto the surface of the brain. MRI scans may also be done, as well as functional MRI scans, during which you are asked to do tasks, like answer questions or look at pictures. This looks at the functions controlled by different sections of the brain.

You may also have a PET scan and a SPECT scan, which use different techniques to better identify the area where



the seizures start. Some specialist centres may also do an MEG scan, which can help work out which parts of the brain are involved in different tasks. A neuropsychology test may also be carried out, to assess any problems with memory and learning, and a neuropsychiatric assessment to see if the epilepsy is causing any mental health problems as well.

The risks following surgery often depend on each person's type of epilepsy and the type of surgery performed. However, they may include memory problems, particularly when temporal lobe surgery is done, problems with language, like struggling to find words, and a dip in your mood soon after surgery. A person's doctor would discuss the risks for them when it comes to surgery and how these balance with the possible benefits.

The benefits of surgery include potentially stopping a person's seizures, or reducing them in number or severity. It could reduce the risk of sudden unexpected death in epilepsy (SUDEP) due to fewer tonic-clonic seizures, improve quality of life and reduce the need for epilepsy medicines. Both children and adults can have epilepsy surgery, and some evidence suggests that having surgery earlier rather than later may be linked to better outcomes.

Surgery might take several hours and you will be in hospital for around five days. You will need to rest and relax in the first few weeks after surgery and gradually become more active. If you usually work or go to school or university, you will need to stay off for around two or three months.

There is more information on the Epilepsy Action website at: epilepsy.org.uk/surgery and epilepsy.org.uk/childrenssurgery

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 eslicarbazepine acetate.

Eslicarbazepine acetate

Eslicarbazepine acetate (ESL) is a prodrug, which means that it is an inactive substance which gets broken down by the body to produce the medicine. It is broken down mainly in the liver into the major active part, S-licarbazepine, which is responsible for its anti-seizure properties. It was first licensed in the UK in 2009, for adults and children, as an add-on treatment for focal seizures whether or not they turn into tonic-clonic seizures. Subsequently, it became available for use on its own for the same seizure types in adults. Its structure is similar to carbamazepine

and oxcarbazepine, but unlike them, ESL can be prescribed to be taken once daily. It has similar potential side-effects to them too, but is generally better tolerated than them. Like these medicines, ESL can worsen generalised absences and myoclonic jerks.

The recommended starting dose of ESL on its own and as an add-on in adults is 400mg once daily, increasing usually to 800mg once daily after a week or two, which means it can be increased relatively fast. The maximum dose of ESL is usually 1200mg once daily, although higher amounts can be tried if needed, depending, of course, on whether it's well tolerated. The use of the medicine as an add-on in children weighing 60kg or more is the same as that in adults. In younger children, the starting dose is 10mg for each kilo of the child's weight a day, increasing every few weeks to a maximum of 30mg a kilo a day as needed, depending on whether it's proving effective and is well tolerated.

The most common side-effects with ESL are dizziness and tiredness. Other complaints are largely related to higher

amounts and include headache, double vision, tremor, nausea, vomiting and poor coordination. Skin rashes and other allergy problems do occur, but less frequently than with carbamazepine and oxcarbazepine. Reduced levels of the mineral sodium in the blood can occur at high ESL doses, particularly in older people also taking water tablets for high blood pressure or heart problems. Blood level measurements of ESL, or the substance that it gets broken down into in the body, are not routinely done.

ESL can reduce the level of a few other medicines in the blood, particularly the hormones that make up the contraceptive pill. Higher hormone doses may be necessary to give optimum protection against unexpected pregnancy. There is very limited data on ESL use in pregnancy, so there is not enough evidence to confirm or rule out a risk of malformations in babies exposed to it during pregnancy. Overall, ESL is a well-tolerated, easy-to-use, once daily anti-seizure medicine that is being increasingly prescribed on its own in adults or as an add-on for focal onset seizures in adults and children.

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.



Professor
Martin
Brodie



Council of Management 5 October

The Council of Management met by remote video conference on 5 October.

Members approved a set of guidance for staff in the preparation of the 2022 revenue budget. This continued the same principles that have successfully guided the charity's finances through the pandemic months.

Council approved the appointment of Siôn Glyn Pritchard and Jeanette Spiers as new members of the charity's National Advisory Council for Wales / Cyngor Ymgynghorol Cenedlaethol Cymru (CYC Cymru).

Members reviewed a report from the Corporate Governance committee regarding the diversity of Council. It was agreed in principle to establish two new advisory panels – one focused on people aged under 45 and one focused on minority ethnic communities.

In other business, members reviewed the charity's current financial position and progress being made with this year's business plan. Every quarter the Council looks at the top ten risks on the corporate risk register and selects one for more in depth analysis. On this occasion members looked at the danger of losing public trust in the charity's fundraising. Members



assured themselves that proportionate measures were in place to manage this risk.

The next meeting of the Council is scheduled to be held on 7 December 2021.

Epilepsy support for you

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

Join one of our virtual groups

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

If you previously went to a local support group, they may also be offering a chance to get together online. You can find out if this applies to the group you attended by emailing iso@epilepsy.org.uk 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](https://www.penpalworld.com), or [ablehere.com](https://www.ablehere.com) for people with disabilities and conditions. Bear in mind that these websites are not part of or run by Epilepsy Action.

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

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

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INTENDED USE / INDICATIONS:

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

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

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

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