



## Ellie's legacy

Ellie's mum Georgina tells Ellie's story ahead of her first Christmas without her daughter

Also in this issue

- fill out our *Epilepsy Today* reader survey and **have your say**
- we call on the government to act on the **cost-of-living crisis**
- read about John, one of the **oldest people to have VNS**



# editor's letter

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

As we head into Christmas, the news all seems very serious. There is once again uncertainty in the political landscape and the cost-of-living crisis is continuing to put a huge strain on our bank accounts.

Many people with epilepsy have shared their concerns about this. People told us they are worried about making ends meet, and having to choose between meals and heating. We've also heard that being cold, being stressed and skipping meals can be triggers for some people's seizures. That makes the prospect of the upcoming winter worrying for many of us. At Epilepsy Action, we're campaigning and urging the government to do more to ensure people with epilepsy have what they need to manage their condition. Find out more on page 20.

On another serious note this issue, we share our cover star Ellie's story. Ellie, who had epilepsy, died earlier this year. Her mum Georgina tells us all about Ellie and about wanting to create a lasting legacy in her daughter's name on page 8. Georgina speaks really movingly and honestly about going through grief in this article and in her YouTube videos – you can find her if you search for The Honest Vocal Coach. And one thing that really stands out is how much Georgina wants to help other people living with epilepsy.

This issue, we have a reader survey (page 17) which we would love for you to fill out to let us know what you like about the magazine and what you would like to see more of. You can send the paper version of the survey back to us in the reply envelope included with your magazine, or you can go online to fill it out there. We really want to hear from you!

We also share some winter warmers this issue. On page 16 you can find out about Dawn's unexpected Christmas present – an absolutely amazing story. And on page 26, Jackie tells us about her and her husband John. They met on holiday in 1976 and have been together ever since. They've had ups and downs with John's epilepsy and depression, and recently, John became one of the oldest people to have a vagus nerve stimulator (VNS) fitted. They're both very happy with the difference it has made.

And there's lots more to find in this issue! We hope you have a good festive season and we will see you in 2023!

Kami Kountcheva  
**Editor**

Editor

**Kami Kountcheva** [kkountcheva@epilepsy.org.uk](mailto:kkountcheva@epilepsy.org.uk)

Publisher

**Epilepsy Action** [epilepsy@epilepsy.org.uk](mailto:epilepsy@epilepsy.org.uk)  
New Anstey House, Gate Way Drive, Yeadon,  
Leeds LS19 7XY, UK  
Tel: 0113 210 8800 Fax: 0113 391 0300  
Freephone Epilepsy Action Helpline:  
0808 800 5050  
[www.epilepsy.org.uk](http://www.epilepsy.org.uk)

Every reasonable effort has been taken to ensure the accuracy of the content, but no responsibility can be taken for any error or



omission. The opinions of contributors do not necessarily reflect the views of the charity, nor does the inclusion of an item constitute a recommendation. *Epilepsy Today* is available on subscription to non-members – £20 a year to UK residents and £45 to non-UK residents.

Please send all letters, articles and so on to the Editor. We are unable to acknowledge receipt of materials, due to cost. We cannot offer payment to authors. Epilepsy Action is the working name of British Epilepsy Association, a registered charity (No. 234343) and a company limited by guarantee (No. 797997) in England and Wales. All income generated by *Epilepsy Today* funds the association's work.

©2022 Epilepsy Action ISSN 0958 496X

All models are used for illustrative purposes only.

Epilepsy Action has revised its privacy statement (September 2022) to better reflect its activities and use of data. Please go to [epilepsy.org.uk/about/our-privacy-statement](http://epilepsy.org.uk/about/our-privacy-statement) to access it.



# this issue...



## 4 News

**This issue: Neuro survey finds lack of care plans and access to specialists, St Elizabeth's Adult Care home to close in November and pharmaceutical companies fined £70m over unfair price hikes**

## 8 The brightest thing

**Facing the first Christmas without Ellie, Georgina tells the story of her daughter and shares why she wants to create a lasting legacy in Ellie's memory**



## 12 Clinics, genes and digital doctors

**We look at how clinical research works, see if gene testing offers new answers and talk digital doctors**

## 16 An unexpected Christmas gift

**Dawn shares her unbelievable Christmas story that resulted in a surprise present**



## 17 Have your say!

**Please fill out our reader survey and let us know your thoughts about *Epilepsy Today* magazine**



## 20 Making ends meet

**Epilepsy Action calls on the government to reduce health inequalities as the cost-of-living crisis escalates in the coming winter months**

## 24 Help to break barriers

**Epilepsy railroaded Olympic hopeful Blake Allsop's plans, so he focused on supporting others**

## 26 My Journal: Jackie and John

**Jackie describes John's experiences with epilepsy, depression and being one of the oldest people to have VNS**

## Lack of care plans and access to specialists

Around seven in ten people (69%) with epilepsy reported that they did not have a care plan, according to the Neurological Alliance Survey carried out in 2021/22.

The survey included over 8,500 people with neurological conditions, and for the first time included people from across the UK.

The findings also showed that of the respondents with epilepsy who did have a care plan, nearly a third (29%) said they did not have a say in theirs.

Care plans are an important part of helping people with epilepsy and their families manage their own condition and have a say in their care. They are also intended to help people with epilepsy to be confident in saying what they need and get the support they choose, Epilepsy Action says.

The results also showed that people with epilepsy want more access to specialists. Over a third (37%) said they find it difficult to contact specialists and one in five

people (21%) said they don't have access to an epilepsy specialist nurse but would like to be able to see one.

People with epilepsy also reportedly had trouble getting mental health support. About seven in ten people (71%) said their epilepsy affected their quality of life to a moderate or great extent. Six in ten people (61%) said they would like to be referred for counselling but had not been. Almost the same number of people (59%) said they had not been asked about their mental health during their epilepsy appointments in three years.

Alison Fuller, director of health improvement and influencing at Epilepsy Action, said: "It's very worrying to hear that so many people with epilepsy do not have a care plan, or feel they are not being involved in their care or given the right information to manage their condition. It is vitally important that people with epilepsy are involved every step of the way with individual plans which focus on treatment options and quality of care. Everyone's experience of



epilepsy is different, and it is crucial people feel involved and confident in all aspects of their care.

"Epilepsy can have a major impact on people's mental health and it's concerning to hear people feel their needs aren't being met. We also know people with epilepsy are more likely to experience mental health problems such as depression. We have highlighted the importance of mental health support for people with epilepsy as part of our response to the Department of Health's new 10-year plan to improve mental health.

"Epilepsy, if poorly treated and managed, can be fatal. It's more vital than ever that we have a joined-up approach to healthcare to ensure both the physical and mental wellbeing

of patients. We will be writing to the new Secretary of State, when they are appointed in September, to call for the necessary improvements to epilepsy services. Together with the Neurological Alliance, we're also calling on UK governments to establish a Neuro Taskforce to address common problems including health and care workforce shortages, growing waiting lists and barriers to accessing mental wellbeing support. You can sign the petition on the MS Society website."

The full Neuro Survey report is available on the Neurological Alliance website at: [neural.org.uk/togetherforthe1in6](https://neural.org.uk/togetherforthe1in6).

Epilepsy Action has more information on care plans ([bit.ly/3eeWQZD](https://bit.ly/3eeWQZD)) and mental health ([epilepsy.org.uk/living/health](https://epilepsy.org.uk/living/health)).

## Fenfluramine recommended for use in Dravet syndrome

Fenfluramine has been recommended by the National Institute for Health and Care Excellence (NICE) as an add-on medicine for Dravet syndrome.

Dravet syndrome is a severe form of epilepsy and is one of the syndromes most resistant to epilepsy medicines. It is a condition for which some epilepsy

medicines actually need to be avoided, as they can make seizures worse.

Research has shown that fenfluramine added to other epilepsy medicines can reduce the number of convulsive seizures. Some evidence also suggests that it can help improve the quality of life of people with Dravet syndrome and their carers.

NICE recommended fenfluramine in July for treating Dravet syndrome in anyone aged two years and over if seizures have not been controlled after trying two or more epilepsy medicines, NICE says.

The organisation adds that the number of convulsive seizures should be monitored every six

months. Fenfluramine should be stopped if convulsive seizures aren't fewer by at least a third (30%) compared to what they were before starting the treatment.

Fenfluramine has been previously used as an appetite suppressant in treating obesity. It was approved for use in Dravet syndrome in the US in 2020.

## Residents needing homes after care home closure

St Elizabeth's Adult Care Home for people with epilepsy and learning disabilities, in Hertfordshire, will close on 30 November, leaving 83 current residents needing new accommodation.

St Elizabeth's said the Covid-19 pandemic and "a chronic national shortage of trained staff" had put the

centre under "relentless pressure". The centre said it initially "prevented the closure from taking effect by making an appeal" to a tribunal.

However, after consultations with the families affected by the closure, the centre has "reluctantly" decided to close the facility. It said there is "no prospect of safely staffing the

service in the longer term or meeting the standards required of us".

St Elizabeth's is working with the families, Hertfordshire County Council and the CQC to transfer their residents to new homes. Epilepsy Action has been in contact with the Local Authority to ensure that residents will be offered alternative accommodation before the centre is closed.

Daniel Jennings, senior policy and campaigns officer at Epilepsy Action, said: "This is a desperate situation for the residents, their families and staff affected at the centre. It is really concerning to know people with epilepsy and learning disabilities are facing losing their home and support.

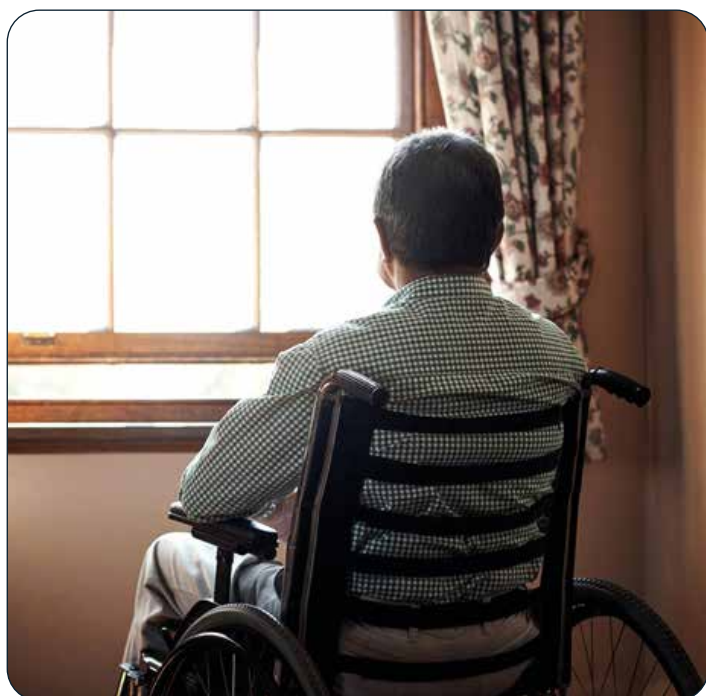
"With the consultation period now over and the closure still planned for the end of November, the clock is ticking to find new homes for the residents. We are working

with families to signpost them to alternative centres. But many of these are far from home and will place extra burdens on the residents moving, many of whom have very complex needs, and on their loved ones, at an already challenging time.

"In the meantime, we are continuing to raise this issue with Hertfordshire County Council and the local MP, Julie Marson, to ensure that alternative accommodation is found for residents before the centre is closed."

St Elizabeth's has confirmed that it will continue to operate as a residential school and college for children and young people with epilepsy and other complex conditions.

There is more information on St Elizabeth's website: [stelizabeths.org.uk](http://stelizabeths.org.uk). For advice and information, you can reach the Epilepsy Action Helpline on 0808 800 5050 or email [helpline@epilepsy.org.uk](mailto:helpline@epilepsy.org.uk).



brief news brief news brief news brief news brief news brief news brief news

## Milpharm 1000mg levetiracetam tablets out of stock

Levetiracetam 1000mg tablets made by Milpharm are temporarily out of stock. Milpharm were not able to say when they will be back in stock.

Milpharm levetiracetam 250mg and 500mg tablets are still in stock. Other manufacturers' versions of levetiracetam are also available.

Epilepsy Action advises that if people have any concerns about getting their usual medicine, they should speak to their pharmacist or GP for advice.

People can keep up to date with stock levels of this and other medicines by visiting [epilepsy.org.uk/news](http://epilepsy.org.uk/news).

Epilepsy Action also has more information about switching between different

versions of epilepsy medicines online at: [bit.ly/3CLQIRZ](http://bit.ly/3CLQIRZ).





## Pharmaceutical companies fined £70 million



Pharmaceutical companies Pfizer and Flynn Pharma have been fined nearly £70 million after the Competition and Markets Authority (CMA) found in July that they had overcharged the NHS for an epilepsy medicine.

The CMA ruled that Pfizer and Flynn Pharma “abused their dominant positions” and charged “unfairly high prices” for the medicine phenytoin sodium over four years between 2012-16.

The companies initially came under investigation for these price hikes in 2016. At that time, the CMA issued a fine of £89 million for the two companies, after prices for the medicine went up 2600% overnight in 2012.

The companies appealed against this decision and in 2018 a tribunal overturned the decision to fine. The tribunal ruled that the CMA had not correctly applied the legal test needed to make their decision, but that there was “much in the

[CMA’s] decision with which we agree”.

In 2020, the CMA reopened its investigation, which included additional evidence, and found that the companies had abused their dominant positions in the market by unfairly overcharging the NHS for this medicine.

Andrea Coscelli, chief executive of the CMA, stressed that phenytoin is an essential epilepsy medicine that many people rely on to manage their seizures. She added: “These firms illegally exploited their dominant positions to charge the NHS excessive prices and make more money for themselves – meaning patients and taxpayers lost out.

“Such behaviour will not be tolerated, and the companies must now face the consequences of their illegal action.”

The NHS is currently in the process of a court claim for damages against the two companies.

## Grant secured for bilingual therapy service

Epilepsy Action Cymru was recently awarded a £328,875 grant from the National Lottery Community Fund to provide online bilingual talking therapy in Wales.

The free Wellbeing Service will comprise one-to-one or group talking therapy sessions, available to adults with epilepsy, as well as parents and carers of people with the condition, based in Wales. They will be available in both English and Welsh, and be tailored for each individual. The organisation will be working on setting up this project in the next few months and will announce the launch of the service early next year.

Jan Paterson, manager at Epilepsy Action Cymru, said: “Epilepsy affects around 32,000 people in Wales and can have a devastating impact on people’s lives and those of their families. Talking to someone can make a

huge difference and help people feel less alone. This new service will provide timely access to talking therapies for people affected by epilepsy across Wales.”

Earlier this year, Epilepsy Action Northern Ireland also secured a grant to expand its counselling service in Northern Ireland. The funding from the Northern Ireland Department of Health’s Mental Health Support Fund is helping the organisation add online therapy groups for people and develop training materials and resources for counsellors.

Other recipients of a slice of the National Lottery fund, totalling over £4million, include Solva Care, Newport and Gwent Samaritans and The Big Skill CIC. These organisations help communities thrive, run craft and recycling workshops and provide support for people in distress and despair.



## Study on “revolutionary” EEG tech launched

A new study into “game-changing” long-term seizure-monitoring technology launched in October 2022.

The Real World Testing and Cost-effectiveness Analysis of Subcutaneous EEG (REAL-ASE) will recruit 33 people with drug-resistant epilepsy in centres in London, Newcastle, Cardiff and Manchester, to trial the small EEG device for six months. Drug-resistance is when two or more epilepsy medicines have not worked to control a person’s seizures.

Through the study, the researchers are hoping to find out what it would cost for the NHS to incorporate this technology into its work, and what the benefits would be.

The new EEG technology being studied, developed by Danish company UNEEG medical, can be used to monitor brainwaves continuously for up to 15 months, while the person gets on with daily life. A small device is placed under the scalp during a 20 minute procedure under local anaesthetic.

The research team at the Institute of Psychiatry, Psychology & Neuroscience (IoPPN) at King’s College London, explained that the device can accurately monitor a person’s seizures and could replace seizure diaries which can be unreliable.

The team also added that it could improve on typical EEG monitoring, which can only be done for a few days at a time, requires a hospital stay, and for which there can be long NHS waiting lists.

Alison Fuller, director of health improvement and influencing at Epilepsy Action, said: “This new technology has the advantage of overcoming some of the limitations or disruption people experience with more conventional EEGs. These often require extended hospital stays or the need for sleep deprivation which can have a knock-on negative impact on seizures.

“Having better evidence and knowledge will undoubtedly improve outcomes in safety and quality of care, which could



ultimately help to reduce epilepsy-related deaths.”

The study’s principal investigator, Prof Mark Richardson from King’s College London, said: “Clinicians treating people with epilepsy frequently make changes to therapy in the hope of improving the lives of the third of people whose seizures have not yet responded to treatment. We don’t know whether a change in treatment has been helpful without a very accurate count of seizures. Unfortunately, seizure diaries are often not accurate enough to judge whether treatment has led to any improvement.

“What the use of ultra long-term EEG opens up is the possibility, in future, of very accurately

judging the effect of a change in treatment. We also anticipate that ultra long-term EEG will allow us to quickly identify that someone’s epilepsy is deteriorating so that we can immediately step up their care. This has the potential to be truly revolutionary for people living with a difficult illness.”

The research is funded by a £1.8 million grant from the National Institute for Health & Care Research (NIHR).

For more information on the device, you can visit the UNEEG website at [uneeg.com](http://uneeg.com). Anyone interested in taking part in the trial should speak to their neurologist who can contact the nearest participating centre.

brief news brief news brief news brief news brief news brief news brief news

## Accord clobazam out of stock

Clobazam 10mg tablets made by Accord are now long term out of stock. Accord have told Epilepsy Action they won’t be back in stock until 31 December 2022.

For anyone who usually takes this medicine, pharmacists

may be able to offer a different manufacturer’s version until the Accord version is back in stock.

If you have any concerns about getting your usual medicine, please speak to your pharmacist or GP for advice.

There is also more information about switching between different versions of epilepsy medicines at: [bit.ly/3CLQIRZ](https://bit.ly/3CLQIRZ).







# The brightest thing

**Georgina Hill-Brown, better known on YouTube as The Honest Vocal Coach, tells the story of her daughter Ellie, who died this year, and explains why she is an ambassador for Epilepsy Action.**

*Words by Georgina Hill-Brown and Chantal Spittles.*

Georgina, 46, from West Yorkshire, is best known for being The Honest Vocal Coach on YouTube. She is an expert singing teacher, specialising in teaching children and young adults in singing and musical theatre.

She has also worked with famous bands and singers, including The Saturdays and Natasha Hamilton from Atomic Kitten, and she creates videos reacting to famous performances for her 249,000 subscribers on YouTube.

Georgina has lived through every parent's worst nightmare when she lost her daughter, Ellie, earlier this year. She

wants to help spread more awareness and information about epilepsy so others don't have to go through what she has. Georgina shares her story.

"My life has been very strange ever since Ellie died. I feel like I am in a movie and it's very odd.

"Ellie was a huge part of my life – she was a headstrong young woman and we were the best of friends and we both loved music and singing.

"She was working as a vocal coach, but didn't have a main job at that time. Her

dream career was either to be like me, or to work with animals. She was due to go back to university this September to restart an animal care course.

"Ellie was diagnosed with epilepsy at the age of 19, although it took at least a year and a half to get to that point.

"She started off having focal seizures – fortunately after a while these stopped but then she started having sleep seizures. This seemed to happen as she started to take medication following her diagnosis.

"She tended to have seizures about once every two weeks – they tended to get worse if she was particularly stressed or upset about something. So we were kind of prepared for that.

"We don't have any history of epilepsy in our family, so it's not something we were really aware of or knew much about.

"When Ellie was diagnosed with epilepsy, we had no idea that sudden unexpected death in epilepsy (SUDEP) was a possibility. She had appointments every three months and the chats would last five minutes – it was always very much focused on the medication she needed to take.

"There was no mention of support for families, even a leaflet to give to the patient that they can share with their friends and family so they know how to help. We were just told, 'she's got epilepsy,



we're going to try her on this medication, come back every three months to check how the medication is doing, and don't drive any more'. That was it.

"There was no other practical information or support. Having a leaflet to talk about things people can do to help loved ones and signposting to other sources of support would have made such a difference."

### Hard to cope

"I used to think epilepsy was just about having a seizure and taking medication for it. But it was about so much more than that.

"It was a real struggle for Ellie and she found it very hard to cope with as it had such a big impact on so many areas of her life.

There was  
**no practical  
information or  
support**

"When she was first diagnosed, we looked into safety monitors to have in her bedroom but that's a really difficult thing for a 19-year-old girl who wants her own privacy and independence. You don't want to interfere, but as a mum you want to protect your daughter at the same time, so it's really difficult.

"She really struggled with it in the beginning and didn't always tell everyone about her epilepsy, so it was a shock for some people when they found out.

"She started to find it easier to tell employers, but it was hard for her to keep a job – some workplaces just didn't understand it or try to help.

"If she ended up working longer hours, she'd get more exhausted, which had an impact on her seizures. I don't think many employers are fully aware of what more they can do to support people with epilepsy.

"We also had challenges with getting PIP and Universal Credit. Her Universal Credit only just covered her rent and what she received from PIP, was just not enough to cover her bills, never mind having anything left for food.

"It seems so arbitrary as to what support people get on PIP – she often had no money and it really used to get her down.

"We did think about her moving back home but she was so headstrong and wanted her own independence and it would have felt like a step back to move home. She had her own place about 10 minutes from home.

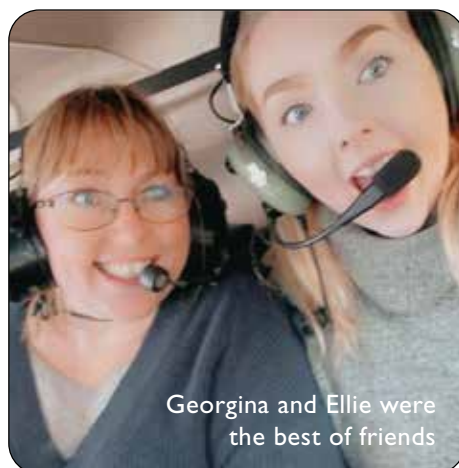
"But I knew she was struggling and it got to the point where she had no money. I thought if she lived back with us, we knew she'd always be fed and looked after and we could try to get her back on her feet again."

### Losing Ellie

"Ellie and I met up on her 23rd birthday (Monday 4th July) – we went for a Chinese buffet, as she adored Chinese, then went to Wetherspoons for her favourite chocolate fudge cake with ice cream.

"She drove away so happy – she was driving again and we'd also made plans to go to Alton Towers on the Wednesday of that week. She seemed a bit tired but in good spirits – I remember her waving me goodbye as she went home to relax and watch some nice TV that evening.

"The next morning I went to the garden centre and tried to phone her – I always used to phone her in the morning and last thing at night. That Tuesday morning there



Georgina and Ellie were the best of friends

was no answer and my stomach started to churn as I instantly knew something was wrong.

"Ellie lived about 10 minutes from mine so I decided to go to over. We always had this agreement where she locked the front door but didn't push the key fully in, so we could get in if we had to in case of an emergency. I went in and started checking the rooms around the house and that's when I found her."

### Going day to day

"Things escalated very quickly from that point. Police, ambulance, funeral homes and coroners calling and all kinds of horrendous things I've had to deal with.

"We still don't have a definite cause of death but there's an investigation going on – we think it's epilepsy-related but don't know yet. I can't tell you how horrific it is.

"I'm trying to not let it get to me, but I'm constantly thinking things over and ruminating about what happened. I took two months off initially, because it was very difficult to do anything.



Ellie's dream career was to be a vocal coach or to work with animals



Ellie was a very energetic and social person

“The hardest thing was knowing she had been all alone that night and I couldn’t be with her to help. I still have nightmares about the sound she used to make just before she had a seizure when she’d take a deep breath, and I still get triggered by it.

“I’ve spent a lot of time with Ellie’s younger sibling Alex, and also Ellie’s dad, who I’m divorced from but we’ve grown much closer again now, which is great. Alex has been really struggling without their sister and is finding it hard to talk about things. But I have told Alex to just take it day by day – it’s very early days. And luckily, Alex’s friends have been brilliant.

“Now I’m just going day to day as best I can. I’m generally a positive person. But sometimes it just gets too much and you don’t see it coming.

“My brother and I went to a little park with his two kids near where he lives. One of them was coming down the slide and I suddenly got flashbacks about Ellie and couldn’t function for the rest of the day. I couldn’t think straight. I didn’t know



Ellie loved music and singing

what day it was. So I just had to go home and cry for the rest of the day.

“I’m still going through that but I find my work with the Honest Vocal Coach channel on YouTube is helping – I’m trying to put out a positive persona online and keep going.

“You have to keep going, don’t you? What else can we do? Ellie would never want me to be sat at home depressed, she would want me to continue. So I’m just doing the best I can really.

### I don't want to forget Ellie, I want her memory to live on

“I’ve managed to juggle things about with teaching, vocal tutoring and making videos for my channel, so it all balances out, which is great.”

#### Create a legacy

“When I made the ‘What happened to Ellie’ video, people started to comment how they had also lost someone to epilepsy.

“I want to be able to ensure that people facing a diagnosis like Ellie do get all the information they need about their epilepsy.

“Since we lost Ellie, I’ve done a lot of research and learned a great deal. I have always believed that knowledge is power. If

we’d have had the knowledge we have now, it may not have changed the outcome, but at least we would have been able to make more informed decision as a family.

“Epilepsy Action gives people that knowledge. Through its website, freephone helpline and support groups, it provides people with the expert advice and practical information they need to live safely with epilepsy. It gives people a place to turn to when they need it most.

“I think it’s wonderful that Epilepsy Action has support groups too, where people can share experiences and ask questions, as there’s so much to think about when you have epilepsy.

“I want to create a lasting tribute in Ellie’s memory. I want to ensure that people facing a diagnosis like Ellie’s get all the information they need about their epilepsy - the advice and information I wish we had received when Ellie was first diagnosed.

“Epilepsy Action supports thousands of people every year, but they can only do this with the support of people like you. A donation from you today will ensure that Epilepsy Action can be there for all those diagnosed with epilepsy and their families now and into the future. You can make a donation now by filling out the form on the next page and returning it in the freepost envelope provided. If you’d prefer, you can also donate to Ellie’s appeal online or set up a regular gift by visiting [epilepsy.org.uk/donate](https://epilepsy.org.uk/donate).

“Where I’m at now is that I don’t want to forget Ellie. I sometimes think people might get irritated by me when I’m still talking about her in 20 years’ time. But I want her memory to live on.

“I’m glad that Ellie really lived the life she did. She never stood still– she just wanted to do things. She was the energy of every party. She socialised with everyone. She was just the brightest thing.”

If you are struggling with any of the topics mentioned in the article, you can speak to the Epilepsy Action Helpline by calling 0808 800 5050 or emailing [helpline@epilepsy.org.uk](mailto:helpline@epilepsy.org.uk).



# Yes! I want to help Ellie's appeal!

I want to help with a gift of  £10  £20  £30 or my choice of £

I enclose a cheque payable to Epilepsy Action

Please debit my card

Card number

Security code

Valid from (if applicable)  /  Expiry date  /

Issue number (if applicable)

Name on card: \_\_\_\_\_

*giftaid it*

Yes, I want to Gift Aid my donations/subscriptions to Epilepsy Action, including any I make in the future, or have made in the past four years. I am a UK taxpayer and I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference.

First name \_\_\_\_\_ Last name \_\_\_\_\_

Address line 1 \_\_\_\_\_

Address line 2 \_\_\_\_\_

City \_\_\_\_\_ County/ Region \_\_\_\_\_

Post Code \_\_\_\_\_ Telephone number \_\_\_\_\_

Email address \_\_\_\_\_ Date of Birth \_\_\_\_\_

Tick this box if you would like to request anonymity regarding:

The value of your gift  Your name

I have made a gift in my will to support Epilepsy Action.

I would like further information about making a gift in my will to support Epilepsy Action

You can update your contact preferences at any time – simply call 0113 210 8800 (9am-5pm weekdays) or complete the form at [epilepsy.org.uk/contact](http://epilepsy.org.uk/contact)

Please return in the freepost envelope included with your magazine.





It definitely sounds like something you'd expect to find in the medical bay aboard the Starship Enterprise, doesn't it? Genetics testing. Digital doctor. There's almost a futuristic, sci-fi feel about the whole thing.

But it's not futuristic or fictional at all. It's here and now, on planet Earth, happening as you read this very sentence.

Researchers and scientists are looking at the many different ways to use clinical research to improve diagnosis, treatment and long-term outcomes for people with epilepsy. This involves complicated, but extremely promising gene research, and advancing technology to create a digital doctor that can diagnose epilepsy.

This amazing work was presented at the Epilepsy Research UK Shape Network Conference this summer, and we bring you the roundup of the session and the answers to some of the big questions from the audience.

#### **The many faces of clinical research**

Dr Rhys Thomas from the Royal Victoria Infirmary opened the session, answering the question: what is clinical research?

Dr Thomas described the origins of the word 'clinic' as meaning 'bed-side' – or close to the person you're treating. And, in line with this, clinical research is about being with people, he said. Clinical research could look many different ways. It could involve giving patients something, like conversational therapy or a medical treatment, for example. Or it could be taking something from the patient, such as information or DNA.

Clinical research is very variable, Dr Thomas explained. It could be treatment research, looking at whether therapies are safe and effective. It could be prevention research, for example looking at effectiveness of preventing brain injury. It could be screening research (can people be found and treated before they've had a seizure?), or registries for rarer conditions, genetic research, imaging research, data analysis research...

# Clinics, genes and **digital doctors**

**We get the 101 on clinical research, see if gene testing can offer new answers, and talk digital doctors in the second of a three-part feature on the Epilepsy Research UK's Shape Network Conference.**

*Words by Kami Kountcheva.*



After listing some of the many forms of clinical research, Dr Thomas noted that clinical researchers have to be like Swiss army knives, able to turn their hand to a lot of different areas.

He warned that this type of research is all very expensive to do, and added that the patient experience has been missing so far. Clinicians don't always know what it feels like to the people involved in the trials and it could be different from one trial to the next. They may be based at home, they may have to come into hospital for monitoring, they may or may not know what the researchers are studying.

Dr Thomas concluded that it's important to have the patients as partners in research. With so many avenues and so much money at stake, it's important to find those key questions to focus on – and they often come directly from the patient, he said.

### The answer's in the genes

Dr Kate Baker from the University of Cambridge started off by saying that a gene is an instruction to build a protein, and proteins are the building blocks of a cell. She said proteins are important for your brain and that just one tiny change in the DNA can change the amount, shape or function of a protein and have a drastic effect on a person's life. This can sometimes be the cause of someone's epilepsy.

There has been a "technological revolution" in genetic testing ability, and now there is an up to 50% chance of finding a diagnosis from it, Dr Baker explained. She said the chances of getting a diagnosis is higher in people who had early-onset epilepsy, whose epilepsy is medicine resistant and in those who may have additional problems, such as learning difficulties.

Dr Baker said new knowledge from genetic testing offers a new window of opportunity. The genetics service in England has been reorganised to centralise the sequencing work. There are seven laboratory hubs and 13 genomics medicine centres, Dr Baker explained.

There is also a national genomics reference library, and this all helps to remove the postcode lottery.

People with epilepsy benefit from this because it helps them understand the condition better, and what it may mean for the future, Dr Baker explained. At the moment, genetic treatment may help

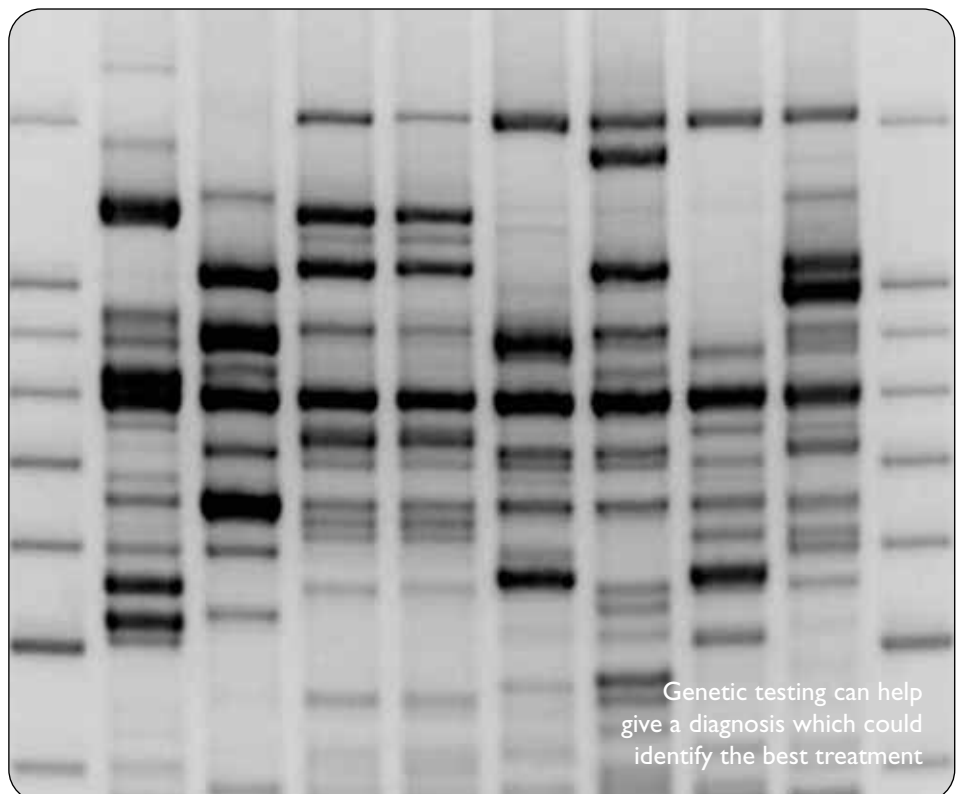
There has been a "technological revolution" in genetic testing ability and now there is an **up to 50% chance of finding a diagnosis from it**

identify the best treatment by giving an accurate diagnosis. While targeted treatment is something researchers are still working towards, Dr Baker said: "Diagnosis turns the key towards personalised treatment."

Dr Baker's research team is now looking at different groups of epilepsies, and looking at how they're different and how they're similar. They are also focusing on how epilepsy really affects people, and looking at the mental health of parents and carers.

### The digital doctor will see you now

Prof Markus Reuber from the University of Sheffield appeared, fittingly, in digital form to deliver the last talk of the session on technology in epilepsy clinics. He explained that there is a lot more technology involved in certain points in epilepsy care compared to others. Prof Reuber explained that for things like diagnosis we still rely on a doctor's knowledge and we still use things like seizure diaries to monitor seizures, even though they are known to be unreliable.



Genetic testing can help give a diagnosis which could identify the best treatment



Smart watches are always advancing in identifying tonic-clonic and other types of seizures

Meanwhile, in other areas of epilepsy care, technology is booming. Prof Reuber said that imaging technology has advanced further than our knowledge for interpreting the images. Technology is more involved in things like pre-surgical investigations and surgery itself. Prof Reuber also mentioned treatments like deep brain stimulation (DBS) (which is available to some people with drug-resistant epilepsy in the UK) and vagus nerve stimulation (VNS) as examples of big developments.

He suggested that more technological innovations could be made in areas where we still rely on older methods. He said, for example, a digital doctor is currently being developed by programming a computer with data, to train it to distinguish epilepsy from another condition. At some point in the future, this could be a reality for diagnosing epilepsy.

Wearable devices are among the biggest changes in recent epilepsy technology, Prof Reuber noted. This includes smart watches and seizure forecasting and automatic seizure recording devices.

He said smart watches are getting good at identifying tonic-clonic seizures, and getting better with other types of seizure too. He added that there are also now things like smart pills that can tell your phone that the pill has been taken, and smart pill bottles that can tell your phone that the bottle has been opened at around the right time of day. This can be an easy way for doctors to monitor treatments and how well they're working.

He concluded by saying we need to figure out how much transparency with your medical team is too much, as there is a lot of information that you could share with your doctors.

### **Answering your questions**

#### *How do you choose which clinical research questions to answer?*

Dr Kate Barker (KB) said: "This is one of the most fun and challenging parts of the work. The first essential ingredient for a clinical research question comes from the clinic. It comes from a patient or family member asking you a question you can't answer. As a clinical researcher, you feel really frustrated that you don't have

an answer to give. It might come from a clinical interaction or an observation, or something that doesn't fit the picture – a puzzle you really can't solve.

"The second way I choose a research question is to think: 'Is there a chain of research I can build on?' Because starting it from scratch is very hard. So, I think: 'What do I already know about this problem or this patient's condition? And how can I bring this new question onto an existing chain?'

In 10 years' time, a fair proportion of people with epilepsy could have wrist-worn devices **that would tell them that they're at a low or high risk of an epileptic seizure**

"As an example, I have a team member working on a project with a rare genetic cause of epilepsy and learning disability, a change in a gene called DDX3X, which is quite a common cause of epilepsy and learning problems in girls. We've observed that high anxiety levels and anxiety disorders are particularly common in this group of young women. Their family members are asking us why. So there's a partnering of the concerns that are really bothering patients and families, and our existing research, and they're coming together in a new line of research.

"The third thing is called feasibility. So, is this a question I can answer? What do I need for that? I need a method that allows me to answer that question, and I need people – partners, patients, participants and families – and I need skills in the collaborators around me. So, these are the



three components I need – the question, the research history and the feasibility.”

Dr Rhys Thomas (RT) said: “Sometimes we can get distracted by a ‘new project’ energy, that buzz you get about something new and shiny and exciting. And, unfortunately, the research funding landscape can reward that. But, actually, some of the more successful teams are the ones who pick a theme and become experts within that area. I see Prof Reuber as someone like that, who’s got some very clear areas that he’s recognised to be an expert in.”

Prof Markus Reuber (MR) said: “The only additional idea I’d have is that many of the methods, especially advanced complex ones, involve quite a lot of learning. And once you’ve learned the method, you’re likely to look for questions you can answer with it. This can sometimes be a good thing, but sometimes there’s a risk that research funders could waste money on somebody who’s looking for questions they can answer, even if they’re not relevant.”

*Is there an overlap between epileptic and functional (non-epileptic) seizures and how do you go about researching both of these?*

MR: “There are overlaps and I think it’s wrong for neurologists, who are experts in diagnosing different types of seizures, to regard functional seizures as something that’s got nothing to do with them. Given

that we are experts in the diagnoses and like to claim that we have an increasing understanding in functional seizures, we should treat them just like we treat epilepsy. It should just be a part of what neurologists do. We shouldn’t just send people away after diagnosis.

“In terms of overlap of epilepsy and functional seizures, I do think the mechanisms are different between functional seizures and epileptic seizures. But epileptic seizures, for instance, are a risk factor for developing functional seizures, so there is a group of people who will have both epileptic and functional seizures. There can be a range of different types of relationships between epilepsy and functional seizures. Sometimes people can have a focal epileptic seizure that immediately goes into a functional seizure, or have epileptic and functional seizures at different times.

“Research in this area involves recording seizures with video EEG to try and get a better understanding of transitions and what kind of epileptic seizures and what kind of brain structures might be involved in those who then go on to have functional seizures. You could also do research on the incidence of these conditions, on psychotherapy, on types of treatments – there are many questions that this area raises.”

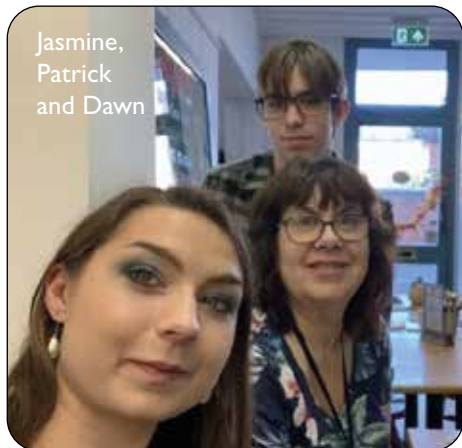
*Where do you see seizure forecasting in the next five to 10 years?*

MR: “There’s some really interesting research data from an implantable device. It continuously records EEG and also then stimulates the brain. And what I find most interesting there is the recording bit.

“We know very well, from the people who have had these devices, when exactly the brain has been producing these epileptic discharges and when they’ve had seizures. And it turns out that maybe three quarters of the time, there is some kind of pattern to the seizures – they happen in the morning, or every 10 days, or once a week, or once a month. So there are certain clusters. And these rhythms were often unknown to the individuals who had the seizures before the research was done. So just by recording seizures exactly with these devices, you often get some kind of rhythm or pattern.

“In addition, we are learning more and more about the autonomic nervous system (which controls things like heart rate and digestion) and how this responds to epileptic activity in the brain. I think, in 10 years’ time, a fair proportion of people with epilepsy could have devices that they could wear on their wrist that would tell them that they’re either at low risk or at high risk of an epileptic seizure. I think that is a realistic prediction.”





# An unexpected **Christmas gift**

**Dawn Barnard describes an absolutely unforgettable and unbelievable Christmas.**

*Words by Dawn Barnard.*

One of my most memorable Christmases was in 2003. I was pregnant with my son at the time. I had had a few more seizures than normal and on Christmas Day, I really struggled to wake up enough to get up.

I agreed to go to hospital. That was the last thing I remember until waking up to some focal seizures in intensive care, having lost two days.

In those two days, I had gone into a prolonged seizure (status epilepticus) and had not responded to the epilepsy medicines I was given. I had needed to have more which would have affected my baby, so I had had a C-section and had then been placed in a medically induced coma while my brain recovered.

Everything that had happened was a huge shock to me. I had had my daughter Jasmine some years before, but I wasn't expecting to meet my son until March the following year.

I found out that he had been transferred to another hospital equipped with everything a premature baby needed. I got transferred there as soon as possible, but it was Christmas and a lot of women had had babies, so beds were in short supply. It really felt like there was no room at the inn!

### **Tense and emotional**

When I met my son, I couldn't believe he was real at first – he was so small. I felt worried and guilty that I had been so ill he had to be born early, and I was quite scared to touch him because of his size.

It took time for us both to recover. There were hospital transfers, surgeries, improvements and setbacks. It was a very tense and emotional time. It was hard to bond with him with everything going on.

One day, he fixed his gaze on me, and that was it – I was in love. We named him Patrick, after his grandfathers, and his sister gave him his middle name Oliver. Holding Patrick for the first time was really emotional.

When he got up to 3lbs and had no tubes in, it was a big relief. In the last week he was in hospital (it was now March) he came back to our local hospital. We were greeted with 'I remember you! I was just going home for Christmas when you came in.' It was strange to be known by so many staff who we had never met. I feel we owe them so much!

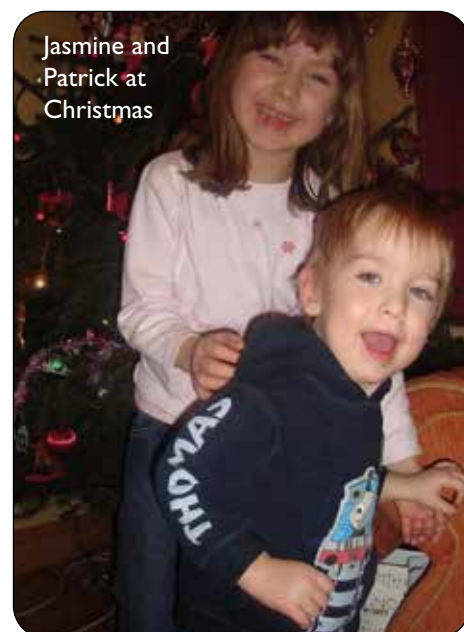
### **Extra special Christmas**

For me, my memory was jolted. Old memories were back and recent ones had gone. Some memories had gone for good, it was explained, but I don't worry about that. Emotionally, my confidence had taken

a knock and I had delayed shock. I was helped with all this, but it took time.

Though my health has declined in recent years, I recovered enough to be part of his life and see him grow and tower over me. I'm proud of both of my children and their achievements. I would have preferred epilepsy not to get in the way so much. But both my children have gained something they may not have if things had been different – empathy, not just for epilepsy, but for other conditions that affect people around them.

Patrick's birthday on Boxing Day is very special. We both went through a lot, individually and together, and have been lucky enough to come out the other side. I see him as an unexpected Christmas present, and it makes Christmas extra special.



# Have your say!

## We want to hear your thoughts on *Epilepsy Today* magazine

As a member of Epilepsy Action, *Epilepsy Today* magazine is one of the membership benefits you receive. So, we want to make sure it's as useful and interesting to you as possible.

Below are a set of questions to find out more about you, our reader, and your connection to epilepsy. We also want to know more about what you like about *Epilepsy Today*, what you want to see more of in the magazine, and how we can best extend our content online. This will all help to inform the stories we tell and the information we share.

The survey should take around 10-15 minutes – so grab a cup of tea and let us know what you think. You can stay anonymous, or, if you'd be happy for us to ask you some more questions about the magazine, you can leave your contact details at the end.

Once you've completed the survey, please cut out this page and return it to us in the prepaid envelope enclosed with your magazine. If you would prefer to do the survey online, visit [bit.ly/3RY9tGh](https://bit.ly/3RY9tGh) or scan the QR code with your phone camera.

Thank you!



### About you

1. What is your age? \_\_\_\_\_

2. Where do you live?

- North of England     Midlands  
 South of England     Scotland  
 Northern Ireland     Wales

3. What is your gender?

- Female     Non-binary  
 Male     Prefer not to say

4. What is your employment status?

- Employed     Retired  
 Self-employed     Studying  
 Unemployed

5. What is your connection to epilepsy?

- I have epilepsy  
 My child has epilepsy  
 Another family member or friend has epilepsy  
 My work involves epilepsy  
 I have lost someone to epilepsy  
 Other \_\_\_\_\_

6. What kind of membership do you have?

- Standard (full member)  
 E-member  
 Professional member  
 Nurse member  
 Reduced (reduced rate member)  
 Life (lifetime member)  
 I don't know

### About your epilepsy

If you don't have epilepsy, please answer about the person or people you are connected to who do.

7. How long have you been diagnosed with epilepsy? \_\_\_\_\_

8. What kind of seizures do you or did you have? (tick all that apply)

- Tonic-clonic     Focal aware  
 Absence     Myoclonic  
 Focal     Tonic  
 Dissociative (non-epileptic) seizures  
 Other \_\_\_\_\_

9. What kind of epilepsy do you have?

- Generalised  
 Temporal lobe  
 Frontal lobe  
 An epilepsy syndrome (such as JME, Dravet, Lennox-Gastaut)  
 I don't know  
 Other \_\_\_\_\_

10. Is your epilepsy controlled at the moment?

- Yes, no seizures     No  
 Yes, with some seizures

11. What kind of treatment do you have or have you had for your epilepsy? (tick all that apply)

- One epilepsy medicine  
 More than one epilepsy medicine  
 VNS  
 Ketogenic diet  
 Surgery  
 Other \_\_\_\_\_

12. How much does your epilepsy impact these aspects of your life?

	Strong impact	Medium impact	Small impact	No impact	Not relevant
Work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Driving	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Education	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Relationships/friendships	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hobbies/activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

PTO →



# epilepsy survey

## About Epilepsy Today magazine

13. What do you like best about *Epilepsy Today*? (tick as many as apply)

- News
- Stories about research
- Stories about people's experiences
- Stories about Epilepsy Action
- Other \_\_\_\_\_

14. What would you like to see more of in the magazine?

15. What do you enjoy about reading *Epilepsy Today*? (tick as many as apply)

- I feel like part of a community/like I'm not alone
- Feel better about my epilepsy and experiences
- I like getting information about epilepsy treatments, lifestyle and research
- I feel more confident about sharing my views about my epilepsy and treatment with my doctor/nurse
- For fun/a distraction
- To connect with others

16. How much do you like the following?

	Really like it	Like it	No opinion	Dislike it	Really dislike it
The size of the magazine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The look of the magazine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The length of the magazine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The length of the main articles	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The number of issues a year (four)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

We would like to ask you some more in-depth questions about *Epilepsy Today* magazine. If you are happy for us to contact you about this, please leave your details below. **Thank you!**

Name: \_\_\_\_\_  
Phone number: \_\_\_\_\_  
E-mail: \_\_\_\_\_

17. How many people in your household read your copy of *Epilepsy Today*?

- Just me
- One other person
- Two other people
- Three or more other people

18. How much do you value *Epilepsy Today* as part of your Epilepsy Action membership package?

- Very much
- Quite a lot
- Average
- Not a lot
- Not at all

19. Do you have any additional comments about *Epilepsy Today*?

20. Do you feel more inspired to take part in a fundraising event or donate to Epilepsy Action after reading the stories in *Epilepsy Today*?

- Yes
- No

## About reading news and stories online

21. Do you have easy access to the internet?

- Yes
- No (If no, skip this section)

22. Where do you prefer to read *Epilepsy Today*?

- Printed magazine
- Online on smartphone
- Online on tablet
- Online on laptop or desktop computer

23. How often do you visit the Epilepsy Action website?

- Daily
- Weekly
- Monthly
- A few times a year
- Rarely
- Never

24. What do you usually do online? (pick all that apply)

- Play games
- Chat to others
- Look for information
- Browse social media
- Watch videos
- Other

25. What epilepsy information do you usually look for online? (pick all that apply)

- Real life stories
- News about epilepsy
- Information on epilepsy
- Support groups
- Events

26. Where do you look for epilepsy information? (pick all that apply)

- Websites
- Forums
- Blogs
- Videos
- Podcasts
- Other

27. What online platforms do you use? (pick all that apply)

- Facebook
- Instagram
- Twitter
- YouTube
- Reddit
- Discord
- Tik-Tok

## A big break

Derrick, 33, has landed a dream freelance job on social media platform TikTok, after years of making videos and online content about his epilepsy and his job as a railway worker.

Derrick became a media volunteer for Epilepsy Action in 2016, raising awareness about epilepsy through interviews on SKY News and BBC3. He has grown his YouTube channel, and branching out into new media has brought him new fortunes.

Chantal Spittles, PR and media manager at Epilepsy Action, said: "We suggested to Derrick last year that he should make TikToks, which he started doing about epilepsy and his job as a railway worker. His videos have since caught the eye of a media agency who loved his storytelling skills and have recruited him as a freelancer!"

Derrick said: "Epilepsy Action has been there for me since day one, encouraging me to share my story and help to give me a platform to do what I love. Thank you

so much for suggesting I start doing TikToks – I didn't expect them to take off as they did and it's amazing to see how it's all working out."



## Outstanding courage in emergency

Sunny, seven, from Wrexham, has received a North Wales Police award for "outstanding courage and bravery", after calling 999 when he found his mum unconscious after a seizure.

Sunny's mum, Siobhan Roberts, 23, who has epilepsy, had taught him to dial 999 and ask for help in case of an emergency.



On 21 August, Sunny, who was at home with his younger brother, six, and baby sister, 11 months, found his mum unconscious. He called for an ambulance and waited with his mum and siblings.

Ms Roberts said she "couldn't be prouder" of Sunny. PC Horne, one of the officers who arrived at Sunny's house that day, said: "We don't often see many calls where a seven-year-old has been so brave to pick up the phone and call 999."

"Sunny is truly deserving of this reward for his outstanding courage and bravery during what we could only imagine was a very scary time."

Inspector Luke Hughes, who presented Sunny with the award, said: "Sunny told me in detail how he stayed calm, rang 999 and asked for an ambulance before staying with his mum until help arrived."

"It was absolutely right that we recognise exactly how brave Sunny was and it was a privilege to meet him and present him with a certificate."

"Well done, Sunny, you were amazing."



# Making ends meet

**Epilepsy Action is calling on the government to reduce ‘health inequalities’, as the cost-of-living crisis escalates in the coming winter months.**

*Words by Chantal Spittles and Rebecca Lock.*

Many of us are already feeling the stress from the cost-of-living crisis. We’re all noticing the prices of everything going up – most worryingly those of our most basic needs, like food and heating. But at Epilepsy Action, we know that disabled people will bear the brunt of the crisis, with life already costing more for this group.

A recent Epilepsy Action survey of nearly 600 people with epilepsy, carried out between August and September, has shown that the cost-of-living crisis is taking its toll already, even before energy bills go up during the winter months.

In the survey, two in five people said they are already having more seizures due to stress about managing the rising cost of living. Nearly three in five said they are worried about being able to afford their bills, including the cost of running potentially life-saving equipment, such as seizure alarms and monitors.

Nearly two in five said they are feeling more isolated due to having limited money, which is something that can already particularly affect people with epilepsy. People reported taking drastic action to cover basic bills, including missing meals or not heating their home. Many said even with cost-cutting measures like this, they’re still struggling to pay the bills.

Many also said they’re worried about the cost of getting to work and medical

appointments or are anxious about how they’ll be able to support themselves if their Personal Independence Payments (PIP) stopped.

The government announced a one-off payment of £650 for people on Universal Credit to help with the cost-of-living crisis, but people who only receive PIP will only get £150. This is despite research showing that even before the cost-of-living crisis began, extra costs faced by disabled people added up to £583 a month on average.

We know many people already struggle to afford the costs of having a hidden disability, and the ‘impending timebomb’ could cost lives.

## **Choice between heating or eating**

Martin, 62, has drug-resistant epilepsy, and is unable to work. Martin worked as a registered nurse until 1999 when he had to take medical retirement. His wife, who was also a nurse, has recently retired to support and care for Martin.

The cost-of-living crisis has put a huge strain on Martin’s life, and he is worried about having to prioritise essentials in the coming months. Martin receives PIP but he thinks there needs to be more support for people on PIP or with a disability as the cost of living rises.

Martin said: “I’m worried that in the coming months I will have to make a choice between heating or eating. I find





Martin

I have more seizures when I feel cold, so **not being able to heat my home could have a significant effect**

that I have more seizures when I feel cold and so not being able to heat my home could have a significant effect on my health. I also rely on seizure alarms that need to be on all the time, to alert someone if I have a seizure when I'm alone. My electric bill has already gone up so much and I'm worried about the cost of having to keep these alarms on.

"I much prefer taking taxis to taking the bus as it gives me peace of mind that I will get to wherever I'm going safely, especially if I have a seizure. But with prices going up, I now get the bus more often than not. I was recently admitted to hospital after a seizure and although it would've been much safer to take a taxi home, I had to take the bus.

"The rising cost of everything has made me feel stressed and I'm worried about the future. I've noticed that I've been having more partial (focal) seizures in the last few months, which could be linked to the stress I'm feeling. I wouldn't be able to cope with the rising costs without the support of my wife and I



People have said they're worried about having to choose between eating meals and switching on the heating

think more needs to be done to help people with disabilities, especially for those who live alone."

#### Extra costs to having epilepsy

Sarah, 42, has had epilepsy since she was seven years old and, because of her seizures, she has been unable to work for 18 months. Sarah receives Universal Credit and PIP, but this isn't covering the rising costs of energy and food for her and her family.

She said: "We're having to rely on foodbanks for almost all our food now. Anything we can't get from the foodbanks, such as fresh and frozen food, we're shopping around for things on offer or reduced. This sometimes means going to five supermarkets. There have been times when we haven't even been able to afford basics like bread and milk.

"People don't realise but there are extra costs to having epilepsy. For example, I have to wash my clothes more than most people because sometimes my seizures cause incontinence, and it's

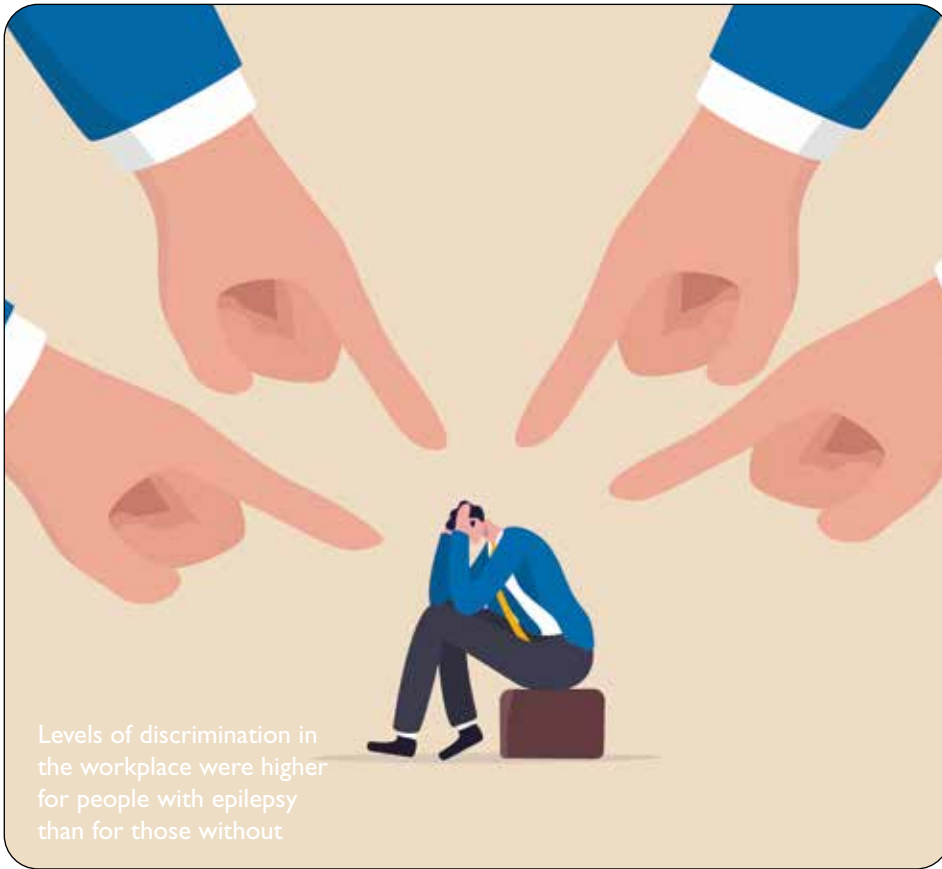


Sarah

getting more and more expensive to run my washing machine.

"I feel so stressed about being able to afford the basics we need to live and I'm losing sleep because of this stress. This has meant that I've had more seizures recently as stress and lack of sleep can be seizure triggers for me.

"I do some volunteering work when I'm able to and my husband works 12 hours a week, but because he cares for me, he can't take on any more hours. I think



Levels of discrimination in the workplace were higher for people with epilepsy than for those without

there needs to be more financial support for people on Universal Credit and PIP because the extra cost-of-living payment doesn't cover the rising costs of bills and food. I don't know how we'll cope with things going up even more when we're already so stretched."

### **Bleak winter**

Daniel Jennings, senior policy and campaigns officer at Epilepsy Action, said: "It's sobering to hear that people with epilepsy are already struggling to make ends meet – and this is before the cost of living is due to rise even further.

"At a time when we are hearing of record profit for energy companies, no-one in this day and age should be having to be miss meals or worry about how they're going to pay their electricity bill. Even with the new energy plan announced by former Prime Minister Liz Truss in September, people will still be paying more than double what they were last winter.

"Combine this with the struggles we know people with epilepsy face in finding work and the impact of increased

seizures, and we are heading towards a bleak winter which could have devastating repercussions and put further pressure on the NHS. The government needs to give targeted support for people with disabilities to ensure they are on a more level playing field."

### **Impact of health inequalities**

Mr Jennings said: "Of people who took part in our survey, 47% receive PIP to help them with the additional costs of living with a fluctuating and unpredictable condition, such as being able to pay for seizure alarms in the home or cook a meal safely. Yet the extra support they will get will be a drop in the ocean compared to what they need to survive this winter.

"The Prime Minister has spoken of her commitment to helping working people during the cost-of-living crisis, but research from the Institute of Economic Studies identified that there are many barriers preventing people with epilepsy getting, and staying in, jobs.

"We also know that only 42% of people with epilepsy of working-age are in work

I've had more seizures recently as **stress and lack of sleep are triggers for me**

– this is among the lowest employment rates for disabled people in the UK. In a recent Neurological Alliance survey, 47% of people with epilepsy said they had left work because of their symptoms, while levels of discrimination in the workplace were higher for those with the condition than for those without.

"It's really worrying to hear that people with epilepsy are already facing extra seizures as a result of stress and running out of road to be able to afford essentials many take for granted. Uncontrolled seizures can be dangerous and ultimately fatal.

"People with epilepsy living in more deprived areas are at higher risk of death than people in wealthier areas, with their life expectancy around eight years less than average. The impact of health inequalities on people with epilepsy is growing even greater. We call on the Prime Minister and Secretary of State for Work and Pensions to take action now to ensure people with epilepsy are given the support and help they need to manage their condition."

### **Winter advice and support**

While the next few months will likely be tough on many of us, we may be able to help ourselves in some small ways. One thing is to know what you might be entitled to.

- **Universal Credit** – if you are on low income, can't work because of a health condition, or you are a student in full-time education, you may be eligible for Universal Credit. If you claim Universal Credit, there are other benefits

that you may also be eligible for. You may be eligible for **Discretionary Housing Payment**, which can help with things like rent shortfalls and rent deposits. You may also be eligible for a **Jobcentre Plus Travel Discount Card** for 50% off selected rail tickets if you claim Universal Credit or Jobseekers Allowance. If you are in a position to save money, and claim Universal Credit, Working Tax Credit or Child Tax Credit, you may also be eligible for **Help to Save**.

- Local support – if you are on a low income, you may be eligible for **Home Care** from your local authority. Disabled people can also get assistance with expenses related to their disability and some housing costs, as well as helping with food, bills and insurance through the **Minimum Income Guarantee**. You may also be able to get support from the **Local Welfare Assistance Scheme** or from **End Furniture Poverty** ([endfurnityrepoverty.org](http://endfurnityrepoverty.org)).
- Families – Parents may be eligible for **Tax-Free Childcare** of up to £500 every three months, and **Child Benefit** for children under 16 years old, or under 20 years old if they are still in education or training. On top of that, if your family is eligible for Universal Credit, you may **claim back childcare costs** up to 85% and you may be able to claim **Free School Meals**.
- **Pension Credit** – If you are over the State Pension age with a low income, you may be eligible for Pension Credit. This can help people obtain **Housing**

It's really worrying to hear that people with epilepsy are **already facing extra seizures as a result of stress**

**Benefit, Council Tax Discount, help with glasses and NHS dental treatments, transport costs** for hospital appointments and the **Warm House Discount Scheme**. If you claim Pension Credit, you may also be eligible for a **Budgeting Loan**, where you can borrow between £100 and £812 depending on your situation. You may also be eligible for **Household Support Fund** to cover essential daily costs if you are over the State Pension age and are struggling financially.

You may also be able to help save a bit on your energy bills. The Energy Saving Trust ([energysavingtrust.org.uk](http://energysavingtrust.org.uk)) can help with practical advice on heating your home, saving water and staying energy efficient.

Check that your heaters and meters are working properly and try to help insulate your house by using draught excluders or closing the curtains in the evening to keep the heat in.

To save on energy, you could try to avoid using the tumble dryer and run your washing machine only when it's full and at 30 degrees.

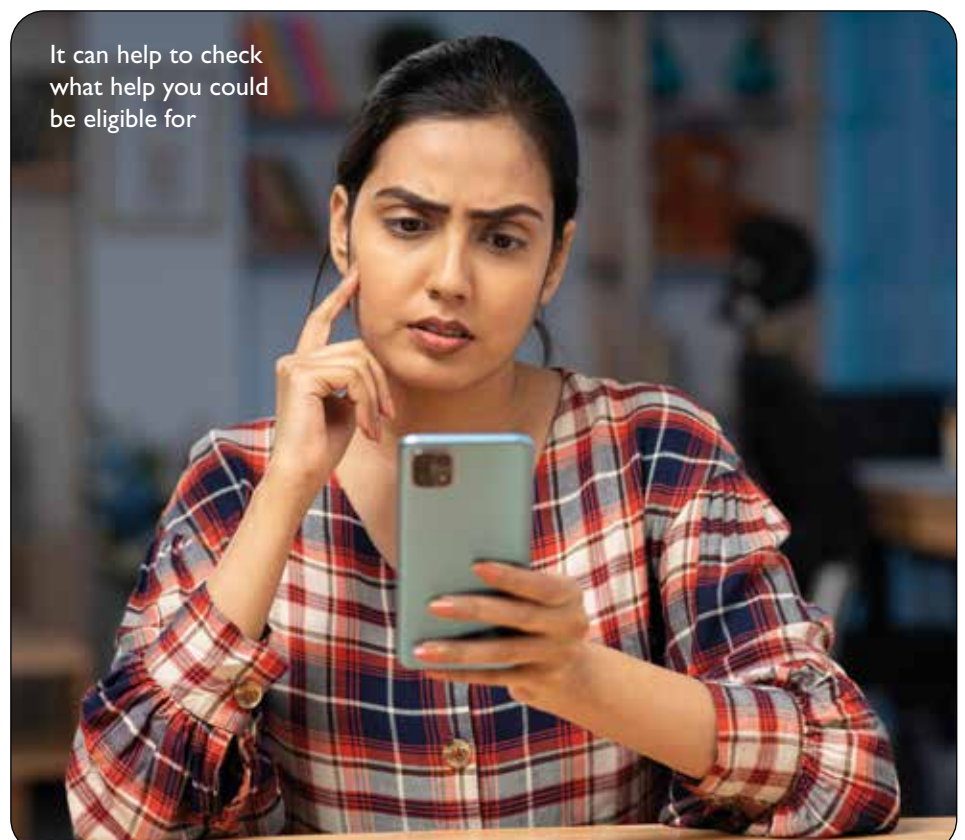
You could also switch to LED or other energy-efficient lightbulbs and turn off plug sockets on the wall when you are not using them.

Also, setting your fridge to between three and five degrees can be helpful, as well as defrosting the freezer regularly.

Most importantly, don't forget to look after your own health and wellbeing. This winter will likely be a challenge for many of us and it can have an impact on our mental and physical health.

You can speak to the Epilepsy Action Helpline on 0808 800 5050 or by emailing [helpline@epilepsy.org.uk](mailto:helpline@epilepsy.org.uk) about how the cost-of-living crisis is affecting you. If you think it may have an impact on your condition, please speak to your doctor.

It's a very scary and challenging time for everyone, and if you are worried about the months to come, you are not alone. We are here to help and listen, and we are continuing to campaign for more support for people with epilepsy through this difficult time.







# Help to break barriers

**Olympic hopeful Blake Allsop has had to face losing his promising career just as it was starting after being diagnosed with epilepsy. He ran the London Marathon in 2022 to help support others living with epilepsy**

*Words by Rebecca Lock.*

It must take a tremendous number of hours to train for the Olympics. It must take nerve and energy and discipline to keep going. And it can be one of the most exciting times in a person's life, to work towards such a revered goal.

That was 25-year-old Blake Allsop's life in the run-up to the Tokyo 2020 Olympics.

A keen slalom kayaker, he was working hard towards his dream of competing in the Olympics when epilepsy struck and derailed Blake's plans.

Blake had his first seizure when he was 19 years old. He said: "It was completely out of the blue and happened whilst I was on shift. At the time, I was in Australia

working on a construction site alone. Luckily someone was passing by and found me unconscious, so I was taken to hospital immediately. I was in denial to begin with as I thought it was just a one-off seizure but when I returned to the UK and the seizures continued, I realised this was very real."

A rising star in slalom kayaking, Blake was training to compete in the Tokyo 2020 Olympics until his epilepsy diagnosis meant that he had to change the course of his dreams. Blake said: "Epilepsy has changed my life in so many ways, but the biggest is that I've had to completely change my career.

"I left school when I was 15, with no qualifications, to pursue a career in slalom kayaking. I was travelling the world, training with Team GB and coaching alongside. I had the full support of my local community who supplied grants to help me achieve my ambition of racing at Tokyo 2020.

"After my first seizure, I knew that kayaking for Team GB would no longer

be an option for me. I was offered a job in New Zealand coaching young athletes, but the offer was withdrawn when they discovered I had epilepsy. I was distraught and couldn't believe it, so I travelled to New Zealand, desperate to try and change their minds. Unfortunately, I was met with the same answer.

"I'd like to think it was simply because they didn't want me to be at risk in the white-water conditions, but since then I've learnt that epilepsy is so misunderstood around the world. Even the simplest jobs have been hesitant to accept my application due to my medical condition. I felt as though no one wanted me for who I was, and people were afraid of my epilepsy."

Blake's epilepsy diagnosis has been difficult to come to terms with and has impacted many aspects of his life.

"Not only has my diagnosis been distressing for my physical and mental health, but my family and loved ones have felt the impact too. Although epilepsy isn't visible to all, the black eyes, broken bones, scars and sores inside my mouth will stay with me for a lifetime.

"The diagnosis was really hard for me to accept, and I constantly felt isolated, anxious and fearful of the unknown. One of the biggest impacts has been the side effects of taking 10 tablets a day. They've affected my short-term memory and I also feel exhaustion, changes in my personality, numbness and irritability.

"The constant trial and error in the hope to find the correct combination of tablets is exhausting. It's hard to remain positive but I want to believe that I can be seizure free with the correct medication. Each time I go a little longer without a seizure, I hope that I'm finally seizure free, but this hope soon disappears."

Blake took on this year's London Marathon alongside his partner Jess to raise money for Epilepsy Action. The marathon was a huge challenge for Blake as he is new to running but knowing that he did this to support

people affected by epilepsy was his motivation. Jess, who lives with Blake, said: "I've used Epilepsy Action for advice when I've been anxious and needed some support. I also massively support that Epilepsy Action help to break barriers for people with epilepsy and campaign to improve public attitudes and awareness."

Blake has faced huge disappointments as a result of his epilepsy but his determination to help support others is phenomenal.

Water sports can be enjoyed by people with epilepsy whose seizures are well controlled. For people with seizures, there are safety issues to consider, such as wearing a life jacket and not swimming or doing water sports alone. It can vary person to person, so assessing your own individual risk is important. There is more information on water sports and activities on the Epilepsy Action website, at: [bit.ly/3CEMJqc](https://bit.ly/3CEMJqc).

The Epilepsy Action Helpline is there for anyone facing similar struggles with their epilepsy, and can offer support and advice. You can call 0808 800 5050 or email [helpline@epilepsy.org.uk](mailto:helpline@epilepsy.org.uk).

Blake and Jess



Blake slalom kayaking



Blake was training for the Tokyo 2020 Olympics when his diagnosis changed things



# My journal



*John's wife, Jackie, talks about John's epilepsy, how it has affected their lives and the difference having a vagus nerve stimulation device fitted has made.*



I met John in March 1976 when we were both on holiday in Majorca. I was 22 and John 27. After we returned home, we kept in contact and we would take it in turn to visit each other about every three or four weeks. John lived in Leicestershire and I lived in Derbyshire, so this involved travelling on three different buses, which took a minimum of three hours.

Over the months, our friendship grew, and we became a 'couple'. I eventually bought my first car, and from then on, I would drive to Leicestershire after work on Friday and return early Sunday evening, staying with John and his parents. The journey by car took just under one hour. I recall asking John why he didn't learn to drive, and his response was that he wasn't interested.

In late December of that year, I was surprised to see John walk into the bank I worked for in Heanor. I met him on my lunch break and he told me he had something to tell me, this is when

he told me he had epilepsy. He thought that I would not want to continue with our relationship, or I would need time to think about it. I must admit I knew very little about epilepsy, but it didn't change my feelings for John.

John loved football and was an avid football player for a local team. On Sunday mornings, no matter what the weather, I would go and watch him play. John told me about a time when he was playing football when he was younger, and all he remembered was waking up at home, having no recollection of the match he had been playing in. Ironically, the other players later commented on what an excellent game John had had. Not long after this, John began having seizures. The first time was a couple of days after Christmas 1964, when John's brothers alerted his parents that John appeared to be having some sort of episode and was not responding to them. John was seen by his doctor, and he was referred to a neurologist at the Leicester Royal Infirmary.



In 1965 John was diagnosed as having left lobal focal epilepsy and he was prescribed Mysoline (primidone) and phenytoin. John had recently passed his driving test and had to hand in his license. He told me it was easier to tell people he was not interested in driving, rather than to tell them he had epilepsy. He did not want others to know, and he was frightened to talk about it. John was also doing an apprenticeship in carpentry, but with him no longer holding a driving license, he could not drive the company's van and had to give up his apprenticeship.

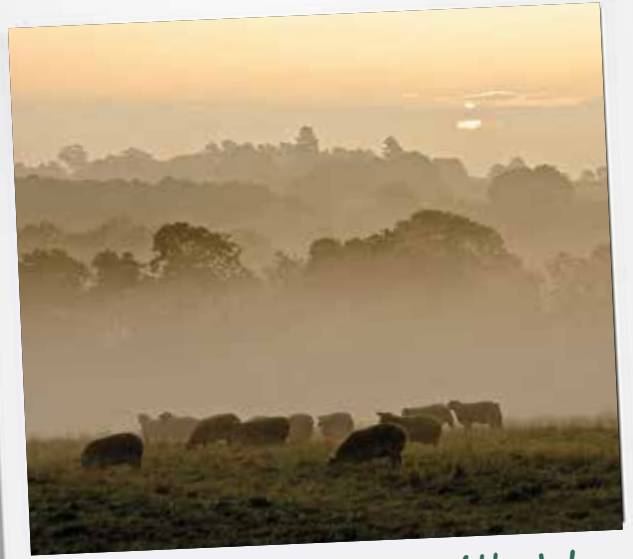
We were married in May 1979. At that time John worked at construction machinery and equipment company Caterpillar, and with it being easier for me to get a transfer with the bank, I moved to Hinckley in Leicestershire.

*John had recently passed his driving test and had to hand in his licence. He told me it was easier to tell people he was not interested in driving than to tell them he had epilepsy*

John mainly had sleep seizures and the first time I witnessed John have a seizure, I found it upsetting and I did not know what to do. Over time, I became used to John having seizures and soon learnt that there was nothing I needed to do, except ensure he did not harm himself. At that time, there was no



*John's a huge football fan and got to hold the Premiership cup*



*Jackie moved to live with John in Leicestershire in 1979*

pattern to when John had a seizure, they averaged between two and three a month. Unfortunately, John does not get any warning and very rarely recalls having had a seizure.

Throughout the years John had numerous jobs, which was mainly warehouse and packing work. Unfortunately, once John had a seizure at work, the company would find an excuse to terminate his employment.

*John had numerous jobs, but, unfortunately, once John had a seizure at work, the company would find an excuse to terminate his employment*

While at work in May 2004, John broke a bone in his left foot. About a week afterwards he had an ongoing cluster of seizures with prolonged post-ictal confusion. He was admitted into hospital having had 33 seizures in three days. He was now having more awake seizures than sleep seizures and his neurologist prescribed him topiramate.

Towards the end of 2005, the company John worked for was struggling and all the employees went on a three day week, with John subsequently being made redundant in February 2006. Despite trying numerous places to try to find work, John was unsuccessful. Not long after, John very reluctantly made the decision to take an early retirement.



*John started experiencing major mood swings*

In April 2006, John began to have major mood swings which caused him to become aggressive, which was totally out of character for him. We celebrated John's mum's 80th birthday with a family meal at a restaurant. During the meal John became clearly psychologically unwell and was trying to pick a fight with all the family members. This was an extremely upsetting and frightening time, and I began to struggle to cope. Thankfully, I had taken a redundancy/early retirement package after working for the same bank for 35 years, in the previous April. John went on to fluctuate between periods of appearing subdued, pre-occupied, agitated and fidgety. During April/May John had 46 seizures over a period of 38 days.

I believe that topiramate made the situation worse, being known to sometimes cause behavioural side effects.

John saw his neurologist in June 2006, and he noticed that John was in an odd mental state, appeared distracted and kept referring to things in his past. It became clear that the change in John's condition occurred after he was made redundant, and the stress was a factor in his seizures. However, his consultant advised that he believed some of the current attacks were non-epileptic due to John's psychological state. John was admitted into hospital for a period of observation, a prolonged EEG recording and to have a consultation with a psychiatrist. Again, I found this to be incredibly stressful, upsetting and I found that I was having panic attacks and difficulty coping. I ended up on medication to help me through this very difficult time.

The psychiatrist diagnosed John with clinical depression and he was prescribed citalopram. Once discharged from hospital, John had regular follow-up appointments with the psychiatrist. During one of these sessions John spoke for the first time about when

he had been told he had epilepsy. Sadly, no one had sat down with John and explained what epilepsy was when he had been diagnosed with the condition in 1964. John knew nothing about epilepsy, and he thought he was going to die.

At an appointment with the psychiatrist in February 2008, he noticed that John's mood was bright and his self-esteem good. John's antidepressants were slowly reduced and eventually stopped.

*No one had sat down with John and explained what epilepsy was when he had been diagnosed in 1964. He knew nothing about epilepsy and he thought he was dying*

Over the next few years John continued to have about the same number of seizures. During June/July 2017, he had a flurry of seizures for no apparent reason. A couple of these resulted in him injuring himself quite badly, damaging his face and another when he fell downstairs. Since then, he has had more awake seizures than he used to have.

What was noticeable was that the time John was in a seizure was increasing and he took a lot longer to recover.



*John was diagnosed with clinical depression in 2006*

At a routine appointment in March 2018 with the epilepsy specialist nurse (ESN), who had recently joined the neurology team at Leicester General Hospital, she told us about some other options that were available. She discussed the surgical options and VNS. John dismissed having brain surgery, but he was interested in finding more out about VNS. We were given details of a meeting at the Queen Elizabeth Hospital in Birmingham, to chat with other patients that had undergone this treatment.

We both attended the meeting, and it was good to discuss with others the pros and cons of having this treatment. John immediately decided that he wished to be considered for having the implant. We both appreciated that we did not expect the VNS to make John seizure free, but if it reduced the severity and the recovery time, it would be a win-win.

Over the next 18 months, John had several appointments at the Queen Elizabeth Hospital with members of the neurology team. John was advised of the risk of having the operation, particularly with him not only having epilepsy, but previously

*John initially had some side effects which he had been made aware of before. The ESN reduced the settings on a couple of occasions, which made the VNS more comfortable*



*John was told he was the oldest person to have the VNS implant*

having had a heart attack and being 71 years old. Despite these factors, it did not deter John from having the procedure. John was told that he was the oldest person to have the VNS implant. He received a letter that the operation would take place on the 19th February 2020.

John was taken to the operating theatre about 2.45pm. I became quite concerned when he had not returned to the ward by 8.30pm. John came back onto the ward just before 10pm and with him still being very drowsy it was obvious that he would not be leaving the hospital that night. We had previously been told that usually having the implant was a day procedure, with some patients needing to stay overnight. Thankfully, I had booked the hotel for two nights.

The VNS was activated about a month after being fitted. John initially had some side effects – pain in his jaw, coughing and his voice changing – which we had been made aware of before. The ESN reduced the frequency and settings on a couple of occasions, which made the VNS more comfortable. Over time John has got used to the side effects and very rarely notices them.

Having the VNS has definitely benefitted both of us. Whilst the number of seizures John continues to have remain about the same, they are nowhere near as long-lasting, are less severe and John's recovery time is quicker.

We are so thankful that the ESN mentioned the VNS as an option. We just wish this had been offered to John earlier, with this making life for both of us much easier.

John is now 74 and I am 68 and we have been married for 43 years – who says holiday romances don't last!



*John's seizures have got shorter and less severe since having VNS*



# 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 ethosuximide.

## Ethosuximide

Ethosuximide (ESM) was first introduced in 1958 in the United Kingdom. ESM has long been seen as the medicine of choice for children with generalised absence seizures, who do not also have myoclonic or tonic-clonic seizures. ESM is also effective for atypical absences, but doesn't work for myoclonic, tonic-clonic and focal seizures. Its use is now recommended as the first choice for people of all ages with absence seizures alone.

In children aged five years or less, the current recommended dose is 5mg for each kilo the child weighs, twice daily,



Professor  
Martin  
Brodie



with a maximum of 125mg a dose. The amount that usually works is between 10-20mg a kilo twice daily. Children aged 6-17 years should be started on 250mg twice daily, increasing in steps of 250mg, aiming for somewhere between 500-700mg twice daily depending on seizure control. Maximum doses should not normally exceed 1g twice daily. Treatment with ESM in adults should start at 500mg twice daily and can be increased as necessary to a maximum of 1g twice daily.

Side effects with ESM are common and occur in approximately two-fifths of treated children. The most common problems relate to the digestive system and include hiccoughs, nausea, vomiting and stomach pain. Headache, dizziness, drowsiness, poor balance, loss of appetite and weight loss can also occur. Allergic rashes can also occur in some cases. Other reported side effects are less common and include aggression, depression, sleep problems and bad behaviour in young children. Very rarely, allergic damage to the bone marrow can develop on starting treatment with ESM. ESM also doesn't tend to affect the amount or effectiveness of other

medicines if taken at the same time. Certain types of epilepsy medicine, such as carbamazepine and phenytoin can reduce the level of ESM in the blood. However, these medicines are unlikely to be used together, because carbamazepine and phenytoin are known to make generalised absences worse.

ESM is recommended as the first choice for generalised absence seizures alone. If a person develops other seizure types in addition to absences, sodium valproate can be considered in boys, girls under 10 years old who are unlikely to need treatment when they are old enough to have children, and women unable to have children. Lamotrigine or levetiracetam should be considered as the first option in women and girls able to have children. Sodium valproate should only be considered for this group if other treatment options have not worked. Risks and benefits of sodium valproate should be discussed and, where appropriate, a pregnancy prevention programme put in place.

With the exception of phenobarbital, ESM is the oldest antiseizure medicine still in everyday clinical use.

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

## Council of Management 12 July and 4 October

The Council of Management met at New Anstey House on 12 July. This was the first meeting of the Council after the Association's Annual General Meeting held on 14 June. Members were pleased to welcome two new colleagues who were elected this year – Tom McLaughlan and Katie Stevens.

Jane Riley was elected as the new Chair of Council. Peter Clough was elected as the new Vice Chair of Council. Nicholas Hutton was elected as the Association's new Honorary Treasurer.

The following people were elected to the Corporate Governance committee: Jayne Burton, Diane Hockley, Sarah Lawson, Tom McLaughlan, Katie Stevens and Ian Walker.

The following people were elected to the Finance and Strategic Policy committee: Richard Chapman, Mike Harnor, Sarah Lawson, June Massey and Katie Stevens. Jane Riley, Peter Clough and Nicholas Hutton are all ex-officio members of the committee as Officers of Council.

Annual reports were received from Council's diversity champion and its champion for research. Katie Stevens was appointed to be Council's diversity champion for the next 12 months. Peter Clough was re-appointed as Council's champion for research.

In other business, Council reviewed the charity's financial position and progress being made with this year's business plan. Members

were content that objectives were on target to be delivered. 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 the turbulent macro economic conditions were looked at. Members assured themselves that proportionate measures were in place to manage this risk.

Members approved a set of guidance for staff in the preparation of the 2023 revenue budget. This continued the same principles that have successfully guided the charity's finances through the pandemic months.

Council approved the appointment of Chloe Noot as a new member of the charity's National Advisory Council for Wales / Cyngor Ymgynghorol Cenedlaethol Cymru (CYC Cymru).

Professor Yuwu Jiang was confirmed in his appointment as a new social media editor for the charity's scientific journal Seizure.

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 membership and assured themselves that proportionate measures were in place to manage the risks. Reports were received on progress being made with the charity's CRM database project and the review of the charity's strategic plan.

The next meeting of the Council is scheduled to be held on 6 December 2022.

### Epilepsy support for you

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

#### Join one of our virtual groups

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

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

#### Online resources

There are many ways to be part of Epilepsy Action's online epilepsy community. You can find us on HealthUnlocked ([healthunlocked.com/epilepsyaction](https://healthunlocked.com/epilepsyaction)), Discord, ([bit.ly/3vHLOkT](https://bit.ly/3vHLOkT)), Facebook ([facebook.com/epilepsyaction](https://facebook.com/epilepsyaction)), Twitter ([@epilepsyaction](https://@epilepsyaction)) and Instagram ([bit.ly/3zSKMVM](https://bit.ly/3zSKMVM)).

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

# Medication alone isn't the answer for 1 in 3 people with epilepsy.



After at least 2 anti-seizure medications fail to control seizures, alternative treatment options like VNS Therapy™ should be considered.



VNS Therapy™ is a **safe** and **effective** treatment used alongside medication for people with drug-resistant epilepsy (DRE).



It's designed to reduce the **frequency of seizures** in people with drug-resistant epilepsy.



It can also **shorten seizures**, reduce the **intensity of seizures** and **improve recovery** after seizures.



Scan to learn more about DRE

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.

The most common side effects with VNS Therapy are hoarseness, shortness of breath, sore throat and coughing. These side effects generally only occur during stimulation and usually decrease over time. The most common side effect of the surgical procedure is infection.

For important safety information, visit [www.vnstherapy.co.uk/safety-information](http://www.vnstherapy.co.uk/safety-information)

LivaNova Belgium NV  
Ikaroslaan 83  
1930 Zaventem  
Belgique  
Tel: +32.2.720.95.93  
Fax: +32.2.720.60.53

[www.VNSTherapy.co.uk](http://www.VNSTherapy.co.uk)

LivaNova USA, Inc.  
100 Cyberonics Boulevard  
Houston, Texas 77058, USA  
Tel: +1.800.332.1375  
Fax: +1.281.218.9332

[www.livanova.com](http://www.livanova.com)