Issue 26, Spring 2022

Epilepsy Review

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epilepsy society

We are living in uncertain times. Just as the world began to return to some sort of tentative normality following the pandemic, so we have been faced with the horrors of war, not a million miles from home. It is little wonder that people are reporting increasing feelings of anxiety via our Helpline and social media, as they struggle to cope with their own epilepsy in a largely broken world.

So, this edition of *Epilepsy Review* is focusing on the positives. Not in relation to Covid. Not in relation to the war. But in relation to epilepsy and the hurdles it presents. We all need a breather. We all need a break – respite from the news and devastation. And hopefully, in some small way, *Epilepsy Review* will help to confirm that good things are happening, too.

We are thrilled to be able to share with you an interview with the wonderful comedian, Jake Lambert who is using his own experience of epilepsy to raise awareness of the condition at gigs around the country. Jake gives audiences licence to laugh at his epilepsy – and he stresses that the joke is specifically on him. Epilepsy itself, he says, is not funny. He was a joy to talk to and in the weirdness of the new world, I tend to forget that we met on Zoom – I wasn't sitting opposite him in his kitchen with his lovely cat, Richard Parker. I hope you will enjoy catching up with him, too (pages 8-10).

On page 6, Imy Gosling talks about how a combination of Covid-19 and her epilepsy stopped her taking an overseas posting with the Foreign Office, but how finally she is off to Vienna. And on page 21, Sharon Ross explains how the government's Access to Work scheme, has helped her to set up her own business ghostwriting autobiographies.

We have inspiring tales of fundraisers who are going the extra mile – or 100 – to raise money to support people with epilepsy (pages 18-19). And on pages 14-16, you can read about the difference our research is making to people's lives.

Importantly, our clinical director, Dr Fergus Rugg-Gunn, talks about ways to look after yourself as more and more people are faced with long waits in between health appointments (pages 11-13). We know that since the pandemic, waiting times have increased and we hope that his tips and advice will go some way towards helping to cope with the frustrations this presents.

2022 is proving quite a rough ride, but we must all take time to be kind to ourselves. Hopefully, *Epilepsy Review* will provide some calm in the storm. Happy reading.

Nicola Swanborough
Editor

Front cover
Meet comedian, Jake Lambert and his cat Richard Parker who only has one eye. Jake talks about his own epilepsy and how he is using the comedy circuit to raise awareness of the condition. *(page 8)*.

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CAMPAIGNS

How we are making social media safe

After 18 months of campaigning against the online trolling of people with epilepsy, we have now reached crunch time as the government's Online Safety Bill is published.

Our campaign, named Zach's Law after 10-year-old campaigner Zach Eagling, has called for a new criminal offence to be created which would make it illegal to send flashing images to a person with epilepsy with the intent of triggering a seizure. Sadly, no such law currently exists.

Zach's Law has recently gained the unanimous backing of two important parliamentary committees – one of which was specifically set up to scrutinise the Draft Online Safety Bill. Despite this support, the new criminal offence has not been included in the first reading of the Bill. Earlier this year, the Epilepsy Society met with policy experts from the Ministry of Justice and were warned that there were a number of potential loopholes with Zach's Law, due to it being untested and a world first.

We are currently working with the Ministry of Justice to address these loopholes. But the fight to protect people with epilepsy from vicious online bullying continues.

Now that the Bill has been introduced in Parliament, there will be much to-ing and fro-ing between the House's two chambers before it is passed into law – possibly in early 2023. We will be campaigning hard to ensure that Zach's Law is included in the Bill.

Aside from trying to change the law, we have also been working hard to find technological solutions to flashing images. Of course, the use of these images on social media and other platforms is not always deliberate, so we have been collaborating with leading tech companies to try and restrict both malicious and non-malicious use.

Over the last six months we have worked closely with experts from Twitter, GIPHY, Facebook and TikTok to encourage the development of safe and effective tools which stop the use of harmful images. We are in the early stages of discussions but have been impressed with the commitment shown by the tech industry.
We hope to have exciting news to share in the summer.

RESEARCH

Research that really matters

The Epilepsy Society is pleased to be collaborating with other UK epilepsy charities, clinicians and people affected by the condition, to establish which areas of healthcare can best be improved by research.

We have been collectively running a national survey – the UK Priority Setting Partnership – to collate views from across the epilepsy community and identify questions which remain unanswered by current research.

A steering group for the project has been brought together by Epilepsy Research UK.

The survey closed on 24 February. Results are now being analysed and a shortlist of priorities is being drawn up. The top ten priorities for epilepsy research will then be determined from this list by a Priority Setting Workshop, including up to 30 individuals affected by epilepsy, either personally or professionally.

The hope is that this will result in higher quality research studies that are relevant to people's lives, and greater investment.

At the Epilepsy Society, we believe that research offers the greatest hope of seizure freedom for people with epilepsy.

We will look forward to sharing the results of the survey with you.

Talking about epilepsy

Tune into BBC Radio 4's *The Listening Project*, to hear a conversation between Hamsia, right, and Alex who both have epilepsy.

The two women discuss their different experiences and the impact that epilepsy has on their lives. Hamsia, 33, comes from a Somali background and explains how she was initially too upset to discuss how she felt about her epilepsy with her family. Alex, 35, talks about how her seizures became progressively worse in her 20s and how her parents have to accompany her everywhere to make sure she is safe.

Scroll to 11:13 at https://www.bbc.co.uk/sounds/play/m0013qx8 to hear their conversation. You can also read more about Hamsia's story at **epilepsysociety.org.uk/hamsia**

POLICY

MP calls on Boris to act

The Epilepsy Society's local constituency MP, Sarah Green, used her first ever question to the Prime Minister to call for research funding into the impact of climate change on people with epilepsy.

Sarah Green represents Chesham and Amersham in Buckinghamshire where the Epilepsy Society is based. Speaking at Prime Minister's Questions (PMQs), she said:

"The Epilepsy Society are a charity with a world-leading research centre based in my constituency. They've started the Epilepsy Climate Change Initiative to better understand the effects of climate change on epilepsy, and the impact is already clear. A recent survey showed that 62 per cent of those whose seizures were uncontrolled experienced an increase in seizure frequency or severity during hot weather.

"Will the Prime Minister put human health on the climate change agenda, endorse the Epilepsy Climate Change Initiative and commit to more funding to research the impact of climate change on human health?'

Prime Minister Boris Johnson replied: "We're funding epilepsy research with another £54 million over the last few years (sic) and this issue that she raises of any particular link between hot weather or climate change and epilepsy is one that we will be going into."

Clare Pelham, Chief Executive at the Epilepsy Society said the Prime Minister was welcome to visit the charity and find out more.

CAMPAIGNS

Why we must tackle impact of climate change on health

As world leaders met in Glasgow at the end of last year to discuss the challenges of climate change, scientists, led by the Epilepsy Society's Professor Sanjay Sisodiya, stressed the need to address the impact of global warming on human health.

Sanjay Sisodiya is Director of Genomics at the Epilepsy Society and founder of Epilepsy Climate Change (EpiCC), a worldwide initiative to generate research, tackle climate change and mitigate its impact for people with epilepsy.

In recent editions of *Epilepsy Review* he has written about his growing concerns of the negative impact that rising temperatures can have on people with heat sensitive epilepsies such as Dravet syndrome, where changes in temperature can result in seizures.

But during COP26, he highlighted his worries and the need for action in a special eight-page newspaper, *The EnvironMental Issue*, dedicated to emphasising why neurological conditions –and all human health – must be on the climate change agenda. The publication was distributed during the UN conference.

Writing in the paper, Professor Sisodiya said it was vital that leaders don't just pay lip service to climate change issues or those related to its impact on health.

"They need to act to reduce carbon emissions and adapt to the inevitable changes ahead," he wrote. "This is important for everyone and has to be the single most important thing.

"But along with this, in all the calculations, we also have to think about health. People with diseases, including neurological diseases, will probably be among the first of those to be affected, and may be least able to respond.

"There has to be more attention paid to health and the effects of climate change and we have to think about further research. Some of the vast amounts of money being pledged and spent has to be focused on diseases because this can tell us more about what is going to happen to human health: it's like an early warning system for everybody."

Joining Professor Sisodiya in *The EnvironMental Issue*, Clare Pelham, Chief Executive at the Epilepsy Society, called on Britain's two "venerable institutions", the NHS and the BBC, to take a dramatic stand.

CAMPAIGNS

Home Secretary calls for answers on Safe Mum, Safe Baby campaign

In January we were thrilled to receive a response from the Home Secretary, Priti Patel, to a letter calling for safer epilepsy medicine for pregnant women.

In the letter, Ms Patel said that she had spoken with Sajid Javid, the Health Secretary, and asked him what steps were being taken to fund research into safer treatments for pregnant women with epilepsy. And she promised to provide further information as soon as possible.

Ms Patel received the letter from an Essex constituent who was calling for the government to back the Epilepsy Society's Safe Mum, Safe Baby campaign.

Top award for *The EnvironMental Issue*

The EnvironMental Issue was printed on Mohawk paper using recycled fibre, with renewable Algae Ink™ which removes carbon from the atmosphere as it's produced, to highlight the importance of fighting climate change on every level possible. The newspaper was voted the top COP26 PR Week UK campaign.

https://epilepsysociety.org.uk/news/the-environmental-issue

"My ask to the BBC would be for it to commission a programme with David Attenborough covering the impact of climate change on the human animal."

And calling on the UK to take a lead in bringing together nation states to address the worldwide public health consequences of climate change, she continued:

"My ask of Health Secretary Sajid Javid would be that the NHS take a global leadership position on climate change and health, in the way it took a lead on the position of free medical care following World War II."

To read more about climate change and its impact on human health, download *The Environmental Issue* at **theenvironmentalissue.com/**

As part of this campaign, we are asking for investment into research to find safer treatments for pregnant women with epilepsy. This follows the publication of a government-backed report in 2021 which showed that some commonly prescribed epilepsy drugs pose a risk of physical and neurodevelopmental harm to a baby during pregnancy. After many years of concern about the use of sodium valproate, we believe it is vital history does not repeat itself.

#SafeMumSafeBaby

Watch it on video

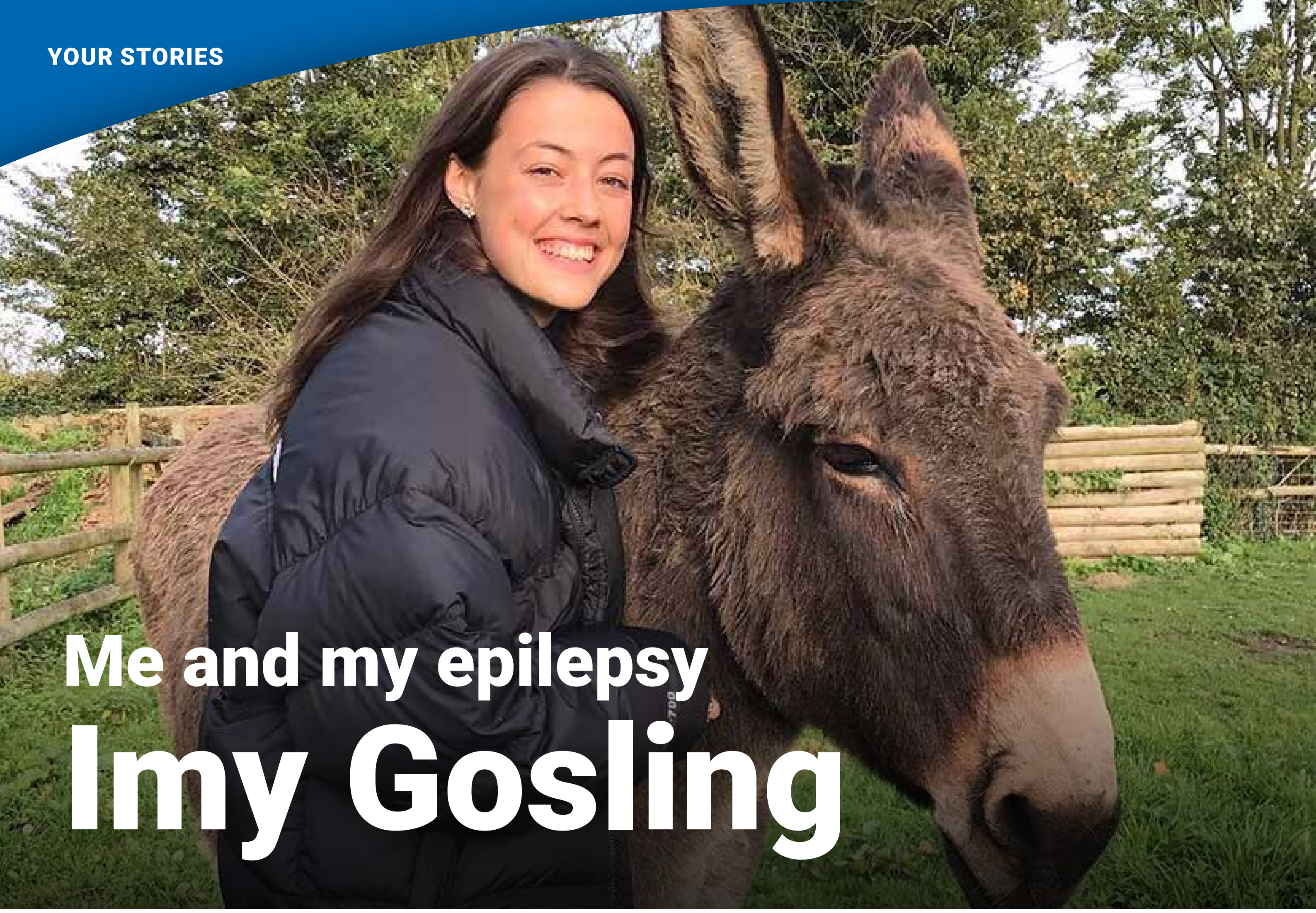
You can view these videos at
youtube.com/epilepsysociety

No spoilers. Just watch this. Jaxon is out of this world. We are watching it on repeat.

See how we are using TMS-EEG – a non-invasive scanning technique, to look inside the brain and understand more about epilepsy.

Epilepsy midwife, Kim Morley explains why it is so important for anyone considering having a baby, to talk about their epilepsy medication with their doctor.

Nicola Davies talks about what life is like at the Epilepsy Society for her daughter, Emma, who lives in residential care.



Me and my epilepsy

Imy Gosling

Imy Gosling is 26 and works for the Foreign Office. She is about to start a four-year posting in Vienna. Here she talks about the challenges of her epilepsy and how she wishes she had understood the path her seizures would take from the start

Epilepsy diagnosis

I had my first seizure at the age of 15. It came right out of the blue – no-one else in my family has epilepsy. But I wasn't diagnosed with the condition until after my second seizure when I was 16. Initially I was on a relatively low dose of epilepsy medication and I was lucky in that I didn't have any seizures during the sixth form. But when I went off to Oxford uni, I had four seizures in six months.

My medication was changed. I was put on three different drugs, including valproate, and I had four or five years of being seizure free. Then, again out of the blue, I had another couple of seizures and that seems to have become a pattern for me in recent years. I have a seizure every six to eight weeks and often more frequently. When I had covid, I had three seizures in a day.

Understanding seizures

When I was first diagnosed, I thought I would take some medication and it would control my seizures and everything would be ok. And that was the case for a while. But I find it hard that I didn't understand the path my seizures would take and that, over time, my seizures would change. I find it strange that initially I was on a low dose and my seizures were controlled, but now I am taking the maximum dose of several medications and I still have seizures. Also, I don't seem to have any triggers.

I am still taking valproate and consequently have to take an effective contraceptive and sign an annual risk awareness form. My neurologist is keen for me to eventually come off this medication and I know it will be a consideration when the time comes to planning a family.

Most of my seizures happen in my sleep. I have a monitor and these are picked up by my family or boyfriend. But I also have absence seizures during the day and these can be more frequent. On a day when I feel that my epilepsy is bad, I take clobazam in the hope that it will stop things developing into a tonic clonic seizure.

Clockwise from left: Imy and donkey, Shadow; with mum, dad and sister, Serena; boyfriend Alex; with school friend and runner Julia

Impact of epilepsy

My epilepsy can slow me down which can be frustrating when I'm at work. It can affect my cognition and thinking can be difficult. If I feel I am having a rough day, I try to do more admin that doesn't require quite as much brain power.

I have had a couple of seizures while working at the Foreign Office. One of the seizures was at the top of a small flight of stairs so I ended up quite bruised. Both times, the first aiders called an ambulance, just to be on the safe side.

> **“I don't think you can underestimate the stress my family experience when I have a seizure. I may lose time but I don't see what they see**

A year ago I was due to be posted overseas but that was when I was recovering from covid and had multiple seizures. The Foreign Office didn't feel they could clear me to work abroad, so I had to do an extra year in London while my contemporaries went overseas. However, I am off to Vienna in April to work for four years at the OSCE – the Organization for Security and Co-operation in Europe – and very much looking forward to it.

Living on my own

It will be the first time I have lived on my own. At the moment I live with my sister and have family, friends and my boyfriend nearby in London, so there is a sense of security in that. I know my family worry about me living abroad by myself and I don't think you can underestimate the stress and upset they experience every time I have a seizure. I may lose time but I don't see what they see.

My friend, Julia

The first weekend that I am in Vienna, my friend, Julia Gargan will be joining me as she is running the Vienna Marathon to raise money for the Epilepsy Society. I am glad I will be there to cheer her on. I really hope that the money raised will help with research into epilepsy. It would be so good if people were able to be given the right drug for their epilepsy from the start, so that they don't have to keep switching between medications which can take a long time and be very stressful.

I would also like to see more research into the risks around some of the medications during pregnancy.

www.justgiving.com/fundraising/julia-gargan2

The joke's on Jake

Comedian **Jake Lambert** explains why he is telling the world about his epilepsy

> **“I say I have epilepsy, not that I am epileptic. When people ask the difference, I explain that I have a Ford Focus but I'm not a Ford Focus"**

Comedian Jake Lambert is 32 and on a mission to get people talking – and laughing – about epilepsy, more specifically his epilepsy. He uses his stand-up comedy gigs up and down the country to bring the house down while at the same time breaking down the stigma around the condition. And it’s working.

As a comedian, Jake Lambert admits there could be few better places to have had a first seizure than while trying on a pair of jeans in Top Shop.

“The irony is, I had my first seizure in a fitting room,” laughs Jake. And the moment has now become a pivotal part of a career that puts epilepsy well and truly in the spotlight.

Jake has built a name for himself on the comedy circuit, laughing about his epilepsy. He regularly supports big acts including Michael McIntyre, Alan Carr and Jack Dee, as well as headlining himself in sell-out tours.

He has made it to the finals and semi-finals of an impressive line up of comedy awards. And he regularly writes for Mock the Week, 8 out of 10 Cats, The Great British Bake Off: An Extra Slice and The Apprentice: You’re Fired!, to name but a few.

Yet though he admits he can see audiences sitting up and listening with a different kind of attentiveness when he talks about epilepsy, he is still nervous about how his ‘epilepsy material’ will land.

“I mean epilepsy isn’t funny. At all. And I would hate anyone in the audience with epilepsy to think that I was laughing at them or mocking the condition. I’m not and I wouldn’t,” stresses Jake.

“I only ever laugh about my own epilepsy and the way I have dealt with it or failed to deal with it. I am absolutely always the butt of my jokes. But I would really like to think that it helps to normalise the condition for other people and increases awareness of what it is like to have seizures.

“I own my epilepsy so I think it gives me a right to talk about it in a way that someone who hasn’t had seizures would not be able to. The moment I mention this huge, heavy subject, I can see the mood in the audience change and then change again with a sort of relief when they hear me joking about it. It makes the whole thing feel far less scary.”

Jake also admits he is shameless in capitalising on his epilepsy in a way that has won the admiration and envy of other comedians.

“When I start talking about my epilepsy, I reassure the audience that I don’t have the sort of seizures that are triggered by flashing lights. My seizures are triggered by stress, tiredness (both true) and people not laughing at my jokes. Jack Dee loves that one. The audience sits up and thinks we’d better laugh in case he falls over.”

Jake is also quick to point out his condition has perks. “I got my covid vaccine way beyond my peers. Not because I’m 75 but because I have epilepsy.”

It would be hard not to laugh at Jake Lambert. Even sitting at his kitchen worktop on a Zoom call, his one-eyed cat, Richard Parker, curled at his feet, he just is funny. His one-liners take on the stigma around epilepsy with a punch that cuts to the core.

“I don’t want to be branded as ‘an epileptic comedian’. Epilepsy isn’t a label. I say I have epilepsy, not that I am epileptic – it's something I have, not something I am. When people ask the difference ,I explain that I have a Ford Focus but I’m not a Ford Focus.”

And his anecdotes allow comedy to kiss and tell all about epilepsy in a way that delivers insight into a condition that rarely takes centre stage.

“When I tell people I have epilepsy, I can see them thinking ‘ah that makes sense’,” laughs Jake. “I imagine they think ‘that’s why he keeps wondering off topic.’ ”

And he refuses to worry that his epilepsy will deter agents from booking him. “If I can drive at 70mph down the motorway, I’m pretty sure I can stand on stage. I would not want to work for anyone who thought otherwise.”

Jake was diagnosed with epilepsy in his first year at university, although he was no stranger to the condition.

“My older sister, Claire, had epilepsy when we were growing up,” he explains. “I had never seen her having a seizure but I was always aware of the times my dad had to kick down the bathroom door

▸

when we heard her having a seizure in the shower.

"My parents would put Claire to bed and check that she could recognise them and knew what day of the week it was."

When Jake had his first seizure in the changing room at Top Shop, he didn't tell his parents. "I genuinely didn't want to bother them and I was worried they would insist that I went home, or they would come up and put me to bed.

"I was very lucky in that my seizures were quickly brought under control with medication. At the time I just took it for granted that you go to the doctor and whatever you have is sorted with medicine. If I was going through the same experience now, I would be much more grateful and amazed that the medicine was able to sort out my epilepsy.

"My doctor said my seizures were triggered by lack of sleep, stress and alcohol, three words that could really be used to describe uni. I'm surprised we weren't all having seizures. I tried to make sure I was safe by putting pillows around my desk and a duvet on the floor if I thought I might have a seizure. But to be honest, I was young and a bit silly. I thought I was untouchable and put my own health second to having a good time.

"Once the medicines had sorted my seizures out, I just sent my parents a text to say what had happened and that I was fine and, in fact, they were ok about it. I think they thought I was being more sensible than I actually was.

"My friends were also great and supportive. They called me 'Shaky Jake', so I finally had a nickname. It was like it had been written in the stars."

Jake is uncertain about whether he had seizures as a child. "My doctor said absence seizures of 5-15 seconds were quite common in children. If I was having them, it doesn't say much about my in-put at school, that no-one noticed."

Jake did however experience what he calls 'Alice in Wonderland syndrome' where his perspective on his surroundings kept changing. "I would be lying in bed and everything would either seem very big and really close, or very small and far away," he explains. "The bedroom door would suddenly feel as though it was an inch from my face and closing in on me. Then the perspective would change completely. I don't know if this was an aura or not, but I knew I had to sleep. Other times I would be able to just gather myself together until things felt normal again."

Jake's commitment to continuing the conversation about epilepsy is driven by his desire to support other people and increase understanding of the condition. He has an hour-long show 'Shimmy Shake' planned for the Edinburgh Festival in 2022, which will be solely about his epilepsy. And he has written a sit com about his experiences which has been picked up by a production company.

Again, his nerves surface: "I am a bit worried about whether people will be happy to see epilepsy represented in a light-hearted way but I will be consulting with other people with epilepsy to make sure I get it right."

Shimmy Shake will be joke heavy. The sit com will have more light and shade. "When I first started out in comedy, I wouldn't have had the skills and tools to talk about my epilepsy in the way that I do now. I couldn't have made it funny," says Jake. "But now, it is almost a way of saying to my epilepsy that I am in control, it hasn't got me. It's probably a very British way of dealing with it. My family is the same. My sister and nephew both have epilepsy but we all get on with our lives."

After one of Jake's recent gigs, a member of the audience thanked him for talking about his epilepsy. She told him her son had just been diagnosed with the condition and it was good to hear someone talk about it so openly.

"It was so nice of her to come and tell me that," says Jake, with a palpable sense of relief and gratitude. "I really hope that my comedy and experience will help her son, and others like him, realise that you can live with epilepsy and laugh."

> **"My seizures are triggered by stress and tiredness (both true) and people not laughing at my jokes. Jack Dee loves that one. The audience thinks we'd better laugh in case he falls over"**

While you wait

Following the pandemic, many people are facing long waits in between health appointments. Our Clinical Director, **Dr Fergus Rugg-Gunn** provides practical advice for looking after yourself while you wait.

Restrictions may have been lifted and life may have returned to near normal, but one of the long-term legacies of the pandemic, is increased waiting times for medical appointments.

With essential resources having been diverted to deal with a surge in hospital admissions and delivery of the nationwide vaccination and booster programmes, people are still seeing delays and cancellations for routine health appointments – including those for epilepsy. And this can cause anxiety.

According to NHS figures analysed by the Neurological Alliance, there has been a 5,000 per cent rise in the number of neurology patients who are having to wait more than a year for an appointment. This includes people with epilepsy, multiple sclerosis, dementia, Parkinson's disease and motor neurone disease.

Via our Helpline and social media, we regularly hear from people who are facing long delays for an appointment to see their neurologist or doctor. Or who are still awaiting a diagnosis of epilepsy after a first seizure. Delays can be lonely and frustrating with people left in a vacuum feeling unsupported and worried.

It is hard to predict when waiting times will return to their pre-pandemic levels and, as in so many aspects of daily life, we are having to live with the new normality and are having to find ways to cope.

Our Clinical Director at the Epilepsy Society, Dr Fergus Rugg-Gunn, has drawn up some advice on how to look after yourself in between appointments and where you can get support while you wait. ▶

Seeking help from others

The important thing to remember is that you are not alone. We live in a digital world and there are many information resources that you can access online (see page 13), as well as peer support.

One of the benefits of social media is that, night or day, you can engage with other people affected by epilepsy who may be going through the same experience as yourself. Social media is not a place for seeking medical advice – this should always be from your doctor – but Facebook, Twitter and Instagram are good platforms for talking and exchanging ideas.

Every day we see an outpouring of support from people as they confirm 'yes that's normal for me' or 'that's exactly how I feel' or 'lack of sleep is one of the big triggers for me, too.' Talking with people who understand just how a seizure makes you feel, is a shortcut to coping and getting through.

Knowing there are others out there going through the same thing as you, really can help, even if it's only the reassurance that others are also having to wait for their regular appointment.

If you're looking for information, always choose a reliable site such as epilepsysociety.org.uk or nhs.uk

Technology offers plenty of opportunities for connecting with friends and family online but, not everyone is confident with using Facetime, Teams, Zoom or any of the other platforms that have become part of our lives.

If you are struggling with technology, ask for help from a friend, relative or neighbour. Or www.digitalunite.com/technology-guides offers useful how-to guides to get connected.

Calling our Helpline

Of course, not everyone is online. Which is where our Helpline comes in. Every weekday from 9am-4pm and until 7.30pm on Wednesdays, you can pick up the phone and speak to one of our Helpline operators. Each of them has an in-depth knowledge of epilepsy, and understands the challenges of living with the condition.

The team is also very good at listening and providing emotional support which can be vital for people affected by epilepsy. Time constraints within the NHS mean that, at the best of times, neurology appointments provide little opportunity to really talk about how epilepsy makes you feel.

As doctors, our focus is often about ensuring correct medication levels in order to optimize seizure control. There isn't always time to talk about driving regulations and epilepsy, or the challenges of telling your employer about your seizures. There isn't always time to talk about personal relationships or feelings of isolation. But this is where our Helpline team is there with a listening ear.

In these difficult times, remember we're here for you

Helpline number

01494 601 400

Line are open
9am – 4pm (Mon, Tues, Thurs, Fri)
9am – 7:30pm (Wed)

Or email us at
helpline@epilepsysociety.org.uk

Contacting a healthcare professional

Even if you are having to wait for an appointment to see your GP, you may be able to seek support through the GP's online service. Ask at your surgery whether they have an online service that you could access. This is useful for booking and changing appointments, ordering repeat prescriptions and getting advice.

If you feel your epilepsy has changed or, for example, your seizures have become more frequent or severe, let your surgery or epilepsy clinic know – they may be able to prioritise you.

Your local pharmacist can also be a good person to ask if you have questions about your medications. Many pharmacies have a separate consultation room where you can talk in private about any issues you are having with your medication. They are often open late into the evening and at weekends, and you don't need to book an appointment.

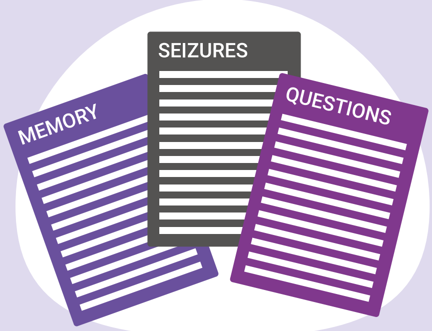
From time to time, people experience problems in getting their prescription. This is often because of local supply issues as opposed to shortages. To help you get your medicine as prescribed, always take your prescription to your pharmacy in good time – up to seven days before you need the medication. That way, if the pharmacy does not have your drugs in stock, it gives the pharmacist time to order stock from suppliers or to ring other pharmacies or suppliers.

If you are experiencing problems getting your medication, you should always call the customer service desk for your particular medicine. You will find the number on the patient information leaflet that comes with your medication.

Taking care of yourself

We are living in uncertain times and this can cause anxiety and stress, both of which can trigger seizures for some people with epilepsy. This is why it is vital to keep your body and mind as healthy as possible:

- make sure you are eating regular, nutritious meals and drink plenty of water to keep hydrated
- try to get the amount of sleep you know your body needs. There is no magic formula and it is a myth that you need eight hours a day. The rule of thumb is that you need enough sleep to enable you to feel alert during the day
- take regular exercise where possible, even if this is only a walk around your garden or around the block. Enjoy listening to birdsong or looking out for seasonal changes. If possible, go for a walk with a friend
- try to get as much sun light as possible. Even if you are unable to go out, try to sit by a window or on your doorstep. Make sure you ventilate your home so that fresh air is circulating
- watching the television can be relaxing but the news can also be stressful. Recognise when the television is starting to make you feel anxious and take a break
- keep in contact with friends and relatives. Call or join them on a video call
- if you find yourself feeling anxious, take a look at some of our tips for dealing with this epilepsysociety.org.uk/living-epilepsy/wellbeing/anxiety.



Be prepared for your doctor's appointment

- keep a record of your seizures. Ask someone to film you if they witness you having a seizure. This can help your doctor understand your seizures. epilepsysociety.org.uk/seizure-diaries
- keep a note of issues you want to discuss. This could include side effects of medication. Or it could be that you're having trouble remembering to take your medication. Your doctor will be able to help with this
- if you are experiencing memory issues, make a note to tell your doctor. They may be able to refer you to a clinical psychologist who will suggest strategies to help
- you may be looking forward to a change in lifestyle which is important to discuss with your doctor. Perhaps you are starting university; you may need to transfer your medical care to a doctor close to your university. Or you may be planning a family: your doctor will refer you to a specialist
- some women feel that their seizures are worse around the time of their monthly period; others find that the menopause or hormone replacement therapy can affect their seizure patterns. These are important to note, ready to share with your doctor
- many people experience anxiety and depression and it can be very common in epilepsy. You may like to discuss ways of coping with these feelings
- SUDEP, or sudden unexpected death in epilepsy, affects a very small number of people with epilepsy – around 1 in 1,000. But it is good to discuss your individual risk with your doctor so that you can reduce that risk.

Shortcuts to epilepsy information

Here are links to some of our most popular website pages at epilepsysociety.org.uk You can also find information at nhs.uk/conditions/epilepsy/

Ways you can improve your well-being

Includes sleep, diet and nutrition, exercise, relationships and anxiety

epilepsysociety.org.uk/wellbeing

Women and epilepsy

Includes puberty, contraception, pregnancy and the menopause

epilepsysociety.org.uk/women-and-epilepsy

Older people and epilepsy

Includes coming to terms with a diagnosis of epilepsy

epilepsysociety.org.uk/older-people-and-epilepsy

Seizure diaries

Find out how to download or order a diary from our online shop

epilepsysociety.org.uk/seizure-diaries

Going to university

Making sure you have all the support you need to enjoy your time at uni

epilepsysociety.org.uk/university-and-epilepsy

Social media

Join the online conversation. Follow us at:

facebook.com/EpilepsySociety
twitter.com/EpilepsySociety
instagram.com/EpilepsySociety

Hope, even after many years

Every day, science is shedding new light on epilepsy, increasing our understanding of the condition and offering better treatment options. In the following pages, we look at three of our research studies and how they are bringing hope

Our research at the Epilepsy Society is transforming lives – literally. Here we explain how, for some people, genetic testing is helping to unlock their epilepsy after many years, leading to better, more appropriate treatments. And how our researchers believe a simple genetic test could turn round the lives of many more in adult social care.

Researchers at the Epilepsy Society fear that adults in social care with epilepsy and learning disabilities could be receiving the wrong medication or treatment due to a lack of diagnosis.

And they are recommending that all adults with complex epilepsy and associated disabilities should be offered genetic testing to ensure that their healthcare needs are properly met.

Researchers at the Epilepsy Society carried out a study of 1,078 individuals with complex epilepsy who underwent whole genome sequencing through Genomics England's 100,000 genomes project. Individuals were tested for mutations in a single gene – SCN1A – which can cause the severe childhood condition, Dravet syndrome.

Eight people were found to have mutations in this gene, which gives rise to Dravet syndrome, associated with multiple issues including frequent and prolonged seizures and developmental delay. There is also an elevated risk of Sudden Unexpected Death in Epilepsy for people with the syndrome.

Professor Sanjay Sisodiya, Director of Genomics at the Epilepsy Society said: "To discover eight people with a specific rare syndrome in a group of people this size, is relatively high. This means those individuals could never have been properly diagnosed and may not have been receiving the most appropriate medications and treatments to optimise their care.

"Some commonly prescribed seizure medications actually exacerbate seizures in people with Dravet syndrome and should be avoided. But without a diagnosis, this may not be considered.

"In an ideal world we would review the childhood notes of all adults with refractory epilepsy for features of the syndromic diagnosis, but this is just not practical in a busy clinic and often the notes are not available.

“A comprehensive screening test is a cost effective way to screen for variants in multiple genes that might be associated with Dravet syndrome. And it could make a big difference to the individual and to their families.”

Clare Pelham, Chief Executive at the Epilepsy Society said the study offered real hope and potential relief for families who have been through decades of a diagnostic odyssey with no real answers.

“This study shows how genetic testing can unlock a condition many years down the line and offer hope of better treatments, even in adult life.

“It is heart-breaking to think there could be people in adult social services whose lives might be turned around by a simple genetic test, but who aren’t being given the opportunity to find out. It is imperative that the incredible breakthroughs that science is able to offer are made available to those who need them most.

“We are pioneering the use of genetic testing in epilepsy through our genetic clinics at the Epilepsy Society. But it is important that this becomes routine practice across the NHS.”

> **“It is heart-breaking to think there could be people in adult social services whose lives could be turned round by a simple genetic test**

Daniel’s story

Chris and Marilyn Pinchen’s son, Daniel, was one of the eight people to be diagnosed with Dravet syndrome as part of the study. Daniel is 48 and had his first seizure at 11 weeks. He has spent most of his life in residential care.

Chris and Marilyn Pinchen describe the moment they received a genetic diagnosis for Daniel. “We were both shocked and surprised,” says Marilyn, “but suddenly everything fell into place. We had never heard of Dravet syndrome but all the problems and troubles that Daniel had experienced throughout his life, finally made sense.”

The Pinchens knew Daniel had epilepsy but they did not know why he was so severely affected. For the Pinchens, the diagnosis comes after almost five decades of uncertainties and unknowns, referrals to specialists, different treatment plans, medication changes and a slew of medical tests.

Marilyn recalls: “At one point Daniel’s medication was changed to try and control his seizures and he ended up in a wheelchair. We didn’t know that the medication he had been prescribed made seizures worse in people with Dravet syndrome. If we had known years ago, it would have made such a difference to Daniel’s life. However, when Daniel was born, Dravet syndrome had not even been described in the medical books. We were always very appreciative of the medical care he received which was the best at the time.”

Daniel’s current medication is now being adjusted to optimise his health. He is taking four different seizure medications and although three of them are thought to be fine in Dravet syndrome, one of them is generally not recommended.

Chris and Marilyn are also relieved to find that Daniel’s posture – he leans forward and is slightly bent at the knee – is also characteristic of Dravet syndrome.

“In the past we have been told that he had scoliosis and that he should undergo physiotherapy for his knees. One teacher described him as lazy because he could not catch a ball. But we now know that both issues are part of having Dravet syndrome.

“Doctors have also been able to tell us that Daniel may develop problems with swallowing as he gets older and that his gait may be affected further. Although we cannot stop this happening, it is reassuring to know so we can be prepared and ensure Daniel has the right support.”

Chris and Marilyn have also undergone genetic testing to check whether Daniel’s condition has been inherited from either of them. The majority of SCN1A mutations are not found in either parent, but there is a small chance of the mutation having been inherited.

“We were very relieved to find that neither of us had the mutation,’” said Chris. “We have three other children and grandchildren, and it has been a great relief to be able to reassure them that the syndrome is not going to affect them.”

Possibility of seizure freedom for those with drug-resistant epilepsy

A new study has raised hopes that people who live with long-term drug resistant epilepsy may still enjoy a period of seizure freedom in later life. And it has thrown a spotlight on the complex relationship between epilepsy and the ageing process.

For people with long-term uncontrolled seizures, it is generally thought that there is a low chance of achieving seizure freedom in later life.

But a study, carried out at the Epilepsy Society, has shown that seizure freedom is still possible, even for those whose seizures have not responded to anti-seizure medications. And the natural ageing process may play a significant role in this.

The research, led by Professor Ley Sander, Medical Director at the charity, carried out a study of 226 people with severe epilepsy who lived at the Society's Chalfont Centre. The study covered a period of 20 years from 1998 to 2008.

Results showed that 17 per cent of the group enjoyed a period of at least two years seizure freedom in later life, in spite of having lived with long-term drug resistant epilepsy. The average age for achieving this goal was 68 and the average duration of seizure freedom was seven years.

People most likely to achieve seizure freedom were those who had experienced fewer numbers of seizures from the onset of their epilepsy, had no history of status epilepticus and no accompanying psychiatric conditions.

Professor Sander said: "Our data reflects a group of people with the most severe epilepsies and associated learning disabilities. It also reflects a period when some of the newer, more effective drugs were not available. Consequently, our findings may underestimate the number who are likely to achieve seizure freedom."

Importantly, the study also raises fundamental questions about the role that ageing may play in achieving seizure freedom.

The highest incidence of epilepsy is in people over the age of 65, yet people in this group also respond well to anti-seizure medications, have reasonable seizure control and seem to experience fewer convulsive seizures.

Professor Sander said: "It may be possible that some of the causes of epilepsy in later-life are also responsible for the more favourable outcomes in controlling seizures.

"Vascular damage that causes lesions to the brain may result in epilepsy, but there is also evidence to suggest that the same damage may protect the brain from generalised convulsive seizures.

"It may be possible that late-onset seizure freedom is due to changes in the structure and connectivity of the brain in later years. The electrical activity that generates seizures needs clear pathways between the two hemispheres of the brain in order to spread and result in a convulsive seizure.

"Vascular damage that causes lesions and the epilepsy may interrupt these networks and stop the spread of the seizure."

> **"Our findings may underestimate the number who are likely to achieve seizure freedom**

Feeling the heat

Scientists at the Epilepsy Society are already looking at how climate change is affecting people with severe epilepsy. But now they are also trying to find out how a fluctuation in temperature inside residential care homes could impact seizures.

Our researchers are working in collaboration with ClimaCare, a group of built environment and public health scientists from UCL and other universities, to monitor indoor temperature changes in care homes and assess whether, when the heat rises, the frequency or severity of a person's seizures also increases.

And they hope that the research could help inform building design in the future for people whose seizures may be sensitive to temperature changes.

Jonny Anders-Cannon, Director of Care Services at the Epilepsy Society said that for over three quarters of the 93 residents living in the charity's six care homes, their seizures were uncontrolled.

"Everyone's epilepsy is different and the trigger points for seizures can be very individual," he said.

"Sometimes it could be an infection that will trigger a seizure – but we also see an increase in seizures during heatwaves. We have people who struggle to regulate their body temperatures in extreme heat and then end up having a seizure.

"Night-time is definitely the worst when you can't leave the bedroom door open."

Sensors have been placed in seven residents' rooms and shared spaces, enabling researchers to collect data on internal temperature changes and compare them with changes in external temperatures.

Professor Sanjay Sisodiya, Director of Genomics at the Epilepsy Society, is leading on the study with ClimaCare. "We have a mixture of old and new buildings here at the Chalfont Centre," he explained.

"Some of them are have good thermoregulation, while others less so. When it is hot outside, it can also become hot inside the care homes. I hope we will be able to gather robust data that will help us to understand the impact of buildings on temperature and seizures.

"The more we understand about the way buildings affect human health, the more adaptations we can put in place to help regulate the temperature and prevent seizures happening for people whose epilepsy may be more temperature sensitive. It could be something as simple as avoiding south facing accommodation for a resident with Dravet syndrome – one of the severe epilepsies which seems to be associated with heat sensitivity."

> **"I hope we will be able to gather robust data that will help us to understand the impact of buildings on temperature and seizures… the more we understand… the more adaptations we can put in place**

Challenge 100 returns for 2022!

On 1 January hundreds of fundraisers dusted off their trainers, went on New Year's Day walks and took on their first cycle ride of the year to knock off their first miles of Challenge 100.

Launched in 2021, Challenge 100 is Epilepsy Society's very own virtual challenge that asks supporters to complete 100 miles in 100 days. In 2021, an incredible team of challengers raised over £93,000 by walking, running, cycling or swimming 100 miles between 1 January and 10 April.

Over 1,000 epilepsy heroes signed up to support Challenge 100 2022 and this year's event is set to raise over £100,000 – a phenomenal amount that will help to transform the lives of people with epilepsy through advocacy, research and care.

We loved seeing photos of our Challenge 100 participants in their Challenge 100 t-shirts and completing their miles. We followed of all their 100 mile journeys with admiration and pride.

Kelly Cornish signed up to complete Challenge 100 in support of her daughter Lily. Kelly has raised over £1,000 – a phenomenal amount!

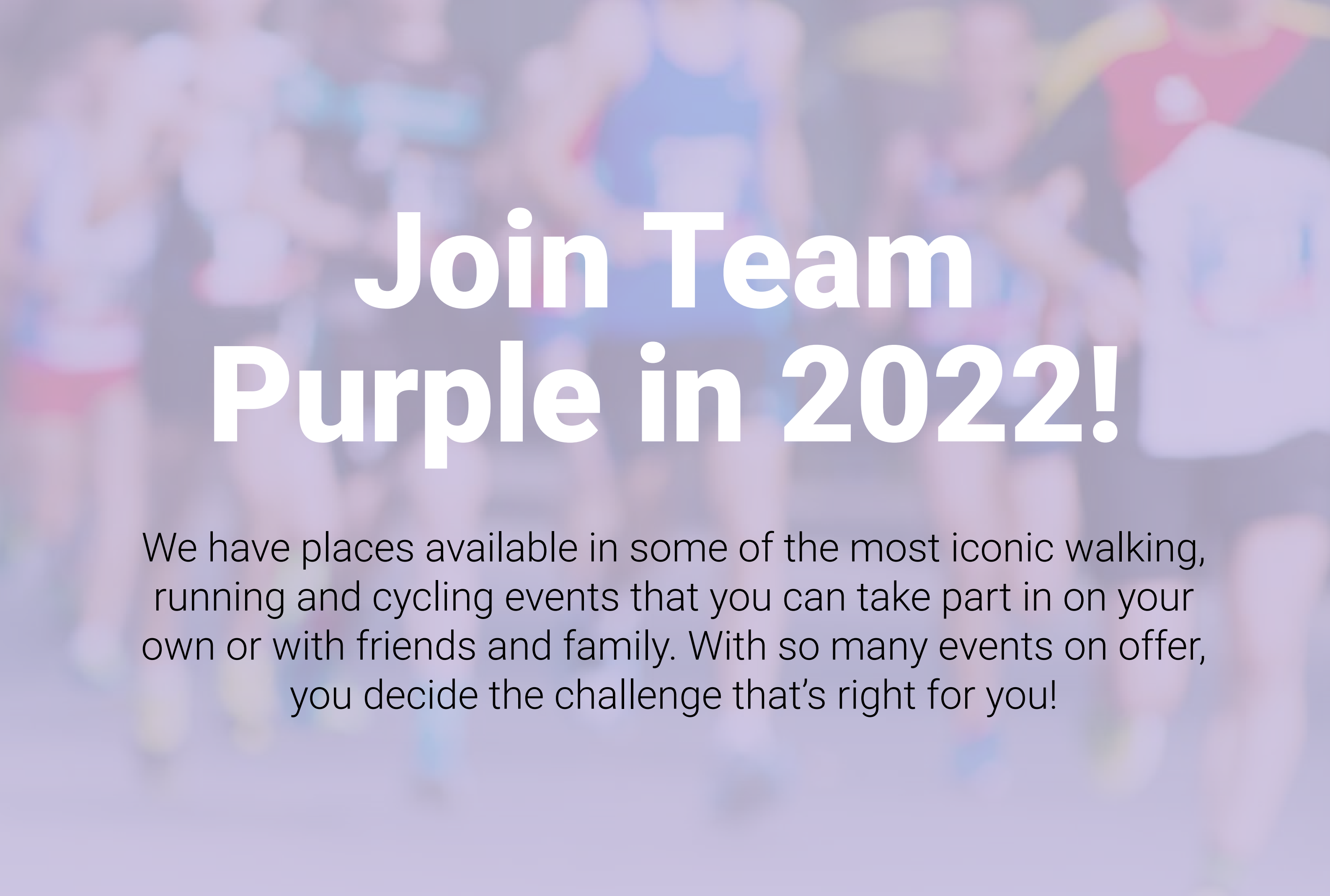
'One in 100 people in the UK live with epilepsy. This includes my incredible daughter, Lily who was diagnosed when she was 13. Her seizures are not yet controlled by medication and are getting worse and that's why I wanted to raise money towards vital research in the hope that one day she might be able to live seizure-free.'

Keep an eye out on our social media channels for details of how you can sign up to support Challenge 100 2023!

Jackie Smith completed Challenge 100 on her bike – 'Really enjoyed being back on my bike at 64! Thank you for making it happen!'

Bina Patel took on Challenge 100 for the second year in a row!

Paul Browne raised an incredible £350 after completing his 100 miles!



Join Team Purple in 2022!

We have places available in some of the most iconic walking, running and cycling events that you can take part in on your own or with friends and family. With so many events on offer, you decide the challenge that's right for you!

22 May
Great Manchester Run

19 June
London 2 Brighton Bike Ride

4 September
Big Half

10-11 September
Thames Path Challenge/Thames Bridges Trek

11 September
Great North Run

2 October
Virtual London Marathon

9 October
Royal Parks Half Marathon

To sign up and browse our full list of fundraising events visit **epilepsysociety.org.uk/fundraising-events**

How we'll support you

All of our Team Purple fundraisers will receive an Epilepsy Society t-shirt, cycling jersey or running vest. We'll also be here to support you with your training and fundraising all the way to the finish line.

Why your support is so important

It is thanks to our incredible fundraisers that we can continue to transform the lives of people living with epilepsy through advocacy, research and care. By taking on a challenge for us in 2022, you could help us be there for someone when they need us most or help us to push forward the boundaries of pioneering epilepsy research.

Give a little love
Leave a lasting legacy

By leaving just 1 per cent of your total worth to the Epilepsy Society in your will, you can help fund valuable scientific research to help us treat and beat epilepsy.

To receive your legacy pack call us on 01494 601414
or email donor.support@epilepsysociety.org.uk

epilepsy
society

To find out more about
leaving a lasting legacy visit
epilepsysociety.org.uk/loveliveson

How Access to Work helped Sharon start her own business

Sharon Ross has set up her own business ghostwriting autobiographies to enable people to capture and tell their own stories. Here she explains how the government's Access to Work scheme has helped her overcome some of the challenges presented by her epilepsy.

A couple of years ago, I came up with the idea of setting up a business, ghostwriting autobiographies for everyday people to share their story with family and friends. I called my company Prashker – in memory of my grandfather, who I never met, and whose full story I will never know.

As a writer, I knew I had the skill-set to carry out the core of the work. But there was a snag. Although my seizures are controlled, my cognition is poor. Setting up a business involves planning, organisation and decision-making skills, and this is where I knew I would struggle.

That is where Access to Work came in. A friend told me about the scheme, and I applied for a grant online. The application process, which included sending them my business plan and medical reports, was straightforward, as was an online assessment that took about 45 minutes. The assessor recommended Disability Impact and Coping Strategy training, recruiting a support worker and several software packages. All of these have proved invaluable.

I was able to fund Executive Function coaching instead of Disability Impact and Coping Strategy training using the grant, and found a coach using a company called Connections in Mind. My coach, who I met with online weekly, took time to understand me and the business I was setting up. I felt that she appreciated the cognitive struggles that I faced. The coaching wasn't a one-size-fits-all approach, but an exercise to see what strategies would help me.

> **"I would encourage disabled people in work or about to start a business to apply to the Access to Work scheme**

I needed to do a certain amount of paperwork to obtain the grant for the support worker. This included writing a job description, listing the tasks I wanted the support worker to do, together with how long I thought each task would take. I was lucky to find atwsolutions, employment recruitment consultants, who helped me with this paperwork as well as finding me a support worker. My support worker's role is to assist me with planning, goal setting, problem-solving and some administrative tasks, and I meet with her via Zoom.

The software packages Access to Work provided included Otter, which records and transcribes conversations and Text To Type, which reads out the text on the screen. These packages help me remember and process information.

Access to Work can also provide tailored mental health support for those in work. It can also pay for taxis if you cannot use public transport because of your disability. A disabled person can also apply for funding for communication resources needed for an interview.

I have had to pay upfront for some of the resources and claim the money back from Access to Work. This process can be difficult for a small business. However, I would encourage disabled people in work or about to start a business to apply to the Access to Work scheme. It could make the difference between being in work or not. In my experience, so-called 'dis' abled people are very able indeed and deserve all the possibilities that work can offer.

Find out more

Prashker autobiography ghostwriting prashker.co.uk
gov.uk/access-to-work
connectionsinmind.com
atwsolutions.co.uk

Tonic comic

All-round funny girl Juliet Stephens has the last laugh when it comes to her epilepsy

It's funny how sometimes, echoes of our past ripple back into our present. I had this recently when I learned that the comedy club that I set up and ran in London for three years had recently opened a second venue – just down the road from where I live now (no longer in London!). My comedy life has come back to haunt me!

On a similar note, I was thrilled to read about the very funny and talented comedian Jake Lambert in this issue. It's great that Jake offers audiences a lighter view on his own epilepsy, and that he really emphasises how the joke is on him, not on people with epilepsy in general.

Stand-up comedians draw on stories from their own lives and mine them for laughs. During my years on the comedy circuit I also spoke (inevitably!) about my epilepsy and, like Jake, I never experienced any hostility because of it. In fact, people often approached me after the gig to tell me about their epilepsy or how they'd supported their friend/sibling/pet after a seizure. I'm not even joking – in some families it is genetic, but in my family the only ones with epilepsy were me and the Labrador.

When audience members came for a chat after a gig I often felt like they were sharing their experience for the first time, and that my making jokes about my epilepsy somehow gave them permission to talk about it. As Jake notes, it is often a feeling of great relief that someone is talking about it openly.

It also really helped my relationship with my own epilepsy which, let's face it can be a scary, frustrating and worrying condition. Being able to poke fun at it offered me a sense of power over it. There's an expression that "Most jokes start with a bitter truth", and there's a (not totally inaccurate) cliché that comedians are 'sad clowns' looking to transform sadness to laughter. Finding "the funny" in any situation reframes it in a new light so the "bitter truth" becomes more palatable.

The very public nature of being on stage can be, frankly, terrifying, and if your seizures are stress related (as so many are!) this can create profound anxiety of having a seizure, literally 'on display'. I'm lucky in that if I am going to have a seizure, it'll start sometime between 11am-3pm. This is handy when you're doing gigs in the evening as I never worried that I would collapse on stage! Not the case for famous American comedian Bud Abbott (of iconic comedy double-act Abbott and Costello), who was known to occasionally have seizures on stage and have to be dragged off by Costello.

> **"In my family the only ones with epilepsy were me and the Labrador**

I doubt Abbott or Costello would ever have mentioned anything about epilepsy, even after a very public seizure. But they were performing in the 1940s and 50s. The conversation around epilepsy, or indeed anything medical, is much more open these days. There's a very real recognition that we've nearly all got something: epilepsy, dyslexia, autism, asthma, the list goes on... Being able to talk about it lets people into the reality of our lives.

How brilliant then, that Jake is doing a whole hour-long show at the Edinburgh Festival this year about his epilepsy.

These days I work as a counsellor, helping other people to tell their stories. I see how powerful it is for people to talk about their experiences, understand themselves better and ultimately, treat themselves with more kindness as a result.

It's also helpful to note the other characters in our stories. The nice lady who sat with me on a bench while I cried; the waiter who gave me a free coffee when he saw my bruised and bleeding face from a bad fall during a seizure; the doctor whose bottom I pinched when I was in my haze of 'affectionate child-like delight'. In telling our story we also notice that we are part of other people's stories, too. Even if they forget us within the grand scheme of things, on that one day that our stories crossed, when their friend or partner asked them how their day was, one lady said "I met a crying woman at the station and I just sat with her for a while", the waiter said "well, what's one free coffee –she was in a lot of pain", and one A&E doctor would have said "a smiling and dreamy epileptic patient grabbed my butt. I've had worse days."

Juliet Stephens
Laughing allowed

Society matters

Purple power

Thank you to everyone who helped to make Purple Day on 26 March, such a fantastic occasion.

The international day for epilepsy proved, once again, to be 24 hours of non-stop fun, with people from around the world raising awareness of the condition and making an invisible condition visible.

We have been overwhelmed by the fantastic events organised by our supporters, all keen not only to share their experiences and stories, but also to raise vital funds for the Epilepsy Society.

Funds raised will go towards supporting people with epilepsy through vital research and our all important Helpline which is there when people need to talk.

As Epilepsy Review went to press, MP Sarah Green was also planning to take a stand for people with epilepsy, by changing her name from Sarah Green to Sarah Purple for the day.

Sarah is the local MP for Chalfont St Peter where the Epilepsy Society is based in Buckinghamshire. After visiting our site and hearing about the amazing research that happens on her doorstep, she was keen to support the charity.

Thank you, Sarah. And thank you to everyone who baked cakes, dyed their hair, ran, walked and skipped long distances and kept the conversation going about epilepsy.

Why it’s a MaCCCy D for us

A big thanks to McDonald's for going the extra mile when a customer had a cluster of seizures in one of their branches. Not only did staff treat her with kindness and sensitivity, but the fast-food chain also shared our ‘Calm, Cushion, Call’ messaging on their social media. So now their 240k followers will also know how to help someone who is having a seizure.

epilepsysociety.org.uk/news/MaCCy-D-for-us

And from purple to green

Eagle-eyed supporters of the Epilepsy Society who follow us on social media, may have spotted a change of colour for the charity back in November last year.

In a radical move that we hoped would jar and get people asking ‘why?’, we changed our much loved purple logo green for two weeks. During COP26, we wanted to highlight the omission of human health on the agenda at the climate change summit (see page 4).

Evidence is already suggesting a link between rising temperatures and some neurological conditions, including epilepsy. People with severe epilepsies such as Dravet syndrome are seeing increased seizures during exceptionally hot summers. And, in our survey of 1,000 people with epilepsy, 62 per cent of those with uncontrolled seizures said they saw an increase in seizure frequency or severity.

The green branding was short-term but our commitment is long-term. As a charity we are reviewing our work practices to ensure that, wherever possible, our choices are green and kind to the planet. Members of our team are making personal decisions to reduce the use of single-use plastics, walk or take public transport where possible, and wage a war on waste.

Find out more at epilepsysociety.org.uk/news/green-new-purple

epilepsy
society

Helpline

01494 601 400

Monday to Friday 9am to 4pm,
Wednesday 9am to 7.30pm.
Confidential, national call rate.
Information and emotional support.
helpline@epilepsysociety.org.uk

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Chalfont St Peter
Buckinghamshire
SL9 0RJ
Enquiries 01494 601 300
Fundraising 01494 601 414

epilepsysociety.org.uk

/epilepsysociety

Registered with FUNDRAISING REGULATOR

> **"For almost every call we receive, there is another that we have been unable to answer"**
>
> Andrée Mayne,
> Helpline Manager

With the NHS under pressure, many people affected by epilepsy aren't receiving the urgent support they need.

Please support the Epilepsy Society Helpline today. Your gift could make a big difference to people with nowhere else to turn.

Please give to our
Spring Helpline Appeal

Donate at epilepsysociety.org.uk/help or by calling our Donor Care Team on 01494 601 414