

Epilepsy Review



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exposes life with
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to five days a week
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In the run up to Christmas, we inevitably receive an influx of calls about flashing lights. Although only around three per cent of people with epilepsy are photosensitive, the stress caused by Christmas lights that flash and flicker throughout the festive season, is significant. But this year, Christmas lights and photosensitivity reached a new peak.



One of our supporters had arranged a series of fundraising events at local Christmas fairs, to help raise money for our research, information services and Helpline.

The first three fairs had gone well. She was just preparing for her fourth and final event at a local community centre where there would be a Christmas grotto and the usual array of festive stalls.

But just a couple of weeks before the event was due to take place, our supporter was contacted by the community event team to say they were sorry that she would not be able to have a stall due to the flashing Christmas lights decorating the centre. They feared it might trigger a seizure, but they would refund her money.

Our supporter was aghast. "I do have photosensitive epilepsy," she explained, "but they were not aware of that. I pointed out that there could be many visitors to the fair with epilepsy and that, in fact, only a very small number of people are photosensitive."

"I also pointed out that under the Equality Act, they should not discriminate against someone with a disability but should make reasonable adjustments to enable them to take part in the fair."

Our supporter saw the situation as an opportunity to educate the management team, and the community centre manager

agreed to meet with her and find out more about epilepsy and how they could work with her to make sure she could have her stall without putting herself at risk of a seizure.

"He has also invited me to hold more stalls in the future, to raise awareness of epilepsy," she said.

So, a potentially negative situation was turned into a positive. As we went to press, our supporter was hoping her stall would go ahead and she would be able to continue with her fundraising for Epilepsy Society. And she had set in motion a programme to raise greater awareness of epilepsy in the future.

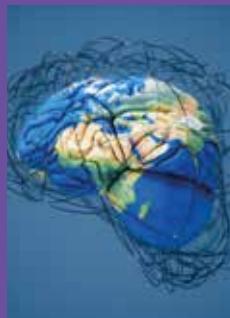
We regularly put out messaging about photosensitive epilepsy through social media and direct communications. But nothing is as powerful as the voice of someone with epilepsy who is prepared to be an ambassador for the condition and turn a situation on its head.

It is a brilliant example of empowerment and what one individual can achieve. And, in fact, empowerment was the theme of our annual conference this year (see page 11).

Bringing about change is not always easy, but even a small change is very worthwhile.

Happy Christmas and a happy New Year.

Nicola Swanborough
Editor



Front cover

The impact of climate change on the planet is well documented. But what is its impact likely to be on the brain, particularly for people with epilepsy? Our Director of Genomics, Professor Sanjay Sisodiya, explains why doctors must ensure their working practices do not have an adverse effect on the health of the people they care for.

Image: iStock by Getty Images

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MEDICATION

Cannabis-based medicine approved on NHS



News that the cannabis-based medicine, Epidyolex, has been approved for use by NHS England, has been cautiously welcomed by Epilepsy Society.

Epidyolex has been given the green light for the treatment of two severe forms of epilepsy that begin in childhood, Dravet and Lennox Gastaut syndromes. It is estimated there are 3,000 people with Dravet and 5,000 with Lennox Gastaut syndrome in England.

Epidyolex has been approved for use with clobazam in the treatment of convulsive seizures in Dravet syndrome and drop seizures in Lennox Gastaut syndrome.

The charity's Medical Director, Professor Ley Sander, said that the news would bring hope to many families but that the long-term effects of the drug on the brain, were still unknown.

Epidyolex is a pharmaceutical grade cannabidiol (CBD) derived from the cannabis plant. Although it contains CBD, it does not contain THC, the psychoactive component of cannabis.

Clinical trials have shown that the drug could reduce the number of seizures significantly in some children.

Epidyolex was approved for use in Europe in September, but in draft

guidance, the drug advisory body, NICE said the cost per patient was too high. The manufacturer, GW Pharmaceuticals, has now agreed a lower discounted price with the NHS. And NICE has issued new guidelines.

Professor Ley Sander said: "News that NICE is recommending the use of the pharmaceutical grade CBD in the treatment of those with Dravet or Lennox Gastaut syndromes, will bring hope to many families affected by these two severe forms of epilepsy. Both syndromes remain stubbornly drug-resistant, often leaving families feeling quite desperate."

"The need for new treatment options is unquestionable and it is reassuring that the medication has been through clinical trials and regulatory processes. But the time frame for these means we still cannot be certain of the long-term efficacy of this CBD product or what its effect might be on the developing brain. It is important to remember that this is not a magic bullet. Like other anti-seizure medications, it is likely to work for some but not for others."

"I hope that this will pave the way for more robust research into other medicinal cannabis products with potential anti-seizure properties."

MEDICATION SHORTAGES

Epilepsy drugs in short supply

A 24-page document circulated to doctors by the Department of Health and Social Care (DHSC) listed many NHS drugs which are currently in short supply, including some medications for epilepsy.

The document was leaked in the media, without specifying which medications were affected.

The DHSC has informed Epilepsy Society that the two epilepsy medications on the list are Epanutin (phenytoin) and Carbagen (carbamazepine).

There have been ongoing issues with both medications, as reported at epilepsysociety.org.uk/medication-updates, and shared on social media.

Epanutin Infatabs 50mg are currently out of stock. Pfizer is importing a generic form of Epanutin from Canada – Dilantin Infatabs – to replace these. Dilantin is unlicensed in the UK. It will be available until mid-2020.

Carbagen 200mg and 400mg Immediate Release Tablets and Carbagen 200mg and 400mg Modified Release Tablets are also unavailable until the first quarter of 2020. Novartis, manufacturer of Tegretol which is the alternative brand of carbamazepine tablets, have confirmed they can support additional demand for all affected strengths and formulations.

Take part in our Valproate And Pregnancy Awareness Survey

Are you a woman or girl under 55 who is taking, or has taken, sodium valproate since 1 August 2018?

We want to find out how much women and girls of childbearing age know about the risks associated with the epilepsy medication during pregnancy. Please help us by taking part in our survey at epilepsysociety.org.uk/SVA-survey

For every baby exposed to sodium valproate during pregnancy, there is up to a 40 per cent risk of

the baby being born with a physical or neurodevelopmental disability.

New regulations around prescribing sodium valproate (also known as Epilim, Episenta, Epival, Convulex, Depakote, Kentilim, Orlept, Syonell, Valpal and Valproic acid) were introduced in April 2018.

The survey has been launched by the three charities Epilepsy Society, Epilepsy Action and Young Epilepsy. Never stop taking sodium valproate without consulting your doctor.



MOBILITY

Blue badge extended

Epilepsy Society welcomed a Government decision to extend its Blue Badge scheme to people with hidden disabilities such as epilepsy.

It is the biggest change to the scheme since the 1970s and extends the eligibility criteria to include anyone who cannot walk as part of a journey, without causing considerable psychological distress or risk of serious harm.

Clare Pelham, Chief Executive at Epilepsy Society said: "Epilepsy can cause significant difficulty for people when walking long distances, and this change will go some way to making their lives easier."

The extension to the scheme is part of a drive for greater parity between physical and mental health which includes plans for fully accessible transport.

The scheme is not condition-specific and eligibility depends on how a person is affected by their condition. A person's mobility will be considered following criteria used for Personal Independence Payment (PIP) and Disability Living Allowance (DLA).

Where anxiety is an issue, this must be evidence based. An applicant would need to prove that they are undergoing a treatment programme for their anxiety at a hospital and that they have appropriate psychiatric or psychological reports.

The Blue Badge is awarded to an individual and does not require the person to have a driving licence or be the driver. Nor do they need to be over the age of 17. This means that even if a person with uncontrolled seizures cannot drive, they can apply for a badge which can then be used by a carer, family, friend or taxi, as long as the badge holder is in the vehicle. This was already specified as part of the scheme.

To find out whether you are eligible for a Blue Badge, search 'Blue Badge' at gov.uk

RESEARCH

AI could offer more hope of surgery

Machine learning – or artificial intelligence – could offer more people with epilepsy the chance of undergoing potentially life-changing brain surgery, says a new study.

Every year 1,000 people are identified in the UK as suitable candidates for epilepsy surgery. These are people whose seizures do not respond to current medications. However, 300 of these will have normal MRI scans that do not show the focal point at which the seizures start, meaning they cannot easily be considered for surgical treatment.

Now a new research study has shown that artificial intelligence is able to read subtle abnormalities on scans that appear completely normal to the human eye. And this could help to guide potentially curative brain surgery in the future.

The team from Epilepsy Society, UCL and King's College, London have developed a visualization technique called 'Importance Maps' to help identify the cause of epilepsy in some of the most challenging cases.

Dr Gavin Winston, Honorary Associate Professor at UCL Queen Square Institute of Neurology said: "Every day we see people in our clinics whose lives are limited by seizures. These can impact on their education, employment and personal lives. And, of course, having seizures means not being able to drive which is one of the biggest impacts for people.

"Our research promises real long-term hope for people with epilepsy whose seizures do not respond to current medication. If machine learning can open the door to surgery for more people, then there is a greater chance of them enjoying a seizure free life."

Clare Pelham, Chief Executive at Epilepsy Society commented: "This is a very exciting study that demonstrates the huge potential of cutting edge technology when it is applied to very real medical issues.

"Hope can be in very short supply for people whose seizures are not controlled by today's treatment options. It is very encouraging when our scientists are able to harness the potential of 21st century technology to bring the promise of seizure freedom within the grasp of many more."

The research, published in *Epilepsia*, is led by Dr Gavin Winston, Honorary Associate Professor at UCL Queen Square Institute of Neurology and now an Associate Professor at Queen's University in Kingston, Canada. He is working with Drs Oscar Bennett and Baris Kanber and colleagues at University College London, Epilepsy Society and King's College London.

Their work was funded by the Medical Research Council, Sobell Foundation and the Engineering and Physical Science Research Council.

<https://onlinelibrary.wiley.com/doi/10.1111/epi.16380>

PHARMACIES

New electronic prescriptions

A new electronic prescription service (EPS) has been rolled out across England after a trial run in 60 GP practices and hundreds of pharmacies.

The new system means that people can get their medication in one of two ways. They can nominate a pharmacy that will receive their details direct from their GP. Or they

can get a paper prescription with a digital barcode. Paper prescriptions will remain available for those who rely on them, but most prescriptions will be processed electronically.

Repeat prescriptions can continue to be ordered in the normal way, but they will be sent direct to the pharmacy or dispenser chosen by the person.

Idris Elba is our super-hero



Image: Harald Krichel creativecommons.org

MEDICATION SHORTAGES

Where to find the latest information

Uncertainty still remains about when the UK will leave the European Union, and what sort of deal this will involve. Brexit negotiations have been extended until 31 January 2020, but the UK can leave as soon as the withdrawal agreement is completed.

There have been many concerns expressed about the impact that Brexit – particularly a no deal Brexit – could have on supplies of medications, including those for epilepsy.

In the last year we have seen an increasing number of shortages of epilepsy medications. Although we know that these pre-date Brexit, we also know that leaving the EU has added to anxieties.

Epilepsy Society has hailed actor Idris Elba a super-hero after he stopped his play, *Tree*, mid-performance to help a woman in the audience who was having a seizure. And the 46-year-old Luther star stayed with her until paramedics arrived. You can read the full story at the link below.

epilepsysociety.org.uk/idris-elba

Epilepsy Society is working closely with the Department of Health and Social Care's medicines supply team so that we can keep you up to date with news of any shortages.

You can find all the latest news at epilepsysociety.org.uk/medication-updates. You can also read about contingency plans for different epilepsy medications in case of a no-deal Brexit. And our Medical Director, Professor Ley Sander talks about how to cope if there is a shortage of your particular medication.

Watch it on video

You can find these videos at youtube.com/epilepsysociety



Richard explains why our Helpline is so important to him, and why it should be open five days a week. See page 16.



Catch up with all our videos from Epilepsy Society's Annual Conference 2019.



Our Chief Executive, Clare Pelham talks on ITV News after a young woman is mugged at a bus stop while having a seizure.



Our Chief Executive, Clare Pelham, talks on ITV News Granada about the impact of medication shortages.



Me and my epilepsy Louise Berry

Louise was written off by her school because of her epilepsy. She was told to get an office job so her seizures wouldn't scare the public. Then 'miracle baby' Millie helped turn her life around.

Miracle baby

I was about 26 when I found out that I was pregnant. It was quite a surprise as I had previously had a coil fitted and wasn't planning on starting a family. My seizures were all over the place. I have a complex epilepsy syndrome and I was having seizure after seizure – sometimes partial complex seizures, sometimes tonic clonics. Having a baby felt like something of a miracle.

The first time I saw a scan picture of my baby, Millie, she was sucking her thumb in the womb. I always thought she was reassuring herself because of all the seizures that she was going through with me.

Positive approach

My epilepsy was very unstable and I'd been through many medication changes. My Mum and Dad didn't know what to do. Nothing would bring my seizures under control. Then Mum found Professor Ley Sander up at the National Hospital for Neurology and Neurosurgery in Queen Square, London.

It was when I met Ley that I started to feel more positive about my epilepsy and seizures. He made me feel better about myself and more confident. He sent me to stay at the Chalfont Centre in Buckinghamshire for three days and I underwent lots of tests – EEG, MRI, video telemetry. I was put on a high dose of

levetiracetam which helped to control my seizures and at 38 weeks, Millie was born by caesarean section, a healthy baby girl. Ley was then able to really start looking at how best to keep my seizures under control.

Sports science

Unfortunately my local Primary Care Trust decided they would no longer pay for me to go to Queen Square so I was referred to Queen Elizabeth Hospital in Birmingham. My seizures finally settled and I decided to start studying for a degree in sports science.

When my epilepsy was first diagnosed I was 12 and at grammar school. I had a high IQ but when the school heard about my epilepsy, they asked my parents to transfer me to a comprehensive school. They said grammar school was no place for someone with epilepsy.

Low self esteem

My parents fought for me to stay at the school but to be honest I had very low self esteem and



Clockwise from far left: Louise and daughter Millie; Millie as a baby; Louise trekking 25km with gus the Gnome at Pen-y-Fan; Louise standing in front of The Red Arrows.

didn't do well. I was always having seizures and would be in trouble for missing parts of lessons. By the time I was 15 or 16, I was pretty vile. I was told I would do badly in my GCSEs and really I gave up on myself. I refused to take my medication and watched as my friends passed me by. I felt pretty worthless.

The careers adviser said I should take a job in an office. She said I would scare customers if they saw me having a seizure.

Getting a first

I did some temporary agency work and got on with my life, but really it was when I came to the Chalfont Centre and got control of my seizures that my life turned round. When I started my course at uni, I was able to access the right help. I got the disabled students' allowance, bought glasses to help with the computer and had a tint fitted to dim the screen slightly. I also had software installed so that the computer would be audio.

After three years I got a first class honours degree and won an

award for my dissertation on sports psychology and disabled sports. I did start doing a PhD but to be honest I found myself struggling with some of the learning. I had to lecture under graduates but when they asked me questions, I couldn't always find the answers, even though I knew them. My professor's wife had epilepsy so he was very understanding and would often step in and answer for me.

Great North Run

I decided to take a leave of absence and take up running. I have joined a running club and have run a couple of half marathons, including the Great North Run. In 2020 I will be running in the London Marathon for Epilepsy Society.

I still have seizures but I don't let them stop me. If I am swimming, my mum sits poolside and the lifeguard is aware of my epilepsy. When I am running, either someone from the club comes with me or Millie trails along behind on her pushbike. We've done a lot together.

Calling the Helpline

When I need to, I call Epilepsy Society's Helpline. Having epilepsy is about so much more than the seizures. It is about the side effects from the medication, the tiredness, anxiety and depression, and aphasia where I can't remember words, names or faces.

Simple things can be so frustrating like when I want my partner to turn on the fire because I'm cold and I'm looking at the fireplace but can only think of the word 'fridge' or 'oven'. I have to work my way through the alphabet, trying to find the right word.

Being able to pick up the phone and call the Helpline is such a lifeline. It is so good to know there is someone there who understands what I am going through and will just listen, even if it's just listening to me cry.

I always come away from the Helpline feeling more confident in myself and that things will be ok again.

[uk.virginmoneygiving.com/
LouiseBerry11](https://uk.virginmoneygiving.com/LouiseBerry11)

A father's grief

It is almost a year since Hamish Roberts lost his beautiful daughter, Amelia, to a fatal seizure. Here the heartbroken father talks about his journey through grief and his struggle to rebuild his family without the vivacious, funny 21-year-old

Grief is such a short word. 'Armageddon' and 'catastrophe' seem far more proportionate in the length-to-impact ratio, but I've learnt that, though short, the word, 'grief' carries a punch. A few days before Christmas, as my family gathered at home in Hertfordshire, my middle daughter Amelia was found by her sisters under water in the bath. At first we believed Amelia had drowned but she had in fact died – suddenly and shockingly – of an epileptic seizure.

Epilepsy is a condition involving irregular electrical short circuits in the brain. It isn't curable or contagious, but it can, in some cases, be controlled. Around 25 people a week die suddenly from a seizure. We had absolutely no idea that Amelia was to be one of those.

My wife Debs and I have three beautiful daughters, Lily, 24, Amelia, 21, and Kitty, 18. Or should that be "had" now there are only two? I'm not sure of anything any longer.

Before December 20th I was bobbing along quite nicely. I had a good job, a lovely home and a loving family. As the pieces of my life have begun to land over the

past few months I have struggled to cope and never cried so much, be it from exhaustion, worry, sadness, shock, the sympathy of others or that I will never see Amelia again. At times, I have felt totally out of control.

Is that how you are meant to feel? Who knows – you so rarely hear men talk about grief? I have come to realise that grief – for me at least – has four distinct stages.

Firstly, let me tell you about Amelia. She was funny, loving, stoic, beautiful and intelligent. She loved drama, choral music and lacrosse. From oysters to water skiing, she would try anything once. Her defining feature, however, was her gentleness.

A few years ago Amelia started to describe feeling "funny" now and then. We didn't think much about it until a friend took her out to eat while she was on work experience. When he asked her what she wanted, she just stared at him and mumbled.

It turned out Amelia had epilepsy. Her condition took the form of Petit Mal seizures, during which she would "zone out". Her fits didn't stop her leading

a normal life, but the drugs used to control her fits, did.

She lost her buzz, her impish humour, her motivation. She was not allowed to drive and we could sense the hurt as she watched her sisters pass their tests. Her consultants tried one drug after another, to no avail. Amelia was classed as drug resistant. She had tried 15 of the 25 known drugs.

In spite of all that, she secured a place to study at Portsmouth University. We worried about her when she got there, especially as she began to experience Grand Mal seizures. They were frightening, as Amelia would drop to the floor without notice, like a felled tree. She broke her jaw on one occasion and would often have cuts and bruises.

We all assumed she would conquer the condition either with drugs or even surgery. Then, on 20th December, Amelia suffered a terminal seizure. This is technically known as Sudden Unexpected Death in Epilepsy or SUDEP. Although we had heard about SUDEP, like most families, we brushed over the subject. How on earth do you even begin to address

the thought that your daughter could suddenly just die?

Stage One of my grief was coping with the immediate aftermath, planning how to bury Amelia and organise her funeral. Writing and delivering a eulogy that could come even close to describing my lovely girl was the most difficult thing I have ever had to do.

Talking to the coroner, talking to the vicar, I survived on vapour. I was numb and empty.

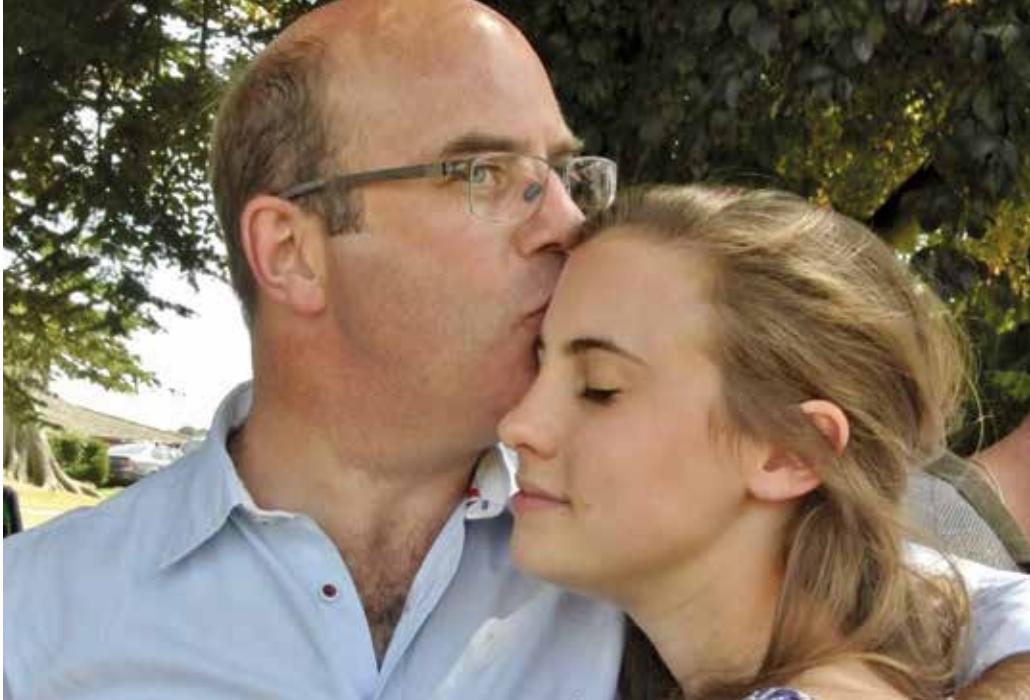
Most difficult was the outpouring of grief from others. We were inundated by people and letters. Amelia's death was shocking. She was so beautiful, she was so young and had died just before Christmas.

Responding politely and sympathetically was difficult. I was tired, worried and needed space to talk to my family. On a couple of occasions I found myself enveloped in a prolonged embrace from some well-meaning person in a way I wasn't accustomed to.

Stage Two was the nervous re-emergence into the world. Back to work. My company was extraordinary in handling this. Colleagues gave me a lot of space.

I found a grief counsellor who told me I was suffering from post-traumatic stress disorder (PTSD). I felt light-headed, a combination of a severe hangover and jet lag. My chest hurt, to the point I felt I was having a heart attack. I had terrible shakes, headaches, heart palpitations and night sweats.

I took a month off work. Stage Three. Switched off. Ignored everyone. Exercised. Stopped drinking. Drank vegetable and fruit juice and did a lot of thinking. This may sound selfish, but I was useless to all those who depended on me. As they say during the safety announcement on the plane, "Put on your own oxygen mask before trying to help others". I have spent a lot of time recently thinking about my life and what Amelia's death means and will mean to me. It has been both therapeutic and terribly sad.



I am so pleased I had the courage to do this.

I have tried to sell myself another version of Amelia's death: it could have been worse, she could have suffered for many years or actually drowned. A perfectly rational thought process I suppose, in an attempt

Delivering a eulogy that could come even close to describing my lovely girl was the most difficult thing I have ever had to do

to placate, but the simple truth is that I lost my beautiful daughter. An utter tragedy.

Amelia sought comfort and advice from the Epilepsy Society. Unbeknown to us, she left them her brain for research. Such a mature gesture for a 21-year-old. The Epilepsy Society has an amazing genomics project that helps them deliver the correct combination of drugs by looking at a patient's eyes, brain activity, facial muscles and sequencing the individual DNA. This project costs more than £10 million and most of their funds come from fundraising. We have raised nearly £80,000 in

Amelia's name. If she had gone through their programme, she might still be here.

I tell myself I am still blessed in many ways. I am so fortunate to have Debs, Lily and Kitty, and to have loved, and been loved by Amelia, for 21 years. Stage Four is rebuilding my family without her, and I am beginning to look forward to a future where we are calm and can have fun without guilt. Love and trust will be the foundation stones of my family: two short words that also have a disproportionate score on the letter-count-to-impact ratio.

Fundraising Supporter Group

Amelia's family are Epilepsy Society's first Fundraising Supporter Group. This enables friends and families to raise funds in memory of a loved one, in honour of someone living with epilepsy, or simply to support our cause. Benefits include: a bespoke logo; a page on our website; support from our team; and a chance to restrict funds to an area that inspires them.

To set up a supporter group, go to epilepsysociety.org.uk/groups or call 01494 601313

This article first appeared in *The Telegraph*. Turn the page to read about Epilepsy Society's research into Sudden Unexpected Death in Epilepsy.

How brain tissue is helping us to understand SUDEP

Examining brain tissue is one of the most important ways to help us investigate the mechanisms responsible for Sudden Unexpected Death in Epilepsy (SUDEP). Which is why we are so grateful to all those who, like Amelia Roberts (see previous page) consent to donate their brains, at the end of their lives, to our Epilepsy Society Brain and Tissue Bank.

Understanding SUDEP

By studying brain tissue samples we have been able to establish a potential link between SUDEP and a depression of the central respiratory system following a seizure, and a link between serotonin pathways and the risk of SUDEP. Serotonin transmits messages between nerve cells and is also thought to play a role in functions such as heart and respiratory rates.

Brain inflammation and SUDEP

We have also studied neuroinflammation in SUDEP. Brain inflammation is thought to be significant in the excitability of neurones and the progress of epilepsy in the brain. In a pilot study of 55 samples, we were able to see a significant increase in neuroinflammation in cases involving SUDEP, compared to those with epilepsy but without SUDEP and to disease-free controls.

Sequencing brain tissue

Our brain tissue samples are preserved in one of two ways. They are either fixed in formalin or they are frozen.

Brain tissue samples donated to us following a person's death, are most commonly fixed. While these are suitable for studying the microanatomy of cells and tissues, it is not so easy to sequence their DNA or RNA (the part of a cell that converts genetic information of DNA into proteins).

New technologies are now available that will allow us to analyse the DNA and RNA of fixed tissue samples, offering the potential to enrich our knowledge of the process by which epilepsy develops within the brain.

One of these platforms is called 'Nanostring' and is available through our academic partners, UCL. Now we want to extract DNA and RNA from fixed tissue samples and see if their quality

will allow us to use Nanostring technology to analyse information about gene expression.

Donating her brain for research was an amazing thing for Amelia to do. We are very grateful for the knowledge that this is helping us to accrue and the lives that might ultimately be saved by her selfless donation. Amelia's family should feel very proud.

Clare Pelham,
Chief Executive, Epilepsy Society

Find out more about donating your brain for research at the end of your life, at: epilepsysociety.org.uk/how-become-donor



Annual Conference



Epilepsy Society's Annual Conference is always a highlight of our calendar year. Every day we engage with a community of some 100,000 supporters across our many digital platforms but there is nothing quite like being in a room and having a chat with people – real time – over a cup of coffee.

Our annual conference provides a chance to catch up with old friends as well as making new ones. And this year was no exception.

The theme was "Empowering You." Sometimes seizures and the impact of epilepsy, can leave you feeling a little out of control. So we wanted to help you gain back that control, wherever possible.

We know from calls to our Helpline and online enquiries just how worried people with epilepsy are about the current medication shortages and problems with applying for benefits. And we know how many people with epilepsy also have to cope with anxiety and depression.

So we invited experts from all three fields to tackle these

subjects and help you cope through information, understanding and shared experiences. You can read excerpts from the speakers' presentations over the page.

We also invited a representative from Transport for London (TfL) to talk about the work they are doing across London's networks to improve accessibility for people with hidden disabilities. You can read how TfL is working with Epilepsy Society to ensure that anyone who has a seizure on the tube, receives correct treatment.

Artist Amanda Smith joined us to discuss how art helps her cope with the anxiety and depression she often experiences as part of her epilepsy. We were treated to a wonderful display of Amanda's

multi-coloured abstract art, hopefully inspiring others to pick up a paintbrush or find a hobby that could help to express their emotions and increase well being.

We were also thrilled to be joined by Epilepsy Society's two professors, Ley Sander and Sanjay Sisodiya, who updated us on the latest developments in epilepsy research, where the future lies and the progress that we are making in genomics.

We have had some excellent feedback from the conference and if you weren't able to join us, you can catch up with our videos at epilepsysociety.org.uk/annual-conference-2019

Watch this space for next year's conference and make sure you join us. We'd love to see you there.



Genetics research update

"We are carrying out research for the simple reason that there are still people living with uncontrolled seizures.

Genetics is helping us to understand epilepsy at a much deeper level. And in some cases it is helping to guide precision medicines tailored to the individual.

We have been working with our partners at Genomics England to sequence DNA samples from 1,100 people with epilepsy. So far we have the results back from 10 per cent of those samples, and for 1 in 3 people we have established a genetic diagnosis where there had not been one before.

Our aim is to bring genetics into clinical use as we did with MRI so that it is available to more people across the country. We are already pioneering this with our own epilepsy genetics clinic. But we can only see eight people per month at the moment. We are making good progress, but we're not there yet."

Professor Sanjay Sisodiya,
Director of Genomics,
Epilepsy Society



Anxiety and depression

"People with epilepsy have a 1 in 3 chance of developing anxiety or depression in their lifetime. This compares with 1 in 6 in the general population. And 1 in 2 people will not be treated for their anxiety or depression.

"There are many reasons for anxiety, including seizures themselves. Seizures are unpredictable – you don't know where or when they might happen – and this can be very stressful.

"NICE recommends counselling and cognitive behaviour therapy

"People with epilepsy have a 1 in 3 chance of developing anxiety or depression."

(CBT) as treatments for both anxiety and depression. While counselling is a listening space, CBT is a more structured programme that challenges negative thought patterns.

"These are both talking therapies and referral on the NHS can be through a GP or you can self-refer. Search online for 'Psychological Therapies (IAPT)."

Dr Pam Thompson, Consultant Clinical Neuropsychologist
Epilepsy Society



Medication shortages

"The medicines supply chain is a very complex, fragile system and shortages can occur for many reasons such as problems with accessing raw ingredients or a fire in one of the factories. Pharmaceutical companies have been asked to ensure they have an extra six weeks' supply of medications in preparation for a no-deal Brexit. And this extra buffer will stay in place as long as it is needed.



There are some simple things which people can do to help themselves if there are medication shortages:

- Take your prescription to your local pharmacy in good time
- Don't stockpile your own medication at home
- Ask for a separate prescription for your epilepsy medication so that if you have problems at your local pharmacy, you can take it to another pharmacy

Sandra Gidley, President of the Royal Pharmaceutical Society



Living with epilepsy

"Back in 2004 I went to San Francisco. It was a great trip

but I then went on to Las Vegas and basically I don't remember anything. On one night I fell down 51 marble steps and lost half of my head. The funny side is that every time I go through an airport, absolutely everything goes off. The bad side is that I have aphasia alongside seizures."

Tom Ryan-Elliott,
Epilepsy Society
Ambassador



Discoveries

"Our gut microbiota (microbe population living in our gut) contains tens of trillions of organisms and seems to play a central role in our health. There is preliminary evidence coming about gut microbiota and epilepsy."

Professor Ley Sander,
Medical Director at Epilepsy Society



The benefits system

"From the cradle to the grave, at some point in our lives, all of us will come into contact with the benefits system. One of the most important things to understand is where having a health condition like epilepsy leads to certain aspects of the benefit system that are relevant to you – things you can access and get help from.

"If you are financially struggling and there is help available, the most empowering thing is to access that help and to understand it."

Alban Hawksworth,
benefits expert



Going underground



Lauren Preteceille, Head of Stakeholder Engagement and Advocacy at Transport for London talked about their work with Epilepsy Society.

- TfL has shared our Calm, Cushion, Call campaign to ensure that staff know what to do if someone has a seizure on a train
- Our Medical Director Professor Ley Sander has worked with TfL to check that new blue, under-platform lighting does not pose a risk for anyone with photosensitive epilepsy
- TfL featured Epilepsy Society's ambassador Tom Ryan-Elliott as their poster boy for their 'Please offer me a seat' campaign
- Epilepsy Society spent a day on the London Underground updating staff on seizure first aid.



Painting epilepsy

"Through art therapy I am trying to find out who my true self is. Who is that person from who I was before my epilepsy. It is a real journey of discovery on the canvas. I don't see myself as an acclaimed artist. To me it's just paint on a canvas."

Amanda Smith, artist

**You can enjoy
videos of many
of the conference
presentations at:**

**[epilepsysociety.org.uk/
annual-conference-2019](http://epilepsysociety.org.uk/annual-conference-2019)**

Flying doctors?

Not such a good idea, say neurologists who fear carbon emissions from air travel to conferences are having an ill effect on the health of the people they care for.

Nicola Swanborough explains

In July next year, our neurologist, Dr Simona Balestrini will travel to Geneva for the European Epilepsy Congress. There is nothing unusual in this. The epilepsy congress is an important date in the calendar when experts in the field of epilepsy share their latest research. The difference is that this year, rather than flying to Geneva, Simona and other young neurologists from across Europe, will be arriving by bike.

Simona is one of a growing number of neurologists who are concerned about the impact that climate change is having on

healthcare, and particularly on those with epilepsy. Flying is a significant contributor to carbon emissions – a key factor in global warming.

"As neurologists we often have to fly around the world to present our research, network and form collaborations for genomic research," says Simona. "But I think the time has come to look at other ways to travel and meet up."

The original plan had been for the neurologists to cycle the full 600 miles from London to Geneva, but time constraints have forced them to make their plans more realistic. Instead the neurologists



from the UK and across Europe, will now travel to Bern in Switzerland by train and then cycle the final 100 miles to Geneva.

"This is undoubtedly a big commitment, but it is a chance to show there is another way to exchange information, ideas and scientific knowledge," says Simona.

"As doctors we must take a lead in ensuring that our work practices and lifestyles do not have a detrimental effect on our patients."

Simona is the Muir Maxwell Research Fellow at Epilepsy Society. She is reminded on a daily basis of the injustice that the impact of climate change is likely to have on people with epilepsy. "Every day in clinic I see people with epilepsy who cannot drive because their seizures are uncontrolled. For many this means that employment opportunities are limited, and holidays abroad are seldom an option.

Consequently, people with uncontrolled seizures are likely to be among those with the lowest carbon footprint and yet, on a global scale, they are likely to be most affected by climate change."

According to the Joseph Rowntree Foundation, 10 per cent of the wealthiest households in Great Britain generate three times as much carbon emissions as the poorest 10 per cent. Doctors are likely to be in the wealthiest group, while many people with epilepsy are in the poorest group. It's a disparity that does not sit comfortably with many doctors.

Three of the world's leading epileptologists are challenging medical professionals – and themselves – to fly less for international conferences in order to

"We can't undo the damage we've already done, but we can wake up to just how fragile the planet is." **Sanjay Sisodiya**

reduce the impact of global warming.

The neurologists, including Professor Sanjay Sisodiya, Director of Genomics at Epilepsy Society, have formed a consortium called 'Epilepsy Climate Change' to tackle some of the effects of this.

In an article in the journal *Epilepsia Open*, 'Climate change and epilepsy: time to take action', members of the group spell out key alarm bells:

- Climate change is already affecting healthcare, and could overwhelm healthcare systems
- Warming and humidity changes will affect human disease risks
- Many of the accompanying environmental, infrastructural and socioeconomic changes will adversely impact the epilepsies.

Sanjay explains: "There are 50 million people living with epilepsy worldwide and 80 per cent of them live in low- and middle-income countries. It is these populations that are likely to be disproportionately affected by climate change.

"Diseases spread by vectors like mosquitoes can cause epilepsy or seizures in the acute stage. If climate change leads to the spread of these vectors, then the risk of infection-related epilepsy will increase. We have recently seen how the outbreak of diseases such as Ebola and Zika viruses can overwhelm a healthcare system."

And it is a problem that could easily hit closer to home. Studies suggest that just a 1°C increase in temperatures could result in some vector-borne diseases associated with epilepsy being transmitted in the South East of England by 2070-2100.

By 2030, the southern half of Great Britain could be climatically

suitable for mosquitoes that transmit malaria associated with epilepsy and seizures.

Temperature changes are known to affect genes and proteins. Anecdotal evidence from the patient support group, Dravet Syndrome UK, has shown that the unusually high temperatures of summer 2018 resulted in more seizures in children with this rare condition, caused by a mutation in the SCN1A gene.

Although evidence is still scarce, there are concerns that a rise in temperatures could put some anti-epileptic medications at risk of degradation. Medicine supply chains may be compromised and loss of biodiversity such as plant, microbial and fungal species, may threaten potential sources for new epilepsy drugs.

Climate-driven food and water stress may lead to worldwide conflicts, resulting in increased head injuries and epilepsy.

Sanjay admits that the picture looks bleak, but he is adamant there is hope.

"We can't undo the damage that we have already done," he says. "But we can put the brakes on and wake up to just how fragile our planet is. It's about education, realisation and acceptance of the role we all play – and the better role we could play."

Sanjay has already committed to walking or running rather than using his car wherever possible. He keeps his office at an ambient temperature; turns off his computer at the end of the day; and he is determined to find new ways to work with colleagues across the world.

"Teleconferencing still falls short of the personal touch but we must apply our brains to finding solutions that will advance science but not cost the earth," he says.

Meantime Simona is busy training for her longest ever journey to an epilepsy congress. Following a 10-hour journey to Bern, she estimates the bike ride to Geneva will take her and her colleagues three days.

Flying is a significant contributor to carbon emissions – a key factor in global warming

Help us open our Helpline 5 days a week

We need to extend our Helpline opening times from three to five days a week, giving more people more time to talk. But it costs money. This year, thanks to a generous donor, every gift donated to, or raised for, our Helpline Appeal before 31 December 2019, will be matched, pound for pound. **Andrée Mayne** explains why this is so important

Thursdays and Fridays are the most worrying days of the week for us at Epilepsy Society. Our Helpline isn't open but we know people will be ringing us and not getting the help they need.

For the last three years, frustratingly, we have only been able to open our Helpline three days a week, from Monday to Wednesday. But we are keen to restore the Helpline to a full service so that we can be here for you five days a week.

Epilepsy Society's Helpline is already in huge demand. We are answering around 3,000 calls every year and respond to around 2,700 emails. However, if we can open five days a week, we could answer an estimated 2,000 additional calls every year from people who urgently need our support.

Epilepsy has no respect for time or occasion. Seizures happen out of the blue, with rarely any warning. We know that if you need

emotional support on a Thursday or Friday, having to wait until Monday to talk to someone who understands, is just not good enough.

If you are looking for information, perhaps about benefits or medication, waiting four days to call us, can result in increased anxiety.

“We’re answering around 3,000 calls every year and respond to around 2,700 emails.”

So, we have launched our Helpline Appeal with the sole aim of making sure that there is someone there for you to talk to five days a week.

With your help, we have already raised half the money needed to enable us to operate a five-day service next year. But now, we need to raise another £125,000.

The great news is that a fantastically generous donor has agreed to match, pound for pound, the first £62,500 we raise before 31 December 2019.

So, for example, if you were able to give £20 today, it would unlock another £20 from our donor. With Gift Aid added, you would be contributing an amazing £50 towards the £62,500 we need to raise by the end of the year.

This incredible match funding opportunity means that if you were to hold, for example, a cake sale, raffle or sponsored carol sing-along before 31 December, all the money you raise for our Helpline appeal would be more than doubled.

Susan's story, opposite, really shows the value of our Helpline. The thing that Susan needed more than anything else, was to be able to talk and to be listened to. She needed to share her fears and find her own way forward.

I don't know how Susan would have coped if we hadn't been there

to pick up her call that day. Especially since, to my knowledge, there is no other helpline service quite like ours.

People with epilepsy, their families and friends are free to talk to us about any epilepsy-related issue, and they can stay on the phone for as long as they need to. Our aim is to listen and provide support for people to help them to see a way through their current difficulties – just like Susan did.

This is what our Helpline is all about and why it is vital that it is open five days a week.

We will be very grateful for any gift you are able to share with us, no matter how small. Your donation could mean that someone affected by epilepsy will be able to call our Helpline when they need us. They won't have to hold on to their worries and anxieties.

From the bottom of my heart, as manager of the Helpline, thank you.

How we can double your money...

£20
from you



£20
from our donor



£10
gift aid



£50
donation!



Susan's story

From the moment we answered Susan's call her voice was shaking. She was clearly very close to tears. Susan explained that her daughter had been having seizures for much of her life but now that she was a student, living away from home, her epilepsy was out of control. Susan had just learned that her daughter was having several seizures a day and had recently been hospitalised.

When our helpline operator mentioned to Susan that she sounded terrified, the floodgates opened. She began crying uncontrollably, saying: "I am absolutely terrified of losing my daughter and I don't know what to do." Susan had always protected her child, just as any mother would. But now that she was an adult, Susan wondered if her daughter was now protecting her. Did she know something about her epilepsy that she wasn't sharing with Susan? Might the next seizure be her last?

Susan's call lasted nearly an hour and our helpline operator listened quietly to her concerns and gently questioned Susan to help her find a way forward. By the time she was ready to put down the phone, Susan was much calmer, and she had resolved to have a heart-to-heart with her daughter. Whatever the future might hold, she wanted them to face it together.

“Thank you so much for listening. I have never felt able to share my fears with anyone before, it means so much. I think I can deal with this now.”

Susan's name has been changed to protect her identity.



Brief encounter

A new exhibition takes an intimate look at what it's like to have epilepsy, through personal testimonies carefully stitched onto Victorian underwear. **Nicola Swanborough** explains

Victorian underwear may seem an unlikely canvas to choose for illustrating the lived experiences of people with epilepsy.

But artist, Susan Aldworth, wanted her latest project *Out of the Blue* to convey the 'hidden' side of epilepsy, a condition which is often under-represented in the media and poorly understood by those with no experience of it.

"I wanted to find a way to portray this condition which is so intimately stitched into the lives of those who have it, and yet so

hidden from the public eye," explains Susan.

"I imagined an installation in which testimonies of people with epilepsy were embroidered into antique undergarments – chemises, nightdresses, bloomers. Garments which, like epilepsy, were concealed beneath the surface."

Susan's vision is now a reality. She has created an installation made up of 106 antique garments embroidered with people's epilepsy – in their own words.

Susan worked closely with Epilepsy Society to build a

collection of powerful, moving and poignant testimonies from people living with the condition. Following a call out on social media, the artist was inundated with people's stories describing, often with frightening honesty, the way they feel before and after a seizure and what epilepsy means to them.

"The worst part is that no one else notices. It feels like I'm going to explode but no one else sees a thing... I'm just stuck, I'm still conscious. I can see, feel, and think. But I can't do anything. I'm

trapped in a body that won't listen to me." Willow

"After a seizure my head feels like it has been smashed against a brick wall and my whole body aches. My epilepsy nurse once told me she had a patient who was hit by a bus and they said that was less painful than a seizure." Sophie

"As an artist I really wanted to explore how it makes people feel to have epilepsy and what it is like to live with it," continues Susan. "I wanted to give people with epilepsy a voice and bring the condition out into the open."

"When we ask the question 'what is epilepsy?', there can be many answers. For the scientists and doctors seeking an effective treatment, it's a neurological conundrum that might have a solution.

"For most of us, by contrast, it's just a word. Although it affects one in a hundred people, it gets few headlines and we know little or nothing about it. In many ways it's a hidden condition.

"But for those who have epilepsy, it is something else. It is a lived and living experience. For them, the question is more personal: what is it like to live with epilepsy? Only they can answer it."

Almost 100 people responded to Susan's request for personal

testimonies, describing the reality of how they – and their families – are affected by the condition.

"I was really blown away by their responses," says Susan. "They described their lived experience of epilepsy with amazing candour and detail. Their testimonies are incredibly emotional and real."

106 antique garments embroidered with people's epilepsy, in their own words.

Out of the Blue was commissioned by the Institute of Neuroscience at Newcastle University and is funded by the Wellcome Trust. Scientists at the institute are developing experimental treatments for epilepsy that use optogenetics, a biological technique that controls the activity of neurons in the brain, using light and genetic engineering.

While Susan's work explores the human side of epilepsy, the science is also reflected in her work through the light-sensitive thread used to sew the testimonies.

Each of the garments is stitched in ultraviolet yellow, light blue and black. These are then suspended from the ceiling on

pulleys programmed by computers to correspond to the algorithms of electrical activity in an epileptic brain. And the fluorescent embroidery is lit by both natural and ultraviolet light to reflect the scientists' light-sensitive gene therapies.

All the Victorian garments have been embroidered with an edited, individual testimony on the front and a single word on the back. The Royal School of Needlework set *Out of the Blue* as a first-year BA embroidery project with 35 of its staff and students taking part. Other embroiderers joined the project resulting in 106 volunteers slowly and painstakingly committing the words to the historic canvases.

"It feels a privilege to represent the stories of people with epilepsy in this way," says Susan. "I hope that it will help to spread greater awareness and understanding of the condition."

***Out of the Blue* is at Hatton Gallery Institute of Neuroscience, Newcastle and runs from 18 January – 9 May 2020. A limited edition book is available by contacting saldworth.t21@btinternet.com**



Photo: Ana Arca 2018

Fundraising in my DNA

Kat Smith, 34, tells *Epilepsy Review* why she abseiled 540 feet down Broadgate Tower in London for Epilepsy Society

I'm grateful that I've been seizure-free for over a year, but my journey with epilepsy hasn't been easy. If I had not sought help and been given the right medication, I fear I could've died from having an epileptic seizure. The risk of SUDEP – Sudden Unexpected Death in Epilepsy – is always a worry for me.

Nobody in my family has epilepsy. When I started to have seizures, I did not know that I'd had a seizure. I'd wake up on the floor with blood in my mouth and I'd have hit my head. I wondered what had happened.

I began to see a neurologist at the Royal Derby Hospital who confirmed that I have generalised epilepsy and experience tonic-clonic seizures.

I have collapsed on hen do's, convulsing and cutting my head open.

I've also had myoclonic seizures. These gave me a warning sign that I was going to have a full seizure, giving me around half-an-hour to get to somewhere safe.

Since my diagnosis in 2010, I have found that triggers for me can be drinking excess alcohol, stress and tiredness.

When I was diagnosed, I was living with a partner and epilepsy completely ruined my life. My relationship broke down, I had to leave my job and I couldn't drive for a year. It was really horrible. I was living in Lancashire at the time and moved back in with my parents in Nottinghamshire.

Initially, I was on medication which 'knocked me out' and then I was switched to a tablet that stabilised my epilepsy. It's one I will stay on for life.

I am now a mum to two-year-old Jack, and I work in marketing for a mental health company in Derby.

I know that I'm one of the lucky ones, I can live normally. I know others who can't, some who need surgery to control their epilepsy, others who literally can't go out at night because of bright and flashing lights.

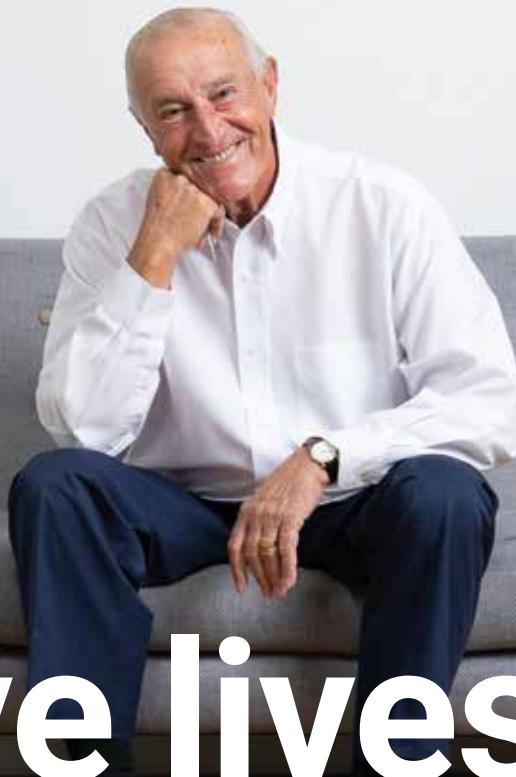
That's why I decided to abseil down Broadgate Tower in London, raising nearly £600 to help support the research that goes into finding new ways to control this horrendous brain disorder, and



help those whose lives have been drastically changed. The more research into possible cures and medication, the safer the condition becomes.

I also wanted to support the charity's important services such as their information and Helpline. I wanted to raise awareness of Sudden Unexpected Death in Epilepsy and make sure people understand the risks.

www.justgiving.com/fundraising/kat-smith9



Love lives on

Epilepsy Society was part of this year's Remember a Charity campaign, encouraging people to leave a gift to charities in their Will. Claire Glazebrook talks about the campaign and why it's not too late to get involved.

What has former Strictly head judge, Len Goodman got to do with epilepsy?

The eagle-eyed among you may have noticed him earlier this year, backing the nationwide campaign, 'Remember a Charity Week', which encouraged people to leave a gift in their wills to charity.

Epilepsy Society was part of that important campaign with our own 'Love lives on' call out to encourage people to remember us with a gift.

More than one third of our voluntary income comes from the gifts our supporters leave in their Will and we could not be more grateful for this. Money from legacies has helped to fund our Helpline, our campaign work to raise awareness of epilepsy and our research into epilepsy.

The UK is renowned as a charitable nation and yet,

according to Remember a Charity, only six in 100 people leave a gift in their Will to charity.

Since becoming an ambassador for the Remember a Charity Week, Len Goodman has updated his Will to include a gift to charity – of course after his own family has been taken care of.

Now he is hoping others will follow in his footsteps and make sure that their money will continue to support causes close to their hearts, after they have gone.

Our 'Love lives on' campaign generated a lot of interest and support. People called to confirm they were planning to remember the Epilepsy Society in their Will, and others ordered our legacy pack.

We have had some wonderful conversations with people who were delighted to know that they could be such an important part of our research and could help to have a positive impact on the

way that epilepsy is treated for generations in the future.

The thing that has impressed people most is how, by leaving just one per cent of their 'estate', they can help Epilepsy Society do amazing things to support people with epilepsy through research, education, training, individual care and the support of our Helpline.

We have lots of information and guidance at epilepsysociety.org.uk/gifts-wills

If you have a family member with epilepsy, you can also find out how you can protect their future through a discretionary trust. Thank you for thinking of us.

We always recommend you seek the guidance of a solicitor or legal adviser when making your Will, to ensure your intentions can be fully carried out. Contact us at fundraising@epilepsysociety.org.uk or call 01494 601414.



Tonic comic

Stand-up comic and all-round funny girl Juliet Stephens has the last laugh when it comes to her epilepsy

What is your relationship like with your epilepsy? I've been considering lately how I feel about epilepsy now, and how that relationship has evolved in the 28 years since I was diagnosed.

I have been reflecting on how my life journey has been shaped by it, from being at school, then university and then through my twenties, thirties and now forties; I have lived with epilepsy for twice as long as I did not.

I didn't meet epilepsy until I was 14, and since then it has been a part of my life; sometimes a frequent visitor, though latterly an absent friend (and yes, I say friend!). It has been five years since my last seizure and though epilepsy is still a fundamental part of my story, it's like the friend who went to live in New Zealand. I still talk about them and tell new friends about our times together in my younger years, but I don't expect to see them again. Of course I may be wrong, but I live my life now as if the friend booked a one-way ticket on Air Keppra and is now a memory.

We humans are creative, inventive creatures, and we express our relationships to our health and bodies in different ways. Many people personify their health condition, giving it a name and even perhaps a personality. I wonder if any readers personify their epilepsy in a similar way: Stacey Seizure, Arthur Absence or Myoclonic Martha?

I sometimes find it a bit strange talking to new friends about having

a 'history' of epilepsy (because it does not feel current) when in truth, it is a history which has shaped me to my present day self. My relationship with the world is affected by my relationship with epilepsy – it shaped the choices I made, and also those that I did not.

There are jobs I did not take because I could not drive, spontaneous trips I did not make because I did not have enough medication on me, relationships I ended because my ex was

“ Epilepsy has shaped me in wonderful ways... my relationships with friends are deeper”

spooked by my epilepsy. In my social life, while some friends of mine were riding the wave of rave culture (including taking recreational drugs) I did not partake, so perhaps some friendships drifted, or did not solidify, because we did not have shared experiences. In this regard, I view my epilepsy as a restriction, a corset, a curfew. It became a 'parent' role in limiting things that I chose to do – things which could have had a positive or a negative outcome.

I must say that epilepsy has also shaped me in wonderful ways. My politics are shaped by having

had so much contact and support from the NHS over the years. My relationships with friends and family are deeper because I have had to lean on them for support and care, and I know that the people in my life love me because they have worried about me, visited me in hospital, cared for me after a seizure.

I also believe that having epilepsy has given me a positive outlook in life. I have regularly experienced the goodness in people who have helped and supported me – ambulance drivers, A&E staff, medical professionals, helpline workers, concerned passers-by. I am grateful to them all, and I think I have internalised that kindness and I try to pay it forward. I also think that having epilepsy has given me a kind of fearlessness, which has strengthened me to make bolder decisions in life and from this perspective, epilepsy feels to have been my guide and my cheerleader.

Today I am reflecting on three 'Good Things' about living with epilepsy. I'm grateful for my epilepsy 'parent' now, as whilst I still definitely had fun and enjoyed my student years and my twenties, it preserved me from recklessness that could have been harmful. I'm also grateful to my 'guide/cheerleader' epilepsy for having defined my values and my life goals. Lastly, I am grateful for all the people epilepsy has brought me into contact with: everyone I have spoken to and also who have read my words in this column and maybe connected to them. I wish you all well.

Juliet Stephens
Laughing allowed

Society matters



Rachel's run for research

Our Director of Medical and People Services, Rachel Perowne had two good reasons to take part in the Great North Run in September.

Rachel was joining her parents, Jeff and Susan Street, who were taking part in the iconic Newcastle run for the 15th time, to celebrate their 70th birthdays. And with husband, Roger, Rachel was also raising money to support our genomic research.

Twenty runners took part in the race for Epilepsy Society, including our Social Media Officer, Paige Dawkins. Thank you to everyone for your amazing support.



Dignity goes global

Staff and people living at Epilepsy Society celebrated Global Dignity Day in October with an event focusing on 'My Life, My Way'. Person centred care is a number one priority at the charity and the aim of the day was to promote self-worth, self-respect and empowerment through music, song and a good deal of cake.



Royal occasion

Raising awareness of hidden disabilities such as epilepsy, was top of our agenda when we joined the National Association of Local Councils to celebrate 125 years of local councils. Guest of honour was the Princess Royal who spoke about the importance of local government. On hand to meet the royal visitor was our Head of External Affairs, Stephen Canning and our Public Affairs Manager, Katie Frank.



Taking fundraising to new heights

Many thanks to all the amazing dare devils who abseiled 540ft down Broadgate Tower, one of London's tallest buildings. This was the second year that we have held the event, and our brilliant team raised more than £25,000 for us.

A huge thanks too, to everyone who took part in RideLondon 2019, cycling 100 miles in under nine

hours and raising more than £18,000 to support people with epilepsy.

If you would like to challenge yourself by running, walking, cycling, swimming or trekking to raise money for Epilepsy Society, have a look at all our fantastic opportunities at epilepsysociety.org.uk/fundraise-events. There is something for everyone and our fundraising team will give you our full support.

A sad farewell to Nik Powell

It is with great sadness that we bring you news of the death of one of our vice presidents, Nik Powell. Nik has died at the age of 69. He was director of the National Film and Television School and a long-term friend and supporter of the charity. Epilepsy was a cause close to Nik's heart as he lived with the condition from the age of eight until his forties. In 2008 he ran the London Marathon for us, raising more than £25,000. Our thoughts are with his friends and family. He will be much missed.





Helpline

01494 601 400

Monday and Tuesday 9am to 4pm,
Wednesday 9am to 7.30pm.
Confidential, national call rate.
Information and emotional support.

Epilepsy Society

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

epilepsysociety.org.uk



"Epilepsy can frighten the daylights out of me"



Our Helpline is a lifeline for Richard when he needs to talk. We want to make sure the Helpline is open five days a week for Richard and others like him.

Please help us raise £125,000 to extend the service. Every gift donated, no matter how small, will be doubled by a generous donor.

Donation Matchfund Gift Aid

£20 + £20 + £10 = £50

Please donate at:
epilepsysociety.org.uk/helplineappeal