

# Epilepsy Review

## Genomics – how big data is unlocking our DNA

PAGE 18

How to manage if  
there are medicine  
shortages

PAGE 8

Calm, cushion, call  
– we launch our new  
seizure first aid  
campaign

PAGE 16



Anti-epileptic medication is the mainstay treatment for most people with epilepsy. For two thirds of people it is a passport to enjoying a seizure free life. For a third it might mean a reduced number or severity of seizures. So we have been alarmed by the increased calls to our helpline and online enquiries from those unable to get their prescribed medication.



We called a meeting with the Department of Health and Social Services' Medicines Supply Team. We wrote to Health Secretary Matt Hancock. And we contacted many of the manufacturers of epilepsy drugs.

As with so many current problems, the difficulty was trying to unpick the role that Brexit was playing in exacerbating the situation and unearthing the true underlying causes for the increased number of drug shortages. We explained at every level the anxiety that drug shortages were causing and how this was putting people at an increased risk of seizures.

You can read on page 4 the response we received from Health Minister Stephen Hammond. And on page 8 you will find an important article from our Medical Director Professor Ley Sander on how to manage if there is a shortage of your medication.

You may have seen and heard our Chief Executive Clare Pelham talking on the radio, and in the media about the importance of ensuring a consistent supply of epilepsy medication for the people we support. We now wait to hear from Matt Hancock as to whether he will commission a review into the medicines supply chain that could pinpoint and address problems that occur in the complex world of manufacture and distribution. Problems which have been

an issue since long before the word 'Brexit' crept into our vocabulary.

Alongside tackling medicines shortages, we have also been working to safeguard people with photosensitive epilepsy from online flashing lights and imagery that could trigger a seizure.

Social media can be a lifeline for many people with epilepsy, providing 24-hour peer support and camaraderie. But videos with potentially seizure-inducing imagery can put users at risk. And malicious posts specifically targeted at people with epilepsy add a whole further layer of anxiety.

We have asked the Government to include safeguarding for people who are photosensitive in its online harms paper and we are asking the social media giants to step up to the plate and take responsibility. Again, Clare Pelham talked across BBC channels, raising awareness of the issue.

Now, as *Epilepsy Review* lands on your doorstep, we launch our third campaign, this time around seizure first aid. You can read about our new messaging 'Calm, Cushion, Call' on page 16 and we hope that you will join us in sharing the message and increasing epilepsy awareness.

Nicola Swanborough  
Editor

#### Front cover

Genomics and how big data is helping us to unlock the secrets of our DNA, leading to better diagnosis and treatment of epilepsy. See page 18.

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## PHOTOSENSITIVE EPILEPSY

# Charity calls on Gov to safeguard people online



**E**pilepsy Society is calling on the Government to safeguard people with photosensitive epilepsy online by regulating flashing images that could induce a seizure.

Around 20,000 people in the UK have photosensitive epilepsy where seizures are triggered by flashing lights or contrasting, quick-fire imagery.

Epilepsy Society is seeing an increasing number of complaints from people with photosensitive epilepsy who feel online content with flashing images leaves them vulnerable to seizures due to lack of warnings.

Alongside this, malicious content is being 'tagged' with keywords around epilepsy to deliberately target those with the condition and induce a seizure.

Now the Epilepsy Society is asking the Government to include regulatory measures in its Online Harms White Paper that will help protect people who are photosensitive from potentially harmful content.

Chief Executive Clare Pelham said: "Many people share videos with potentially dangerous content without realising the danger that it could pose to someone who is photosensitive."

Photosensitive epilepsy is most common in children and young

people. And research shows that children spend two hours a day watching the television and over two hours a day online.

"Traditional television content is well regulated by Ofcom with warnings being given both audibly and visually before any flashing images are shown. Unfortunately the same rules do not apply online and we think that they should," said Clare Pelham.

The charity has written to Jeremy Wright, Secretary of State for Digital, Culture, Media and Sport asking for his reassurance.

Clare Pelham wrote: "We would be grateful if you would kindly make it clear publicly that the deliberate inclusion of flashing images that might trigger a seizure will be explicitly included in the online harms that future legislative and regulatory measures will address. This would be very reassuring to people with epilepsy."

Sophie Harries, 22, was diagnosed with photosensitive epilepsy at the age of 15. She explains how it affects her life.

"When I was first diagnosed with photosensitive epilepsy, social media wasn't as big as it is now, so it wasn't such a problem for me. Now I have to be careful of any videos uploaded to social media that contain strobe lighting or flashing imagery."

## MEDICATION

# New guidance on sodium valproate

New guidance to support regulations around the use of valproate in women and girls of child bearing age with epilepsy has been published by specialists from the Royal Medical Colleges.

In March 2018, the Medicines and Healthcare products Regulatory Agency published guidelines which meant that valproate should no longer be prescribed for girls and women of childbearing age. A year on, implementation of the guidelines has thrown up challenges in relation to some complex issues.

Clare Pelham, Chief Executive at Epilepsy Society, said: "I hope this guidance will help to answer some of the women's and healthcare professional's questions."

The new guidance has been drawn up by Judy Shakespeare of the Royal College of General Practitioners and Sanjay Sisodiya of the Association of British Neurologists and Royal College of Physicians. Sanjay is also Director of Genomics at Epilepsy Society.

He said: "Some of the points raised by the regulations are also complex ethical issues. We do not attempt to address all these issues but hope that it will bring greater clarity for clinicians leading to better care for women and girls with epilepsy."

## Experts gather at Epilepsy Society for neuroimaging courses

Epilepsy experts have shared their knowledge and experience during two educational events at Epilepsy Society's Chalfont Centre.

The 3rd ILAE British Branch Epilepsy Neuroimaging course was held over three days focusing on state-of-the-art MRI (Magnetic Resonance Imaging) and PET (Positron Emission Tomography) scanning in epilepsy.

This was followed by a

symposium on Traumatic Brain Injury also at the Chalfont Centre, organised by Professor John Duncan, former medical director at Epilepsy Society.

This involved researchers who specialise in intensive care of people who have sustained head injuries.

Professor Duncan said: "This was an important opportunity to explore the processes that give rise to epilepsy following a head injury and how this may be best treated."





## Climate change and epilepsy

Three of the world's leading epilepsy specialists have warned that climate change may be damaging the health of their patients.

And they are challenging medical professionals – and themselves – to fly less for international conferences in order to reduce their carbon footprint and the impact of global warming.

The neurologists, including Professor Sanjay Sisodiya, Director of Genomics at Epilepsy Society, say that for some people with epilepsy, climate change can make them more vulnerable to potentially life-threatening seizures.

Anecdotal evidence suggests that heat waves are particularly dangerous for children and adults with Dravet syndrome, a severe form of childhood epilepsy.

Writing in *The Lancet Neurology*, the neurologists said that during the hot summer of 2018, parents of children in the UK with this syndrome reported that their children were experiencing more seizures and increased lethargy.

And in Australia, a girl with Dravet syndrome who had been seizure free for two years, died after walking in temperatures of 46.5 °C.

The neurologists have formed a consortium, 'Epilepsy Climate Change', with a mission to act now as the effects of climate change manifest themselves.

They say air travel is possibly one of the biggest contributors to carbon emissions in their community. They estimate travel to 1500 medical meetings each year, could result in 3m tonnes of carbon dioxide, equal to the annual emissions of Madagascar.

Professor Sisodiya said: "Conferences are important. But we must also consider ways to off-set our carbon footprint. We should consider reducing the number of times we fly. We don't have time to sit back and wait while the temperature rises. We owe it to our patients and our planet to come up with effective solutions now."

## Health Minister reassures people over medication shortages

*Following concerns raised on BBC Newsnight about shortages of epilepsy medications, Epilepsy Society's Chief Executive Clare Pelham wrote to Health Secretary Matt Hancock, asking for clarity, particularly in the context of Brexit.*

*Health minister Stephen Hammond sent a statement to Epilepsy Society on behalf of the Health Secretary. The following is an excerpt from his statement at [epilepsysociety.org.uk/stephen-hammond](http://epilepsysociety.org.uk/stephen-hammond)*

"In the past weeks, there has been speculation in the media about potential shortages of treatments for epilepsy and suggestions that these were linked to our exit from the EU. I know that this has caused worry for many with epilepsy.

"Recent supply issues are in no way linked to our exit from the EU. Medicine supply problems can occur for a wide variety of reasons, and the Department of Health and Social Care has well-established procedures to deal with shortages. We work closely with manufacturers, the NHS and patient groups. We have (also) been working with the Epilepsy Society and wider NHS.

"We continue to work to ensure that there will be no impact on medical supplies caused by our exit from the EU. If we leave under the Prime Minister's Withdrawal Agreement there will be no changes to our current trading arrangements

with the EU during the implementation period. Therefore, while there may still be routine medicines shortages that we will manage through our strong standard procedures, the supply of medical products, including epilepsy drugs, will continue on the same basis.

"As part of our contingency plans (in the case of a no deal exit), we have looked at over 300 different epilepsy medicines provided by nearly 50 different companies. Many companies are holding stocks beyond the six weeks' additional buffer requested. This is one part of the multi-layered approach we have put in place.

"I am also aware of speculation about the impact of the introduction of a Serious Shortage Protocol on patients with epilepsy. This is a tool to manage supply issues when all other measures have been exhausted and would only be issued if clinicians think it is appropriate. This is a business as usual policy, and is not linked to our exit from the EU. A protocol will never be used to substitute a treatment for epilepsy. In the event of a supply issue, a patient with epilepsy would always be referred back to their prescriber."

Whatever the Brexit outcome, it is our priority to make sure the supply of medicines can continue uninterrupted. I will continue to work tirelessly to ensure this is the case."

## Ongoing drug shortages

As soon as Epilepsy Society is made aware of supply issues with any epilepsy medications, we publish details at [epilepsysociety.org.uk/news](http://epilepsysociety.org.uk/news) and share these via social media.

There are still ongoing supply issues with the following drugs:

- Epanutin (phenytoin) Infatabs 50mg from 1 May through to November 2019.
- Topamax (topiramate), 25mg

and 100mg. These will be in stock as soon as possible.

- Oxcarbazepine 150mg tablets will be discontinued in October 2019. The 300mg and 600mg versions have been discontinued.
- Carbagen 200mg and 400mg Immediate Release Tablets until mid 2019.
- Carbagen 200mg and 400mg Modified Release Tablets until late 2019.

## Hooky's legacy for his friend



### DRUG CHANGES

## Pregabalin and gabapentin are now class 3 drugs

If you have been prescribed gabapentin (Neurontin) or pregabalin (Alzain or Lyrica), it is important to be aware that these medications have been re-classified as controlled drugs.

This will affect the way in which you can get these medications. You will generally have to get a written prescription rather than picking it up electronically.

Your GP and local pharmacy will ensure you continue to get the medicines you need. Please remember to order your medicine ahead of time.

There will also be some changes to the rules around these medications, including the following:

- Only 30 days' supply is allowed

A big thank you to Peter Hook, bassist and co-founder of post punk Joy Division, who auctioned off the band's archive collection in memory of lead singer Ian Curtis. Ian had epilepsy and took his own life at the age of 22. Part of the proceeds were donated to support Epilepsy Society's helpline.

[epilepsysociety.org.uk/hooky](http://epilepsysociety.org.uk/hooky)

on one prescription

- You must collect medicines from the pharmacy within 28 days of the date on the prescription
- Any medicine 'owed' to you by the pharmacy must also be collected by that date
- Some GP practices may not be able to send prescriptions electronically to the pharmacy
- All patients will need to request repeat prescriptions from their GP practice. It will no longer be possible to get your medicine from the pharmacy using repeat or 'batch' dispensing.

## Watch it on video

You can find these videos at [youtube.com/epilepsysociety](http://youtube.com/epilepsysociety)



Watch how our trustee, Chris Blue, got on when he changed his name to Chris Purple for Purple Day 2019.



Dr Wendy Jones describes the genomics work we carry out at the Chalfont Centre. See page 16.



Paula Sherriff, MP and Chair of the APPGE, talks about epilepsy awareness to mark Purple Day.



Brothers Billy and Danny Knight are now seizure free after a genetic diagnosis. See page 17.



# Me and my epilepsy Amanda Smith

Amanda Smith explains how picking up a paintbrush has helped her overcome the anxiety and depression that go hand in hand with her epilepsy. And how painting has become her lifeline through art therapy at our Chalfont Centre

## Diagnosis

I was first diagnosed with epilepsy at the age of 23 but I think I had probably been having seizures all through my childhood. I had a lot of déjà vu experiences and would often smell freshly cut grass when there wasn't any around. But I thought all children felt that.

I had my first tonic clonic seizure when I was on holiday on my own in Majorca. I just thought it was a panic attack. It was only some time later when I had another seizure in the car with my mum that we started to think something was wrong. I said I felt ill and Mum told me to get out of the car in case I was sick.

It was then that she noticed I was just wandering around.

## Epilepsy didn't hold me back

At first I didn't let my epilepsy hold me back. It was controlled for a period of time, then I started having four or five seizures a year in spite of being on the maximum dose of drug. I would still go travelling by myself, even though I knew I ran the risk of a seizure. I once woke up in hospital in New Zealand thinking I should be at home.

I was working as an office manager in the head office of high street retailer TK Maxx and they were really supportive of me. My manager was amazing, particularly

when he knew I was having a bad day. If I wasn't feeling well I was always allowed to go home.

## Medication changes

My seizures were not improving. I was having a lot of absence or focal seizures. I would get a rising feeling and my body would jerk and tense for about 30 seconds. I was admitted to the Sir William Gowers Centre at Epilepsy Society where I underwent several drug changes to try and sort out my medication and improve my seizure control. These altered the pattern of my seizures. One medication change led to me having 50 seizures a day – mainly absences. I was literally laid out on the sofa – I could not move. After several different drugs we eventually got my seizures down to eight or 10 a day.

## Losing sense of myself

In October 2017 I left my job as I was no longer fit for work. It was a joint decision and TK Maxx said that if I wanted to come back they would find me something suitable.

By this time I had been diagnosed as having both epileptic and non-epileptic or dissociative seizures. The psychological impact of epilepsy and trying so many drugs is huge. You lose sense of who you are. You don't know your place in the world. You become isolated and live a life of 'what if?' What if I step outside my front door and have a seizure?

## Anxiety and depression

Many times I have wished to give up the fight and admit defeat. I have had anxiety and depression and suicidal thoughts. I have also been diagnosed with borderline personality disorder which is another hurdle I am trying to overcome.

## Losing my independence

Now I have a carer 17 hours a week, including every evening so that I can have a shower and dinner. Food can be a trigger for my seizures and I can't use the oven in case I forget to switch it off.

It's hard to rely on others when you have been used to being

independent. But it's hard to be independent when you have no car, no job and you have a health condition. Having a carer is a major change in my life.

## Art is my lifeline

The one thing that has kept me alive is art therapy. I first started painting at Epilepsy Society's art therapy centre. Initially I didn't know what I was doing. But now art is a lifeline for me to express myself. I switch on the music, switch off the world and just paint. I can't verbalise my emotions but art is a distraction and I talk about what I am doing.

I tend not to have seizures now when painting, but occasionally they happen because that is the uncertainty of my life. Every day tasks get interrupted by

seizures at some point.

## Music and mood

I never plan anything when I am painting. It is just what comes out on the canvas. I let my subconscious guide me. If I am listening to Prodigy, the painting can be very black and grey. If I have easy going music then the paint tends to flow and be brighter. Each colour represents where I am in my life. Pink and yellow show there is hope, but the blue is a reminder that not every day is easy.

I would say that now I am on the road to recovery. My attitude is a bit more if something happens, it happens and I will deal with it. This is the hand I have been dealt. But it's still tough. I haven't totally accepted it. I am still learning to try and overcome things that stand in my path and not let them destroy me.

Clockwise from far left: Amanda in Epilepsy Society's art therapy studio; two cheeky grins with her brother as children; delivering a painting for the Queen to Buckingham Palace; support from her mum; and from her dad.





# Medicine shortages



We are receiving many calls to our Helpline, alongside online enquiries, from people who are experiencing difficulties in getting their epilepsy medication. Here, our Medical Director **Professor Ley Sander** looks at the problem and explains what you can do to manage the situation and how the Government is tackling current shortages

**W**e know that many of you are experiencing problems accessing your epilepsy medication. Understandably this can cause real anxiety and stress. We also know that uncertainties around Brexit are adding to the concerns with people worrying about whether they will be able to continue to access their medication once we leave the European Union.

Epilepsy medication is vital. The last thing you want to hear when you go to pick up a prescription from your pharmacist is that they can't get hold of the medication or are out of stock.

But medicines shortages are an ongoing issue. There are many reasons why drug shortages occur (see box, page 10). But the key thing is that you take sensible precautions to allow for the fact that there may be issues with accessing some medications. And that starts with talking to your GP or epilepsy specialist and, most importantly, building up a good relationship with your local pharmacist.

One of the most useful measures you can take is to ensure that you take your prescription to your pharmacy in good time – up to seven days before you actually 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, to access your medication elsewhere.

## Download our letter to your pharmacist

If you are having problems accessing medication from your regular pharmacy, you might like to take your prescription to a different pharmacy instead to see whether they have stocks of your medication. If your epilepsy drugs are part of a prescription for several different medications for other issues, you could ask your GP in advance for a separate prescription for your epilepsy medication – even a handwritten

## Take your prescription to your pharmacy up to seven days before you actually need the medication.

rather than electronic prescription. That will make it easier for you to take it to different pharmacies if you experience problems.

We are in touch with the pharmaceutical industry to emphasise the importance of people with epilepsy receiving a continuous supply of their medication. And, if you wish to, you can download a letter on our website to take along to your pharmacist supporting this (see box, page 10).

## What the Government is doing?

The Government has a dedicated Medicines Supply Team, made up

of pharmacists, working within the Department of Health and Social Services (DHSC) to address supply issues as they arise. DHSC recognises that medicine shortages are an ongoing issue and they are introducing new strategies to help tackle the problem. This includes the introduction from January this year of new mandatory requirements which mean that manufacturers must notify the DHSC as soon as there is a supply shortage of a particular medication.

This gives the Medicines Supply Team time to conduct a thorough risk assessment and help to resolve the shortages, hopefully minimising the impact on people such as yourselves.

We are in close contact with the team, sometimes on a daily basis when there is a particular issue which needs communicating. So by checking our website and following our social media channels, we will be able to bring you the most up-to-date information about any current supply issues relating to epilepsy medication.

## Worries around Brexit

Brexit has been looming over us for almost three years now and the uncertainties around what will happen if and when we leave the European Union have certainly exacerbated worries around medication supply.

The Government has put in place contingency plans to ensure that manufacturers have at least a six week supply of medication to cover all eventualities. You can





treatments have been excluded from this type of protocol. The Government appreciates that it could be dangerous to switch someone between different therapeutic or generic versions of their drug, and so any changes to medication will have to be done by the person's prescriber after consultation with them.

However, in extreme circumstances, if it was necessary to ration medication, there may be no option but to dispense a different strength of a drug. For example, if you are usually prescribed 400mg of a medication and that strength is not available, it might be necessary to prescribe 2x200mg of the drug instead.

Similarly, if a medication is in short supply, it might be necessary to dispense a reduced quantity of an epilepsy drug. This could mean that instead of having a 28-day supply of a medication, you might be asked to pick up a lower quantity, for example just 14 days supply from your pharmacy. This could be because more supplies are expected in a few weeks' time and you would need to get a new prescription. Or if new supplies are not expected, it would give you enough supply to continue your medication while you make an appointment with your clinician to consider an alternative.

### Make sure you read the label

These sorts of scenarios underline the importance of making sure that you get to know your local pharmacist and that they are aware of the importance of letting you know of any changes. But it also reaffirms the importance of

**“ It reaffirms the importance of reading the label on your medication before you leave the pharmacy... so you can be wise to any changes... ”**

reading the label on your medication before you leave the pharmacy, even if you have been taking the same medication for many years. It is always better to be wise to any changes so you can ask the pharmacist about them while you are still there.

As a patient, you are entitled not to accept a changed prescription but to refer back to your GP. However, these protocols would only ever be used where there was a real crisis, in order to ensure that available medication was sensibly rationed to everyone's benefit, so this must be taken into consideration.

### Keep calm and carry on

There is a much used slogan that crops up in every walk of life at the moment – keep calm and carry on. But I think in this circumstance it is true. There are medicines shortages across all health conditions and sometimes this involves epilepsy drugs. But there are dedicated experts whose sole job is to monitor and mitigate for these shortages and if we can all just stay calm and breathe through Brexit, I cannot guarantee that the problems will go away, but together we will cope. We are on your side.

### Find out more

Go to [epilepsysociety.org.uk/shortages](http://epilepsysociety.org.uk/shortages) to find out:

Why drug shortages occur

Download our letter to your pharmacist

Go to [epilepsysociety.org.uk/contingency-plans](http://epilepsysociety.org.uk/contingency-plans) to read:

Brexit contingency plans

If you are experiencing anxiety around medication and would like to talk to someone, please call our Helpline on 01494 601400 (Mon-Tues 9am-4pm, Wed 9am-7.30pm).

read this on our website (see box below). You can also read in more detail Government plans to ensure that leaving the EU does not impact on supplies of medications.

### Why you shouldn't stockpile medicines

But I know from conversations in clinics that many patients are finding ways to stockpile their medicines themselves. We understand people's concerns, however this has the potential to create a shortage of medication itself. It could mean some people may not get the medication they need. It is important for everyone to stay calm and follow their normal routine when it comes to getting a repeat prescription.

DHSC's post Brexit contingency plans are the most effective way to ensure that everyone has a consistent supply of their medication.

### Serious Shortages Protocol

You may have read about the Serious Shortages Protocol that has been put in place to deal with any serious shortages of medication. This gives pharmacists the power to dispense alternative drugs if those prescribed by the GP are in short supply after Britain leaves the EU.

This would only be used in exceptional circumstances and the good news is that in part, epilepsy

# APPG on Epilepsy



All Party Parliamentary Groups (APPGs) are an opportunity for you to engage with democracy, make sure your voice is heard and encourage your MP to make other members – and parliament – aware of issues that are of concern to you. Our Communications Officer **Rhia Arden** finds out what the APPG for epilepsy does.



**Rhia Arden is our new Communications Officer at Epilepsy Society. She has completed an MA in Journalism, Media and Communications at Cardiff University.**

Did you know that you can attend All-Party Parliamentary Groups (APPGs) to become involved in discussions and influence politicians about issues that are important to you?

There are almost 700 APPGs in the UK covering all different concerns and issues. They have no official status within parliament, but are run by and for members of the Commons and Lords. They often involve individuals, campaign groups, charities and other non-governmental organisations in their administration and activities. And you can ask your local MP to attend an APPG you care about and to feedback to you.

The All-Party Parliamentary Group (APPG) on Epilepsy is a cross-party group of MPs and Peers who represent all political parties with an interest in epilepsy.

The group was set up to raise awareness of issues around epilepsy among parliamentarians and to engage with individuals and organisations in supporting and promoting the concerns of people with epilepsy.

This year, our friends at Epilepsy Action provide the secretariat for the APPG on Epilepsy, helping to run the group on behalf of the Chair, Paula Sherrieff, MP for Dewsbury in West Yorkshire.

Paula has been the Chair for over 18 months and has a personal link with epilepsy as her father has the condition. Paula is passionate about supporting the condition in parliament.

As Chair of the APPG on Epilepsy, her role includes speaking to constituents whose family members have epilepsy, and raising awareness and understanding of epilepsy. She explains what she would like to see this APPG achieve: "I would like to stop people feeling uncomfortable about epilepsy



and to see more awareness around the condition".

Vice-Chairs supporting the APPG on epilepsy are: Dame Cheryl Gillan MP, Valerie Vaz MP, Sir David Amess MP and Baroness Hussein-Ece. Andy McDonald MP is the Treasurer and Teresa Pearce MP is the Secretary.

The APPG on Epilepsy hosts a number of meetings and events in parliament throughout the year. These are usually held in one of the Committee Rooms in the House of Commons. Members of the group can submit responses to inquiries or consultations held by the Government.

**Recent APPGE activity**

The most recent APPG on Epilepsy focused on how to reduce epilepsy-related deaths. The group discussed key findings from the Public Health England Neurology Mortality Report. This followed on from the key recommendations made at the Prevent 21 Summit on Tackling Epilepsy Deaths hosted by SUDEP Action in Oxford last year.

Key findings showed a three per cent increase in the number of people living and dying with epilepsy each year; deprivation makes an individual more likely to develop epilepsy; seizure control varies with deprivation; and high prevalence plus poor seizure control results in more deaths. Suggested solutions include: having an epilepsy lead in each Clinical Commissioning Group or hospital; increasing the number of epilepsy services; and tackling the causes of deprivation.

The APPG on Epilepsy agreed:

- to write a letter to the Health Select Committee asking for an inquiry into epilepsy-related deaths
- to seek a meeting with the Secretary of State for Health and Social Care, Matt Hancock, to highlight Summit recommendations
- for epilepsy-related deaths to become a standing agenda item on the APPG on Epilepsy.

Members of the public who attended asked for more to be done to address the stigma around epilepsy, particularly around young

men with epilepsy who were said to be at greater risk of premature death. Members of the public said men feel stigmatised because they don't want to take anti-epileptic drugs due to side effects and feel a loss of independence when they can no longer drive due to uncontrolled seizures.

Previous APPGs on Epilepsy have included: Purple Day 2019, held on 26 March when the group engaged with MPs, raising awareness of epilepsy, encouraging them to tweet and share 'purple' photos of themselves, and tabling a series of parliamentary questions around epilepsy. An earlier meeting looked at epilepsy and people's experiences of Personal Independence Payments (PIP).

The details and topic of the next meeting have not yet been released. We will keep you updated with more information on upcoming APPGs on Epilepsy at [epilepsysociety.org.uk](http://epilepsysociety.org.uk)

There are around  
**700 APPGs**  
in the country

Members of the  
APPG on Epilepsy  
celebrating  
Purple Day



APPGs are your  
chance to engage  
with democracy



Make sure your  
voice is heard



The APPGE is  
a cross-party  
group of MPs

The group includes MPs,  
from the top: Cheryl Gillan,  
Teresa Pearce,  
Paula Sherriff (chair)  
and Valerie Vaz.



Paula Sherriff, MP, talks about her dad's epilepsy  
and what she hopes to achieve as chair of the APPGE

"I wanted to become involved with the All Party Parliamentary Group on Epilepsy as I have a strong family link with my dad having quite unstable epilepsy."

"Speaking to constituents whose children have epilepsy, I realised there's much more that we need to do to both raise awareness, and to get people talking about the condition more and to understand how it can affect people's lives. Epilepsy is still quite taboo and I think encouraging people to know what to do if somebody has a seizure is so important."

"My dad developed epilepsy in his mid-40s. He was a police officer and was at Manchester Crown Court giving evidence. My mum got a phone call saying 'your husband's fallen ill'. At the time, Dad was in quite good health, we didn't know what was going on."

"My dad once had a seizure in the street when my mum and I were away in Paris on holiday. Bystanders cut off all of his clothes as they thought he'd had a heart attack as he was lying unconscious in the street. I think a lot of people walked past him because they thought he could be drunk."

"Because Dad began having seizures out of the blue, the doctors thought it was a brain tumour, so he had to undergo a lot of tests. His first seizure was a big one and all of his seizures have always been significant."

He has tonic-clonic seizures, but around 10 years ago, he started going into status epilepticus. He almost always now goes into status and sometimes it involves a hospital stay. Sometimes he is put into a medical coma."

"I've seen my dad evolve in his own acceptance of the condition. The biggest thing for him was having to give up his driving licence. He felt it emasculated him as he was always the driver. He used to be in denial and said to people 'I have fits, but I'm not epileptic'. On the brain scans, it didn't show that he had any scars."

"My dad has had mixed experiences with neurologists. My mum said that she wasn't happy with his neurologist. Dad is in his 70s and is a fit man, but Mum felt that the doctor wasn't treating him the same as other patients and didn't feel it was fair."

As I used to work in the NHS, I encouraged my mum to get a second opinion for Dad as there's nothing wrong with asking for one. They saw a different neurologist who changed my dad's medication and added a new drug. He didn't have a seizure for nine months."

"Dad started having seizures again on Christmas Day, but fortunately, he didn't go into status. He's been ok since, so we've got our fingers crossed".

You can contact the APPGE at [appg@epilepsy.org.uk](mailto:appg@epilepsy.org.uk)



# Fundraising in my DNA

Our trustee **Andrew George** explains why he walked 100km to raise money that will help us to analyse genetic data and increase our understanding of epilepsy

of the scope of a ruler, pencil and graph paper! The Epilepsy Society is currently working on getting data from 5,000 people with epilepsy.

When the first human genome was sequenced it cost US\$5 billion and took many years. Now, scientists can sequence a person's DNA in 48 hours, and it costs just a thousand pounds.

This gives scientists and doctors access to information about why one person gets epilepsy and another does not. It also allows them to discover new causes of epilepsy. This makes a difference. Research carried out by the Society at its centre in Chalfont St Peter, together with partners in University College London, showed that for one young man his epilepsy was caused by a single gene mutation. This predicted that a drug, normally used for heart disease and not for epilepsy, might be effective for him.

The bottle neck in this research is analysing the data. The only way to do this is to use new mathematical approaches to analysing the data, and this is why you need a bioinformatician – a person who has the expertise to use these new methods to interpret the information from



each person's genome.

So I walked 100 km to try and raise money to support the work of a bioinformatician for a month. My target is £5000, about 5p for every step that I took. And I'm not far off.

As well as raising money for the Epilepsy Society I was also doing this for myself. I am not the most physically active person, and it was good to do something that was a real challenge for me. Thank you to everyone who has supported me, and it's still not too late to donate at the link below. Thank you.

[justgiving.com/fundraising/andrew-george19](https://justgiving.com/fundraising/andrew-george19)

## Painting tomorrow

Neill Lowdon is an artist from Cornwall who has recently sold 35 of his paintings to raise money for us. Here, he talks about leaving a legacy in his will to Epilepsy Society

I've had epilepsy since I was born, as my brain was damaged during birth. It's had a big impact on my life. I have tried different medications for many years and I have taken around 106,000 tablets to try and help deal with my epilepsy. Unfortunately, the medication hasn't really worked and my consultant thinks I have drug-resistant epilepsy.

I had a Vagus Nerve Stimulator fitted that destroyed my voice for several months. I was desperately trying to communicate and it was very frustrating.

I have seen two examples of epilepsy and what it can do to you on my local news. One girl died of epilepsy at school when she had a seizure. This bothered me a lot and made me emotional.

Another time, I saw a reporter approach someone on the street

and ask her about epilepsy. She had epilepsy and was bitter about her condition. Watching these two examples inspired me to sell my paintings and donate the proceeds to Epilepsy Society.

I've been painting since I attended Falmouth School of Art 40 years ago. I've also cycled over 100,000 miles to get to places where I like to paint. I largely paint landscapes, but I can paint a bit of everything, including still life and portraits. I mainly paint Cornish landscapes near where I live with pastels, oils and watercolours.

An exhibition was held in March in my local town. A lot of people who came were grandparents, desperate to help their grandchildren who had epilepsy. Thirty-five of my paintings were sold raising £1,500 for Epilepsy Society.

Now I've decided to leave a legacy to Epilepsy Society in my will, as I want to give something back. It wasn't until I had my exhibition that it dawned on me how much fundraising mattered to people with epilepsy. I also didn't realise that so many people had epilepsy.

I have asked for my donation to be put towards their ground-breaking research. I would also like to donate my brain at the end of my life to Epilepsy Society's Brain and Tissue Bank, so it can be used for vital research



I think it's important to leave a legacy, particularly to epilepsy charities such as the Epilepsy Society so it can continue its research into determining the causes and treatments of epilepsy.

I recommend others to leave a legacy in their wills to give something back to a cause they care about, as you can never quite tell where life is going to go.

I would like to do another exhibition of my paintings in a few years to donate more money to Epilepsy Society, as there is room for more success.

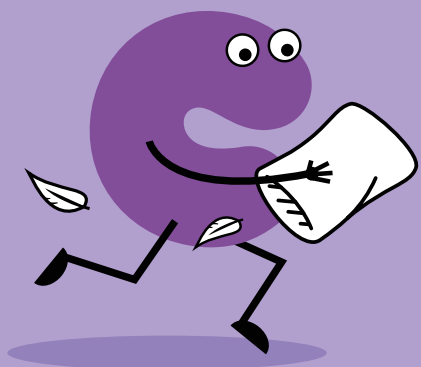
**If you are considering leaving a legacy to Epilepsy Society, we always recommend you take legal advice. You can find information at [epilepsysociety.org.uk/legacy](https://epilepsysociety.org.uk/legacy) or call us on 01494 601300 for a confidential discussion.**

**With your help, we can make a real and lasting contribution to the lives of people with epilepsy.**

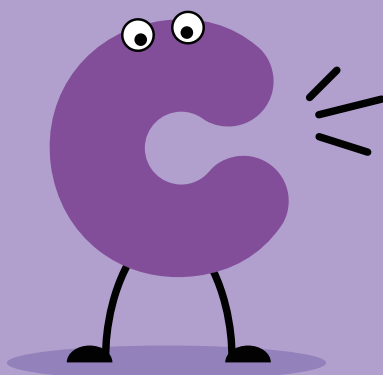




# Calm



# Cushion



# Call

Epilepsy Society launches its new three 'Cs' campaign to raise awareness of seizure first aid and make sure that everyone is #seizuresavvy. Nicola Swanborough writes

**E**pilepsy affects 600,000 people in the UK and 50 million worldwide. Yet research carried out by epilepsy charities\* showed that two out of every three people in the UK who do not have a family member with epilepsy, would not know how to help someone during a seizure.

And many people who have a friend or relative with epilepsy say they would not feel confident of supporting them in a seizure.

That is why this year epilepsy charities in the UK came together to make seizure first aid their main focus for National Epilepsy Week (20-26 May 2019). And at Epilepsy Society, we launched a new campaign to give people the basic tools of seizure first aid that could help save a life.

"It's not that people are unwilling to help," says the charity's chief executive Clare Pelham. "I think more often than not people are only too willing to do the right thing. It's just that they don't know how to."

There are many different seizure types and initially our campaign is focusing on tonic clonic seizures as these are the most easily recognised seizures. However, we also have details on our website about how to support someone during other seizure types. And our aim is to extend the campaign to other seizure types making sure everyone is #seizuresavvy.

Seeing someone having a convulsive seizure where they fall to the ground shaking, can be disconcerting. So the charity's new

**We hope that the three 'Cs' – Calm, Cushion, Call – will stick in people's minds and be easy to recall should the need arise**

*"Calm, Cushion, Call."*

• **Stay CALM** and stay with the person who is having a seizure.

• **CUSHION** their head with a coat or cardigan to stop them injuring themselves.

• **CALL** for help if the seizure does not stop.

campaign gives people three simple instructions to remember in an emergency – Calm, Cushion, Call.

Most seizures will stop of their own accord within a couple of minutes. The person will need to be looked after until a friend or family member is called, but they may not need an ambulance. However, the "Calm, Cushion, Call" campaign is specifically designed to help people cope in an emergency.

Epilepsy Society's Chief Executive Clare Pelham said: "We are very aware that if you encounter someone having a seizure out in public, you won't know their medical history, or indeed if it is an epileptic seizure.

"It is a natural instinct to try to do the very best that you can for that person and call for medical help. We hope that the three 'Cs' – Calm, Cushion, Call – will stick in people's minds and be easy to recall should the need arise."

The charity has initially rolled out the campaign with a series of high impact digital posters across London's Underground stations. These were displayed at Euston, Kings Cross, Oxford Circus, Victoria, Waterloo, Baker Street and Westminster stations.

Digital posters are displayed on a 30 second loop, with our Calm, Cushion, Call posters displayed for five seconds in every 30 second loop.

There are four million tube journeys made across London every day, so we know that this offered a great opportunity to raise awareness of how to support someone during a seizure.

We were also very aware that five seconds is a very short time frame in which to capture commuters' attention. This is why we have gone for very simple and visual messaging. We created three friendly animated Cs which we hope will deliver an important first aid message in a fun way.

The "Calm, Cushion, Call" campaign was also rolled out across social media platforms including Facebook, Twitter and Instagram reaching over 700,000 people on these platforms.

We would be very grateful if you could also help us share the campaign via social media but there are other ways that you can join the campaign too. You could download or order our free Calm, Cushion, Call poster and display it in a prominent place such as a school, workplace, surgery or library, as long as you have permission. More than 700 posters have already been sent out.

Or you could share the campaign with colleagues at work by asking your employer to include our infographics in their internal newsletter. We hear from many people who say that they do not feel supported with their epilepsy in the workplace, and this is a good opportunity to raise awareness. You can request all the materials at [seizuresavvy.org.uk](http://seizuresavvy.org.uk)

More detailed first aid relating to convulsive (tonic clonic) seizures and other types of seizures can be found at [epilepsysociety.org.uk/first-aid-epileptic-seizures](http://epilepsysociety.org.uk/first-aid-epileptic-seizures)

\*These were the findings of a YouGov poll of more than 2,000 UK residents, carried out during National Epilepsy Week 2017. The poll was commissioned by Epilepsy Society and Young Epilepsy.



# Our genomics clinic: helping to change lives

Epilepsy Society's innovative genomics clinic is helping to direct treatment options for epilepsy by unlocking the secrets of our DNA.

**Nicola Swanborough** looks at how it is already bringing hope

**G**enomics is a very new field of medicine but it is already helping us to understand the causes of seizures in some people with difficult-to-treat epilepsy where we think there may be a genetic basis to their condition.

A genetic diagnosis may help us to establish why a person has recurring seizures and can sometimes help to direct treatment options.

At Epilepsy Society we are running an innovative epilepsy genomics clinic. The new clinic at our Chalfont Centre in Buckinghamshire, enables us to see and diagnose people who are thought to have an underlying genetic cause for their epilepsy.

We are the first specialist centre in the country to be running this type of clinic for epilepsy.

Adults with difficult-to-treat epilepsy can be referred to the clinic by a consultant or neurologist from anywhere in the UK ([epilepsysociety.org.uk/getting-referral](http://epilepsysociety.org.uk/getting-referral)). Our doctors investigate each individual's genetic pre-disposition to epilepsy and try to shape individuals' treatments.

For some people genetic diagnosis can lead to a change in medication, diet or supplements, although often we do not necessarily have the required knowledge to redirect treatment.

The clinic also provides the opportunity to counsel patients and their families where there may be a chance of other family members being affected or of children having similar difficulties. And it ties in closely with the ongoing research we are doing into the epilepsies.

## Taking part in our research study

Genomics promises to give us a wealth of information about each different type of epilepsy and a person's individual response to different medications. But our knowledge is still limited. That is why our research is so important in helping to enhance our understanding of the genetic architecture of epilepsy.

At the moment we can only recruit people for our research who are under the care of UCLH. But you can find out how you can be considered for future research at [epilepsysociety.org.uk/recruiting-people-our-research](http://epilepsysociety.org.uk/recruiting-people-our-research)

The aim of our research is to investigate the genetic pre-disposition to epilepsy and its treatment. Our researchers extract DNA from the blood or saliva of those people who have given us consent to use their samples for research purposes. Sequencing their genomes provides us access

to the wealth of valuable genetic information that is embedded in an individual's DNA.

Research in this field has already increased our understanding of some of the genes that can cause epilepsy and determine response to some treatments.

People with changes in these genes are more likely to develop epilepsy or have a different response to their treatment. By looking at a large population, we hope to identify the incidence of these gene changes in the UK and improve our understanding of epilepsy.

Participants involved in our research may be offered a range of tests including genetic tests, neuroimaging (magnetic resonance imaging, electroencephalography and electrocardiography), transcranial magnetic stimulation, optical coherence tomography and 3D stereo photogrammetry. It will vary according to each person's epilepsy which tests they will be offered.

You can find out more about these tests on our research hub at [epilepsysociety.org.uk/genomic-research-breakthroughs](http://epilepsysociety.org.uk/genomic-research-breakthroughs).

You can also watch our video as Dr Wendy Jones discusses her innovative work at the genomics clinic.

## Anna's story



Anna Coe has undergone 27 years of different medications and brain surgery to try to control her epilepsy. She has often felt that the trial and error of medication changes has led her down dead ends and left her feeling exhausted. But now she feels that a diagnosis through sequencing her DNA is offering her real hope of better, more focussed treatments that could work for her

Anna Coe is 36. She was first diagnosed with epilepsy at the age of nine and although she has never let the condition get in the way of her education or employment – she works for a homeless charity in Surrey and was previously a journalist – she describes her life as a constant battle to get her seizures under control.

"I have had 27 years of trial and error with so many different medications, or combinations of medications," she says. "In 2011 I underwent surgery to remove the part of my brain that was causing my seizures. That worked for two and a half years, but then my seizures returned."

Initially Anna experienced complex partial seizures which meant that though she was

conscious, she was unaware of where she was or what she was doing – "I often locked myself out of the house", she says.

Since her surgery, her seizures now happen in her sleep and while they don't have the same impact as her previous day time seizures, there have been times when she has had three or four seizures in a night, leaving her worn out.

Alongside this she has found the constant changing from one medication to another exhausting with little hope of gaining full control of her seizures.

But now Anna is hopeful that her neurologist may have found the cause of her epilepsy and that this could open up new treatment options for her.

Anna has had her DNA sequenced as part of the 100k Genomes Project and her neurologist, Sanjay Sisodiya, Professor of Neurology at UCL Queen Square Institute of Neurology and Director of Genomics at Epilepsy Society, is hopeful they may be able to pinpoint the cause of her epilepsy.

"He thinks they may have found

a biomarker that could explain why I have epilepsy when no-one else in my family does," continues Anna. "The next step is to test my parents' DNA to see if either of them has the same biomarker. Neither of them has epilepsy so if they have the biomarker, maybe it's not the cause. But if neither of them has it then it could explain my seizures.

"I am just really excited that this could open up new avenues of treatment for me that the doctors are confident should work according to my genetic code. I feel a real sense of hope which I haven't felt in a long time. I have been going down dead ends with medications for so many years now, but suddenly, here is this key piece of extra information that could make a difference.

"It feels like such a step forward in medicine and it gives me confidence that for future generations, any child who is diagnosed with epilepsy will not have to go through the endless trials of medications and treatments that I have been through, in the hopes of finding the right one.

"Just to have that genetic blueprint and be able to say, that drug might work for you, is such a major step forward."

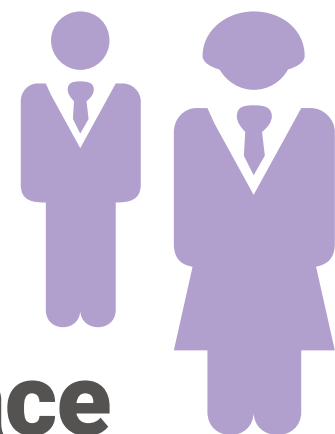
## Billy and Danny's story

Brothers, Billy and Danny Knight both had uncontrolled seizures. Billy was having up to 1,000 seizures a day and neither of the young men responded to epilepsy medication. Then genetic testing helped to diagnose a creatinine deficiency in the brothers. Billy and Danny now take a creatine supplement four times a day and are both seizure free. Their dad, Richard Knight said: "If we were 25 years further on, they would have led a pretty normal life."

Watch Richard talk about his sons' journey at [epilepsysociety.org.uk/genomics-case-studies](http://epilepsysociety.org.uk/genomics-case-studies)

**"I feel a real sense of change which I haven't felt in a long time."**





# Epilepsy in the workplace

Asking your employers and colleagues to support Epilepsy Society at work can help to increase understanding of the condition and raise funds to help change lives through our pioneering research. Communications officer, **Rhia Arden** explains

**H**ave you ever thought about raising awareness of epilepsy in your workplace and at the same time raising vital funds for Epilepsy Society? We are often inspired by the number of people who hold fantastic fundraising events at work, helping to support Epilepsy Society and raise awareness of what it is like to live with seizures.

But we also know that many people find there is little understanding of epilepsy at work and they worry about what will happen if they have a seizure.

We have been working with several organisations to help educate employers and staff about the condition and also to have fun raising money for the charity.

We have been really pleased to have the support of Young's Hotels who have a collection of pubs across the UK, and Sainbury's Argos, one of the UK's leading digital retailers.

Young's Hotels named us as their charity of the year, inspired by one of their managers, Nikki McCarthy, who has epilepsy. Staff have raised over £6,200 for us through bike rides and pub games.

And Sainbury's Argos turned their headquarters in Milton Keynes purple for Purple Day on 26 March, led by staff member Jey Sharman, part-time carer for her brother, Nathan who has severe epilepsy.

You can read more about their stories below.

We would love to hear from you if you think your employers and colleagues could support us by becoming partners of Epilepsy Society. We work with a range of companies, both large and small, and we can adapt to all levels of engagement.

There are several ways that employers can get involved as corporate partners:

- through sponsorship of one of our high profile events. This will help promote your company's charitable support while raising funds for Epilepsy Society
- by making Epilepsy Society your charity of the year. We can work with you to develop individual packages including community engagement and PR opportunities
- by getting involved in one of our volunteering opportunities
- through payroll giving which helps to ensure a steady income

for the charity. (Please contact your HR department to find out more about payroll giving to Epilepsy Society.)

- by taking advantage of our in-house epilepsy awareness training for companies. [epilepsysociety.org.uk/training-courses-epilepsy](http://epilepsysociety.org.uk/training-courses-epilepsy).



## Young's Hotels

Nikki McCarthy, manager writes: "Young's very much care about their staff. So when it came to choosing a charity to support, it asked its general managers to suggest one that had real meaning to them. Epilepsy Society gained the most votes when staff learned that some of their colleagues, including me, have this condition. Young's have been amazing in supporting me to work without fear of prejudice or unfair treatment."



## Sainbury's Argos

Jey Sharman's brother has severe epilepsy so she knows about the impact of seizures. Jey is a member of the Disability, Carers and Age network and arranged for Sainbury's Argos to turn their Head Office in Milton Keynes purple for Purple Day. There were activities to help staff learn more about epilepsy. The network is promoting our #seizuresavvy campaign via their internal platforms.

**"My 22-year-old son has had uncontrolled seizures for eight years. He has tried 12 medications and the ketogenic diet. He is not suitable for surgery and our consultant will not consider medicinal cannabis because the trials have only been done on children. Has anyone else gone through the same experience and how did they overcome it?"**

DARREN, MANCHESTER

## Your replies

These substances can help but need careful consideration of which type and strength. Ask for a second medical opinion from an epilepsy neurologist specialist. Campaign through your MP and local Clinical Commissioning Group for them to get the funding for trials to include your son's type of epilepsy and for him to be included in them. Meanwhile take heart because there are many folk out there with the same dilemma. **Lyn** [facebook.com/epilepsysociety](https://www.facebook.com/epilepsysociety)

Yes, I had the same problem and I pushed for having a VNS (vagus nerve stimulator) implant. It was the best decision ever. I went from having 10 or more seizures a day to four a week. **Hannah**, [facebook.com/epilepsysociety](https://www.facebook.com/epilepsysociety)

I can actually relate to this problem a lot, as someone who also has uncontrolled seizures and has tried all suitable medications. I'm 24 and have had seizures since I was

14. Your life is different with seizures, sometimes it's harder – where day-to-day tasks become near impossible because you can't remember where you are.

Find something you love to do and surround yourself with people who care about you, and your seizures will become background.

Drug trials are ongoing all the time, and better medications will come out, just try to remain positive. Don't be afraid to seek the advice of the epilepsy specialists – I have found the Epilepsy Society helpline wonderful when I've needed advice. **Alice**, [facebook.com/epilepsysociety](https://www.facebook.com/epilepsysociety)

The VNS has been a life saver, although the seizures have not stopped completely. **Sandy**, [facebook.com/epilepsysociety](https://www.facebook.com/epilepsysociety)

We've tried all known medications, medical devices and diets for my soon-to-be 20-year-old son. Sadly none have had a significant beneficial impact on his

## Next issue

**I have an issue with workplaces not training staff about epilepsy, despite having a staff member with epilepsy. Apparently, as it's not a service user who has it, they can't warrant the training, which I found quite irritating! Also, I've found a lack of awareness in workplaces surrounding the memory aspect of epilepsy as it can and does affect day-to-day living. How do I make sure that workplaces warrant the necessary training and awareness surrounding epilepsy?**  
**ANNA MARIA, LEEDS**

**Would you like to share your thoughts with Anna Maria?**  
Email [nicola.swanborough@epilepsysociety.org.uk](mailto:nicola.swanborough@epilepsysociety.org.uk), write to Editor, Epilepsy Review, Epilepsy Society, Chalfont St Peter, Bucks, SL9 0RJ, or reply at: [facebook.com/epilepsysociety](https://www.facebook.com/epilepsysociety)

seizures, which occur typically about 90 to 120 times per month.

It's had a devastating impact on him, but we do what we can to help him enjoy life as much as possible. His time in hydro pools is his great joy. His ability to smile despite the burden of his seizures is extraordinary. I hope Darren has better fortune for his son.

**David**, [facebook.com/epilepsysociety](https://www.facebook.com/epilepsysociety)

Keep trying! Never give up! Finally after over 25 years of trying, I've found a combination of meds that work well enough.

**Melissa**, [facebook.com/epilepsysociety](https://www.facebook.com/epilepsysociety)

Get a second opinion, I always do my research until I get answers. **Sandra**, [facebook.com/epilepsysociety](https://www.facebook.com/epilepsysociety)

**The views here are those of the authors and not necessarily those of Epilepsy Society. You can read more replies to Darren's letter at [facebook.com/epilepsysociety](https://www.facebook.com/epilepsysociety)**



# Tonic comic



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

**A**t the time of writing the UK is racked with seemingly endless uncertainty about the future of our country and its relationship with the EU. Whatever our opinions on the matter, the uncertainty is exhausting. Politics is about day to day life, not just abstract ideas of sovereignty, so the uncertainty carries into our everyday personal lives and can cause a lot of worry. For people with epilepsy this may include worry about whether medications will be available, what would hospital treatment options be if I needed assistance when overseas, will my EU neurologist leave the UK, and if so will there be enough qualified medical professionals to take their place?

As you are reading this, maybe everything has been magically resolved, maybe a decision was finally made, a deal voted for, epilepsy meds and professionals are in plentiful supply, there's extra funding for epilepsy research and support services. Though it's possible we could still be treading water in the Great Uncertain Sea for months to come. \*gulp\*

Having epilepsy teaches us a lot about living with uncertainty. We have to manage this day by day – and the anxiety which all so often comes with it. Having epilepsy introduces daily 'what ifs' to our lives. What if I have a seizure today? Who might be around me who I can trust? What would be the fallout of having a seizure today, when I am:

at work/school/ college?

(Fun fact: I did miss my best friend's wedding when I had a seizure in the taxi on the way to the registry office. Luckily, she had a wedding party a month later so I was able to celebrate with her then.)

We all worry from time to time; like any other emotion on the weathermap of our human experience, feelings come along, and then they tend to pass by when

**You might also recognise that living with epilepsy and the uncertainty this brings, has in fact made you more resilient than you realised**

a different emotion blows in. If they don't, and the feeling gets stuck and you can't seem to shift it, and it's really affecting your day-to-day life, this can be an indication of a mental health problem and something which you can seek advice and support for. Some people develop an anxiety disorder because of their anxiety about epilepsy, or sometimes it can be a side effect of medication. In the same way feeling in a low mood, or feeling down is perfectly normal,

but being stuck there is awful, and a likely sign of depression, which is sadly, closely linked with epilepsy.

In my work as a dramatherapist, I encounter anxiety a lot; with young people and with adults, with people who have a medical condition and those who don't. The important message is that help is available.

You may want to speak to a GP, a counsellor, a cognitive behavioural therapist or an epilepsy nurse. I first spoke to an epilepsy nurse about 12 years after my initial diagnosis and it was a game changer!

Also don't forget about the thousands of people out there who also have epilepsy, who have shared insight into what it's like to live with feelings of anxiety. There are support groups, coffee mornings across the UK and online forums to share experiences, and get support from people who really do understand what it's like. You might also recognise that actually, living with epilepsy and the uncertainty that this brings, has in fact made you more resilient than you realised. You face the uncertainty... and you continue to survive. It's not always easy but your success rate at survival is 100% so far. Winner!

These may be uncertain times, but let's be clear for a moment – all times are uncertain.

Whatever is happening in your life right now, it will eventually pass. If you're having a terrible day, just sit tight, a better day is coming. And if you're having a Mardi Gras kind of a day, it won't always be like this, so savour every moment.

**Juliet Stephens**  
*Laughing allowed*

## Society matters



### Conversation starter

Purple Day this year was our biggest and loudest ever! Over 800 people ordered a fundraising pack and together we raised more than £85,000. Thank you to everyone who baked cakes, face painted, walked, ran, danced and arranged many other fundraising events for us.

Our theme was 'be the conversation starter' encouraging people to talk about epilepsy and raise awareness of the condition. One of our Trustees, Chris Blue, even changed his name to Chris Purple for the day and spent the day out talking to people to explain why. (Watch his video, see page 5.)



### Conference time

We're busy getting ready for our Annual Conference 2019 and very much hope that you will be able to join us. The conference takes place on 14 September 2019 9.30am-5pm at the Holiday Inn, London WC1N 1HT.

Our theme this year will be 'empowerment' and we will be covering a range of topics including: medicine shortages; anxiety and depression; the benefits system and looking after your own well being. Attendance fee is £25, including refreshments and lunch.

Priority booking will open to members soon so look out for details at [epilepsysociety.org.uk](http://epilepsysociety.org.uk)



### Running for victory:

Well done and thank you to everyone who took part in the London Marathon, raising more than £80,000 for us. Our 32 runners were amazing and so were the families and friends who lined the route to support them.

After the race, the runners joined our fundraising team for a post-race reception and sports massage at Westminster Hall.

If you would like to take part in the London Marathon 2020, go to [epilepsysociety.org.uk/virgin-money-london-marathon](http://epilepsysociety.org.uk/virgin-money-london-marathon). You can also find out about other running events for Epilepsy Society.



### Me and My Shadow:

For the second year running we launched our Me and My Shadow scheme on International Women's Day, 8 March. The scheme aims to build confidence and ambition in women with epilepsy and encourage them to think big.

This year, we extended the age range to 18-30, giving more women the chance to shadow women in a range of different careers.

We had a number of hosts, from companies and organisations including our biopharmaceutical partner UCB, to the NHS Middlesex Trust and the Saracens Multi-Academy Trust.

Ankita, 23, who took part in the scheme said it offered an opportunity to ensure epilepsy does not limit her ability to attain her goals.

You can read about some of the shadows' experiences at [epilepsysociety.org.uk/shadow](http://epilepsysociety.org.uk/shadow)



### Life on the edge

Would you like to join Team Purple and abseil down Broadgate Tower in London on 31 August. The tower is one of London's tallest buildings, measuring 540ft. All you need is courage to step over the edge. Find out more at [epilepsysociety.org.uk/broadgate-tower-abseil](http://epilepsysociety.org.uk/broadgate-tower-abseil).



### Epilepsy on display

A big thanks to our friends at Queen's Square library in London who have been holding an exhibition about the history of Epilepsy Society. Running until June 2019, you can find out more at [queenssquare.org.uk/archives/visiting/exhibitions](http://queenssquare.org.uk/archives/visiting/exhibitions)



# epilepsy society

## 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](http://epilepsysociety.org.uk)



Registered with  
**FUNDRAISING  
REGULATOR**

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## Epilepsy Society Annual Conference 14 September 2019

Holiday Inn, Bloomsbury,  
London, WC1N 1HT

9.30am – 5pm

**The theme of this year's conference  
is 'Empowerment'**

Talks will include medicine shortages;  
managing anxiety and depression; navigating  
the benefits system and tips on looking  
after your own well-being.

**Attendance fee is £25 which includes  
refreshments and lunch.**