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## LIFE LESS ORDINARY

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Truck driver Roger Blake on life-changing brain surgery  
Me and my epilepsy, page 6

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## HELP WITH BENEFITS

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Changing over to Personal Independence Payments (PIP)  
Your guide to PIP page 11

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## QUESTION TIME

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Epilepsy Society's chief executive, Clare Pelham, answers the questions people want to ask  
Ask Clare, page 15



# REVIEW

**epilepsy  
society**  
125 years

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

Epilepsy isn't sexy. It's a common complaint we hear at Epilepsy Society. Nobody wants to talk about it. Politicians aren't interested. The public doesn't understand. It's a low priority on the government's agenda. And the media only does dementia. Well, and Alzheimer's disease and cancer. During National Epilepsy Week we struggled to get the sort of engagement from news channels that we felt the condition really deserved.



Our survey showing that two thirds of UK adults would not feel confident in helping someone during or after a seizure, did not get the amount of publicity we would have liked.

Then along came an inspired video from BBC Three – *Things not to say to someone with epilepsy*. The video featured a diverse group of young people with attitude, accents and unreserved honesty, talking about living with seizures or fits (personal preference wins over political correctness here). And suddenly epilepsy is on the agenda. Hooray!

BBC Three's *Things not to say to someone with epilepsy* nails epilepsy. It's edgy, confrontational and above all it's funny. Daniel, Torie, Chloe, Josh, Nick, Kat, Christina and Derek tell it like it is, explaining epilepsy with effortless wit and irony.

As the title suggests, it's all about what not to say to someone with epilepsy and there's headline grabbing stuff in there such as 'have you ever had a seizure during sex?' But the video also tackles tiresome misconceptions such as the belief that everyone with epilepsy is photosensitive.

If the dialogue is #street and #hip, it isn't afraid to pack a punch. The reality is as raw as the delivery is edgy. 'I had 20 seizures on Saturday morning and felt wiped out for the next three days' says one participant. 'I could be walking down the road and could have a seizure. I could be crossing the road and be hit by a car,' man with yellow t-shirt.

It's powerful stuff. In five minutes, eight young people turn epilepsy on its head, normalise it completely while giving incredible insight into the impact of excess electrical activity in the brain.

Stigma is a big issue for people with epilepsy. It's heartening when broadcasting corporations such as the BBC tackle it in this way. It's even more heartening that social media platforms allow us all to enjoy and share its message.

This video will do much to smash that stigma. Make sure you watch it and share it. The link is on Page 5.

Nicola Swanborough  
Editor



**FRONT COVER**  
During National Epilepsy Week, a group of young influencers put their heads together to #explainepilepsy. You can find out more about our cover shot infographics on page 6.

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## SAFETY REVIEW

# Public hearing to be held into the epilepsy drug sodium valproate

Are you a girl or woman of childbearing age and are taking or have taken the epilepsy drug sodium valproate?

A public hearing is to be held on 26 September 2017 to listen to the experiences of women in the EU who have been prescribed valproate-containing medicines<sup>1</sup> for epilepsy, bipolar disorders and migraine.

For some women with serious conditions, valproate may be the best or only treatment option. However, it has long been known that if taken during pregnancy it can affect the unborn baby and cause abnormalities.

The European Medicines Agency (EMA) has already strengthened warnings and restrictions on the use of valproate in women and girls.

However concerns have been raised about how effective these measures are and the EMA has been asked to consider whether further EU-wide action should be recommended to minimise risks.

The public hearing will be held at the EMA's London offices in Canary Wharf and will focus on three questions:

- What is your view of the risks of taking valproate during pregnancy, including its potential effect on the child?
- What are your views on measures

currently in place to reduce the risks of using valproate during pregnancy?

- What other measures should be taken to reduce the risks of using valproate during pregnancy?

Anyone wishing to take part in the hearing, either as a speaker or an observer, should submit an application at the European Medicines Agency's website [www.ema.europa.eu](http://www.ema.europa.eu) by 25 August 2017.

Applicants are asked to give details of their own experience of valproate in no more than 3,000 characters and to say how long they would like to speak for (5- 10 minutes is usually recommended for each speaker).

If you are not selected to make a presentation at the hearing, you can still submit a written statement to [publichearings@ema.europa.eu](mailto:publichearings@ema.europa.eu) which will feed into the review in the same way as presentations at the hearing.

The hearing will be broadcast live on 26 September at the European Medicines Agency website at [www.ema.europa.eu/ema](http://www.ema.europa.eu/ema)

<sup>1</sup> There are various forms of sodium valproate including Epilim, Episenta and Epival. It may also be called 'valproate' or 'valproic acid.'

## BENEFITS

## Damian Green gives his assurance on PIP

Former Secretary of State for Work and Pensions (DWP), Damian Green has assured Epilepsy Society that changes to PIP – Personal Independence Payments – will not result in claimants seeing a reduction in the amount of PIP previously awarded by DWP.

Epilepsy Society's chief executive Clare Pelham met with Damian Green, now First Secretary of State and Minister for the Cabinet Office, to discuss reforms to the benefit.

Changes to PIP followed two tribunal decisions. One tribunal said more points should be awarded where travelling posed 'overwhelming psychological distress'. The second said people should be awarded more points if they needed help to take medication and monitor their health condition.

DWP said the rulings misinterpreted the original intention of PIP and introduced reforms to restore its original aim 'giving the most support to those who need it most'.

Damian Green told Ms Pelham: 'I want to reassure people who are claiming PIP that these changes are not about cutting benefits and they will not result in any claimants seeing a reduction in the amount of PIP previously awarded by DWP. For any individual who received a higher award during the period after the judgements but before DWP clarified its position, we will consider adjusting payments going forward. We will not be claiming back any money.'

See *Your guide to PIP* page 11.

## Students design vest to detect seizures

When Loughborough student Sankha Kahagala-Gamage witnessed someone having a seizure, he was inspired to team up with fellow student David Bernstein, to design a 'Medivest' which they hope might one day help predict when a seizure is likely to happen.

And now the boys, both 16, have been crowned Winners of the GSK

UK Young Engineer of the Year 2017 for their design, which monitors heart rate variability and body temperature, potentially predicting a seizure up to eight minutes in advance. The vest sends a message to the wearer's phone as well as possibly to a carer.

Sankha Kahagala-Gamage, said: 'Winning was one of the greatest achievements of our lives.'



## PREGNANCY

## Maternal obesity risks



New research from Sweden suggests there may be a possible link between maternal obesity and epilepsy. But Epilepsy Society's medical director, Professor Ley Sander, has said the results should be viewed in a wider context.

The study from the Karolinska Institutet looked at more than 1.4 million live births to examine the body mass index (BMI) of women in their first trimester. Of those, 7,592 children – or around 0.5 per cent – had been diagnosed with epilepsy.

Researchers found that the risk of epilepsy increased by 11 per cent in children whose mothers had a BMI of 25 to 30; by 20 per cent in those with a BMI of between 30 and 35; and by 30 per cent when the BMI was between 35 and 40. Women who were above this had an 82 per cent increased risk of having a child with epilepsy.

Professor Ley Sander said that understanding the causes and risks around epilepsy was complex.

'Foetal brain development, particularly during the first trimester of pregnancy, is very sensitive, particularly to inflammatory reactions,' he said. 'It is possible that in some people maternal obesity could contribute to brain injury and a risk factor for neurological conditions such as epilepsy.'

'However, other external factors such as smoking, alcohol and poor nutrition could also be contributory factors. Excess weight can increase the risk of a premature delivery, pre-natal trauma and low oxygen levels, all of which can be additional risk factors for epilepsy.'

## HEALTHCARE

## Neurology care worsens

A survey of thousands of neurology patients, including more than 500 with epilepsy, has shown that health services are worsening across the spectrum of neurological conditions.

Additionally, research by the Neurological Alliance has shown a significant gap between the way the physical and mental needs of people with neurological conditions are met.

The Neurological Alliance is made up of 80 organisations including Epilepsy Society. Its research found:

- 45 per cent of patients described services to meet their physical needs as 'good' or 'excellent', while this figure dropped to 19 per cent when patients described services for their mental needs
- 42 per cent of patients saw their GP five or more times before seeing a neurological specialist – this is an increase from 31.5 per cent in 2014.

The Alliance is now using the results to turn around patient experience for those with neurological experiences. It is also encouraging integrated commissioning and a system-wide approach to meet physical and mental needs, rather than trying to find solutions in individual services.

[www.neural.org.uk](http://www.neural.org.uk)

## DIAGNOSIS

## Value of genetics

Genetic factors were found to be the cause of epilepsy in 40 per cent of young children who presented with first seizures during a study in the US. Genetic testing also gave a diagnosis for 25 per cent of children whose epilepsy was of an unknown cause.

The study looked at 775 children whose seizures had begun before their third birthday at 17 centres across the States.

Lead author of the study published in *JAMA Paediatrics*, Anne T Berg of Stanley Manne Children's Research Institute, Chicago, said the results underlined the need for genetic testing to be part of standard clinical practice.

'Precision medicine means nothing without precision diagnosis, and we can now provide precision diagnosis,' said Berg.

## TERMINOLOGY

## Talking about seizures

The International League Against Epilepsy (ILAE) has updated the way it describes and groups epileptic seizures. This is to reflect increased knowledge about seizures and where they begin in the brain.

It is also intended to help both healthcare professionals and people with epilepsy understand their seizures and provide greater consistency and clarity in describing them.

This does not mean you have to change the way you describe your seizures, but it is important to be aware of the new terminology.

Seizures are now divided into three groups:

- those that begin in one hemisphere of the brain (focal);
- those that appear to begin in both hemispheres (generalised onset);
- and those of unknown origin (unknown seizure onset).

Seizures are also described according to your level of awareness during a seizure and whether or not your seizures involve movement.

You will be able to read the classifications in full at [epilepsysociety.org.uk](http://epilepsysociety.org.uk) where the information is currently being updated.

## HEALTH

## Meningitis vaccination

A group of parents who each lost a teenager to meningitis are urging other parents to ensure their children are vaccinated against the disease, particularly as they go off to university. Children with meningitis are also at risk of developing epilepsy in later life.

The parents are spearheading a campaign by Meningitis Now to increase the uptake of the Men ACWY vaccine, free on the NHS, for all 17 and 18-year-olds and all university entrants aged 19-25. This is to combat a rise in meningitis in adolescents.

Those who are due to leave school this summer, or who are aged 17-18 and not in school (born between 1 September 1998 and 31 August 1999) are now eligible for the vaccine and should contact their GP practice.

[www.meningitisnow.org](http://www.meningitisnow.org)

## Seizure support

# what to do when someone has a convulsive seizure

### DO

- Stay calm ✓
- Make sure they are in a safe place ✓
- Note the time the seizure starts ✓
- Stay with them ✓
- Cushion their head with something soft ✓
- After the seizure has stopped put them into the recovery position ✓
- Stay with them until they are fully recovered ✓



### DON'T

- Don't hold them down ✗
- Don't put anything in their mouth ✗

If a convulsive seizure doesn't stop after 5 minutes, call for an ambulance. If their breathing sounds difficult after the seizure has stopped, call for an ambulance.



## NEUROSCIENCE

### Building a better future

University College London is to create the world's leading translational neuroscience facility, thanks to a £29 million grant from the Higher Education Funding Council for England.

The project will enable interdisciplinary research across the university to find better ways to diagnose and treat neurological disorders including epilepsy, Alzheimer's, dementia and strokes.

Funding has been matched by a consortium of retailers who are donating the levy on plastic bags. This includes Iceland, HSS Hire, Morrisons and Waitrose.

Further funding has also been provided by UCL partnerships with medical charities and industry including Epilepsy Society, the National Brain Appeal, Alzheimer's Research UK, The Stroke Association, Esai and GSK.

Almost two thirds of adults in the UK with no experience of epilepsy, would know how to help someone during a seizure. Our infographic was shared 1,799 times on Facebook as part of our #explainepilepsy campaign during National Epilepsy Week (see page 8).

[epilepsysociety.org.uk/everyone-knows-someone](http://epilepsysociety.org.uk/everyone-knows-someone)

## TRAVEL

### Stress-free airport

Gatwick Airport has launched a special lanyard for passengers with hidden disabilities who may require additional support when travelling through the busy airport.

The lanyard, which is voluntary for passengers with hidden disabilities, will act as a discreet sign for staff that additional support or help may be required for the person and their family.

The lanyards are available for free from Gatwick's assistance desks.

## Watch it on video

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



Watch the round table discussion as part of our #explainepilepsy campaign in National Epilepsy Week.



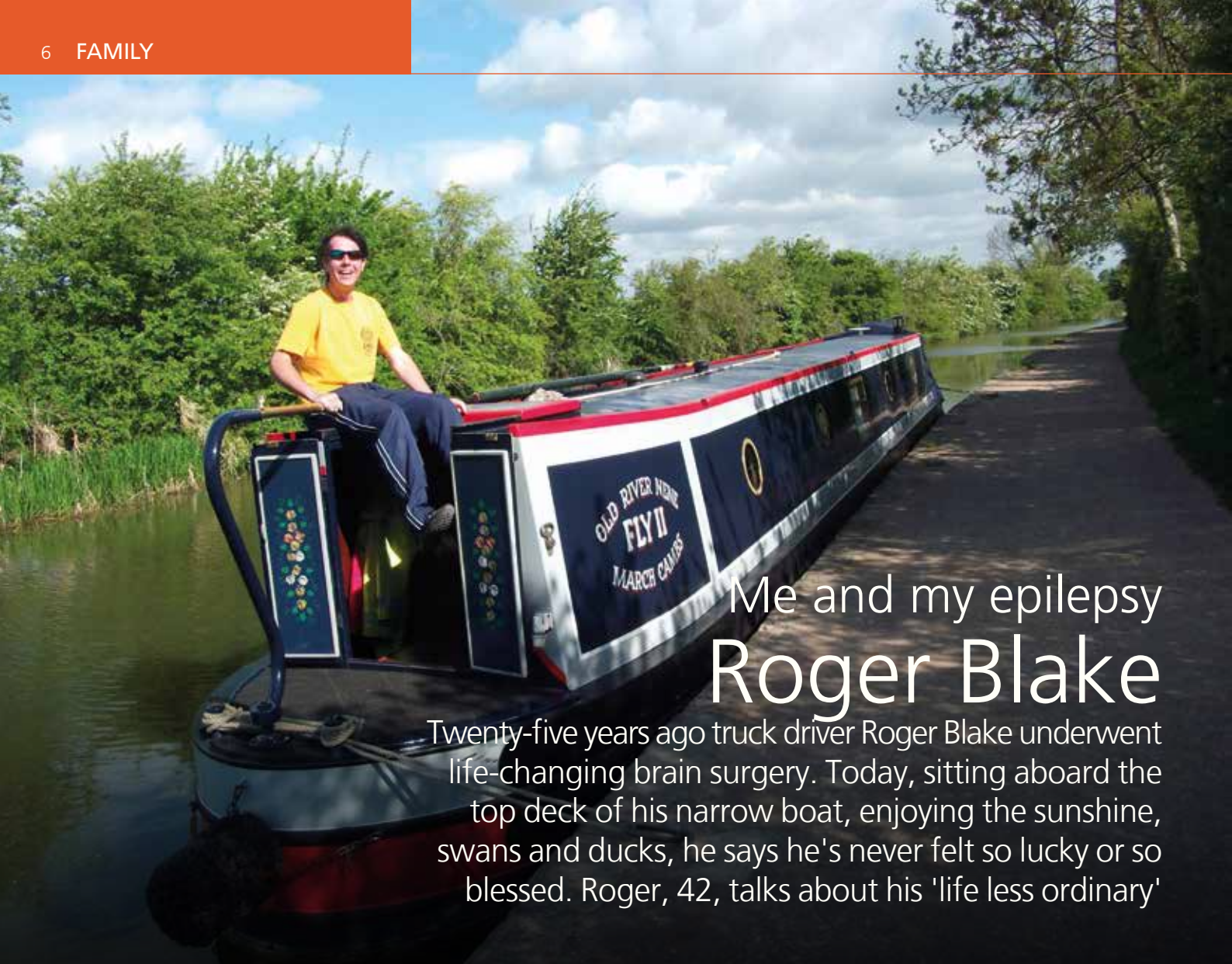
Listen to our group of young influencers talk about their experiences of epilepsy and how it impacts on their lives.



Go to [epilepsysociety.org.uk/turning-epilepsy-its-head](http://epilepsysociety.org.uk/turning-epilepsy-its-head) to hear what not to say.



Take a drone's eye view of residents and staff at Epilepsy Society celebrating 125 years of the charity in numbers.



## Me and my epilepsy Roger Blake

Twenty-five years ago truck driver Roger Blake underwent life-changing brain surgery. Today, sitting aboard the top deck of his narrow boat, enjoying the sunshine, swans and ducks, he says he's never felt so lucky or so blessed. Roger, 42, talks about his 'life less ordinary'

### Diagnosed as teenager

I was 13 when I was diagnosed with epilepsy. It started with peculiar movements or a blink of the eye and a strange sensation on my tongue, perhaps every couple of months. It then increased to once a month, then once a week. Then I started having strange jerking movements and eventually full blown tonic clonic seizures, first weekly, then daily, and finally many times every day.

### Lack of investigations

It was obviously getting worse and worse and my parents felt the cause of my seizures wasn't being properly investigated. I wasn't born with epilepsy and they felt there had to be a reason why I had suddenly started having seizures. I was on a cocktail of different medications and every week I had to have my blood levels checked to make sure I had the right amount in

my blood. And they weren't stopping my seizures. I was in and out of A&E or hospital, and not because of my epilepsy but because of the injuries I sustained while having a seizure.

### Brain surgery

Luckily I was referred to Epilepsy Society's Chalfont Centre where they quickly discovered I had a brain tumour in my right temporal lobe. That was in the days before the centre had an MRI scanner so I had to go up to London for tests.

Professor John Duncan and his team at the Chalfont Centre thought they would be able to get things sorted out for me. They thought brain surgery could be the answer. My parents left me to decide whether or not to have surgery. I felt anything had to be better than what I was experiencing. I went ahead with the surgery just before my 17th birthday.



### Life changing

On the day of my surgery I had a seizure but I haven't had one since and I haven't looked back. I woke up with a bit of a headache but within two years I was off all medication. For the last 25 years I have lived life to the full, doing all the sort of activities that would have been nigh on impossible for me as an epileptic.

### World traveller

I spent most of my 20s working my way around the world. I volunteered to work with kids in Ethiopia and Uganda, went on safaris and climbed the

highest volcano in Rwanda. And I have had the privilege to trek to see rare mountain gorillas in the wild. I worked my way around Australia and New Zealand, cycle-camping, mountain climbing, sky diving and bungee jumping.



### Truck driver

When I came back to England at the age of 30, quite frankly I was lost. I did not know what to do with myself. On a whim I decided to learn to drive an HGV (heavy goods vehicle) and have been a trucker ever since. Life on the road suits me and for nine years I literally ate, slept and lived in my truck. Once a traveller, always a traveller. Of course driving a lorry would be forbidden with epilepsy but given my exceptionally long period seizure and medication free, I gained my licence without obstacles.



### Change of transport

Then two years ago I decided to buy a steel narrow boat. I am marina based for security and convenience but like to take to the waterways at weekends and for my holidays. I'm still trucking, but to be honest, once I had the choice between sleeping on the boat or beside the motorway, the boat won. So now I am a trucker by night and sleep on the boat during the day. And there's a great community at the marina – I have made lots of friends. We sit up on deck, enjoying a drink, and watching the world go by. I've taken to it like a duck to water!



### Raising money for epilepsy

When I gave up travelling and started trucking, I noticed I quickly started to put on weight. So I took up running, gradually building up to being a marathon runner.

I ran my first marathon in 2012 for Epilepsy Society and have run another 12 since, plus countless half marathons. I've also raised more money for the charity by shaving off my dreadlocks that grew during my travelling days.

### Lucky and blessed

I never forget just how lucky and blessed I am to be free from the disruptions of epilepsy. I would never have been able to do all the things I have done if it had not been for the brain surgery and I know that not everyone has the same outcomes as me.

I particularly think about how fortunate I've been around the anniversary of my surgery in June.

## Tell us your story

Would you like to share your story about how epilepsy impacts on your life. You might also like to talk about the effect it has on those around you. Or you might like to talk about how you get on with your life in spite of your epilepsy.

To share your story in *Epilepsy Review*, please:

- Fill in our online form at [epilepsysociety.org.uk/become-media-contact](http://epilepsysociety.org.uk/become-media-contact)
- Download the form at [epilepsysociety.org.uk/yourstoryresearch](http://epilepsysociety.org.uk/yourstoryresearch) and send to: Press Office, Epilepsy Society, Chesham Lane, Chalfont St Peter, Buckinghamshire SL9 0RJ.
- email [pressoffice@epilepsysociety.org.uk](mailto:pressoffice@epilepsysociety.org.uk) for a copy of the form to send to us at the above address.



# #explainepilepsy

Did you know that almost two thirds of adults in the UK with no experience of epilepsy would not know how to support someone during or after a seizure? And more than a quarter of people who have a family member with epilepsy, would not know how to help them.

These were the worrying findings of a YouGov poll of more than 2,000 UK residents, carried out during National Epilepsy Week 2017. For anyone who has a seizure in public, results suggest that they have just a 1 in 3 chance of there being someone to hand who would feel able to help.

Of course that is not to say that other people would not step in to assist, but they would not feel confident of what to do.

Every year, Epilepsy Society collaborates with Young Epilepsy and High Street fashion retailer River Island, to raise awareness of epilepsy with our campaign *Everyone Knows Someone*. And this year, with the startling results

of the poll commissioned as part of the campaign, we set out to try and put things right. Or, in social media terms, we set out to both #explainepilepsy and raise awareness of seizure first aid.

We wanted to get the conversation started in a way that would reach beyond the boundaries of the epilepsy community and engage with audiences that we rarely reach on a daily basis. So we called on the services of some of our dynamic, young supporters so that they could explain epilepsy in their own words, sharing their thoughts and views via River Island's website and the social media channels of both charities.

Working together, we hosted

an event at River Island's Style Studio in Oxford Street, London, chaired by BBC producer and writer Colin Grant. Guests included actors Jennie Jacques (Amazon's Vikings) and Kerry Howard (BBC Three's Him & Her), Cambridge United footballer Leon Legge, singer Stacey McClean (former S Club Juniors), Huff Post blogger Katy Mann, film director Georgina Higgins, YouTuber Lewis Hine and student Olivia Salvati.

New York DJ Chelsea Leyland also made a video about our campaign which was shared via social media.

You can read some of their thoughts here or go to [epilepsysociety.org.uk/everyone-knows-someone](http://epilepsysociety.org.uk/everyone-knows-someone) to hear them talking about epilepsy, stigma, education, employment and life. (Please note the competitions are now closed.)

Opposite you can read in more detail Jennie Jacques and Georgina Higgins talking about epilepsy and over the page, find out what happened when our chief executive Clare Pelham went into battle with an avocado.



**Actress Jennie Jacques (Vikings), and script supervisor Georgina Higgins ('Florence Foster Jenkins' and 'Paddington Bear 2') may be on different sides of the camera, but they are on the same page when it comes to epilepsy. Jennie's youngest sister lives with seizures and Georgina has epilepsy. Here the two friends talk film sets, stigma and why they want more people to understand how to look after someone during a seizure.**

**Jennie:** 'Georgina and I first became friends at an event in London to launch Everyone Knows Someone. When Georgina shared her story with me I felt inspired and proud to have met someone in the industry who was speaking out about epilepsy.'

'There are some really worrying facts around epilepsy. Two thirds of adults in this country who have no experience of epilepsy would not know how to help someone during a seizure. And more than a quarter of people with a family member with epilepsy wouldn't feel confident of looking after them.'

'I am one of seven children and my youngest sister has epilepsy so it's important to me that when she goes out, those people around her know what to do if she had a seizure. As always in life, until you experience something directly, it's hard to fully empathise. But when you nearly lose someone to epilepsy you really learn a lot.'

'I see the way epilepsy affects my little sister's life and it's not just about the seizures. When you are taking certain types of epilepsy medication they can make you very tired and

perhaps even lose confidence to step outside the house – especially if you worry that you might have a seizure.'

'Because there is still a stigma around epilepsy, people don't always want to talk about it. So quite often people aren't aware that someone has epilepsy.'

'I strongly believe with an increased awareness and education that starts with young children, we can all improve our ability to understand epilepsy. We can encourage compassion which will inevitably contribute to making a difference to the lives of people with epilepsy.'

One in 100 people has epilepsy. Taking a moment to know what you would do could be hugely beneficial and it could save a life.'

**Georgina:** 'Jennie is the first actress who has understood what you mean when you say the word "epilepsy".'

My first seizure was when I was 12 years-old playing a computer game at home. I suffer from tonic-clonic

seizures. My seizures are caused by a combination of triggers, usually stress, tiredness and spending too much time at a computer screen. My epilepsy was under control for years until my final year of university due to the lifestyle choices and stress of exams.'

Working on a film set requires long days and can be stressful and tiring for everyone which is not ideal for a person with epilepsy. A few years ago I had a seizure on set and it did delay the schedule of things that afternoon, but the cast and crew were very understanding and as I love my job I returned confidently to set like nothing had happened.'

You should never feel ashamed of your condition. I'm very thankful that my epilepsy hasn't stopped me from pursuing my career, nor has it stopped me from travelling the worlds.'

[epilepsysociety.org.uk/10-first-aid-steps-for-convulsive-seizures](http://epilepsysociety.org.uk/10-first-aid-steps-for-convulsive-seizures) or [/first-aid-all-seizures](http://epilepsysociety.org.uk/first-aid-all-seizures)



**2m+**

Guardian print and online readers reached with avocado letter

**500k**

the reach of our Facebook posts during National Epilepsy Week

**400k**

River Island followers on Twitter saw our posts.

**2m+**

River Island Facebook fans saw our Everyone Knows Someone posts

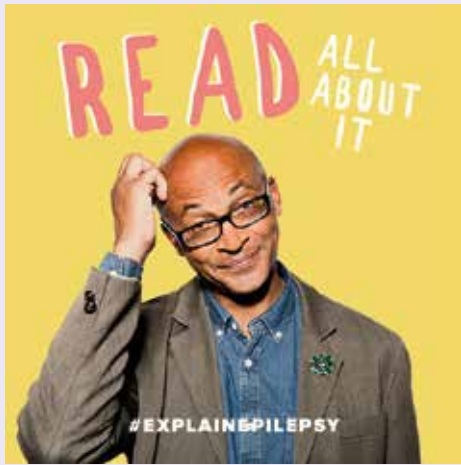
Our campaign **#explainepilepsy** was named by The Drum as the European Creative Work of the Week [www.thedrum.com](http://www.thedrum.com)

**Creative Work of the Week**



**30,000**

people watched our videos showing young people talking about epilepsy



**Colin Grant**, BBC producer 'We have all had negative perceptions about epilepsy. It is only being so close to my brother that these prejudices dropped away.' Colin lost his brother to epilepsy.



**Katy Mann**, HuffPost blogger 'I have days when I can't walk at all without falling down. My 10 year old and five year old constantly look out for me and it should be me looking out for them.'



**Lewis Hine**, YouTube vlogger 'If you are diagnosed with epilepsy, stay positive. I have had tough times but I wake up every morning as my crazy, normal self.'



**Kerry Howard**, actress (Him & Her) 'When we first found Dan (my brother) we did not know what a seizure was. We thought he was dying. Epilepsy has never defined Dan. He has had a very successful career.'



**Olivia Salvati**, English student 'If you're feeling alone and a bit down in the dumps, remember that feeling will go, things are going to get better.'



**Leon Legge**, Cambridge United FC captain. 'Don't let epilepsy get you down. There are things that you can do. Get advice from your doctors. I have always been able to do what I like doing and that's playing football.'



## Avocados and seizure first aid

In the run up to National Epilepsy Week, the media was flooded with articles, videos and emergency information about how to cut an avocado safely. This followed an influx of amateur chefs in A&E with injuries sustained preparing their avocado-based brunch. Chelsea and Westminster Hospital saw four patients in one week.

In traditional 'Go tell 'em, Pelham' style, our feisty chief executive Clare Pelham was on to it. Now that the nation has learned to cut an avocado safely, she wrote in *The Guardian* during National Epilepsy Week,

perhaps they can broaden their knowledge by learning how to assist someone during and after an epileptic seizure. Two thirds of UK adults would not know how to help, yet London Ambulance Service alone attends 40 epileptic seizures a day.

The result – 580 *Guardian* readers went straight from the letter to our seizure first aid page.

**You can read the full letter at [www.theguardian.com/society/2017/may/16/you-can-cut-an-avocado-safely-now-learn-to-help-someone-with-epilepsy](http://www.theguardian.com/society/2017/may/16/you-can-cut-an-avocado-safely-now-learn-to-help-someone-with-epilepsy)**

We receive many calls to our Helpline about problems with benefits, particularly the transition from the old Disability Living Allowance (DLA) to Personal Independence Payment (PIP). We also receive many queries and comments about this via Facebook and Twitter.

Our information officer Andrée Mayne explains how PIP works and how to appeal if you are not happy with a decision.

And on page 14 you can read how one couple appealed against a decision to stop their benefits and finally won their case



## Personal Independence Payments



### Andrée Mayne

Andrée is our epilepsy information officer, responsible for providing up-to-date information about all issues concerning epilepsy, including different types of seizures, medication and how epilepsy may affect employment, education, driving and lifestyle. Andrée has worked at Epilepsy Society for eight years.

Personal Independence Payments (PIP) started to replace Disability Living Allowance (DLA) in April 2013. The payments are designed to help towards the extra costs of living with a long-term health condition or disability such as epilepsy. But it is important to know that the newer benefit PIP is assessed on the impact your condition has on your life rather than on the condition itself.

#### What is PIP?

PIP is a non means-tested benefit. This means it does not depend on your savings or income. It is a tax-free benefit that you can receive whether you are in work or not.

#### Who can claim PIP?

To be eligible to claim PIP you must be aged between 16 and 64 and have needed some help or support with daily living activities, or with getting around for at least the last three months.

PIP is based on your individual circumstances, so it's important to explain exactly how your epilepsy and seizures impact on your day-to-day life.

#### How to apply for PIP

The first step for most people is to call the Department for Work and Pensions (DWP). You'll need to give them some basic information about yourself such as your contact details and date of birth. You'll also need to give your National Insurance number and bank account details so you can be paid directly if you qualify.

If you are not able to call the DWP yourself, you can ask someone else to call on your behalf, but you'll need to be with them when they make the call.

#### What happens next?

If you are eligible to apply for PIP you'll receive a form called 'How your disability affects you'. The

form asks questions about your epilepsy in relation to 12 different daily activities.

Sometimes, explaining about epilepsy and how it affects you can be difficult. The assessors should have an understanding about the impact of epilepsy on daily living, but it is important to explain in full the impact on you as an individual. Think about how it affects you on a bad day, not a good day. Explain what you can't do and what help you need.

When you complete your form include as much information as possible and be as honest as you can so the assessors understand how epilepsy impacts your life.

You'll also need to provide any supporting evidence for your claim. This might be a letter from your doctor or a social worker explaining how your condition affects you. It's always best to send photocopies of any this information instead of the original documents.

Make sure you return your form and any supporting documents, within four weeks. If you're not able to do this you must let the DWP know.

### Face-to-face consultation

After you've completed the form you'll be invited to have a face-to-face consultation with a health care professional chosen by the DWP. This is a chance for you to explain how your epilepsy affects you and to go through the daily activities included in the form.

### PIP assessment and payments

The assessment looks at 12 activities in two categories: daily living and mobility.

For each activity, there is a list of descriptions of how your condition affects you. Each description has a score which is added up to a single total for daily living, and a total for mobility. So for each category, if you score between 8–11 points you will receive the 'standard rate' of PIP. If you score 12 or over, you will receive the 'enhanced rate' (see next column). For example, someone could get 'standard rate

mobility' and 'enhanced rate daily living'. The weekly rates for PIP are:

Standard daily living weekly rate	£55.10
Enhanced daily living weekly rate	£82.30
Standard mobility weekly rate	£21.80
Enhanced mobility weekly rate	£57.45

Visit [epilepsysociety.org.uk/pip-assessment-criteria](http://epilepsysociety.org.uk/pip-assessment-criteria) for detailed information about the daily living and mobility activity descriptions.

### Decisions about your claim

A DWP 'case manager' will write to you to let you know the decision about your claim. If your claim is unsuccessful or your situation has changed, you can appeal and ask the DWP to look at it again. You will need to do this within one calendar month of receiving your letter.

### How to appeal the DWP decision

If you decide to challenge the DWP's decision, complete the following steps in order; you'll also need to respond quickly (usually within one month) at each stage.

#### 1. Ask for a 'mandatory reconsideration'

Write to the DWP within one month of the date of the decision, to ask for a 'mandatory reconsideration'. You won't need to complete a form this time, but you must include the following information in your letter:

- your name, address, date of birth, National Insurance number, and the date of the decision about your benefit;
- contact details and a signed letter of authority from any adviser representative you may have (such as an adviser from an agency like the Citizens Advice Bureau); and
- your explanation of why you think the decision is wrong, pointing out how your situation specifically matches the criteria in the application form, and

1



**Phone the DWP**  
Give them your details:



Contact details



Date of birth

AB 12 34 56 C

National insurance  
number



Bank account  
details

On 5 June, we heard that we had won our case. It is a huge relief. I just want to tell people not to give up fighting. Even though it is hard, you should never give up.

ANNE (See page 14)

2



Form arrives through the post

3



Describe your epilepsy on a bad day

4



Four weeks to send back form

5



Face to face consultation

6



12 activities daily living/ mobility

7



Receiving the decision

enclosing a copy of any supporting 'evidence' for your claim, such as notes from your doctor or other professional involved in your care. Include this even if you have already provided this information with your original claim. Include any new information if your situation has changed.

Being specific about each individual point where you fit the criteria for the benefit will make it easier for the DWP to focus on those specific areas.

A second case manager will look again at your situation and send you a second decision, called a 'mandatory reconsideration notice'.

This could say that the first decision still stands, or that you have been awarded more benefit, or less benefit than you had been awarded at first. The notice will say whether you can appeal against this second decision, if you are not happy with it. If you are told you can appeal, this needs to be done within one month.

## 2. Appeal

You can only appeal if you have had a mandatory reconsideration first. To appeal, send a written letter or 'notice of appeal' form to the tribunal office listed on the DWP's mandatory reconsideration notice, within one calendar month of the date of decision on the

notice. The tribunal service is run by an independent agency called the HM Courts and Tribunal Service (HMCTS). To access the form, go to [hmctsformfinder.justice.gov.uk](http://hmctsformfinder.justice.gov.uk) to

- Download or complete the 'Notice of appeal against a decision of the Department for Work and Pensions – SSCS1' form and send it to the address provided, with a copy of the 'mandatory reconsideration notice'; or
- Download a guide called 'How to appeal against a decision made by the Department for Work and Pensions' – SSCS1A.

Or ask your local Citizens Advice for a paper copy of the appeal form. ►

## Anne and Mark's fight for benefits



Anne has been a carer for her husband Mark for almost 20 years. But in November last year, when Mark had to change from claiming Disability Living Allowance to Personal Independence Payment, the couple were told that both his benefit and Anne's carer's allowance were being stopped. Anne explains how they refused to give up fighting and eventually had their benefits reinstated.

'When Mark went for his assessment to be transferred over from DLA to PIP, we were seen by a very nice lady. We were very comfortable with her. We felt she understood what it was like to have epilepsy and really believed what we were saying.'

Then in November we got the decision through that Mark wasn't going to be getting PIP any more and that I would lose my carer's allowance. It was devastating. Mark wanted to commit suicide. It was tough for us all. My son is 15. I had to stop giving him pocket money.

I felt like giving up. I have my own medical illness to deal with as well, but I am a strong person and I knew that we should fight the decision. We got a mandatory reconsideration but this was turned down and we decided to go to a tribunal. We also sought the help of our local MP.

Mark has had epilepsy since he was seven. He usually has night time attacks but they really impact on him during the day. He is very shaky and not very confident, especially with things like carrying hot teas. He also has depression and needs ongoing support. I have to be there for him.

Mark used to work as a butcher, then he worked in a cereal plant. His employers were aware of his epilepsy as he would have a couple of seizures a week, but it was the depression that forced him to give up his job.

He had a few odd jobs over the years including one at Morrisons. But his epilepsy affects his memory and he couldn't remember things he had been trained to do and had to leave. He applied for another job as a butcher but they said "no" for health and safety reasons. He was left feeling unwanted and unemployable, and it didn't help his depression.

Going to a tribunal takes a lot out of the whole family, not just the person who is being cared for. But on 5 June we heard that we had won our case. Mark now has the standard rate of PIP. He's not getting his mobility allowance as he did before but we don't mind that. I am also getting the carer's allowance again. It is a huge relief.

I just want to tell people not to give up fighting. Even though it is hard, you should never give up.'

### Getting help from your MP

If you are unhappy with the service you have received from the DWP, or if you feel that the PIP rules are unfair, you could seek the help of your local MP.

Contacting your MP may help you to get an explanation of the decision you have received; speed up a decision; or help you to get the law changed.

If you decide to contact your MP, you will need to provide:

- the reference number you have from the DWP for your claim or complaint
- your full name, address, and contact numbers
- explain what has happened, giving dates and how you have been affected
- details of what you would like to see happen to put things right.

You can contact your local MP on the Find your MP page at [www.parliament.uk](http://www.parliament.uk) or at [www.theyworkforyou.com](http://www.theyworkforyou.com)

### Find out more

For more information about applying for benefits and going to appeal, go to [epilepsysociety.org.uk/benefits](http://epilepsysociety.org.uk/benefits)



**epilepsy  
society  
helpline**

**01494 601400**

Monday to Friday 9am to 4pm  
Wednesday 9am to 8pm.  
Confidential. National call rate.



# Ask Clare



Epilepsy Society's chief executive, **Clare Pelham**, invited our supporters to ask her about issues that concern them most, via social media. Here is a selection of questions and answers. If you have a question for Clare, just let us know (see page 17)

**Lesley:** Is the Epilepsy Society going to do a high profile campaign in the media, such as tv, to raise awareness of epilepsy and the effect it has on sufferers and their carers, in the same way that cancer charities often do?

**Clare:** It is incredibly important that we raise awareness of epilepsy so that people who have seizures can be supported when they occur. As you will probably be aware, paid-for advertising is very expensive which

is why only the most well endowed charities buy advertising space. This would be beyond our means at the moment but we can do lots of things to raise our profile.

We regularly place stories in the national media relating to the lives of people with epilepsy. We had a lot of tv coverage about overcharging by the pharmaceutical company, Pfizer, and our campaign run with River Island during National Epilepsy Week was covered in the press.

Alongside this social media allows us to curate and promote our own news. Facebook and Twitter are brilliant tools for sharing information and stories. We have over 50,000 followers on Facebook and 19,500 on Twitter, so this gives us a fantastic reach for epilepsy awareness raising.

**Jennifer:** I'd love to hear about the advent of new medications. It would provide great hope for those with no success on current range of meds.

**Clare:** Whenever there are any exciting new developments in terms of medications or therapies, we make sure we bring them to the attention of people through *Epilepsy Review* and through social media channels. I am not a doctor and am not qualified to comment on different anti-epileptic drugs which are a complex and specialised area. I would always say you should discuss your own medication with your own doctor.

**Jess:** Can guidance be given as to what profession you are capable of depending on your seizure type?

**Clare:** I think, Jess, that a large part of the challenge here for us is about awareness raising and giving employers and employees the confidence to know that seizures can be managed in the workplace. Nobody panics if someone goes home with a headache and the same should apply in the case of a seizure.

I would like to work with employers to provide more opportunities for people with epilepsy. I suspect there are certain areas where employment opportunities are restricted because of a lack of understanding of the

condition and how it is managed. Epilepsy Society can contribute by promoting better understanding and awareness in the work place. This is important work for us in the future.

**Charlotte:** Can schools be given more training and information for both the staff and pupils, especially when it comes to seizures that are hard to see? I feel that because the teachers can't see my son's absence seizures, they don't take them seriously enough.

**Clare:** I think there is a great deal more that could be done to support teachers and raise awareness in schools so children with epilepsy are understood, especially if they have seizures at school.

At the moment we have many priorities for raising awareness but training in schools is something we are very conscious of. We are always willing to support parents and others with leaflets and information, if they want to talk to a group within a school. The most compelling advocates for change are those who have a family member affected by epilepsy.

**Shelley:** I would like to see more joined up thinking in relation to seizures and mental health. Epilepsy is not simply a physical problem. Depression and anxiety related to seizures can affect all areas of life.

**Clare:** Thankfully we now understand that physical health does not exist in a vacuum. We need to look at people in the round so that we don't just see someone with epilepsy, or with red hair, or with a broken leg. But we see a whole person.

The causes of epilepsy are multi-factorial and vary from person to person. It is important for us all to keep well and have the support of friends and family as well as healthcare professionals. I am very pleased that there is now a much greater openness about mental health. We all recognise that we have different challenges at different times in our lives.

**Priya:** When is the Society going to remove the Rt Hon David Cameron MP as a vice president? I recognise that he has personal experience of the condition, and this question is asked with absolute

love and respect for his son, Ivan. The decisions he took as Prime Minister of this nation have had such devastating effects on people with epilepsy.

**Clare:** I have been at Epilepsy Society since just before Christmas, and in that time I have not been part of any discussion with trustees about the selection of vice presidents. But I do not think in any event that it would be appropriate for me to comment on the merits of any of our vice presidents.

As a charity it is important that we recognise that our staff, volunteers, donors and other supporters are all individuals with strong points and less strong points. And as a charity supporting people with epilepsy, we hope we are able to unite people from many different backgrounds. We do not expect to all support or share the same political views or preferences. But we do have common ground in our wish to make the world a better place for people with epilepsy. And I hope that we can all be courteous and respectful of each others' views and choices.

**Richard:** I suggested at an All Party Parliamentary Group epilepsy meeting that I thought Epilepsy Society and Epilepsy Action should link up with the Samaritans. At present Epilepsy Society runs its marvellous Helpline three days a week and Epilepsy Action run theirs five days a week. What about weekends, Christmas, Easter and bank holidays?

If the two groups could link up with the Samaritans and they were all educated in epilepsy, it would be a marvellous thing for so many.

**Clare:** I agree it would be marvellous if our Helpline could be open seven days a week, 365 days a year. I would love to see that happen. I am not going to promise this will happen tomorrow but the Helpline is very high on our list of priorities. We are looking at a number of options and the range of support that we can offer.

There is very high customer satisfaction from people who call us and that is a credit to our Helpline. In any reorganisation it is important we do not lose any of the cherished and unique aspects of the current service. We must proceed with care but I agree this is a great ambition.

**Claire:** Do you have links/ networks in the Midlands? I'm a learning disability nurse with a specialist interest in epilepsy and am looking to make links with other professionals.

**Clare:** Have you tried setting up a network through LinkedIn? This can be really useful for talking to people with similar interests.

**Lynne:** What is cannabidiol treatment?

**Clare:** I must confess, I am not a scientist, so I will hand over here to our medical director Professor Ley Sander, who has written the following explanation about cannabidiol.

'Cannabidiol (CBD) has been shown to be effective in the treatment of refractory epilepsy for some with Dravet and Lennox Gastaut syndromes, tuberous sclerosis and infantile spasms. The drug is also being evaluated as an add-on therapy for adults with poorly controlled focal seizures.

'Cannabidiol contains virtually no THC (tetrahydrocannabinol) – the property of cannabis which is responsible for psychoactive side effects. It is a pharmaceutical product and should not to be confused with the oils often available online.

A new drug application for cannabidiol has been submitted to the US Food and Drug Administration and a European submission is expected to follow.'

**Paul:** Why is the jobcentre making me search for a job using a computer when I've told them I can't use one as it triggers my seizures?

**Clare:** Before the general election I met with Damian Green who was then the secretary of state for work and pensions. It was good to be able to represent the voices of people with epilepsy and hear how the DWP is endeavouring to support disabled people.

We discussed the ways in which people with epilepsy may need support in job seeking. This is something which is perhaps not always well understood.

One suggestion would be to ask for a work coach at your local Job Centre Plus. This would be someone who could support you in your search for work without asking you to use a computer.





**Jeannette:** I have just got my PIP forms from the government and they are overwhelming for me. I have had epilepsy for 30 years and take three different epilepsy drugs but still have seizures and vacant moments. Do you know of any organisation that could help me with these forms?

**Clare:** We frequently get calls to our Helpline about PIP (personal independence payment) and it is a common topic of conversation on our social media channels. We have a detailed section about 'benefits' on our website with information to help with application forms, assessments and appeals. (See also, page 11).

Many people also find it very useful to contact the Citizens Advice Bureau who offer support with these forms.

**Bridget:** Are there support groups where you can meet other people who have epilepsy, to share your experiences? I live in Chicago. I do not discuss my epilepsy with anyone, but it would be nice to share with other people who have the same condition.

**Clare:** The great thing about today's social media, is that you can connect with other people with similar interests from almost anywhere in the world.

Our Facebook page is always a very lively platform for discussion and support about epilepsy, although of course, the discussion is open and not private. But many people find it useful to share their experiences with other people at [Facebook.com/epilepsysociety](https://www.facebook.com/epilepsysociety)



**Peter:** I wonder if any survey has ever been made about the number of neurologists with training in epilepsy. Diagnosis or misdiagnosis can be very important in the early stages and could make a difference to eventual outcome.

**Clare:** In fact I believe that all neurologists are trained in epilepsy to varying degrees, Peter. However, in 2013 the National Audit of Seizure Management in Hospitals showed that across 154 emergency departments, only 55 per cent of first seizure patients were referred to a neurologist or epilepsy specialist. Eighteen per cent of those who already had a diagnosis of epilepsy were not taking any epilepsy drugs and witness histories were only sought in 75 per cent of first seizures. We have a lot of work to do.

**Helen:** Are there plans for more NHS staff to advise and monitor folk with epilepsy?

**Clare:** I think we all know from daily news about the pressures the NHS is under. They have many significant challenges on their plate, including the overwhelming number of patients in A&E and the shortage of doctors and nurses. I think more NHS staff are on everyone's wish list. But if we hear any good news, we will certainly let you know loudly and clearly.

**Pat:** My 76-year-old husband has suffered two 'fits', both while sleeping. He has returned his driving licence to the DVLA. Do you know if he would qualify for a disabled person's rail card?



**Clare:** Yes Pat, your husband would qualify for a disabled person's rail card which costs £20 for a year. You can find out more at [disabledpersons-railcard.co.uk/](https://disabledpersons-railcard.co.uk/) He could also apply for an older person's bus pass at [gov.uk/apply-for-elderly-person-bus-pass](https://gov.uk/apply-for-elderly-person-bus-pass) You might like to check out the driving regulations for people with epilepsy at [epilepsysociety.org.uk/driving-regulations](https://epilepsysociety.org.uk/driving-regulations)

**Julie:** I would like to know why people with non-epileptic seizures are treated so badly by the NHS. It's a condition and a disability but it's a lottery as to whether you get help or not. Why is this?

**Clare:** As far as I am aware there has not been any research into patient experience in this area but we know many NHS staff are too busy to always give patients the support they need.

There is a very real tension between services tailored to local needs and preferences, and a desire for a uniform, standard service across the country.

If you have particular concerns about local services, it is often good to raise this with local providers. The experiences of patients are taken very seriously by NHS bodies.

If you have a question you would like to ask Clare, please email [nicola.swanborough@epilepsysociety.org.uk](mailto:nicola.swanborough@epilepsysociety.org.uk), putting 'Ask Clare' in the subject field. Or you can send your question via Nicola Swanborough at the address on page 2. Please note, Clare cannot answer medical or personal questions.



# Heart of the matter

When Adrian and Sue Perry learnt that not only did their son, Tom, have a rare epilepsy syndrome but that he was also at risk of SUDEP, they set about developing a monitor to detect all his night time seizures and give him the best chance of survival

Sue Perry remembers vividly the moment she was told her son Tom had Dravet syndrome. 'We were out with the dog and were standing by the pond, when Tom's consultant phoned to say Tom had tested positively for Dravet syndrome,' said Sue. 'I just stood and cried. It was such a relief.

'In the back of my mind I had always blamed myself for Tom's epilepsy. I always thought it was something I must have done wrong when I was

pregnant. So to hear that it was caused by a mutation in his genes and was something that was always going to happen, something that we couldn't have stopped, was just such an overwhelming sense of relief for me.'

The diagnosis of Dravet syndrome – a severe form of childhood epilepsy – did not change Tom's treatment but it did explain why, alongside seizures, he also had learning difficulties. At one point he could only rock back and forth and lost his communication skills, although these have gradually returned.

But the relief was overshadowed by a throwaway remark from another consultant. 'She said in passing that Tom was still a high risk for SUDEP,' said Sue. 'We had never heard of sudden unexpected death in epilepsy.'

That was in 2011 and Tom was 17. He had been having seizures since a first tonic clonic seizure at the age of five months left him unconscious for nine hours. A cocktail of drugs had failed to control his epilepsy and at one point he was having myoclonic jerks

## Sudden Unexpected Death in Epilepsy – SUDEP – is very rare.

There are more than half a million people in the UK with epilepsy and 600 die each year from SUDEP. These deaths are thought to be preventable. The risk of SUDEP varies from person to person, but you can find out how you can reduce your risk at [epilepsysociety.org.uk/sudep](http://epilepsysociety.org.uk/sudep)

that Sue describes as 'hitting him like a high voltage cable – it was as though he'd been thrown across the room'.

'It took us some time to process the information about SUDEP,' said Sue. 'This was huge. We have always wanted to be with Tom whenever he had a seizure. We always wanted to make sure he was alright.'

Sudden unexpected death in epilepsy is very rare. There are over half a million people with epilepsy in the UK and 600 die each year from SUDEP. But every one of those deaths is thought to be preventable.



Epilepsy Society has been pioneering the use of Pulseguard in a care home setting where it can be linked into an on-site call alarm system.

Sally Putta is senior occupational therapist at Epilepsy Society which is home to 100 residents with complex epilepsy and associated conditions.

'Over a period of nine months we have been carrying out a small project to see whether Pulseguard would help us to pick up seizures that would not be detected by traditional monitors that rely on sound, movement and moisture,' explained Sally.

'After assessment we selected to use the monitor with three residents who have multiple seizure types and are in the high risk bracket for SUDEP. With all of them we have been able to detect all their seizure types during the night.'

'This enables us to be with the resident promptly and support them through the seizure. It also means staff have a greater chance of stopping a seizure from escalating into status epilepticus by the use of appropriate emergency medication.'

Rebecca Reynolds, left, was one of the residents involved in the project. Rebecca had a difficult sleeping pattern and was afraid of having seizures in her sleep. In her case the

monitor picked up more tonic seizures in the night between 3am and 8am, than staff had previously been aware of.

Sally continued: 'Rebecca was having her last medication at 6pm, but with the seizure pattern observed through the monitoring equipment, our neurologist moved her medication to 10pm. This was with a view to giving her better seizure control and improving her sleep pattern.'

User experience at Epilepsy Society has helped to develop PulseguardPro to work effectively in care home settings across the country.

Adrian Perry of Adris Technologies, said: 'Our work with Epilepsy Society and especially the occupational therapy department, has been invaluable.'

'The funding from the Nominet Trust has meant both our organisations have been able to work closely in developing the PulseGuard Pro system for professional organisations. Epilepsy Society's feedback, patience and support has been fantastic. As we develop new features we look forward to continuing the relationship we have with Epilepsy Society.'

Adrian Perry is a former electrical engineer and describes himself as a problem solver. 'I like to try and solve problems if there is something that needs to be done,' he said. 'In Tom's case we needed to know everything about his condition. We wanted to do everything in our power to preserve life.'

So the Perrys set about developing a monitor that would alert them every time Tom had a seizure. He was having one or two seizures a night and the family were already using an audio monitor and under-mattress seizure detector, to alert them to his seizures.

Adrian continued: 'These worked if Tom had a tonic clonic seizure and there was sound and movement for the monitors to pick up, but his seizures were changing and we noticed via a CCTV camera that the monitors weren't detecting when he had a tonic seizure. He would go totally rigid and just lock down, so there was nothing for the monitors to record.'

Adrian's research helped to identify that a common denominator in Tom's

seizures was a change in his heart rate. So Adrian set about developing a heart rate monitor that would trigger an alarm if Tom's heart rate rose or fell. Not only would this help detect seizure activity but it might suggest the need for medical intervention.

Today, due to the success of the monitor in detecting Tom's seizures, it has been developed as Pulseguard, and made available to the public through Adrian's company Adris Technologies. A watch-type sensor is worn on the wrist or ankle that will read the heart rate, measuring blood flow through capillaries under the skin. Data is then transmitted to a tablet computer and an alarm is activated if it senses the heart rate has exceeded or dipped below the set thresholds. Data can be downloaded for clinical analysis and medical research.

The monitor is not only being used by parents but is now also being used in nursing homes and care homes to improve seizure detection and support people at highest risk. But the



company remains a not-for-profit organisation that is self funded apart from two grants from the Nominet Trust.

Adrian continued: 'We are amazed every day that what we have produced out of love and care for our son is benefiting so many other people.'

Sue added: 'So many parents have told us that they have spent their life sleeping with their child because they are terrified of losing them. Our monitor has allowed children to have independence and parents to have the sleep they need. And that is true for our family, too.'

# Getting involved



Epilepsy Society's director of fundraising, Amanda Ball, is keen for everyone to get involved in our fundraising programme and make a real difference to people with epilepsy. She explains how.



**Here's how you can help:**

**Skydive for us – the ultimate challenge for adrenaline junkies**

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

We are in the process of refreshing our approach to fundraising and our new mission is to deliver a big uplift in our income that will fund more of our flagship programmes, our world class research, campaigning, helpline, information and support services. Together these will help create a better life for both people living with and affected by epilepsy.

We're looking to move from good to great!

But we can't do this entirely on our own and this is where you come in. Whether you want to reach for the skydive, or stay safe on the sofa with a friendly Gus and support our g-nome (geddit?) appeal, there are lots of ways you can help. From buying a raffle ticket, to making a monthly donation or leaving a gift in your will, together we can make a huge difference.

Why not get fit and active and raise money for us through our exciting cycling, swimming and running events, or combine all three and do a triathlon.

And if you're working, why not ask your company to adopt Epilepsy Society as their charity of the year, or contact us about sponsorship options. You can also Give As you Earn.

As the saying goes, every little helps, and we're really grateful for all your support. So from the bottom of our hearts, a massive thank you.

**Run, cycle or swim and be part of Team Purple**

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

**Do your own thing – cake sale, head shave, non-uniform day... We can support you.**

[epilepsysociety.org.uk/do-your-own-thing](http://epilepsysociety.org.uk/do-your-own-thing)

**Adopt Gus the gnome for just £5 and help fund genetic research**

[epilepsysociety.org.uk/gus-gnome-and-new-era](http://epilepsysociety.org.uk/gus-gnome-and-new-era)

**Win £1,000 in our annual draw**

[epilepsysociety.org.uk/annual-draw](http://epilepsysociety.org.uk/annual-draw)

**Make us your workplace charity of the year**

[epilepsysociety.org.uk/corporate-giving](http://epilepsysociety.org.uk/corporate-giving)

**Give as you earn, straight from your salary**

[epilepsysociety.org.uk/payroll-giving](http://epilepsysociety.org.uk/payroll-giving)

**Remember us in your will**

[epilepsysociety.org.uk/leave-legacy](http://epilepsysociety.org.uk/leave-legacy)

**Make a regular monthly donation**

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

*My partner suffers from uncontrolled epilepsy, and has also been told he may be having non-epileptic attacks as well. Last year he had 32 fits.*

*His application for PIP was refused because he was still able to get out of bed by himself, speak to other people and manage to wash and dress by himself.*

*They did not take into account that after a fit he needs looking after 24/7 until he feels better, which can be up to four days. He lost his job because of the time he took off and the stress of having another fit makes things worse.*

*The assessors did not seem interested in his condition at all. We don't know what to do next.*

*Karen, Guildford.*

Appeal it! That's the next step if you haven't already which will then be taken to a tribunal.

We need to come together to make sure they start taking epilepsy seriously! I'm going through the exact same thing right now.

Though I have appealed, my best advice to anyone in the future is get help from Citizens Advice as they deal with these forms day in day out! I'm sorry you're having a hard, I wish there was more I could do to help.

*Aimee-Jo, facebook.com/epilepsysociety*

You can read more replies to Karen's letter at: [facebook.com/epilepsysociety](https://facebook.com/epilepsysociety)

To find out more about help with benefits, read our Guide on page 11 of this issue of *Epilepsy Review* or go to [epilepsysociety.org.uk/benefits](https://epilepsysociety.org.uk/benefits)

## Your replies

I appreciate that we are in a minority as my husband (like yours Karen) has primary generalised epilepsy and NEAD (non epileptic attack disorder). But my husband does receive PIP, has been on it long enough to be reassessed and was still granted it.

The process relies on the subjective views of each individual assessor and there seems to be no consistency – which is inherently wrong and also discriminatory.

I know Citizens Advice support people with epilepsy who are appealing PIP declines. I wish every wronged person luck.

*Hannah, facebook.com/epilepsysociety*

Appeal against the decision and collate all the information from your partner's GP and hospital with regards to the severity of his fits and the amount of medication he needs.

Contact your local MP to see if they can help you with regards to contacting the DWP to overturn the decision. Thinking of you and hope you get the support you need.

*Helen, facebook.com/epilepsysociety*

Because it's epilepsy it shouldn't be assessed as normal. They should be looking at whether it affects your husband for more than 50 per cent of the time. That is how a disability which has good and bad days is worked out with PIP. Appeal, gather evidence and fight the decision. Good luck.

*Julie, facebook.com/epilepsysociety*

I had Citizens Advice help me with the form and they were even willing to come to a tribunal. You literally have to fill forms up as if it is your worst day.

*Jeanette, facebook.com/epilepsysociety*

Exactly the same thing happened to me, for the very same condition. They scored me zero for every section, despite me clearly explaining on the form and in the interview all the ways it affects our daily life. So basically they are saying that my life is absolutely no different to a person who has lived free of any long-term medical condition, which is simply not true. We have struggled significantly financially since the decision. It seems very unfair.

*Jenny, facebook.com/epilepsysociety*

## Next issue

I was diagnosed with epilepsy following a car accident 15 years ago. The diagnosis meant I lost my licence and job as a lorry driver.

The medication I take now works well, and my last seizure was more than 10 years ago. I was able to get my licence back, but I would like to get my group 2 licence back and drive for a living.

The DVLA said I would not be able to apply because I still take medication for my epilepsy. And the regulations say that you must be seizure free and not taking medication for 10 years.

This seems really unfair. Should I stop taking my medication, or will the seizures come back?

*Tony, Bristol.*

### WOULD YOU LIKE TO SHARE YOUR THOUGHTS WITH TONY?

Or do you have a question to ask our readers? 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://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

I was delighted when I saw the Epilepsy Society's 'Everyone Knows Someone' campaign for National Epilepsy Week this year. Personally it's been a bit of a mantra for me, along with my other mantra 'everyone has something', which reminds me of the old adage of how important it is to be kind, because everyone has something that ails them.

With the 'everyone knows someone' idea, I am reminded of the 'Six degrees from Kevin Bacon' game, which if you don't know it, is a parlour game for movie buffs whereby the challenge is to connect any actor to Kevin Bacon in six or fewer steps. In an epilepsy equivalent, you and I, Dear Reader would invariably be connected with only a couple of steps with perhaps only a neurologist and an epilepsy nurse between us.

After my diagnosis it became my Mum's mission to find as many other people with epilepsy as she could from within her friendship group. I was 15 years old when I was diagnosed so not really leaping out of my seat to talk about having epilepsy, but my Mum on the other hand... she's a great talker. It seemed that every time she came home from a church group, drinks party or whatever, she would have another 'you'll never guess who else has epilepsy...'. My godmother's husband, a neighbour's son, Carol who does the coffee at church... Suddenly people with epilepsy were everywhere! What her enthusiasm showed me was that there were plenty of people with epilepsy already in my world, I just hadn't been aware of it yet, because people don't tend to talk about it.

This was truly inspirational to me, not just in brushing away any potential shame or isolation that I might have felt about my diagnosis, but it also came in very handy years later when I came out to my Mum as bisexual. I assured her that she did already know plenty of gay people, she just might not be aware of it yet. My godmother's son, a neighbour's daughter, perhaps even Carol who does the coffee at church...? Once we scratch the surface, we don't need to go far to find the things that we have in common, and all it takes is a conversation to make that connection or build that bridge. As social creatures we always get a kick out of making a connection to someone else (the only exception perhaps being with meeting your partner's exes – that can be uncomfortable. "Oh yoooooo'ure Carol..."). We mostly interact with each other on a pretty superficial

level. That's not necessarily a bad thing. We naturally share the private things only with people closest to us, and who wants to invite every little detail of everyone's lives into their world? We've got our own lives to get on with after all.

But that said, isn't it odd that you could spend eight hours a day, five days a week with someone at work and even after ten years you might not know much more about them than their name and how they take their tea; you might share something really significant in your lives and just never know it. That might be a missed opportunity to be able to offer and receive support, or build a friendship.

There's a general cultural reserve (not exclusively British, but definitely something known to our shores) that there are certain things that would be just terribly awkward to talk about, and how awfully embarrassing to learn and

heavens you really mustn't pry, and well... stiff upper lip, what what. Can you imagine if we did away

with the chit chat, got real about ourselves, our vulnerabilities and experiences? Can you

imagine how much we would learn about each other? How it might be different if

we genuinely didn't feel any shame or embarrassment about something

we have no control over.

I wonder if we knew more about

each other whether that would change our behaviour. Would we be kinder? Would we

take more time to look out for each other? In the

YouGov poll that was published for National Epilepsy Week, I was surprised that two thirds of adults wouldn't feel confident knowing what to do to support someone during and after a seizure. Even more astonishing was the one in four people with a family member with epilepsy who don't feel confident to help. If we talked about it more, would more people look into what they should do, perhaps prepare themselves better and build that confidence?

I confess my own knowledge of First Aid is pretty ropey. I'm vaguely aware of the CPR instruction using the rhythm of the Bee Gees' 'Stayin' Alive', though I certainly wouldn't say that I'm confident. And in a crisis I would desperately hope that someone else did know what to do. In fact you know what, I feel inspired – \*rolls up proverbial sleeves\* – I'm going to sign up to a First Aid training course. I've relied plenty on the kindness of strangers, colleagues and family members. Whether or not they felt confident, the miraculous thing is that they were willing to help me. It's only right that I should be able to pay that forward.

...even Carol has epilepsy!

JULIET STEPHENS  
LAUGHING ALLOWED

## Charity partners with Romans

Epilepsy Society is thrilled to be named as one of eight charity partners by Romans, the property group.

Romans has 29 branches across five counties and in the past has always supported one charity nominated by the business. But this year, for the first time, the company is expanding its charitable giving and is supporting eight charities nominated by staff.

Epilepsy Society was nominated by Kit Rose at Romans in Gerrards Cross.

Vanessa Foot, Romans' new culture and community engagement manager, said: 'Our staff are always very keen to fundraise and particularly asked to support charities in their local communities. We employ many young people and working with

charities is great for employee engagement. Our teams are always up for a challenge. We already have two employees who want to sky dive for the charity, and our managing director of residential lettings and an employee from HR have signed up for the London Marathon next year.

'We are looking forward to working with the Epilepsy Society and supporting their needs in the future.'

Epilepsy Society's director of fundraising Amanda Ball said: 'This is a great opportunity to work with staff at Romans. Work teams can create a wonderful energy and enthusiasm for fundraising and we are really looking forward to our partnership.'

Find out how your workplace could fundraise for Epilepsy Society, email [fundraising@epilepsysociety.org.uk](mailto:fundraising@epilepsysociety.org.uk) or call 01494 601414.



## Epilepsy Society 125

One hundred and 25 residents and staff at the charity's Chalfont Centre in Buckinghamshire, formed the number 125 to celebrate our 125th birthday.

Other celebrations included a week long festival of fun, a party for staff and residents and a party to celebrate the hard work of the 40 volunteers at the Chalfont Centre.



Next year, on 4 March, London will be hosting an entirely new event, The Big Half. The half marathon is run by the organisers of the London Marathon and it is a chance for 15,000 runners of all ages and

abilities to run on a closed road course past some of the capital's famous landmarks.

The event begins in Tower Hamlets and finishes in historic Greenwich. The registration fee to run for Epilepsy Society is £25 and we ask you to raise a minimum of £500. This means that every step you take, from the minute you start training to the time you cross the finishing line, will help to raise crucial funds for our research and support more people with epilepsy.

Don't miss out. Go to [epilepsysociety.org.uk/big-half](http://epilepsysociety.org.uk/big-half) and find out how you can register.



## RideLondon100

A big thank you to our amazing 35 cyclists who took part in Prudential RideLondon100 for us. And thanks to their friends and families who turned out to cheer everyone on. Find out how you can get involved in next year's event at [epilepsysociety.org.uk/prudential-ridelondon-surrey-100](http://epilepsysociety.org.uk/prudential-ridelondon-surrey-100)

## Anna and musical medics

Cellist Anna Frazer made an emotional return to the stage when she played with the Radcliffe Orchestra to help raise money for Epilepsy Society. The orchestra is made up of medics from all over the Oxford area.

It was the first time Anna had played a concerto with a full orchestra since her son William was diagnosed with epilepsy at the age of six.

The concert raised more than £1900 for Epilepsy Society and will help to fund important genomic



research into the causes and treatment of epilepsy, as well as supporting the half a million people in the UK with the condition.

## Keep in touch with us

New data protection regulations mean we must update the way we contact you in the future, so that you only receive information that is relevant to you. Watch out for more details in the next issue of *Epilepsy Review* or go to [epilepsysociety.org.uk/contact-me](http://epilepsysociety.org.uk/contact-me) to create and manage your contact details and preferences.

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Tickets are £1 and by taking part you will be helping us to provide important information for people with epilepsy, when they need it most.

You can take part online at  
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## Epilepsy Review magazine

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