
A VICAR'S LIFE

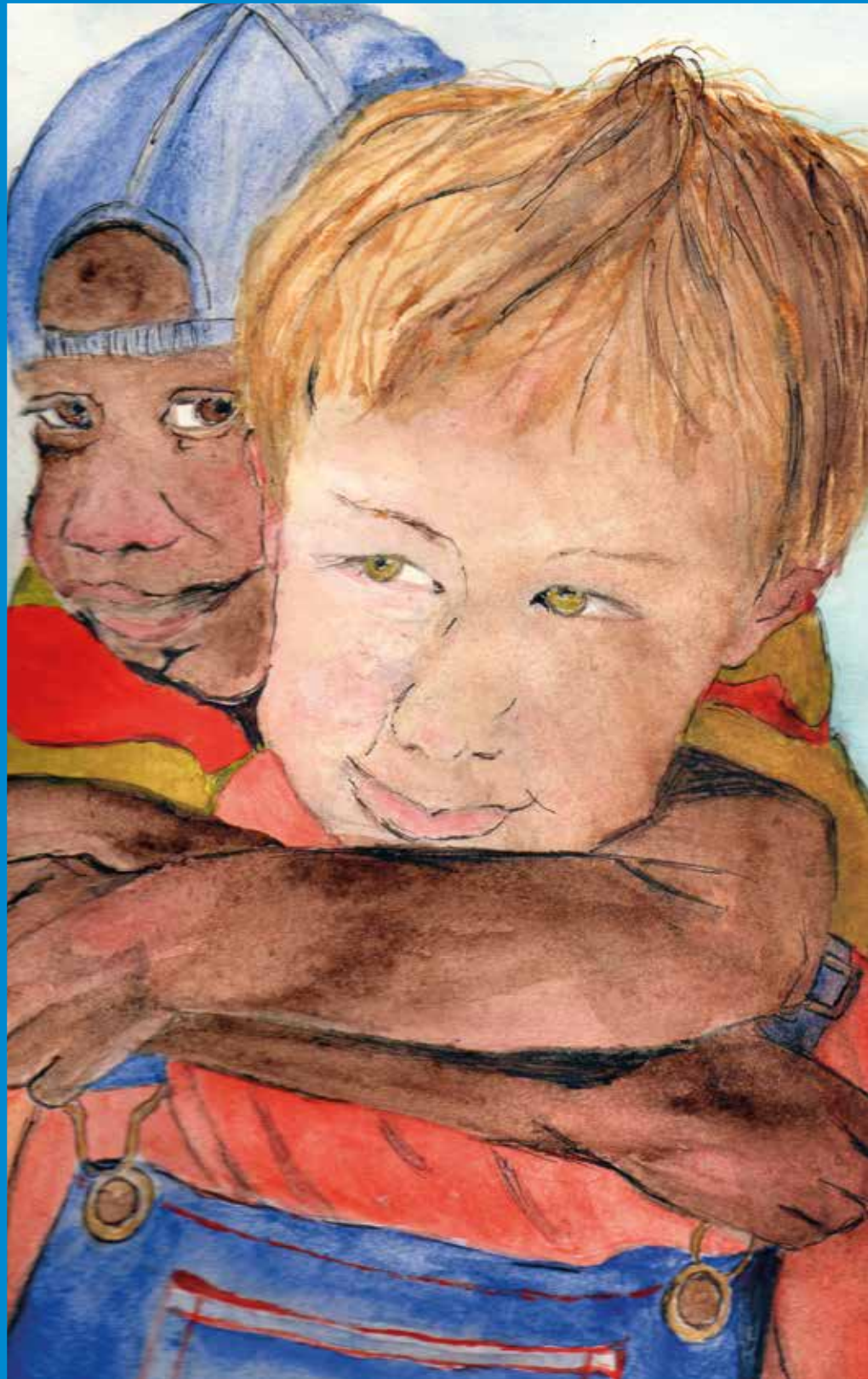
*QPR chaplain Bob Mayo talks about living with epilepsy
Me and my epilepsy, page 6*

DIAGNOSIS

*What the electrical activity inside your brain reveals
Understanding your EEG page 18*

SODIUM VALPROATE

*Our campaign to stop babies being born with avoidable disabilities
Making your voices heard, page 15*



REVIEW

**epilepsy
society**

epilepsysociety.org.uk

The image on our front cover is particularly poignant. Friends at play, the innocence of childhood, the joy of camaraderie. It could be either of the two young boys who is protecting the other: is one giving the other a piggy back or is one hugging the other? It doesn't really matter. The painting is by Tina Thompson who has contributed many pieces of art to our 'artist and epilepsy' gallery (see picture credit below), but this painting has a special resonance.



Children often say and do things in a much clearer, more direct manner than many adults. While we are still pondering, deliberating the facts, the voice of innocence and youth cuts straight to the point. And this has certainly been the case over Christmas and the New Year.

First of all, we received a letter from 10-year-old Ellie from Sheffield, who had lost her friend Patrick to epilepsy at the age of 16. You can read Ellie and Patrick's story on page 8, but the real message in Ellie's short but beautifully written letter, was for 'someone to make a cure' so that others would not also die of epilepsy.

Then we heard from the family of 12-year-old Della Mead. Della was just three when her older sister, Laura, died of epilepsy on Christmas Day in 2007. Christmas is obviously a very painful time for all the family, with constant reminders of the daughter and sister they lost. And Della's mum, Nicola, finds that even fundraising for epilepsy can stir up too many heartbreaking memories.

But Della desperately wanted to mark the

10th anniversary of losing her sister, so she set up a fundraising page on Facebook, asking friends and family to make a donation on her own birthday, with all money going to Epilepsy Society in memory of her sister.

Her fundraising target was £150 but she more than doubled her goal, raising £355. Her mum, Nicola, said she was 'super proud' of her daughter. You can read Della's story at epilepsysociety.org.uk/della

Ellie and Della are truly inspiring. Both girls have ensured that the legacy of Patrick, Ellie's friend, and Laura, Della's sister, will be a better future for others, greater knowledge about the causes of epilepsy and, hopefully, better treatments.

Our researchers never stop in their tireless quest to unravel the complexities of epilepsy, and we know that you never stop in your tireless support of their work.

So from all of us at Epilepsy Society, a huge thanks and a happy new year.

Nicola Swanborough
Editor



FRONT COVER
Friends: Tina Thompson

You can view more of Tina's artwork at epilepsysociety.org.uk/artists-and-epilepsy

If you would like to submit work for Epilepsy Society's online art gallery, please email nicola.swanborough@epilepsysociety.org.uk

Editor Nicola Swanborough
Email nicola.swanborough@epilepsysociety.org.uk
Telephone 01494 601 417
To receive *Epilepsy Review*, email us at the address above, or see back cover

Views expressed by contributors in this publication are not necessarily those of Epilepsy Society

Information may change after printing and is not a substitute for advice from your own doctors. Epilepsy Society is not responsible for any actions taken as a result of using this information

Epilepsy Society
Chalfont St Peter, Bucks SL9 0RJ
epilepsysociety.org.uk
Registered charity no 206186
A company limited by guarantee
Registered number 492761 England

Designed by Ben Dugdale Design
bendugdale.com
Printed by Lefa Print
lefaprint.com
Printed on chlorine free paper from sustainable forests

ANTI-EPILEPTIC DRUGS

Lack of generic epilepsy drugs helps push up NHS bill



Issues around the supply of anti-epileptic drugs have hit the headlines several times since the last edition of *Epilepsy Review*. Over the summer there were particular problems with the supply of clobazam, levetiracetam and lamotrigine.

Although these problems have now been resolved, *The Times* ran an article in December reporting that more than 100 drugs, including some for epilepsy, were in short supply and patients were going without essential medications.

The Times said that supply problems were forcing health officials to approve temporary price rises of up to 4,000 per cent to boost stocks. 'The NHS is spending more than £50 million a month overpaying for the medicines but pharmacies are still running out for days at a time and turning patients away,' wrote journalist Chris Smyth.

Professor Ley Sander, medical director at Epilepsy Society said that while patients were not reporting any current problems with the supply of epilepsy medication, there had been a drop in the number of generic versions.

'At the moment there is a dearth of generic drugs available for epilepsy, so doctors are having to rely on branded drugs and that has a cost implication. At one NHS institution the monthly cost

for epilepsy drugs has gone up by £3,000,' he said.

The Medicines and Healthcare products Regulatory Agency (MHRA) has produced guidelines setting out which epilepsy drugs should not pose a risk if a patient is prescribed a different version (epilepsysociety.org.uk/mhra-guidance-anti-epileptic-drugs).

Epilepsy Society contacted the Department of Health about periodic problems with availability of different versions of epilepsy drugs.

Michelle McDaid from the government's MPD Parliamentary and Public Accountability, said: 'Manufacturers of medicines have a legal duty to ensure continuity of supply of medicines to UK patients. However supply issues do arise and the Department of Health is fully aware of the problems this can cause and acknowledges the concerns raised.'

'The production of medicines is complex and highly regulated. There is a team within the department which deals specifically with medicines supply problems. It works closely with the MHRA, the pharmaceutical industry and NHS England to help prevent shortages and to ensure that the risks to patients are minimised when they do arise.'

DRIVING

Hope on road ahead?

Research at Epilepsy Society has shown that people who only experience auras following epilepsy surgery may be as safe to drive as those who are under 25 or over 75 in the general population.

Current UK driving regulations may allow a person to drive if they have focal seizures with no impairment of awareness or disturbance that would affect their ability to control a vehicle, as long as they have never had a seizure with loss of awareness.

People who have epilepsy surgery will almost inevitably have a history of seizures with loss of awareness. Consequently they cannot drive after surgery if they continue to have auras.

Recent research, led by Epilepsy Society's former medical director, Professor John Duncan, has shown that those who only experience auras with no impaired awareness following surgery, may not be at a higher risk of causing an accident than under 25s and over 75s in the general population.

The research calculated the 'chance of a seizure in the next year' (COSY) for 819 surgery patients. People with auras only in the last year had a COSY score of 11.3 per cent. UK driving regulations allow driving a private motor vehicle if the COSY is less than 20 per cent.

Professor Duncan said: 'If a COSY of below 20 per cent is regarded as an acceptable risk, it may be suggested that those with auras only in a given year might be allowed to drive.'

• **This does not alter current driving regulations for people with epilepsy. Go to epilepsysociety.org.uk/driving for any future updates.**

New year, new chairman

Epilepsy Society has a new chairman. Peter Worthington has been elected as chairman of the board of trustees, taking over from interim chairman Adrian Waddingham.

Peter, who is also chairman of the London North West NHS Healthcare University Trust Board, said: 'I feel I am joining Epilepsy Society at a very exciting time with the promise of breakthroughs in

our pioneering research, both in genomics and brain imaging; the ever-developing provision of life enhancing care services for those with the most severe forms of epilepsy; and the amazing work of fundraising, marketing and information teams in supporting the 600,000 people across the UK with epilepsy. It is truly inspiring to be a small part of this.'



AWARD

All rise for the prof



Epilepsy Society's Professor Philip Patsalos received a standing ovation when he was awarded the 2016 Excellence in Epilepsy Award by the British Chapter of the International League Against Epilepsy (ILAE).

It was the first time anyone has received a standing ovation for the prestigious award given for lifetime achievement in the field of epilepsy.

Professor Patsalos is head of the charity's Therapeutic Drug Monitoring (TDM) Unit in Buckinghamshire, where he has worked for 34 years. He is also professor of clinical pharmacology at the Institute of Neurology, University College London.

The award recognises his commitment to the studies of new anti-epileptic drugs and the implementation of therapeutic drug monitoring around the world.

His work has been critical in ensuring that several high risk groups in epilepsy – children, pregnant women and the elderly – are prescribed the dose of medication that will give them optimum seizure control and minimum side effects.

John Paul Leach, president of the ILAE British Chapter, said: 'Professor Patsalos is held in such warm and high regard and the ILAE council recognise that he is a particularly fitting recipient of this year's award.'

Professor Patsalos said: 'I am delighted to receive this award. However, I must thank my many colleagues, collaborators and students who have been very much a part of all that we have achieved together.'

SCIENCE

Cooling powers?

Scientists in Japan are using computer stimulation techniques to show how lowering the temperature of specific regions in the brain could potentially be used to treat epileptic seizures.

Treatment with medication or surgery does not work for some people, so scientists have been looking at a potential alternative called focal cooling, in which a device would be implanted in the brain to suppress the electrical signals – discharges – that characterise epileptic seizures.

To date, the technique has been tested only temporarily in epilepsy patients as intra-operative studies, but it has shown consistent success in rats. However, the research team at Nara Institute of Science and Technology caution that focal cooling can sometimes slightly increase frequency of epileptic discharges in rats, even while suppressing their strength.

To investigate focal cooling, scientists used a computational model of a rat brain. The scientists hope that focal cooling might one day offer an alternative treatment for people who do not respond to medication and who are not candidates for surgery. journals.plos.org

AWARD

OU doctorate for Clare

Epilepsy Society's chief executive Clare Pelham has been awarded an honorary doctorate from the Open University in recognition of her charity work with Epilepsy Society and Leonard Cheshire Disability.

The university recognised her as a 'powerful champion of those with particular needs and disabilities' and as 'an advocate and ally, transforming attitudes and driving change which is helping build a more compassionate and inclusive society.'

Professor Kieron Sheehy said Clare was 'one of the UK's most influential and effective charitable leaders, whose work has made a significant contribution to equality and justice in this country.'

Clare was awarded her doctorate at the Barbican Centre, London.

MEDICATION

Switching between drugs

People's feelings and perceptions should be taken into consideration when switching between different versions of their epilepsy drugs. The Medicines and Healthcare products Regulatory Agency (MHRA) has updated its advice for doctors, following a campaign by Epilepsy Society and Epilepsy Action.

Epilepsy drugs are divided into three categories, according to risks associated with switching between different versions. Category 1 drugs should never be switched; category 2 drugs should only be switched if the doctor thinks it is safe to do so, and category 3 drugs are not thought to pose a risk if switching between versions.

The new guidelines say doctors should take into consideration the feelings and perceptions of a person if they are given a different version of drugs in categories 2 and 3. This recognises that different packaging can cause anxiety in some people and may affect their medication routine, making them vulnerable to breakthrough or increased seizures.

Doctors should also take into account whether a person has a mental health issue or learning disability.

RESEARCH

A 'nose' for epilepsy

An electronic 'nose' that measures compounds in exhaled breath could be a reliable tool for diagnosing epilepsy in the future, according to new research from Canada and the Netherlands. The technology has been used before in other conditions but never in neurology.

Presenting their findings at the American Epilepsy Society 2017 meeting, researchers explained the technology involved people placing a small device into their mouth and breathing into it for five minutes.

The 'Aeonose' uses sensor arrays and learning algorithms to recognise potential 'danger signals' in complex exhaled breath mixtures from patients with epilepsy. Such patients have a unique 'breath print,' said researcher Dr Cecile de Vos.

Real snow, real joy, real freedom



SEIZURES

How do dogs know?

A new study, Epidogs, is trying to find out how some dogs are able to predict seizures. The research team from Ghent University, Belgium, would love to hear from you, even if your own dog does not alert you to your seizures.

Researchers hope to establish why some dogs react to epileptic seizures and others don't and will investigate the underlying mechanisms of this behaviour in the hopes of making it possible to train more seizure dogs.

As well as owners of seizure dogs, they are keen to hear from people with epilepsy whose dogs aren't sensitive to seizures so that they can compare them with dogs that can detect seizures. You will be asked questions about your dog's behaviour, personality and interaction with you, plus you will be asked about your seizures. To take part in the study go to epidogsproject.net

Residents with complex epilepsy and associated conditions at Epilepsy Society's Chalfont Centre, experienced all the thrill of the ski slopes when they visited Hemel Hempstead's Snow Centre for the first time. Here Rebecca Reynolds gets ready for the ride in a sit-ski.

epilepsysociety.org.uk/snow

CHARITY

Financial review

The Charity Tax Commission is to begin the first review in 20 years of how the tax system works for charities and how it can maximise benefits for the public.

Epilepsy Society's chief executive officer Clare Pelham is one of a board of six commissioners with charity, economic and fiscal expertise who will be carrying out the review.

ncvo.org.uk/policy-and-research/funding/tax-and-reliefs/charity-tax-commission

Watch it on video

You can find these videos at youtube.com/epilepsysociety



Katie Russell tells neurologist Professor John Duncan how her life has changed since undergoing epilepsy surgery.



Bob Mayo, QPR Football Club chaplain and London vicar performs his powerful poem about seizures. Page 6.



Ellie visits Epilepsy Society after losing her friend to SUDEP, and finds out about our research



Our director of genomics Professor Sanjay Sisodiya reads your wishes, sent in as part of our Christmas appeal.

Me and my epilepsy Rev Bob Mayo

Rev Bob Mayo is chaplain at Queens Park Rangers Football Club and vicar at a London church. His shoulder has been broken so many times during a seizure that it is beyond repair. He has woken in the night with his teeth 'cracked open like celery', has broken his nose, many of his joints and has disfigured his face in the past. But here he explains how he sees his epilepsy as a blessing

Epilepsy has driven me to the edges

The negative script of my epilepsy is that I know I will hit the floor every six weeks – a hard, thumping smash. I have fallen on my shoulder so many times that it can't be repaired and it is an 18-month waiting list to get a new shoulder on the NHS.

On the positive side, I often only sleep for a couple of hours because when I roll on my shoulder it is so painful it jerks me awake. So sometimes I leave a note on my pillow for my wife, Sylvia, then catch a train



to the other side of London and walk back, talking to the homeless. Epilepsy has driven me to the edges.

When surgery didn't work

I have lived with epilepsy since I was in my 30s and it can be a hard slog. In 2011 I underwent brain surgery but I'm afraid I'm not one of the 'happy-ever afters'. Although it is successful for many people, it didn't work for me. Before the surgery I was experiencing a full-on seizure every two years as well as more frequent absence seizures. Now I fall to the floor every five or six weeks and I have two to three absence seizures every week.

After my surgery, I said to the doctors: "Look, we took the choice together, we tried together, it didn't work. Let it go." They need experiences like mine to make them hungry to keep on improving surgery further.

After my operation I kept falling on my face which, at the time, ended up disfigured. My community put me forward to carry the Olympic torch in 2012, so my epilepsy became quite unifying and my disfigured face became owned by the community.

Making a friend of my epilepsy

I have tried to make a friend of my epilepsy. It helps me to connect with all the vulnerable souls out there. It teaches me empathy and vulnerability. If I am sitting with someone who is crying, that is me. If I am sitting with someone who is bereaved, that is me. I am grieving for the life I have not had.

If someone is scared, that is me, waiting for the next seizure to happen, knowing that it is going to come. God has taken the vulnerable soul that epilepsy has made me, and used it for the good of others.



Seizures during a church service

Stress is never caused by the seizure itself, but by people's reaction to it. Epilepsy gives people the chance to be their best self and their worst self. I have known people to laugh and jeer at me, but people can also be wonderful.

When I am leading a church service, I always mark where I am with a yellow highlighter so that if I have an absence seizure, I can resume where I left off. Members of my congregation are great and completely understand. They say "If you have a seizure, we will just wait for you." They are conscious of why I may sometimes repeat a prayer.

Wedding ceremony

Normally, I get a 20, 30, 40 second warning before a seizure. I have an intense feeling of sickness in my stomach. Images freeze frame and I usually get time to lie down. I always carry a rucksack with me and a little pillow. It enables me to be quite rooted and chilled.

I am a marathon runner and am currently training for the Brighton Marathon. When I am out running – which I choose to do – the adrenaline often means that I don't recognise a seizure coming on. I once had a seizure while running out in the countryside. When I got up, I carried on running for about five miles, not knowing where I was. It was quite magical. As a precaution I always allow myself extra time and keep the address of where I'm supposed to be on a piece of paper inside my shoe. It was when I looked at it that I realised I was a vicar about to take a wedding and was able to get back on track.



On another occasion when I came out of a seizure, I thought I was homeless and sat outside a church in the country, begging. Then I realised I wasn't homeless, I was a vicar.

Rediscovering my wife

Having epilepsy is a strange blessing. It allows you to re-find your life and your story anew. Sometimes I come back from a seizure and see a lady in front of me and think "she looks nice". Then I realise it's my wife, Sylvia, and I have the joy of re-learning my life story and recognising once again that I love her. For people without this disability, they live with their life story all the time, but mine is given back to me.

Banter at QPR Football Club

QPR is in my constituency so I go to the training ground every couple of weeks and hang out with the lads and enjoy some banter. It is about building relationships and building bridges. There is no need for the players to know about my epilepsy. QPR is full of dreams and possibilities and hopes. At the training ground you see football in its cleanest form. You have a group of guys doing their best to do the best.

That is what epilepsy has taught me. I must make the most of what I have got. I am going to hit the floor in the next six weeks but in between times I am going to make the most of my time. I am not living my five and a half weeks on the basis of what will happen in the sixth.

Kinsmanship with 92-year-old lady

Recently I went to visit a lady called Sarah who is in her 90s and who

had fallen in the middle of the night. She had to stay on the floor till the morning when her carer came. When I asked her what she had felt lying on the floor, she said "I know now what it feels like for you Bob." For a priest there can be no greater honour than to have kinsmanship with a 92-year-old lady at three in the morning. I am that broken lady.

Rev Bob Mayo is vicar of the Church of St Stephen and St Thomas in Shepherd's Bush. He is running the Sussex Coastal Marathon for Epilepsy Society on 17 March 2018. justgiving.com/fundraising/bob-mayo3

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
- Download the form at epilepsysociety.org.uk/yourstoryresearch and send to: Press Office, Epilepsy Society, Chesham Lane, Chalfont St Peter, Buckinghamshire SL9 0RJ.
- email pressoffice@epilepsysociety.org.uk for a copy of the form to send to us at the above address.



The story behind our Christmas Wishes Appeal

In 2017 our Christmas appeal focused on a friendship between two young people, 16-year-old Patrick and 10-year-old Ellie. Tragically, Patrick died due to his epilepsy in May while on holiday with his family. But Ellie was determined that her friend should not have died in vain. We pick up their story.

Ellie Paul had always felt a great sense of injustice that her friend Patrick, 16, was not able to lead the same full life that she could enjoy.

Patrick had severe disabilities caused by complications at birth. He had limited mobility and limited communication skills but was very much a part of Ellie's community. Ellie saw him every Sunday at church.

'Patrick really tugged at Ellie's heartstrings,' said her mum, Roisin. 'She is very empathetic towards people

and really understands how they feel. She just felt for him in a very human way.'

But when Ellie heard in a school assembly that Patrick had died from an epileptic seizure in the night while on holiday with his family in Northern Ireland, her sense of injustice turned to heart break and Ellie resolved to take matters into her own hands.

She wrote to a high profile public figure who she hoped might be able to help. By coincidence, the person that

Ellie reached out to is also one of Epilepsy Society's supporters.

Our supporter has asked to remain anonymous, but you can read Ellie's letter opposite.

The first that Ellie's parents, Roisin and Ralph, knew about Ellie's letter was when their daughter received a reply from our supporter expressing her sympathies at the 'tragic loss' of Patrick but also offering Ellie a glimmer of hope.

She told Ellie she would forward

her letter to us at Epilepsy Society where she knew our researchers are working hard to find out what causes epilepsy and why some people die at an early age due to the condition.

Ellie's mum, Roisin Paul said: 'Ellie was thrilled and touched to receive the letter. She really felt she had been listened to.'

'But then she also received a letter from Epilepsy Society telling her about the research that they carry out, particularly looking at what causes some people with epilepsy to die suddenly and with no warning.

'Ellie watches lots of medical programmes and is very aware that science can lead to cures for some conditions. The letter from Epilepsy Society really helped Ellie to understand and make sense of everything that had happened to Patrick.

'She felt reassured that there was a group of people out there doing something about epilepsy. It gave her a real sense of hope for the future.

'Ellie is very excited that this appeal, in her name, is helping to raise funds towards research that could change the lives of people like Patrick in the future, and may even help to save lives.

'It is very exciting for all of us that the letter Ellie wrote, totally off her own back, could help other people, like Patrick, who have epilepsy. We are very proud of her.'

I felt a mix of emotions when Patrick died. I felt happy that he wasn't going to suffer anymore but I also felt sad that he wasn't here for when there might have been a cure made. I also felt a bit nervous, like how many more people are going to die at such a young age?'

ELLIE

Dear [REDACTED]

I am Eleanor
I am 10 years
old. a person that
I know has just
died of an epileptic
stroke at the age
of 16 please do
something about
it and try to
get someone to
make a cure for
other people who
are suffering from the
same, please help
from Eleanor

Sheffield

please make a
difference

You can help make Ellie's wish of a 'cure' for epilepsy come true by donating to our appeal at epilepsysociety.org.uk/ellie



Patrick
...in the words of his mum,
Liesa Harrison

'Patrick was one of those boys who once you'd met him, you'd never forget him. He had no speech but he had a great sense of humour and great cognition.

'Patrick was a full-term baby but he was starved of oxygen at birth and had quadriplegic cerebral palsy as a result. But we always found a way to make sure he was able to do everything he wanted to.

'He loved holidays in France and really loved the seaside. He was never happier than when we wheeled him into the sea in a Hippocampe beach wheelchair. He loved being in the water with the waves coming at him.

'My biggest fear was that something would happen to Patrick but I never thought of sudden unexpected death in epilepsy. We were never told that it was a risk. We were visiting our family in Northern Ireland when my husband found Patrick in the front sitting room at eight in the morning on 31 May.

'Our family life has changed massively without Patrick. His brother Fergal is 13 and life is now very different for all of us.

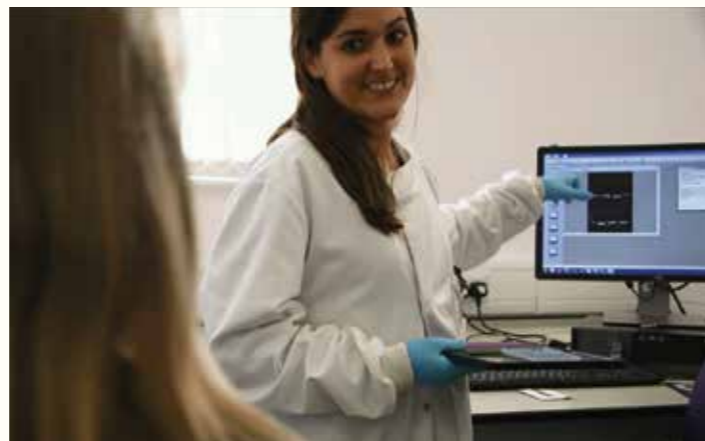
'We didn't know anything about Ellie's letter until she got a reply. Ellie is a great example of someone who really cares about others. She is a testimony to her whole family.'



Ellie's visit to Epilepsy Society

Ellie and her family visited the Epilepsy Society Research Centre in Buckinghamshire to meet Professor Sanjay Sisodiya, our director of genomics. Ellie and her family were able to see for themselves the research which is giving us a better understanding of the causes of epilepsy and how it will lead to more personalised treatments for people whose lives are dominated by seizures.

They were also able to see how, by looking at people's DNA, we are hoping to find out why some people with epilepsy die at a young age. Like Ellie, we want to stop this happening. Below, Ellie had a 3D image made of her face using a technique that can help explore links between face shape and epilepsy.



It's only three months to go until Purple Day – 26 March 2018. We know from your feedback in the past that you like us to give you plenty of time to prepare for the day and help us to raise funds to support people with epilepsy. So on the following four pages we have put

together a guide to Purple Day 2018, with an invitation to put on your pyjamas for epilepsy. A strange request maybe, but we want everyone to get into their PJs and join us for a purple pyjama party, packed with fun, friends and fundraising. We can't wait.



Purple Day Pyjama Party



Katrina Jones is community fundraising manager at Epilepsy Society. She has worked for the charity for six years, helping our supporters to have fun, raise money and change lives. So her life is full of balloons, cup cakes, marathon vests and – this year – pyjamas.

Who doesn't like to spend the day in their pyjamas? They're the ultimate comfort clothes allowing you to express your inner Disney princess, identify with a superhero, festoon your legs with hearts, flowers and teddy bears or go all out in multi-coloured stripes.

Well now you have the perfect excuse to wear your PJs from dawn to dusk by holding a purple pyjama party to help raise money to support people with epilepsy on Purple Day.

We have lots of party ideas over the page but of course you will have many more and it's really up to you what you do. For starters, it may be a purple pyjama party, but you don't have to wear purple pyjamas – the day is purple but the PJs can be any colour.

You can party with friends, family or work colleagues or just go about your normal routine in your pyjamas. It's a great conversation starter to roll up at

the supermarket, gym, post office or school gates looking as though you are dressed for bed. What a great opportunity to tell people about epilepsy and ask them to make a donation at the same time.

On the following pages we also look at the work of Epilepsy Society over the past 12 months and show you how your money has helped to make a difference. There are 600,000 people in the UK with epilepsy and more than a third of them do not respond to medication. This means they have to live with the possibility of seizures on a daily basis, affecting education, employment, social life, driving and the ability to support a family. We're here to support them.

Changing into your pyjamas could change the life of someone with epilepsy. That has to be a good reason to join our purple pyjama party and stand up for epilepsy in your slippers.



Pyjama party Get into your pyjamas for epilepsy

1 Dig out your pyjamas or head down to your local supermarket and buy a pair. With a bit of luck, they may have been on your Christmas list and you will have the perfect pair, personalised to your taste.

2 Invite friends and family round for your purple pyjama party. You could make it a film night, a midnight feast, a pillow fight for those feeling adventurous,

old fashioned card and board games, a karaoke night, or just a chance to catch up over a mug of hot chocolate and some home-baked goodies. We have 'counting sheep' sheepstakes, purple selfie props and more for you to download at epilepsysociety.org.uk/purple-day-extras. You can also order Epilepsy Society balloons and banners.

3 Take the party to work with you. Ask colleagues to come to work in their pyjamas and charge them for the privilege. You could provide a midday midnight feast, a lunchtime ghost story

To find out more about Purple Day and our purple pyjama party go to epilepsysociety.org.uk/purpleday, email fundraising@epilepsysociety.org.uk or call 01494 601414



Every purple pound raised will help change lives...



£5 could help us distribute vital information about epilepsy to people across the UK, ensuring the first five leaflets are free to those who need them

£10 could help to ensure that someone who needs to talk about their epilepsy can call our Helpline

£15 could help provide everyday equipment for one of our laboratories where we carry out groundbreaking research

£30 could fund a blood test to fine tune medication levels so as to maximise seizure control and minimise side effects for someone

£100 could help fund a DNA test, helping our scientists to unravel the causes of epilepsy, leading the way to quicker diagnosis and better treatments.

session or an hour of school games such as sleeping lions. Sensible rarely happens in pyjamas – silly often does.

4 Hit the town in your PJs. Party on down to the school gates, supermarket or local cafe in your pyjamas or onesie and explain that it is Purple Day.

You may find it is an opportunity for others to talk about their own experiences of epilepsy. One in 100 people has the condition, so friends and colleagues are likely to know other people in their circle with epilepsy.

Make sure you share pictures of yourself in your pyjamas on social media. We will be keeping an eye out for the wackiest places that people turn up in their pyjamas.

5 Set up a Purple Day fundraising post on Facebook, post some pictures of you and friends in pyjamas and ask friends to donate.

Go purple, but not in PJs

Socialising in pyjamas is not for everyone but you can still help us to raise money for epilepsy on Purple Day in many other ways. You could:

- Organise a bake sale or coffee morning at home, work or school. Cup cakes with purple icing are always popular and people really appreciate home-baked goodies so don't hold back
- Set yourself a sponsored challenge
- Take part in a Purple Walk
- Organise a 'wear purple' dress down day
- Shave your head for Epilepsy Society.

How our supporters helped raise money for Epilepsy Society in 2017



1,300 Epilepsy Society members and payroll givers brought in **£100,000**



£580,000 was raised through legacies



Gifts from supporters around the world **£241,000**



Trusts and foundations raised **£153,000**



Company donations **£49,000**



75 people raised almost **£20,000** on Purple Day 2017 through events at home, work and in the community



250+ runners, walkers and trekkers raised over **£158,000**



50+ cyclists raised over **£45,000** in RideLondon 100



200+ community fundraisers baked, danced and partied their way to almost **£90,000**

This is how Epilepsy Society has supported people in the last year. Our helpline, information services, research, communication and campaigns are only possible thanks to your kind donations and continuing support.



Helpline

In 2017, our helpline took 3,600 calls and spent 850 hours talking to callers. The average call time is 17 minutes.



Medical

2,800+ patients seen by our doctors
800+ MRI scans carried out
21 3D face images photographed
433 blood samples taken for DNA testing
34 examinations to look at retinal fibres at the back of the eye
48 Transcranial Magnetic Stimulation scans performed
900+ patients have undergone videotelemetry



Therapeutic Drug Monitoring

13,729 blood samples from across the UK analysed for epilepsy medication levels



Information

100,000 leaflets, factsheets, booklets and DVDs sent out to people affected by epilepsy



Digital

2 million visitors to our website
51k Facebook fans with a reach of 6 million and 100,000 engagements
20k Twitter followers with a reach of 2 million and 40,000 engagements
450,000 video views



Campaigns

Sodium valproate awareness campaign
2,350 women and girls took part in our sodium valproate awareness campaign which showed 70 per cent of women taking sodium valproate have not received the MHRA sodium valproate toolkit explaining risks associated with the drug during pregnancy

Epilepsy Society's campaign featured across all media channels and was discussed in the House of Commons and at the European Medicines Agency public hearing

Everyone Knows Someone #explainepilepsy campaign

We generated 500k reach and 11k engagements on Epilepsy Society's Twitter and Facebook over National Epilepsy Week (14-21 May)
Our Facebook page was the most engaged epilepsy Facebook page in the world over 14-21 May.
2m Guardian readers reached through our #explainepilepsy letter
30,000 watched our campaign videos

Campaign around seizures being mistaken for drunken behaviour

Featured in HuffPost with 10.7m monthly viewers and the Mirror Online with five million daily viewers
Facebook posts shared 2,200 times reaching over 200,000 people



Care services

100 residents with complex epilepsy and associated conditions are empowered to lead as full a life as possible that includes swimming, horse riding, gardening and ski-ing.

epilepsy society helpline

01494 601400

Monday and Tuesday 9am to 4pm
and Wednesday 9am to 7.30pm
Confidential. National call rate.

How your voices made the world listen

As *Epilepsy Review* went to print, we were awaiting the results of a public hearing into the epilepsy medication, sodium valproate. We would like to thank all of you who took part in our sodium valproate awareness survey. Here, editor Nicola Swanborough explains how your voices helped us raise awareness of risks associated with the drug, in the House of Commons, across all media channels including the BBC, and across Europe



In August we carried out a survey to find out how aware women and girls of childbearing age are of the risks associated with the epilepsy drug sodium valproate during pregnancy.

Although the medication is very effective in controlling seizures and for many is a life-saving drug, it can pose a serious risk for babies exposed to the medication in the womb. Ten per cent of babies born to women who are taking sodium valproate have physical disabilities and up to 40 per cent go on to experience learning difficulties.

Over 2,000 women took part in our survey, carried out in conjunction with Epilepsy Action and Young Epilepsy.

The results showed that in spite of a valproate toolkit introduced last year to inform women and healthcare professionals about the risks, 20 per cent of women taking sodium valproate either don't know of the risks or haven't been given any information about them.

And worryingly, 70 per cent have not received the valproate toolkit developed by the Medicines Healthcare and products Regulatory Agency. You can read the results over the page.

These statistics – your voices – enabled us to win valuable airtime on the BBC, with BBC News covering the story on the 6pm and 10pm news on

21 September. By the next morning BBC Radio 4's flagship programme Today was talking about the statistics and the issues around valproate.

At 10am, our chief executive Clare Pelham was on Radio 4's Woman Hour explaining the crisis which has affected thousands of families in the UK since sodium valproate was first licensed here in 1974. It gave her a platform to call on health secretary Jeremy Hunt to make it mandatory for all women taking sodium valproate to have a yearly review before their prescription is renewed.

From Woman's Hour, Clare was rushed to the Victoria Derbyshire



Epilepsy Society's Clare Pelham is interviewed by BBC's Nicki Stiastry

studios, three floors underground at the BBC where, with Deborah Mann and her daughter Branwen, they were able to explain the impact of sodium valproate.

Deborah was prescribed 5,000mg of sodium valproate during pregnancy. Both her daughters – Branwen and her sister Rhonnie – were born with physical and neurodevelopmental disabilities. Branwen knows that she could die at any time.

Clare was then whisked to a garden near the BBC for a walk-and-talk interview with the BBC One O' Clock News (above). By this time the World Service were calling and we hurried back to BBC Broadcasting House. But in the short, 10 minute walk, news broke that Uber had lost its licence in London and the news agenda moved on. We were dropped.

The BBC took complete ownership of the sodium valproate story. Their two journalists, Sophie Hutchinson and Nicki Stiastry had been working closely with us at Epilepsy Society since last year, assimilating facts and building

the story in anticipation of the public hearing into sodium valproate at the European Medicines Agency (EMA) on 26 September. This was the first time the EMA had held a public hearing as part of a safety review of a drug.

Other broadcasting channels had been reluctant to follow up the BBC's exclusive on sodium valproate, but they waited for their moment to come at the hearing. Clare Pelham was submitting evidence at the hearing on behalf of Epilepsy Society and Epilepsy Action, and again the statistics from our survey were presented to an audience of healthcare professionals and women from across Europe.

Clare was again interviewed for the BBC and also ITN with Channel 4 and Sky News also picking up the story.

We are expecting results from the hearing to be announced soon.

On 13 October we also learned that Norman Lamb MP had been successful in tabling a motion about sodium valproate in the House of Commons on 19 October. With just six days to prepare, we were able to brief MPs,

again using our survey results to highlight the lack of awareness around sodium valproate risks during pregnancy.

The two-hour debate was lively, full and unanimous in MPs' desire to ensure that all women who are prescribed sodium valproate have a right to be told of the risks during pregnancy. Time and again, MPs from across the country quoted our survey.

But not all the activity around sodium valproate has been in the public arena. Clare Pelham has been in correspondence with health secretary Jeremy Hunt, calling for mandatory reviews for women taking sodium valproate, before their prescriptions are renewed. Lord O'Shaughnessy, parliamentary under secretary of state for health has replied on behalf of Mr Hunt, underlining his recognition of the need for further action, but the conversation is ongoing.

Clare has also written to Arlene Foster, leader of the Democratic Unionist Party and First Minister for Northern Ireland. Ms Foster has pledged her support for Epilepsy Society's campaign for mandatory reviews for women taking valproate.

But we could not have done it without you. By taking 15 minutes to fill in our survey over the summer, you have enabled us to raise the voices of all women and girls taking sodium valproate, throughout parliament, across Europe, and across all forms of media.

For more than four decades, women have too often been prescribed sodium valproate without being told of the full risks during pregnancy. The result has been thousands of babies born with avoidable disabilities.

We are as close as we have ever come to ensuring that all women and girls are given the full facts, in a timely manner and on a regular basis, so that they can make an informed choice about their treatment and pregnancy. For some women – those for whom sodium valproate is the only drug that will control their seizures — that choice remains a difficult one as is so often the case with epilepsy.

But the world is listening and we won't let politicians and policy makers off the hook. We feel cautiously

confident that issues around sodium valproate will finally be resolved. In fact we know they will, because we won't stop until they are.

And we would like to thank each one of you who filled in our survey or shared it with others through social media or in conversation. By standing with us, you are helping turn the tide.

You can read more about the campaign and catch up with media footage and reports at epilepsysociety.org.uk/yourvoices

Follow Nicola Swanborough on Twitter @liasw



Michelle's story

Twenty-four hours after having her first baby at 16, Michelle Hackett started having multiple seizures and was prescribed sodium valproate. Less than a year later, her second baby was born with six toes on each of his feet, an underlying jaw and, when his teeth came through, eight of them were black and rotten.

Michelle says: 'I had a scan and the hospital told me that because I was on Epilim (sodium valproate), I would have to get rid of the baby. They said it could be born with cerebral palsy. I refused. I asked why I hadn't been told about the dangers around Epilim but they said because I was young, they didn't think I would get pregnant again.'

'I was very relieved Stephen didn't have cerebral palsy. I really feel he was one of the lucky ones but as a baby and toddler he had to have a lot of operations to correct his problems.'

'I feel absolutely furious that I wasn't told about the side effects of Epilim. When I hear about mums with Epilim and what they go through, it is heart-breaking. It is terrible to be given a drug for a severe illness and not be told about the side effects.'

Michelle is now taking a different epilepsy medication and a year ago gave birth to a healthy baby girl, Thea.

2,350 women and girls with epilepsy under the age of 50 in the UK took part in our survey. 661 of them were taking sodium valproate. Results shown are for this group of women:



20% did not know that sodium valproate can affect the health of babies exposed to the drug during pregnancy



70% had not received the valproate toolkit materials released in February 2016



33% had not been given any information about the risks associated with the drug during pregnancy



14% had not seen a healthcare professional in 2017



51% had not been given information about contraception

But the world is listening and we won't let politicians and policy makers off the hook. We feel cautiously confident that issues around sodium valproate will finally be resolved. In fact we know they will, because we won't stop until they are.



EEGs are an important test in helping to diagnose epilepsy. Here, Dr Arjuna Nagendran explains what the test involves and what it can reveal about electrical activity in your brain



The EEG is one of the most common investigations performed for people with epilepsy. EEG stands for electroencephalograph and means an instrument for writing or recording electrical activity within the brain.

A neurologist, or another doctor, may request an EEG for many reasons, but for people with epilepsy this is commonly after a first seizure

to help establish your diagnosis or after further seizures to help classify your epilepsy type.

Human EEG was devised and first recorded by Hans Berger in Germany in 1924 and it soon became apparent that this represented the coordinated electrical impulses of brain cells. Within around 10 years, scientists were demonstrating both that "spikes" on the EEG could be seen between seizures and that particular seizures called "absences", involving blank spells, had a clear EEG pattern to identify them. EEG has remained an

important investigation tool ever since.

The EEG appointment

EEG recordings are performed in neurophysiology departments, by a physiologist trained to perform these procedures. The typical EEG lasts around 20-40 minutes although recordings can be extended to include sleep.

Special sensors, called electrodes, can detect the electrical activity from beneath your skull and a number of these – usually 25-30 – are positioned on different places of the scalp, stuck on using a special gel.

These electrodes are put in specific positions on the person's head, which means that individual electrodes can record the activity from different areas of the brain.

When the technician or doctor is looking at the results of the EEG, they can tell what brain activity is happening, and where in the brain it is happening.

Each electrode has a number; all the odd numbers are on the left side of the head, and the even numbers on the right. The electrodes also have a letter, depending on the area of brain that it is recording from: F for frontal lobe, T for temporal lobe, P for parietal and O for occipital lobes. The letter Z is used for the line of electrodes sited on the midline of the head.

When the EEG is being recorded, the physiologist will try to help you feel more relaxed. They may either ask you to perform certain simple tasks such as closing your eyes, or they may carry out special tests. This might include a test with flashing light stimulation to see if you are photosensitive.

A video recording is often carried out with your EEG to help us coordinate the events with your brain activity.

Even if you have epilepsy, an EEG like this can be completely normal and if your doctor feels it is necessary, a longer one might be needed. Your brain activity changes a lot in sleep and we sometimes try to include this, particularly in children.

Where diagnosis is difficult or treatment with surgery is being considered, prolonged EEG recording may be carried out in a hospital video telemetry unit (see image, left). This is to try to capture your typical seizures both on video and EEG at the same time. Sometimes people may have an ambulatory EEG where they take the EEG home for 24 hours. In this case there will not be a video recording.

Alongside the EEG we also record a simplified sample of an ECG (electrocardiograph for monitoring the heart)

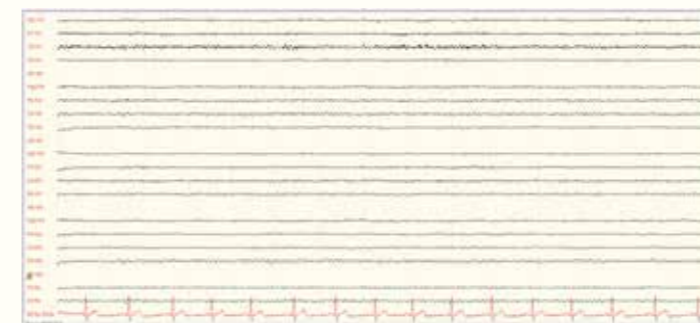
Interpreting your EEG

After the test is finished, the physiologist writes a summarised description of your EEG patterns. The EEG is then analysed by specialist doctors called clinical neurophysiologists, who write a report based on the clinical information they are given about the patient for the doctor who requested it.

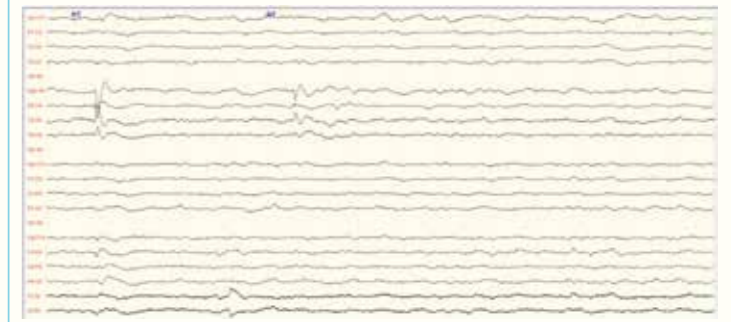
What does it look like?

Below is an example of about 15 seconds of a normal adult EEG. Each horizontal squiggly line represents the electrical activity beneath two of the electrodes on the scalp and the exact appearance changes from one second to the next. The normal appearance changes a lot in childhood and then more slowly as we get older.

Figure 1: shows 15 secs of a normal EEG while the patient is awake, but with their eyes closed. At the bottom of the trace, in red, there is a recording of electrical activity from their heart.



In patients with suspected epilepsy one of the main things we look for are unusual sharpened changes, commonly referred to as 'spikes' but also called epileptiform discharges. In figure 2 (next column), the EEG shows spikes over the right side of the brain, seen during sleep.



Spikes can often be seen in people with epilepsy and they are useful because you don't need to be having a seizure for us to see them. In particular, their location is important and this is useful in helping us to decide what type of epilepsy a patient may have.

How is it used?

EEG reports will give our impression to your neurologist about what we found in your EEG. This will include whether it was normal or not and whether we saw any spikes or seizures you weren't aware of. We may also be able to provide information to help classify your seizures into a particular type of epilepsy, which may lead to different choices of treatment.

Dr Arjuna Nagendran is a clinical neurophysiology specialist registrar at the National Hospital for Neurology and Neurosurgery, Queen Square, London.

Inside your brain

Frontal lobes – the area at the front of the brain, behind the forehead. The frontal lobes are responsible for voluntary movement, conscious thought, learning, speech and personality.

Temporal lobes – the areas of the brain at the side of the head, above your ears. The temporal lobes are responsible for making memories and remembering, and emotions. They are also involved in speech, hearing and perception

Parietal lobes – the area of the brain at the top of your head behind your frontal lobes. The parietal lobes control how we feel and understand sensations. They also control how we judge spatial relationships, our coordination and our ability to read, write and do maths.

Occipital lobes – the area at the back of the brain. They are responsible for our sense of sight: receiving information from our eyes and translating it into what we see around us.

Personal Independence Payments (PIP)

In recent months the Government announced changes to two benefits – Personal Independence Payments (PIP) and Universal Credit. Here, our social affairs adviser, Peter Hand, looks at what the changes will mean for people with epilepsy



Personal Independence Payments (PIP)

At the beginning of November the Government announced a variety of changes to the guidelines used for assessors of Personal Independence Payments or PIP. These might make the process for claiming the benefit better for people with epilepsy.

We are hopeful that the revised guidance should mean those making the assessment will be better placed to understand the impact of epilepsy on someone's everyday life.

Under the new guidance, assessors will have to take into consideration claimants' abilities to carry out unsupervised daily tasks safely. This means some PIP claimants could receive higher benefit rates.

The Department for Work and Pensions (DWP) made the changes following a recent legal decision on the interpretation of people's needs for supervision in order to carry out activities safely.

In a written statement to the Commons, Penny Mordaunt, the former minister of state for disabled people, health and work, said this would increase entitlement for a number of new and existing claimants, 'largely those with conditions such as epilepsy, which affect consciousness.'

The Department for Work and Pensions (DWP) estimates that around 10,000 claimants will benefit by £70-£90 per week by 2023.

The DWP will be going through all existing cases to identify anyone who

may be entitled to more money. They will then contact those people who are affected and all payments will be backdated to March 2017.

If you already receive PIP, it is likely that your claim will be reviewed to check that the new guidelines are being adhered to – however it is not clear how long the review process for everyone will take. The Government has also said that people with epilepsy who were unsuccessful in claiming PIP – from 9 March 2017 onwards – will also receive a review of their original assessment.

We are hopeful that the new rules should be better placed to take into consideration the complexity of epilepsy and the impact of seizures. We hope they will make it easier for people with epilepsy to receive what they are entitled to, and so live more independently.

Universal Credit

Also in November the Chancellor announced a series of measures in his budget, designed to improve the roll out of Universal Credit.

Universal Credit is a single benefit that replaces six other benefits for those who are out of work or on a low income.

The new work and pensions secretary David Gauke, said the measures meant the benefit would become fairer and more generous and do more than just cut waiting times for claimants applying for the benefit.

Improvements to the benefit include:

- a reduction of the waiting period for the benefit from six weeks to five as of February 2018
- easier access to advance loans, with claimants able to get a loan of 100 per cent of their monthly payment, up from the current 50 per cent
- an extra two weeks' housing benefit for those who receive housing support
- and rent reforms which will mean claimants can now get rent paid directly to their landlords if they wish, to reduce the risk of falling behind.

Universal Credit is the Government's new monthly benefit whereby six means-tested benefits – housing benefit, income support, income-based jobseeker's allowance, income-related employment and support allowance, child tax credit and working tax credit – are replaced and all rolled into one single payment instead.

Universal credit is being rolled out nationally on a gradual basis and the Government intends that all new claimants for the benefit should be able to claim it before September of next year.

For those people currently claiming any of the six benefits listed above, the Government says the change to Universal Credit will not take place until at least 2019. However, if there is a change in someone's circumstances, they might be moved onto it sooner.

You can follow Peter Hand on Twitter @HandMadePeter

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

Your replies

It sounds like you have waited so long to be able to drive again, it may not be worth the risk of coming off your medication so you can drive for a living.

Although a job is at stake, coming off the medication may have an impact on other areas of your life, too, and may make it more difficult to live life to the full if your seizures were to come back.

Sarah, London

If your medication is working it doesn't make sense to stop. Especially as you don't know what affect that could have on your seizures. And 10 years is a long time to wait. Have you thought about looking at other jobs? You never know, you could find something you enjoy doing more. And at least you can drive!

Stacey, Brentwood.

I don't know much about driving rules, but I do know that stopping meds can be very dangerous. You'd be at risk of having a fit and losing your licence completely if you did.

Carole, Swansea

It's great that you haven't had a seizure for 10 years so don't stop taking meds and risk changing that. Just enjoy what you have.

Andy, Leeds

I was a driving instructor but had to give up teaching when I was diagnosed with epilepsy. My seizures are now under control and I am able to drive again, but I would not want to risk driving commercially, even if I was allowed to.

I am now working in the online shopping department of a local supermarket, and although it's a complete career change for me, I'm really enjoying having colleagues to work with. Driving used to be quite a lonely profession.

Mark, Reading

It's a tough one when epilepsy gets in the way of your life but I would just enjoy the fact that you can at least drive. For so many of us, me included, I have never had a licence. Every time it gets close to me being a year seizure free, the inevitable happens.

I would love to have the

independence of my own car instead of relying on others for lifts, or hanging around for what is a very sparse bus system, but I just have to get on with it.

The real problem is that Government and planners assume everyone can drive to the shops, work, swimming pool or cinema, but we can't. It is a failure of our system that nationally we have such a poor or non-existent public transport system.

It is my choice to live in the countryside but this is where my friends and life are. If I moved to the city, I would be able to get around but wouldn't have anyone to visit. At least I'm not polluting the environment.

Jack, Lincolnshire

To find out more about driving regulations and how they affect you, go to epilepsysociety.org.uk/driving

Next issue

I used to have seizures every week but now I generally only have one a month. But the trouble is, because I can't predict when the next fit will happen, I get nervous about going out.

I had a seizure in the supermarket recently and although the staff were lovely, I felt really embarrassed. I don't like sharing my problems with friends and if they invite me out I usually find an excuse not to go.

I know I'm probably being silly, but I have lost all my self-confidence. I wonder if other people have experienced this and how they overcome it.

Donna, Manchester.

WOULD YOU LIKE TO SHARE YOUR THOUGHTS WITH DONNA? Or do you have a question to ask our readers? Email nicola.swanborough@epilepsysociety.org.uk, write to Editor, *Epilepsy Review*, Epilepsy Society, Chalfont St Peter, Bucks SL9 0RJ, or reply at: 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

2017 is behind us. It's over, the Christmas leftovers are finished, the cut-price Advent calendars have all been either sold to bargain-hunters like me or squashed into landfill.

So what are your hopes for 2018? A fit-free year? A reduction in meds? Talking more openly about your epilepsy? Committing to wearing a Medic-Alert bracelet? Finally getting your driving licence? Running a marathon for Epilepsy Society? (They'd love to hear from you!)

Despite starting in the dead of winter, the new year does have a feeling of springtime optimism about it. 'New Year, New Me,' people say, as if the shift from Sunday to Monday will miraculously bring about a personality transplant.

'This year it'll be different,' people say, unconvincingly, an anxious furrow in their brow betraying their confidence that dawn jogging is something they'll suddenly discover was missing from their lives.

It is a time of resolution and good intentions but it's not realistic. It's a cruelty that at the coldest, darkest time of year, when we are at our fullest, fattest and laziest, we feel we 'ought' to be out in public in tight fitting clothing, doing unfamiliar exercises that our bodies are not used to.

Other animals sensibly hibernate at this time of year and we're heading out to a Park run! So if you're feeling blue having already trashed your resolutions, do not fear. Personally, I'm not one for resolutions – they seem to me a cruel and elaborate trick of delusion and guilt. We even have a proverb to describe it: 'The path to hell is paved with good intentions.' HELL, guys, Hell! Let that be a warning to you. Resolutions will make you feel miserable and maybe also lead to flaming molten sulphur.

That's not to say I'm not one for self-improvement, though. On the contrary, I think taking on personal challenges, trying new things, changing up the routine, these are all terrific things – just keep it realistic.

So I urge you: if you do have a resolution, resolve only to do it for one month, one week or even one day! Not for the whole year or, Heaven forbid, the rest of your life. Be kind to yourself, take it one step at a time. Doing something for 30 days is achievable. And if it's tough, do it in February, the shortest of all the months.

You may have noticed that in recent years various causes have hijacked our calendar. The same calendar that has served us for thousands of years has become hostage to people becoming a better person or creating a better world.

The year now starts with 'Veganuary' (go vegan), then 'Februhairy' (grow your hair for charity..?) all the way through to Steptember (walk more), Stoptober (stop smoking), Movember (grow a moustache) and Decem-beard (yes, this really is apparently a thing).

I wonder if Epilepsy Society might launch 'Aprilepsy' – an awareness and fundraising month with programmes to educate people with what to do in the event of a seizure, and to be aware of how having epilepsy affects?

Yes, it's a bit corny, not to mention an assault on the English language – but the spirit is right. A short-term resolution is achievable, and may even be fun. If talking about having epilepsy is difficult, perhaps a month of awareness raising activities might give you the opportunity to talk more openly about it.

It's also important to remember that – you know what – maybe you absolutely don't need any flipping resolutions at all. Maybe accept that you're good enough and beautiful just the way you are. In a society which tells us all the time that we ought to be and look different, acceptance is the greatest challenge!

Back to the new year. We will soon be entering the Chinese Year of the Dog. I used to have a dog called Holly.

We were a lot alike: dark hair, brown eyes, friendly, loyal, greedy. We also both had epilepsy. We both felt a frustration at not being able to drive, instead having to hang around the front door looking mournful, waiting for Mum or Dad to drive us to the park. We were kindred spirits, Holly and I; we shared so much – though I drew the line at sharing meds. I always made sure that when my neurologist wanted to try something new, that it wouldn't be something that Holly could 'share': typical sibling jealousy.

It has been several years now since Holly died, and though of course she is irreplaceable, she is very fondly remembered. One of my hopes for 2018 was to get a dog. Obviously this is very much a lifestyle choice and not a resolution. It's only because of the accumulation of big and small choices in recent years: moving to a house near a park, feeling more settled in my life and having a partner to share the load, that I'm even considering this.

But since learning that the Chinese new year is dog-shaped, it now suddenly seems like destiny.

That's what I'll tell my husband. It's destiny. An Ancient Chinese prophecy. Yeah, that should persuade him.

JULIET STEPHENS
LAUGHING ALLOWED

One step at a time



Santas' hopes dashed but Clare's not beaten

It was with a heavy heart that we had to cancel our first ever Festive Family Fun Day on 10 December due to snow. The day included an ice rink and a 2km Santa Dash, but with Epilepsy Society based in the Chiltern Hills, snow quickly rendered all roads impassable.

Not to be beaten, our intrepid chief executive Clare Pelham, decamped to her local gym and notched up more than her planned 2km on the treadmill, raising over £1,000 for our research. You can still sponsor Clare at justgiving.com/fundraising/clare-pelham

Generous gift furthers our research



Thanks to a grant from The Hospital Saturday Fund we have bought a brand new freezer for storing DNA samples.

The freezer operates from a temperature of -40°C to -86°C and the racks store 5000 samples of DNA in 2ml tubes.

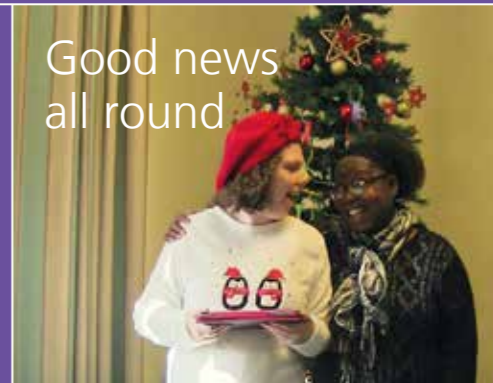
This gives us the opportunity to increase the recruitment of patients, which will in turn benefit the patients and improve our research looking at the underlying causes of epilepsy and individual reactions to treatments.

The Hospital Saturday Fund helps people with medical conditions and disabilities and supports medical projects of health charities in the UK and Ireland.



#Giving Tuesday

A massive thanks to everyone who donated to us on #Giving Tuesday (28 November). For 24 hours only, Facebook was doubling all donations made to Epilepsy Society via their pages, with an upper limit of £400 per person. This meant that on one day we raised £1,595 through your donations on Facebook and £813 through Just Giving, making a total of £2,408.



Good news all round

It's good news all round at Epilepsy Society, as Micholls House, one of our six residential care homes for people with epilepsy and learning difficulties, was rated 'good' in every area by the Care Quality Commission (CQC).

Inspectors from the CQC paid an unannounced visit to the home for up to 20 residents in October and found the services to be safe, effective, caring, responsive and well led.

CQC inspectors said people were happy with the care and had positive relationships with staff. Relatives were also happy. One relative described it as: 'Home from home where my family member is happy.'



Do things by half

Do you fancy running for Epilepsy Society but don't quite feel up to a marathon? Then why not sign up for The Big Half on 4 March 2018. This is a fantastic new 13.1 mile run from Tower Bridge to Greenwich and it costs just £1 to register.

We will support you with a T-shirt, running vest and fundraising pack, and just ask you to raise £500 to support our work. To find out more, call Team Purple on 01494 601414 or email fundraising@epilepsysociety.org.uk



Gus the gnome spots Tree-sa May

We were very proud to be part of this year's fundraising Christmas Tree Festival at St Luke's Church, Maidenhead, in the constituency of prime minister Theresa May. Gus, our beady eyed gnome had pride of place on top of our tree and spotted Mrs May admiring her own tree, decorated with her trademark stiletto heels.

epilepsy society

26 march

purple pyjama party

join us for the biggest and comfiest purple day ever!

Fundraise in your PJs and help change the lives of people affected by epilepsy.



Find out more and order your free Pyjama Party fundraising pack online at epilepsysociety.org.uk/purpleday

epilepsy society

a full life for everyone affected by epilepsy

epilepsysociety.org.uk
01494 601 300

Confidential Helpline – 01494 601 400
Monday and Tuesday 9am to 4pm,
Wednesday 9am – 7:30pm.
National call rate. Information and emotional support.



Epilepsy Review magazine

If you would like to receive future copies of *Epilepsy Review*, call our membership office on 01494 601 414 or visit epilepsysociety.org.uk/membership