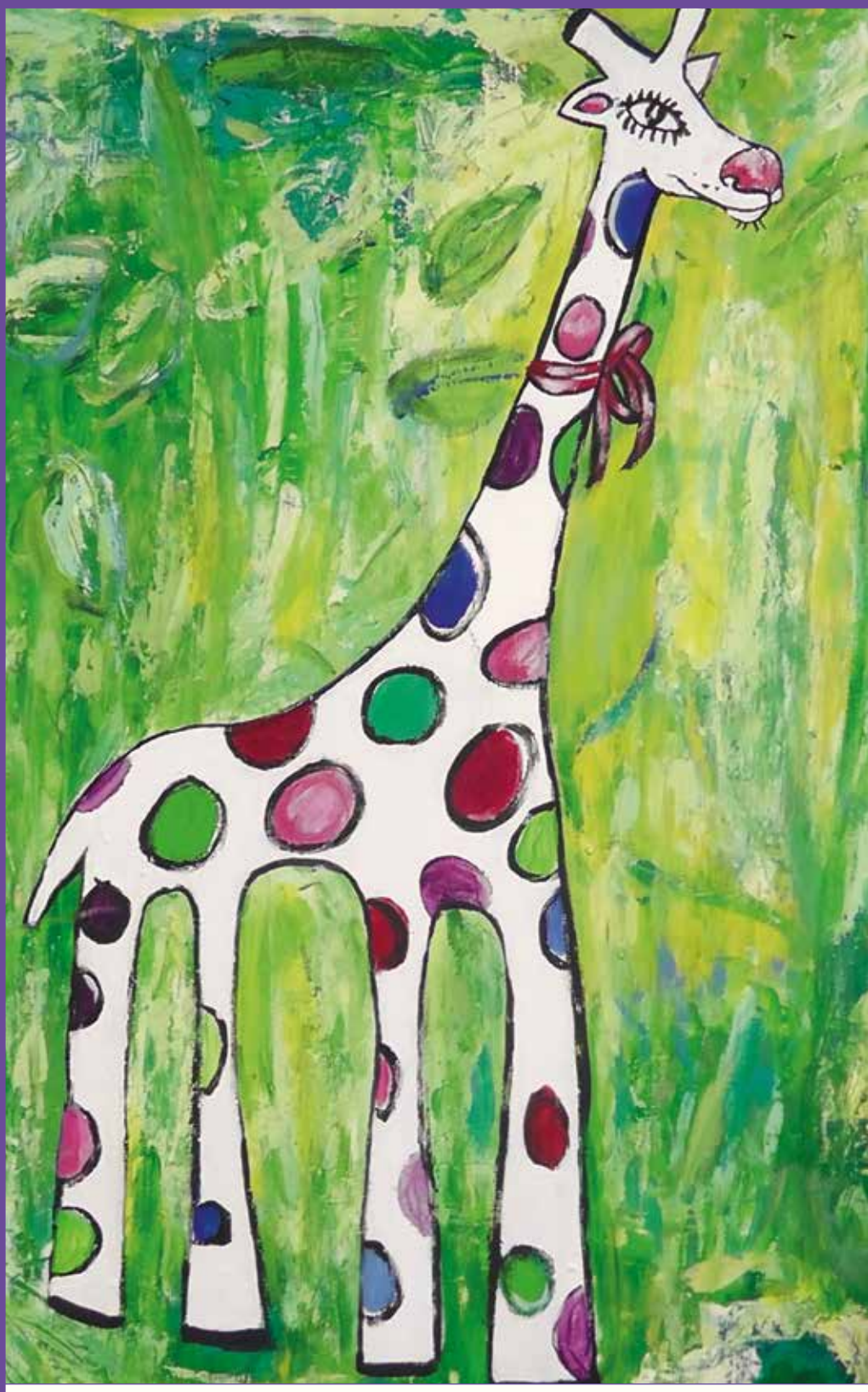
EPILEPSY REVIEW

Issue 15, Spring/Summer 2016



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REVIEW

epilepsy society

epilepsysociety.org.uk

I have just donated my car to Epilepsy Society via Giveacar, a not-for-profit social enterprise that turns your old car into cash for charity. It was a bit of an old banger, so I'm afraid the gesture was greater than the gift. It will only fetch scrap value – £10 at a push (something my car required on many an occasion). By the time Giveacar's admin fees have been taken into account, I think Epilepsy Society will receive the princely sum of £7.50 (again, at a push).

Several people have asked me the same two questions: firstly, did I feel sentimental about sending the car for scrap; and secondly, was it worth it?

Prior to the car being picked up, I said I was definitely not sentimental about it going. I said I was not a car person and felt no emotional attachment. It was simply a means of getting from A to B. Then the scrap merchant turned up, hoisted my car onto the tow bar and my eyes welled up.

Watching my faithful, if unreliable, car being towed away brought home the enormity of just how devastating it must be for anyone with epilepsy who has to rescind their driving licence due to seizures.

Our society is built around our cars. We depend on them for getting to work, shopping at out-of-town malls, socialising, accessing services, transporting children and the list goes on.

A bus pass may be some compensation but only if you're lucky enough to live in a city where there is a viable service. And if you live in an area that is enlightened enough to allow you to use your pass before 9am. If not, it's rubbish.

For anyone with seizures, not being able to drive is huge. Many people with controlled seizures say that one of the key reasons they take their medication regularly is the fear of losing their licence should they have a breakthrough seizure.

So was donating the scrap value of the car worth it? Absolutely. £7.50 may be a drop in the ocean, or in the petrol tank, but if it goes in any small way to helping researchers here, at Epilepsy Society, understand more about seizures and more importantly stopping them, then my rusty old banger has gone to a good cause.

I don't like to think of it being crushed into an unrecognisable pile of metal but I would like to think that one day we'll nail epilepsy and the open road will be there for everyone.

Nicola Swanborough
Editor

FRONT COVER
Giraffe: by a patient at Epilepsy Society's Sir William Gowers Assessment Centre, Chalfont St Peter, Buckinghamshire.

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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

GOVERNMENT

Department of health fails to prioritise epilepsy

Epilepsy Society has expressed its disappointment at the government's failure to prioritise services for people with neurological conditions, including epilepsy, over the next year.

A Public Accounts Committee (PAC) report had made it clear that NHS services for people with neurological conditions 'are not consistently good enough.'

In its Treasury Minutes from last month, the department of health rejected several key recommendations by the PAC including calls to retain the position of the national clinical director for neurological conditions and to deliver a personalised care plan for everyone with a long-term health condition.

Epilepsy Society's interim chief executive David Marshall, said: 'We are disappointed to see the government's admission that NHS England will not be prioritising services for people with neurological conditions in the next year.

'The choice not to retain the national clinical director for adult neurology, or to deliver personalised care plans are decisions that will not make a positive impact on the lives of people with epilepsy and other neurological conditions at a time when it is vital progress is being made.'

However David Marshall welcomed the department of health's decision to accept new commissioning for value data packs which could help clinical commissioning groups recognise and address poor outcomes for people with epilepsy in their areas.

The department has also accepted recommendations to reduce variations in access to neurologists and to give clarification to commissioning responsibilities for neurology.

There are over 12 million people in England with neurological conditions. The Neurological Alliance represents 80 organisations working to improve the lives of those people. In a statement it said the government's response meant that neurology services would continue to lag behind other areas in standards and patient outcomes.

It said there is considerable evidence that neurology services suffer from enormous regional variation in access to services and widespread disengagement by local commissioners.

Arlene Wilkie, chief executive of the Neurological Alliance, said: 'Once again, the government has sent a message that the needs of people with neurological conditions are simply not important enough to focus on.'

HELPLINE

Power of listening is recognised

For the third time in succession, Epilepsy Society's Helpline has been awarded the Helpline Partnership Standard mark.

The mark is renewed every three years and reflects best practise. Epilepsy Society is the only epilepsy charity to have this standard.

The helpline has been offering support and a listening ear to callers since it opened in 1990. In the financial year, 2015-2016, it took 6,223 calls.

Sarah Hill, head of services at the Helpline Partnership said: 'The Helpline at Epilepsy Society has provided some excellent examples of a high quality service.'

Epilepsy Society helpline manager, Christine Brock outlined the value of the helpline: "It is very powerful for a caller to know that someone is listening. Often it isn't just a practical response that is needed, but an opportunity to talk through the emotional impact of epilepsy.'

One caller explained what the helpline meant to them: 'I felt I could say everything I needed to say and was able to cry. I needed someone who had the time to listen to me and who knew about epilepsy.'

Epilepsy Society Helpline
01494 601 400
Daytime: Monday, Tuesday, Thursday and Friday 9am – 4pm
Extended hours: Wednesday 9am – 8pm.
National call rate.

Drug monitoring unit wins accreditation

Epilepsy Society's Therapeutic Drug Monitoring Unit (TDMU) in Buckinghamshire has been awarded accreditation by the UK Accreditation Service (UKAS).

The unit carries out clinical analysis of drug levels so that a person's epilepsy drug therapy can be individualised to their own therapeutic range.

The award is the first of its kind given to a UCLH 'pathology; clinical biochemistry' provider, as well as being the first awarded to any London-based hospital.

Professor Philip Patsalos head of the unit said: 'This is a great accolade. It is a real tribute to the vital work which we do, analysing drug levels so that drug efficacy is maximised and side effects are kept to a minimum. "

GENETICS

New chief executive

Epilepsy Society has a new interim chief executive, David Marshall.

David joined the charity in February after six years as chief executive of the Hospital of St John and St Elizabeth and its on site hospice St John's, in London. Prior to that he was their finance director.

David brings 20 years of healthcare management experience from the public and private sector in the UK, Australia and the Middle East. He has extensive knowledge of the UK healthcare sector – and has achieved both turnarounds and culture change within the sector.

David said: 'It is wonderful to be part of such a great organisation. Epilepsy Society has a very rich history and has really changed the landscape for people with epilepsy over the last 124 years. But there is still much to be done.

'This is a very exciting time in the field of epilepsy. We are on the cusp of a genomic revolution which could totally change the way epilepsy is diagnosed and treated in the future.

'But there are still very pressing issues which need to be addressed now in improving epilepsy services and the way that people access them. We know that 39 per cent of premature deaths from epilepsy are potentially avoidable. That is not a comfortable statistic.

'Nor is it comfortable when we hear people talk about stigma and prejudice in the workplace in the 21st century. Like our founding fathers, we need to make sure the epilepsy landscape continues to change radically.'

WOMEN

Infertility risks

A new study has shown that women with epilepsy have no more infertility risks than women without the condition. Nor do they have a significantly greater risk of miscarriage.

Eighty-eight women with epilepsy took part in the research and 109 women without the condition. The women were asked questions about pregnancy and their menstrual cycle during their childbearing years. They were also asked to keep a daily electronic diary.

Results showed that there was an almost equivalent rate of pregnancies in the two groups - 61.4 per cent in the epilepsy group and 60.6 per cent in the healthy controls. The study also found that there was an identical proportion of live births.

The findings were based on the Women with Epilepsy: Pregnancy Outcomes and Deliveries study. Similar studies had been done before but using older medication.

The study runs counter to older ones that found women with epilepsy were at risk for miscarriage, infertility, and had lower chances of carrying a pregnancy to term.

AUTISM

Link with epilepsy

New research from Sweden has highlighted epilepsy as one of the two leading causes of premature mortality in people with autism.

A study from the Karolinska Institute has shown that people with autism die 16 years younger than the general population. Those who also have a learning disability die more than 30 years prematurely at an average age of 39.

The study analysed data from 27,000 people with autism compared with almost three million people without the condition. Experts could not say why so many people with epilepsy die young.

Epilepsy Society's medical director Professor Ley Sander said: 'We know that there is a strong link between epilepsy and cancer, cardiovascular and cerebrovascular disease. This report confirms autism as another major consideration that must be addressed.'

PREGNANCY

Sodium valproate survey

The UK's leading epilepsy charities have carried out a survey to find out how aware women are of the potential dangers around the epilepsy drug sodium valproate, during pregnancy.

The survey was developed by Epilepsy Society, Epilepsy Action and Young Epilepsy and was aimed at women with epilepsy between the ages of 16 and 50.

The questionnaire aimed to find out how aware women, young girls and healthcare professionals are of the potential harm to babies exposed to sodium valproate in pregnancy.

Up to 10 per cent of babies exposed to sodium valproate in the womb are at risk of being born with a birth defect while up to 40 per cent are at risk of problems with learning and development.

The survey was developed using input from the MHRA, the UK regulator for all medicines and medical devices. It will seek to discover the impact of the organisation's Valproate Toolkit, which was created to make sure all women and healthcare professionals are aware of the potential dangers of sodium valproate during pregnancy.

PREGNANCY

Seizure increase

Epilepsy Society's medical director Professor Ley Sander has advised women who are taking pregabalin not to panic over new research which suggests the drug could pose risks for an unborn child if taken during pregnancy.

Research in the journal Neurology, showed babies of women who were taking pregabalin in the first trimester of pregnancy, were three times more likely to have a birth defect than babies of women who weren't taking epilepsy drugs. The study also showed babies exposed to pregabalin in the womb were six times more likely to have a major defect in the central nervous system.

Professor Sander said the study was very small, involving 164 women on pregabalin (five with epilepsy) and 656 not taking anti-seizure drugs. He said no firm conclusions could be drawn but further investigation was necessary.

Everyone knows someone

National Epilepsy Week ran from 15-21 May and Epilepsy Society teamed up with Young Epilepsy to run its 'Everyone Knows Someone' campaign in association with fashion giant River Island. You can read the stories of Chris, Iza and Jade at the website below.

everyoneknowssomeone.org.uk

EMPLOYMENT

Lack of support at work

A new YouGov survey has shown that more than 1 in 4 of workers in Great Britain would be concerned about working alongside a colleague with epilepsy. The majority said their concern was due to having no idea how to support someone who was having a seizure.

The survey of over 2,000 people also showed that 76 per cent of people had not been offered training to support people with seizures.

Matthew Sowemimo, director of external affairs and fundraising at Epilepsy Society said: 'This problem would be reduced if there was training to inform people about what to do if someone had a seizure at work. People with epilepsy would feel safer and more supported if they know that colleagues are better informed about epilepsy.'

TERMINOLOGY

Is 'epileptic' negative?

'Epileptic' or 'person with epilepsy' – which do you prefer?

Two studies have compared the effect of using the terms 'epileptic' and 'person with epilepsy'. In Brazil a study showed that the word 'epileptic' provoked more negative attitudes than 'person with epilepsy'. But in the UK the word 'epileptic', in English, was not deemed as negative.

Tell us what you think at press.office@epilepsysociety.org.uk

Watch it on video

You can find these videos at facebook.com/epilepsysociety

Mum of two Laura Grainger talks about coping with memory loss. Also page 6.

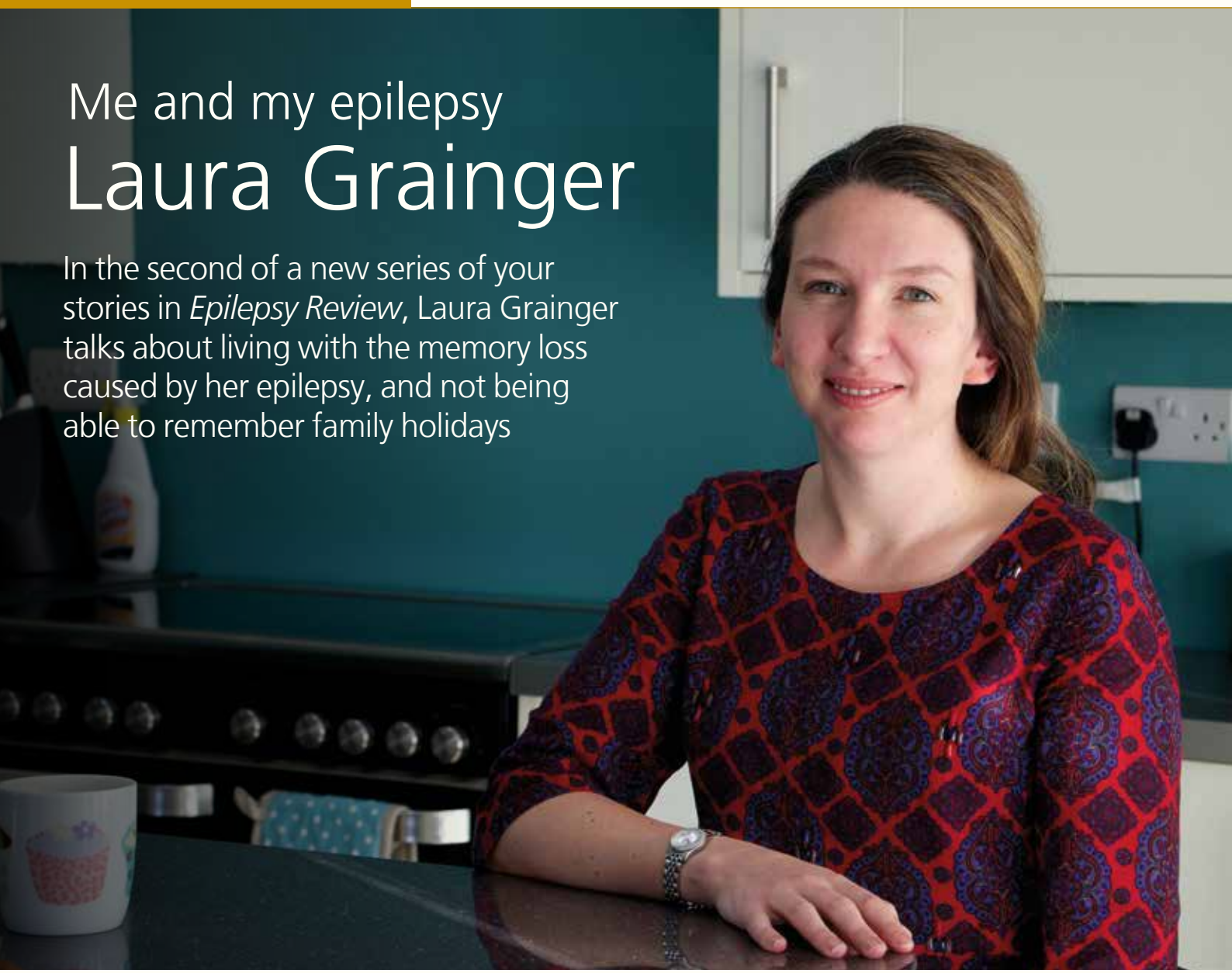
Amazing grandmother Jennifer Barker, 81, completes London marathon.

Interim chief executive at Epilepsy Society talks about premature mortality on London Live. Also page 18.

Find out how to store emergency details on your mobile phone.

Me and my epilepsy
Laura Grainger

In the second of a new series of your stories in *Epilepsy Review*, Laura Grainger talks about living with the memory loss caused by her epilepsy, and not being able to remember family holidays



Diagnosis

I am 34 and was diagnosed with epilepsy four years ago. I was in my car with my oldest son Sidney, who was six months old at the time, and I was driving to the local Sainsbury's. It's a route I do all the time, and I've lived in Witney all my life, but when I got to the roundabout at the end of the road, I was completely lost. I couldn't work out which exit to take. I circled the roundabout three times in total confusion, and then I chose an exit but it was the wrong one. I got very scared and came home straight away. That's when I knew I needed to see the doctor.

I was referred to the neurology department at John Radcliffe Hospital where I was diagnosed with temporal lobe epilepsy with autobiographical and topographical amnesia.

When I got the epilepsy diagnosis, it was such a relief to finally know what it was… I generally see it as a positive thing. My absences aren't as severe as some people have them and mine are under control.

First absence seizure

I think I had my first absence when I was 16 on holiday in Turkey. I was waiting for my friend so we could go out for the evening, and I just remember an intense feeling of déjà vu. I felt it coming on as though I was watching myself, then I got very hot and had to be sick. I just put it down to too much sun and exercise.

I was too embarrassed to tell anyone but then over the years it happened more and more and I was starting to feel like a different person. I thought I was going crazy.

Seizure freedom

I was prescribed lamotrigine which has controlled my absence seizures. My dose was increased gradually when I was pregnant with my second son Arthur who is now five months old. Since having Arthur I have remained seizure-free; this has been a very different experience to after I had Sidney when I was having multiple seizures a day.

Memory loss is the hardest thing

The hardest thing, though, is knowing I won't get my memories back. The doctors have explained that every time I have an absence seizure, my brain wipes a section of my long-term memory bank. Now I don't remember family holidays I've been on.

Coping with memory loss

My memory loss means that I have had to develop coping strategies to keep my life as normal as possible. Everything in my life is over-planned and very organised. I know where everything is around the house, and I keep photos of all my memories in date order in boxes. That way, if friends mention a holiday or something I don't remember, I come straight home and look at the photos.

I love making lists – they're all around the house. I even have a tea chart in the kitchen with the drink preferences of all my friends and family.

Explaining epilepsy

I've always been awful at remembering people's faces, and it's especially difficult if I'm out and about and bump into someone out of context because I can't remember how well I know them. Even with friends, I find it hard to remember the details of our last conversation, so I have to ask generic questions to draw out the information. It's like putting the jigsaw pieces back together each time.

I used to feel really embarrassed and thought I was a bad friend for not remembering, and I would play along in conversations as though I knew what people were talking about. Now though, I realise it's not me being a bad listener, so if someone

asks if I remember something, I'll just say 'no, remind me'. Also now that my friends know, they'll prompt me and jog my memory.

Coping with epilepsy at work

I told my boss about my memory loss and he has been incredible. He said 'we're really benefiting from your organisation skills and quick-thinking'. He made me feel my condition was a very positive part of me. Not for one moment did I feel he was judging me. Work has been fantastic about my hospital appointments and they let me work from home when I had my ambulatory EEG.

I still always plan what I'm going to say before I say it. I have a job that requires me to be professional and I take my work seriously. I need colleagues to take me seriously too. I always worry that people might think 'will she be a liability?' I'm so concerned about people using my memory loss against me.

Love and laughter

My family help me see the humour but they can be so mean though. One year after my diagnosis, my brother was planning to Photoshop some family photos to add an extra person – and then ask me whether I remembered having a fifth sibling that moved away!

You can watch Laura talk about epilepsy and memory loss at epilepsysociety.org.uk/laura

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. If you would be happy to share your story in *Epilepsy Review*, please:

- Fill in our online form at epilepsysociety.org.uk/become-media-contact
- If you would like a printed copy of the form, email pressoffice@epilepsysociety.org.uk or call 01494 601417. Send your completed form to: Press Office, Epilepsy Society, Chesham Lane, Chalfont St Peter, Buckinghamshire SL9 0RJ.

We look forward to hearing from you.

This spring, Epilepsy Society launched a political campaign to end avoidable premature deaths in epilepsy. The campaign launch was a major success attracting national media coverage, including Sky TV News, Channel Five and the Independent On Sunday. Our policy advisor Finn O'Dwyer-Cunliffe explains why he feels encouraged by the response but still thinks more should be done by our Government

Speak up for epilepsy

Around 500,000 people in England have epilepsy, and although figures show that the condition carries with it a greater risk of premature death, over a third (39 per cent) of those deaths are thought to be avoidable through better care, treatments and services. This result was found in the National Audit that took place in 2002.

We believe that a new clinical audit will help identify regional disparities in epilepsy care and increase understanding of current weaknesses in care management so that resources can be directed where needed.

Figures show that you are two to three times more likely to die prematurely if you have epilepsy, but data collected from the Office of National Statistics from 2009-2013, shows that rates of premature death vary vastly within England and create a postcode lottery: for example, someone with epilepsy is 49 per cent more likely to die prematurely in West Yorkshire than in Cheshire.

New scientific evidence published in the *Neurology Journal* also demonstrates that people with epilepsy often have other serious health conditions which go undetected, some of which could bring about premature death.

Most premature deaths in people with epilepsy are related to other health conditions, particularly cancers and cardiovascular or cerebrovascular disease.

So far we have had a remarkable response from our supporters to our political campaign highlighting avoidable deaths in epilepsy. Close to 2,000 people across England emailed their local MP, asking them to lobby health secretary, Jeremy Hunt to commission a new National Clinical Audit on all epilepsy deaths. We want to thank all our supporters who took part in the campaign action – 512 MPs were emailed as a result of your letters.

We have seen replies sent to a number of our supporters, both from Government and opposition MPs, and it is clear there is concern within the House of Commons about the overall quality of care for people with epilepsy, and the highly variable outcomes uncovered by our campaign.

Awareness of the unacceptable rate of avoidable deaths has been helped by three MPs writing questions to the Secretary of State about plans to commission a new audit, and this was replicated by a group of seven members sponsoring an early day motion calling for Mr Hunt to take this action.

The Government's response to the written parliamentary questions, provided by minister for public health Jane Ellison, has mirrored the answer many received to their campaign emails. We are pleased that the department of health has recognised the importance of this campaign and has circulated a letter to Government MPs, which provides a detailed response to the campaign's arguments. However, it must be said that this response fails to adequately address the central concerns raised by this campaign.

'We will be pushing for a parliamentary debate on premature epilepsy deaths'

The department's letter points to a few healthcare initiatives involving epilepsy patients, including the Epilepsy 12 audit and the National Mortality Case Record Review. The Epilepsy 12 audit has been an important piece of work in the field of paediatric epilepsy, as it has highlighted common trends over the past few years in epilepsy care for children and young people, with some positive and negative results.

The National Mortality Case Record Review is a broader piece of work that will look into case records of people with any condition or health issue who have died in acute hospital settings, and will eventually aim to create a nationally standardised process for these reviews, particularly in respect to problems in care that may have contributed to these deaths.

Both of these pieces of work are relevant to the overall understanding of how poor access and deficiencies in care in the NHS may be contributing to adverse outcomes for patients. However, none of the studies highlighted by the

department of health have focused on uncovering the extent of avoidable epilepsy deaths since 2002, and the Government's response has failed to explain why little has been done to address geographical disparities in outcomes and quality of care in recent years.

The response given to our supporters has not ruled out a full audit on epilepsy deaths taking place in the future, nor has it suggested that such a study is not needed. Indeed, the department's answer suggests an acknowledgement that more information is necessary in order to improve the quality of services and the lives of people with epilepsy across the country.

We have been encouraged by the Government's willingness to listen to our supporters, and we are hopeful that further engagement with health ministers and other members of parliament will further our cause. We're also grateful to those MPs who have taken the time to reply individually to those supporters who have offered their own personal stories. We will be pushing for a parliamentary debate on the issue of premature epilepsy deaths to continue our lobby for a full National Clinical Audit.

Our campaign has raised awareness of the 39 per cent of epilepsy deaths that could be avoided with better access to care, and of the large variation in outcomes for people with epilepsy across England. It is clear that these uncomfortable facts have struck a nerve in Westminster, so we must continue to seek the vital information that will help eliminate avoidable deaths and create an effective and efficient health service for people with epilepsy that is truly national.

'I recently came across the Epilepsy Society's campaign to "Speak up for epilepsy'" to stop avoidable deaths in epilepsy and will be fully backing this campaign alongside many other Labour MPs who have already shown their support.

'The statistics you have provided are shocking and more needs to be done. Considering around 500,000 people have this condition, it has not been effectively acknowledged. A new audit regarding avoidable deaths in epilepsy is needed in order to identify how best to tackle this issue effectively. Along with my Labour colleagues, I will continue to press for this and will support the issue wherever possible.'

Dan Jarvis MP, in reply to an email from his constituent, Laura Johnson

Samantha's story

Nineteen-year-old Samantha Ahearn died of SUDEP (sudden unexpected death in epilepsy) just six months after her first seizure

Samantha had barely had time to come to terms with her diagnosis of epilepsy when she had a seizure on the stairs of her family home. Samantha died at the bottom of the stairs with her mum, Lynn McGoff beside her.

'It was only Samantha's sixth seizure and it was not as vigorous as her previous ones,' said Lynn. 'Everything seemed to just suddenly stop for her. It was as though a light bulb had switched off and she had gone. I couldn't believe she had died. I kept expecting her to start snoring as she usually did after a seizure. I was trying to reassure her.'

Bubbly and outgoing, Samantha was a big sister with everything to live for. She had just finished her A' levels and was looking forward to studying ▶

to be a social worker at Huddersfield University.

She doted on her two-year-old sister Alice and the day Samantha died she had been out to buy a present for her 16-year-old brother Adam. It was his birthday.

Samantha died in the summer of 2009 but mum Lynn says the family has still not recovered from the loss of her precious daughter. 'It is the worst thing that can happen to a parent,' she continued. 'My life is in devastation.

'Parents should be informed of the risks. It is us who find them dead.'

'After Samantha died I rang her consultant and said to him "you can't just die of epilepsy." It was only then that he said "you can" and he told us about SUDEP. When I asked him why we had not been told about this before, he said that Samantha was not in the high risk category for SUDEP.

'I was appalled. Are we not proof enough that epilepsy is the risk? I know that because Samantha was diagnosed as an adult, we could not automatically be involved in her appointments, but I think as long as the person themselves is happy, as was Samantha, parents should be informed of the risks. It is us who find our children dead.'

Lynn and her family have now moved house. 'We stayed living in our home for a couple of years, but I couldn't cope with going up and down the stairs everyday where Samantha had died,' said Lynn. 'It was too much for me.

'Now I worry that the same could happen to my other two children. I was dreading Adam reaching 19 and am so relieved that he is now 22 and past the age that Samantha was when she developed epilepsy.

'My younger daughter Alice cannot accept that she will never see her big sister again.

'Samantha was very sensible with her epilepsy. She always took her medication. She wasn't a party animal or big drinker. She always showered rather than had a bath and did everything she could to stay safe. The day after she died she was due to go on holiday to Tenerife with friends and was making sure she had all the right medication. She was just changing from lamotrigine to levetiracetam because lamotrigine had given her hand tremors.

'Six days after Samantha died, the coroner's secretary said a post mortem showed that Samantha had not been taking her drugs and had been drinking. We knew this was untrue. It was unbearable.

'Because we were so adamant, the coroner sought a second opinion which proved that Samantha had been taking her drugs, as prescribed, and had not been drinking.

'Samantha would be 26 now. All her friends are starting to have children. They bring them round to see us which is lovely but my life is not the same without my daughter.'

Understanding risks and epilepsy

In the UK there are around 1,200 epilepsy related deaths each year.

Some of these may be caused by complications during or after a seizure. Others may be due to accidents such as falls or drowning. Some may be due to suicide.

Recent studies show that the majority of premature deaths in people with epilepsy may be caused by another condition the person has alongside their epilepsy. These include underlying neurological problems which may have caused the epilepsy, heart or breathing conditions, anxiety, depression or other mental health conditions, and some cancers. Other deaths in people with epilepsy may relate to drug or alcohol abuse.

You can find out more about risks and epilepsy at epilepsysociety.org.uk/risks-epilepsy

To talk about concerns around epilepsy and premature mortality, please call the Epilepsy Society helpline on 01494 601 400. Epilepsy deaths are not common but do happen, and while not all deaths are avoidable, some are.

SUDEP Action specialises in supporting and involving people bereaved by epilepsy. If you have been affected by an epilepsy death please contact the SUDEP Action support team on 01235 772852.

More than 200 delegates joined us for Epilepsy Society's annual conference, held this year at the magnificent Central Hall in Westminster, London. The conference is an opportunity for us to share our most exciting developments and research, but it is also a chance for delegates to meet and share stories and experiences. Here we bring you extracts from some of our key speakers. You can also hear their presentations and watch their slides at epilepsysociety.org.uk/conference-catchup

Epilepsy conference

Dr Fergus Rugg-Gunn, clinical lead at Epilepsy Society's Chalfont Centre, looks at SUDEP – Sudden Unexpected Death in Epilepsy.

Understanding the risk factors around SUDEP is key in reducing the number of deaths caused by epilepsy, said Dr Fergus Rugg-Gunn.

Both patients and healthcare professionals need to talk openly and honestly about SUDEP so as to modify risk factors and to put in place appropriate support. 'Educate to protect' was his take-home message.

'In 2006, a questionnaire of 288 UK neurologists showed that only 4.7 per cent always discussed SUDEP with their epilepsy patients. Just over 25 per cent discussed it with the majority of epilepsy patients, 61.2 per cent discussed it with very few patients and 7.5 per cent never discussed it,' he said.

This was in spite of a 2002 national audit into epilepsy-related deaths which showed that 39 per cent of deaths in adults were potentially preventable.

Inadequate services highlighted in the report included:

- poor access to outpatients
- inadequate drug management
- lack of investigations
- not seen by a consultant
- lost in translation from paediatric to adult services
- and lack of a care package.

Dr Rugg-Gunn emphasised that these were all issues which should and could be addressed.

'Every patient has the right to know the full consequences of their illness,' he told delegates. 'The potential risks should be disclosed in the context of comprehensive education. There are circumstances where it is imperative to emphasise the risk of SUDEP so that the person recognises the importance of taking their medication regularly, following a healthy lifestyle with a balanced diet and adequate sleep, and having regular medical appointments.'

Dr Rugg-Gunn said that much could be done to support self-management through seizure alarms, smartphone seizure diaries and SUDEP Action's EpSMon which monitors health and risks in between GP visits.

Epilepsy Society's medical director Professor Ley Sander bemoans the 'frustrating' lack of advances in epilepsy treatment over the last 30 years and stresses the need for a new treatment model

'We treat seizures and not epilepsy,' he said. 'We need a "curative" disease-modifying treatment that is lacking and urgently needed.

'We are treating the symptom and not the cause of epilepsy. It's like giving someone with anaemia iron tablets rather than treating the root cause.

'Before I retire, I want to see treatments that are tailored to the person in front of me.'

Professor Sander said that while the US Food and Drug Administration (FDA) consider a 50 per cent reduction in seizures as a valid outcome in the trial of anti-epileptic drugs (AEDs), 50 per cent does not make a difference in people's lives.

He said epilepsy often imposes social disadvantage. It can be a disability that affects education and employment prospects. 'Telling someone they will have half the seizures they currently do is like telling someone to jump from the fifth storey of a building rather than the tenth.'

Professor Sander said that 90-95 per cent of people with epilepsy use AEDs as they are still the mainstay of current treatment. He said that although AEDs are not perfect they would remain an important element of treatment even in a few years' time in the age of genomics.

He said that even though there are more than 25 AEDs currently available, up to 30 per cent of people with epilepsy do not respond to the current drugs, a figure that has not changed during his career.

He said there is an urgent need for new AEDs to reduce and stop seizures, morbidity and premature mortality, and to provide better, more cost-effective options.

He also argued for a shift in treatment model for epilepsy that would affect epileptogenesis rather than simply treating the symptoms of epilepsy.

Professor Sander explained that in his clinic, he lives by two mantras: 'Is it really epilepsy?' and 'epilepsy and what else?'

The first reflects the 20 per cent misdiagnosis in epilepsy and the second underlines the number of people with epilepsy who also have other accompanying conditions.

He called for a better relationship between physicians and patients, emphasising the importance of regular treatment reviews and advocating discussing surgical options at the earliest possibility for those who may be candidates for this treatment.'

Professor Sanjay Sisodiya, director of genomics at Epilepsy Society, on the role of science in epilepsy

'Through genetics we are aiming to get the best treatment for everyone with epilepsy. Precision medicine combines precise diagnosis with precise data analysis and precise treatment. It is about getting the right treatment to the right patient at the right time.

This presents specific challenges with epilepsy. We know that it is not one condition but rather a collection of different types of conditions. For each individual we must work out the type of epilepsy they have and what will be the right treatment for them. This may be a particular epilepsy drug or it could be surgery or a dietary therapy.

There are many occasions when it may not be clear what is happening with a person's epilepsy. The picture may be complicated with lots of seizures, lots of medication and admissions to hospital.

Science is helping us to undo this complicated picture by building up layers of information. First of all we take a detailed history of the person's epilepsy. We then carry out tests – for example, MRI, EEG, blood tests. Now we are starting to look at a person's genetic make-up so that gradually we begin to understand more about epilepsy in some people and how we can improve their treatment.

Aidan is a young man who was referred to Epilepsy Society with multiple seizures and was in and out of hospital. By listening to his history and advising for him to undergo genetic tests, we were able to confirm that Aidan has Dravet syndrome.

We know that with Dravet syndrome some treatments will work well, while others may make things worse. In Aidan's case we have been able to make drug changes that have had a huge benefit for him.

Aidan's seizures have become much less frequent. He is speaking again and finding out about the world. He is developing a sense of humour and even a sense of sarcasm.

Genetics is playing a huge part in helping to deepen our understanding of epilepsy. But to really make progress it is important for us to join the world of big data.

Looking at one person with epilepsy would be like looking at one oak tree in a forest of oak trees. We could learn a limited amount of information but if we look at the whole forest we could learn so much more.

Epilepsy Society is joining the world of big data. We have been leading on EpiPGX, a multi-centre project involving scientists from across Europe who have been investigating the way a person's genes affect their response to different medications.

We hope that this will help us to identify genome-based biomarkers that will show who will respond to which drug, at which dose and with fewest side effects.

With genetics we are now looking at the acorns but again it is only by looking at many acorns that we are able to start unravelling the genetic architecture and understanding its impact.'

'People with long-term conditions spend an average of just three hours a year with healthcare professionals. They should be given the required support to live the other 8,757 hours of the year looking after themselves'

Juliet Ashton, Sapphire nurse consultant for epilepsy, commissioning and education

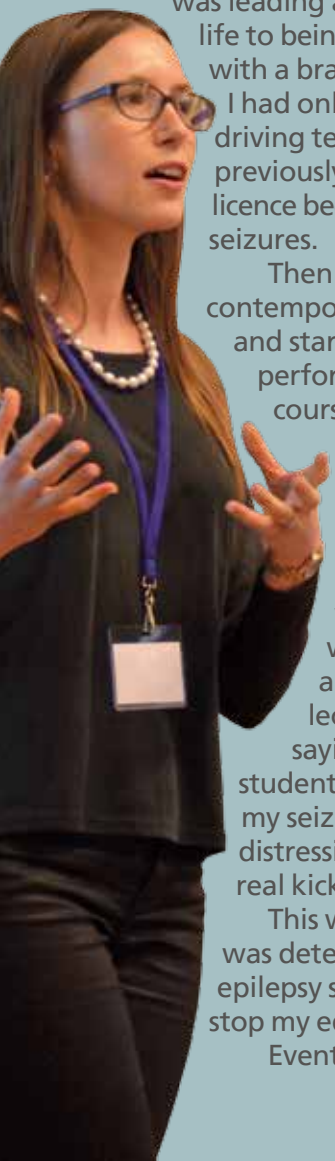
Jasmine Smith was 17 when she was diagnosed with epilepsy. Here she talks about how it changed her life

'Eight years ago I was a healthy, happy, lucky teenager. At 17 I was training to be a ballet dancer. I had passed my driving test and was out clubbing at weekends.

But I started to feel really tired. I also started talking nonsense. I was in the car with my mother and started talking about my brother. This was strange as I don't have a brother. It was only later I realised I was having a seizure.

I went to see my GP and was sent for tests including an MRI scan. This was when I was told I had a brain tumour and epilepsy. I started having generalised tonic clonic seizures which were very scary.

I went from being someone who was leading a very normal life to being someone with a brain tumour.



I had only passed my driving test four months previously but lost my licence because of the seizures.

Then I discovered contemporary dance and started on a performing arts course. I was still having two or three seizures a week. Two months into the course I was in hospital when I received a letter from my lecturer at uni saying other students were finding my seizures too distressing. It was a real kick in the teeth.

This was when I was determined that epilepsy should not stop my education.

Eventually my consultant decided that surgery could be an option for me and in June 2011 Andrew McEvoy, my brilliant surgeon at the NHNN in London, operated on me to remove my brain tumour. After the surgery a cyst started growing in its place so I had to have further surgery.

I then began working at Epilepsy Society as a volunteer. I wanted people with epilepsy to have as much help as I had enjoyed. I was working with people with severe epilepsy and learned about the work that epilepsy specialist nurses do. Suddenly I realised what I wanted to do with my life.

I got a place at uni to train as a nurse. But on my placement I was working night shifts and I had my first seizure since my surgery. The tumour was growing back. I was in hospital in a coma for a week.

After that I took six months off from my nursing course and booked an 11-day holiday in Croatia on my own. My family thought I was mad but during that holiday I told everyone I met that I had epilepsy. It was amazing the amount of people I told who knew others with epilepsy.

Six weeks ago I got my nursing degree. Now I am looking to the future. I would not wish epilepsy on anyone. It is not just the seizures. It is the loss of independence. Not being able to have a bath on your own or use curling irons. All the little things that people don't think about.

But epilepsy isn't the end of everything. I have learned so much about myself through my epilepsy. One minute I was dancing, now I have a whole new career. I would urge anyone with epilepsy to have the best life possible.

'I have learned so much through my epilepsy. One minute I was dancing, now I have a whole new career.'

Your thoughts

'I am a special needs teacher of primary school aged children. The majority of my class have a diagnosis of epilepsy so I've come along to find out how I can support them. It is good to be around other people who experience epilepsy daily. It is definitely worth coming, especially if you are supporting people with epilepsy.'

'What I have gained from the conference is around the holistic approach to epilepsy care and that it's not just about medication and treating the symptoms. It is much more around the individual person's care and what they want to get out of it.'

'I have found it really interesting hearing about genetics and how that can help us in the future with new treatments.'

epilepsy society helpline

01494 601400

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

Hens and coconuts and the ketogenic diet

Katrin Augustin keeps hens. She is also one of the researchers who have identified the anti-seizure mechanism behind a specific ketogenic diet therapy. Here she explains how a fatty acid in coconut oil could affect our brain and could hold future promise for people with epilepsy

Gwendolyn was three years old when she had her first seizure. She started with rare, short attacks that built up over the following seven years until she was experiencing between 60 to 100 seizures a day. Finally, when she failed to respond to any treatment, her doctors decided to try a new approach recommended by French clinicians. They put her to bed, withdrew all food and kept her on a light broth for the next three weeks. Within three days, her seizures had stopped, but as soon as she went back to her everyday activities a few weeks later, her epilepsy relapsed.

That was in 1922. A year before Gwendolyn's story was published in the *Canadian Medical Association Journal*, Dr Wilder from the Mayo Clinic in the US, set out to develop a diet that could mimic the effects of starvation without having to keep children from eating.

He knew that when people fasted their brains no longer received sugar to keep working but relied only on ketones, small molecules that are metabolised from fats. He believed that these ketones changed the brain chemistry to prevent seizures and therefore predicted that replacing most carbohydrates in the diet with fats would have the same effect as starving. Based on that he designed the ketogenic diet which consists of a ratio of four grams of fat for every gram of carbohydrates.

Today, almost 100 years later, the diet is still being used successfully in children and adolescents who do not respond well to anti-epileptic drugs. But it is still not understood how sugar reduction and ketone production help reduce seizures.

Over time, different versions of the ketogenic diet, such as the medium chain triglyceride (or MCT) ketogenic diet and, more recently, the modified Atkins diet, have been developed that offer more flexibility by allowing more carbohydrates and less fat.

The MCT ketogenic diet contains medium-chain fatty acids rather than the usual long-chain fatty acids found in most foods. Medium-chain fats are naturally found in goat's and horse's milk, and coconut and palm kernel oil. In the MCT ketogenic diet they are provided as an oil supplement.

Because they are smaller, they are absorbed that much faster and generate ketones more readily than long-chain fats.

The medium chain fatty acid that has caused most excitement is decanoic acid, found in coconut oil. Our research at Royal Holloway University of London and University College London has shown that this, rather than the ketones in the MCT ketogenic diet, has strong anti-seizure effects.

Decanoic acid has been shown to block seizure activity and may also induce fewer side effects than many of the traditional anti-epileptic medications.

Results show that the direct inhibition of excitatory transmission in the brain by decanoic acid contributes to the anti-convulsant effect of the MCT diet. Furthermore, this effect is through inhibition of AMPA receptors in the brain, a target shared by one of the newest anti-epileptic drugs, perampanel.

Researchers at UCL also showed that adding decanoic acid to neuronal cells helped to increase the number of mitochondria in the cells – these are the parts of the cell which generate most of the energy needed to keep it alive. By increasing the number of mitochondria, the MCT ketogenic diet might also prevent cells from dying during seizures.

Surprisingly, the MCT ketogenic diet is not used a lot outside of the UK and Canada – even though it is the first diet for which two independent mechanisms of action in epilepsy have been demonstrated.

Patients and dieticians have often criticised that there is a poor correlation between ketone levels and seizure control. A mechanism that involves fats included in the diet rather than ketones could help explain this discrepancy. Currently, research into a role for ketones in seizure control is still ongoing. There is evidence that ketones alone can delay seizures and that they have a similar protective effect on mitochondria as decanoic acid.

Considering the benefits from decanoic acid itself, could there be an easier way to achieve seizure control than the diet, by only using decanoic acid? In that case, decanoic acid could be another anti-epileptic drug. There are already two medications that block the same receptors as decanoic acid, but their exact mechanisms may vary resulting in different side effects or levels of seizure control. How effective decanoic acid is compared to these anti-epileptic drugs still requires more investigation. Also, the efficacy of decanoic acid does not explain why the classic ketogenic diet, which does not use medium-chain fatty acids, is similarly effective.

Even though the ketogenic diets were designed use in epilepsy, recently more and more conditions have been suggested to benefit from ketones provided by the MCT ketogenic diet.

'Decanoic acid has been shown to block seizure activity and may induce fewer side effects than many anti-epileptic medications'

For instance, ketones may slow the progression of Alzheimer's disease. A study from 2008 found that neurons in patients with Alzheimer's disease could not take up enough glucose and so starved, a phenomenon that they said could explain some of the cell death in Alzheimer's. Patients who received a ketogenic compound derived from medium-chain fatty acids did better in cognitive tasks than other patients.

The MCT ketogenic diet might also be beneficial in the treatment of brain cancers. In 1995, two children who had advanced brain cancer were treated with the diet. Cancer cells live on glucose, but in contrast to healthy cells, they cannot use ketones when glucose levels are low. As a result of the high-fat diet, the tumours of both children shrank by 20 per cent and they did not progress in their disease.

So, if it is so healthy, should we all live on a ketogenic diet? That is probably not necessary. First of all, the diet is not easy to stick to. Fat-rich foods are hard to digest resulting in an upset stomach and nausea and there are other side-effects such as constipation and kidney stones that a healthy person need not risk. It is true, however, that reduced sugar intake is associated with weight loss leading to a lower risk for heart disease and diabetes.

The question that remains is, why the ketogenic diets are not used in all children with hard-to-treat epilepsy. One reason is that many doctors are still not aware that an alternative to anti-epileptic drugs even exists. The other reason is that, unfortunately, just as with anti-epileptic drugs, not everyone on the ketogenic diet becomes seizure free and some do not respond at all. However, what makes the ketogenic diet so special is that it has worked in some patients where medication had failed. For the first time, we can see that fats and their metabolites can alter brain function – and that may be a first glimpse of how our diet can affect our brain.

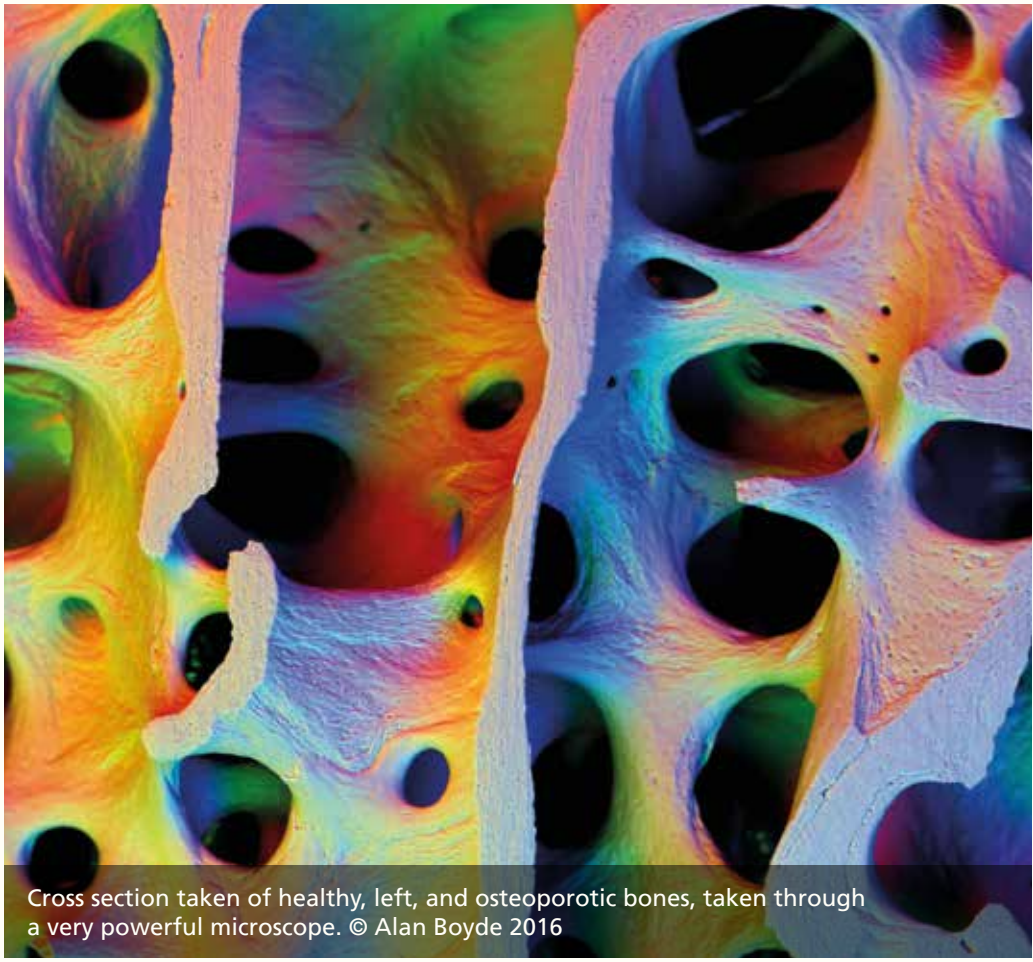
Katrin Augustin is a post graduate research student at the School of Biological Sciences at Royal Holloway University of London.

Tales from the hen house: watch Katrin Augustin explain about the ketogenic diet at http://bit.ly/25jVv7r And you can read Katrin's blog about studying as a postgraduate research student while having young children at epilepsysociety.org.uk/blog/katrin

Photograph: Rachel Lewis

Should you worry about osteoporosis?

Osteoporosis is a condition which causes bones to weaken and break easily. It is often thought of as mainly affecting the elderly. Sadly, as a result of the action some epilepsy drugs have on bones, it can also cause problems for those with epilepsy. National Osteoporosis Society Helpline Nurse Tina Stoodley explains



Cross section taken of healthy, left, and osteoporotic bones, taken through a very powerful microscope. © Alan Boyde 2016

What is osteoporosis? First, a bit of Latin, because there's a clue in the name. The word osteoporosis means porous bones and it occurs when the struts which make up the mesh-like structure within bones become thin. This causes them to become fragile and break easily following what could be just a minor bump or fall.

That's osteoporosis and it's surprisingly common: almost one in two women and one in five men over the age of 50 will break a bone, mainly due to poor bone health. Today, the National Osteoporosis Society estimates there are more than three million people in the UK affected by the condition.

While many of these have developed osteoporosis because of their age, family history, body weight or because of conditions such as coeliac disease, some will have developed the condition because they are taking anti-epileptic drugs (AEDs).

Anti-epileptic drugs and bones

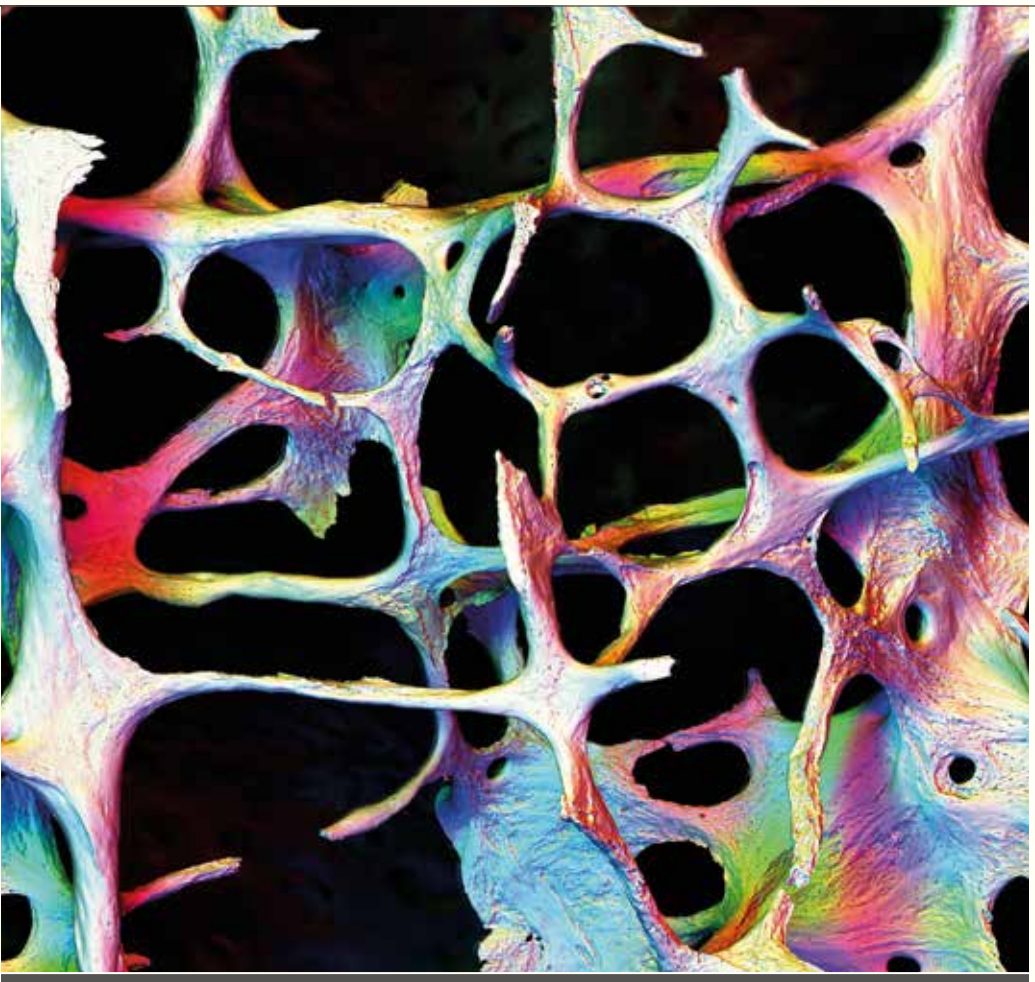
Although more research is needed, scientists are aware that AEDs can be associated with an increased risk for osteoporosis and fractures.

For some people, the drugs can cause drowsiness and slowing down of the body's reflexes, as well as affecting balance and coordination leading to an increased risk of falling. But it has also been shown that taking anti-epileptic drugs for a long period can decrease bone density.

It is also thought that some anti-epileptic drugs alter the way vitamin D, which helps with the absorption of calcium, is broken down and used by the body. Some of the older anti-epileptic drugs are thought to stimulate a liver enzyme which destroys vitamin D. This family of drugs, which include phenytoin, phenobarbital, carbamazepine and primidone are known as enzyme inducing anti-epileptic drugs.

Because of these findings, drug safety group the MHRA – looked at all the evidence and found that long-term treatment with carbamazepine, phenytoin and primidone and also another drug called sodium valproate can reduce bone density and may lead to osteoporosis in certain 'risk' groups.

These groups include those immobilised for long periods, those not getting enough calcium in their



If you are considered to be at a high risk of breaking bones easily, the good news is, there is plenty you can do to keep your bones strong:

- Eat a well-balanced calcium-rich diet
- Make sure you get adequate vitamin D through safe sunlight exposure
- A calcium and vitamin D supplement may be prescribed if intake of these needs to be boosted
- A drug treatment to make weak bones stronger and less likely to break may be prescribed by your doctor
- Pain relieving medications will help if fractures have already occurred
- Take plenty of weight-bearing exercise – any exercise in which you are supporting your own body weight through your feet or legs

diet or having insufficient exposure to sunlight through the summer months to maintain adequate vitamin D levels.

Currently there is very limited and conflicting evidence about the long-term effects of non-enzyme inducing AEDs on bone. These newer drugs include gabapentin, lamotrigine, topiramate and levetiracetam. More research is needed, but it is thought that, when used for a long period of time, most AEDs are likely to be linked to an increased risk of breaking bones.

Other risk factors for fractures

So, those who have epilepsy are more likely to have fractures, but this is likely to be due to a combination of factors including the direct effects of the AEDs, but also the seizures themselves that can cause falls and bones to break.

Other contributory factors if you have epilepsy include lack of exposure to sunlight which can cause lower vitamin D levels, and reduced activity levels or physical restrictions which can impair bone health and consequently increase fracture risk.

Protecting bones

For those affected by epilepsy and osteoporosis, it's important to continue to take the AEDs as prescribed. Eating a well-balanced calcium-rich diet and incorporating as much weight bearing exercise as possible will also help to keep bones healthy and strong.

The National Institute for Health and Care Excellence (NICE) recommends that vitamin D levels and other checks to assess bone health are carried out every 2-5 years for all adults who take enzyme inducing AEDs. UK guidance also suggests a vitamin D supplement for those on long term AEDs.

Assessing bone health, especially if you are over 50, may also show that a DXA bone density scan may be useful. These scans may help a doctor decide whether a drug treatment for bone protection should be prescribed.

Although there are no definitive recommendations for people with epilepsy, if you have been taking AEDs long-term and if you have other risk factors, it may be useful to discuss your possible risk of osteoporosis and fracture with your doctor.

Helen's story

Helen, 60, has both osteoporosis and epilepsy. She is gradually being moved to a new treatment because her existing AED may have been affecting her bone density.

She found out she had osteoporosis when she was around 50 and suffered a fractured wrist.

'My doctor told me I had osteoporosis in my hips and spine and I started taking alendronic acid. I haven't suffered any major fractures, though I have broken a rib. I also have rheumatoid arthritis,' she says.

Helen found out she had epilepsy during the summer of 2015. She has asleep seizures.

'I only became aware of it because my partner noticed something was happening when I was asleep. I went to see the doctor and was diagnosed and started taking sodium valproate.

'My doctor told me the drug might have an effect on my bone density and could be related to osteoporosis, so I'm gradually being moved to a new treatment,' she says.

More information:

nos.org.uk
Freephone Helpline: 0808 800 0035
Email: nurses@nos.org.uk
epilepsysociety.org.uk/osteoporosis-and-epilepsy

Recovery position

Do you know how to put someone in the recovery position following a tonic clonic seizure? Our step-by-step guide shows you what to do once the person has stopped shaking

Get all our first aid information from our free app at epilepsysociety.org.uk/free-epilepsy-smartphone-app

Watch our recovery position video at epilepsysociety.org.uk/recovery-position-video

Step-by-step recovery position

1 Kneel on the floor to one side of the person.

2 Place the person's arm that is nearest you at a right angle to their body, so that it is bent at the elbow with the hand pointing upwards. This will keep it out of the way when you roll them over.

3 Gently pick up their other hand with your palm against theirs (palm to palm). Now place the back of their hand onto their opposite cheek (for example, against their left cheek if it is their right hand). Keep your hand there to guide and support their head as you roll them.

4 Use your other arm to reach across to the person's knee that is furthest from you, and pull it up so that their leg is bent and their foot is flat on the floor.

5 Gently pull their knee towards you so that they roll over onto their side, facing you. Their body weight should help them to roll over quite easily.

6 Move the bent leg that is nearest to you, in front of their body so that it is resting on the floor. This position will help to balance them.

7 Gently raise their chin to tilt their head back slightly, as this will open up their airway and help them to breathe. Check that nothing is blocking their airway. If there is an obstruction, such as food in their mouth, remove this if you can do so safely. Stay with them, giving reassurance, until they have fully recovered.

In the last three years I have had six or seven seizures all brought on by late night partying. My neurologist prescribed anti-epileptic drugs but I was reluctant to take them as I felt I could avoid further seizures by changing my lifestyle. However I recently had another seizure after a particularly stressful time at work.

I am still reluctant to take the drugs as I am worried about the side effects. My neurologist is very understanding but thinks I should start on a low dose of levetiracetam.

I am really torn. I obviously want to be safe but I don't want a lifetime of drugs if I can control the seizures through lifestyle choices. Does anyone have any advice?

James, Preston

Your replies

I have been in your position in the past and I know exactly how you feel. I found it emotionally and physically hard trying to find the right medication. (Medication reacts differently for everyone.) Having said that it is worth it to protect yourself as frequency of seizures can change over time. Unfortunately you can't rely on lifestyle changes to help with your seizures. Being on a low dose should help you see how reactive you are to the side effects and being on a low dose might be enough anyway to protect you.
Kirsty, facebook.com/epilepsysociety

I thought I could do similar. I wanted to experience my body and mind bare, without meds after being on them since age of 11, so I stopped. I was 20 at the time. I suffered in shocking ways, from approx two (seizures) a year to one a month. But of course, I thought life style changes and methods to de-stress would solve it. Eventually I had an encounter of status epilepticus which was frightening for all around me. Since then I returned to meds. Tried various types and happily rejoicing a year without a seizure.
Clarissa, facebook.com/epilepsysociety

Just as my daughter's epilepsy came under control, we found out she was having non-epileptic seizures which are similar, but brought about by stress and tiredness. Would be worth getting an EEG if you haven't already, just to check if it is epilepsy. Non-epileptic seizures can't normally be controlled by medication, but seeing a psychologist has really helped my daughter to control hers.
Geoff, facebook.com/epilepsysociety

My advice take the advice of your neurologist. My seizures are triggered by stress, lack of sleep and hormones. I can go years without any then when they kick in I can have multiple ones back to back or monthly. Meds don't always control but worth a shot. Also if bad side effects there are a number of meds they can try. I've been on a ton of different meds until they stop working or bad side effects and we change.
Michelle facebook.com/epilepsysociety

I would ask your neurologist if they can send you for a video telemetry EEG and MRI to try and find where your seizures are originating.

Changing lifestyle can never hurt. I would keep a record of the changes you make though and do them gradually to see if certain things make a difference.

In terms of medication, I would strongly recommend taking it, but through discussions with your neurologist see if you can be on a low dose and have your blood levels checked regularly,to see how much the medication is affecting you and how much is in your system.

Sadly sometimes if epilepsy goes untreated, or if you start having more seizures, it can have a bigger impact on your life.
David facebook.com/epilepsysociety

You can read more replies to James' letter at: facebook.com/epilepsysociety

Next issue

I have had epilepsy since I was 12 years old. I'm 31 now and planning to start a family. I still have seizures every six months or so – sometimes just one or sometimes I have a cluster of them.

I know I am not on one of the drugs that can be risky for an unborn baby during pregnancy but does anyone have any advice about pregnancy and epilepsy and also childbirth and breastfeeding? I am starting to feel quite anxious.

I'm also worried about my baby inheriting my epilepsy. One of my aunts and a cousin on my mum's side both have it, although their epilepsy is milder than mine?
Alison, Brighton

WOULD YOU LIKE TO SHARE YOUR THOUGHTS WITH ALISON? 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

In the last issue I reflected on what a drag I find it to constantly reintroduce my epilepsy to new people I encounter in life. Oh what a terrible burden, to have explain to the uninitiated again and again, to answer their questions, dispel their myths, hear about their schoolfriend who once had a seizure during breaktime, experience their concern and curiosity. What a chore!

For the hashtag happy amongst us, this kind of dilemma really does fall under the well worn hashtag #firstworldproblems in that it's really not a problem that people care enough to find out about my epilepsy. Actually it is pretty cool.

It's nearly 25 years since I was diagnosed and these days I tend to wear my epilepsy like a comfortable cardi. It's so familiar, it can be traced through different memories from my life, as if I'm flipping through a virtual album of memorable seizures from across the years – seizures on holidays and at parties, that time I was at the airport, another time in Pret a Manger – after which they sent me a 'Get Well Soon' bunch of flowers (personally I'd have preferred free sandwiches for life, but what can you do?), that office, different ambulance drivers, different A&Es, the people who have been with me during and after a seizure – memories of friends, ex-boyfriends and ex-girlfriends, family members, all of whom have taken a role in being part of my life's story, even if only for a short while.

My story of epilepsy is kind of the story of me; the places I've been and worked and the people I have known and loved. I can make some peace with that now. Of course it helps I haven't had a seizure for nearly 18 months, but if I did, these days I increasingly feel 'oh, this again' and I run through the familiar cycle of disappointment, sadness and frustration which heal slowly, as my body recovers.

A friend of mine was diagnosed with bi-polar disorder a few years ago, and she recently asked me if we could chat because she wanted to speak to someone 'who understands what it's like for your brain to make you ill'.

I had never really thought of it before in those terms, but she's absolutely right that epilepsy is the brain making the body ill. I was so glad that she reached out; she's still adjusting to her diagnosis – it's a slow and sometimes hard slog, after all – and it really struck me that she was getting to know herself in a new way.

She is starting slowly to identify triggers for her manic episodes and feeling paralysed with the meds she is prescribed to calm her down. Like many people with mental health problems, she has been prescribed anti-convulsants as a default med, so we have that in common too.

She was struggling with the invisibility of mental illness, which I can obviously relate to, and the stigma that comes with an invisible disease – again, check.

She knows that the law of probability means that she's likely to know already somebody with bi polar disorder but, because it is unfortunately not talked about more, she doesn't know who that someone is. She's really looking for other people who understand, and I really relate to that. I'm really glad that we found a new way to connect and understand each other's experience that little bit better.

Like our treetop chattering, preening primate cousins, we are social creatures, and looking for connections is just a thing that we do. We need to find 'our people', and these days our communities tend to be based on shared interests and experiences rather than which village you hail from.

Epilepsy on parade

The LGBT (Lesbian, Gay, Bisexual and Transgendered) community is built on a mutual recognition of being 'other' than the heterosexual mainstream. Lesbians and gay men don't really have much to do with each other (think about it), but within the LGBT community these micro communities are united under a beautiful rainbow umbrella.

I wonder if we can build a LTMC (Long Term Medical Condition) community, based on a mutual recognition of a medical condition being a significant part of your life experience, with all that means for you: hospital visits, medication, the emotional cycle of frustration and disappointment after a relapse and hope for being well, feeling vulnerable and hating it, coming out to people about our condition.

All us people with epilepsy could come together with people with mental illness, asthma, diabetes, irritable bowel syndrome, arthritis etc and celebrate our diversity and our sameness. We could unite under a beautiful, I don't know, patchwork? banner (rainbows having already been taken) and create community action groups, discussion forums, share experiences beyond the reach of our own medical condition, lobby for fundamental rights and visibility in the media. And we could have a parade!

Really I just want a parade. Who's with me? *explodes glitter cannon.

JULIET STEPHENS
LAUGHING ALLOWED

Wishing 'Team Purple' cyclists good luck

Epilepsy Society would like to wish all our cyclists the best of luck for the Ride London 100. On 31 July, our 'Team Purple' riders will cycle the 2012 Olympic road race route, completing 100 miles in less than nine hours. Ride London-Surrey 100 starts in Queen Elizabeth Olympic Park, and follows a 100-mile route on closed roads through the capital and into Surrey's stunning countryside before finishing on The Mall in central London.

If you have a ballot place we would love to welcome you to our team prudentialridelondon.co.uk/charity/ride-charity/i-have-ballot-place/

If you missed out this year, Epilepsy Society has places for 2017 so please get in touch via fundraising@epilepsysociety.org.uk

If you're not ready for the full 100 how about Ride London 46, a great traffic-free route for your first sportive.

Community spirit

Epilepsy Society said a huge thank you to CAWC International for giving 27 years of support to people with epilepsy.

CAWC International (the Chilterns American Women's Club, pictured above outside our Epilepsy Society Research Centre) have recently celebrated 65 years of community activity in the Chilterns, and have raised over £160,000 for Epilepsy Society since 1989.

Epilepsy Society fundraising officer, Chloe Chambers said: 'We are hugely grateful for all their support.'

Long running support

... and a big thank you to all our 32 amazing runners who took part in the 2016 London Marathon.

The fastest runner this year was Zac Peel who completed the run in 3 hours 28 minutes and 30 seconds, followed just six seconds later by David Poole. Eighty-one-year-old runner Jennifer Barker delighted us all by completing the marathon in 7 hours and 21 minutes.

Epilepsy Society fundraising officer, Ben O'Keefe said: 'We are extremely proud of our 2016 London Marathon team.'

Tea for the Queen

Her Majesty the Queen has had a long relationship with Epilepsy Society, since becoming patron in 1952. On Sunday 12 June 2016, The Mall in St James' Park will be transformed for its largest ever street party to celebrate The Queen's patronage of over 600 charities and organisations on the occasion of her 90th birthday.

Our supporters will also be holding their own 'Tea for the Queen' parties up and down the country, to mark the day and raise money for epilepsy. Enjoy the party, wherever you are.

Purple power

Thanks to all your amazing efforts, we raised over £40,000 on Purple Day, 26 March. You baked, you ran, you dressed up, dressed down, painted the town – and your fingernails – purple, some of you even skydived to raise funds. And the money is still pouring in. We would like to thank every one of you. Your money will help to provide vital services for people affected by epilepsy, including our confidential helpline. It will also help to fund research into epilepsy and hopefully, one day, find a cure.

Helpline appeal

Our helpline takes calls from thousands of people each year, providing support, information and a listening ear at a time when it is needed most. But the helpline costs around £163,000 a year to run and relies on donations from our supporters to ensure there is always someone there when needed.

This is why we are launching our helpline appeal so that we can continue and increase this service. To find out more or to donate, please visit epilepsysociety.org.uk/donate

HELPLINE APPEAL

'Crying always feels worse when you are alone but if you phone the helpline you can have a good cry and they can point you in the right direction... I felt like a weight had been lifted off my shoulders. I felt I wasn't alone.'

We rely on donations from you to ensure our helpline is there when callers, like Sarah, need it. In our latest appeal, Sarah asks for your urgent help in enabling us to continue providing this vital lifeline for everyone affected by epilepsy.

Callers need our help now, so please donate today

by calling **01494 601410** or visit **epilepsysociety.org.uk/donate**

epilepsy society

a full life for everyone affected by epilepsy

epilepsysociety.org.uk
01494 601 300

Confidential Helpline – 01494 601 400
Monday to Friday 9am – 4pm,
Wednesday 9am – 8pm.
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 601 402 or visit epilepsysociety.org.uk/membership