EPILEPSY REVIEW

Issue 16, Autumn 2016

SLEEP

Find out how you can help yourself to get a good night's sleep

Your guide to sleep, page 11

CANNABIS

Could a new cannabis-based drug be a magic bullet for people with epilepsy?

The results are in, page 18

21 YEARS OF MRI

Professor John Duncan looks at how MRI scans have changed the diagnosis and treatment of epilepsy

MRI comes of age, page 8

REVIEW

epilepsy society

epilepsysociety.org.uk

Epilepsy tends to throw up more challenges than causes for celebration. Too often *Epilepsy Review* reports on what is not being done for people with epilepsy, and how we struggle to get epilepsy prioritised as a health condition. But this issue brings two very good reasons to feel positive. Both involve public transport – a mainstay for many people with uncontrolled seizures – and both are about goodwill and generosity.

First there was a trial carried out by Transport for London into a new scheme encouraging passengers to consider offering their seat to people with invisible conditions, including epilepsy (see page 4).

The trial is believed to be the first of its kind in Europe and involved 1,000 passengers wearing a badge with the message 'please offer me a seat'. It's a simple form of communication which overrides the need to explain that though you may look fine, standing on a crowded tube or train could increase your risk of having a seizure.

Then there was the bus. A big, proud, silver bus celebrating the generosity of staff at London Arriva, who have given to their favourite charities through payroll giving (see page 5). Twenty per cent of staff give to 160 charities, including Epilepsy Society.

Arriva has won a Platinum Quality Mark award and has decorated the bus with more than 70 of the charities' logos, including our own.

Both stories put a smile on our faces at Epilepsy Society. Both stories have a positive vibe and in different ways raise awareness about epilepsy.

Increasing public understanding of epilepsy is a key focus for us at Epilepsy Society. We work hard to engage with national media and broadcasting to raise the profile of the condition.

A tragic story about epilepsy hit the headlines of all the main tabloids just recently. It was a heart-breaking story that left no room for positivity, just feelings of despair at the cruelty of a condition which can invisibly and unpredictably steal a life when no-one is watching.

The story was harrowing. We asked *The Sun*, *Mirror* and *Mail* to add our Epilepsy Society Helpline details to the story so that readers would have someone to talk to, if needed.

Without question and without delay, they did. With the season of goodwill just around the corner, it's good to recognise when the world cares.

Nicola Swanborough
Editor

FRONT COVER
Penguins: Lucy Campbell
You can view more of Lucy's work at epilepsysociety.org.uk/artists-and-epilepsy
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PREGNANCY

Call for better advice over epilepsy drug risk

One in five women taking the epilepsy drug sodium valproate, do not know that it can cause developmental problems or birth defects in an unborn child during pregnancy.

And over a quarter of women (27 per cent) prescribed the drug have not had a discussion led by their healthcare professional about the risks involved in pregnancy.

The worrying statistics were revealed in a survey of more than 2,700 women with epilepsy, carried out by the UK's three leading epilepsy charities, Epilepsy Society, Epilepsy Action and Young Epilepsy.

The charities say the survey highlights the need for healthcare professionals to talk to women and girls with epilepsy about pregnancy and associated risks before they conceive.

Sodium valproate (often known under brand names such as Epilim, Epival, Episenta, Convulex and Orlept) is currently the third most-prescribed anti-epilepsy medicine. According to the Medicines and Healthcare products Regulatory Agency (MHRA), up to four in 10 babies are at risk of developmental disorders if sodium valproate is taken during pregnancy and one in 10 babies are at risk of being born with a birth defect. Women and girls of child-bearing potential should only be treated with sodium valproate if nothing else works.

The MHRA recently launched a toolkit to help healthcare professionals talk to women with epilepsy about the risks during pregnancy. The toolkit features a credit card-sized patient card to be issued by pharmacists, booklets for healthcare professionals and women taking sodium valproate, and a checklist of discussion points.

The charities are now calling on the Department of Health to continue to support efforts to ensure that all women are aware of the risks, and are supported to make informed decisions about their care.

Professor Ley Sander, medical director of Epilepsy Society, said: 'The majority of women with epilepsy enjoy healthy pregnancies and give birth to healthy babies. However, these figures highlight a pressing need for women to have the right information about pregnancy and the risks linked with sodium valproate. It is crucial women do not stop taking their epilepsy medication without talking to a healthcare professional first.' Search 'valproate guidelines' at gov.uk

HEALTHCARE

Owen Smith MP hits out at 'system'

Former shadow cabinet minister Owen Smith has criticised the way the 'system' cares for people with epilepsy and mental health issues. The Labour MP for Pontypridd described how his older brother Aled has not worked for a decade or more and lives with his parents because he has severe epilepsy.

'Aled is on Employment and Support Allowance and had to have the Work Capability Test. It is grim and degrading,' he said. 'The whole thing is ostensibly about getting people back to work but he got parked in a charity shop unloading clothes when he has two degrees and was a film-maker before he became ill.'

Earlier this year Mr Smith's brother had a serious seizure and had to be rushed to hospital by ambulance. 'For someone who has epilepsy and mental health issues the system is useless,' said Mr Smith.

'That day we went back and forth between two hospitals and ended up in A&E for 48 hours. It was grim. The care he finally got was great but the system can't cope.'

Epilepsy Society's chief executive Rosemarie Finley said: 'Although many people receive excellent care, we regularly hear from people with epilepsy about how the system has let them down, both with health care and with the benefits system.

'We provide extensive information via our website and helpline to help guide and support people.'

Changes to helpline hours

Epilepsy Society is now operating new helpline hours. Our confidential helpline is open as follows:

Epilepsy Society helpline
01494 601 400
Monday and Tuesday 9am to 4pm
Wednesday 9am to 7.30pm

Our helpline team will be there to offer emotional support and information to people affected by epilepsy, including those with the condition, family, carers and healthcare professionals.

As of 1 November we have closed our forum. We very much hope forum members will join our online communities at facebook.com/epilepsysociety and twitter.com/epilepsysociety

TRANSPORT

TfL trials badge scheme

Epilepsy Society has praised a new initiative for ensuring people with invisible health conditions, such as epilepsy, can access a seat on public transport.

Transport for London (TfL) has trialled a card and a badge to show that people with hidden health conditions may need a seat on public transport.

The blue badge, which bears the words 'Please offer me a seat' follows the success of TfL's 'Baby on board' badge. TfL wants to see whether the badge will help those who need to access a seat and also hopes to find out how other passengers will react.

One thousand people took part in the trial, believed to be the first of its kind in Europe. TfL is now awaiting results from the research team.

Epilepsy Society information officer Stella Pearson said: 'People who have uncontrolled seizures are unable to drive and often rely on public transport. Unless someone has a convulsive seizure in public, their epilepsy is usually invisible to the public. It may not be obvious that they would benefit from being able to sit down, particularly when a bus or tube is crowded, and the heat and stress may trigger a seizure.

'More often than not, people on public transport are happy to give up their seat if they know someone may need to sit down, even if they appear fit and well.'

Mayor of London, Sadiq Khan said he hoped the badges would give confidence to people who may find standing on public transport difficult.

PREGNANCY

Morning-after pill

Women with epilepsy are being advised to consult their doctor, pharmacist or specialist nurse if they are using the morning-after pill containing levonorgestrel.

The medicines regulatory body, MHRA, has issued new guidance on the emergency contraception after it was found to be less effective for some women, including those taking certain epilepsy drugs. It said it had data on 400 unwanted pregnancies in women taking levonorgestrel since the 1970s.

It is thought that some epilepsy drugs including the barbiturates primidone, phenytoin and carbamazepine may reduce how well the morning-after pill works.

MHRA is advising that women taking these medications may need to take a double dose of the emergency contraceptive. They may also need to consider using another type of emergency contraception called a copper intrauterine device or 'coil' inserted into the womb, as this does not interfere with the action of other medicines. Read more at epilepsysociety.org.uk/morning-after-pill

RESEARCH

Headache and epilepsy

A study has found that headaches cause a 'burden' to the quality of life of many people with epilepsy. The study, carried out by scientists from Vilnius University in Lithuania, looked at 280 adults (61.4 per cent women) who had had epilepsy for around 12 years.

Researchers found that 83.2 per cent of respondents reported a headache. Over 77 per cent of participants had inter-ictal headaches, of whom 39 per cent reported tension headaches, and 31.7 per cent migraine. Nearly eight per cent had medication-overuse headaches, while 16 per cent had a persistent headache possibly caused by traumatic head injury.

While headache prevalence was similar among people with epilepsy and the general population, migraine was more common in men with epilepsy, and medication-overuse headache was more common in people with epilepsy.

Medical director at Epilepsy Society, Professor Ley Sander, said: 'As clinicians we should be sensitive to the potential prevalence of both headaches and epilepsy in a person and treat them accordingly.'

HEALTH

Smoking link to epilepsy

A study of people in Switzerland has found a correlation between epilepsy and smoking.The study analysed 429 people, aged 16 years and older, who had epilepsy and lived in French-speaking Switzerland. Those who had had at least one cigarette per day for the previous six months were classed as 'current smokers'.

The results showed that 32.1 per cent of people with epilepsy were smokers, compared to 19 per cent of the 'general' French-speaking Swiss population.

It has not been established whether or not having epilepsy is the reason why people take up smoking. However, there appears to be a genetic link between epilepsy and nicotine addiction. There also seems to be a pattern of people smoking in order to relieve stress or depression from epilepsy.

MEDICATION

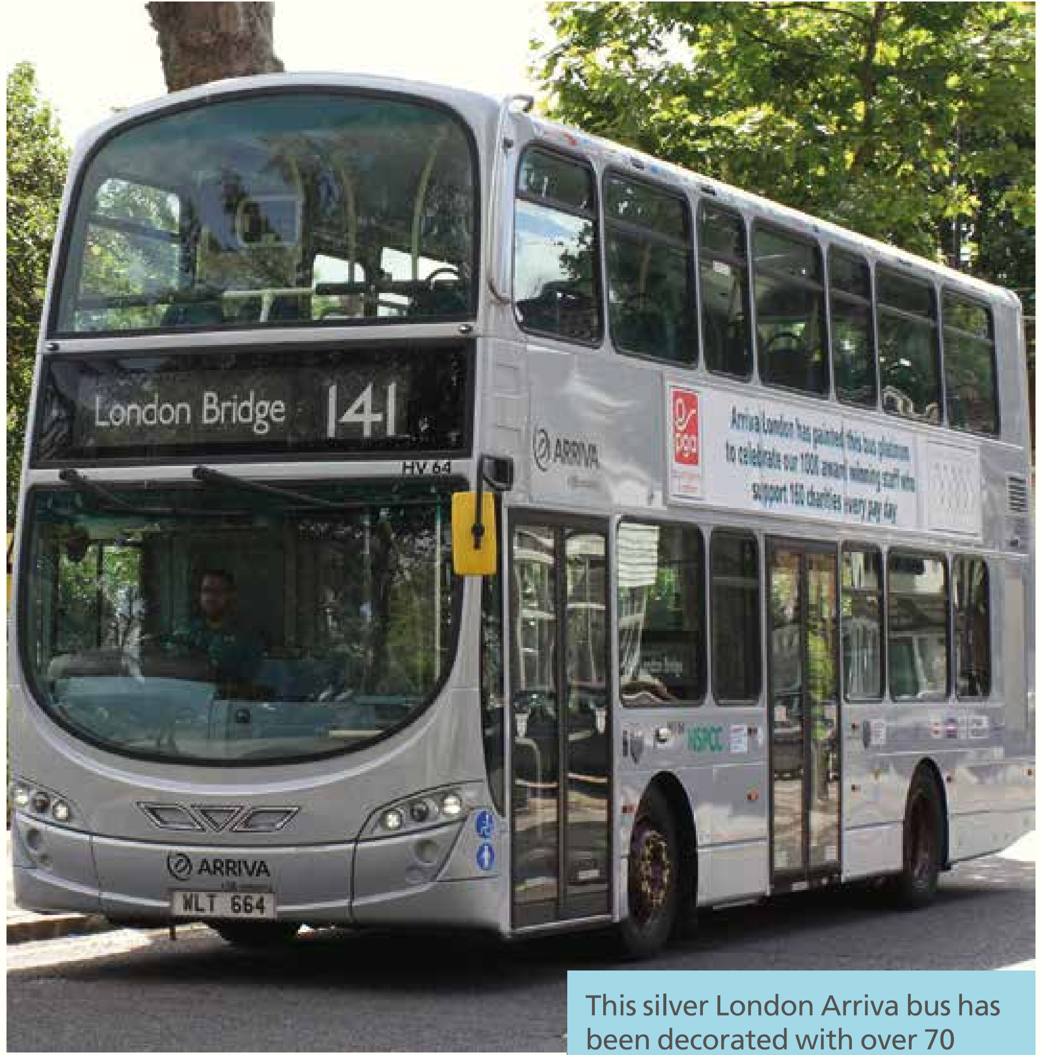
Trobalt to be withdrawn

The epilepsy drug Trobalt (retigabine), is to be discontinued and will no longer be available after June 2017.

In 2013, GlaxonSmithKline (GSK) who make the drug, announced there were safety issues around Trobalt as it could cause a blue discolouration of the skin and eyes. Now GSK is discontinuing the drug on a permanent basis. Healthcare professionals are advised to seek alternative medicines for existing patients as soon as possible and to ensure that all patients are withdrawn from Trobalt with a gradual dose reduction by the end of June 2017 at the latest.

All patients should continue to receive safety monitoring in line with the local prescribing information while they remain on treatment with Trobalt. No new patients should now start on this medication.

Bus celebrates big-hearted staff



This silver London Arriva bus has been decorated with over 70 charity logos, including Epilepsy Society, to celebrate generous staff who gave to their favourite charities through payroll giving. Find out how you can donate to Epilepsy Society through payroll giving at the link below.

epilepsysociety.org.uk/payroll-giving

TECHNOLOGY

News app

Keep up to date with the latest epilepsy news by downloading our Epilepsy Society News app for both Android and iPhones.

The app is designed to help you stay informed about everything that is happening in the world of epilepsy. The app includes:

- an automated news feed tracking the latest epilepsy news in real time
- push notifications to keep users informed of breaking news
- access to 'Epilepsy TV' featuring a selection of videos including personal stories
- direct access to the Epilepsy Society Facebook page and website.

The app is available to download free on Google Play or iTunes.

Epilepsy Society welcomes comments on the app which can be added at the iPhone and Android sites.

ENVIRONMENT

Green seizure control

Researchers in Brazil believe that green spaces may help reduce the risk of Sudden Unexpected Death in Epilepsy (SUDEP). The scientists suggest that urban living poses a greater risk of stress and seizures for people with epilepsy and may add to the risk of SUDEP. Access to green spaces may help reduce this risk by lowering stress levels and improving seizure control. Read more at epilepsysociety.org.uk/greenspaces

Watch it on video

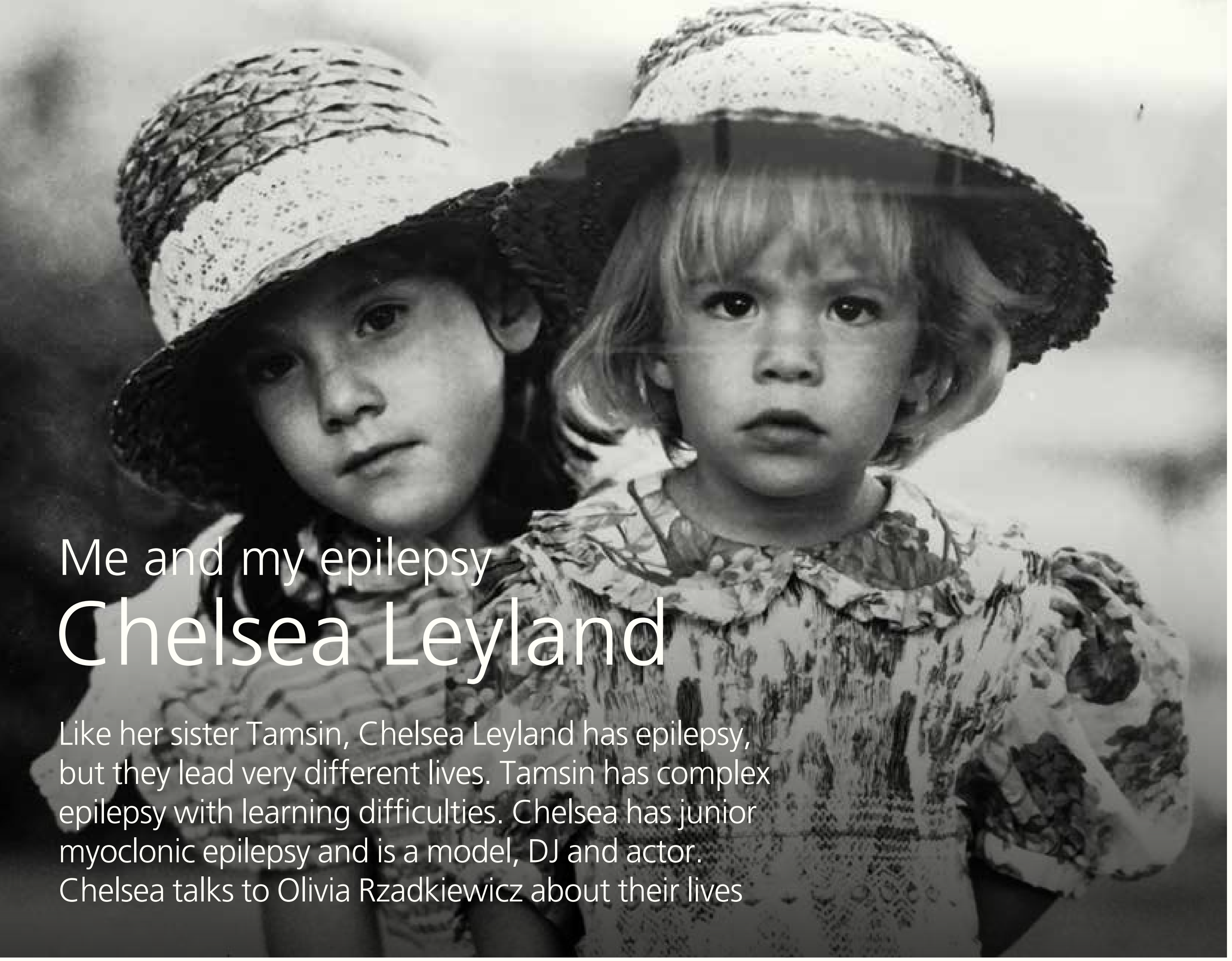
You can find these videos at epilepsysociety.org.uk/epilepsytv

Colin Grant talks about *A Smell of Burning: The Story of Epilepsy*. For a chance to win his book, see page 15.

Professor John Duncan and his team look back over 21 years of MRI at Epilepsy Society. See page 8.

Emma Johnstone, page 8, talks about how brain surgery for her epilepsy has changed her life.

People with epilepsy share their tips for preparing for an appointment with your GP or neurologist.



Me and my epilepsy
Chelsea Leyland

Like her sister Tamsin, Chelsea Leyland has epilepsy, but they lead very different lives. Tamsin has complex epilepsy with learning difficulties. Chelsea has junior myoclonic epilepsy and is a model, DJ and actor. Chelsea talks to Olivia Rzadkiewicz about their lives

Early childhood

Epilepsy has always been a part of my life. People used to say I was a great little helper because from the age of about four or five I was picking Tamsin up after a seizure or calling an ambulance. I had fun in hospital – we spent so much time in A&E for Tamsin that it became normal. I even had my hair braided by the nurses. It was still quite hard though, because I remember numerous occasions just waiting in hospital with our parents to see whether Tamsin would make it through the night.

School days

I was at the same primary school as Tamsin in Wandsworth. It accepted children with special needs so we were exposed to people with all sorts of conditions.

Role reversal

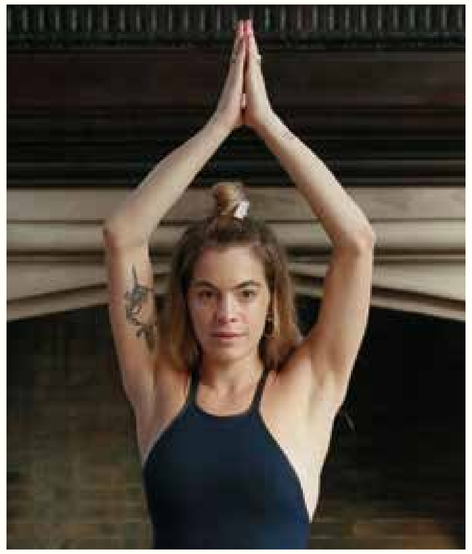
There was a time when our roles inverted. I remember us both playing with Polly Pockets. Tamsin stayed at that level, but I moved on and sort of became her big sister. Tamsin left home at seven and went to live at Lingfield and then moved up north to Cheshire. We had to keep family Christmases quiet because we had so many Christmases of opening stockings and then spending the rest of the day in hospital because Tamsin became over excited and had a seizure.

Boarding school

I went to Bedales boarding school when I was 13. It was quite a tough time. I just wanted a 'normal' sibling, and felt that I was missing out. It was quite painful if people asked me whether or not I had any siblings. I didn't really talk about Tamsin, even though some of my friends were aware of her epilepsy and they would have awkward conversations about it.

My diagnosis

I'd had myoclonic jerks for a long time, when the light was dappled, and it got worse when I was tired. I would drop things too. Even so, my diagnosis with epilepsy came as a shock. I was 15 and had been to the doctor at school, who said my symptoms were as a result of my paranoia around Tamsin's epilepsy. He told me 'just to let go of it'. The third time I saw him, he sent me to a neurologist to put my mind at ease. But I was diagnosed with juvenile myoclonic epilepsy instead.



Family worries

My parents felt quite let down by the doctor, and my mum especially took the diagnosis really badly. She blamed herself for having two daughters with epilepsy. It was hell on earth for my parents who had seen Tamsin's epilepsy, which was uncontrolled by medication. There was a lot of asking why it had happened to our family.

Side effects from medication

I was put on lamotrigine for the first two years, and then levetiracetam and zonisamide. I became very frustrated with levetiracetam because I had rage and was very irritable. It was a relief to read a blog that explained that these were side-effects of the drugs.

DJ-ing and drama

When I was 19 I moved to New York to go to the Lee Strasberg Theatre & Film Institute to study drama. A fashion photographer got me to DJ. There were not many female DJs, but there was a lot of demand for them. My heart still lies more with acting, but DJ-ing has opened a lot of doors for me. I'm collaborating to design a bag, and casting for a TV show, all thanks to that first break.

Photosensitive epilepsy and gigs

I have photosensitivity so I have to make sure the gigs I play use lasers instead of strobe lights. I'm very lucky in that I live a normal life for the most part. I haven't had a seizure for a couple of years, but epilepsy is always there even when I'm having a good day – I'm always conscious of it. I can't drink if I haven't had enough sleep, and I have terrible anxiety around catching early flights for the same reason.

Finding the positive

Epilepsy has given me more drive, more hop in my step to succeed where it made me feel so weak before. I once told a journalist about my epilepsy without quite meaning to, and that was the beginning of my new journey.

The epilepsy world back at home had felt very real, and then I entered the ridiculously chichi world of fashion, beauty and acting in New York. I realised I didn't have to turn my back on either one of those worlds, so I went back to my roots, being honest to my truth and my experience of epilepsy. As soon as I did that I started to feel better, and strangely, I was able to enjoy the glamorous side of life much more freely.

Making some noise about epilepsy

I have been through a time when it was a challenge to talk about my epilepsy and now talking about it with power is really different. I'm trying to make it positive and upbeat, so I'm trying to use my position as an 'influencer' to make an impact. I had a voice but I wasn't using it – now I want to make some noise and help people understand what epilepsy is. I want to give people strength by telling my own story. When I was first diagnosed, I would have loved to meet someone who understood. I have so many reasons to speak out – I want to do it for Tamsin, I owe it to her, and also to empower other young people.

American dream

Tamsin has always had an obsession with America. Sadly, she can't fly to come and visit me – the journey would be too disruptive and would put her at too much risk of seizures.

She has lived at Epilepsy Society since she was 18, and absolutely loves it. She's the happiest she's ever been. Some people think she'd rather be at home, but that's wrong – there's a big part of her that's very independent, like any adult. She knows exactly what she wants, and she wouldn't have that same freedom if she was at home.

The strength of my family

My family has always had a great sense of humour around our epilepsy, in spite of the pain. We like to keep it light, even when people are staring at us in a restaurant because Tamsin's had a seizure and fallen into her food. We just laugh and have great fun.

• Chelsea designed a unitard with lifestyle brand Live The Process and raised £10,000 for Epilepsy Society.

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.

Celebrating 21 years of MRI at Epilepsy Society

Professor John Duncan looks back over more than two decades of magnetic resonance imaging and explains what the future holds for people with epilepsy

When did you first realise the potential for MRI (magnetic resonance imaging) in the diagnosis and treatment of people with epilepsy?

Clinical MRI was really invented in the early 1980s and it was evident right away that it had the potential to show us the causes for epilepsy in the brain. We realised at the end of the 1980s that this was potentially of huge importance for epilepsy surgery.

One in three people who develop epilepsy are not controlled with medication. If one can identify abnormalities in one part of the brain causing the seizures, one can target that area and plan to remove the piece you think is causing the epilepsy and so effectively cure the person of their epilepsy.

Did Epilepsy Society invest in a scanner straight away?

No, initially we bought time by using the MRI scanners at St Mary's Hospital and Great Ormond Street Hospital in London. Twenty-one years ago there were very few MRI scanners in the country.

So at Epilepsy Society we had a fundraising campaign to create the building and raise money for the first 1.5 Tesla magnet which opened at our Chalfont Centre in Buckinghamshire in May 1995.

Has the scanner been upgraded since it was first installed at Epilepsy Society?

In 2003 it was completely replaced with a more powerful 3 Tesla scanner. In 2013 the magnet remained the same but the computing hardware was replaced. For this reason, people who we have seen in clinic 5-10 years ago, have been invited back and re-scanned with the latest technology. This has given us the possibility of finding something subtle that wasn't picked up before.

Emma Johnstone had experienced partial seizures since the age of seven. She underwent brain surgery for temporal lobe epilepsy eight years ago and has been seizure free ever since. She has now qualified as a nurse and on 6 September 2016 gave birth to her new baby son, Archie, weighing 6lb 4oz. Emma said: *'I'm so lucky to be where I am now, thanks to Professor Duncan and everyone at Epilepsy Society. If I hadn't had that operation I'm not sure my life would have been quite the same. Archie is gorgeous.'*

At 26 **Katie Beck** was experiencing 15 seizures a night and some during the day. She was constantly tired and muddled from medication.

In 2011 Katie underwent brain surgery using the very latest 'satnav' or 3D multi-modal imaging to create a map of her brain. This enabled Professor Duncan and his team at the National Hospital for Neurology and Neurosurgery to locate where her seizures were coming from in a thumb sized section of her brain called the right supplementary motor area.

Katie has not had a seizure since and is now off all epilepsy medication.

'I'd ruled out having a baby because I was always so drugged up,' said Katie, 'but as I was off all the medication, my husband and I decided to have a baby. Tilly is now two.

'I am looking after our wonderful daughter, I am no longer living in a fog and I am seizure free. I hope more epilepsy patients are able to benefit from this procedure.'

Are MRIs only useful for people who are being considered for epilepsy surgery?

MRI scanning can also help to provide useful information for people who aren't candidates for surgery. For example, we may be able to identify a malformation of the brain in someone. If we are able to show this to the person and their family, it can take a lot of the mystique out of the problem. It does not take the problem away but it does help to understand it better.

How exciting has it been to see deeper and deeper into the brain?

It has been fascinating. What gets me up in the morning is the ability to make new scientific advances and to apply them to people who one sees in the clinics – real people with real problems.

What exactly do the latest scientific advances allow you to see?

As well as looking at brain structure we can also see white matter networks in the brain. These form the critical connections or 'wiring' between different areas of the brain. If these pathways are unable to communicate, the brain may not be able to function. This helps us to plan our surgical approach so we don't cause harm.

Over the last 10 years we have developed functional MRI (fMRI) here to see where different functions are occurring. For example we can see where in the brain a person thinks of words, names pictures and describes objects verbally. We can see how some medications may affect these different functions.

Many people with epilepsy report memory problems. Are you able to use MRI scanning to look at memory function in the brain?

Memory is an area of ongoing work here at the Chalfont Centre. In the last few years we've developed tests for memory for words and memory for pictures. We know how this works in the temporal lobes of the brain which are a common source of the type of epilepsy that doesn't respond well to medication.

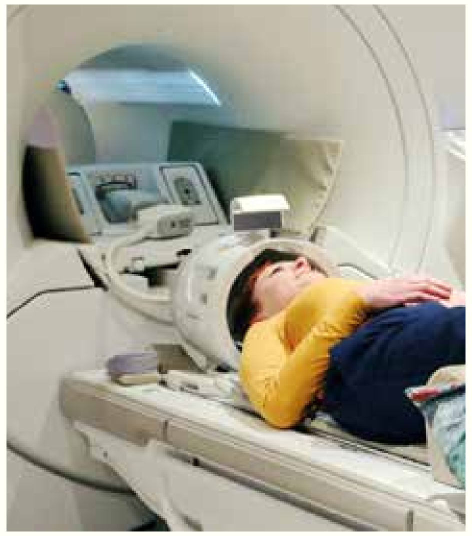
This is very important work that has been taken up around the globe. Whether ▶

The latest scanning techniques produce increasingly sophisticated images of the brain.

we can use this to determine the effect of medication on memory function is not yet clear, and that is one of the avenues of research to follow in the next couple of years.

Does knowledge of the risks involved make it harder for someone to decide whether to have surgery themselves?

The decision to undergo surgery is obviously a huge one. We can't say for definite 'this is what will happen to you, this will be the outcome'. The best we can do is to give someone the odds. We have carried out brain surgery on a thousand people and we can use their scans and outcomes to work out the risks for other people. MRI and fMRI enable us to sophisticate the odds much better in terms of benefit and risks.



Undergoing an MRI scan at Epilepsy Society's Chalfont Centre.

How much does computer technology guide surgery?

Further development over the last five years has been putting all of the imaging data together into one 3D space. Working with computer scientists, we are now able to look in 3D at all these scans on one computer model which we can make transparent or opaque.

This enables us to plan our surgical approach to remove an area of abnormality. 3D maps can be used in the operating theatre to precisely guide the surgery in exactly the same way as pilots use automatic pilot. This is 3D multi-modal imaging (3DMMI).

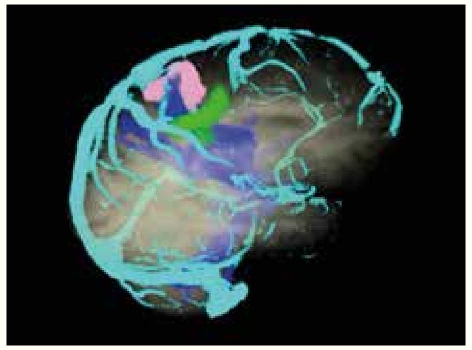
What other applications does 3DMMI have in brain surgery?

In a quarter of people considered for surgery, we may not be exactly certain where their seizures are coming from. In these cases we need to put recording wires into the brain to pinpoint which part of the brain is causing the trouble. These must be precisely navigated so as not to damage any arteries or veins as this could cause a haemorrhage.

Using computerised 3DMMI, we can find the best trajectory to get from the skull to the target. We have developed a computer programme for doing this very swiftly and accurately. We are now developing a small robot that will execute trajectories with much greater accuracy and speed.

How do you feel when you are able to reduce or cure seizures in someone whose life is highly affected by their epilepsy?

It feels fantastic. It is a huge reward to see people come back well. If I had to pick out a small group of people in particular, it would be people who have had seizures in teenage years and haven't been able to get to college, but who have then had surgery and become free of seizures. They have then gone on to train as nurses or doctors and are now delivering healthcare. It is wonderful to see the transition.



3D multi-modal image of the brain, used to guide surgery.

What is the future for MRI?

The main steps over the next five years will be to invest in a more powerful magnet. 7 Tesla MRI scanners are just coming in although they are not ready yet for full routine clinical use. We will also see the linking of all the magnetic resonance data with new genetic data. We are just at the threshold with this development and we hope to start seeing results.

Professor John Duncan is clinical director at the National Hospital for Neurology and Neurosurgery and former medical director at Epilepsy Society. You can read the full version of his interview about MRI at epilepsysociety.org.uk/21MRI and view the video at epilepsysociety.org.uk/epilepsytv

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There are few things worse than lying awake at night unable to sleep, or struggling to stay awake during the day. Sleep problems are not unusual. Most sources say that 10 per cent of adults have a clinically significant sleep problem. But for people with epilepsy the problem can be made worse as sleep deprivation can trigger seizures – and seizures, both during the day and at night, can disrupt sleep. Here, Dr Sofia Eriksson looks at the links between sleep and epilepsy and how you can help yourself get a good night's sleep. And over the page, Dr Hugh Selsick explains how cognitive behavioural therapy can help to overcome insomnia.

Sleep

* * *

Dr Sofia Eriksson is a consultant neurologist at the National Hospital for Neurology and Neurosurgery in London and is clinical lead for neurological sleep disorders. Originally from Sweden, she has two children.

In many ways we know very little about the function of sleep which is weird considering we spend so much time sleeping. We know that the sleeping brain involves many active states during which important biological processes occur, including filtering through the mass information of our daily experiences to consolidate and optimise important memories.

We know that synaptic connections between the neurons in our brains are more plastic or pliable during sleep. And we know that one size does not fit all. Limited research suggests that seven and a half to eight hours is the average amount of sleep needed per night, but we know some people need nine hours while others can survive on six hours of sleep.

One thing we know for certain, and which we are constantly reminded of in clinics, is that there is a close association between sleep and epilepsy. We know that lack of sleep can precipitate seizures and seizures – both during the day and the night – can disrupt sleep. We know that when people are sleep deprived, the side of the brain where epileptic seizures start is more easily excited.

Sleep issues – either trouble going to sleep at night or staying awake during the day – are widely reported in epilepsy and both impact heavily on quality of life and seizure control.

Many people report excessive daytime sleepiness and this may be due to their medication, asleep seizures or to co-existing sleep disorders. Others say that though they have slept, they do not awake feeling refreshed.

It is easy to assume that all sleep problems in people with epilepsy are a result of the condition or medication, but this may not be the case and it is important first to look at the architecture of sleep or the way our sleep is built, in order to understand the links between sleep and seizures. Only then can we start to look at ways to maximise sleep and improve quality of life.

SLEEP ARCHITECTURE

Sleep can be divided into two categories: non-rapid eye movement (NREM) sleep and rapid eye movement (REM) sleep.

NREM sleep is divided into light and deep sleep. The first stage of light sleep lasts around 10 minutes. Muscles relax and although we are just falling asleep, we can easily be awoken. The second stage lasts around 20 minutes and this is when our heart rate and breathing slows down. For some people with epilepsy, this is when seizures are most likely to happen as they transition from this stage into deep sleep.

Deep sleep is sometimes called slow wave sleep as breathing and heart rate continue to slow down and our brains produce 'delta waves.' This type of electrical activity increases as sleep gets deeper and it is difficult to be awoken at this stage.

REM sleep is when we do most of our dreaming. All the muscles apart from our eyes go floppy, so that we can't do the things we are dreaming about. Scientifically, we don't know the significance of REM sleep, although it is thought to be important for organising our thoughts, experiences and memories. A lack of sleep can affect our memory and judgement, the way we feel and the way our immune system functions.

These sleep states come in 90 minute cycles throughout the night with more deep sleep early after sleep onset and more REM sleep later at night.

Sleep and seizure types

Different seizures and types of epilepsy occur in different sleep stages or states, so the timing of events during the night is important for diagnosis. In juvenile myoclonic epilepsy, seizures occur shortly after waking. Asleep seizures tend to be typical of frontal lobe epilepsy, occurring more frequently during the light stages of NREM sleep. If temporal lobe seizures occur during the night, they are more likely to be secondary generalised seizures.

Seizures and epileptic activity in the brain are more commonly seen as a person transitions between different sleep stages. The majority of seizures occur during light sleep and rarely during REM sleep.

Excessive daytime sleepiness is commonplace in people with epilepsy and while this is often attributed to the medication or the seizures, it can also be a sign of undiagnosed asleep seizures.

Undoubtedly, seizures can disturb a person's sleep architecture both in partial and generalised seizures. People with epilepsy tend to experience an increased number of awakenings in the night and a reduction or fragmentation of REM sleep.

Sleep studies have shown that a person experiences a reduced amount of REM sleep after complex partial seizures. This was most pronounced in asleep seizures when the percentage of REM sleep fell from 16 to seven per cent. But even the day after a seizure had occurred, REM sleep dropped from 18 to 12 per cent.

It could be that this reduction in REM sleep caused by seizure activity contributes to issues with memory and cognitive functions for people with epilepsy, but more research is necessary.

Other causes of sleep disruption

Although medication is probably the most common cause of sleepiness in people with epilepsy, other causes include accompanying conditions such as periodic limb movements and sleep apnoea.

Periodic limb movements (PLMS) are when you have repeated episodes of movement, usually in your legs, while you are sleeping. Most people are unaware of these but they can disrupt your sleep. These are very different from hypnic jerks, which are involuntary twitches that many of us experience as we are falling off to sleep at night and which are absolutely normal.

Sometimes we will use a sleep study to diagnose periodic limb movement. This may be through video telemetry or polysomnography which records a person's brain waves, blood oxygen levels, heart rate and breathing as well as eye and leg movements. If we are able to diagnose PLMS, it may be possible to treat with iron which is

▶

At night your body wants to lose heat. Warmth is disruptive.

The ideal temperature for your bedroom is 18°C.

Sleep can precipitate seizures and seizures can disrupt sleep.

It is important to get up at the same time every day, seven days a week.

Cognitive behavioural therapy for insomnia is all about harnessing your innate sleep drive.

Whatever causes insomnia, it is not a barrier to it getting better.

Can't sleep?

Dr Hugh Selsick looks at how cognitive behavioural therapy may be the answer to your insomnia

Cognitive behavioural therapy (CBT) is a talking therapy that helps you manage problems by changing the way you think and behave. CBT for insomnia (CBT-i) is about changing the way you think about sleep and then addressing dysfunctional sleep habits and anxieties.

People think that insomnia is not fixable without drugs, that they will never re-establish a healthy sleep/wake balance. But this is almost never true, even with conditions such as epilepsy.

We see many people with epilepsy in our clinics and CBT-i can be very helpful. However, because treatment can lead to a brief period where people sleep a bit less before they sleep more, and a reduction in sleep time can trigger seizures for some people with the condition, *the therapy has to be taken at a slower pace and should always be managed by a healthcare professional, as described below.*

How we think about sleep

We begin by changing the way people think about sleep. People think that if they don't sleep, their body won't recover from the day and that the insomnia will shorten their life span. But there is very little evidence to suggest that this is the case and just knowing that insomnia is not going to kill them, often reduces anxiety considerably.

People who are struggling with sleep often have a fantasy that 'good' sleepers sleep all night and are awake and alert all day. But even good sleepers can wake several times a night and will have occasional sleepless nights. No-one is alert and lively all day every day.

Then there is the myth of the eight hour sleep. But the truth is that the amount of sleep that is right for us varies. We each need the amount of sleep that will allow us to feel alert most of the time, most days of the week.

Good sleeping habits

Our behavioural techniques begin with two golden rules:

– make sure you have a cut off point for caffeine intake, ideally 1 or 2pm
– keep your bedroom cool.

It is a myth that a warm room is good for sleeping. At night your body wants to lose heat. The ideal temperature for your bedroom is 18ºC. You should be warm under a duvet but a little nippy if you go to the bathroom. This enables you to regulate your body temperature.

Setting your alarm

People often think that a good night's sleep is dependent on keeping a constant bedtime but it is the time that you get up that is the regulator. It is the one thing you can absolutely control. So, get an alarm clock.

Fatigue makes you feel sleepy. From the moment you wake up you start to accumulate sleepiness. You are filling up your sleep fuel tank. When it is full, you fall asleep.

If you sleep for five hours, you will be awake for 19 hours – that is 19 hours to re-fill your sleep fuel tank. If you wake at 7am, you will need to sleep again at 2am. If you wake at 9am, you will only be ready for sleep at 4am. So the time that you get up is critical.

Staying awake

It is important to jealously guard your sleep fuel by not sleeping during the day. This will only steal some of your sleep from the night. Try to avoid falling asleep by exposing yourself to bright light, getting fresh air, taking exercise, and, within limits, having some caffeine. Chewing gum is also efficient at keeping you awake. They give it to soldiers in the army to keep them awake when they are on duty.

Quality of sleep

With CBT-i we look at improving quality of sleep before we look at quantity. But this comes with a warning for people with epilepsy. *If sleep deprivation triggers your seizures, it is important that this is managed by an expert and is taken in easy steps.*

We ask patients to work out the average amount of time they are asleep. This is then subtracted from their wake up time. We then say don't go to bed until that time. For example, if you sleep for six hours on average and your wake up time is 7am, you shouldn't go to bed before 1am. This greatly improves the sleep quality. For people with epilepsy, it is important to achieve this by moving the bedtime later in very small steps, 15 minutes a week, rather than in one go. This takes longer but it is worth taking things slowly.

As sleep improves, we gradually make the bedtime earlier to increase the sleep quantity as well.

Relaxation

Progressive muscle relaxation is also helpful for everyone. This is a matter of working through the body, tensing muscles in turn for five seconds and then relaxing them. We also look at ways of reducing anxiety.

CBT-i is all about harnessing your innate sleep drive and 80 per cent of people who try it, say it works. Not everyone shows a complete recovery, but there is usually great improvement.

Sleep disorders are a huge risk factor for depression and that is ample reason to ask your doctor for a referral to a sleep clinic.

Dr Hugh Selsick is a consultant psychiatrist working in sleep medicine, based at the Royal London Hospital for Integrated Medicine.

often deficient in the person, or medication specifically aimed to treat the movements such as dopa agonists.

Obstructive sleep apnoea (OSA) is also common in people with epilepsy, occurring in up to 10 per cent of those with the condition. This is where a person snores and may momentarily stop breathing. This can be caused by low muscle tone around the airways, causing them to collapse.

> From the moment you wake up you start to accumulate sleepiness. You are filling up your sleep fuel tank.

OSA can make people feel tired during the day and more prone to seizures. Those at greatest risk are older men with a tendency to be overweight. If you suspect that you have sleep apnoea, it is advisable to ask your GP for a test to monitor blood oxygen levels at night.

Some people also experience parasomnias which can be difficult to distinguish from epilepsy. NREM parasomnias are incomplete arousal from deep sleep and take the form of night terrors, sleep walking, or waking up and looking around. While seizures in the night tend to follow a certain pattern, parasomnias are more random with no clear end, and this can help distinguish between the two.

Unsurprisingly some anti-epileptic drugs can also have a complex effect on sleep ranging from hypersomnolence, where you can't stop sleeping, to insomnia. Gabapentin and pregabalin increase deep sleep and reduce insomnia. Sodium valproate and lamotrigine can disrupt specific stages of sleep.

> When people are sleep deprived, the side of the brain with epilepsy is more easily excited.

What to do if you have sleep problems?

It may seem obvious, but if you are either overly tired during the day, or can't sleep at night, you should discuss this with your doctor or epilepsy specialist nurse. It could be that your medication is causing the problem and a change of drug or adjustment to the dose, might help.

In a short consultation, it may be that you think sleep isn't a major issue and there are other issues you wish to discuss, but sleep impacts on seizure control and quality of life; it impacts on concentration, cognitive abilities and memory.

Sometimes it may be necessary to refer you to a sleep clinic where video-telemetry can monitor your sleep patterns. Brain waves look different during the different stages of sleep, so we can tell what type of sleep you are having.

However, although we know that asleep seizures affect a person's sleep more than daytime seizures, it does not necessarily mean that the person is more tired during the day. Similarly, we often find that people who feel they can't sleep, actually sleep more than they are aware.

Helping yourself to sleep better
We call this good sleep hygiene – making sure you have the best chance to get a good night's sleep:

- take a reasonable amount of exercise during the day but don't make yourself feel shattered or you will crash with chronic fatigue

- if you feel the need to nap during the day, limit yourself to 15 minutes to reduce the risk of going into a deep sleep that will be hard to wake up from. Anything more than 15 minutes will interfere with deep sleep

- our bodies follow a 24-hour circadian rhythm which dictates when we should feel tired and go to sleep. But we can easily disrupt this by over-stimulating our brains with computer screens and mobile phones. It is best to avoid electronic devices and too much television at bed time. Don't sleep with a mobile phone in the same room. Use an alarm clock to wake you up in the morning

- reading can help you fall asleep

- if you have any worries, write these down rather than taking them with you to bed

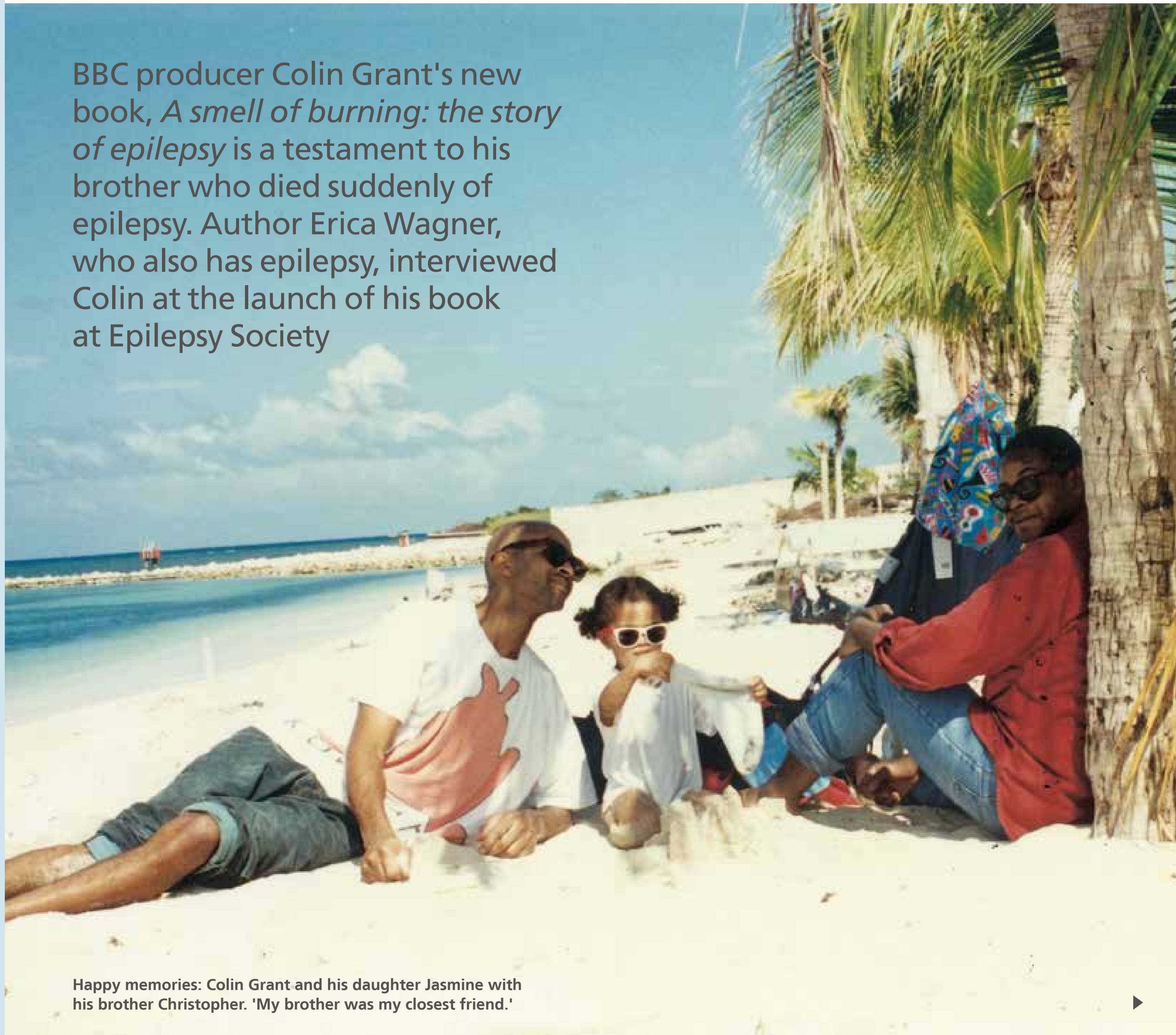
- if you usually have a drink before bed, have a milky drink rather than one that contains caffeine

- try to avoid eating and drinking before you go to bed

- make sure your room is as dark as possible and that your bed and pillow are comfortable

- try to get up at the same time each morning. (See Can't sleep? by Dr Hugh Selsick, *page 12*).

Remembering Christopher



BBC producer Colin Grant's new book, *A smell of burning: the story of epilepsy* is a testament to his brother who died suddenly of epilepsy. Author Erica Wagner, who also has epilepsy, interviewed Colin at the launch of his book at Epilepsy Society

Happy memories: Colin Grant and his daughter Jasmine with his brother Christopher. 'My brother was my closest friend.'

Erica: So, Colin, tell us a bit about what prompted your book.

Colin: I think that when someone close to you dies, not just the physical presence goes but all the conversation, all the quirky relationships, all the quirky points of view disappear as well. My brother was my closest friend. I wanted to bring him back to life. I wanted to resurrect him. I wanted to write in a way that captured Christopher as a human being. He was not just defined by his epilepsy.

Erica: You use the word 'epileptic' in your book, a word not everybody likes. They see it as too defining. How do you view that discussion?

Colin: I was writing a book that included history and it would be odd to replace the word 'epileptic' with a more comfortable word.

I am aware that some of these words are offensive. They have quite a historical tag. It is important not to erase words, because you are erasing history. I wanted, where possible, to use those old words contemporaneously to the time they were used.

One man who I interviewed for the book felt epilepsy impacted on every aspect of his life, therefore he was epileptic. By taking the word on yourself, you rob people of their power to hurt you with it.

Erica: You started off training to be a doctor. How did your medical background influence this book?

Colin: I felt when my brother was dealing with doctors they were really antipathetic towards him. In their mind, he was non-compliant with his medication. I was sympathetic to why he would be non-compliant. At the time, and it may have changed now, there was a hard and fast mindset that if you didn't take your medication you were a wronger and you deserved everything you had coming to you.

I always admired my brother. I always thought that my brother and other people with epilepsy were rather special. I always wanted to challenge the rather reductive idea that some of the medical profession seemed to have about his epilepsy. That is partly also why I wanted to write the book because sometimes I think although medicine has made leaps and bounds in the understanding of epilepsy, the medicalisation of epilepsy sometimes robs people of their individuality.

Erica: Your brother died very suddenly. I had not come across SUDEP (sudden unexpected death in epilepsy) before, though for personal reasons I have been interested in epilepsy for many years. Do you think it is something that should be discussed?

Colin: When the coroner's report came back with SUDEP, I had never heard the word before. It is alarming but thankfully affects only a very small percentage of people with epilepsy. Once you give people the relevant information they can make judgements themselves. Some doctors are reluctant to discuss SUDEP because they worry about frightening their patients. I think it is something that should be discussed as widely as possible. When did you find out about SUDEP, Erica?

Erica: When I read your book. I was surprised. When I was diagnosed at 12, I had a wonderful doctor. Eighteen months before, I had broken my leg. I never had the sense from him or anybody else that epilepsy was any more frightening or different than my broken leg. It was just something you managed and I was put on medication. It was only fairly recently that I realised how fortunate I was to never see it as anything other than interesting. Never frightening except when I was in it, then it was terrifying.

What did you take away from studying both the medical and the cultural history of epilepsy?

Colin: People are trying to do good. And that is true of the medical profession. There are many people who are altruistic – the founding of the epileptic colony at the Chalfont Centre by people who were selfless. I was enthralled by their stories and wanted to honour them.

Even now there is still a stigma around epilepsy. My brother and I had a kind of code. Every time Christopher had a seizure, I would lean over him to greet him. He would say 'what happened?' I would say 'you had a visitor'. He would say 'oh, a gentleman caller. Any message?' I would say, 'he said he would come again'.

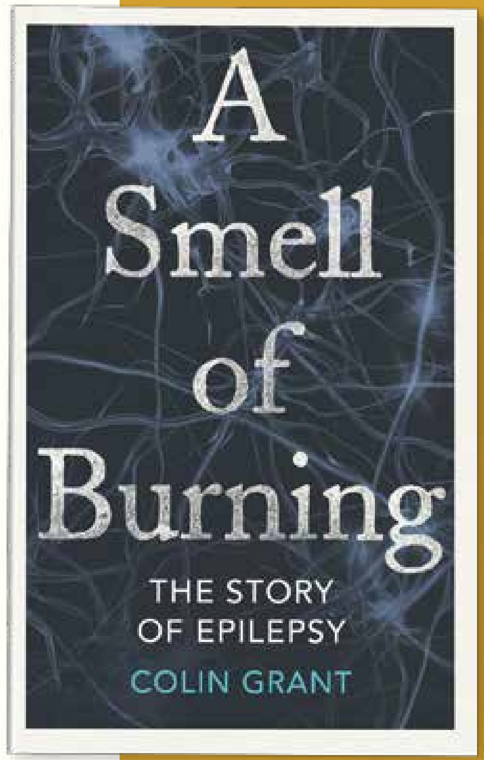
Even in the midst of this debilitating condition, there is humour to be found.

You can watch Colin Grant's interview at epilepsysociety.org.uk/epilepsytv

COMPETITION

For the chance to win a copy of Colin's book, email Colin's code word for his brother's epilepsy to nicola.swanborough@epilepsysociety.org.uk, or send to our address on page 2.

Growing up together: Colin and Christopher with brothers, sisters and cousins.



ERICA WAGNER REVIEWS

A smell of burning: the story of epilepsy

by Colin Grant

Christopher is clever, mischievous, bold; he knows how he wants to live his life. Christopher was Colin Grant's younger brother; he died in 2008, of SUDEP: sudden unexpected death in epilepsy. A smell of burning is his elder brother's memorial for Christopher, and a thoughtful history of how epilepsy has been viewed and treated over the ages.

Grant's attitude to epilepsy is complicated. His family is of Caribbean heritage, devout churchgoers – once, when Christopher had a seizure in church, the congregation prayed over him as if in exorcism. Grant's book offers a fascinating insight into the way in which, people who live with epilepsy have been viewed from Ancient Greece to Britain in the present day.

These days Grant is a radio producer working for the World Service; but he spent five years training to be a doctor before abandoning his studies – in part because he found it difficult to reconcile his chosen profession's stance on the treatment of epilepsy, with Christopher's own wishes.

Christopher was 'non-compliant' – often refusing to take the medication which had been prescribed for him, feeling that it affected his personality, made him less himself. Grant is torn between his brother's unhappiness at the side-effects his medication causes and his desire, as a nascent medical professional, to keep his brother on the drugs he knows will help him, despite their side-effects.

This is a book which deserves a much wider readership than those who are already interested in its subject. The history of treatment offered is a history of neurology itself, for one of the pioneers in the field was John Hughlings Jackson (1835-1911). Jackson helped to found the National Hospital for Neurology and Neurosurgery, and what is now the Epilepsy Society's Chalfont Centre in Buckinghamshire, its work still at the heart of a worldwide effort to understand a condition which affects half a million people in the UK alone.

A smell of burning: the story of epilepsy, **Jonathan Cape, £16.99.** If you buy the book through Amazon, around five per cent of the price will go to Epilepsy Society. Find out more at epilepsysociety.org.uk/more-ways-give

Erica Wagner's novel Seizure is published by Faber and Faber: ericawagner.co.uk

This year, results have been announced for trials into cannabidiol, a cannabis-based drug with the potential to treat epilepsy. But what do the results show and is the new drug likely to be a magic bullet for people with epilepsy? Epilepsy Society's medical director Professor Ley Sander looks at results so far

Cannabis
The results are in

It is just over 100 years since the first anti-epileptic drug, phenobarbital, revolutionised the treatment of epilepsy. Today, we have 27 anti-epileptic drugs (AEDs) to choose from, with the newer medications being better tolerated with fewer side effects and a more favourable efficacy profile.

But there is still a frustrating element of luck as to which drug will work best for which patient, with many having to undergo a trial and error cocktail of drugs before achieving optimum seizure control with minimum side effects.

It is frustrating to report that current therapeutic treatments will potentially still only result in seizure freedom for 70 per cent of those with the condition. It is even more frustrating to note that in reality only 52 per cent of patients achieve that holy grail of seizure freedom, with an 18 per cent treatment gap borne out of poor access to epilepsy services, lack of epilepsy specialists and too few epilepsy specialist nurses.

The epilepsy community – both patients and professionals – are crying out for change and progress, so it is no surprise that a potential new drug, with a controversial tag line, should be causing such universal excitement.

Cannabidiol is a cannabis-based drug which is currently being trialled for the treatment of refractory epilepsy in those with Dravet syndrome, Lennox-Gastaut syndrome, tuberous sclerosis and infantile spasms.

This group of epilepsies typically starts in infancy and can involve multiple seizures on a daily basis with little respite, cognitive impairment, developmental delays and behavioural disturbances. Those with the condition tend to be on a regime of multiple drugs. The condition can be distressing both for them and their families.

Cannabidiol is also being evaluated as an add-on therapy for 130 adults with poorly controlled focal seizures. This is a double-blind, randomised, placebo-controlled trial.

Cannabis has been used recreationally and medicinally for thousands of years with many claiming it has helped them with their epilepsy or other conditions. But in the 1960s and '70s it was widely stigmatised as the drug which gave you a high and its potential medicinal value was largely overlooked.

But times have changed. In 2013, the media was flooded with news that medical marijuana was being used to reduce the seizures of eight-year-old Charlotte Figi from Colorado, US. Legalisation campaigns began across the States. Everyone was talking.

But it was at Reading University in the UK that the work of Dr Ben Whalley and his team of scientists really lit the touch paper for medical marijuana. For 15 years the scientists had been working to isolate the components of Cannabis sativa, otherwise known as cannabis, which seemed to have anti-seizure properties and furthermore were non-psychogenic. Cannabis without the high.

Since 2007, GW Pharmaceuticals, in the UK, has been developing cannabidiol as Epidiolex, a liquid formulation of pure plant-derived cannabidiol.

This year, results of the first pivotal phase III trials (see box, left) of cannabidiol for the treatment of Dravet syndrome and the first and second phase III trials for Lennox-Gastaut syndrome have been announced.

Trials are under way for the use of Epidiolex in tuberous sclerosis complex with a phase III trial into infantile spasms to follow. Data from the focal seizure trial in adults is expected early in 2017.

So what do the results so far tell us? Participants in the first phase III trial for the treatment of Dravet syndrome with Epidiolex achieved an average reduction in monthly convulsive seizures of 39 per cent compared with 13 per cent in the placebo group (see table, below).

In the first trial for those with Lennox-Gastaut syndrome, those taking Epidiolex achieved a 44 per cent drop in seizure frequency compared with 22 per cent for those on a placebo.

In the second trial involving patients with Lennox-Gastaut, those taking 20mg/kg Epidiolex per day achieved an average monthly drop in seizures of 42 per cent in comparison with a reduction of 17 per cent in those on a placebo. Those taking 10mg/kg Epidiolex a day achieved a 37 per cent drop in comparison with 17 per cent for those on a placebo. Common adverse effects in all trials included somnolence, diarrhoea and vomiting.

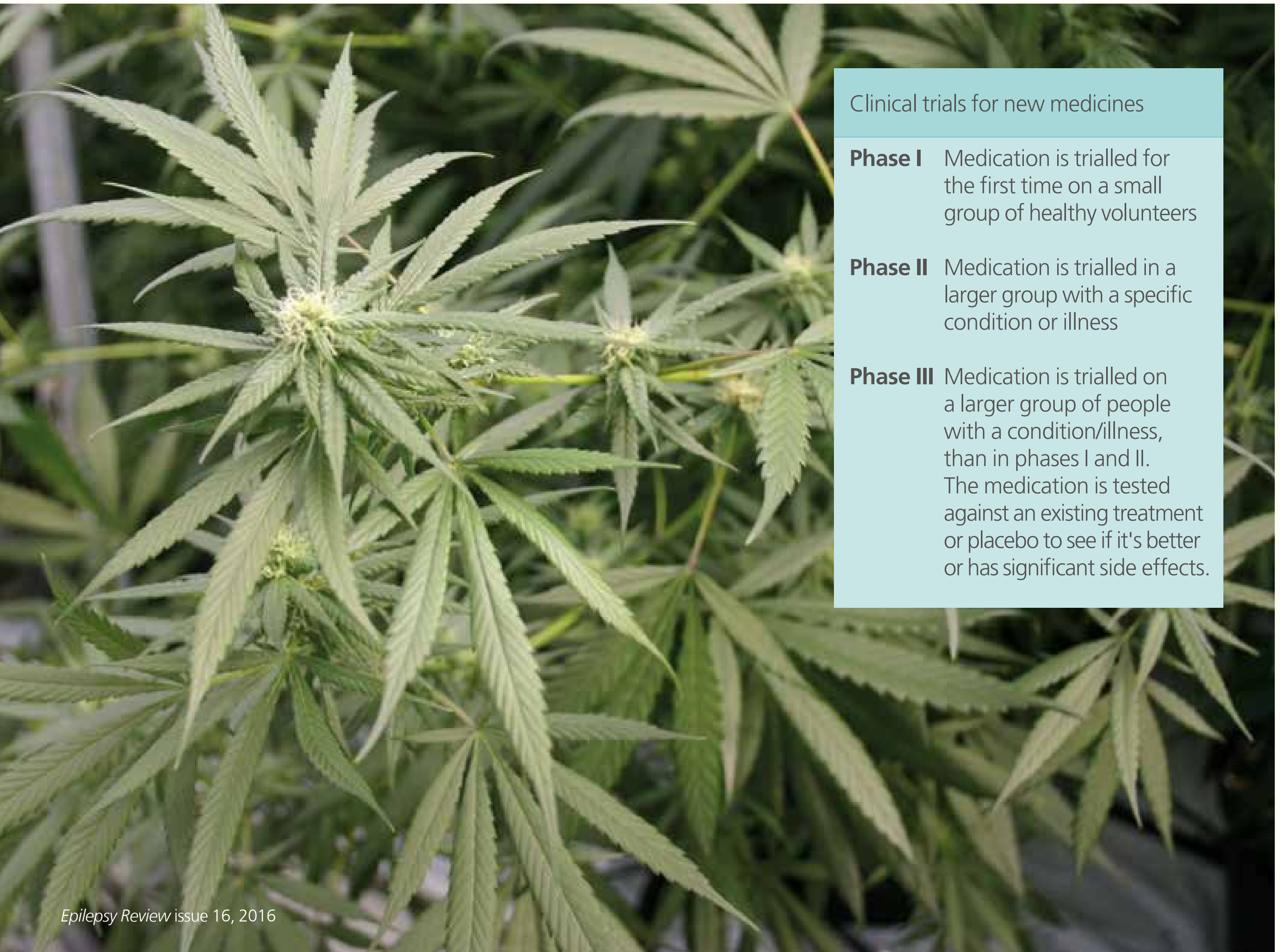
The results are promising. GW Pharmaceuticals expect to submit a new drug application for Epidiolex to the US Food and Drug Administration in the first half of 2017, to include both Dravet and Lennox-Gastaut syndromes. European submissions could follow.

The results spell hope for families who live with the heartache of watching their children endure multiple seizures on a daily basis. They offer the potential of another drug treatment for those who have exhausted everything conventional medicine has to offer. But do they offer a magic bullet for people with epilepsy? Probably not.

Much as we would like nature to yield a potential cure for epilepsy, to date cannabidiol, like the complete armamentarium of epilepsy drugs, would seem to work for a specific group of people but not for others. This is so, even when looking at the severe childhood syndromes. The difference in seizure reduction for those on Epidiolex, compared to those on a placebo, is significant, yes, but dramatic, no.

Alongside this, we still know very little about the long-term effects of cannabidiol on the developing brain, a vital consideration when prescribing to young children and adolescents. The trial results underline the importance of understanding the genetic architecture of epilepsy so that we can confidently predict for each person which drug will work best for them as an individual, from the point of diagnosis. This is personalised medicine. At the moment we do not have enough treatment options. If cannabidiol offers an alternative for some, that has to be good news.

> 'The difference in seizure reduction for those on Epidiolex' compared to those on a placebo, is significant, yes, but dramatic, no.'



Clinical trials for new medicines

Phase I	Medication is trialled for the first time on a small group of healthy volunteers
Phase II	Medication is trialled in a larger group with a specific condition or illness
Phase III	Medication is trialled on a larger group of people with a condition/illness, than in phases I and II. The medication is tested against an existing treatment or placebo to see if it's better or has significant side effects.

	Number of patients	Average age	Dose	Reduction in seizures
Dravet syndrome First phase III pivotal trial	120	10	20mg/day Epidiolex (61 patients) Placebo (59 patients)	39% 13%
Lennox-Gastaut syndrome First phase III pivotal trial	171	15	20mg/day Epidiolex (86 patients) Placebo (85 patients)	44% 22%
Lennox-Gastaut syndrome Second phase III pivotal trial	225	16	20mg/day Epidiolex (76 patients) 10mg/day Epidiolex (73 patients) Placebo (76 patients)	42% 37% 17%

Free prescriptions for epilepsy

... but you must have a certificate. If you have epilepsy you are entitled to free prescriptions on the NHS. However, in England you must make sure you carry your medical exemption certificate with you whenever you pick up your medication or you could face a penalty charge. Here we explain how to apply for your certificate

Did you know that if you are living in the UK and have epilepsy, you are entitled to free prescriptions on the NHS? However, if you are living in England, you must be able to produce a valid medical exemption certificate in order to claim free prescriptions.

The medical exemption certificate is easy to apply for via your GP and is printed on a white plastic card which you can carry in your wallet or purse.

Healthcare in Scotland, Wales and Northern Ireland is administered independently, and all prescriptions are free.

NHS England is clamping down on patients claiming free NHS prescriptions without a valid medical exemption certificate by issuing penalty charge notices. This is in order to help protect NHS resources.

Fine up to £100

In England, if a person with epilepsy declares they do not have to pay for their prescription on medical grounds but is not carrying a valid certificate, they could be issued with a penalty charge notice covering the payment of the original prescription charge as well as a penalty of up to £100.

A person issued with a penalty charge notice will be given 60 days to apply for a medical exemption certificate. If the application is successful, the penalty charge will be removed. Prescription charges will also be refunded as long as you can produce a refund receipt (FP57).

If you have epilepsy and are taking anti-epileptic medication, follow our step-by-step guide to make sure you have your exemption certificate:

Ask your GP whether you qualify for a medical exemption certificate.

If you do, you will be given an application form (FP92A) to fill in for an exemption certificate.

Once you have filled this in, your GP practice should forward it to: NHS Help With Health Costs, Medical Exemption, Bridge House, 152 Pilgrim Street, Newcastle Upon Tyne NE1 6SN.

If you require medication while you are waiting, you should ask for an NHS refund receipt (FP57) so that you can claim for a refund for the charges you pay, once you have your certificate.

A medical exemption certificate is valid for five years or until you are 60, whichever is the sooner. The NHS will send you a reminder when your certificate is due to expire and you should then see your GP again.

A medical exemption certificate entitles you to free prescriptions for epilepsy and other conditions but does not cover eye tests or dental charges.

If your name or address changes, make sure you inform your GP practice.

If you're not entitled to a medical exemption certificate but need more than 12 prescription medicines per year, you could still save money by applying for a 12-month prescription prepayment certificate. You can find out more at nhsbsa.nhs.uk/ppc

You can also find out if you are entitled to free prescriptions on any other grounds at nhs.uk/healthcosts

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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

Your replies

I take Tegretol prolonged release. I started taking folic acid a few months before getting pregnant and carried on taking it throughout. I didn't breastfeed as it was not recommended. No guarantees but my 16 year old is fine.
Vicki, facebook.com/epilepsysociety

I have two children aged four and one. During my first pregnancy, I was on lamotrigine, then Keppra for the second. I had two very different pregnancy experiences . One was very medicalised and the other very natural. I also breastfed both my children with no problems. I am passionate about helping women feel more confident about starting a family, less alone and more empowered to make decisions about their pregnancy, labour and parenting choices. Once you feel informed and empowered, everything is much less scary. I hope my blog helps becomingamumwithepilepsy.blogspot.co.uk
Clair, facebook.com/epilepsysociety

Please do not let epilepsy get in the way of you starting a family. I am lucky that my seizures had been controlled for over two years when I was pregnant with my daughter. I was told to take a high dose of folic acid before conception and throughout the pregnancy to help baby grow properly.

I was monitored closely through the pregnancy and was induced two weeks early so there was minimal chance of my going into labour on my own at home and my epilepsy possibly causing a problem.

I have other medical conditions so because of those and the epilepsy, I gave birth in a high dependency unit and there were neurologists, doctors and nurses on hand for me as well as baby. I would suggest talking to your GP and neurologist.
Lauren, facebook.com/epilepsysociety

My daughter has had epilepsy since she was six. She took folic acid before and during pregnancy. Her first labour was extremely traumatic not because of her epilepsy but because of the duration (nearly 24 hours). Eventually she was taken to theatre for a Caesarean section. One of the triggers for her seizures is pain but incredibly she did not have a seizure. She recovered and went on to have a second child and chose to have this one delivered by C-section. Neither of her children have inherited epilepsy even though it is a very prominent condition on my side of the family.
Maureen, facebook.com/epilepsysociety

My problems were associated with becoming a single parent when my little one was two months old. The children's social work department asked me to consider giving my parental control over to the father as my seizures are not controlled. After further talks with my consultant and GP, I got a wrist and bed alarm and this gave everyone peace of mind.
Tina, facebook.com/epilepsysociety

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

Next issue

I have recently been diagnosed with epilepsy. I have had three tonic clonic seizures in all, mainly after being out late with friends.

I work in a department store and have a lot of interaction with customers which I love. I have been in my job for just under two years and have always had great support in general from my managers. The staff are all also lovely.

However, I am worried about telling my boss about my epilepsy. I am on medication and am hoping that will fully control my seizures. I also don't want people to treat me differently or for epilepsy to affect my chances of promotion. Does anyone have any advice?
Josh, Southampton

WOULD YOU LIKE TO SHARE YOUR THOUGHTS WITH JOSH? 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 was reflecting on the ways in which having epilepsy has shaped my life story, and how all people with long-term medical conditions are united in the fact that our life experiences are affected by our 'condition'. This issue I am looking forward, really quite a long way forward as it goes, because I've been making some pretty long-term decisions lately. My partner and I bought a house back in June and in July, Reader, I married him. Add these two major life events with having just recently also finished a Masters and I've had a pretty chaotic year.

Those in the know who are fount of so much wisdom, say that big life events can take a tremendous toll on the body. This is not new information or ground breaking science, though it's easy to get distracted from this stress, especially when there is also something exciting to look forward to.

By now I think we are all familiar with some of the key symptoms of stress – difficulty sleeping, irritability, anxiety, tearfulness. My Masters was in drama therapy – a specialist form of psychotherapy – which involved being immersed 'in emotional process' (mine and my clients') pretty much all of the time. My life has basically been an emotional Magimix with grief and joy bumping shoulders with fear, anxiety, hate, love and compassion. Add to this mix the stress of buying our dream home and planning a wedding, and you're cooking up a pretty stressy pie.

Of course we wanted to make all of these things as stress-free as possible, so as to reduce my risk of having a seizure. My husband (!) and I specifically set out to keep the wedding simple and not get distracted by too much wedding 'guff'. We hadn't intended to have any bridesmaids, for example, but after we told my nephews and nieces, they were all so damned excited for us, we had to find jobs for everyone. Agh!

The problem with stress is that it is often a snake in the grass. You don't really notice it immediately, partly because you're so preoccupied with the things that make you stressed that you don't have the perspective to step outside of yourself and realise – 'woah your shoulders are way tense!', 'hmmm, I am having trouble sleeping.' Or, 'yes, I have been crying at adverts more than usual'.

And so my wedding day arrived. I was delighted that the morning, getting ready at my parents' house was surprisingly relaxed. Or so I thought. Everything that needed to happen was happening and everyone was happy. My sister heroically squeezed me into the acres of beautiful ivory silk, doing up hundreds of fiddly buttons.

Perhaps it was the tightness of the dress, perhaps it was excitement, perhaps it was finally realising I didn't need to plan or worry about anything, just to get to the venue and marry the man I love, but I had a bit of a wobble. I was dizzy, I felt the world go somehow in slow motion, and I thought I might have a seizure. I pinched myself hard – I'm not sure if this is effective, but it's an old wives' cure/distraction technique that I heard from someone years ago.

My sister sat me down and told me to just breathe. She got me some water and made sure nobody else came upstairs. I took an extra tablet of Keppra and sat on the bed, telling myself 'no'. Not today. No seizure. Not in this beautiful dress, not at the beautiful venue (grass stains on silk – agh!), not in front of my new in-laws. Also, we had worked so damn hard – even though we were trying to make it so simple – to make it our beautiful day. What were the chances that we could assemble all of these family, cousins and friends together all over again?

Reader, I married him

Also, I had form in this department. I had a seizure in the taxi on my way to my best friend's wedding. My sister was with me then too, and was just as heroic. Though we missed my friend's wedding, I was uninjured and safe enough to be at part of the reception. There is a photo on my friend's mantlepiece of the whole wedding party clustered together smiling and looking joyful. Off to the centre of the frame, I am staring into the distance, right through the ducks that were as oblivious to me as I was to them. My best friend has also looked after me multiple times after seizures and we have always laughed at that photo, captured for eternity, to be looked at by generations to come.

As it transpired I did not have a seizure on my wedding day. I had the most beautiful and memorable day. I did get a picture with my best friend of us both looking blankly in opposite directions, and it felt like a lovely way to immortalise both of our weddings. I realise that perhaps I had a near miss, but also that I am blessed with many heroes — my husband, my sister and my best friend among them, who have supported me in my epilepsy and all the other aspects of my life. Truly it was a day to celebrate.

JULIET STEPHENS
LAUGHING ALLOWED

£200,000 donation for research

Epilepsy Society has said a huge 'thank you' to Gravesend Epilepsy Network after they made a donation of £200,000 for epilepsy research.

This generous gift will help our researchers understand more about the underlying genetic causes of epilepsy and improve the diagnosis and treatment of the condition.

Epilepsy Society's acting chief executive, Rosemarie Finley said: 'Over the years Gravesend Epilepsy Network has donated hundreds of thousands of pounds to help us support people with epilepsy. Although epilepsy is one of the most common neurological conditions, in many cases the cause is unknown. This very generous donation will help us to carry out vital research looking at people's genetic makeup to try and understand what causes epilepsy and how best to treat it.'

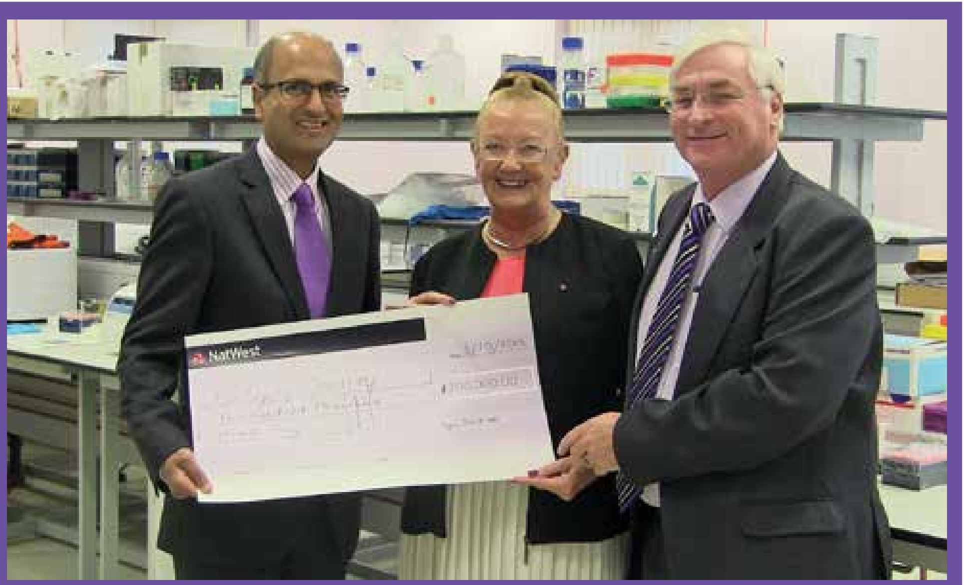
Gravesend Epilepsy Network was co-founded 35 years ago by Lynn Savill MBE, and is chaired by her husband Fred Savill. The group has around 300 members.

Lynn and Fred said they hoped that the money would help the charity understand how a person's DNA contributes to their epilepsy. 'Our dream would be individualised treatment for everyone with epilepsy,' said Lynn.

Fred explained that the latest donation for Epilepsy Society came from a property that was left to Gravesend Epilepsy Network. 'The property was left by a gentleman called Frank Coleman from Doncaster. He had one seizure when he was young and was then on epilepsy medication all his life. He was frightened to stop taking the drugs in case the seizures returned. He wanted to leave his estate to an epilepsy charity.'

Gravesend Epilepsy Network meets on a regular basis to provide social support to people affected by epilepsy. 'It was the charity that brought us together,' continued Fred. 'Lynn and I both have children with epilepsy from previous marriages. Lynn has a daughter, Susan who is now 45 and I have a son, Paul who is 43.

'It is important for people to know they are not alone with epilepsy.'



Lynn and Fred Savill present a cheque for £200,000 to Epilepsy Society's director of genomics, Professor Sanjay Sisodiya, left.

Help children like Sianna-Rose save the lives of their mums and dads

Sianna-Rose was just three years old when she witnessed her mum Charlotte having a seizure – often a frightening ordeal for anyone to go through, let alone a toddler. Now six, Sianna-Rose uses our first aid information and epilepsy phone app regularly to help her mum stay safe. Everyone should know how to deal with a seizure and when it's an emergency situation. A donation from you today could help us deliver vital first aid information to schools, children, parents and professionals. To find out more or to donate, visit **epilepsysociety.org.uk/donate**

Christmas cards

Spread some festive cheer and raise awareness of epilepsy with our new selection of Christmas cards. The full range can be found at shop.epilepsysociety.org.uk or you can call us on 01494 601 414 to place your order.

epilepsy: past, present, and future

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epilepsy society

Annual conference

Holiday Inn, Bloomsbury, London

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Professor Sanjay Sisodiya, director of genomics, Epilepsy Society, and **Louise Monaghan**, BBC Radio 4 playwright.

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a full life for everyone affected by epilepsy

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