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REVIEW

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Three billion has been a significant number this summer. First the spacecraft New Horizons travelled three billion miles to send back images from Pluto, the last unexplored major body in our solar system. The excitement of scientists at NASA rippled around the world. Closer to home, there were ripples of excitement on a smaller, but still significant scale, as research into the three billion bases that make up our DNA, shone a light on the genetics of epilepsy.



While space exploration reveals the secrets of a world at the far edge of our solar system, epilepsy research is beginning to reveal the secrets deep within our DNA, secrets that are slowly helping to identify the causes of epilepsy.

Our researchers at Epilepsy Society have made ground-breaking progress in three key areas associated with epilepsy: sudden unexpected death in epilepsy (SUDEP), photosensitivity and the ketogenic diet.

Using the most advanced technology, our researchers can look in minute detail at the genomes of people with epilepsy and begin to unravel the complex genetic architecture that contributes to the condition. This is helping scientists begin to understand why some people could be at a higher risk of SUDEP, why some people may be sensitive to flashing lights and why some people with drug resistant epilepsy respond well to the ketogenic diet while others don't.

Director of clinical genetics at Epilepsy Society, Professor Sanjay Sisodiya is quick to point out that these are all small steps. There are no absolute answers yet, but pieces of the jigsaw are gradually emerging.

It's a jigsaw where we don't even know how many pieces will be in the final picture. Our research is ongoing and you can help us to shape the direction it will follow by taking part in our online research survey. When it comes to epilepsy research we want to know what is important to you, what you hope we will achieve and how this could make a difference to your life. You can find out how to take part in the survey on page 23.

Research and exploration are full of surprises and one revelation that has caught NASA scientists off guard is news that Pluto has a plasma tail caused by the planet's atmosphere being stripped away by solar winds. This edition of *Epilepsy Review* reveals that epilepsy too can have a tail. Turn to page 8 to read about canine epilepsy and how research into dogs with epilepsy – and tails – could contribute to a better understanding of the condition in humans.

Nicola Swanborough
Editor



FRONT COVER

Best friends: Tina Thompson
You can view more of Tina's work at www.epilepsysociety.org.uk/artists-and-epilepsy

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

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

RESEARCH

Breakthrough in understanding causes of SUDEP

Scientists have made an important breakthrough in understanding the causes of premature death in people with epilepsy.

Researchers, led by those from Epilepsy Society and University College London, have discovered that an individual's genetic make-up may contribute to the risk of sudden unexpected death in epilepsy (SUDEP).

SUDEP causes the death of 600 people each year in the UK. It is thought to be more likely in people with frequent convulsive seizures, than in those with infrequent seizures.

This latest breakthrough brings us a step closer to determining risk in individual people, with the eventual aim of preventing deaths through personalised diagnosis and treatment.

By analysing the genes of a person with epilepsy, medical professionals may, in the future, be able to identify the heightened risk of SUDEP in advance, contributing towards the quest for prevention.

Genetic sequencing is playing an increasingly important role in healthcare, as it may help patients receive more tailored treatment for their conditions. Epilepsy affects more than half a million people in the UK

and a greater genetic understanding will help identify precision treatments, as well as pinpointing the causes and risk factors associated with the condition.

This study is the largest of its kind so far, analysing the sequences of 18 people who died of SUDEP, 87 living people with epilepsy and 1,479 non-epilepsy disease controls.

Sanjay Sisodiya, director of clinical genetics at Epilepsy Society and professor of neurology at University College London said: 'This discovery is an important step in understanding the causes of sudden death in epilepsy. It gives the scientific community a further hint at how the genetic make-up of a person with epilepsy might contribute to the risk of this devastating outcome.'

'As we look towards more accurate estimation of individual risk, more personalised treatment and perhaps prevention of SUDEP in the future, we need to test our findings further and would welcome further collaboration.'

This research was funded by Dravet Syndrome UK with contributions from other bodies. SUDEP can occur in any epilepsy, but is more common in some, such as Dravet Syndrome, a severe form of childhood epilepsy.

www.epilepsysociety.org.uk/sudep

AEDs

Perampanel offers greater hope

A new treatment option is offering hope of better seizure control and potential seizure freedom for people with drug-resistant generalised tonic clonic seizures (GTC).

Perampanel, developed by Eisai and licensed in the UK in 2013 for the treatment of focal seizures, has now been approved for use in generalised seizures that affect both sides of the brain at once.

People with these seizures often fall resulting in potential physical injuries. Frequent generalised tonic clonic seizures can also increase a person's risk of Sudden Unexpected Death in Epilepsy (SUDEP).

Until recently there have been limited medications licensed for these seizures. But now the European Commission has granted marketing authorisation approval for perampanel, for use as an add-on therapy for generalised tonic clonic seizures in adults and adolescents over 12.

Clinical data for the drug, was presented at the European Academy of Neurology in Berlin and showed:

- 30.9 per cent of people taking perampanel were free of GTC seizures compared with 12.3 per cent taking a placebo
- there was a greater reduction in GTC seizures in those on perampanel (76.5 per cent) compared to those who took placebo (38.4 per cent)
- people treated with perampanel had an improved quality of life compared to those taking a placebo.

Epilepsy app for healthcare professionals

Epilepsy Society is launching its new app for healthcare professionals to help support them in treating and caring for people with epilepsy. The *Epilepsy Manual* will be free to download and will provide instant access to comprehensive information about epilepsy for non-specialists.

Jenny Nightingale, epilepsy specialist nurse said: 'This resource

will enable clinicians to access up-to-date information about all aspects of epilepsy care and management at the click of a button. It has the potential to have a real impact on the lives of people with epilepsy.' The app will be available this summer on Android and iOS: www.epilepsysociety.org.uk/manual



GENETIC RESEARCH

Ketogenic diet



A new study has highlighted the importance of exploring further genetic factors which may explain why some people with epilepsy respond to ketogenic diet therapies while others don't.

Ketogenic diet therapies switch the body's energy fuels from glucose to 'ketone bodies'. This is particularly beneficial for those with glucose transporter type-1 deficiency syndrome (GLUT1-DS) where glucose is unable to cross the blood-brain barrier into the brain. This deficiency is caused by mutations in the gene SLC2A1.

People with mutations in this gene tend to respond more favourably to the ketogenic diet therapies, with some achieving seizure freedom.

But the study, led by Epilepsy Society's director of clinical genetics Professor Sanjay Sisodiya, has shown that other genetic factors beside mutations in the SLC2A1 gene may be involved in a good response to ketogenic diets.

The research team looked at 246 people on a ketogenic diet therapy who had not been diagnosed with GLUT1-DS. Their seizure frequency was recorded at regular intervals.

Three were seizure-free at every interval, but only one had an SLC2A1 mutation thought to be undiagnosed GLUT1-DS. The other two had no mutations in SLC2A1.

Professor Sanjay Sisodiya said: 'Our study shows that a favourable response to ketogenic diet therapies cannot be solely explained by this gene.'

A&E

Postcode lottery

There is a wide disparity in the treatment of people with epilepsy who are taken to A&E following a seizure, a recent study reveals. NASH – the National Audit of Seizure management in Hospitals – looked at the services and care available to people with epilepsy and found considerable variability across the entire care path with the need for more organised and accessible care.

The study looked at over 4,500 attendances in 154 emergency departments across the UK. Assessments were often found to be incomplete. Witness statements were only taken in 75 per cent of first seizure patients. In this same group, only 55 per cent were referred to a neurologist or epilepsy specialist and only 27 per cent were given advice on further seizure management.

This was the second NASH audit. For the sites which took part in both, there was a slight improvement in services. NASH hopes to raise the profile of epilepsy and encourage clinicians and commissioners to include it when planning services.

NEUROLOGY SERVICES

Failing patients

A new report by the National Audit Office (NAO) has criticised the government for failing to improve services for people with neurological conditions, including epilepsy.

According to the NAO, the government has failed to improve access to services, collection of neurology data and better care planning. Only the appointment of a clinical lead for neurology and the creation of neurological networks have been labelled as 'good progress'.

The Neurological Alliance, supported by Epilepsy Society, is calling for a full review of neurological services. Arlene Wilkie, chief executive of the Neurological Alliance, said: 'It is unacceptable that so little progress has been made. It only adds to the sense that people with neurological conditions are not seen as a priority in today's NHS.'

GOVERNMENT

Backing genomics

The world's only minister for life sciences, George Freeman, has underlined the Government's commitment to genomics and its support for centres of excellence that are promoting innovative healthcare across the UK.

Genomics is the diagnosis and treatment of an individual by looking at their DNA. This is being pioneered in the treatment of epilepsy at Epilepsy Society's Chalfont Centre in Buckinghamshire.

Speaking in Westminster at the launch of the All Party Parliamentary Group for Life Sciences, the UK parliamentary under secretary of state for health said: 'We must unlock the power of genomics and data and bring them more quickly to patients. We need to embrace challenging innovation that will deliver better health. We need to diagnose earlier, treat smarter and embrace technology.'

Kit Malthouse, MP and chair of the APPG for Life Sciences said the new group was a fantastic opportunity to raise awareness of the life science industry in parliament.

SEIZURES

First aid course

Do you feel confident in managing your own epilepsy? Do you feel confident about supporting a friend or family member with their epilepsy? Would you know when to call an ambulance in response to a seizure?

Epilepsy Society is working with the University of Liverpool to develop a short course on seizure first aid. Now researchers are looking for people with epilepsy to try the course with a family member or friend so they can give their feedback. The study is open to anyone over the age of 16 with epilepsy who is taking epilepsy medication. To take part you must have visited A&E in recent years for your epilepsy. The courses will be in English in Liverpool so you will need to live in the North West. To take part or to find out more information, call 0151 794 5993 or email seizure.firstaidproject@liverpool.ac.uk

Epilepsy apps – man and dog’s best friend



WHO

Global epilepsy

Epilepsy Society’s medical director Professor Ley Sander has welcomed a new World Health Assembly resolution urging countries around the world to strengthen their efforts to provide care for people with epilepsy.

Professor Sander works with the World Health Organization’s (WHO) global campaign against epilepsy to improve the way epilepsy is managed in resource-poor countries including China, Brazil, Ecuador, Georgia, Bulgaria, Kenya and Senegal.

He said: ‘It’s excellent news that delegates at the World Health Assembly, including those from the UK, have endorsed this resolution in support of improving epilepsy care and research for people across the globe. Now that the resolution is approved, epilepsy and the issues surrounding it will be firmly in the spotlight.’

The Royal Veterinary College has worked with Epilepsy Society to produce an app for the owners of dogs with seizures. Read about the parallels – and differences – between canine and human epilepsy and find out how research into one could benefit the other.

An app for dogs? Page 8
The latest apps, page 20

SEIZURE CONTROL

Omega-3

A low dose of omega-3 fatty acids contained in fish oil capsules may help reduce seizure frequency by up to 33 per cent in those with uncontrolled epilepsy. This is according to a small study by researchers at UCLA School of Medicine, Los Angeles. The scientists caution however that the results are preliminary and a larger study is needed to confirm findings. Previous studies using high doses of omega-3 fatty acids showed no clear benefits.

News in brief



In 2014 70% of 211 commissioning groups had no plans to assess needs of neurology patients. Page 4



Only 55% of first seizure patients in emergency departments referred to a neurologist.

Page 4



This award is a great honour which I dedicate to all the children with epilepsy with whom I have had contact.



Professor Helen Cross, Prince of Wales Chair of Childhood Epilepsy, on receiving an OBE



\$137,000 awarded by Health Research Council in New Zealand to develop nose-to-brain epilepsy drug delivery.

Photosensitive epilepsy

WARNING

The following report may contain flash photography

One in 20 people with epilepsy also has photosensitive epilepsy. Now researchers at Epilepsy Society, working with colleagues across the world, have for the first time identified a genetic cause for this type of epilepsy.

'Warning – the following report may contain flash photography.' Sound familiar? Without doubt, this is one of the most frequently broadcast alerts on British television. Whenever a bank of photographers are gathered in numbers – a royal baby, David Beckham's 40th birthday, the arrival of One Direction at the Brit awards – the newsreaders are never far behind them, waving a proverbial red flag.

From Huw Edwards and Fiona Bruce through to George Alagiah, the warning is the same. There is rarely any mention of epilepsy, but the underlying message is clear: this report could cause a seizure for anyone who has photosensitive epilepsy.

Photosensitive epilepsy is a type of reflex epilepsy, triggered by flickering or intermittent light or repetitive patterns. It is the most common type of reflex epilepsy but in broader terms it is still comparatively rare. While 1 in 100 people has epilepsy, less than five per cent of them have photosensitive epilepsy. Yet the public perception is that the condition is much more common – largely due to the number of warnings, a regulatory requirement by Ofcom.

Now, however, groundbreaking research can tell us exactly why flickering lights can cause seizures in some people. Researchers at Epilepsy Society, working as part of an international consortium, have identified a genetic mutation which is a risk factor for some people with photosensitive epilepsy.

The researchers, led by Professor Sanjay Sisodiya, have been investigating the underlying cause of photosensitive epilepsy for some years. They carried out a DNA test on a woman with photosensitive epilepsy that showed a deletion involving a small number of genes. The researchers

suspected one of these may have been causing her epilepsy.

Working as part of an international collaboration, Professor Sisodiya then began to look at these genes in a far larger group of people with epilepsy. Mutations in the gene CHD2 had already been linked to photosensitivity in some very rare epilepsies, so researchers set out to compare the sequence of this gene among participants in their study.

Research was carried out on 580 people with various types of photosensitive epilepsy and nearly 34,500 people without the condition. Participants came from nine different countries.

Researchers identified 11 unique variants in CHD2 (10 of them new variants) among the 580 people with photosensitive epilepsy, suggesting that disruptions in this gene could also be associated with more common forms of photosensitive epilepsy. The scientists believe the photosensitivity may be caused by the mutations partially, or fully, deactivating the gene and causing heightened light sensitivity.

Professor Sanjay Sisodiya said: 'This finding helps to explain photosensitivity in a small percentage of people and will eventually help us understand why they have it and maybe lead to rational treatment. But it also shows that one can find answers!'

He explained that although the functions of CHD2 are not yet fully understood, they know that the gene does not instruct proteins that are crucial for directly generating nerve impulses – a trademark of epilepsy.

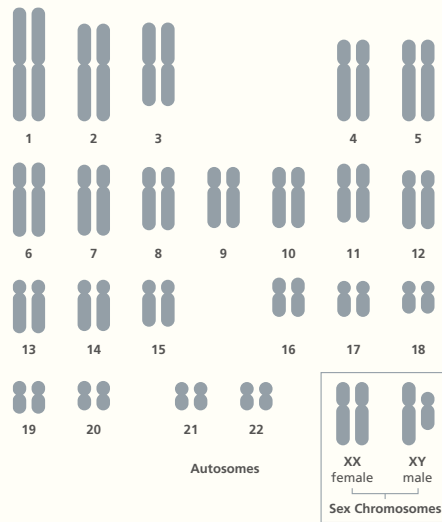
'This opens up new avenues of research into human cortical excitability,' continued Professor Sisodiya. 'This is an area of research that we are focusing on at Epilepsy Society Research Centre. Working with collaborators, we will now be looking for further mutations that may cause photosensitivity and cortical excitability.'

The pioneering research isn't the end of the story. It doesn't mean that the six-o'clock news warnings will stop but it does mean that scientists are starting to unlock the genetic code of particular types of epilepsy in some people. They are now able to pinpoint an exact genetic mutation that means a bank of photographers with flashing lights, or equally strobe lights, certain video games, films and YouTube clips, may spell trouble for some people with photosensitive epilepsy.

Locating CHD2

Your chromosomes

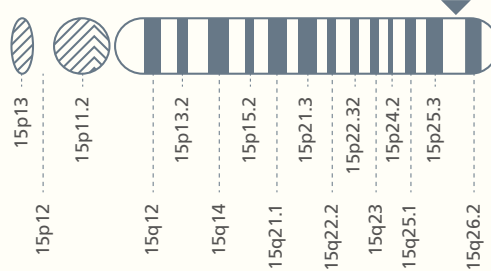
Each cell in your body has 46 chromosomes arranged in pairs.



Chromosome 15

There are between 600-700 genes on chromosome 15. These are made up of 102 million DNA building blocks (base pairs), representing 3% of the DNA in your cells. Many genetic conditions are related to changes in particular genes on chromosome 15. Mutations in one of these genes, CHD2, have been identified as a cause of photosensitive epilepsy.

CHD2 is located at position 26 on the long arm of chromosome 15, between base pairs 93,028,006 and 92,900,320.



Sophie's story

Sophie Harries, 19, from Somerset, has photosensitive epilepsy. Here she explains how it affects her life.

'I was diagnosed with photosensitive epilepsy at 15. I also have idiopathic generalised epilepsy. At the time I thought photosensitivity was common and only applied to strobe lighting, however I was wrong.

For me the photosensitive element of my epilepsy means that I can't go to nightclubs like my friends do and have to be careful which bars I go to due to the lights. When watching TV or films I have to cover my eyes when there is a warning about flashing images. When I watch films or TV I have to make sure all the lights are on in the room as well, so that means no cinema either. The most peculiar trigger though is the flickering of sunlight through trees or off water. I have to cover my eyes immediately and have been given some strange looks on the bus. Fireworks and surprisingly ceiling fans are also issues.

My main trigger though is flickering lights, so every new light is checked by friends and family for flickering. Lights in public places that only turn on in response to movement can also be an issue due to them normally flickering while turning on.'

CHD2

CHD2 spans over 127,000 base pairs. This is where the 10 new unique variants, identified as a cause of photosensitive epilepsy, are found.

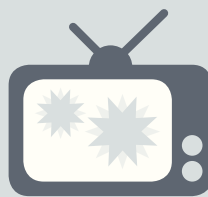
About photosensitive epilepsy



1 in 20 people with epilepsy has photosensitive epilepsy.



Flashing lights between the frequencies of 3 and 30 hertz (flashes per second) are most likely to trigger a seizure in 60% of people with photosensitive epilepsy, but some may be sensitive outside this range.



Photosensitive epilepsy first came to prominence in the 1950s and was known as 'television epilepsy' but it is more than a modern phenomenon.



Photosensitivity can also be hereditary. If a woman has photosensitive epilepsy, her children have a 25% chance of developing it.



Professor Holger Volk and Dr Rowena Packer at the CT scanner with Betty, almost a staff member at the RVC. Tests for dogs with seizures include MRI scans, EEGs and CT scans. Dogs usually have to be mildly sedated for tests, although co-operative dogs can sometimes have an EEG without sedation.

An app for dogs?

... well not quite, but certainly an app for dog owners. The Royal Veterinary College has worked with Epilepsy Society to develop the first ever app that allows dog owners to monitor their pets with epilepsy. The RVC Pet Epilepsy Tracker is based on the charity's epilepsy toolkit app. Canine epilepsy experts Professor Holger Volk and Dr Rowena Packer hope that not only will it bring a better understanding of seizures in dogs but it could also contribute to a wider understanding of the condition in humans. Here they talk about what epilepsy is like for our canine friends

How common is epilepsy in dogs?

Rowena It is very common. In fact it is the most common long-term neurological condition in dogs. There are 9.4 million dogs in the UK and 50,000 of them have epilepsy. That is a prevalence of 0.6 per cent. Certain breeds seem to be more likely to develop epilepsy such as Border Collies, German shepherd dogs, Staffordshire bull terriers and Labrador retrievers. Studies show that male dogs are more prone to seizures than females.

What sort of seizures do dogs generally have?

Holger We tend to see dogs that have focal seizures with secondary generalised seizures. If a dog is lying on the ground shaking, that is very easy to detect. It would be difficult to detect if a dog was experiencing lapses in consciousness, sight or vision. As in humans, there is often a genetic component to the epilepsy or it could be as a direct result of a stroke, brain tumour, cortical inflammation or hydrocephalus. We see a lot of dogs with seizures caused by head injuries from traffic accidents or from running into trees and other obstacles.

Does epilepsy affect dogs in the same way that it affects humans?

Holger Very much so but there are differences. As with people, seizures in dogs are unpredictable and often uncontrollable. In humans, two thirds of people with

epilepsy will respond to anti-epileptic medication. In dogs only one third respond well to this treatment.

Dogs with recurrent seizures have an increased risk of experiencing fear, anxiety and depression. They are also more likely to develop behavioural changes, have learning difficulties, develop defensive aggression and to have a reduced quality of life. Even when the medication works, there can be side effects, just as in humans. Anti-epileptic drugs can make dogs sleep a lot, drink a lot and need to go to the toilet much more. This all impacts on their quality of life.

The stigma around epilepsy is very different for people and dogs. I notice on the internet that if someone posts a video of a person having a seizure there are often a lot of insensitive and negative comments. If someone posts a video of a dog having a seizure, there will be more sympathetic comments. People seem to be much nicer to dogs than they are to their own species.

How does epilepsy impact on the dog's owners?

Rowena Studies have shown that when a dog has a seizure, not only does the dog's stress levels rise but so does the owner's. It can be very distressing to witness a dog having a seizure. Looking after a sick pet can present an emotional burden, as well as practical issues such as constantly medicating the dog, checking for side effects and coping with ongoing financial costs.

Many owners are reluctant to start AED treatment with their pets for fear of reduced quality of life. Side effects from AEDs were one of the top reasons cited by around one third of owners for a decreased quality of life in their dogs.

Epilepsy in dogs can present specific issues for dog owners who rely on dog sitters and dog walkers during the working week. Often they are unable to find someone who is willing to take on a dog that is likely to have a seizure and this can make life very difficult.

Holger We also see owners who totally change their lives around to look after their dog. The bond between owner and dog can be very strong, especially when they spend so much time with them.

Of course all dog owners hope that treatment will result in complete seizure freedom for their pet, although statistically there is only a 33 per cent chance of this happening. Many consider one seizure every three months to be tolerable for the dog. In some cases, where this is not achievable and the owner feels the dog is suffering, they may make the difficult decision to elect euthanasia.

As a vet it is very important to interact with the dogs we see in order to build up their trust. Stroking them and talking to them helps to build up a bond and of course, it is hard not to become attached to the dogs. This makes it very hard when it is bad news.

Do dogs take the same anti-epileptic medication as people?

Holger Much of the time yes. Dogs can be prescribed levetiracetam, zonisamide, gabapentin, pregabalin and topiramate but the two most commonly prescribed anti-epileptic drugs for dogs are phenobarbital and potassium bromide.

Recently a new drug has been introduced - imepitoin. Some years ago this was prescribed in human epilepsy but it was not found to be suitable for people who smoked and so was withdrawn. However it is a very safe drug for dogs and may have the potential to help with fear and anxiety.

Interestingly, in the veterinary field we take a different approach to prescribing medication in dogs. In humans, the protocol is always to start low and go slow whenever a new or additional drug is introduced. With dogs we tend to start with the dose for optimum seizure control and tolerate a bit of initial wobbling or co-ordination problems while the dog is adjusting to the medication.

Are there any other treatment options for dogs?

Holger We have carried out a small study into the use of a modified version of the ketogenic diet in 21 dogs. The ketogenic diet relies on inducing ketosis so that the body obtains its energy from fat rather than glucose. It is actually very hard to induce ketosis in dogs as they are descended from wolves and are biologically programmed to survive a degree of starvation. Feeding them regularly as we do is not natural for dogs.

We trialled a version of the ketogenic diet that allows for more carbohydrates and protein than the traditional high fat ketogenic diet. More than half of the dogs had more than 50 per cent reduction in seizure frequency when on the diet. Fourteen per cent became seizure free.

Can we learn anything about epilepsy in humans by looking at epilepsy in dogs?

Holger Most definitely. Research at our canine epilepsy clinic showed that the more accurate indication of whether a dog will achieve seizure freedom is the closeness of its seizures rather than the number of seizures it is having. Similar results have been found in human epilepsy, highlighting the dog as a naturally occurring model of epilepsy. Our research into drug treatments for epilepsy in dogs could help to further our understanding of the condition in humans.

Our new app for dogs with epilepsy will allow owners to record patterns of seizure activity and medication diaries and send this directly to their vet. It will also give them the opportunity to share their records anonymously with the Royal Veterinary College. This could revolutionise our understanding of the way that epilepsy progresses in individual dogs and provide data for long-term studies of seizure activity in canine epilepsy.

In turn, this could advance our understanding of human epilepsy.

Professor Holger Volk is professor of veterinary neurology and neurosurgery and clinical director of the RVC Queen Mother Hospital for Animals.

Dr Rowena Packer is clinical investigation research assistant at the RVC.



◀ A dog called Casey

Casey is a beautiful three-year-old Border Collie. She had her first seizure at 11 months and is going through her first change of anti-epileptic medication. Her owner, Fran Agnew, talks about the impact of Casey's seizures

'The first time Casey had a seizure I thought she had been poisoned. She was sick and shaking. I put my hand in her mouth thinking I needed to remove something toxic and she bit me quite badly. I was mortified to see her like that and really panicked. The neighbours heard me screaming and came and took control. After that I went on to Google to find out everything I could about seizures.

I wanted to make sure that if it happened again, I would be prepared.

Casey's seizures are grand mal. She falls to the ground, starts paddling her legs, loses control of her bowels and starts snapping. It is very distressing to witness. The seizures often happen as she is falling asleep or coming out of a deep sleep. They always seem to be when she is resting. When she is busy and active they don't seem to bother her so much. That is one of the reasons why we got a second dog, Enzo, to play with her and help keep her occupied. She loves to compete in flyball, a four-dog relay race over jumps, and her epilepsy never bothers her then.

Casey's seizures usually last two to three minutes and tend to leave her very tired and hungry. She can also become extremely hot so we try to cool her down by placing ice on her back and between her shoulders.

When she comes out of a seizure she doesn't know where she is and starts sniffing everything as though she has only just arrived. She doesn't recognise Enzo or our cats. After about 40 minutes of stroking her and talking to her she usually falls into a very deep, hard sleep for a couple of hours. When she wakes up she is as right as rain. We take her out for a run and you wouldn't know anything has happened to her.

Casey didn't have her second seizure for nine months and then they started to come more frequently. Although the vet thought from the outset that it was likely she had epilepsy, we wanted to see if they could be controlled another way and have all the tests to rule out other causes. It was only after a few more months when she started having two in a week that she was put on imepitoin,

a relatively new drug thought to be the least invasive of the epileptic drugs.

For 18 months her epilepsy seemed to be well controlled and then she started having breakthrough seizures, sometimes two in a day. She is now slowly changing to phenobarbital. The side effects from the drugs mean she is a little overweight and can be quite sleepy. Since starting phenobarbital her back legs seem quite wobbly and uncoordinated. She also has a lot of head twitches which we hope will diminish as she adapts to the new drug.

Casey has to take her medication at 12-hourly intervals on the dot – 6am and 6pm so there are no lie-ins for us. She is very good at reminding us about her medication. Quarter of an hour before it is due, she will either whimper to wake us up or tap us on the arm. She is a very intelligent dog. Casey now has to have regular blood tests to check her therapeutic drug levels. This is very stressful for her.

I have given up work so that I can look after Casey full time. She is totally reliant on my husband Shane and myself. The emotional, physical and financial burden of looking after her can be quite difficult to cope with but we wouldn't want to be without her. She is our responsibility and we want her to have the best life possible.

When Shane and I got married two years ago, we left Casey with a neighbour while we went to Mauritius for our honeymoon. While we were away she had two seizures. Now we have bought a caravan so that we can holiday in the UK with Casey and, of course, Enzo. We are hoping that in time, Enzo might learn to recognise Casey's seizures and be able to warn us when they are going to happen.'

Epilepsy app – man and dog's best friend



Epilepsy toolkit app for people

Epilepsy Society

Available from: App store or Google Play (search: epilepsy toolkit)

Features include:

- seizure diary and medication reminder
- medication details, record and photograph your drugs
- video recording your seizures
- first aid and recovery position guide.



RVC pet epilepsy tracker for dogs

Royal Veterinary College

Available from: App store or Google Play

Features include:

- seizure types, diagnosis and managing epilepsy
- seizure diary
- medication reminder
- option to share data for research purposes.

When was the last time you called in to see your local pharmacist? The chances are it was when you picked up a prescription for your epilepsy medication. But pharmacies can offer so much more than a dispensing service for drugs. Pharmacies are an integrated part of the NHS at the heart of the community, offering expert advice on medications, side

effects from drugs and living with seizures. What is more, community pharmacists are often open longer than many GP surgeries, are generally just a short walk or drive away, and you don't need to make an appointment – you can just drop in. Eisha Gosrani explains why getting to know your pharmacist makes sense for anyone with epilepsy



Your local pharmacy



Eisha Gosrani

Eisha Gosrani is Epilepsy Society's resident pharmacist. Her work includes dispensing new medicines and changes to anti-epileptic drugs, giving patient medication counselling and discussing treatment plans.

Getting to know your local pharmacist could help you to manage your epilepsy better and make sure that you are getting the most out of your medication.

The role of the community pharmacist is often seen as purely dispensing drugs prescribed by the GP or other prescriber. But pharmacists can play a key role in delivering healthcare in the high street, neighbourhood centre or the supermarket.

Pharmacists train for five years, including four years at a school of pharmacy. This means they have an in-depth knowledge of how your anti-epileptic drugs (AEDs) – and other medicines – work and the potential effects of a medication or combination of medications.

AEDs work best when taken regularly at around the same time every day. The aim of any treatment is to stop seizures with the lowest dose of the fewest

number of AEDs and with the least side effects. Finding the right drug at the right dose can sometimes take time as it differs in each person.

If you have a query about your medication, the dose you have been prescribed, how and when to take your drugs or whether they are likely to interact with other medication, your pharmacist will be able to help.

Alongside medicinal advice, pharmacists can help and advise on wider health and well-being issues such as healthy eating, exercise and losing weight. They can provide the type of support and information to help you self-manage your health without you having to visit your GP.

Over the page we look in detail at some of the services pharmacists provide and how they can help you. And on page 20 you will find details of the *Find a pharmacy* app.

YOUR LOCAL PHARMACY SERVICE

All pharmacies provide the following services

Dispensing medication Of course the primary role of the pharmacist is to dispense your medication, make sure that you understand how and when to take it and to make sure that your medication is compatible with any other drugs you may have been prescribed.

Dispensing repeat prescriptions You can get a prescription from your GP for up to a year so that you can get your medication dispensed on a regular basis at your local pharmacy without having to make repeat visits to your GP.

Safely disposing of unused or out of date medication If your medication is out of date, unwanted or left over after you have stopped taking it, your pharmacist can dispose of it safely. Never throw away a medicine in the bin, burn it or flush it down the toilet as this can harm the environment.

Interactions between different medications Your pharmacist can advise on possible interactions between different prescribed or over-the-counter medicines.

Medication aids Your pharmacist will be able to give advice about medication aids, such as drug wallets or blister packs. Some pharmacists will organise your medication into blister packs, marked with the day and time of day when different tablets should be taken.

Giving information on how to keep healthy Your pharmacist can give you advice and tips about how to stay well, including good nutrition, exercise, losing weight and stopping smoking. They may be able to provide you with information and leaflets about issues which concern you.

Signposting you to other services If your pharmacist feels you need help from another healthcare

professional, social services or voluntary organisation, they will refer you to the most appropriate service to help you to manage your condition.

Some pharmacies provide these additional services

Delivering prescription medication to your home The pharmacy may arrange to collect your prescription from your GP, where necessary, and may deliver your medication to your home.

Health checks Some pharmacies have the facilities to carry out blood pressure tests, cholesterol tests or blood glucose tests.

Minor ailments service Pharmacists can provide information on how to treat minor health conditions such as coughs and colds, stomach upsets and headaches.

Medicines use reviews This is a free NHS consultation with your pharmacist about your medication. You can read more about medicines use reviews on page 14.

New medicine appointments This is a free NHS service for anyone who has been newly prescribed a medication to thin the blood or treat asthma, chronic obstructive pulmonary disease, diabetes (type 2) or high blood pressure. At the moment this service is not available for epilepsy.

GETTING THE SAME MEDICATION

It is recommended that people with epilepsy take the same version of their medication every time. There are often several different versions of each anti-epileptic drug – branded and generic – but different versions of the drug can vary slightly and this could affect seizure control for some people.

If your prescription only has the generic name of the drug, your pharmacist can give you any

The stats



Over
3m

MURs at pharm
in England 201

14

number of times
people visit their
pharmacy each year



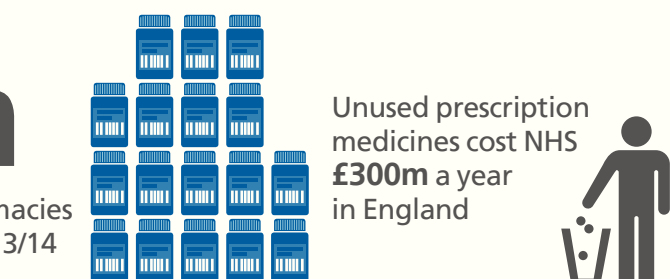
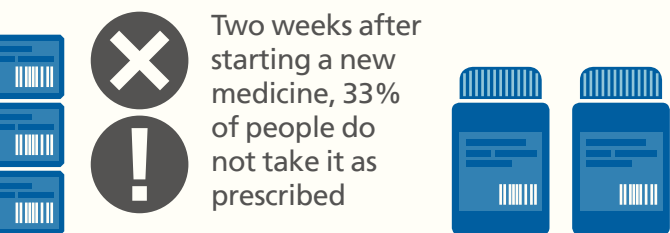
52,500

registered
pharmacists

version of the drug with that generic name. However, if your prescription has the branded name, your pharmacist has to give you that brand.

Going to the same pharmacy each time and getting to know your pharmacist may help make sure you get a consistent supply of medication.

Your pharmacist will keep a record of any medicines they have dispensed to you and if you ask, will try to ensure consistency of supply. Check that you have the correct AEDs while you are at the counter, as your pharmacist will not be able to change them once you have left.



'A medicines use review is a free NHS consultation with your pharmacist about your medication'

REPORTING A PROBLEM WITH YOUR MEDICATION

Yellow Card Scheme

For some people, anti-epileptic drugs can cause side effects. Many of these are known side effects and are listed in the patient information leaflet that comes with your medication. However, if you experience a side effect that is not listed, you should report this through the Yellow Card Scheme. The Yellow Card Scheme has been set up by the Medicines and Healthcare Products Regulatory Agency (MHRA) to monitor the

side effects of medication and identify any problems that may not be known.

You can also use the Yellow Card Scheme to report any problems you may encounter by switching between different versions of an AED, adverse incidents with medical devices, defective medication or counterfeit/fake medication.

You can ask your pharmacist or GP for a yellow card to send to the MHRA. Or you can fill in a form online at www.yellowcard.mhra.gov.uk/the-yellow-card-scheme/ or call 0808 100 3352.

MEDICINES USE REVIEW



A medicines use review (MUR) is a chance for you to talk to your local pharmacist about the medication you are taking and how you are getting on with it. The service is provided by the NHS at most pharmacies throughout England and Wales, and is completely free. Similar services are available in Scotland and Northern Ireland.

Of course you can ask your pharmacist questions at any time, but this is a concentrated time for you to focus on your medication during a private consultation and discuss any problems or queries you may have.

Who is eligible for a review?

You will be eligible for a review if you are taking one or more prescription medicines or if you have a long-term health condition such as epilepsy. However, you are still welcome to talk to your pharmacist at any time even if you don't meet these criteria.

You can arrange a review through your pharmacist, or they may even suggest one. However if you have an urgent problem with your medication such as severe side effects or if you have taken too much medication, do not wait for a review. See your GP or pharmacist straight away.

What happens at an MUR?

Your MUR will take place in a private consultation room where you will be able to sit down with your pharmacist and will not be overheard by staff or customers.

Your pharmacist may ask you questions about your medication and how you are getting on with it, but you may also like to ask questions. It is helpful to take along a list of all the medications you are taking, how much you take and when. Include any over-the-counter medicines and herbal remedies too. Your pharmacist will only know about medication you have received through that pharmacy. They do not usually have access to medical records.

Issues you might like to discuss include:

- how effective is your medication
- is it giving you seizure control
- are you experiencing any side effects
- is it easy to remember when to take your medication
- are there any reminders/alerts that could help you to take them regularly
- are there any containers that might be easier to open if you are having difficulty getting your medication out of its present container
- are there any alternatives to your current treatment
- how can you be certain that you are prescribed the same version of your medication every time, without your medication being switched to a cheaper version?

What happens after an MUR?

After your MUR your pharmacist will draw up an action plan, recording when the meeting took place, what was discussed and any actions that you agreed. You will receive a copy of the plan and you can ask for it to be sent to your GP, epilepsy specialist nurse or your carer.

If your pharmacist recommends a change to your prescription, this will need to be agreed by you and the person who usually prescribes your medication – usually your GP.

Find out more at:

www.epilepsysociety.org.uk/making-most-your-pharmacist



**epilepsy
society
helpline**

01494 601400

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

Erectile dysfunction

It's a man thing



At Epilepsy Society's conference, we asked what you would like to read more about in *Epilepsy Review*. One of the most requested topics was erectile dysfunction and the impact of epilepsy on sex, particularly for men. Here Nicola Swanborough talks to the experts

More than 50 per cent of men with epilepsy experience sexual health problems at some point in their life. While many enjoy a healthy and fulfilling sex life, research shows that for others low sex drive, erectile dysfunction and lowered fertility rates can be significant issues. Yet experts say men are often reluctant to talk about these issues with their doctor or healthcare professional.

'Ask any man with epilepsy how his condition impacts on his day-to-day life and he will talk about worries with work, the limitations of not being able to drive and the cognitive side effects from medication,' says Professor Matthias Koepp, consultant neurologist at Epilepsy Society. 'Rarely will he talk about sexual problems.'

'Despite living in a society where we are bombarded with sexual imagery, when it comes to talking about sex on a personal level, we don't – and men are particularly bad. We can't find the language to express something that can affect us both at a physical and psychological level and that can have a major impact on our quality of life, particularly on our relationships. We'd rather suffer in silence than open up to a GP or neurologist.'

Lowered sex drive or libido is the reluctance to get

involved in sexual activity, given the right stimulus. Erectile dysfunction is the inability to achieve and maintain an erection. Both are surprisingly common in all men – not just those with epilepsy.

Most men experience a lowered sex drive or erectile dysfunction at some point in their life, for example at times of increased stress or as a symptom of low mood and depression. In the general population 7-8 per cent of 20-40 year olds experience erectile dysfunction, with this figure increasing to 11 per cent for 40-50 year olds, 40 per cent in the over 60s and 50 per cent in the over 70s.

Studies show that men with epilepsy have an increased risk of erectile dysfunction of up to 57 per cent, but the risk can vary according to severity of the condition and whether they also have depression. Among those attending appointments at outpatient clinics the rate can be as low as three per cent, but it can increase to more than 50 per cent for people being evaluated for epilepsy surgery.

Infertility, where a couple struggle to fall pregnant after more than a year of trying to have a baby, is again quite common among those with epilepsy but also in the general population. Around 15 per cent of all couples experience



More than 50 per cent of men with epilepsy experience sexual health problems at some point in their life



Twenty per cent of people in the UK experience depression at some point in their lives, but for people with epilepsy, this figure rises to between 30-55 per cent.



◀ some difficulties although this rate seems to be slightly higher for men with epilepsy.

The relationship between epilepsy and sexual dysfunction is complex. Evidence points to several potential contributory factors: the location of the epilepsy in the brain, seizure frequency and severity and the side effects of some anti-epileptic drugs. But accompanying conditions such as depression and anxiety can also be significant.

Professor Koepp explains: 'Sexual arousal begins in the brain with neurotransmitters increasing the communication between brain cells and triggering an increase in the flow of blood to the sex organs. This causes tissues to expand and harden.

'Anything that interferes with the nervous system or blood circulation could potentially lead to erectile dysfunction. Anything that affects a person's sex drive will make it more difficult for the brain to trigger an erection.

'Epilepsy, of course, is generated in the brain and seizures occurring in regions of the brain linked to sexuality – the frontal and temporal lobes – may impact on sexual functions.'

A small study, reported in the *British Journal of Psychiatry*, looked at 44 adults with temporal lobe epilepsy and 47 with generalised epilepsy. The study showed that 63 per cent of the men with temporal lobe epilepsy had a low sex drive while only 12 per cent of the men with generalised epilepsy reported problems.

Frequency of seizures and severity of seizures have

also been shown to increase the risk of problems with sex, indicating that better seizure control may lead to a more satisfactory sex life. But as is so often the case with epilepsy, there can be a delicate balance between optimising both seizure control and a healthy sex life.

Epileptic seizures are caused by the random and excessive firing of certain cells in the brain. Epilepsy medication targets the chemical imbalance that causes this to happen and is specifically directed at the brain cells responsible. But the medication may also affect other parts of the brain including those involved with sex.

Evidence shows that some anti-epileptic drugs can affect the cerebral cortex, or outer area of the brain, compromising a person's ability to feel sexual desire. At the same time, certain drugs can alter hormone metabolism, affecting a person's ability to become sexually aroused.

Professor Koepp continues: 'Sexual desire is dependent on correct levels of hormones, especially testosterone. Some enzyme-inducing epilepsy drugs make your liver work harder and so reduce the levels of testosterone in your body. This is particularly true of carbamazepine, oxcarbazepine, phenytoin, phenobarbital, primidone and topiramate (see table, opposite).

'If epilepsy drugs appear to be contributing to sexual health problems, then alternatives should always be considered – lamotrigine and leviteracetam tend to

be a better choice of drugs. If erectile dysfunction continues to be a problem, then specific medication such as sildenafil citrate (Viagra) may be prescribed.

'Men with temporal lobe epilepsy tend to have a higher prevalence of sexual problems but they are also more likely to be candidates for epilepsy surgery. Evidence suggests that sexual dysfunction appears to improve after surgery but this could just be a reflection of better seizure control and improved mood.'

Research shows that lowered fertility rates also seem to affect men with focal epilepsy more than those with primary generalised seizures. However it remains unclear as to whether this is a direct result of the epileptic activity in the temporal lobe, or whether it could be caused by enzyme-inducing medication which may be prescribed at higher doses for men with focal seizures.

Writing in *The treatment of epilepsy* (Shorvon, Perucca, Engel), Swedish epileptologist Torbjörn Tomson says that infertility may be related to the impaired formation and maturation of sperm in the testes. 'Poor sperm motility is noted in patients on long-term anti-epileptic drug treatment,' he says. '...studies suggest a direct effect of phenytoin, carbamazepine and valproic acid on sperm membrane function.'

Professor Koepp continues: 'If you are experiencing fertility issues, it is always important to consult your GP, talk about your epilepsy medication and, if necessary, ask for a referral to your neurologist.'

Medication that may affect a man's sex life

Medication that may reduce testosterone levels

Carbamazepine, oxcarbazepine, phenobarbital, phenytoin, primidone, topiramate

Medication that may reduce sex drive

Carbamazepine, clobazam, clonazepam, oxcarbazepine, phenytoin, phenobarbital, pregabalin, primidone and topiramate

Medication that may contribute to erectile dysfunction

Carbamazepine, clonazepam, gabapentin, oxcarbazepine, phenobarbital, pregabalin, primidone and topiramate

Medication that may affect sperm quality or quantity

Carbamazepine, oxcarbazepine and possibly sodium valproate

Worries about sex?

The working relationship between mind and body is also important for sexual activity. Dr Pam Thompson is head of psychology at Epilepsy Society. She says that alongside the physical causes of erectile dysfunction and low sex drive, mental health can also play a significant role.

Twenty per cent of people in the UK experience depression at some point in their lives, but for people with epilepsy, this figure rises to between 30-55 per cent. The rate of sexual dysfunction among men with depression is 25-30 per cent. Alongside this, some anti-depressant medications – modern SSRI (selective serotonin reuptake inhibitors) – can also contribute to sexual dysfunction.

'Anxiety and depression are very common among people with epilepsy and can impact on all areas of their lives,' says Dr Thompson. 'Sex is a very intimate activity involving two people. If one of them is anxious that a seizure may happen during intercourse, or may even be triggered by sexual activity, then this is likely to impact on the pleasure and fulfilment of the experience.'

'In fact having a seizure is no more likely to happen during sex than at any other time, and if it does then it is not the end of the world. If you can share your worries and concerns with your partner and talk through the possibilities, this may help to allay concerns.'

'Equally, having an erection does not have to be the primary goal of sexual intimacy. Deriving pleasure from the physical act of sex without it having to end in an erection can remove the pressure. If someone is experiencing problems, then making intercourse the goal can put a dampener on what should be a shared and fulfilling experience.'

Sexual problems can also stem from social experience. Ongoing seizures may have resulted in a person being reluctant to engage in an active, healthy sex life, or to form relationships. Lack of experience due to opportunity and personal fears may form barriers later in life, even if seizures are brought under control.

Dr Thompson stresses that recognising there is a problem, talking about it and seeking help are the first steps to finding a solution. 'If erectile dysfunction happens and it is a problem, then it is always worthy of further investigations.'

There are many causes for erectile dysfunction that affect men in general, not just men with epilepsy. Heart disease, diabetes, raised blood pressure, raised cholesterol and low testosterone can all cause problems. So too can certain prescription drugs, alcohol, recreational drugs and smoking.

'Physical causes should first be investigated by a GP,' continues Dr Thompson. 'If these are ruled out and anxiety or depression seem to be the driver, then a referral for psychological therapy should be made by a GP or neurologist. Cognitive behavioural therapy is a therapy that can help you manage problems by changing the way you think and behave. Cognitive behavioural therapy that targets sexual functioning may be a positive way to go.'

You can find out more about epilepsy and sex at www.epilepsysociety.org.uk/sex

Epilepsy by degrees

Peter Nagle was diagnosed with epilepsy at the age of 17. He studied economics at the University of Exeter and took his masters at the University of Bristol. Now 25, Peter is an economist with the Bank of England.

'Student life can be pretty random

– late nights, lack of sleep, poor diet, too much alcohol. You're all away from home and trying new things and even though it may not be obvious, there is a lot of pressure to conform. You don't want to be the odd one out but you have to know what will work for you.

Think about what triggers your seizures

and how you can make sure having a good time does not compromise your health – or your degree. My seizures were generally triggered by computers and staying out late. I tried to minimise my screen time – no computer games and I would print out material I had to read. I would also write by hand first.

In my second year I had a seizure due to lack of sleep and not taking my medication. When I was at home I was quite independent but I relied on my parents a fair bit to make sure I was taking my medication. That seizure was a wake-up call.

I played a lot of water polo at uni which my parents weren't too happy about. My personal view was that I was unlikely to have a seizure while swimming but I made sure everyone in the pool knew about my epilepsy.

Understand why it is important to take your medication

and how a missed dose could result in a breakthrough seizure, as it did for me, or how alcohol and drugs can increase your risk of a seizure (www.talktofrank.com/). Be aware of Sudden Unexpected Death in Epilepsy. It is very rare – about 1 in 1,000 people with epilepsy die of SUDEP – but in many

Going to uni can be one of the best experiences of your life – new friends, new independence, new opportunities. Having epilepsy shouldn't stop you enjoying any of these but it has to be a consideration. Former student Peter Nagle gives his tips on coping with epilepsy at uni while Sophie Harries shares her experiences at the end of her first year studying dietetics

cases it can be preventable. Discuss your own risks with a healthcare professional. Find out more at www.epilepsysociety.org.uk/sudep

Before you head off to uni go and see your GP or epilepsy specialist.

Have a chat with them about lifestyle changes and any issues with your medication. I am lucky that my sister is a doctor, so before I went to uni she made sure that I had all the right medication with me.

When you get to uni register with your uni GP and find out where your local pharmacist is

(Find a pharmacy app, see page 20). You might like to have a chat with either or both of them about your epilepsy and your medication. Some people choose to wear some sort of medical jewellery or carry an ID card with them with details about medication, seizures and who to contact if they have a seizure.

I am very open about my epilepsy and quite happy to tell friends about it

– it stops it from becoming a big deal and gets rid of the fear of the unknown. Also, telling friends about your epilepsy means they will know how to help you if you have a seizure.

Once you know who you are going to be living with at uni, you might like to get to know them via Facebook. Whether you choose to tell people



about your epilepsy is up to you but making friends in advance may help you decide who you would feel most comfortable about telling when term starts.

Memory was a big issue for me when I was a student. I was taking carbamazepine which slightly dulled my thoughts. Through the university I was able to arrange to have extra time during my exams. This just helped to take the edge off things and make revision less of an ordeal.

Before going off to study, I suggest you contact your uni's disability advisory service and have a chat about your epilepsy, how it affects you and whether you might need extra support with issues such as memory and concentration.

Through the disability student allowance you can apply for financial help to buy equipment that will help you overcome these sort of problems. This could be anything from a dictaphone for recording lectures or a laptop for accessing and storing information. You might even be able to pay for someone to take notes for you during lectures. Find out more at www.gov.uk/disabled-students-allowances-dsas

There is lots of help out there, as and when you need it. I had a bus pass which meant I could take a four-hour bus ride along the Jurassic coast from Exeter to my home in Bournemouth (www.gov.uk/apply-for-disabled-bus-pass). A good tip is to buy a disabled person's railcard rather than a young person's railcard as this will work out cheaper. (<http://www.disabledpersons-railcard.co.uk/>).

Download Epilepsy Society's epilepsy toolkit app to your mobile. That way, wherever you are, you will have up-to-date information about epilepsy at your fingertips, including your seizure diary and details of the meds you are taking. www.epilepsysociety.org.uk/app

Good luck with your degree and enjoy. Find out more about university life at www.epilepsysociety.org.uk/university



Sophie Harries, 19, is studying dietetics at the University of Plymouth. She has idiopathic generalised epilepsy with photosensitivity.

'My first year at university has been amazing. I have made some amazing friends who don't care about my epilepsy and see me for who I am. At college I was known as 'Epi' or 'the girl

with epilepsy' whereas at uni people are genuinely interested and ask me questions.

I'm not going to dress it up though. I was incredibly worried about how living alone in a flat of complete strangers would pan out and during freshers' week I did feel a little isolated as I wasn't able to go out with everyone. However as time went on and people became more knowledgeable, events were arranged taking my epilepsy into consideration.

The support I've received from my lecturers is outstanding. The university's disability assist team make sure everything I possibly need is in place such as extra time in exams, a separate room and they even provide voice recorders for lectures if I need one.

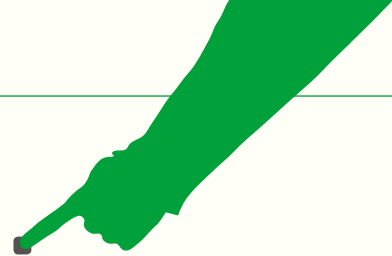
However my shiny star award goes to the maintenance team for my halls. My first room had steps in it which were a big no-no, so they moved me to another room. The main light in this room flickered like mad which was a problem as I also have photosensitive epilepsy. Straight away the maintenance team swapped the light with a brand new LED one. They also replaced the light in my bathroom and in all the communal areas of the flat. I also have a specialist nurse at the local hospital who I meet regularly to make sure everything is ok and to support me which is helpful.

Overall I would say that the 'uni experience' hasn't been affected by my epilepsy greatly as I still go out to pubs with my friends. We do a pub quiz every Tuesday (each time coming very close to winning £200 but never winning!), we have flat meals and just generally have an amazing time. It's not all about drinking and going to clubs, it's about making friends for life and they will accept you for you, epilepsy and all.

I would say don't leave work to the last minute, get ahead and plan assignments and revision. It will pay off. To someone with epilepsy who is worried about going to uni or to someone who doesn't want to go because of their epilepsy, I would say speak to the uni, take a look at the support you can get, speak to your future lecturers and if you feel comfortable then go for it! Don't let your epilepsy hold you back, I'm not! I am on my way to fulfilling my dream of becoming a dietitian, I have my first placement in the summer which I am so excited about I can't even explain!

You can read about Sophie's photosensitivity on page 7 or to read her full university blog go to www.epilepsysociety.org.uk/sophiestory

There's an app for that



Epilepsy Society's digital expert Ben O'Keefe browses a selection of the latest apps which you may find useful for helping to manage your epilepsy and other related issues such as poor memory and stress



Any.do Task List & To-do List Google play

What they say

Any.do is an all-in-one life manager. Save time organizing your family tasks, work projects and personal to do's in one place.

What we say

This app is fairly easy to use. You can set up reminders for your day and have them recurring either daily, weekly, monthly or yearly. You'll need to create an account to sync information across other devices such as your tablet and share with friends and family who also have the app.

What we like

Has voice recognition.
Easy to set up reminders.

What we don't like

'Permissions' required are quite extensive and potentially off putting.



Breathe2Relax App store

What they say

A portable stress management tool to help with mood and anxiety. Practice exercises to learn stress management through diaphragmatic breathing.

What we say

This may certainly help with relaxation. But be careful not to set the inhale/exhale breaths too high (start around 4/5 seconds) or do too many repeats. Slow, deep breathing over long periods can cause dizziness and may induce seizures in some people.

What we like

Simple to follow and can be adapted to your own individual needs.



Simple Log Google play

What they say

Log and track any type of data easily then view as a list, graph or exported as a spreadsheet.

What we say

Easy way to track anything, including seizures. Basic but it does the job well. You don't need to register.

What we like

Easy to use.
Good to have data in a graph.

What we don't like

Doesn't have reminders.



ColorNote Notepad Google play

What they say

A simple notepad, perfect for writing notes, memos and to-do lists.

What we say

One of the more basic apps but with all the features that you would expect including a calendar which flags up the number of notes you have for each day. You can change the text size.

What we like

Easy to set up and use – no registration.

What we don't like

The interface is functional but not especially attractive.



Epilepsy Toolkit Google play and App store

Read about our free epilepsy app on page 10.



MediSafe Meds & Pill Reminder Google play

What they say

An app with a virtual drugs box to help you take your medicine on time and safely.

What we say

A comprehensive app which divides your medication into either morning, noon, evening or night. It also has a handy 'weekly adherence' report which can be exported and shared with your doctor. You can also add 'as needed' medication such as buccal midazolam, so you can keep track of how often it has been used.

What we like

Nice visual representation of a drugs box.
Easy to set up your reminders.

What we don't like

If you take a lot of medication the drugs box can get quite cluttered.



Find a pharmacy App store

What they say

Need to pick up a prescription and not sure where your nearest pharmacy is? This app will find all those in your local area.

What we say

Easy to use, this app will find and list all the pharmacies in your locality giving you exact distances to each. You can get directions and a phone number.

What we like

Wherever you are, you can always find a pharmacy where you can get your epilepsy medication or ask a pharmacist for advice.

✦ *I have recently been diagnosed with epilepsy at the age of 46. It has come totally out of the blue and while I have told my close family about it, I don't know how to tell my friends – especially those who I only see occasionally. I don't really know how to start the conversation and I am concerned that some of them may start treating me differently. I even worry that they won't want to see me any more in case I have a fit. My husband tries to reassure me this won't happen but it's all going round in my head. I wish there was someone else with epilepsy who I could talk to.*
Geraldine, Staffordshire

YOUR REPLIES

➔ I was diagnosed with epilepsy last January at the age of 24. I have been very open about my epilepsy with friends, family, colleagues and actually most people.

There are a few reasons for this. Firstly, while I am suffering from seizures, I wanted people to have an idea of what was happening and how to look after me if I had a seizure in their company. Secondly, I wanted them to try and understand what I have been through and how having epilepsy has affected my life. Thirdly, I wanted to raise awareness and understanding of epilepsy.

To start the conversation you could tell them that you're having to take medication every day now, or that you're currently unable to drive.
Charley, facebook.com/epilepsysociety

➔ My epilepsy came completely out of the blue too. I was 17 and thankfully the majority of people I told reacted well. Many people asked how they should deal with a seizure in case I had one but nobody avoided me because of it. I'm 34 now and just tell new people if/when it comes into conversation. I don't remember any negative reactions.

I'm quite confident regarding my epilepsy – I'm not ashamed of it. I'm quite open about it and I think that helps because people feel free to ask questions, which helps them feel less scared about what might happen if I have a seizure.

I think this is particularly important

at work and when I started my current job I spoke to the whole team about what to do. Epilepsy Society has some great info you can print out – www.epilepsysociety.org.uk/first-aid-seizures
Amanda, facebook.com/epilepsysociety

➔ I would be up front and honest about having epilepsy and if your friends are truly your friends they shouldn't treat you any differently. They should support you no matter what has happened.

I wear hearing aids and I worry when I meet new people that they will treat me differently when they see them. I am still the same person, and you are too.
Stephanie, facebook.com/epilepsysociety

➔ I'm 33 and was diagnosed with epilepsy out of the blue two months ago. Epilepsy is part of who I am now. I gradually and naturally told all my friends as I saw them rather than making a point of it.

Everyone has been cool. Life goes on, we adapt, we embrace change and create new routines. Some things get me down such as the no driving, no being left alone with my kids, no swimming alone...

If anyone sees me having a fit, it will simply enhance their understanding of epilepsy and strengthen the bond of our friendship. Surprising how many people live with epilepsy or know someone who does. I find that reassuring.

Michael, facebook.com/epilepsysociety

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

NEXT ISSUE

I have complex partial seizures and often find myself in unexpected places and feeling quite confused and very tired. I recently found myself wondering around someone's back garden having got off the bus in an area I was not familiar with. On several occasions the police have been called.

I have consequently become quite an anxious person. I have to really force myself to go out on my own, often feeling the safe option is to stay at home.

My wife is very supportive but she cannot be with me all the time. Does anyone else experience similar problems? Do you have any tips for coping.

Neil, Doncaster

WOULD YOU LIKE TO SHARE YOUR THOUGHTS WITH NEIL?

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 either address below:
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Tonic comic



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

Recently I moved out from the big city to the 'Shire. I left behind the bright lights and relentless distractions of metropolitan living after 16 years, and I finally have a garden. I still don't drive, on account of my epilepsy, and this makes me anxious about getting around these gorgeous, leafy, sparsely scattered villages. Or even around this specific village – I still haven't done the four mile round trip to the supermarket, for example, though I'm confident that I will. Eventually. It's a quick run that would take ten minutes in a car, but many more minutes on foot, and then there's heaving the groceries home again afterwards. Perhaps I'll take inspiration from our Scandinavian friends and their Huskies and fashion some kind of harness-and-sledge.

I've arrived at these life changes – cohabitation and commitment – years, almost decades after some of my peers, and I find myself finally quite comfortably on a trajectory that involves pets, children and finger-paintings on the fridge. I don't have any kids yet, however. Like the Ascent of Man, my progress in terms of taking care of another life will likely start with the pitter patter of four paws before thinking about the lifelong commitment of supporting life with two legs.

I grew up with dogs – beautiful black Labradors, so adorable with their deep brown, almost mournful eyes and 'why on earth wouldn't you give me that biscuit' expression.

Our second dog, Holly, was a fellow epileptic and though I only saw her having a seizure once, she and I shared the morning and evening medication ritual. She was prescribed phenobarbital, so whenever I saw my neurologist to talk about my meds, I always said I'd be open to trying most things, but I didn't want to be able to share meds with the dog.

A twist of circumstance in recent years now means that my Mum and also my eight-year-old nephew have both been diagnosed with different kinds of epilepsy, and all three of us take leviteracetam (albeit different doses). I feel less conflicted about potentially lending or borrowing tablets from my human relatives than from my canine ones.

In this issue of *Epilepsy Review* there's a wonderful feature about canine epilepsy and how research into epileptic woofers may translate to benefitting human people with epilepsy. I think it's great – and I wonder

if there's any way we can get scientists to also work on other canine traits that might be transferable to humans. Personally, I'd love some of that unquenchable joy at retrieving a tennis ball, no matter how many times it's thrown. And if there's any reverse process, that we might affect dogs with human traits, I might ask if the scientists wanted to have a go at combatting dog breath...?

It wasn't until about five years ago that I first became aware of seizure alert dogs. My first encounter was at a workshop for teens with epilepsy up in Sheffield. I was one of three invited guests, alongside a neurologist from the Sheffield hospital and a lady from the seizure alert dog training centre. That she brought a puppy with her to the workshop naturally and inevitably meant she was the most popular speaker, leaving me and the neurologist to sip our cold tea at the side of the room while

the teens launched a barrage of questions and clambered over each other to pet the dog.

It was fascinating to hear about the training process, and that the dog is trained to respond to the individual's triggers, which may be undetectable to the human eye/nose/sense.

I don't have any 'aura' before my seizures, so I tend to drop like a stone and take down any furniture etc. with me on my way. I think it would be wonderful to have a trained dog to nudge me to lie down, to minimise damage to myself. (NB – it is crucial that dogs are trained. I've heard that some people with epilepsy say their pet dog 'tells' them that they're about to have a seizure, but as I learned from the lady in Sheffield, the dog's changed behaviour is precisely because it does know, but is acting out of fear and distress. The training is so the dog can learn the client's signals and overcome the anxiety of the oncoming seizure).

My darling Mum is forever suggesting to me whatever she has recently read is helpful for people with epilepsy – valium suppositories, a ketogenic diet, a seizure alert dog. The infrequency of my seizures makes me ineligible for a seizure alert dog – they are rightly for people with severe epilepsy and regular seizures. So I think I'll find my four-legged friend via a more traditional route. Maybe they'll also turn out to have epilepsy – they say pets are like their owners – so we could bond over that. But I won't share their drugs, y'hear!

Dog days

JULIET STEPHENS
LAUGHING ALLOWED



Conference update

So that we can bring you the most up-to-date news about exciting developments in our genetics research, our Epilepsy Society conference will take place in spring 2016.

The conference will be held at the impressive and accessible Central Hall in Westminster, London, just opposite Westminster Abbey. Past speakers at Central Hall have included Winston Churchill, Gandhi and Martin Luther King.

We are looking forward to sharing some ground-breaking news with you and hope that you will be able to join us there. Epilepsy Society's medical director, Professor Ley Sander and our director of clinical genetics, Professor Sanjay Sisodiya will present our exciting new focus on world class research and advances in treatment.

We will also be welcoming other renowned epilepsy experts who will be talking about their work in pushing forward medical and research boundaries to really make a difference to epilepsy treatments. We will also hear about the vital work in improving NHS epilepsy services, from Juliet Ashton, national nurse consultant, epilepsy commissioning.

You don't need to be a member to come along, everyone is welcome, but please contact us to reserve your place in advance. Watch out for more details at www.epilepsysociety.org.uk/conference or call our membership office on 01494 601420.

To attend the conference, we ask for a £25 donation which includes lunch and refreshments.

On set with Emmerdale

Epilepsy Society's Zelma Hutchinson has been on set with the cast of ITV's Emmerdale, advising on the continuing storyline around vicar Ashley Thomas' epilepsy.

Ashley, played by actor John Middleton, (right) was diagnosed with epilepsy in June following a car crash. But as the storyline unfolds, the tv studio was keen to call in the experts to ensure that they were giving an accurate representation of Ashley's seizures and the impact on his life.

Zelma, who is regional team manager at Epilepsy Society, spent the day advising John Middleton on the real-life experiences of people with epilepsy.

'John was really well informed about the condition and had taken



his own research very seriously,' said Zelma. 'He was very keen to hear about the impact of seizures on the lives of people with epilepsy.'

'He said that rehearsing tonic clonic seizures before filming on set was exhausting and gave him an incredible insight into what it can be like to live with seizures.'

The episodes featuring Ashley's epilepsy are due to be broadcast on ITV from 20 August 2015 at 7pm.

RideLondon-Surrey100

A huge congratulations to our 83 cyclists who rode 100 miles in less than nine hours to support people with epilepsy. If you have been inspired by their amazing achievement, why not apply now for your chance to join Team Purple in 2016. We have a number of Golden Bond places available for supporters. These places come with fundraising targets that allow you to run for a cause that is close to your heart and help to fund our vital medical research into epilepsy. Or you could apply for a ballot place (the ballot opens on 10 August 2015) and still ride as part of our team. You can find out more at www.epilepsysociety.org.uk/cycling



Help inform our research

At Epilepsy Society, medical research is key to our work to improve the diagnosis and treatment of epilepsy and, hopefully, one day to find a cure.

Now we are keen to hear what is important to you when it comes to epilepsy research, what you hope we will achieve and how this could make a difference to your life. For example, do you think our research should focus on epilepsy genetics, new drug treatments, brain surgery or the psychological impact of epilepsy?

We would be very grateful if you could take the time to fill in our online survey at www.epilepsysociety.org.uk/researchsurvey which will help us to understand your views and inform our work. If you would prefer a paper copy of the survey, email rona.eade@epilepsysociety.org.uk We look forward to hearing from you.

In memory of Tom



The Scott family lost their son, Tom, to SUDEP (Sudden Unexpected Death in Epilepsy) last year, aged 23. Please support our research team who are working hard to identify the causes of SUDEP so that other families don't have to go through such pain. To find out more or to donate, please visit www.epilepsysociety.org.uk/tom

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