WELL BEING

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FAMILY FOCUS

ADOPTION HAS ALLOWED US TO GIVE A HOME TO TWO WONDERFUL CHILDREN

Kate Jennings page 17
Taking anti-epileptic drugs (AEDs) is often a definitive part of people’s experience of epilepsy. Getting the right dose of the right medication can make all the difference, and can sometimes take years to achieve. But is it about to become even more difficult?

The Government is considering changes across the NHS to substitute branded AEDs with cheaper generic versions. This means that people with epilepsy could end up with a different formulation of their AED, and there is concern that this could affect many people’s seizure control.

If you are taking an AED that is giving you good seizure control it is important to take exactly the same formulation of your AED each time. That’s relatively straightforward with a branded (named) drug. But if you are taking a generic AED make sure your pharmacist gives you precisely the same manufacturer’s version that you usually have. If they don’t stock it, perhaps try another pharmacist.

AEDs are made of the active ingredient and the excipients (the stuff that ‘holds the medication together’). It is the latter that changes with the formulations and makes the difference to the drug’s therapeutic effect. Slow-release medication in particular should never be substituted for non-slow-release versions.

So do, please, take care with your AEDs and look out for the Department of Health consultation on the issue promised for this Autumn (see news story opposite).

On a lighter note, welcome to your redesigned Epilepsy Review, which we want to be the voice for anyone whose life is affected by epilepsy. Throughout the magazine you will find familiar in-depth medical features and news articles, plus we have created some new sections in response to your requests to read about the lives of other people with epilepsy.

We hope you enjoy your new-look Epilepsy Review. Good reading.

Nicola Swanborough
Editor
CHEAPER AEDS COULD INCREASE SEIZURES

The Department of Health intends to introduce cost-cutting plans for anti-epileptic drugs (AEDs) which could affect seizure control for people with epilepsy

From January 2010 pharmacists may be obliged to substitute expensive branded drugs (those with a brand name) with a cheaper generic version. Although essentially the same, there are subtle differences in how different generic forms of a drug are made up and for people with epilepsy those differences could have a serious effect.

Professor John Duncan, medical director of the National Society for Epilepsy (NSE), said: ‘Epilepsy is different from other conditions. A single seizure has severe consequences. It impacts on the ability to drive, employment and well being, and increases the risk of injury and harm.

‘The cost saving on the drug budget is not worth the potential harm caused and the cost of dealing with seizures.’

The Department of Health’s plans are part of the Pharmaceutical Price Regulation Scheme.

NSE’s chief executive Graham Faulkner said: ‘As the UK’s leading medical epilepsy charity our message is clear – anti epileptic drugs must be exempt from the scheme.

‘We are not arguing for branded over generic, or for one generic over another. There is no inherent superiority, and all versions can be usefully taken. It is switching between different versions of the same drug that brings about risks. Consistency of supply is key.’

NSE has submitted to the Department of Health recommendations from a round table discussion with pharmacists and key representatives from the pharmaceutical industry.

The Department of Health has responded saying it is currently refining its proposals and will formally consult in the Autumn.

To read NSE’s report and recommendations go to www.epilepsysociety.org.uk

To register your views on the proposals write to: Mike O’Brien, Minister of State for Health Services, Richmond House, 79 Whitehall, London SW1A 2NS.

It is hoped that new research into light box therapy for people with epilepsy will begin in 2010 to explore the relationship between sunlight and seizures.

Dr Sallie Baxendale, a neuropsychologist at the National Society for Epilepsy (NSE), found that epileptic seizures – particularly complex partial seizures – are less likely to occur on bright sunny days than they are on dull days.

Now she is hoping to build on her research with clinical trials to see how people with difficult to control seizures respond to light box treatment.

Sallie said: ‘Sunlight is important in the body’s production and regulation of melatonin and vitamin D, both of which may influence seizure thresholds.’

SEEING THE LIGHT?

TIM E 2 TAKE YR MEDICINE

Your favourite ringtone could soon be reminding you that it is time to take your medication.

A new text messaging service to alert people with epilepsy they should be taking their drugs is being rolled out by the National Hospital for Neurology and Neurosurgery (NHNN).

Outpatients at the epilepsy service at the NHNN can sign up for the 12-month pilot project looking at whether text reminders could improve the efficiency with which people take medication.

The project is being carried out in partnership with mobile health specialist iPLATO Healthcare and supported by UCB Pharma Ltd and the National Hospital Development Foundation.

If you are an outpatient at NHNN and would like to take part in the project, call Anthony Linklater on 0203 108 0127 or email epilepsy@uclh.nhs.uk

For one hour, on one day, one woman stood on a plinth in Trafalgar Square and made epilepsy count. To find out more, turn to the inside back cover.
RISK FOR UNBORN CHILD

Children exposed during pregnancy to the anti-epileptic drug sodium valproate may show lower IQs as toddlers than those children whose mothers took other epilepsy drugs, say researchers at the University of Liverpool.

The interim study suggests that children exposed to valproate had IQs that were six to nine points lower than average. The preliminary findings follow other British studies which have raised concerns over an increased risk of autism and birth defects in children exposed to the drug during foetal development.

Researchers emphasised, however, that pregnant women taking valproate should not stop their medication without seeking the advice of their GP as the effects of a seizure can also pose a risk for both mother and unborn child.

OF MICE AND MEN

A new study identifying a way in which epilepsy can be caused and prevented in mice may provide clues to potential causes, therapies and preventive measures in human epilepsy.

Scientists at the University of Leeds have pinpointed a genetic defect which they say could be one cause of epilepsy. The findings, published in the journal Proceedings of the National Academy of Science (PNAS), show that a mutation in the key gene ATP1A3 can lead to a severe form of epilepsy in mice.

If the findings can be repeated in human studies, it could open new avenues for the prevention and treatment of inherited epilepsy.

Although the human ATP1A3 gene is more than 99 per cent the same as the mouse version, lead researcher Dr Steve Clapcote stressed the need for caution. ‘Our results are very promising,’ he said, ‘but there’s a long way to go before this research could yield new anti-epileptic therapies.’

Work has already begun screening DNA samples from epilepsy patients to investigate whether the ATP1A3 gene also plays a role in human epilepsy. In both mice and humans the gene has already been identified as being involved in regulating levels of sodium and potassium in the brain. Imbalances in these chemicals have been linked to epilepsy in humans.

The ATP1A3 gene produces an enzyme that regulates sodium and potassium levels in the brain. In a strain of mouse with epilepsy, a defect in the ATP1A3 gene means an inactive version of the enzyme is produced, leading to sodium and potassium imbalances and subsequent seizures.

If the study’s findings translate to humans, researchers say it may be possible to give patients a synthetic version of the sodium/potassium enzyme to help regulate levels of the chemicals in their brain.

THIS IS CERTAINLY AN INTERESTING AND POTENTIALLY IMPORTANT FINDING. OUR RESEARCH SUGGESTS THAT THE GENETIC CONTRIBUTION TO EPILEPSY IS VERY COMPLICATED AND THERE WILL NOT BE ONE STRAIGHTFORWARD SOLUTION BUT MANY DIFFERENT GENETIC PERMUTATIONS.

NSE’s medical director Professor John Duncan
NEW AED LAUNCHED

A new, once-a-day anti-epileptic drug for patients with partial-onset seizures has been approved by the European Commission. Zebinex® is believed to exert an anti-epileptic effect by regulating the activity of sodium channels in the brain. In extensive tests across 23 countries, involving 1000 patients with refractory partial onset seizures, Zebinex® showed a significant reduction in seizure frequency and an improvement in the quality of life for patients.

Eisai Europe obtained the rights for Zebinex® from the international pharmaceutical group Bial and will launch the drug across Europe during 2009 and 2010.

ON TRACK

Keep track of your seizures at www.seizuretracker.com. The site will help you track the frequency and pattern of your seizures and also make a note of your doctor appointments.

OPERATION MRI

The first surgery for epilepsy using an operating table that can go into an MRI scanner has been carried out at the National Hospital of Neurology and Neurosurgery, London.

MRI scans can now be taken during surgery to guide the operation and reduce the risk of damaging critical areas. The ground-breaking surgery programme is the result of a collaboration between the National Society for Epilepsy led by medical director John Duncan, and the NHNN.

SHAPING THE FUTURE TOGETHER

Disability organisations are urging the Government to clarify what proposed reforms to the current care and support system would mean for disabled adults of working age.

While the 2009 Green Paper Shaping the future of care together has been welcomed as a radical step in addressing the crisis in social care, concerns have been raised that the proposed new National Care Service fails to meet the needs of adults with learning disabilities and epilepsy who need life-long care and rarely have any savings.

At the core of the Green Paper is the proposal to introduce a universal minimum care entitlement, so ending the postcode lottery and ensuring that everyone gets some government support. But disability organisations say there is not enough information as to how this will be implemented for disabled adults of working age.

Fears have also been voiced over suggestions to integrate disability benefits – such as the Attendance Allowance and Disability Living Allowance – with care funding, to bring more money into the social care system.

The Voluntary Organisations Disability Group will meet with care services minister Phil Hope, to present its views.

To find out more go to www.careandsupport.direct.gov.uk. To join the Big Care Debate email careandsupport@dh.gsi.gov.uk or write to Care and Support Team, Room 149, Richmond House, 79 Whitehall, London SW1A 2NS.

EDITOR’S CHOICE

READ ALL ABOUT IT
Max Clifford and Angela Levin

It is a little known fact that Max Clifford, the brash media mogul, had epilepsy. Here we see another side to him as he talks about the ‘funny turns’ he had in the 1980s and how he now speaks openly about his epilepsy in order to break down the stigma – one of the very few celebrities willing to share their experiences of the condition and a tireless campaigner for charitable causes.

THE MUSIC ROOM
William Fiennes

Richard Fiennes developed epilepsy at the age of two and a half. Here, his brother William, 11 years his junior, writes a moving tribute to his much loved brother who died a few years ago at the age of 41. In a gentle and touching way, The Music Room explores severe epilepsy and its impact on the family, weaving detailed brain research with the emotional journey of two devoted siblings.

EPILEPSY – THE ESSENTIAL GUIDE
Louise Bolotin

Aimed at people with epilepsy, their friends and family, this guide covers a wide range of subjects from first aid, benefits and employment, to hormones, pregnancy and issues that affect children and teenagers. There are also sections on surgery, travelling abroad with medication, managing anxiety and improving sleeping patterns. An easy and useful read, very thorough, and good at getting straight to the point.

▶ Buy the books at Amazon via www.epilepsy society.org.uk/Donate/Morewaystogive and five per cent of the total sale will go to NSE.
THE PROFESSIONAL  At 37, rugby legend Tom Smith – prop forward for Northampton, former Scotland captain and one of the cornerstones of the British and Irish Lions pack – has bowed gracefully out of the game.

With the same quiet modesty and a fortitude that earned him worldwide respect and an impressive string of victories on the field, Tom has decided to hang up his boots and draw a line under a stellar career which very nearly didn’t happen.

At the age of 18, Tom was diagnosed with epilepsy. ‘The seizures started totally out of the blue,’ he explains. ‘There was no warning, no trigger. I had not suffered any head injury in spite of the amount of rugby I played. It literally happened over night – nocturnal seizures. At the time it was quite distressing.’

Tom’s consultant was not impressed with his passion for rugby, a game renowned for its harsh and unforgiving environment, not to mention its trademark scrums, tackles and blood-gushing wounds. ‘My consultant’s immediate reaction was to tell me to forget rugby.

That was quite devastating. At 18 my big dream was to play rugby professionally and to be told that everything I had aspired to should be forgotten was a big blow. ‘Fortunately we sought a second opinion from another consultant who said there was no reason why I shouldn’t continue playing and that was the advice I took.’

I HAVE BEEN LUCKY TO BE JUDGED ON MY ABILITY TO PLAY RUGBY AND TO HAVE WORKED WITH COACHES WHO DO NOT HAVE PREJUDICES

Tom is keen to encourage youngsters with epilepsy who aspire to a professional career in sport or who simply enjoy sport for fun. ‘Epilepsy does not have to be a barrier to achievement,’ he says. ‘You have to see it as a hurdle you just need to get over. People are not always terribly knowledgeable about epilepsy and there are bound to be times that you will come up against a degree of negativity but you just have to deal with it. ‘I have not let my epilepsy hold me back. I have been lucky to be judged on my ability to play rugby and to have worked with coaches who do not have prejudices about the condition. The players have been great too. They don’t care about the epilepsy – they just judge me as their prop.’

Since his diagnosis, Tom has been on regular medication although he recalls times that his seizures have marked his game. ‘During one nocturnal seizure I fell out of bed and broke my toe,’ he recalls. ‘That was a bit difficult with a high impact game.

‘Then four or five years ago I started having daytime seizures which caused short-term memory loss and pretty nasty headaches. I played a Calcutta match against England after having a seizure on the day of the game, and that was definitely not the best afternoon I have had, nor was it the best game I have ever played.’

Tom has had three one-year driving bans due to seizures which
THE AMATEUR Gillian McCluskey believes her trips to the gym three times a week help to combat the stress that can trigger her seizures.

‘I have had regular seizures since the age of three but have always been determined not to let epilepsy interfere with my life,’ she says. ‘I think that fitness has a very positive effect on the condition. It takes my mind off things if I am feeling groggy, it helps me keep my stress levels down and it helps me to keep to an ideal size.

‘When you exercise, your body naturally produces more endorphins which make you feel better.’

Gillian, 45, is able to exercise safely at her local gym at Dorking Leisure Centre, thanks to her seizure-alert dog, Harvey, who is trained to detect electrical changes in her brain and changes in body odour that alert him to an imminent seizure.

‘Harvey will start to shiver and whimper to let me know that I am likely to have a seizure,’ says Gillian. ‘He then leads me to a mat where I can sit quietly until the seizure comes. They tend to be quite violent, so Harvey lies along my torso with his paws either side of my head to stop me rocking and hurting myself.’

\[Image -2x402 to 194x755\]

THE EXPERT Tony Linklater, Epilepsy Specialist Nurse at the National Hospital of Neurology and Neurosurgery, says:

‘Exercise makes us all feel fitter and better regardless of whether you have epilepsy. Keeping fit can reduce our vulnerability to common illnesses and help reduce our risk of strokes and heart disease.

‘If you have epilepsy, it is important to do a risk assessment before participating in any sport. Ask yourself what is the worst thing that could happen while you are cycling, riding, swimming and so on. The worst-case scenario if you have a seizure when you are swimming is that you could drown, so only swim in a pool where there is supervision.

‘Bear in mind, too, that there are activities such as scuba diving which are not suitable if you have epilepsy.

‘Team sports should be encouraged as they can help reduce the sense of isolation that often goes hand in hand with epilepsy.’

For more information about epilepsy and sport go to www.epilepsysociety.org.uk
A QUESTION OF COMPENSATION

Taxi drivers have long been renowned for their encyclopaedic mind maps, otherwise known as ‘the knowledge’. Without so much as a sideways glance at an A to Z, they can get you from Buckingham Palace to Bishopsgate, from Marble Arch to Monument, all while discussing politics, the World Cup and anything but the directions.

Their secret lies not in the triumph of satellite navigation but in the capacity of the right side of their brains. A recent study showed that taxi drivers have highly developed right temporal lobes, the part of the brain which is crucial for visual memory such as faces, places and routes. Rather than memorising a map by street names, taxi drivers visualise the directions in pictures: Buckingham Palace, Marble Arch, Trafalgar Square, St Paul’s Cathedral...

When it comes to memory and language, the left and right sides of the brain perform different functions. Memory is the brain’s ability to record information and then later retrieve it. While the right temporal lobe largely deals with visual memory as in the case of the taxi drivers, the left temporal lobe is particularly important for verbal memory such as learning people’s names and remembering information for exams.

WE CAN IDENTIFY THE PARTS OF THE BRAIN USED FOR LANGUAGE AND MEMORY AND SO PREDICT THE LIKELY IMPACT OF SURGERY ON THESE SKILLS

Language is important on many different levels from communication and speech to understanding and thought. Most people use the left temporal lobe and frontal lobe for these skills.

Important new findings show that when there is damage to one side of the brain, as in the case of left temporal lobe epilepsy (TLE), the right side of the brain can begin to compensate for disruption to the left, with language and memory migrating to the right side.

With magnetic resonance imaging (MRI), we can see that connections to and from the Broca’s area – crucial to language processing – are weaker in people with left TLE and that there is an increase in connections on the right side of the brain compensating for damage to the left.

The significance of these findings is far reaching. Memory decline is a frequent concern for people with epilepsy and is the most frequently observed complaint in people following surgery for epilepsy.

Through functional MRI which highlights the areas of the brain activated during certain tasks, we can identify the parts of the brain which are used for language and memory and so predict the impact that surgery is likely to have on these skills. For example, the more you use the left temporal lobe to remember things, the bigger hit your memory is likely to have after surgery to this area. In the same way, the more you use the right temporal lobe, the greater the decline in visual memory will be if it is removed.

However, if language and memory skills have already begun to migrate from the left to the right side of the brain to compensate for left temporal lobe epilepsy, the chances of brain surgery having a bad effect are considerably reduced.

Sophisticated imaging that reveals our ability to transfer key functions from the left side of the brain to the right, is proving vital in assessing a patient’s suitability for surgery, writes Professor John Duncan.
There is very tentative evidence to show that if a function migrates on the same side of the brain, there is likely to be an even better outcome in terms of memory.

Memory for both words and faces is of great importance as are language skills.

Surgery leads to seizure freedom in up to 70 per cent of patients with medically refractory TLE, but language and memory skills may decline significantly in 30 per cent of individuals. Functional MRI enables us to make more sophisticated predictions and give useful advice on the effect that surgery is likely to have in both these areas as well as on stopping seizures. This then helps a patient make an informed decision about whether to undergo surgery.

We know that reorganisation of the brain is better earlier in life: the younger you are the easier it is for language to migrate from the left to the right side of the brain. The more mature you are, the harder it becomes. However, although there used to be an upper age limit of 40 for brain surgery, age is no longer a barrier with a patient’s suitability being based on their biological age - if you are in good shape, there is no reason not to consider surgery.

We are just beginning to explore the benefits of memory training on memory function, including the use of external aids such as diaries, post-its and lists, and using techniques such as encoding strategies to make new memories more memorable. We are also in the early stages of looking at ways to encourage reorganisation of the brain functions prior to surgery, so as to reduce the impact on memory and language.

Memory for both words and faces is of great importance as are language skills. The more we can do to predict for every patient the effect that surgery is likely to have on these skills, the easier it will be for the patient to decide whether to elect to undergo brain surgery.

Professor John Duncan is medical director of the National Society for Epilepsy, Professor of Neurology at UCL Institute of Neurology and consultant neurologist at the National Hospital of Neurology and Neurosurgery.

NSE/UCL are the first researchers globally to put prediction of language and memory difficulties after surgery into clinical practice for people with TLE. These findings were presented at the 100th Anniversary conference of ILAE - the International League Against Epilepsy - in Budapest.
ARE YOUR ANTI-EPILEPTIC DRUGS WORKING FOR YOU?

Are you achieving the maximum benefits and minimum side effects from your prescription? Nicola Swanborough discusses therapeutic drug monitoring with Professor Philip Patsalos

We all handle drugs differently according to age, gender, metabolic capacity, weight and fitness. The dose needed by a child will be significantly different to that of an adult. Pregnancy, the interaction of drugs - both AEDs and non-AEDs - renal and hepatic disease, strokes, burns and cardiac failure, can all alter the way in which a drug distributes in the body.

Even switching from a branded to a generic drug, or from an immediate-release formulation to a sustained-release formulation can alter the way the drug is distributed in the blood (see p2).

So how can you tell that your anti-epileptic drugs (AEDs) are delivering the optimum effect for you as an individual? Is a repeat prescription enough to guarantee that your drug level (concentrations) will be the same now as when you agreed your dose with your doctor?

The answer lies in therapeutic drug monitoring (TDM), the clinical analysis of drug levels that allows a person’s AED therapy to be individualised to their own therapeutic range.

By measuring serum/plasma drug levels from a blood sample, TDM can be used to adjust the patient’s individual dosage and schedule to their own therapeutic requirement. In this way, drug efficacy is maximised and side effects minimised.

Professor Philip Patsalos is the Consultant Clinical Pharmacologist at the UK’s largest AED TDM unit based at the National Society for Epilepsy in Buckinghamshire. With referrals from across the UK and Europe, the role of the unit is to analyse the full range of 19 AEDs licensed in this country, including the most recently licensed lacosamide. Clinicians use highly developed interpretive skills to assess how the drugs are working in the body.

‘There are many situations in which TDM is appropriate and desirable,’ explains Philip Patsalos. ‘The gold standard is to establish an individual therapeutic concentration whereby a person has either no seizures or minimal seizures. This can then be used to assess potential causes of any future changes in response to a drug, such as a decrease in seizure control or increase in adverse affects.’

TDM is also applicable in the case of uncontrolled seizures and suspected toxicity. It can be used where potential changes in distribution of the drug are anticipated such as during pregnancy, polytherapy with other AEDs or when AEDs are taken with further drugs to treat different conditions.

Philip continues: ‘Special risk groups where TDM is particularly relevant include children and the elderly. Children may not be able to metabolise some drugs until they are two years old. In the elderly the metabolic capacity declines, so the dosage required is smaller than that for an adult. Missed doses, under dosing or catch-up doses can all bring about significant changes in drug levels.

‘TDM allows us to look at drug levels in conjunction with knowledge of the patient, the seizure type and the drug, and then develop an individualised AED therapy for the patient.’

The service can be accessed by referral from a GP, neurologist or other healthcare professional.

For more information:
PROFESSOR PHILIP PATSALOS
Therapeutic Drug Monitoring Unit (NSE TDM)
The Chalfont Centre for Epilepsy
Chalfont St Peter, Chesham Lane
Buckinghamshire, SL9 0RJ, UK
Email NSE_TDM@epilepsysociety.org.uk
Planning and preparation are the cornerstones of every successful holiday, and even more so when epilepsy is part of the equation. Travelling with epilepsy is not necessarily a problem but it is a consideration, undoubtedly posing its own set of questions.

Our four-page supplement looks at ways in which you can manage your epilepsy well in advance of booking your ticket. While we can’t guarantee perfect weather, we can help you stay safe and enjoy yourself.

Bon voyage!

AM I FIT TO TRAVEL?
If you are in any doubt then arrange to chat to your GP about your health before booking your holiday or before your departure. It may be helpful to take a doctor’s letter with you itemising details of your current medications, just in case you are taken ill while you are away. This is also very useful for when taking medicines through customs.

IS IT SAFE TO FLY?
Having epilepsy does not usually prevent people from travelling by air, but if your seizures are triggered by extreme tiredness (such as jet lag), dehydration, excitement or anxiety, it may be advisable to inform the airline or the person you are travelling with.

Before you go, check with the airline company about access to medical services. For example, at British Airways, all cabin crew are trained in advanced first aid which includes how to cope if a passenger experiences a seizure on board. Ground and cabin crew have access to 24-hour medical assistance, enabling them to access a health care professional for advice at any time of the day or night.

A spokesperson for British Airways explained: ‘The only advice we give for epilepsy is not to travel within 24 hours of a major seizure. If a customer has special seating requirements relating to their condition, this should be discussed at the time of reservation.’
**How Can I Reduce the Stress Levels of Flying?**

If your seizures are triggered by stress, then it is important to minimise stress levels. Flying can be particularly stressful as it generally involves a long journey to the airport, curtailed sleep and the need to walk long distances in the terminal building. If you have access to a computer, checking in online can limit the time you have to queue at the terminal. Also, arriving at the airport in plenty of time can help keep stress to a minimum.

**What Can I Do About Jet Lag?**

Jet lag cannot be prevented but there are ways to reduce its effects. The World Health Organisation has some simple suggestions:

- Be as rested as possible before departure and rest during the flight, taking short naps whenever possible.
- Eat light meals and limit consumption of alcohol. Keep your caffeine intake to a normal level.
- When reaching your destination, try to get your usual amount of sleep every 24 hours. A minimum block of four hours sleep during the local night – known as the ‘anchor night’ – is thought to be necessary to allow the body’s internal clock to adapt to the new time zone. If possible, try to make up total sleep time with short naps during the day.
- Exposure to daylight at your destination will help to reset your body clock.

**What About My Medication?**

It is vital that you take an adequate supply of medication with you on holiday, plus a few extra doses in case of delays. Medical facilities when you are travelling or at your destination may be poor or different to those at home. Familiar medications may not be available and trade names may be different.

When you are flying, it is important that you keep your complete supply of medication in your hand luggage or even in a personalised medical kit bag. Medicines should be kept in their original containers and liquids should not exceed 100ml. It is wise to carry a copy of your prescription with you to prove that they are prescription drugs. To carry larger quantities of liquid you must obtain permission from the airline and a medical professional.

If you are planning a trip of more than three months, your GP may not be able to prescribe you medication for this length of time. To arrange to have medication sent out to you from the UK while you are travelling, email John Bell and Croyden at jbc@johnbellcroyden.co.uk or call 020 7935 5555. Always carry a spare prescription in case your medication is lost or stolen. This will also be useful for proving your legitimate need for the drugs in countries where legalisation differs from the UK.

**What Happens If I Am Crossing Time Zones?**

It is important to continue to take your anti-epileptic drugs at the prescribed intervals. Some people wear two watches, keeping one at British time so that they know exactly when to take their AEDs. However, some slight adjustment may be necessary if you end up needing to take your medication in the middle of the night. Any changes will depend on how far you are travelling, how many
time zones you pass through and how long you are away. Ask your GP for help in planning any adjustments.

**WHAT ABOUT INSURANCE?**
Travel insurance is vital no matter which countries you are visiting. Be certain to provide your insurance company with as much information as possible about the type, frequency and severity of your seizures. This will affect the premium on your policy, but it will also give you peace of mind that you will be covered if necessary. If your insurance is part of a holiday package booked through a travel agent, check the package thoroughly to know exactly what you are covered for. Be aware that some companies keep ongoing conditions as an exclusion.

**CAN I USE MY EHIC CARD?**
Yes. The European Health Insurance Card replaces the old E111 and entitles UK residents to free or reduced cost emergency medical treatment in other European countries plus Iceland, Lichtenstein, Norway and Switzerland. The EHIC is free and can be obtained at www.ehic.org.uk or through your local post office.

**SHOULD I WORRY ABOUT VACCINATIONS AND ANTI-MALARIAL MEDICATION?**
Recommended travel vaccinations depend on which country you are visiting, the time of year you are travelling and your own medical history. Most types of vaccine will not affect epilepsy, seizure control or anti-epileptic drugs, however some problems can occur when taking anti-malarial and anti-epileptic drugs together. You may like to discuss the best options with your GP.

The Hospital for Tropical Diseases recommends the following anti-malarial treatments: proguanil (Paludrine); Malarone; and doxycycline (Vibramycin). The anti-malarial medications chloroquine and mefloquine (Larium) can cause seizures in some people, however, and should be avoided.

Anti-malarial medications are not always 100 per cent effective and it is important to take measures to avoid being bitten:
- Wear long-sleeved clothing and trousers when outdoors after sunset. Light colours are less attractive to mosquitoes.
- Use insect repellents.
- Whenever possible sleep in screened rooms, using a fly-spray to kill any mosquitoes.

Electric vapourisers should be used throughout the night.
- If your room is not air conditioned, permethrin-impregnated mosquito nets provide the best protection.

**WHAT HAPPENS IF I HAVE A SEIZURE IN A COUNTRY WHERE I DO NOT SPEAK THE LANGUAGE?**
There are a number of emergency identification systems which enable you to carry your medical details on you at all times.

FAYE CHAMBERS was very glad of her Medicalert wrist band when she was caught out by a freak cyclone while in Fiji. ‘The drastic weather conditions combining heat and rain rendered all my AEDs unfit,’ recalled Faye. ‘Their outershells expanded and split. It was at the end of three and a half months of travelling and although I had taken almost double the amount of medication I needed, everything was ruined.

‘Luckily I made it safely home but I did start experiencing auras and had a nasty black out. It was good to know that if anything happened someone could access my medical details through Medicalert.’

www.medicalert.org.uk

Organisations such as MedicAlert can supply a necklet or bracelet engraved with a person’s medical information, personal identification number and a 24-hour emergency contact. The service is available from over 100 countries, 365 days a year.

Particularly useful for travelling abroad are the medical translation services which help you to communicate your medical condition in different languages. YellowCross will supply a credit-card sized card about epilepsy in seven
languages (English, Spanish, Portuguese, Italian, French, Greek and German), together with a help card should you need to call an ambulance. www.yellowcross.co.uk

There is also a new service, Doctor Babel, which will create an online personal medical record for you in many different languages. To find out more go to www.doctorbabel.com

**WHAT ABOUT DRIVING ABROAD?**
The rules for driving with epilepsy vary from country to country. However if you hold a UK driving licence, the DVLA regulations about epilepsy still apply to you when driving abroad, rather than the regulations of the country you are visiting. For further information go to www.dvla.gov.uk. For travel information for different countries visit the Foreign & Commonwealth Office at www.fco.gov.uk

**WHAT ABOUT SPORT AND ENTERTAINMENT ON HOLIDAY?**
The same advice and restrictions apply to sport on holiday as at other times.

- **Cycling and horse riding:** helmets should always be worn.
- **Swimming:** it is safer to swim in a pool rather than in a river or the sea where there will be currents and tides. It may be harder for someone to rescue you if you have a seizure in open water. If you are at a swimming pool, tell the lifeguard you may need help if you have a seizure.
- **Scuba diving:** not recommended for people who have seizures. The British Sub-Aqua Club asks that people are free of seizures for five years (three years with nocturnal seizures).
- **Sailing:** always wear a life jacket and only sail under supervision.
- **Bungee jumping, unsupervised potholing and mountain climbing:** not recommended for people with seizures. Find out more at www.bsac.com

**WHAT SORT OF ACCOMMODATION SHOULD I BE LOOKING FOR?**
If you have frequent seizures, you may prefer ground level accommodation that is a safe distance from any easily accessible swimming pools. It may be worth asking to see a plan of your hotel or villa.

If you are not driving, try to book accommodation that is close to the local public transport system.

**MY CHILD HAS EPILEPSY. SHOULD I LET THE CHILDREN’S CLUB AT OUR HOLIDAY CENTRE KNOW?**
Yes. It is always wise to discreetly inform staff of your child’s condition so they can be prepared should they have a seizure. It is also a good opportunity to discuss with club organisers whether their staff are trained to cope with epilepsy. At Center Parcs, for example, all nurses are fully qualified to deal with seizures and work in liaison with the Time Out Clubs where staff are trained in paediatric first aid.

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September 2009
www.epilepsy-society.org.uk

Epilepsy Helpline
01494 601 400

Monday – Friday 10am-4pm
National call rate

HARRY MEAD

AGE 18 GAP YEAR STUDENT VISITING South Africa, Canada, New Zealand and Mexico

Harry’s seizures are completely controlled but he has been keen to factor his epilepsy into his 12-month trip from the word go.

‘The first thing I did was to visit The Travel Doctor (www.traveldoctor.co.uk), an interactive website that provides specialist health information for travellers plus customised lists of medication,’ says Harry.

‘They were great for telling me what jabs I need in each country, whether there will be any conflict with my medicine and for advising on which anti-malaria medicine I should take. I also consulted my GP.’

‘I shall carry all medication in my hand luggage and will take more with me than required.’

In Canada Harry will be training to be a ski instructor with Ski le Gap.

‘The company is fully informed about my epilepsy. It’s compulsory for all ski instructors to wear a helmet and Ski le Gap has a medical bank account which you can contribute to so as to cover yourself for any medical needs.

‘The friends I am travelling with are all aware of my epilepsy and what to do if I have a seizure,’ he explains. ‘I also wear a Medicalert tag so that my medical records can be quickly accessed if necessary.’

Stress can be a trigger for Harry so he runs every day which he says helps to combat stress and reduce the risk of seizures.
Living with epilepsy can be struggle enough. For some people it is only part of profound health problems that bring substantial challenges to everyday life, writes editor in chief Jenny Rush.

For many people living with epilepsy it is a stand-alone condition. Perhaps they developed it in childhood. Perhaps it kicked in as a teenager. Perhaps a head injury started it all off.

But for some people living with disability, epilepsy is one more thing to contend with in a life of multiple challenges. Any disabling condition that affects the brain is likely to also bring epilepsy with it.

One in 131 people will experience epilepsy. But the incidence increases considerably for those with complex medical conditions. And they are also more likely to be contending with frequent and severe seizures that are hard to control.

Childhood syndromes often bring severe epilepsy with them, as do learning disabilities, cerebral palsy and many forms of physical disability.

Thirty per cent of people (almost one in three) who have a mild to moderate learning disability will also have epilepsy. The more severe the disability, the more likely it will be that the person will experience the condition. Fifty per cent of those with profound learning disabilities also have epilepsy.

For many people with complex epilepsy and related health problems whose seizures are severe and difficult to control, residential care often offers the best chance of an independent life with round-the-clock support providing specialist medical and nursing back-up when needed.

Queen Elizabeth House is one of the specialist residential care homes at the National Society for Epilepsy’s (NSE) Chalfont Centre in Buckinghamshire which cares for people with extensive medical and care needs, profound multiple learning disabilities, or needs that have arisen from head injuries, accidents, strokes or other neurological conditions.

The ethos at Queen Elizabeth House, set in the heart of the green and rolling Chiltern Hills, is based on individualised care plans involving the person and those who are important to them. A high ratio of staff to residents means that individuals can be fully supported in their particular needs and interests.

QEH manager Andrew Ferguson, said: ‘Our ethos is very much to empower our residents in the life they would like to lead. We aim to help them achieve their highest potential and maximise their quality of life.’

All residents have access to a full inter-disciplinary team including neurologists with a specific interest in epilepsy, neuro-psychologists, psychiatrists and specialist nurses.

Residents also have regular contact with speech and language therapists and are encouraged to take part in art and music as well as using a sensory unit and therapy gym.

Accommodation is provided in two light and airy single-storey apartments, each with six spacious bedrooms with en suite facilities and on-hand nursing. Andrew continues: ‘We try to create a home from home while at the same time providing 24-hour care, with expert nursing and social care.’

For more information log on to www.epilepsysociety.org.uk or call 01494 601 374.
Looking at Kate Jennings as she reads a favourite story to her two children Charlotte and Tom, one would never guess at their different and sometimes difficult journey to become a happy family.

Kate, not her real name – all names have been changed – has lived with epilepsy all her life. She had her first tonic clonic seizure aged five, although her mother believes that even as a toddler she was having absences.

‘My Dad had epilepsy, so Mum was well aware of the signs and knew there was also the chance that I could inherit a low seizure threshold resulting in my developing epilepsy,’ said Kate.

‘I was diagnosed at seven, but as most of my seizures happened when I was asleep, I was never really aware and not really worried.’

However, when Kate reached puberty, hormonal changes seemed to make things worse and she needed medication to try to control the seizures which were becoming more frequent.

She explained: ‘My teenage years were unsettled. Medication worked for a while and then it didn’t. By the time I was 17 my epilepsy had become very challenging and I noticed that my memory was badly affected. It was a horrible time, a family member died and stress made my epilepsy even harder to control.’

Kate felt her epilepsy was taking over. She said: ‘There were so many things I wanted to do and couldn’t. Driving was out of the question, I have a good brain and wanted to teach. However, my poor memory meant I’d not got the A levels needed, so I could not apply for a teaching degree. What’s more I was not allowed to train to teach while still having seizures. My life was so frustrating. I couldn’t be like my friends and drink alcohol, I couldn’t even lock the bathroom door!

‘I remember thinking about the future and children, but my life felt totally out of control and any thought I had about being a mother seemed completely unachievable.’

‘I NEVER WANTED TO GO BACK TO FEELING SO POWERLESS AND UNCONTROLLED AGAIN’

However, Kate never gave up on her dreams and one by one she has realised both professional and personal goals which she once feared would be beyond her grasp.

To begin with Kate refused to take a stress-free job to try and regain control of her seizures. It was a hard time but Kate’s great passion for music – she plays the piano, flute and saxophone – helped her to...
cope with life. Kate's music teacher believed in her potential and gave her the inspiration, courage and confidence to keep aiming for the things she wanted to achieve.

Although Kate was still having seizures, she taught herself techniques to help remember things, got a place at university and got her degree.

'I learnt to accept that epilepsy was a part of me and part of my life,' said Kate. 'I was also given a different drug which stabilised my seizures.'

Once Kate became seizure free she was able to complete her post graduate degree in teaching and finally learn to drive.

Then came new challenges. When Kate met and married Paul, both of them knew they wanted children, but there was a problem. Kate's new anti-epileptic drug was controlling her seizures, but it was relatively unknown as to whether it would be advisable for her to keep taking it during pregnancy.

Kate continued: ‘Paul and I talked things through with my consultant, but for me there were too many ifs and buts. I knew I never wanted to go back to feeling so powerless and uncontrolled again.

‘Paul and I agreed the most important thing was to be the best parents we could be. I knew that if I was to achieve this I had to stay on my drugs and keep as healthy as I could. The only way for us to have a family was to adopt and, as neither of us had any issues with this, it was the way we chose to go.’

A few years ago their parenting dream became a reality and they were able to throw open their arms and home to a brother and sister who had not had the best start in life and desperately needed both stability and love.

ADOPTION HAS ALLOWED US TO GIVE A HOME TO TWO WONDERFUL CHILDREN

Kate said: ‘Now we are just a normal, happy, loving family with all the usual ups and downs and I wouldn’t want it any other way!’

Seizure free now for 11 years, Kate says she’s still cautious, but tries to keep herself on track by taking her medication, exercising, managing stress and getting enough sleep.

Kate knows she and Paul made the right decision for them, but she points out that everyone is different and just because adoption worked for her family – it may not be right for everyone.

‘Adoption has allowed us to give love and a home to two wonderful children and experience all the pleasures being a parent brings,’ said Kate.
Real listening can make all the difference to our partners, families and friends. But do we really know how to listen or how to ensure we are heard? Expert listener Chris Brock, head of NSE’s Epilepsy Helpline, explains.
ARE YOU LISTENING?

Listening isn’t always as simple as it seems. Our own fears can get in the way. How is the listener going to deal with whatever is said? Could it upset them or you? Will you get it wrong and make things worse? Is someone really offering to listen, or just being kind?

Achieving the balance between listening, hearing and responding is a skill. Simply being genuinely interested, relaxed and trying to understand the person’s meaning can help them feel safe and heard.

Giving all your attention to someone is a powerful experience. When someone feels listened to, it enables them to think, to express what it is that is worrying them, to offload thoughts and emotions, or start to unravel complicated situations. Listening helps them find answers that are right for them and to solve their own problems.

Blocked emotions stop people thinking clearly, so allowing someone to express painful emotions can free up their thinking and give them the ability to find solutions they couldn’t think of before.

Our thought speed is faster than our speech speed, so we can be tempted to finish someone’s sentence for them or to fill in the spaces with our own words rather than listening to what the other person has to say. We may think that we know better than them and give advice about what we would do in their situation. This can be very undermining.

‘SILENT’ IS AN ANAGRAM OF ‘LISTEN’

One key aspect to listening is believing in the other person - knowing and trusting that they are capable of making decisions for themselves about their own situation. You are there to offer them time and space for reflection and to share often difficult thoughts. It is not our responsibility to own their problems, imply that they can’t cope and to rob them of the chance to find the best solutions for themselves. So the key is to be quiet and just listen.

HOW TO LISTEN

- Remove all distractions. Give the person your full attention. Turn off the tv and mobile phone. Stop talking! It is impossible to listen and talk at the same time.
- Being relaxed yourself will help the other person relax as well.
- Show the person that you want to hear what they say.
- When listening try to get an understanding of the bigger picture.
- Show you understand what they are saying by stating back to them what you have heard using the same language that they have used.
- Be patient, leave lots of spaces for the person to have ‘thinking’ space.
- When emotions are being expressed try to stay calm. The emotions are theirs not yours, but be aware of how they are affecting you.
- Ask occasional questions encouraging them to say more, or ask them to explain if something is unclear.
- Respect their confidence. If you are not sure what is ok to talk about afterwards, ask them when they have finished. Honour their trust in you!

THANK YOU FOR LETTING ME TALK, NOBODY SEEMS TO HAVE THE TIME TO LISTEN

The National Society for Epilepsy’s confidential helpline offers:
- a completely confidential service
- the chance to ask questions
- emotional support
- up-to-date information
- and time to talk (translation service available)

The helpline was awarded the Quality Assurance mark from the Telephone Helpline Association in October 2008.

**NSE Epilepsy Helpline** - information...time to talk...emotional support...translation

01494 601 400
Monday - Friday 10am-4pm (national call rate)
The new Employment and Support Allowance is designed to help people with a disability or health condition such as epilepsy move into suitable work. But finding your way around the new benefit can be confusing and time consuming. Alan White, welfare benefits adviser, answers some of your most frequently asked questions.

**WHAT IS EMPLOYMENT AND SUPPORT ALLOWANCE (ESA)?**
ESA is a new way of helping people with a disability or health condition to move into work, if they are able. Introduced in October 2008, it replaces Income Benefit and Income Support paid on incapacity grounds for new claimants.

**HOW DOES IT DIFFER FROM OTHER BENEFITS?**
ESA offers personalised support and financial help to people who are not working due to a health condition or disability. Central to the allowance is a new medical assessment which examines what the person can do rather than what they can’t do.

**WHAT ABOUT PEOPLE WHO ARE ALREADY CLAIMING INCAPACITY BENEFITS?**
For the time being they will continue to receive their current benefits although, in the long term, everyone will move on to ESA. You should receive plenty of warning before any changes are made to your benefits and you should not see a reduction in the amount you are paid.

**IS ESA DEPENDENT ON NATIONAL INSURANCE CONTRIBUTIONS OR IS IT MEANS TESTED?**
There are two elements to ESA: contributory ESA which, like Incapacity Benefit, is linked to the person’s National Insurance contribution records; and income-related ESA which, like Income Support, is means tested.

Entitlement to contribution-based ESA will be considered for all applications and may be granted if the person has paid enough National Insurance contributions.

An applicant may get income-related ESA if the money they have coming in – including their ESA – is less than the amount that applies to their circumstances; and if their capital, including savings and investments, is less than £16,000.

A person may also receive income-related ESA if they require additional financial support as a result of housing costs or disability or caring responsibilities, for example.

**HOW DO I APPLY FOR ESA?**
Call 0800 055 6688 or textphone 0800 023 4888. You can also claim online at www.jobcentreplus.gov.uk. The ESA assessment phase lasts 13 weeks. During this period you will receive a basic rate payment of £64.30 a week for a single person aged 25 or over; £50.95 a week if you are under 25; or where income-related ESA is payable, £100.95 for a couple.

**WHAT DOES THE ASSESSMENT PHASE INVOLVE?**
The assessment takes the form of a Work Capability Assessment carried out by healthcare professionals, but not your own GP.

The assessment will determine whether you are entitled to receive ESA and whether you qualify for membership of the Support Group or Work-related Activity Group.

People in the Work-related Activity Group will also receive up to £89.80 per week. Those whose health conditions mean it would be unreasonable to expect them to work will, in addition, receive up to £95.15 a week.

**WHERE CAN I GET MORE INFORMATION?**
Visit www.dwp.gov.uk/esa

Alan White is welfare benefits adviser at Buckinghamshire County Council.
My husband has always been a very outgoing, happy person but was recently diagnosed with epilepsy. He finds it very difficult to talk about it and has increasingly retreated into his own little world. I know he feels there is some stigma attached to the condition. I really want to help him but feel I can now hardly recognise the person he has become. He has lost all interest in life but when I try to talk to him about things, he just asks me to leave him alone. He is taking anti-epileptic drugs.

ERIN, Nottinghamshire

YOUR REPLIES

I’m my husband’s support person, and we began dating a few years after his first seizure. He was also in denial, fairly withdrawn, angry yet also afraid to do much for fear of his tonic clonic seizures. Men dislike being sick or showing weakness in general so I think they have a harder time getting to grips with something that requires them to accept help, whether it is medication or reliance on people to care for them.

My approach was to not focus on his health issues while we were together. I did research for him when necessary and made it very clear that I knew what to do in an emergency (I was a hurricane of research on my own!!). Otherwise I didn’t ask him to talk about his epilepsy and just let him be when he sunk into a mood.

I didn’t leave him alone physically, I simply didn’t push him to talk about anything at all. Silent support and going about life as if everything was completely normal were the key for my husband. It’s very hard to leave him be when I know he’s depressed, frightened or suffering in any way but he tells me that my calm, laid back manner gives him time to work things through and inspires him to remember there’s far more to life than his health issues. In time you’ll learn how to be concerned about your husband without showing it or hovering over him. It’s also important to take care of yourself. It’s emotionally, mentally and sometimes physically draining to be the support person and you can only be of help if you’re feeling well yourself.

JENNIFER, USA

Watching a loved one having seizures, adapting to medications and coping with the diagnosis is hard. Don’t underestimate the affects of time: I thought I’d lost my foster son as I knew him, but he came back to me.

GABRIELLE, West Midlands

As someone who has epilepsy, I have found that my anti-epileptic drugs seem to dampen my brain slightly and make it harder for me to concentrate, especially if I am watching the television or following a conversation. However the effects tend to wear off after a few weeks.

Being a typical man, communication is not my strongest point and I tend to prefer to deal with my problems myself which can be difficult for those who patiently try to support me with good advice and understanding.

My epilepsy is under control and thankfully I am able to get on with my life, but I am always very much aware of the unfair stigma that is attached to epilepsy. I think that’s possibly another reason I have struggled to talk about it, although I am trying to overcome this as I know that shared experiences can really help.

Name and address supplied

NEXT ISSUE

My seven year old daughter has uncontrolled seizures both day and night. We have tried various drugs but nothing seems to work. I can’t remember the last time I had a full night’s sleep and feel constantly shattered. This doesn’t help during the day when my little girl’s seizures can be both lengthy and frequent.

Friends and family are supportive but are reluctant to look after my daughter as they fear they won’t cope with her seizures. I am finding it increasingly hard to cope.

RACHEL, Essex

WOULD YOU LIKE TO SHARE YOUR THOUGHTS WITH RACHEL?
Email nicola.swanborough@epilepsysociety.org.uk or write to Editor, Epilepsy Review, The National Society for Epilepsy, Chesham Lane, Chalfont St Peter, Bucks SL9 0RJ
My name is Juliet and I have epilepsy – waits for supportive round of applause from others in the help group... No? oh ok. In one of my guises as a stand-up comic I explain to audiences that I have tonic clonic epilepsy, and that I affectionately refer to my seizures as ‘gin and tonic colonics’ because of how they make me feel afterwards... (there’s some artistic license here – actually I feel incredibly serene after a seizure).

Now I’m certainly no expert on neurology or science, but I have lived with my epilepsy for more than half my life. I say ‘my’ epilepsy as what strikes me is how very personal epilepsy is. Not just in the nature, frequency and severity of seizures, nor even the experience of different medications. For me the most personal aspect is the relationship with epilepsy itself.

I have the most common form of generalised epilepsy – idiopathic generalised tonic clonic seizures. The ‘idiopathic’, or ‘of unknown cause’ part has, for me, been the most frustrating thing to deal with. I had kidney failure as a child, is it connected to my adolescent-onset epilepsy? We don’t know. Is there any physiological cause? We don’t know. Might I grow out of having seizures? We don’t know. If I change medication might I experience awful side effects? We don’t know. Hmmmm. Frustrating.

My journey to understand my epilepsy has taken me through, in no particular order, denial, frustration, vulnerability, sadness, anger and sometimes even joy. Yes, joy. Without epilepsy I would not have the insight that I do into the kindness of strangers that I have so often depended on, the fine work of the ambulance service and hospital staff, the support and love from friends and family, the miracle and complexity of the human brain, the hard work of researchers to understand the brain, the mutual support from other people with epilepsy at meetings and in online chatrooms, and the dedication of individuals who run marathons, bake cakes, shave their heads and do parachute jumps to raise money for various epilepsy charities.

It is often said that the worst thing is not knowing and I would agree – it makes you powerless. Like many people, I have no prior warning if I am about to have a seizure, so only find out after the event (sometimes a long while after, depending on how many seizures I have had and if I was alone at the time). This can be really terrifying. The best solution I have come up with is to try and understand my epilepsy and resign myself that if I have to live with not knowing, I would rather live in a general state of positivity which may be interrupted by seizures, rather than a perpetual state of fearful paranoia. I choose to be as ok as possible with not knowing.

I have learned a respect for my body, which has healed itself so admirably after I have been injured during a seizure, and actually I have come to enjoy my cuts, scars, burns and grazes as they present a living testimony to my epilepsy. ‘The scar on my nose is from a seizure in the office... the piece of tarmac in my chin was accidentally left there after I was stitched up following a seizure in Tasmania... the burn on the back of my leg is from a hot water bottle I was unconsciously lying on after a seizure... etc.’

I now work as a journalist, writer and stand-up comic and yes, I do talk about epilepsy on stage. The relationship between comedy and epilepsy is a complex and often contentious one. People’s individual relationship with their epilepsy affects how appropriate they feel it is to make jokes about it. I can only speak from my own experience and for me comedy is a crucial coping mechanism. Quite often I will be approached after a gig by a fellow act or audience member who tell me about their own experience of epilepsy. I find it a great opportunity to engage with people and de-bunk some long held myths. Sometimes it can be surprising how much ignorance is still out there, but thankfully I’ve not yet had a crowd of angry villagers cry out for the ducking stool.

It’s been some nine months since my last seizure (in a comedy club – definitely not part of my act!). I keep taking my medication, ensuring I rest if I need to and making certain people in my life know what to do should I have a seizure. If I do have another seizure, well I’ll just have to recover, reassess my meds with my neurologist and carry on. Life is precious and short – too precious and too short not to enjoy!

JULIET STEPHENS

LAUGHING ALLOWED
ANNUAL DRAW

Put your persuasive powers to the test and help raise money for people with epilepsy. The National Society for Epilepsy (NSE) have some fantastic prizes in this year’s annual draw – first prize is £3000 with runner-up prizes of £500, £100 and a Harrods’ hamper and teddy bear.

Tickets are just £1 each. For books of tickets contact Alina Isherwood on 01494 601 410 or email fundraising@epilepsysociety.org.uk

CARING2GIVE

NSE’s Caring2Give range of alternative gifts make ideal presents for people who like to care and share with others. We have two types of packages to choose from: seven nationwide gifts that help people across the country, and nine residential packages benefiting those in our residential care homes in Buckinghamshire.

For example, our £10 ‘First Aid cards’ package pays for the production of over 100 pocket-sized first aid cards explaining what to do if you see someone having a seizure. Our £25 ‘Art therapy’ package buys materials such as paints or clay for sessions that encourage expression and creativity.

For our full range order a Caring2give brochure. Call 01494 601 332 or email fundraising@epilepsysociety.org.uk. You can also view the packages on our website.

TAKING EPILEPSY TO NEW HEIGHTS

It’s a good job associate member Jean Paul has a head for heights. On 20 August she took her place on top of the 22ft-high fourth plinth in Trafalgar Square, London to raise awareness of epilepsy.

As one of the lucky few to get a place in Antony Gormley’s Living Art Project, Jean dedicated her 2-3pm slot to her 20-year-old son David who has epilepsy and to the National Society for Epilepsy (NSE).

Jean, who lives in Welwyn Garden City, said: ‘I had such a wonderful time up there on the plinth. It was a fantastic day. I used my time to tell people about David and our experience of living with his epilepsy and the work of the NSE.’ Jean raised more than £800 for NSE by being sponsored to stand on the plinth.

CHRISTMAS CARDS

Make your Christmas cards count for people with epilepsy this year by ordering from our fantastic brochure. This year we have an even bigger and better selection for you to choose from and, unlike charity cards bought from high street shops, all the proceeds will go to charity. For a brochure call 01484 601 332 or view online at www.epilepsysociety.org.uk

HAVING A BALL

What do Twiggy, Alan Titchmarsh, Jo Brand and Robbie Coltrane have in common? They are just a few of the high-profile celebrities who have decorated masks to be auctioned at our annual fundraising ball on 16 October at the Hurlingham Club, London. Come with your partner or book a table for colleagues and friends and join us for a night of glittering entertainment including a champagne reception, three-course dinner and dancing to live music. To book your ticket email fundraising@epilepsysociety.org.uk or call Jo on 01494 601 450. Tickets are £130 per person, or why not book a table with your friends or colleagues – 12 tickets are £1560.
Epilepsy affects over half a million people in the UK

The National Society for Epilepsy (NSE) provides expert care and treatment, information and support and undertakes pioneering medical research.

Please remember the NSE in your will.

‘Once in a while something happens to me which really scares other people’