SOCIETY

'I want people to see that epilepsy is nothing out of the ordinary'
Paul Maynard MP page 8

WELL BEING

Changing how we think can help us achieve our hopes and dreams
Goal mapping page 6

EPILEPSY PLUS

Soaps are a good medium for conveying just what it is like to have epilepsy
Coronation Street page 18
In the midst of government spending reviews and fears over the future of services for people with epilepsy, two personal stories stand out. The first is of Patrick Clancy who has negotiated tirelessly to win hospital transport home for those admitted following a seizure. The second is of David Smyth and his wife Deborah, both 44, whose quality of life could be severely affected if the mobility allowance is withdrawn for people with epilepsy in residential care.

Two years after taking on his local hospital, Patrick Clancy won his battle. For David and Deborah the battle has only just begun.

In fact it is David’s mother, Patricia King, who is taking up the case on behalf of her son and daughter-in-law. She has written to Prime Minister David Cameron, members of the cabinet and her local MP in the hopes of making the government see the devastating affect the cuts will have on some of the most vulnerable members of society (see page 4).

Both Patrick and Patricia are an inspiration, working selflessly to achieve a better outcome for people with epilepsy. And it is the many people like them who have greatly influenced our thinking as we reshape the National Society for Epilepsy to strengthen and develop it and make it truly fit for the challenges of the future.

From January 2011, NSE will become the Epilepsy Society. We aim to be a vibrant, welcoming community working to change society and bring about a full life for everyone affected by epilepsy. We want to create a dynamic forum and a campaigning community that decides together what our priorities are.

Achieving change is no longer restricted to placards outside Westminster. Online communities such as facebook and twitter are empowering tools for making a difference and we would encourage you to sign up and be a part of the possibilities at www.epilepsysociety.com

Finally, many thanks to all of you who completed our Epilepsy Review survey. A full report will be in our next issue.
Better epilepsy services make economic sense

As the government plans to introduce ‘efficiency savings’ to the NHS of £15–£20 billion, a leading charity is urging ministers to save millions by preventing unnecessary seizures.

Government ministers should spend money on improving epilepsy services so that people get the right treatment and medical costs are reduced. That was the message of Graham Faulkner, chief executive of the National Society for Epilepsy, following the government’s controversial spending review.

While the government has pledged to increase NHS spending by 0.4 per cent annually over the next four years, it has also set out billions of pounds of ‘efficiency savings’ that could have a serious impact on the NHS.

‘Inefficiency within the NHS in terms of epilepsy services is a disgrace,’ said Graham Faulkner. ‘The government has turned a blind eye to problems within NHS epilepsy services so we still have a dramatic lack of epilepsy specialist neurologists – there are only about 30 in England. This means that people may get the wrong diagnosis and so are taking unnecessary or wrong drugs or having unnecessary seizures. ‘This is costing the NHS millions each year on emergency treatment and extra GP and outpatient appointments.’

Graham Faulkner, who is also vice-chair of the Joint Epilepsy Council, said a recent adjournment debate instigated by MPs Paul Maynard and Laura Sandys gave him hope that at last someone may be listening to the economic arguments that epilepsy charities have been making.

Mr Maynard said that better care and treatment were more cost effective and criticised the NHS for not making NICE guidelines mandatory. His plea for improved services was echoed by Laura Sandys who also has epilepsy.

Health minister Paul Burstow MP acknowledged the current failings of the NHS which he said had ‘gaping holes.’ He has agreed to meet with voluntary organisations to look at ways of addressing the failings of the NHS for people with epilepsy.

‘We shall be keeping a close watch on how his words are turned into action,’ said Graham Faulkner.

New scans bring hope of seizure freedom

Dramatic advances in brain imaging could offer real hope of seizure freedom to those with drug-resistant epilepsy says Professor John Duncan, medical director of the National Society for Epilepsy.

The leading expert in research into brain mapping is underlining the importance of rescanning those people with medically refractory epilepsy who have previously been considered unsuitable for surgery.

‘We have made great strides in developing new and more sophisticated scanning techniques that give us a far clearer window into the brain,’ said Professor Duncan. ‘We are now much better placed to locate the point of seizures in patients whose MRI scans have hitherto proved inconclusive. This could increase the number of patients who are suitable for surgery and offer the very real possibility of seizure freedom for many more people.’

The pioneering scanning techniques are also enabling neurologists to map crucial pathways between functional areas of the brain and minimise the impact of surgery on memory, language and vision.

Ask Laura

Laura Sandys is MP for Thanet South and chair of the All Party Parliamentary Group for epilepsy. Laura is also one of just two MPs to openly disclose their epilepsy (see story above).

Laura has agreed to answer any questions you would like to ask her about issues relating to epilepsy. A selection of the questions and answers will be published in the next issue of Epilepsy Review and on NSE’s website.

You can submit your questions in one of the following ways: email nicola.swanborough@epilepsysociety.org.uk, send via NSE’s facebook or forum at www.epilepsysociety.org.uk, post a question on twitter at @epilepsysociety or write to Epilepsy Review, National Society for Epilepsy, Chalfont St Peter, SL9 0RJ.
University challenge

New research shows students with epilepsy are not getting the support they need from university websites

With UCAS applications now open the National Society for Epilepsy was alarmed to discover that 75 per cent of more than 300 university and college websites visited, failed to mention epilepsy and did not signpost students to the financial, practical and emotional help available.

On 15 per cent of websites only a passing reference to the condition was mentioned in the long-term conditions or disability sections, and only four universities and colleges had any detailed information.

Amanda Cleaver, NSE’s communications manager, said: ‘Many websites have information for students with dyslexia and autism but not for students with epilepsy.’

As part of its University Challenge campaign NSE has devised a downloadable information pack containing everything a student with epilepsy may need to know. It is asking universities to make this information available via their websites. Also included is a comic strip (above) looking at the challenges faced by students with epilepsy.

Amanda added: ‘Research by the Higher Education Council for England (HECFE) has shown that students willing to disclose health issues like epilepsy to their university achieve better results and are less likely to drop out of the education system.’ To find out more visit www.epilepsysociety.org.uk/universitychallenge

Dose of good news

Epilepsy campaigners are celebrating the news that the government has decided not to make generic prescription of NHS drugs compulsory.

Supporters of the National Society for Epilepsy (NSE) Count Epilepsy Out campaign sent postcards and letters to the minister of state for health saying that cutting costs on epilepsy drugs doesn’t add up. It could provoke seizures or side effects – with a high cost to both the NHS and the person with epilepsy.

NSE also submitted an in-depth response to the consultation laying out the potential dangers of generic substitution to people with epilepsy.

This influential campaign contributed to the government’s rejection of the scheme.

Department of health minister Lord Howe said: ‘We have listened to concerns from the public, patients and other interested parties. It is not clear whether the proposals would have provided a substantial benefit to the NHS.’

Professor John Duncan, NSE’s medical director, said: ‘It is a great relief to see that patient safety and common sense have prevailed. Although we note that the department is talking about more ‘appropriate ways of supporting the use of generic medicines and, in the long term, value-based pricing.’

‘We will be keeping a close eye on any future plans for cost cutting of drugs to make absolutely sure that the safety of people with epilepsy remains of paramount importance.’

DLA cuts met with anger

Plans to cut the mobility allowance for people living in state-funded residential homes have been slammed by major disability charities.

People with disabilities, their families and charities say the cut will leave 60,000 people living in care homes unable to get out and with reduced quality of life. And all to save £135m a year – just 0.2 per cent of proposed spending cuts.

The plans would mean that people in residential care would lose up to £49.85 per week. Said Esther Foreman, campaigns and policy manager at Mencap: ‘People rely on this money to get them to the hospital or to the dentist. The government is effectively saying you’re disabled, you stay at home.’

The Voluntary Organisations Disability Group (VODG) hopes to demonstrate the impact of this change and persuade the government to reconsider.

Advice for mums to be

Women taking the anti-epileptic drug sodium valproate should not panic and stop taking their medication following news reports linking the drug with possible birth defects.

Medical director at the National Society for Epilepsy, Professor John Duncan stressed that sodium valproate was an effective AED though it could be associated with an increased risk of birth defects at higher doses.

He said seizures caused by stopping or changing drugs could also be life threatening or cause injury to the mother and baby. Medication choices should be taken with specialist advice.
Could the music you listen to impact on your epilepsy? If you’re listening to the Teletubbies Say-Eh-Oh the answer is likely to be ‘no,’ but if your tastes are more classical, well, read on…

In 1781 Wolfgang Mozart wrote his Sonata for Two Pianos in D Major. More than 200 years later the composition has taken on a new life beyond being an example of the young musician’s genius.

Scientific studies have suggested that the sonata may have a positive impact on brain activity, inducing short-term improvements to certain cognitive abilities. But more recent studies have shown that the piece may also be good news for people with epilepsy. At the University of Illinois Medical Centre, 29 patients with epilepsy were exposed to the sonata for five minutes, with 23 of them showing a significant decrease in epileptic activity.

Now the Department of Paediatric Neurosciences at the Royal Hospital for Sick Children in Edinburgh has conducted its own study into the ‘Mozart Effect’ and found that the Sonata for Two Pianos in D Major can reduce the number of epileptic discharges in children.

Forty-five children took part in the study which compared the number of epileptic spikes recorded on an EEG when the children were listening to Mozart, a control piece of music and silence. The control music was Teletubbies Say-Eh-Oh, The Singing Kettle Eely-Ally-O or Busted Year 3000.

Dr Ailsa McLellan who led the study reported a significant reduction in epileptic spikes when children were listening to Mozart. The mean number of spikes was 2.85 per 10 secs compared with 3.23 before listening to the music.

Speaking at the International League Against Epilepsy’s annual scientific meeting, Dr McLellan said: ‘The results raise the question of whether Mozart therapy could have a therapeutic role in the management of uncontrolled epilepsy.’ To hear the sonata visit http://tinyurl.com/mozartD

Could statins reduce risk of seizures?

A family of drugs commonly used to lower cholesterol may also help reduce the risk of seizures in people with heart disease, according to new research.

A statistical study of 2,400 people aged 65 and over, has shown that those taking anti-cholesterol statins were 35 per cent less likely to be hospitalised with a diagnosis of epilepsy than those not taking the drug.

The study has been carried out by a drug safety expert at the University of British Columbia and Vancouver Coastal Health Research Institute and could form the basis for randomised clinical trials to test the efficacy of statins as anti-epileptic medication.

Co-author of the report Ali Samii said: ‘Our study suggests that statins reduce the risk of developing epilepsy in people over the age of 65 with cardiovascular disease. The most plausible explanation is that statins reduce the risk of stroke in this population, and since strokes can increase the risk of epilepsy, statins reduce the risk of epilepsy because of stroke prevention.’

It is rocket science!

A revolutionary scanner, designed to look like a space rocket, will soon allow doctors to scan toddlers as they play. The £2 million paediatric magnetoencephalogram (MEG) will make it possible for the first time to carry out surgery on children as young as two years old who have recurrent seizures.

The MEG measures brain waves using a helmet containing 300 detectors sensitive to tiny magnetic fluctuations induced by neuron activity and shows precisely which parts of the brain can be targeted safely for surgery. A unique feature of the machine is that children will not have to keep completely still while the brain scan takes place.

Said Professor Paul Furlong, leading the design team: ‘Our new scanner will be fun for children to sit in. You can let them play their favourite video games but while they are moving the joystick you can assess their motor and visual function.’

The scanner is due to be installed in around 18 months at a brain unit opening next year at Aston University in Birmingham.
Changing the way we think and setting ourselves positive goals can help us to maximise our true potential, says life coach Ruth Oshikanlu. By creating a goal map of our hopes and dreams in words and pictures, both sides of our brain will persuade our subconscious to pursue positive goals. Here 24-year-old Isabella Ghawi, who has uncontrolled seizures, follows Ruth’s seven-step guide to make her own goal map. Her dream is of a first independent holiday in Spain with friends.

**Step 1: DREAM What do you want to achieve?**

*Ruth:* Try not to think too long about each question but answer instinctively – our hearts usually know what we really want.

*If you won £1 million on the lottery, what would you do differently in your life?*

*Isabella:* I would go on holiday to Madrid with my friends from church.

*If for the next six months you could enjoy absolute perfect health, what would you do differently with your time?*

*Isabella:* I would spend more time with my family and friends.

*What have you always wanted to do, but have maybe been afraid to attempt?*

*Isabella:* I would really love to be more independent and live by myself. I live at home with my mum.
and she finds my seizures really worrying but she is scared of not being there for me.

If you could be granted any one skill or ability, what would you choose?
Isabella: I am dyslexic so I would like to be able to write better.

What gives you your greatest feeling of pleasure and satisfaction?
Isabella: Before my epilepsy it would have been academic success – 98 per cent in an exam gave me immense pleasure. Now I find happiness in cheering other people up.

What legacy would you like to leave; how do you want to be remembered?
Isabella: As someone who made other people happy.

If you knew you were guaranteed to succeed, what one great achievement would you dare to dream for yourself?
Isabella: Freedom from my seizures.

Step 2: ORDER Which goals take priority?
Ruth: From your list, decide what is your top priority, then place your answer in the central yellow box of the left-brain map using words. Choose four more top priorities from your list and place in the blue boxes. See Isabella’s goal map, left.

Step 3: DRAW Communicate your goals to your subconscious
Ruth: Turn your goals into pictures using the right-brain map template. Images are vital to stimulate the right side of your brain. As you fill in the following questions on your left-brain template, add more pictures on the right-brain map.

Step 4: WHY? Identify your emotional drivers
Ruth: Pin point the emotional reasons why you want to achieve your goals – such as ‘love’, ‘freedom’ and ‘family’. Emotion acts as a fuel for motivation.

Step 5: WHEN? Define your timeline
Ruth: Goals without deadlines are just wishes – they lack the magic of commitment. Write today’s date in the date box and your achievement date in the box below your main goal.

Step 6: HOW What actions you need to take
Ruth: Identify three actions you need to take to work towards your goal, such as studying, saving, or learning new skills.

Step 7: WHO Choose people or organisations to support you
Ruth: Identify family, friends or professionals who can help you achieve your goal.

Now that you have your goal map, commit to it: Sign it, visualise it, read it aloud, believe in your goal, share it with family and friends.

We would like to wish Isabella good luck – and maybe happy holiday – in achieving her goal.

To find out more about goal mapping contact Ruth on 07955 873565 or email ruth@goalmind.co.uk
Create your own goal map online at www.goalmappingonline.com
Paul Maynard MP
Man with a Plan

When Paul Maynard was diagnosed with epilepsy at the age of 22, it had a huge impact on his life. Now, a newly elected MP at 34, he is determined to make an impact on epilepsy, as he explains to Nicola Swanborough.

It’s seven months since Paul Maynard MP took up his seat in Westminster and the novelty has yet to wear off. The 34 year old is still unashamedly excited about all things parliamentarian and, more specifically, Portcullis House, the impressive Thames-side home he shares with some 200 members.

‘Isn’t this great,’ he says, embracing with one sweep of his hand the massive tree-lined atrium where café-style culture allows MPs to meet constituents and delegates. ‘I mean forget the House of Commons – this is where it’s all happening. And when we need to slip across to Westminster for a debate, there’s a secret tunnel that leads us straight under the road to the Commons – well, via that escalator over there.’

MPs are gliding in and out all the time. Ed Miliband, Labour’s new captain, saunters past in a mist of oblivion, looking for the world like a boy who’s won a fight with his older brother but found victory to be less than sweet. Paul, by contrast, is the cat who got the cream. He can’t stop smiling. The Conservative representative for Blackpool North and Cleveleys is parliament’s only second-ever MP with cerebral palsy. He also has epilepsy and is one of just two MPs to go public with the condition. Laura Sandys is the other. But while Paul refuses to be defined by either his cerebral palsy or his epilepsy, he’s also determined not to miss the opportunities afforded him as an MP to make a difference in both fields. Paul Maynard is a man with a plan.

‘I am absolutely determined to make a difference... I certainly intend to kick up a stink’

‘Every MP brings with them a unique perspective,’ he says. ‘Mine happens to be cerebral palsy and epilepsy. I believe it can only benefit the country to have as many MPs from as wide a diversity of backgrounds as possible and that includes people with disabilities.

‘Every MP has a duty to make a robust contribution to public life and I am absolutely determined to make a difference for people with disabilities. Time will tell whether I achieve that difference, but it won’t be for lack of trying. I certainly intend to kick up a stink!’

So what is Paul’s plan? ‘For me the most important thing is to normalise epilepsy and remove the stigma surrounding it,’ he says. ‘I want people to see that epilepsy is nothing out of the ordinary. It is a condition like any other medical condition and is not something to be afraid of. I am determined to challenge some of the misconceptions, myths, prejudices, fears and suspicions that go with the condition and with cerebral palsy too.’ He hopes his own willingness to talk openly about his conditions will help to make inroads.

Paul was born with mild cerebral palsy but was not diagnosed with epilepsy until he was 22. Of the two, he says his epilepsy has had a far greater impact on his life and came as something of a shock. Although epilepsy is more common in children with cerebral palsy than in those without a neurological condition, Paul was unaware of any connection.

‘In 22 years of hospital and doctor appointments, no-one had ever mentioned the possibility of seizures,’ he says. ‘When I suddenly developed epilepsy out of the blue, it really knocked me for six. I had just finished
my history degree at Oxford University and was working as a management consultant in London when I had my first seizure. It meant I really had to change the way I lived.’

Both driving and drinking had to go, and in that order. ‘Giving up my driving licence for a year until my seizures were under control was a major thing,’ he recalls. ‘I was very lucky to be living in London with a good transport system, but it made me realise what an impact this could have for someone living in a rural area without a good service of trains and buses.’

Then came the second blow. ‘After some time we narrowed the trigger for my seizures down to alcohol which obviously meant me giving up drink altogether,’ continues Paul. ‘I wouldn’t say I was a prolific drinker, but like many students I had enjoyed a certain amount of beer and wine.’

Now the slightest hint of alcohol will trigger nocturnal seizures for Paul and avoiding it is harder than he first imagined. ‘The big problem is alcohol in food,’ he explains. ‘Just a tiny amount of brandy in a mince pie is enough to cause a fit so I permanently have to check menus and consult with chefs.

‘In Portcullis House the restaurant is marvellous and lists a whole range of allergies such as wheat, gluten and nuts, but there’s nothing at all about alcohol. At every meal I have to check whether any sauces have been made with wine, or whether the meat has been marinated in alcohol.

‘I have been caught out at another restaurant when I ordered fish cakes. The waiter assured me in good faith they were alcohol free, not knowing that the chef had added a quick slug of wine. It was enough to cause a seizure.’

Paul counts himself lucky now to only have nocturnal seizures although he emphasises that they are far from pleasant. ‘I have partial tonic clonic seizures – you certainly don’t wake up feeling great,’ he says.

‘My short-term memory is always affected. And it’s not as though the memories eventually come back either – I just have to slowly deduce where I have been, who I have spoken to, what I saw and did until I eventually build up a picture of the missing time.

‘In 22 years of hospital appointments no-one mentioned the possibility of seizures’

‘I haven’t had a seizure since becoming an MP thank goodness but that is why I am always very careful. With late-night meetings, there is something of a sub-culture of drinking in Westminster, but going to the bar isn’t a problem for me – I just order a soft drink.’

Paul has been careful to inform his colleagues of his epilepsy and what to do if he has a seizure. ‘It’s not that I want to make a fuss,’ he says, ‘but a seizure can often be worse for the person who witnesses it, so I think it is very important for those around me to understand what is happening and to know what to do if I have a fit.

‘Everyone needs to know about seizures – this is why we must raise awareness so that people aren’t afraid to deal with them. This is one of my greatest challenges.’

Turn the page to read about Paul Maynard’s political views...
Paul Maynard on...

The NHS

‘Planned reforms of the NHS mean GPs will be responsible for commissioning many health services. But how can anyone commission for epilepsy when existing Primary Care Trusts don’t know how many people there are in their areas with epilepsy? GPs need to build up a database of people with the condition so they are more informed about what is required.’

Work Capability Assessment (WCA)

‘It is vital that people are assessed for work by a health specialist who is knowledgeable about their condition. In my constituency, someone with HIV was assessed by a non-HIV specialist and the outcome was not accurate. I have already taken up the issue of WCAs with disability minister Maria Miller.’

Disabled Living Allowance (DLA)

‘DLA needs reforming. The status quo is not an option. The extent to which the numbers claiming the benefit have increased is just not credible. The system needs to be reassessed to make sure that those who need the benefit get it. Anyone with good cause will have nothing to worry about.

‘I firmly believe though that we should not force individuals to fit the tick boxes, but should make the boxes fit the individuals. The government must think very carefully about reforms and that is why we are consulting charities. We really want to hear what they think.’

Specialist schools

‘You can’t have a blanket rule for every pupil. Most children with epilepsy will thrive in mainstream education while others will need specialist schools. Both should be available and parents must be involved every step of the way in deciding which path is best for their child.’

Political campaigning

‘It took me 10 years to get into parliament but I don’t think my struggle has been any greater than anyone else’s on account of my conditions. Of course there have been people who have been more supportive than others along the way, but that is life. When I stood for Twickenham at the previous election, someone said I was possessed of the devil because of my epilepsy. This is just ignorance. I didn’t dignify the remark with a reply. We must educate people.’

Coalition government

‘I am very happy with the coalition. We didn’t win the election so must work together with the Lib Dems. We must work out our disagreements. That is one of the great strengths of our democracy.’
As far back as 400BC, Hippocrates recognised that ‘from the brain and the brain alone arise our pleasures, joys, laughter and jests… our sorrows, pains and griefs.’ But it is only in the last 200 years that we have begun to understand this pivotal organ and how disruption of electrical communication between neurons can give rise to seizures.

To understand the way that epilepsy arises in the brain, we must first look at its geography and basic structure. The human brain is a soft jelly-like substance made up of 100 billion neurons – enough to stretch from here to the moon – and weighs approximately 1.4kg (3lbs). The size of the first human being’s brain some two million years ago was thought to have been a lightweight 575g (1lb 4oz) – little more than one third of its current size. Contrary to popular belief, there is no relationship between the weight of the brain and intelligence – it’s the number of brain cells that matter.

Although the brain only constitutes two per cent of our total body weight, it uses 20 per cent of our body’s oxygen supply and blood flow. By comparison the brains of apes use just eight per cent of their body’s energy.

Structure of the brain
Inside our skulls our brains are protected by three special coverings known as the meninges. Between these sheets, cerebrospinal fluid protects and cushions the brain, for example when we shake or nod our head.

Over the course of its long evolution, the brain has developed three major parts: the cerebrum or cerebral cortex which is the large mass of tissue shaped like a cauliflower; the cerebellum which is the fist-like structure at the base of the brain; and the brain stem which connects to the spinal cord.
Neurons have different shapes according to their function. A neuron has five parts: a cell body, dendrites, axon, myelin sheath and synaptic terminal. The cell body contains all the genetic material which directs the neuron. This is surrounded by thin dendrites that receive messages from other cells. The axon is insulated by a myelin sheath and carries an electrical charge to the synaptic terminal that connects with the next cell, releasing neurotransmitting chemicals. These cross the narrow gap known as the synapse and attach to the neighbouring cell body’s dendrites. It is the neurotransmitters that cause the cell either to fire or cease firing and are particularly significant in epilepsy since excess firing may give rise to seizures.

The cerebrum is divided into two halves or hemispheres which transfer information via the corpus callosum, a bridge of nerve fibres. The left hemisphere controls the right side of our body, while the right hemisphere controls the left side. Opposite you will see how each hemisphere is divided into four areas or lobes: the frontal, temporal, parietal and occipital lobes each with their own special functions. But while each lobe may have its own specific roles to play, the brain works as a whole organ through an elaborate network of complex connections.

The outer layer of the brain is made up of grey matter and covers the cerebral hemisphere called the white matter. Grey matter includes regions of the brain essential for functions such as muscle control and our sensory perceptions – seeing, hearing, memory, emotions and speech. White matter is the intricate wiring of the brain which relays sensory information from the rest of the body to the cerebrum.

The brain is made up of two types of brain cells: neurons and glia cells. Neurons (see the illustration below) are responsible for carrying messages to and from the brain with connections from groups of neurons forming nerves. Glia cells play a supporting role in maintaining the signalling ability of neurons. It is estimated that there are three times as many glia cells as neurons.

Neurons require oxygen to function and will die within 3-5 minutes without it. They are also quite fragile and require extensive protection to avoid damage, infection and harm.

How the brain works
Electrical impulses pass along neurons and are transmitted to neighbouring neurons with the help of chemical messengers or neurotransmitters. When an impulse reaches the end of a neuron, a chemical substance is released which stimulates a reaction in the next nerve cell, enabling the impulse to travel onwards. In this way, impulses are passed along innumerable neuron chains throughout the brain.

The outcome of these messages depends on which neuron chains are involved. If the impulse comes from the areas of the brain responsible for language, the chain reaction enables us to speak. If it comes from an area responsible for memory, the chain reaction enables us to recall events, names and places. Millions of neuron networks enable the brain to control the countless functions it is responsible for.

More recent scanning techniques have shown how similar functions such as language and memory may also be located in various areas of the brain. This is particularly significant if injury or surgery affects a specific part of the brain – other areas may begin to compensate by taking over its tasks.

Neurons, however, can be overly eager to transmit messages so the brain employs its own tailor-made braking system. Individual neuron networks can have either a stimulating or inhibiting effect, depending on its neurotransmitter.

Some neurotransmitters such as glutamate, have an excitatory effect and promote increased transmission of impulses, while inhibitory neurotransmitters such as GABA (gamma-amino-butyric-acid) aim to slow down further impulse transmission. It is this imbalance of neurotransmitters that is thought to be a possible cause of epilepsy.
### The brain and epilepsy

Seizures occur when there is a synchronised surge of electrical impulses in the brain. This may involve a large or small group of neurons or possibly all the neurons in the brain.

If the inhibitory neuron network is not functioning properly, this gives other neurons the freedom to fire at will, possibly transmitting uncontrolled epileptic impulses. This may happen if there is a low concentration of the inhibitory neurotransmitter GABA.

If the inhibitory network is functioning effectively but there is too high a concentration of the excitatory neurotransmitter glutamate, there is increased risk of a seizure. Some of the newer anti-epileptic drugs directly target these anomalies and are designed to increase the level of inhibitory neurotransmitters, particularly GABA, or decrease the levels of the excitatory ones such as glutamate.

A sudden burst of neuronal firing may not be sufficient to cause an obvious seizure (though it may show up as a spike on an electroencephalogram – EEG), but if the electrical energy is strong enough and affects enough neurons it will produce symptoms with the characteristics of the area in which it was produced. This could result in sudden muscle movement, a fall or impaired vision. If increased neuronal firing involves the whole brain, the result may be a seizure that affects many functions of the entire brain.

It is this balance between inhibitory and excitatory neurotransmitters that also gives rise to the concept of seizure threshold. While the majority of people will tolerate lack of sleep or an excessive amount of alcohol without experiencing a seizure, for those individuals with a lower seizure threshold, the change in circumstances can be enough to trigger a seizure.
Looking after your brain

As we have already seen, the brain is an energy-hungry organ requiring the right nutrients to help it function effectively. A healthy diet may not impact directly on your epilepsy, but it will help you build a stronger brain and body which may help you cope with seizures. So how can you feed your brain and treat it well?

Drink plenty of water
Your brain is 78 per cent water so dehydration is likely to affect its performance. Remember that by the time you feel thirsty you will already be dehydrated. In order to think clearly, you need to drink at least six glasses of water a day – this has been shown to help reduce headaches and tiredness.

Follow a healthy diet
Feeding a healthy brain follows the same principles as feeding a healthy body. The first step is to ensure a steady intake of calories throughout the day. It sounds old fashioned advice, but three healthy meals a day really does work.

In the same way that your muscles won't function to the best of their ability if you don’t provide them with the right fuel, your brain also requires the right nutrients to keep messages flowing freely between brain cells and maximise your ability to concentrate and remember.

A steady calorie intake will keep your blood-sugar levels up, helping you to stay focused and alert. Omega-3 oils found mainly in oily fish, walnuts, pumpkins and flax will help you deal with stress. Make sure you include a wide variety of food from the three food groups: fats (olive oil and olive oil spreads), carbohydrates (wholegrain bread, cereal, pasta and rice) and proteins (meat, fish, tofu, nuts, seeds, dairy produce, pulses and beans). And get your five fruit and vegetables each day.

Avoid stress
Stress can reduce our ability to learn and remember – especially cumulative stress. Often it is impossible to avoid a certain amount of stress but we can take steps to reduce its effects by actively remembering to relax. Simply by taking time out to go for a walk, meditate or exercise can help us cope and recover from stress.

Sleep
Sleep deprivation will undoubtedly have an adverse impact on your brain and its ability to function effectively. Over time this can lead to fatigue, feeling low and difficulties with memory and concentration. Late or sleepless nights may also make people more susceptible to seizures. Nocturnal seizures can interrupt a restful night’s sleep and interfere with the laying down of memories.

Exercise
Like the rest of your body, your brain will thank you for a little exercise. Any form of exercise, no matter how gentle, will help to pump oxygen-rich blood into every capillary of your brain. Remember those billions of neurons in your brain all require oxygen to function properly.

Use both hands
Research has suggested that this may help to stimulate parts of your brain that you don’t normally use.
One of the most decisive factors in electing to undergo surgery for epilepsy is the risk of a post-operative decline in language, memory and vision.

For those with intractable epilepsy, surgery offers a very real possibility of freedom from seizures – up to 70 per cent of those with temporal lobe epilepsy (TLE) who undergo surgery achieve freedom from their seizures.

But alongside this ultimate goal of a life without epilepsy, is the fact that up to 40 per cent of those who have temporal lobe surgery are at risk of a small decline in every day functions such as speech, memory and vision.

Those considering surgery must weigh up, with their neurologist, the chances of seizure freedom through surgery against the possible impact on their quality of life – ‘If surgery is going to impair my speech or memory, would it be better to live with my seizures?’

In recent years researchers have striven to predict and minimise the risks to patients, using functional magnetic resonance imaging (fMRI) and magnetoencephalography (MEG) to attempt to demonstrate where these critical functions are carried out in the brain and whether they are at risk from brain surgery.

The brain is made up of grey and white matter, with grey matter carrying out most of the ‘thinking’ functions of the brain, and white matter forming the connections or ‘wiring’ between these different areas. If these pathways are unable to communicate, the brain may not be able to function properly even though separate areas are working.

Traditional MRI scans have been able to provide a useful snapshot of the overall grey and white matter structures of the brain, but it is only now that a newer diffusion-based scanning technique – diffusion tensor imaging (DTI) with tractography – is enabling neurologists to study the intricate white matter networks in much greater detail.

A recently published study by the National Society for Epilepsy (NSE) in the journal Brain shows how DTI with tractography can help to visualise previously unseen white matter connections. By providing surgeons with images that show where connections are, damage to crucial functions can be minimised.

NSE’s study also shows that while in some patients there may be a reduction in the white matter connections associated with language in the area of surgery, white matter networks in other parts of the brain, also connected with language, increase their capacity to compensate. In other words, the brain begins to rewire itself with a more positive long-term outlook for the patient’s communication skills.

These exciting findings raise the prospect that DTI with tractography may allow doctors to predict the change in language function that could occur after surgery. This information can then be used to help patients make an informed decision about associated risks and whether to elect to undergo epilepsy surgery.

Dr Mahinda Yogarajah is a clinical research fellow at the National Society for Epilepsy and University College London.

One of the most decisive factors in electing to undergo surgery for epilepsy is the risk of a post-operative decline in language, memory and vision.

For those with intractable epilepsy, surgery offers a very real possibility of freedom from seizures – up to 70 per cent of those with temporal lobe epilepsy (TLE) who undergo surgery achieve freedom from their seizures.

But alongside this ultimate goal of a life without epilepsy, is the fact that up to 40 per cent of those who have temporal lobe surgery are at risk of a small decline in every day functions such as speech, memory and vision.

Those considering surgery must weigh up, with their neurologist, the chances of seizure freedom through surgery against the possible impact on their quality of life – ‘If surgery is going to impair my speech or memory, would it be better to live with my seizures?’

In recent years researchers have striven to predict and minimise the risks to patients, using functional magnetic resonance imaging (fMRI) and magnetoencephalography (MEG) to attempt to demonstrate where these critical functions are carried out in the brain and whether they are at risk from brain surgery.

The brain is made up of grey and white matter, with grey matter carrying out most of the ‘thinking’ functions of the brain, and white matter forming the connections or ‘wiring’ between these different areas. If these pathways are unable to communicate, the brain may not be able to function properly even though separate areas are working.

Traditional MRI scans have been able to provide a useful snapshot of the overall grey and white matter structures of the brain, but it is only now that a newer diffusion-based scanning technique – diffusion tensor imaging (DTI) with tractography – is enabling neurologists to study the intricate white matter networks in much greater detail.

A recently published study by the National Society for Epilepsy (NSE) in the journal Brain shows how DTI with tractography can help to visualise previously unseen white matter connections. By providing surgeons with images that show where connections are, damage to crucial functions can be minimised.

NSE’s study also shows that while in some patients there may be a reduction in the white matter connections associated with language in the area of surgery, white matter networks in other parts of the brain, also connected with language, increase their capacity to compensate. In other words, the brain begins to rewire itself with a more positive long-term outlook for the patient’s communication skills.

These exciting findings raise the prospect that DTI with tractography may allow doctors to predict the change in language function that could occur after surgery. This information can then be used to help patients make an informed decision about associated risks and whether to elect to undergo epilepsy surgery.

Dr Mahinda Yogarajah is a clinical research fellow at the National Society for Epilepsy and University College London.
Astrocytes are the most abundant cells in the brain but until recently the role they play in the generation and control of seizures has been largely overlooked. New research is hoping to throw light on their significance and may lead to new treatments for epilepsy. Professor Arthur Butt explains this specialised function of astrocytes. Kir4.1 is a type of potassium channel located in the cell membrane of astrocytes which allows the movement of potassium ions between the inside and outside of the cell, across the cell membrane. A characteristic of these channels is that they have a greater tendency to allow potassium to flow into the cell and are perfectly suited for removal of potassium from the space around neurons.

The Kir4.1 channel is encoded by a gene called the KCNJ10 gene. This means that, using chemically coded messages, the gene issues instructions to the cell to make a protein that the cell can use. Mutations in this specific gene are associated with idiopathic epilepsy where the condition is genetic or inherited.

The most prominent kind of epilepsy thought to be associated with astrocyte activity and variations in the KCNJ10 gene is medial temporal lobe epilepsy (TLE). Research, however, is at an early stage and it is hoped that studies will determine exactly how alterations of the Kir4.1 channel in astrocytes may cause TLE.

As neurons fire off signals, they release chemicals into the brain which are ‘mopped up’ by astrocytes.

For about a third of people with epilepsy, seizures are not controlled by current therapies. There is therefore a need for new therapies and new therapeutic targets. Changes in astrocyte functioning in epilepsy have largely been overlooked, but it is now clear they have a role in the generation and spread of seizure activity.

Our research aims to improve our knowledge of astrocytes and the mechanisms by which Kir4.1 regulates their functions. This will provide a deeper understanding of the cellular basis of hyperexcitability and synchronisation, which is critical if we are to develop new treatments for epilepsy.

Arthur Butt is Professor of Cellular Neurophysiology at the University of Portsmouth.
Epilepsy gets Street wise

Amanda Cleaver, at the National Society for Epilepsy, has always been a big Corrie fan. So when ITV asked her to advise on a storyline involving bad boy David Platt and his epilepsy, she was straight up the motorway to Weatherfield and the iconic studio that has gripped a nation for the last 50 years.

For those not up to date on all things Corrie, here’s the story so far. David Platt is not good news. He tried to murder his mum Gail (formerly Tilsley for fans from the ’70s), was driven into a canal by his killer stepdad and caused his niece to take ecstasy. He’s done time in jail and has loved, and lost, one of Weatherfield’s hottest babes. Then comes the car crash.

In true Coronation Street style, David has a row in the Rovers with butcher boy Graeme over kebab queen Tina, storms off in a rage to ‘nick’ Audrey’s car (wife of roly poly Alf Roberts during less volatile times) and finally runs aggrieved Graeme down flat as he crosses the road. A clear case of attempted murder?

The police think so, as does everyone who’s anyone, until David falls dramatically to the ground during a court appearance. And then the question of epilepsy arises.

David has complex partial seizures which until now have gone undiagnosed. He’s had what he describes as ‘funny turns’ – Corrie Epilepsy gets Street wise

Amanda Cleaver, at the National Society for Epilepsy, has always been a big Corrie fan. So when ITV asked her to advise on a storyline involving bad boy David Platt and his epilepsy, she was straight up the motorway to Weatherfield and the iconic studio that has gripped a nation for the last 50 years.

For those not up to date on all things Corrie, here’s the story so far. David Platt is not good news. He tried to murder his mum Gail (formerly Tilsley for fans from the ’70s), was driven into a canal by his killer stepdad and caused his niece to take ecstasy. He’s done time in jail and has loved, and lost, one of Weatherfield’s hottest babes. Then comes the car crash.

In true Coronation Street style, David has a row in the Rovers with butcher boy Graeme over kebab queen Tina, storms off in a rage to ‘nick’ Audrey’s car (wife of roly poly Alf Roberts during less volatile times) and finally runs aggrieved Graeme down flat as he crosses the road. A clear case of attempted murder?

The police think so, as does everyone who’s anyone, until David falls dramatically to the ground during a court appearance. And then the question of epilepsy arises.

David has complex partial seizures which until now have gone undiagnosed. He’s had what he describes as ‘funny turns’ – Corrie

‘Serious until proven otherwise’

Around half the UK population may experience a blackout at some time in their lives, although in most cases these will have a simple explanation such as stress, anxiety or maybe standing still for too long.

However, blackouts may also have a neurological or cardiovascular cause such as epilepsy or heart disease. NICE (the National Institute for Clinical Excellence) is calling for healthcare professionals to assume symptoms are serious until proven otherwise. They have drawn up clinical guidelines which aim to improve diagnosis and management of this potentially serious symptom. Once specific circumstances of the blackout are established, NICE advises one of three courses of action:

- If the initial assessment does not give any cause for concern, no further immediate action may be required.
- If the person has experienced limb jerking or tongue biting during the blackout, or confusion or disorientation after, they should be seen by an epilepsy specialist within two weeks.
- If there are uncertainties, the person should be offered a number of tests including an ECG.
characters think they’re an elaborate hoax to get him off a murder charge – but eventually the MRI scan cannot lie and it becomes clear that David may well have had a seizure behind the wheel of his – or Audrey’s – car, the night he knocked down Graeme.

‘And that is where we came in,’ explained NSE’s communications manager Amanda Cleaver, fresh back from Corrie’s Green Room. ‘The writers and actors on Coronation Street were keen to ensure that they gave an accurate portrayal of seizures, the diagnosis of epilepsy and the way the character was treated.

‘The storyline raises a lot of issues surrounding epilepsy such as how easy it is for blackouts to go undiagnosed, how epilepsy can affect anyone without warning, and the health and legal implications that the condition can have.

‘It provided a great platform for raising public awareness about seizures: for us to be involved and to be able to ensure the accuracy of the storyline was a brilliant opportunity. It is amazing the impact that a few minutes prime time TV can have with scripted characters debating David’s epilepsy, initially dismissing it because it doesn’t fit the full tonic clonic profile and only gradually coming to understand the many forms that epilepsy can take.

‘Some people have been concerned that David Platt, played by Jack P Shepherd, is not a good model to link with epilepsy, but in fact people engage with the storyline because it is tense and dramatic. And we have had great feedback.

‘Not only have we managed to raise the profile of epilepsy through the broader media but social networking sites including NSE’s forum, twitter and facebook have been buzzing with comment and observation.’

NSE’s consultant neuropsychologist Sallie Baxendale, an expert in the depiction of epilepsy through the media and particularly film, added: ‘Soaps really are a good medium for conveying just what an impact epilepsy can have on a person’s life – they deal with very real everyday situations and are watched by millions of people.

And epilepsy doesn’t just happen to good people.’

Amanda draws a comparison with the recent blockbuster film My Sister’s Keeper, starring Cameron Diaz, Alec Baldwin and Abigail Breslin. ‘Alec Baldwin plays a street savvy lawyer who has epilepsy and a seizure dog. During one scene, the court has to be adjourned because Alec’s character has a seizure. Three days later he is back behind the wheel of his racy open-top sports car with his seizure dog standing in the back. That is not reality.’

Coronation Street’s chief publicity manager Alison Sinclair, commended NSE for its contribution to the development of the long-running soap’s storyline. ‘We were really keen to get it right where epilepsy was concerned,’ she said. ‘We did our own research into the condition and Jack spent a lot of time doing personal research via YouTube. But it was invaluable to have input from NSE and to have someone on set who could ensure that we were giving an accurate portrayal of epilepsy.’
Getting a fair deal

Over the last year Martin has had to take time off work on several occasions due to his seizures. Now his employers say they are letting him go because ‘things aren’t working out.’ They claim it is a performance related issue but Martin thinks this is unfair.

Gemma is living independently and coping well with her epilepsy although because her seizures are uncontrolled, she feels she would benefit from having an alarm fitted in her flat. Her neighbour suggested she could get help via social services with some of her personal care, but last time Gemma spoke to social services they said she did not qualify.

There are often times when it seems people with epilepsy and other long-term health conditions are treated unfairly. Martin thought he should be protected by the Disability Discrimination Act, but his employers said this was not relevant. Gemma found her social service department helpful but seemed to fall outside the boundaries of their services. So what next?

One-stop shop
Disability Law Service (DLS) is a one-stop shop which can provide free information, advice and legal representation on issues ranging from employment to welfare and education. It is available for anyone with epilepsy.

‘We have a large number of enquiries from people with epilepsy, with more than half involving discrimination in the work place,’ said communications manager Chris Buck.

‘Many people become concerned when they are applying for a job and are asked to declare whether or not they have epilepsy. Then there are those who are diagnosed with epilepsy and find their employers reluctant to make reasonable adjustments to their jobs to enable them to continue working.

‘Disability Law Service aims to demystify the system and give people appropriate advice and information. We are very much about empowering people.’

Disability Law Service covers the following areas:

Disability discrimination including employment, access to goods and services such as health and social care entitlement, and further and higher education.

Consumer goods and services The Disability Discrimination Act provides additional rights for people with disabilities.

Community care services All aspects of community care law including: social services assessments; NHS responsibilities; and direct payments. In some instances DLS may be able to take on a case under the Legal Service Commission’s Legal Help scheme.

Further and higher education Ensuring reasonable adjustments are made to enable equal educational opportunities for anyone with a health issue.

Employment All types of employment law ranging from dismissal and redundancy to victimisation and queries over hours, shifts and rosters.

Welfare benefits Disability Living Allowance, Attendance Allowance, statutory sick pay, incapacity benefit and working tax credits.

Contacting DLS
DLS can be contacted via their national advice line, fax or email and can provide anything from one-to-one consultations to legal representation in the courts. Each individual is offered quality advice by phone or email from a solicitor or case worker. Only if they are assessed as having a legitimate case, will DLS step in and advocate for them.

DLS aims to respond to all enquiries within 24 hours and to book a telephone appointment with a legal adviser within two weeks.

If you have an issue which you feel DLS may be able to help with, visit www.dls.org.uk or call 020 7791 9800, 020 7791 9801 (Minicom) Mon-Fri 10am-5pm, email advice@dls.org.uk or write to Disability Law Service, 39-45 Cavell Street, London E1 2BP.
My daughter will soon celebrate her second birthday. While I love being a mum I sometimes find the responsibility of caring for her overwhelming. My seizures are not fully controlled and, now that my little girl is more mobile, I worry about her safety should I have a seizure. Does anyone have any advice on how to cope? I know things will get easier when she’s older but in the meantime I worry that this stress is making my condition worse. I don’t feel I can talk to anyone about my fears as they might think I’m not capable of being a mum.

Amy, Gloucestershire

YOUR REPLIES

As soon as they were able to walk and talk I taught my kids how to look after me and phone 999 if necessary. They were taught the words ‘fits’, ‘epilepsy’ and ‘seizures’ as soon as possible. If their dad wasn’t with us the kids knew to get a card out of my pocket with his phone number on it. The card also contained my medication details.

When I started wearing a MedicAlert bracelet they were told to show it to emergency services – this was to prevent people telling them I was drunk or high on drugs.

Julie, Cornwall

I can only say that I have three children and none of them have come to any harm as result of my seizures, even though my epilepsy has never been fully controlled. I had plenty of partial seizures while caring for them, but fortunately, they were always sleeping in bed when generalised ones occurred – we always used safety gates. I felt there was some maternal protective mechanism that prevented seizures spreading, though it may just have been luck.

When I was having bad clusters (soon after each birth), I was fortunate to have family members to support me by staying with me until my husband came home.

Having an excellent neurologist also helped to gain improved control and obtain good advice.

As well as safety gates, obvious safety measures included playpen, fireguard, socket covers and keeping all medications out of reach.

Outdoors, ensure your child is properly strapped into the pram. If you’re finding it difficult to manage, you should contact your neurologist or epilepsy nurse for support. Your concerns are perfectly rational and nobody should think negatively of you. They should just try to help you obtain better support.

Name and address supplied

Eileen, Wiltshire

When my little boy was three years old, he was found wandering along the road after I had a seizure while walking him to the park. Luckily a passer-by stopped, assessed the situation and made sure my son, my baby who was in the pushchair and myself were safe. I could not have been more grateful.

Since then, I always kept my son attached to me via a wrist band so that if I should have another seizure while out, he would not be able to wander away. I also got identity bracelets for both children with my name and contact details.

My epilepsy specialist nurse advised me to also label the pushchair with my contact details and to get a pram which automatically brakes if you release the handle. These small measures have helped to make me feel far more confident.

Eileen, Wiltshire

NEXT ISSUE

I’m travelling to Australia in the new year to see my daughter who has just had her first baby, but I am worried about how I will cope with my epilepsy. Although I am traveling with my husband I still feel really anxious. What sorts of things should I be thinking about? Do I have to tell anyone about my condition and what would happen if I was to have a seizure on the flight? Stress is already making my seizures worse and all I want is to be able to help my daughter with our grandchild for the short time we will see them on the other side of the world.

Rita, Merseyside

WOULD YOU LIKE TO SHARE YOUR THOUGHTS WITH RITA?

Email nicola.swanborough@epilepsysociety.org.uk or write to Editor, Epilepsy Review, National Society for Epilepsy, Chalfont St Peter, Bucks SL9 0RJ. You can also reply via our forum at www.epilepsysociety.org.uk
In Britain we pride ourselves on being a polite society, where manners are important. Equally we ridicule ourselves for being an overly apologetic nation – I’m sorry, but it’s true!

Exactly why we obsessively apologise is a matter for separate consideration, but it strikes me that ‘please and thank you’ – the grand old bookends of polite conversation, are not rolled out with the same enthusiasm.

I know that I become enthusiastically grateful – adoring even – after I’ve had a seizure. When I’m in this ‘Bambi-state’ a sort of ‘pink mist’ descends over me and the world is wonderful, everyone is beautiful and I am utterly in love. Usually this adoration of those around me is entirely sweet and innocent. Sometimes, however, my gratitude can be somewhat bizarre.

Like many other people with epilepsy, I often get very restless after a seizure. I fidget and get up, wander around with a tremendous sense of purpose (though of course I don’t know what I’m doing quite so determinedly.)

On one such occasion, my lovely sister was trying to encourage me to just lie down and rest, but each time up I sprang up like a Jack-in-the-box on an urgent mission back into uncertain action. She had called an ambulance and, by the time it arrived, had managed to get me to lie down. But it wasn’t for long.

Hearing her talking to the nice ambulance man, I was back up again. I wandered wonkily over to the door, looked vacantly at her, at him, at her again, squeezed her bum and turned and went back to the sofa. That was my contribution, and I suppose in my own bizarre way, some kind of thank you.

It is one thing to be gushingly grateful after a seizure, but back in day-to-day life, it’s easy to forget to thank those around us. Of course I don’t just mean in situations relating to epilepsy, but while we’re on the subject…

I was waiting for a bus in South London recently and noticed two people in the unmistakable green uniform of the ambulance driver, who were also waiting for the bus (their shift had finished – they weren’t on their way to an emergency…) I’ve always felt that ambulance drivers are woefully unappreciated so I sidled up to one of them and said ‘thank you’. We struck up a conversation and I explained that I was something of a regular ambulance passenger, although thankfully not for some time! I showed him my MedicAlert bracelet by way of proof of identity, and he said that he’d had a few people with epilepsy in his ambulance that very day.

I can’t be certain, but I hope that just saying ‘thank you’ and showing some appreciation to these hard-working and (in my opinion) under appreciated ambulance workers would not only be a boost for them personally, but might make their next shift that bit more rewarding.

I have battled for my whole life against feeling that I am dependent, or (and I wince at the word) needy. I have felt that saying thank you was an act of submission, perhaps even deference; that I was weak and needed someone else’s strength. And I hated that. Nothing worse than being pitied, I always felt. I don’t want to be the victim. Don’t feel sorry for me it’s patronising; don’t ask me if I need help, I’m fine on my own etc…

What I have started to learn is that being grateful, and expressing it even with just a smile or a kind word, not only makes me feel better but is empowering. Sincere gratitude – and it’s important to distinguish between a true sentiment and an empty politeness – celebrates our connections to each other. It affirms that others have the capacity to contribute to our well-being. And what do we want out of life if not to know that we have had a positive impact on other people. Appreciation of a kindness or a generous act is more likely to encourage more of the same.

I do appreciate the generosity of the people who have helped me out of scrapes, or given good advice, or listened to me, or supported me (friends and medical professionals). I appreciate all the people who have made the cup of tea I’m drinking possible – from the person who picked the leaves thousands of miles away in Sri Lanka, through the complex series of events that brought the box of tea bags to my supermarket shelf. I can’t thank all of these people individually. But there are plenty of people in my day to day life who I can thank, and who would no doubt feel valued if I did.

Goodness, I am starting to sound sanctimonious. Sorry. (Though truthfully, I’m not really sorry!)
Northern lights

This year we received the third instalment of a three-year grant, generously given to us by The Henry Smith Charity, specifically to support our work in the north of England.

The grant has enabled us to bring vital services to hundreds of people affected by epilepsy. We now have 39 information stands across the region – 20 of them staffed by our volunteers – with seven new services including Blackpool, Newcastle, Huddersfield and Pontefract. In the last year we have welcomed 10 new volunteers to the network and distributed more than 34,000 of our information leaflets.

Bridget Gardiner, NSE’s director of fundraising and marketing, said: ‘We are extremely grateful for the support of The Henry Smith Charity. It has really enabled us to grow our services in the north and reach out to so many more people with epilepsy. Thank you.’

Royal visit

Her Royal Highness The Princess Royal flew into NSE’s Chalfont Centre in Buckinghamshire to officially declare Queen Elizabeth House open.

Set in the Chiltern Hills, the light and airy residential home provides tailor-made accommodation for up to 20 residents with complex needs.

The Princess Royal arrived by helicopter and met residents, families and staff before unveiling a plaque to mark her visit. Said chief executive Graham Faulkner: ‘The day was a great success – our residents really enjoyed having a royal visitor.’

Oh what a night!

It was a night of sheer glamour and elegance when 180 guests turned out for NSE’s annual charity dinner at sky-high Altitude 360 on the 29th floor of Millbank Tower in Westminster.

With dizzying panoramic views across the capital, the glitzy occasion was hosted by tv presenter, adventurer and writer Ben Fogle, pictured above with supporter Cosi Pole. The dinner raised an amazing £60,000 for NSE.

Guests included a group of our Epilepsy Information Network (EIN) volunteers whose table was funded by a benefactor as one in a year-long series of celebrations to mark the network’s 10th anniversary.

Said volunteer Ruth de Grey who attended the dinner: ‘It was a super evening and a brilliant venue. It was wonderful to see so many turning out to raise funds for the charity.’

Listening ear

NSE’s helpline manager Chris Brock (below) was joined by helpline operators past and present to celebrate 20 years of the service with a tea party. In spite of information being available online, the emotional support provided by our helpline team today is just as vital as it was in 1990. The helpline takes almost 6,000 calls in a year, with callers continuing to raise concerns about diagnosis, medication and first aid. More recently there has been an increase in calls about changes to the benefits system.

Epilepsy Helpline
01494 601 400
Mon-Fri 10am-4pm

Counting on the Countess

NSE is pleased to welcome Countess Howe as its new president. The countess takes over from her husband Earl Howe who has been a supporter and president of the charity for more than 25 years.

Countess Howe is also High Sheriff of Buckinghamshire. Graham Faulkner, the charity’s chief executive said: ‘We are delighted Countess Howe is taking on the role of president. We look forward to working together.’

Christmas giving

There’s still time to order your NSE Christmas cards and gifts from our 2010 catalogue which is packed full of cards, wrapping paper and stocking fillers. And don’t forget Caring2Give, our alternative gift selection supporting NSE’s work including medical research.

Call 01494 601 414 or visit www.epilepsysociety.org.uk
Jo had a rough night during freshers’ week

but it wasn’t because of the party

find out more...

www.epilepsysociety.org.uk
/universitychallenge

Did you know if you have epilepsy you can get financial, practical & emotional support for university? See the website or call the epilepsy helpline on:

01494 601 400
Mon-Fri 10am-4pm (national call rate)

Website – for epilepsy information or to get involved
www.epilepsysociety.org.uk

Epilepsy Helpline – information…time to talk…emotional support…translation
01494 601 400
Monday – Friday 10am-4pm (national call rate)

Epilepsy Review – the definitive magazine written by experts. See the flap attached or log on to www.epilepsysociety.org.uk/shop

Research – find out about our pioneering medical research. Log on to www.epilepsysociety.org.uk/whatwedo/pioneeringresearch

Information – check out our leaflets, booklets and dvds. Call 01494 601 392 for a full list or log on to www.epilepsysociety.org.uk/aboutepilepsy

Seizure management – NHS referrals can be made to our epilepsy specialists, assessment centre, or therapeutic drug monitoring service. Have a look at the website www.epilepsysociety.org.uk/whatwedo

Referral by GP or consultant’s letter to NSE Medical Department, Chesham Lane, Chalfont St Peter, Bucks SL9 ORJ or call 01494 601 349

E-newsletter – news and information direct to your computer. Sign up at www.epilepsysociety.org.uk

Forum – want to talk online to other people affected by epilepsy? Join us at www.epilepsyforum.org.uk

Facebook – connect with NSE online. Find us at www.facebook.com

Volunteer – could you help us inform people at an epilepsy clinic or school near you? Call the Epilepsy Information Network on 01494 601 391 or see www.epilepsysociety.org.uk/getinvolved/ein

Expert care – we offer day care, supported living, respite care and residential care for people with complex epilepsy. Have a look at www.epilepsysociety.org.uk/residentialcare or call us on 01494 601 374

Health professionals – for expert medical information and research. Log on to our dedicated website for health professionals www.epilepsysociety.org.uk/forprofessionals

Membership – get involved and keep informed. See flap attached or log on to www.epilepsysociety.org.uk/getinvolved/becomeamember

Pioneering research, providing expert care, promoting awareness
01494 601 300