FAMILY FOCUS

Talking about your epilepsy – who do you choose to confide in or do you keep it to yourself? To tell or not to tell page 6

WELL BEING

In the dentist’s chair – we investigate the issues surrounding seizures and teeth Open wide page 8

MEDICAL RESEARCH

Could the way a person describes their seizures help to determine whether they have epilepsy? The language of seizures page 15
2012 looks set to be an Olympic year in every sense of the word. Boxing champ and carer Andrew Lofthouse will be flying the flag for all those who look after people with epilepsy when he carries the Olympic torch on its journey to London. World champion hurdler Dai Greene will be carrying the hopes of a nation on his shoulders as one of Britain’s top gold medal contenders – proof that having epilepsy need not stop you becoming an elite athlete. And Epilepsy Society is marking its 120th year!

Epilepsy Society was founded in 1892, four years before the first of the modern games organised by the International Olympic Committee. And in the same way that the Olympics have grown beyond anything Victorian life could have imagined, so have we. From being a philanthropic institute that sought to offer a better life in the countryside for a limited number of people with epilepsy, we now work with you towards a full life for everyone affected by the condition. And the impact of people power is ever apparent.

At the end of last year a cheer went up as the Government bowed to public pressure not to cut the mobility component of Disability Living Allowance (DLA) for people with epilepsy in residential care. A sure sign that if we shout loud enough, the Government will listen.

And health minister Paul Burstow agreed to meet with epilepsy charities to discuss how commissioning changes within the NHS could bring about better services for people with epilepsy. At last epilepsy has a real voice.

Throughout our 120 years we too have learned the importance of listening. So when you told us better seizure control is key to living a full life, we took note.

We have launched a major campaign Targeting Seizures which we hope will help bring about the changes needed to give people the best possible seizure control. It’s an Olympic challenge but we’re up for it.

Our first step is to look at why people choose – or don’t choose – to take the very tablets that could help minimise their seizures. And we would be grateful if you could take part in our Epilepsy – taking the tablets? survey at www.epilepsysociety.org.uk/targetingseizures

Your help is very much valued. Thank you and a happy new year to you all.

Nicola Swanborough
Editor
People power wins the day

When the Government announced plans to withdraw the mobility allowance for people in residential care, those affected refused to keep quiet – and their voices were heard.

It’s official! People with epilepsy living in residential care can keep their mobility allowance. The news follows a powerful campaign by Voluntary Organisations Disability Group (VODG) to persuade the Government to review plans to scrap the £51-a-week benefit payment.

Campaigners had warned that removing the allowance would rob some of the most vulnerable people of their independence. It would leave as many as 80,000 people with disabilities living in care homes unable to get out and with a reduced quality of life.

The cuts could have saved £135m a year, just 0.2 per cent of proposed public spending cuts.

In December, parliamentary under-secretary of state for work and pensions, Maria Miller, confirmed that the mobility component of Disability Living Allowance (DLA) will not be removed from those living in residential care homes. DLA is to be replaced by the Personal Independence Payment (PIP) and Ms Miller gave her assurance that the mobility component would continue to be paid to those who met the entitlement conditions.

‘Our aims have always been to ensure that disabled people in residential care homes retain their independence and are not prevented from getting out and about,’ said Ms Miller.

VODG campaigned to demonstrate the impact of the cuts on people with disabilities and to persuade the Government to reconsider. An independent review of personal mobility in state-funded residential homes was also led by Lord Low and found that removal of the mobility allowance would lead to severe loss of independence for those with disabilities.

Ms Miller said the review highlighted the lack of evidence to justify withdrawal of the mobility allowance.

Graham Faulkner, chief executive of Epilepsy Society and vice chair of VODG said: ‘This is excellent news for people with complex epilepsy in residential care! It is good to know that if we make enough noise sometimes the Government does sit up and listen.’

Older AEDs linked to hardening of the arteries

New research shows that people with epilepsy who were treated for long periods with older generation anti-epileptic drugs (AEDs) may be at increased risk of developing atherosclerosis, a common disorder more usually known as hardening of the arteries.

Researchers at Kaohsiung Chang Gung Memorial Hospital in Taiwan looked at 160 adults with epilepsy who had received a single AED for more than two years and a comparative group of 60 healthy adults. Those people who had taken long-term phenytoin, carbamazepine or valproic acid were found to be at increased risk of hardening of the arteries.

Researchers suggested that drugs should be carefully selected for people with epilepsy who require long-term AED treatment, particularly in the elderly or those at risk of vascular disease.

Lead author Dr Yao-Chung Chuang said: ‘Our findings suggest that newer AEDS such as lamotrigine, may minimise metabolic disturbances and reduce the risk of atherosclerosis.’

Epilepsy Society’s medical director Professor John Duncan commented: ‘This is an interesting finding, but we should be cautious in concluding that an association between AEDs and hardening of the arteries proves a cause. ‘It may be, for example, that for those people with premature atherosclerosis this may have been an initial cause of their epilepsy.’

Caught on camera

In a new initiative in South Tyneside, parents are to be given video recorders to capture their children’s seizures and make diagnosis of epilepsy easier.

Seizures often happen in the home and although parents are able to describe to doctors what has happened, it can be difficult for medical experts to make a definite diagnosis and decide how best to treat the condition.

The children’s community nursing team at South Tyneside NHS Foundation Trust have been given the cameras by the League of Friends. The cameras will be lent to families as necessary depending on the frequency of seizures.

The nursing team hopes that assessment in the home may help avoid hospital admission altogether.

www.shieldsgazette.com
Call for more epilepsy surgery

Jasmine Smith and Elyse Westrip are two of the lucky ones. Jasmine, 20, underwent brain surgery for her epilepsy last year. Elyse, 19, had surgery in 2010. For both girls the operation was life changing.

‘Since my operation I really appreciate everything about my life,’ says Jasmine. ‘I don’t take anything for granted.

‘I’ve not had a single seizure since my operation,’ says Elyse. ‘It has changed my life completely. I’m far more confident now.’

New research published in The Lancet shows that the long-term outcome of surgery for patients is good. Almost 50 per cent of patients remain seizure free after undergoing surgery and no candidates experience worsening of their seizures.

But not everyone is as lucky. Professor John Duncan, lead author of the research and Epilepsy Society’s medical director, said that many people with epilepsy are having to wait as long as 20 years before being referred for surgical treatment.

Professor Duncan said: ‘Surgery is not suitable for everyone with epilepsy, only those with focal epilepsy where the source of the seizure can be identified. But the long-term outcomes are very positive and can turn people’s lives around. Prompt referral is key.

‘If patients with focal epilepsy have tried two or three AEDs and are not gaining seizure control, they should be referred for surgery.

‘At £25,000, the cost of surgery may seem expensive to the NHS but in the longer term there is a cost efficiency with people needing less medical input, being able to work and easing the costs to society and themselves.’

Epilepsy Society’s medical director Professor John Duncan has been appointed clinical director of the National Hospital for Neurology and Neurosurgery (NHNN), London. Professor Duncan will continue to be involved in epilepsy research and his new appointment will strengthen the charity’s position on the neurological platform. Epilepsy Society’s chair of epilepsy, Professor Ley Sander will act as interim medical director.

Emergency services come under scrutiny

A National Audit of Seizure management in Hospitals (NASH) across the UK is due to be published imminently. The extensive study has looked at facilities and care available to patients with epilepsy at 127 NHS emergency departments. The aim is to identify how best to improve services and reduce the numbers admitted to hospitals as an emergency.

The audit, co-ordinated by the University of Liverpool, is hoped to have a major impact on patient care nationwide. Subject to funding, it will be repeated in two years time to measure the outcome for people with epilepsy.

Caring about carers

Epilepsy poses a unique set of challenges for those who care for someone with the condition. That is the finding of Connecting with carers, a new report which focuses on the impact of caring for a person with epilepsy.

Unlike many other long-term health conditions epilepsy is unpredictable and often invisible says the report, with carers finding it difficult to know exactly when care is needed and at what level. This can make it particularly difficult for carers to plan their routine and arrange with their employers for time off from work.

Connecting with carers has been produced by Epilepsy Society and funded by the Department of Health’s Reaching out to Carers Innovation Fund. Said Rona Eade, epilepsy information manager and author of the report: ‘The project enabled us to really look at the needs of those who look after people with epilepsy and to develop the way we support them through our website, helpline and forum.

‘The contributions of carers to the individual and to society are far reaching. For example, supporting an individual with epilepsy may help reduce the number of times they are admitted to hospital following a seizure.

‘If resources permit, we hope to work with the health service, employers and other agencies to raise the profile of carers and measure their value in society.’

Well done to carer and Thai boxing champ Andrew Lofthouse who has been chosen as a 2012 Olympic torch bearer

www.oldham-chronicle.co.uk
Local service for local people

Health minister Paul Burstow has pledged to meet with epilepsy charities to discuss how new NHS commissioning will work on a local level to provide the right services for people with epilepsy and reduce the number of sudden unexpected deaths.

Speaking during a debate in Westminster Hall on ‘prevention of avoidable deaths from epilepsy’, the minister emphasised that the future of public services would sit within a local context rather than a national one led by the Department of Health.

‘It is about clinical commissioning groups working locally with patient groups and others to understand local needs and to ensure that they structure services with those in mind,’ said Mr Burstow.

The minister said that the publication of the first NHS outcomes framework would help drive up performance further and identified four specific areas that would help people with epilepsy judge the overall performance of the NHS.

The outcomes framework would look at how the NHS was:

– preventing people from dying prematurely from causes considered amenable to healthcare
– enhancing quality of life for people with long-term health conditions
– helping people to recover from episodes of ill health
– providing positive experiences of healthcare.

‘There will still be a rich conversation at national level about action,’ the minister concluded, ‘but there will be an even richer conversation about outcomes, performance and commissioning at a local level.’

Over 1,000 people die from epilepsy in the UK each year. Four hundred of those deaths could potentially be avoidable.

Medicines update

Retigabine
Recently licensed retigabine, manufactured as Trobalt, has been blacklisted by some Primary Care Trusts according to GP Magazine, because of the cost. If you have any problems with your prescription call Epilepsy Society on 01494 601 300.

Buccal midazolam
Emergency seizure drug Buccolam, produced by Viropharma and used to treat prolonged convulsive seizures, has been given European approval for the treatment of babies over three months old and children under the age of 18.

Levetiracetam
Keppra, the brand name of levetiracetam made by UCB, is now off brand, and the first generic version is available. As with all drugs the branded version is not necessarily better than the generic version but it can be useful to keep to the same version. For enquiries about Keppra, contact UCB on 01753 534 400.

EDITOR’S CHOICE

Epilepsy: Complementary and alternative treatments
By Dr Sallie Baxendale

More than half a million people in the UK have epilepsy and for 30 per cent of them AEDs fail to bring their seizures under control.

It is little wonder that those who have to live with seizures often look beyond their pills for treatments which might help them live with their condition. And it is for these people that Dr Sallie Baxendale has written this book.

Will homeopathy control your seizures? Could Chinese medicine or Ayurvedic medicine provide a safe alternative to anti-epileptic drugs? Can epilepsy be controlled through diet? Does light therapy work?

Dr Baxendale is a consultant clinical neuropsychologist at Epilepsy Society. Her aim in writing this book is to present objective scientific evidence for and against some of the most popular complementary treatments available for epilepsy today.

As one might expect Dr Baxendale does not find a great deal of scientific evidence for the helpfulness of complementary therapies in epilepsy, as the medical research has just not been carried out. There are few scientific trials of complementary therapy for any health condition, and this is much the same for epilepsy.

But she makes a thorough search of the scientific literature to bring to us whatever is there, and does identify some encouraging evidence for a few therapies.

If you would like a medic’s perspective on the scientific evidence for complementary therapy in epilepsy – then this may just be the book for you.

Jenny Rush, editor-in-chief, Epilepsy Review

Buy the book (£8.99) at Amazon via www.epilepsysociety.org.uk/fundraiseforfree and five per cent of the total sale will go to Epilepsy Society.
To tell or not to tell?

Deciding to tell someone about your epilepsy can be difficult. Epilepsy Society’s Jenny Rush asks who do people choose to open up to, and why?

Mention the word ‘epilepsy’ and it can evoke unpredictable responses. Many people are fine with it. But sometimes the look of initial panic in the eye of someone you’ve just told about your epilepsy or seizures can be palpable.

The awkward responses to epilepsy can be perplexing. And that means that when someone affected by epilepsy walks into a room there can often be a decision to be made. To tell or not to tell? We decided to ask the question and 100 people filled in our survey.

Their responses show that it’s a dilemma. Tell people and you may get a perfectly fine and sensitive response, but you also risk an inappropriate, hurtful and even aggressive outburst. Don’t tell people and you can become isolated and begin to think of epilepsy as something too scary to talk about. There can be a real sense of ‘damned if you do and damned if you don’t’.

People affected by epilepsy said they react in different ways to this. Some keep themselves to themselves and only tell the people closest to them. It’s a personal matter and of no concern to the rest of the world. Others become campaigning about epilepsy and tell everyone they come across in order to make people realise it’s a long-term health condition that can speak its name.

For some people with epilepsy, their seizures make the choice for them – announcing it to the world whether they want they it to know, or not. About half said they talked about their experiences in case others become scared of them having a seizure. Other worries are that ‘they might try and stop me doing things’, ‘they might worry about me’ or ‘it might affect our relationship’. Another concern was ‘they might make assumptions’ or ‘judge me’.

An equally valid point is that ‘it’s personal to me’. Not everybody walks into a room and announces their health condition. Embarrassment can play a part, however, as it does so often – for ourselves or for others. A few felt that other people have ‘got enough on their plate already’.

Sadly, about a fifth thought that other people would ‘never understand’. Many people don’t even try to explain. They may be connected to the few who said ‘I wouldn’t know what to say’ and ‘I’d like to tell them but I don’t know how’.

Given that people have fears and concerns about telling people about epilepsy, why do people decide to tell?

The most important reason people talk about epilepsy is to let other people know how to handle a seizure. So seizures are obviously at the heart of the matter on the ‘do I?’ or ‘don’t I?’ scale.

But close on the heels of the seizure factor is the wish to be close and to communicate. Just under half of people said they would ‘tell’ because ‘it’s good to talk it through sometimes’ and half also said they tell ‘because we care about each other’. Many said ‘I feel better if I can talk about it’.

Confidence in a positive response is important, with many saying they would tell if ‘I think they will be understanding’ or ‘I think they will offer me support’.

Make the Connection survey and report, Jenny Rush, Epilepsy Society, 2012
www.epilepsysociety.org.uk
They don’t really want to know
To protect my spouse and his job
It would involve long explanations
It wouldn’t be relevant – they don’t know me very well
I only talk about my husband’s epilepsy if I am asked about it – I feel everyone has problems to deal with and this is one of ours

I do ‘tell’ about my experiences with epilepsy because...
They may be interested
There are implications regarding my work and voluntary work
I know my friends understand – I usually only mention it if I have a bad seizure, otherwise I just want to be like everyone else
The impact of epilepsy and medications affects my memory and mood state and I need people to understand

Quotes taken from the Make the Connection survey
Open wide

Living with epilepsy often means living with recurrent dental injuries or oral side effects from medication. And one too many visits by the tooth fairy. Here we look at some of the issues surrounding seizures and teeth, while over the page Dr Guy Hollis gives his top tips for dental healthcare.

When Louise Bolotin from Manchester transferred to a new dentist, she couldn’t believe her luck. ‘For the first time ever I had found a dentist who completely “gets” epilepsy,’ she explains. ‘With my previous dentists, as soon as I mentioned the word “epilepsy” you could see the fear in their eyes as they worried they were going to get their fingers bitten off if I had a seizure in the dental chair.

‘On top of that, I had lived with 15 years of constant plaque which I had been trying to manage myself in between appointments. It was only when I saw my new dentist that he explained the plaque could be all part of problems caused by my anti-epileptic drugs.’

Louise’s story is not unusual. The unpredictable nature of seizures combined with side effects from some medications can add to the long-term impact of epilepsy. Issues range from experiences in the dental chair to gum disease, broken or lost teeth and the stigma associated with dental injuries.

Research has shown epileptic seizures to be the most common medical incident in the dental surgery – stress is often a trigger for seizures. Dental injuries rate as the third most common non-fatal seizure related injury after head injuries and burns and scalds. And dental treatment – unless you are on means-tested benefits – is not free for people with epilepsy. NHS prices can range from £17 for a check up to £204 for dentures, crowns and bridges.

In a study of 1,673 people with epilepsy in Gloucestershire, researchers found that dental injury occurs in approximately one per cent of people with epilepsy and for those with juvenile myoclonic epilepsy (JME) which starts in adolescence, this figure rises to around 10 per cent.

Lead researcher Dr Rhys Thomas from Wales Epilepsy Research Network at Swansea University said the significant increase in dental injury in people with JME was probably due to the sudden onset of a seizure without an aura, giving the person no time to take any safety precautions.

‘A build-up of myoclonic jerks prior to a generalised seizure should act as a warning, but because it also promotes a loss of power and sudden falling forwards it results in more injuries to the front teeth in those with JME,’ he said.

‘There may be other factors too that account for the increase. For example in JME, seizures are more likely to occur first thing in the morning in the bathroom, providing more hard surfaces for the person to fall against than in other settings during the day.’

A further research study into dental care in Nigeria may at first glance seem to have little relevance to the UK experience. Out of 56 patients with epilepsy, 46 per cent were found to have injuries to their front teeth attributed to the traditional practice of forcing spoons and other hard objects into the mouth during seizures.

Although this was outside the findings of the WERN research, Christine Brock, manager of Epilepsy Society’s Helpline, said that in spite of awareness raising, the helpline still occasionally receives calls from people who believe you should place a stick or spoon in a person’s mouth if they are having a seizure.

‘Anecdotally, while mouth guards obviously won’t stop seizures, they can reduce injuries, particularly for those who have asleep seizures,’ says Dr Rhys Thomas of WERN. ‘People express their concern that they might swallow the guard, but I have never heard of this happening and
All dentists are fully trained to treat people with epilepsy, giving you the best possible chance of receiving quality oral health care.

in fact they are too large to be swallowed.

I have even heard of someone using their guard from their teeth whitening kit to prevent damage to their teeth and mouth during a seizure.

Oral health educator for Buckinghamshire, Julie Ailward warned, however, that while a guard may be good for protecting teeth in some circumstances, it could have a detrimental effect in terms of communication and social interaction.

I would recommend that any mouth guard is made professionally to match the person’s own teeth and bite,’ she stressed.

But issues surrounding dental care extend beyond dental injuries. At the University of Bonn, research has shown that phenytoin can cause gingival hyperplasia or gum overgrowth in 50–60 per cent of people who are prescribed it, with inflamed gums threatening to engulf the tooth and cause sensitivity and bleeding. Treatment includes a switch to alternative anti-epileptic drugs and improved oral hygiene (see page 10).

Dr Guy Hollis, Epilepsy Society’s dental expert said that in the wider community of people with epilepsy, the problems caused by phenytoin should be self-limiting as the medication is no longer prescribed as a first choice of treatment for this very reason, although there are still many people taking it.

However, many other problems persist such as dry mouth (xerostomia), broken teeth due to jaw clenching plus sores on the tongue and inside of the mouth caused by biting during a seizure and sometimes as a reaction to medication,’ he said.

Alongside these issues comes the relationship between patient and dentist and the search for a dentist who ‘gets’ epilepsy. While many report a very positive patient experience with the dentist proving informed, relaxed and empathetic, others report a nervousness and tension with the dentist fearing the onset of a seizure during a routine check-up.

His eyes were round as saucers when I zoned out,’ said one patient. ‘I was only trying a bit of mind over matter in the dental chair, but he thought I’d had a seizure and whipped everything out of my mouth.’

Chief Executive of the British Dental Health Foundation, Dr Nigel Carter emphasised the importance of communication in the dental surgery and the commitment of dentists to provide a supportive and safe service for people with epilepsy.

‘All dentists are fully trained to treat people with epilepsy, giving you the best possible chance of receiving quality oral health care,’ he said.

It is important to tell your dentist if you have epilepsy, or have ever had any sort of fit in the past. This is to make sure the dental team is fully prepared if you do fall ill during treatment and can respond accordingly if necessary.

‘Patients with epilepsy may find they are more likely to have fits when they are anxious. Tell your dentist if you have any concerns before or during your treatment. The dental team will make sure the surgery is safe for you and there is no risk of harm to you.

‘If you undergo treatment the dentist will be unable to administer the usual adrenaline anaesthetics, as there could be a risk of it going into the bloodstream and possibly resulting in stress for you. Instead, dentists will use a non-adrenaline based anaesthetic, which might not last as long, but will perform exactly the same function.’

Read Guy Hollis’ top tips for dental care over the page.
1. Make sure you tell your dentist about your epilepsy, seizure type, frequency and triggers. It may be useful to take along your seizure diary to your appointment and a list of your medications. Be open about any fears and anxieties you may have.

2. Discuss with your dentist what action to take should an emergency occur in the surgery. Seizures are one of the most frequent incidents in the dental chair and dentists are trained to deal with such emergencies.

3. Good nutrition is vital for dental care. Avoid sweet, sugary foods and liquids which can contribute to tooth decay. Acidic drinks may cause erosion. Avoid coffee, alcohol and smoking.

4. Brush your teeth twice daily for at least two minutes, preferably with a small-headed electric toothbrush. Flossing your teeth daily can help to keep gums healthy and remove any build up of plaque. Rinse with a chlorhexidine gluconate (Corsodyl) mouthwash in the morning to help kill bacteria and a fluoride mouthwash in the evening to help strengthen your teeth.

5. Phenytoin can cause enlarged gums (gingival hyperplasia) which may lead to halitosis (bad breath) and a susceptibility to gum disease. Good oral hygiene is important but you should always seek the advice of your dentist and GP and discuss changing to a different medication.

6. Some medication can cause dry mouth (xerostomia), causing constant thirst and difficulty when eating and speaking. Reduced saliva can encourage the growth of bacteria in the mouth and increase the risk of tooth decay, gum disease and disease in the lining of the mouth. Take regular sips of water, chew gum or use artificial saliva as prescribed by your dentist.

7. Biting the tongue or the inside of the mouth during a seizure can result in painful ulcers. If brushing your teeth is uncomfortable, try rinsing with Corsodyl or applying medication such as Iglu until the swelling subsides. Sucking an ice cube and taking painkillers may also help with ulcers. If you have painless ulcers for more than 14 days, make sure you see a dentist.

8. If you fall during a seizure and damage your teeth, arrange an emergency appointment with your dentist as soon as possible. If injury or side effects from drugs affect your appearance and self confidence, discuss the possibility of cosmetic treatment with your dentist.

9. See your dentist regularly to ensure problems are prevented or treated.

10. Don’t get too hung up about your epilepsy. For the average person with epilepsy, their oral hygiene is as good as in the general population.

In an emergency

If a tooth is knocked out
You or someone with you should handle the tooth carefully by the crown, not the root. If it is clean, replant the tooth in its socket immediately and bite on a clean handkerchief to keep the tooth in position until you seek advice from your dentist.

If the tooth is dirty, rinse in milk or under cold water but do not scrub. If you are unable to replant the tooth or do not feel confident in doing so, store in milk or place in saliva, for example in the person’s mouth, next to the cheek. Seek medical advice as quickly as possible.

If a tooth or denture is inhaled
If the airway is mildly blocked but the person can speak and breathe, encourage them to cough to dislodge the tooth.

If the airway is severely obstructed and the person is having difficulty breathing, administer five back blows between the shoulder blades followed by five abdominal thrusts. If you are unable to dislodge the tooth, call for an ambulance.
For those whose seizures are well controlled, safety in the home may be no more of an issue than for anyone else. But when seizures are a regular occurrence it can be wise to consider extra safety measures that will minimise risks at home.

When we are at home we tend to relax and are less alert. In 2004, a European study showed that people with epilepsy have a seven per cent chance of an injury in the home while for others the risk is three per cent. Further studies have shown that for people with epilepsy the majority of burns happen while cooking, ironing, blow-drying hair and bathing.

Social worker Sally Garrett-Smith looks at some basic safety measures around the home while Epilepsy Society’s Lukasz Abramowicz investigates personal safety alarms.

Safety in the home

It is the simple everyday activities that we take for granted that can put anyone with seizures at risk of injury. Bathing, cooking, carrying a cup of coffee from one room to another – even sleeping in a warm, comfortable bed can pose certain risks if you have asleep seizures.

For anyone with epilepsy, singing in the bath takes on a greater significance, while microwaving dinner may be more than a shortcut to a quick meal. Locked doors can spell untold danger. Tales of people having seizures in the bathroom and falling against the locked door are all too common. Injuries sustained by those who fall on hard wooden floors are all too visible.

We all want to feel safe and confident within our own homes. We want to be able to relax and unwind in our own independent space while enjoying an expected amount of privacy.

The following safety advice is designed to help make your home safer. It may not all be relevant to your particular circumstances but will hopefully help you to identify the most appropriate safety measures for you.

AROUND THE HOME

Stairs
Stairs can pose certain dangers if you have seizures. If you are worried you may fall down the stairs, it is wise – as far as is practical – to minimise the number of times you use them during the day. Some people who are concerned about falling from top to bottom in the event of a seizure on the landing choose to fit a stair gate. Placing a non-slip rug at the foot of the stairs can also help reduce the impact should you fall.

Asking someone else to assist you on the staircase can pose a risk to that person. If you fall you may hurt them, making it difficult for them to access help on your behalf if necessary. Handrails on the staircase may be useful, however. If you have seizures frequently, you may like to consider going upstairs on hands and knees and coming down on your bottom, so minimising risk of a fall.

Fires and radiators
If you have an open fire it is recommended that you use a fireguard that can be securely fixed to the ground to stop you falling into the fire. Covers or a large towel
are recommended for radiators and lagging for exposed pipes. Use thermostatic controls to keep the temperature on your radiators at a low, safe level, minimising the risk of burns should you fall against them. Placing a piece of furniture such as a table or sofa in front of a radiator can create a barrier and save you from potential harm.

**Floors and upholstery**
When choosing flooring and furnishings you might wish to think about your risk of injury should you fall against them. Try to avoid hard surfaces such as ceramic tiles, rough carpets which could result in friction burns, rugs that slip and loose stair carpet fittings. Non-slip flooring, cushioned floor covering and carpet may help reduce risk.

Fitting protective covers over the corners of furniture or using round tables may help you avoid injury should you fall against them. Protective corners are available from many high street shops.

**Doors and windows**
Toughened safety glass is designed to be hard to break or to hold together if it is broken. It may be worth checking if your doors and windows have been fitted with safety glass and, if not, to consider fitting it. An alternative is to use safety glass film which prevents the glass shattering if it is broken. This is available from DIY or hardware stores.

Rounded door handles may be less likely to cause injury should you fall against them. Fitting double-hinged doors that can open both in and out in the event of an emergency may be a sensible precaution. People who tend to wander during a seizure often choose to install double locks on external doors.

**Electrical appliances**
Wherever possible, use cordless equipment with automatic cut-outs. It is better to use additional power sockets rather than to run extension cables and multipoint plugs. Kettles, irons, hairdryers and DIY tools can be dropped during a seizure causing serious burns, scalds, injuries and fires. If possible it is best to avoid using these appliances if you have seizures, or make sure you have someone with you when you do.

**Storing medication**
Keep medication securely out of reach of young children. You might like to keep your tablets in a drug wallet or dispensing box, available from your local pharmacy or [www.epilepsysociety.org.uk/shop](http://www.epilepsysociety.org.uk/shop). You could use your mobile phone to set an alarm to remind you to take your medication. Make sure that old medications are disposed of safely by returning them to your local pharmacy.

**Lighting**
Make sure you have adequate lighting, especially at night if seizures cause you to get up and wander around. Night lights give low level lighting and can be plugged directly into sockets. Sensor lights are an option as they automatically turn on when they sense movement.

**Fire safety**
Install a smoke detector and fire alarm. Contact your local fire service for free smoke detectors and a home visit about fire awareness. If you have seizures it is worth assessing the risks of smoking indoors. Having a seizure while smoking could cause a fire or a nasty burn.

**ROOM BY ROOM**

**Bedroom**
It may be useful to remove unnecessary furniture from the bedroom to reduce the number of obstacles that may cause injury. Consider using a bed seizure alarm (see overleaf) and having a telephone next to your bed in case you need to call anyone in an emergency. Choose a bed without a hard frame, a divan type bed with a
padded headboard will reduce injury. If you are worried about falling out of bed, sleep on a mattress on the floor. A futon may be an option. Avoid soft feather pillows which increase the risk of suffocation. Breathable safety pillows are available from www.sleep-safe.co.uk

Wheat heatable beanbags are recommended instead of hot water bottles. The beanbags can be heated in the microwave, reducing the risk of burns from hot water (beanbags are available from your local pharmacy). If using an electric blanket, remember to turn it off before going to bed.

Kitchen
It is safer to heat food in a microwave rather than a conventional oven as this will reduce risk of burns. When heating or cooking foods, a microwave doesn’t get hot to the touch so you are unlikely to burn yourself if you should touch it during a seizure. Microwaves also switch off automatically when the food is cooked so there is less chance of food burning or a fire starting if you leave it unattended.

If you’re making a hot drink there are several options:
– Use a microwave as above to heat the water
– Use a kettle tipper with your kettle.
– Disabled Living Foundation has information about these and other safety products (see overleaf)
– Use a one-cup hot water dispenser (www.argos.co.uk)
– Use a small hot water urn (www.hygienesuppliesdirect.com)

When transferring hot liquids and foods from the microwave or cooker, use a trolley rather than carrying them. Think about using shatterproof crockery to reduce the risk of injury from sharp edges if broken.

If you are using a cooker make sure the heat can be quickly controlled. Use the back hot plates rather than the front ones and turn the saucepan handles outwards to the side of the hot plates.

Grilling food is safer than frying (avoid eye level grills). Health grills with a time control are a safer option (from mainstream stores such as Argos). If you are boiling vegetables in a saucepan, use a cooking basket as this can be lifted out and drained, avoiding potential burns and scalds from carrying saucepans with boiling water.

If you are worried about knives, consider using a manual or electric chopper to chop vegetables and fruit.

Bathroom
Choosing between a bath and a shower is, of course a personal choice, but a shower remains the safest option as the water drains away so reducing the risk of drowning. Level access or walk-in showers are the best option and sitting on a padded shower seat under the shower may minimise the risk of falling. Thermostatically controlled taps are also recommended.

A shower curtain rather than a screen or door might make it easier for someone to get to you in an emergency. Non-slip shower mats are also recommended.

If you choose to have a bath, do so while someone else is around so that help is at hand. Using a monitor might make it easier for someone outside to check that all is well while also giving you your privacy. Don’t lock the door – you can always hang an engaged sign on the door. And singing loudly is a sure sign that all is well.

Ensure the water is not too hot by running the cold water first. That way, if you have a seizure and fall in you won’t scald yourself. Don’t fill the bath more than a few inches deep and use a floating bath plug.

You could think about sitting in the bath on a non-slip mat and pouring water over yourself or using the shower on the mixer taps.

Floor tiles made of rubber or other soft material may be safer than hard or polished floors. If you need a grab rail, try a Prima rail which has a softer surface than mainstream rails (www.homecraft-roylan.com).

Garden
Avoid rough/concrete surfaces, uncovered ponds, prickly shrubs and hedges. Use plants, shrubs and rubber matting to cover hard surfaces. Keep a strong netting over ponds. If you experience auras, find a safe area to retreat to. Use powered mowers with care, avoid flexes and use equipment with automatic circuit breakers.

FIRST AID AND EMERGENCIES

Keep a first aid box handy and explain to friends and family what to do if you have a seizure. First aid and information about epilepsy can be downloaded via Epilepsy Society’s app (www.epilepsysociety.org.uk/digital).

Keep a list of emergency contacts handy with a description of your seizures and what should be done if you have a seizure. Think about a ‘keepsafe’ key box for house keys to be kept securely outside for use by emergency services or an identified key holder.

Wear a MedicAlert bracelet or necklace with immediate access to your details.

Keep a list of emergency contacts handy with a description of your seizures and what should be done if you have a seizure
**ALARMS**

You may like to consider a safety aid or alarm that will notify friends, family, carers or emergency services if you have a seizure or a fall.

**Telecare alarms**

Telecare means ‘care delivered from a distance’ for people living in their own homes and in many ways is a step forward from the community alarms that were introduced in the ‘60s and ‘70s.

Community alarms with pull cords or panic buttons are still popular and work by sounding an alarm so carers know that something has happened to the person using it. However, research shows that they are not always easy to access in emergencies. People may be reluctant to use them, often fearing they may end up in hospital or simply choosing not to sound the alarm because they don’t want to trouble others.

In recent years these issues have played a part in the development of telecare in the form of so-called ‘smart sensors’. Smart sensors are designed to detect specific dangers, for example a seizure, fall or the fact that someone may have stopped breathing. The sensor will detect the danger, activate itself automatically without any input from the person using it and sound the alarm.

**How does the alarm work?**

The sensor can be linked by a phone line to a monitoring centre. When the person using the seizure alarm has a seizure the sensor recognises the change in heart rate or breathing pattern and alerts the centre. The monitoring centre can then make a call directly to the person to check if they are alright.

If there is no response an operator at the centre can call a family member, friend, warden or an ambulance. Usually the person using the alarm decides who they would like to be contacted in the event of an emergency.

**What alarm sensors are available?**

There is a wide choice of sensors that can be used. Some, such as bed seizure alarms, are designed specifically for people with epilepsy. These are placed under the mattress and can detect when someone starts to have convulsions (jerking and shaking). Some can detect moisture in the bed or even pick up a sudden noise for those who tend to cry out during their seizures.

Other sensors detect if someone falls in their home or garden. The fall alarm is a small box that can be worn on a waist belt and detects any sudden movements that may be related to a fall. In the event of a fall a carer can be alerted and come to the person’s aid.

Other sensors can detect if someone has fallen out of bed or forgotten to switch off the cooker. These alarms can either let carers know about the fall or just switch off the cooker. There are also medication dispensers which can remind the owner about medication at the right time and if necessary call them to find out what has happened.

**How can I get an alarm?**

There are different ways of obtaining alarms. Often the quickest way is to contact one of the companies that produce telecare equipment (see opposite). They can usually advise on what would be the most suitable product for someone. A bed seizure alarm can cost between £170-£600 + VAT depending on the company and product. In some areas, telecare systems might be available on the NHS so it is always worth asking your GP.

It may also be possible to get an alarm through your housing association or social services. You can ask your social services for an ‘assessment of needs’.

There are also charities and funds that can help such as Turn2us, an organisation that can help you search for funding.
The rate of misdiagnosis in epilepsy is high. As many as 20 per cent of patients may be initially misdiagnosed resulting in one in five patients taking anti-epileptic drugs (AEDs) when epilepsy is not the cause of their seizures. Meanwhile the real cause goes undetected. So why is the diagnosis of epilepsy so challenging and what are we doing about it?

There are more than 40 types of epilepsy and many different seizures. To complicate matters further seizures which may appear similar to an observer can have very different causes requiring different treatment. For instance, attacks with loss of awareness, collapse and shaking may have one of three causes. They may be caused by abnormal electrical activity in the brain, as in epileptic seizures; by a temporary reduction of the blood supply to the brain, as in faints; or by a sequence of events in which the brain ‘switches off’ because it is overwhelmed by distressing feelings, thoughts or memories as in non-epileptic attack disorder (NEAD). The greatest difficulty is distinguishing between epilepsy and NEAD.

Traditional tests such as electrical heart or brainwave recordings or brain scans are normal in most patients when they are not having one of their attacks and are therefore of limited use for diagnosis.

The limitations of these tests in achieving satisfactory outcomes have led us to think more innovatively about the process of making a diagnosis and to examine whether something as simple as the way a person describes their seizures could give us clues as to their origins.

Twenty years ago researchers from Bethel Epilepsy Centre in Bielefeld, Germany began to examine the language of patients describing their seizures to differentiate between epileptic and non-epileptic seizures. As well as looking at what patients said about their seizures, they focused on how patients talked to the doctor. They felt that although the visible symptoms of a seizure may be similar in both epileptic and non-epileptic patients, the person’s own experiences and the way they described them should be different and helpful in diagnosis. To ensure they were tapping into the patient’s own seizure experience, unprompted by leading questions from the doctor, they devised a method of history-taking beginning with an open question making no mention of seizures.

For example they might ask ‘what can I do for you today?’ before moving on to similarly open prompts about memorable seizure episodes – ‘can you tell me about your first/last/worst seizure?’

Using this sort of clinical interviewing, researchers showed that the way a patient described their seizures differed depending on whether they were epileptic and non-epileptic seizures. Language, it seemed, may well help doctors differentiate between epilepsy and NEAD.

Almost 10 years ago, we began to apply these methods in Sheffield. We also began our own studies looking at the language of seizures, using conversation analysis, the close examination of metaphors (or figures of speech patients use to describe seizures) and the diagnostic labels they attach to their seizures. Our studies were based on 20 interviews at our video-EEG unit to confirm epilepsy or NEAD.

Both linguists correctly predicted the final diagnosis in 17 out of 20 patients... quite an achievement considering only eight out of 20 patients had been given a correct diagnosis prior to admission.’
and ‘focusing resistance.’ ‘Detailing block’ refers to the small amount of information volunteered by patients with NEAD about their own seizure symptoms. ‘Focusing resistance’ describes their inability or unwillingness to focus on their seizure symptoms.

While people with epilepsy tended to describe subjective seizure symptoms in great detail, those with NEAD preferred to talk about the situations in which their seizures occurred or the consequences of their seizures.

‘Focusing resistance’ becomes particularly apparent when patients are prompted to speak about particular seizure episodes but don’t provide much information. They might say things such as ‘I can’t remember my first seizure’ or ‘they are all the same.’

In this study two linguists were asked independently to predict the diagnosis eventually proven by video-EEG. The linguists did not have any other information about the patient than video recordings and transcripts of the conversation between the neurologist and the patient. Both linguists correctly predicted the final medical diagnosis in 17 out of 20 patients. This is quite an achievement considering that only eight out of 20 patients had been given a correct clinical diagnosis prior to their admission.

**Metaphors**

We then examined the metaphors patients used to describe their seizures. All metaphors were separated into three groups with different meanings.

In the first group seizures were described as an agent or force. These metaphors imply that the seizure does something to the patient and the patient is the victim of the seizure. In the second group seizures were depicted as an event or situation. Here the seizure can act on its own but the patient is a witness of the seizure’s actions rather than a victim. The third group were metaphors where seizures were a space or place patients travel through. In these the patient was active and the seizure was quite passive.

The table below gives examples of the 383 metaphors we identified. Our study showed that patients with epilepsy preferred metaphors depicting the seizure as an agent/force or event/situation. By contrast, patients with NEAD more often used metaphors of space/place for their attacks.

**Seizure labels**

We also analysed patients’ use of diagnostic labels. Whereas ‘fit’ and ‘blackout’ were used as lay terms, the word ‘seizure’ was typically only used for attacks which had been diagnosed by a health professional.

Patients with NEAD used fewer symptom labels than patients with epilepsy and often resisted using the word ‘seizure’.

Analysing how people speak not only helps with the diagnosis of the different seizure disorders but also helps us to understand these disorders better. For instance, the ‘detailing block’ and ‘focusing resistance’ seen in patients with NEAD may reflect the fact that these attacks have something to do with processing distress by blanking out difficult situations or memories.

Metaphors preferred by people with epilepsy may help doctors understand why epileptic seizures can cause quite disabling anxiety. Patients may feel better understood by physicians who pay attention to how they describe their seizures and who then use similar metaphors when they talk to them.

In the same way, patients’ resistance to the term ‘seizure’ is not only useful as a pointer to the diagnosis of NEAD but also communicates an important message to the doctor. Some patients may be in doubt about the medical nature of their problem and may be ready to accept a psychological explanation for their seizures.

Further research into the language of seizures is now under way.

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**Dr Markus Reuber** is a reader at the University of Sheffield and honorary consultant neurologist at the Royal Hallamshire and Chesterfield Hospitals. He has pioneered use of conversation analysis in neurological settings. www.nonepilepticattacks.info/
drifting off creep up on you not being there witnessed being off somewhere else run their course through seizures are straight there

Artists and epilepsy: Symphonia 5, Douglas Capron, Canada (one of the entries in the IBE Epilepsy without words photography competition)
Brain surgery for epilepsy changed Carey Bovington’s life completely and also led her to a decision which she hopes could help change the lives of other people with the condition, many years from now.

Carey Bovington describes her years since undergoing brain surgery for epilepsy as ‘the best time of my life.’

‘Following my operation for temporal lobe epilepsy I had some initial difficulties with speech and memory, but once I had overcome these I was a different person and both my speech and memory are now better than before surgery,’ explains Carey from Nottingham.

‘The world took on a whole new meaning for me. After years of having seizures – sometimes seven or eight a day – I was finally fit free and could get on with my life. It was wonderful!’

Thirty-three-year-old Carey’s joy at a life unhindered by complex partial seizures has led her to a decision which many might describe as ‘brave’, although Carey insists it is simply the obvious and most appropriate decision in the world. She has decided to offer her brain for research at the end of her life.

‘It’s not something I really had to think about,’ she continues, ‘it just makes perfect sense. I am all for donating organs and for me donating my brain is a priority.

‘Before surgery I had little self confidence. I would always worry when talking to people that I might suddenly have a seizure.

‘Now I can just get on with my life. I have a driving licence and commute to work or go out socialising with renewed self confidence. It is hard to describe how good that feels.

‘Surgery worked for me but obviously it’s not for everyone. I would like to think that by donating my brain in years to come, it may help researchers discover more treatments for people with epilepsy that will give other people back their lives in the way surgery gave me back mine.’

Brain donations are not covered by standard organ donation schemes which are for transplant rather than medical research. And there are no donor cards which individuals can carry expressing their wish to leave their brain for research. Anyone wishing to support epilepsy research in this way can do so by registering with the Institute of Neurology (ION) at University College London.

Epilepsy Society’s Professor Sanjay Sisodiya is part of a research team at ION studying how epilepsy affects the brain in the hopes of throwing new light on the causes of the condition. He emphasises the significance and value of the decision by those who, like Carey, choose to donate their brains after death for research.

‘Advanced scanning techniques enable us to see the effects of seizures in a person’s lifetime and to assess the impact on different parts of the brain,’ he says. ‘But we still cannot explain exactly how any one single seizure happens – what is that final event that causes excess electrical activity in the brain to generate a seizure.

‘It is only by studying whole brain tissue from people with epilepsy that we can really advance our understanding of the causes of the condition and the way individuals respond to different medication.

‘We are fortunate that many people...'
who undergo epilepsy surgery consent to allow us to study the brain tissue that is removed (shown above) and this is invaluable. But it still doesn’t allow us to get a complete picture by exploring other parts of the brain in the way that we can through whole brain donation.

‘We can look at post mortem brain tissue of animals with epilepsy1 but these are a pale representation of human brain tissue. There are all sorts of differences between animal and human brains, making comparisons quite difficult.’

Professor Sisodiya describes the possibilities of research into whole brain human tissue as almost endless: ‘We can look at the demise of a cell and at how a new cell is born. We can look at the way the brain rewires itself and at how various areas are affected by seizures. By studying DNA and RNA molecules of the brain we can look at genetic expression in different cells, the way they are controlled and how they are affected by epilepsy.’

At ION’s Department of Clinical and Experimental Epilepsy – a partner of Epilepsy Society – Professor Sisodiya and his colleague neuropathologist Dr Maria Thom have a bank of 150 brains, all donated with personal and family consent by people with epilepsy.

‘Each and every one of these brains is carefully archived, may be used in varied projects and is very much valued,’ says Dr Thom. ‘Their significance is already apparent and will continue to be so indefinitely into the future.’

For example, research on this brain bank has helped to establish that it is the number of times a person hits their head rather than the number of seizures they experience that can cause cumulative damage to the brain. This has underlined the importance of wearing helmets for those with seizures that might cause recurrent falls and head injury.

Research has also contributed to findings which show that a correct diagnosis in adult life of Dravet syndrome – a difficult-to-treat form of epilepsy that usually appears in early infancy – and appropriate adjustment to medication could lead to improved quality of life and cognitive performance.

But to make further advances researchers need to study the brains of people across the full spectrum of epilepsies as well as the brains of a comparative group of healthy people.

Professors Thom cites SUDEP as an example: ‘We need to find out why 600 people a year are dying from sudden unexpected death in epilepsy. This is a very neglected area and there are many questions we need to answer. We can only do this by examining brain tissue from those who have lost their lives to SUDEP. This tissue allows us to study the brain more extensively and to assess how seizures may have altered the brain.’

Current research is focusing on the expression of proteins in brain cells. It is hoped that any abnormalities might help indicate the cause of the epilepsy and why the brain did not respond to drugs. Further research is looking at the distribution of neurons and glia cells which help maintain the electrical balance of the brain, and examining their contribution to epilepsy.

Professor Sisodiya continues: ‘Some people may find the thought of a loved one donating their brain quite distressing. And obviously it is friends and relatives who ultimately have to help facilitate that decision at a very sensitive time. But leaving your brain for research will help make a huge difference to our understanding and treatment of epilepsy. The generosity of people like Carey who have made that decision will have a major impact on our research into epilepsy. Brain donation really is the most amazing gift.’

1 Epilepsy Society does not conduct research on animals.

To find out more about donating your brain for research contact Dr Maria Thom on 020 344 84234, email m.thom@ion.ucl.ac.uk or go to www.epilepsysociety.org.uk/brainedonation
Equality Act 2010
Know your rights

Many people with epilepsy complain of being harassed or discriminated against in everyday life, at work, in education or even when just popping to the shops, but you don’t have to ‘put up and shut up’. Angie King explains how the Equality Act 2010 protects you from discrimination.

In October 2010 the Equality Act was introduced to replace and bring together nine previous laws including the Disability Discrimination Act 1995 (DDA), aimed at protecting people from discrimination.

The Equality Act 2010 states that someone has a disability if they have ‘a physical or mental impairment which has a substantial and long-term adverse effect on the ability to carry out normal day-to-day activities.’ Here ‘substantial’ means it is difficult to carry out activities compared to someone without a disability. ‘Long-term’ means at least 12 months. ‘Day-to-day activities’ include being able to get around, hear, see, remember and concentrate.

As epilepsy is both a physical and long-term condition, people who have the condition are protected under the Equality Act even if seizures are controlled and they do not consider themselves to be ‘disabled’.

Know your rights in everyday life
If you have epilepsy, the Equality Act 2010 protects you from discrimination and harassment in all areas of life. Protection is also given to anyone who is discriminated against because of their association with someone who has epilepsy.

EMPLOYMENT
The Equality Act 2010 protects from several different types of discrimination in terms of employment, but does not cover volunteers.

Direct discrimination
This includes:
Perceived discrimination
where someone – such as a person with epilepsy – is treated unfairly because it is assumed that they have a disability which affects their ability to carry out day to day activities.

Associative discrimination
where someone is treated unfairly because they are connected to someone else with a disability.

Harassment
where a person is treated differently because of a disability, in a way that is humiliating or offensive.

Indirect discrimination
is where treating everyone the same puts someone with a disability at a disadvantage.

Discrimination arising from disability
is where someone is treated unfairly because of something connected with their disability. For example, someone with a visual impairment is told they can’t bring their guide dog to work.

Failure to make reasonable adjustments
Reasonable adjustments are changes that employers are expected to make so that a person with a disability is not put at disadvantage. For example time off work for medical appointments should be recorded separately from sick leave; shift work should be avoided if your seizures are brought on by tiredness.

Victimisation
This is treating someone unfairly because they have complained about any type of discrimination. This can be complaining on behalf of themselves or another.

EDUCATION
Pupils, students and adult learners have rights under the Act too. It is unlawful for education providers to discriminate against anyone with a disability.

HEALTH
The Equality Act covers your right not to be discriminated against or harassed on access to health and social services including doctors’ surgeries and hospitals.

TRANSPORT
People with epilepsy are entitled not to be discriminated against in the use of transport.

EVERYDAY SERVICES
People providing a public service such as workers in councils and shops are not allowed to treat people less favourably because they have a disability.

Find out more at http://www.direct.gov.uk/en/DisabledPeople/RightsAndObligations/DisabilityRights/DG_4001068
Or read Epilepsy Society’s employment leaflet available at www.epilepsysociety.org.uk/employment
I have had catamenial epilepsy since the age of 16. This means that I tend to have more seizures around the time of my period. My GP disagrees and says it is just a coincidence but I have kept a very detailed diary and am sure there is a link between my hormones and seizures. Does anyone have a similar experience or know if there is anything I could take as well as my anti-epileptic drugs to help control the seizures? I would love to see someone who specialises in women’s issues.

Steph, Plymouth

YOUR REPLIES

A week before my period I tend to have a cluster of seizures. My GP and previous neurologist disagreed. I am now under a very good neurologist at the National Hospital for Neurology and Neurosurgery in London. He said that even if they increased my medication at that time it would have no real effect.

I make sure I am well rested at the time my period and seizures are due. I eat well and have lots of protein as that helps me to cope better. I also carry lavender around that time as I find it helps with my auras.

Helen, Epilepsy Society facebook

I have seizures in the week before my period. My doctor put me on the Pill to help us predict the actual days of the week that my fits will come and it’s really helped. I also take Clobazam (Frisium) in the evenings for the week before and during my period. This helps to calm my body and that has had a positive effect on the number of seizures I have.

Sarah, Epilepsy Society facebook

My epilepsy started at the age of 12, the same time that my periods kicked in. My specialist or GP always said there was no connection between the two.

I am now 65 and my periods have stopped but I still have clusters of seizures around the time of the month.

Less of them thankfully and I think this is as my hormones are settling down. I have always kept a seizure diary and if I feel catamenial seizures coming on in relation to my monthly cycle I go and sit down in a café or somewhere safe.

Wendy, Hove

I always have more seizures the three days before the start of my period. I haven’t been able to find anything that controls this but I think it’s also related to our body temperature – it goes up in every woman pre-menstrually, so that doesn’t help. Do you have an epilepsy specialist nurse who you could ask to have a chat with rather than the GP? Just because a GP doesn’t know about catamenial epilepsy doesn’t mean it doesn’t exist.

Mo, Epilepsy Society forum

It’s been common knowledge for many years that there is a link between hormones and seizures in many people and your GP should know this. You should insist on a referral to an epileptologist who can go through your history and suggest possible adjunctive hormone treatment or add another medication around the time of your period. I wouldn’t take anything else until this has been done. Some things such as natural progesterone cream can cause dangerous side effects if not used properly.

Marie, Epilepsy Society forum

I read that although many women think they have more seizures around the time of their period, when they keep a diary, it is not consistent with that pattern. Perhaps it is just that we like to identify a trigger.

Kate, Epilepsy Society forum

NEXT ISSUE

I have tried many anti-epileptic drugs and although they control my seizures, the side effects impact on my quality of life. I am constantly tired and depressed and although I can drive being seizure free, I don’t feel like going out and I can’t go into work. Part of me thinks I would prefer to put up with the seizures rather than the side effects but my neurologist is not keen for me to come off my drugs. He says seizures will have a greater impact on my life and on my family but I’m not sure. Does anyone have any advice?

Trevor, Ealing

WOULD YOU LIKE TO SHARE YOUR THOUGHTS WITH TREVOR? Or do you have a question to ask our readers? Email Nicola.

swanborough@epilepsysociety.org.uk, write to Editor, Epilepsy Review, Epilepsy Society, Chalfont St Peter, Bucks SL9 0RJ, or reply via our forum or facebook at www.epilepsysociety.org.uk
The British consciousness is, like most national characters, a strange mass of contradictions. Our behaviour is driven by unique social mores and etiquette.

In general conversation ‘How are you’ is more often than not a simple pleasantry. It is the conversational stepping stone after ‘Hello’, before we get into the awkward and messy arena of ‘small talk’ – usually involving weather and/or transport, often how the weather affects transport.

Perhaps this is why we as a nation have developed such a proud pub culture? We need a drink to oil the conversational cogs. We have a rather ugly tendency to sneer at our American counterparts for being so forthcoming, often actually telling us how they are. We’ve asked, we must be interested they deduce – credit to their logic, but they’ve missed the point entirely.

In a medical situation it really is genuinely important to be honest and forthcoming with how you are. When in appointment with your neurologist, be as American as possible and share just how you are – physically, emotionally, the whole kit and caboodle. Fill your star spangled boots.

It tickles me that the default British response to ‘How are you?’ is ‘Mustn’t grumble’, when the truth is we love nothing more than indulging in a good old grumble. Our penchant for impotent moaning forms the foundation of our national character.

Monty Python’s brilliant Four Yorkshire men sketch portrays in escalating ridiculousness, the one-upmanship of four men, competitively grumbling about how tough their childhoods were.

Another peculiarity in our politeness rulebook is the ‘oh no, no, no… after you’ mentality. Brits can be stuck at doorways for literally minutes in a battle of wits, both trying to let the other go first.

I have a very dear friend called Kevin, who as it happens has temporal lobe epilepsy. I had dinner with Kevin not long ago and we were (sincerely!) asking ‘how are you’, with regard to our respective epilepsies.

I’m happy to report that we are both well, in case you were wondering. What amused me was that, unlike the Four Yorkshire men sketch when they were outdoing each other’s tribulations, Kevin and I got into a polite tangle over who had it worse. Which ran something like: ‘No, no, no, it’s you. I insist.’

He felt strongly that I, in the tonic clonic corner, had it harder because I lost consciousness, often injured myself and the whole muscle spasm thing leaves me with cramps and soreness. I countered that I was in fact really quite fortunate, seeing as I have seizures that, to the untrained eye, are most widely recognised as epilepsy. People see it, they know roughly what’s happening.

My sympathy was with Kevin, in the temporal lobe corner, because I’m sure I would find the sensation of dreamlike disconnect that often accompanies TLE very disturbing. I insisted his descriptions of existential uncertainty were much more difficult to navigate than my ctrl+alt+delete seizures.

I wondered if other people with epilepsy get caught up in these dilemmas. Where do you see your epilepsy in the Top Trump deck of cards? Do you consider nocturnal epilepsy to have an ‘Inconvenience Power’ greater or lesser than, say, absence seizures? For me, tonic clonic seizures with no aura score higher on ‘Injury Risk’ points than tonic clonic seizures with an aura (as you have an opportunity to lie down and hopefully minimise any damage).

For sure, uncontrolled epilepsy would score higher in terms of ‘Lifestyle Inhibition’ than controlled seizures. Similarly having had brain surgery does, to my mind, score far higher in ‘Hospital Experience’ points than my tonic clonics in A&E. That said, successful people may have no need for medication, which brings the ‘Pharmaceutical Power’ right down again.

Kevin and I never reached any conclusions, but what struck me is that we definitely weren’t grumbling! Quite the opposite, we were looking on the bright side of our own epilepsies. This ‘Top Trumps’ exchange made superheroes out of us both! And our glasses were half full.

As people with epilepsy, we all recognise the power of the brain, but what of the power of the mind, and the attitudes that we carry towards ourselves, our epilepsy and to others. I am reminded (as so often!) by the wisdom of Plato, who said: ‘Be kind, for everyone you meet is fighting a hard battle.’ By which I like to think he meant: ‘We’re all superheroes, but with different strengths’.

I insisted his descriptions of existential uncertainty were much more difficult than my ctrl+alt+delete seizures.
Encouraging words

Epilepsy is not the worst thing in the world… please try to enjoy life to the fullest.

That was just one of the many messages of support you have sent us as part of our ‘Dealing with Diagnosis’ Christmas appeal.

We have been overwhelmed by your thoughts and words of encouragement for others with epilepsy. You can read the many messages at www.epilepsysociety.org.uk/messageofsupport

And it’s not too late to leave a message or make a donation if you have not done so already.

Help with benefits

Some people with epilepsy may be eligible for benefits. Our new factsheet Completing benefits forms offers useful ideas and suggestions that may help when you are applying for benefits.

For example, when filling in forms you need to think of ‘the worst case scenario’ of what could happen if you have a seizure and what help you might need.

The factsheet explains the importance of making sure the person assessing the form fully understands the risks you face every day. This includes what happens to you before and after having a seizure and how epilepsy affects your life.

You can read or download the factsheet at www.epilepsysociety.org.uk/benefitsforms

120 years of Epilepsy Society

This year sees a special milestone for Epilepsy Society – it’s our 120th birthday and we are hoping as many of you as possible will join in the celebrations.

To mark the occasion we are hoping to finish building our world class Epilepsy Society Research Centre and work is already well under way at the Chalfont Centre in Buckinghamshire. You can follow the progress of the centre at www.epilepsysociety.org.uk/epilepsysocietyresearchcentre

At the same time we are launching our Targeting Seizures campaign to ensure that as many people with epilepsy achieve the best possible seizure control.

We would love to hear your plans to help us celebrate. Will you take on The Big 120 to help raise an extra £120,000 for Epilepsy Society this year? Whatever you do for our Big 120, whether you donate £12 or raise £1,200, you can be sure that your funds will help to run our vital services.

To find out more visit www.epilepsysociety.org.uk/120, email fundraising@epilepsysociety.org.uk or call 01494 601 300

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And it’s not too late to leave a message or make a donation if you have not done so already.

The sky’s the limit

How do you fancy jumping out of an aeroplane to raise money for Epilepsy Society? As part of The Big 120, we are looking for 120 fundraisers to take part in our skydiving day on 20 May 2012, during this year’s National Epilepsy Week.

Brackley Airfield, Oxfordshire, will be the hub site for the day but you can take part at other sites throughout England. We can also offer alternative dates for those who can’t make 20 May.

The minimum sponsorship target is £395 for a tandem skydive with a professional and if you reach this sponsorship target you will get to jump for free!

For more information please call us on 01494 601 414 or email fundraising@epilepsysociety.org.uk

Our press officer Angie King jumped last year. ‘It was the most amazing experience ever,’ she said. ‘I’d encourage everyone to be brave and have a go.’

Dinner date

Many thanks to all who helped us to raise £40,000 at our annual dinner at BAFTA, London.
Epilepsy Helpline – information...time to talk...emotional support...translation
01494 601 400 Monday to Friday
10am – 4pm (national call rate)

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

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

Information – see our website, leaflets and dvds. Call 01494 601 392 for a full list or go to www.epilepsysociety.org.uk/aboutepilepsy

Seizure management – NHS referrals can be made to our epilepsy specialists, assessment centre, or therapeutic drug monitoring service. Go to www.epilepsysociety.org.uk/whatwedo
Referral by GP or consultant’s letter to Epilepsy Society 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 – talk to others affected by epilepsy at www.epilepsysociety.org.uk/forum/

Facebook – www.facebook.com/epilepsysociety

Twitter – keep up with all the latest epilepsy news at www.twitter.com/epilepsysociety

YouTube – check out our YouTube channel at www.youtube.com/epilepsysociety

Volunteer – could you help us inform people at an epilepsy clinic or school near you? Call the Regional Services Network on 01494 601 391 or go to www.epilepsysociety.org.uk/regionalservicesvolunteer

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

Health professionals – for expert medical information and research. Call 01494 601 341 or go to www.epilepsysociety.org.uk/forprofessionals

Membership – get involved and keep informed. See flap attached or go to www.epilepsysociety.org.uk/newgetinvolved/becomeamember