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‘I had no idea of the impact that epilepsy would have on my mental health’
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REVIEW

THE NATIONAL SOCIETY FOR EPILEPSY

ISSUE 1 2010

£3.50
www.epilepsysociety.org.uk
As you sit down to read this issue of *Epilepsy Review* the chances are we shall be in the grips of general election fever. With parliamentary candidates anxious to engage with constituents, the coming election offers a golden opportunity to put pressure on all political parties to address issues which are important to people with epilepsy.

This election promises the biggest change in the make-up of parliament since the end of the Second World War. With the resignation of so many MPs following the expenses scandal, new parliamentary candidates are keen to listen to the views of their constituents and are more likely to address changes which could improve their voters’ lives.

At grass root level we are in a powerful position to tell candidates on our own doorstep what changes we want to see. This is our opportunity to spell out the need for more epilepsy specialist nurses and neurologists, better local NHS services, improved training for medical professionals and better information that could reduce the number of preventable deaths through epilepsy each year.

Now is the time to reach out to all 646 incoming MPs and to influence the new government on a long-term basis. The National Society for Epilepsy (NSE) has put together a 2010 election sheet to help you decide what to say to your local candidates, either in person or in writing. Alongside this, the Joint Epilepsy Council which represents 24 epilepsy charities including NSE, has drafted a call-to-action leaflet with a particular focus on the election. To access both documents, go to www.epilepsysociety.org.uk.

We have already seen that the Department of Health is willing to listen to people with epilepsy. They took notice when we told them that substitution of anti-epileptic drugs posed too high a risk for those with the condition. We are still awaiting the outcome of their consultation period but we have very real evidence that epilepsy is on the political agenda.

Let’s continue to make sure our voices are heard on all issues that affect the 456,000 people in the UK with epilepsy. Let’s continue to make sure our voices are heard on all issues that affect the 456,000 people in the UK with epilepsy.

Nicola Swanborough
Editor

**Fast forward for epilepsy services**

A powerful collaboration of epilepsy charities, NHS leaders, people affected by epilepsy, civil servants and Health Minister Ann Keen came together in a landmark conference in February to drive the development of better NHS epilepsy services.

The conference Better value. Better care set out to put epilepsy on the map with those responsible for commissioning NHS services.

Undersecretary of State for Health Ann Keen called for people across the NHS to address the lack of services for people with epilepsy, stressing the particular need for epilepsy specialist nurses. She recalled her own days as a nurse in A&E caring for people after a seizure, knowing there was no local epilepsy clinic to refer them to. ‘We now have a duty – all of us – to act together and really make a difference,’ she said.

The health minister spoke of her frustration that NICE guidelines and the National Service Framework (NSF) for the condition were not being implemented everywhere, leading to a big difference between best and worst services. And she lamented the lack of both epilepsy specialists and access to care plans. ‘Nowhere is health inequality more obvious than in epilepsy,’ she continued.

Initiatives discussed include the work of the Long Term Conditions Delivery Support Team; development of Neuroscience Networks; comparison of neurological data between NHS providers; NHS provider ‘quality accounts’ and the development of clinical champions. Since the conference members of the Joint Epilepsy Council (JEC) have visited strategic health authorities across the country to encourage them to carry this work forward.

**Sticky problem**

Brain development disorders (DBS) could offer new hope for people with epilepsy who fail to respond to drugs. The surgical treatment involves implantation of a medical device called a brain pacemaker which sends electrical impulses to parts of the brain.

In a clinical trial of 110 patients, US researchers from Stanford University reported that 41 per cent of patients undergoing DBS showed a reduction in seizures after 13 months while 56 per cent showed a reduction after two years. This compares with a 14.5 per cent reduction in seizures in a control group which did not receive DBS.

**Impulsive behaviour**

Now scientists believe glial cells could be crucial to conditions such as epilepsy. Arthur Butt, professor of neurophysiology at the University of Portsmouth is studying the protein Ki.4.1. His work has already shown that loss of the protein which helps to mop up certain chemicals in the brain can cause brain damage.

**High five for ketogenic diet**

For years, the high-fat, low-carbohydrate ketogenic diet has been used to treat seizures in children. But only now are scientists able to offer reassurance that the diet appears to have no long-lasting side effects.

In the short term the diet can cause bowel disturbance, raise cholesterol and in rare cases lead to kidney stones. But researchers at John Hopkins Children Centre (JHCC) in Baltimore, USA have found that once the diet is stopped, most patients remain seizure free or have fewer seizures and rarely suffer health problems. Most children catch up with their peers in height and weight and few continue with a high-fat diet.
Fit to work

A new initiative to help people back to work after a period of ill health has been welcomed by Professor John Duncan, medical director of the National Society for Epilepsy. The ‘statement of fitness for work’ will replace the traditional sick note this month providing parliament gives its consent.

The new note allows GPs to specify whether you are ready to go back to work and how simple changes to the job you do may speed up your return to the workplace.

Professor Duncan said: ‘Anything that helps individuals get back to work when they are able to be welcomed, is the adaptations to the workplace. Individuals who have had periods of unemployment are often unfairly discriminated against at work.’

A question of immunity

Could the immune system play a role in epilepsy? Our immune systems defend our bodies from infection and foreign bodies by producing antibodies to destroy any unwanted agents. Occasionally the body produces antibodies against one of its own proteins, causing ill health. This is known as autoimmunity, and the antibodies are known as auto-antibodies. Type 1 diabetes, rheumatoid arthritis and multiple sclerosis are all autoimmune conditions, but now researchers suspect that autoimmunity may be involved in some forms of epilepsy.

A recent review published in Current Opinion Neurology gives hope that auto-antibody testing may play an important role in future diagnosis and treatment of epilepsy in people who do not respond to anti-epileptic drugs. Since 1980, scientists have been trying to prove the existence of auto-antibodies to brain proteins, in the hopes that if autoimmune forms of epilepsy are discovered, these might respond to immunotherapy where AEDs have not worked.

Giving hope where AEDs have not worked?

Scientists have been looking at limbic encephalitis (LE), an acute inflammation in the brain which can affect the hippocampus giving rise to temporal lobe epilepsy. Evidence suggests that the cause of LE can be autoimmune and that seizures can result from the direct effects of auto-antibodies. Four auto-antibodies have been linked to LE and these are increasingly being detected in some people with epilepsy.

The review concludes that as yet there is insufficient evidence to justify routine antibody tests in epilepsy. They recommend, however, that anyone with acute onset of seizures which cannot be explained, should be tested for antibodies.

World focus: Africa

Ten million people in Africa are affected by epilepsy, and 80 per cent of these people are treated with readily available modern drugs. Professor Ley Sander, a leading neurologist at the National Society for Epilepsy, describes the challenges of working in Africa.

‘There are very few neurologists in sub-Saharan Africa. In some countries there is one neurologist for every 5-10 million people. There are only five or six centres throughout the whole continent with up-to-date MRI scanners and on top of this, epilepsy is amazingly stigmatised. One young lady almost died in hospital with her family preferring to say her injuries were the result of physical abuse within the family rather than admitting she had epilepsy.’

‘A joint project spearheaded by the World Health Organization (WHO), the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE), has been working in African regions to increase the percentage of people with epilepsy who receive appropriate treatment. ‘Because our aim is to establish a sustainable model of care and support we can only go into countries which already have some form of primary care.

‘The challenge of Africa is that it is made up of more than 50 countries all with different attitudes, beliefs and governments, some of which can be very dysfunctional. What works on one side of the river does not necessarily work on the other side. But what is universal throughout the challenge of the four ‘As’: accessibility, affordability, availability and awareness.

‘The vastness of the territory and the sparseness of medical services make accessibility a huge problem. Poverty and lack of human resources mean that cheap, once-a-day drugs are often in short supply and the stigma attached to epilepsy leaves people frightened to seek medical treatment. The first port of call is frequently the traditional healer.

‘Some areas are more receptive than others to Western intervention. In one of my early experiences, we set up an epilepsy clinic but initially no one came. Then we had a referral through a psychiatrist and people saw how effective anti-epileptic drugs could be. Suddenly everyone came.

‘But in general the word of the traditional healer is law: they believe that epilepsy is caused by supernatural forces and that the demons are treated. The Therapeutic Drug Monitoring (TDM) Unit at the National Society for Epilepsy in Buckinghamshire, has extended its services to veterinary practices and its clients already include cats, dogs and monkeys.

Professor Philip Patsalos, consultant clinical pharmacologist at the TDM Unit said: ‘One of our most unusual clients is a squirrel monkey which is being treated with valproate. By measuring the drug levels from a blood sample, the animal’s dosage can be adjusted to its specific therapeutic requirement.’

For more information email NSE_TDM@epilepsysociety.org.uk

As in human beings, epilepsy is the most common neurological disorder in cats and dogs, with seizures being treated by a range of anti-epileptic drugs (AEDs).

Now pets can benefit from the same level of therapeutic drug monitoring as people with epilepsy, to maximise the efficiency of their medication and decrease side effects such as sleepiness and wobbliness.

Herbal warning

Scientists have warned that the popular herbal remedy, ginkgo biloba, may increase the risk of seizures in people with epilepsy. Ginkgo biloba remedies are often used for health problems ranging from dizziness to memory loss. But German scientists from the University of Bonn have found 10 written reports of seizures linked to the herb.

Professor John Duncan, medical director of the National Society for Epilepsy, reacted cautiously: ‘We believe that some herbs such as St John’s Wort, are linked to a higher risk of seizures, but there is still not a great deal of evidence relating to ginkgo. If someone with epilepsy wants to take this remedy, they should simply be aware of the possibility.’

EDITOR’S CHOICE

FOR CENTURIES

EPILEPSY was confined to a shadowy world of shame and denial. Secrecy was considered the best form of treatment.

The legacy of this is a wealth of unsolved mysteries surrounding the lives of those whose eccentricities or withdrawal from society was often explained away as detachment on account of unfounded love or isolation due to tuberculosis.

Emily Dickinson, considered to be one of the finest poets of all time, is a prime example. The conventional portrayal of the American writer is of a sedated character who shut herself away from life, only to correspond through poems and letters with a trusted circle of friends.

But as Lyndall Gordon’s new biography Lives Like Loaded Guns: Emily Dickinson and Her Family’s Feuds reveals, there was something more explosive than a broken heart keeping the young poet apart from every day life. Emily Dickinson’s secret existence could well have been a result of epilepsy – the ‘loaded gun’ that waited to ricochet through her body.

Gordon puts up a good case, drawing on Dickinson’s secret prescriptions for a medicine made of glycerine, often used at that time to treat epilepsy. Her father would travel long distances to have the prescription prepared in Boston, far from prying eyes in her home town.

Most poignantly she draws on Dickinson’s poems which describe with metaphor and spasmodic rhythm, the dysfunction inside her brain: ‘I felt a cleaving in my mind / As if my brain had split / I tried to match it –’

‘But could not make them fit.’

Gordon’s book is both compelling and fascinating, but perhaps most importantly it encourages the reader to examine the evidence themselves through the prolific genius of Dickinson’s poems.

Lives Like Loaded Guns: Emily Dickinson and Her Family’s Feuds by Lyndall Gordon, published by Virago, price £20
FAMILY FOCUS

Epilepsy and mood

Over the page we look at the links between epilepsy and mood. Here Miles and his wife Fiona describe the effect they had on their relationship, while over the page we look at the links between epilepsy and mood.

MILES: ‘When I was first diagnosed with epilepsy I thought I would be able to just throw a few tablets at the condition and that everything would be all right. I had no idea of the impact that epilepsy would have on my mental health.

‘It is only now, when I look back over the last 10 years, that I can see how my mood swings and anxiety have been linked to the condition. My epilepsy seemed to make me over anxious – I have been like a man walking along the road flapping his arms for fear of being charged at by a herd of elephants.

‘I remember the first time my behaviour became irrational following the onset of my seizures. Fiona had asked me to check that our two children had brushed their teeth. When she asked me again 20 minutes later, I lost my temper and became very angry. I told Fiona she was trying to ruin my life.

‘The whole incident was very frightening. I have always been quite a placid person but suddenly I was out of control. I became bad tempered and irrational with the children and very controlling of Fiona.

‘Four years after being diagnosed with epilepsy I elected to have brain surgery. I was having around three complex partial seizures a week. The operation was successful and I haven’t had a seizure since for which I am very grateful.

‘But after surgery I became even more paranoid and agitated. I was over sensitive and convinced that everyone else was wrong. The hospital explained that the source of my seizures was an area of the brain that helps to control mood and emotions. This is likely to have affected my mental health before the surgery, and the removal of a large part of this area may have a more prolonged impact.

‘Most of my anxiety was directed at Fiona, the very person who was trying to help me. I only felt secure if she was with me. But when she was there, I blamed her for my misery.

‘Eventually Fiona told me to go and see a psychotherapist. We also sought counselling as a couple but no one was really able to help.

‘It was only when we saw a psychiatrist at Southampton General Hospital that things started to make sense and I began to rebuild my life. I was given some self-help books on cognitive behaviour therapy and I began to learn how to manage my moods. I can at last recognise that it is not everyone else who is wrong, it is me.

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‘I rely on anti-depressants and anti-convulsants to help control my moods.

‘I feel very positive about my 50s at long last.

‘I have been a long haul and we have had some very bleak times, but Miles is very self-analytical and that has helped a great deal. It has been a long haul and we have had some very bleak times, but Miles is very self-analytical and that has helped a great deal. It has really been his determination with self-management that has helped him control his moods and anxiety.

‘I really feel we’re through the worst and I have got the old Miles back. I feel very positive about our future. As a reflection of this, I recently decided to give up the horse after four years. My friend, who I shared him with, was no longer able to do so, and while previously I would have clung on to the horse at all costs, I felt the time was right to let go.’

Epilepsy was a tough diagnosis for Miles Seymour shortly after his 40th birthday, but tougher still was coping with the accompanying mood swings and anxiety. Here Miles and his wife Fiona describe the effect they had on their relationship, while over the page we look at the links between epilepsy and mood.
At some point in our lives at least one in four of us will experience a mental health issue which may include mood problems. People with epilepsy may be twice as likely to have problems with anxiety or depression as the general population. Stella Pearson looks at the links between mood and epilepsy.

We all feel low, anxious, angry or depressed at times without it necessarily becoming a problem. Experiencing and expressing different moods and emotions are a useful and healthy part of how we function, and our mental health is key to how we live.

Moods, however, may become ‘mood problems’ when they begin to affect everyday actions such as eating, sleeping, communicating and being able to get out of bed or out of the house. If the way you feel is affecting the way you live and this has been happening for some time, then this may be classed as a mood problem.

For some people with epilepsy, their mood may be linked to their condition. Potential links between epilepsy and mood are multi-faceted and can include the type of epilepsy a person has or perhaps the effects of their anti-epileptic drugs. Receiving a diagnosis of epilepsy can also have a marked impact on the way a person feels.

FOR SOME PEOPLE physical and chemical changes in the brain can contribute to mood. These changes may happen just before or during a seizure or may be related to the after effects of seizures on the brain. The likelihood of developing depression is higher in people with complex partial seizures, especially if their seizures start in the temporal lobe which is responsible for the processing of emotions.

Identifying any patterns to low mood, anxiety or irritability may help in working out whether mood problems are related to seizure activity. For example, an intense feeling of fear is common during partial seizures. Some people feel anxious, irritable, aggressive or depressed a few hours or a few days before a seizure. Feeling depressed after a seizure can be common, particularly after partial seizures, and the confusion or memory loss resulting from a seizure can be worrying or depressing in themselves. On the other hand, some people find their mood improves after a seizure. Anti-epileptic drugs can have both positive and negative effects on mood, although side effects relating to mood may be less common than you think.

An external factor such as a change in medication may seem like the obvious cause of a new mood problem, but the cause may actually be something more complex or subtle that is hard to identify.

Keeping a written record in your seizure diary can help you to work out whether it is related to your medication.

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Keeping a written record in your seizure diary can help you to work out whether it is related to your medication.

The Bigger Picture focuses on the way you are feeling and uses comic strip-style stories to show the impact that a diagnosis of epilepsy and living with the condition may have on a person’s life and mood.

For some people the effects of being diagnosed with epilepsy can have far more impact than the seizures. The leaflet can be read without the accompanying text and has self-help ideas as well as encouragement to seek medical advice if necessary. You can order a copy online at www.epilepsysociety.org.uk/shop or by calling the Epilepsy Information Services on 01494 601 392.

Health care professionals can also order Epilepsy in Mind, NSE’s pack on epilepsy, anxiety and depression.
Feeling blue

Rabbi Lionel Blue believes that if you can laugh about your epilepsy, it can help dispel melancholy and myths. Here he shares his uplifting take on life with Amanda Cleaver

The creases on Rabbi Lionel Blue’s face bear testament to the fact that laughter really is the best medicine. The 80-year-old Rabbi, who has entertained millions of Radio 4 listeners for many years, makes no secret of his epilepsy.

At the start of his one-man stage show An Audience with Rabbi Lionel Blue, he insists on the house lights being up and explains that flickering or flashing lights may cause him to have a seizure.

Although that is the truth, the Rabbi also uses it as an excuse to engage with his audience. He likes to see their faces and gauge how his witticisms are being received. He also likes to be the last to leave after his performance and enjoys a personal drink and a chat with the audience during the interval and after the curtain comes down.

It’s during those moments that people tell him how pleased they are that he talks about his epilepsy.

‘For some people epilepsy is a sort of “spook” in their mind,’ says Rabbi Blue, ‘but when you talk about it the horror goes. And if you can laugh about it then even better.

Laughter is a way of coping with problems. To my mind, bitterness and anger hurt you – humour and laughter release you.’

For Rabbi Blue a diagnosis of epilepsy took many years to reach. For a long time he put up with odd feelings of “fuzziness”, which he likens to a badly tuned radio.

And although he had the odd fall, because he didn’t lose consciousness, the connection with epilepsy was never made.

Today he makes light of his first tonic clonic seizure which occurred while he was conducting a funeral.

‘I had seizures in all sorts of places – even by the side of a canal in Belgium,’ he says. ‘It took time for doctors to piece together my history and come to a diagnosis. During my worst period I was having two or three seizures a day.’

Rabbi Blue’s seizures were often at their worst during periods of emotional stress. He was devastated when his first long-term relationship ended. ‘To be honest at that time the seizures were a release,’ he continues. ‘The epilepsy somehow cleared my mind of the woe I was suffering. It seemed to release me from a ball of anger. And the fact that I ended up on a hospital ward on several occasions also brought me peace. I realised that while I was in hospital all my problems were on the other side of the ward window. The medical staff were all so kind.’

He also believes that thanks to his epilepsy, he experiences more than his fair share of human kindness.

‘On one occasion I had an aura before a seizure and knew I had to get myself to a place of safety. I was passing an antiques shop! I explained to the antiques dealer and then want to help.

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Rabbi Lionel Blue will be back on Radio 4’s Thought for the Day later in the year.

Photosensitive epilepsy

Photosensitive epilepsy first came to prominence in the 1950s with the advent of television. Indeed, at the time it was known as ‘television epilepsy’. But though the condition has undoubtedly been exacerbated by the dominance of technology, it is more than a modern phenomena.

Photosensitivity can be caused by sunlight reflecting on water or flickering through a row of trees. Graham Harding, the world’s leading expert on photosensitive epilepsy, explains the causes of this rare condition and how it can be managed.

Photosensitive epilepsy

Photosensitivity is a rare type of epilepsy in which seizures are triggered by flickering or intermittent light stimulation or repetitive patterns. Unlike most forms of epilepsy where seizures are not predictable, photosensitivity is a form of reflex epilepsy with seizures caused by specific triggers. Some people only have this form of epilepsy, while others may also experience photosensitivity for life.

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The mechanisms that make the brain hyper excitable when the retina is stimulated in a certain way are still not fully understood. However, scientists have been able to identify many of the triggers which induce photosensitive seizures in some people’s brains.

Rate of flicker of the light source
This is measured in hertz, with one hertz representing the number of times a light source flashes per second. Flashing lights between the frequencies of 10 and 30 flashes per second (hertz), are most likely to trigger a seizure in over 60 per cent of the photosensitive population, but some people may find they are sensitive at higher than 30 hertz or below 3 hertz.

Intensity of the light source
The brightness of the light and the contrast between light and dark during the flicker can also determine whether a light source will provoke a seizure.

The area the light occupies
in your field of vision
There is more chance of a seizure if you are watching a large TV screen as opposed to a smaller one, or if you are sitting close to the screen rather than three metres away.

Colours
Pairs of rapidly changing red and blue colours are more provocative.

Patterns
About 30 per cent of people who are sensitive to flashing lights are also sensitive to patterns. Static or moving patterns of light and dark stripes can have the same effect as flashing lights. The most provocative patterns are those which are superimposed on the light and dark areas. Patterns which slowly drift in one direction across the field of vision are not provocative.

What are the most common triggers of photosensitive epilepsy?

Television
More than 60 per cent of people with photosensitive epilepsy have their first seizure when sitting in front of a television screen. Television screens with cathode ray tubes or poorly tuned TV channels may cause seizures due to the flickering of the display. Television screens with cathode ray tubes always flicker at the frequency of the mains (50 hertz in the UK). Digital TV does not present the same problem: cathode ray tubes have been replaced by Liquid Crystal Display (LCD) or plasma screens which do not have the inherent flicker. However, the contrast level on newer sets can be altered to increase brightness. Whenever possible people who are photosensitive should adjust the contrast to a lower level.

Ofcom, the organisation that regulates material shown on TV, has issued guidelines setting out the limits of both flash rate and the area of flashing lights which are suitable for broadcasting and which are not. There are similar limits on the number of black and white stripes which may be broadcast. These guidelines apply to broadcast material, irrespective of what sort of TV set or computer screen is used for the display.

Computer screens
There is no evidence to suggest that using a computer or a Visual Display Unit (VDU) will cause epilepsy. The flicker on modern computer screens is too fast to trigger a seizure and LCD screens such as those on lap top computers do not flicker at all. However, it is worth remembering that intense periods spent in front of a computer screen may be stressful and cause tiredness which could trigger a seizure in someone with epilepsy.

Similar limits to those of Ofcom apply to websites in the United States of America, since it is the material presented on the screen which represents the risk. Unfortunately there have been cases where websites for people with epilepsy have been deliberately hacked into with superimposed flashes which have caused seizures.

Interactive whiteboards, sometimes used in schools, have not been found to trigger seizures as they do not flicker.

Computer games and graphics
While it is widely agreed that video and computer games do not cause epilepsy, they may trigger seizures if there is an underlying tendency to have them.

While the television industry must comply with Ofcom guidelines on photosensitivity, no such guidelines have yet been adopted for computer and video games. Games of this type often invite the player to control their own visual experience, thereby creating unexpected risks for themselves. There is currently pressure on the computer game industry to voluntarily adopt guidelines similar to those of Ofcom.

If you have photosensitive epilepsy, games with patterns of flashing lights may provoke a seizure as may sustained concentration for a long time in front of a screen.

In general, computer games are considered to be safer than video games as it is better to use a computer screen than TV screen.

Christmas tree lights
The flash rate of Christmas tree lights is usually slow, about once per second. For flashing to be a risk it usually has to be above three flashes per second. Some LED circuits have caused a problem with fast flashing as have bicycle rear lights and birthday badges.

Cinema and 3D films
There are relatively few cases of photosensitive seizures in cinemas. The size of the screen and the low intensity of the light mean it is rare for a seizure to be triggered by watching a film at the cinema. The frame rate of ordinary cinema films is 24 frames per second which would produce a noticeable flicker and pose a risk to photosensitive people. However, this is balanced by the intensity of the image on the screen at the cinema which is very low (about one hundredth of a television set). 3D films are no riskier. With 3D films such as Avatar or Alice in Wonderland, three images are projected at a combined rate of 48 flashes per second. Because the projected images are polarised – aimed at each eye separately – this equates to 24 flashes per second to each eye. Although you only get half the intensity of a normal cinema, all your surroundings have a similar reduction so the contrast remains the same. This is the equivalent of wearing sunglasses in a normal cinema.

Flash photography
While there is not usually a problem with a domestic camera, motorised cameras which reload instantly can reach a high enough flash rate to affect people who are photosensitive. This is particularly true when large numbers of press cameras are involved, hence the warning broadcast on TV news coverage.

Strobe lighting
Strobe lights can trigger seizures in those who are photosensitive, although this will depend on the speed at which the lights are flashing and whether the background illumination is low. At a disco or nightclub other triggers may contribute such as stress, excitement, hunger, tiredness and alcohol. Some local authorities have rules concerning the flash frequency of strobe lighting. Health and Safety Executive guidelines advise limiting the rate of flashing to 4 hertz, restricting the location of strobe lighting and providing warnings to the public at venue entrances, or in an event programme.

Sunlight
Both natural and artificial light sources can trigger photosensitivity. While sunlight by itself is unlikely to cause epilepsy, light flashing through bicycle wheels, rows of tall trees or through church or school railings may induce a seizure, as may light reflecting on water or snow.
Diagnosis of photosensitivity is made through an EEG (electroencephalogram) which includes photic stimulation (flashing light test). In some instances, anti-epileptic drugs such as sodium valproate or lamotrigine, may help in preventing photosensitive seizures.

People with photosensitive epilepsy can help to reduce the risks of a seizure in several ways:

- **Avoid stimulants.** A lot of people are triggered by viewing the stimulus through the eyelids producing a flicker. It is triggered by viewing the stimulus through the eyelids producing a flicker. Remember, too, that heat, noise, tiredness and alcohol may trigger a seizure. Do not become dehydrated. Drink plenty of water and take regular breaks.

- **Use a TV.** Make sure the room is well lit. Placing a subdued light on top of the TV may help to balance the brightness of the screen. If possible turn down the brightness of the screen and adjust the light levels of the room. Take regular breaks (five minutes every 30 minutes).

- **Sit a sensible distance from the TV, either three metres away or four times the size of the screen. Change channels with a remote control or cover one eye to reduce the flicker effect if you go near the screen.**

- **Do not watch the TV screen when fast forwarding or rewinding a video.** A small TV screen is preferable to a larger screen. Most preferable is a flat screen TV which does not flicker.

- **When using a computer, take regular breaks (five minutes every 15 minutes if you are playing computer games).** Intense concentration may cause stress and tiredness and trigger a seizure. If you feel unwell or have dizziness, blurred vision or twitching muscles, turn away from the screen.

- **Make sure those around you are aware of your photosensitivity affects you and know what to do if you have a seizure.**

A pot noodles advert in 1993 induced photosensitive seizures in three people, and precipitated the introduction of Television Guidelines in the UK.

In June 2007, a short film to launch the new logo for the London 2012 Olympics triggered what is believed to have been the biggest episode of photosensitive epilepsy in the UK. The film featured a diving pool with animated ripples in bright contrasting flashing colours and patterns.

In December 1997 685 children and young people were admitted to hospital in Japan due to seizures which occurred while watching the cartoon Pokemon. The seizure epidemic was triggered by a four-second sequence with flashing red and blue colours occupying the whole screen.

Graham Harding is Emeritus Professor of Clinical Neurophysiology at Aston University.
There can be few women with epilepsy who have not considered how their condition and its treatment might affect their ability to have children.

Women with epilepsy know that their condition may affect them during pregnancy and that it may be necessary to continue regular treatment throughout term. Their questions about pregnancy—both before and after conception—may require a combination of both obstetric and neurological knowledge. For example, ‘what happens if I have a seizure during delivery?’ or ‘is an epidural safe?’

‘More than 400 women with neurological conditions have been seen in the clinic—approximately 200 of these were women with epilepsy.’

Yet the worlds of obstetrics and neurology can seem worlds apart. Maternity units are often sited separately from neurology services. Certainly, midwives and obstetricians may seem to have little in common with neurologists and epilepsy specialist nurses. The National Institute for Clinical Excellence (NICE) acknowledges the need for good communication between obstetrician and neurologist—but in reality how does this happen?

In fact, women may find that both their neurologist and obstetrician are more familiar with many of the key issues surrounding epilepsy and pregnancy than they might expect. Certain facts—such as the need to take folic acid, the importance of reviewing anti-epileptic drugs, and the need to avoid seizures during pregnancy—are well known and communicated by both services. But sometimes questions may be more difficult to answer, such as ‘I’m taking anti-epileptic drugs—should I be worried that my baby will be born with a birth deformity such as a cleft palate?’ The current situation often relies on phone calls and letters between healthcare professionals—which result in delays and concern.

Pregnancy can pose specific concerns for women with epilepsy, both in terms of ante-natal care and treatment for their condition. But at one clinic, a pioneering collaboration between neurologist and obstetrician offers mums-to-be the very best of both worlds. Dr Dominic Heaney, consultant neurologist explains...
University College London Hospital (UCLH) has developed an obstetric-neurology clinic to meet the needs of all women with neurological conditions in pregnancy. In common with most obstetric units, UCLH had been offering specific antenatal clinics for women with medical problems, with liaison between neurologist and obstetrician through the traditional ‘as required’ basis.

Four years ago, this arrangement was formalised. An individual consultant neurologist was assigned to provide regular input by attending a specific ‘medical-complications’ antenatal clinic. This was designated as an ‘obstetric-neurology’ clinic, and referrals were accepted from GPs, midwives and other specialists. The obstetric neurology clinic now offers a consultant neurologist together with a consultant obstetrician with rapid access to all the standard obstetric support services such as midwives, ultrasound, sonographers and specialist laboratory testing. At UCLH, we have the additional benefit of a physician in attendance who is expert in obstetric medicine.

This service allows face-to-face discussion of issues concerning individual mums-to-be. For example, many women ask about the risk of congenital malformations in association with their anti-epileptic treatment. Discussions can take place based on the most up-to-date evidence, with the obstetrician also able to comment on any other factors that may be relevant such as the significance of foetal scars or previous pregnancies.

The clinic allows clear and standardised advice about a wide range of issues including the use of folic acid in the first trimester, anti-epileptic drug dose adjustment after birth, breast feeding and nursing skills are discussed and communicated to her neurologist and epilepsy specialist nurse.

The clinic has allowed any misconceptions held by neurologists and obstetricians to be abolished. For example, obstetricians have become aware of the wide variety of ways in which individuals can be affected by seizures and the impact they may have on a woman’s condition. The neurologist has become informed about the benefits and risks of different modes of delivery and analgesia.

In this way women can decide about their birth plan, drawing on the experience of both neurologist and obstetrician to weigh up the benefits of different options such as how the use of an epidural may significantly reduce the risk of sleep deprivation during a long labour.

Even with this concentration of expertise, women may present challenges or ask questions for which an answer is not obvious or where information is not available in published literature. In these cases, informed discussion between obstetrician, neurologist and other relevant specialists can help determine the best possible solution.

In a relatively short space of time, more than 400 women with a variety of neurological conditions have been seen in the clinic. Approximately 200 of these were women with epilepsy. Through this unique experience, the doctors and midwives have gained new insights, which helps to inform practice at the clinic. The medical community will benefit from more formal audit and research. Junior doctors from both specialties are part of this process and will go elsewhere to spread best practice. This model of care works well at UCLH and is hopeful it will be adopted elsewhere.

Dr Dominic Heaney is a consultant neurologist at the National Hospital for Neurology and Neurosurgery in London.

Although women are not usually seen in the obstetric clinic after their baby is born, the issues of anti-epileptic drug dose adjustment after birth, breastfeeding and nursing skills are discussed and communicated to her neurologist and epilepsy specialist nurse.

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Dr Dominic Heaney is a consultant neurologist at the National Hospital for Neurology and Neurosurgery in London.
Through its Putting People First initiative, the Government is giving individuals the right to control their own social care services using direct payments and personal budgets. Graham Faulkner, chief executive of the National Society for Epilepsy looks at how much choice and control the revised system gives you.

Direct payments

These are available for: older people who have been assessed as needing community care services; disabled people aged 16 and over, including those with short and long-term needs, and carers aged 16 and over, including people with parental responsibility for a disabled child.

It is now possible for direct payments to be made to a family member or friend on behalf of someone who does not have the capacity to consent to the direct payment themselves. This is particularly important where a friend or relative has been given power of attorney.

Direct payments are cash payments given in lieu of community care services. The individual becomes the employer taking on all relevant responsibilities such as payroll, meeting minimum wage requirements and establishing contracts of employment. Many councils have commissioned organisations to help people handle these responsibilities.

Direct payments cannot be used to pay for permanent residential accommodation but, at your council’s discretion, may be used to pay for short periods in residential accommodation. Other than in exceptional circumstances, they cannot be used to pay for a service from a spouse, partner or relative you live with. As they do not replace income, direct payments do not affect any other benefits.

Personal budgets

As with direct payments, these are allocated following an assessment by a qualified local authority professional. Only those under £23,000 and/or a limited source of other income are eligible. A personal budget can be used to buy anything that helps you to meet your assessed needs. This can include short breaks and personal care.

Personal budgets can be used to employ a close family member as long as that person does not live with you. If you choose to, you can employ a personal assistant to provide practical services or even to act as a companion when going out. Independent employment support services, arranged through your local council, can help to set you up as an employer. Personal budgets can be taken in one of three ways: as a direct cash payment by the individual or ‘a suitable person’; through an account held and managed by the council in line with the person’s wishes; or as a mixture of the two above.

To find out more go to www.direct.gov.uk

More than 54,000 people now buy their care services through direct payments or money allocated to them by their local authority. Direct payments are local council payments for people who need help from social services but who would like to arrange and pay for their own care and support rather than having them organised by the council. These are generally restricted to conventional services that a person has been assessed as needing by their local council.

Personal budgets, which are still being piloted across the UK, are a step on from direct payments. These are a sum of council money allocated for an individual’s lifestyle is not limited to the services provided by the council. For example, a person may use their budget to finance transport to a community-based leisure activity rather than a council-run session.

More than 31,000 people in England now have a personal budget and it is hoped that by 2011 all 150 councils with social services responsibilities will be offering personal budgets to those who are eligible.

I am 17 and have epilepsy. I generally have a good relationship with both my parents, but whenever they come with me to see my neurologist they take over. They seem to forget that I’m not seven any more and that I can speak for myself. I know they have my best interests at heart but they don’t seem to listen to my side of things, how I feel, whether I’m happy with my AEDs and so on. They say they are always aware that my appointment is short and there is a lot to discuss. I often feel like standing up and shouting: ‘I’m the one with epilepsy.’

Alex, Cambridgeshire

YOUR REPLIES

➡️ My parents were similar to yours, Alex. They always insisted that I kept quiet and let them do all the talking when we were seeing GPs, neurologists, nurses and teachers. I felt they took control of my medicines, my education and ultimately my employment choices and personal life.

➡️ Remember that now you are 17 you are able to make your own decisions. If you are able to work and use computers, then so do. There are of course jobs that won’t be suitable for you, such as being a pilot, because of the dangers of having a seizure, but there are plenty of careers that you will be able to choose.

➡️ As a child much of my epilepsy was caused by stress but now with the help of my neurologist I have decreased the number of pills I take and consequently decreased the number of seizures I have. I now have about 40 seizures a year whereas at one time I was having 40 a month. These changes have all been the result of taking control of my own life.

➡️ It is so important to be in charge of your health. I have had epilepsy for 14 years. At one clinic that I attended I actually saw a teenager stand up and shout at his mother: ‘I am the one with epilepsy’. He then refused to let her in to see the epilepsy specialist nurse with him.

➡️ Parents rightly feel responsible for their children, even more so when a child has a long-term condition, but it is easy for a parent to end up over-mothering a child.

➡️ I have seen teenagers and young people benefit from being encouraged towards self help.

John, NSE volunteer

YOUR THOUGHTS WITH JEAN?

➡️ My son, Peter, is 23 years old and has had epilepsy since he was eight. I found it very hard letting go when it comes to allowing Peter to take responsibility for his own epilepsy. After so many years of appointments with GPs, epilepsy specialist nurses and neurologists, I know how difficult it can be to ask the right questions, remember all the vital information you are given and make sense of new treatments.

➡️ Peter was about 17 when he suddenly decided he didn’t want his parents to attend appointments with him, but he was also at an age where he thought he was immortal, staying up all night, forgetting to take his tablets and drinking too much. I think a good idea would be split appointments so teenagers can see their GP by themselves first and then parents can join them for the final five minutes.

Jackie, Staffordshire

NEXT ISSUE

I have just had my first tonic clonic seizure at the age of 64. The first I knew about it was when I woke up in Accident and Emergency. I have had no history of seizures, just the occasional headache.

I am now on a low dose of anti-epileptic medication and I feel quite confused and slightly frightened.

My doctor has told me I can’t drive but I don’t know what else I should or shouldn’t do. I live on my own and am quite scared I could have another seizure without anyone knowing.

Does anyone have any advice or suggestions that might help?

Jean, Oxfordshire

WOULD YOU LIKE TO SHARE YOUR THOUGHTS WITH JEAN?

Email nicola.swanborough@epilepsysociety.org.uk or write to Editor, Epilepsy Review, National Society for Epilepsy, Chesham Lane, Chaplin St Peter, Bucks SL9 0RJ
In the last issue I wrote about how not being able to drive can be infantilising. How despite being ‘grown up’ and independent, I still feel like my 15-year-old self who needs to ask my Mum for a lift from the station. Add to that the lectures during the car journey of ‘you must talk care of yourself’ and ‘you mustn’t drink too much’ and I start to adopt the classic teen pose: my neck recoils into my collar, my arms fold closed and I become monosyllabic. Suddenly I want to paint my bedroom black. I huff and puff at Mum for pointing out the blatantly obvious, why is simply to look after myself. Yes, of course. Finding myself in A&E without another seizure is no picnic for me either, you know.

This is ludicrous, right? I’m a grown up, I have a job, I pay taxes, I send letters to my local parliamentarian. Why do I become such an obvious parody just because they care? Unlike my older siblings, I do not have children (and so, my parent’s logic would have it, do not comprehend responsibility). As I am the only one with a chunky medical file and without a driving licence I am the one most resembling the ‘dependent child’, the one who needs worrying about. I imagine for the parents of people with epilepsy it is especially hard to resist the urge to bubble-wrap the child. It is surely the very simple and natural act of loving.

I recently had the privilege of speaking at a workshop for teenagers with epilepsy. Young people get a pretty bad press these days. Pick up any newspaper and you’ll find plenty of disparaging chat about hoodies, bullies, ASBOS, teen mothers, gang culture, knife crime, drugs, booze, incoherent text messages, and ambition-only girls who especially criers or pole dancers. Britain is apparently breaking and it’s the nation’s ‘feral youth’ that is to blame.

Well just hold on there a minute, the group of teens that I met were all lovely, friendly, intelligent, caring and polite. They all share the experience of having epilepsy and despite having never met each other before, they were courageous and forthcoming with their opinions.

It seems that there are quite enough disempowering messages out there for young people already. If we want to build a strong society we have to build through empowerment and taking responsibility (and yes, in the next issue I will be outlining my 16 point plan for a utopian dream). In my journey with epilepsy, starting to have consultations with my neurologist on my own was a big step in taking that responsibility on. And it was liberating. Feeling able to ask your own questions, on your own terms is really important. You actually get to ask the questions about things that, as a teenager, you probably wouldn’t dream of talking about with your parents in the room – s-e-x and the suchlike. I was well into my 20s before I had my first solo consultation, and wish it had happened sooner. Taking ownership of epilepsy is an important part of taking responsibility for ourselves.

Adolescence is a sensitive time of identifying who you are and having a health condition like epilepsy can seem like it defines you. But we are just people who happen to have epilepsy, we are not epilepsy itself. Adolescence is also that stage when we shift from childhood into adulthood and, hopefully, independence. Having epilepsy is something that can distort your independence, so at some levels it feels we are restricted, still perhaps childlike.

I asked the group of teens during the workshop ‘what’s bad about having epilepsy?’ A pretty straightforward question, with plenty of answers, ranging across the physical, emotional and social. The more curious question was ‘what’s good about having epilepsy?’ Answers don’t perhaps naturally leap off the page, but I’ve considered some of the ways that epilepsy has really shaped me in a positive way. I have seen kindness in my friends and also strangers, I have seen health professionals at work and been in those cool scanner machines (very Star Trek, the MRI machine). I’m less afraid of hospitals than others who perhaps don’t visit them as frequently (I’ve been in the MRI machine), I’m less afraid of hospitals than others who perhaps don’t visit them as frequently. I was well into my 20s before I had my first solo consultation, and wish it had happened sooner. Taking ownership of epilepsy is an important part of taking responsibility for ourselves.

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JULIET STEPHENS
LAUGHING ALLOWED

Blooming marvellous

A horticulture project is springing to life following a £50k grant to the National Society for Epilepsy’s (NSE) Chalfont Centre in Bucks.

Residents with epilepsy and complex needs will soon be able to enjoy the large greenhouse and field next door.

Green-fingered residents have already been tending the seeds for the project and the growing tables inside the greenhouse are heavy with a healthy display of onions, exotic salad leaves and greens. Three giant tubs are also being used to grow giant parsnips which residents hope to enter for competitions. Pictured are horticulturist Allison Wragg and gardener Graham Felkins.

Russell Howard’s good news

Funny man Russell Howard has good news for NSE. The star of BBC 3’s Russell Howard’s Good News is running the 2010 Virgin London Marathon for us on 25 April 2010.

Russell will be joined by his brother Daniel, who has had epilepsy since he was a child, and Daniel’s twin sister actor Kerry. The three siblings will be among 40 runners all pounding the streets of London to raise money for NSE. To sponsor the Howards in the marathon go to http://uk.virginmoneygiving.com/team/russellhowardrunning

Find out about our research

Join us for our Research Seminar on 7 May at NSE in Chalfont St Peter, Bucks.

Speakers will include: professor of neurology Sanjay Sidisodiya (above); consultant neuropsychologist Pam Thompson; and clinical research fellow Rachel Thornton. You will also be among the first to receive a detailed report on all NSE’s current research projects. The seminar is open to our Research Associate Members. To find out more or to become a Research Associate Member call 01494 601402 or email members@epilepsysociety.org.uk

New research associate members or associate members who upgrade to become a research member before 7 May will receive a free copy of The Music Room by William Fiennes (p15).

Booklet helps pharmacists with AEDs

A booklet on anti-epileptic drugs (AEDs) produced by NSE is being sent to health care professionals and pharmacists across the country to help ensure people get the AED they need.

The new pocket-sized booklet has images of all currently used in the UK.

NSE MATTERS

13–19 June 2010 is National Epilepsy Week. Join us on our West Midlands Roadshow for the chance to listen to leading experts in epilepsy and meet others who are affected by the condition. We shall be in Birmingham on 15 June, Walsall on 16 June and Coventry on 17 June.

25 September 2010. Don’t miss our National Conference, Epilepsy: breaking you right, at the UCH Education Centre London.

21 October 2010. Altitude 360 is the date and venue for this year’s all-new annual dinner. Join us on the 29th floor of Millbank Tower, Westminster for iconic views across London, fine dining and dancing to raise money for NSE.

To find out more or to book places email enquiries@epilepsysociety.org.uk or call 01494 601 414.
Epilepsy Information

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.epilepsy.org.uk/shop

Research – find out about our pioneering medical research. Log on to www.epilepsy.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.epilepsy.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.epilepsy.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.epilepsy.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.epilepsy.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.epilepsy.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.epilepsy.org.uk/forprofessionals

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

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

Epilepsy Annual Conference
Central London
25 September 2010

EPILEPSY TREATING YOU RIGHT

PEOPLE WITH EPILEPSY NEED TO BE TREATED RIGHT – BY THEIR FAMILY AND FRIENDS, BY SOCIETY AND BY THEIR DOCTOR. COULD YOU BE TREATED BETTER?

WHY NOT JOIN US FOR A DAY OF LEARNING ABOUT HOW TO GET THE CONSIDERATION YOU NEED AND THE RIGHT INFORMATION, DIAGNOSIS AND TREATMENT?

• Why is choosing the right anti-epileptic drug (AED) so challenging?
• Do you feel right about taking your tablets? We look at the factors involved.
• How can you get what is right from your doctor’s appointment?
• Hear from people with epilepsy about their own journey with the condition.
• Top epilepsy specialist and consultant neurologist NSE’s Professor Sanjay Sisodiya is one of the key speakers

BREAKOUT SESSIONS:
• Life coaching. ‘Lift International’ look at how life coaching can help you make the right choices for your life.
• How people communicate. We look at how we interact with each other and with health professionals, to give us a better chance of being treated right.

PLACE
University College Hospital Education Centre, Central London
Railway stations nearby include Euston, Kings Cross and St Pancras. Easily accessible by tube, bus or taxi.

DETAILS
10.00am – 4.00pm
£30 per person
Concessionary rate for associate members £17.50
01494 601 402
www.epilepsy.org.uk

Drinks
Free Refreshments will be available at lunchtime

Further information
For further information please telephone 01494 601 402 or e-mail admin@epilepsy.org.uk

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www.epilepsy.org.uk/whatwedo