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REVIEW

**epilepsy
society**

www.epilepsysociety.org.uk

This year, as they say, things have really kicked off in the world of epilepsy. First there was the nationwide launch of *Electricity*, a powerful new film about a young woman’s struggle with epilepsy. Then the World Health Organization (WHO) put forward a new resolution which, if passed in May, could make epilepsy a priority in countries around the world. Finally, closer to home, MPs held a two-hour debate about epilepsy in the House of Commons.



Suddenly everyone’s talking epilepsy: from the local cinemas where the poshest thing on the menu is popcorn and hot dogs, to Westminster where nobody speaks without addressing their colleagues as ‘the right honourable.’ Epilepsy shows no respect for race, creed, education, wealth or age, and this year proves the point. Conversation is good. But just as we are all wallowing in words and enjoying a cross-party celebration that epilepsy is climbing up the political pole, along comes a window into someone else’s world that delivers a harsh reality check. How do you share a diagnosis of epilepsy with those around you? How do you find the words to explain the impact of living with seizures and all the fears and concerns that go hand in hand with them? Geraldine from Staffordshire wrote to ‘problem shared’ on page 21 about her own diagnosis at 46. ‘I don’t really know how to start the conversation,’ she said. ‘I wish there was someone else with epilepsy who I could talk to about my fears.’ It’s easy to have a skewed perception of just how ‘shared’ epilepsy is. When it comes

to structured society the conversation is beginning to flow. When it comes to the very personal level that involves a prescription of uncertainties, tablets and side effects, the conversation can easily become internalised. There is a constant conversation about epilepsy on our Facebook, Twitter and forum. But not everyone is on social media and it’s not always possible to shoehorn epilepsy into 140 characters. That is where our epilepsy helpline comes in. In January, for example, we spent 150 hours talking to 555 callers about epilepsy. The calls are confidential and there is no time limit. We will listen as long as you want to talk. You may have been recently diagnosed with epilepsy, you may have been living with the condition for many years. Whatever your circumstances, our friendly team are here to take your call on 01494 601 400, Monday to Friday 9am-4pm and 9am-8pm on Wednesday. Just pick up the phone.

Nicola Swanborough
Editor



FRONT COVER
Purple flower: photographer Tom Crawford. You can view more of Tom’s work at www.epilepsysociety.org.uk/artists-and-epilepsy or www.spottybadger.com

Follow the link to read more at epilepsysociety.org.uk

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GOVERNMENT

Epilepsy debate – now write to your MP



MPs and medical professionals are calling on people with epilepsy and the government to make sure issues raised in a recent House of Commons debate are addressed. MPs Laura Sandys and Cheryl Gillan are asking people to keep up the pressure on government to improve epilepsy services following the two hour debate which highlighted the need for greater funding for research into epilepsy, better commissioning and better access to epilepsy specialists. The two MPs said it was now up to people to write to their MPs to ensure their voices continue to be heard. Epilepsy Society communications manager Amanda Cleaver said: ‘There is clear evidence that the government and health regulatory bodies are starting to address concerns voiced by people affected by epilepsy and charities such as Epilepsy Society. ‘A prime example is the recent Europe wide review of the anti-epileptic drug sodium valproate which resulted in the government sending strengthened warnings to doctors and pharmacists. The review is the result of campaigns by patient groups and epilepsy charities.’ When sodium valproate is taken during pregnancy it can affect how the

baby develops in the womb and cause birth defects such as malformations or developmental disorders. New guidance issued by the Medicines and Healthcare Products Regulatory Agency (MHRA) stated valproate should not be prescribed to girls, women of childbearing age or pregnant women unless other treatments do not work. In the debate health minister Norman Lamb hinted that the Department of Health was considering an even stronger ‘red flag’ warning to notify GPs of the risks posed for women of childbearing age. Epilepsy Society’s medical director Professor Ley Sander said: ‘Doctors must ensure that all female patients understand the risks associated with valproate. Women currently taking this AED should not stop taking it – but should seek advice from an epilepsy specialist as soon as possible and together consider the options.’

To read the latest guidelines about prescribing of sodium valproate go to www.epilepsysociety.org.uk/sodium-valproate-guidelines

Read more about the debate on page 18 and how to write to your MP on page 20.

GENETICS

The brain and why size matters

An international consortium of scientists, including researchers from Epilepsy Society, has identified five genetic variants that influence the size of structures within the brain. The structures include the hippocampus which plays a key part in memory. The consortium is called ENIGMA which stands for Enhancing Neuro Imaging Genetics through Meta-Analysis. Almost 300 scientists from 193 institutes shared results from analyses of genetic data and more than 30,000 MRI scans. The study, published in *Nature*, looked at sub-cortical regions involved in basic functions such as memory, movement, learning and motivation. Abnormalities in these regions are associated with neurological and mental health issues. Professor Sanjay Sisodiya, Epilepsy Society’s lead geneticist said: ‘This important study, brings together genetics and imaging, two strengths of research at Epilepsy Society. ‘Epileptic seizures arise in the brain. The study has started the process of showing how genes influence the size, shape and other aspects of different parts of the brain. ‘This will help us understand how genes that cause epilepsy might act on the brain itself. It could help us to understand how gene changes might lead to epilepsy, and how epilepsy can in turn affect the brain in the setting of a particular genetic makeup.’

Electricity – now on DVD

Electricity, the powerful new film that documents the story of Lily O’Connor, a young woman with epilepsy, is now out on DVD. *Electricity* was nominated as best screenplay in the National Film Awards 2015 and has met with rave reviews. Epilepsy specialist nurse Jenny Nightingale said: ‘This is the first film I have seen that truly depicts the reality of seizures.’

Electricity (certificate 15) is available from 6 April 2015. If you shop online with Amazon using our Amazon online shopping link (see www.epilepsysociety.org.uk/fundraise-free) about 5 per cent of the purchase price will be donated to Epilepsy Society.

Cat no: SODA233
DVD barcode: 5060238031486



SUDEP

Identifying those at greatest risk



GPs could be key to identifying those people who are most at risk of premature death due to epilepsy, says Leone Ridsdale, above, professor of neurology and general practice at King's College London. Around 1.16 per 1,000 people with epilepsy die suddenly each year.

In an article in the BMJ, Professor Ridsdale wrote: 'General practitioners routinely identify risks of heart disease and stroke in the UK using electronic records. National strategy also supports risk identification for cancer in primary care.'

'With others I conducted a pilot study that showed it was feasible to identify specific risk factors for death in epilepsy, using routine data from GPs' electronic records.'

The study showed:

- people with epilepsy and alcohol problems had a threefold risk of death
- risk was almost doubled in people who had not collected their prescription in the past three to six months
- a history of injury or treatment for depression during the previous year, increased risk by around 40 per cent.

Professor Ridsdale continued: 'Risk assessment tools which have already been developed for other conditions in primary care... should be developed and piloted for people with epilepsy.'

'GPs could monitor, manage and refer patients to community or secondary care teams.'

BMJ2015;350:h718

GLOBAL

WHO resolution

A new resolution to prioritise epilepsy care around the world is to be put before the general assembly of the World Health Organization – WHO – in May. If approved it will become a formal policy of the WHO and could underline the need for greater research and epilepsy services in different countries. WHO has the power to influence health policies of governments around the world.

Epilepsy Society medical director Professor Ley Sander said: 'This is excellent news. If the resolution is approved, epilepsy and the issues surrounding it will be firmly in the spotlight.'

Professor Sander works closely with the WHO to improve epilepsy care in resource-poor countries.

NEUROLOGY

Invisible patients

More than half of people with epilepsy say they have experienced problems or delays when accessing health care, according to a report *The invisible patients: revealing the state of neurology services*.

The report, published by the Neurological Alliance which includes Epilepsy Society, is based on a survey representing the views of 7,000 people with around 80 different neurological conditions. The third largest group of responders were people with epilepsy.

The Neurological Alliance recommends that clinical commissioning groups – CCGs – should:

- collate up-to-date local neurology data
- capture patient feedback and encourage input into the development of neurology services
- work together to identify clinical and research trials.

Sarah Vibert, Epilepsy Society director of external affairs said: 'We have already started to address these issues – our first ever national nurse consultant for epilepsy commissioning is focusing on strategies to improve local services, patient pathways and outcomes for people with epilepsy.'

MENTAL HEALTH

Size of anxiety

People with epilepsy often experience anxiety too. New research, looking at 88 children aged between eight and 18 years and led by the University of Wisconsin, has shown that patients with anxiety generally have larger volumes in the amygdala – the almond shaped mass of nuclei inside the temporal lobe – than those without anxiety. Those with anxiety also had thinning in the cortical thickness of some regions of the brain. The results were published in the journal *Epilepsia* and researchers believe they show that anxiety disorders may be linked to structural abnormalities in the brain.

The scientists hope their findings will be significant for the future diagnosis and treatment of anxiety. Around one in 25 people in the UK experience anxiety.

LIFE EXPECTANCY

Register of hope

A study in Finland, reported in the journal *Neurology*, has confirmed the overall mortality risk for people with epilepsy is increased three-fold in comparison with the general population. However risk is dependent on cause. Newly diagnosed patients who become seizure free do not have a significantly increased risk. Nor do those with idiopathic epilepsy, thought to have a genetic base.

The epilepsy charity SUDEP Action has set up an on-line Epilepsy Deaths Register – EDR – to gather information about epilepsy related deaths. It is helping researchers understand and ultimately prevent epilepsy-related deaths. The EDR team works with the Epilepsy Society Brain and Tissue Bank, helping to maximise brain and tissue donations available for vital research.

Healthcare professionals or families and friends who have lost someone to epilepsy can add their details to the register (see below). The data could help improve services for people with epilepsy, reduce deaths and improve public awareness of Sudden Unexpected Death in Epilepsy. www.epilepsydeathsregister.org or call 0330 088 1220 www.epilepsysociety.org.uk/brainbank

Scream with a pearl earring



John Daniels is an artist from the North East of England. He has had left temporal lobe epilepsy for 16 years and finds his art helps him cope with the condition. This painting combines two famous pieces of art: Vermeer's *Girl with a Pearl Earring* and Edvard Munch's *The Scream*.

www.epilepsysociety.org.uk/artists-and-epilepsy

PHARMACY

Help in the high street

Pharmacists are being urged to make people with epilepsy a priority, by the Royal Pharmaceutical Society (RPS).

Working with Epilepsy Society, the RPS has developed a 'medicines optimisation' briefing for community pharmacies in the UK.

The briefing encourages pharmacists to get to know their patients with epilepsy and suggests a number of ways they can help people better understand their medication. This includes understanding the importance of taking a consistent supply of their epilepsy medications at regular times, discussing any side effects they may be experiencing and advising women who are planning a pregnancy to seek pre-conception advice.

Pharmacists can also discuss issues such as memory and anxiety and signpost to a relevant service.

AED WITHDRAWAL

Coming off the drugs?

Researchers at the University of Liverpool have highlighted the need for more research into the optimal time for medically supervised withdrawal of anti-epileptic drugs (AEDs) for those in remission, and risk factors that could predict a relapse in adults. Early AED withdrawal seemed to result in greater relapse for those with partial rather than absence seizures. The study was published in the Cochrane Database of Systematic Reviews.

News in brief



Our free updated epilepsy toolkit app will help you manage your epilepsy
See page 23



Study shows 1 in 5 adults with epilepsy has symptoms of ADHD – attention deficit hyperactivity disorder*
*Neurological Surgery, P.C., New York. Published in *Epilepsia*



We broke the rules of the House saying anyone with epilepsy is not allowed to go to the top of Big Ben.



Laura Sandys MP. Epilepsy debate see page 18



120 seconds
Extra time given in NHS pilot for 999 service to decide whether to send an ambulance

In the last 15 years studies have shown that exercise can, in many cases, help with seizure control and increase your sense of well being. Nicola Swanborough looks at the evidence

How exercise can help with seizures

Trudy Kerr took up running to try to regain some control in her life. She had been diagnosed with epilepsy in 2010 following a horse riding accident which resulted in two brain haemorrhages and a ruptured spleen. She was experiencing clusters of 25-60 simple partial seizures on a regular basis which she found challenging.

'I never knew when the seizures would happen, how severe they would be and how long they would last,' says Trudy who is a TV and radio presenter in Malta and also owns her own design agency and TV production company.

'It was scary and inconvenient but at the same time I didn't want to take medication – this was a decision I discussed with my neurologist. Instead I decided to start running to try to regain control of one part of my life. I could not have predicted the difference exercise would make.'

'By taking time out for myself and really making physical exercise a part of my routine I felt an increased sense of well being and personal achievement. What is more, my seizures stopped. I had my last seizure as I crossed the starting line in my first half-marathon and I haven't had another one since.'

'I cannot say whether this is because of the running but I do feel that by increasing my oxygen uptake I have somehow helped restore my brain to its normal state. All the time that I had seizures, I never dreamt. Now my dreams have returned and it's wonderful.'

Trudy's experience is rare but there is growing evidence about the positive effects of exercise for both increased seizure control and quality of life. And there is a groundswell of support for



Trudy Kerr is running in the Virgin Money London Marathon 2015 for Epilepsy Society

the integration of exercise as a complementary non-pharmacological treatment of epilepsy alongside anti-epileptic medication. (*You should never stop taking medication without consulting your epilepsy specialist.*)

In Norway, a study involving women with uncontrolled epilepsy showed that regular sessions of aerobic exercise for 60 minutes, twice a week for 15 weeks, resulted in a significant drop in the number of seizures.

Participants also reported a reduction in muscle pains, sleep problems and fatigue with reduced levels of cholesterol and improved utilisation of oxygen by the body.

Dr Eleanor Tillett is honorary consultant in sports and exercise medicine at The Institute for Sport, Exercise and Health, University College Hospital, London. 'There is evidence to suggest that people with epilepsy who take exercise regularly may have less frequent seizures than those who are less active,' she says.

'Exercise can help with anxiety, depression, obesity and osteoporosis'

'Scientists still cannot fully explain the numerous health benefits of exercise to the brain. However, the most common explanation is that exercise increases our metabolism and flow of blood to the brain which increases growth factors and reduces loss of cells.'

'For people with epilepsy, it would seem that exercise increases the level of neurotransmitters in the brain, so helping to increase seizure threshold. There is also some evidence to suggest that exercise in early and mid life may help to protect against the risk of brain disorders later in life.'

Dr Tillett points out that with epilepsy, one size rarely fits all and that a minority of people with the condition may find that exercise triggers a seizure. 'In addition, there can be a concern that if seizures are triggered by fatigue and stress, exercise may make things worse. However research shows that the fatigue and physical stress of moderate exercise does not usually trigger a seizure, even for those

who would find these factors a problem in other environments.'

The International League against Epilepsy (ILAE) recognises the potential of exercise in the self-management of epilepsy. In its report *About epilepsy and sports*, ILAE stresses: 'For people who have infrequent seizures – or have not had a seizure for a long time – it is rare to have a seizure during exercise. If seizures are frequent, the probability of a seizure occurring during sports activities is higher simply due to chance.'

While some people express concerns about exercising if they have epilepsy, Dr Tillett says that for the majority of people, exercise can be done safely with a few simple precautions. However, if you have a chronic medical condition, it is always sensible to consult your doctor before starting a new exercise regime. The potential benefits though are clear.

'Epilepsy is often accompanied by anxiety and depression, osteoporosis and obesity. Exercise can help with all of these,' says Dr Tillett. 'As with the general population – it can also help to reduce the risk of other potentially fatal conditions.'

'Exercise helps to reduce the risk of ischaemic heart disease by 40 per cent, stroke by 27 per cent, colon cancer by 25 per cent, breast cancer by 24 per cent, type 2 diabetes by 30 per cent and high blood pressure by 50 per cent.'

Ricardo Arida from the Federal University of Sao Paulo, Brazil has looked at the relationship between exercise and seizure control. Writing in the journal *Epilepsy & Behavior*, he says: 'Studies with patients with epilepsy have demonstrated that active subjects have significantly lower levels of depression than inactive subjects. Some anti-epileptic drugs are correlated not only to weight gain but also to reduced bone density. Exercise induces positive effects on bone health.'

'People with epilepsy should include exercise as a complementary therapy not only for seizure control but also for physical health promotion and mental state. To reach these goals, support of health authorities, social workers and sport instructors, and campaigns to inform patients to become more active are necessary.'

Exercise and you

Dr Eleanor Tillett advises

- a small change can have the biggest impact on your health. Going from nothing to something, even 10 minutes exercise a day, can make a difference
- think about the kind of exercise you might enjoy: in a group/on your own, sporting/general activity, outdoors/indoors. Join your local sports centre
- think about the benefits of being physically active
- walking is fantastic. It's weight bearing, it's free and it's outdoors
- any moderate intensity activity that leaves you slightly short of breath and sweaty is beneficial
- make your daily routine more active. Get off the bus a stop early and walk the last leg of your journey. Take the stairs, not the lift
- if you're not used to being active, talk to your GP about how to get started
- the safest forms of exercise are non-contact, non-height and non-water
- cycling, climbing and contact sports such as football and rugby, are slightly risky but should not be ruled out. Ask your healthcare professional for a risk assessment
- exercise should include aerobic exercise, strength building, flexibility and balance but many activities will incorporate all of these
- enjoy and feel the change.

The menopause

Will it affect your epilepsy?

At Epilepsy Society's annual conference, we asked you which topics you would like us to feature in *Epilepsy Review*. Many women asked to read more about the menopause. In response Dr Dominic Heaney, consultant neurologist, discusses some of the issues around this time of change and explains why the menopause is not something to be afraid of

If you want to find out about the menopause and epilepsy you need to be prepared to scroll down – down to the bottom of the web page or to read through to the final paragraph at the end of your book. The relationship between the menopause and epilepsy is poorly researched and information is sparse. It often feels like an afterthought. Yet around 240,000 women in the UK live with epilepsy and are likely, in the course of their lifetime, to experience the menopause alongside their condition.

The menopause is the time in a woman's life when menstruation stops and her ovaries no longer produce eggs. The average age for UK women to hit the menopause is 51 although some may experience it as early as in their '30s or '40s. And women with epilepsy often worry about how hormonal changes at this important time might affect their condition.

In my clinics many women in their '40s will be concerned about how the menopause may affect them. Probably the most common questions are about its effects on seizure control, whether it is advisable for them to consider HRT – hormone replacement therapy – and whether they are likely to be at a greater risk of osteoporosis – bone thinning – because of their epilepsy medication. These are all very real concerns.

Obviously, the menopause is not

a 'neurological' condition. It is a normal process and if a patient has concerns about their gynaecological health, I always encourage them to discuss these with their GP or gynaecologist. But if they are worried about how the menopause might affect or is affecting their epilepsy or anti-epileptic treatment, it is perfectly reasonable for them to ask for a referral to a neurologist to discuss any concerns. This should be done through the GP.

'One of the main concerns with HRT is the possibility of drug interactions with epilepsy medications'

Undoubtedly, the menopause can be a rocky time for some women with epilepsy, but it is not something to be afraid of: by planning properly and being well informed, many of the potential difficulties can be avoided.

As is the case with epilepsy, the menopause affects individual women differently. The rule of thirds tends to apply – for a third of women their seizures will remain the same, for a third their seizures will improve and for a third seizures may worsen. For a small number of women, they may be diagnosed with epilepsy around the time of their menopause and fear there could be a connection. However, as epilepsy can begin at any time in life,

this would seem to be a coincidence.

Epilepsy itself does not have a strong effect on the onset of the menopause. A minority of women with epilepsy may experience a slightly earlier menopause but for the majority it will follow the usual pattern of the general population. The age of menopause is strongly inherited maternally – so a woman is most likely to experience the same time line as her mother, whether she had epilepsy or not.

Many women associate their seizures with their menstrual cycle and there is evidence to show that some women with 'catamenial epilepsy' find that their seizures improve or disappear after the menopause. However it is important here to define exactly what catamenial epilepsy is.

Most women find that there is some link between their seizures and their menstrual cycle, but catamenial epilepsy is typically defined when 75 per cent of a woman's seizures occur during a specific and predictable part of her menstrual cycle. This may be just before or on the first day of her period; at ovulation; or during the second half of a 28-day cycle. But 75 per cent or more of the seizures should follow this predictable pattern. This is most likely due to changes in the levels of the sex hormones, oestrogen and progesterone, in the body.

Oestrogen is responsible for the onset of bleeding during menstruation and for ovulation. It is also known to be slightly pro-convulsant or seizure inducing and can easily cross the blood-brain barrier and affect brain cells. Progesterone is responsible for keeping the lining of the uterus rich in preparation for a fertilised egg and is thought to be mildly anti-convulsant, possibly providing some protection against seizures.

If you have true catamenial epilepsy then seizures may improve after the

menopause because you are not going through that permanent cycling of hormones. However, I am always wary of raising hopes and expectations. It can be very easy to associate seizures with the menstrual cycle but when these are recorded in a diary, the pattern often shows that they still don't fall into that very specific category of 'true' catamenial epilepsy, and so the beneficial changes may be less likely to occur.

Nevertheless, it is important for all women, if they suspect that there is a link between their seizures and their periods, to get this properly diagnosed – and seizure diaries can be very helpful in this regard. Specific medication can then be prescribed for targeted times of the month to help optimise seizure control.

During the menopause reduced oestrogen levels often cause symptoms such as hot flushes, mood swings, irritability, sweating and insomnia. HRT – hormone replacement therapy – contains either oestrogen or more typically a combination of oestrogen and progesterone to supplement the diminished levels of naturally occurring hormones and is often prescribed to help relieve unpleasant symptoms.

One of the main concerns I have with HRT in epilepsy is the possibility of drug interactions with epilepsy medications. Many epilepsy drugs are ▶

Enzyme-inducing epilepsy medication

These medications may interact with hormonal replacement therapy

carbamazepine (Tegretol)
phenytoin (Epanutin)
phenobarbital (Phenobarbitone)
primidone (Mysoline)
topiramate (Topamax)
oxcarbazepine (Trileptal)
rufinamide (Inovelon)
Eslicarbazepine (Zebinix)

Lamotrigine (Lamictal) and levetiracetam (Keppra) are not enzyme-inducing but HRT has been shown to lower levels in the blood, with the potential to give rise to seizures. Perampanel (Fycompa) is an enzyme inducer but is described as 'weakly' inducing. It may reduce the efficacy of HRT.



◀ enzyme inducing (see on page 8) and may interact with hormonal therapy, which also affects liver metabolism. We often see levels of these epilepsy drugs plummet when a woman is prescribed HRT, so putting her at risk of increased seizures. This can be addressed, however, through anticipating these changes and in many cases, therapeutic drug monitoring where blood levels are checked.

If a woman is considering HRT and is also taking one of the listed medications, therapeutic drug monitoring should be used to measure drug levels in her blood ('trough' levels, first thing in the morning) before HRT begins and again a couple of weeks into treatment. If the levels of her epilepsy drugs have dropped, her prescription can then be adjusted to optimise her seizure control.

It can also be very useful to measure drug levels when HRT is stopped so as to avoid potential toxicity with too high a dose of epilepsy medication in the blood. Therapeutic drug monitoring is cheap, easy, reliable and makes good sense. I would advise women to be pro-active and suggest it to their GP or neurologist. Don't wait for them to offer it. (You can read more about therapeutic drug monitoring in *Epilepsy Review*, issue 11, Winter 2014/2015 or at www.epilepsysociety.org.uk/tdm)

HRT is also commonly prescribed to prevent and treat osteoporosis or bone thinning. Unfortunately, a high percentage of women with epilepsy have reduced bone density. Changes in oestrogen levels during the menopause can exacerbate this problem in all women, regardless of their epilepsy. However, a variety of factors common among women with epilepsy – including some epilepsy drugs – can also contribute to bone thinning. HRT can lessen this effect.

But the drugs and hormones are not the full story. All of us can do much to protect ourselves against osteoporosis through lifestyle choices: a healthy, balanced diet, regular load-bearing exercise such as walking, ensuring we get of plenty of vitamin D by being out of doors, and avoiding smoking and excess alcohol intake. These are all areas where it is beneficial to make positive changes earlier rather than

later, particularly if you have epilepsy. Bone density is 'accumulated' and good habits from an early age will protect in later life.

'Discuss concerns around the menopause with your GP... ask to be referred to a neurologist'

Risk for osteoporosis is commonly gauged using FRAX, the fracture risk assessment tool developed by the World Health Organization. This looks at health risks including age, height, weight, smoking and alcohol consumption plus related health conditions such as rheumatoid arthritis. But it does not include epilepsy. Don't be afraid to bring up any concerns you might have about your epilepsy and osteoporosis with your GP or neurologist.

Finally, some women worry that taking HRT on a long-term basis may increase their risk of breast cancer yet

at the same time are concerned that stopping it may mean increased seizures due to hormonal changes. Discussing this with your GP or neurologist and taking things slowly so the menopause is managed properly should minimise any risk of problems.

In all instances, if a woman with epilepsy could benefit from HRT to alleviate symptoms of the menopause, it should be considered, notwithstanding her epilepsy. With careful planning, the menopause should not need to be a time when women with epilepsy need to worry unduly. As with all aspects of epilepsy, discuss any concerns around the menopause with your GP and, if necessary, ask to be referred to a neurologist.

Dr Dominic Heaney is consultant neurologist at the National Hospital for Neurology and Neurosurgery, London. Look out in the next issue of *Epilepsy Review* for our second article in response to reader requests: erectile dysfunction



Menopause at a glance

For most women, epilepsy does not result in an early onset of the menopause

Women with 'true catamenial epilepsy'* may find their seizures reduce after the menopause

Oestrogen can be slightly seizure-inducing. Progesterone is thought to be mildly anti-convulsant

HRT may reduce the levels of some epilepsy drugs leading to seizures – this can be checked through therapeutic drug monitoring

If you are concerned about your epilepsy and the menopause, ask your GP for a referral to your neurologist

The menopause and epilepsy drugs can contribute to osteoporosis, but so can an unhealthy lifestyle

*See page 8

If tests show that your seizures are generated in a specific area of your brain, it is possible that you may be considered for epilepsy surgery. More than 60 per cent of people who undergo this type of surgery become seizure free and this can have a huge impact on their life. Freedom from seizures can mean increased employment possibilities, freedom

to drive and a better lifestyle. However, there are risks involved in surgery and complete seizure freedom cannot be guaranteed. Opting for surgery is a big decision. Sue Usiskin looks at what surgery involves at the National Hospital for Neurology and Neurosurgery, London, and the risks you may have to consider



Epilepsy surgery



Sue Usiskin MBE



Sue Usiskin MBE is the epilepsy clinic counsellor at the National Hospital for Neurology and Neurosurgery. She underwent epilepsy surgery – an awake craniotomy – in 1994 for her epilepsy which reduced her seizures from as many as six to ten a month to two to three a year. Since taking levetiracetam, she has been free of generalised seizures for nine years and only has occasional auras.

What is epilepsy surgery?

Epilepsy surgery is a type of brain surgery carried out by neurosurgeons to help treat people who do not respond to anti-epileptic medication or who experience unacceptable side-effects. Surgery involves removing a small, localised structural abnormality in the brain where this is known to be the cause of the person's seizures. It may involve preventing electrical activity spreading from the abnormality to other parts of the brain. However, not all types of epilepsy are suitable for surgery.

Who may be considered for epilepsy surgery?

You may be considered as a candidate for surgery if your epilepsy is caused by a specific structural problem in your brain. This may relate to a brain injury at birth, a head trauma or from

a brain infection. You may have some scarring to your brain, or a tumour or lesion that developed before or since birth. If the focal point of your seizures can be identified, you may be considered for surgery.

Surgery will normally be considered if:

- you have tried several anti-epileptic drugs but your seizures have continued or side effects from the medication have been unacceptable
- tests have identified the area of your brain that is giving rise to your seizures
- the part of your brain causing the seizures can be safely accessed by the surgeon without damaging other functions of your brain such as vision, language, movement, hearing or memory
- you have no other medical problem that would make you unsuitable for surgery

– your medical team think that surgery will give you a good chance of becoming seizure free.

What is the assessment process for surgery?

Epilepsy surgery is only ever undertaken after a long and detailed investigation that will assess both the risks and benefits of surgery for you as an individual. This will be carried out by a team of specialists including your neurologist, neurosurgeon, neuropsychologist and neuropsychiatrist. You may also see the specialist epilepsy counsellor who is part of this team. The assessment process can take as long as a year and will involve routine tests as well as further tests if your neurologist feels they are necessary.

What are the routine tests?

Most of the tests for epilepsy surgery are carried out on an out-patient basis, with the exception of video-EEG-telemetry (see below).

Magnetic resonance imaging (MRI) is a scanning technique that produces very detailed images of your brain. It can show areas of scarring, small tumours, developmental abnormalities and minor brain damage that may be causing your epilepsy.

EEG (electroencephalograph) uses electrodes attached to the scalp to record any electrical activity in your brain.

EEG video-telemetry is similar to the EEG above except that it captures a continuous recording of your brain waves using small discs attached to your scalp over a period of five days. This means you will need to be admitted as an in-patient to a telemetry ward.

Neuropsychology assessments are carried out to look at how your brain works and which parts are affected by your epilepsy. This helps the surgical team to decide whether surgery may be suitable for you. The tests usually last between two and three hours and will include some memory, reading

‘Many studies have shown that patients who achieve seizure freedom following epilepsy surgery have an improved quality of life, although this improvement may take up to two years to establish’

Simon V Liubinas, departments of neurosurgery and neurology, The Royal Melbourne Hospital, Australia

Percentage of people who are still free of seizures after...



From a study carried out by University College London into the long term outcome of brain surgery for epilepsy.

30 per cent of people who undergo epilepsy surgery, experience anxiety or depression after the operation

About **10 per cent** may experience a more significant form of depression requiring more treatment

3-4 per cent experience more serious psychiatric problems requiring hospital treatment

and drawing tasks as well as puzzles.

If you are thought to be suitable for surgery, you will also be offered the opportunity to discuss the likely impact that surgery may have on your memory and other mental abilities. For 1 in 3 people with temporal lobe epilepsy, memory problems may get worse after surgery but this can depend on your age, type of operation and your pre-surgery memory skills. The psychologist will be able to suggest strategies to manage any additional memory problems you may have following surgery.

Neuropsychiatry is important in assessing whether there could be other reasons such as emotional difficulties why surgery may not be an option for you. In some people surgery can give rise to emotional

‘There was a time none of us would have dared go this close to a river so what a nice sight to think all of us did without fearing the worst!’

Epilepsy surgery friends: a network of friends, led by Anthony Williams, who share their experiences of epilepsy surgery on Facebook, both before and after surgery

From left to right: Carl, Val, Richard and Nick.

300 people undergo surgery in UK each year but **10-15,000** could benefit from the procedure

problems, even in those who have not experienced them before. If surgery is an option for you, the neuropsychiatry team will see you as part of the evaluation process. They will also see you after surgery, if the need arises, so that further help can be given.

What are the less common diagnostic tests?

Sometimes the tests above do not give a clear enough picture of what is happening in your brain and how your epilepsy affects you. Your medical team may wish to carry out further tests to decide conclusively whether surgery is right for you. These include:

PET (positron emission tomography) scan which involves injecting a small amount of sugar with a radio-active label into a vein.

The sugar is taken up by the brain and is detected by the scanner.

MEG (magnetoencephalogram) is used to measure the magnetic field in your brain and help identify any abnormalities that may be giving rise to your seizures.

Functional MRI (fMRI) scans may be used to look at the parts of your brain that are used for speech, vision, hearing, movement and memory. This will help to ensure that these important networks are not damaged during surgery. You may also have a combined MRI and EEG to show the brain’s electrical activity during the scan.

Intracranial EEG telemetry This is only necessary for a small number of people. If it is not possible to determine the exact location of the epileptic focus using EEG and telemetry recordings, the surgeon

may decide to place electrodes either on the surface of your scalp or within the actual brain tissue. This has to be done under general anaesthetic and you may need to spend one or two days on the surgical ward to recover from the affects of the anaesthetic before recordings can begin. Recordings may continue over a period of two or more weeks to enable the team to collect enough information. The electrodes will then be removed and, after discussion with the surgical team, you will be sent home. If you are thought to be suitable for surgery an admission date will be arranged.

Making a decision about surgery

Once all the investigations have been carried out, the specialist team will assess whether they feel surgery is appropriate for you. If it is, your neurosurgeon will discuss with you your individual risks and benefits. This is also an opportunity for you to discuss any concerns you may have. You may also be referred for epilepsy counselling, when you and your family can discuss further any queries or concerns.

Talking to other epilepsy surgery patients

At the National Hospital for Neurology and Neurosurgery we are able to put potential surgery candidates in touch with other people who have been through epilepsy surgery so that they can ask them about their experience and discuss the issues that may concern them. We have ‘expert patients’ who can talk about their own personal outcomes, how successful they feel their surgery was, and whether they feel it has had a positive impact on their lives.

What are the risks involved in surgery?

The risks involved in epilepsy surgery will largely depend on the part of your brain that your seizures are coming from. Sophisticated scanning techniques mean that neurologists are able to map crucial pathways between

functional areas of the brain so minimising the impact of surgery on vision, memory and language. They will be able to look at your scans and discuss with you any potential risk to your communication skills, visual field and memory.

Up to 30 per cent of people who undergo epilepsy surgery, experience some form of anxiety or depression after the operation. This is usually temporary but may require extra medication or additional support.

About 10 per cent may experience a more significant form of depression requiring formal treatment and support, but this usually responds to treatment within a six-month period.

In a small number of cases – three to four per cent – more serious psychiatric problems may develop and these may require a hospital admission.

The risk of death from epilepsy surgery is very low – less than one per cent.

What are the benefits of surgery?

Your neurologist will help you to weigh up the risks of epilepsy surgery for you against the benefits. Again, the benefits will be very individual to you and it is always important to have realistic expectations of your surgery. Benefits include:

- potential seizure freedom, although you may have to continue with your medication
- reduced seizures
- long-term improvement in quality of life although some people initially experience a degree of anxiety or depression
- the ability to drive if you become seizure free and do not experience any significant loss of visual field
- better employment prospects.

Awake surgery

If the part of your brain that is to be removed is close to areas which control important functions such as speech or movement, your neurosurgeon may suggest that

you remain awake during part of the operation. This is quite routine and you will not feel anything. This ensures that the surgeon will be able to check throughout the procedure that no brain function is being affected.

Coming into hospital for epilepsy surgery

You will usually be admitted the day before your operation, when you will be asked to sign consent forms for the operation. The day before surgery you will usually have a special MRI scan that will be loaded onto a computer navigation system in the operating theatre and used as a guide for your surgery. A small strip of hair will be shaved from your head where the incision will be made. Surgery usually lasts four to six hours but this may vary according to the type of surgery that is being carried out.

How will I feel after surgery?

After the operation you will wake up in the recovery room but, provided all is well, you will be transferred to the surgical intensive therapy unit for 12-24 hours. You will then be moved to the surgical ward where you will stay until you are discharged. You are likely to feel the effects of the anaesthetic for some weeks after surgery. You may experience seizures within the first week following your surgery but this does not mean it has failed. You may need to have your medication adjusted. You would usually be discharged five to seven days after the operation.

Recovery at home

You should expect to spend the first three to four weeks recovering at home. As a guide, every hour of anaesthetic that you have experienced will take a week to leave your system. Generally you should be back to almost normal activity levels within six to ten weeks. You may still feel tired although you will gradually begin to build up your stamina.

When will I be seen again?

The surgical team will usually review you six to eight weeks following surgery. You will also have an MRI scan and memory tests three to four months after surgery. You will then be followed up by your neurologist at regular intervals during the first year. You may see other members of the team according to need. You will probably stay on the same medication for the first 12-18 months after surgery and any changes will only be considered in discussion with your neurologist. You will also have a further assessment with a neuropsychologist one year after the operation to assess the effects of surgery on your daily life. A further MRI and EEG are carried out if necessary.

What if surgery fails?

There is never any guarantee that surgery will be completely successful. Your surgeon will give you the expected success rate prior to surgery and this will be discussed in full. If surgery is not successful, it may be possible to consider more extensive surgery after a year and it is important to keep in contact with your specialist team and GP.



**epilepsy
society
helpline**

01494 601400

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

Life-changing decisions

Choosing to undergo epilepsy surgery can be a huge decision to make. Here people who have had surgery discuss the changes it has made to their lives, while one mum who is still considering surgery, shares both her hopes and her concerns

Anthony's story

Anthony Williams was diagnosed with epilepsy at 20 and underwent surgery just before his 29th birthday. He has been seizure free for 12 years, and is working as an engineer.



'I had probably been having simple and complex partial seizures all through my childhood but they were put down to bad behaviour and I was packed off to a special school.

When I was 17 I passed my driving test and immediately had an accident, running down two pedestrians who both

suffered broken bones. I broke my shoulder and knee caps and was done for driving without due care and attention. No-one considered that I might have had a seizure at the wheel.

The turning point came when I was 20. I was working as an engineer, inside the pipe of an industrial pump. My colleagues were trying to communicate with me but I was

totally unresponsive. The company I worked for sent me to the local hospital and it was from there that I finally got to see a specialist and was diagnosed with temporal lobe epilepsy.

Epilepsy completely stole my '20s from me – they were a lost decade. I felt I was on the scrap heap. I was having panic attacks, severe seizures, mood swings and thoughts of suicide.

Opting for surgery was a big decision but I had no life as it was. I was virtually housebound with no work and no social life. Surgery offered me hope.

I have now been seizure free for 12 years and am not taking any medications but it probably took me 10 years to really pick myself up after surgery. The initial months were very worrying, wondering whether surgery had worked. I felt very delicate and vulnerable to injuries and worried about what would happen if I had a seizure and landed on my head so soon after surgery.

I faced many challenges in getting my confidence back. One of the biggest challenges was finding a house. I worried that if the seizures returned and I lost my job, I could lose the house too. Now I have my driving licence, my own home and a social life with friends and colleagues again. I have also set up a Facebook page for people who have had epilepsy surgery or who are thinking about it, so that they can support one another. It's really important to me to support other people whose lives could be changed through surgery.'

The case for surgery

- Currently epilepsy surgery is often viewed as a last resort with patients only being considered after several years of seizures

- NICE – the National Institute for Health and Care Excellence – recommends that if someone's

epilepsy is not controlled within two years, they should be referred to a tertiary specialist centre so that other treatments, such as surgery, may be considered

- Evidence shows that epilepsy surgery is a cost-effective treatment with financial savings

in health care for seizure-free people as medications are reduced or stopped, and hospital admissions eliminated

- Research, reported in the journal *Neurology*, found that two years after surgery, total costs for seizure free patients had declined by 32 per cent.



Tone's story

Tone Sarjanen underwent epilepsy surgery at the National Hospital for Neurology and Neurosurgery, London on 29 February 2008 – leap day. She hasn't had a seizure since. She describes the difference it has made to her life but says it wasn't always an easy ride

When I was offered the possibility of surgery for my epilepsy, I knew it could pose a risk for both my speech and memory which worried me. My husband and I are very close, so we talked a lot, discussing the pros and cons. For us the worst case scenario would have been if I had suffered a stroke as a result of the surgery or if my memory had been compromised.

In the end we made the decision quickly. I was diagnosed with epilepsy only a few years earlier which forced some restrictions in my life. I was unable to do things I had previously taken for granted – driving, having a bath, swimming, being totally independent. I had tried a series of drugs, but none of them helped with my partial seizures.

I had total faith in my neurology team including Professor Ley Sander, Dr Michael Johnson and my surgeon Andrew McEvoy. I felt I was very lucky to be one of the few people with epilepsy for whom surgery and a potential cure for my seizures was a possibility. We were considering a risk of getting injured every day for the rest of my life versus the possibility of being completely seizure free. That risk was well worth taking. Being positive and optimistic was at the core throughout. The neurology team were brilliant, having

a laugh with me when I needed it and giving reassurance when I was emotional or worried.

After the operation, the feeling of relief was overwhelming – I could remember and recognise family and friends and even my surgeon immediately when I woke. And my language and speech were unaffected. I felt invincible; it was as though I had beaten something unbeatable.

The reality, however, was that although the operation had cured my epilepsy, physically and mentally I still had a long way to go. I had a heightened awareness of sound for a while. I was less tolerant and could not read or focus on anything.

Then, when I felt that the worst was over, a cloud of depression hit me. It was as though I was in the clutch of something that would not let me go. Family and friends were very supportive but unable to understand why I was feeling as I did. Even I could not recognise myself. I was free from seizures and healing well physically – why was I unable to be happy?

I had to give myself time, time for my body to repair both physically and mentally. Gradually I came through it and I am now stronger, happier and both humble and grateful for the life I have. In 2011 I came off my medication, the fog dulling my senses lifted and I had such renewed energy again and needed far less sleep.

I am incredibly appreciative of the here and now in a way that I never was before. Since the operation I have taken up horse riding and I now have my own horse, Ester. We have been competing at dressage, show jumping and cross country. Prior to surgery, I could not safely walk along the platform at the tube station for the risk of a seizure. Now, to go full gallop on my horse and jump fences is fantastic. The feeling of freedom is amazing.

The moment I was allowed to drive again, my husband and I got in our car and I drove us all the way from London to St Andrews as a celebration – awesome.

Carl's story

Carl Bennet was astonished when he was told he could be a candidate for epilepsy surgery. In spite of living with seizures all his life, he had never realised that surgery could be an option for some people. He tells his story



'For the first 18 years of my life I was on an ever-increasing cocktail of epilepsy medication, none of which controlled my seizures. And the more drugs I took, the more tired I got and the worse my memory became. At school both my concentration and attention were really poor.

It was only when I was referred to the Walton Centre in Liverpool that anyone suggested surgery to me. I was gobsmacked, astonished. They said I could be a candidate as I had temporal lobe epilepsy. I had no idea that you could have surgery for epilepsy and I was really excited about it. Then as time wore on, I started to get a bit anxious. The area of my brain that my seizures were coming from was very close to the area responsible for speech so I was quite a high risk. Nevertheless I decided to opt for surgery when I was in my mid '20s.

When I came round after the operation, I must have started mumbling because the first thing I heard was my mum shouting: 'He can speak!' It was such a relief.

Surgery made a massive difference to my life. Up until that point my social life had been very limited. I had missed important milestones in my life because of my seizures. For example I had never gone to discos for fear of flashing lights even though I didn't have photosensitive epilepsy. But once I had recovered from surgery, a close friend was determined that I should experience a night out in Liverpool. It was one of the best night's of my life. I have never experienced such friendliness. It really opened up a life of freedom for me.

I am now 46 and working as a warehouse operative for the NHS. I'm no longer on anti-epileptic drugs so the difference to my memory is amazing. But I think the best thing is the freedom that surgery has given me as a keen walker.

I have joined the Ramblers Association and can trek along ridges or to the summit of mountains with wonderful panoramic views without the fear of seizures or of injuring myself. It is the best feeling in the world.'

Tina's story

Tina Thompson is currently going through tests at Epilepsy Society to see whether she is suitable for epilepsy surgery. She talks about why her family has concerns and why opting for surgery is not an easy decision



'My husband's father had a brain tumour and underwent surgery as an emergency. It was a matter of life or death for him and there was really no question but to opt for surgery. With epilepsy it is different, I have a choice and I think that makes it much harder.

I have right temporal lobe epilepsy and have scar tissue on the right side of my brain. I still have tonic clonic seizures. I also have spastic quadriparesis which is a weakness in my limbs.

Over the years my memory has taken a big hit, both from the seizures and from the medication. The drugs also slow my brain process down so I never feel as though I am living life to my full potential.

'I am in the middle of my life and am potentially contemplating another 20 or 30 years of medication without knowing for sure that it will help me to control my seizures. There are only so many anti-epileptic drugs to try and then you begin to run out of options. I am also aware that in rare events, people can die from their epilepsy.

'I love the idea of being completely free from my seizures. I am in awe of how the brain surgery team can pinpoint exactly where in my brain my seizures are coming from and assess how close this is to important networks for functions such as language, vision and memory. But I also know that there is no guarantee that complete seizure freedom would be the outcome of surgery. Alongside this, I worry that surgery could make my memory worse.

'I am married with two daughters. My husband and daughters are very concerned about me having surgery. They cannot contemplate anything that could risk my memory, speech or vision. They would rather I continued as I am but I haven't made up my mind yet. I am still gathering all the information and have every faith that together, my family and the neurologist at Epilepsy Society will guide me in the right direction. It is individual for everyone.'

You can read more epilepsy surgery stories at www.epilepsysociety.org/choosingepilepsysurgery



Epilepsy

in

parliament

During a landmark debate in the House of Commons, MPs spelled out to minister of health Norman Lamb, just what is wrong with epilepsy services and why they want to see action from the government. Here is an extract from the two-hour debate led by MPs Laura Sandys, above right, and Cheryl Gillan, left

Laura Sandys, South Thanet

Addressing stigma is at the heart of the treatment, care and funding for epilepsy. The level of support for research on epilepsy is significantly lower than for other conditions. We need a lot more research, but this comes down to people being clear that epilepsy matters.

We need to ensure that there is a greater understanding at the core

of our health sector so that there is more referral to tertiary care. We need more specialists.

Following diagnosis, there are straightforward NICE – National Institute for Health and Care Excellence – guidelines that lay out a clear pathway. There must be a wrap-around package that allows people to live their lives and take control of their chronic condition.

We have a serious problem with SUDEP, or sudden unexpected death in epilepsy. Many of those who lose their lives are younger people who are just moving from youth to adult services. There are examples of countries in Europe that are doing better. It is crucial that we do not fall behind the standards of other European countries.

I want people with epilepsy to come out and talk about epilepsy. I want charities to work together so their voices are unified. I call on the government to address the Cinderella status of epilepsy.

Kate Hoey, Vauxhall

Referrals (to a specialist) are in theory currently meant to take two weeks, but I have had constituents who have had to wait well over two months.

I want to check what the Minister is doing to urge commissioning groups and others to speed that up.

Norman Lamb, Minister of Health

NICE guideline recommends referrals for patients with suspected epilepsy are urgent, with patients being seen within two weeks, if possible. Local organisations responsible for delays should be held to account.

Cheryl Gillan, Chesham and Amersham

Epilepsy Society has been working with people affected by epilepsy for 123 years. At its Chalfont centre, groundbreaking research led by medical director Professor Ley Sander and head of genetics Professor Sanjay Sisodiya, demonstrates the breadth of genetic influences in epilepsy.

However there are issues facing the society's specialised medical and research facilities. Under the Health and Social Care Act 2012, the responsibility and budget for specialised services were brought together in NHS England as the sole national commissioner of specialised services, but since May 2014, it has U-turned on national commissioning. Instead, the new proposals for co-commissioning would see responsibility for the vast majority of specialised services shared with local clinical commissioning groups (CCGs).

Epilepsy Society is opposed to

the co-commissioning of specialised epilepsy services. If CCGs are allowed to reinvest savings from specialised commissioning in other areas of their budget, it might create an incentive to under spend on specialised services.

Norman Lamb

It is critical that those who require more specialised care can access the right services and treatments which is why NHS England commissions such services nationally. That need not be undermined by co-commissioning with local areas.

Teresa Pearce, Erith and Thamesmead

Women with epilepsy remain uninformed about their choices and medication. They lack the specialised care and support they need, and they are at increased risk of maternal death. Given the repeated concerns raised over decades about sodium valproate and its links to the development of birth defects and foetal anti-convulsant syndrome, commonly known as FACS, this is nothing short of a scandal.

In 2012 NICE recommended a new indicator to encourage GPs to tell girls and women of child-bearing age about the risks posed by anti-epileptic drugs. Sodium valproate was specifically named as a drug that should be discussed.

Norman Lamb

I take this issue extremely seriously. There has been an EU-wide review of the risks involved. The Medicines

and Healthcare Products Regulatory Agency issued new guidance in January, and the British National Formulary has also been updated. The department is considering the introduction of a 'red flag' system to notify GPs of the risks posed to women of child-bearing age, and I personally am very keen to introduce such a system.

Women with epilepsy wanting to conceive must – absolutely must – be given accurate information and counselling about medication such as sodium valproate.

Valerie Vaz, Walsall South

Only three out of 140 health and wellbeing boards are making plans for people with epilepsy. Some 78 per cent of CCGs have not developed and do not intend to develop a written needs assessment for people with epilepsy – that must change. Evidence also shows people with epilepsy have poor access to epilepsy specialists and do not have regular reviews of their epilepsy. We need referrals from GP specialists to tertiary specialists without going through a generalist consultant.

Sir David Amess, Southend West

I have received complaints regarding the prescription of generic drugs, despite evidence suggesting that their use leads to an increased risk of seizures. Even more alarmingly, I was informed that the latest drugs are not made available to patients, as older and less effective drugs are cheaper to use. That is just not acceptable.

Norman Lamb

The government is committed to securing high-quality outcomes for people in England living with epilepsy. The government recognises the importance of ensuring that patients with suspected epilepsy are diagnosed swiftly and accurately. GPs should be able to manage, monitor and appropriately refer epileptic patients in their care.

In secondary care, there are nearly 2,000 full-time equivalent neurologists, and for 2015-16 Health Education England has made a commitment to invest in 217 neurological speciality training places. In addition, specialist epilepsy nurses should be a key element of both routine and specialist neurological care.

This has been an incredibly important debate, and I will do everything I can to follow up all the important points raised.

Laura Sandys

In conclusion I want the Minister to do three things: the first is to talk to NHS England and work out a pathway to reduce by 400 the unnecessary deaths caused by SUDEP each year.

The second is to kick and beat the more than 90 per cent of CCGs that do not have a pathway (for epilepsy). That is not acceptable. It is letting down many people in this country.

The third is to determine how best to implement the NICE guidelines to ensure the pathway of the long-term chronic care of people with epilepsy.

MPs highlight impact of epilepsy on people in their constituencies !!!

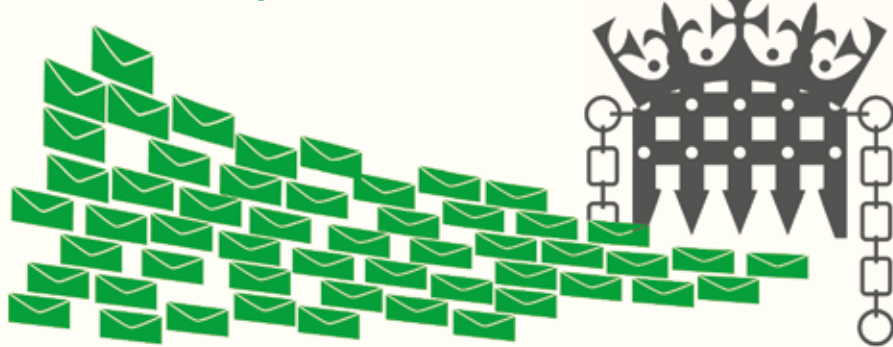
Karen Guyott, 29, 'dismissed due to her epilepsy' from her job with London Underground .
Kate Hoey, Vauxhall

Emily Sumaria, a young student, died in her sleep after she was 'thought to have been prescribed the wrong dosage of epilepsy medication' at university. Emily had not been told the risks of SUDEP.
Martin Horwood, Cheltenham

Jessica Monks, died by suicide in January, thought to be related to a psychotic episode linked to her epilepsy medication.
Steve Baker, Wycombe

Adam Lane, father to a two-year-old son, unable to work because of his seizures and now facing a second tribunal to fight for his rights to benefits.
George Howarth, Knowsley

Contact your MP



Lobbying your MP can be a powerful way of helping to improve epilepsy services. Following the recent epilepsy debate in the House of Commons (see page 18), MP Laura Sandys called on people with the condition to write to their MPs, putting pressure on the government to improve services across the country. The general election in May is another ideal opportunity for contacting your MP – and those competing to be your new MP. Epilepsy Society's policy adviser Katharine McIntosh explains how.



Writing to your MP – or lobbying your MP as it is often referred to – is easy and your voice can really help to inform your MP and parliamentary candidates about issues that affect you.

How to find your MP

You may already know who your current MP is or you may want to find out who represents your area. Either way, you will find their up-to-date contact details at www.parliament.uk/mps-lords-and-offices/mps

You can search for your MP by name, constituency or postcode. This will enable you to access your MP's parliamentary and constituency email address and their postal address so you can choose how you wish to contact them.

How to find your prospective parliamentary candidates

The three main political parties list prospective parliamentary candidates on their websites (below) but you should also be able to find candidates for other parties in your area at <https://yournextmp.com/>.
www.conservatives.com/OurTeam/Prospective_Parliamentary_Candidates.aspx
www.labour.org.uk/people
www.libdems.org.uk/general_election_candidates

What should you write?

The most powerful letters are those written in your own voice and words. It is important to be clear and concise. Explain how your epilepsy affects you or the friend or family member you are writing about. But remember to include a 'call to action' for your MP. What do you want your MP to do to improve epilepsy services for you or to make a difference to your life?

If you are writing a personal story, you might like to include some of the following details. Remember only to talk about the issues which are relevant to you and be as brief as possible:

- the type of epilepsy you have and frequency of seizures
- any difficulties you've had with your diagnosis or treatment for your epilepsy
- how your seizures affect employment, your ability to drive or to support a family
- other issues you may have alongside your epilepsy such as anxiety, depression and memory problems
- any stigma you may feel around your epilepsy
- worries around benefits and changes to the welfare system
- specific concerns relating to your epilepsy medication such as the worry about your drugs being switched from a branded to a

- generic drug with the fear of a breakthrough seizure
- if you are a woman of childbearing age, you may have concerns about the effect that certain medications may have on unborn babies.

Be very specific about the changes which could make a difference to your life and how your MP could help to bring about these changes. Again, only talk about the issues that are relevant to you. You might like to ask your MP:

- to call for improvement in the funding of medical research which could lead to better treatments
- to call for improvement in access to epilepsy specialists including the need for more epilepsy specialist nurses and GPs with an enhanced interest in epilepsy
- to call for shorter waiting times when being referred to a specialist, following the NICE guidance for epilepsy. (NICE is the National Institute for Health and Care Excellence)
- to ensure that the NICE guidelines on the care of people with long-term chronic epilepsy are adhered to
- to keep up pressure on CCGs – clinical commissioning groups – to develop written needs assessments for people with epilepsy
- to pressurise the government into providing a pathway that will reduce the 400 unnecessary deaths from sudden unexpected death in epilepsy each year in the UK
- to look at issues around the benefits and welfare system to ensure that people with epilepsy are not disadvantaged.

Help with writing a letter

On our website we have a dedicated General Election section with information and resources to help you campaign for better services for people with epilepsy. Included here, you will find some suggested text that you might like to use when writing to your MP or prospective parliamentary candidates. You can also read about other ways to speak up for people with epilepsy during the general election campaign.
www.epilepsysociety.org.uk/generalelection2015

← I am currently considering epilepsy surgery. I have had epilepsy since I was 20 and although it doesn't control me, it has a big impact on my life. Tests have shown that surgery could pose a slight risk to both my memory and speech but the risk is not high enough to rule out surgery. I already have memory issues and often can't find the right word. My family is constantly having to remind me about things we've done. I don't want things to get worse but I would also like to be free of my seizures. Has anybody else had to make a similar decision? How did you decide what to do?
 Harriet, Leicester

YOUR REPLIES

➔ I took the decision to have surgery two and a half years ago after 19 years of seizures. I was told I had a high risk of losing part of my sight and memory. I took the risk and it was my decision, no one else's. It's the best thing I've ever done. I've now been seizure free for two years. I lost little bit of my sight but not enough to stop me driving.

It took two years to come off my meds and now I am a completely different person. I'm so much brighter and not sleeping all the time. I would defo recommend it.

The docs have to tell you the risks and it can be worrying but I don't think they would suggest surgery if there wasn't a high risk of it being successful. Good luck Harriet with whatever you decide.

Natasha, facebook.com/epilepsysociety

➔ I had uncontrolled epilepsy for about 30 years and it definitely restricted my options. About 10 years ago I had a successful temporal lobe resection. For me the positives outweigh the negatives. I no longer take any medication, I have learnt to drive and am taking my motorbike test.

I went to uni and graduated and now work as a practitioner. I manage my memory with things like meditation, brain training and lots of lists.
 Pam, facebook.com/epilepsysociety

➔ I underwent epilepsy surgery some 20 years ago. I was suffering fits very often, sometimes two or three per day, never knowing when the next fit

would be. My surgery proved a huge success and after waiting 12 months to see if any attacks occurred, I could happily say I was at last free from fits.
 Lesley, email

➔ My sister made the decision to have surgery and unfortunately it made things worse for her. Now she is using the ketogenic diet to control her seizures and has never felt better. Food has such a huge impact on the way we function and no, we don't understand how it works, but it does.
 Alikee, facebook.com/epilepsysociety

Editor's note: You can read more about the ketogenic diet at www.epilepsysociety.org.uk/ketogenic-diet

➔ I had to make exactly the same decision as Harriet. My epilepsy got suddenly quite severe and I had surgery on my left temporal lobe in August 2013. My seizures are still here but I only have absences. I've been able to reduce medication which has brought my personality back to normal.
 Elizabeth, facebook.com/epilepsysociety

➔ My son has just been making these decisions. Surgery has turned out to be more complicated than initially expected and chances of a good recovery went from 70 per cent to 30 per cent for him. He is so desperate this seemed like good odds to him. He has now been offered vagus nerve stimulation as an alternative.
 Jan, facebook.com/epilepsysociety

You can read more replies to Harriet's letter at:
www.facebook.com/epilepsysociety
<http://forum.epilepsysociety.org.uk>

NEXT ISSUE

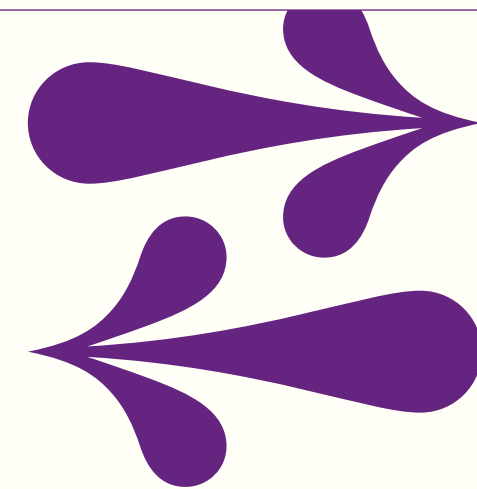
I have recently been diagnosed with epilepsy at the age of 46. It has come totally out of the blue and while I have told my close family about it, I don't know how to tell my friends - especially those who I only see occasionally.

I don't really know how to start the conversation and I am concerned that some of them may start treating me differently. I even worry that they won't want to see me any more in case I have a fit. My husband tries to reassure me this won't happen but it's all going round and round in my head. I wish there was someone else with epilepsy who I could talk to about my fears.

Geraldine, Staffordshire

WOULD YOU LIKE TO SHARE YOUR THOUGHTS WITH GERALDINE?

Or do you have a question to ask our readers? Email nicola.swanborough@epilepsysociety.org.uk, write to Editor, *Epilepsy Review*, Epilepsy Society, Chalfont St Peter, Bucks SL9 0RJ, or reply at either address below:
facebook.com/epilepsysociety
forum.epilepsysociety.org.uk



Tonic comic

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

Last week I received a text from my new friend Laura. It read: 'Just been back to neurology. Diagnosed epileptic now.' Laura and I became 'broken brain buddies' last year after a mutual friend from our university put us in touch (I am doing a postgraduate training course to be a drama therapist).

I had a bout of seizures in October, so I 'came out' to my classmates as epileptic. Laura had first started having seizures in September last year and they were occurring more and more frequently. I offered to talk to her, to try and answer any questions or just listen to her frustrations. So we started meeting up for chats.

It was weird and lovely to be a sort of epilepsy mentor, a sponsor in a 12-step programme of sorts, with the local pub a venue for our Epileptics Anonymous meetings.

Laura is in her early 20s, and being brand new to university, her support network was still forming when the seizures started. Her flatmates (randomly allocated through the accommodation lottery system), were pleasant enough but the friendships had not really been forged to weather storms. She was also hundreds of miles away from home and she had been reluctant to tell her mum the full story, for fear of worrying her. She felt pretty alone.

When I first sat down with Laura, her relief of being able to discuss having seizures was palpable. Even though she was still undiagnosed, and we have different kinds of seizures, I 'got' what she was talking about. She had been reluctant to talk about it to anyone else, partly because talking about it would have made it real, and partly because she didn't know anyone to talk to.

One frustration for her was that the university's efforts to support her – and they really were trying – were in fact incredibly stressful. I volunteered to accompany Laura to her next meeting with the faculty, as an ally and advocate, so she wouldn't feel so alone.

Sitting in front of an academic review panel, Laura was anxious enough about the unexplained seizures she kept having. But then also feeling that her university place was in jeopardy because of it, added to her anxiety. It was hard for her to hear the support they were offering because she felt she was being punished.

In truth the university was doing everything they could, but it's funny how people think they're being sympathetic

and supportive and how often those efforts miss the mark. The words 'we understand this is a very stressful time' don't alone convey the feeling they are intended to, especially to a stressed person, distracted by anxiety.

Moments after the meeting, Laura went into a seizure. It was a first for me to be so close to the action, to watch it happen. It was a bit like an out of body experience. As she fell forward from the chair and I helped lower her gently to the ground, I thought of all the people who have in the past helped lower me to the ground.

I sat with her and watched her transition back into consciousness after the seizure, and then slowly into awareness. It was all so familiar to me: the grogginess, the exhaustion and disappointment, the feeling of the brain re-setting after the seizure.

There were various members of staff buzzing around like mosquitoes, thrusting plastic cups of water towards Laura. I just wanted everyone to clear away for a bit and give her some room. She wasn't hurt – I had checked – and I knew she just needed time to come round.

One of the staff members kept shrilly reminding everyone that she had done a first aid course, and was therefore best placed to administer healing hands. But she was bombarding Laura with stressful questions about what month it was and who the Prime Minister was.

I suggested that with 22 years of familiarity with this process, I knew Laura just needed to rest, but she was having none of it. She had done a First Aid Course! I went with Laura in the ambulance – strange to be in the chair instead of on the stretcher, strange to wait to be seen in A&E and feel the concern that I felt for Laura. It was like watching myself through the eyes of my best friend/ sister, a strange body-swap situation, surreal and fascinating to watch the familiar from the other person's perspective.

Laura now has her diagnosis. She's taken the first steps of adjusting to taking meds and I'm happy to be her broken brain buddy. She talked to an epilepsy nurse and the anxieties over her university course are now resolved. My anxiety, or denial, over my diagnosis lasted about 10 years, so I'm so glad Laura is tackling it head on. Much more mature than I was.

Since the body-swap day of being in the shoes of so many who have helped me over the years, I've made phone calls and visits, bought pints of beer and boxes of chocolates and sent cards of thanks. It's cost me an arm and a leg. So, jeez, thanks for the experience, Laura. I guess.

JULIET STEPHENS
LAUGHING ALLOWED

Brain buddies

Later life survey

Are you over 60? Do you have 20 minutes to spare? We are looking at the experiences of older adults who are living with epilepsy, and would be grateful if you could fill in our survey.

Later life is the most common time for epilepsy to develop and we want to understand the impact it can have on a person's life and how we can best support them.

You can fill in our survey online at www.epilepsysociety.org.uk/older-life-survey If you would prefer a paper version, please contact ben.o'keefe@epilepsysociety.org.uk

Impact report 2014



How many people with epilepsy have been refused insurance? What percentage of people with epilepsy have experienced delays in treatment? Find the answers and much more in our 2014 impact report at www.epilepsysociety.org.uk/impact-report-2014

Annual conference autumn 2015 – London

We are just finalising details for this key event and there is up-to-date information in the covering letter with this issue of *Epilepsy Review*.

Our expert speakers will focus on our world class genetics and other research. We will also look at the deeper impact of epilepsy and accompanying conditions, as well as practical self-management and getting more involved in your healthcare. Join us to learn more, meet others affected by epilepsy, and hear how epilepsy research and treatment is moving forward.

Purple praise



A huge thank you to everyone who helped to turn the world purple on 26 March, Purple Day, the worldwide day to mark epilepsy.

As we went to press we had not finalised the total amount of money that you raised for us by wearing purple, cooking purple cakes, dying your hair, texting a purple PDay26£1 to 70070, or by wearing our purple ribbon which you can buy for £1 at shop.epilepsysociety.org.uk/ Every penny goes to help people affected by epilepsy.

But we know from the purple conversation on Facebook and Twitter just how many thousands of you engaged with us via social media – it was fantastic to share the day with you.

RideLondon 2 for 1 sign up



We're looking for more people than ever to join Team Purple for RideLondon 100 on Sunday 2 August 2015.

We know how daunting it can be to take on a fundraising challenge alone, so this year we are offering 2 for 1 on our registration fees so you can sign up with someone else.

To sign up or find out more visit www.epilepsysociety.org.uk/ridelondon100, call 01494 601358 or email fundraising@epilepsysociety.org.uk



Epilepsy toolkit app

We have updated our free epilepsy phone app to make it even more useful for you in managing your epilepsy. Extra features on the epilepsy toolkit app include:

- a new page explaining how a video recording of your seizures

may help your neurologist to diagnose your epilepsy

- an option to audio record information such as questions for your GP, or their answers
- the ability to transfer your seizure diary into a spreadsheet that will be easier to email to your healthcare professional
- a new page to record a summary of results from tests and scans such as your EEG and MRI.

And you'll find lots more new features besides. You can access the app via iTunes or Google play. To find out more go to www.epilepsysociety.org.uk/app

Remembering someone special

If you have lost someone who is special to you, you might like to create an online tribute page in memory of them.

A tribute page is a way to share memories, photos and videos of your loved one. If you wish, you can also use the page to raise money in their memory in support of Epilepsy Society. Setting up a page is easy. You will find all the information you need at www.epilepsysociety.org.uk/donate-memory



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