CALL FOR ACTION

A hard-hitting report into the human and economic costs of epilepsy in England has condemned the Government, saying it continues to fail to meet the needs of people living with the condition.

The report, *Wasted money, wasted lives*, lists a catalogue of failures in the system that result in £189 million in wasted funds and, tragically, around 400 potentially avoidable deaths every year.

It calls on Government to urgently make significant improvements to epilepsy services to redress these failures.

The report draws together the findings of a comprehensive Inquiry by the All Party Parliamentary Group (APPG) on Epilepsy in Westminster – a group made up of parliamentarians from all parties and from both the Commons and the Lords.

The Inquiry was launched to spread awareness of the nature of epilepsy amongst parliamentarians and to raise the political profile of epilepsy and related problems.

But the Inquiry made it clear that that the National Health Service is failing people with epilepsy and that a much improved service could be delivered at the same time as making significant cost savings.

Chaired by Baroness Gould of Potternewton, the APPG gathered written and oral evidence from several individuals, including people with epilepsy, clinicians and voluntary sector representatives. This provided a realistic picture of epilepsy services today and highlighted the issues caused by poor service provision. Evidence from patients and their families also highlighted the challenges of living with the condition.

The report, which has the full backing of the Joint Epilepsy Council (JEC), states: “Even in this world of competing health interests, the case for improving epilepsy services is overwhelming. A vicious circle of social stigma, secrecy and widespread medical ignorance has led to a poor service, from which patients cannot confidently expect good treatment at primary or secondary level.

“The waste of money in delivering this inadequate service is almost as appalling as the unnecessary deaths and damage to quality of life experienced by people with epilepsy.”

Now the APPG is calling on the Government to accept responsibility for the shortfall in services and to ensure that healthcare providers implement guidelines. It also urges the Government to address workforce shortages by increasing the numbers of doctors and nurses with a special interest in epilepsy as a matter of urgency.

The APPG invites the Government’s Health Select Committee to drive progress by examining the provision of health services for people with epilepsy in England and looks to the Government to “formally account for decades of under-investment in this neglected condition”.

NSE Chief Executive Graham Faulkner, who was elected to the executive of the JEC earlier this month, was among those giving evidence to the Inquiry. He later commented: “We wholeheartedly support this report which shows that, despite the development of effective treatments in recent years, almost 70,000 people in England are still living with unnecessary seizures and 74,000 are taking powerful epilepsy drugs that they do not need.

“Through the work of NSE’s epilepsy assessment centre at Chalfont, we are aware that misdiagnosis rates remain unacceptably high. As many as 30 per cent of people referred to us for a detailed assessment of their diagnosis are found not to have epilepsy at all.”

Graham also submitted evidence on behalf of the residential care sector. The led to the APPG calling for Government to develop a national plan for specialist residential care. This would bridge the gap between policy and practice, by developing guidance to local authorities to ensure resources follow the individual when moving from residential care into supported housing. The latter theme is strongly echoed in a subsequent report from the Voluntary Organisations Disability Group (see page 5).

To read the report in full, please visit www.jointepilepsycouncil.org.uk/inquiry.asp
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Care for the future
NSE has taken its first significant steps towards the realisation of its vision for the future, outlined following the strategic review of all the charity’s services in 2006.

The first of a series of planning applications for new-build care homes at the Chalfont Centre has been submitted. The plans are beginning to take shape for the first off-site registered care home. And the first residents have moved off site into flats in Aylesbury as part of the STEPS programme (STEPS = Supporting and Enabling Positive LifeStyles).

The first planning application is for an extension to Queen Elizabeth House (QEH). This is the most recently opened of NSE’s care homes at Chalfont. It was newly created out of the former Queen Elizabeth Medical Centre in 2005 and fully complies with the required care standards.

QEH currently provides a total of 12 bedrooms in two adjoining self-contained units. The extension will add two further units with four bedrooms each, creating a single care home with 20 en suite rooms.

It is intended that three further care homes, each also providing 20 en suite bedrooms in small self-contained units, will be built at Chalfont over the next few years. The planning applications will be submitted one by one over the coming months. They will replace existing houses which will gradually be closed down and demolished to make way for the new build.

None of the houses that are to be closed complies with the environmental standards required under the Care Standards Act 2000, although all the homes have passed stringent inspections by the Commission for Social Care Inspection for the quality of care that is provided.

Graham Faulkner, NSE Chief Executive, said: “We are being cautious in our approach as we submit these planning applications through 2007 as it is important to us that we ‘get it right’. This is why we are submitting the plans one by one. We have consulted widely with the planning authorities, the local community and others and are optimistic that we are on the right track to secure planning consent for these new homes."

The new homes will all be built at the north end of NSE’s site, close to the medical facilities. Buildings at the south end of the site, that will become surplus to requirement, are likely to be sold to fund the redevelopment.

In addition to the new care homes at the Chalfont Centre, NSE hopes to build a further home for tenants who are able to live more independently but who require support from NSE’s staff. NSE is in negotiations with a benefactor who, it is hoped, will fund this building.

Off site, NSE has bought a former care home which is close by. This will be completely refurbished and, when it opens early next year, it will be the charity’s first off-site registered care home.

Further afield, in Aylesbury, NSE bought and fully refurbished a pair of semi-detached properties to create five self-contained flats. The property has now passed into the ownership of McIntyre Housing who will manage the tenancies while NSE will provide support through its STEPS programme.

Graham commented: “It is a very exciting time for NSE – and very appropriate as 2007 is a centenary year for us. It is 100 years since the charity officially became the National Society for Epilepsy. Previously we had been known as the National Society for the Employment of Epileptics.”

01494 601400: Your Helpline, Your call
NSE is currently evaluating its confidential Helpline service and your views are very important to us. If you have used the line recently, we would value your comments. This will help us to provide the best service we can to anyone who has concerns and questions around the condition of epilepsy. The evaluation form can be accessed via our website on www.epilepsynse.org.uk/evaluation or by speaking to the helpline worker and asking for information to be sent direct. Please help us to ensure we are providing the service that best suits your needs.
Employment survey findings

Around a quarter of people with epilepsy claim to have lost their job because of their epilepsy according to the survey carried out amongst NSE Associate Members earlier this year for National Epilepsy Week. And almost three quarters of respondents said their career had been affected by the condition.

According to the survey more than 40 per cent felt they had been unfairly treated by their employer even though employers have a duty under the Disability Discrimination Act to make ‘reasonable adjustments’ to enable someone to work. Many others, almost 40 per cent, felt they hadn’t been successful at job interviews because they had mentioned their epilepsy. Around three quarters said they would like their colleagues to be more understanding. More than 80 per cent of those surveyed were of employable age.

Senior Communications Officer Amanda Cleaver said: “This year we worked with the Employers’ Forum on Disability and National Workwise Week – a five-year initiative to encourage the wider adoption of smarter working practices – to raise awareness of some of the issues facing people with epilepsy when it comes to employment.”

The NSE communications team produced a media pack which included a press release summarising the findings of the survey and quotes from the above organisations. This was mailed to hundreds of the UK’s leading local newspapers and radio stations.

Commented Amanda: “We received a very positive response. National Epilepsy Week kicked off with a Channel 4 interview with EIN Regional Manager Suzannah Clarke. Many regional papers carried the survey results and used the stories of some of our case studies. Several radio broadcasts were aired, either interviewing case studies or members of the communications office team.

“We could not have secured so much coverage without the support of so many of our volunteers and associate members.”

In addition the communications team secured a 30 second advertisement about the work of NSE that featured on the Pharmacy Channel several times a day for the whole of May. The Pharmacy Channel is the world’s largest pharmacy digital media network, is available in around 800 pharmacies the length and breadth of the UK and reaches around eight million consumers and pharmacists.

Trail-blazing epilepsy counsellor awarded MBE for epilepsy work

Sue Usiskin’s name will be well known to many Epilepsy Review readers, both as a specialist epilepsy counsellor and as a writer whose works have helped support many people with the condition.

Sue has now been named in the Queen’s birthday honours list for dedicating her life to helping others with epilepsy.

Sue has had frequent seizures for more than 40 years and three brain haemorrhages, but it was her battle with the condition that inspired her to establish the first epilepsy counselling clinic in the UK in 1989 on behalf of NSE.

Through the clinic, at the National Hospital for Neurology and Neurosurgery (NHNN), she has helped many thousands of patients and now receives referrals from neurologists, psychiatrists, practice nurses and GPs all over the UK.

In 1995, a year after having epilepsy surgery herself, Sue expanded the clinic to include a special epilepsy surgery counselling service to help prepare patients at the NHNN for epilepsy surgery.

She commented: “Eighty per cent of my work is with chronic epilepsy patients who are not suitable surgical cases. I see them and help them with all their various problems – including emotional problems, psychological problems and social problems. I also help with any educational, family and housing difficulties they might have. This maybe something that really takes over people’s lives.

“The other 20 per cent is dealing with suitable surgical candidates and making sure patients understand what the procedure consists of, what the after-affects might be, what the chances of success are and the risks they face and help them come to a decision that is right for them.”

She added: “I absolutely love my job. The most exciting thing is giving people the opportunity to change – to change from complete despair and living life full of fear to a situation where given time and encouragement they can learn to cope and take their lives forward.”

Commenting on her MBE Sue said: “I was surprised and shocked – it’s all a bit much to take in. It was lovely and touching to see how pleased all my colleagues were.”

In addition to her work as a counsellor, Sue is active in lecturing, writing, broadcasting and making films drawing widely from her unique experience of the difficulties of living with active seizures.

Her contribution to the BBC Horizon documentary on epilepsy, The Spike, was felt to have played a major part in the programme winning the best medical documentary of 1980 BAFTA award. Sue has appeared in a range of subsequent television programmes on epilepsy and disability as well as educational videos on the same subject.

She is co-author of Living with Epilepsy, now in its third edition, and has contributed chapters to many other publications. In 1992 she was awarded the Bateman Prize for epilepsy and in 1995 was made an International Ambassador For Epilepsy by the International League Against Epilepsy and the International Bureau For Epilepsy.
Early Day Motions

Two MPs launched Early Day Motions (EDM) in the House of Commons during National Epilepsy Week.

Cheryl Gillan, Conservative MP for Chesham and Amersham (NSE’s constituency) congratulated NSE’s progress in establishing links between epilepsy and genetic makeup in her EDM (1550).

In it, she noted that genetic profiling will revolutionise diagnosis, assist in understanding the cause of epilepsy and help clinicians in choosing which anti-epileptic medication to prescribe and at what dose.

The EDM further highlighted that NSE’s genetic research will “help to save some of the vast sums, estimated at over £225 million, that are wasted as a result of trial and error applications as well as providing patients with more effective treatments.”

The EDM concluded by stating support for NSE “in its efforts to raise the £5 million needed to develop a dedicated genetics research facility at its Chalfont Centre to take forward this vital research”.

Chris McCafferty, Labour MP for the Calder Valley, highlighted employment issues in EDM 1510, noting that people with epilepsy are more than twice as likely as the national average to be at risk of unemployment or under-employment.

She called upon Government to take steps to promote equality, opportunity and understanding for people with epilepsy in the workplace much more effectively.

Early Day Motions are formal motions submitted for debate in the House of Commons. Although very few EDMs are actually debated, MPs use them to publicise their views and draw attention to specific events or campaigns.

They can also be used to demonstrate the extent of parliamentary support for a particular cause or point of view.

New epilepsy professors

Three leading epilepsy specialists have all been awarded professorships. They are consultant neurologists Sanjay Sisodiya, Matthew Walker and Helen Cross.

Professor Sisodiya heads the Sir William Gowers Assessment Centre at NSE. He is also a leading player in NSE’s research into epilepsy and genetics.

Professor Matthew Walker is a member of the team of epilepsy specialists at the National Hospital for Neurology and Neurosurgery.

Professor Helen Cross is a leading specialist in paediatric epilepsy, working at Great Ormond Street Hospital.

All three are well known to NSE and all have been speakers at past Associate Members’ Conferences.

Professors Matthew Walker and Helen Cross both feature on manyLives, NSE’s most recent DVD package which highlights good practice for medical professionals working in the field of epilepsy.

NSE congratulates all three for their achievements.

Getting the best...

The Neurological Alliance has published a revised version of its popular booklet Getting the Best from Neurological Services.

The Department of Health has funded 20,000 copies, 15,000 of which have been sent to neurology and neurosurgery departments, primary care trust patient advice and liaison service managers and to key professional and stakeholder organisations to support implementation of the National Service Framework for Long-term Conditions.

The booklet is available either in electronic format from the Department of Health website, or in paper copy by contacting the DH Publications Orderline (tel 08701 555455 or email to dh@prolog.uk.com). Quote reference 280484/Getting the best from neurological services.

Epilepsy nurses

Member of Parliament Ivan Lewis has thrown his weight behind a campaign to support the future of specialist nurses, whose role has increasingly become a soft target amid health budget cuts.

The Parliamentary Under Secretary of State for Health has backed the campaign, in which three neurological charities representing three neurological conditions including epilepsy, are seeking to highlight the vital role of specialist nurses.

Epilepsy Action, the MS Society and the Parkinson’s Disease Society held a joint summit in May, when it was announced that a guidance document about the role of specialist nursing would be launched at a national conference in early 2008. The document will outline best practice and educate health commissioners on the benefits of protecting the specialist nurse post.

Following the summit, Mr Lewis commented that local health commissioners need to better understand the direct and indirect benefits of specialist nursing. He added that the aim now is to make the case for specialist nurses becoming mainstream in services available to people with long-term conditions.

NEWS IN BRIEF

● The Department of Health is exploring the possibility of introducing an information accreditation scheme for NHS England. This would allow organisations that produce health and social care information to be accredited, setting standards so that the public and patients can be assured that the information they are using is reliable. NSE is participating in the development of the scheme.

● Calling all young carers. YCNet, the online discussion forum for young carers at www.youngcarers.net, has been updated and improved. Log on and join in a conversation with other young carers. The forum provides — the Princess Royal Trust for Carers — is also looking for young carers to join a User Group to share ideas and opinions and help the Trust to ensure it is providing the right services for young people. New members are recruited to the user group every six months or so. If you are interested, email to youngcarers@carers.org

● MedicAlert, the charity which provides emergency identification for people with hidden medical conditions and allergies, has launched the MedicAlert Healthcare Professional of the Year Awards. For people with hidden medical conditions or allergies, support and advice from healthcare professionals makes a huge difference to their lives. MedicAlert wants to recognise what this means to their members, so they are asking them to nominate the healthcare professional who has made the greatest difference in their life over the past year. There are three categories — Community Care, Hospital Care and Emergency Care. Nomination forms can be found at http://www.medicalert.org.uk/ifhpoy.doc.
Thousands of disabled people’s human rights have been violated and millions of taxpayers’ pounds have been wasted, a key investigation has revealed.

The Voluntary Organisations Disability Group (VODG) is urging the Government to take immediate action to give disabled people back their independence and resolve disputes amongst local authorities about who should take responsibility for supporting them.

The VODG report No Place Like Home, published on July 5, reveals that the disputes over who should pay for their care compromises Government policy and at times leaves disabled people caught in ‘no man’s land’.

“This is simply unacceptable. VODG is calling on the Government to act immediately to resolve this issue and give potentially thousands of disabled people back their basic human rights,” said Graham Faulkner, NSE Chief Executive who is also VODG vice chair.

Many disabled people’s attempts to move into the wider community are being blocked by the disputes – the root cause being the interpretation of someone’s ‘place of ordinary residence’.

“This not only flies in the face of recent Government policy on promoting independence, it also traps disabled people in residential care and prevents them from moving into more independent accommodation,” said Mr Faulkner. “These bureaucratic bun-fights waste huge amounts of money in keeping people in facilities where their care often costs more than if they were living more independently, as well as legal fees and administrative costs.”

The problem is caused by arguments about the definition of ‘place of ordinary residence’ – the current Department of Health guidance is unclear and local authorities use this as a way to delay, or avoid paying for, disabled people’s support.

Disputes between local authorities over ‘ordinary residence’ arise:

• When someone who receives support to move into independent accommodation, their place of ‘ordinary residence’ is deemed to have changed, transferring their funding responsibility to the new authority
• When someone is funded ‘out-of-area’ in a care home which then ceases to be registered as a care home
• When someone leaves a residential college but wishes to stay in the locality
• When someone who receives support to live in the community wants to move to another authority area – perhaps just a mile or two down the road.

“In some cases people are caught in a Catch-22 situation of being unable to move until an assessment has been made, but being unable to receive an assessment until they have moved,” one of the report’s authors, Roger Blunden, said.

VODG estimates that at least 500 people are caught up in these ‘ordinary residence’ disputes at any one time, costing an estimated £3m a year in legal fees and administrative costs. Government policy currently encourages transition to more community-based living and this issue potentially affects thousands of people. There are around 20,000 adults in England in out of area placements.

The report urges the Department of Health to take three immediate actions:

• Establish and enforce the principle that a person should receive appropriate social care and support from the authority where they are currently living, or wish to live, regardless of circumstances
• Update the guidance to social services and PCTs to ensure they implement this principle in a person-centred way that removes barriers to choice and independence
• Put in place a framework for the transfer of funds between authorities so that the issue of ordinary residence can no longer be used as a basis for refusing to provide care and support.

The VODG is an umbrella group of national voluntary sector providers of social care support to disabled people.

Controversial logo

An internal enquiry has been launched by the London Olympics organisers since it was claimed that a number of people with epilepsy had experienced seizures after viewing the animated version of the 2012 Olympics logo.

The controversial logo has been produced both as a static logo for print and in animation for broadcast media. In the animated version, NSE understands there was a five-second clip in a swimming pool setting which included flashing lights. It was this section that was said to cause the seizures. As soon as this was known to the organisers, they acted quickly and responsibly and the clip was cut from the animation immediately.

Around five per cent of people with epilepsy have photosensitive epilepsy – when seizures can be triggered by flashing lights and images. NSE’s helpline received no calls from people reporting that they experienced a seizure as a result of seeing the footage, though anecdotally NSE’s communications team has heard of one person that had a seizure and a couple of others who felt ‘sick’ or ‘queasy’.

On a positive note, the Helpline did receive a number of calls from companies who wanted to know how they could ensure their logos wouldn’t cause seizures. These callers were referred to the Independent Television Commission (ITC) Guidelines on the broadcast of flashing images (www.ofcom.org.uk).

The furore prompted a lively debate on NSE’s web forum, most of which concerned the cost of developing the logo and criticism of the design itself. (Join the forum at www.epilepsyforum.org.uk.)

If you experienced any problems as a result of watching the footage, please let us know by writing to the Editor, address on page 2.

NEWS IN BRIEF

• Tooth-brushing may trigger seizures in certain people with epilepsy, according to researchers in an article published in Neurology, the scientific journal of the American Academy of Neurology. The article looked at the cases of three adults with epilepsy who had seizures while brushing their teeth. Two of them said that some of their seizures happened when they brushed certain areas of their mouth. Professor John Duncan commented: “This is a rare but recognized form of reflex epilepsy.”

• NSE’s residents are to be web-enabled thanks to an award from the Alison Hillman Trust. The Trust has donated more than £11,000 to fund six new computers in an internet café at NSE’s Chalfont Centre. Two will have adaptive technology – such as touch screens, large keys and special mouse devices. NSE Learning & Skills instructor Jacek Debowski said: “Without the award our more disabled residents would never be able to access the net.”
Employ Ability

Employ Ability is a new Government initiative that was announced by John Hutton, then Secretary of State for Work and Pensions, on June 11.

Employ Ability is aimed at highlighting the benefits of employing disabled people and will challenge negative assumptions about the skills and talent disabled workers have to offer. It also promises to build the confidence of employers to recruit and retain disabled workers and improve employers’ access to practical information.

The initiative will be piloted in Leeds, Bradford, Manchester and Liverpool from September before being rolled out nationally next year.

Mr Hutton made the announcement at a meeting to launch a new report, titled "Disability, Skills and Work", which says that investing in improving the skills of disabled people to world-class levels by 2020 would boost the economy by £35 billion over 30 years.

The report explores the value of raising disabled people’s skills for the British economy and makes recommendations to reduce the skills gap between disabled and non-disabled people.

It is published by the Social Market Foundation (SMF) in association with the Disability Rights Commission (DRC). SMF is an independent thinktank that provides economic and social policy ideas.

Remploy is branching out

Remploy has been helping people with disabilities within the workplace for more than 60 years. Looking back, the majority of jobs Remploy found were in its own chain of factories. But now Remploy is branching out.

Although the company still has a number of very active businesses of its own, employing many people with disabilities, Remploy is now refocused on finding more jobs for disabled people with other employers.

Just five years ago, Remploy found fewer than 500 jobs for disabled people outside of their own businesses. The latest results show that, during last year alone, 5,200 jobs were found for disabled people with employers such as Marks & Spencer, Asda, Christian Salvesen and BT. The company’s ambition is to quadruple that figure over the next five years.

Driving this change is Remploy’s expanding network of high street specialist recruitment branches. Branches currently exist in Leeds, Birmingham, Nottingham, Leicester, Coventry and Plymouth, but more are being planned. The branches are purposely located close to other big recruitment firms and within easy reach of Jobcentre Plus offices.

Each provides a range of specialist recruitment and development services for disabled jobseekers, including basic skills and vocational training, help with completing application forms, advice on benefits, how to make the most of a job interview and arranging job tasters – as well as practical assistance with job searching.

Clare Wilson, 24, from Middleton, near Leeds, was forced to resign from her job more than a year ago because of health issues, including epilepsy and a physical disability.

Now, thanks to the flexibility of Leeds University Union and the support of Remploy, she’s now back in work. Clare said: “By pure chance, I called in at Remploy’s new branch in Leeds to see if they could help and I signed up for training with them almost straightaway. “Three months later I’m back in work which means, at last, I have a life outside of my home again. All I have ever wanted is for my employer to understand my disability and then treat me just like everyone else – and that’s exactly what I’ve now got.”

And Adam Girling from Nottingham, who also has epilepsy, is celebrating being back in work after applying for almost 1,000 jobs in four years without success. He has joined Powegen’s owners E.ON.

Adam (30) said: “I heard every excuse under the sun why I was not being selected for jobs, but it was obvious that my health issue was the real reason. Employers seemed to be afraid of me having a seizure and refused to listen when I said that, with a little planning and flexibility, I rarely had a problem.”

Adam discovered that trying to absorb too much information first thing in the day was likely to result in a seizure, and that he could avoid potential problems by structuring his morning and starting work a little later. His employer was happy to adjust his working hours so that he could benefit from a later start and finish to his working day.

Adam recalls the day he received a phone call from E.ON to say he’d got the job. “Finally, I got to the summit of a mountain I had been walking up for several years – it was a euphoric moment! My medical team says that my epilepsy is linked to stress – and now I’m working again, I don’t have any!”

Remploy can be contacted on 0845 601 5878.

BE A TRUSTEE AT NSE

Every year fully paid-up Associate Members, and now Research Associate Members, are invited to offer themselves as candidates for election to NSE’s Board of Governors, to serve as an Additional Governor.

There is currently one Additional Governor position available and the successful candidate would be confirmed as a Board member at the charity’s AGM on October 20. Additional Governors are expected, in the first instance, to serve for one year and to attend approximately six Board Meetings a year at Chalfont. They may also be invited to sit on a sub-committee, depending on the interest, background or skills that they bring to the Board.

Over the years, Additional Governors have represented the views of the Associate Membership to the Board during their strategic and policy making processes. These contributions have been very valuable and much appreciated by Board members. Occasionally, Associate Members have been invited to become full members and trustees of the Society.

If you are interested in offering yourself as a candidate, please complete the application form (enclosed with this issue of Epilepsy Review, giving a brief ‘pen picture’ outlining why you feel you should become an Additional Governor, and what contribution you would make if elected to the Board. If you submitted an application for election in 2006 and would like to reapply, we would be very pleased to hear from you. Applications must be received by August 13, 2007 (address on form).
Hollyoaks star Carley Stenson has given her backing to a new informative podcast from NSE. The podcast aims to dispel some of the myths surrounding epilepsy as well as giving first aid information about what to do in the event of a seizure.

Misconceptions dispelled by the new podcast include restraining someone who is having a seizure and putting something in the person’s mouth, such as a wooden spoon. The four-minute recording occupies just 2.78MB of space and can be downloaded in a few minutes. It explains what a seizure is, who can be affected, what to do if someone has one … and what not to do!

Channel 4’s Carley Stenson, who plays Steph Dean in Hollyoaks, has shown her support for the new podcast. She said: “The character I play in Hollyoaks has helped me understand more about epilepsy. It is important that people know what to do if someone has a seizure.

“NSE’s podcasts are a great way of making information available in an appealing format.”

Other podcasts on NSE’s website at www.epilepsyse.org.uk include an interview with NSE’s Medical Director Professor John Duncan by students from the University of Westminster, and the first-hand experiences of two young people living with epilepsy.

The podcasts have generated regional and national press coverage. The Guardian ran an article stating: “Podcasting is opening up communications for often unheard minorities suffering very real problems and keen to inform others about it. With almost half a million people suffering the condition in the UK, epilepsy had been an exception. But now a series of podcasts have been made for the NSE website”.

NSE has also updated its first aid leaflet which now includes more information and photographs illustrating recovery position. Call the NSE helpline on 01494 601 400 for a copy or download from the website.
In the seventh of our Back to Basics series, we follow on from looking at EEGs to look at MRI – another test that is commonly used when a diagnosis of epilepsy is being considered.

### Back2Basics:

### Diagnostic tests – MRI

In B2B 6 we looked at how an EEG is used to help diagnose epilepsy. Another test that is often used is the MRI or Magnetic Resonance Imaging scan.

An MRI scan will not say for certain whether the person has epilepsy or not. But alongside other information, these might help the specialist to decide if epilepsy is a likely cause of the seizures.

#### Magnetic Resonance Imaging - MRI

MRI stands for Magnetic Resonance Imaging, which is a technique used to create an image or scan of the brain. MRI scans can be used to look at the structure of the person’s brain (how their brain is made up). In people with epilepsy it can be used to see if there is an obvious reason (structural cause) for their seizures. This might be a scar or lesion on their brain that can be seen on the image. However, many people have brain lesions without having epilepsy, and many people with epilepsy do not have any scars or lesions on their brain.

#### How does MRI work?

Basically the MRI scanner uses magnetic fields and radio waves to create an image of the brain. But of course it is not that simple!

#### Atoms and protons – the science bit!

To understand how MRI works, we need to know a little bit about the tiny particles that make up the cells in our bodies.

Atoms are the tiny particles which make up all types of matter and everyday objects. Atoms themselves are made up of three even tinier particles called protons, electrons and neutrons. The protons and neutrons make up the atom’s nucleus (centre), which is surrounded by the electrons.

The human body is mainly made up of water, and water contains hydrogen atoms. Hydrogen atoms have a special property known as ‘spin’, which is like a tiny magnetic field. MRI works by using this property of hydrogen atoms. This means that the nucleus of each hydrogen atom responds to radio waves that are produced by the MRI scanner, and this causes the nuclei to produce an MRI signal.

#### Why is this important?

At the centre of the MRI scanner is a strong magnet, made up of coils of wire. An electrical current is passed through the coils to create a magnetic field. The coils are often ‘supercooled’ (cooled to a very low temperature) which allows the current to keep flowing through the coils (as long as they stay at this temperature). This means that the magnetic field created by the scanner is always ‘switched on’.

At the start of the scan the person having the scan is moved inside the scanner. The scanner is usually shaped like a cylinder or tube, and the person lies inside the tube, inside the coils of the magnet. At this point the nuclei of the hydrogen atoms in the body are not organised in any particular direction (they are randomly arranged).

Once inside the scanner, the magnetic field causes the nuclei in the body to ‘line up’ in the same direction as the magnetic field (this is called the ‘equilibrium position’).

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**Glossary**

- **Atom** the smallest unit of matter, made up of protons (positively charged particles), electrons (negatively charged particles) and neutrons (uncharged particles).
- **Epilepsy surgery** an operation done to try and stop someone’s seizures by removing the part of their brain that causes the seizures.
- **Functional imaging** – when scans are used to look at how the brain is working (how it functions).
- **Hydrogen** a chemical element (the most abundant element in the universe). Hydrogen atoms, along with oxygen atoms, make up water.
- **Magnetic Resonance Imaging (MRI)** a type of brain scanning technique that uses magnetic fields.
- **Nerve fibres** groups of neurones, bunched together.
- **Neurones** the individual cells that make up the nervous system. Also called nerve cells.
- **Structural cause** a physical cause for a person’s epilepsy, such as a lesion, tumour or scar tissue.
- **Structural imaging** when scans are used to look at the structure of the brain.
Next, radio waves (pulses of electromagnetic energy) are created by the MRI scanner. The energy is absorbed by the nuclei in the body, which causes them to move away from the direction they were lined up in (becoming disturbed from the equilibrium position).

The radio signals are then switched off, and the nuclei return to line up with the magnetic field again (returning to the equilibrium position). To do this, the nuclei release energy as radio waves. Different types of tissue in the body (such as the muscles or brain) are made of different substances and have different densities. Because of this, the nuclei of different tissues return to equilibrium at different times. The radio waves produced by the nuclei are picked up and measured by the MRI scanner, and are used to create the picture of the body or brain.

How are these signals used to create a picture?
The MRI scanner uses a computer to make complicated calculations to generate a picture from the strength and location of the radio wave signals. The strength of the signal is shown as different shades of grey.

There are many different types of MRI scan, using different types of radio-frequency pulses, and these give different types of images.

How strong?
AT NSE we have a 3 Tesla MRI scanner. The Earth’s magnetic field is about 0.5 gauss (1 Tesla = 10,000 gauss). So our MRI is about 60,000 times more powerful than the earth’s magnetic field!

Other uses of MRI
The type of MRI technique described above is used for structural imaging – that is creating an image of the brain to see how it is made up. Structural imaging is used to look for the cause of someone’s epilepsy. But different MRI techniques have many other uses, showing us how our brains work and what functions or activities each area of the brain is responsible for.

Functional MRI
Another use of MRI is for functional imaging. Functional MRI (or fMRI) is used to look at the brain while the person is doing a task, to see which parts of the brain are involved in the task and how they are working. For example, this might be when the person is looking at pictures, thinking of words or making physical movements.

To do an fMRI scan, the normal MRI machine is used but in a special way: it is set up to look at how blood flows around the brain. The parts of the brain that are involved or ‘active’ during a task have more blood flowing to them than other areas of the brain that are not involved in the task. The fMRI scan shows up these areas of the brain that have an increased blood flow (the areas that are active and involved in the task) as bright colours on the scan images. This means that we can look at which parts of the brain are involved in different types of tasks and activities, and also see how different parts of the brain work together.

For someone with epilepsy, this type of scan can be used to look at which part of their brain is affected by their seizures, and what happens to their brain activity when seizures happen. It can also be used for people who are being considered for epilepsy surgery. In epilepsy surgery, the part of the brain that is causing seizures to happen is removed, to try and stop seizures from happening. With fMRI we can look at what this part of the brain does, and what effect removing it by surgery will have.

Spectroscopy
Spectroscopy is used to look at the amount of different chemicals in the brain. By studying these chemicals, we can see which chemicals are used when the brain works, and can also see how brain activity can be affected by seizures.

Epileptic? Sufferer?
Think about the times you’ve heard someone tell you they have epilepsy. What exactly did they say? Was it: “I have epilepsy”, or “I’m an epileptic”, or maybe “I suffer with epilepsy”. And if you can only count on one hand the number of people who’ve ever told you they have epilepsy then think about this – how does the press introduce people with epilepsy to the public? Easy PC would argue that more often than not it’s as a “sufferer” or a “victim”.

It’s very unusual to see a “good news” epilepsy story, mostly because good news in general doesn’t sell. So when we do see someone in the press with epilepsy they are often labelled as being an “epilepsy sufferer”. But what message does this send? Could it be instilling an inherent message in all of us that if a person has epilepsy they “can’t do”. That if a person has epilepsy they are automatically powerless and incapable?

What then would it feel like to be diagnosed with epilepsy, if the majority of information you’ve ever read about epilepsy has told you that you too are now “a victim”? No wonder a diagnosis of epilepsy can feel like a double blow – not just a health condition to live with but a sentence of victimhood too.

And how unsettling would it be to feel like this and then to be met with the statistics and facts that undermine your feelings by telling you that chances are you’ll have a perfectly “normal” life anyway and to stop worrying about it. When at that point in time the only thing you want is for someone to acknowledge how you’re feeling, rather than painting over the cracks with facts.

So how can charities like NSE help to break this cycle? It’s a good question. Undoubtedly NSE relies on press coverage to promote the work that we do, reporting our success stories and helping our fundraising. But NSE also has the dual role of educating and informing people about epilepsy. And if we’re to do that, we need to educate the people who get the message out there – the journalists. This is why NSE has guidelines on the correct terminology for journalists to use when writing about epilepsy. And it is why we reward responsible reporting with our Journalist of the Year award, now in its 5th year.

But it’s not just down to NSE to stand up and say “no” to the way that having epilepsy is misrepresented. Let’s all challenge the improper use of the phrase of being an “epilepsy sufferer” or a “victim of epilepsy.” We know that a lot of people do suffer because of their epilepsy and it’s often accurate and appropriate to say that. What isn’t fair is to use the phrase in a way to suggest that simply by having epilepsy you are automatically a sufferer and a victim.

Do you agree? Send your thoughts and comments to the editor of Epilepsy Review (address on page 2).
ON THE WEB

Directgov (employment)
www.direct.gov.uk/employment
The name Directgov is simple yet clever, as it is a directory of UK Government public information, as well as being ‘direct’ in style. Directgov is about signposting, and therefore it is full of links, rather than a lot of text. The employment section is very large in itself, but there are links to other areas, such as education, housing, money, and health. The employment section gives information for Jobseekers and Employees, with subheadings covering careers advice, training and educational courses, contracts, health and safety at work, disputes at work, and organisations that can help such as trade unions and advice agencies. There is a ‘See also’ guide at the bottom of each page for related topics, which avoids a lot of scrolling down the page. The design is bright and clean, and navigating this huge directory is made easier by the simple structure.
See also the Directgov section for Disabled People, which covers employment, the Disability Discrimination Act, employment rights and support for people with a disability: www.direct.gov.uk/disabledpeople

Disability Rights Commission (employment)
www.drc.org.uk/employment
The DRC is an independent body set up in 2000 to tackle discrimination and promote equality of opportunity for disabled people in England, Scotland and Wales*, by raising awareness and campaigning, and providing information and advice. Their employment section is broadly divided into two main headings: What should I do if... and What are my rights? Under these headings are links to information, guidance, tips and new ideas. There is information on current disability law, including the Disability Equality Duty 2006 which targets public bodies such as local authorities.
A great feature of the DRC site is the use of different formats; not just standard text, but also DVDs, British Sign Language, quizzes, lists of top tips, Easy Read, and various community languages. You can change the text size and colour, or download software that enables you to listen to the site’s information.
Considering that the DRC often deals with potentially negative subjects such as discrimination and injustice, there is a bright, interesting, positive feel to the whole site.
Please note: From October 2007 the new Commission for Equality and Human Rights (CEHR) will incorporate the DRC, the Equal Opportunities Commission and the Commission for Racial Equality.

*the DRC website points to a separate body for Northern Ireland

Latest drug trial findings
A clinical trial involving more than 2,000 patients has compared the use of different epilepsy drugs in adults and children.
The trial, led researchers at the University of Liverpool and known as the SANAD trial, found that valproate is the most clinically effective drug for people with generalised epilepsy, though topiramate may be a cost-effective alternative for some patients. It also found that lamotrigine is a clinically superior and cost effective alternative to carbamazepine for the majority of patients with partial seizures.
The trial compared use of newer anti-epileptic drugs (introduced over the last 15 years) with older, more established drugs. Carbamazepine was compared to newer drugs gabapentin, lamotrigine and oxcarbazepine and topiramate in patients with partial seizures, and valproate was compared with lamotrigine and topiramate in patients with generalised seizures.
The results will provide important evidence when the National Institute for Health and Clinical Excellence (NICE) re-appraises epilepsy drugs. The last appraisal was in 2004 and a review is now due.

Epilepsy and hemiplegia
NSE has worked with the charity HemiHelp to develop a leaflet about epilepsy and childhood hemiplegia. Around 12,000 children in the UK have hemiplegia. Around 20 per cent (equating to 2,400 or 1 in 5) of these children will also have epilepsy.
Epilepsy – hemiplegia: an introduction to epilepsy for people with childhood hemiplegia is available from NSE and HemiHelp. Copies are also available from the websites of both organisations.
Is scuba diving safe?

A leading epilepsy expert is calling for a review of the regulations relating to scuba diving.

This increasingly popular sport is governed in the UK by the Sport Diving Medical Committee who advise that to dive someone with epilepsy must be seizure-free and off medication for at least five years. This view is shared by the Professional Association of Diving Instructors and the National Association of Underwater Instructors.

But NSE’s Professor Ley Sander is calling for a review which would allow people who have been seizure-free and on stable medication for at least four years to be considered to be allowed to dive to shallow depths.

Professor Sander said: “The reasons for the current restrictions are mainly theoretical. Exercise is often beneficial for people with epilepsy. My advice would be that people wanting to take part in this pastime, who have been seizure-free for four years, should build up their exercise tolerance and if they remain seizure-free should be allowed to take part.”

The research recently published in the journal Epilepsia looked at six key areas:

• The physiological risks for anyone scuba diving
• Whether those risks were greater for someone with a history of seizures
• Whether anti-epileptic drugs themselves posed a risk for someone scuba diving
• Whether seizures were likely to be induced by recreational scuba diving in people with epilepsy controlled by medication
• Whether recreational diving by a person with controlled epilepsy was likely to endanger the life of others
• The benefits of diving to people with epilepsy.

Commented Professor Sander: “In the first instance we looked at the inherent risks of scuba diving – decompression sickness, oxygen toxicity and nitrogen narcosis, – and whether those risks were increased in someone with controlled epilepsy. It was felt that someone with uncontrolled epilepsy might experience decompression illness if they had a seizure under water and a rapid ascent was necessary.

“As far as oxygen toxicity is concerned, very little information is available – just two reports in connection with seizures, for which there could have been another explanation. There is no reason to suspect that people with a history of seizures would be more likely to suffer from nitrogen narcosis.”

The risks were then looked at again in relation to someone taking anti-epileptic drugs (AED).

Professor Sander said: “Again the risks did not seem to be increased. The only note of caution was in relation to someone who knew that their AED had a sedative effect which might impair their performance and reaction time.

“One thing that does need consideration is the health and safety of the diving buddy. If a diver had a seizure at depth, the buddy would need to reach the surface quickly, putting himself at risk of decompression illness.”

When considering the likelihood of seizures being induced by scuba diving, Professor Sander said that regular exercise was proven to be positively beneficial to people with the condition.

He continued: “I would suggest that potential divers should be given the best individualised advice available and should be warned of the risks and dangers so they can make an informed decision.

“It is a controversial issue and more research is needed to evaluate the risks. The practitioner can only give the patient the best currently available information and then the decision as to whether to dive has to be the result of a consensus between the person with controlled seizures, the diving buddy, the insurer and the family.”

New research laboratories at NSE

This month saw an exciting development in the research capability at NSE.

After many months of preparation and building work, the Therapeutic Drug Monitoring Laboratories have transferred from the National Hospital in Queen Square, London, to new laboratories in the Queen Elizabeth Medical Centre at NSE’s Chalfont site.

The establishment of these laboratories means that, for the very first time, the measurement of all anti-epileptic drugs will be possible on the Chalfont site. Previously many measurements could only be carried out at Queen Square.

This new facility will not only underpin NSE’s research efforts into the action and effects of drug used to treat epilepsy, but will also greatly enhance our ability to fine tune treatments for individual patients.

The new laboratories will also underpin the development of our research into pharmacogenomics – that is the study and understanding of how an individual’s genetic make-up affects how the different drugs have both good and adverse effects in different individuals.

This is an important step towards our goal to establish an epilepsy genetics research centre at Chalfont, which is now being planned and for which we are in the process of trying to raise the necessary £5 million.

The laboratories are directed by Professor Philip Patsalos and run with his staff of Dr Neville Ratnaraj, Dr Majid Elyas and Miss Sandirap Ghattaura and phlebotomists Pam Ward and Jen Atlee and with the excellent administrative support of Jo Taylor and Linda Dooley.

Professor John Duncan, NSE Medical Director
Bristol University was the setting for this year’s NSE Regional Associate Members’ Conference, held in May at the start of National Epilepsy Week.

The packed programme kept delegates enthralled throughout the day. All the presentations are reported over the following pages, with the exception of Professor Sanjay Sisodiya’s talk about epilepsy and genetics. This presentation had previously been given to Associate Members at last October’s national conference at Chalfont and was reported in the last issue of Epilepsy Review.

Don’t forget to make a date for the next national conference, which will be held at Chalfont on Saturday, October 20. For more details, see page 14.

**The surgical option**

Dr Sam Lhatoo captivated NSE’s associate members with his presentation on surgery for epilepsy.

The consultant neurologist from Frenchay Hospital, Bristol, began with a history of epilepsy surgery using examples to illustrate the complexities of some of the procedures. Delegates left the conference with a clear understanding about the different types of epilepsy surgical procedures and the situations in which they are used.

Some of the highlights of Dr Lhatoo’s presentation are outlined below.

**History**

Sir Victor Horsley began the era of modern surgery with a targeted approach to epilepsy surgery. Aged 29, in 1886, he operated and successfully removed epileptogenic lesions on three patients. His findings started epilepsy surgery across western society. From the end of the 19th century to the beginning of the 20th century, several hundred patients underwent surgery. But in 1912, drug treatment became available and the interest in surgery subsided. The focus on epilepsy surgery moved to Germany with Fedor Krause and Otfrid Foerster continuing to operate on patients who were not responding to medication. Foerster passed on his skills and techniques to Wilder Penfield who started the Montreal Neurological Institute in 1934. Penfield’s work was very important. He determined the parts of the brain responsible for particular functions to help minimise the risk of damage from surgery.

Other causes for epilepsy include stroke, encephalitis and meningitis. This has growing importance as a public health issue. As our population is living longer, the incidence of stroke – and therefore of epilepsy – is going to increase in people over 60, as five per cent of people (1 in 20) who have a stroke will go on to develop epilepsy. Ten to 30 per cent of people who have encephalitis (inflammation of the brain) will develop epilepsy, as will three to ten per cent of those who have bacterial meningitis.

Misdiagnosis is a very common problem. 15 to 20 per cent of people who have their diagnosis of epilepsy re-assessed turn out not to have the condition. Conditions that can be mistaken for epilepsy can be viewed broadly as ‘hearts’ and ‘minds’. Under ‘hearts’ are syncope (faints), asystole (in which the heart temporarily stops) and Long QT syndrome (when a certain interval between heartbeats is longer than it should be). Under ‘minds’ are anxiety, panic attacks, hyperventilation and dissociation (also known as non-epileptic seizures, or non-epileptic attack disorder).

However, if the diagnosis of epilepsy remains after assessment, then the main treatment options will usually be anti-epileptic drugs (AEDs). Current figures suggest that 47 per cent of people will successfully achieve seizure-freedom with the first AED they are prescribed, with 32 per cent of the remainder having success with the second drug they try. The chances of becoming seizure-free reduce as more drugs are tried.

Specialists should aim to prescribe the lowest number of drugs possible. If some-
MRI scans can show where abnormalities may lie in the brain (see feature about MRI on pages 8-10). The more advanced MRI machines with higher strength magnets are more likely to reveal the abnormalities.

“Not all patients are straightforward,” said Dr Lhatoo. “An MRI scan can sometimes show two abnormalities in one brain. Either one of these could be causing epilepsy, or both. This is often a conundrum we face in epilepsy surgery programmes – we have to make a distinction between the different parts of the brain which may cause the seizure to occur.”

Other scanning techniques include PET (Positron Emission Tomography) and SPET (Single Positron Emission Tomography), which can detect abnormal brain functions through injecting tiny traces of radioactive substances into the body. These scans are not as accurate as an MRI scan but can be helpful in supporting the case for someone to have surgery.

EEGs (electroencephalograms) are still extremely important in determining whether to recommend a patient for epilepsy surgery. If abnormal electrical activity occurs on one side of the brain an EEG produces a graph of where the problem lies. An EEG can show where the epilepsy is coming from and if it is the same as the MRI, then “this is very good news”. (For more about EEGs see Back 2 Basics in the last issue of Epilepsy Review.)

Before finally deciding to admit a patient to an epilepsy surgery programme, EEG video telemetry may be used. In this, the seizure will be filmed on video while the electrical activity is recorded on EEG. Sometimes medication may be decreased or the person may be deprived of sleep to encourage a seizure to occur and enable it to be recorded. These tests are done in a video telemetry unit in hospital.

The types of surgical procedures performed are mostly resective, ie the offending part of the brain is removed. A common resective procedure is temporal lobectomy in which a part of the temporal lobe is removed (mainly the right side). Frontal lobe surgery is less common as it is a relatively new procedure and the technology is still being refined.

**Does surgery work?**

Many scientific articles have been published that report on the success rates for surgical techniques.

These indicate that 70 per cent of people who were followed up five years after having a temporal lobectomy, and 50 per cent of people followed up five years after having frontal lobe surgery, were continuing to be seizure-free.

These are actually big numbers for patients with difficult epilepsy, said Dr Lhatoo, because these individuals will have tried many different drugs which have not stopped their seizures.

He concluded that, for carefully-select-ed patients undergoing surgery, seizure freedom can last for a very long time – some people would even call it “a cure”.

One is on AEDs but the attacks continue, it is worth the specialist checking that the patient understands how to take their medication correctly. Up to 50 per cent of all prescribed drugs are not taken properly or at all.

To summarise, two thirds, or 66 per cent of people, are easy to treat successfully with AEDs, while for the remaining 33 per cent, it is more difficult.

Despite there being several AEDs already available, there is a need for more new drugs to improve the chance of success for those 33 per cent who continue to have seizures, and to improve how well the drugs work in terms of efficacy, safety, cost-effectiveness, and interaction with other drugs.

Professor Duncan described some of the features of three relatively new AEDs in the UK – Pregabalin, Zonisamide, and Stiripentol (specifically licensed for the rare syndrome Severe Myoclonic Epilepsy of Infancy) – as well as some drugs that will be forthcoming in the next few years.

The current main treatment options focus on suppressing seizures, but is it possible to prevent the underlying causes of the epilepsy? There are as yet no known medications that cure epilepsy, nor that will protect the brain from developing the condition. However, for some people, primary prevention might have been enough to stop them developing epilepsy.

A successful example of this is improved obstetric and neonatal care – the incidence of childhood epilepsy has reduced by over 30 per cent in recent years.

A small percentage of people whose epilepsy does not respond to medication may be suitable candidates for surgery to stop their seizures. Before surgery is considered, the potential risks and benefits should be considered, from the safety aspects to the psychosocial effects of living with uncontrolled epilepsy. Recent advances in brain imaging mean that we can pinpoint to with-

**Carers: responsibilities and rights**

Conference delegates came away from Neil McIntosh’s presentation on carers with an insight into the challenges carers face and how they can be supported.

Neil, a member of the Princess Royal Trust for Carers, based in Bristol and South Gloucestershire, told associate members that carers are often unaware of the fact that they are carers.

The term ‘carer’ refers to people who provide care for others in an informal manner (ie on an unpaid basis). “One in eight adults are carers. That is around six million people in the UK,” Neil said. “Caring can be something that’s drifted into over time, or something that’s suddenly a part of your life as a result of accident or illness.”

The latest census revealed that more than 2 million people become carers in the UK every year. This means that every day, another six thousand people take on a caring responsibility.

“It is important to realise that every caring situation is different and unique. Each caring situation will present a different set of caring responsibilities and difficulties. Caring for a parent with dementia can create different demands from caring for a child with a learning disability.”

Neil said carers of people with epilepsy can face particular difficulties. Referring to the carers’ information on NSE’s website, he said: “Epilepsy can be different for each person, so the need for care can vary greatly. Some people with epilepsy do not need any additional support to live independent lives. Others may need a lot of care. Some may need care only when they have had a seizure.”

“Sometimes the need for care during or after a seizure may be urgent even if the person doesn’t have seizures very often. Because seizures can be unpredictable – someone with epilepsy may be unlikely to be able to plan when they will need help.

“Because seizures can be infrequent or unseen by others, epilepsy can be a ‘hidden’ condition.”

Continued overleaf
Diary date

The 2007 national Associate Members’ conference will be held at Chalfont on Saturday October 20. Once again the Society’s Annual General Meeting will be held during the conference. This is a formula that has proved very popular with Associate Members, as it recognises their importance in the charity’s operations. Advances in neurosurgery, brain imaging and how epilepsy is portrayed in the movies are all on the agenda. And there will be a return to having mini-seminars during the afternoon. Delegates will be able to choose between EIN regional manager Suzannah Clarke’s personal experience of epilepsy, or Lynn Savill and Susan Griffin giving a mother and daughter perspective of living with the condition. Guest speaker at the AGM will be Professor David Chadwick, consultant neurologist from the Walton Centre for Neurology and Neurosurgery in Liverpool. To book your place, contact the Associate Membership office (address on p2.)

WHAT’S NEW IN EPILEPSY?

Continued from previous page

A millimetre the right part of the brain to remove, whilst avoiding damage to the surrounding ‘normal’ areas.

Functional MRI tests before surgery can show exactly which part of the patient’s temporal lobe is being used for memory, and so protect that function for them during surgery. An imaging technique called tractography can show connections within the brain via the nerves. Such techniques tell us more about how our brains work and help reduce some of the risks of brain surgery.

Prof Duncan concluded his highly informative talk by mentioning some forthcoming or possible developments. These included the possibility of predicting when seizures will happen and whether, in the case of tonic clonic seizures, oxygen and suction (for excess saliva) should be made available to use at home.

Carers: responsibilities and rights

Continued from previous page

“The responsibilities of caring for someone with epilepsy can include:
• keeping them safe during a seizure
• calling for medical help, or giving first aid or medication
• staying with them or seeing them home safely after a seizure
• noting any pattern or trigger to their seizures, which may help if they don’t recall their seizures
• helping with their routine of taking anti-epileptic drugs (AEDs)
• accompanying them to appointments, helping to take notes, or providing descriptions of seizures for medical practitioners
• acting as facilitator or advocate for the person, with others involved in their care
• joining in with activities that might pose a safety risk if they were to have a seizure
• adapting the home or lifestyle to provide a safe living environment.

Any of the above, individually or in combination, can mean a lot of responsibility for the carer.

The conference delegates heard Neil talk about caring being a “multi-skilled endeavour” which, he said: “can involve combining a number of skills: technical tasks such as dealing with medical equipment; emotional support; being able to adapt if needs change; or working with professionals involved in the person’s care.

“It can mean acting as a nurse, an advocate, a personal assistant, taxi driver, cook, cleaner and laundry service all rolled into one.

“These roles may be in addition to other demands – your family; other relationships; work; home; financial constraints; social life; your health; and your own hopes and wishes. You may cope well with multi-tasking in this way, or you may find that some areas of your life are being neglected.”

Neil talked through the recent changes to carers legislation, highlighting the new rights for carers looking after people who have been discharged from hospital, which came into effect in October 2003.

“If someone is being discharged from hospital and you (the carer) will be providing regular and substantial care you have the right to request an assessment,” Neil told the audience.

“Social services must carry it out before the patient leaves hospital. If you are already caring and have had a carer’s assessment in the last 12 months, then social services must re-assess your needs... If the hospital thinks that the patient will need community care services, they must contact social services to carry out an assessment. If social services decide community care services are needed, these services have to be provided.”

Neil said about 1.25 million people provided over 50 hours of care per week.

“In many cases, carers benefit from support, advice and advocacy to help them define their own boundaries and responsibilities.

“This can then help them exercise their rights to negotiate and access the appropriate services and support from the maze of providers across the private, statutory and voluntary sectors.”

Neil is a member of the Princess Royal Trust for Carers – the largest provider of comprehensive carers’ support services in the UK.

The Trust acts independently in the interests of carers through research, development and consultation; influence on national, regional and local policy; and partnerships with other national organisations including Carers UK and Crossroads. Visit the website for more information at www.carers.org
The day that changed my life

A year has passed since Highworth Mayor Steve Weisinger had successful surgery for epilepsy – a day he says he will never forget.

"Since that day my life has changed," he told delegates. "I feel more secure and relaxed. My family and friends are overwhelmed with the success of the operation and how it has gone. Hopefully by the end of August I will be able to drive again."

Steve, now 44, had his first epileptic seizure at 10 months old. He always said that although he was born with epilepsy, he resolved that it was not going to beat him. "Even though I was born with epilepsy I have not let it stop me doing things. For the last seven years I have been a local town councillor. Two years ago I was the Mayor of Highworth – the town where I live. In that year I raised £5000 for NSE. I was re-elected back on to the town council two weeks ago for another four years," he said.

Steve has maintained a positive mindset for dealing with his epilepsy, which began as early as he can remember. Following tests confirming he had epilepsy after his first seizure, Steve continued to have simple partial seizures every six to eight weeks while he was at nursery and junior school but it didn’t let him stop making friends and having fun.

"I got involved in everything I could. 'Do your best' is what I learned, nobody can ask for more than that," he said. During his life he has been on many anti-epileptic drugs. His epilepsy ebbed and flowed, from simple partial seizures to seizure-free for three years during junior school, then to complex partial seizures.

Throughout he maintained his resolution that ‘the epilepsy was not going to beat me’.

More than three years ago Steve was referred to Professor John Duncan who arranged for him to have various scans and tests done at NSE. The scans revealed scarring on the left side of Steve’s brain. Professor Duncan and his team analysed the test results concluding that an operation was possible and surgery could go ahead.

Steve discussed the risks associated with the surgery with family and friends but eventually decided that the potential benefits outweighed them and he would proceed with the surgery.

The date he will never forget was Thursday, June 29, 2006 – the day he had the operation at the National Hospital for Neurology and Neurosurgery in London.

"Andrew McEvoy, my surgeon, asked me if I had any concerns or worries. He told me he and his team were all ready to operate. As I entered the surgery preparation area I felt a bit nervous, but still very positive. I met the rest of the team who were helping him with the operation. Five hours later the operation was over,” Steve recalled.

He had headaches every day during the week he was in hospital following the operation and has more headaches now than before the surgery. He says however that it’s “a very small price to pay to no longer suffer with epilepsy”.

"It has been a complete success. I have not had a single fit since that day – and it is a day I will never forget."

NSE is aiming to double its fundraising efforts during the next few years, said NSE Director of Fundraising & Marketing Bridget Gardiner.

Bridget joined NSE in January 2007 after being in a similar role at London’s first children’s hospice, Richard House. She said epilepsy is not considered a fashionable or popular cause, whereas hospices are. With almost 170,000 registered charities in England and Wales plus schools, churches, campaigning groups and many other organisations making a case for support, people probably have at least 300,000 choices for donating their money. The challenge for NSE is to get a fair share of the support available.

Ninety per cent of the £35 billion per annum given to charity in this country is distributed to slightly more than seven per cent of existing charities, with animal and cancer charities amongst the most popular. Around three fifths of the population give to charity each month. Charities for the disabled have become less popular. According to the Charities Aid Foundation, people with disabilities are now seen as empowered individuals rather than victims, and disability charities are paying the price of their own success.

Bridget told delegates it was important to focus on raising the profile of epilepsy, and in turn NSE. She has been fascinated by the fundraising efforts involving people throwing themselves out of aeroplanes and running astonishing numbers of miles – all to raise money for NSE. Many people do it because they have, or had, epilepsy themselves, or they care for or love someone who has or had the condition and are consequently highly motivated.

NSE’s fundraising work has to be targeted at the 456,000 people with the condition, plus their family and friends. Some won’t want to get involved as they just want to get on with their lives, or they may have other family issues, or epilepsy might not be the only condition they or their loved one has.

Our target audience is consequently less than one per cent of the population. The way to reach this audience without spending millions of pounds is through raising awareness in the media, via NSE’s website and word of mouth.

So if someone enjoyed the Seahorse Ball, or taking part in the Seahorse Cycle Challenge, they need to pass this message on. NSE needs to offer a range of fun and rewarding opportunities which are easily accessible and do not depend on large scale events or hefty entry fees, such as regional walks, or activities that can be undertaken in the home, or online.

Legacy also needs to be promoted as a way of supporting NSE. Legacies currently contribute around half a million pounds a year (donations NSE is extremely grateful for). But the Multiple Sclerosis Society, whose work helps 85,000 people in the UK, receives around £8 million a year from its legacy income – 16 times as much as NSE – and the Motor Neuron Disease Association received over £3 million in legacy income last year, with only about 4,200 having MND in the UK.

Research also requires funding. NSE is at the very early stages of establishing a world-class genetics research centre at Chalfont. Around £5 million needs to be raised with the aim to have the centre operating by 2011. NSE has already secured around £500,000 in pledges and will up the ante once the outcome of a forthcoming planning application to build the new centre is established.

NSE will also increase its efforts to engage with corporate entities, grant-mak- ing trusts and foundations, and wealthy individuals – all of whom can make a huge difference to fundraising targets.

Bridge said it would take investment and time to increase NSE’s fundraising income. She has just completed a new strategy for fundraising at NSE, identifying ways in which we will reach out to more people affected by epilepsy in order to achieve our goals and take NSE forward into the next decade.
Atlantic Nick’s oarsome challenge

When Nick Histon takes on the challenge of rowing 2,550 nautical miles across the Atlantic to raise money for NSE, it won’t be a drop in the ocean.

“[It’s been] a lot harder than [I anticipated],” he admitted. “But I want to prove that young people with epilepsy can achieve anything.”

Nick (24) first had the idea to row from La Gomera in the Canary Isles across the Atlantic Ocean to Antigua in the West Indies when his cousin Michael Elliott did it 10 years ago. “When I saw him leave I thought ‘one day I’d like to do that’ and now it’s actually happening,” he said. “Back then many people didn’t know if they would come back.”

The race, which is gaining popularity and leaves this year on December 2, is considered one of the toughest nautical challenges on the annual rowing calendar. In all recorded history only about 300 rowers can be added to the list.

Nick is preparing for his magnificent rowing challenge across the Atlantic.

“[To be honest] I haven’t really thought about the row. I’ve just been so busy trying to fundraise and finish building the boat,” said Nick, a high dependency nurse at Southampton General Hospital.

“Most people who enter this race don’t have full-time jobs, but we have to raise the money around our jobs. Plus, we’re rowing two hours a day, up to twice a day on rowing machines.”

The race will take about 50 days. Nick said: “Each of us will be rowing for two hours on, two hours off to keep the boat constantly moving, it means we will be rowing about 12 hours each in a 24-hour period. It’s going to be hard but I know we can do it.”

People can make donations in support of Nick’s row across the Atlantic by visiting the secure Just Giving website at www.justgiving.com/histon.

Businesses can also advertise their corporate logo on the side of the boat or contribute to the challenge by visiting www.row4cornwall.co.uk.
**RUN, RUN, RUN, AND HAVE FUN!**

While the Seahorse Cycle riders were getting their wheels rolling, others have been putting their legs in motion to support NSE through a variety of nationwide runs.

**Turner runs up funds for NSE**

Katherine Turner’s life was remembered when her brother pounded the pavements in the British 10K London Run on Sunday, July 1.

Katherine, who lived and worked in London, died from Sudden Unexpected Death in Epilepsy (SUDEP), aged 29, late last year and her brother Stuart (pictured left) was running to raise money for NSE in her memory.

”Whilst Katherine lived her life to the full, there are many others who need a great deal of support living with this condition,” Stuart says on his fundraising website www.justgiving.com/stuartturner

”NSE provides various forms of support to these people and their families, along with funding numerous research projects into the causes of and potential cures for epilepsy.”

The unexpected nature of Katherine’s death was one of the things that spurred Stuart towards raising much-needed funds for NSE by taking part in the London Run. “She was not having seizures on a regular basis – she thought she had the condition under control. This is why we need more research,” he said.

Stuart, of Kenilworth in Warwickshire, has so far raised more than £3,000 for NSE, far exceeding his initial target of £250. Stuart and his family have been “overwhelmed” by the support they have received since Katherine’s death.

More than £3,500 from Katherine’s family, friends and colleagues was donated to the NSE earlier in the year following her death. The family’s fundraising efforts will continue into next year when Katherine’s sister Hazel plans to walk part of the Great Wall of China.

NSE’s director of Services Karen Lane also ran in the London event, achieving a personal best time of 1hr 5mins – eight minutes quicker than her previous best time.

**Pouring rain doesn’t dampen fun run spirits**

It was going to take more than the bucketing rain to dampen running spirit at NSE’s 5K Seahorse Fun Run in May. More than 200 runners braved foul weather and raised almost £6000 for NSE.

Event organiser Jo Wengler said: “It was a terrific event with a fun, competitive atmosphere. We were really pleased with the turnout – despite the appalling weather.”

Solicitors BP Collins sponsored the event for the first time this year and their runners raised £700. BP Collins was supported by GE Healthcare, Baxter Storey, the Buckinghamshire Advertiser and the Buckinghamshire Examiner. The Chiltern American Women’s Club held one of their renowned ‘just a second’ sales immediately after the Fun Run, raising a further £1,700 for NSE.
Have a ball with NSE

The exclusive Hurlingham Club, on the banks of the River Thames at Fulham, will be the spectacular setting for this year’s Seahorse Ball on November 2.

The evening will begin with a sparkling champagne reception in the stunning Palm Court with its soaring glazed roofline (picture below), followed by dinner in the elegant Broomhouse Suite. Dancing to live music will continue until 1am.

NSE events manager Jo Wengler said: “The Seahorse Ball is always a really high point on NSE’s fundraising calendar. It regularly attracts support from a host of celebrities who bring a real touch of glamour and help to raise the profile of the event.

“It’s too early to say which celebrities might be attending this year’s Ball as it depends on their acting and other commitments — but you never know who might be bopping away next to you, and who you might be rubbing shoulders with as the evening progresses.”

In recent years, celebrities at the Seahorse Ball have included NSE ambassadors Bill Nighy, Robert Powell, Hustle star Marc Warren and stars from Holby City, The Bill and Eastenders.

Jo added: “We aim to break new ground this year with many new features to make the evening really go with a swing and to help swell our fundraising coffers. For example, our raffle will be irresistible as, for the first time, it will offer the chance for someone from every single table to win a valuable prize. All the money raised will go towards our important medical research programme.”

Holding the Ball at the Hurlingham Club is breaking new ground too. Previous Balls have been held in four and five star hotels in Central London, but the Hurlingham is a truly unique setting that is not normally open to members of the public. The Hurlingham is a private club of international renown, with a waiting list of more than a thousand people wanting to become members. Only very recently, a suite within the neo-classic mansion has been available for hire for private functions such as the Seahorse Ball.

Tickets are priced at £120 and tables can be for 10 or 12 people. To reserve your table or tickets, or to find out more, call Jo on 01494 601 450 or email jo.wengler@epilepsynse.org.uk

Cycling the South Downs Way

Ben Burrows and sons Edward (15) and Henry (12), from Pulborough in West Sussex raised a fantastic £3,200 for NSE when they cycled the 100 mile South Downs Way from Eastbourne to Winchester – and thanks to support from numerous friends, supporters and well-wishers, the money is still coming in.

They were motivated to raise money for NSE because the boys’ teenage cousin Ella was recently diagnosed with epilepsy. Their adventure took two-and-a-half days, with valuable support and refreshments being provided by mum Sarah.

She said: “The boys managed it all fine, although day two was a bit tough. But they were very enthusiastic and were determined to complete the distance.”

Sarah added: “They had all planned to cycle the route anyway for personal achievement, but with Ella having epilepsy, they wanted to do something to help. They wanted to raise money for a charity and NSE seemed the natural choice.”
Over six days in March this year, GE Healthcare employee Keith Flood competed in the Marathon des Sables – the ‘toughest foot race on earth’ – to raise much needed funds for NSE. Keith set himself the already hard target of £10,000 but went on to raise the extraordinary sum of £23,700 – the most ever raised by an individual taking part in any sort of sponsored event on behalf of NSE. Keith said he had been overwhelmed by the way the public responded to his call for sponsorship. Keith endured incredible hardship during the 151-mile endurance race, running the equivalent of the London Marathon each day for six days – not on roads, but across the sands of the Sahara in Morocco, in temperatures of over 120ºF. Incredible though it seems, now that his blistered feet have recovered from the pounding they took, Keith has set himself a new challenge – this will be over snow and ice. Once again in aid of NSE, Keith has signed up to the 2009 6633 Arctic Challenge, an extreme challenge event that takes competitors over a 352.6-mile course across the Canadian wilderness. Although the event is still a year and a half away, Keith has already raised £2,000 towards his £30,000 target. There will be update bulletins on this super-human’s sponsorship progress posted on the www.epilepsynse.org.uk website and detailed in forthcoming issues of Epilepsy Review.
Pedal power hits Edinburgh

NSE’s sponsored cyclists received a truly royal welcome when they pedalled into Edinburgh at the end of their 430-mile journey from London.

As they journeyed up the Royal Mile to the gates of Edinburgh Castle, champagne and well wishers were on hand to mark their achievement. Among them was newly elected Scottish MP Alasdair Allan, who has epilepsy himself.

Alasdair also tabled a congratulatory motion in the Scottish Parliament which commended the cyclists for their sporting achievement and the attention they drew to the issues of epilepsy and epilepsy research. The motion was supported by 21 other Scottish MPs.

He said: “I was delighted to welcome the cyclists to Edinburgh Castle. Their achievement is one I greatly admire and I hope they raised a lot of money for NSE.”

The 2007 Seahorse Cycle took on a new format this year. For the first time an NSE resident, Paul Seager, expressed an interest in taking part with support from NSE’s sports instructors. ‘Team Seager’, as the quintet became known, began their epic journey to Scotland four days before the other five cyclists (Team Deep Heat!) which included NSE’s Assistant Director of Personnel Peter Jackson and EIN volunteer Lyn Walden. The two teams then met 20 miles outside Edinburgh to make their final assault together to the finish line at the Castle.

Tim Smalley, Assistant Manager of the Therapy Centre at Chalfont was one of the four support staff who accompanied Paul. He said: “During our training sessions it became obvious that the special recumbent bikes ridden by Paul with support from myself and the sports instructors in rotation, just wouldn’t cover the same mileage each day as the conventional bikes.

“They were looking at a total mileage of between 80 and 90 miles each day, but we felt that between 50 and 60 miles daily was more achievable for our team so we decided to set out a few days earlier so we could all reach Edinburgh together.”

As in previous years, the teams were blessed with dry weather, although early morning mists spoilt views over the Yorkshire Moors and the Scottish border.

The two teams were supported by vans donated by Thrifty so energy drinks and supplies of fruit were always on tap.

Team Seager’s journey was closely monitored by the media. Tim Smalley was interviewed by BBC Three Counties radio before they set off and on two occasions en route. A letter from Paul, inviting people to sponsor him, was carried in a number of local papers and The Scotsman newspaper carried the story.

NSE events manager Jo Wengler said: “It was a fantastic achievement. Special mention should go to David Russell who took part in the event for the third time, to NSE’s Graham Judge who drove one of the vans and to Liza Grant who ensured the whole trip went smoothly.

“Otterburn Hall in Yorkshire deserve a special thank you as they gave both teams accommodation and food free of charge. Sponsorship money is still coming in, but looks to be in excess of £10,000.”

giftaid it

You can make every gift since April 6 2001 worth even more, simply by signing the declaration below. The Government will then top up your donation, providing NSE with 28p more for every £1 given.

Declaration: Please treat all my donations to NSE since April 6 2001 until further notice, as Gift Aid. My annual income tax and/or capital gains tax is greater than the tax NSE will reclaim.

Full name: __________________________ Date: __________

Signature: ___________________________ Address: ___________________________

____________________________________ Postcode: ________

Phone: _______________________________

Please return this form to: NSE, Freepost SL766, Gerrards Cross, SL9 7BR

Making every penny count

According to the Charities Aid Foundation the charity sector is currently missing out on between £600 and £700 million in unclaimed tax relief. This is a staggering sum by any measure. The Gift Aid scheme that was introduced in 2000 to help charities reclaim the basic rate tax element that is included in donations is relatively straightforward, but confusion still remains about its use.

NSE recently carried out a search of its database to identify donors who had not used or been asked to use Gift Aid over the past six years. We can reclaim tax on donations whether they are current donors or not.

As a result of a subsequent mail-out, we have been able to reclaim £40,000 from the Inland Revenue. However, among in the replies were several letters from pensioners who said they could not sign a Gift Aid declaration as they were no longer working.

Contrary to popular belief, many pensioners are still taxpayers. You do not have to be in paid employment to pay tax! Gift Aid may be applied to tax on savings, such as building society accounts, as well as income tax.

If you have made a donation to NSE since becoming a pensioner, your payment could be made more valuable under Gift Aid. All that is required is a simple Gift Aid declaration to be completed. This can be done over the telephone, or fill in the adjacent form and return to us using the Freepost address given.

If you would like to know more about the Gift Aid scheme, please call the fundraising department on 01494 601415.
Tricks of the Mind

By: Derren Brown

Price: £11.99

Publisher: Channel 4 Books

ISBN: 9781905026388

Let's get this straight from the start – I think Derren Brown is a very clever man, having seen his TV and theatre shows. I also have a naïve wonder about magic, growing up, as it were, with Paul Daniels.

Brown is open about the methods he uses in his shows – combining magic, suggestion, psychology, misdirection and showmanship – to great effect. The book cover promises to reveal the structure and psychology of magic. It is aimed at “the intelligent reader with a layman’s interest in things mind related”, and is a collection of the author’s thoughts on topics such as magic, hypnosis and ‘pseudo-science’.

Along the way you can learn a few tricks; like a coin slight or simple card trick, as Brown shares the methods of how to do the trick and also how the audience is manipulated by the magician.

Reader note: if you don’t want the ‘mystery’ taken out of ‘magic’ this might not be the book for you!

OK, so I really enjoyed this book. But why is it relevant to Epilepsy Review readers? Bear with me here. I was thinking about our memory leaflet, and the tips and techniques we include in it, information and help. To order or download a copy of New to Caring, visit www.carersuk.org or telephone 0845 241 0963.

I first read this book at Christmas. When I came to read it again four months later, I surprised myself by remembering 12 of the 20 words from the linking technique (and an image of a drunken mouse sitting in the bottom of a huge glass with a party hat and streamers). The chapter on memory might only be part of the book, but its impact and usefulness may be really helpful.

One criticism of the book would be that it is not very accessible – including ‘the esoteric idiom of the thamaturge’ illustrates this. And I wonder, if you are not familiar with his ‘style’, how well this book would read? It is not always clear if he is being sincere or sarcastic, for example saying: “a desire to make the contents of the book as worthwhile and unpatronizing as possible (‘patronizing, of course, means to ‘talk down to people’).”

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New to Caring

The charity Carers UK has launched a new booklet for people who are new to caring. The booklet contains advice from experienced carers and covers all the basics that one needs to know about the financial, practical and emotional aspects of caring – and the range of help available.

It includes an entertaining foreword by Hugh Marriott, the well-known author of ‘The selfish pig’s guide to caring’, which was reviewed in the last issue of Epilepsy Review. Hugh’s wife Cathie has Huntington’s disease and he understands only too well the emotions, the battles and the rewards of caring and the time it takes to even recognise oneself as a carer.

Also included are handy contact details of other sources of information and help. To order or download a copy of New to Caring, visit www.carersuk.org or telephone 0845 241 0963.

Linking technique – used to remember lists of words, it creates a visual link from one word to the next. These images have to be vivid, interactive and unusual; working “with your memory’s tendency to store vivid images much better than dry information”. Brown teaches you to remember 20 unrelated words by using the linking system, which you can then recite “backwards from memory as easily as forwards, and still remember the list forwards and backwards for days afterwards”. This sounded too much like hard work – to be honest, I was too lazy to really try following the instructions. Imagine my surprise then when, darn it – it worked!

Loci system – teaches you to visually ‘attach’ images representing things you need to remember (like a shopping list), to images along a real-life journey you know well (like from the shops to your home). By retracing the route in your mind, you come across the images and so remember the things on your shopping list.

Memory palaces – expanding on the loci system, this can be used to remember information you want to keep for longer. Rather than using a journey, memory palaces are ‘rooms’ that you imagine, filled with images that represent what you want to remember.

The peg system – is for remembering numbers. For example, using similar sounding words (one = bun, two = shoe) and using images to link the words, like someone putting on an iced bun instead of a shoe). This can help you to remember phone numbers, birthdays etc.

This chapter is so useful because it explains the logic behind how and why the systems work, and gives you examples to practise.

Conclusion?

This book is a combination of biography, history and ‘self-development’. I found it interesting and very thought provoking. Brown shares his thoughts, and can be quite challenging and sceptical of things that other people hold sacred. I enjoyed reading it because it flowed like talking to a friend. OK, a sarcastic and slightly smug friend. But I guess you can be that smug when you are that clever.

One criticism of the book would be that it is not very accessible – including ‘the esoteric idiom of the thamaturge’ illustrates this. And I wonder, if you are not familiar with his ‘style’, how well this book would read? It is not always clear if he is being sincere or sarcastic, for example saying: “a desire to make the contents of the book as worthwhile and unpatronizing as possible (‘patronizing, of course, means to ‘talk down to people’).”

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Now, if only I could find a cure for laziness!

Rona Gibb

Epilepsy Information Manager

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If you are buying books, CDs, DVDs, games, electronics, photographic equipment, toys and a whole host of other items. click through to Amazon from NSE’s website at www.epilepsynse.org.uk (Amazon button on the home page). Amazon will make a donation to NSE for every item you buy.
There are many books about epilepsy. Some will be in print and available to buy in bookshops, others can be purchased online, or perhaps to borrow from your local library if you’re lucky! Our new occasional feature, On the shelf, outlines a selection of epilepsy books. There are too many to cover in one article, so our first On the shelf covers general interest books about epilepsy, which give a good overview of the condition. Some of the titles have been reviewed in past issues of Epilepsy Review.

If you wish to buy one or more of these books online, see our Epilepsy Reading list on the NSE website at www.epilepsynse.org.uk/readinglist

If you click on a title on our website reading list, you will be redirected to Amazon, an online bookseller, where you can buy the item. By going through NSE’s site in this way, you will be donating 7.5 per cent of the price to NSE, at no extra cost to you!

All the titles listed below are available to buy from Amazon, unless where stated. Prices and delivery charges may vary. They may also be available through other online booksellers.

On the shelf will return in future issues of ER. Possible themes could include books about epilepsy for parents, for children, for professionals, fiction, or personal experience. Let us know what you would like to see On the shelf cover in future?

Epilepsy
A Hanscomb & L Hughes Cassell 2002
ISBN 18844031470
Available from NSE – through the online shop at www.epilepsynse.org.uk/shop or phone 01494 601392 for an order form

A good starting point for learning about epilepsy, Epilepsy explains what the condition is, covering types of seizure, causes, diagnosis and treatment. With clear headings, large photos and diagrams, the book doesn’t feel overwhelming for someone who is new to the condition. Key points and questions are in coloured boxes so they stand out. Practical tips are given, such as ‘Examples of questions to ask the consultant’. The book feels like it addresses the person affected by epilepsy directly, and in a very ‘human’ way, putting emphasis on managing your own condition and living positively with epilepsy. Be aware of the publication date, as there may be more current information about one or two topics; for example, the list of anti-epileptic drugs does not include the very newest drugs available. This does not detract from the value of this highly readable text.

• For current information, see NSE leaflets epilepsy – medication for adults or epilepsy – medication for children.

Understanding Epilepsy
S Shorvon & M Walker
Family Doctor Publications 2005
ISBN 1898205752

A pocket-sized, affordable volume which is part of a series covering several conditions. Using colourful illustrations and diagrams, it covers medical and social aspects of epilepsy.

Sections are kept fairly short and simple, and each chapter ends with a short ‘key points’ summary. This book is also available under a different publisher as: The British Medical Association Family Doctor Guide to Epilepsy, M Walker & S Shorvon, Dorling Kindersley 2005, ISBN 0751306827

Epilepsy Explained: a book for people who want to know more about epilepsy
Ulrich Altrup, Christian E Elger, Markus Reuber
Publisher: Medicine Explained Publishing, 2005
ISBN: 3980963810
Available to buy from Dr Markus Reuber at Dept of Neurology, Royal Hallamshire Hospital, Glossop Rd, Sheffield S10 2JF, by sending a cheque for £16.50 made payable to Sheffield Teaching Hospitals NHS Foundation Trust. Any income will go to the research fund for clinical (non-laboratory) epilepsy research.

A colourfully presented book which explains epilepsy in clear terms and assumes no prior knowledge. Uses accessible language and style, making points very clear. Rather than offering advice, it gives people the information needed to make their own choices. The comprehensive coverage includes the basics of definition, seizure types and treatment, as well as everyday life with epilepsy, epilepsy and the law, and people’s attitudes to the condition. It also tackles some challenging topics including sudden unexpected death in epilepsy, and prejudice.

Epilepsy at your Fingertips
B Chappell & P Crawford
Class Publishing 2001 (2nd edition)
ISBN 1872362516

Using a question and answer format, this book invites you to dip in at the sections you need, rather than read it from cover to cover. Most of the questions are ones originally asked by people affected by epilepsy, and they are asked in an informal, chatty style, as if you were having a conversation. Like other books in this list, the topics covered include basic definitions of epilepsy and seizure types, diagnosis and treatment, managing seizures and first aid, employment, driving and travel, and social life and relationships. The practical concerns are balanced by the more emotional aspects – coming to terms with a diagnosis, how you might feel about your epilepsy, and how other people may react. Again, be aware of the publication date – topics such as pregnancy and anti-epileptic drugs will have more current information available.

• For current information, see NSE leaflets epilepsy – pregnancy and parenting and epilepsy – medication for adults or epilepsy – medication for children.

Coping with epilepsy
F Marshall and P Crawford
Sheldon Press, 2006 (2nd ed)
ISBN 0859699765

A book not just for those who are new to epilepsy, but also anyone who has lived with the condition for many years. The authors stress that epilepsy is a dynamic condition which can need regular review by those who have epilepsy and their doctors. The book starts with basic facts about seizures, diagnosis and treatment. There is then a focus on women, covering issues such as contraception, pregnancy and anti-epileptic drugs and how women can discuss these with their doctors. The final part of the book covers the psychological and social impact of epilepsy, including the less frequently featured issues of therapy, seizure alert dogs and diet. In each section there are snippets of real life stories, so you can see how other people feel about their epilepsy.

If you wish to buy one or more of these books online, see our Epilepsy Reading list on the NSE website at www.epilepsynse.org.uk/readinglist

If you click on a title on our website reading list, you will be redirected to Amazon, an online bookseller, where you can buy the item. By going through NSE’s site in this way, you will be donating 7.5 per cent of the price to NSE, at no extra cost to you!

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Epilepsy Information Network

Epilepsy week round-up

Epilepsy Information Network volunteers and Regional Managers were very busy raising public awareness about epilepsy, especially epilepsy and employment, throughout May. All EIN volunteers received copies of the epilepsy and employment posters and were asked to display them in appropriate venues to mark National Epilepsy Week (NEW). They also manned information stands, did radio broadcasts, raised awareness in libraries, read on...

South: Trevor Hutton
If you entered a bus in Eastbourne during National Epilepsy Week, your attention would have been drawn to an NSE poster at the front of the bus, as every bus in Eastbourne carried NSE posters during and beyond the week. This masterpiece of advertising was the brainchild of volunteer Andy Evans.

Other activities in Eastbourne included posters in all surgeries, hospitals and colleges, plus John Lumm had three epilepsy information days within the Asda shopping mall. John had the help of Paul Ryan who went on to support Andy Evans on the Saturday, running an information stand within the Asda shopping Mall on Brighton Marina.

West Midlands: Geraldine Walker
On the first Saturday of NEW, the EIN had an information stand in the main Pallisades shopping centre in Birmingham, EIN volunteers, Mandy, Geoff and Arshad, helped out as well as the Regional Manager, and over 80 people were given information.

During the rest of the week information stands and support were available every day in the Health Exchange hub in the Central Library. This was also the venue for a seminar on epilepsy and employment, for employers, with input from NSE, Queen Elizabeth Hospital epilepsy services and Birmingham Disability Resource centre – 25 local employers attended.

This was followed up in the afternoon with employment support for people with epilepsy provided by BDRC. Another day featured a coffee morning plus a stand in the local carers’ centre (with Epilepsy Action).

Information stands were also located at Coventry and Warwick hospital (by Bev and Bridie who are both EIN and Epilepsy Action volunteers) and the Samuel Johnson Hospital Lichfield at a Learning Disability Carers event.

A full programme of events for clinicians was also held at Queen Elizabeth Hospital during the week covering all aspects of epilepsy: pregnancy; the elderly; children; mental health issues and community services for epilepsy. On the QE site, there was also a scientific open afternoon in the EEG Dept and a meeting of the Vagus Nerve Support group.

Volunteers and the public were very supportive of what we were trying to do and we had good independent feedback via our forum which was great.

East Midlands: Kim Barlow-Miles
EIN volunteers were very busy covering the East Midlands with the new employment posters: notice boards in supermarkets, health centres, libraries, Job Centres (of course!) and very importantly, targeting workplaces with lots of employees. Everyone knew someone, who knew someone else, in this environment. It was true NETWORKING!

Almost all the main hospitals in the area agreed to allow stands to be put up close to reception areas or the main staff/visitor restaurant. These attracted much interest, with members of the public and professionals all eager for information and leaflets to take away.

Special mention for the Nottingham Queen’s Medical Centre team, especially Jo-Anne and Alan, and in Northampton, as I wish this service had been around when Alan was first diagnosed.

What do you particularly like about it? Passing knowledge on to other people so that they don’t have to go through the same problems that we incurred all those years ago (19).

Continued overleaf

Focus on: Valerie Hopkinson
EIN Volunteer in Taylor Street Clinic, Heywood, Lancashire

How did you hear about being an EIN volunteer? Through my husband Alan’s Epilepsy Specialist Nurse, Jan Bagshaw.

How long have you been a volunteer? Five years on November 16 2007.

What do you do? I sit in the clinic and provide information to patients seeing the ESN, who have been sent from the consultant at Birch Hill hospital or people just calling in.

What attracted you to the role? I was already helping at the ‘Heywood Epilepsy Help Group – with Alan having epilepsy I like to know what’s happening. I also wanted to pass on information to others, as I wish this service had been around when Alan was first diagnosed.

What do you enjoy doing for entertainment? Socialising with family and friends.

If you could have a wish granted what would it be? All people with epilepsy could be seizure free.

WHO’S WHO

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**Epilepsy week round-up**

Continued from previous page

Linda, who were present in their hospitals every day of NEW!

Kim Barlow-Miles, Regional Manager, did two radio broadcasts and volunteers also rose to the challenge of engaging with the media: Linda with the *Chronicle and Echo* in Northampton, Alan with Nottingham Radio Trent and Denise (via her Fashion Shoot!), spreading the word to the Nottingham Evening Post.

**East Anglia: Paul Seekings**

EIN had an information stand in the Welwyn Garden City Library for two weeks including NEW, with EIN volunteer James in attendance. The display had information about the epilepsy and employment survey as well as general info.

In Norfolk and Norwich hospital, EIN volunteer Helen teamed up with the hospital’s epilepsy services to have information on hand in the main dining area for all of NEW. Both James and Helen saw part of their role as helping to dispel myths around epilepsy.

**London and Home Counties: Suzannah Clarke**

Jenny Ford, one of NSE’s long-serving and dedicated volunteers, ran an information stall in the main Outpatients hall at the Royal London Hospital on Thursday May 24, together with another hard-working and much appreciated NSE volunteer Sophie Bryant.

The stall was also supported by the epilepsy nurses Adele Larkin and Faith Ruru and four volunteers from Epilepsy Action East London, Ian and Ute Granville, Kath Gillet and Tony Murphy. Tosh Denholm, matron, and Chris, a staff nurse, also gave practical help. Both NSE and EA leaflets and posters were on display and contact was made with about 50 people. As a bonus, a raffle was held, raising £50 for NSE and the hospital epilepsy fund.

Suzannah also appeared on a Channel 4 news broadcast during the week (pictured left), when she highlighted the pressing need for more epilepsy specialists in the UK.

**North East: Dee Moore**

EIN had a stand in the BBC centre in Hull all week, set up by volunteer Linda Kelly, staffed through the week partly, by volunteer Diane Ford then, Regional Managers Dee and Joyce. A busy venue with lots of opportunities to promote and be seen, Dee even managed an interview on one of the morning shows on Radio Hull.

Volunteers Kathryn Thomas and Adam Cunningham set up a stand in Halifax Royal Infirmary in a good prominent position, giving information to both professionals and patients! On Thursday morning a stand in Wakefields Pinderfields Hospital was set up and staffed by focus volunteer Jan Powers and new volunteer Kate Brain. The trust took several photos of the stand and they were interviewed for an article for the hospital newsletter!