



MP Paul Maynard
Speaks about life,
epilepsy & politics



Raising awareness
The importance of
involving educators

**MEDIA
PLANET**

EPILEPSY

4
TIPS



HOW TO MANAGE

Living with epilepsy: A look at alternatives to
anticonvulsants, education and research

PHOTO: NICOLA SCHAFER



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CHALLENGES

Epilepsy affects many people and can have a considerable impact on life – but armed with knowledge and information, it need not be an obstacle. Increasing awareness – both about epilepsy itself among the general public and among those with epilepsy – of the support and resources available is key

Moving ahead

Epilepsy affects around half a million people in the UK. It is a hidden condition that can have far-reaching consequences for the people it affects. Some people with epilepsy receive the right treatment soon after diagnosis and have their seizures controlled relatively easily. For others, however, epilepsy can have a serious impact on education, employment and social life in a way that dramatically affects a person's quality of life.

Raising awareness

1 This week is National Epilepsy Week. The purpose of National Epilepsy Week is to raise awareness of epilepsy among the general public and to make people affected by the condition aware that the voluntary sector can provide them with help and support. The Joint Epilepsy Council of the



Sharon Wood
Chief Executive, Joint Epilepsy Council

UK and Ireland (JEC) is an umbrella group designed to provide a unified voice of the whole epilepsy community to UK government and the public sector. Various member organisations of the JEC have contributed to this supplement and we are pleased to help raise awareness of the condition in this way.

What's happening now – and next

2 This supplement covers some important epilepsy-related issues, from current treatment op-

tions to research that indicates what the future of epilepsy might look like. It also looks at issues affecting specific groups of people with epilepsy, such as those whose education might be hampered by epilepsy or pregnant women taking drugs that could affect their unborn children, and there is information about a special online radio day taking place this week, from Epilepsy Action. Finally, there is also an interview with Paul Maynard MP, the first MP to be open about his epilepsy.

Creating a discussion and understanding

3 It is important that we talk about epilepsy, as it is a condition that is often stigmatised and misunderstood. This National Epilepsy Week, take a few minutes to read this publication and find out about the condition and the organisations working to support those affected.



WE RECOMMEND



Dr Imad Soryal
Consultant neurologist at University Hospital Birmingham

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“The level of awareness about non-medical treatments is quite low among patient groups”

MEDIA PLANET

We make our readers succeed!

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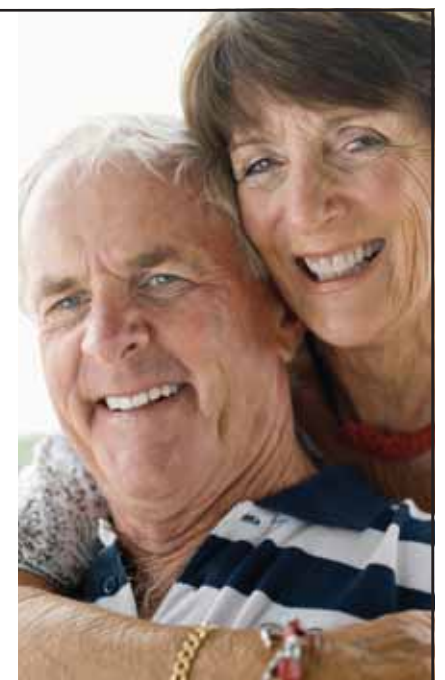
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How will you reach your potential?

Introducing David Lewis

David Lewis is dedicated to improving the life experiences of people with complex epilepsy, autism, learning and physical disabilities.

We have a successful track record, built up over 100 years, with expertise in specialist residential, education and medical services.

What does David Lewis offer?

As the UK's largest provider, we operate 24 hours a day, 7 days a week, 52 weeks of the year. Our highly trained staff teams provide dedicated individual support to over 250 young people and adults. Our services are accessed by people with complex needs aged 14 upwards from across the UK. Our main site is located in Cheshire and we have six community homes in local towns and villages.

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- Footsteps- supported employment and work opportunity programmes.
- Care at Home Service- flexible packages of support in your home including people with individualised budgets and direct payments.

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- Our excellent facilities include a newly refurbished pool, hydrotherapy pool, fully equipped gym, bowling green, café, coffee bar, media and IT suite and animal centre.
- Within the local community, our Footsteps programme offers supported employment opportunities in our model office, arts and crafts shop and garden maintenance business.
- Our residential properties are designed and furnished to the highest quality to meet the needs of the individuals we support.



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INSPIRATION

Question: What are the most important things to know about epilepsy – and why?

Answer: Patient empowerment – and their best care – begins with accurate diagnosis and is supported by continually good assessment and the right medication

The impact of knowledge

LEADER TO LEADER

Only 52 per cent of people with epilepsy in the UK are seizure-free – but it is estimated that 70 per cent could be as long as medication is prescribed and taken correctly, according to the Epilepsy Society.

Epilepsy can affect anyone, at any age, explains Professor John Duncan, medical director of the Epilepsy Society and Professor of Neurology, Institute of Neurology, UCL. “Anything that affects the brain can give rise to epilepsy: congenital malformations, damage from trauma, stroke, infection, tumours.” There is also an inherited genetic tendency, which significantly contributes in 40 per cent of individuals.

“There are many different types of epilepsy and some forms only respond to particular anti-epileptic drugs (AEDs), and some may be made worse

by some drugs. Thus, accurate diagnosis is essential, leading to prescription of the most suitable AED. Further, there is a lot of individual variability, so whilst one AED may be good for one person, it may not suit another. It is important to use drugs effectively: start with a low dose and build it up slowly to reduce the risk of adverse effects. Continue to build up the dose if seizures continue, provided there are no side-effects. If there are, switch to another AED.” Consistency is crucial, Professor Duncan points out. “If medication is omitted, the defences are down and the risk of a seizure is much increased.”

Recent proposals which allow the generic substitution of drugs pose a risk to those with epilepsy, says Professor Duncan. Generic substitution would allow pharmacists to change the brand of drug given to a person if a cheaper version is available. “Whilst generic AEDs contain



‘It’s important that everyone knows how epilepsy can be well treated’

Professor John Duncan, Medical Director of the Epilepsy Society and Professor of Neurology, Institute of Neurology, UCL

the same active ingredient, the other ingredients of the tablets may vary, resulting in differing rates and completeness of absorption of the drug from the gut. This may result in more or less drug being present in the brain. This may result in either lower levels, increasing the risk of seizures, or higher levels, resulting in increased risk of side-effects,” says Professor Duncan.

It is also vital, says Professor Duncan, that the person understands their condition and its treatment.

“It’s important that everyone knows how epilepsy can be well treated – and that the public at large realises that epilepsy is a physical condition that can be well treated and most of those with epilepsy can lead entirely normal lives, but that it can be serious.”

EMILY DAVIES

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UNDERSTANDING IS KEY
 Knowing what works for individuals is vital for the management of epilepsy and leading a normal life
 PHOTO: MAGA/SHUTTERSTOCK

The key to good management

Anthony Linklater, epilepsy specialist nurse, National Hospital for Neurology and Neurosurgery, London

The prognosis for people with epilepsy is often positive and with good management around 70% of people with the condition could have their seizures well controlled with medication.

Some individuals may benefit from the use of alarms and sensors which help to alert family and carers when seizures occur. These include bed monitoring devices, which are designed to detect movements associated with seizures whilst the individual is asleep, and devices which alert if a person falls to the ground.

Some people will use their mobile phone alarms to help to remind them to take medication when it is due. We have also set up a mobile phone text messaging service to send medication reminders at times specified by individuals.

It is also important for individuals with poorly controlled epilepsy to be under the care of a responsive epilepsy service which has the resources and expertise required to meet their needs.

How will you reach your potential?

"I had severe seizures and behaviour problems which affected every part of my life. David Lewis has helped me to control how I think and feel and I now have the confidence to enjoy my life, with support when needed." Jake, 21

Jake is ready to move into his new home thanks to the specialist, committed, treatment and support from David Lewis staff.



David Lewis is dedicated to improving the life experiences of people with complex epilepsy, autism, learning and physical disabilities. To see how we can make a difference to your life, contact our friendly team on 01565 640193 or email assessmentandtreatment@davidlewis.org.uk

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INSPIRATION

TIP

1

INVOLVE
TEACHERS

SCHOOL LIFE
Coping with being an adolescent is difficult enough without having epilepsy. It is important that the school is educated in the condition to make the experience as smooth as possible
PHOTO: MONKEY BUSINESS IMAGES

The power of learning

■ **Question:** For children and young people, epilepsy can bring particular challenges – especially with regard to education. What can be done to limit damage?

■ **Answer:** Knowledge empowers parents, teachers and the child or young person themselves – to enable a tailored approach that maximises the benefits of education

HOW WE MADE IT

“For those with epilepsy, the normal adolescent feelings of low self-esteem and lack of confidence can be seriously compounded,” says Jon Sharpe, Principal of the National Centre for Young People with Epilepsy School and Further Education College. “It is also a time well known for rebellion and this can have serious implications as it is not uncommon for teenagers to resist taking medication as a gesture of defiance or even in denial of their condition.

“Psychosocial factors such as school and parental expectations can have an impact on learning: these can be both the cause and a consequence of difficulties. A



Jon Sharpe
Principal of the National Centre for Young People with Epilepsy School and Further Education College

continuing spiral of reduced performance in learning and decreasing self-esteem can be a severe problem,” explains Jon.

Seizures themselves can have a devastating effect: for instance, a child’s memory can be adversely affected by tonic-clonic seizures, and absence seizures which may prevent a young person from seeing or hearing what is happening in his/her class. Children may also suffer from missing school for medical appointments or recovering from seizures, and some common medications’ side effects include drowsiness, inattention and restlessness.

In many cases, epilepsy is combined with other neurological conditions or developmental disorders that can affect learning. These may include autistic spectrum conditions, attention deficit hyperactivity disorder, learning difficulties and disabilities in addition to developmental delay. Repeated seizures can have a drastic effect on the development of the brain.

It is essential that difficulties are identified at the earliest possible stage so that a management plan can be put in place, which will involve the school and parents working in partnership. It is important to include the school in raising awareness of epilepsy generally: in many schools the standard response to a seizure is to call the emergency services which in many cases is unnecessary and may result in emergency hospital admission, meaning the child missing more time from school.

The NYCPE’s Champions for Childhood Epilepsy campaign can help schools meet the challenges of educating students with epilepsy: schools join the campaign by nominating a member of staff to become their School Epilepsy Champion and arranging for them to receive training.

“The difference that having expert teaching staff, occupational therapy, physiotherapy and the onsite medical team at college has made is phenomenal – there’s been a definite improvement”, say Kim and Billy Deville, parents of William, who has epilepsy and attends NYCPE.

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Why you should listen in

The charity Epilepsy Action will host the world’s first ever ‘epilepsy radio day’. The 12-hour live show will be broadcast online during National Epilepsy Week (15–21 May) on Wednesday 18 May

The event will involve a day of radio programmes all about epilepsy, broadcast online. Listeners will be able to listen live, or download the programmes from Epilepsy Action’s website after the event. The programmes will be of interest to anyone affected by epilepsy or wanting to find out more.

“The focus of this year’s National Epilepsy Week is information,” says Aimee Gee, campaigns manager at Epilepsy Action. “This is about making sure people affected by epilepsy have everything they need to make informed decisions about their health and lifestyle. The radio day is a new way of getting this information out. We hope it will help people gain a better understanding of epilepsy and how to deal with it.

“We will be producing all kinds of programmes including a traditional breakfast show full of interviews and chat, as well as more serious programmes on benefits and social care. There will be a live phone-in session with a member of our helpline team and a look at health services for people with epilepsy.

To listen to Epilepsy Action Radio, or for more information, visit www.epilepsy.org.uk/radio

EMILY DAVIES

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How will David Lewis help you reach your potential?

The David Lewis School & College is part of our inspirational organisation based in Cheshire. It offers a unique specialist education service for people aged 14 -25, with complex needs, epilepsy, autism and other neurological conditions.

At the David Lewis School :

- Whether you are a full or part time; day or residential learner, you will follow the City and Guilds Personal Progress Foundation Learning programme, which offers increased choice and flexibility on your journey to an independent life.
- Our unique residential assessment service focuses on the young person's epilepsy, learning difficulty and behaviour, through analytics and medical review.
- Our team of specialists in Paediatric Neurology, Child and Adolescent Psychiatry, Speech and Language and Psychology will identify bespoke programmes of support. Assessments can extend from 6 weeks to 6 months.

" Outstanding care, guidance and support enables pupils to reach challenging targets, resulting in the achievement of outstanding personal development and well- being." Ofsted

At the David Lewis College :

- Our curriculum is inspired by choice and individualised programmes of learning, support people to achieve their goals.
- Our commitment and passion enables our learners to make the optimum transition into adult life.
 - Communication is at the heart of the curriculum, with ICT, work related learning, physical education and therapies integrated into the programmes.
 - Our quality residential homes range from a highly supported environment to one which promotes increasing levels of independence. Our excellent facilities promote a rich and varied learning experience.

"I enjoy coming to college and all of my timetable" Andrew, learner

Adult Education- Footsteps :

- Our vibrant social enterprises offer excellent vocational, training and real work opportunities for people all year round.
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" I've never had these chances before. The work I do is important to me." Neil, Footsteps



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NEWS

TIP

2

FIND OUT
WHAT WORKS
FOR YOU

Question: If a first attempt at medication does not help, what should be done next?

Answer: There are several treatment options of proven safety and efficacy that provide good alternatives to medication in children and adults

THE IMPORTANCE OF KNOWING WHAT'S NEXT

■ In children and adults with medically intractable epilepsy (epilepsy not controlled by adequate trial of appropriate two first-line anticonvulsants) alternative treatment must be considered, says Dr Sunny Philip, consultant paediatric neurologist and honorary senior lecturer at Birmingham Children's Hospital. "Pharmacoresistant patients have a greater risk of SUDEP (sudden unexplained death in epilepsy) than patients whose epilepsy is well controlled; they are at greater risk of mood disorders, have higher depression rates and negative effects of seizures on the development of children."

"The alternate treatment modalities are — epilepsy surgery, ketogenic diet, vagal nerve stimu-

lation: safety and efficacy of these treatments are well established. Every child or adult with medically intractable epilepsy must be assessed for suitability for these. These must not be viewed as a last option but be considered early when medical intractability is established," he says.

The ketogenic diet is a high fat, adequate protein, low carbohydrate diet designed to mimic many of the biochemical changes associated with prolonged starvation. In 30 per cent put on the



Dr Imad Soryal,
Consultant
Neurologist at
University Hospital
Birmingham NHS
Foundation Trust

diet, seizures are well controlled and another 30 per cent have a significant reduction of seizures. The availability of different types of ketogenic diets has made the diet easier to give and more acceptable.

"Vagal nerve stimulation (VNS) involves a neuroprosthetic implant under the skin below the collarbone on the left. It is connected to, and stimulates, the left vagal nerve by an automatic program: it is effective in reducing seizure frequency and severity by 50 per cent in one third of the patients implanted. It takes six months to one year for it to be effective, which is then generally maintained. The device can be activated externally by a handheld magnet allowing it to be

used as a boost just before or during a seizure to try and reduce the impact of the seizure," explains Dr Philip.

"The level of awareness about non-medical treatment is quite low among patient groups — it is of high importance that patients are aware of alternative medical treatment, particularly as we hope that patients will have more of a say in the choice they make about adopting different modalities of treatment and understanding the advantages and disadvantages of each," says Dr Imad Soryal, Consultant Neurologist at University Hospital Birmingham NHS Foundation Trust.

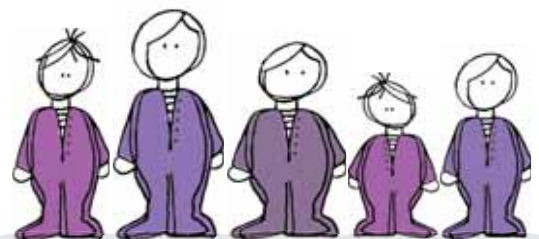
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Nutricia. Making the Ketogenic diet a little easier.

For many years Nutricia has offered products to provide dietitians and carers with the ideal nutritional formulae to manage patients with intractable epilepsy on the ketogenic diet.

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MANAGING YOUR DIET
 A controlled ketogenic diet is one non-medical way of managing epilepsy. However, it must be supervised by the relevant professional
 PHOTOS: SHUTTERSTOCK



THE KETOGENIC DIET



Gwyneth Magrath
 Paediatric specialist dietitian

The four ketogenic diets

- The Classical Ketogenic Diet
- The Medium Chain Triglyceride Ketogenic Diet
- The Modified Atkins Diet
- The Low Glycaemic Index Treatment

➤ This offers some choice: the last 2 listed are slightly more relaxed but not appropriate for all age groups. The choice of diet used should be made on clinical grounds by the team in charge.

➤ All are high in fat and have a very restricted amount of carbohydrate in most instances provided by small amounts of fruits and vegetables. There can be no sweets, cakes and sweetened fizzy drinks.

➤ These diets only work if strictly adhered to and are only safe if supervised by a paediatric neurologist and a registered paediatric dietitian who has had training in these diet treatments.



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 26th March

Our Services include:

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- Starter packs (inc Scales)
- Information Home files for all patients



NEWS



How we coped — and thrive

■ **Question:** What are the extra concerns that epilepsy can bring for many women?

■ **Answer:** The combination of life events, such as pregnancy, and various hormonal changes throughout a woman's life can introduce an additional element of anxiety

Nicola Schafer, 37, has had epilepsy for seven years; she has two young children. "I was worried about the higher risk of major birth malformations that comes with having epilepsy and taking anti-epilepsy drugs (AEDs) during pregnancy," Nicola explains. "My risk was around triple that for a 'normal' pregnancy — although only a small percentage, it was scary."

Nicola's other concern was having a seizure during the birth; she was assured that she would be on a high-risk ward, with additional medication where necessary.

When she fell pregnant with Oliver, now three, Nicola's seizures were initially under control but she soon started having more seizures, due to the way her body was dealing with the medication differently.

Her dose was increased, to no avail. "In the third trimester I started taking a second AED which worked. Taking two drugs from the beginning would have



FAMILY TIME. Nicola advises others with epilepsy to go ahead and have children as the reward is worth it

PHOTO: NICOLA SCHAFFER

been even riskier as the key time is the first trimester when the baby's spine and major organs are formed. As it was, I already found

it worrying, with all the seizures and medication.

"It was also frustrating that we could only make an educated

guess on the best course of action as there is very little data. The Epilepsy Pregnancy Register monitors the results for pregnancies — it is important to register while you are pregnant.

"The way I coped was to try not to think too much: I knew that we were making the best decisions we could and that I had excellent medical care.

"My second pregnancy with Eleanor, almost 2, was completely different. I had changed to a different medication, with better statistics; I didn't have any seizures during pregnancy and I didn't have to increase the dose. I didn't worry anything like as much."

To other women with epilepsy considering pregnancy, Nicola says simply — "Go for it". "The risks are higher but the support is there — make sure you are assertive in getting it. Register with the Epilepsy Pregnancy Register to help other women and their neurologists make better, informed choices. And keep the end game in sight — being a mum is hard work but so worth it."

For further detail on women with epilepsy on pregnancy and motherhood visit: www.epilepsy.org.uk/info/women/having-baby/pregnancy-diaries

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FACTS

■ **Some women** tend to have seizures around their periods. If you think this is the case for you, keep a note of the dates of your period and when you have seizures. Your doctor may be able to give you some treatment to help.

■ **Some medicines** for epilepsy can make some types of contraception work less well, while some types of contraception can interfere with

epilepsy medicines.

■ **If you are** going through the menopause your epilepsy could change. If you notice a difference, talk to your doctor or nurse. You could be at risk of developing brittle or softening bones. Some epilepsy medicines increase this risk. Treatment is available — so ask your doctor or nurse if they think you are likely to be at risk.

SOURCE: EPILEPSY ACTION

epilepsy society

A full life for everyone affected by epilepsy



Concerned about epilepsy?
Are you or someone close to you experiencing seizures, newly diagnosed or needing some support?

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epilepsy



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Ways we can support you

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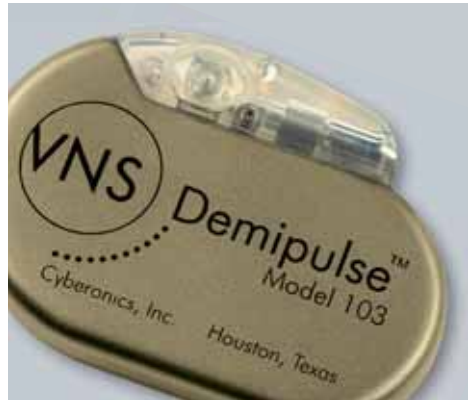
helpline

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www.epilepsysociety.org.uk

Epilepsy Society is the working name for The National Society for Epilepsy
Registered charity number 206186



VAGUS NERVE STIMULATION

EUROPEAN INDICATION FOR USE:The VNS Therapy System is indicated for use as an adjunctive therapy in reducing the frequency of seizures in patients whose epileptic disorder is dominated by partial seizures (with or without secondary generalisation) or generalised seizures, which are refractory to antiepileptic medications.

CONTRAINDICATIONS:The VNS Therapy System cannot be used in patients after a bilateral or left cervical vagotomy. Do not use short-wave diathermy, microwave diathermy, or therapeutic ultrasound diathermy on patients implanted with the VNS Therapy System. Diagnostic ultrasound is not included in this contraindication.

WARNINGS: Physicians should inform patients about all potential risks and adverse events discussed in the VNS Therapy System Physician's Manual including information that VNS Therapy may not be a cure for epilepsy. Since seizures may occur unexpectedly, patients should consult with a physician before engaging in unsupervised activities, such as driving, swimming and bathing, or in strenuous sports that could harm them or others. Patients who have pre-existing swallowing, cardiac or respiratory difficulties (including, but not limited to, obstructive sleep apnea and chronic pulmonary disease) should discuss with their physicians whether VNS Therapy is appropriate for them since there is the possibility that stimulation might worsen their condition. The VNS Therapy System may affect other medical devices and other medical devices may affect the VNS Therapy System. MRI can be safely performed; however, special equipment must be used.

ADVERSE EVENTS:The most common reported side effects from stimulation include hoarseness, paresthesia (prickling feeling in the skin), dyspnea (shortness of breath) and increased coughing. The most common reported side effect from implant surgery is infection.

REFERENCES: Morris G.L. et al. *Neurology* 1999; 53(7):1731-1735 • Tatum W.O. et al. *Neurology* 2001; 56(4):561-563 • VNS Therapy Patients Registry, April 25, 2003. Data on file, Cyberonics, Inc. Houston, Tex. • Fromes G.A. et al. *Epilepsia* 2000; 41(7):117

A small change can make a big difference

I spent years seeking an effective treatment for my epilepsy. Together with my doctor we have been struggling to find the best combination of drugs. However, despite trying many different types of medication, I always felt a sense of disappointment until my doctor introduced me to VNS Therapy.

Once the VNS Therapy device was implanted, I began to notice that my seizures were decreasing both in terms of frequency and intensity. Now I feel more alert, more confident and more independent. Put simply, I can now go out and do things that I could only dream of doing before VNS Therapy.

The reality is that VNS Therapy has enabled me to enjoy those little things in life that most people take for granted. And this means that epilepsy no longer controls my life as it previously did – now I control my life.

**Ask your doctor about VNS Therapy.
It could be the first step towards a better life.**

This is the experience of one individual who tried VNS Therapy. Similar results cannot be guaranteed for other patients using this treatment.

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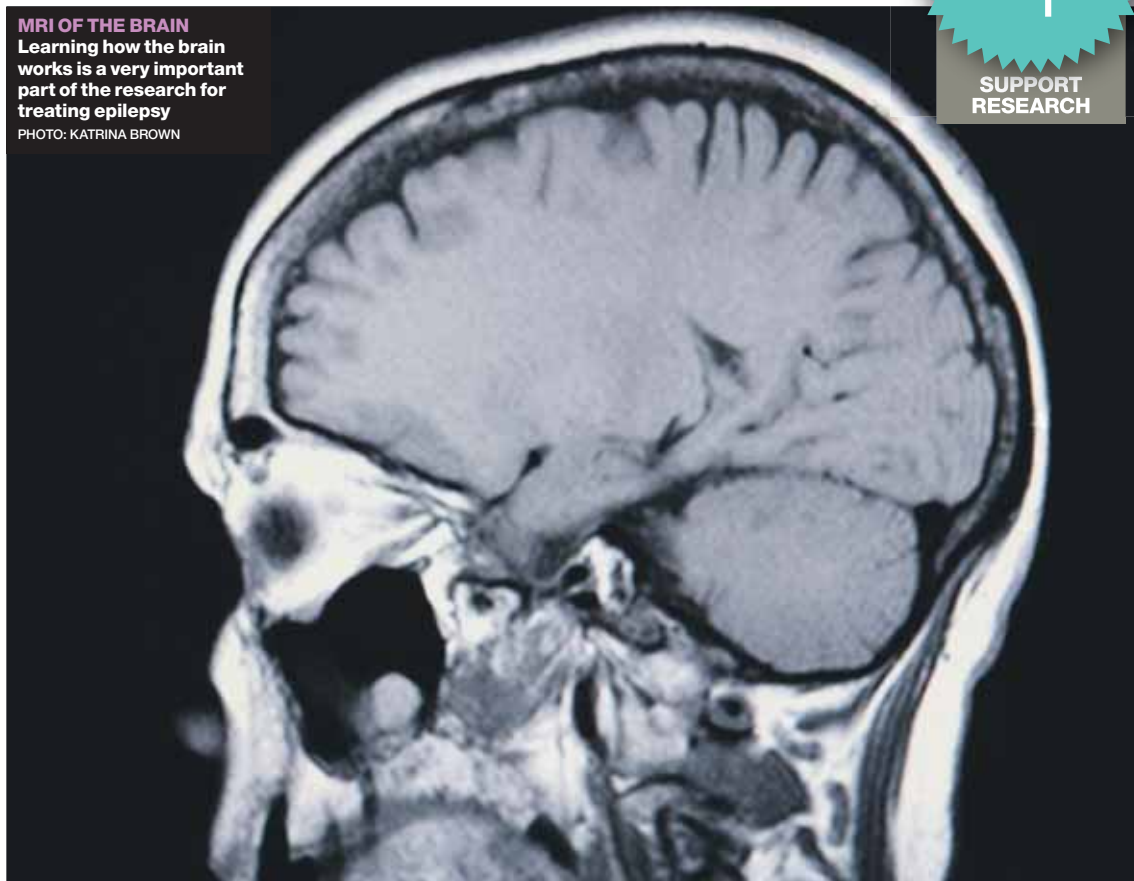
NEWS

TIP

4

SUPPORT
RESEARCH

MRI OF THE BRAIN
Learning how the brain works is a very important part of the research for treating epilepsy
PHOTO: KATRINA BROWN



Jane Hanna OBE
Director, Epilepsy Bereaved

What is SUDEP?

Sudden Unexpected Death in Epilepsy (SUDEP) is uncommon but is a recognised syndrome about which there should be more awareness

Sudden Unexpected Death in Epilepsy (SUDEP) is when a person with a history of epilepsy or seizures dies suddenly and prematurely and no other cause of death is found. SUDEP is associated with seizures but its exact cause remains unknown. The most likely explanation is that a seizure interferes with the part of the brain that controls breathing or the heart.

Given the many different types of epilepsy, the risk of SUDEP will vary (about 1:1,000 people with epilepsy or less) and is rarer in children.

Nevertheless, SUDEP accounts for at least 500 of over 1,000 epilepsy-related deaths each year in the UK.

Decreasing risk, increasing knowledge

Research this year from the SUDEP Research Initiative shows that lives could be saved if we were to unlock the cultural and service barriers that hinder doctors in the community identifying people at risk. We know that many doctors report that they do not discuss risk of SUDEP; attitudes towards epilepsy may in part be responsible for the lack of attention to addressing epilepsy mortality.

That deaths in people with epilepsy appear to be rising when death rates have fallen for other conditions highlights the urgency for ongoing research. Research in development includes new monitoring devices which alert to potentially fatal seizures.

For more information visit:
www.sudep.org

The future is brighter

■ **Question:** What do research and development suggest for epilepsy treatment and knowledge in the years ahead?

■ **Answer:** Advances are being made that will enable both better understanding of epilepsy and more effective treatment

A particular focus of current research is the applications of imaging, of brain structure and function, to show physical abnormalities and disturbances of function in the brain that may indicate the causes of epilepsy, that differ from one person to the next, explains Professor John Duncan, Medical Director of the Epilepsy Society and Professor of Neurology at the Institute of Neurology, University College London.

The Epilepsy Society works on research in collaboration with the Department of Clinical & Experimental Epilepsy (DCEE) of the Institute of Neurology UCL, and the National Hospital for Neurology and Neurosurgery.

One example is the development of the use of the MRI scanner to visualise the site in the brain of cru-



Professor John Duncan
Medical Director of the Epilepsy Society

cial functions, such as language and memory. This is very important when trying to determine the effects of brain surgery, and to understand the effects of epilepsy on brain functions. This method can predict, for individual patients, the likely effects of temporal lobe surgery on their memory, says Professor Duncan.

Imaging is also helping researchers understand the relationship between the progression of

R & D

■ **Key areas** of research and development in the field of epilepsy currently include imaging, genetics, pharmacology and epidemiology. The hope is to gain a greater understanding of epilepsy and in doing so, enable better diagnosis, care and treatment for all.

epilepsy and structural changes in the brain and to increase our understanding of the underlying cellular mechanisms, and to develop methods to examine the connections in the brain that are necessary for vital functions to be carried out. We are now beginning to use this information to reduce the risk of neurosurgery.

Other strong points of interest include genetics — the causes of epilepsy and the genetic differences between people that affect how drugs work — as well as the development of miniaturised electronic devices to monitor breathing and circulation so that serious seizures may be detected early, if a person is alone, and help summoned.

“These advances will help improve our understanding of the causes of epilepsy, and will improve treatment because it will lead to specific treatments that are individualised for each person, so that each person may be offered the best treatment right at the outset,” explains Professor Duncan.

EMILY DAVIES

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DRAVET Syndrome UK has 3 aims:

- 1) To fund medical research into Dravet Syndrome and other related genetic sodium channel epilepsies
- 2) To raise awareness of Dravet Syndrome, and other related genetic sodium channel epilepsies
- 3) To support families affected by Dravet Syndrome, and other related genetic sodium channel epilepsies, emotionally, practically and financially

At this moment in time there is no cure for Dravet Syndrome and precious children are being lost to this catastrophic condition. DRAVET Syndrome UK are members of the JEC and work alongside other epilepsy charities and organisations both in the UK and worldwide to find that cure, while improving the lives of those affected along the way.

To Donate visit

www.justgiving.com/dravetsyndromeuk or for more information visit our website www.dravet.org.uk

PERSONAL INSIGHT

Paul Maynard is the Conservative MP for Blackpool North and Cleveleys. He has had epilepsy most of his adult life, as a result of the cerebral palsy he was born with. He is the **first MP to talk openly about his epilepsy**. He is now an honorary vice-president of Epilepsy Action

The secret of my success

“I was around 22 when I was diagnosed with epilepsy. When I graduated from university and moved to London, I discovered I was throwing myself out of my bed. I was living alone and waking up in a very disoriented state sometimes; I wasn't sure what had happened.

Eventually I went to the GP, who straight away twigged what it might be, so we got it diagnosed. It was quite a shock, I must say. I thought epilepsy was what happened to other people. How could I possibly have epilepsy? But I had. And I had to deal with it — so I did.

Gradually, over time, I learned about the condition and the importance of self-management, keeping to medication regimes, eating well, not getting overly stressed — although politics is not the best career for that! Gradually I worked out how to manage my own condition. It takes quite a while, and I'm still doing it in some ways.

Now the epilepsy is part of who

I am, like the cerebral palsy that caused it. You make your own decisions about what you can and cannot do and who you are. In a way, it's never been an obstacle for me, although it may have been an obstacle for other people in terms of how they dealt with me — but that's their problem not mine. I just get on and do what I want to do.

I do feel a certain responsibility that there are groups of people whose voices aren't heard in the political sphere as they should be and that I've got an opportunity to be heard. While I don't want to be pigeon-holed by it, I don't equally feel that I can say, 'I do have cerebral palsy and I do have epilepsy, but I'm not talking about it in Parliament.' Because somebody has to. I want to stand up and say, 'Look — here I am.' I'm the first MP who went to a special school. I'm the second MP to have cerebral palsy. There are two MPs — including myself — who have epilepsy.

You hope that you'll never have a seizure in Parliament, but it doesn't

BREAKING THE STIGMA

“I think that one of the important parts of being an MP is being able to talk about yourself”



Paul Maynard
Conservative MP for
Blackpool North and Cleveleys

worry me. I think that one of the important parts of being an MP is being able to talk about yourself. Partly to make politicians seem a bit more human — but perhaps it also aids understanding. Many people don't understand epilepsy; they're very nervous about it.

The key thing I want to change is to de-stigmatise epilepsy. I think we are a large part of the way there, but when I do encounter ignorance, it still astounds me and it makes me realise that a lot of the ignorance is hidden and isn't really vocalised.

It's also vital to make sure that the information is there when people need it — when people are diagnosed they need to be helped to understand what they have been diagnosed with, particularly when it comes suddenly. I don't feel I was given enough information. Not everybody wants to know everything; but I think they should have access and know it's there if they want it.”

*Based on an original interview by Peter Fox, editor of Epilepsy Action's *Epilepsy Today* magazine



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