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Understanding the Brain

HEALTHAWARENESS.CO.UK

PHOTO: 'Sunset of hope'
Liliana Vezetiu (Romania)

"My goal is to travel as much as I can. Even though I have multiple sclerosis and travel difficulties, I like to spend a lot of time in nature, to watch the sunset and to enjoy every moment. I am in this photo and it was made by my husband in Ramnicu Valcea, Romania."

This photo is from the competition #BrainLifeGoals
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'Girlfriends for Life'

Karin's best friend Aischa has MS, but despite the disability they are a heart and a soul.

#LIFEGOALS vs. #BRAINLIFEGOALS

Sharing #LifeGoals has become a popular trend in social media. These #LifeGoals are often frivolous wishes like living in a beach hut in the Bahamas, driving a Maserati or buying a ridiculously expensive designer handbag! So, what are #BrainLifeGoals?

WRITTEN BY:
DONNA WALSH
Executive Director,
European Federation of Neurological Associations

The European Federation of Neurological Associations [EFNA] has put a new spin on this trend by asking the community of people living with neurological disorders to share their life goals: #BrainLifeGoals.

Many of those affected by neurological disorders have joined the conservation to highlight fundamental goals that they are striving towards.

Goals have included: riding a bike again, driving a car without pain, being a more active parent, staying at work full-time, or just having society understand.

"Things many of us take for granted are just dreams for those living with neurological disorders" says Donna Walsh, EFNA Executive Director.

"This campaign is about collecting these dreams but then taking them to our politicians, doctors, researchers and wider society to make them understand how we can and should be helping those affected.

"Many patients will live for many years – sometimes a lifetime – with these debilitating conditions, so we really need to focus on quality of life and on what we can do that will make a real difference."

The campaign, which has been running for over a year, has also extended its reach beyond social media.

EFNA provided grants to eight patient organisations across Europe – covering ADHD, Parkinson's, stroke, myalgic encephalomyelitis (ME), cavernoma and restless legs syndrome – to develop disease-specific or national awareness raising initiatives.

The campaign has also been taken to medical congresses, policy forums and advocacy meetings as a key tool in raising awareness and advocating for the needs of those living with neurological disorders. ■

Get involved

To celebrate Brain Awareness Week, why not join the conversation? Search for and use #BrainLifeGoals on Twitter, Facebook or Instagram.

About EFNA

The European Federation of Neurological Associations is an umbrella group representing pan-European neurology patient groups. It works in the areas of advocacy, awareness, empowerment and engagement to improve the quality of life of all those living with a neurological disorders in Europe.

www.efna.net

Read more at
healthawareness.co.uk

The silent emergency of brain disorders

The human brain is immensely complex. It is the control centre of our bodies, directly affecting every vital function, ranging from our heartbeats, breathing, food and fluid intake, sleep, emotions and sex.

WRITTEN BY:
FRÉDÉRIC DESTREBECQ
Executive Director,
European Brain Council

A healthy brain is the ultimate prerequisite for quality of life and sustainable wellbeing. 2014 figures indicate that 179 million Europeans live with disorders of the brain. These include both mental and neurological disorders, such as Alzheimer's disease, Parkinson's disease, multiple sclerosis, migraine, depression, schizophrenia, bipolar disorder, eating disorders and addiction. Forty-five million of these cases are in the UK alone. Worryingly, these numbers are increasing steadily.

These statistics, coupled with the estimated yearly cost for management of these diseases (€800 billion or an estimated £670 billion), make the immensity of the problem quite clear.

The latest figures from the UK – published in 2010 – put the cost of brain disorders for the country at €134 billion (£112 billion) per annum. Addressing these major human and financial costs for society requires an intensified research effort and the creation of novel solutions.

However, disorders of the brain and the need for investment into brain research lack the awareness and recognition they are due.

> *"The latest figures from the UK – published in 2010 – put the cost of brain disorders for the country at €134 billion (£112 billion) per annum"*

The brain mission

With an ageing population in Europe, the prevalence of the most common neurological and psychiatric disorders will dramatically increase and we are still striving to find cures or truly effective means of delaying or reducing the burden they place on individuals and society.

It is evident that understanding the brain is a mission on its own. Though commitment to basic neuroscience research has advanced our understanding of the nervous system – as well as the practical and clinical application of this knowledge—the inherent complexity of the nervous system has hampered our translational capacity. This suggests a higher level of understanding is required to efficiently cure brain disorders. Sustained funding is necessary to expand and boost brain research in Europe.

Investing for the future

Timelines for developing medicines and devices required to treat central nervous system (CNS) conditions alone can take up to 18 years (compared to the average 12 years for other drug pipelines).

Decision-makers need to take further steps to improve treatment development by creating an innovation-friendly environment and sustain scientific breakthroughs in the field of brain disorders.

Unprecedented innovation in technology and medical processes is rapidly revolutionising our day-to-day living. Over recent decades, various technologies have emerged that hold the promise of dramatically reshaping the way we deliver healthcare.

Research plays a heavy role in this process, without which progress would be stalled. In business, we look at investment as a means for future capabilities, such as new products, processes, and services. In health research, steady and proportional support is an investment for future capabilities of detection, treatment and life-saving, life-changing tools.

It is clear that we need this situation to change. We need to improve the lives of people living with these life-disrupting disorders. We need robust research, improved care and a society that prioritises the health and wellbeing of all its citizens.

The silent emergency of brain disorders can no longer be allowed to thrive under the radar, as an unbeknownst burden to our societies and to the lives of fellow citizens. ■

References: The size, burden and cost of disorders of the brain in the UK; Naomi A Fineberg, Peter M Haddad, Lewis Carpenter, Brenda Gannon, Rachel Sharpe, Allan H Young, Eileen Joyce, James Rowe, David Wellsted, David J Nutt, Barbara J Sahakian; J Psychopharmacol. 2013 Sep; 27(9): 761-770. doi: 10.1177/0269881113495118

DiLuca, M. & Olesen, J. The Cost of Brain Diseases: A Burden or a Challenge? Neuron 82, 1205–1208 (2014)

Mohs, R. C. & Greig, N. H. Drug discovery and development: Role of basic biological research. Alzheimer's Dement. (New York, N. Y.) 3, 651–657 (2017)

Torjesen, I. Drug development: the journey of a medicine from lab to shelf | Career Feature | Pharmaceutical Journal. The Pharmaceutical Journal Available at: https://www.pharmaceutical-journal.com/publications/tomorrows-pharmacist/drug-development-the-journey-of-a-medicine-from-lab-to-shelf/20068196.article?firstPass=false. (Accessed: 26th February 2019)

Read more at
healthawareness.co.uk

Less stagnation, more innovation — Removing barriers to advancing mental health therapies

There haven't been any major innovations in mental health therapies since the 1990s. Why is progress so slow, and what can we do about it?

WRITTEN BY:
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At any one time, one in six people in England are affected by common mental health disorders, which vary in symptoms, recurrence and severity, and ultimately impact individuals and their communities.[1] Depression, in particular, is a major contributor to the overall burden of disease on individuals, health systems and society.[2]

Addressing the needs of individuals affected by mental health disorders is complex. Mental health inequalities in access, experience and outcomes are often linked with wider cultural and societal systems of disadvantage that affect a person's wellbeing,[3] which means a holistic, patient-centred approach to care is needed. However, medications remain a critical option as part of treatment of mental illness.[4]

The challenges of treating major depressive disorder

A particularly common mental health issue is major depressive disorder (MDD), a severe condition that can have a profound and devastating impact on individuals and their loved ones.[4-6]

MDD carries a significant societal and economic burden in the UK. In 2007, the estimated cost in England alone was £1.7 billion, a number projected to reach £3 billion by 2026.[7,8]

Current pharmacological treatments for MDD target the serotonin pathway, which regulates several processes within the brain including mood, emotions and sleep.[9] Yet, with up to 30% of MDD sufferers failing to respond to these medications, innovative new treatments are sorely needed.[10] There has not been a major treatment breakthrough in psychiatric medicines since the 1990s.

> *"When new treatments and innovations do emerge, there are still barriers to overcome in order to gain access for UK patients"*

What is halting much-needed progress in this area?

Research and development in psychiatric and neurological disorders is notoriously challenging. Issues with recruitment and retention are common in these trials, leading to additional costs and delays.[11] Furthermore, the complexity of the biological processes driving these disorders means that central nervous system (CNS) compounds take longer to develop and have lower success rates than non-CNS treatments. By this point, a pharmaceutical company may have already invested significant costs into developing a new compound.[12] As such, many pharmaceutical companies have stepped away from neuroscience and psychiatry research because of its complexity and risk of failure.[13]

Is this the only issue?

No, when new treatments and innovations do emerge, there are still barriers to overcome in order to gain access for UK patients.

Lack of funding is a huge barrier to innovation. Mental health accounts for 28% of the burden on the NHS, but only 13% of its CCG budget.[14] Funding allocation through block contracts (where providers are paid in advance) presents another issue, as unexpected pressures such as increased patient demand or cost of care are not taken into account. Block contracts have also been critiqued for not incentivising improved clinical care or innovation in this area.[15]

Additionally, the National Institute for Health and Care Excellence (NICE) assesses medicines for the treatment of mental health conditions in the same way as medicines used to treat physical health. This process does not factor in the substantial differences between mental and physical health.

Lastly, UK mental health services remain a long way behind physical health services. This lack of parity of esteem means that patients with MDD may be at a disadvantage in accessing the care they need.[16] Ultimately, these barriers to innovation lead to a lack of clarity and awareness of suitable treatments and create challenges for HCPs, patients and their carers.[6,17]

A unified approach

The NHS Long-Term Plan has outlined its ambition to improve mental health care, yet these proposals must come with adequate resourcing for them to be delivered. [3,16]

True innovation will require a multi-stakeholder approach involving the NHS, the pharmaceutical industry, governmental bodies and academia. The needs of carers and patients should be at the heart of any change, to banish stigma, remove barriers in access, and offer the holistic care that is lacking. ■

References:
1. NHS Digital. (2014) Mental Health and Wellbeing in England: Adult Psychiatric Morbidity Survey. Available at: https://files.digital.nhs.uk/pdf/q/3/mental_health_and_wellbeing_in_england_full_report.pdf. Accessed March 2020.
2. WHO. (2020) Depression. Available at: https://www.who.int/news-room/fact-sheets/detail/depression. Accessed March 2020.
3. NHS. (2019) NHS mental health implementation plan 2019/20 - 2023/24. Available at: https://www.longtermplan.nhs.uk/publication/nhs-mental-health-implementation-plan-2019-20-2023-24/. Accessed March 2020.
4. NICE. (2009) Depression in adults: recognition and management. Available at: https://www.nice.org.uk/guidance/cg90. Accessed March 2020.
5. American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). Arlington, VA: American Psychiatric Publishing.
6. Shah AJ, et al. (2010) Psychological Distress in Carers of People with Mental Disorders. BJMP;3(3):a327.
7. Department of Health. (2011) No health without mental health: a cross-government mental health outcomes strategy for people of all ages. Supporting document –the economic case for improving efficiency and quality in mental health. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/138253/dh_124058.pdf. Accessed March 2020.
8. McCrone P, et al. (2008) Paying the price. The cost of Mental health care in England to 2026. Available at: www.kingsfund.org.uk/sites/default/files/Paying-the-Price-the-cost-of-mental-health-care-England-2026-McCrone-Dhanasiri-Patel-Knapp-Lawton-Smith-Kings-Fund-May-2008_0.pdf. Accessed March 2020.
9. NHS (2020) Overview: Selective serotonin reuptake inhibitors (SSRIs)'. Available at: https://www.nhs.uk/conditions/ssri-antidepressants/. Accessed March 2020.
10. Al-Harbi KS. (2012) Treatment-resistant depression: therapeutic trends, challenges and future directions. Patient Pref Adherence;6:369–388.
11. Liu Y, et al. (2018) Recruitment and retention strategies in mental health trials – A systematic review. PLOS ONE;13(8):e0203127.
12. Tufts. (2012) Pace of CNS drug development and FDA approvals lags other drug classes. Available at: https://csdd.tufts.edu/impact-reports. Accessed March 2020.
13. The New Yorker. (2013) The psychiatric drug crisis. Available at: https://www.newyorker.com/tech/annals-of-technology/the-psychiatric-drug-crisis. Accessed March 2020.
14. BMA. (2018) Lost in transit? Funding for mental health services in England. Available at: https://www.bma.org.uk/collective-voice/policy-and-research/public-and-population-health/mental-health/funding-mental-health-services. Accessed March 2020.
15. BMA. (2018) Models for paying providers: Block contracts. Available at: https://www.bma.org.uk/collective-voice/policy-and-research/nhs-structure-and-delivery/nhs-structures-and-integration/models-for-paying-providers/block-contracts. Accessed March 2020.
16. BMA. (2020) Beyond parity of esteem report. Available at: https://www.bma.org.uk/collective-voice/policy-and-research/public-and-population-health/mental-health/beyond-parity-of-esteem-report. Accessed March 2020.
17. Ramanuj P, et al. (2019) Depression in primary care: part 2—management. BMJ;365:l1835.

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We're on the cusp of stopping MS

WRITTEN BY:
DR SUSAN KOHLHAAS
Director of Research and External Affairs, MS Society

With 130 people diagnosed in the UK each week, MS remains a devastating blow. But research has got us to a critical point, and the future could look very different.

Twenty-five years ago, a multiple sclerosis (MS) diagnosis was even more terrifying than it is today. With no treatment available on the NHS, it meant going through life not knowing if you'd wake up with numb legs or a loss of vision, or what else might be around the corner. For many people, these episodes led to a decline in their body's ability to perform basic functions like walking, speaking, and eating.

Today, however, if you live with relapsing MS – where symptoms come and go – there are over a dozen licensed treatments. Relapses happen when the immune system mistakenly attacks myelin – the protective coating around our nerves. But in just two decades, we've learnt how to stop this from happening as often. And yet, people with MS still face a scary and uncertain future.

Until recently, we had no idea how to stop MS decline. Although preventing immune attacks helps keep myelin intact, it doesn't repair the damage from attacks that do happen, and it doesn't stop nerve cells from dying off in the progressive phase of the condition. And when a nerve is destroyed, there's no way to bring it back. We desperately need to find a way to protect nerves and repair damaged myelin.

Unlocking existing drugs' potential

Recent scientific breakthroughs give us reason to hope, and we now know myelin repair happens naturally in the brain. In MS, there's a problem with that natural process, so scientists have been trying to get it working properly again.

Using brain tissue from our MS Society Tissue Bank at Imperial College London – which allows people to donate their brain and spinal cord tissue for MS research after their death – they found a drug originally used to treat skin cancer could stimulate a molecule partially responsible for promoting myelin repair.

At the MS Society Cambridge Centre for Myelin Repair, researchers have also discovered that a certain

> *"Recent scientific breakthroughs give us reason to hope, and we now know myelin repair happens naturally in the brain"*

diabetes drug can trick older myelin-making cells in rats into behaving like younger, more efficient cells.

And it's not just in the lab; over 750 people are already taking part in one of the largest ever trials for MS progression. MS STAT2, funded by a partnership between the MS Society, the National Institute for Health Research, the National MS Society (in the USA) and sponsored by University College London, is testing whether a common cholesterol-lowering drug slows progression, by protecting nerves.

A new type of trial

While progress has been accelerating, for people with MS it still feels agonisingly slow. It takes years to go from a discovery in the lab to demonstrating that a treatment is safe and effective: our challenge is to speed this up.

We've been working on new ways to test potential treatments much more quickly. The MS-SMART trial showed it was possible to test three drugs in a single trial – the first time this has been attempted for a progressive neurological condition. While none of these drugs slowed progression, MS-SMART gave us both the tools and momentum to transform how we run clinical trials. Our ambition is to launch a trial with multiple drugs and also multiple stages. Instead of stopping and starting separate trials, we'll have a programme that adapts with each new discovery.

What the next decade holds

We can see a future where nobody needs to worry about MS getting worse. By 2025, we plan to be in the final stages of testing a range of treatments for everyone with MS. Some of the best minds in the country are working together to make it happen, drawn to an area of research with so much excitement. There's still a long way to go but, for the first time, there's genuine hope that we can stop MS. ■

Get involved

Donate today to the Stop MS Appeal and help find treatments for everyone with MS.

Visit **mssociety.org.uk/stop** or text FUTURE6 to 70800 to donate £5.

Messages cost £5 plus your standard network rate. 100% of your donation will be received by the MS Society.

Jacqueline Krarup and her family pictured after celebrating her son finishing the London Marathon to raise money for MS Society

MS research could change lives like mine

Jacqueline Krarup is one of over 130,000 people living with MS in the UK. She explains why research is so important to her, and why she believes MS can be stopped.

When I woke up one morning in 2008, with double vision, I brushed it off as a problem with my glasses' prescription. But, after a visit to the optician and a referral to a neurologist, I soon realised it was something more serious.

A brain scan revealed areas of scarring on my brain known as lesions – an instantly recognisable feature of MS.

Looking back now, I know I'd experienced my first symptoms almost 20 years earlier when I woke up with numbness down one side of my body. But at the time I was working in a demanding job, and didn't really give it much thought.

For the first few years after my diagnosis I experienced niggling symptoms, but was adamant I was going to carry on as normal – I didn't want to make a fuss. But recently MS has become harder to ignore. About five years ago, I began to have difficulties with my mobility and cognitive processing. Since then, MS has crept in slowly but surely, and I'm able to do less than I used to.

Living with my glass half-full

Around the time I was diagnosed, my sister Yolanda began asking how my first symptoms had felt, and was soon diagnosed with the primary progressive form of MS. What followed was, for her, a very quick downward spiral where she suffered terribly with her fatigue and mobility. She lives over 130 miles away, but we talk every day – about our MS and how we're dealing with it, but everything else too! We support each other completely.

We both try to live with our glasses half-full, and are incredibly fortunate to have strong support networks. My husband and children are fantastic. My son even ran the London Marathon to raise money for the MS Society, and appeared alongside me in their TV advert!

With the family's help I've taken steps to look after myself. I stopped working, try to eat a healthy diet and get enough rest. I led a very active life before MS, so still try to get out when I can. I'm looking forward to using my new all-terrain mobility scooter – a Christmas present to myself – when the weather is better!

My hopes for the future

When I was first diagnosed there were very few MS treatments. Now, thanks to research, people living with relapsing MS have a range of options that can help. Sadly, the treatments available for progressive types of MS are still very limited, and there are still thousands of people – like my sister and me – without any treatment at all.

> *"There are still thousands of people – like my sister and me – without any treatment at all"*

Excitingly, research has reached a critical point. We've seen unprecedented success in finding treatments for people with relapsing forms of MS, and I'm optimistic that with the right research we might one day see the same transformation for progressive MS.

For me, getting involved in MS research helps me stay positive about the future. I've been fortunate to be part of a group of volunteers with the MS Society who help decide which research projects are a priority to fund. This gives me the opportunity to hear first-hand about the fascinating work researchers are doing to help stop MS. I'm even taking part in a clinical trial myself, testing whether a drug normally used to treat high cholesterol could work as a treatment for secondary progressive MS.

I'm realistic with my expectations, but think the next few years will be massively exciting, and I firmly believe that researchers will find treatments for progressive MS. Donations to the likes of the MS Society's Stop MS Appeal will drive forward that life-changing work and take it to the next stage. While it may not mean a cure for Yolanda and me, I'm confident that research happening today will help confine MS to the history books. ■

Read more at **healthawareness.co.uk**

Left: Nina with her family. In Uganda, epilepsy is thought – among other things – to be a curse on the family.

Dealing with the myths and stigma attached to epilepsy

When Nina Mago was a toddler, she would sometimes run to one of her parents and hug them tightly around the legs. They assumed she was frightened or just being affectionate, but in hindsight, it's likely that Nina was having a seizure and needed something to hold onto.

INTERVIEW WITH:
NINA MAGO
Epilepsy Advocate, Uganda

At first, doctors in Uganda told Anita that the birthmark on Nina's face was the problem: They said it was affecting her brain. "Not understanding what your child is suffering from is very stressful," said her mother, Anita. "It caused a lot of anxiety."

When Nina was six years old, the family moved to Moscow for her father's job. There, she was diagnosed with epilepsy. She was taking medicine, but still having seizures; however, her teachers and fellow students understood and accepted her condition. They took care of her.

My friends in Moscow made me feel normal

Her best friend tried to visit whenever Nina had a seizure in school and ended up in a cot in the nurse's office. "If I was still asleep when she came, she would put her watch on my wrist so that I would know she'd been there," Nina said. Even though Nina really didn't understand what happened when she had a seizure, she had friends and felt like a normal kid.

In Uganda, some people thought I was possessed

Seven years later, when the family returned to Uganda, Nina lost her support system. She was bullied because of her epilepsy and forced to change schools multiple times. Teachers were afraid of her, too.

In Uganda, epilepsy is considered to have supernatural causes. It's said to be the result of a curse on the family, or a demonic possession. There's also a widespread belief that epilepsy is contagious, so people may drown or receive third-degree burns while having a seizure because bystanders refuse to touch them.

Nina shared her memories with the Epilepsy Foundation of America: "I would wake up [at school] on a dusty floor, wounded and disoriented, while children made a spectacle of me through the window. Not being able to run to someone older for safety and not waking up in the comfort of my teacher marked the beginning of a very scary new world; one that I was not ready for at the time.

I was constantly bullied and always made fun of, always! The terror of exposure keeps one burdened by secrecy. It brings you face to face with loneliness, discrimination, and stigmatisation, and drowns you in depression."

I became the role model that I needed as a child

Despite the bullying, Nina made it through school and earned a college degree in 2011. She's now seizure-free.

Nina and her mother started the Purple Bench Initiative, a nonprofit that supports people with epilepsy and their caregivers, and does outreach to schools, colleges and Rotary clubs.

The group has a presence on Facebook and Twitter, sharing information about epilepsy and encouraging people to share their stories. "I kept waiting to meet someone who was speaking out about epilepsy and talking about what it is, offering hope to people," Nina said. "That did not happen – so I decided to be that person." ■

Epilepsy: the common disease that's still in the shadows

Epilepsy affects more than 50 million people worldwide—but most of them aren't receiving treatment. Why?

WRITTEN BY:
SAMUEL WIEBE
President,
International League Against Epilepsy

Epilepsy seizures are caused by abnormal electrical signaling in the brain. Most people probably think of a seizure as jerking or thrashing, but there are other types too. Some look like the person is 'spacing out'; during other types, people may see or hear things that aren't there, scream or make other noises, or collapse on the ground. When someone has a seizure, they usually don't know what's going on around them.

Worldwide, most people with epilepsy are not getting the treatment they need

Two-thirds of people with epilepsy can avoid all or most of their seizures by taking daily medicines. Others may be able to have brain surgery, follow a special diet, or receive other therapies. Treatment gives people the chance to lead full, productive lives.

Unfortunately, of the 50 million people with epilepsy worldwide, more than 30 million are not being treated. The 'treatment gap' in low- and middle-income countries is estimated at about 75% (so three-quarters of people don't get treatment), but in some areas of Africa and Asia, it exceeds 90%.

This treatment gap exists for a few reasons. One is a lack of awareness and understanding of epilepsy. Some cultures don't view epilepsy as a medical condition; they believe that it has a spiritual or supernatural cause, and will visit traditional healers, rather than medical personnel.

Historically, people with epilepsy were often discriminated against. Even today they can be targets of bias and human-rights violations. Some countries even accept epilepsy as a valid reason for divorce or marriage annulment.

> *"About two-thirds of people can avoid seizures by taking medicines. Unfortunately, of the 50 million people with epilepsy, more than 30 million are not being treated"*

The name of the disease itself can be demeaning; for example, in some Asian countries, the term for 'epilepsy' translates to something like 'mad pig disease.'

This stigma and discrimination are frightening. People isolate themselves and keep their epilepsy a secret.

Even in countries where treatment is readily available, the death rate in people with epilepsy is twice as high as in the general population. In regions with large treatment gaps, as many as 20% of people with epilepsy will die prematurely, mostly from seizure-related drowning or injuries. Some also die from suicide; suicide risk is two to five times higher in people with epilepsy.

Some people have little to no access to epilepsy treatments

There are more than 25 anti-seizure medicines; some cost as little as $5 US per person, per year. But they are not available in some countries. Others have inconsistent supplies. Many people with epilepsy can have trouble finding enough money to pay for medication – especially if seizures leave them unable to work.

Access to healthcare is another barrier. Neurologists usually diagnose epilepsy and coordinate care, but in many areas, there aren't enough of these doctors.

Everything is connected. Fear and stigma can keep people from seeking medical treatment or talking about epilepsy. Therefore, governmental bodies may not know that epilepsy is important, so medicines and medical training are not a priority.

Let's bring epilepsy out of the shadows, for everyone's sake

Epilepsy is mostly invisible, unless someone is having a seizure. Within the field, we often talk about 'coming out of the shadows.' We want to erase the stigma so that people who have seizures don't feel ashamed or afraid, and so that everyone can understand how epilepsy affects people's lives. Many people with epilepsy and their families have come out of the shadows, but they need support. The public, healthcare professionals, the media, schools—every part of each community has a role in improving epilepsy awareness and breaking down barriers to treatment. Together, we can work toward a world where no person's life is limited by their seizures. ■

Read more at
healthawareness.co.uk

Why epilepsy is about more than coping with seizures

Epilepsy can cause seizures and developmental problems, and may not respond to medication. Yet those with a drug-resistant form of the condition still have treatment options.

INTERVIEW WITH:
MR MICHAEL CARTER
Consultant Paediatric Neurosurgeon, Bristol Royal Hospital for Children

INTERVIEW WITH:
DR ANDREW MALLICK
Consultant Paediatric Neurologist, Bristol Royal Hospital for Children

Epilepsy — a serious neurological condition that can cause seizures — affects around 600,000 people in the UK and is a surprisingly common childhood disorder.

"Thankfully, the majority of children will be able to control their epilepsy with medication," says Dr Andrew Mallick, Consultant Paediatric Neurologist at the Bristol Royal Hospital for Children. "But a proportion of them will be drug-resistant — which means medication won't control their condition." In fact, drug-resistant epilepsy (DRE) affects around 30% of the epilepsy population.

"Poorly controlled seizures are a major problem for a number of reasons," explains Mr Michael Carter, Consultant Paediatric Neurosurgeon at Bristol Royal Hospital for Children. "One of which is a phenomenon called SUDEP – or Sudden Unexpected Death in Epilepsy – which is a significant risk for those with uncontrolled seizures," he says.

Yet seizures aren't the only concerning aspect of epilepsy, because it can also cause psychological, educational, emotional, behavioural, social and development issues. "This is why we say that epilepsy doesn't just affect the patient..." says Mr Carter, "it affects entire families. If you're living with a child who has epilepsy, you're completely focused on dealing with them and the risks and issues associated with their condition."

Early treatment options for the best results

There is, however, hope for those with DRE. If medicine doesn't work, brain surgery (to either remove or disconnect an area of brain acting as a seizure source) may either reduce the frequency of seizures or stop them altogether.

Patients with DRE who are unsuitable for brain surgery may benefit from VNS (vagus nerve stimulation) therapy, where a pacemaker-like device sends mild pulses to the vagus nerve at regular intervals throughout the day in an effort to stop seizures before they start.

The VNS device is implanted under the skin of the chest during a procedure which usually takes an hour-and-a-half, and patients are normally able to go home on the same day as surgery.

Although the therapy may not work for everyone and usually doesn't result in complete seizure freedom, "the VNS device can be extraordinarily effective in suppressing seizures and improving the quality of life of children with drug-resistant epilepsy and their families too." says Mr Carter.

Dr Mallick stresses that whatever treatment drug-resistant patients are given, receiving it earlier is likely to yield the best results.

"The longer their epilepsy continues, the more developmental challenges they're likely to face," he says. "However, evidence shows that early intervention can reverse this." ■

WRITTEN BY
TONY GREENWAY

Measuring successful treatment outcomes for epilepsy

Successfully treating epilepsy isn't simply about reducing seizures, say two lead nurses for epilepsy surgery. It's also about improving the quality of life for patients and their families.

INTERVIEW WITH:
KATE WATTS
Lead Nurse for Epilepsy Surgery at Bristol Royal Hospital for Children

INTERVIEW WITH:
MICHELLE SEYMOUR
Lead Nurse for Epilepsy Surgery at Bristol Royal Hospital for Children

Treatment for epilepsy — drug-resistant or otherwise — can be challenging and vary for everyone. Ultimately, the aim of any treatment is to stop, reduce or control seizures and improve the quality of life for patients and their families.

Drug resistant epilepsy is such a complex condition that every patient's needs are different, say Michelle Seymour and Kate Watts, Lead Nurses for the Children's Epilepsy Surgery Service at Bristol Royal Hospital for Children.

"At the beginning of vagus nerve stimulation (VNS) therapy, we'll establish what the family and the patient want to achieve," says Watts. "Some parents simply tell us: 'We want to reduce our child's seizures.' Others will be more specific and say: 'We want them to attend school for longer so their education isn't interrupted'; or 'We want them to be able to go to sleepovers with their friends and become more independent.'"

Seymour and Watts stress that it's their role to manage expectations of what any treatment can do. "VNS therapy is not a cure for epilepsy, but we see many cases where quality of life improves," says Seymour. "It not only can reduce seizure duration, frequency and severity, but can have other benefits, such as improving a patient's mood and increasing alertness. That might not sound like very much, but if it can keep a child at school and help them retain more information, it will have a massive impact on their learning."

Successful treatment can have knock-on effects in all kinds of ways, explains Watts. "One family told us that, thanks to VNS therapy, their daughter's communication had improved, which had increased her interactions with other children. This, in turn, had improved her behaviour because she wasn't so frustrated all the time. So it helped her from a social perspective, which benefitted the whole family." ■

WRITTEN BY
TONY GREENWAY

"How VNS treatment improved my son's quality of life"

After being diagnosed with Dravet Syndrome, a drug resistant epilepsy, Harry Smith — now nine years old — had VNS therapy to reduce the frequency and severity of his seizures.

INTERVIEW WITH:
MARTINA SMITH AND SON, HARRY
Harry is a patient with drug resistant epilepsy

Harry had his first seizure when he was five months old. These became more frequent, could be prolonged and he would sometimes need medical intervention to make them stop. I was constantly worried about him.

As he grew, Harry's epilepsy started to affect his cognitive development. He was having seizures in his sleep that would affect his day-to-day life and he got tired more quickly than other children of his age.

I was always on the alert for his next seizure. I was also terrified of seizures happening to him in his sleep, so my sleep was massively affected too. I began having panic attacks and suffered from anxiety.

We tried various anti-epileptic drugs in various combinations, but none worked. Then, just before Harry turned six, he had a VNS device implanted.

The impact of the VNS therapy has been life-changing. We were well informed that it wouldn't be a cure, but it has dramatically reduced the frequency and severity of Harry's seizures. He's calmer, his progress academically and socially has accelerated — and, it has improved life for us as a family. ■

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VNS Therapy is suitable for both adults and children with drug-resistant epilepsy. To hear Harry's full story and more personal experiences, visit

vnstherapy.co.uk/learn-more/stories

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New facilities and staff-led projects at The National Hospital and the UCL Queen Square Institute of Neurology

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You can help the one in six living with a neurological disorder

WRITTEN BY:
THERESA DAUNCEY
Chief Executive,
The National Brain Appeal

One in six of us in the UK has a neurological disorder. That's more than those affected by coronary heart disease, cancer and diabetes *combined*. Supporting these 14.7 million people is therefore vital, if costly, work.

It is a staggering statistic, that one in six of us suffers from a neurological disorder, such as stroke, brain tumours, multiple sclerosis, Parkinson's disease, epilepsy and dementia. At The National Brain Appeal we work closely with the world-leading doctors, surgeons and researchers at The National Hospital for Neurology and Neurosurgery and the UCL Queen Square Institute of Neurology, London, to fund their pioneering research, provide access to the best technology for expert diagnosis and treatment for their patients, and train tomorrow's clinicians.

Since 1984 we have raised more than £45 million that we have invested in major new developments, patient care and research, including the UK's first dedicated Brain Tumour Unit, the Dementia Research Centre and the MRC Centre for Neuromuscular Diseases.

This would not have been possible without the incredible donors and supporters who have run marathons, cycled the length and breadth of the country, climbed mountains, held events in memory of loved ones, left a legacy in their Will, as well as generous support from grant-making trusts, companies and community groups.

> *"Leaving just 1% of your estate can make a real difference and is an investment in the future"*

Our current appeals include:

Aphasia

A transformative high dose therapy programme, providing 100 hours of therapy for patients with aphasia — speech and language difficulties following stroke, traumatic brain injury or brain tumours. The programme began in July 2019 with very encouraging results to date.

Rare Dementia Support

The world's first dedicated specialist support service, providing information and guidance for people living with rare dementias, their carers, their families and their friends; support groups that bring people together to share their experiences and access to specialist doctors, nurses and researchers.

Immunotherapy

The UK's first large scale immunotherapy clinical trial for NHS patients recently diagnosed with glioblastoma brain cancer, the most common type of primary, malignant and very aggressive brain tumour. This is currently underway and will be recruiting patients until the end of June 2020.

As well as our big appeals, we have a Small Acorns Fund, where front-line staff have the chance to apply for funding to fast-track smaller scale projects that will have a big impact and benefit to patients, such as mindfulness training to help staff teach their patients how to manage neuropathic pain and mobile arm supports to aid those affected by a stroke. These might be small changes, but the difference they can make to people's lives are enormous.

There are many ways that you can support our work: by making a donation, taking on a fundraising challenge, getting your company involved, volunteering for us, becoming one of our Ambassadors for Innovation and leaving a legacy in your Will.

Legacies represent around a third of our annual income. Leaving just 1% of your estate can make a real difference and is an investment in the future. The more money we receive, the more support we can give to The National Hospital, which in turn improves the prospects for those affected by neurological disorders. ■

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The National Brain Appeal helps to provide much-needed funds to support the National Hospital for Neurology & Neurosurgery and the UCL Queen Square Institute of Neurology – together known as Queen Square. This is one of the world's leading centres for the diagnosis, treatment and care of patients with neurological and neuromuscular conditions.

For more information about our work and how you can get involved

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