epilepsy action

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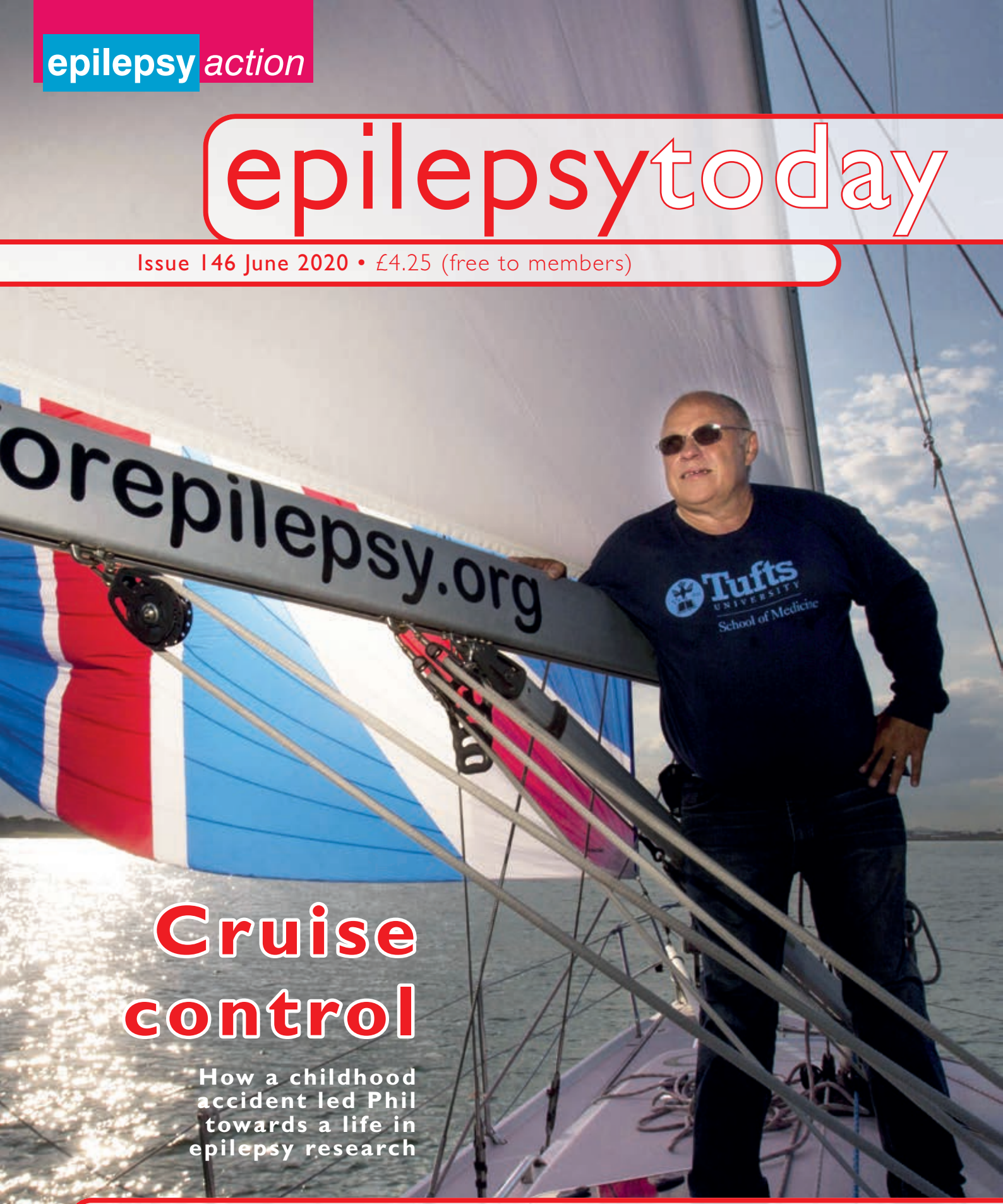

Cruise control

How a childhood accident led Phil towards a life in epilepsy research

Also in this issue

editor's **letter**

Welcome to the June 2020 issue of *Epilepsy Today*

Well, what a difference a couple of months makes. At the time of writing this in April, only last month, I remember laughing off having to queue for toilet roll and pasta. And then it happened. I remember shrugging off worries about a lockdown on this scale. Where everyone is supposed to stay at home aside from essential jobs, shopping and exercise. And then it happened.

I wonder what the next few months will bring.

The first few weeks were tough, and I narrowed my own feeling to grief. And grief is what we're all feeling now. We're mourning the loss of our normal lives – going to the pub, attending a friend's wedding, enjoying a concert or competing in a sports tournament. These were the things that we plan for and look forward to.

However, the paths that we thought our lives would be taking are now verging off course, way off where we thought we'd be.

Where do we go from here? Well, remember in times as tragic and awful as this coronavirus pandemic, is when we start seeing the very best of human nature.

Despite most of us being house-bound, our sense of community and togetherness has never been stronger. People like bandying around Captain Tom Moore, who raised more than £20m for the NHS simply doing laps around his garden.

People offering to check-in on the more vulnerable, and drop off supplies for them. People hand making masks and other protective equipment out of the goodness out their hearts. We won't forget these collective efforts, the ones that came to our aid when we needed them the most, anytime soon.

In times like these it's important to reach out if you're feeling isolated or lonely. We are always here for you at Epilepsy Action. Though our regular coffee and chat groups are suspended for the time being, you can connect and share experiences through our online forum, Forum4e and social media channels. We also have plans to launch online support groups. Visit our coronavirus page on ***epilepsy.org.uk/coronavirus*** for the latest information.

Together, we'll get through this. Enjoy the issue.

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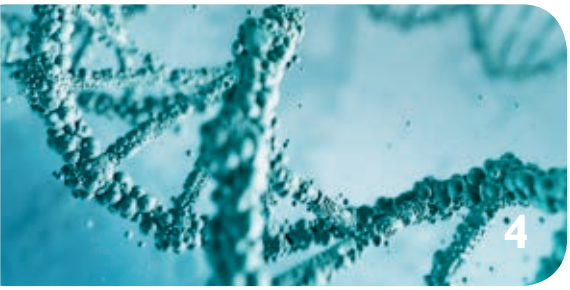

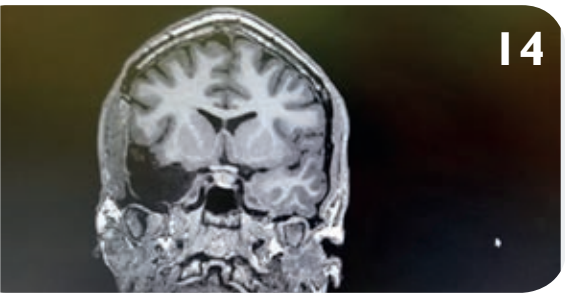

Advice and information on coronavirus (COVID-19)

Epilepsy Action is closely monitoring the unfolding COVID-19 situation and acting on any advice given by the UK government. We will provide regular updates as well as advice and information to anyone affected, especially people or carers of those with epilepsy. Our dedicated COVID-19 online support page carries information on:

Frequently asked questions (FAQs)
Find out answers to the most common questions asked during these times. They include whether having epilepsy puts you at greater risk of contracting COVID-19, or if epilepsy medicines affect your immune system.

Forum4e
Epilepsy Action's forum4e is an online community exclusively for people affected by epilepsy. Staying at home doesn't have to mean you're on your own. Check out the forum and chat with people who can offer practical tips and support during these challenging times.

For more help, advice and useful information on the ongoing COVID-19 situation please visit: *epilepsy.org.uk/coronavirus*

Fruit-flies shed light on brain plasticity

Researchers at the University of Birmingham have studied the fruit-fly and uncovered genetic mechanisms behind brain plasticity, the brain's ability to change and adapt.

Fruit-flies are common insects used in the study of neuroscience. This is because researchers are able to study their entire nervous system. Their genes can be identified and linked to specific neurons, brain circuits, brain structure and behaviour.

This research is lighting the way for a deeper understanding of how the human brain adapts over time, including the link between plasticity and neurological conditions such as epilepsy.

It has been understood for some time that human brains are adaptable, with a certain amount of plasticity. Brains change as new things are learned, and enable people to adapt after the loss of a limb or after brain injury.

How it does this, however, is not yet fully known.

The new study, published in *eLife* in February 2020, identifies a specific set of genes that are responsible for brain plasticity. These genes encode proteins known as Toll receptors, responsible for receiving and transmitting signals within cells. Tolls are known to play a key role in the body's immune system.

The team have also discovered they influence the formation of the nervous system. This link between Tolls and brain plasticity is an unexpected development.

Professor Alicia Hidalgo explains: "The molecules we identified are well known for the role they play in regulating the body's immune system. We think that perhaps in evolution, the nervous system and the immune system shared a common origin, as they share similar functions. For example, the immune system helps to protect us from microbes, while our nervous system plays a role in protecting us from larger dangers, like reacting to threats. It seems that brain plasticity re-activates mechanisms that operate during the formation of the brain in development."

The team found these Toll receptors were present across different areas of the brain and dedicated to different functions.

"This arrangement of the Tolls suggests they can work independently of each other, perhaps to control the response to different sensory stimuli such as smell, or vision," says Professor Hidalgo.

"These can then be modulated to influence the formation and maintenance of particular types of neurons in response to experience."

It's still unknown how close these mechanisms in fruit-flies match those in a human brain. However, the study offers some insight into where to look to further understand plasticity.

"With fruit-flies we can show brain plasticity has a genetic basis and identify how genes control this process." says Professor Hidalgo. "This gives us a really useful set of clues and insights into the molecular mechanisms of plasticity also in human brains."

For the full study visit: *https://doi.org/10.7554/eLife.52743*

EU funds project to develop nanodevices against epilepsy

Nanotechnology is being studied to develop revolutionary treatments for neurological conditions such as epilepsy. This technology involves the study and development of devices that could control extremely small objects such as atoms and molecules.

Researchers hope that these nanodevices could be used as brain implants that control the activity of neurons, reducing or stopping seizures.

The IN-FET project (Ion Neuromodulation for Epilepsy Treatment) was launched in January 2020 and has recently been given a €3million grant from the European Union. With the approved funding, the team will be looking at using nanotechnology and looking at ions such as magnesium, potassium and calcium.

These are the chemicals which allow neurons to communicate. Nanodevices could look at and control these ions, and importantly, their concentration. From here it should be possible to change their cell activity, meaning activating or turning off certain neurons. In epilepsy, it's the flow of ions that leads to the burst of electrical activity in the neurons, leading to seizures. Here, the nanodevices would act as an ion trap, so they no longer excite the cells, preventing such seizures.

Professor Michele Giugliano, is director of the Neuronal Dynamics Lab at SISSA (Scuola Internazionale Superiore di Studi Avanzati) in Italy. She says, "Epilepsy is one of the most common neurological conditions, affecting 50 million people worldwide. Drug treatment is a widespread approach to fight it, but for many people, medication is no help. Epilepsy drugs prove ineffective with 7% to 20% of children with the condition. Drug resistance amongst adults ranges between 30% and 40%."

The European project brings together experts in nanoengineering, information technology and neurobiology, and is funded by the European programme Future Emerging Technologies (FET) Open. The initiative will involve IBM Research, Multi Channel Systems, the Universities of Geneva and Sheffield and the Italian Inter-University Consortium for Nanoelectronics, amongst other parties.

The aim of the group will be to develop implantable devices that can alter the concentration of these microscopic ions. These devices will be able to measure the electrical activity of neurons and actively work to correct it.

"Today's experimental therapies for restoring or repairing brain functions in neural conditions often involve changing or silencing hyperactive brain circuits," explains Professor Giugliano.

"This can be done with medicines, gene therapy, or electrical or magnetic techniques to affect the brain. However, all of these come with serious drawbacks. They unnaturally try and control these neurons. Our idea is to control ions, the very substances that the brain normally uses to function. Through this we'll be able to discover and test new treatments for epilepsy."

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More than 40% of people experiencing status epilepticus have adverse outcomes

Finnish researchers at Kuopio University Hospital have been studying the short-term outcomes of people treated for status epilepticus (SE).

Some types of status epilepticus are considered a life-threatening medical emergency. Because of this, the Finnish study team have been exploring outcomes in people with SE. The experiment looked at 137 people with SE during 2015. Their medical outcomes were looked at one month after discharge from hospital by phone interview, as well as by people recording their own experiences using a diary.

Published in *Seizure* journal, the team found there was a 9% risk of death and a 32% risk of functional loss one month after SE. Functional loss includes a loss of body movement, communication skills, changes in behaviour, a person's ability to look after themselves or memory issues.

It was also discovered that the risk of death could be predicted relatively accurately in the emergency department, using SE prognosis tools. These tools included STESS (Status Epilepticus Severity Score) and EMSE (Epidemiology-based Mortality score in Status Epilepticus). With these the team were able to predict survival with a certainty of more than 95% in many SE cases. These scores were determined from the condition and clinical nature of the SE presented case as well as the age and other medical conditions of the person.

For the full study visit *bit.ly/32IRGdX*

For more information on status epilepticus, visit: *https://bit.ly/2Y6a3sS*

New therapy could stop seizures in rare epilepsies

A type of gene therapy could help those with rare forms of childhood epilepsy, including Dravet syndrome. This breakthrough could lead to treatments for developmental epileptic encephalopathies developing from a single genetic mutation. Encephalopathy is when brain function is impaired by a condition such as viral infection or toxins in the blood.

Within the brain, the gene SCN8A controls a sodium channel that allows neurons to transmit an electric signal. Sodium channels are membranes in the brain responsible for allowing neurons to communicate. Mutated versions of the SCN8A gene can cause these channels to become hyperactive and bring on repeated seizures. This condition is known as SCN8A-Related Epilepsy, and average onset age is just four months old.

Miriam Meisler is professor of neurology at U-M Medical School in the US. Her team have studied the condition for many years and are trying new therapies to treat this epilepsy. She says: "Approximately half of these people affected are severely impaired and cannot walk or talk."

The breakthrough, using antisense oligonucleotide (ASOs), which are short DNA or Ribonucleic acid (RNA) molecules, enabled researchers to control how much genes communicate with the body. RNA acts as a messenger carrying information from the DNA about specific proteins. By controlling the amount of RNA expressed by the mutated genes, the team found they could reduce its effects on the body.

By using mice with the same mutated gene, they were able to develop an 'off' switch for the gene by activating the ASOs. "The effect was dramatic and unambiguous," says Meisler. "We had a four-fold increase in lifespan, with added effects of repeated treatments." There was no evidence of low-level seizure activity in the treated mice.

The level of RNA expressed was reduced by half after the treatment. It was also discovered that the technique was effective against other types of epilepsies including Dravet syndrome.

The team is now carrying out further testing to see how effective they are against other seizure types. The results are published in *Annals of Neurology*. For the full study visit: *https://onlinelibrary.wiley.com/doi/full/10.1002/ana.25676*

Graphene-based implant could lead to new epilepsy treatments

A material called graphene has been successfully used in recording electrical activity in the brain, potentially unlocking the door for new epilepsy treatments.

Graphene is a new type of graphite. It is extremely thin and is considered one of the strongest materials in the world. It is more than 100 times stronger than steel.

New graphene-based brain implants have been developed by a partnership known as Graphene Flagship working across Europe. They are able to record brain activity at extremely low frequencies and over large areas.

For decades electrodes have been used to record electrical brain signals, offering scientists a map of activity throughout the various areas of the brain. However, these systems have only been able to read activity over a set group of frequencies.

This new technology uses a transistor-based system which strengthens the brain's signals at their source, then sends them to a receiver. By using graphene, the implant can record more information than normal electrodes can. They are also slim and flexible enough to be used over large areas of the brain without interfering with normal brain functions.

Importantly, these implants can offer unprecedented mapping of low-frequency brain activity. These brain signals are known to carry critical information about the start and progression of seizures and strokes.

In neurology, this may shed light about what we only barely know about the human brain. Applications of this technology could reveal insights into where and how seizures begin and end. This has the potential to allow experts to discover new techniques into the diagnosis and treatment of epilepsy.

José Antonio Garrido is co-leading the study working at Graphene Flagship Partner ICN2. He said: "Beyond epilepsy, this precise mapping and interaction with the brain has exciting applications. In contrast to today's electrodes, graphene-based technology will boost the number of recording sites in the brain. This will lead to the development of a new brain to computer interfaces."

Kostas Kostarelos is leader of the Health, Medicine and Sensors Division of the Graphene Flagship. He comments: "This technology can offer capabilities beyond what is achievable today and open up tremendous possibilities for studying unexplored frequencies of neurological activity."

Antibodies in the brain trigger can epilepsy

A German study has found a link between antibodies, which are proteins used by the body to fight off bacteria and viruses, and epilepsy.

With this knowledge, scientists at the University of Bonn think they can develop new therapies for some types of epilepsy;

These forms of epilepsy are accompanied by the inflammation of important brain regions. The researchers have identified a mechanism that explains this link, and published their findings in *Annals of Neurology*.

Epilepsy can be a hereditary condition. However, in other cases, it develops in people only as a result of a brain injury, after a stroke or triggered by a tumour. Inflammation of the meninges, the membrane that surrounds the brain, or the brain itself can also result in developing epilepsy.

Particularly dangerous is inflammation of the hippocampus, the part of the brain that plays a part in memory and emotions. Doctors call this condition limbic encephalitis.

Professor Albert Becker oversees the Section for Translational Epilepsy Research at the University Hospital Bonn. He says, "In many cases it is still not clear what causes such inflammation."

Now researchers have found an antibody that is believed to be responsible for encephalitis in some people. Unlike normal antibodies that target molecules that enter the body from the outside, this antibody works against the body's own cells.

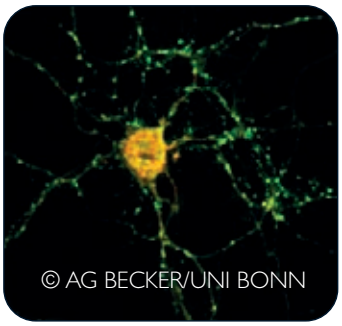
The researchers discovered it in the spinal fluid of people with epilepsy who have inflammation of the hippocampus. This antibody targets the protein Drebrin, which ensures the contact points between nerve cells function correctly. When the antibody encounters the Drebrin, it disrupts the communication between nerve cells. At the same time, it alerts the immune system, which then activates an inflammatory mode, which produces even more of the antibodies.

"However, Drebrin is located inside the synapses, whereas this antibody is located in the tissue fluid," says Dr Julika Pitsch. "These two should therefore normally never come into contact with each other."

It was discovered that the antibody uses a back door to enter the cell, piggybacking on to neurotransmitters to gain access into the synapses. In experiments using live cultures, the researchers showed what happened next. When the antibodies entered the synapses, the nerve cells started firing wildly with electrical activity, simulating a seizure.

These discoveries may lead the team on to new treatment approaches. For example, the drug cortisone can suppress the immune system and perhaps prevent the mass production of these antibodies. It might also be possible to intercept and disable them with other drugs. However, scientists say that there is a long way to go before treatments become a reality.

For the full study visit: *http://dx.doi.org/10.1002/ana.25720*



In memoriam: Ron Radley

We are saddened to report that Ron Radley sadly passed away on Sunday 12 April 2020 following a hospital admission with Covid-19. Ron had experienced poor health for a number of years, something he had borne with great courage and fortitude.

Ron devoted his working and voluntary life to furthering understanding about the educational needs of children and young people with epilepsy. He was a tireless and dedicated advocate and an authoritative voice on epilepsy and educational issues. He taught at both the Hospital for Sick Children, Great Ormond Street and at St Piers Lingfield, now known as Young Epilepsy. He was also the youngest ever head of a residential school for children with epilepsy, Sedgwick House.

Throughout his teaching career, Ron used approaches which were groundbreaking in their time. He was responsible for a number of pioneering curriculum initiatives for children and young people with epilepsy, notably outdoor education challenges, including sailing and abseiling. Many of these have since been adopted by education authorities as common practice in both mainstream and specialist schools.

Beyond his working life, Ron's interest and commitment to epilepsy extended into his voluntary roles. He served on the Council of Management of British Epilepsy Association (Epilepsy Action) for a total of 15 years over two periods of time between 1991 and 2007. During that time he served as Vice Chair of Council for three years between 2000 and 2003 and as Chair of Council for three years between 2003 and 2006. He also served on a total of eleven different Council committees, five of which related to education and young people with epilepsy. Closer to home, Ron also found time in his busy life to Chair the Kendal branch of Epilepsy Action and support his local Cumbria forum.

In June 2008 Ron was awarded Epilepsy Action's highest honour, the Lord Hastings Award, and was made an Honorary Life Member of the British Epilepsy Association, for his outstanding personal contribution to improving the lives of people with epilepsy.

Ron was a staunch supporter of Epilepsy Action over many years. His passionate advocacy will continue to inspire all of us who knew him and worked with him as we remember him with great affection and warmth.

Desperate measures

Karen resorted to smuggling illegal cannabis drugs into the UK to help treat her son, who has severe epilepsy. She speaks exclusively to *Epilepsy Today*.

At some point in your life, you've likely broken the law. You might have been speeding on your way to work because you were running late. Or perhaps there was an extra item in your shopping bag that didn't scan at the till, yet you said nothing. But few people have ever had to smuggle drugs illegally into the country. That's exactly what Karen Gray, a mother of three from Edinburgh, had to do for her son Murray.

It was from the age of two when Murray started having infrequent tonic-clonic seizures - he had three that year. However, he started having more over the years, and by the time he was four he could be having 12 in a single month.

In December 2017, he was diagnosed with Doose Syndrome (also known as myoclonic astatic epilepsy), a rare and severe form of epilepsy. It affects one to two out of every 100 children with epilepsy, and it can be devastating. Those with the condition can experience dozens of seizures a day.

After his diagnosis, Murray was put on a variety of anti-epileptic drugs – firstly sodium valproate, then clobazam. However, one time he went into non-convulsive status epilepticus (SE) and needed to be taken to hospital and given phenobarbitone. He slept for three days before he recovered.

Over time, Murray started to have jerks, absence seizures and drop seizures. He was given more drugs, including levetiracetam, ketamine, zonisamide and steroids. Murray even tried the high-fat, low-carb ketogenic diet, but unfortunately didn't take to the food.

In August 2018, hope arrived. Murray was allowed to be treated with Epidyolex on compassionate grounds. The drug is derived from the cannabis plant, without any of the tetrahydrocannabinol (THC) ingredient which normally provides a 'high'.

It managed to control Murray's jerks, absence seizures and drop seizures, but he was still having tonic-clonic seizures at night. Still, he was able to go to school for around an hour a day.

A few months later however, the Epidyolex stopped working altogether, and Murray was soon back in the hospital after another bout of status epilepticus. He was getting worse.

"He was very ill," says Karen. "He was lying in the hospital bed unable to move, eat, drink or talk. He had to be fed with a tube. His muscle tone went and then his breathing started to decline."

The toll was horrible on Karen and her family. "It's caused a lot of stress. Having to live at the hospital and watch Murray suffer horrifically. My other two children have also suffered, seeing Murray have seizures and not have their mum at home with them."

Not only that, the various drugs he was on had severe side-effects. He had stopped producing red blood cells and needed a number of blood transfusions.

Steroids made him put on two stones in weight, and the ketamine "made him like a zombie", according to Karen. Other drugs caused uncontrollable diarrhoea and affected his ability to speak.

Despite this, the doctors told Karen there was nothing they could do. For her, that was the final straw. Up to this point, Murray was having up to 600 myoclonic jerks and absence seizures every day, along with dozens of tonic-clonic seizures. After one drop seizure, he cracked his head open and needed medical treatment to glue it shut again. Karen had heard of Bedrolite, a new cannabis medicine containing THC that she suspected might work on Murray. "I read an article about Alfie Dingley and how the cannabis oil was helping to control his seizures. I contacted his mum, started researching myself and got a lot of information from abroad and the UK cannabis community."

She made the trip over to Amsterdam and found a doctor who was willing to prescribe the medicine. Karen collected it from the pharmacy where the oil was made, and illegally smuggled it through customs on her return visit, back into Scotland. Her only worry was not being able to provide Murray with the drug if she was caught.

> **"It's caused a lot of stress, living at the hospital and watching Murray suffer horrifically"**

Karen has thankfully not had any trouble from the authorities regarding the smuggling. "I was very open and honest about needing the oil to help Murray. It was our last hope of giving him quality of life."

She began giving doses to Murray while he was at the hospital. She went to Amsterdam a second time to get more oil. This time, Bedica, another CBD oil, was added to her prescription. By then, the oils were having an effect, and Karen was amazed by the results. "The difference is quite unbelievable. He went from being confined to a wheelchair and having no education to being able to walk to school every day. A recent EEG showed no seizure activity."

Karen made the trip to Holland for a third time to smuggle more oils into the UK, until she found an importer who was willing to ship them direct to her home.

"A private neurologist writes Murray's prescriptions and they have never charged me a single penny for doing this. They truly deserve a medal for helping our children."

Murray has now been seizure-free since June 2019. "He's not been in SE or back in hospital since. He even learned to walk and eat again."

Karen now spends much of her time campaigning for the government to make faster progress on releasing the THC cannabis oils on NHS prescription. In autumn of 2019, she had planned to go on hunger strike to encourage the government to act. However, the strike was called off when a general election was announced.

The medicines cost a hefty £1,300 per month, and Karen is only able to maintain Murray's supply through fundraising and help from family. "It is a struggle," she admits.

Murray, before the CBD treatment...

...and after

Karen contacted the government in September to request additional funding, but has received no response. Since then, she's been in circles dealing with both the UK and Scottish governments.

"In England, funding appears to be the problem, even though Secretary for Health Matt Hancock said funding was not an issue. In Scotland, my Health Minister, Jeane Freeman, has always stated that funding is not a problem. She advised me that if an NHS prescription is written and given to the pharmacy, Murray's cannabis oils will be dispensed free of charge. The actual problem is that clinicians across the UK will not prescribe any cannabis oils apart from those without THC. This is due to the safety issues of it not being trialled in this country."

The government says that more clinical evidence is needed before it can support prescribing cannabis-derived products containing THC.

Karen says they need to take a more proactive step: "They need to catch up very quickly. There are lots of children taking the oils who have very good seizure control. These children ARE the trials. It is a travesty that the NHS and government have kept their heads in the sand as they could have acquired very good clinical data from our children."

"The government needs to catch up quickly. There are lots of children taking the oils who have very good seizure control"

Though the treatments have allowed Murray to enjoy being a kid again, it's been a stressful few months for Karen's family. They rely on the generosity of others to secure much of Murray's treatment, not knowing if or when the funds coming in could dry up. She is pushing for the cannabis oils to be released on the NHS.

"I hope that cannabis oils are fast-tracked so that no parent or child need go through what we have been through. I have no choice but to spend £1,300 a month – the oils are giving him a much better quality of life."

Epilepsy Action statement
"Current barriers to accessing cannabis-based medicines on the NHS have left some people feeling forced to access these drugs privately. Or they are forced to source them from other countries where access is less restrictive. Epilepsy Action recognise the incredibly challenging situation of people affected by severe and treatment-resistant epilepsies such as Karen and her son Murray. No-one should feel forced to break the law to ensure their child can access the most appropriate treatment for their health condition.

This is why Epilepsy Action will continue to push for improved access to cannabis-based medicines on the NHS for those who could benefit from them. This is to ensure that no-one feels forced to break the law or break the bank to pay for a private prescription.

We recognise the severity of the situation faced by Karen and Murray. However, it is important to note that Epilepsy Action does not endorse or encourage the illegal importation of cannabis-based medicines or any other controlled drugs.

Any products containing more than 0.2% THC that are not prescribed by a specialist clinician are illegal to possess in the UK. There are additional risks associated with cannabis or cannabis products obtained on the black market. These products are untested and unregulated with no reliable information about quality and strength. Any decision to stop, start or alter medicines should be made by an appropriate clinician in consultation with patients and parents/ carers where appropriate."

Sam Mountney
Senior policy & campaigns officer
Epilepsy Action

epilepsy action

epilepsy.org.uk/yourchild

Your child and epilepsy

Grow your confidence managing epilepsy in your family

Your child and epilepsy is a new online course for parents and carers of children with epilepsy. It's been developed with parents, epilepsy nurses and psychologists.

This course is a helping hand to support families on their epilepsy journey. It's full of advice and stories from parents. It aims to give parents and carers the confidence, skills and knowledge to support their child to manage their epilepsy.

There are eight parts that cover:

- Understanding epilepsy
- Supporting your child with their epilepsy
- Keeping your child safe
- The impact of epilepsy on family life
- Your child's wellbeing
- Learning and behaviour
- Growing up and independence
- Sources of help and support

Free course

The course is free and flexible. It can be accessed at any time on a computer, tablet or smartphone with internet access.

Get started at: **epilepsy.org.uk/yourchild**

Get in touch: **learning@epilepsy.org.uk**

Epilepsy Action
Information you can trust

Find out more
epilepsy.org.uk/trust

Research update

Shelda-Jane Smith, PhD student from the University of Liverpool, received a grant from Epilepsy Action. She explored healthcare for adolescents with epilepsy and a learning disability, when moving from children to adult services.

When adolescents with a long-term health condition, such as epilepsy, move from children's healthcare services to services for adults, this is called 'transition'. Transition is a planned process, which involves adolescents, their families and carers and healthcare professionals.

The aim is to promote independence and self-management in adolescents for their ongoing health and care needs in adult life. However, transition creates many challenges. These include a reluctance for young patients and their families to leave their familiar paediatric health service. Another challenge is the increase in the risk of psychological distress.

To find out more about these challenges, I carried out a study of a teenage epilepsy clinic. I used a research approach called ethnography, which means looking at different cultures, customs and habits. In particular, I focused on the experiences of transition for adolescents with epilepsy and severe forms of a learning disability. This is a condition often found in people with epilepsy.

People who have epilepsy and a learning disability [ELD] may not always reach complete independence from their family or carers. Therefore, there are questions about whether the aims of transition, with its focus on independence and self-management, are actually helpful for them.

Over a period of 12 months I observed the daily work involved in transitional care for young people with ELD in two hospitals in the north of England. I also observed transitional care in wider social settings. This included the family home and social care environments, such as day trips with a supported-living care company and community learning disability arts workshops.

In addition to my observations, I carried out interviews with parents and carers of young people with ELD and also with health professionals.

The research findings revealed that transitional care for young people with ELD is a practice bound up in common cultural stereotypes about what it means to be an adolescent. It frequently discusses the 'expectations' of adolescents based on their chronological age rather than their development stage. As such, these expectations did not always reflect the experience of those living with ELD. In particular, during the transition to adult services, adolescents were expected to:

- Rely less upon their families when managing their healthcare (for example, adolescents, where possible, were prompted to attend clinic appointments alone)
- To show maturity and responsibility when interacting with health and social care services (such as booking their own appointments or knowing their own medication regime)

This study showed common cultural stereotypes of adolescence do not reflect the needs and experiences of all adolescents and therefore should not be treated as such. Interviews carried out suggest that treating everyone the same during transitional care can harm parents of children who will not move out of adolescence and become socially independent adults.

Results show that when transitional care promoted patients to become independent and responsible young adults, feelings of stress were prompted in parents caring for young people with ELD.

Parents commented on the 'burden' of responsibility that would always remain with them as their child moves into adulthood. They also underlined the lack of clinical and social care support in these situations.

The experience of being a carer for a young person with ELD also caused new perceptions on caregiving itself. This is best shown by the following quote from the father of a 17-year-old male who was approaching adult epilepsy services:

"I take my time to think about his future. It really breaks my heart. If I could have him as a little kid all over again I would. There's more acceptance for disabled kids. Kids are supposed to be dependant and reliant on mum and dad…It [caregiving] is hard, hard work but you see life for what it is and you take nothing for granted. It makes you a better, kinder person when you realise that to be human means to be many different ways."

This study into transitional care for people with epilepsy offers an alternative viewpoint on this increasingly important practice. It should persuade health and social care providers to reflect on how they work with different people with different needs.

Additionally, this study shows us the important and continuing role that parents play – not just in a paediatric clinic but also in adolescent and adult settings.

For people with ELD, their relationship with their parents is crucial for their future health and wellbeing. Therefore, healthcare professionals who practice and develop transitional care would benefit from reviewing the overemphasis placed on adolescence as a time of increasing independence and responsibility. At present, transitional care focuses on building independence in adolescent patients. This has the effect of diminishing parental or carer involvement, as young people move into adulthood. However, this study suggests that the practice of transitional care would benefit from supporting and strengthening this relationship. As the quote above suggests, a step towards building more inclusive transition services for people with ELD is recognising that to be human means 'many different ways'.

Shelda-Jane Smith
Institute of Population Health Sciences, The University of Liverpool

Shelda-Jane Smith is a social scientist with interests in psychological anthropology, neurology, adolescence and epilepsy.

Under the knife

Undergoing epilepsy surgery can be daunting. Simon Breeds talks about his experience.

Tell me a bit about your background

I'm 38 years old with one brother and a sister. I grew up in Framfield, and I now live in Uckfield in East Sussex. I have been married for nearly 10 years to my amazing wife called Jo and we have a brilliant daughter, Evie. I also have three great stepchildren who have been very good throughout my surgery.

What do you do for work?

I work for East Sussex County Council Health and Social Care Connect as a telephone assessment officer. I assess a variety of needs for people who need adult social care to maintain their wellbeing at home and support their discharge from hospital. I have been doing this job for the past five years and enjoy it.

What do you do for fun?

I love sport, especially football, as a Manchester United fan. I also enjoy running, sometimes on my own or with my wife and daughter. If I run on my own, I must take my epilepsy card with me, should anything happen. Riding my bike is another thing I like to do, but football is the main sport for me – I coach kids' football at the weekends. On top of this, spending time with my family and friends is the most important to me.

Tell me about your first encounter with epilepsy

At the age of seven, my parents took my brother, sister and me on a treasure hunt by car. However, all I remember is feeling very sick and dizzy during the trip and waking up in Eastbourne District Hospital.

Did your symptoms continue or worsen after this?

To begin with my symptoms stayed the same, but then I started to have tonic-clonic seizures, about once every three years. When I was 16, I started to have them much more often. I would say the feeling was like a kettle boiling – I was wanting the seizure to just happen hoping to get rid of the feeling. And then after it did, I would be in pain with a very sore head, swollen tongue and usually other injuries. This lasted for up to a week. After my first seizure in 1989 I had a CT scan. At the time it showed my brain function was normal. It was not until 1992 that I got a confirmed diagnosis of epilepsy.

It wasn't until 2012 when I went to University College London Hospital to see an epilepsy consultant. I was referred to the Chalfont Centre in Buckinghamshire. It was there that they diagnosed me with experiencing three types of seizures: absence, complex partial and tonic-clonic seizures. I think this may have explained some of the odd feelings I often had growing up, but I tried to find coping mechanisms to carry on with life and not tell anyone.

How did you feel after your diagnosis?

I felt unsure to begin with – life just carried on as normal for me, although I knew my dad was keeping an extra eye on me. It wasn't until my late teens that my epilepsy started to affect me more with people's reactions and perceptions of the condition. It was my gran that I went to the most – we used to talk for ages, she listened to me and encouraged me all the time. Unfortunately, she passed away a few years ago, which hit me hard.

Were you put on medication?

I didn't take any medication until I was 16. This was mainly due to my parents' worries of what they might do to me, and the side-effects they might have on my wellbeing. They thought medication would turn me into a 'zombie'. At the time, my parents didn't have much information regarding epilepsy. Looking back, I think they didn't always make the right decisions for my condition.

Over the years I have tried many types of medication, which came with various side-effects. Some affected me more quickly than others, but with most drugs, it can be trial and error, and there are some types I can't take.

How did your epilepsy affect your relationship with your friends and family?

As I was a child when it all started, nothing changed that much. But I didn't tell anyone about my condition as to be honest I was embarrassed about it. I gave everything a go when I was younger, but going from secondary school to college aged 17, I noticed my epilepsy had changed again. I felt a little in control as I noticed signs and symptoms of when a seizure was coming on.

> **"I didn't take any medication until I was 16. This was mainly due to my parents' worries of what they might do to me"**

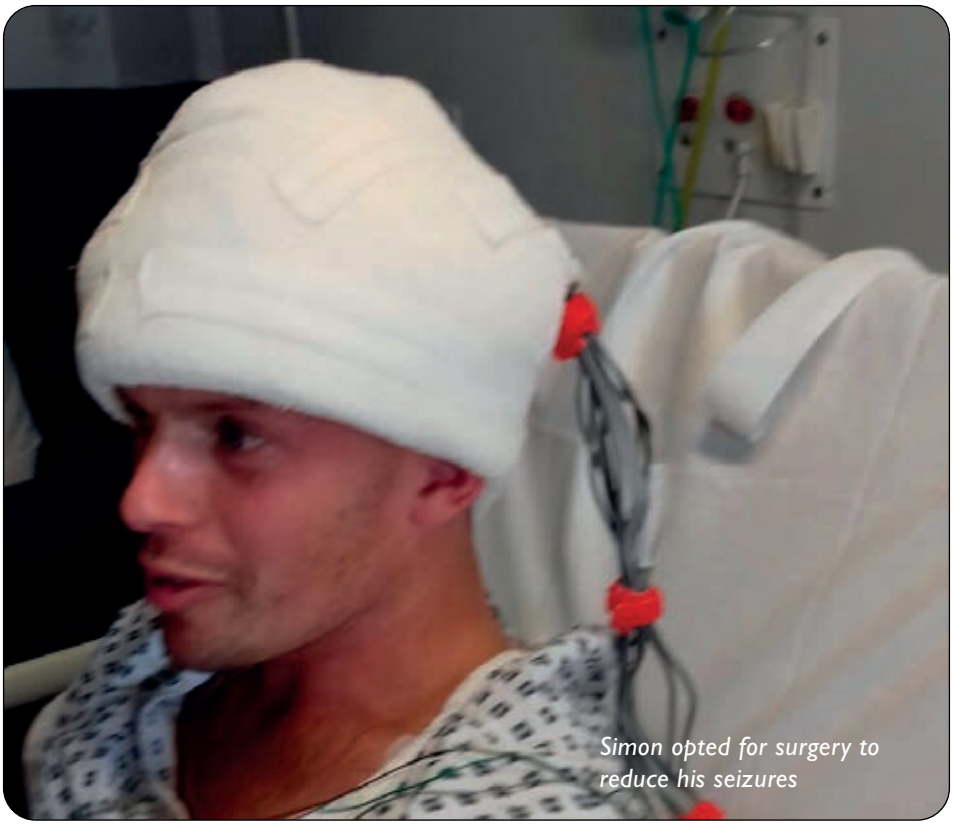
During this time I was on a childcare course. The theory side of things was poor due to my dyslexia but my practical skills of working with the children was excellent. But it was then that the head tutor told me that I would never be able to work with children on my own.

Not only that, I was told I'd find it difficult to find work supporting them because of the risk my epilepsy would impose on them. I never told anyone at the time, but I went home and cried. I decided this would make me stronger, but that I would never let anyone see my emotions if someone knocked me down for it.

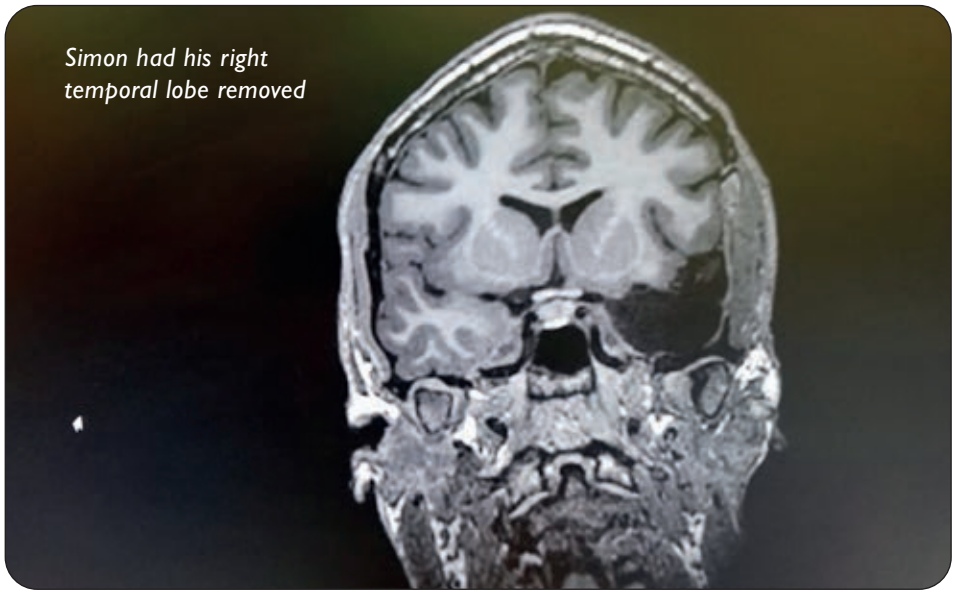
How does your epilepsy affect your work?

To begin with, I didn't tell employers about my condition out of fear of not getting a job. In 2011, I worked for the East Sussex County Council, supporting clients out in the community and I took the move to be open and honest about my epilepsy. At the time I thought my epilepsy was 'fine', and they made a risk assessment of my needs. Deep down I resented this, but it was done not only to support me but to support my clients too.

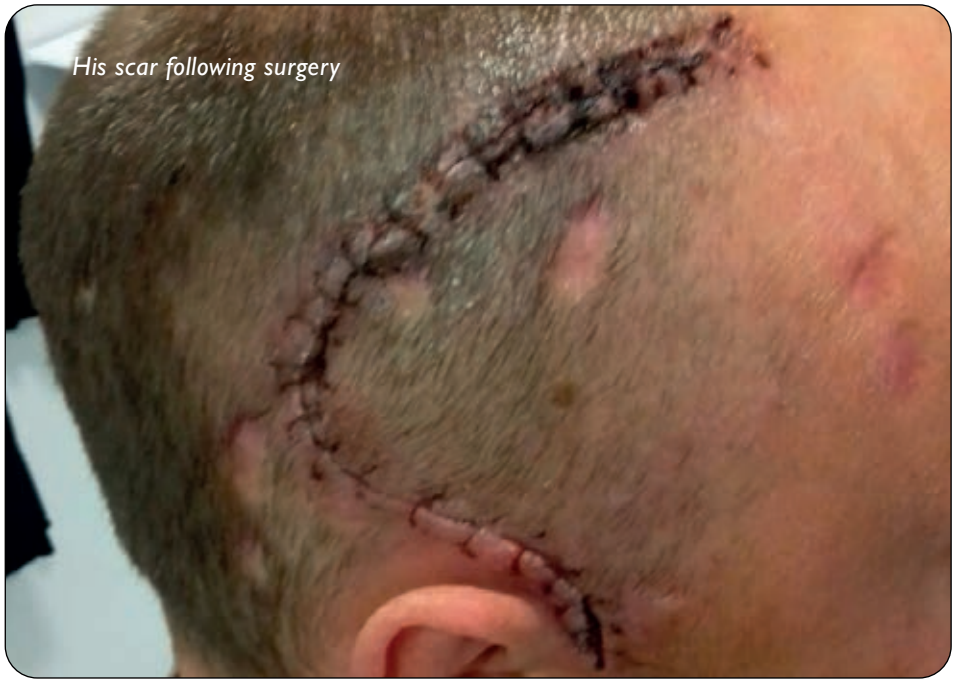
I was able to support clients with learning difficulties out in the community up until 2013, when it was deemed I could be putting them and myself at risk. I was then redeployed as a senior support worker for carers. The manager at the time didn't want to give me a chance and hoped I would be reassigned



Simon opted for surgery to reduce his seizures



Simon had his right temporal lobe removed



His scar following surgery

again or out of the job because of my epilepsy. I then got redeployed to where I am at now at Social Care Connect and enjoy every minute of it supporting clients over the phone.

How did surgery come up as an option?

In 2012 my seizures had worsened and were now affecting my everyday life. I was referred to UCL Hospital where I had full support from Dr Sophia Eriksson, who sent me to the Chalfont Centre for three days of tests. A while after this in February 2015, I had a week's further testing at UCL, where I was able to see myself have a tonic-clonic seizure from a video.

Unfortunately, these tests were not conclusive as to where in the brain my epilepsy was coming from. I then went on to have intracranial surgery in September 2017, which meant having nine probes drilled into my brain that recorded my brain activity. This recorded 43 seizures I had over two to three days.

At this time, I was told I was at high risk of sudden death in epilepsy. I was now faced with the option of brain surgery to remove my right temporal lobe. I spent a couple of months taking this all in and deciding about whether to have the operation or not. I finally decided to go ahead with it, and in July 2018 I underwent a reduction in the brain area.

How did you feel before your procedure?

It was all a rush leading up to the operation with only one week's notice. There was no time for anxiety to dawn on me until I left work on the Friday, knowing I wouldn't return for some time. It was strange travelling to London on the Sunday with my family, then watching them leave that evening and having time to reflect on the situation.

The following morning was the day of the operation. Everything was so quick, with medics in and out of the ward getting me ready for the procedure. I didn't have much time to think about anything, and before I knew it, I was off to theatre. The only panic I had was not being able to contact my wife to speak to her just before.

How was your recovery afterwards?

My recovery was much harder and slower than I expected – inside I felt lost and in pain. I kept thinking, "My head is killing me, I can't sleep. But no-one wants to keep hearing your story and you're all alone." I reached my lowest point in February 2019 and I really felt like I couldn't go on.

But with support from my GP and wife, and getting involved in Epilepsy Action by speaking to others with the condition meant I got the help I needed.

My determination meant a return to work in November 2019, I even had to relearn how to buy a bus ticket and make the 1 hour 20-minute journey to and from work, as well as trying to do my job to the best of my ability. Some days are great, and yet some days it feels like you're trying to climb Everest. You just need to get the right support at the right time to get you through the tough times.

Was the surgery effective?

Surgery has reduced my seizures, but I still have them, mainly the complex partial and absence seizures – my last tonic-clonic was 10 months ago. My symptoms have slightly reduced after some changes to my medication.

Were there any things that got worse after surgery?

My memory – this has massively declined, and it's taken some time to rebuild in terms of learning other ways to help prompt me to remember things. My short-term memory was awful – I couldn't remember where my stepson lived, and he's only 800 yards from my house. I couldn't remember faces, the alphabet or everyday things. My speech has suffered too.

In addition, my mental health declined. At first I didn't notice anything, but I found it hard to sleep because of the headaches. It was like sleeping on concrete. I was tired, irritable and snappy with my family, and I couldn't get my words out to join in with conversations.

Were your relationships tested after your procedure?

After the surgery, my wife, daughter and stepchildren were great. They were doing what they could for me and learning themselves that my memory was now very bad. They realised that I could no longer remember how to do simple tasks that most of us take for granted. So they had to explain things more to me, usually more than once This was quite frustrating for all of us. I also became a bit aggressive but without really realising it. I think this was mainly when I wasn't feeling good. I also couldn't remember people who I had spoken to; my wife then had to explain the reason why.

Keeping up with conversations is hard too – with more than two people I struggle. I can't take anything in and I'd back away, and it didn't help either that my speech was not always good. One of my best mates at the time saw me four days before my surgery but didn't come to see me after or call. I bumped into him a few months later, and although I had a head full of scars, he just said I 'looked fine'. That was hurtful and I've not seen him since.

I found things like Epilepsy Action, Brain Buddies and joining the Facebook group Epilepsy Friends helped me.

My memory loss was hard and left me feeling lonely and isolated. This had an impact on my wife and daughter too as there wasn't much support for them.

> **"My recovery was much harder and slower than I expected – inside I felt lost and in pain"**

I felt isolated from my parents after my surgery as I found they were not there for me emotionally when I needed them. I distanced myself from them for about six weeks following my surgery after a big argument about them not being understanding about my condition. At the time, it was tough – some of this goes back to when my gran passed away in 2014 of cancer. There was a family argument after the funeral for which I was held responsible for. This has never been sorted, and I don't think many people realise how much support my gran gave me over the years for my condition.

What didn't help was people saying, 'you look fine', thinking I was suddenly cured – if only that were true. People couldn't understand what I was going through, when at the time I felt so low. Luckily, with support from my incredible wife, I probably wouldn't be writing these words today. This seems selfish, but now I look on it like it was a massive learning curve. I have everything: my health, my job and my family. My sister Melinda was also amazing throughout, albeit on the end of the phone.

What's your message to those worrying about epilepsy surgery?

Build up relationships with your family and friends, and be honest about how you are feeling. Gather as much information as you can regarding surgery and the benefits for YOU. Talk with your consultant and epilepsy nurse with any concerns.

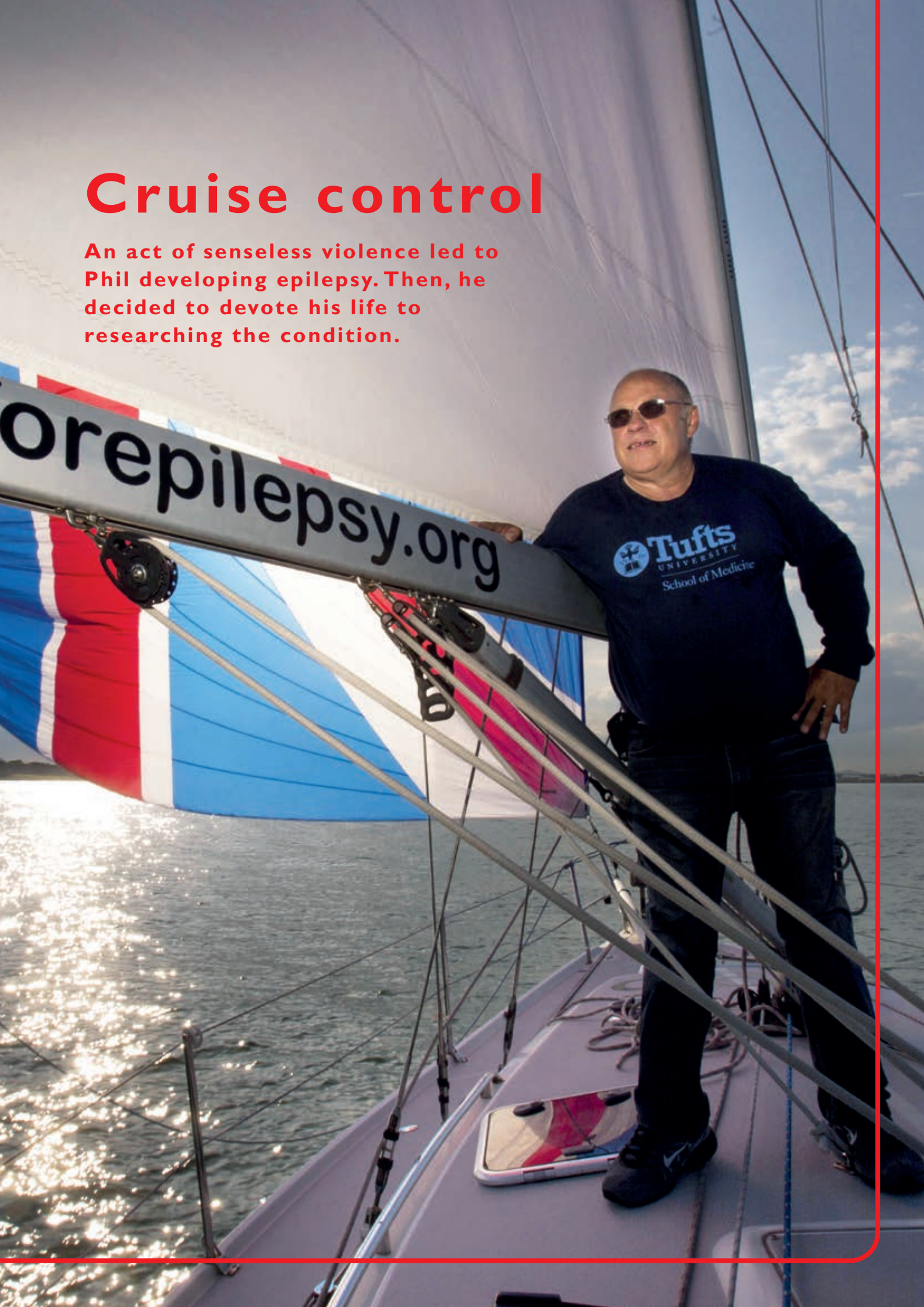
I always say enjoy life and give everything a try. It's been a long process, and I'm still recovering two years down the line, but I'm doing well.

If you're considering surgery for your epilepsy, Epilepsy Action can offer further information and support about your procedure: *epilepsy.org.uk/surgery*

Simon still enjoys coaching football

Cruise control

An act of senseless violence led to Phil developing epilepsy. Then, he decided to devote his life to researching the condition.



Phil Haydon remembers the day that changed his life forever. For many, it was a sunny day in 1972, in the south of England. For Phil, who was 15 at the time, it was the last day of school before the holidays, and the exciting start of weeks of freedom.

He and a friend were cycling home, when he suddenly felt a heavy thud on the left side of his forehead.

"I didn't realise at the time," says Phil. "A drunken teenager with a grudge had thrown a house brick at my friend, but his poor aim meant I was the victim. The blow caused me to veer across the road. Blood streamed down my face, so much that I couldn't see out of my left eye."

As the pair weren't far from school, they decided to backtrack there, rather than go home. Phil thought he'd just suffered a bad cut. But on arrival, the school secretary's face told a different story. "Her face turned white and she almost fainted at the sight of me."

Before Phil knew it, he was rushed to hospital in an ambulance where his parents were waiting. Yet the local infirmary didn't have the facilities needed, so he diverted to Radcliffe Infirmary in Oxford and underwent emergency surgery.

Doctors had to remove a shard of brick lodged in his forehead. It was here that Phil found out how serious his injury was.

"It wasn't just a bad cut. The impact of the brick on my head was sufficiently violent to crush part of my skull. A surgeon had to remove a two-inch diameter piece of my skull behind the forehead."

That first week after the accident was a blur for Phil. After arriving at the hospital, he started having multiple tonic-clonic seizures. He spent another week in hospital, after which he was discharged with prescribed epilepsy medicines phenobarbitone and phenytoin.

"I didn't realise the magnitude of what had happened to me nor did I understand the potential long-term consequences. Perhaps this was lucky, as it meant I was not holding back from moving forward.

Phil spent the rest of the summer recovering, and when he went back to school, he found it a struggle. It was difficult to concentrate and he frequently felt dizzy. But his parents were adamant that he attended every day and told him to do his best. Phil later discovered that his dad told his teachers not to go easy on him, and to treat him like any other student. His dad was concerned about Phil using his condition as an excuse not to try.

> **"Part of my skull was crushed. They had to remove a two-inch piece of my skull behind the forehead"**

"This was tough love, and not something I'm certain I could do, but for me it was effective. Despite my hard work however, I still failed half of my O-Level classes. But I scored well enough in my A-Levels to be accepted into The University of Leeds in 1976."

It was Phil's personal experience with seizures that inspired him to study a subject that could reveal more about the mysteries of the human brain. "Just before a seizure, I would get an aura. It feels like the beginning of a seizure, but you're still conscious, and then your brain suddenly takes over. I remember thinking, 'Oh my goodness, I think I have control, but I do not'. The brain is just allowing me to think I have voluntary control.

"To this day, over 40 years later, I still remember the auras that came with my seizures. I started to ask, how does one have a seizure? What happens to the neurons and the networks in the brain?"

Phil became fascinated to know more, to help him gain a better understanding of what was happening to himself. He chose to study physiology, and then began to specialise in neuroscience as soon as he could. This led to him researching various neurological conditions, such as Alzheimer's, depression and epilepsy. His first two years at university were a struggle, he admits. "I don't do well remembering facts and when combined with being a bit of a rascal when I was younger, I didn't perform too well in my exams in those years."

However, in his third year Phil found his calling: his classes were almost exclusively focused on practical lab research. "It was logical thinking and practical work, and that's where I really caught fire in terms of what I wanted to do."

Following this, Phil wanted to pursue his education towards a doctorate but hit a stumbling block. "My professors at Leeds dissuaded me from pursuing a PhD, saying that my grades weren't good enough. I argued with them, then offered to pay my own way, using funds I'd gotten as compensation for my injury. The reality was I only had enough funding to support myself for one term."

However, Phil's motivation and passion for his field meant he wasn't about to give up. He applied anyway. "When I want to do something, I try not to let obstacles get in my way. I had no idea how I would pay for the second term, but I thought if I let that get in the way I would never succeed."

Phil also managed to land a weekend job as an ECG technician in the local hospital to help fund his studies. Then one day, the chair of his department encouraged him to apply for the Emma and Leslie Reid Fellowship for post-doctoral studies. Phil thought this was a little unusual, applying for a post-doctoral fund, despite not being a post-doctoral student, but went for it anyway. When he heard back, it was bad news, or so he thought.

"I was told I interviewed well but couldn't be awarded a fellowship since I wasn't a post-doctoral student. I had a sinking feeling – I thought it was all over


Phil is careful about monitoring his medication and tiredness

and that I would need to go to back to my hometown to find a job. But in the next sentence, the panel told me they would be granting me the first annual Emma and Leslie Reid scholarship for graduate studies. What an emotional swing in just a few sentences!"

Phil was over the moon. He had landed a scholarship that paid for his entire three years of PhD study. "Words cannot describe the feeling. They believed in me and now the only obstacle to my getting a PhD was whether I was creative enough to perform the science. It was remarkable."

Phil initially studied synapses, the gaps at the end of neurons that allow signals to pass between one another. Then, a chance encounter led them to examine glial cells, which are cells that provide vital support for the neurons in the brain. Phil and his team discovered astrocytes, a type of glial cell, could also release chemical transmitters.

"This was one of the observations that we had to follow up on since it was so novel. We published the first paper on this in 1994 and since then it has been our focus. We have been able to identify more roles of astrocytes. We looked at how they control synapses, regulate sleep and wakefulness, and how they contribute to epilepsy, among other conditions of the nervous system."

Phil went on to complete his PhD in physiology and undertake his post-doctorate training at the University of Iowa in the United States. "I was attracted to neuroscience because there was a certain degree of being able to relate to it."

> **"I was attracted to neuroscience because there was a certain degree of being able to relate to it"**

Phil studied fundamental neuroscience for several years and while working as a Professor at the University of Pennsylvania School of Medicine, he collaborated with Professor Doug Coulter. He was an expert in epilepsy, and together with him, Phil was able to focus some of his work into this area.

"It's been so rewarding to identify potential mechanisms underlying epilepsy. When I moved to Tufts University to be the Annetta and Gustav Grisard Professor and Chair of neuroscience, I was fortunate to be able to hire several new colleagues. One of the areas that I emphasised research was in epilepsy. I hope that by doing so I have been able to help the community and to accelerate research in this area."

Today, Phil has been seizure-free for more than 40 years thanks to his epilepsy being medically controlled. However, he finds discussing his auras difficult. "If I'm asked, I describe them but generally stop before finishing. Even the thought of auras is so vivid and realistic that I need to stop, as I'm concerned it might trigger a seizure.

When he's not conducting research in neurology, Phil dedicates his life pursuing another passion: sailing. Before his injury, Phil was a competitive white-water kayaker, which he then had to give up on due to his condition.

"That got pushed aside as I went to college and had a family. As my kids started to leave home for college it was time to find a hobby that I was passionate about. Being on the water was what I loved. Kayaking, I can't do that – it'd be too dangerous. So, I decided to give sailing a shot. In 2007 I took classes on the Delaware River. And then I got hooked."

While Phil was living in Boston, he bought a boat in 2009 that he named Prairie Gold and has sailed on it for around 18,000 nautical miles. Then, in 2015 Phil decided to take it up competitively, entering a 2015 New Year's Day race.

"I was immediately bitten by the racing bug and that summer went to compete in more events further afield."

Phil now sails on a Quest 33S named Cepheus, a 33-foot sailboat. "She is quite amazing to sail. With just a little wind she picks up and gets moving. There aren't many creature comforts on her but feeling her move through the water is quite thrilling."

Despite Phil being seizure-free, he still has to be careful with his epilepsy when he's on the water. "With any medical condition you have to put boundary conditions on what's reasonable. So, for example, sleep deprivation can be a trigger for seizures in some people."

So before Phil went offshore sailing, he practised sleep deprivation at home. He took an hour's nap at night, woke for an hour, slept for an hour, then woke for another hour. He'd do that for several days to discover how his body would react, within the relatively safety of being at home.

Luckily for Phil, his seizures never emerged, and he was comfortable with doing longer trips and races.

"Kayaking was too dangerous... I decided to give sailing a shot. I took classes and I got hooked"

"Another concern is taking medications on time. I have a logbook where I document the boat and my medications. If I'm sailing for several days, I can get fatigued. This logbook helps make sure I don't forget to take my medicines. I also have an app on my phone to measure my reaction time, which can highlight how tired I am. I calculate this in advance and use it as a method to let me know when I should take a nap."

As well as this, Phil makes use of safeguards that are recommended for any sailor out on the water.

- Being attached by a tether to the boat
- Using a satellite tracker so people can monitor his journey
- Having regular check-ins with satellite phone calls and emails
- Filing a plan with crew onshore, so they understand the journey and can see if there are any changes in his route. In 2019 Phil had a problem with his boat that caused an alteration to his route. Thankfully with his safety measures, his crew knew he was fine

Phil also knows that sailing can be a dangerous experience, especially alone. To prepare, he hits the gym several times a week with a trainer, to gain strength and endurance. Funnily enough, he also practises napping, which is essential to staying alert and able when sailing. "This is very important, as it allows me to very quickly take a 20-minute invigorating nap." Phil also attends safety seminars and medical training, including learning how to self-treat if he ever needed.

Phil has since sailed as far north as Maine to destinations as far south as New York, Bermuda and the Caribbean. Along the way, he's learned how to deal with some challenging situations. In 2019, during a solo race to Bermuda, Phil's boat hit some turbulent conditions. He had a problem with one of the boat systems and needed to fetch some tools from below deck. The next thing he knew, a wave slammed into the hull, throwing him across the boat. Phil landed on a piece of wood and suspected that he'd broken some ribs.

"I decided for safety that I should turn around. I activated my safety measures and the shore crew were told I would be

coming back. The voyage home took two days. The hardest part was getting the sails down so that I could dock. I was alone and had to do this with one arm – the other was tightly held against my rib cage. I have learned through experiences that it is quite incredible what a motivated mind and body can do and overcome."

Despite this scary encounter, Phil has learned not to hold back. He says that sailing has unlocked a real passion in him. "When you're on a boat, you're the

Phil caught the sailing bug and has never looked back

skipper. You forget about everything at work and what's going on with your health. You just have to focus on sailing, making sure you're safe. Then, with time, I learned to love the sound of the water just rushing by the boat and trimming the sails just to get that extra little bit of speed.

"And, there are the stars. There's an incredibly starry night, and you're just at one with the environment, your boat and your mind. I can't fully describe the sensation. It's just amazing. You're looking after the boat; you're checking for issues. Then, you're looking at the Milky Way stream across the sky like you've never seen before in your life. And then you have time for your thoughts."

Phil is now preparing for the challenge of a lifetime in 2021: a three-year voyage that will take him around the world. And he's doing it in aid of a condition he developed that fateful day, and what motivated him to devote a lifetime of research towards: epilepsy.

"Our Sail for Epilepsy mission is to inspire people with epilepsy to take one more step towards achieving a fuller life. Our three-year circumnavigation will inspire people with epilepsy, raise funds to support research into the causes of intractable epilepsy and to raise awareness about epilepsy."

During the team's voyage, Phil plans to disembark at stages to meet with epilepsy communities around the world. These destinations include Bermuda, Panama, Tahiti, Sydney, Bali, Madagascar, Cape Town, Rio de Janeiro and the Caribbean, before returning home to Boston.

The Sail for Epilepsy endeavour will also post photos, videos and blogs as they travel around the world. People will be able to track Phil's ship via the Sail for Epilepsy website, and they plan to have live interactions with people living with epilepsy. For those who want to follow their voyage, there will be a weekly email newsletter available as well as regular posts to social media.

Like the scientist within him, Phil is being readily prepared for his voyage. "I will monitor and analyse my sleep patterns, stress levels and any medical challenges I face while sailing. Our hope is that this voyage will inspire epilepsy patients, their families, and their caregivers to ask themselves, are you able to do something to improve your quality of life? Can you take one extra step to do something you haven't done before, with the necessary guardrails in place?"

"When you're on a boat, you're the skipper. You forget about everything at work... it's just amazing"

"We want those affected by epilepsy to join us on this journey and are planning an online community to share inspirational stories of taking one more step towards a fuller life."

Despite Phil's impressive research profile within epilepsy, he wanted to give even more. "I want to give back to the community. Can you imagine if one person got inspired and it changed their life? What if one person learns that epilepsy doesn't have to be awful and they told their family and friends? I think big things can come from little steps."

A proportion of all the funds donated will go towards the partners of Sail for Epilepsy: Epilepsy Foundation New England, and Tufts University School of Medicine. Then, at the end of the five-year program all assets will be sold, and all funds will also be donated towards them.

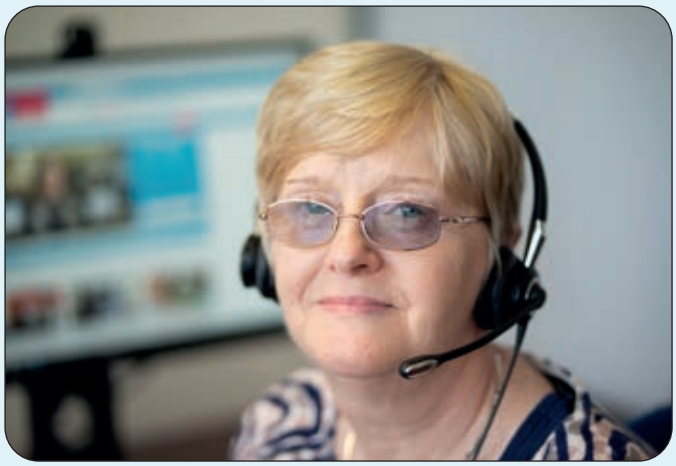
Funds going to Tufts will be used for research into the basic causes of epilepsy. "From this work, the goal is to identify new causes for epilepsy. This will set the stage for discovery of the next medicines designed for those patients who are currently treatment-resistant."

With the Epilepsy Foundation New England, Phil plans to help support people and families with epilepsy. "We'll also contribute to their camps that allow patients to enter programmes, including sailing camps! These programmes resonate with our ambition of inspiring people to take an extra step and to try to accomplish new goals."

For more information on Phil's voyage, visit *sailforepilepsy.org*
Facebook: *facebook.com/sailforepilepsy*
Instagram: *instagram.com/sail_for_epilepsy*
Twitter: *twitter.com/sailforepilepsy*
LinkedIn: *linkedin.com/company/sail-for-epilepsy*

Phil is currently training for a three-year trip around the world

Epilepsy Action Emergency Appeal: update



In these challenging times, Epilepsy Action remains committed to helping everyone affected by epilepsy to live their best possible life. Everyone at the charity wants to be here for people affected by the condition – whether you have epilepsy yourself or someone close to you does.

The coronavirus outbreak and resulting lockdown have presented real challenges to this. Of all the uncertainties Epilepsy Action is facing right now, loss of income is by far the most worrying.

As a charity, Epilepsy Action is completely reliant on fundraising and donations to fund the services we provide for people with epilepsy.

All the charity's usual income sources are affected by the coronavirus outbreak. People making donations or raising money by taking part in events and sporting challenges. People joining as a member or renewing their subscription. It's all affected.

Losing this income makes it more difficult to keep services going. Services like the Epilepsy Action Helpline and the advice available from the Epilepsy Action website. Work that people rely on for advice and support they know they can trust.

The coronavirus outbreak also means putting on hold other areas of the charity's work. These include local group meetings, relied on by many people as a vital source of understanding and support.

Epilepsy Action is working hard to keep services going wherever possible. Where work must be postponed or cancelled, the charity is trying to find other ways of delivering the same support.

The charity is also in regular contact with the Department of Health and Social Care to keep up with the ever-changing advice about coronavirus itself. The policy and campaigns team is monitoring government activity to ensure you can get the latest on how coronavirus could affect people with epilepsy.

This increased demand and requirement to work in new ways has placed unprecedented demand on the charity's resources. Coming at a time when income is already down because of the outbreak means there has never been a greater need for financial support.

Epilepsy Action members and donors have responded heroically to this increased need. Thank you to everyone who has donated so far. Your gift means that anyone who needs a little extra support at this time has somewhere they can turn.

Philippa Cartwright
Director of Fundraising

If you haven't yet donated to Epilepsy Action's emergency appeal, you can still do so at: *epilepsy.org.uk/emergency*

You can also donate by calling 0113 210 8851, or by using the enclosed reply envelope to return to donation form on the reverse of the address sheet.

PURPLE DAY 2020: uniting the epilepsy community during COVID-19

Purple Day plays a huge part in raising epilepsy awareness throughout the world. It is a day dedicated to encouraging people to open up about their condition, share their stories and get talking about epilepsy.

Purple Day fell on Thursday 26 March, just as the coronavirus outbreak went global and the UK went into lockdown. This year's celebrations were very different. It was not going to be all purple balloons, pom poms, cupcakes, selfies and dance routines. With group events cancelled due to social distancing measures and the world's media consumed with news of COVID-19, it presented challenging new circumstances. Now, more than ever, the feeling was that people with epilepsy needed to feel united, albeit virtually. Purple Day was still going to be important in achieving that.

Across the charity, we had to respond to a fast-moving situation. Crucially, we needed to ensure everyone was kept up-to-date with the ever-unfolding safety information. With calls to our helpline rising five-fold in the first week alone, it was vital we were there to support people during the initial stages of this uncertain and challenging time.

We had regular conversations with the Department of Health & Social Care to make sure our helpline team could relay all the latest updates to the public. We also created new webpages with answers to some of the most frequently asked questions about coronavirus.

We had a series of videos in the can and ready to go for 26 March. Filmed five weeks before, they focused on group of people from all walks of life. They met as strangers on a rainy Friday in Leeds and the cameras captured their conversations about the impact of epilepsy.

Whether they were parents of children with epilepsy, teenagers or young people trying to find their independence and career paths, they found common bonds in some unlikely places. The losses they'd experienced due to epilepsy were profound, but they had also gained some positives along the way.

- Harry is a student from Belfast. He was diagnosed two years ago and can have weekly seizures. He has struggled with his memory and people's misconceptions of epilepsy. He shared his thoughts and frustrations with Rosie.

Actress Freema Agyeman posted on Instagram in support

Helen Davis and her daughter Lucy Davis speaks to Patience about being diagnosed with epilepsy as young adults

- Rosie was diagnosed as a teenager. She talked to Harry about the impact of epilepsy on her independence and confidence. She has also lost work due to shame about seizure injuries. Losing friendships and trusting others has also been a struggle.

- Paul is dad to twin teenage boys, who both have uncontrolled seizures and complex needs. He talked to Lauren about the stigma around epilepsy, and how he and husband Michael fight to give their boys the best family life possible despite everything they face.

- Lauren lost her confidence as a teenager dealing with epilepsy at school. She talked to Paul about her later rebellion and denial while at university. Her career as an artist was the change she needed in helping her manage her condition and her stress levels.

- Patience, 20, was diagnosed in her teens and it came as a huge shock to her family. She talked to Helen and Lucy, who was diagnosed at the same age, about the stigma she feels and how she has missed out on university and relationships.

- Helen talked about how frightening it was to witness daughter Lucy's first tonic-clonic seizure and how they learned to cope as a family. They shared a lot of their worries with Patience, who had been through similar problems in her teens and was trying to regain her lost confidence.

Media stories had to be turned on their head, so they were relevant to the coronavirus outbreak. Harry, who appeared in our video, shared his 'quarantine diary' with Metro UK. He talked about managing his condition, his sleep and stress levels, while working in a frenzied Belfast supermarket at a time when the public were panic buying and social distancing was being ignored.

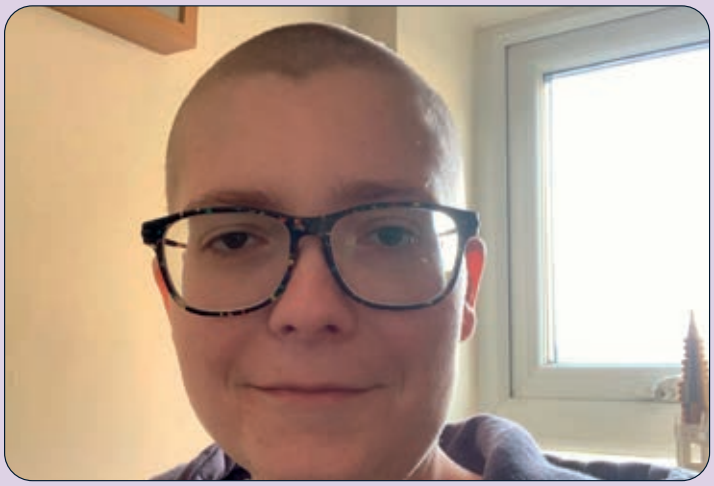
The media still supported us on Purple Day, in the *Metro*, on BBC radio stations and on CBBC Newsround. Dozens of staff worked from home to bring Purple Day to life, all in appropriate attire – even pets and children embraced the purple theme.

Fundraising got ever more inventive as virtual events quickly took shape. We encouraged people to set themselves a virtual challenge and seek sponsorship to reach their goal. Challenges ranged from walking 10,000 steps a day to organising virtual purple parties. Katie Gutteridge, who volunteers for Epilepsy Action, decided to shave her head on Purple Day. She saw how the charity stood to lose vital funds after mass events like the Virgin Money London Marathon were postponed or cancelled, due to COVID-19. Armed with her boyfriend's clippers, she took the plunge and raised over £600. A fantastic achievement!

There are lots of virtual events you can still get involved with including taking part in the Epilepsy Action online Quiz or organising a Virtual Tea Break. Visit *epilepsy.org.uk/support-our-work/virtual* for further details. More events will be taking place later in the year, as lockdown eases, so you can still order a fundraising pack and plan your Purple Day event for a few months' time.

Our fundraising appeal had to be rewritten at the last minute. Suddenly the most pressing need became protecting the income that ensures we can run vital services for people with epilepsy. It was brilliant to see people donating, especially with world events taking such a dramatic turn: an uplifting reminder that people with epilepsy weren't being forgotten.

Lauren speaks to Paul about changing careers and the stigma surrounding epilepsy



Volunteer Katie Gutteridge shaved her head on Purple Day

Social media is always a positive, vibrant space for the global epilepsy community to come together on Purple Day. It was crucial to still reach out to them, despite news feeds full of coronavirus posts. Our new videos were liked over 1,700 times and shared over 750 times. Purple posts and first-person stories were also a great way to help people feel connected and uplifted at a time of uncertainty. A personal post from actor, and Epilepsy Action supporter, Freema Agyeman, was a huge boost on the day, with 4,500 likes.

Epilepsy Action's Phil Lee said, "It was wonderful to see the way people responded to Purple Day, especially at such a time of national crisis. Virtual events sprang up in creative and inspiring ways, ensuring we could continue to provide essential services for people and still bring communities together. Thank you to everyone who took part, shared their stories, liked our posts on social media, and donated – showing your unwavering support for people with epilepsy on Purple Day and beyond."

My journal

Cathy loved playing videogames, but a car accident left her with photosensitive epilepsy. But today, she's working with the industry to help ensure people with epilepsy still get to enjoy games.

It was August 2005. A month earlier, I'd turned 16. I was on the road to recovery from a serious car accident in late 2003 that left me broken and battered. A dozen surgeries and 20 months of physical therapy followed, but at long last, it seemed like life was almost back to normal.

That all changed one morning. I was walking into the kitchen to join my parents for breakfast. Then, the next thing I knew, I was on a gurney in a hospital emergency room. The nurses and doctors were asking me questions, but I didn't understand why they were there, where they came from or how I got there. I remember catching a glimpse of my parents, and I saw the utter terror on their faces. That's when I got scared because I knew whatever happened, it was bad. It was hours before things seemed normal again. My dad was holding my hand while my mum was pacing back and forth. "What happened? Why am I here?" I asked. My dad looked at me puzzled, because I'd been told why multiple times. "You had a seizure, sweetheart. Don't you remember?"

I thought my life as I knew it was over.

You see, up to that point, video games were my entire life. I'm on the autism spectrum. I had very, very few friends. I didn't emote well. I had trouble expressing myself. None of that mattered with my beloved video games. I could go on

"What happened? Why am I here?" I asked. My dad looked at me puzzled as they told me before. 'You had a seizure, sweetheart. Don't you remember?'"

fantastic adventures with them - solve mysteries or save whole kingdoms. I could be a spy or a turtle-fighting plumber or guide my Golden State Warriors to the National Basketball Association finals. I got a PlayStation on Christmas morning,

A serious car accident led to Cathy developing epilepsy

1996, which planted the seeds for gaming's complete takeover of my life. Then a Nintendo 64 a few years after that.

From that day onward, I averaged 12 hours a day on my consoles. My parents recognised early on what a positive impact they had on my life - one of the only sources of self-esteem I had. Following my accident in 2003, I couldn't even hold a cup for months. The thing that kept me going, that got me through the painful surgeries and rehab, was my desire to get gaming back. In fact, I believe once I was able to hold a controller or operate a mouse, it sped my recovery along. By August of 2005, I was still in physical therapy, but I had my games. I knew I'd be okay.

"My parents recognised early on what a positive impact videogames had on my life - one of the only sources of self-esteem I had"

Then epilepsy became part of my life. Because of the trauma I'd sustained from the accident, I started having generalised seizures at regular intervals. Even worse, I had the double whammy of also being photosensitive, meaning flashing or flickering lights and images triggered my seizures. I spent nearly two weeks in hospital before I was put on medication and sent home.

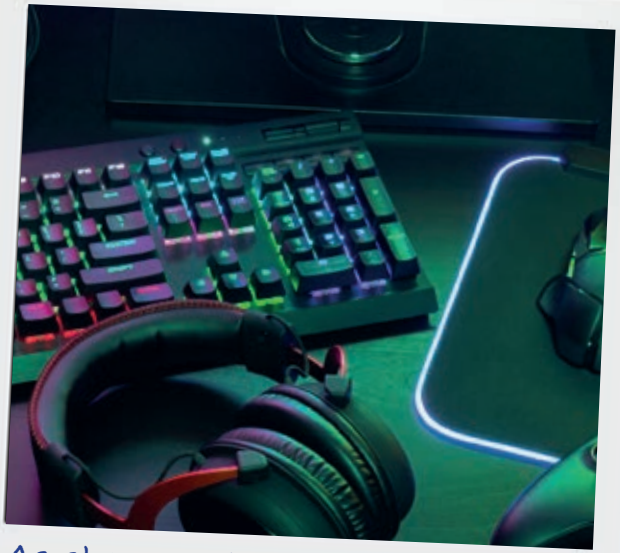
A verdict on my gaming future wasn't presented to me at that time, but I figured I knew the answer. Like so many people, I thought being photosensitive meant I couldn't play games at all. At the age of 16, with all I'd already been through and the pain I was still in, I couldn't imagine a life without them.

In early October 2005, doctors had everything they needed to know about me. We met with the main doctor on my case, but I was so frightened to ask about games. Finally, my parents asked for me. I felt the weight lift from my heart when he told me with caution and proper set-up and supervision, I could still play. He wanted me to stabilise on my new meds first, but hell, a month was nothing compared to the wait I'd had a year earlier. It was probably the happiest moment of my entire life.

About a month later, my parents asked me to come into the living room. They had a surprise for me - they didn't want to wait until Christmas. The doctors had given me the all-clear. They presented me with a present to celebrate: the newly released Xbox 360, with Perfect Dark Zero and other games. I was overwhelmed with joy as I set up my new console and linked my account to it. The room was heavily lit and I had to be quite far from the screen, but hey, controllers were wireless now, no big deal!

"Like so many people, I thought being photosensitive meant I couldn't play games at all. At the age of 16, I couldn't imagine a life without them"

I went to pop a disc in the drive. But, as the tray came out, suddenly my brand new Xbox 360 wasn't a game machine. It was a revolver, and I was loading a bullet in the chamber. I felt like I wasn't just about to play a game. I'd also be playing Russian Roulette with it. That day, I lost my nerve to play it, or any game. I wouldn't even watch television. I went from being devastated at the thought of losing gaming to being too scared to even look at a game.



As she was photosensitive, Cathy thought could no longer game

Cathy could play games, as long as she was careful

It took me almost two weeks to build up the courage to start playing games. I started as small as I could get, using a simple game called Lost in Blue on my handheld Nintendo DS. I was so on the edge playing it at first that I wondered if I would ever enjoy gaming ever again. Five minutes later, I was lost in the experience, and gaming once again returned to my life. For good this time.

Looking back on this time in my life, I realise the nightmares, anxiety, and fear would have been significantly lessened through better education to the general public about epilepsy. The biggest misconception about epilepsy and gaming is simple to explain:

"I felt my console had become a gun, and I wasn't just about to play a game, I'd also be playing Russian Roulette with it"

people with epilepsy can't play video games. Game developers assume it. Gamers assume it. The general public assumes it. I've even met medical professionals who assume it. But those living with this condition can and do play games.

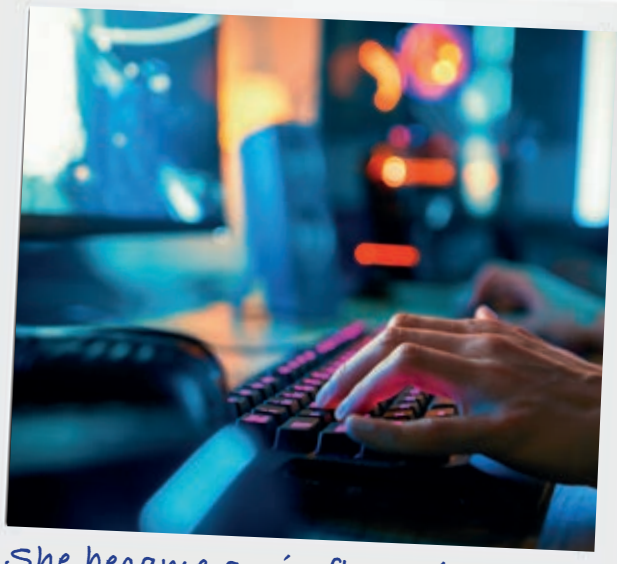
Of course, gaming had changed for me. It was no longer as simple as turning a game on, and never would be again. It took a LOT of experimenting to figure out what made playing safer for me. Distance from the screen was a major part for me. The less of your field of vision contains the triggering elements, the safer you are. It was a pretty hard pill to swallow for someone who used to sit close to large televisions. Rooms with screens had to go through several rounds of reorientation.

Lighting is important too. I could never play games in the dark again, which took the fun out of the horror genre. Early on, we tended to overdo the light, probably thanks to the saying "better safe than sorry." Now I find it's best to have a couple of lights placed alongside the viewing area that are brighter than the TV itself. Finally, if push came to shove, I could throw some sunglasses on for higher-risk sequences. These worked for me, and if I wasn't lazy and took the time to set everything up, I could play most games. Not all, but hey, some people can't play games at all. I genuinely consider myself lucky.

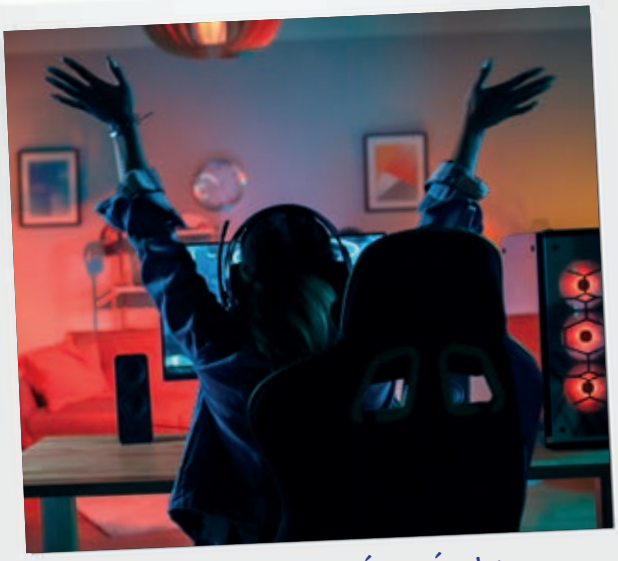
In July 2011, I started blogging under the name Indie Gamer Chick. It caught on quickly, and before I knew it, I was having a fairly

"It took a LOT of experimenting to figure out what made playing safer for me. Distance from the screen was a major part for me"

significant influence on the independent game scene. I wanted to be different from other game critics, so I made a policy that I would never turn away a review request. The one exception I had to make was games with effects that could trigger my epilepsy. This had an unexpected side-effect: game creators started asking what they could do for me, and people like me. Before I knew it, I was having a major impact on game accessibility. Not just from small indie studios, either. Directors or project managers from major game studios were asking me questions about how photosensitivity works and how to handle it in their games. Like so many others, they believed that those with epilepsy couldn't



She became an influential blogger on videogaming



She turns her passion into helping more gamers like her

play their games at all. Once they got to know me and see my passion for games, epilepsy was no longer an unknown concept to them. Something that happened to other people. It was something that people who love video games might have too. It was real now to them, and it had to be dealt with.

Of course, epilepsy is so much more complicated than people realise. I had to squash so many misconceptions about it that developers realised there was no possible way their games could accommodate every form it takes. Thankfully, they still wanted to do whatever they could and continued to seek advice. I wasn't alone in this, either.

"I wish I could go back in time and tell that frightened little 16-year-old girl everything would work out. I'd tell her that she'd be making gaming better for everyone someday"

Soon, developers who had studied the issue, accessibility supporters and fans who followed my game reviews joined forces. They were working with me to help spread the word and add options to games to make them safer. It was a turning point in my life, for sure. I'd amassed a pretty good Twitter following for a niche game critic known for having a foul mouth and no tact.

Today, literally thousands of those followers act as guardian angels for me, alerting me about games or other media that potentially pose a risk to me. There's something about having complete strangers looking out for you that you can't imagine how amazing it feels. We live in troubling times. But my faith in humanity is restored by people seeing strobes in a movie or a video game and their first thought is to warn me. It's special. I'm so lucky.

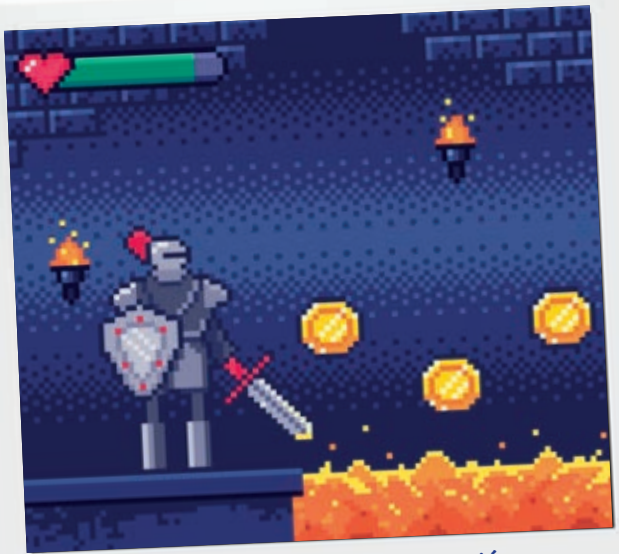
That's really my story. The luck. Because I could have just as easily lost games in 2005. If medication couldn't properly manage my condition. If all the tricks we used didn't work. It could happen to anyone, and almost happened to me. The world isn't made for people with photosensitive epilepsy. Movies, concerts, sporting events, and especially video games typically don't have us in mind. That was certainly the case in 2005, when the best you could hope for was a warning screen when a game started up. Even by 2011, when I started Indie Gamer Chick, it was rare for a game to include options to disable the especially bad effects. But, it's not that rare today. For me personally, it makes me proud that I played a role in making that happen.

I thought that having epilepsy would be the end of my life in gaming, and maybe even the end of my life altogether. I wish I could go back in time and tell that frightened little sixteen-year-old girl that everything would work out. I'd tell her that she'd contribute to making gaming better for everyone someday. It's something she needed very much to hear - that her story had a happy ending.

About photosensitive epilepsy

Around three in every 100 people with epilepsy are photosensitive, meaning some or all their seizures are triggered by flickering or flashing lights or images. If you suspect you may have photosensitive epilepsy, please consult your doctor before playing videogames or watching films with strobe effects.

For more information and advice about photosensitive epilepsy, visit: *epilepsy.org.uk/info/photosensitive-epilepsy*



She even helps game studios make more accessible games

Medical files

Every issue, Professor Martin Brodie looks briefly at the various anti-seizure medicines for people with epilepsy. This time round, he talks about pregabalin.

Pregabalin (PGB) first became available in the UK in 2005 as an add-on treatment for focal epilepsy with or without secondary generalisation.

It is also licensed for generalised anxiety conditions and neuropathic pain syndromes, which is chronic pain caused by an injury to the nervous system. The starting dose is usually 150mg daily in two doses. It is then increased to 150mg twice daily or 100mg three times daily. If the drug is effective and well tolerated, the maximum is 300mg twice daily.

PGB is not licensed for use in children. It's not metabolised in the liver but passes unchanged through the kidneys. This means it doesn't interact with any other drugs, which makes it easy to use as an add-on treatment.

Shortly after it was first introduced, people who were taking large doses of PGB reported feeling "high"

Common dose-related side-effects of PGB are tiredness, weight gain, unsteadiness and constipation. Other less common side-effects include headache, double vision, dizziness, ankle swelling and tremors. Some men and women have painful breast swelling. Sexual dysfunction can be a rare side-effect for some men. PGB doesn't cause skin rashes or any other allergic side-effects. When taken by pregnant women, it does not damage the unborn baby.

Shortly after it was first introduced, people who were taking large doses of PGB reported feeling "high". This has made it popular with people who misuse drugs and it is now often sold on the streets by people who also use morphine and other opioid drugs. As a result, prescriptions are restricted in some parts of the world.

PGB is an effective treatment for a range of conditions, including focal epilepsy, particularly if you also have anxiety or neuropathic pain.

If you are experiencing any problems with your epilepsy medicine, it's important that you don't stop taking them without discussing it with your GP. Suddenly stopping your epilepsy medicine could cause you to have more, or more severe, seizures.

Council of Management Update

Due to the ongoing coronavirus pandemic, we have updated our schedule in regard to our Annual General Meeting and Council election processes for 2020:

1 February to 4 August
The nomination period has been extended from its original deadline of 21 April to 4 August. This will be promoted through Epilepsy Action's website and other communications channels. Nomination enquiries and queries are fielded by staff. Once received, nominations are received and processed, including checking qualifying criteria and referral to the nomination panel if requested.

21 July to 4 August
Nominations for the Council election can be accepted from 21 July (90 days before the AGM) and must be received by 4 August (56 days before the AGM). Nominations can be received at any time, but will not be formally accepted until 21 July.

8 September
AGM papers and council member voting papers will arrive with members in the September issue of *Epilepsy Today*.

29 September
Epilepsy Action's AGM and Council elections will take place.

30 September
Election candidates will be notified of the results. These are then made public.

Epilepsy support for you

For some of us, epilepsy can be an isolating condition which can make us feel lonely and misunderstood. But there are actually many people in the UK and around the world with the condition. One of Epilepsy Action's roles is bringing people together to share their knowledge and experiences and talk to others going through similar situations.

Local groups: update

We know that many of you take comfort from meeting others affected by epilepsy through our branches and coffee and chat groups. As we aren't currently able to offer that support, we're working hard to find new ways to help you stay connected to other people who understand.

Our local services team are looking into providing online support groups. We are looking forward to bringing you further news on this. You can find information on all our support services at: ***epilepsy.org.uk/info/daily-life/safety/coronavirus-and-epilepsy-action***

For more information about these, you can visit: ***epilepsy.org.uk/coffeeandchat*** or ***epilepsy.org.uk/nearme***. You can also get more details by calling us on: **0113 210 8800**.

Online resources

Epilepsy Action also has an online space where people can meet others with epilepsy and exchange stories and information about their condition. This is called forum4e and can be found at ***forum.epilepsy.org.uk***. You can also find us on social media.

There are also a number of websites which can help people find pen pals, such as ***penpalworld.com***, or ***ablehere.com*** for people with disabilities and conditions. Bear in mind that these websites are not part of or run by Epilepsy Action.

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Visit www.vnstherapy.com to learn more and view important safety information. Not approved in all geographies, consult your labeling. Individual results may vary.