Purple Day
Helping children live better with epilepsy

Also in this issue
• why it’s still a challenge accessing cannabis-based medicines
• UK epilepsy scientific meeting reveals latest research and information
• 61-year-old Terry describes his battle with epilepsy over the years
Welcome to the first issue of Epilepsy Today in 2019!

We hope you’ve had a happy and relaxing winter break.

There is a topic that has been dominating headlines for months now, and that is cannabis-based medicines. The UK’s position on cannabis-based medicines has changed dramatically over the last few months. In November, it finally became legal for UK specialist clinicians to prescribe cannabis-based medicines. This was set to be an important step for people with epilepsy who are in exceptional need of a new treatment. But unfortunately, many people are still finding they can’t access this type of medicine. On page 8, we look into why this is happening.

This issue, we also bring you some interesting epilepsy research. On page 12, we look at a recent study looking at public attitudes in the UK towards people with epilepsy. The research shows a positive outlook, but it highlights that there is still more work to be done to reduce stigma and spread accurate information about epilepsy. Meanwhile on page 20, we have the first in a two-part article summarising the main sessions from the recent International League Against Epilepsy scientific meeting. The meeting highlights what specialists are working on to improve care for people with epilepsy and what researchers are focusing on next.

We also have some wonderful real life stories for you this issue. Terry was diagnosed with epilepsy at 22 years old and had to leave his career in the navy. On page 14, he talks about the struggle to get his seizures as controlled as possible, their return years later and finding solace at a local drama group. On page 27, you can read about Francesca’s experiences with epilepsy and mental health, her many seizures and having to miss a lot of school. She talks about deciding to get fit and take on a new challenge – Tough Mudder. This is an obstacle course designed to challenge participants physically and mentally.

Finally, don’t miss our ‘Epilepsy, my family and me’ events calendar on page 24. These events are held around the country to offer information, support and fun to families with children affected by epilepsy. On page 18, you can find out how you can get involved with Purple Day this year and help support children living with epilepsy.

We hope you enjoy this issue and have a great start to the new year!

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NHS England makes everolimus available

NHS England has agreed to make available a treatment for hard-to-treat focal onset seizures caused by the condition tuberous sclerosis complex (TSC). This has come after the organisation initially decided not to commission the medicine – everolimus – in June 2018.

NHS England has said that from 1 April 2019, everolimus can be given to patients two years and older with TSC-related seizures alongside their current medicines. This is in cases where seizures have not responded to at least two different epilepsy medicines and where surgery is not considered appropriate. It followed recommendations made by the Clinical Priorities Advisory Group that everolimus be made available.

TSC is a genetic condition affecting fewer than six in 100,000 people. It can lead to growths developing in parts of the body including the brain. NHS England’s Commissioning Policy, published in December 2018, says that seizures are one of the most common neurological features, occurring in more than four in five people with TSC (84%).

TSC-related seizures are currently treated with epilepsy medicines. Other treatments, such as the ketogenic diet, vagus nerve stimulation and epilepsy surgery are also considered. There is more information on these on the Epilepsy Action website at epilepsy.org.uk/ketogenic, epilepsy.org.uk/VNS and epilepsy.org.uk/surgery.

Epilepsy medicines not part of plans to let pharmacists ration medicines in UK

The government has said epilepsy medicines will not be included in plans to allow pharmacists to ration medicines in the case of a no-deal Brexit, The Times has reported.

In December 2018, the government set out plans to avoid shortages of medicines, which it called a “serious shortage protocol”. This would be in the event that no Brexit deal is made and the UK leaves the EU without one.

As part of this plan, the government would allow pharmacists to ration medicines in order to avoid extreme shortages. This includes changing prescriptions without having to contact GPs first.

Epilepsy Action chief executive Philip Lee said: “We are pleased to hear the government would allow pharmacists to ration medicines in the case of a no-deal Brexit.

“There is strong evidence that changing or stopping medication for many people with epilepsy can cause breakthrough seizures or make seizures worse. These are major issues for people with epilepsy and can have a significant impact on all areas of life, from education to employment. For example, a single seizure can cause someone to lose their driving licence for a year. At worst, it could be fatal.”

Mr Lee added: “We will continue to work with other epilepsy organisations on this important issue. As part of this we will be seeking further assurances from the government that people with epilepsy will continue to be able to access necessary medicines and treatments after Brexit, deal or no deal.”

The Department of Health and Social Care explained that the protocol would be developed in collaboration with doctors. “In the unlikely event of a shortage of any medicine, it is vital that patients continue to receive the high level of treatment they expect.”
Child health in England and Wales poorer than other western countries, report shows

Child health in England and across the UK is falling behind other western countries, according to a report by the Royal College of Paediatrics and Child Health (RCPCH).

The report, published in October, features figures showing that death rates in 1-19-year-olds with epilepsy in England and Wales are higher than those in other western countries. The RCPCH report compared data on death rates between 2001 and 2015. It added that this trend is despite substantial falls in death rates in England and Wales in that time.

The report predicts that if current trends continue, death rates in children with epilepsy in England and Wales are likely to remain higher than those in the EU15+ countries by 2030.

President of the RCPCH and author of the report, Professor Russel Viner, said that England is at risk of falling further behind the EU15+ countries. He added that the current trends “could be turned around if key actions are taken”. The RCPCH has called on policymakers in the NHS to improve the health of children and young people as part of their long-term plan.

Epilepsy Action’s chief executive, Philip Lee, said: “It is hard to believe that in 21st century Britain we are falling behind in providing quality healthcare for children with epilepsy. The figures paint a worrying picture for children and young people with the condition and these health inequalities must be addressed immediately.

“Better seizure control and more support for families to help them manage the risks associated with epilepsy would significantly improve the lives of children with the condition. This will ultimately reduce the likelihood of death associated with epilepsy. The government must act now and give children with epilepsy the attention – and future – they deserve.”

The report also focuses on concerns around higher death rates in babies compared to the EU15+ countries and a predicted increase in reported mental health problems. It states that trips to A&E for children and young people could increase by 2030 and that obesity may be an increasing problem in deprived areas.

The negative effects of poverty and deprivation on the health of children across England and Wales is also highlighted.

The RCPCH report includes recommendations, such as the development of a Children and Young People’s Health Strategy and a joined-up approach from the NHS to healthcare planning.

The Epilepsy Action website has information on staying safe in- and outdoors (epilepsy.org.uk/safety) if you have epilepsy, as well as tips for caring for a child with epilepsy (epilepsy.org.uk/children).

Poor mental health support for children in epilepsy clinics

Almost nine in 10 Health Boards and Trusts in England and Wales do not enable mental health provision within epilepsy clinics. This is despite research showing that children with epilepsy are four times more likely to experience a mental health problem than their peers.

This is a finding in the new Epilepsy12 National Audit report from the Royal College of Paediatrics and Child Health (RCPCH). The report also found that nearly a quarter of Health Boards and Trusts are failing to provide routine and comprehensive care planning for children with epilepsy.

The report also highlighted areas of improvement. The number of epilepsy specialist nurses (ESNs) across England and Wales has increased significantly since 2014, when the last audit was published. ESNs are a key part of the epilepsy team, providing essential support to children, young people and families.

However, the report also found that almost a quarter of Health Boards and Trusts were not able to provide access to ESNs. Philip Lee, chief executive of Epilepsy Action, said: “It is encouraging to see that clear improvements have been made in some areas of children’s epilepsy services.

“Despite this, there are still too many children and young people with epilepsy whose health, wellbeing and safety is being put at risk. There needs to be a stronger focus on good care plans and support between appointments to improve epilepsy services and outcomes for young people. The report does a good job of highlighting best practice in this area and provides an opportunity for those services that are still lagging behind to step up.”

The Epilepsy12 National Audit was introduced to assess epilepsy care for children and young people in England and Wales. Care is measured against national guidelines and standards as set out by the National Institute for Health and Care Excellence (NICHE).
Epilepsy medicines pregabalin and gabapentin to be reclassified as class C drugs to help minimise possible misuse

The UK government announced last week that the medicines pregabalin and gabapentin will be reclassified as class C under the Misuse of Drugs Act 1971. The change will take place in April 2019.

Class C is the third in the government’s three-tier system for categorising controlled substances. Drugs in class C are associated with the least amount of harm compared with those in classes A or B.

Pregabalin and gabapentin are currently used to treat conditions like epilepsy, nerve pain and anxiety.

The Home Office has said that these medicines will still be available for legitimate use on prescription by a doctor after the change in law. The change means that doctors will now have to physically sign prescriptions rather than use electronic copies.

The medicines will have to be dispensed within 28 days of the prescription being written.

It said that the change means that it will be illegal to possess these medicines without a prescription. It will also be illegal to supply or sell them. This is an effort towards stronger controls, accountability and a reduction in the potential for misuse of these medicines.

The concerns with pregabalin and gabapentin relate to misuse of these medicines. This may include taking them if you don’t have a prescription or taking them in a way that is not prescribed by your doctor.

The concerns do not relate to taking the medicines for epilepsy as prescribed by your epilepsy specialist.

The government’s decision to reclassify these medicines follows experts highlighting a rising number of deaths linked to their misuse. However, according to researchers from the University of Bristol, more than four in five deaths (80%) involved the misuse of these medicines alongside street drugs, such as heroin.

In 2016, the Advisory Council on the Misuse of Drugs (ACMD) raised concerns over the possibility of addiction and misuse of these medicines. It called for them to be reclassified as class C. The government consulted pharmacists, pharmaceutical companies, doctors and patients, who backed tighter controls.

Minister for Crime, Safeguarding and Vulnerability Victoria Atkins said: “Any death related to the misuse of drugs is a tragedy. We accepted expert advice and will now change the law to help prevent misuse of pregabalin and gabapentin and addiction to them.”

“While drug misuse is lower now than it was 10 years ago, we remain committed to reducing it and the harm it causes.”

This is not the first medicine used for epilepsy to be classified as a class C drug. Midazolam and diazepam, used as emergency medicine for prolonged seizures, have been listed as class C for around 30 years.

If you are concerned about your medicines, you can speak to your GP or epilepsy specialist. You can also call the Epilepsy Action Helpline free on 0808 800 5050.
Guidelines for prescribing cannabis-based medicines called too restrictive

The 2018 guidance for clinicians prescribing cannabis-based medicines has been criticised by organisations for being too restrictive.

The guidance was published by the British Paediatric Neurology Association (BPNA) and the Royal College of Physicians (RCP) on October 31. This was a day before the new legislation came into force on 1 November, allowing UK specialist clinicians to prescribe cannabis-based medicines.

Specialists can now prescribe cannabis-based medicines to patients with “exceptional clinical need”. However, they have to ensure that there is clear evidence of a benefit and that other treatment options have been unsuccessful. Prescriptions also need to be in line with available clinical guidance.

Some organisations, including Epilepsy Action, are concerned over how restrictive the guidance provided is. The BPNA has stated in its guidance that it does not recommend the prescription of non-licensed cannabis-based products except Epidiolex.

Epidiolex is the brand name of cannabidiol (CBD). This is only one type of cannabis-based product. Others, including cannabis oil, which was at the centre of the case that sparked off the government’s review of cannabis-based medicines, are not recommended.

Epilepsy Action’s deputy chief executive, Simon Wigglesworth, said: “[The] change in the law should open the door for some children and adults with severe epilepsy to access potentially life-changing treatment. While this change is an important step forward, the guidance we have seen so far on how it will work in practice seems extremely restrictive.”

Epilepsy Action has said it recognises that good evidence of the effectiveness of cannabis-based medicines is currently limited to a few, rare childhood epilepsy syndromes. However, the organisation believes adults and children with other treatment-resistant epilepsies should also be able to access these medicines. This is in cases where there is some evidence of potential effectiveness and no other treatment has worked. The organisation also stressed that this should be done under the care of an epilepsy specialist and closely monitored.

The National Institute for health and Care Excellence (NICE) is expected to publish guidelines about cannabis-based medicines later in 2019.

There is more information about cannabis-based medicines on the Epilepsy Action website at: epilepsy.org.uk/medicalcannabis

Read more on this on page 8.

Brivaracetam approved for children in Scotland and Wales

The epilepsy medicine Briviact (brivaracetam) will now be available within NHS Scotland and NHS Wales for children over four years old for focal-onset seizures. This will be used as an add-on medicine taken alongside the person’s other medicines.

Brivaracetam is already available for use in children four years and older across Europe, authorised by the European Medicines Agency in July 2018.

The Scottish Medicines Consortium accepted expanding the use of this medicine in Scotland on 10 December 2018. The All Wales Medicines Strategy Group also extended the license for the medicine in December to include children over four years old in Wales. UCB, the manufacturer of Briviact, said that this decision will give children with uncontrolled epilepsy another option.

Laura Byram, ecosystem head of neurology at UCB called epilepsy an area of unmet need. She added that “more [epilepsy medicines] need to be made available to children in order to maximise the potential of achieving seizure control.”

The company explained that the safety and effectiveness of brivaracetam has been studied in adults, with additional safety studies in children over four. UCB added that focal-onset seizures in children are similar to those in adults and similar effects of epilepsy medicines have been seen. The dose is adjusted for children.

The possible side-effects from this medicine in children are similar to those seen in adults. These include drowsiness, dizziness, headaches and tiredness. However, an additional side-effect reported in children was restlessness, called psychomotor hyperactivity.
It’s legal – now what?

Prescribing cannabis-based medicines became legal in November – so why isn’t everyone celebrating? We look at what the change in law means in practice.

It looked as though 1 November 2018 was the date when a new leaf would be turned in the UK. From this day, UK specialist clinicians could prescribe cannabis-based medicines. Although riddled with a great many clauses, this was set to be like a brick wall coming down for many people with severe forms of epilepsy and other conditions.

Before the change in law, it was extremely difficult to get a prescription for a cannabis-based medicine. In April 2017, a Northern Ireland GP tried to prescribe a cannabis oil to a young boy called Billy Caldwell. Billy has a severe form of epilepsy. But shortly after issuing the prescription, Dr Brendan O’Hare was told not to do it again by the Department of Health. This meant the family could not get a repeat prescription for Billy’s daily medicine in the UK.

Many families like Billy’s, and Alfie Dingley’s, another young boy with a severe form of epilepsy, have been battling for their children to have access to cannabis-based medicines. Many have had to travel abroad to access these treatments and had been urging the government to make this available in the UK too.

So, it was a big step when, in 2018, a review into cannabis-based medicines was announced by the Home Secretary, Sajid Javid. And it was momentous when, a few months later, this review led to a change of the law allowing these medicines to be prescribed.

But unfortunately, since 1 November, many people are still finding that they can’t access this treatment. So, why is this happening? We take a more in-depth look.

Restrictions and clauses
It was clear that a few clauses would be in place even before the change in law came into force. It was announced that cannabis-based medicines would only be available to those with “exceptional clinical need”. As well as that, only specialist clinicians would be able to prescribe these medicines – not GPs. There would need to be clear evidence that there would be a benefit from the cannabis-based medicine. And all other treatment options must have been tried and shown to be unsuccessful.

Another issue, which was evident early on, was that there are no licensed cannabis-based medicine products in the UK for epilepsy yet. In the UK, medicines need a licence before they can be routinely prescribed. If a specialist decided to prescribe a medicine without a licence, they would need to accept the responsibility for prescribing it and overseeing the care. The decision would also need to be approved by the hospital and the NHS would need to agree to pay for this.

All of these things arguably already made it clear that accessing cannabis-based medicines would be quite restrictive. These clauses were put in place to make sure that only those people in critical need are given this type of treatment. And there are good reasons why the government has to be cautious.

Evidence of effectiveness and safety of some cannabis-based medicines in epilepsy is still quite limited.

There is some good evidence for the effectiveness of one part of the cannabis plant – cannabidiol (CBD). This is the part of the cannabis plant which does not cause the effect of a ‘high’. A CBD medicine, under the brand name Epidiolex,
is now approved for use in the US and a decision is expected for Europe from the European Medicines Agency later this year. However, the evidence for Epidiolex focuses on Dravet and Lennox-Gastaut syndromes in children. Evidence for its use for other conditions and in other age groups is limited.

Other medicines made from more or different parts of the cannabis plant are even less well studied and understood in epilepsy. There is not enough evidence to say if other components are of additional benefit or how safe they are. There is also not much evidence on using cannabis-based medicines alone, without being used alongside other epilepsy medicines. There haven’t yet been any studies comparing cannabis-based medicines with other epilepsy medicines either.

Epilepsy Action also warns that CBD oils sold in health food shops and online cannot be guaranteed for quality. These are not licensed as medicines and can’t make claims about treating any condition. The organisation says it is extremely unlikely that they will be made to the same standard as medicines. It adds that it is important for anyone choosing to use these types of products to let their specialist know. That way they can monitor the person and how their epilepsy medicines might be affected.

It is part of the government’s job to protect public health and safety

It is part of the government’s job to protect public health and safety. This is why the Medicines and Healthcare products Regulatory Agency (MHRA) regulates all the medicines that are available in the UK. This includes making sure that medicines are safe for use and that they actually work. With limited evidence, it can be difficult for cannabis-based medicines to be made more widely available.

Professor Hannah Cock is a consultant neurologist at St George’s Hospital, specialising in epilepsy. She told the BBC that out of 2,000 patients on her list, she would only consider cannabis-based medicines in a handful of cases where other options have run out. She stressed that cannabis-based medicines are not a miracle medicine.

Dr Michael Bloomfield, a psychiatrist at University College London also told the BBC that more scientific evidence is needed, as cannabis products can cause side-effects. He suggested that because of this, a slow prescribing process is the right thing to do.

While the change in law doesn’t restrict the age range or condition that specialists can prescribe cannabis-based medicine for, the guidance has focused on only a few areas. These are severe childhood epilepsy syndromes, chronic pain and nausea from cancer treatment.

Specialist clinicians are told they need to follow the available guidance when prescribing

The BPNA’s guidance focused on cannabis-based medicines in severe epilepsy in children. It recommended that cannabis-based medicines be used only as a last resort. All other available licensed medicines need to have been tried without success. The ketogenic diet must have either been tried unsuccessfully or not be suitable. Epilepsy surgery must also not be suitable. If these conditions are met, the BPNA only recommends prescribing Epidiolex. It does not recommend cannabis oil or any other cannabis-based medicine.
It’s worth remembering that the whole change in law was sparked off by Billy Caldwell and his cannabis oil for his epilepsy. This is not Epidiolex. It is a different cannabis-based medicine and it is the medicine that has been working for him. His medicine was confiscated from his mother Charlotte at Heathrow airport, after she had travelled to Canada to source it for him. Without his medicine, a few days later, Billy was admitted to hospital, when the government issued a special licence for his cannabis oil. This was when the government decided to review cannabis-based medicines in the UK.

Alfie Dingley was also given a special licence for a cannabis oil before the law change. His mother, Hannah Deacon, has said that since the law change, Alfie’s licence has been taken away. The Home Office told Ms Deacon that with the new regulations, Alfie doesn’t need the licence anymore. But she said she is concerned that “no doctor in [the UK] is brave enough to want to prescribe [cannabis-based medicines]”.

Before the law change, the MHRA was tasked with defining what is included under the term ‘cannabis-based medicine’. The MHRA concluded that it has to contain cannabis, cannabis resin, cannabidiol or a cannabinol derivative. It said it needs to be produced for medical use in humans and that it needs to be a medical product or an ingredient for one.

This definition means that many forms of cannabis-based medicines can be considered by specialist clinicians. However, the guidance says only Epidiolex should be used in children with epilepsy.

The positive and negative effects of many of these parts are not very well understood yet. Professor Barnes said in a Facebook Live video that Epidiolex has shown some good results in children with severe forms of epilepsy. But he argues that full extract cannabis medicines may help in cases where medicines like Epidiolex don’t work as well.

So, the guidance so far means that only one cannabis-based medicine is recommended in epilepsy. This is only in children and only with a few severe forms of epilepsy. Since 1 November, many families who had hoped that their children with severe and drug-resistant epilepsies could try the medicine, have spoken out. Former minister Sir Mike Penning has called the guidance “cruel and botched”.

Epilepsy Action’s deputy chief executive, Simon Wigglesworth, said: “The change in law should open the door for some children and adults with severe epilepsy to access potentially life-changing treatment. While this change is an important step forward, the guidance we have seen so far on how it will work in practice seems extremely restrictive.

“It suggests that cannabis-based medicines will only be an option for a very limited number of people with epilepsy – children with Dravet and Lennox-Gastaut syndromes. Though this is welcome, there are children and adults with other complex and treatment-resistant epilepsy syndromes who could potentially also benefit.”

**What next?**

Later this year, the National Institute for Health and Care Excellence (NICE) is expected to publish its own guidelines for specialist clinicians. Epilepsy Action is a registered stakeholder with NICE and is engaging with them around the guidelines through the formal consultation process. Once they are published, these guidelines will replace the guidance which is currently available.

Epilepsy Action is also in conversation with the BPNA to share its concerns regarding the current clinical guidance that was published ahead of the change in law. It is also working with other...
organisations, such as the MS Society, to raise more general concerns around the restrictive nature of this guidance. The organisations are working towards raising this issue in Parliament.

As well as that, Epilepsy Action is submitting evidence to the Health and Social Care Select Committee on its inquiry about the usage of medicinal cannabis products. This committee examines the policy, administration and expenditure of the Department of Health. Its inquiry is looking into the impact of drugs policy on public health in the UK.

There have also been concerns about current access to Epidiolex. This is the only cannabis-based medicine recommended by the guidance, but the guidance is still very restrictive over its use. The fact that it is not licensed yet and the high costs associated with it are also creating a problem in terms of access. Epilepsy Action is in contact with NHS England about these issues. Later this year, this medicine is expected to be licensed for prescription in the UK. When this happens, access to this medicine should become easier, but its high cost may still form a barrier.

Steps have been taken towards making cannabis-based medicines more available in the UK, but there is still more that needs to be done. With the expected Epidiolex licence and the new guidelines from NICE on the horizon, the situation is likely to continue to change in the next year. Organisations like Epilepsy Action are working hard to help make cannabis-based medicine accessible to everyone who really needs it.

There are children and adults with other treatment-resistant epilepsy syndromes who could also benefit

Timeline of some key moments around cannabis-based medicines for epilepsy in the UK

1843 – The first detailed modern description of cannabis-based products as an anti-seizure medicine is published by W. B. O’Shaughnessy

2013 – Pharmaceutical company GW Pharmaceuticals begins Phase I trial (first trial in humans looking at medicine doses and how it is processed by the body) of a new epilepsy medicine – Epidiolex (cannabidiol)

2016 – GW Pharmaceuticals present positive results from Phase 3 trial (looking at safety, tolerability, effectiveness and how the medicine is processed by the body) for use of Epidiolex in rare and severe childhood syndromes

19 April 2017 – Billy Caldwell is prescribed cannabis oil by an NHS doctor in what is called ‘the first case of its kind’

2017 – Dr Brendan O’Hare who prescribed the cannabis oil is told by the Department of Health and the health board not to prescribe the medicine again

11 June 2018 – Billy’s mum Charlotte returns from the US where she has gone to get cannabis oil for Billy. The cannabis oil is confiscated at Heathrow Airport by the Home Office

12 June 2018 – Billy has his first seizure in months

15 June 2018 – Billy is taken into hospital because of his epilepsy

16 June 2018 – Home Secretary Sajid Javid uses ‘exceptional power’ to grant a 20-day licence to Billy for cannabis oil. Other families, including Alfie Dingley’s family, ask for similar measures for their children

19 June 2018 – A review into medical cannabis is launched by the government after Mr Javid says ‘the position we find ourselves in is not satisfactory’. A licence is granted to Alfie for cannabis-based medicine for his rare form of epilepsy

25 June 2018 – GW Pharmaceuticals’ Epidiolex is approved by the US Food and Drug Agency for treatment in Lennox-Gastaut and Dravet syndromes

26 July 2018 – following the conclusions of the review, Home Office announces that specialist clinicians will be able to prescribe cannabis-based medicines from the autumn

31 October 2018 – Guidance from the British Paediatric Neurology Association (BPNA) and the Royal College of Physicians (RCP) is published. This is to help guide specialist clinicians when prescribing cannabis-based medicines

1 November 2018 – Specialist clinicians in the UK can prescribe cannabis-based medicines

Professor Barnes says ‘full extract’ cannabis medicines may help when cannabidiol doesn’t work
We often talk about stigma in epilepsy. The World Health Organisation (WHO) says that “fear, misunderstanding, discrimination and social stigma have surrounded epilepsy for centuries. This stigma continues in many countries today and can impact on the quality of life for people with the disorder and their families.”

People with epilepsy still report experiencing stigma, prejudice and discrimination today, and this represents an important challenge for those going through it. But there have also been many positive changes over the years. Awareness about epilepsy has increased, myths have declined and more and more people with the condition are speaking out about their experiences.

A new research study published in the scientific journal Seizure has looked into public attitudes towards people with epilepsy in the UK. This aimed to shed light on stigma around the UK and give up-to-date evidence on people’s attitudes and beliefs about the condition.

The study was carried out by Dr Emily Holmes, Siobhan Bourke and Dr Catrin Plumpton at Bangor University and funded by Epilepsy Action. It consisted of an online survey of 3,875 people. The sample of people represented the UK based on population characteristics such as age, gender, ethnicity and education.

The survey results were split into different categories. These included ‘risk and safety concerns’, ‘personal fear and social avoidance’, ‘work and role expectations’, and ‘negative stereotypes’.

Encouraging results
The results showed that the average UK person’s attitude towards people with epilepsy is fairly positive. However, the results also showed that 10 in 100 people had a negative attitude towards epilepsy and one in 100 had a very negative attitude.

The results also differed for each category. For risk and safety concerns, people’s views were very divided. This was in reference to questions about driving and children. Half of people said they would not let their child ride in a car with a driver who has epilepsy. Almost half said they would not feel comfortable if their child rode in a car with a driver with epilepsy. Just over a third of people said they would not hire someone with epilepsy to babysit their child.

In the category looking at personal fear and social avoidance, stigma was showed to be low. According to the results, people’s responses showed that they would not be embarrassed if someone in their family had epilepsy. Most also said they would be happy to work with or date someone with epilepsy. But a quarter of people said they would be afraid to be alone with someone with epilepsy. And just under a quarter said they would be nervous to be around a person with epilepsy because he or she may have a seizure.

In the category of work and role expectations, the overall score showed low stigma again. However, around a quarter of people said they believe there are many work activities people with epilepsy cannot do safely that others can. On the positive side, most respondents said they believed people with epilepsy can be as successful as others at work and can lead normal lives.

The negative stereotypes category showed the lowest score for stigma. The scores indicated that most people didn’t believe people with epilepsy were possessed by supernatural spirits. They didn’t believe that people with epilepsy weren’t as smart as others, or that they shouldn’t marry or have children.

More work to be done
Many of the research findings are very encouraging. In the past, myths have spread through word of mouth, which may have added to negative stereotypes. But the research shows that the majority of people don’t believe these myths and disagree with them. Many of the categories revealed that stigma is relatively low, which is very reassuring. However, the research also showed that there is more work to be done.

There is an important need for awareness. The fact that a quarter of people said they would be nervous to be alone
with someone with epilepsy in case they had a seizure shows this. If people have never seen a seizure, it can be very frightening. They might not be sure how to help or they may not even recognise some seizures, such as absences. More awareness about what happens during different seizures and seizure first aid can really work to tackle this. Epilepsy Action’s website has a lot of information on seizure first aid (epilepsy.org.uk/firstaid) and seizures (epilepsy.org.uk/seizures).

The research also revealed a tendency for people to overestimate their knowledge around epilepsy. People who believed they knew a lot about epilepsy appeared to score lower in the questions assessing knowledge than people who didn’t believe they knew as much. This shows how important spreading the right information is.

More information
The research is an important step to being able to measure the change in public attitudes towards epilepsy over time. While it showed a positive picture of the level of stigma in the UK, this isn’t necessarily the whole story. There are areas where more awareness and information can help to reduce stigma even further. Even if the level of stigma is shown to be low in many areas, people with epilepsy may still be experiencing or feeling stigma. This can be damaging to people’s health and debilitating for them. Work is still needed to boost the confidence of people with epilepsy and spread more awareness among the general public.

Epilepsy Action will be using the research to inform the organisation’s future work. What do you think about the results of this study? Do you have a story to tell about being discriminated against or feeling stigmatised? Get in touch and let us know. Email press@epilepsy.org.uk.

Bangor University, where the research was carried out

Your life-changing birthday present
Thank you to everyone who raised an absolutely fantastic £44,200 through your birthdays last year – we think you’re brilliant!

You can set up your very own birthday fundraiser on Facebook by visiting: facebook.com/epilepsyaction

To find out more, call Lisa on 0113 210 8816 or email celebrate@epilepsy.org.uk

Sign up for more from your membership!

The 2018 surveys of Epilepsy Action members showed there was a clear demand from members for more information about epilepsy and living with the condition.

As such, Epilepsy Action has pledged to set up a regular monthly email exclusively for members, starting in 2019.

The content of the emails will aim to keep you posted in between editions of Epilepsy Today. Topics covered will include the latest research findings, updates on available treatments and where to find support.

To sign up for this service and to stay up-to-date with all the latest epilepsy-related news, views and information, simply complete the online form at epilepsy.org.uk/membermail
“I was 22 at the time and on board a ship in Portsmouth Harbour – a normal day,” recalled 61-year-old Terry Denman. “I had bedded down in my bunk for the night and drifted off into nice dreams like all sailors do. When I woke up, I was in a grey room in the shore-side hospital wondering what in the world had happened to me. My first thought was – had we been attacked?”

Terry had been interested in the military from a young age. It sparked off during his school years, when he had had a particularly difficult spell. “At school, I had a very bad time. I was bullied to the point where I had a nervous breakdown at the age of 13. I hated my last two years there.”

As a result of his nervous breakdown, Terry was off school for a number of weeks. When he came back, he found that his classmates had been told off by the teachers and instructed to leave him alone. His brothers, who were at the school too, also helped to look after Terry if he got into any difficulties. But he decided then that things needed to change and left when he was 16.

“I had always loved the idea of being in the military. The travel aspect of the Royal Navy made my choice easy for me. I joined as soon as I could and I never looked back – it was a fresh start with fresh faces. The Royal Navy gave me a life.”

Unfortunately, while he was serving, Terry’s seizures started. He explained that after waking up in hospital, he received the news quite abruptly. “An orderly came in and just said: ‘Morning, so you have epilepsy now – that’s you out’ and then walked off. Of course,
he should have said nothing, but that was the level of training back then. The doctor came in about an hour later and explained things to me. But I could tell he didn’t really know much about epilepsy either.”

Terry was diagnosed with generalised epilepsy with no known cause. He was prescribed sodium valproate (Epilim) at the time, but this didn’t manage to control his epilepsy. His seizures were mainly sleep seizures, but they took their toll on him. “I would have convulsions, chew my tongue to bits, foam at the mouth and wake up feeling like I’d just run three marathons in record times.”

Out of my depth
Having to leave the Royal Navy was very difficult for Terry, as it was a career he really loved. He had to start getting to grips with what industries he might be able to get into and what job prospects he had. “I was not prepared, I felt out of my depth and I’d had no time to get ready for a regular life, let alone one with restrictions. Coming back to my home town before was only to see family and a couple of friends. Now I had to learn about the whole area again.

“There was a local security company that needed static guards – that was something that I could do. They had to lay me off after about 18 months, but they hired me again a few years later. Unfortunately, the company eventually went bust.”

Job-hunting was not the only new challenge that Terry had to face at that time. He was also trying to get his seizures under control and get to grips with his epilepsy medicine.

“At the time, I found straight away that many people thought ‘he’s one of them, don’t touch!’” Terry explained. “Very few people had any idea what to do if I had a seizure. I was very relieved that they were happening at night, when my family could look after me.

“I made a promise to myself that everyone I knew and got to know would learn what to do if I had a seizure. I have stuck with that promise, and have been surprised to see that most people are interested and accepting.

“I was lucky that my epilepsy specialist at the time used to be a Royal Navy surgeon, so we spoke the same language. He asked if I was happy to try new epilepsy medicines coming on the market and I said yes. We went through at least a dozen epilepsy medicines as I recall – it didn’t always go too well and there were some unusual side-effects. One medicine I tried was a new one from the US. The first night I tried it, I woke up the next morning and my entire body had turned bright red!

“I think it must have been about 12 years in when we talked and decided that I had got my seizures settled to a level I could cope with. We decided I would stay on the lamotrigine (Lamictal), as with this, I was down to around two or three seizures a year.”

Living alone
Today, Terry lives in Haslemere in Surrey with his two canaries and “at least seven hedgehogs that will be back for breakfast in the spring”.

He explained that despite living alone, he has an alarm which means his brother or sister-in-law get a call if he presses it. “I’ve had to use it a few times when I’ve taken a fall which knocked me into radiators.

“My family I’m sure are frightened, although my brother would never tell you so. They all coped better than I did. My late mum was the one who used to deal with things the most. She could handle anything.
“The friends I have now where I live are ones that I met after coming back from the navy. If it had been any of the people I’d gone to school with, I’d be a very lonely man.”

The biggest challenges for Terry have been around work. He explained that his epilepsy has made it very difficult for him to find work. He said that many jobs seem to require a driving licence, which rules him out. However, not having a licence itself is not something he struggles with. “The driving I can live without,” he said. “But it’s by chance that I found out I could claim a free bus pass. I missed out on this for years and I guess I’m not the only one.”

Seizures out in public view
Over the years, coping with his seizures and epilepsy has been a challenge for Terry. “For the 40 years where it was just night-time seizures, I started hating epilepsy because of how it wrecked my life. But I hid that away so as not to upset my family.”

Initially, Terry found that the restrictions that came with epilepsy were tough too. In the past, he had enjoyed having a few drinks and he found cutting these out difficult. Getting to understand his own epilepsy a bit better over the years, he decided that he would have a drink in moderation at special events like birthdays and weddings. “I started to just accept my situation and learn more and more about my epilepsy.”

Having lived with epilepsy over a long period of time, Terry’s seizures changed after a while. “I found I was sleep walking at one point. But the dose of my medicine was raised, and it appeared to stop it.”

However, in 2013, Terry began to have seizures again – and this time they were not happening during sleep. “The first one where I knew something was different was when I was with my neighbour, who told me the details later. Another time, I was in the middle of the high street and started to hallucinate. One seizure included me ripping off my own coat and startling a delivery driver. A few days later I did the same while on a bus, which really alarmed the driver. Luckily, I had my sister with me.

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“Seizures out in public view. While they were just in my bedroom at night, they were out of sight and out of mind. But everything I’ve told those close to me about my epilepsy meant that I’ve had no problems with friends.”

“Since then I have had lots of different types of seizures – ones which caused me to sleep walk, day dream... Most I don’t remember, but some are reported back to me in terrible detail. My specialist and I had to start experimenting with different medicines once again.”

Terry explained that he is now also taking topiramate (Topamax) to try to control his seizures again. He said this medicine is helping, although he is not seizure free at the moment. His previous specialist retired, and now he and his new specialist are increasing the dose slowly. “The wide range of seizures I have and the new drug I take can often mess up my speech, making me mispronounce words. Do that with every other word, and it suddenly cuts out a vast number of options.”

At the moment, Terry is not in work and he is waiting for surgery on his knee. But he is worried about the prospect of job-hunting once he’s recovered from the surgery. “The problem will be work. No one will want me. I am now 61 years old, I have bad arthritis and epilepsy with seizures that could happen at any time in a number of different ways. I feel like at the job centre, the attitude is that employers are not allowed to say no because of epilepsy these days. I feel like the implication is that I’m not trying hard enough to find a job.”

Best choice I ever made
One thing that has brought Terry a lot of happiness and benefit is becoming part of a local drama group – the Haslemere Thespians.

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said to me: ‘We’ve got the perfect part for you, Terry – Panto Bear! We won’t need to hire a costume...’

“I went over to the auditions and watched. Everyone got assigned their part and they glanced back at me and said ‘Oh, and Terry is Panto Bear this year.’ Well, I’m a sailor and we don’t back down. So how could I back down now?”

When it came to his epilepsy, the drama group never questioned his condition at all. “I was upfront with them about my epilepsy, although I think my friend had already let them know. I found myself among a range of people who were very different to those I used to know. Theatre knows no bounds, and I found people who already knew what to do if I had a seizure – something I had rarely found before. Theatre knows no bounds, and I found people who already knew what to do if I had a seizure – something I had rarely found before. Everyone just accepted me and it was wonderful. It was the best choice I ever made.”

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“I made a great bear that year and have taken part in many different ways since – acted, stage managed and directed. It was the best choice I ever made.”

Take the fear away
Terry is very keen to raise awareness of epilepsy – and not just with his family and friends. He believes that strides have been made in the right direction. More people know about epilepsy and there is more awareness about seizure first aid. But he says that more still needs to be done.

“I had no idea how common epilepsy was when I was diagnosed, it was one of the biggest surprises to me. I think the more people who know about it, and the more about it they know, the better.

“Educating people is what matters to me most. Most people know that epilepsy exists, but very little else about it. I’ve had seizures in places like supermarkets and as I begin to recover, I see people around looking either terrified or with an ‘it’s one of them’ face. I’m used to it now and much of it comes from fear – a full-flood seizure can be a nasty thing to see. But let’s teach people more and take that fear away.”

More information

Travel
If you have epilepsy and would be refused a driving licence, or have had your driving licence revoked, you are entitled to a disabled person’s bus pass in Scotland, England and Wales. In Northern Ireland, you are entitled to a Half Fare SmartPass. For more information visit the Epilepsy Action website at: epilepsy.org.uk/buspass

You may also be able to get a disabled person’s railcard in England, Scotland and Wales. You would be entitled to this if you still have seizures despite taking epilepsy medicines, or if you are not allowed to drive because of your epilepsy. You may also be able to get discounted rail travel in Northern Ireland. There is more information at epilepsy.org.uk/railcard

Work and the Armed Forces
Employers should not refuse a person with epilepsy a job because of their condition without having a very good reason. But jobs in the Armed Forces are not covered by the Equality Act 2010. This means you can be refused a job in the Armed Forces if you are diagnosed with epilepsy. There is more information about work and your rights on the Epilepsy Action website at: epilepsy.org.uk/employment

Epilepsy medicines and side-effects
You can find more information about different epilepsy medicines, their possible side-effects and potential interactions with other medicines at: epilepsy.org.uk/treatment

Alcohol
If you choose to drink alcohol, Epilepsy Action has more information at: epilepsy.org.uk/alcohol

Near me
If finding a local epilepsy group is something that could help you, Epilepsy Action has branches and coffee and chat groups all around the country. Find out more at: epilepsy.org.uk/nearme
Finding out you have epilepsy is scary at any age. For young children and their families, it can be terrifying.

For Purple Day 2019 Epilepsy Action is aiming to help more children and families come to terms with epilepsy.

Purple Day is an international event held on 26 March every year to raise awareness and funds to help people living with epilepsy.

All the money raised by Epilepsy Action supporters for Purple Day this year will go towards services for young children and their families. This vital work helps children learn about epilepsy, lets them know they’re not alone and gives them the confidence to deal with their diagnosis.

Your support on Purple Day this year can help get specially-designed ‘Just for Kids’ packs to more nurses so they can explain epilepsy to children in a way they understand. By joining in, you can help more children make sense of what’s happening to them and feel more involved in their own treatment. One such child is Harriette, whose mum Suzanne recently told Epilepsy Action about how the pack had helped her daughter.

“We hadn’t had epilepsy in the family before and it had never been something I was aware of.

“Harriette used to find it really hard to explain what was going on for her. But the ‘Just for Kids’ pack really helped her understand what was happening. Harriette’s school has been brilliant too. The staff have been on training so that they can support her in any way they can.”

Your support on Purple Day can help provide more resources and training for teachers, helping them understand what it
means to have epilepsy. This means they’ll be better equipped to support children with epilepsy to succeed at school.

The money raised on Purple Day will also help to grow Epilepsy Action’s UK-wide network of local support groups. That means more parents and carers can find support locally and feel less alone as they try to help their children live better with epilepsy. Steph, whose young son has epilepsy, explained how important the groups have been for her.

“I’m the mother of a little boy aged two who has had epilepsy since he was 10 months old.

“‘I hadn’t been able to talk about my son’s epilepsy with anyone other than my husband. And when I did, people didn’t understand or I got too emotional to speak. A friend of a friend told me about the coffee and chat group.

“Just being able to talk about my situation was invaluable. It helped just knowing I could express myself and talk to others about my concerns and worries and have a cry without being judged. The others understood. They had experience and could empathise and advise me.

“I spoke with the group organiser and she enabled me to talk to the right agencies and got the ball rolling for me. Within a week, I got a special mat and alarm supplied for my son’s bed. This alerts us if he has a seizure in bed. It’s vital – with him being so tiny there’s not much noise to wake us at night when he has a seizure.

“We’re all mums at the coffee and chat group. I’m the youngest but I don’t feel any different. If anything, I feel I benefit more as I can draw upon the experience of the others and how they managed at different stages of their child’s development. We just all happen to be mums of children with epilepsy, and it’s really worked out well.

“The group has changed my life, honestly, it really has! It’s therapeutic and I couldn’t be without that support now.”

Every penny Epilepsy Action raises for Purple Day 2019 will mean more support for more children just like Harriette and parents like Steph. There are many ways you can get involved and help make a difference.

Organise your own Purple Day event
From purple cake sales to purple fancy dress, there’s so much you can do to join in and make a difference!

To organise a purple-packed event on 26 March (or any other date that works for you), you can request a fundraising pack by calling 0113 210 8851 or completing the form online at epilepsy.org.uk/purple

Get your Purple Day 2019 wristband
You can show your support for people living with epilepsy and wear your brand new Epilepsy Action purple wristband with pride. Order yours today for just £2 each. You can return the order form enclosed with your copy of Epilepsy Today or buy online at epilepsy.org.uk/wristband

How your support and donations will make a difference on Purple Day:

£3 can print and send a kids’ pack to an epilepsy specialist nurse

£30 will help more schools get the resources and training they need to support kids with epilepsy

£300 will help set up a new group so more parents and carers can find support locally

The group has changed my life and I couldn’t be without that support now

The ‘Just for Kids’ packs help children to understand their condition better

Epilepsy Action Purple Day wristbands
There’s a good chance you might have heard of the International League Against Epilepsy (ILAE). This is an organisation set up for specialists and researchers more than 100 years ago to help expand what we know and understand about epilepsy. The organisation’s goals include advancing knowledge about the condition, promoting research and training and improving services for people with epilepsy.

The ILAE has more than 100 branches in different countries around the world. It holds yearly meetings, as well as training courses and workshops. At these meetings, healthcare professionals present their research in different areas of epilepsy and share their knowledge with their colleagues.

The UK Branch of the ILAE had its 2018 meeting in Birmingham in September. Over the three days, many epilepsy professionals presented their research to a packed room, uncovering many exciting projects and findings.

We went along to find out what research is taking place across the UK. In the first of a two-part article, we look at the session on hard-to-treat epilepsies and a session entitled ‘How to…’

**Session 1: Complex epilepsies and complex treatments**

*Revisiting past medicines*

First up, the president of the ILAE UK Branch, Professor John Paul Leach from the University of Glasgow, spoke about very hard-to-treat epilepsy.

Hard-to-treat epilepsies represent a big challenge for people and their doctors. In these types of epilepsy, the medicines that are available don’t seem to stop a person’s seizures. If a person is not suitable for other treatments like surgery, this can be very difficult.

Professor Leach looked back at the epilepsy medicines that were available in the 1990s, and a few that came in but quickly went out of favour. These included vigabatrin and felbamate. He warned that both of these medicines carry significant side-effects. Vigabatrin is linked to sight problems, while felbamate caused an increased risk of anaemia and liver failure. Vigabatrin is still sometimes
used in the UK, under expert supervision, while felbamate is only available on a very limited basis.

Professor Leach suggested that in cases where a person’s seizures are very difficult to treat, revisiting some medicines from the past could be an option. He added that this should be done with caution, common sense and careful monitoring.

**Treating Dravet syndrome**

Next Professor Helen Cross from UCL Institute of Neurology London presented on the treatments and challenges in Dravet syndrome. This severe form of epilepsy is very rare and people with this condition often have hard-to-treat seizures. Professor Cross explained that as well as causing seizures, this syndrome also affects things like memory, problem solving and decision-making.

She explained that effective treatments for Dravet syndrome include sodium valproate, clobazam and stiripentol as an addition to these medicines. Topiramate, levetiracetam and the ketogenic diet can also be effective treatments.

But Professor Cross warned that a few epilepsy medicines are believed to actually increase seizures in Dravet syndrome. These include carbamazepine, phenytoin and lamotrigine.

While a few different medicines and treatments can help, the nature of this syndrome means that seizures don’t always respond to treatment. There can also be other problems. For example, stiripentol, which can boost the effects of clobazam and valproate, is only licensed up to the age of 18. Professor Cross explained that this creates a problem when the person on this medicine grows to adulthood. The ketogenic diet could also be problematic. While a benefit has been seen, Professor Cross noted that some people with Dravet syndrome have problems with eating.

She added that it is never too late to review the syndrome and think about a change in medicine. She said that with additional challenges such as difficulty walking, sleep problems and eating disorders, perhaps healthcare professionals should be looking at more than just the seizures.

**Tuberous sclerosis complex**

Next Professor Matthias Koepp from University College London discussed treatment for a condition called tuberous sclerosis complex (TSC). This is a rare genetic condition where non-cancerous tumours develop on different parts of the body. These can affect different organs, including the skin, kidneys, eyes and the heart. They can also affect the brain, which can result in seizures.

Professor Koepp explained that it is sometimes possible to predict while a baby is still in the womb that they may develop this condition. While not everyone with TSC will develop epilepsy, seizures are a common feature of the condition. Professor Koepp said that it’s important for the medical community to identify a characteristic that would signal that seizures might start in that person. This is known as a biomarker.

He also mentioned trials done with a medicine called everolimus. NHS England recently said it will make this available for treating TSC-related focal seizures. It is intended to be used in addition to a person’s current treatments. Professor Koepp said that trials showed that this medicine caused people’s seizures to reduce significantly. The reduction was higher with a higher dose and the effect of the medicine increased over time.

**A more precise diagnosis**

Finally, Dr Amy McTague from Great Ormond Street Hospital spoke about new medicines and repurposing old ones.

She started off by saying that precision medicine is big news at the moment. This is the idea that decisions, treatments and practices can be tailored to each individual depending on their exact situation. She said that before this, we need more precise diagnoses of people’s conditions. She said we are in the era of more precise diagnoses with things like genetic testing being more and more available.

Dr McTague explained that technology for genetic testing has come into force over the last 10 years, and has become more affordable. She said that as a result, recently there have been many revelations about genes which are related to different syndromes. These include genes involved in Dravet syndrome and Lennox-Gastaut syndrome, among others.
While this is an important step in a more precise diagnosis, there are many different types of abnormalities that can occur in each different gene. Also, some conditions can involve abnormalities in a number of different genes. All of this makes precision medicine complicated.

Dr McTague explained that mutations in the different genes can give clues about the type of medicines that can be effective. For example, some genes may affect a pathway for an important chemical that the brain needs. Some medicines work on those specific pathways to allow the chemical to work properly.

She said while we don’t currently have a lot of opportunity to provide precision medicine, we are working towards this with a more precise way of diagnosing conditions.

**Session 2: How to…**

**EEG**

The second session of the congress focussed on updates of some of the widely-used tools and commonly seen cases in epilepsy. First up, Dr Nick Kane from North Bristol NHS Trust presented on electroencephalograms (EEGs).

Most people with epilepsy will have come across an EEG before. Dr Kane started off by saying that there are benefits to EEG testing. It is a safe test, it won’t do any harm and it’s well tolerated. But he added that the EEG has a reputation for being a very successful diagnostic test, but its limitations are not as widely appreciated. For example, he explained that an EEG cannot exclude the possibility of epilepsy. He said there are questions that EEG alone can’t answer.

However, Dr Kane said there are ways to increase how sensitive EEG testing is. These include selecting when to use it carefully, good reporting on what the EEG shows and repeating the test. Long-term recording can also be helpful, as sometimes the EEG is completely regular between seizures.

According to Dr Kane, in the future we need more specialists that can understand and explain the data from EEGs. He added that technology is likely to become smaller and more user-friendly and allow for hours of recordings to be done more easily.

**MRI**

The second speaker of the session was Dr Andrew Bagshaw from the University of Birmingham, discussing magnetic resonance imaging (MRI) scanning. This is another scan that many people with epilepsy may have heard of or had done before.

Dr Bagshaw explained that MRI is not a silver bullet but it provides a different piece of the puzzle. It should fit in among the rest of the information from scans and each person’s medical history.

MRIs can look for damaged parts of the brain, called lesions. But they can’t say for sure if that lesion is what is causing a person’s epilepsy. This is where the skill of the epilepsy specialist comes in, to fit this information in with all the other information they have on the person, Dr Bagshaw added.

He explained that different parts of the brain and body have different properties. He said MRI scans look at the magnetic properties. In order for a lesion to be seen on an MRI scan, it needs to have different magnetic properties to what’s around it. MRI scans can therefore miss some lesions, if they have the same magnetic properties as the surrounding area. He explained that doing lots of different images and using the scanner as much as possible can help identify problems more clearly.

Dr Bagshaw also mentioned fMRI – functional MRI. This scan looks at the areas in the brain that perform important functions in a person. If a person might be looking at epilepsy surgery, this scan can give the surgeon an idea of which
areas of the brain are important and should be avoided.

**Neuropsychology**

Neuropsychology looks at the structure and function of the brain and how it relates to a person’s psychology and behaviour. Dr Sallie Baxendale from University College London presented on this topic.

She started off saying that people often come to her clinic saying that they have had a few seizures recently and feel like their memory is worsening. She said that in order to assess how much a person’s memory has worsened, she needs to know where it started from. She said that there are ways to work this out. Doctors can perform some tests and find out more information about the person themselves.

She explained that age has a big effect on all people’s minds. How long it takes a person to perform a mental task increases with age. Memory also starts to decline with age. She explained that people with epilepsy might be more sensitive to this change, particularly if their epilepsy has already been affecting their memory. But she explained that it is important to consider if problems with worsening memory are a normal age-related change. This might help to prevent making unnecessary changes to a person’s medicines, for example.

Dr Baxendale also noted that studies have shown that obesity can play a part in memory and other brain processes. She explained that research shows this can have more of an impact on functions like memory than conditions such as anxiety and depression. She added that the positive thing is that this is something that doctors can help people to change.

She concluded that it is really important for doctors to build a relationship with people in order to be able to help them most effectively.

**Neuropathology**

Finally, Dr Tom Jacques led a presentation about neuropathology in epilepsy. Neuropathology is the part of medicine working on diseases of the brain and nervous system.

Dr Jacques explained that to the doctors working in this area – neuropathologists – epilepsy is a symptom of an underlying disease. He said that the work of this part of medicine often links to epilepsy surgery. The aim is to be able to predict the likely outcome of surgery and what treatments a person might respond to. He said that at the moment, this is better understood for some diseases than others.

Dr Jacques said that studies have looked into what kind of underlying problems might be commonly seen in people undergoing epilepsy surgery. They found three main ones. One is hippocampal sclerosis, a condition in which there is a loss of nerve cells in the area of the brain called the hippocampus. This can result in temporal lobe epilepsy. The second is brain tumours. The last are abnormalities on the surface of the brain.

However, it is not always very easy to identify the problem. Neuropathologists usually need to examine small samples from the brain or spinal cord. Dr Jacques explained that genetics also play a part. Gene abnormalities are now taken into consideration when looking at the features of a disease.

**In part II...**

Research is really important in driving forward the field of epilepsy. It helps develop and test new treatments and better understand different types of epilepsy and why they happen. In part II of the article in the next issue of ET, we look at presentations on some of the biggest studies on epilepsy. We will also cover the session dealing with epilepsy and stress, depression and mental health in young people.
Last year, Epilepsy Action rolled out its brand new ‘Epilepsy, my family and me events’. These were set up to support young people with epilepsy and their families. They were an opportunity for families to meet others in similar situations and take part in exciting activities. Parents could also attend informative presentations about epilepsy led by health professionals.

Helen Murray-Sharpe, national manager for local services at Epilepsy Action explained: “We wanted to provide support to children with epilepsy, and we realised we weren’t reaching this group. We thought family events would be a good way to achieve this.

“We also wanted to acknowledge the effect of epilepsy on the brothers and sisters of children with the condition. We wanted to help them meet other children who have brothers and sisters with epilepsy, and get parents to meet other parents as well.”

The 2018 events were a big success. People attended in their droves, and came away happy, better informed and more confident.

The children at the events took part in a whole host of different activities. They went rock climbing, canoeing with their families, played games like football and table tennis, and took part in arts and crafts.

At the end of the events, many children said they enjoyed the activities and that they’d had fun. One child said: “It was amazing and I made new friends.” Another said: “It is very good and you do amazing stuff.”

The events had an important impact on the children’s relationship to epilepsy too. One child commented: “Today was really fun and I feel better about epilepsy”, while another said: “I am not alone in having epilepsy”. A sibling of a child with epilepsy told Epilepsy Action: “I felt that meeting someone that also had epilepsy helped me to understand my brother more.”

Feedback from one of the events, held in Bristol, showed that about three in five children made new friends (62%) as a result of the day. Half said they felt better about epilepsy (50%) and just under half said they gained new interests (46%).

Last year’s ‘Epilepsy, my family and me’ events were valuable for many parents too. Many said that their highlights were meeting other parents and seeing their children meet others and take part in the activities. One parent said: “The day was a fantastic success on every level and has enhanced our whole family. I felt very emotional at times.”

At a Northern Ireland event, feedback from the parents showed that more than nine in 10 people (94%) felt better about their family and epilepsy after the day. Just under nine in 10 people (87%) said they met other parents and felt more connected to people affected by epilepsy.

This year’s events promise to deliver even more adventures, great information days, fun football games and exciting activities like athletics, climbing and canoeing. They will shine the spotlight on children with epilepsy and their siblings, and help the whole family have fun together and learn more about epilepsy.

To find more about the events or book your place, please visit: epilepsy.org.uk/familyevents
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<th>Month</th>
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For updates on the dates and times of events, please visit: epilepsy.org.uk/familyevents
Medical files

Epilepsy medicines underpin the way most of us manage our epilepsy. Some people may have tried many, others might have only had the one. Some of us might be taking a few on a daily basis, while others may just be taking one.

Whatever your experience of epilepsy medicines, getting a little more information on what is out there and available is always useful.

There is always research going on into the medicines that we have and take every day. There are also new medicines being developed all the time. Our understanding of epilepsy medicines is always advancing, so it is important to keep up to date.

In this new feature, we will open up the medical files and read up on an epilepsy medicine each issue. In this edition, Professor Martin Brodie, president of the International Bureau for Epilepsy (IBE), puts sodium valproate under the microscope.

Sodium valproate

The anti-seizure properties of sodium valproate were first recognised by chance in France in 1963. The medicine was licensed there in 1967 and became available for general use in the UK in 1977. Valproate is widely considered as the epilepsy medicine with the broadest activity. It is probably the most effective treatment for generalised epilepsies which affect both sides of the brain from the start. These include absence seizures, myoclonic jerks and generalised tonic seizures. But valproate can also be effective for focal seizures — originating in one part of the brain — whether or not they then spread to both sides. There is good evidence that combining valproate with lamotrigine can be particularly effective.

The most common side-effects with valproate include weight gain (as it increases appetite), tremors, drowsiness, hair loss and stomach problems. These side-effects are usually dose-related, being more likely to occur with higher amounts. Some women taking valproate complain of irregular periods or even loss of their periods. A few may develop a condition called polycystic ovarian syndrome, which affects how a woman’s ovaries work. This problem can be linked to obesity, excess unwanted hair growth and infertility. At high doses of valproate, the amount of blood cells called platelets can fall, but rarely to dangerous levels. Platelets help stop bleeding if a blood vessel is damaged.

More serious side-effects are unusual, but can include pancreatitis (inflammation of the pancreas), liver damage and impaired consciousness. This can happen because of increased levels of a chemical called ammonia in the blood. Valproate can also reduce how fast other medicines are broken down by the body, increasing their levels in the blood. These include some epilepsy medicines, such as phenobarbital and lamotrigine, and some medicines for other conditions, such as antidepressants, blood pressure medicines and anti-cancer treatments.

One of the biggest concerns with valproate is the possibility of side-effects on the development of babies who are exposed to the medicine in the womb. Serious conditions include birth problems such as spina bifida, heart conditions and cleft lip and palate. These are also related to dose — so the higher the amount taken by the mother, the more likely these problems are to affect the baby. There is also some evidence that cognitive development and IQ can be lowered in some babies who are exposed to high doses of valproate. Cognitive development is the building of thought processes linked to memory, problem solving and decision-making.

More recently, there has also been the suggestion that autistic spectrum disorders are more common in children exposed to valproate in the womb.

The causes of these worrying developments are unclear. However, this information has resulted in the recent setting up of the ‘Pregnancy Prevention Programme’ in the UK. This means that before prescribing sodium valproate, doctors must discuss the risks of valproate in pregnancy with girls and women of childbearing potential. They also need to arrange highly effective birth control for them to start using before taking valproate. The woman needs to sign an acknowledgement form and be seen by a specialist at least once a year.

It is usually children, adolescents and young adults who develop epilepsy without a physical cause, for which valproate can be the best medicine. This may have a major effect on their seizure control, as many girls and young women are now unlikely to be prescribed valproate or agree to take it.
Francesca’s epilepsy was very hard on her during her school years. Having become good at overcoming challenges, she decided to take on another one – get fit and run Tough Mudder.

The first time I had a seizure was actually while sailing in France. I was wearing sunglasses so at first my family didn’t realise I was having a seizure. They only noticed when my sister told me to stop kicking her. My parents were steering the boat and managed to moor during the chaos. I was 14 at the time.

I’m 23 now and living in Bristol with a lovely girl called Jasmine while I’m at university doing my master’s degree in Social and Cultural Theory.

I was diagnosed with epilepsy after my second seizure. I went to school one morning with a really bad headache and by midday, I had a black eye. We went to hospital and pieced it together to realise I had had a seizure in the shower that morning and hadn’t remembered.

I have a mixture of different seizures. I have tonic-clonic seizures, absences and myoclonic seizures. I’ve been told that I am also slightly photosensitive, which could cause a seizure, but I am yet to experience this. I also have eyelid myoclonia but this was not actually diagnosed until I went to see a private epilepsy specialist. I realised then that I must have had epilepsy for a lot longer than we first thought. I used to have periods of what we called ‘flicky eyes’ when I was younger, without realising it was epilepsy.

I realised then that I must have had epilepsy a lot longer than we first thought.

My seizures both are and aren’t controlled. I would consider them controlled, as my tonic-clonics have stopped, which was the most important thing to me. There was one time in the last year when I felt a tonic-clonic seizure coming on. This was after...
travelling to Malaysia, so I was suffering from jet lag. But I took emergency medicine that stopped it. I still have myoclonics and eyelid myoclonia when my epilepsy is bad or I'm very tired. But I feel extremely lucky that I only have these now.

**Made me who I am**

When I first got epilepsy, I think I was too young to understand it properly and so at first I felt there was no real impact. Eventually my seizures started getting worse and more frequent, and the side-effects of the medicines meant I was missing school. I was only making it in to school a quarter of the time, at a push. I then realised that it would have more of an impact than I first thought. You are going through so much as a teenager that having this extra thing just became too much.

I was diagnosed with depression after a suicide attempt. They thought the depression was a side-effect from the medicine I take, Keppra (levetiracetam). But looking back, I think it was a mixture of that and me coming to terms with my epilepsy. This was a particularly bad period of my life. I had to leave school on my doctor's advice. I realised that my friends just couldn't understand my condition and it caused me to feel extremely isolated.

After a year off from school, I started sixth form at a new school and things improved from then. Although there was this period of my life, where it felt like my life was torn apart, I now don’t look at epilepsy as a bad thing. In some ways, epilepsy has affected my life for the better and it has led me to where I am now. Going through something so young taught me to grow up and to be more sensitive to what other people are going through. I am really grateful for that.

There are times where I don’t feel so positive about it, admittedly. I’ll be annoyed that I can’t stay up as late as my friends on a night out in case I get too exhausted and have a seizure. Sometimes I feel like I’m going to have a seizure and horrible anxiety sweeps over me – something some people with epilepsy might recognise. But honestly, I would not say that it has affected my life for the worst, because it has made me who I am today.

But it has definitely been hard for my family. At times, I think it was harder for them than me. It was really difficult for my parents to see me go through so much emotionally, let alone see me have seizures. But they have been amazingly supportive and I can’t thank them enough for that.

I’m lucky enough to have a boyfriend, who I met at university, who has also been incredibly supportive. He researched epilepsy when I first told him about it and he brings me junk food whenever I’m not feeling well. He told me that my epilepsy has taught him more about the condition itself, but also more about invisible conditions. It’s made him think about what people with these conditions might be going through, which I think is really great.
Getting into gear

For me, doing Tough Mudder was a bit of a random decision. Some of my friends said they were going to do it and I said I would as well. My boyfriend had done it before, so he agreed to do it with me again. Running it to raise money for Epilepsy Action was the obvious choice. I had been wanting to raise money for the organisation for a while but just wasn’t sure how I would do it.

I had not done anything like it before. At school I was allowed to miss PE lessons to try to catch up on my classes or get some extra rest. It was only a year before Tough Mudder that I had started going to the gym and getting into some exercise. I hadn’t done cardio exercises since the age of about 15. When I first tried to run after signing up for Tough Mudder, I could just about run 1km on a treadmill!

I started trying to get a bit further each time. This was a really slow process at first because I was extremely unfit. I ran about three times a week and slowly made progress until I could run 5km. When I went home to Hertfordshire for the summer after finishing university, I started to run outside, which I found to be a lot more fun. Slowly, the running turned from a chore to something I actually really enjoyed.

I didn’t do any running in April and June as I was busy enjoying the holidays and going to festivals. In July, I realised I only had a month left until Tough Mudder so I had to get into gear. I ran two or three times a week, slowly working up to 10km, which is the longest distance I did before Tough Mudder.

On the actual day, the toughest bit was the running because I’m still not great at controlling my breathing when I run. But to be honest, the whole event was enjoyable – which I never thought I would say!

I was quite convinced that I was going to cry throughout the race and have to stop a lot. But on the day, I was shocked to find myself absolutely loving it. The obstacle which I dreaded the most was called the Arctic Enema – it’s where you are plunged into freezing cold water with ice in it. It actually ended up being my favourite bit. Of course, when I was in shock from the cold, I didn’t love it. But straight afterwards, I was so proud of myself and exhilarated that I’d pushed myself through it.

Taking precautions

Before doing Tough Mudder, I definitely had concerns about my epilepsy. I was worried that I was putting my body under a lot more stress than I ever had before. I worried that this would lead to a seizure either during or after the race. If I had had a seizure during the race, I know how frustrated I would have been to not be able to finish the course. I definitely couldn’t help but worry and feel anxious that after the race I would have a seizure.

During the actual event, I did also have to take a few precautions. The main one was that I didn’t take part in the
obstacle called Electroshock Therapy, where you get electric shocks from dangling wires. The website advises people with epilepsy not to do this one. I was really gutted about missing an obstacle and felt kind of like I was cheating at first, by skipping it. But I realised it wasn’t something that I should feel bad about as it was out of my control. I made an effort to attempt all the other obstacles, making sure I didn’t leave any out, so I would feel more like I wasn’t cheating. Also, when I saw my friends falling to the floor and screaming from the electric shocks, I had a moment of gratitude for my epilepsy and wasn’t so bothered about missing it.

The only other precaution I took really was that my boyfriend made sure to be next to me during any obstacles in the water, in case I had a seizure. There are also safety people on hand the whole time during the race. There are people at each obstacle specifically to look out for any danger or if anyone is hurt.

I think anyone considering taking part in Tough Mudder should definitely do it. During the training process itself, I actually found that my epilepsy settled a bit. All the exercise I was doing was helping me sleep better. I think exercise can be really beneficial for your mental and physical health, so it’s great if you can use an event like Tough Mudder to get you into it. I think it’s sometimes easier to focus on what you can’t do than what you are actually able to do. Running Tough Mudder opened my eyes to all the things I can do and made me realise I am a lot stronger – mentally and physically – than I thought.

I felt so proud finishing the race wearing the Epilepsy Action vest. Not only was I raising money for Epilepsy Action but I was someone with epilepsy finishing that race. I would encourage anyone to take part in Tough Mudder – and you will surprise yourself seeing all the things you can do. And it was definitely worth doing for the guilt-free takeaway meal afterwards!

Taking on Tough Mudder

You can take part in a Tough Mudder event for Epilepsy Action in 2019. There are many events throughout the year at various locations.

- North London (Urban 5k) – 12 and 13 April
- London West – 4 and 5 May
- Midlands – 18 and 19 May
- Northampton (Urban 5k) – 31 May and 1 June
- Scotland – 15 and 16 June
- Bristol (Urban 5k) – 5 and 6 July
- Yorkshire – 27 and 28 July
- South West – 17 and 18 August
- North West – 7 and 8 September
- London South – 21 and 22 September

For more information, to book a place or to find out how you can support Epilepsy Action through this event, visit: epilepsy.org.uk/toughmudder
The Council of Management met on 4 December and made the following decisions.

- It approved a revenue budget and a business plan to run through 2019.
- It approved an amended protocol for communications by Council members.
- It approved an amended protocol for the Epilepsy Action Awards.
- It reviewed and renewed the charity’s advisory panels covering scientific awards, research, women and health and clinical practice.
- It reviewed, updated and renewed its scheme of delegation. This is the record of how the Council manages its authority.
- It reviewed the top ten risks the charity is exposed to and ensured adequate measures are in place to manage those risks.
- It reappointed William Fiennes as a vice President of the Association when his current term of office expires at the date of the AGM in June 2019.

The next meeting of the Council of Management will be on 5 February 2019.

Stronger together

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

Epilepsy Action puts on monthly coffee and chat groups around the country where you can meet other people living with epilepsy. We have groups in:


There are also Epilepsy Action branches and other support groups in a number of areas all over the UK, which also hold monthly meetings:

Abergavenny, Aberystwyth and District, Bournemouth and Poole, Burry Port and Pembrey, Cardiff, Carmarthen, Chelmsford, Colchester, Coventry, Foyle, Guildford and Godalming, Harrow, Huddersfield, Mid Ulster, North London, Nuneaton, Queens University Belfast, Saffron Walden, Scarborough, Sheffield, South West Wales, Stoke-On-Trent, Tendring, Truro, Tyneside, West London, Wigan, Wolverhampton and District, and York.

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 online spaces 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.

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.
20 Years of treating drug-resistant epilepsy

Fewer seizures.\(^1\)
Shorter seizures.\(^2\)
Faster recovery.\(^2,3\)

Why wait?

Ask your GP, Epilepsy Nurse or Neurology Specialist for more information on VNS Therapy

www.vnstherapy.co.uk

References:
3. Data on File, LivaNova, Houston, TX.

INTENDED USE / INDICATIONS:
Epilepsy (Non-US)—The VNS Therapy System is indicated for use as an adjunctive therapy in reducing the frequency of seizures in patients whose epileptic disorder is dominated by partial seizures (with or without secondary generalization) or generalized seizures that are refractory to seizure medications. AspireSR\(^\text{®}\) and SenTiva\(^\text{™}\) feature an Automatic Stimulation Mode which is intended for patients who experience seizures that are associated with cardiac rhythm increases known as ictal tachycardia.

The most commonly reported side effects are hoarseness, sore throat, shortness of breath, and coughing.

Visit http://www.vnstherapy.co.uk/safety-information to learn more and view important safety information.