Epilepsy on stage

Find out how Tom changed his life around after his epilepsy diagnosis derailed his plans

Also in this issue

• Prof Sanjay Sisodiya discusses the role of genes in epilepsy
• new study looks into problems and solutions around epilepsy and work
• a few highlights from Purple Day 2019
Welcome to the June issue of Epilepsy Today!

It’s hard to believe that Purple Day was over a month ago. It feels like only yesterday we were picking out our purple outfits, throwing purple food colouring into cake mixture in abundance and preparing to show our support. On the day itself, Epilepsy Action unveiled its Purple Day video, showing nine fantastic children sharing their epilepsy stories. Find out more about some of the highlights of Purple Day on page 18. You can also find another inspirational personal story from our cover star this issue, Tom Ryalls. Tom’s epilepsy started in a very dramatic fashion and his diagnosis scuppered his future plans to go on adventures in space. But Tom decided if he can’t go on adventures, maybe he could write them. Read more on page 27.

In this issue, we have the second part of our research update from the International League Against Epilepsy’s UK meeting in 2018, on page 20. The sessions we look at cover some of the most influential studies that have helped inform epilepsy care, and the important topic of mental health in people with epilepsy. We also bring you a piece of research looking at problems and solutions around epilepsy and work on page 12. Find out what the study found were the biggest barriers, and the ways it proposes these could be tackled. Meanwhile, on page 8, we take a more in-depth look at epilepsy and genetics. This fast-growing area is helping to answer questions around why some people have epilepsy without an obvious cause and why some medicines do and don’t work.

We also take a look back at 2018 in this edition. In some respects, this was a great year for Epilepsy Action. Your generosity has helped Epilepsy Action increase its resources for people with epilepsy and offer essential support to the people who need it most (page 16). However, in 2018 we also lost one of the leading figures in the field of photosensitive epilepsy, Professor Graham Harding. You may have heard of the Harding test for flashing images in video footage – just one of his many contributions. We celebrate the work and life of this remarkable man on page 26.

It’s also that time of year again – time to cast your votes for the members of the Epilepsy Action Council of Management. Your voting documents are enclosed with this issue.

Enjoy this issue and have a wonderful spring and start to the summer!

Kami Kountcheva
Editor
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When an epilepsy diagnosis derailed Tom’s career plans, he decided to turn to the theatre and bring his story to the stage
Some epilepsy medicines “cannot be stockpiled”

On 3 April, BBC Newsnight reported that some medicines, including some for epilepsy, bipolar disorder and neuropathic pain, cannot be stockpiled. This comes after the Health Secretary Matthew Hancock said in parliament that medical suppliers had been asked to stockpile an extra six-weeks’ worth of medicines to ensure medicine supply continues in all Brexit scenarios.

Newsnight revealed that the NHS has shared a list of the medicines that cannot be stockpiled with just a handful of senior clinicians who had been asked to keep quiet. Consultant neurologist David Nicholl, one of the recipients, shared the information with Newsnight, saying it is a “public interest issue”. He told Newsnight the problems could have been solved more easily months ago if the documents had been more widely shared.

The list of specific medicines has not been made public. Reasons for not being able to stockpile them include capacity problems and “disruption in production”.

Epilepsy Action’s chief executive Philip Lee and the chair of the All Party Parliamentary Group (APPG) on epilepsy, Paula Sherriff have written to the Health secretary. They have urged the government to share their concerns with the people to get in touch with people who would be affected.

They have urged the government to share what is being done to protect people who would be affected. Epilepsy Action has asked people to get in touch with their local MPs calling on them to raise their concerns with the health secretary. The full report is available at: bbc.in/2YYj4D4

Experts from 13 national organisations have launched new practical guidance for healthcare professionals prescribing sodium valproate to girls and women in the UK.

The guidance, published on 29 March, includes the 2018 regulations from the Medicines and Healthcare products Regulatory Agency (MHRA), but also addresses other challenges and issues prescribers might face.

Sodium valproate is an epilepsy medicine which can be very effective in controlling seizures. In some girls and women, it may be the only medicine that works.

However, taking sodium valproate during pregnancy is linked to an increased risk of birth defects and problems with development in babies. The MHRA has said that this medicine should not be prescribed to girls or women of childbearing age without a pregnancy prevention plan.

The practical guidance offers prescribers data and best practice information, as well as directing them to other useful resources.

Seven of the UK’s Royal Colleges were part of the organisations putting the guidance together. The clinical lead for the Royal College of Paediatrics and Child Health, Dr Daniel Hawcutt, said: “The dangers of valproate to the unborn child are now well recognised, so prescribing in women is now limited. However, it can be an effective medicine to treat seizures, especially in children.”

He said that the guidance will help healthcare professionals apply the MHRA’s guidance effectively across age groups. He added that it will help make treatment decisions in complicated circumstances, such as around puberty in girls and in women with learning disabilities.

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Healthcare professionals can face complicated situations when prescribing sodium valproate. They include teenagers moving from children’s to adult services, questions around consent, and issues with privacy.

The MHRA has said that women with epilepsy taking sodium valproate are reviewed in line with all recent guidance and regulations.

“it is crucial that this guidance is effectively publicised and disseminated, so that all relevant clinicians are aware of it. It is vitally important that healthcare professionals ensure that women with epilepsy taking sodium valproate are reviewed in line with all recent guidance and regulations.”

The National Institute for Health and Care Excellence (NICE) also recently published a summary of its recommendations around sodium valproate for healthcare professionals. NICE said it brings together information on safe prescribing from other sources, including the MHRA, and offers easy-to-access and practical information.

Epilepsy Action advises that women taking this medicine continue to do as prescribed, unless advised otherwise by their doctor. Women should speak to their doctor if they have concerns about their medicine. Stopping taking epilepsy medicine could result in breakthrough or worsened seizures, which could harm the mother and baby.
Changes to prescribing rules around pregabalin and gabapentin following reclassification

Epilepsy medicines pregabalin and gabapentin were reclassified as controlled medicines under the Misuse of Drugs Act 1971 from 1 April 2019.

This means there will be stricter legal controls over these medicines to prevent them from being misused, causing harm or being sourced illegally.

Doctors can still prescribe pregabalin (brand names Axalid, Lecaent and Lyrica) and gabapentin (brand name Neurotin) to people who need them. However, NHS England has explained there are some changes to the rules around their prescription.

Only a 30 days’ supply is allowed on one prescription. People will need to request repeat prescriptions from their GP each month and pick up their medicines within 28 days of the date on the prescription.

NHS England explains GP practices that don’t use the electronic prescription service for controlled drugs may not be able to send electronic prescriptions for these medicines to the pharmacy. People will need to go to the GP to collect their prescription in person. If they can’t, a representative can also be set up through their GP practice, who can do this in their place.

The person picking up the prescription will need to show proof of ID and sign for their medicines at the pharmacy.

NHS England advises that if people run out or need an emergency supply of pregabalin or gabapentin, they will need to contact their GP’s out-of-hours service.

The government announced its plans to make the change to the classification of pregabalin and gabapentin in October 2018. The decision followed concerns raised by the Advisory Council on the Misuse of Drugs over the potential for misuse of or addiction to these medicines. Misuse could include taking the medicines without having a prescription or taking them in a way that is not prescribed by a doctor.

They will now be a Class C controlled substance. This is the third in the government’s three-tier categorising system. Substances in class C are associated with the least amount of harm compared with those in classes A or B.

Other controlled medicines used for epilepsy include the emergency medicines midazolam and diazepam.

If you are concerned about your medicines, you can speak to your GP or epilepsy specialist. You can also call the Epilepsy Action Helpline on 0808 800 5050.

Teva oxcarbazepine tablets discontinued in the UK

Pharmaceutical company Teva is discontinuing its version of oxcarbazepine tablets. It has already discontinued the 600mg and 300mg tablets, and will discontinue the 150mg tablets later this year when current stock runs out.

Other manufacturers’ versions of oxcarbazepine tablets are still available. If people have any concerns about taking a different version of oxcarbazepine, Epilepsy Action advises they speak to their GP, epilepsy nurse or epilepsy specialist.

The 15mg tablets of the epilepsy medicine Gabitril (generic name tiagabine) are temporarily out of stock.

Teva, the pharmaceutical company that makes Gabitril, expects to have them back in stock towards the end of May 2019.

The 5mg and 10mg tablets are in stock, but they may not be available at all wholesalers. Epilepsy Action advises that if people’s pharmacists are having trouble getting hold of Gabitril tablets, they can contact Teva for help.
Cannabis oil prescription given for nine-year-old

A nine-year-old girl, whose cannabis oil had been confiscated at the airport, has been given a prescription from a UK specialist.

Teagan’s medicine had been taken after her mother Emma Appleby brought the three-month supply into the UK illegally from the Netherlands on 6 April.

Teagan, from Aylesham, has a rare disorder and Lennox-Gastaut syndrome, and she can have up to 300 seizures a day.

The medicine had originally been prescribed by a paediatric neurologist in Rotterdam and had cost the family over £4,500.

The confiscation left Ms Appleby in tears. She said she had been “passed from pillar to post” trying to access the medicine in the UK and that she was at her “wits’ end”. She had reportedly been refused an import licence on compassionate grounds.

The law in the UK changed in November 2018 to allow specialist clinicians to prescribe cannabis-based medicines. However, since then the guidance produced for prescribers has been criticised for being too restrictive.

Health Secretary Matt Hancock said that without clinical authorisation, it is not possible to bring controlled substances into the country. However, the government had given the family the opportunity for a second clinical opinion.

The UK’s House of Lords held a debate on the safety of medicines and medical devices on 28 February, discussing issues around sodium valproate.

Sodium valproate is an epilepsy medicine. Its use during pregnancy has been linked with an increased risk of developmental problems and birth defects in babies. However, it can be a very effective epilepsy medicine, and in some women, it can be the only medicine that works.

The debate follows the government’s Independent Medicines and Medical Devices review into three ‘public health scandals’, which was launched on 22 February 2018. Baroness Cumberlege is chairing the review, which is looking into three separate scandals surrounding medicines and medical devices. These are sodium valproate, the pregnancy test drug Primodos, and the vaginal mesh implant. The findings of the review are expected to be reported later this year, alongside recommendations for improvements. Several organisations and patient groups, including Epilepsy Action, have submitted evidence for the review.

The debate was secured and opened by Lord O’Shaughnessey. He quoted figures from the Independent Fetal Anti Convulsant Trust (In-FACT), suggesting that prescription numbers of sodium valproate for women remain similar to those in 2015.

However, Lord O’Shaughnessey also mentioned the Medicines and Healthcare products Regulatory Agency (MHRA) pregnancy prevention programme, which came in in April 2018. This programme was put together to ensure that girls or women of childbearing age have effective birth control if they are prescribed sodium valproate.

Baroness Blackwood from the Department of Health and Social Care said that the government’s aim is to “reduce and eliminate pregnancies being exposed to valproate”. She said that healthcare professionals are responsible for making women aware of the risks of this medicine and ensuring they are on the pregnancy prevention programme.

Baroness Walmsley added that Philip Lee, chief executive of Epilepsy Action, had stressed the importance of a mandatory discussion of the risks with a health professional for all women with epilepsy on sodium valproate. This is to ensure they can make an informed choice before conceiving. Mr Lee’s comment had followed two surveys in 2016 and 2017 showing that around one-fifth of women were not aware of the risks of this medicine in pregnancy.

She also suggested that community pharmacies have a role to play in ensuring the safe and cost-effective use of medicines and seeking feedback from patients.

The debate also saw calls made for compensation to be provided to people who have suffered from unsafe medicines or devices.

Epilepsy Action has said it is pleased that the issues with sodium valproate have been raised in the House of Lords. The organisation said it will continue to campaign to ensure every woman prescribed sodium valproate is aware of the risks.

Epilepsy Action advises that women taking this medicine continue to do so as prescribed, unless advised otherwise by their doctor. Women should speak to their doctor if they have concerns about their medicine. Stopping epilepsy medicine could result in breakthrough or worsened seizures, which could harm the mother and baby.
**UK government brings in serious shortage protocols in case of medicine shortages**

The UK government's serious shortage protocol (SSP), giving pharmacists extra power to amend prescriptions when there is a medicine shortage, became law in February.

Epilepsy medicines can be subject to an SSP, but additional protections are in place because of regulations around medicine switching.

The SSP is designed to reduce the impact of medicine shortages on people and is a change to the Human Medicines Regulations 2012.

An SSP can be issued if there is a serious shortage of a particular medicine. If one is issued, it would specify in what way pharmacists would be able to amend prescriptions.

Pharmacists may be advised to give a different dose, such as two 5mg tablets instead of one 10mg. Alternatively, they may need to supply a reduced quantity, for example changing a six-week supply to a four-week supply.

They may be asked to give a different medicine that has the same effect as the one originally prescribed, or a generic form of the original medicine.

While it was previously reported that epilepsy medicines would not be part of the government shortage plans, pharmacists will be able to give a different dose or reduced quantity. But protections are in place, saying that "protocols for therapeutic or generic equivalents will not be suitable for all medicines and patients".

This means people with epilepsy won't be offered a different medicine, or a different form of their original medicine. In these cases, they would be referred back to their prescribing doctor.

Epilepsy Action explains that SSPs are necessary as medicine shortages have become more common since 2017.

The organisation said more clarity is needed around how a 'serious shortage' would be measured and when an SSP would be used. It added that no SSPs have yet been issued.

**Cannabidiol in the long term**

A new US study in the journal *Epilepsy Research* has found that cannabidiol is safe and effective in the long term in hard-to-treat epilepsies.

Dr Laux and colleagues looked at seizures and side-effects in 607 people with Dravet syndrome, Lennox-Gastaut syndrome and other hard-to-treat epilepsies taking cannabidiol in addition to their other epilepsy medicines.

They were evaluated every 12 weeks for a total of 96 weeks. Throughout that time, the researchers found that the reduction in seizures stayed the same. They called the safety "acceptable", with the most common side-effects being drowsiness and diarrhoea.

Previous studies have focused on the short term, but the current study concluded that cannabidiol is also safe and effective in the long-term.

**Seizures have a specific smell, study suggests**

A new French study in the journal *Scientific Reports* has found that seizures are associated with a specific smell.

Researcher Amélie Catala and her colleagues set out to test whether trained dogs could identify the smell of a seizure. They used samples of breath and sweat from five different people who all had different types of epilepsy. One odour sample from each person was taken during a seizure and the rest were taken at other times – during calm activities and physical exercise.

Five dogs were used in the study. The dogs were trained to identify seizures but had never come in to contact with the people in the study. Each dog was tested on the five different people to see if it could identify the odour linked to a seizure.

For each person, the dogs were presented with seven identical-looking cans with the different smells from the different activities. All the dogs responded to the seizure smell but not the other smells.

The researchers explained that the study showed that each dog could distinguish the seizure smell from the odour of the person the rest of the time. The dogs could also identify the smell of a seizure in different individuals.

The study authors suggest that this means there is a particular odour associated with seizures.

The authors said that this doesn't necessarily explain what cues seizure alert dogs use, as this looked at the smell during a seizure and not before one happened. However, they said their findings pave the way for future studies into how a person's odour changes during a seizure. They say it could be a stepping stone towards electronic prediction devices or a better understanding on the cues used by trained dogs.
How genes affect epilepsy is of ever increasing interest in epilepsy research. Kami Kountcheva talks to Professor Sanjay Sisodiya from University College London about the roles genes may play in epilepsy.

When I was younger, the first thing we were taught about genes is that they form the code that makes up who we are. Our eye colour, our hair colour, blood type, whether our earlobes are attached or free – everything is coded for in our genes.

But the plot thickened when we were told that genes aren’t all that’s involved in shaping us. The environment we grow up and live in can have an effect on things like our behaviour and personality. For example, something like learning a new language isn’t something a person’s genes are coded for. It’s something the person may have had the opportunity or need to do. Or having a job that requires manual work means a person will become stronger – this is also something dictated by their circumstances, not their genes.

This forms the basis of the famous ‘nature versus nurture’ debate, asking which has more influence over us, our genes or our environment. And in reality, the answer is that it’s probably a mixture of the two.

Some people believe that there is a genetic contribution to most epilepsies

The way genes can be involved in epilepsy is far from simple. There are various different changes – or mutations – that can happen in our genetic code that can have an effect. Sections of the code could become changed, deleted, added or repeated in error. These changes may affect the structure of the gene or the way it works. On top of this, epilepsy could be due to changes in one gene or a combination of several genes. This all makes the role of genes in epilepsy very complicated.

Epilepsy studies are focusing more and more on this area. A recent review from researchers in Canada looked at our current knowledge of epilepsy genetics and what the future holds. The review explains that already clinical testing for epilepsy genetics is available and has helped to offer diagnoses and a better understanding of the condition to some people. The researchers said that new epilepsy gene discoveries and advances are now being made at a quick pace. They added that development in technology is the reason why this is able to happen faster and faster. But there is still a way to go, as more work is needed – and taking place – in this area. The hope is that the more we understand about epilepsy genes, the more information doctors will have about different epilepsies and the more we’ll know about the way to treat them.

With the fast developments in this complicated area, we wanted to find out more about what we know so far and what this might mean for people with epilepsy in the future.

Professor Sisodiya is a professor of neurology at University College London and a consultant neurologist at the National Hospital for Neurology and Neurosurgery and the Epilepsy Society. He is one of the people working in this area to expand the knowledge we have of genes involved in epilepsy. He tells Epilepsy...
Today about the progress we’ve made understanding genes in epilepsy, what this means for possible treatments and what the future may hold.

What role do genes play in epilepsy?
As more and more studies are completed, it is becoming clear that genes play an important role in epilepsy. While most of the genes we carry are the same from one person to another, there are differences. Some differences are common (known as common variation) and others are rare (known as rare variation). We are learning that rare genetic changes are often the cause of many rare, severe epilepsies. But rare genetic changes can also be a cause of some of the more common epilepsies.

We have also found out that common genetic changes contribute to many of the more common epilepsies, increasing the chance that an individual might develop epilepsy. Some people believe that there is a genetic contribution of some sort – greater or lesser – to most epilepsies.

In what ways might genes cause epilepsy?
It may seem an obvious thing to say, but the brain is a very complicated thing. There are many ways in which the working of the brain can be disrupted to cause epilepsy. We are learning that changes in many different genes can cause epilepsy. One of the more frequent ways in which genes, when they are not working properly, can cause epilepsy is by changing the way electrical signals in the brain are moved about. These epilepsies are called channelopathies because the channels that allow the signals to move are not working properly. But there are many other ways that altered genes can lead to epilepsy.

How long has research been happening around this?
Genetics as an idea in epilepsy has been considered for two thousand years! But today’s rapid advances were unimaginable even 20 years ago. They have been brought about by enormous progress in technology, as well as vital international research like the Human Genome Project (HGP). This project set out to map all the genes in human DNA. Strong international links between doctors, scientists and people with epilepsy all working to the same goal have also made this important progress possible.

We are learning more and more, and learning this at a rapid rate. We are finding new genes associated with epilepsy on a monthly basis – and usually more frequently than that. Often, the challenge with today’s genetic tests is to sort out from the huge amount of information the tests generate which results are relevant and which are not. And with each new gene we find to be associated with epilepsy, we then start on a whole new journey of trying to understand how changes in that gene might cause epilepsy. So, we know a fair amount – but there is still a huge amount to learn.

What examples are there of known genes involved in epilepsy?
There are many important examples of how genes are involved in particular epilepsies. One, perhaps among the best understood, is Dravet syndrome. This is one of the more commonly seen of the rare epilepsies. In most people with Dravet syndrome, the cause is a change in a gene called SCN1A. This change is usually found only in the affected person, and not the parents. Dravet syndrome has certain recognisable characteristic features, and often the seizures with which it is associated are difficult to treat.

Research has helped us understand how seizures arise in Dravet syndrome, and how they are driven by the underlying
Epilepsy feature

Finding out a cause for epilepsy can bring relief but also lead to new worries

Epilepsy Action has more information on inheritance at: epilepsy.org.uk/inheritance

What does identifying a genetic cause mean for treatment and therapy?
This depends very much on the actual genetic cause. Finding a genetic cause is important because it can provide an answer to the question ‘why do I (or my child) have epilepsy?’ Finding a cause can provide information about what the future might hold and ensure that other problems (for example in the eyes or the heart) associated with changes in that gene are treated.

Occasionally, finding a cause may directly influence the treatment that is thought to be most effective. This is clearly important. At the moment, it is still relatively uncommon for an identified genetic cause to lead to a change in treatment. But, as our knowledge about genetic causes of epilepsy grows, it will become more and more important – taking us increasingly to treatments determined by cause.

What is research looking into at the moment?
There are many areas of active research in genetics. These are things like which genes cause epilepsy, the roles of common and rare gene changes and how they interact, and how genetic changes can lead to epilepsy. We are also looking into treatment. For example, we want to know how finding the genetic cause can lead to better treatment of that epilepsy and how genes affect the way current epilepsy medicines work. We also want to know how knowledge of genes might lead us to find new treatments. Research is also going on into what controls genes, how genes and the environment interact, and many other areas.

For many people and families, finding a cause can bring relief and help better understand a person’s epilepsy

What does the future look like for people with epilepsy from a genetic cause?
It is impossible to predict the future of course – few of us could have predicted much about the world around us today. But if I had to make some informed guesses, I would say that genetics will have a huge impact on how we understand and treat the epilepsies. For some genetic causes, these benefits will come sooner, for others not so quickly. But I expect that in time, genetics will be important for everyone with epilepsy. Twenty years or so ago, MRI was just starting to be used in epilepsy, and now most people with epilepsy will have an MRI brain scan. I expect genetic testing in epilepsy will also become routine, hopefully quicker than MRI did. By providing more information about each person’s epilepsy, genetics will have, in my view, at least as much impact as EEG and MRI have had – if not more.

What are the risks of a person passing on epilepsy from a genetic cause to their children?
This is an important and complicated area. Anyone concerned by this should speak to their doctor. In some cases, especially when a genetic cause is known or suspected, it may be important for the person to see a clinical geneticist. This is a type of doctor who works with people affected by or at risk of a genetic disorder.

We have learnt that not all causes that are genetic are passed on by the parents. An individual may have a new genetic change that neither parent has. If the person is able to have children, they may potentially be able to pass on the genetic cause. But we have also learnt that passing on a genetic cause does not always mean that epilepsy itself is also passed on. And if it is, it is usually not possible to predict how severe that epilepsy might be. The risk of passing on a genetic cause of an epilepsy will depend on the gene involved and the type of change in that gene.

In this complicated and rapidly moving area, it is important that anyone concerned see their doctor.

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tea break
friday 18 october

Sign up now to receive a fundraising pack using the included address sheet or online at epilepsy.org.uk/teabreak
Getting a job is something most of us strive for. Work can be a way to earn a living and offer a feeling of security. But it’s also about more than that. It’s an opportunity for us to follow our interests and ambitions. It is linked to our confidence and self-esteem. And it can add to our social life and create a routine for us.

Finding a job is undeniably an important part of life for many of us. So, it makes it even more of a serious problem that people with epilepsy report facing challenges in this arena. Past research has confirmed this. It has shown that people with epilepsy are more than twice as likely to be unemployed as people without the condition.

Epilepsy Action wanted to better understand the reasons for this and what can be done to improve the situation. To do this, the organisation requested a piece of research from the Institute for Employment Studies (IES). This aimed to find out what barriers exist for employers and people with epilepsy and find ways to tackle them.

The IES researchers interviewed six employers and four experts in employment, clinical practice and research. They also held focus groups with people with different forms of epilepsy and different employment experiences. They wanted to compare epilepsy and other long-term conditions when it comes to employment support. They also set out to find out what information would reassure an employer. Finally, they wanted to know what employment support would be useful for people with epilepsy.

Employers were nervous about how clients or colleagues would react seeing someone have a seizure.

Epilepsy Action wanted to better understand the reasons for this and what can be done to improve the situation. To do this, the organisation requested a piece of research from the Institute for Employment Studies (IES). This aimed to find out what barriers exist for employers and people with epilepsy and find ways to tackle them.

The IES researchers interviewed six employers and four experts in employment, clinical practice and research. They also held focus groups with people with different forms of epilepsy and different employment experiences. They wanted to compare epilepsy and other long-term conditions when it comes to employment support. They also set out to find out what information would reassure an employer. Finally, they wanted to know what employment support would be useful for people with epilepsy.
A knowledge barrier
Throughout the interviews, the researchers realised that a lack of understanding of epilepsy created a big problem. Employers were often not familiar with the different types of epilepsy. They were not aware of the different ways in which epilepsy can affect different people. They also didn’t realise that epilepsy medicines could control the condition in some people. Employers often weren’t aware that not everyone’s seizures are triggered by flashing or flickering lights. They also weren’t familiar with the fact that not everyone has tonic-clonic seizures.

The research found that this often left employers worried about health and safety. They were nervous about how clients or colleagues would react seeing someone have a seizure. Employers also said that it could be costly and impractical to make adjustments for people with epilepsy in some circumstances.

Employers were generally “not positive” about employing someone with epilepsy, the research found. However, when they were given more information, they seemed more willing to keep an open mind. As well as that, employers seemed to be happier to make adjustments for an existing employee if they were newly diagnosed with epilepsy.

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The experts compared the stigma to that people with mental health conditions might experience. They said that past research has shown that employers were particularly wary of employing people with invisible conditions.

The experts acknowledged that epilepsy can often come with mental health conditions like depression and anxiety. They noted that these conditions can also affect people’s confidence and self-esteem. Both having epilepsy and having an additional mental health condition could affect the jobs and opportunities people went for. The research found that people may not be going for jobs that use their talents and skills. It suggested they were often held back by a lack of confidence.

To say or not to say
Generally, employers aren’t allowed to ask people questions about their health without a good reason. In applications and job interviews, they would only be allowed to ask if it is linked to an essential part of the job. They could also ask in case they need to make reasonable adjustments.

Once a person is offered the job, they don’t automatically have to tell their employer about their epilepsy either. But this is as long as they believe it won’t affect their ability to do the job safely and effectively. This is, for example, if their seizures happen at night, or are such that they can still do the job. If a person doesn’t tell their employer about their epilepsy and it does affect their ability to do their job safely, their employer could dismiss them.

Not telling an employer about epilepsy could also mean that a person is not covered by their employer’s insurance. Without knowing about their epilepsy, employers also won’t be able to make reasonable adjustments for employees. These could include making changes to working hours, making alteration to working space or allowing a person to use different equipment. There is more information about work and epilepsy on the Epilepsy Action website:
epilepsy.org.uk/employment

It’s not always easy to know the right thing to do about whether or not to let an employer know about epilepsy. But the IES research found that people with epilepsy and employers had very different views on this issue.
The employers interviewed expected people to disclose their epilepsy at the application stage, at their interview or immediately after starting the job. The reasons given were around safety and managing any adjustments. Almost all of the employers said they would take a ‘dim view’ of not being told about an employee’s epilepsy and finding out at a later date.

In stark contrast, the people with epilepsy in the focus groups didn’t feel comfortable telling their employers about their condition until they were established in a job. Many people felt that they had faced discrimination in the past. This had made them fearful of letting employers know about their condition. As well as that, a lack of knowledge about epilepsy meant people didn’t feel confident in explaining their epilepsy to their employer.

Supporting open conversation
The research found that there is a gap in communication between people with epilepsy and employers. A lack of understanding breeds fear and stigma in potential employers. But people with epilepsy feel like they need support to be able to explain their condition effectively. The researchers suggested that a personalised online toolkit that people could use would guide conversations between employees and employers. It would have information about health and safety, reasonable adjustments and common concerns.

The researchers also found that self-management tools would help people with epilepsy to build their confidence. This could help them to feel more comfortable understanding and describing their epilepsy to an employer. People also thought having someone with them to help them talk about epilepsy would be helpful.

A personalised online toolkit that people could use would guide conversations between employees and employers.

The study showed that helping to better inform employers about epilepsy worked to dismiss some of the myths around the condition. The researchers concluded that online learning packages for employers could help with this. It would allow employers to gain a better understanding of the different aspects of the condition and how varied it can be.

Campaigns to help change attitudes around epilepsy were also suggested by the researchers.

Steps towards supporting people
Epilepsy can be a difficult condition to get to grips with. The unpredictability of seizures can make it difficult to speak confidently about it. While they may help, medicines don’t always fully control a person’s seizures. This can also add uncertainty. It is no surprise that people find it difficult to explain their experiences to a potential employer.

The fact that it is an often misunderstood condition will also come as no surprise. How much people know about it can vary, and sometimes people are still led by myths. All of these things can create challenges for people with epilepsy when trying to find a job.

Epilepsy Action has already been taking steps towards supporting people with epilepsy looking for work. The organisation offers a range of advice and information materials about epilepsy and work. It also regularly trains employers about epilepsy and the reasonable adjustments that can be made.

Plans for other resources, including online tools to help employers support people with epilepsy in the workplace, are currently being developed. Epilepsy Action also has the ‘Epilepsy and you’ online self-management tool. This was designed to help people live better with epilepsy and become an expert in their own condition.

Epilepsy Action also works to influence the government and other organisations. It aims to make sure they understand the needs of people with epilepsy. It also works towards making sure there is support with employment for people with epilepsy written into legislation. The charity will be continuing this work throughout the year and beyond.

If you’d be happy to share your experiences of work or employment issues (both positive and negative) with Epilepsy Action, please contact the campaigns team at campaigns@epilepsy.org.uk
Be a Facebook fundraiser!

Joshua’s birthday fundraiser for Epilepsy Action

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<th>Donate to Charity</th>
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<tr>
<td>📲 Invite</td>
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<td>🔗 Share</td>
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<tr>
<td>⚙ More ▼</td>
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</table>

Fundraiser has ended
Joshua reached his birthday goal! Thanks to everyone who donated.

£550/£300 raised

This year, if you are celebrating an anniversary, birthday or wedding, please consider dedicating your celebration to people affected by epilepsy.

Winner winner!

Epilepsy Action is part of Unity Lottery – the nation’s weekly fundraising lottery. From every £1 played, 50p goes to support Epilepsy Action’s work to help people living with epilepsy. That means the Unity weekly lottery helps to pay for vital work that helps so many people. This includes services like the Epilepsy Action Helpline, the website and Epilepsy Action’s UK-wide network of local support groups.

Janice Fidler played and won £1,000! She said: “I was thrilled to receive my cheque in the post – what a lovely surprise! Epilepsy Action is a charity very close to our hearts, as my daughter has epilepsy, and we are always happy to support the brilliant work you all do. My daughter is getting married in May, so the winnings will come in very useful!”

You can start playing for as little as £1 a week. You can play straight away by signing-up online at epilepsy.org.uk/win or request an entry form by calling Jenny on 0113 210 8822.

Apply now for London Marathon 2020

Has running the Virgin Money London Marathon always been on your bucket list? Have you been tempted by London’s iconic backdrop of famous sights, the sound of crowds cheering you on and the incredible sense of achievement at the end? If so, why not apply for an Epilepsy Action charity place in the 2020 event?

Next year’s event is set to take place on Sunday 19 April. By running the marathon for Epilepsy Action, you will help to provide invaluable support to people with epilepsy. We will be on hand with fundraising advice, and you will get a free technical vest with your name on it, refreshments and a sports massage after the race!

Applications are now open and will be allocated in mid-June. To give your application the best chance of being successful, please answer the questions in as much detail as possible. We’ll then be in touch either way. You can apply now at: epilepsy.org.uk/londonmarathon

Did you know Facebook users can now launch their very own fundraiser and donate directly to a charity close to their hearts?

How does it work?
It’s simple to set up. Select Fundraisers from the menu options on your Facebook page. Choose Epilepsy Action as your chosen charity and set up your fundraiser.

Friends can donate to your fundraisers in just a few clicks – all without leaving Facebook. You can share your fundraiser through email, Instagram, Twitter or wherever else you connect with your friends.

Epilepsy Action will receive 100% of the money you raise direct from Facebook, meaning no hassle for you!

You can set up a Facebook fundraiser now by visiting facebook.com/epilepsyaction

Be a Facebook fundraiser!

Winner winner!

Apply now for London Marathon 2020

Be a Facebook fundraiser!

Winner winner!

Apply now for London Marathon 2020

Be a Facebook fundraiser!

Winner winner!

Apply now for London Marathon 2020

Be a Facebook fundraiser!

Winner winner!

Apply now for London Marathon 2020

Be a Facebook fundraiser!
The challenges and successes of 2018 were many and varied. Over the year, we worked with decision makers and regulators to try to avoid people with epilepsy being treated unfairly. For example, we have pushed for changes around the benefits system and access to epilepsy medicines, old and new. We’ve had some important successes in each of these areas and more. But it’s vital that we keep challenging unfair systems, the lack of understanding of epilepsy and its impact on day-to-day life.

Last year again saw a rise in demand for our services. So, I was delighted when, thanks to your support and generosity, we were able to expand our helpline and face-to-face services. Being able to talk to a real person, on the phone or face-to-face, can and does change lives. Sarah’s story on page 17 reminds us all why Epilepsy Action exists.

Another success story in 2018 was the growth of our training service. Employers, care staff, schools, families – our volunteer and e-learning training reached more people than ever before. We know from feedback that this is changing the way people think about epilepsy.

What makes Epilepsy Action special is you and all our other members and supporters. You make it possible for Epilepsy Action to be so successful. You are the reason we have such a positive impact on people’s lives. Thank you!

Philip Lee, chief executive

What people said about our local groups

“The branch and members have made me feel much less isolated and more valued.”

“I feel the coffee and chat group has helped me realise I’m not alone as a parent of a child with epilepsy.”

A snapshot of Epilepsy Action’s work in 2018

Growth in services

<table>
<thead>
<tr>
<th>Description</th>
<th>Count</th>
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<tbody>
<tr>
<td>1 new quarterly publication for health professionals: Paediatric Epilepsy</td>
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</tr>
<tr>
<td>7 more local groups</td>
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<tr>
<td>139 more active members joined Forum4e</td>
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<tr>
<td>172 more people attended regional conferences</td>
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<tr>
<td>759 more people received epilepsy awareness training</td>
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<tr>
<td>1,042 more people used helpline service</td>
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<tr>
<td>4,863 more e-learning registrations</td>
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<tr>
<td>5,296 more visits to e-learning site</td>
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<tr>
<td>73,694 more viewings of epilepsy first aid films</td>
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<tr>
<td>93,878 more unique visitors to advice and information web pages</td>
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Media coverage

<table>
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<tr>
<th>Description</th>
<th>Count</th>
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<tbody>
<tr>
<td>82 pieces of coverage in the national media</td>
<td></td>
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<tr>
<td>125 pieces of TV or radio coverage</td>
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<tr>
<td>889 pieces of coverage in the media in total</td>
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Supporting healthcare services

<table>
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<tr>
<th>Description</th>
<th>Count</th>
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<tbody>
<tr>
<td>24 NHS trusts and commissioners received our support to improve epilepsy services</td>
<td></td>
</tr>
<tr>
<td>62 nurses received our epilepsy training</td>
<td></td>
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<tr>
<td>512 health service commissioners used our epilepsy toolkit</td>
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Making a difference

<table>
<thead>
<tr>
<th>Description</th>
<th>Count</th>
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<tbody>
<tr>
<td>2,347 people attended epilepsy awareness sessions and</td>
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<tr>
<td>98% rated them excellent</td>
<td></td>
</tr>
<tr>
<td>99% would recommend it to others</td>
<td></td>
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<tr>
<td>56,119 hours were donated by our volunteers to help support people with epilepsy</td>
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Sarah’s story
“ I don’t think I’d be here if I didn’t know about Epilepsy Action”

For Sarah Baker, this is no throwaway comment. She means every word.

“All I remember of my teenage years is being angry all the time. I was 14 when I started having seizures, but by the time I was diagnosed, I was 17. At first they thought it was panic attacks, then serious migraine and then chronic fatigue. They were baffled.

“I just thought, ‘Oh they’re panic attacks’. I just wanted to ignore it.”

As Sarah’s seizures went undiagnosed, being constantly tired rapidly affected her life. She took to walking out of school – simply to sleep. Her mum and step-dad were threatened with fines because she missed so much school.

“It was just too tiring to be at school. We didn’t know what it was, so we couldn’t say ‘Oh, she’s got epilepsy’. I was set to get all As and A-stars in my GCSEs, but I couldn’t make the mock exams. So they moved me down the classes. All because I was in this tired blur. Most of the time I didn’t know what day it was.

“Then we saw a GP who said it might be epilepsy, but he doubted it because he said it’s very rare. We were worried it might be a tumour or something. Mum had to ask for a neurology referral.”

The neurologist confirmed the diagnosis of epilepsy and prescribed tablets. But Sarah’s continuing seizures cast further doubt on her diagnosis. Sarah’s parents asked for a second opinion and a specialist again confirmed she had epilepsy.

“Until I was 24 I never accepted having epilepsy. With all the misdiagnoses, we lost a bit of faith in the NHS. To trust a doctor again after all that was really hard.

“I used to think I couldn’t do anything at all, and this is when I got really, really depressed. Really anxious. I would just lock myself in my room. Mum had to reduce her hours at work because of my seizures. I’ve had seizures so many times in public. I even got banned from National Express. I’m on first name terms with all the local paramedics.

“I’ve had really bad depression all the time I’ve had epilepsy – we didn’t really put two and two together. It took mental health intervention to help in the end. It really helped to have someone say your mental health issues are a result of your epilepsy.”

Sarah had found the side-effects of her medication affected her concentration, behaviour and even left her thinking suicidal thoughts.

“Because my depression was so bad I’ve had a couple of attempts with the intention not to be here anymore. I don’t think I’d be here if I didn’t know about Epilepsy Action.

“I felt like I’d been drugged up so much over the years, I said to my mum ‘I’m never taking them anymore’. That’s when I called the Epilepsy Action Helpline. They referred us to the mental health team, they sorted all that out for us. At my worst possible time, the charity was there to point me in the right direction. I couldn’t see myself here if I didn’t have Epilepsy Action.”

Sarah also found an Epilepsy Action group local to her in Chelmsford, and met Liz – and this made a big difference to Sarah.

“Liz and the group said ‘Sarah, it’s not your fault. You didn’t ask for this.’ Slowly that got in my head. And this is when I started getting to acceptance. I felt more comfortable. It’s taken 10 years. And more! Since finding the group, now I say ‘I’ve got epilepsy, yeah’. I’ve got loads of help. I’m more bubbly with it now. I’ve accepted I’ve got epilepsy, but it doesn’t define me.”
It’s good to talk

We share a few highlights from Purple Day 2019

On Purple Day, Epilepsy Action launched a video of nine children talking about epilepsy. The video shows the spirited youngsters describe their seizures and their medicines, and share how their epilepsy makes them feel, or how they support brothers, sisters or friends.

If you didn’t catch it on the day, you can see Alfie, Amrit, Darcie, Freddie, Harriette, Jenson, Oscar, Sophie and William talk about how epilepsy affects them at: epilepsy.org.uk/purple-blog

On the day of the filming, the children and their families gathered in a London studio from all over the UK, full of nerves and excitement for the day ahead. They were welcomed by Epilepsy Action’s Chantal Spittles and Louise Cousins, and the friendly filming crew.

Chantal said: “This was the first time they had met. But any nerves and shyness soon disappeared when they all realised they had something in common – epilepsy.”

It’s clear from the video that the children quickly bonded and felt encouraged to share their feelings about all different aspects of epilepsy. They speak in their own words – describing their seizures as feeling “a bit wonky”, having a “wobbly thumb” or eyes going “really, really black”. They joke about the taste of their medicines and talk about what happens when they have a seizure at home or at school.

The video ends on the words: “It doesn’t matter how old you are, it’s good to talk about epilepsy”.

Life has changed

We know that talking about epilepsy is at the heart of Purple Day. The international day of epilepsy awareness was set up in 2008 by Cassidy Megan from Canada, who has epilepsy. She wanted a day where people with epilepsy could realise they weren’t alone and others could show their support.

More than 10 years on, the reach of this day continues to grow and the message behind it is stronger than ever.

To mark the day, Epilepsy Action wanted to take the opportunity to support children with epilepsy and their families.

One of the ways in which they wanted to do this was to supply more epilepsy specialist nurses with the Epilepsy Action ‘Just for Kids’ packs to give out. These bundles include a DVD with the stories of three children, a children’s book about epilepsy, stickers, pages for colouring and more. All of this was developed to help children understand their condition and talk about how they feel more easily.

Suzanne, mum of one of the girls in the video, Harriette, said: “I still vividly remember the day my three-year-old daughter Harriette had her first seizure. For a terrifying moment, I thought I had lost her forever. Then she started shaking, but she still wasn’t coming round.

“I knew Harriette’s life had changed forever that day. My husband and I were beside ourselves.

“The ‘Just for Kids’ pack gave Harriette a way of talking about her condition and helped the other children realise what was happening to her. The children were so supportive and the pack really helped.”

Another star of the video, Amrit, started having seizures at just three days old. She has had epilepsy surgery to help control her seizures. Her mum Gurvinder said Amrit doesn’t really see herself as different to any other children as she’s had epilepsy all her life.

Rachael, mum of Jenson, William and Darcie, said as her children have got older, they are becoming more aware about seizures. She said they take their epilepsy in their stride and support each other through it.

She added: “As parents, Ben and I are very positive about their epilepsy, as we don’t want it to hold them back. If
anything, we want them to feel proud of how strong and brave they are. I would like to think their epilepsy has helped to show true friendships and we have made friends aware they may need help if they have a seizure.”

**A different way to communicate**

But we all know it’s not always that easy to talk about epilepsy or explain how it feels, and it can be as hard for adults as it is for children. Sometimes it’s difficult to open up, or other times we just don’t know how to describe what’s happening. But for many, an artistic outlet can really help to express themselves and share their experiences with the world in a unique way.

In this spirit, Epilepsy Action Northern Ireland put together a special event for Purple Day. A set of workshops were held with a trained artist, where participants were supported to create their own piece of glass art. Everyone who took part wove into their artwork their journey with epilepsy, challenges they have overcome with the condition and their thoughts. As well as creating beautiful pieces of artwork, people had a natural environment to connect with everyone else creating their glass art.

On Purple Day, the finished pieces were displayed in an exhibition in the centre of Belfast to help raise awareness of epilepsy.

Debbie McCrudden was diagnosed with epilepsy in 2015 after a series of tonic-clonic seizures. She explained that her glass art piece started quite negatively, but she then decided to include positive aspects like her family who love her regardless of her epilepsy.

“She said: ‘My glasswork hopes to embody the contradiction of emotions, the unanswered questions and the many unknowns. Reach for opportunities to pull you ashore to firmer ground when they appear. In time, you will realise that everyone, not just those with epilepsy, are simply swans floating on a river, paddling manically underfoot, trying to manage their own struggles.’”

**A relief to share**

‘It’s good to talk’ doesn’t just mean telling the world about epilepsy. It also means that it’s a relief to share how you are feeling and seek help and advice. Epilepsy is a life-changing diagnosis at any age, and it can be really difficult to come to terms with and navigate. This is true for those of us with epilepsy, as well as family, friends and loved ones.

This is why Epilepsy Action strives to give people as many opportunities as possible to connect with others or find advice and information.

Epilepsy Action’s local branches and coffee and chat groups can provide a great environment for people to talk about how they’re feeling with others in a similar position. It can be very isolating to think you are the only person with epilepsy or having seizures. A connection with people who understand and who have similar experiences can be incredibly important.

You can find more about Epilepsy Action groups on page 31 or online at epilepsy.org.uk/coffeeandchat

The Epilepsy Action Helpline is also available to offer help and support to people with epilepsy. The helpline and the resources available have helped a huge number of people to gain a better understanding of their or a loved one’s epilepsy as well as find advice and information.

The helpline is open Monday to Thursday 8.30am-8.00pm, Friday 8.30am-4.30pm and Saturday 10.00am-4.00pm. You can also email helpline@epilepsy.org.uk or tweet @epilepsyadvice

People can also find support online. Epilepsy Action’s forum4e (forum.epilepsy.org.uk) gives people the opportunity to chat to others with epilepsy. Meanwhile, the My Story section on the Epilepsy Action website is also a good place to find real life experiences from lots of other people living with epilepsy. You can find this at epilepsy.org.uk/my-story

**Thank you**

This year’s Purple Day successes are down to everyone’s support and generosity. Wearing purple, buying wristbands, dyeing your hair, baking cakes, fundraising — everything you did has helped people see they are not alone and feel encouraged to share. Together, for Purple Day, you also helped raise over £27,000 to date, a huge amount that will make a world of difference to people living with epilepsy. Thank you.
In part I of this article, published in the previous issue of Epilepsy Today, we looked at a few of the sessions from the 2018 International League Against Epilepsy (ILAE) scientific meeting. These focused on complex epilepsies and treatments, epilepsy tests and scans, memory problems and more. In part II we look at some of the biggest studies in epilepsy, as well as presentations covering depression and mental health in epilepsy.

**Session 3: Studies that will change our practice**

**Epilepsy medicines (SANAD Trial)**

Professor Tony Marson from the University of Liverpool presented first on the standard and new anti-epileptic drug (SANAD) trial. This was carried out and published in 2007. It looked at how effective and well tolerated different epilepsy medicines were for focal (starting in one part of the brain) and generalised (affecting both sides of the brain) epilepsy. The study showed that lamotrigine and carbamazepine were equally effective in treating focal epilepsy, but that lamotrigine was better tolerated. For generalised epilepsy, sodium valproate was found to be the most effective.

Professor Marson explained that the results of the SANAD study has helped inform guidelines for clinicians from the National Institute for Health and Care Excellence (NICE). He added that DNA was also collected from the people in the study as part of the trial. This will now allow the data to be used to answer questions about genetics in epilepsy and the way they affect how epilepsy medicines work.

SANAD II, a second large-scale study on epilepsy medicines, is currently being carried out which will help to add to the information that we have. Professor Marson expects the results of this to be available in 2019.

Visit epilepsy.org.uk/takingmedicine for more information on epilepsy medicines.

**Status epilepticus treatment (ESETT study)**

Professor Hannah Cock from St George's London spoke about the established status epilepticus treatment trial (ESETT). Status epilepticus is a long seizure that lasts over five minutes. It can also be when a person goes in and out of seizures without recovering in between. This condition requires emergency treatment. Professor Cock explained that there is good evidence to say that the first treatment tried should be benzodiazepines, which are usually the medicines midazolam or diazepam. But if these don’t work, she said it is not very clear what medicine should be tried next. Her study aimed to find this out.

She said that previously, phenytoin or phosphenytoin have been used. But there are now new options, which may be safer, easier to administer and more effective. These include levetiracetam and sodium valproate. Professor Cock explained that the study was still ongoing, so she couldn’t report on the results. But she did share some findings around the use of the first-option medicines (benzodiazepines). She noted that the study had found that on many occasions, healthcare professionals were not administering a high enough
Dose. She said that parents and carers were sticking more closely to the correct dose. She said these results showed that doctors were being too cautious to give a dose for which there was good evidence of effectiveness.

Epilepsy Action has more information on status epilepticus at epilepsy.org.uk/emergencytreatment

Medicines in pregnancy (EMPIRE study)
The EMPIRE study looked at epilepsy medicine management in pregnancy. During pregnancy, the level of some epilepsy medicines in the blood can change. This study aimed to look at the best way to manage pregnant women with epilepsy, in whom the level of epilepsy medicine has dropped.

Dr Doug McCorry from Queen Elizabeth Hospital in Birmingham presented on this study. The research included women taking the epilepsy medicines lamotrigine, carbamazepine, phenytoin and levetiracetam. It also included various combinations of medicines. The two management strategies the study looked at were measuring the level of medicine in the blood or just managing the symptoms in the clinic. The study found that there wasn't a difference between the two management strategies in terms of reducing the risk of worsening seizures.

Dr McCorry concluded saying that good pregnancy care for women with epilepsy is far more than just checking epilepsy medicine levels in the blood.

There is more information on epilepsy and pregnancy at epilepsy.org.uk/pregnancy

Infantile spasms (UKISS and ICISS studies)
Dr Finbar O’Callaghan from University College London gave a talk on two studies: the UK infantile spasms study (UKISS) and the international collaborative infantile spasms study (ICISS). Infantile spasms are also known as West syndrome, a type of childhood epilepsy.

Dr O’Callaghan said that the thought is that with ongoing seizures, there is a worsening effect on development and brain functions in children. The UKISS study aimed to compare two treatments for infantile spasms – hormonal therapy and the medicine vigabatrin. The results of this study showed that hormonal therapy was the more effective treatment.

The ICISS study aimed to build on these findings. It wanted to see whether infantile spasms could be controlled for at least a four-week period two weeks after treatment was started. This time, the treatment was either hormonal therapy, or hormonal therapy combined with vigabatrin. The results showed that the combination of hormonal therapy with vigabatrin was the more effective and faster treatment for stopping infantile seizures.

When the study authors looked at development, they didn’t see a difference between children taking hormonal therapy and those taking hormonal therapy with vigabatrin. However, Dr O’Callaghan said that there was a difference between those children who responded early to treatment and those who didn’t. The children responding early had a better outcome in terms of their development and their seizures. He concluded that hormonal therapy combined with vigabatrin has made a big difference to the treatment of this condition.

For more information on infantile spasms, visit epilepsy.org.uk/west

Non-epileptic seizures (CODES study)
Dissociative seizures are ones that happen for psychological rather than physical reasons. This is a different condition to epilepsy but it can often be confused with epilepsy. It is very important that people have the right diagnosis so they can receive the correct treatment.

Professor Laura Goldstein from King’s College London presented on the CODES study looking at cognitive behavioural therapy (CBT) for dissociative (non-epileptic) seizures. CBT aims to help a person explore and change how they feel about their life and reduce unhelpful patterns of behaviour.

In this study, people were split up into two groups – one receiving standard medical care and CBT, and the other receiving just standard medical care. Professor Goldstein said she could not reveal the results of the study yet, as it had not been completed. However, she could share some details of the people in the study affected by dissociative seizures. She said that almost three-quarters were
women. On average, people had had the condition for about six years before getting a diagnosis. Over a quarter said they had received a previous diagnosis of epilepsy and around one-fifth were currently being prescribed epilepsy medicines. Dr Goldstein added that many people with dissociative seizures also had other conditions, including anxiety, depression and psychological distress.

Epilepsy Action has more information on dissociative seizures at epilepsy.org.uk/nead

**Epilepsy incidence in Cork, Ireland**

Last up at this session, Dr Danny Costello from Cork University Hospital spoke about the study on incidence of first seizures newly diagnosed and seizure mimics in Cork, Ireland. The incidence shows the rate of occurrence of epilepsy over a given time. Seizure mimics are events that can be mistaken for seizures.

Dr Costello began by saying that there has not yet been a good study showing the incidence of epilepsy in Ireland. He said this information is important in showing when and where healthcare resources are needed.

The study was carried out over the calendar year 2017. The team estimated that there were 280 new epilepsy cases in every 100,000 people. Dr Costello added that this number could be used to estimate the incidence of epilepsy in other parts of Ireland and many parts of Europe. He said this is because there is no reason to believe that this population is different to the populations in those areas. He said the information can help to estimate how many people are likely to go to hospital for a first seizure over a year. This can therefore be used to plan healthcare and decide how to allocate resources appropriately.

**Session 5: Epilepsy, depression, treatment and suicide**

**Stress and epilepsy**

Dr Christoph Bernard, director of research at Inserm France was first up in this session. He started off by suggesting that stress may make some individuals more vulnerable to the development of epilepsy than others. He said that if it is possible to identify those who are vulnerable, it may allow them to be treated before epilepsy develops.

Dr Bernard explained that a very stressful event may cause a drop in the level of a protein called BDNF in the blood. This protein acts on the nervous system to support its function. He suggested that in some individuals the level of this recovers back to normal, while in others it doesn’t. He proposed that if BDNF levels remain low, this creates vulnerability to epilepsy.

Dr Bernard said that this vulnerability could explain why a history of stress may make some people sensitive to epilepsy and additional conditions like depression, but not others.

He suggested that in the future, treatment to boost BDNF levels in individuals where the level of this protein is low could be useful. It may not stop epilepsy from developing but could prevent additional conditions like depression. Dr Bernard added that another possible future treatment in people with epilepsy brought on by stress could be antioxidants. They may help slow the progression of the epilepsy and that of any additional conditions.

For more information on stress, visit: epilepsy.org.uk/stress

**Screening for depression in epilepsy**

Dr Marco Mula from St George’s University Hospitals NHS Foundation Trust in London presented next on depression and suicide in epilepsy. He explained that all patients with epilepsy should be routinely assessed for depression at least once a year. He stressed that it’s important to tackle depression as it is associated with reduced quality of life and a higher risk of premature death.

Dr Mula said that he believed there are a few different barriers to screening and getting appropriate care for depression in epilepsy. One barrier is what he called the double stigma. This is stigma resulting from having both epilepsy and having a mental health condition. He added that a lack of resources and a lack of time can play a part.

Another problem, Dr Mula said, is that there is a lack of training and education among healthcare professionals about
speaking to people with epilepsy about mental health. He added that some doctors fear that asking about suicidal thoughts may increase the risk of someone feeling suicidal. But he stressed that research shows this isn’t the case – and that, in fact, the opposite is true.

Dr Mula mentioned that depression and anxiety are highly under-diagnosed in children with epilepsy. He said that he believes more focus needs to be paid to treating anxiety in children. He said that around half of adults with depression had anxiety in childhood, making it very important to recognise and treat. He concluded that screening for mental health conditions is really important in the epilepsy clinic, and more joined-up services are needed to provide effective care.

Epilepsy Action has more information on depression at epilepsy.org.uk/depression

If you are having feelings of distress, despair or suicidal thoughts, the Samaritans offer 24-hour confidential emotional support. You can reach them by calling 116 123 or on their website samaritans.org

Antidepressants in epilepsy

Dr John Mellers from Maudsley Hospital in London took to the podium next to discuss the use of antidepressants in epilepsy. He started off by saying that many people with milder forms of epilepsy don’t have a higher risk of depression than people without epilepsy. However, in people with severe epilepsy, the risk is greatly increased.

Dr Mellers also echoed Dr Mula, saying that depression is underdiagnosed in people with epilepsy and that epilepsy professionals may not be asking the right questions around mental health. He said this may be because they may not have the confidence around treating mental health conditions.

In some instances, side-effects from epilepsy medicines can be the cause of mental health conditions in people with epilepsy, Dr Mellers acknowledged. He said that these side-effects are dose-related.

Talking about antidepressants, Dr Mellers said that there is a small risk of seizures in people taking antidepressants. However, he said these results come from studies of people being treated for depression who did not have epilepsy. He said that in looking at the risk of increased seizures in people with epilepsy being treated with antidepressants, the results were “overwhelmingly reassuring”. Most studies involving people with epilepsy show no, or a very slight increase in seizures. Some studies have even shown a reduction in seizures in people with epilepsy taking antidepressants.

Prof Heyman said that young people with epilepsy don’t have “weird and wonderful” mental health conditions, they have common ones. She explained that there is no reason to believe standard mental health treatments won’t work in children with epilepsy, and urged her colleagues to start with these. She said that a child’s wellbeing and adjustment to having epilepsy is the responsibility of any clinician who they come in contact with.

Studies have also shown that people with complex epilepsy have an almost two-thirds chance of having a mental health condition, Prof Heyman said. These can include anxiety, depression, attention-deficit/hyperactivity disorder (ADHD), contact problems or autism spectrum disorder (ASD).

Another study found that according to both children and their parents, having a mental health condition had a bigger impact on a child’s quality of life than seizures. Prof Heyman added that mental health can also have an impact on seizure control.

Prof Heyman concluded that more joined-up care is needed to detect, diagnose and treat mental health conditions in children with epilepsy. She added that more research is also needed.

There are good treatments for mental health conditions, but only a small number of people are accessing them

Epilepsy and mental health in young people

Professor Isobel Heyman was last up this session, talking about mental health in young people with epilepsy. One of the first things she stressed was that there are very good treatments for mental health conditions, but only a small number of people who need them are accessing them.
You might have always been tempted to try something new. Maybe you’ve been thinking of conquering the highest peaks or trekking over some of the world’s most unbelievable landscapes. With Epilepsy Action, you can sign up to take part in some once-in-a-lifetime challenges and adventures in the UK and abroad. And the best part is that all the while, you would also be helping to support people living with epilepsy. Take a look at the incredible events you can do in 2020 below!

To get in touch to book your place, call the Epilepsy Action events team on 0113 210 881, email events@epilepsy.org.uk, or sign up online at epilepsy.org.uk/events

**Adventure for epilepsy**

You can take part in some fantastic challenges or take a trip-of-a-lifetime, while also doing something incredible for people with epilepsy.

**London to Paris Cycle**

Pedal your way through two iconic capital cities, whilst taking in the picturesque scenery. You will celebrate reaching the finish with a spectacular view of the Eiffel Tower.

3-7 June 2020 | 9-13 September 2020

**Euro City Cycle**

Take part in an exciting cycle through breathtaking city sights and make the most of this European adventure! This superb bike ride caters for every level of cyclist.

2-6 September 2020

**Great Wall of China Trek**

Conquer this challenge and see one of the New Seven Wonders of the World. You will hike for five days along this magnificent man-made structure, zig-zag your way across China and snake across mountains and through valleys.

9-17 May 2020 | 12-20 September 2020 | 10-28 October 2020

**The Inca Trail Trek**

Trek your way along the incredible Inca Trail to Machu Picchu, where you will see one of the New Seven Wonders of the World! You will cover three high mountain passes and see the breathtaking views across the Andes.

15-24 May 2020
31 July-9 August 2020
6-15 November 2020

**Kilimanjaro Trek**

Climb the highest free-standing mountain in the world. On reaching the summit, you will feel a sense of overwhelming achievement, with this truly unforgettable challenge.

18-28 June 2020
17-27 September 2020

**Everest Base Camp Trek**

With this challenge, you can reach the foot of the world’s highest mountain, and if you have enough energy, push yourself to the summit of Kala Patthar. This will give you the best views of Everest’s majestic peak.

12-29 March 2020
12-29 November 2020

**Vietnam to Cambodia Cycle Challenge**

This breathtaking bike ride will take you from Vietnam’s Ho Chi Minh City through the border into Cambodia where you will cycle to the world famous temple site of Angkor Wat.

7-17 March 2020
14-24 November 2020
Ben Nevis Trek
This challenge takes you into the heart of the breathtaking Western Highlands in order to conquer the highest peak in Britain.
27-29 September 2019

TrekFest – The Peaks
Push your limits while trekking across the picturesque and ancient landscapes of the Peak District.
31 August 2019

Snowdon Trek
You can trek up the tallest peak in Wales to conquer Mount Snowdon, taking in spectacular views along the way.
21-22 September 2019

TrekFest - The Beacons
You’ll start near the town of Brecon and head out through the heart of the National Park, passing incredible landscapes and reservoirs as you go.
6 July 2019

Cotswold Way Challenge
You will cross areas of outstanding natural beauty, with fantastic views and picturesque villages of the magical Cotswold Way. The full challenge is 100km, half is 50km and a quarter is 25km.
29-30 June 2019

Yorkshire Three Peaks
With every summit you conquer, you will be rewarded with stunning views across the Yorkshire Dales.
31 July-2 August 2020

Chiltern Challenge
Starting and finishing in Henley-on-Thames you’ll head out along the South’s most iconic trails the Ridgeway, Icknield Way and Chiltern Way. The route will take you through nature reserves and forests and over the Chiltern hills.
27-28 July 2019

Thames Path Challenge
Follow England’s greatest river and meander from its source in the Cotswolds and on through London, with the city section voted one of the world’s best urban treks! The full challenge is 100km, half is 50km and a quarter is 25km.
7-8 July 2019

South Coast Challenge
Stunning views, sunset and sunrise all lie ahead before the cathedral spire of historic Arundel welcomes you across the finish line. The full challenge is 100km, half is 50km and a quarter is 25km.
31 August -1 September 2019

North Downs 50 Challenge
Challenge yourself and trek 50km through outstanding natural beauty and wonderful Surrey countryside where you will climb up the impressive Box Hill to take in the fantastic views.
28 September 2019
Professor Graham Harding

Professor Graham Harding, who developed the Harding test, died in October 2018. Epilepsy Action celebrates Professor Harding's important and influential work in the field of photosensitive epilepsy.

Many of us know about photosensitive epilepsy – the type where seizures are triggered by flashing or flickering lights. For some of us, we know it all too well, living with it every day. For others, it might be what our epilepsy is mistaken for by people misinformed about the condition.

It can be very difficult to avoid triggers if you have photosensitive epilepsy. Something as simple as sunlight flickering from behind trees while you’re on the bus can be enough to cause a seizure. Young people may not be able to go out on nights out with flashing lights, affecting their social life. Not to mention the risk of a flickering image just appearing in front of us on places like social media.

All of this makes the work of Professor Graham Frederick Anthony Harding all the more important. Professor Harding died in October 2018 at the age of 81. But he leaves behind an incredible legacy, not least of which is the Harding test for flashing and flickering images in video content.

During this time, Japanese television broadcasters and medical officials worked to make sure this doesn’t happen again. Professor Harding was asked to help with this and he took part in putting together guidelines for broadcasting in Japan.

Professor Harding had already drafted the UK’s Office of Communications (Ofcom) guidelines around flashing and flickering images being broadcast on TV. He had recognised early on the potential problems that some games and video footage could create for people with photosensitive epilepsy. That realisation came from all the work he had done in this field.

Research into photosensitive epilepsy formed a significant part of Professor Harding’s work throughout his life. He was born in Birmingham in March 1937. He studied psychology at University College London, where he became interested in EEG recordings of brain activity. Professor Harding went on to do a doctorate on EEG in psychiatry at Birmingham University and later opened a clinical neurophysiology unit at Aston University.

With a keen interest in epilepsy and EEG, Professor Harding and his friend and colleague, paediatric neurologist Peter Jeavons, studied what aspects of flickering lights affected people with photosensitive epilepsy. Professor Harding published a lot of research and two books on this.

As well as informing Ofcom’s guidelines on flashing images, Professor Harding’s work led to the development of the Harding flash and pattern analyser, which you might know as the Harding test. This was created to make reviewing video content easier, and is now used to automatically test video footage for any parts that might trigger seizures.

Professor Harding has helped organisations like Epilepsy Action to put together information about photosensitive epilepsy to support people with the condition. But his work has been invaluable in other areas as well. He was among the earliest to realise that the epilepsy medicine vigabatrin, widely used in the 80s and 90s, was associated with potential visual problems. Professor Harding created a new test (the H stimulus) that was better tolerated by children, which could check whether this medicine was affecting eye function. He was also among the first in the UK to take an interest in magnetoencephalography (MEG), a new technique for studying brain function.

Through his work in this area, the UK’s first MEG system was secured in 2000.

Professor Harding has been championed by those who knew him for his passion both for his work and for helping people with epilepsy. Professor Stefano Seri, a friend and colleague to Professor Harding, said: “Those of us who had the fortune to work with him, or have been inspired by his vision, will miss him dearly for his energy and dedication to science and patients’ welfare.”

Professor Harding’s work and boundless enthusiasm have made an incredibly important difference to the understanding of epilepsy and to the lives of people with the condition.
When I was eight, I went camping with my dad. We went to a place called Wetwang (honestly) near Scarborough and camped out one summer in a pretty desolate camp site. We were sharing a tent we had bought especially for this trip. The last thing I remember is playing cards and going to sleep. The next thing I knew, I was waking up in Scarborough hospital.

My dad remembers it differently. He was woken up in the night as I had begun kicking his back in the throes of what would turn out to be a seizure. He tried to tell me to stop but I wouldn’t, and when he really looked at me, he knew something was wrong. Suddenly, I had stopped convulsing and I wasn’t breathing. He attempted CPR but was restricted in the tent so he dragged me out and tried again. He was in so much shock that he couldn’t do it properly. He picked me up and ran with my lifeless body across the field towards the club house shouting for help. It dawned on him that nobody would be there as it was the middle of the night and I think in that moment he thought I wouldn’t take a breath again.

Thankfully, an off-duty fireman (he thinks – if you’re out there I’d love to hear from you) heard his shouting. He took over CPR and his kids called 999. Luckily, the ambulance wait point was only down the road so they arrived in minutes and began to work on me in the field. What follows is pretty blurred for my parents. My dad remembers going with me to the hospital in the ambulance and calling my mum to let her know. She doesn’t drive, so she asked our neighbour to drive her halfway to where we were, in the middle of the night. She was picked up by a family friend to take her the rest of the way. I can’t even begin to imagine how fast they must have been driving. It took me a long time to recover from this first seizure. I didn’t wake up all day and they thought I might be in a coma until I finally came around in the evening. I woke up to a world where I had epilepsy.

Some of my first thoughts were that this scuppered my plans to become an astronaut. This was the career I thought would help me to get out of my small village.

I grew up just in Askern outside of Doncaster. Recently, someone told me Askern was one of the most “deprived” wards in Doncaster. I don’t really like that word, I think people there have a lot to offer.
the world. But, it does give you a sense of the environment I grew up in. There was always a lot of focus on ‘getting out’.

When I started school, it became apparent I was quite bright. I was a whizz at maths and even went to competitions. I had decided I was going to be the first astronaut from Doncaster. That was going to be my way to ‘get out’. All the adults in my life endlessly told me to make sure I continued to work hard at maths and become an astronaut, and it became a bit of an obsession.

Once I was diagnosed with epilepsy, it became clear that I would have to find a new way to ‘get out’. The diagnosis and its impact on my future plans felt like a real failure. I felt like I was trapped and it became quite isolating. I also don’t think I realised how serious the diagnosis was. What I took from it was that bad things kept happening to me but I kept surviving, so that was good. I rarely remembered my seizures.

A childhood epilepsy diagnosis isn’t easy for any family. For me, I would only ever have seizures in my sleep. For the first six months, while we were grappling to get a diagnosis, medicines and control over the seizures, I think my parents hardly slept. My dad would stay up until about three or four in the morning and then get a few hours’ sleep before work. He would wake my mum up to finish the shift watching over me. There was a lot of effort from the hospital going into controlling the seizures. But I don’t think anybody thought about how my parents would cope.

Eventually we got an intercom and a monitor in my bed which would set off an alarm if I had a seizure. This helped my parents to get some sleep, but it wasn’t ideal for me at that age. I don’t know if you’ve tried being a teenage boy in a bed where the slightest movement sets off an alarm in your parents’ room but it wasn’t the most fun experience.

Amid all the panic about my medicines and seizures, I think we all forgot the other things that childhood epilepsy does. I couldn’t go to sleepovers with my friends or on many school trips (at first), unless my parents came with me. This was quite isolating and I eventually became a pretty quiet teenager. There were many reasons for this, but epilepsy was a big contributing factor. While everyone else was worrying about my brain, I was mainly concerned with more teenager-y things; would I ever have a boyfriend? Would I ever be able to leave home?

The diagnosis of epilepsy felt like a real failure.

I also didn’t know anyone else who had epilepsy. The first time I saw someone else who had seizures was at Doncaster train station. A woman dropped to the floor in front of me and started to have a seizure. I instantly froze out of shock. I had never seen it happen to someone else. Other people rushed to help the woman and were really great at supporting her. I couldn’t do anything but run away. I was so isolated for so long that I couldn’t comprehend someone else having a seizure and I really regret how I reacted then.

As I went further and further into quietness, I began to read a lot of books. I had always loved reading, but now I had a lot of time for books compared to many of my peers. It was in the pages of these books that I started to form a plan of a new way to ‘get out’. I began to wonder if instead of physically going on adventures I could write them. At the very last minute (my teachers will tell you there was a lot of furious UCAS form rewriting) I applied to study English Literature at university and that was that. It took me 10 years, but I had found a new direction.

Graduating with a Master’s degree!
The idea of going to university scared my parents. But it was different for me. I was pretty determined I would go to university. I've always been quite a fearless person in terms of my health. The opposite happened to my parents, which made for a pretty tense time. Although I had been seizure free for over a year, we had been in this place before and I had relapsed and started to have seizures again. We always talked about safety and practical aspects of my condition, but we never really spoke about how we all felt, which took its toll.

When I left home, I settled in to university and I was fine. My mum was too – eventually – as long as she got lots of phone calls. She's always been more optimistic around the medical side of things than my dad because she works for the NHS. But I think it was especially scary for him, as he had watched me stop breathing that night in Wetwang. I didn’t know this at the time, but after I left home, my dad was treated for depression. He really struggled to cope with the idea that nobody was watching over me at night.

Six years later, and a lot has changed now. I have a Master's degree and I make a living working in theatre in London. I’m also now a really experienced first aider and have supported a number of people through seizures. I have even successfully performed CPR. I felt a lot of guilt from the day I saw the woman have a seizure at Doncaster train station and couldn’t help. I also think if my dad had known CPR, it would have been a lot easier for him on the night of my first seizure. Also, you would be surprised at how much first aid is needed in a theatre! A few years ago, I was working front of house at a musical in London and there was a situation that needed first aid. I realised I had no idea what to do, so I decided I would train and become a first aider. It’s pretty common now that I’m known as the ‘seizure guy’ at work, if anything happens to someone else. It’s a really nice feeling and I feel like I get to be a bit like the fireman that helped save my life.

I remained seizure free throughout university. What was more problematic for me was that I found socialising difficult. But eventually I made a lot of friends and it was a really happy time. During my time there, I didn’t focus on my degree enough, because I was too busy doing shows with the drama society. I found that I really enjoy writing shows for theatre, and it’s where I wrote my first play. I’ve written all kinds of shows and I always end up writing about health and science without realising, probably because my early life was so defined by a ‘chronic condition’. But it took me a long time until I was ready to write one about epilepsy.

A large part of my decision to write a show about epilepsy was that I wanted to help others feel less isolated. I often wonder about that day in Doncaster train station. If I had known someone else who had epilepsy, if I had even had one conversation with someone, would I have been less shocked and able to help?

So, I interviewed my parents about my childhood and we made a show exploring the complexities of families living with epilepsy. We were hoping to show people how much can change. The production is called Can you see into a black hole? and was shown in April in Camden People’s Theatre. It’s quite a heavy, but ultimately joyous, show about finding a new dream when one is lost. With the support of the Arts Council England, the show has also been extended into a wider project. It includes a series of workshops, an industry survey into epilepsy awareness and an e-zine about epilepsy for young people. I really hope it can make someone somewhere feel a little bit less alone.
Medical files

Epilepsy medicines underpin the way most of us manage our epilepsy. Some people may have tried many, others might have had only 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 levetiracetam under the microscope.

Levetiracetam

Levetiracetam (brand name Keppra) is the most commercially successful of the newer epilepsy medicines, largely due to how easy to use and well tolerated it is. It was first approved for use in the US in 1999 and later in the UK in 2000. It is widely available around the world as a stand-alone medicine, as well as for use in combination with other epilepsy medicines. It can be used in children, teenagers and adults.

For most teenagers and adults, if levetiracetam is effective on its own, it will work at a dose of around 500mg taken twice daily. A person’s doctor may decide to try a higher dose in some cases. But, unlike most other epilepsy medicines, evidence suggests that increasing the dose of levetiracetam is unlikely to improve its effectiveness in most cases.

Levetiracetam is effective for focal (starting in one part of the brain) and generalised (affecting both sides of the brain) tonic-clonic seizures. It sometimes helps to reduce myoclonic seizures (short jerks), but has only a modest effect on absences (where you lose consciousness but don’t fall to the ground). Its dose can be increased quickly, which is another potential advantage of this medicine. There are no important problematic interactions with other medicines. The level of levetiracetam in the blood may drop a little during pregnancy. However, there is no evidence that this medicine is associated with birth defects in babies who are exposed to it during pregnancy.

Levetiracetam is generally well tolerated, although headache, tiredness, poor appetite, nausea and vomiting have been reported. Sleepiness is the most common of these usually dose-related complaints. Skin rashes are rare.

Some behavioural and mental-health side-effects can also occur. These are the most concerning negative aspects of levetiracetam. Some mental health conditions can be caused or worsened by the use of levetiracetam. Some, such as anxiety and depression, are more common than others, such as psychosis. Psychosis is a mental health condition where people stop being able to tell what is real and what isn’t, and may hear voices or see things that aren’t there. These kinds of side-effects are more likely to occur if there is a current, past, or even a family history of mental health issues.

The range of behavioural problems that can be side-effects of levetiracetam is varied. It includes agitation, irritability, bad temper, aggression and hostility, resulting occasionally in violent behaviour. Care should be taken to recognise behavioural side-effects early in people starting on levetiracetam who have a learning disability or dementia. Teenagers, particularly those with juvenile myoclonic epilepsy, are at risk of worsening irritability, bad temper or even aggression. This is especially so if there have been problems in the past with impulsive behaviour. Levetiracetam use should be avoided altogether in people with a history of serious anger management issues involving aggression and violence.

All these potential complications usually start within the first month or two after levetiracetam has been introduced. Doctors should discuss these issues with the person taking the medicine and their family when levetiracetam is first prescribed, to manage any possible problems. Stopping the medicine usually quickly resolves these side-effects.

Anyone experiencing any side-effects from their medicine should report this to their epilepsy specialist.
The Council of Management met on 5 February. Included within the business of the meeting, the Council agreed to recommend the re-appointment of RSM UK Audit LLP as auditors to the Association at the AGM in June later this year. The Council also conducted its annual comprehensive risk assessment for the charity and satisfied itself that risks had been appropriately identified and were being suitably managed.

Council gave the go ahead to its Corporate Governance Committee to carry out a detailed review of Council policies and guidelines to ensure these are all up to date.

Council reviewed and revised the role descriptions of the three officers – the Chair of Council, the vice Chair of Council and the Honorary Treasurer.

A set of 26 Key Performance Indicators (KPIs) for 2019 were reviewed and agreed. Three new items are to be introduced this year to measure performance in raising awareness.

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.

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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.

**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:


The Council of Management met again on 9 April and approved the 2018 trustees’ annual report and annual accounts. These reports will now be circulated to the members of the charity and presented at the Annual General Meeting (AGM) on 11 June. They will show that Epilepsy Action enjoyed another very successful year – having contact with more than 2 million people and raising more than 3.7 million pounds.

This year’s elections to the Council of Management are about to start. During every election it’s not possible for people to become members of the charity. The Council confirmed that entry to membership of the charity will be closed this year from 13 May to 11 June 2019.

At the beginning of the meeting, the trustees received their annual presentation about the performance of the charity’s investments from Steve Scott representing Brewin Dolphin Securities Limited, investment managers. The Council was pleased to note that the charity’s investments had once again performed well against their benchmark target over the previous year and continued to provide a very healthy income that is used to fund the charity’s services.

The next meeting of the Council is scheduled to take place on 14 May 2019.
20 Years of treating drug-resistant epilepsy

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

Why wait?

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\(^{®}\) and SenTiva\(^{®}\) 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.vnsthapy.co.uk/safety-information to learn more and view important safety information.

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

www.vnsthapy.co.uk