

epilepsytoday

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Epilepsy and you

The online course
that empowered
Maggie to take
control of her
epilepsy

Also in this issue

- Fraser's mum Sally tells us how his life changed after getting a **VNS**
 - musician VC Pines talks about being creative **using his epilepsy**
 - is there potential for the **modified ketogenic diet in adults?**



editor's letter

Welcome to the December 2020 issue of *Epilepsy Today*.

It's hard not to mention the elephant in the room, so let's face it head on. Lockdown restrictions continue and the pandemic is still affecting our lives in all different ways. This continues to affect those of us with epilepsy and the healthcare services that we rely on.

One thing that has become very widespread is the use of video clinics. This is not ideal for everyone, but it has been instrumental in keeping communication open with specialists while we've not been able to see them face to face. On page 20 we look at some of the benefits and challenges of this type of communication.

A recent International League Against Epilepsy (ILAE) virtual symposium also looked at COVID-19 and how it has affected people with epilepsy. A panel of specialists identified issues, such as mental health problems, disruptions in routine and lack of access to specialists, which are worsening seizures in some people with epilepsy. But the Epilepsy Action 'Epilepsy and you' course is available to help with problems just like those. On page 16, we hear from three people who took the course and changed their lives for the better.

This issue, we are lucky to hear some wonderful and varied personal stories. On page 8, you can read about the huge effect a vagus nerve stimulation device had on Fraser's once life-threatening seizures. On page 12, Katy shares her experience of following the modified ketogenic diet (MKD) as an adult. She enjoys cooking and likes to get creative with recipes, and has seen a profound difference in her epilepsy because of this treatment. On page 10, Anne McHardy summarises some recent research into MKD in adults.

Musician VC Pines has come to really look at and embrace the symptoms of his epilepsy, and use them in writing his music. He is a champion for getting creative and turning something difficult into a positive. Read more on page 14. Our My Journal story on page 26 comes from Andrew Jackson, who found his confidence through taking part in an activity – for him, it was Taekwondo.

While the continuing pandemic can be very disheartening, I hope you can find some joy and light in some of the stories we have this issue. And let's hope things look brighter in the New Year.

For now, we wish you all a happy holiday season.

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Andrew struggled with bullying when he was younger, but he found something that sharpened his coordination and bolstered his confidence – Taekwondo

EMA backs perampanel for younger patients

The European Medicines Agency (EMA) has adopted a positive opinion recommending an extension to the existing prescription regulations of the epilepsy medicine perampanel. The EMA is looking at Eisai's version of perampanel, called Fycompa.

The EMA's Committee for Medicinal Products for Human Use (CHMP) is backing a change to the regulations to allow the medicine to be prescribed to younger patients.

Extended regulations would allow perampanel to be used as an add-on treatment for focal-onset seizures (starting in one part of the brain) in children four years old or above. This is whether or not the seizures spread to both sides of the brain.

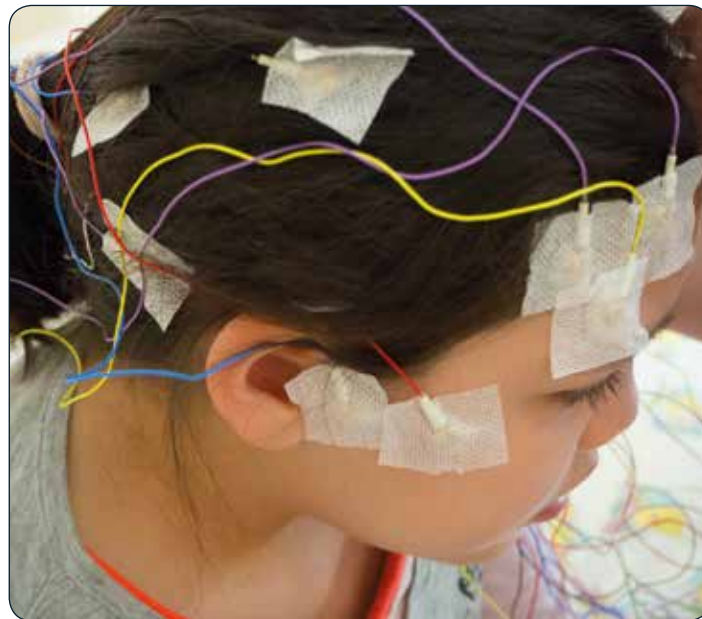
It can also be used as an add-on treatment for primary generalised (starting on both sides of the brain) tonic-clonic seizures in people who have genetic generalised epilepsy. A change in regulations would now allow it to be prescribed to children who are seven years old or above.

Previously, the age for its use in both of these circumstances was 12 years old and above.

The EMA has yet to make the final decision. For more information, visit bit.ly/3iYk16x



Children missing out on diagnostic tests and epilepsy treatment



More than two-thirds (70%) of children eligible for epilepsy surgery to treat their seizures were not referred, a new report has found.

The Royal College of Paediatrics and Child Health (RCPCH) published the latest Epilepsy12 report on 10 September. The report highlights the experiences of children with epilepsy services across England and Wales between 2018-19.

Epilepsy surgery has the potential to stop seizures for children with some types of epilepsy. It can be a life-changing treatment for those who are eligible.

As well as finding that children were not being referred for surgery, the report revealed delays in children receiving tests and scans. Around a third (31%) of children who should have had an MRI scan to help with diagnosis and treatment, did not receive one. Just under half (44%) of children with epilepsy also didn't have an EEG within four weeks, as

recommended by the National Institute of Health and Care Excellence (NICE).

Additional gaps were shown in mental health provision, with only 14% of health boards and trusts being able to integrate these services into children's epilepsy care. Transition from children's to adult epilepsy services was also highlighted as an issue. Four-fifths (81%) of children's services reported that there are no agreed pathways for children to move from children's to adult services.

The Epilepsy12 report has also shown improvements in some areas of epilepsy care, such as increased access to epilepsy specialist nurses (ESNs). ESNs are a key part of the epilepsy team and can make a big difference to patient care.

Chief executive of the charity Young Epilepsy, Mark Devlin, said: "The Epilepsy12 report shows great work being done by many children's epilepsy services across the country, but the report also shows that too many

children are waiting too long for diagnostic tests or not even having the recommended tests. The NHS Commissioner must ensure that every child with epilepsy has timely access to the investigations and treatments they should have to help families manage this serious condition.

"Children with epilepsy rely on investigations to help pinpoint a diagnosis and get the right treatment to control seizures. These seizures can significantly disrupt children's day-to-day lives at home, at school and with their friends. The sooner the right treatment can be identified by specialists, the better chance families have to manage their child's condition and enable them to achieve their full potential."

Angie Pullen, epilepsy services director at Epilepsy Action, added: "The report shows many encouraging improvements in epilepsy services for children, with better access to and input from epilepsy nurses and doctors with expertise in the condition.

"In November 2019, we were looking at an improving picture of access to care. However, in September 2020, services may not be sustaining those improvements. The response to COVID-19 has focused attention and led to increased waiting times for diagnostic tests like MRI scans. Appointments are now often [over] telephone, and though sometimes very helpful, we question if best care can always be delivered from a distance."

The full report is available at bit.ly/3dGiEs3

Sleep apnoea more common in generalised epilepsy



People with generalised epilepsy (where seizures start in both sides of the brain) are at a higher risk of obstructive sleep apnoea, according to a new study from the US.

Obstructive sleep apnoea (OSA) is a sleep disorder where breathing repeatedly stops and starts. Study author Matthew Scharf and his colleagues said OSA is

common in people with epilepsy and treating it could improve seizure control. However, they note that this is often undiagnosed in people with epilepsy.

The study authors recruited 115 people with generalised and focal (starting in one part of the brain) epilepsies. The researchers found that risk of OSA was significantly higher in people with generalised epilepsy.

Other risk factors for OSA were older age, higher body mass index and a history of high blood pressure.

OSA can result in tiredness or sleepiness in the day due to poor sleep quality, which could affect seizures. People should speak to their doctor if they suspect they have OSA

The research is published in the journal *Epilepsy & Behavior*.

Some brain cells more affected by epilepsy than others

A new study has identified which subtypes of brain cell are most affected by epilepsy.

Researchers from the University of Copenhagen and Rigshospitalet looked at brain cell subtypes from people with and without epilepsy. They wanted to identify which subtypes were more likely to become damaged and allow for seizures to happen.

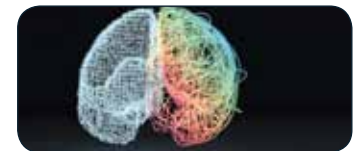
The research, published in the journal *Nature Communications*, included an analysis of more than 117,000 brain cells. It found that some subtypes of brain cell were more likely to become affected by epilepsy than others.

The study also suggests that there is a change in the function of thousands of genes in affected brain cells in epilepsy, rather than hundreds as other studies have found.

Previous studies have looked at a damaged area of the brain in epilepsy as a whole, rather than the individual brain cell subtypes. The current research offers a more in-depth and accurate target for future treatments.

Study author and associate professor Konstantin Khodosevich explained: “Our findings potentially allow for the development of entirely new therapeutic approaches tailored towards specific neurons, which are malfunctioning in cases of epilepsy. This could be a breakthrough in personalised medicine-based treatment of patients suffering from epileptic seizures.”

The full article is available at: go.nature.com/346cvCD



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Five-year-old “hero” helps mum during seizure

A five-year-old girl has been called a “hero” for getting help when her mum had a seizure.

Lisa Wainwright had a seizure out of the blue at her Derbyshire home when she was alone with her daughters Esme, five and Amelia, two.

When the seizure started, Esme handed her mum the phone, who then typed a message to her husband Ash.

When Ash rang back Esme picked up and told him what had happened. She unlocked the door when he came home. He saw that she had covered her mum over with a blanket and had stopped her little sister from crying by setting up her tablet for entertainment.

The 34-year-old mum of two called Esme a “hero” and a “superstar”, and said she’s really proud of Esme.

Seizure prediction device could give hour’s notice

A wearable device has been developed that can predict a seizure an hour before onset with potentially 97% accuracy.

The device, called Epiness, has been developed by Israeli researchers at Ben-Gurion University of the Negev. The device uses machine learning algorithms and EEG-based monitoring of brain activity.

The product, which is not

available to buy yet, is due to undergo clinical trials later this year.

In development and testing, large EEG datasets were used, and the prediction performance reached 97% accuracy.

For people with epilepsy whose seizures are not controlled, an effective prediction device could help reduce injuries and increase independence.

Anxiety and depression care a priority in epilepsy

Anxiety and depression treatment is a priority for people with epilepsy, according to research presented at the Annual Meeting of the American Neurological Association.

Dr Heidi Munger Clary, neurologist at Wake Forest Baptist Health in Winston-Salem and colleagues carried out a survey on US adults with epilepsy, as well as anxiety and depression. Nearly two thirds of respondents had focal epilepsy. Only a third reported being seizure free for the previous six months.

About a third of respondents reported having had to go to hospital for their mental health and two thirds said they are currently taking a medicine that may affect their mood. Nearly half of people said they'd had mental health care in the past, but less than one in five said they have current treatment for their mental health.

The research showed that people preferred medicines as treatment for mental health conditions and they preferred this to be prescribed and managed by their neurologist, rather than a psychiatrist. Respondents were also likely to take part in wellness strategies, such as eating well, getting enough sleep, and exercising.



Epilepsy specialist nurses and ongoing epilepsy care lacking in Northern Ireland, study shows



A new 2020 study from Northern Ireland suggests that people with epilepsy are not getting access to vital epilepsy support. This includes lacking access to epilepsy specialist nurses (ESNs) and ongoing care for their condition.

The research was carried out by Epilepsy Action Northern Ireland between July and August 2020, focusing on people's experiences of services before the COVID-19 pandemic. The study found that one in three study participants did not have access to an ESN. Of those who did, more than half did not get to see their ESN often enough. This included people who are at higher risk of harm from their condition, such as people with epilepsy who have daily seizures, learning disabilities, autism or mental health conditions.

According to Epilepsy Action Northern Ireland, there should be around 30 ESNs to provide adequate care to adults with epilepsy in the country. There are currently only three ESNs in a full-time position and one who is part-time. Three out of five health trusts do not have an ESN in employment.

ESNs can be a lifeline for people with epilepsy, helping with medicine, managing risks from seizures and supporting people to cope with daily life. They can also offer help with

benefits applications, education and employment.

Dr Michael Kinney, consultant neurologist with subspecialist interest in epilepsy in Northern Ireland and member of Epilepsy Action Northern Ireland advisory council, said: "Epilepsy specialist nurses are vital team members providing care to people with epilepsy. They work alongside consultant neurologists and other healthcare professionals to provide essential advice and support during and, as importantly, in-between appointments.

"This study highlights that people with epilepsy could benefit from an expansion of the epilepsy specialist nursing services across the entire region of Northern Ireland. This is something we recognise and must all work towards."

The study also found there was a lack of ongoing care and support for people with epilepsy in Northern Ireland. Two-thirds of participants did not have a written care plan in place for their epilepsy. One-third had not had an epilepsy review in the last year.

Epilepsy Action Northern Ireland explains that people with an ESN are more likely to have these aspects of their healthcare in place. It adds that people who have access to an ESN are more likely to be satisfied with their healthcare.

Carla Smyth, manager of Epilepsy Action Northern Ireland, said: "This study has confirmed what we already knew – that far too many people with epilepsy in Northern Ireland are not receiving the support they

need from the health service. We know that some people are waiting for an extremely long time to see neurologists and epilepsy doctors. In 2020, many of these appointments have become virtual, or even been cancelled. The lack of access to epilepsy specialist nurses will mean that a lot of people are at risk of falling through the gaps.

"Epilepsy is a condition that can be devastating, or even life-threatening. Without proper, ongoing healthcare support, people are far less likely to gain control of their seizures or learn how to manage their epilepsy in their day-to-day reality. The ongoing Review of Neurology Services is an important step towards identifying and addressing the challenges facing neurology services and people with neurological conditions in Northern Ireland.

"It's vital that this review succeeds where others have not, with recommendations fully implemented and a comprehensive funding package made available to bring about real and lasting change now and for the future. Without this, people with epilepsy in Northern Ireland will continue to be deprived of the care they deserve."

Epilepsy Action Northern Ireland is calling for more ESN posts to be created and funded in Northern Ireland. The organisation is writing to Health Minister, Robin Swann, and speaking to health trusts about their plans to increase epilepsy specialist healthcare staff.

More information about Epilepsy Action's campaign for improved healthcare provision in Northern Ireland is available at epilepsy.org.uk/nursesNI

New focal-onset seizure medicine gets Promising Innovative Medicine designation by MHRA



A new medicine for hard-to-treat focal-onset seizures in adults was given a Promising Innovative Medicine (PIM) designation by the Medicines and Healthcare products Regulatory Agency (MHRA) in August 2020.

The PIM designation from the UK's MHRA is an early

indication that this medicine could be a candidate for the Early Access to Medicines Scheme (EAMS), according to Arvelle Therapeutics. This scheme can give people with life-threatening or seriously debilitating conditions access to medicines that do not yet have full approval for use in the UK. This is where there is a clear unmet medical need.

The medicine cenobamate is produced by Arvelle Therapeutics International.

Cenobamate has been approved for use in the US by the Food and Drugs Administration (FDA) as an add-on anti-seizure medicine. The European Medicines Agency (EMA) also approved it for use in the European Union in March 2020.

Cenobamate has undergone clinical trials to check its safety and effectiveness. The trials showed it was more effective than currently available medicines in achieving seizure freedom in adults with hard-to-treat focal-onset seizures.

In an expert opinion piece, Dr James Wheless, professor and chief of the Department of Pediatric Neurology at The University of Tennessee, reviewed cenobamate as an add-on treatment. In the *Expert Review of*

Neurotherapeutics article, he said cenobamate shows “a high level of efficacy” in treating medicine-resistant focal epilepsy. He said for some participants in the clinical studies carried out on this medicine, seizure frequency halved. Just under a third of people became seizure free during the trials.

Dr Wheless said: “If efficacy responses in real-world use reflect what have been observed in clinical studies, cenobamate would be a welcome new treatment option and could become a mainstay over the next five years.”

If the MHRA includes cenobamate in the EAMS, it will evaluate the risk and benefit of the medicine and offer a scientific opinion on it. This does not replace licensing procedure, but can support a doctor in prescribing a medicine which is not yet licensed.

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New children's ESN in Scotland health board

A new children's epilepsy specialist nurse (ESN) has been appointed by the NHS Dumfries and Galloway health board. For years, this was reportedly the only mainland health board without a specialist paediatric ESN in Scotland.

Sarah Gemmel has taken the new role of epilepsy and complex needs lead at the

health board. The charity Epilepsy Scotland and families of children with epilepsy have campaigned for this appointment.

Sarah Gemmel said: “I am excited to take on this new role that will provide the essential service for offering practical and emotional support to children and families in Dumfries and Galloway.”

Five-year-old praised for saving mum

A five-year-old boy from the US has been praised for helping his mother after she had a seizure.

Tyrion Spann was at home with his mum Jasmine, when she had a seizure. Tyrion used his Amazon Alexa device to call his grandmother for help.

His grandmother, Natalie Neal, said her heart dropped

after hearing Tyrion say he couldn't wake his mum up. She said this was a call she was worried about getting, as her daughter had lived her whole life with epilepsy. She called an ambulance to go to Jasmine's house.

Tyrion has been commended by his family for staying calm and finding help for his mum.



Fraser with his dad
on their bikes

Single most positive effect

Fraser's mum Sally talks about Fraser's epilepsy, the positive effect that VNS treatment has had on his seizures and choosing not to live life in fear

Fraser is a fun-loving and active 18-year-old, like many others his age. "He is the most active young man I can imagine there ever was," Fraser's mum Sally said. "He wants to be out and doing things 24/7. Riding his bike, going on buses, cycling, swimming, walking, trampolining, playing football – you name it, he'll do it."

But despite what his outdoorsy nature might suggest, life is not all fun and games for Fraser. He has been living with a health condition since he was a young child.

"Fraser began having seizures when he was around five years old," said Sally. "The

first time I noticed him suddenly 'flop' I wasn't sure what I was seeing. When it happened again a few days later, I took him to the GP who referred us to the local paediatric team.

"Fraser was diagnosed with Lennox-Gastaut syndrome, and has focal, tonic and atonic seizures. He has severe learning disabilities and needs support to take part in all activities of daily living. He does not have speech and can say only a handful of words. However, he has no problems in communicating his likes and dislikes!

"It seems like a long time ago, but I don't remember the process up to diagnosis

being very long. What has been more problematic is what to do about it!"

Fraser's seizures affect every aspect of his life and are a constant consideration for his family, especially with such a love of being active. Sally explained: "One of the most frustrating things is the unpredictability of the seizures. Whatever we have planned, we always have a 'plan B' in the event of a seizure. And it isn't just the seizure itself – sometimes the seizure might be very short-lived, but he needs a long time to recover from it and sleep it off.

"However, we try not to let the seizures stop Fraser doing much – it's just that whatever we do, we have to think, 'what would happen if he had a seizure while we are doing this?' This is basically like 'risk assessing' our activities.

"For example, we haven't stopped going swimming, but Fraser wears a life jacket in our local pool so that if he has a seizure, he doesn't sink to the bottom before we can get to him."

Risk management is something many people whose seizures aren't fully controlled have to do all the time when planning their day. It becomes second nature for many of us, but it is undeniably draining and stressful.

Unfortunately for Fraser and his family, having a ‘plan B’ is something that has continued over the years, as his seizures have proven difficult to control.

“Fraser has tried a range of epilepsy medicines, none of which appears to have much of an effect on his seizures,” Sally said. “We also tried the ketogenic diet, but due to his severe learning disabilities, it was really difficult for him to understand the importance of strictly following the plan.”

During this challenging and turbulent time, Sally found a lot of support from the Ipswich Epilepsy Group and the members of the group have been there for her over the years. Sally continued to search for treatment options for Fraser, and one day, she came across vagus nerve stimulation (VNS) in Epilepsy Action’s information.

VNS is a treatment which involves putting in a small electrical device, like a pacemaker, under the skin of a person’s chest. This device sends electrical impulses to their brain through a thin flexible wire attached to a nerve in the neck called the vagus nerve. This treatment can help to reduce the number and severity of a person’s seizures.

The VNS device is programmed to send regular impulses at intervals throughout the day. The person having the VNS device put in also has a hand-held magnet. The magnet can be swept over the device to prompt it to send extra impulses if they feel a seizure coming on.

Newer models of the VNS device can also detect increases in a person’s heart rate. In some people, a rise in heart rate could be a sign of a seizure, so the VNS would automatically send out extra electrical impulses in this event. This could help stop a seizure or make it less severe.

VNS is an important option for people whose seizures can’t be controlled with medicines, epilepsy brain surgery or other treatments. While it may not fully control a person’s seizures, it can make a big difference, as Sally and Fraser found.

Fraser’s situation was assessed by his specialist and it was found that he was suitable for a VNS. “The VNS was fitted at Addenbrooke’s Hospital in Cambridge

in 2016,” Sally recalled. “We met the consultant who explained what he was going to do and answered all our questions. It was done first thing in the morning and we were able to go home later that evening. I can’t speak for Fraser, as it wasn’t me who had the operation, but it seemed quite straightforward.

“Without a doubt, the VNS has had the single most positive effect on Fraser’s seizures. Before the VNS, Fraser was having very severe seizures which affected his breathing and also resulted in status epilepticus (prolonged seizures). He’s had this a few times and it was very frightening. The seizures just don’t stop. For us, Fraser kept going in and out of them for hours. It’s draining and you just keep thinking ‘this time it will stop’. But it doesn’t. After a couple of times of this happening, I knew which medicine he needed to bring him out of it.

Without a doubt
the VNS has had
the single most
positive effect on
Fraser’s seizures

“But since the VNS was put in, even though the seizures have not gone away, they are nowhere near as long-lasting, severe nor distressing as they were before the VNS.”

VNS devices need maintenance and replacement after a while, to make sure they continue to work well, so they do require further appointments at the hospital. Fraser had his replaced this summer – despite the challenging circumstances around the COVID-19 pandemic.

“The VNS needed to be replaced in the middle of the first lockdown. That resulted in a bit of drama. Our hospital had to outsource their routine operations to the private hospital. However, when the private hospital found out that Fraser has severe learning disabilities, they said that they were not ‘set up to cope’ with his needs, so his operation was cancelled. The operation was eventually rescheduled and went ahead in June.

“A lot of planning went into getting a COVID test for Fraser at his pre-op (thanks to all those involved in that saga, including the learning disabilities specialist nurse). The hospital around June was like a ghost town. But the operation went smoothly and we got discharged as quickly as possible.”

As well as requiring some maintenance every so often, the VNS device can also have some side-effects, like most treatments.

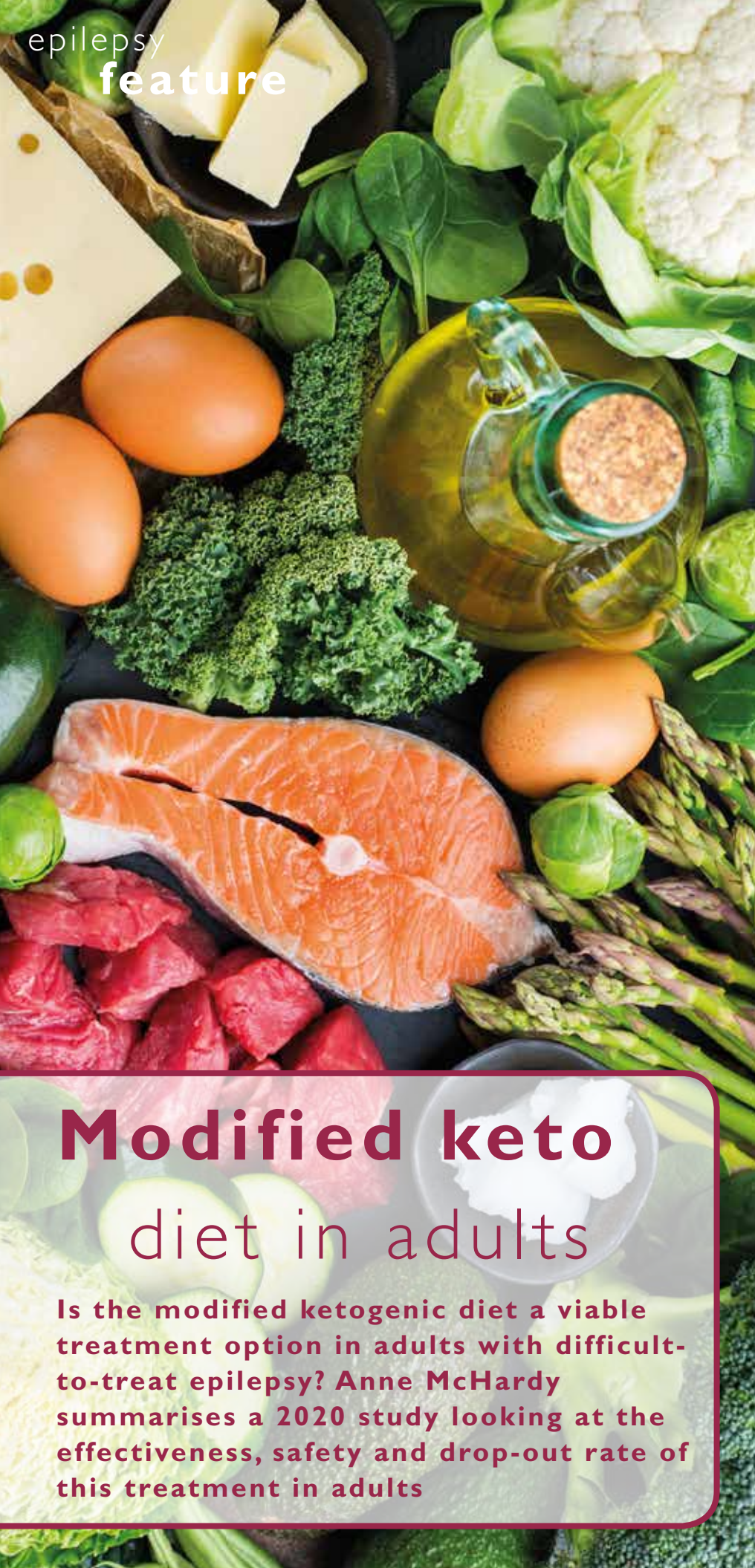
Sally said: “It’s difficult to say what side-effects there are, because I am not the one with the VNS. But I know that Fraser has a rather funny cough since the VNS was fitted which I understand to be the outcome of the VNS ‘doing its thing’. For me, one constant worry is knowing if the VNS is working properly, or if it has somehow been turned up and gone into overdrive. This has never actually happened, as far as I’m aware. But how can I know? It’s not easy to check at home and outpatient appointments to check it are every year! I think this is one of the things I just have to trust.”

Fraser is currently living in a children’s residential home. He usually has many visits from family, including his parents, grandparents and uncle. The pandemic stopped all of that and no family were allowed to visit for months – even over Fraser’s 18th birthday. Sally said for her this was a very painful time. But with Fraser’s VNS, at least Sally knew that during this difficult time apart, Fraser’s seizures were a lot less severe. “When Fraser’s seizures were at their most severe, his consultant did tell me that his epilepsy might have a fatal outcome one day. I was terrified. Seeing some of his seizures, it was obvious that this might have been the case.

“Since the VNS was fitted, there has been such a reduction in Fraser’s seizures that I hardly think about this anymore.

“Neither Fraser nor I choose to live our lives in fear! What can you do other than carry on enjoying life?”

You can find more information on VNS on the Epilepsy Action website at epilepsy.org.uk/VNS



Modified keto diet in adults

Is the modified ketogenic diet a viable treatment option in adults with difficult-to-treat epilepsy? Anne McHardy summarises a 2020 study looking at the effectiveness, safety and drop-out rate of this treatment in adults

A modified ketogenic diet therapy (MKD) for adults with drug-resistant epilepsy showed “good effectiveness” in reducing both seizure frequency and duration. This is according to a year-long study conducted at the National Hospital for Neurology and Neurosurgery (NHNN), Queen Square, London. A third of those involved also reported improved mental alertness and mood. However, a third reported worsening seizures.

The epilepsy service at the NHNN is the largest tertiary level epilepsy treatment centre in the UK. Prompted by the worldwide rising demand for ketogenic therapy for adults with drug-resistant epilepsy, the service introduced MKD treatment in 2016. The team from the NHNN carried out this research between January 2016 and January 2018, using the first 100 patients referred to the hospital’s Adult Ketogenic Diet Service. The team recognised the need for “research describing the real-life effectiveness, retention, and safety of relevant services”, the study said. This study is the first anywhere in the world to look at those aspects beyond a three-month period for the MKD. It was published online in the *Journal of Neurology* in January 2020. Further research is needed, but the COVID-19 crisis is absorbing both time and research resource.

According to the study authors, approximately one-third of adult epilepsy patients do not achieve seizure freedom with epilepsy medicines. Those who have not responded to two epilepsy medicines have only a 5% (one in 20) chance of succeeding on a third. “These patients with drug-resistant epilepsy carry a significant disease burden. In addition, many are either not amenable to or decline surgical intervention, further underpinning the need for effective, alternative treatment options.”

Ketogenic diet therapy is widely used for children “for whom there is a strong evidence base” that it could work, the study reports. Feasibility studies worldwide “have endorsed the use of ketogenic diets in adults.” The mechanism behind the perceived benefits of changes in diet are not clear. However, a 2018 study from the

journal *Epilepsia Open* showed that “53% of patients with intractable epilepsy can achieve a reduction in seizure frequency of 50% with a ketogenic diet.” Use of MKD therapy is, however, limited by a lack of suitably trained dietitians.

The classic ketogenic diet has a strict 3.1-4.1 ratio of carbohydrates to combined fats and protein. It is hard to stick to outside of a hospital setting, which is where it is often introduced for children. A variety of more palatable and easier to prepare alternative diets have been developed as well as the MKD used in this study, including the modified Atkins diet (MAD). The nutrient ratios in both MKD and MAD are similar, with the MKD having a target of 80% of a person’s daily calories coming from fats.

This study demonstrates that **MKD can be effective in adults**

Before being accepted for MKD treatment, each patient referred was assessed for general health, with blood tests, weight and height checks. Their readiness to comply with the strict diet and keep a food diary was also considered. Those offered the treatment were first invited to group sessions to be taught the dietary principles of MKD. They were taught about the nutrients of different foods and shown how to plan meals to meet their targets. Targets were worked out individually to meet their estimated energy requirements. Between 10 and 25 grams of carbohydrate were prescribed a day to make up approximately 5% of their calorie intake. Of the group of 100, only 42 agreed to take part, and, of those, 60% dropped out in the first three months. Only 29% - 12 people - continued for the year. The MKD requires careful measurement of all meals and snacks. The number of people in the study who didn’t take up the diet or dropped out reflects how unpalatable the diet appears from the outset and the difficulty in sticking to it. Among the

60% who dropped out in the first three months, difficulty with the diet was the most common reason given. The 29% who stayed the year were likely encouraged by early improvement in their seizure control, the researchers found.

The treatment involved a prescribed individual diet of very low carbohydrate, high fats and moderate protein to be taken as three main meals and three snacks. Extensive weight checks and body measurements were also taken. Each participant also had to have a person who was prepared to work with them on their food for the first three months. They also had to take part in the initial assessment and education sessions. The intention was to adapt their normal diet using ordinary foods, but with some use of some prescribed MKD products. All participants were prescribed vitamin supplements to make up for an anticipated lack in the diet.

Recipes and guidance on food values were provided and people were required to keep daily diaries of food and seizures. They also needed to take daily blood or urine tests at home, and record any other changes in digestion and bowel function. They were telephoned twice a week by the dietitians but could email or phone to check if problems arose. Regular outpatient blood and urine tests were also required to monitor for potential adverse effects including a change to cholesterol levels and potential heart problems. They also had to have bone density scans because the diet might be low in calcium. There were periodic group meetings too and some food preparation sessions were available, as were recipe and advice books, although most of these were originally developed for children. They were provided by Matthew’s Friends, a charity set up in 2004 by the family of a boy with epilepsy, Vitaflow, a Nestle Health Science company, and the research foundation, Nutricia Metabolics.

Of the 42 people who started the diet, 31 were women and 11 men, with an average age of around 37. All had not responded to three or four epilepsy medicines. Of the 12 who continued for the year, three-fifths (60%) reported an improvement in seizure frequency. Nearly two-fifths (38%)

reported that their seizures had fallen by half (50% reduction) and 13% reported a period of seizure freedom. However, 30% of the original 100 people referred for the study reported a worsening in seizure frequency at some point during MKD therapy. The most common detrimental side-effects were weight loss, digestive problems and low mood.

The report also compared the MKD results with studies using MAD, which had some better results, or other variations of ketogenic diet. The researchers concluded: “This study demonstrates that MKD can be effective in adults, although, even with regular dietetic support, retention rates remain low, and periods of worsening seizure frequency are common.” Since this was an observational study, as most ketogenic diet studies are, there was no way to compare the efficacy of MKD against a dummy diet. Another weakness was that the group of participants was random, with no common pattern of seizure type or frequency, although everyone had long-term serious conditions.

However, as the use of MKD increases, and the epilepsy centre at the NHNN expands its practice, the dietitians are hopeful that retention rates will increase. “In summary, this observational study suggests that MKD may be effective as an outpatient treatment option for adults with epilepsy.”



The MKD can be an alternative option for people whom epilepsy medicines aren’t effective

Keeping up the keto

Katy started on the modified ketogenic diet in 2017. She discusses overhearing that she has epilepsy, following the diet and whether she can be tempted off it by a jam doughnut

I was referred for ketogenic therapy by the National Hospital for Neurology and Neurosurgery, Queen Square, where I am a patient. I had had epilepsy for 18 years before that. I have never regretted starting for the simple reason that it has reduced my seizures from eight or 10 tonic-clonics a month to two or three, and far fewer other seizures.

I started having seizures when I was 12. It was very strange for me because it just came on with no explanation. The only thing the doctors suggested as a reason was puberty. My first seizure was in school. I just remember waking up with my friends looking at me with such shocked expressions on their faces. I had no idea what was going on. The problem was no one else did either. The school nurse took me to the health room to call my parents. I was sitting there in such a disorientated state. Nothing felt right. I kept thinking to myself: "What is going on?"

Then I heard the nurse pick up the phone to speak to my parents - and she was telling them off! "Why didn't you tell us she was epileptic? It's so dangerous." It was then I noticed I had blood on my cheek. What?

I tapped her on the shoulder. "Hang on, wait! I am not! I don't have epilepsy! You're wrong! No, not me! I know someone who does but I don't."

"Just sit down Katy," she said to me. "I'm talking to your mum. Sit down."

"No. Really something else must have happened. I am not epileptic."

I feel this was the first time I was diagnosed as having epilepsy, although it was four months before the neurologists confirmed it. I sat down and waited for my father to take me home. Being 12, I thought I understood what epilepsy was having met someone in primary school who had seizures. But I didn't realise how complicated epilepsy is and how hard it can be to control. It's important to every person, whether they have a disability or

When the treatment began to reduce my seizures I was so pleased

not, to have a fulfilled, enjoyable life. But this is hard to maintain when there is so much misunderstanding surrounding something like epilepsy, even among doctors. It is particularly difficult with my type of unpredictable epilepsy which is generalised, idiopathic and medicine resistant, with seizures from tonic-clonic to atonic seizures and absences.

You can see why people are shocked when you collapse on the floor and start shaking. The first time I saw somebody else have a seizure, it scared me so much that I had a seizure too.

Luckily, I was with my family at The Globe Theatre and their staff were wonderful, dealing with both of us without interrupting the performance.

Epilepsy medicines can have awkward and unpleasant side-effects. They don't work for everyone. I went through many medicines, and hormonal treatment which had the worst side-effects. The medicines didn't reduce my seizures.

I was considered for surgery but I was not suitable. I also had been accepted for an alert dog from the organisation Support Dogs UK. I was being trained and keeping a daily diary for them, which would make keeping a food diary for the ketogenic diet easier later on.

I managed to carry on with school and college, and did a modern drama degree at Brunel University. I also started a juggling group with my brothers. Research shows juggling helps memory, as well as being fun, which is an extra benefit. I worked as a school assistant for a while as well, but my seizures got worse.

Then, in 2017, I was referred for ketogenic therapy at Queen Square. I was a participant in research published in the *Journal of Neurology* on the effectiveness of the modified ketogenic diet (MKD) in adults.

The diet is a high fat, low carbohydrate diet which means your digestive system produces chemicals called ketones which

act as your energy source rather than glucose. That seems to affect the electrical activity in your brain and reduce seizures.

It has worked amazingly for me, but it does start out feeling very tedious. You have to reorganise your whole intake of food and measure everything. It takes away the convenience of just being able to grab a sandwich or a pizza. Looking into my diet has been hard, working with the dieticians and having to note every bite of food. The diary keeping and ketones tests are tedious too. But it is very interesting as well, so long as you enjoy cooking.

I was given information about the amount of carbohydrates in foods and recipes from the dieticians. But I had to work things out, finding information for myself, like how a red pepper has a higher carbohydrate content than a green one. I also found that carrots and bananas, two foods I love, are really high in carbohydrates. Some seem strange, for example not having milk in your tea but being allowed double cream, and being recommended to have a cocoa drink at night. I found coconut oil worked best for cooking, together with homemade mayonnaise with olive oil and nuts, especially brazil nuts.

I have been able to safely create my own recipes and food lists which work for me. They would have helped when I started the diet, so I put recipes online to help others, although obviously I remind people to consult their dietician. Epilepsy is complicated which I think is why the ketogenic diet could work for more people, because it focuses on them as individuals.

I don't know how I could maintain my life without my family. I am just so grateful to them. I do get worried that I'm putting a burden on them, but they tell me to stop being stupid. Some people aren't so lucky.

When the treatments began to reduce my seizures, I was so pleased. I was looking forward to fewer seizures and the safety and security of an epilepsy alert dog. I just wanted to feel safe popping to the shops when nobody was around, so I could live by my own schedule. But then my seizures reduced

so much that the charity could no longer train a dog for me.

I wish the epilepsy could disappear as quickly as it arrived. Even if it did, I am not sure I would be able to relax. I'd be so scared to do something like drive a car, but it would be interesting to be able to consider it.

I would say to everybody looking at trying this diet, it might seem complicated but just have patience and listen to your dietician. It becomes simple and you can think that just eating every day is giving yourself an important and necessary treatment.

You just have to find foods to replace the ones you take out. You will find yourself enjoying ones you never knew were there even more than the ones you thought you could never replace.

For me, a doughnut or pizza were those foods that I thought I couldn't be without. I still find myself smelling them and considering cheating occasionally. But is it worth it to cheat and increase my seizures again to have a jam doughnut when my diet is so beneficial to me?

I don't think so.



Katy started a juggling group with her brothers

The ketogenic and modified ketogenic diets should only be undertaken under medical supervision. For more information about ketogenic therapy speak to your epilepsy specialist or visit [epilepsy.org.uk/ketogenic](https://www.epilepsy.org.uk/ketogenic)



Katy took part in research on the modified ketogenic diet



@Henry.Ager.Photos

The sound of purple

Musician VC Pines talks hearing colour, growing up on his dad's music collection and the need for better understanding of different forms of epilepsy and seizure

"I've always loved music," says Jack Mercer, who you might know better by his stage name VC Pines. "Ever since I was 10 years old, I knew I wanted to play music. I discovered Soul and Punk music from an early age. Then I heard Jimi Hendrix and I was hooked."

Jack grew up in South London. He spent much of his childhood sneaking into his dad's CD collection and discovering the works of artists like The Stranglers, Iggy Pop, Curtis Mayfield and Otis Redding. "I was definitely pulled in by New Rose by The Damned", Jack says, recalling playing it at school concerts much to his classmates' bewilderment. These and many other musicians formed the soundtrack of Jack's youth and fostered his lasting love of music.

Jack's music career began as front man of London indie-rock band The Carnabys, before branching into new genres through his solo music. His work today is in part influenced by a wealth of artists and genres, as well as poetry and his lived experiences.

One huge part of his life that he channels into his music is his epilepsy.

Jack was diagnosed with temporal lobe epilepsy at 17. "Before I was diagnosed, I had other symptoms, like panic attacks, depression and anxiety, as well as bizarre daily focal seizures. I thought I was losing my mind at 17. I never thought it could be something like epilepsy as I wasn't aware of all the different types that people had. I was exhausted every day and I didn't know how to deal with it.

"I had an MRI and an EEG in order to get a diagnosis. For the EEG I was asked to stay awake for 24 hours prior, to irritate my brain in the hope that I had a seizure during the one-hour test. I didn't, so I was diagnosed from my symptoms rather than a visible seizure during the test. Then I was given an epilepsy medicine – lamotrigine – and sent on my way without much information.

"I felt better after the diagnosis, knowing what condition I had, but I didn't think anything like this would happen to me. Then the medicine started to change me as a person and I lost a lot of friends, not knowing how to deal with it. I fell into a bit of a hole and felt like the world owed me something."

Jack struggled with side-effects from his medication and coming to terms with his condition. But with time, his outlook turned positive as he found the uniqueness in his experiences, and he started to incorporate his condition into his music.

"Epilepsy is a part of me that's never going to go away. So, I might as well befriend it and learn to use it rather than see it as something that holds me back. I understand how this might be very different for someone who has more and worse seizures than mine, but I try to look at the positives. If it wasn't music, I'd try to use it to paint how my seizures look or write about it in a creative way. It's what Fyodor Dostoevsky did when writing 'The Idiot' and his other works. It's actually the way that he wrote and described things that helped with his diagnosis of epilepsy.

“When I was first making and performing music, my epilepsy was a hindrance, but huge adrenaline surges would push me through a performance and then I’d collapse after a show.”

Jack’s epilepsy affects his memory a lot. He has episodes of nostalgia and overwhelming déjà vu and jamais vu (where a situation a person’s been in before seems unfamiliar). “They stop me in my tracks and I’m in another world or memory for a short time. I also get very anxious at times and feel uncomfortable in my own skin. Sometimes I feel hot and itchy under my skin all over and my head feels tight if I’m about to have a seizure.”

But when Jack’s focus turned to writing and producing music, he started to try to use his epilepsy in his process. Jack’s music is often guided by his chromesthesia, a condition where sounds bring about visions of colour, shape or movement. While he’s not written specifically about his epilepsy, it is still subtly woven into a lot of Jack’s music, which you can pick up in some of his song lyrics. Even the name he performs under is a product of the unique way his brain sees the world. So, why VC Pines?

“I wasn’t aware that I had chromesthesia until I was 19. I thought that’s how everyone’s brains worked. But once I knew what it was, that’s when I tried to use it as a tool. If I think of a number or a letter, or I’m working on a song or a particular chord sequence, a colour appears in my head. My favourite tunes that I’ve written, or songs that I tend to like, are usually purple or violet in colour. The pines section of my name comes from some nostalgic episodes or feelings of déjà vu that I used to have. I don’t remember it, but my parents took me to New Hampshire in the US when I was a kid and they had all these massive pine trees. I was remembering a lot of that and I didn’t really know where it was coming from. So, that’s where Violet Coloured – or VC – Pines came from.

“Once I’d come to terms with my epilepsy, I tried to use the symptoms that come with it to create my music. So, I try to use my chromesthesia as a tool to paint the songs in my head and work out where I want to go while writing a song.”



VC Pines uses the symptoms of his epilepsy to help create his music

@JoeHuntPhotography

Channelling his experiences with his conditions into his music has been a way for Jack to have control over his conditions and turn it into a positive. But things aren’t always sunny.

“I still get asked all the time how I deal with having epilepsy and lights on stage and rigorous touring schedules. The lights aren’t something that will make me have a seizure, but they can make me haze over a bit and feel drowsy.

“For me, it’s more tiredness, stress and depression that can make me have a seizure. I sometimes get chest pains, intrusive thoughts, feelings of guilt for no reason, feeling on edge or sudden outbursts of emotion. I’m sometimes not able to sleep or end up picking at my nails or my skin, and there are lots more things that people don’t realise are symptoms of anxiety. I can go through weeks of having this, but then I remind myself that it is just my anxiety and it goes away for a few days. Sometimes music can exacerbate this if I’m particularly stressed about finalising my own music. It’s easy to lose your head.

“I think people should be taught the different types of seizures and the different symptoms that come with epilepsy. There are clearly different types of epilepsy, so this could even help people to go and get a diagnosis for something that happens to them that they wouldn’t otherwise have recognised as epilepsy. I also think there should be a stronger

point of contact for people with epilepsy to get information. Everything I know about my condition is from reading online rather than a neurologist helping me through it.”

Throughout the pandemic, Jack has been carrying on with his work and looking forward to a time when he can do shows again. “I’ve been mainly writing and recording, so I feel like I’ve strengthened my relationship with epilepsy. Well, except for the seizure I had in May. I’ve felt safe as I’ve been at home rather than out in public. Lots of new music has been written and I will be releasing new music early next year and hopefully doing a run of UK shows too.” There are already dates for the calendar in April 2021 for VC Pines fans in Bristol, Brighton and London. More information is available at vcpines.com and bit.ly/3lgM3M9.

It’s clear that Jack likes to make the best of a situation, even when it’s as challenging as epilepsy can be. He is a champion for creativity and that is reflected in his parting message.

“Again, I appreciate the fact that I’m able to deal with my epilepsy in a way that many can’t. But, I’d say to people in a similar position, try to look at the positives and to use it for yourself. Do something creative with it in mind. Use it to make, write, create, even if you never have before. You might find something new about your condition that you didn’t know was there.”



Empowering you

The pandemic has put pressure on all of us. For some of us it has had an effect on our mental health and seizures. We look at some challenges from the COVID-19 pandemic, highlighted by a specialist panel at an online symposium, and how the online course 'Epilepsy and you' can help

It's hard not to look at everything in daily life through the COVID-19 lens. Whatever we talk about, it's tempered by the continuing coronavirus threat and the restrictions we have in place – still – to try to control it. It touches everyday life, from doing a big shop, to socialising

with others, to transport, childcare and – crucially – healthcare.

Many healthcare services were affected when the pandemic first caused a national emergency and country-wide lockdown. But as time passed, it became important for those services to resume care. Organisations like Epilepsy Action, alongside a number of leading neurologists, called for epilepsy services to start up again swiftly and promptly as soon as it was safe to do so, so people could have access to this vital care.

While there has been an effort towards this, the impact of the pandemic is still evident. There are reports of big delays with appointments, and video clinics are beginning

to become more commonplace to try to avoid unnecessary face-to-face interactions.

The International League Against Epilepsy (ILAE) recently held a virtual symposium discussing epilepsy and COVID-19. The panel included renowned epilepsy specialists Prof Helen Cross, Prof Samuel Wiebe, Prof Ingmar Blumcke and Prof Emilio Perucca.

The panel discussed many aspects of the pandemic, including its effect on mental health, the increasing use of virtual clinics and the importance of effective treatment management. One thing that the panel all agreed on was that healthcare services must not stop, even when there are national emergencies like COVID-19. They said going forward, there need to be plans in place in order to continue to deliver care in exceptional circumstances like this.

However, the specialists noted that recent events showed an increasing need for people to become more engaged with their own healthcare. They explained that taking more control of their conditions and looking after their wellbeing can be really important for people during a time when contact with specialists can be harder.

It can be difficult to know what that means in practice, or where to begin being more aware of your own healthcare. But Epilepsy Action has developed an online course – 'Epilepsy



and you’ – which can help. This is an online self-management course that helps people live well with epilepsy. We speak to three people who completed the course to explore some of the ways it has helped with some of the challenges people face in these times.

Mental health

Prof Samuel Wiebe is a professor at the Department of Clinical Neurosciences at the University of Calgary. He told the symposium that for a lot of people with epilepsy, the pandemic has uncovered pre-existing mental health conditions. Prof Helen Cross, the Prince of Wales’s chair of childhood epilepsy and honorary consultant in paediatric neurology, said this was true in children as well as adults. She said behavioural changes, anxiety, depression and sleep disturbance have been reported during the pandemic.

Prof Wiebe said for younger people, it’s important to ask the right questions in order to uncover any mental health conditions. He added that as well as the burden of the mental health problem itself, it can also affect seizures. This could be through things like not taking epilepsy medicines as prescribed or not getting enough sleep.

Problems with money, work, family dynamics and routine are also factors affecting many people’s mental health throughout lockdown.

All members of the symposium panel agreed that mental health is something that epilepsy specialists need to address for people with epilepsy, alongside its effect on people’s seizures. Prof Cross said it is particularly important to ensure patients with epilepsy know where to go for advice and support for mental health problems during this time.

Vicky

For Vicky, looking after her mental health is hugely important. Doing the ‘Epilepsy and you’ course gave her a push to contact her GP and put steps in place to get help with her low mood.

“I have focal seizures and I was diagnosed in 2015. My seizures manifest as déjà vu, a rising feeling from stomach up to my throat, or a lump in my throat. It can be a

feeling of overwhelming emotion, fidgeting with my fingers, or zoning out. My limbs can twitch and jerk too. I’ve tried a few epilepsy medicines to control my seizures, and I’m now on sodium valproate and topiramate together to see if this combination works.

“I feel like epilepsy has had quite a negative effect on my life. I was very independent before, but losing my driving licence has been very difficult. My memory and concentration are now very poor, and I get very tired.

“I really enjoyed the ‘Epilepsy and you’ course. It was easy to do and manage, time-wise. Even with my poor concentration, it was easy to follow.

“Reading other people’s stories and actions, I realised I needed to do something about my own mental health. I think the loss of independence, the feeling tired and lack of energy brings my mood down. But since doing the course, I have felt motivated to work on this. I also phoned my GP and sought help and I am getting out for a walk every day. Some days are easier than others, but I’m doing more than I was a few weeks ago.

Reading other people's stories and actions, I realised I needed to do something about my own mental health

“The course has helped me to look at my epilepsy, look at my triggers, record more evidence in my seizure diary, and take notice of my mood. It’s made me look at ways to improve my mood and think more positively. I highly recommend for anyone with epilepsy to do this course. It’s really helped me learn new things and helped me get on track to better mental health.”

Triggers

The symposium heard that there have been reports from people with epilepsy of increased seizures during the pandemic.



The ‘Epilepsy and you’ course encouraged Vicky to get help for her mental health

For some people, seizures are more likely to happen when they are unwell. Outside of this, the panel of specialists said that there is no evidence to say COVID-19 makes seizures worse.

Prof Wiebe told the symposium that the disruption from the pandemic could be affecting people’s mental health and seizures. The change in routine it has caused, in terms of sleep, eating patterns and exercise, could be affecting the frequency of people’s seizures. Prof Cross added that possible factors for an increase in seizures may include difficulty accessing epilepsy medicines, inability to see neurologists and concerns about going to hospital.

Prof Wiebe said that the pandemic has highlighted the need to empower people to take control of their own conditions when access to specialists is difficult. This can be through people with epilepsy and their families understanding the condition better, as well as aspects like medicines, doses and seizure triggers.

Maggie

Maggie’s epilepsy means she has a range of different seizures with a number of different triggers, which she has to be mindful of. The ‘Epilepsy and

Since doing the course, Maggie has been able to pinpoint a few more seizure triggers



'you' course helped her recognise these more clearly through reading other people's experiences.

"I had my first tonic-clonic seizure in the middle of the night two years ago. I've had a few of these, as well as focal seizures, myoclonic seizures and absences. I had an absence during a meeting at work which scared my colleagues. My focal seizures make me feel disoriented, distant and fuzzy, and then I have the worst headache which lasts for hours.

"I was prescribed lamotrigine, but this isn't helping with my myoclonic seizures, so I'm slowly transferring to levetiracetam. I've found the transition from one to the other, while I'm taking both medicines, was making me feel rough. Thankfully this has now settled down.

"The diagnosis process was difficult for me. I had to wait three months to see a neurologist. I had four tonic-clonic seizures in this time and it was incredibly difficult for me and my partner. I don't think he

slept for those months, worried in case I had another seizure in my sleep. Before my seizures started, I had been under a lot of stress at work and also had a lot of physical stress. I had knee and gallbladder surgery within a few months of each other. I'd been really unwell following the gallbladder surgery. My neurologist thinks the first seizure may have been triggered by all of this, and that I'd had three pints of beer the previous evening. Apparently, it was a perfect storm to set it all off.

"Triggers are still a big thing when it comes to my epilepsy. My triggers include stress, tiredness, being unwell, alcohol, caffeine and poor diet.

"My epilepsy specialist nurse (ESN) put me onto the 'Epilepsy and you' course. Even though I've had epilepsy for two years, there was so much I didn't know! I didn't realise I had so many different types of seizures. I found it incredibly helpful and well written. It was very easy to follow, and I found that I completed it quickly as it was so interesting.

"Reading about other people's experiences and being able to ask questions was invaluable. There were times when I recognised I had similar symptoms to other people, such as memory loss, and everything made more sense.

"Since doing the course, I realised that eating too much sugar makes my twitches worse. It's made me look at myself a bit closer and concentrate on being well and healthy. I'm trying to look after myself, eat better and I've also taken up swimming three times a week, which has been great for my mental health. I struggled with having to give up my beer, but had happily replaced it with cake. I'm now trying to cut that down too, but I'm only human!

"My epilepsy reviews with my ESN have been made easier since the course too. I'm now able to discuss the types of seizures I've had and the effects of the medicine I'm on. It's helped me identify if I've triggered my seizures or if they are down to the changes in my medicines.

"I definitely think the course has been a great help to me and I would recommend it to anyone who has been diagnosed with epilepsy. It has given me more confidence in myself and in coming to terms with the fact that I will have epilepsy for the rest of my life. I'm not going to let epilepsy rule my life and I finally feel more like the old me than I've done for a long time. I'm definitely moving forward, and if I can, then others can too."

Taking control

The symposium panel also said that the pandemic has created a lot of stress for people, which could affect epilepsy. Uncertainty with work and finances can put a strain on adults, while a lack of social life and a feeling of isolation can affect anyone – younger and older. In younger people, the panel highlighted that communication can be an issue, and they might not be forthcoming with concerns about their mental health.

Another problem highlighted by the panel was that older people may be experiencing problems at home but be worried about going to see specialists or going into hospital. They recognised this group of people may be dealing with

other conditions and possible medicine interactions, which may need extra care from healthcare services. Good, open and consistent communication was stressed as an increasingly important part of healthcare in the current situation.

Robert

Robert did the ‘Epilepsy and you’ course, and it helped him to have more constructive discussions with his epilepsy specialists and be more open with his family.

“I have focal impaired awareness seizures. I am usually aware of a shooting pain on

Following the course, I have more **constructive conversations with my ESN about my epilepsy**

my left arm before a seizure begins. I am changing medicines at the moment. I was originally taking levetiracetam but now I’m slowly moving to lacosamide. Since changing medicines, I am now conscious while a seizure is happening. They were occurring weekly during the night, but now they are fortnightly and the time between them is getting longer.

“I first started having seizures when I was in hospital. I was in for a long time – over a year – with acute pancreatitis. During my hospital stay, I started having seizures and they continued after my discharge. I was referred to a consultant at the hospital who arranged for an EEG.

“My life has been significantly impacted by my epilepsy. I was initially not aware what was happening and found it very scary not to be in control of my body. I had a significant fall from my bed during a seizure, which required specialist care, and I began to realise I needed to be careful. I no longer work full time, as I find that stressful situations can make the risk of a seizure higher. I have now gone part-time and work at home more. As part of this, I no longer do full days, but half days

with several breaks, which makes work possible and less stressful.

“The ‘Epilepsy and you’ course is excellent. It helped me understand what’s happening to me and, more importantly, opened a network of other people who had similar problems. Reading how they were coping with their seizures – and in some cases they were far more frequent and severe than mine – gave me a perspective on my life. The course did not go into too much medical details and terminology.

“I especially liked that you did a section a week, which allowed you to understand and process the information. It was key for me that the course didn’t feel like an exam that you need to do quickly. You can do the sections at your own speed and think how the sections reflect on your own life.

“I am lucky to have an ESN. Following the course, we have more constructive conversations about my epilepsy. Being able to use her as a filter means my appointments with the consultant

are more focussed. It was a call with my ESN that resulted in my medicine being changed to lacosamide after my consultant agreed it was worth trying.


“Since doing the course, I am aware how to put myself in a safe environment if I feel a seizure could be about to happen. I am fully transparent with my wife, who has been fantastic in helping and supporting me. She has encouraged me to change from an incredibly stressful job to a new job that is less stressful and part time. The course educated me in how to cope with epilepsy and adapt my life to do as much as I can. I have a better understanding of how to change my work and personal life and be positive.

“I’d recommend for people to sign up for the course, keep an open mind and slowly think about each section and how it impacts on you. It is worth the time to invest in your wellbeing.”

You can now sign up for the ‘Epilepsy and you’ course for free at epilepsy.org.uk/epilepsyandyou

Robert has had more constructive appointments with his epilepsy specialists since doing the course





The service originally set up its video clinics for transitions from children's to adult epilepsy services

Video clinics

During this turbulent year, we've all had to do a lot of adapting. Every one of us has been affected in one way or another by the coronavirus pandemic and lockdown. Even with lockdown restrictions changing as time goes by, the general view is that things will not be the same for a long time.

New measures, adaptations and lessons learned from the last few months will be adopted as we continue to move forward.

One aspect that is likely to continue to play a big part in our lives – be it personally, for work or for healthcare – is the video call. Whether we used it to keep in touch with family, to have meetings with colleagues or to see our healthcare specialists, these have become ever more popular over the last seven or eight months.

It should be said – and it is well recognised and often reaffirmed by healthcare professionals – that this type

As video clinics and virtual appointments continue to be widespread during the pandemic, we look at some positives and negatives of this method in epilepsy services

of contact with healthcare providers is not for everyone. Some of us may find it difficult or uncomfortable, and we may not have the internet access or technology necessary to communicate in this way. In these cases, healthcare professionals are prepared to use different methods, such as normal phone calls, to continue to provide the service people need.

But in other cases, video calls have been a really important stopgap while face-to-face clinics have been difficult. Luton children's Epilepsy Specialist Nurse (ESN) Liz Stevens and Assistant Practitioner Mary Hunt describe using video link virtual clinics in their service. They share some of the positives that people have found with this approach, as well as some of the challenges.

Using video link virtual clinics

Video link clinics are being used increasingly to support many areas of healthcare. We had been developing

our virtual clinics for the last three or four years, ahead of any sign of a global pandemic.

We first identified a need for the video link service within the transition pathway from children's epilepsy services to adult services. This was because this group of young people require additional appointments and regular reviews. This could result in missed school time and parents requesting time off from work, which could be an added burden. It was also important to consider whether the video link format would be more appropriate and help engage young people with their epilepsy.

We explored technology options and involved parents and young people in the process. As we progressed, there was a steep learning curve with this type of care. However, by the end, it was clear that video links could be used in all areas of epilepsy care, not just transition support.

Having this in place allowed us to offer families indirect face-to-face contact as soon as the lockdown started. We found that this type of service has been welcomed during this challenging time.

Benefits

For the staff, the experience of virtual clinics has been largely positive. We found we could be more efficient and had more time for clinical care. We found we could see recordings of seizures fairly clearly over the video link where internet connection was sufficient. Parents could demonstrate seizures as they would in a face-to-face clinic. Young people could engage with their healthcare after a new diagnosis or with managing complex epilepsy.

We found the video format has allowed us to support people around issues with medicines, including helping with doses and checking labels. It is also useful where English is not a person's first language.

The format has allowed us to avoid unnecessary face-to-face appointments. It can help us make quick assessments of patients, being able to see and hear them, and help navigate appropriate healthcare for families.

For families, it has also had benefits. Feedback suggests that video links help families access care, who find it difficult to attend clinics, who have many appointments or who have more than one child with epilepsy.

Parents and carers said video links made it easier to access care and support, and reduced travel and parking time. One parent said: "The convenience of it all was great. It can be difficult travelling to the appointment and getting time off work." Others said they saved time by not having to travel and wait at the hospital. One parent said the video call format meant they didn't have to do all the talking, like with a phone call, but their child could speak too. Another parent said: "My son has been able to talk more openly." One parent found her teenage son, who has autism, engaged better with the video format.

Feedback from young people was similar – they felt there was less waiting

and travel time, also finding it more private and more personal. We also found that young people may not like to go to children's outpatients for their appointments now that they were older, so some preferred the video calls.

Video calls help to have better discussions, more engagement and better information exchange but care needs to be taken when discussing sensitive information. The clinics make it clear that parents and children need to be in a safe and secure space for video link appointments. People often do these at home.

Challenges

We recognise that virtual clinics cannot replace face-to-face clinical contact and review. Supporting children and young people with additional conditions, behavioural problems or learning disabilities is possible to some extent, but may still require a face-to-face appointment. The same is also sometimes true for seizure management.

We found that young people and adults may need one or two sessions to become more comfortable with using video links to contact their healthcare professional. Early on, there was also a problem with young people and adults not always contacting the clinic as planned, as video calls were not seen as formal appointments. This was addressed by sending SMS message reminders. Other

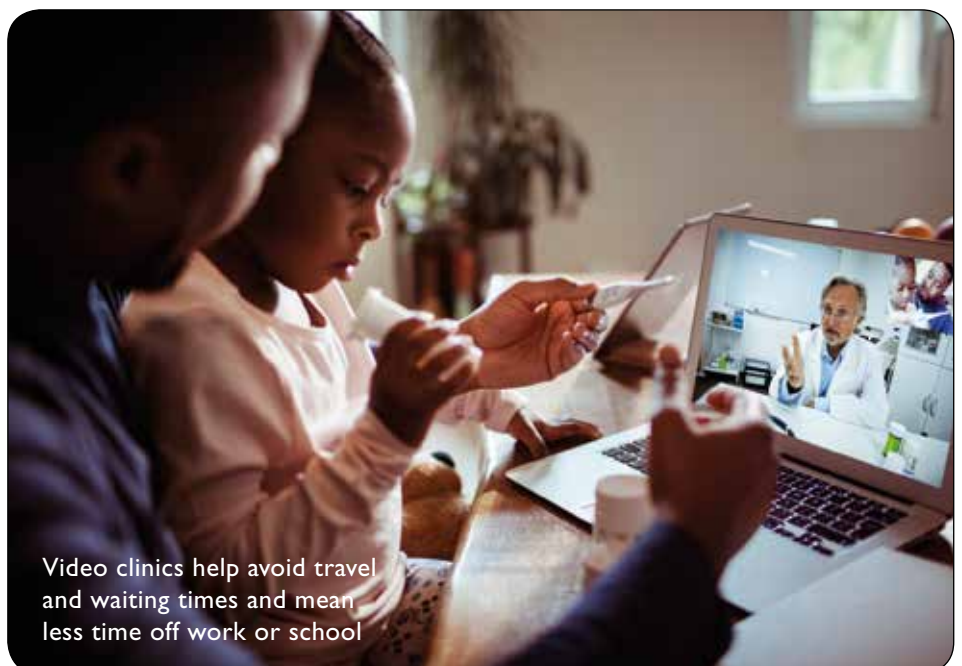
problems included some people declining video clinics. This could have been because of a lack of familiarity with this approach, lack of confidence with computer skills or concerns about safety.

However, use of video clinics picked up a lot during lockdown, without anyone declining a video clinic. Where there were problems in setting up the links, we sometimes did home visits to help set up the technology and help people build confidence in using it. There are also sometimes audio-visual problems with the picture or the sound. We found it was important to recognise when to abandon the video call approach and try another option.

Future use

During the pandemic, epilepsy services have been widely adopting video clinics as part of daily care. It has offered a lot of flexibility to young people and their parents and it is no longer an unusual thing to have these types of clinics.

Video clinics have been a supportive resource to support patients during the pandemic. We continue to learn how to make best use of them and when they are and are not appropriate. Despite the challenges, virtual clinics are now embedded in our service and continue to offer increased flexibility and efficiency in providing and effective service.



Video clinics help avoid travel and waiting times and mean less time off work or school

Helping hands

**Nine people
recognised
with Epilepsy
Action Helping
Hands awards**

Richard McGhee's first seizure was a big one. On his way to the village shop with his son Jack, he suddenly fell to the floor, unconscious. He fractured his skull and broke his shoulder and his collarbone in the throes of his first seizure. For his eight-year-old son, it may well have been the scariest experience. But, in that moment, Jack showed a huge amount of bravery. He shouted for help and started to call the emergency services, before a passer-by came to his and his dad's aid.

It is courage and strength of character like this which led to Jack winning an Epilepsy Action Helping Hands award this year. His dad nominated him, saying that day was a life-changer for both him and Jack.

**Jack will always
be my hero** for his
actions on that day



Richard and Jack
McGhee

"He is only eight years old and he dealt with all this in such a calm and grown-up way," Richard said. "It makes me feel so proud and safe to be around him. He will always be my hero for his actions on that day."

Jack is one of nine recipients of this award, given for showing outstanding support to people with epilepsy. Also receiving this award this year are two women who have worked tirelessly to campaign for recognition and overdue support for families with children born with foetal valproate syndrome.

Emma Murphy and Janet Williams are founders of the Independent Fetal Anti Convulsant Trust (IN-FACT). Both women have epilepsy and were prescribed sodium valproate for their conditions without being told of the risks in pregnancy. Emma and Janet both have children with foetal valproate syndrome.

Their work has been instrumental in bringing about awareness of the risks valproate carries if taken during pregnancy. They are also a key source of support for families affected by valproate. As an indication of the significant support they have provided to others in a similar situation, Emma and Janet were nominated by 12 other parents for the Helping Hands award.

One parent praised them, saying they have to manage their own epilepsy and the conditions of their children, and they still find time to support other families affected by foetal valproate syndrome. "I believe they are truly worthy of this award as true epilepsy heroes," the parent added.

Janet said: "We are extremely touched to be nominated for this award by our



Emma Murphy and
Janet Williams

I believe Emma and Janet are **truly worthy of this award as true epilepsy heroes**

families, and it means a great deal to us both having supportive parents onboard with the campaign and personally. Our work in Parliament has been demanding, a great commitment, but has been truly fulfilling, a huge journey and learning curve. We have every intention on continuing with the work we do to support every family affected by anti-convulsants in pregnancy."

Emma added: "We are very grateful and proud to now be receiving this recognition from Epilepsy Action. It has been an arduous eight-year parliamentary campaign for IN-FACT alongside helping parents and families through our support group FACSA."

Showing support can be as much about amplifying people's voices as it can be about quietly being your family's rock.

Paul Thirkettle is exactly that. He is no stranger to epilepsy, having been around the condition since he was 13 years old, when his mum, Melony, was diagnosed. Then, years later, when he met his wife Rachel, he found out that she had lived most of her life with epilepsy too. They now have two children – Dorothy, 12 and Georgie, 10 – and Georgie is also living with epilepsy, alongside some other medical conditions.

Rachel nominated Paul for a Helping Hands award, saying he is completely invaluable to his whole family. “He never moans about anything, it’s second nature to him. He records the dose of all our epilepsy medication and he comes to every hospital appointment, making note of what the doctor says to help us remember. Most importantly, Paul remains positive, encouraging us to do all that we can.”

All the recipients of this year’s Epilepsy Action Helping Hands awards have different and unique stories and experiences. Sienna is only eight, but she supports her sister with her epilepsy and takes the difficult parts in her stride. Nine-year-old Reggie has been able to recognise when his friend Ellis is about to have a seizure and has called for help and kept him safe. Rachael and Danielle continually support their mum Belinda and have helped her see that “life is worth living”. And Ysgol Llwyn-Yr-Eos, a school in Aberystwyth, Wales, has helped Seren get back into education, make friends and take part in her first Christmas production.

Every situation is vastly different, but one thing all of this year’s award recipients have in common is a huge amount of care, kindness and generosity for others living with epilepsy. Congratulations to all the winners, you are all brilliant!



Paul Thirkettle and his family

Paul remains positive, encouraging us to do all that we can

You can read each winner’s individual story in full on the Epilepsy Action website at epilepsy.org.uk/news



Order your Christmas cards, wrap and stocking fillers today! You can find the 2020 Christmas catalogue in your September edition of *Epilepsy Today*. It’s easy to place your order through our online Christmas shop or you can call 0113 210 8800.

Why not visit our Christmas shop online and view the full range of our exclusive Christmas products and our new stocking fillers.

- Melting snowman: £3.50**
- Light up lantern springs: £2.50**
- Make your own festive figures: £2.50**



Find our Christmas collection online at epilepsy.org.uk/christmasshop

Epilepsy Action Christmas 2020 fundraising appeal

Throughout November and December, we will be writing to supporters to say thank you for helping during what has been an incredibly difficult year.

We have seen the charity's income drastically reduced in 2020 as the coronavirus pandemic caused the cancellation of thousands of fundraising events. Even huge annual events like the Great North Run and London Marathon had to change their plans.

Our Christmas fundraising appeal is, through necessity, a continuation of the appeals in Spring and Summer. Our members and donors responded magnificently to these 'emergency appeals', donating in record numbers.

But with the restrictions triggered by the coronavirus pandemic still in place, and with no end in sight, we are once again asking you directly for donations.

For people affected by epilepsy, the pandemic has meant a drastic reduction in funding for services that thousands of people every year have come to rely upon. Services like the advice and information available through the Epilepsy Action Helpline and website.

These services are funded almost entirely by Epilepsy Action's fundraising. They help thousands of people every year. That may be someone newly diagnosed with epilepsy, or a family member desperate to keep a loved one safe. It could even be someone who has been living with epilepsy for a while, but is struggling to find the help they need. Fortunately, with your support, services like the Epilepsy Action Helpline can provide that support. Here is what some people who used these services said:

"Many thanks for talking to me yesterday. You were so kind and helpful. Epilepsy is new to me and you really made me realise how much help and support there is. I am truly grateful for the advice and reassurance you gave me." Mr K, Epilepsy Action Helpline user

"My husband was diagnosed with epilepsy following surgery for a brain injury. I had an awful lot to learn very quickly. I think the website is brilliant, it's been a fantastic support. I have been able to find out really important information that I've needed, quickly and clearly 24 hours a day without frightening myself. I hugely appreciate the work [Epilepsy Action's staff] do to make things better not just for the people with epilepsy but for the people who support them." Mrs D, Epilepsy Action website user

"The Epilepsy Action website is a fantastic source of information, being thorough yet concise. The helpline is also

invaluable and has provided me with support that I was unable to access from anywhere else." Mr B, Epilepsy Action website and Helpline user

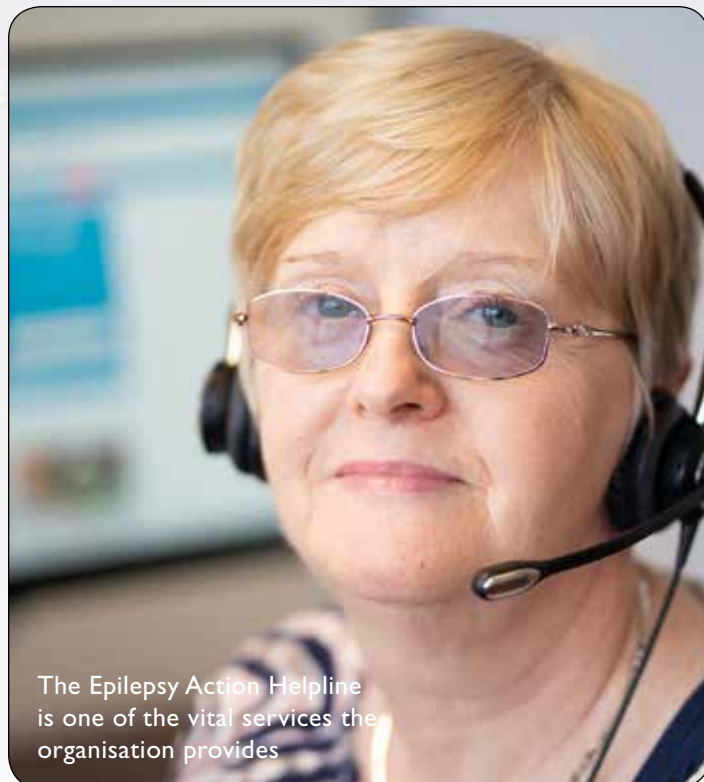
This year has been a year of challenges and change that would have seemed impossible just 12 months ago. But, as these quotes show, the generosity of our members and donors means people affected by epilepsy can still get the help they need.

That is why, as well as thanking everyone who has helped this year, we are also asking: **once you've taken care of your loved ones, can you spare an extra gift this Christmas?**

Every donation to Epilepsy Action gives hope to more people living with epilepsy. Hope that 2021 might see an end to their isolation. Hope that they will be able to find the support they need. Hope that they can find the right treatment to control or even stop their seizures.

To give that gift, you can return the form on the address insert of your copy of *Epilepsy Today*. Alternatively, you can call the Epilepsy Action fundraising team on 0113 210 8851 or donate online at epilepsy.org.uk/hope

Thank you!



The Epilepsy Action Helpline is one of the vital services the organisation provides



purple day friday 26 march

Show your support, your way

See how you can help change lives at
epilepsy.org.uk/purple
or call **0113 210 8851**



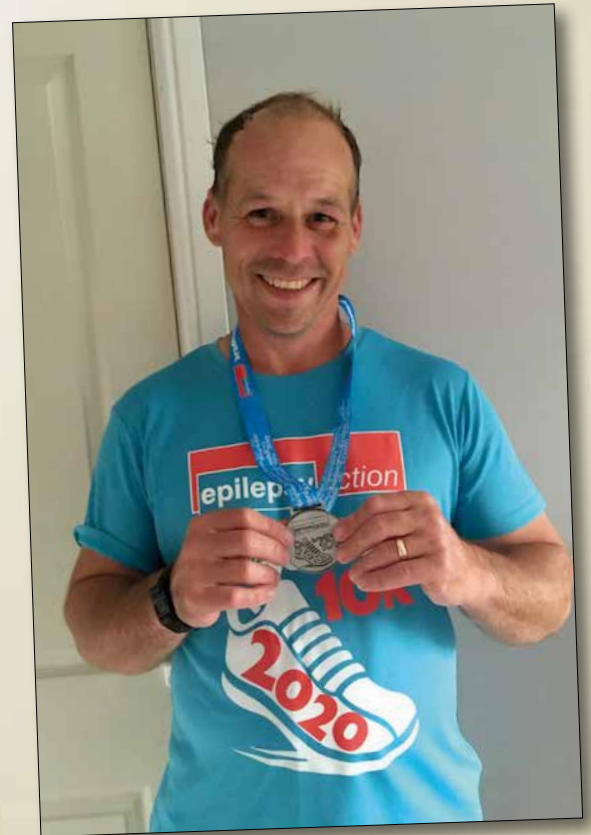
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My journal



Andrew Jackson has had epilepsy for 41 years. Andrew talks about dealing with school bullies, going into status epilepticus and finding something that gave him confidence, coordination and enjoyment - Taekwondo



I remember being on top of the climbing frame at school when I was about six years old and I had a seizure and fell to the floor. I bit my tongue very badly and was rushed to hospital.

I was three years old when I was first diagnosed with epilepsy. The diagnosis came after I had measles. I don't remember it, but my mother and father said I would have absences and atonic seizures. At the time, my parents couldn't find any information about epilepsy. To keep me safe at school, I had to wear a bicycle helmet given to my parents by a friend. It helped stop me from banging my head, but it did also make my confidence hit rock bottom. The other pupils were wondering why I was wearing a helmet and why the teachers were keeping an eye on me. Fortunately, my headmistress at the school, who also didn't have any knowledge about epilepsy (it was the 1980s!) was a very supportive lady.

Every time I had a seizure, I would be really confused. I remember having absences at school, and feeling very tired, which was probably due to my medicines. Sometimes I would

even fall asleep in class. When I had atonic seizures, I just kept thinking "Why me? Why do I have to have this happen to me?" I didn't fully understand what epilepsy or seizures were and just thought I was alone.

Eventually, I was referred to a neurologist in Sheffield who I had to see twice a year, but I didn't understand why I was going there. When I was about nine years old, I asked my parents what epilepsy was, and they explained my condition to me. They said I had to keep going to Sheffield for check-ups and tests. When I was around 14, my sleep seizures became more frequent. One tonic-clonic seizure I had turned into status epilepticus (a dangerous, prolonged seizure), and I ended up in hospital for two weeks.

The diagnosis process took a long time. I tried a lot of different medicines but was eventually prescribed carbamazepine. It mostly controlled my seizures, even though I had the occasional stay in hospital after having a tonic-clonic seizure. For about 14 years I was on carbamazepine and lamotrigine, which

controlled my seizures. At first, when I was prescribed my medicines, I was extremely tired but when my body adjusted to the new medicines, I began to get less tired and less anxious about my epilepsy.

Then when I was 32, I ended up having status epilepticus again, which I nearly lost my life to. I was admitted to hospital and I ended up there for six weeks recovering and having tests and video telemetry. I was then taken off carbamazepine and put on sodium valproate, levetiracetam, clobazam and lamotrigine. It took a long time to get the correct balance of medicines. The lamotrigine was going to be lowered, but I got anxious about lowering my doses further, as they were controlling my seizures. But I am still seizure free.

Martial arts

My desire to learn martial arts started from an early age. I was bullied from the age of seven until I was about 16. At 7 I was no longer wearing my helmet, as my seizures were mainly during sleep. But I started to get bullied, maybe because of my lack of confidence. They would call me names and sometimes hit me. They also threatened my friends about speaking to me, which I found very upsetting. I would dread going to school most days and sometimes, when school was over, I would cry. At one point the bullying was worse than the effects of my epilepsy, so you can imagine how bad it was.

Every year, my parents used to take us to Ashbourne on holiday and we would go to Alton Towers. One year, Frank Bruno was opening a new ride, called the Thunder Looper. I remember thinking "I wish I could be as strong as Frank Bruno – I wouldn't get bullied anymore!"

"To keep me safe at school, I had to wear a bicycle helmet - it helped stop me from banging my head but it did also make my confidence hit rock bottom"

When I passed my driving test at 17, I thought I would see if there was a local boxing club. There wasn't, but there was a kickboxing club about ten miles away. When I signed up, I told the instructor that I had epilepsy. I mainly did bag work and occasionally sparred, which was controlled and often I was sparring with the coach who knew about my epilepsy. He could coach me how to block and do other techniques. It wouldn't have been safe if I was in the ring with other people, as they wouldn't be aware of my epilepsy or possibly even know what it is.

My mother and father didn't know I was kickboxing until they asked where I was going twice a week. Naturally, they were concerned, but my dad came to watch one time and saw how my coordination, fitness and confidence had improved. Unfortunately, the club closed and I had to stop.



Meeting Frank Bruno inspired Andrew's love for sport

One year after my status epilepticus, when I got my driving licence back, I found a nearby Taekwondo club. I went to watch one evening and then the following week I decided to become a member and I began to train in traditional Taekwondo. If we sparred, we would wear head protection and all the other sparring gear. There would be around three of us in a group, with one refereeing and two sparring. With Taekwondo, regardless whether someone has a medical condition or not, we all wear full body armour and sparring is a very small part of the martial art. We do patterns which is a sequence of movements involving stances, kicks, blocking and punches. This is performed on your own, and the higher the grade, the more complex the moves are. I think when people see Taekwondo in the Olympics, they just see the sparring side and not all the other important parts of the sport.

Even though my coordination is good in a lot of other areas, I did struggle with some techniques and exercises at the start, due to the part of my brain affected by my epilepsy. It took me longer to learn some techniques or patterns than other people. I always aim for manageable goals, though, such as passing the next grading, and after a lot of hard work, I gained my blackbelt. I passed my third dan grading in November 2017, which is quite a high rank in the sport. Hopefully, I will be able to take my fourth dan this November, if the sports clubs are open around the COVID-19 pandemic. I have also passed the level 2 coaching course.

My doctors were not too concerned about my Taekwondo. My parents and wife were with me and they told the doctors how it had improved my coordination and it was something I enjoyed. The outcome was that as long as I was careful, I would be okay. They had come across many people in a similar situation who had done contact sports.

epilepsy experience

Family and friends

I had tried other forms of exercise in the past. Keeping fit through exercise has boosted my confidence since I was 17 years old. As well as martial arts, I went running and to the local gym. I also went swimming with my family when I was about seven years old, but I ended up having a seizure in the pool and banging my head. My parents were always very careful and planned what activities I could do safely. So, after this, it was decided that it was not a good idea for me to go swimming, even with supervision. Years later, I decided to have swimming lessons, but on one occasion when I went swimming on my own, I had a very quick seizure and went under the water. After that, I was too frightened to go again.

I'm fortunate that I've been able to do quite a lot of the things I enjoy despite my epilepsy. I'm very open about my epilepsy to anyone who would like to know about it – whether it's at work or at Taekwondo. But it's not all been smooth sailing. I passed my driving test at 17, after four months of lessons and I was so proud of my achievement and so excited to gain my independence! Just five months later, after my status epilepticus, I had to surrender my licence. I was absolutely distraught to have my independence taken away. I have had to surrender my driving licence twice – once at 17 and once at 32. On



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Taekwondo helped Andrew with his coordination and confidence

both occasions, some people thought I'd lost it through drunk driving. I found that very upsetting – I don't even drink alcohol! I'm self-employed as a gardener, and both times I was without my licence, my family and friends helped me keep my business running. They would drive me to jobs and work with me. My

"My doctors were not too concerned about my Taekwondo - my parents and wife told them how much it had improved my coordination"

family have been very supportive. Obviously, it was upsetting for them seeing me having seizures. I'm lucky to have my lovely wife of 18 years and our three children. I've learned to deal with my epilepsy, whether it's at home, at work, or doing sports. I try to take the right precautions.

I really enjoy doing Taekwondo. It has helped me in so many ways, and it can help others. Two of my children also train in this martial art. There is so much to Taekwondo, such as patterns, fitness, coordination and meeting new people. There are so many benefits to be gained through this excellent sport!

Martial arts

If you have seizures, it would be best to ask your doctor for advice before practising martial arts. Whatever type of martial art you choose, you should make sure that the people in charge know about your epilepsy and what to do if you have a seizure.

Medical files

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

Clobazam

The value of 'calming' drugs for the treatment of the epilepsies was first recognised as long ago as the 1960s. Clobazam (CLB) was licensed in the UK in 1977 and is the most widely used of the group of medicines called benzodiazepines, which is administered by mouth. It is effective for a range of hard-to-treat epilepsies. Because of its different chemical structure, CLB is less sedating than the other medicines in this group. It is recommended as an add-on treatment for a number of seizure types, including focal and generalised epilepsies. It can also be

used in babies and children with a range of complex syndromes.

CLB can be taken once or twice daily in a dosage range of 10-60mg, depending on how effective and well tolerated it is. If the total daily amount exceeds 30mg, it is preferable to take it in two separate doses a day. Short-term administration, such as taking 20mg once daily for three days, can have a useful effect in some circumstances. For example, taking it immediately after the first episode in people with regular clusters of focal or generalised seizures. Another example is in women who only have seizures just before their periods. Children with Lennox-Gastaut syndrome can be treated with 0.5-2mg a day for each kilogram of the child's weight. Not everyone started on CLB will have a continued response, as occasionally people can develop a tolerance to its effects. It can have a potentially beneficial effect in people with epilepsy who have anxiety, for which it is also licensed.

The most common side-effects associated with CLB are tiredness,

dizziness and unsteadiness when walking. These problems are more likely to occur at higher doses of the medicine. People can also experience depression and irritability with higher daily doses of CLB of 30mg or more. For other people, CLB can have a sedative effect at lower doses as their bodies take longer to break down the medicine. If this happens, taking a low dose of the drug at bedtime may solve the problem and still control the seizures. Very rarely an allergic rash can occur soon after CLB is started. This should be immediately reported to the doctor and they should take the person off the medicine. If the medicine is withdrawn because of lack of effectiveness, however, this should be done slowly. This helps avoid making the seizures worse or causing rebound irritability, restlessness and sleeplessness. There is no evidence that CLB can damage babies in the womb. All in all, CLB is a useful, easy-to-use, add-on treatment for a range of seizure types and epilepsies. Its efficacy and tolerability have withstood the test of time.



Professor
Martin
Brodie

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

Annual General Meeting 29 August 2020 ballot results

1. Summary of Response

	Number	Percentage
Electorate	8,604	100
Valid proxies returned	283	3.29
Invalid proxies returned	12	0.14
Total proxies returned	295	3.43
Members voting at AGM	0	0.00
Total response	295	3.43

2. Election of Members of the Council of Management

Candidate	Votes received	Percentage share	Outcome
Jane Riley	255	19.45	Elected
Gavin Barlow	206	15.71	Elected
Ian Walker	197	15.03	Elected
Mike Harnor	185	14.11	Elected
Diane Hockley	170	12.97	Elected
Ellie Wilmshurst	96	7.32	Not elected
Nathan Sivapatham	77	5.87	Not elected
Jim Berrington	76	5.80	Not elected
Esther Johnson	49	3.74	Not elected

3. Confirmation of appointment of Vice Presidents

	Votes in favour of confirmation	Percentage in favour of confirmation	Votes against confirmation	Percentage against confirmation
Karen Armstrong	244	92.08	21	7.92
Evan Harris	226	86.59	35	13.41
Paul Maynard	247	91.48	23	8.52
Lord Smith	242	91.67	22	8.33
Ray Tallis	244	92.78	19	7.22

4. Result of resolution 1

Resolution 1	Number for	Percentage for	Number against	Percentage against
To re-appoint RSM UK Audit LLP as auditors	261	97.03	8	2.97

Council of Management 6 October

The Council of Management met by remote video conference on 6 October. This was the first meeting of the Council after the Association's Annual General Meeting held on 29 September.

Richard Chapman was elected as Chair of Council. Jane Riley was elected as Vice-Chair of Council and June Massey was elected as Honorary Treasurer.

The following people were elected to the Corporate Governance Committee: Jayne Burton, Diane Hockley, Sarah Lawson, June Massey and Torie Robinson. Richard Chapman is an ex-officio member of the Committee as Chair of Council.

The following people were elected to the Finance and Strategic Policy Committee: Gavin Barlow, Peter Clough, Mike Harnor, Sarah Lawson and Stephen Timewell. June Massey, Richard Chapman and Jane Riley are all ex-officio members of the Committee as Officers of Council.

Annual reports were received from Council's diversity champion and its champion for research. Jayne Burton and Diane Hockley were appointed jointly to be Council's new diversity champion in succession to Ellie Wilmshurst who has now left Council. Jim Morrow was re-appointed as Council's champion for research.

In other business, Council reviewed the charity's financial position and progress being made on preparing a revenue



budget for 2021. Every quarter the Council looks at the top ten risks on the corporate risk register and selects one for more in depth analysis. On this occasion the threat of cyber-attack on the charity was looked at. Members assured themselves that proportionate measures were in place to protect the charity.

The next meeting of the Council is scheduled to be held on 8 December 2020.

Epilepsy support for you

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

Join one of our virtual groups

We know many of you take comfort from connecting with others affected by epilepsy. The traditional face-to-face group meetings just aren't possible right now, so the local services team have set up online meetings using video calls instead (technical support is available). If this is of interest, you can find out more at [epilepsy.org.uk/virtual-groups](https://www.epilepsy.org.uk/virtual-groups) or by calling **0113 210 8800**.

If you previously went to a local support group, they may also be offering a chance to get together online. You can find out if this applies to the group you attended by emailing iso@epilepsy.org.uk or calling **0113 210 8899**.

Online resources

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

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



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