

## Epilepsy at 71

Val shares her story of getting diagnosed and why it wasn't the shock it could have been



Also in this issue

- Prof Gus Baker provides an update on **epilepsy and COVID-19**
- we mark Epilepsy Action's 70th anniversary with **seven key milestones**
  - we hear about the rewards and challenges of **being a carer**



# editor's letter

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

It is an incredibly strange time for all of us. It's hard not to let the uncertainty of the coming months bring on some stress and anxiety. But as we pull together to protect ourselves and the more vulnerable members in our communities, we are taking the next steps we can towards a better time.

COVID-19 is really altering the landscape. Epilepsy services have changed to minimise the spread of coronavirus – an incredibly important goal, but to some detriment to people with epilepsy. While lockdown restrictions are easing, the possibility of more regular local lockdowns makes it impossible to predict what the rest of 2020 holds. But, as Prof Gus Baker says in our COVID-19 update on page 14, you can bet the NHS staff are making every effort for people with epilepsy.

The pandemic also had huge implications for fundraising, which is the backbone of the organisation and makes it possible for us to support people with epilepsy. Luckily, the fundraising team at Epilepsy Action is creative and enthusiastic, and has come up with some great, lockdown-friendly ways to get you involved. And you have really rallied behind us, for which we are extremely grateful. You can read more on page 12 about some of the brilliant activities people have done to support others with epilepsy.

This year also marks Epilepsy Action's platinum anniversary – 70 years! In the spirit of holding on to the positives, we have put together seven key milestones Epilepsy Action has worked towards for people with epilepsy in the last 70 years (page 24). No matter what is happening, we're here and we have your back.

We also have some fantastic stories about successful epilepsy surgeries (page 8), the realities of being a carer to someone with epilepsy (page 16), and what it's like to be diagnosed with epilepsy at age 71 (page 28). On page 21, we also pay a heartfelt tribute to a long-serving supporter, council member, branch chair and volunteer for Epilepsy Action, David Streets, who died in June this year.

We hope you are staying safe and well.

Kami Kountcheva  
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**Val was diagnosed with epilepsy at age 71 – but this wasn't her first run-in with the condition**



## Gap in genetics testing access

There is a gap in the diagnosis of genetic epilepsies in people with epilepsy and intellectual disability, a new Spanish study suggests.

Published recently in the journal *Epilepsy & Behavior*, the study looked at the epilepsy units in two hospitals in Madrid. The researchers included people with epilepsy and intellectual disability, where the underlying cause of their epilepsy wasn't known.

From the 124 people included in the study, around two-thirds (58%) had had advanced neuroimaging. Two-fifths (41%) had had prolonged video EEG and two-fifths (40%) had had a genetic test. A diagnosis of the cause was reached in less than one-fifth (18.5%) of people. The work to diagnose the cause of the condition was considered incomplete in two thirds of people (67%).

Study authors Aledo-Serrano and colleagues concluded that a large proportion of patients with epilepsy and intellectual disability did not get access to modern diagnostic techniques. This was especially true for those whose seizures were controlled and those who were older.



## Government issues apology over 'public health scandals'



The UK government has apologised after the Independent Medicines and Medical Devices Safety Review called for a “fulsome apology” to the families affected by sodium valproate, Primodos and pelvic mesh.

This was one of nine “wide-ranging and radical” recommendations for improvements in the health system set out by the review team’s report, *First Do No Harm*, published on 8 July. Other recommendations include the appointment of a Patient Safety Commissioner to advocate for patients and the establishment of schemes to meet the cost of additional care for those affected.

The report follows a two-year review, chaired by Baroness Julia Cumberlege, into three “public health scandals” around medical interventions, one of which is sodium valproate.

Sodium valproate is an effective epilepsy medicine, but it is known to cause birth defects and developmental problems in babies born to

mothers taking the medicine. Knowledge of these effects had been around since the 1970s, but this information wasn’t made widely available until years later.

The review aimed to determine what was known about the effects of this medicine by manufacturers, regulators, clinicians and policy makers. It further investigated what decisions were made and actions taken in light of this knowledge.

Baroness Cumberlege said: “I have conducted many reviews and inquiries over the years, but I have never encountered anything like this; the intensity of suffering experienced by so many families, and the fact that they have endured it for decades. Much of this suffering was entirely avoidable, caused and compounded by failings in the health system itself.

“We met with people, more often than not women, whose worlds have been turned upside down, their whole lives, and often their children’s lives, shaped by the pain, anguish and guilt they feel as a result of Primodos, sodium valproate or pelvic mesh.

“We are urging the system to do what it should have done years ago, to help those who have suffered and put in place the processes that will enable it to learn from past mistakes so that we can spare other families from such anguish.”

Epilepsy Action’s deputy chief executive, Simon Wigglesworth, said: “Nothing can undo the avoidable harm and distress that has been caused by the decades of government silence

and inaction. However, with the publication of the report and these recommendations, we can now start to move forward.”

“We welcome the suggestion of a registry for all women on anti-epileptic drugs who become pregnant and are encouraged that this will not be limited to women taking sodium valproate. This is something Epilepsy Action has been calling for and is an important first step in ensuring that all women with epilepsy are fully informed of the risks of all anti-epileptic drugs.

“The report is an important milestone in the journey to address the historic issues around valproate but there is still more work to be done. We will continue to put pressure on the Medicines and Healthcare products Regulatory Agency, the Department of Health and Social Care, and others, to ensure that these recommendations are fully implemented.”

Independent Fetal Anti Convulsant Trust (INFACT)’s managing director Emma Murphy and CEO Janet Williams said they are delighted with the recommendations from the review. “We are pleased to see that the review not only took on board our evidence found at National Archives, but, most importantly, acknowledged the many heart-breaking stories from families that have been affected by sodium valproate. An apology has been a long time coming.”

You can find more information and read the full list of recommendations at [immdsreview.org.uk](http://immdsreview.org.uk)

## Share your views on ambulance services for epilepsy

Researchers from the University of Liverpool are asking people with epilepsy, their family and friends to complete a survey looking at ambulance service care.

Senior lecturer at the Department of Health Services Research, Dr Adam Noble, is looking to find out how people with epilepsy want to be cared for by the ambulance service. He hopes the research can help the NHS offer the kind of care people with epilepsy and their families want.

The survey can be done online and takes 20-40 minutes. You will be asked about yourself, your connection with epilepsy, the impact epilepsy has on your life and any recent contact with the NHS. You will be shown some examples of seizure stories and asked to choose what you would prefer

from possible types of care from the ambulance service.

You can take part if you have an epilepsy diagnosis or are a family member or a friend to someone who does. You have to have had contact with an ambulance service in the last 12 months. You must be able to complete a survey in English by yourself and you must live in England. If you have epilepsy, you must be at least 18 years old and be prescribed epilepsy medicines. If you are a friend or family member of someone with epilepsy, you need to be 16 years old or over.

The survey is available at [bit.ly/2ZNCprl](https://bit.ly/2ZNCprl) and will be open until the end of November 2020. Anyone taking part can be entered into a prize draw for the chance to win one of four £50 shopping vouchers.

## Potential for development of new epilepsy medicines

A new international study, led by Morten Venø, has discovered three new molecules that can be used to develop new epilepsy medicines.

For this large study, the researchers measured levels of over a billion molecules, called microRNAs, involved in gene activity in the brain, in people with epilepsy. They discovered that levels of a few of these microRNAs were always high in people with epilepsy.

The research team created medicine-like molecules to try to target these high levels of microRNAs. Three of these molecules appeared to stop seizures in temporal lobe epilepsy. Computer models showed how these molecules may have impacted on the brain cells to suppress seizures.

The research is published in the journal *Proceedings of the*



*National Academy of Sciences (PNAS) USA* in June. It involved 35 scientists from across Europe working in different fields, including neuroscience, genetics and computer science.

An “urgent and unmet need” for new medicines is acknowledged by the authors, as around a third of people with epilepsy are resistant to currently available treatments.

Study author Dr Cristina Reschke, said: “Our approach to drug discovery has led us to new types of molecules that can be targeted to prevent seizures with hopefully fewer side-effects.”

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## Long term VNS effectiveness

A new study from the journal *Epilepsy & Behavior* suggests that vagus nerve stimulation (VNS) is effective and safe for children in the long term.

Study authors Dilek Yalnizoglu and colleagues investigated 58 children in Turkey with hard-to-treat epilepsy who had VNS put in between 1997 and 2018. The average follow-up was around six years, although it ranged from three months to 20 years.

The researchers found that just under half of

the children had their seizures reduce by at least half, with three children becoming seizure free. The effectiveness of the VNS wasn't affected by the cause of the epilepsy, how long they had had epilepsy or what age they had the VNS put in. However, it worked better in the children who had focal seizures. According to the researchers, more than half of the children also had a better quality of life.

The most common side-effects were voice changes and a pins-and-needles sensation.

## Sheffield teens help man having a seizure

Three teenage boys from Sheffield, Joshua Williamson, Geraint Jeffries and Kiarn Rose, have been praised for coming to the aid of a man having a seizure.

The teenagers, who were out on their bikes, rushed over to the man who started having a seizure by the side of the road.

One of the boys, Joshua, has a five-year-old brother with epilepsy, so he recognised the seizure and knew how to help. Joshua put the man

in the recovery position and the boys called an ambulance. They waited with the man until the emergency services arrived.

Kay Williamson, Joshua's mum, said: “Many teenagers would have been scared and not known what to do. They knew what to do and stayed with the man. I'm so proud of them.”

A Facebook post praising the boys for their actions has gone viral.

## Call for urgent restart of epilepsy services

Epilepsy services need to resume as quickly and safely as possible, say leading epilepsy charities and health professionals. In a statement released in July, they have urged decision makers and clinicians to prioritise neurology, including epilepsy, as lockdown eases and services resume.

The coalition of organisations and neurologists includes the International League Against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE) and the Epilepsy Nurses Association (ESNA). Epilepsy Action, SUDEP Action, Young Epilepsy and Epilepsy Scotland are also among the organisations involved, alongside a number of specialists, including consultant neurologist Dr Rhys Thomas and professor of neurology Prof Tony Marson.

The coalition say that health leaders need to act quickly to

minimise additional risks for people with epilepsy, reverse reported falls in hospital attendance and prevent premature epilepsy-related deaths. They say at a minimum, people with suspected first seizures must have access to a consultation with an epilepsy expert. People should also be able to contact neurology services and receive a meaningful response.

Epilepsy Action chief executive Philip Lee said epilepsy services had understandably taken a back seat to maintain critical NHS capacity during the pandemic outbreak. However, he warned that current service provision could not be the 'new normal' for people with epilepsy.

Mr Lee said: "Health services were rightly reorganised at pace to maintain critical NHS capacity during the

COVID-19 pandemic. The same pace and leadership initially shown, and subsequently demonstrated in restarting cancer and fertility services, must now be applied to restarting neurology services.

"We need to act quickly to minimise additional risks people with epilepsy continue to face. These include reduced access to services, telephone-only support, cancelled appointments and diagnosis delays."

The NHS response to the pandemic has had a negative impact on diagnosis in neurology services, the coalition warns. People with possible seizures have not been assessed with speed or had access to all the usual tests. There is a risk if people remain untreated. Every week, 21 epilepsy-related deaths are recorded in the UK, nearly

half of which are thought to be avoidable.

Telephone consultations have replaced face-to-face appointments in many cases, but Mr Lee stresses that assessing the effects of a neurological condition can be very challenging over the phone. "It is not appropriate for this to be adopted as the 'norm' in the longer term unless there is solid medical evidence to support this and no likelihood of worsening health inequalities."

Epilepsy Action, Dr Thomas and Prof Marson have developed the statement with the support of the other members of the coalition. The document sets out expected service provision during the COVID-19 pandemic and it is hoped it will encourage clinicians and NHS decision makers to prioritise epilepsy services.

## Mozart's Sonata calms epileptic activity in the brain

Listening to Mozart's Sonata for Two Pianos in D could reduce seizures in people with epilepsy by up to a third. This is according to new research from Canada, published recently in the journal *Epilepsia Open*.



Study author Marjan Rafiee and her colleagues wanted to compare the effects of Mozart's sonata with that of a similar piece of music that was not rhythmic, used as a control. They included 13 people with epilepsy in their research.

Each participant spent three months listening to the first six minutes of Mozart's sonata once a day and three months listening to the control music. Using three sets of statistical analyses, the researchers found that listening to Mozart's music once a day reduced seizures in people with epilepsy by around 35%.

The study authors acknowledged that their study

was quite small, using only 13 participants. However, they said they hope it paves the way for further research looking at the mechanism behind this effect.

This study is available online at [bit.ly/37UjBtT](https://bit.ly/37UjBtT).

Another recent study from Thailand has looked at the effect of Mozart's sonata on patterns of brainwave activity seen in children with epilepsy between seizures. The research, by Tanitnun Paprad and colleagues, included 32 children from birth to 18 years old.

Some of the children were in the treatment group and listened to eight minutes of

Mozart's sonata while having an EEG recording. The other children were in the control group who had an EEG recording in a quiet room.

The results of this study are published in the journal *Epilepsy & Behavior*. They showed that brainwave activity between seizures decreased in about two-thirds (67%) of the children in the treatment group. This is compared to two-fifths (42%) of the control group. The study authors say the study should be replicated with more participants but that it showed the "considerable potential of music" in treating children with epilepsy.

You can find out more about this study at [bit.ly/2Z1mjtE](https://bit.ly/2Z1mjtE).

## Discussions around valproate risks in pregnancy still not being had

More than two-fifths (44%) of women with epilepsy say they have not discussed the risks of taking valproate during pregnancy with their healthcare professional in the last 12 months. This is according to a new survey of 751 women published by three epilepsy charities: Epilepsy Action, Epilepsy Society and Young Epilepsy.

The survey also found that only two-fifths (41%) of respondents taking valproate said they had signed an Annual Risk Acknowledgement Form. The Medicines and Healthcare products Regulatory Agency (MHRA) says this should be completed every time a woman's treatment is reviewed by a specialist, at least annually.

Valproate medicines include the epilepsy medicines sodium valproate and valproic acid. They are very effective in controlling seizures for some

people. However, it is now widely acknowledged that valproate can cause problems to an unborn baby if taken during pregnancy.

Risks include birth defects in around one in 10 babies born to women taking valproate, and developmental problems in around two-fifths of babies, according to the MHRA.

In 2018, the MHRA changed its regulations, advising healthcare professionals that valproate medicine should not be given to women with epilepsy who can become pregnant, unless it is the only medicine that works for them. If it is, a Pregnancy Prevention Programme (PPP) must be put in place, where women are made aware of the risks and how to avoid becoming pregnant while on the medicine.

Discussions about these risks with healthcare professionals

are key in helping women make informed choices about their health and that of any children they may have.

The survey showed that among women who had not received any PPP information, knowledge of the risks around valproate was much lower. One-third (34%) of these women were not aware that valproate can cause birth defects, compared to one-tenth (11%) of respondents overall. Also, over two-fifths (43%) of these women were not aware of the risks of learning and developmental problems, compared with just under one-fifth (18%) overall.

The charities behind the survey are pushing for more resources and encouragement for healthcare professionals – epilepsy specialists and others, such as GPs – to have these conversations.



Simon Wigglesworth, deputy chief executive of Epilepsy Action, said: "It's simply unacceptable that some women with epilepsy are still in the dark about the dangers of taking valproate in pregnancy.

"With a wealth of resources now available for health professionals to facilitate conversations, there is just no excuse for not explaining the risks to every woman taking valproate.

"Change needs to happen now to prevent babies being needlessly harmed and the devastating, life-long impact this has on families."

For more information on valproate and pregnancy, visit [epilepsy.org.uk/valproatepregnancy](http://epilepsy.org.uk/valproatepregnancy)

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## Six-year-old praised for saving mum

Six-year-old Kelsie Cassidy has been praised for helping her mum who had a seizure in their home in Blackburn.

Kelsie's mum Karen has epilepsy and started having a seizure one morning. The youngster remained calm and tried to call for help.

Her dad Tim was on his way to work, so she couldn't get through to him. But she did get hold of her uncle. She stayed with her mum, holding her

hand and comforting her, until help arrived.

Tim told the Lancashire Telegraph that he and his wife "couldn't be prouder of the way she handled the whole situation." This was the first time Kelsie had had to deal with a seizure, he added.

Kelsie's Primary School, St Antony's RC Primary School, gave her a special achievement award for her brave actions.

## Link between gout and epilepsy

A new Taiwanese study published in the journal *Medicine* has found that people who have gout, have a higher risk of developing epilepsy. Gout is a condition causing sudden, severe joint pain.

Dr Chen and colleagues decided to study the link between gout and epilepsy as inflammation can be associated with both conditions. They studied 104,238 people aged over 20 years old, who were diagnosed with gout between 2000 and 2011. Compared with people without gout, who were matched for

factors like age and sex, those with gout had a higher risk of developing epilepsy.

The study authors propose that either the inflammation or the pain from gout could be the reason for this link with epilepsy. However, they say more research is needed.







Geoff with a duplicate bridge cup he won

# Surgery successes

**After featuring Simon’s surgery experiences in the last issue, many of you got in touch to tell your positive surgery stories. Geoff and Sammy share their experiences**

## **Fifty years seizure free**

Geoff Foster wasn’t a surgery candidate until a sleep EEG showed up a slight scar on his right temporal lobe. His surgeon said it was probably a result of lack of oxygen during Geoff’s birth, as he’d had to be delivered by forceps. The surgeon told Geoff that having surgery to cut off the small piece of the brain with the scar should stop his seizures – words most of us would long to hear.

Geoff was born in Cheltenham in 1949. Despite his birth being traced back as the likely cause for his epilepsy, Geoff’s seizures didn’t start then.

Growing up, Geoff was an A grade student at school. He went off to Nottingham University to study Mathematics and Chemistry which he planned to follow up with training to become a secondary school teacher. But

it was during his first term at university that Geoff had his first seizure.

“I had an absence seizure. At the time, I was playing table football with a group of friends, so afterwards they gave me a full description of what happened. It was scary to hear about it. The epilepsy was probably triggered by stress and not enough sleep at that time. The seizures gradually became regular and continued through my three years at university, when I averaged three absence seizures each week with an occasional tonic-clonic seizure.

“I was expected to get an honours degree but, struggling with the epilepsy and the side-effects of the medicines, I only managed an ordinary degree. Following that, I stayed on to study for a postgraduate teaching qualification. But after only one term, the epilepsy got worse, so I withdrew.

“I went back to live at home with my mother and grandmother and tried to find work, but, with epilepsy, no employer wanted to know. After six months on the dole, it was summer, and my summer holiday employer was expecting me back from university. This was a job in a sales office at a factory. When they heard about my epilepsy, they kindly took me on permanently and I stayed there for 20 years! They accommodated me by changing my role so I didn’t have to spend time on the shop floor, which could have been dangerous, but spent all my time in the office. I feel lucky that they kept me on.”

I had the operation in 1973. I was nervous before, but I just wanted to get rid of my seizures

While Geoff managed to land on his feet with work, his epilepsy caused many struggles throughout his life. He found his diagnosis scary and was frustrated to have to surrender his driving licence. Over the years, he also battled with medicine side-effects.

“I took various medicines – some helped a little. Side-effects varied between depression, double vision, tiredness, swollen gums and reduced libido.”



Geoff ended up losing some friends because he couldn't go out as much as he wanted. However, having moved in with his mother and grandmother, he grew closer to his family. During the more challenging times, he also found comfort in his faith. And when an opportunity arrived for Geoff to have a chance at seizure freedom, he took it with both hands.

Ahead of his surgery, Geoff was made aware that the surgery to stop his seizures might cause him a slight blind spot and some memory problems. This proved to be correct.

"I don't remember much, but the surgeon exuded confidence. After several tests to confirm the exact position of the scar and to see that I wouldn't lose too much memory, I eventually had the operation in 1973. I was nervous before the operation, but the hospital staff were very good. And I just wanted to get rid of my seizures.

"After the operation, I was sent home after only a few days. After a while, I went back to work – mornings only until I felt less tired.

"The main thing was, I had one seizure about a month after the operation but since then I have been seizure free. It's been nearly 50 years!"

For Geoff, the lack of seizures was not all. Other lifestyle improvements followed for him in the wake of his surgery. "I was able to get my driving licence back, but I get very tired if I drive a lot. I was able to hold down several office jobs and have a decent



Geoff has been seizure free for 50 years after his surgery

social life too. I got married at the age of 52. Late for a first marriage, I know. But that's what happens after epilepsy in your youth reduces your confidence and your ability to socialise, and your medicines cause depression and reduced sexual interest!"

Geoff has also been able to be an activist for the Green Party and enjoy activities like league table tennis and duplicate bridge.

"I love playing duplicate bridge," he said. "I've qualified as a club director, so I can run sessions. I would be a better player if I had a better memory.

"My memory occasionally lets me down, but I have learned to live with it by writing a lot of things down. Living with slight memory loss is much better than living with seizures. I also have a small blind spot causing me to bang my head occasionally, but I can live with this. I also get tired easily and need plenty of sleep."

Geoff's message to others worrying about undergoing epilepsy surgery is simple. "Don't be frightened – the doctors know what they're doing, and they've done it a lot before."

#### Awake during surgery

"The date was set for my surgery," Sammy Rose said. "Thursday 16 January 2020. I was to have an awake craniotomy (where a section of skull is temporarily removed to get to the brain) to remove the focal dysplasia on my right temporal lobe."

Sammy, 23, is a student from Radlett in Hertfordshire. He currently lives at home with his younger sister Aimee, 21, his parents, Leslie and Andrew, and his cockapoo Buddy.

Sammy's epilepsy started when he was about five years old. He was doing arts and crafts with his mum on a Saturday afternoon and he suddenly froze on the spot. He couldn't talk for about 20 seconds and one side of his face appeared to droop.

Initial tests done by the neurologist came back as normal. Sammy's mum Leslie said: "Sammy was only five years old and it was very upsetting to see him go through these original tests. The neurologist we saw made me feel like I was completely

neurotic and that there was nothing really wrong with Sammy."

But during another set of tests, Sammy had a seizure and the health professional there at the time told the family that what he saw was definitely epilepsy.

Sammy eventually started on epilepsy medicines. His first was carbamazepine, but it seemed to worsen his seizures. He would sometimes fall over, but he never lost consciousness. This was a difficult time for Leslie, as she was afraid to let Sammy go to nursery and school where she couldn't protect him. "It was made even harder, because the school was not very obliging or particularly supportive," Leslie said. "I remember feeling very grateful that the school was actually allowing Sammy to attend while his epilepsy was not totally controlled. I am sure I would react very differently today!"

Sammy went through a spell of swapping and changing the medicines he was on, to try to find one that worked, and experiencing a number of different side-effects. He finally started taking lamotrigine and reached a dose that seemed to work for him. Sammy carried on as normal, doing well in his GCSEs and A Levels and even completing the Silver Duke of Edinburgh award.

At 18, Sammy transitioned out of paediatric services and was referred to the National Hospital for Neurology and Surgery in Queens Square, London. He had some new tests done, including a high-resolution MRI, which, for the first time, highlighted a focal cortical dysplasia



Sammy one day after his brain surgery



Sammy's scar one week after his operation

(FCD). This is a small damaged area of the brain causing Sammy's seizures.

"By this stage, my epilepsy affected me during sleep or upon waking," Sammy said. "But I never had seizures during the day, so I was able to drive."

Throughout all this time, Sammy took epilepsy in his stride. He didn't let it stop him taking a gap year, heading off to university and enjoying pastimes like watching football, playing golf and gaming. His new neurologist was keen to try some more epilepsy medicines to try to control Sammy's sleep seizures, but they didn't work. And then things got worse.

Sammy's sleep seizures were leaving him exhausted. His epilepsy started to make him depressed and the sleep deprivation started to affect his studies. One morning in January 2019, Sammy had his first tonic-clonic seizure. Sammy lost his driving licence, which was a blow to his independence. A few months later, he had another tonic-clonic seizure.

Sammy had spoken to his neurologist about surgery before, and had undergone some initial tests to see if he was a suitable candidate. But the tonic-clonic seizures really made him seriously consider this option, as he worried they were a sign his epilepsy was getting worse. In April, he met with a neurosurgeon and soon after took the decision to have brain surgery.

"I was made aware that all brain operations carry a risk to life as there

is a risk of bleeding out, infection and stroke," Sammy said. "There could also be problems with vision, movement and sensation. I was told the risk of a permanent problem as a result of one of these complications was no more than 2%. I know my parents were still hesitant as, of course, they were worried about the risks involved. But for me, if I was to have the chance for some sort of life without epilepsy, I had to try."

Finally, the day arrived, Thursday 16 January. Sammy was settled into the ward the day before, and spent the evening going for a meal and playing a game with his family.

"On the morning of my operation my family arrived bright and early. My surgeon, Mr McEvoy, and the anaesthetist came to see me first thing. Mr McEvoy explained that I would be put to sleep and then would be awoken midway through the operation. This was to make sure I didn't lose function in my left side during the operation.

Being woken up during an operation must have been strange, but **it's just a hazy memory for Sammy**

"He assured me that if I could not cope with being awake, I could return to have my surgery another day, as it was important that I was calm and relaxed. But, surprisingly, I was.

"My parents walked down to the theatre with me and hugged and kissed me as I went to sleep. I remember my dad saying: "When you wake up, Tottenham will be a great team." The anaesthetist replied that I would not be asleep for that long!"

Sammy's surgery was long. It was 11 hours after sending him off that his family were told they could visit him in recovery.

Leslie said: "I remember when the nurses came and told us that we could go and visit Sammy. It really was the longest day

and the stress was something we had never experienced. Although we were excited to see Sammy, we were also nervous as we weren't sure what we would see when we were allowed in the room. But as soon as we saw Sammy he smiled and waved. I remember feeling relieved that, considering his ordeal, he looked amazing."

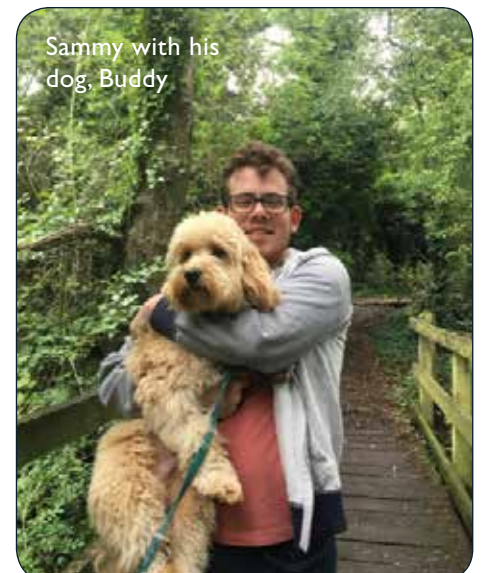
Being woken up during an operation must have been a strange feeling for Sammy. But it's just a hazy memory for him. "I can't really remember that much about it, except that I could hear the team talking during the operation and knew there was someone reassuring by my side throughout."

Sammy's recovery went well. Things were tough to begin with, and he had to work through the initial weakness in his left side and have intensive rehabilitation. But a few weeks later, he was home.

And the million-dollar question – he has been seizure free ever since.

"Of course, it's still early days," Sammy said, "and I'm still taking my medicines. We will review things after 12 months and I'm not in a rush to adjust things. But I can't describe what a change it has made knowing that I'm going to get a full night's sleep and not wake up exhausted.

"I don't think surgery should be considered as a 'last resort'. If your medical professionals believe you are a surgical candidate, have faith and explore this as a positive option. Keep an open mind."



Sammy with his dog, Buddy

## The Epilepsy Space



**Learn · Share · Grow**

### The mobile friendly website is a helping hand for 16-25 year olds to live their best life with epilepsy

The Epilepsy Space will help young people to:

- Manage their epilepsy
- Feel less alone
- Increase their confidence
- Get the support they need

There's lots of epilepsy facts, tips and stories from young people sharing their experience.

The content is short and interactive. It's not all reading, there's video and young people can share their own quotes, stories and videos too.

It's been created with young people and reviewed by epilepsy nurses.

Take a look at:  
**[epilepsyspace.org.uk](http://epilepsyspace.org.uk)**

Get in touch:  
**[learning@epilepsy.org.uk](mailto:learning@epilepsy.org.uk)**



# Fundraising with a twist!

Lockdown has been hard on charities, but Epilepsy Action supporters are getting creative to carry on raising vital funds



Antony Cunningham-Smith  
ran 20 miles in his garden

Fundraising events have been hit hard this year due to the coronavirus outbreak. With mass-participation events being cancelled or postponed across the UK, many supporters have been unable to take part in the fundraising activities they originally had planned.

Despite this, many Epilepsy Action supporters are getting creative during their time at home. From sponsored head shaves, online tea breaks and celebrating birthdays on Facebook, to virtual climbs to Everest Base Camp, the range of ways people are fundraising is amazing! Every penny helps fund vital services for people with epilepsy.

Due to the coronavirus outbreak, Epilepsy Action stands to lose up to 40% of the income the charity was expecting from fundraising in 2020. Epilepsy Action is an irreplaceable source of help and support for so many people trying to beat the

challenges of life with epilepsy. But, without you, we cannot be there for everyone who needs us in the future.

Here are a few fundraising stories from the past few difficult months. Thank you to everyone who has taken part. And if you haven't yet, it's never too late – read on for some fantastic inspiration!

Antony Cunningham-Smith had his first seizure at the age of 30, and as a result of his epilepsy, lost his job as a nurse after 22 years. He was able to gain another job as a sales assistant at Gap, however when he

was at risk of losing his job again due to his epilepsy, he contacted Epilepsy Action.

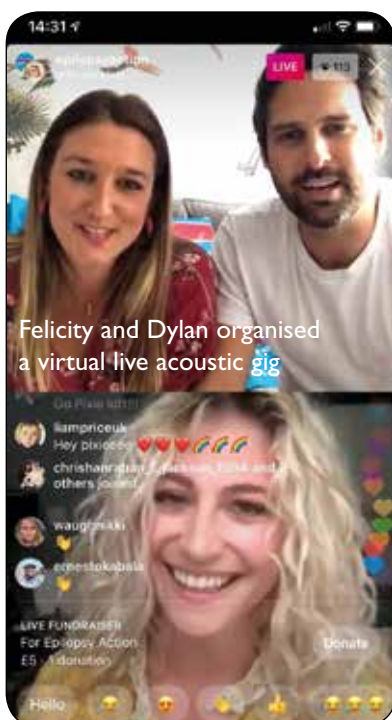
Antony said: "Epilepsy Action were amazing, providing me with advice, an ear to talk to and resources to teach my fellow employees about epilepsy and seizures. As a result, I was able to keep my job and educate others how to care for someone suffering a seizure."

Due to the coronavirus outbreak, Antony was furloughed and chose to use the time to get fit. He decided to set himself a challenge while continuing to help others affected by the condition. "People more than ever are having to turn to charity organisations like Epilepsy Action for help" he explained. "As I was in lockdown, I had to get creative about how to raise money around the house, hence the virtual challenge. My first idea was to run around the garden just like I had seen on breakfast telly. So, I ran in a circle round and round which I did for over five hours, running 20 miles."

Antony's challenge didn't stop there! He completed a five-hour stair-a-thon, climbing up and down the stairs in his house 529 times. With the support of his family, he organised a four-hour penalty shootout challenge with his daughter and, as restrictions started to ease, recently completed seven half marathons in seven days. "The challenge, although difficult, has given me a great sense of achievement and pride! And despite the sweat and blood (literally in the case of the stair challenge), it has been so rewarding. And a successful worthy effort too, raising £775."

Supporters Felicity Rankin and fiancé Dylan Gower hosted a live international acoustic gig to mark the end of National Epilepsy Week in May, in memory of Felicity's sister, Carla. Several outstanding musicians from the UK and Australia joined the event live on Instagram, including Pixie Lott and the incredible VC Pines. Over £1,700 was raised to support people living with epilepsy.

Felicity said: "Music was Carla's absolute life. She was an incredible pianist and trumpet player and could entertain any



Felicity and Dylan organised a virtual live acoustic gig

party with a huge medley of absolute classics from memory. We know that she would have been playing music endlessly in lockdown! We continue to have the support of her closest friends but also of people who have only known of the cause afterwards, which means she is still making a fabulous impression on our world.”

Glynis Wiles was due to take part in the 2020 London Marathon and chose to support Epilepsy Action as her son, Alex, was diagnosed with epilepsy when he was five years old.

Glynis said: “We still struggle with Alex’s diagnosis. But we help Alex to understand that, while it is a small part of who he is, it does not define who he is. The last six years have been a difficult and very frustrating time for us all. We watched for triggers, dealt with seizures and strived to find the right medication to control it. Luckily for us all, he has been seizure free for just over one year now, for which we are all extremely grateful. He is such a brave boy and takes it all in his stride - he always has. I am so proud to be his mummy!”

Despite the marathon being postponed until later in the year, Glynis was determined to do something to mark the event, after weeks of dedicated training. She decided, with her husband and Alex, to take part in the 2.6 challenge together, a nationwide virtual challenge on Sunday 26 April, the original date of this year’s London Marathon. As a family, they came up with 26 different challenges to complete in a day!

“Our list of 26 challenges began with a 2.6 mile run together and then another 25 throughout the day including 26-star jumps, 26 squats and holding a plank for 26 seconds. We also had to think of 26 famous people, put on as many T-shirts in 26 seconds as we could and see how many chocolate buttons we could fit into our mouths in 26 seconds! The hardest challenges were running up and down the stairs 26 times (quads were on fire!) and bouncing on a pogo stick as my son loves doing that. We laughed so much doing that one.

“It was all good fun and kept us all entertained for a whole day, while raising £570 in a week for Epilepsy Action. The children and parents of my school have continued to be very supportive and some even took part on the day with their own



Glynis and her family took part in the 2.6 challenge



2.6 challenge and made donations (some children donating their own pocket money) which I am very grateful for.”

Daxa Patel has supported the charity for several years and was set to take part in Epilepsy Action's flagship event, the Bradford 10k, for the fourth year.

Unfortunately, due to the pandemic and social distancing measures in place for the foreseeable future, Epilepsy Action decided to make the Bradford 10k virtual. While it means everyone can't gather together in Bradford in September, it is a great way for participants to still be able to take part.

Daxa explained that running has been very important for her during the pandemic. “I have been working from home and I find running helps with my emotional and physical wellbeing. So, when I heard the event organisers had taken a decision to allow participants to do this as a virtual run, I was happy.”

As a Healthcare Solicitor, Daxa acts for people, including children with brain trauma and epilepsy, and she explains about the difficulties many families face living with epilepsy,

“Often families receive little support except for help from good charities like Epilepsy Action who really understand what it is like to live with this condition. Living with seizures and not knowing when this may happen – and where – can be frightening. Charities like Epilepsy Action equip families with the knowledge and tools they need to manage life better.”

Daxa completed the Epilepsy Action Virtual Bradford 10k recently in a good time. “It was nice to run for such a good cause and getting my first medal of the year was a bonus too.”

If you are interested in taking part in the Epilepsy Action Virtual Bradford 10k, there is still time to enter. For more information, visit [epilepsy.org.uk/bradford](https://epilepsy.org.uk/bradford)

Thank you to all our supporters who have donated and organised fantastic events. It's fantastic supporters like you who fund the vital services relied on by so many people with epilepsy. Thanks to you, people can still get the help they need through work like the Epilepsy Action Helpline and website and virtual support groups.

To set your own fundraiser or make a donation to our emergency appeal contact the fundraising team on [funding@epilepsy.org.uk](mailto:funding@epilepsy.org.uk) or see [epilepsy.org.uk/fundraise](https://epilepsy.org.uk/fundraise)



Daxa Patel took part in the Epilepsy Action Virtual Bradford 10k





# COVID-19 update

We speak to Prof Gus Baker to bring you an update on epilepsy and Covid-19

The coronavirus pandemic has really put us all to the test. Without warning or preparation, we've all had to adapt to a completely new and scary world. With medical efforts being concentrated on managing COVID-19 patients and restrictions leaving us home bound, it's understandable that many people have worried about the effect of COVID-19 on their epilepsy.

This is a fast-moving landscape, so rules and restrictions continue to change at a rapid pace depending on where in the UK people live and how the management of the pandemic is progressing. This makes it almost impossible to speak specifically, but we can look at a few worries people have shared more generally.

In an update for the International Bureau for Epilepsy (IBE), professor of clinical neuropsychology and vice president of Epilepsy Action Prof Gus Baker and professor of clinical neuropsychology Prof Steven Kemp looked at COVID-19 and epilepsy. Consulting with Dr Sallie Baxendale and Prof Martin Bunnage, they identified some common concerns people with epilepsy have had. They include questions around whether epilepsy makes them more vulnerable to COVID-19, whether the pandemic would affect access to specialists and treatments, and how their seizures might be affected.

## Vulnerability

There is no evidence to suggest that epilepsy itself makes people more likely to catch coronavirus or have more severe symptoms. However, some people may have other conditions alongside their epilepsy which could put them at an increased risk.

Epilepsy Action explains that some people are more likely to have a seizure when they are unwell and especially if they have a high temperature. The organisation recommends that the best way to protect yourself from

having a seizure is to take your epilepsy medicines as usual. If you do get a high temperature, the NHS recommends taking paracetamol or ibuprofen to bring the fever down. They are safe for most people with epilepsy, but you can check with your pharmacist that they won't interact with your epilepsy medicines.

## Services

The way epilepsy services are provided has changed over the last few months as a result of the pandemic. Prof Baker explains that the situation with epilepsy services now and in the coming months is far from clear. "I think it's fair to say that usual epilepsy services have not been able to continue in light of COVID-19, particularly in respect of face-to-face clinics in some cases. A lot of patients will now be expected to consult their epilepsy experts by video call or email.

"While this is helpful, it will not be satisfactory for some people. This is particularly so for those who are not used to video calls or who want the assurance of seeing the same neurologist or epilepsy specialist nurse about their epilepsy. It's inevitable that COVID-19 would have an effect on service delivery just because there are changes in the way services are provided in the NHS and in the community."

Epilepsy Action has recently called for epilepsy services to resume urgently and safely, now that lockdown has begun to ease. The organisation believes this is needed to tackle reduced access to services, telephone-only support, cancelled appointments and diagnosis delays.

Service provision will vary from area to area, and may be affected by local lockdowns, so it is likely the situation is different for everyone. But, for many, there may be delays in accessing certain treatments, like surgery.



Prof Baker says that looking ahead, it's impossible to predict where we will be in the next few months. "There is an incredible level of uncertainty about what the nature of services will look like now and in six months' time, and how services will be provided. It's difficult to know whether services will ever resume as they were before."

"But there is no doubt that there will be an effort to maximise the way that service delivery takes place. We have to be confident that our NHS colleagues are doing the best they can for people with epilepsy."

### Mental health

Prof Baker says: "Obviously, it's demanding enough to have epilepsy in terms of the impact it has on people's lives. Then, to add on top of that further restrictions on social interactions, employment, and many other aspects of our lives, is an extra burden on top of epilepsy. For some people, this will have significant

psychological consequences in terms of their coping abilities, general mood, behaviour and ability to socialise."

Prof Baker explains that while some people have found their seizures reducing during lockdown, for others, worries and anxiety around COVID-19 may be making seizures worse. This is a reason to get in touch with your doctors and seek advice, he says. Additionally, stress and worry around COVID-19 could be worsening existing mental health problems in some people with epilepsy, such as depression, anxiety, irritability, anger and social isolation.

Prof Baker and Prof Kemp suggest a few ways in which to minimise the issues brought on by COVID-19 and spending more time at home. Keeping up with a regular routine can help with adverse mental health impacts. They recommend staying mentally and physically active where possible. Be mindful of things that trigger worries and try to limit these. Rely on reputable news sources for information



Staying connected, even while maintaining social distance, is important

about COVID-19. Finally, where possible, try to stay connected to others.

There is more information about COVID-19 and epilepsy on the Epilepsy Action website at [epilepsy.org.uk/coronavirus](http://epilepsy.org.uk/coronavirus) as well as more tips for coping with lockdown at [epilepsy.org.uk/lockdowntips](http://epilepsy.org.uk/lockdowntips)

## Reach out this Christmas

It may feel early to be thinking about Christmas, but it's coming round soon! To help you get organised early, take a look at our Christmas collection, included with this issue of *Epilepsy Today*. This is just a small selection of our products.

This year there are some new products in this catalogue and more online at [epilepsy.org.uk/christmasshop](http://epilepsy.org.uk/christmasshop).

You can buy some brilliant stocking fillers for under £5. Some of these will keep the young ones busy and

entertained, while others will help spread awareness about epilepsy. Have a browse and enjoy that festive feeling early!

With restrictions slowly starting to ease we are all looking forward to seeing more of our family and friends over the coming months. Although our Christmas festivities may be different this year, we can all enjoy the experience of spreading a little Christmas joy with a hand written Christmas card.

You will also be raising vital funds and awareness of epilepsy, and making a difference to thousands of lives in 2020 and beyond.



# Unsung heroes

Derrick Young, Jo Crabtree and Joe Bagshaw share their experiences of being carers to people with epilepsy. We look at the ups and downs of this generous but challenging work

In June, many of us celebrated National Carers Week. This is a time to pay tribute to those who give their time and energy to support others who need their help. The contribution that carers make to the lives of individuals, and to whole communities, is vast. And yet, so often it can go under the radar.

Caring for another person is a huge act of kindness, love and selflessness, and when it's family, it feels like second nature rather than a 'role'. But, whatever we call it, it can come at a significant personal cost financially, emotionally and physically. People often take on responsibilities, make hard decisions and fill up their to-do lists with extra tasks. Meanwhile, they give up their free time, sometimes cut down their work hours (and their income) and put their energy into supporting another person. Even when being a carer is a person's job, it takes a lot of compassion and understanding to do.

Unfortunately, many of these everyday heroes can often go unrecognised and unsupported.

Derrick Young lives in London with his wife, who has complex epilepsy, physical injuries and post-traumatic stress disorder (PTSD). Derrick cares for his wife, supporting her in a number of different ways.

It's very challenging knowing if you are doing the right thing and **it's hard fearing you may be going down a wrong path**

From the moment Derrick wakes up, he is thinking about his wife. "I have to feel my way through the mood and the health of my wife. Having done this, I make up ideas for the day and suggest what we need or will choose to do. I have been encouraging her to make a positive input into her daily activity to

help her severe depression. She became depressed after losing her job because of her epilepsy."

As well as supporting his wife through her mental illness, which can be a heavy load for a loved one, Derrick also takes care of the practical side of things. "I help her with her clothes, encourage her to go places without me. I deal with all the paperwork and remind her of appointments and where she's going. I make sure her seizure record is kept up to date as she has no memory of her epilepsy or seizures, and when and where they take place."

Derrick has to take the lead during his wife's neurologist appointments, speaking to the doctors. He also helps to fill in the gaps in his wife's memory after she's had a seizure.

While Derrick explained that he knew about most of his wife's health conditions from the beginning, the journey with her healthcare providers has been tough. Over many years of taking epilepsy medicines, Derrick's wife's seizures are



still not controlled. While she still takes Keppra, Derrick has started considering different types of treatment and wondering whether his wife may also be experiencing dissociative seizures.

Uncontrolled epilepsy in a loved one is hard at the best of times, but Derrick feels an extra weight from this. Choices around his wife's treatment have divided opinions and increased tensions in the family. Derrick explained that, as the person looking after his wife, he feels a responsibility and blame for her seizures not being controlled.

"It's very challenging knowing if you are doing the right thing," Derrick said. "And it's hard fearing that a lack of knowledge means you may be going down the wrong path. What damage could you be doing without knowing?"

"The worst is being ignored by doctors when you ask questions that they regard as nonsense. Eventually, it feels like they stop taking notice of you at all."

#### Nowhere to go

The overwhelming sense of responsibility of helping another person manage their epilepsy can be extremely difficult to bear. And with the lack of support out there, people's mental health can suffer, as Jo Crabtree found out.

Jo cares for her daughter Emily who has epilepsy and experiences tonic-clonic seizures. Emily, from Lancashire, was diagnosed when she was 17 years old. She was in her first year of A Levels and her epilepsy took its toll on her memory and grades.

Emily had to cope with extreme tiredness at the beginning, caused by her seizures and increasing medicine doses.

Jo said: "Emily's dad, Nick, and I spent our time making sure she slept, ate and kept healthy. Initially we made sure one of us was with her all the time. As time passed, we realised that one of our roles was to give her the skills and confidence to become herself again."

Jo and Nick worked with staff at Emily's school to create a care plan

for her in case she has a seizure. They also initially oversaw Emily's treatment, setting reminders for her to take her lamotrigine. However, that didn't last long.

In front of Emily I was strong and tried to do everything for her to get well, but on the inside I was crumbling

"Emily is a fiercely independent young lady and soon took over the responsibility of taking her medicine herself.

"Currently, she lives in Manchester and has to control the condition herself. Obviously, this causes us concern, but she has surrounded herself with good friends who all know what to do should she have a seizure.

"One of the most challenging parts of Emily's diagnosis and the following 12 months was the lack of support we felt for us, the people who cared and worried about her 24 hours a day. She was still having seizures and it was difficult to see the positives. Emily was receiving support from her epilepsy specialist nurse, Stephanie, who she could call any time. But the family had nowhere to go. I felt desperate.

"In front of Emily I was strong and tried to do everything I needed to for her to get well and achieve her dreams. But on the inside, I was crumbling.

"Eventually, I was referred to a psychiatric nurse who helped me to balance

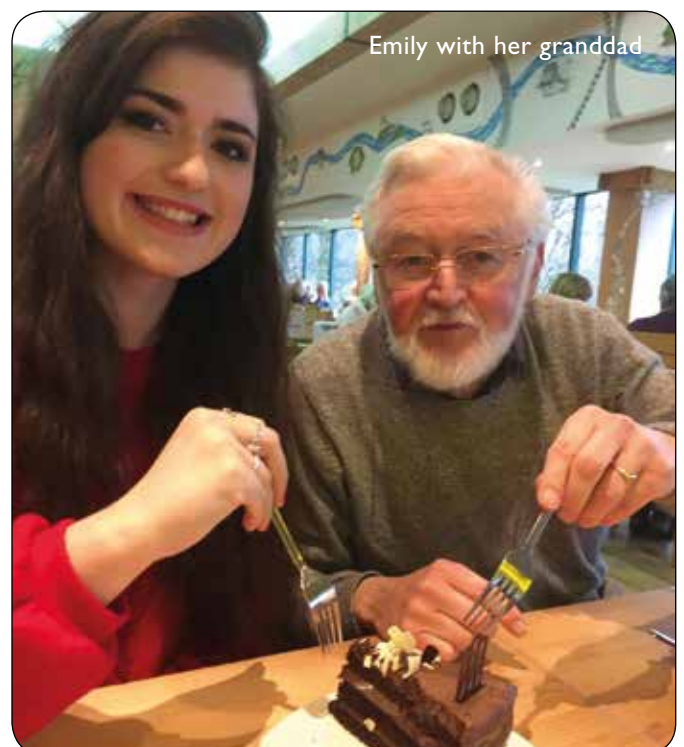
reality with what I was experiencing. I felt that, as Emily's carer, I needed to do everything myself and that no-one could do it like I could, not even her dad!"

Jo realised that the whole family needed a helping hand in order to care for Emily in the best way. Jo's doctor told her that while there isn't much the NHS can do, a charity may be able to help. She then discovered Epilepsy Action and found a great amount of solace in the helpline. "I rang the number many times and each time, the person on the other end of the phone talked me down and gave me a sense of calm," she said.

"I have good times and bad times. I am much calmer than I was at the start of Emily's journey, but can still have moments of panic. The helpline is still there for me and I still use it. Going to the support group that Emily's grandparents helped set up with the help of Epilepsy Action is an ongoing help. It's reassuring to speak to people who know exactly how I feel."

#### The best buzz

Despite the challenges, for Jo and Derrick, there is reward in seeing their loved ones thrive. Derrick is happy to know that because of his efforts, no harm is coming to his wife. Meanwhile, Emily has been



Emily with her granddad





Joe works as a carer to people with epilepsy and has epilepsy himself

able to achieve what she wanted and gain some independence in going away to university and living away from home. This is a credit to Emily and is something the whole family worked towards.

And there is reward in caring for people as a job too. Joe Bagshaw works as a carer for adults with health conditions, including epilepsy. He deals with overseeing medicines, assessing risks if seizures happen and helping people with everyday tasks, like shopping, banking or housework and bills. He also supports people with appointments, offers advice about health issues and helps them to have awareness of their condition. A lot of his work centred on supporting people to live their life as independently as possible.

“It is often an inspiration how motivated and keen the people I work with are to live independently despite the challenges they face, like learning disabilities and mental health issues.”

Seeing the people Joe cares for go through a rough patch can be difficult for him. Joe has epilepsy himself, so it hits home. But Joe says this just drives him to do his job to the best of his ability.

“Being able to support an individual to do something in life that they couldn’t do without your help and see them benefit from that is potentially the best buzz I have felt in my life. Coming to terms with my own diagnosis was a real struggle when I was growing up.

Knowing how lonely you can feel in that situation helps me empathise with the people I support. I feel a great sense of self-worth, being able to bring my own experiences and knowledge of epilepsy to the table when needed.”

The way people support others with epilepsy is as different as epilepsy itself. But for many, it’s a constant responsibility, so taking time away is important. Anything, such as going to the theatre, listening to music, going for a walk or seeing friends, can help a person recharge.

Jo found that there wasn’t enough support she and her family could access. “Charities were the only route available to take. But without carers, the government would be in difficulty, and yet we still don’t get the support we need.” Derrick also found this, and the absence of any help left him hopeless. But he also found a bit of comfort in his local Epilepsy Action coffee and chat group and he felt he could confide in the leader of the group.

Meanwhile Joe considers himself lucky, as his employers are very supportive of him and understanding about his condition.

#### Must be recognised

Being a carer can be very taxing, and Joe recommends being conscious about how you’re feeling. “Don’t allow yourself to get overwhelmed. If you find yourself struggling mentally, seek help.”

Derrick advises that having faith in your judgement is vital in order to stay

afloat, while Jo suggests connecting with others and remembering that you’re not alone.

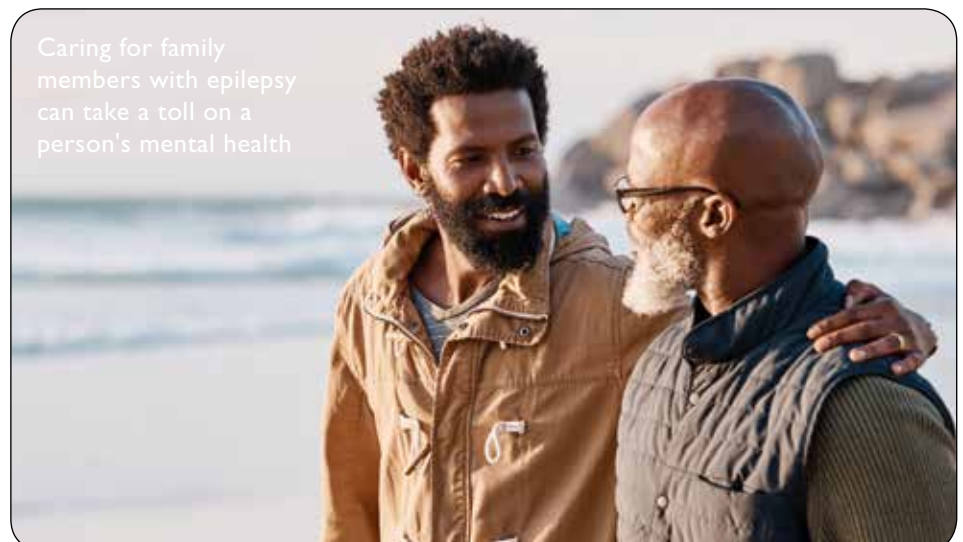
Joe, Derrick and Jo all know the ups and downs of being a carer very well. Jo and Derrick both agree that more support and recognition is needed.

“Our contribution must be recognised instead of the carer getting totally let down and having to do all this alone,” Derrick said. Jo added: “As much as you love the person you’re caring for, you need time away from the situation occasionally to recharge and feel able to carry on.”

Joe believes that the life of carers of people with epilepsy would also be improved with better understanding about the condition. “There are a lot of people out there who don’t have a clue about epilepsy past the word seizures.”

Those looking after loved ones with health conditions seem largely overlooked by society, despite the large toll it takes. For anyone looking after a loved one with epilepsy, a better public understanding of the condition would make the world of difference. It would help people understand the scope of this responsibility – much bigger than seizure management alone – and it would pinpoint ways that carers could be supported.

During National Carers Week, we pay tribute to those doing this important work. But we must continue to show our appreciation and support all year round.



Caring for family members with epilepsy can take a toll on a person's mental health

# A family dynamic

Epilepsy Action presents a new online course to help families with children who have epilepsy

Having a child with epilepsy in the family can have an impact on everyone. There's a lot of research about the challenges that parents face when managing epilepsy in their family. Some challenges include:

- Learning about epilepsy and how to help their child manage the condition
- High levels of stress and anxiety
- Feeling isolated and not knowing where to get information or support
- Managing their child's behaviour if it's affected by epilepsy

Epilepsy can affect siblings, as well as the relationships of parents with each other and other family and friends.

Epilepsy Action has developed an online course, *Your child and epilepsy*, to help parents and carers manage these challenges.

For the course, parents were interviewed to find out first-hand about their experiences and what advice they would give to others. Over 350 parents were involved in developing the course through giving their views in a survey, interviews and giving feedback on the course. It was also reviewed by epilepsy nurses, a paediatric neuropsychologist and parenting coach.

The course covers:

- Understanding epilepsy
- Supporting your child with their epilepsy



- **54%** of people surveyed about the course said "I have a better understanding of my child's epilepsy"
- **76%** said "I have a better understanding of the issues to do with epilepsy."
- **48%** said "I know more about sources of support."
- **88%** of people said that they thought the course was good or very good.

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

Laura Eden, project manager for online services at Epilepsy Action, said: "Every family's journey with epilepsy is unique. But there are also often similarities. Parents very generously gave their time to tell us about their experiences."

"We interviewed parents whose children were different ages, diagnosed at different ages, had different seizure types, other health conditions, learning difficulties and behavioural difficulties. We also interviewed some parents whose children are now grown up. We thought it would be really useful to find out, with the benefit of hindsight, what advice and tips they would give to other parents navigating the teenage years."

"Despite all those differences, one very common issue was the amount of stress and anxiety that parents experienced. So, we were really keen to give parents some tools to manage that, as well as information about epilepsy."

Lots of practical tips from parents for parents are featured throughout the course, in stories and animated videos.

Laura said: "One parent, Rachel, told us about a time that her daughter went to hospital in an ambulance, dressed in a mermaid costume, after having a seizure. Her daughter was sick on her costume. So, one of her tips was to keep a bag packed with a change of clothes ready for trips to hospital. This is a bit like having a hospital bag ready when you're having a baby."

“Some parents have said how surprised, but pleased they are that the course focuses on the whole family, not just the child with epilepsy. One of the things we’ve tried to do is help parents be in the best place they can be. Often, as a parent, it can be hard to get your own needs met. Everyone else comes first. There’s lots in the course about parents looking after themselves, so they’re in the best shape to be the best parent they can be.

“We’ve also found that an awful lot of school staff are doing Your child and epilepsy. Teachers are saying they are doing the course so they can understand how epilepsy affects the whole family and how they can support the whole family. It’s great that so many teachers are taking the time to understand how they can best support families. A learning support assistant from Hampshire, said ‘I have so much more appreciation for all families that are faced with not only one condition but the added complication of a secondary special need. I have come away from this course feeling a lot more informed and confident come September.’”

The course is flexible and is created for the different stages that families might be at with their child’s condition. This includes everything from being newly diagnosed to experiencing new challenges as a child grows up and becomes more independent. People can dip in and out of the course, or do it from start to finish, as they need to. Surveyed parents said they would be quite likely to do the course on a smartphone, so the course was built with this in mind, though it works on laptops and desktops too.

Activities called ‘Over to YOU’ form part of the course, where parents can reflect on how the information in the course applies to their family’s situation. A course notebook has been designed to go with the course and all the ‘Over to YOU’ activities. The course is free and you can sign up at [epilepsy.org.uk/yourchild](https://epilepsy.org.uk/yourchild)

## What people said

“I’ve learned to stay calm when my daughter has a seizure.”  
“I understand my child better and I can help him better.”  
“I have a better idea about the types of [seizure] monitors available and I intend to find one for my son.”  
“I’m going to look after myself by eating healthy and exercising more.”  
“I’m not going to take on too much that causes stress.”  
“I have changed the way I speak to my daughter when disciplining her.”  
“I have been more patient since I did the course.”  
“I now help family members to understand my daughter.”  
“It is an extremely useful and carefully put together course. I wish it had been available when my child was first diagnosed. I think it will help a lot of people.”



## National Doodle Day 2020

If this year has taught us anything, it’s that our homes are our little sanctuaries and safe havens. We stayed at home to save lives. And while we stayed home, we baked until the flour ran out. We gardened so much that DIY shops were deemed essential by the government. We started fixing those things around the house that we’d been getting around to for months.

In making our homes a cosy place to spend week after week, something that adds a lot of joy is a little piece of affordable artwork.

This year’s National Doodle Day is the perfect opportunity to find something to brighten up your walls! Celebrities, illustrators and artists have put their talents to good use and produced some amazing doodles that you can bid on from 25-27 September on eBay.

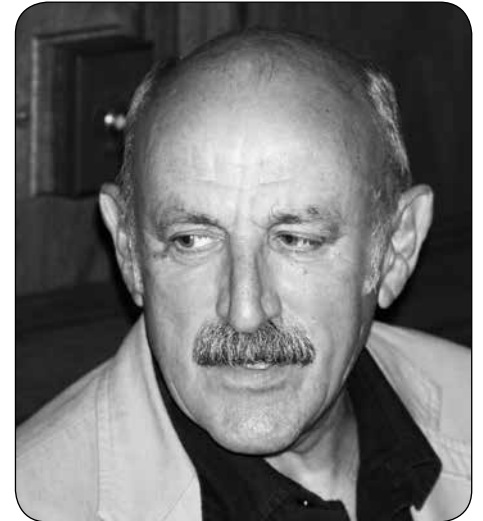
You can view this year’s doodles and pick your favourites right now on [epilepsy.org.uk/doodleday](https://epilepsy.org.uk/doodleday)

To whet your appetite, here are some of last year’s doodles!



# In memory of David Streets

Epilepsy Action pays tribute to a selfless individual whose immense contribution to the work of the charity touched the lives of many



It was with great sadness that Epilepsy Action learned of the death of David Streets on 21 June 2020 as a result of Covid-19. Our thoughts and condolences at this sad time go to David's wife Joan and to their children and grandchildren for their loss. Our sympathies also go to David's many friends in the Epilepsy Action Sheffield and District branch.

David was an engineer by trade but spent most of his working life as a lecturer at Sheffield College, serving as a member of the college's senior management team in his later years. David's interest in epilepsy started when his otherwise healthy nineteen-year-old son had his first seizure. This gave David first-hand experience of the fears and concerns of parents of children with epilepsy and a desire to find out more about the condition. This is what led him to help set up Epilepsy Action's Sheffield and District Branch in 1989. David soon took on the role of Treasurer. He later served as branch Chair and spent a long spell as Vice Chair focusing on public relations.

David also became an Accredited Volunteer and speaker early in his association with the charity, a role he continued and which he said gave him enormous personal satisfaction. As he put it himself: "I will talk about epilepsy to anyone who is prepared to listen!" Over the years David must have spoken to hundreds of individuals, businesses and organisations about epilepsy. He was passionate about raising awareness of the condition and educating people.

David was a mainstay of the Sheffield branch giving freely of his time, skills and knowledge. He was a key figure in so many activities – raising money, raising awareness, providing advice and information, organising social events, supporting and caring for others. The success of the branch and its tremendous reputation in the city and throughout South Yorkshire was due in no small part to his tireless effort and commitment.

In 2000 David received a BEA Golden Jubilee Award in recognition of his outstanding services to people with epilepsy. A year later in 2001, the Sheffield and District branch was awarded BEA Branch of the Year. In 2018, with another Sheffield branch member Maureen Taylor, David was the recipient of Epilepsy Action's special Hilary Figg Award for long and distinguished service. Despite these awards, David was always typically humble and self-effacing about his contribution.

Between 2003 and 2009 David was a member of Epilepsy Action's Council of Management. He was elected by the Council members as their Vice Chair between 2006 and 2007. In just six years as a Council member, David threw himself into the role and made a huge impact. He served on Council's Education committee from 2003 to 2009 and was the Chair of the committee from 2005 to 2008. From 2006 to 2007 he was a member of the Standing Committee and he was the Vice Chair of the Finance and Strategic Policy Committee. He served two stints on the Corporate Governance committee from

2004 to 2006 and 2007 to 2009. David also served on Council's staff appeals panel from 2004 to 2009, Chairing the panel between 2006 and 2007.

Contemporaries who served on Council with David will remember him with great affection for his calm, common-sense approach, his cheerfulness and his warmth and good humour. Perhaps it was his branch background, but David always made a point of personally welcoming all new members of Council and making them feel comfortable. He will be equally fondly remembered by members of staff of the charity for the consideration he always showed to them.

Richard Chapman, the current Chair of the Council of Management said: "I came to know David from his time on the Council of Management. He was a much valued and respected colleague who brought a wealth of experience and understanding to our discussions. A selfless individual, he was well liked by colleagues who found him to be an easy going, amiable man who was always willing to help. David's input to Council was a very small part of the immense contribution he made to the Association's work, mainly in the Sheffield area, over decades. He will be greatly missed by the many, many friends he made along the way."

Philip Lee  
Chief Executive  
Epilepsy Action



# Learning from you

Thank you for taking part in our recent members survey – here's what you told us

A big thank you to everyone who filled in our recent member survey, either online or via the paper form sent in the March edition of *Epilepsy Today*. We received 942 survey responses.

### Why we do it

As a member-led organisation, it is vital that we know what you, our members, think. We've made a commitment to send you a yearly survey where you can share your thoughts and help us continually improve membership as something that works for you.

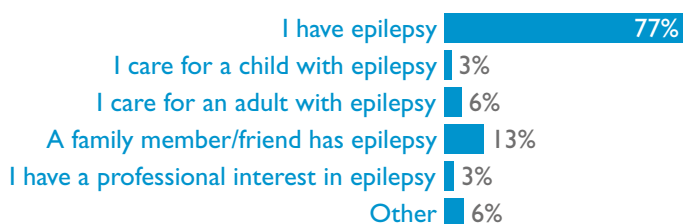
As we all know from 2020 so far, people and situations change. It is important that Epilepsy Action membership evolves alongside you, your needs and your life. By sharing your opinions and telling us about the issues affecting you right now, we can make sure that we are giving you exactly what you need. So again, thank you for participating this year.

### Our focus for 2020

In this year's survey, we were particularly keen to find out about our communications. You told us what you wanted to hear about and how you would like us to communicate with you. You also told us all about what epilepsy related issues you would like us to consider in our campaigning over the coming year.

Below you'll find some of the highlights. The full survey results will be published on our website soon. You'll be able to request a paper copy if you would prefer.

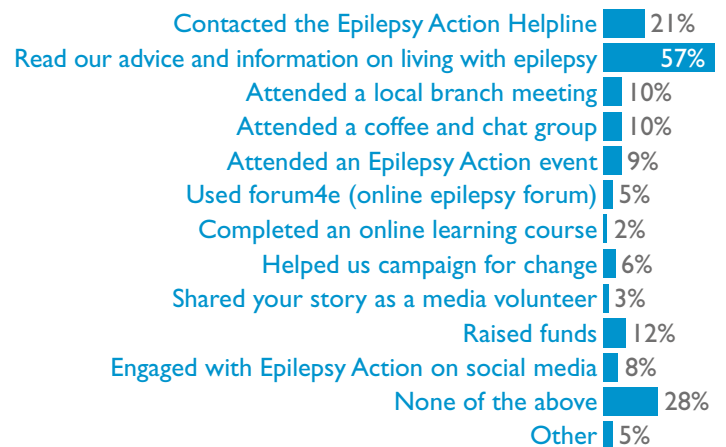
### Your relationship with epilepsy



\* People could select more than one option

The vast majority of respondents have epilepsy, however many are now seizure free. We also learned that many of you are related to someone who has died due to epilepsy. It is important that we bear this in mind in our future communications and will seek to ensure that we are always here for you, however you need us.

### Your involvement with Epilepsy Action

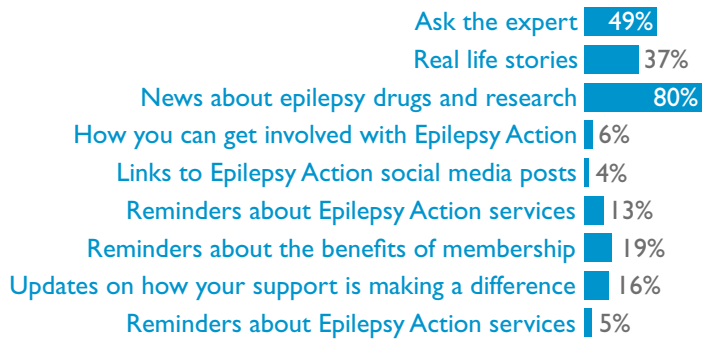


\* People could select more than one option

It is clear that advice and information are still important to members, with nearly 60% of respondents telling us that they'd used it in the last year, either online or in print. Nearly a third of respondents told us that they had not had any additional involvement with Epilepsy Action. So, we'll make sure that in future member updates we include more about how we can help you or you can help others affected by epilepsy.

The survey also told us that many of our members are also volunteers, either for Epilepsy Action or through their own work. This was heartening to find out – without volunteers we simply would not exist. Thank you for all you do for everyone affected by epilepsy.

### Regular member email updates



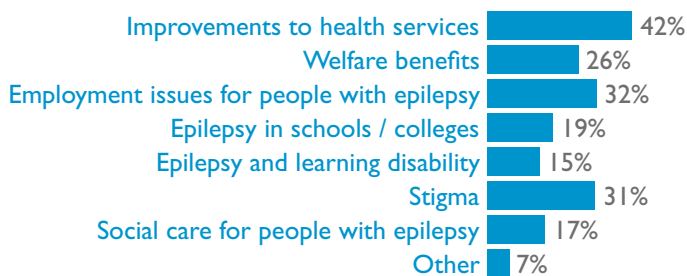
\* People could select more than one option

Many of you told us that news about epilepsy medicines and research was top of your list in your regular member email updates. We're currently working hard to make sure that you get that tailored information right to your inbox.

There was also support for the majority of our other member update ideas. This will ensure that member updates are packed with a wide variety of content. We will continue to keep asking for your ideas so that member updates stay fresh and relevant.

In this section we also learned that many of you do not have access to email, but would still like updates. We're currently looking into how we can get the same content to you and will keep you updated with any developments.

### Which epilepsy related issues should receive more public and political attention



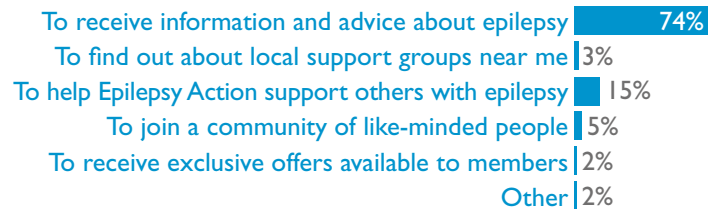
\* People could select more than one option

This survey was sent out before coronavirus had become an issue in the UK, so it is likely these results might look quite different if we conducted it again today! However, at the time of sending, nearly half of respondents said they wanted to see more action being taken to improve health services for people affected by epilepsy.

In the 'other' section, many of you talked to us about better awareness of epilepsy both among healthcare professionals and the general public. Our campaigns team will be kept up to date with all of your ideas, and we will keep asking you for more input in future surveys. The campaigns team will always work hard to

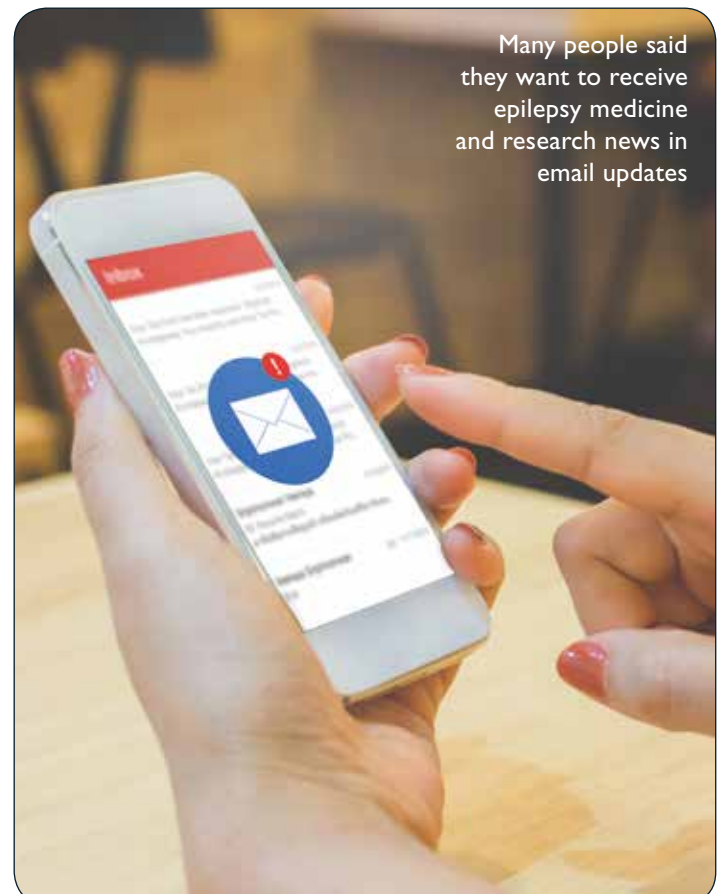
make your voices heard and fight for greater public and political attention for epilepsy.

### What you want from your membership



Three quarters of respondents told us that you joined Epilepsy Action in order to receive information and advice. We've listened and will be doing more to send you relevant information based on your relationship with epilepsy. This will be sent by email if we have an email address for you. If not, this will be sent by post in a quarterly update. If you've not yet told us about your relationship with epilepsy or let us know your email address, you can do so here: [epilepsy.org.uk/evenbetter](https://epilepsy.org.uk/evenbetter) or call 0113 210 8810 and ask for a paper form.

To everyone who took part, a huge thank you once again. If you have any questions about the survey please contact [cwhite@epilepsy.org.uk](mailto:cwhite@epilepsy.org.uk) or call 0113 210 8908.



Many people said they want to receive epilepsy medicine and research news in email updates





# 70 years of Epilepsy Action

## We look at seven of the biggest milestones for Epilepsy Action to mark the organisation's 70th anniversary

This year has been unlike anything any of us ever expected. It has come with great hardships and losses for many people, and brings new challenges and uncertainty for the coming months.

But 2020 also marks a significant milestone in Epilepsy Action's existence – its 70th anniversary. In such a strange climate, it's hard to feel particularly celebratory, but where possible, it's good to take stock of the positives that we have.

Over the last 70 years, the epilepsy landscape has changed a lot. In 1950, when the British Epilepsy Association (BEA) was created – later renamed Epilepsy Action – life for someone with epilepsy looked very different. Some people might remember people with epilepsy being cared for in old asylums or epilepsy colonies in the early years of the decade. They might remember a time when a marriage could be annulled because of epilepsy. This was a time when epilepsy was very poorly understood and rarely spoken about.

So, the creation of the BEA marked an important moment in history.

An organisation was finally set up to influence healthcare, policy and public understanding, and be a source of support for people with epilepsy.

The ways in which epilepsy touches our lives are numerous. Aside from the frightening and frustrating seizures themselves, it can affect our lifestyles, jobs, travel, livelihood, mental health, relationships and much more. It can feel lonely to be dealing with these challenges on your own. But with organisations like Epilepsy Action, you know someone has your back. They understand what you're going through and they work to enact change for the better.

To mark its 70th anniversary, we look at seven ways that Epilepsy Action has been instrumental in driving change for people with epilepsy over the last seven decades.

### 1. From colonies to communities (1963)

Seventy years ago, and longer, the way people with epilepsy were treated and cared for was entirely different. Many myths and misconceptions underpinned a reluctance

for people to disclose their condition to anyone, until a seizure was witnessed.

Children and adults could be sent to colonies, asylums or psychiatric hospitals as a treatment for their condition. But in 1959, the Mental Health Act set the framework to move from care in institutions to care in the community. The BEA shared this view and believed that colonies were not as effective in rehabilitating people with epilepsy as they should have been.

In 1963, the BEA published a report, *The Adult Population of Epileptic Colonies*. This identified that many people living with epilepsy were confined to colonies when they could – and should – be living in the community. The report challenged people's thinking and helped lead to changes in practices enabling thousands of people living with epilepsy to leave asylums, psychiatric hospitals and colonies.

### 2. Driving change (1968)

One part of epilepsy that many people find very frustrating is losing their driving licence. It might be that you've been itching to get behind the wheel and enjoy the freedoms driving affords. It might be that you have come to rely on your car to get to work or to the shops. Not having this option is yet another lifestyle adjustment to add to the pile.

It goes without saying that giving up your licence when you have uncontrolled awake seizures is important for your safety and that of others. But once your seizures are under control, there is no reason why you shouldn't be allowed to drive.

But this wasn't always the case. Before 1968, people with epilepsy weren't allowed to drive. Understanding the value of having the option to drive, Epilepsy Action lobbied the government for the regulations to be changed for people with controlled or sleep seizures. The campaign was a success and, for the very first time, people free from awake seizures for more than three years could apply for a driving licence. This was a huge moment for people with epilepsy.

Epilepsy Action later led another campaign to reduce the amount of time being seizure free before you can apply for your licence from three years to two. This was another success and the law was revised in 1982.

### 3. National helpline (1994)

To this day, one of the most invaluable resources from Epilepsy Action is its helpline. Even with today's advancements in healthcare and public attitudes, an epilepsy diagnosis can leave any of us feeling lost, confused or lonely. Twenty-five years ago, things would have been even more so, with much less public awareness and understanding of the condition.

In 1994, Epilepsy Action launched its free national helpline. For the first time, people with epilepsy had a dedicated number they could call to speak to a specialist epilepsy advisor. Not only did this create a point of contact for people with someone who understands what they're going through, it was a way for people to get clarity and advice on their condition. They could be pointed in the right direction and receive advice about the care they should seek and the support they could have.

People often reach out to the helpline when they are feeling at their lowest, overwhelmed or when they are in desperate situations. In 2014, Rob had his first seizure, which threatened to derail his life and career plans, and left him confused and frightened. He said: "I didn't know what to do with myself, so I called the Epilepsy Action Helpline. It's a phenomenal service."

In 2016, Jo called the Epilepsy Action Helpline to speak about her son, Charlie.

Charlie has epilepsy and he was going through a bad patch. His seizures had increased and Jo felt like he had lost his personality. Jo said: "I was at a bit of a low ebb, to be honest, and that's when I contacted the Epilepsy Action Helpline. At the time when Charlie was having a lot of seizures, he was losing a lot of time. It was the day that he had three seizures in a day that I wanted some reassurance, as his mum, that I wasn't overreacting and that I was okay to push for a little bit more medical help."

Jo spoke to the helpline and was given encouragement and advice about asking Charlie's specialists to review his medicine. She said: "Having changed his medication and now that his seizures are controlled, we said it was like having our Charlie back."

The value of the Epilepsy Action Helpline is immeasurable. It is a resource reachable from the most remote corners of the country and it's here for everyone. Its creation is a standout moment for Epilepsy Action.

Having contact with people who understand what we're going through often makes a big difference to how we feel. As well as the helpline, Epilepsy Action's local branches and coffee and chat groups have been a consistent help and point of contact for people with epilepsy over the years.

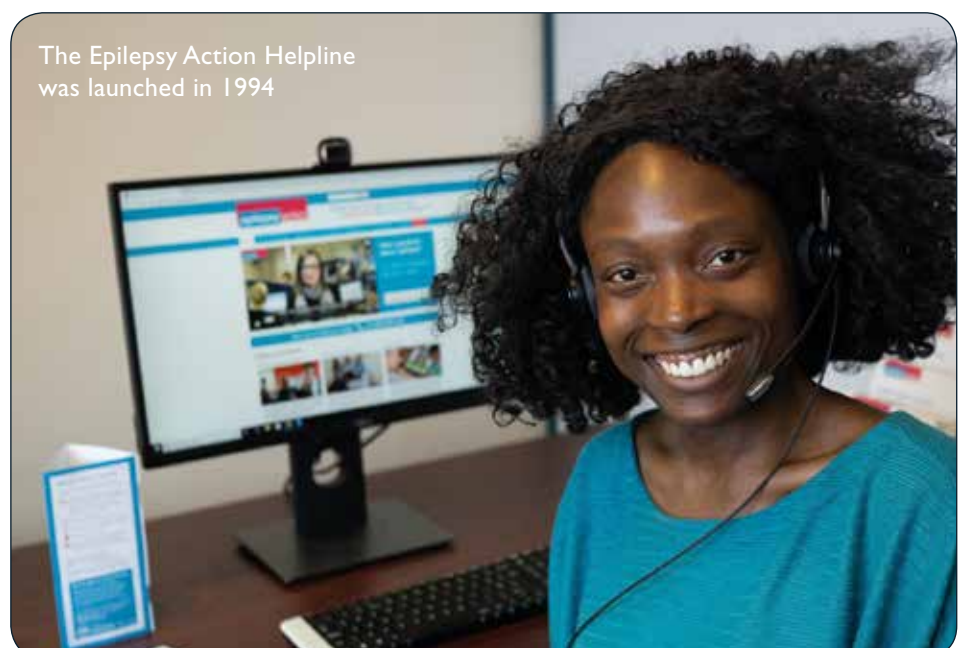
### 4. Sapphire Epilepsy Specialist Nurses (1995)

Some of us will have experienced first-hand exactly how fantastic epilepsy specialist nurses (ESNs) are. They are a part of the epilepsy specialist team and they often leave a huge impression on the people they care for. They are often a friendly face and a more accessible point of contact to answer questions and offer specialist advice. They also build a relationship with their patients and offer an incredible support to people. An ESN's work also involves raising awareness and spreading information about epilepsy in the health service and the community.

But there is always a need for more. To mark the organisation's 45th (or sapphire) anniversary, Epilepsy Action launched its Sapphire Nurse Scheme, which ran for several years, and funded the first Sapphire ESN place in 1995. Karen Evans was appointed in this role, working at Hull Royal Infirmary until her retirement in 2018. Since 1995, 92 nurse places for Sapphire nurses have been created around the country.

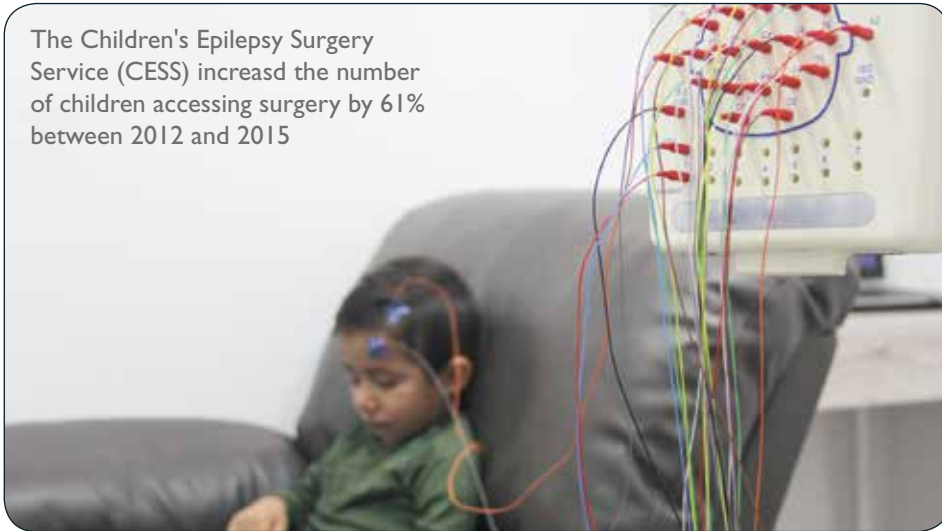
### 5. Disability Discrimination Act (1995)

Discrimination is a concern that comes up time and again for people with epilepsy. This is particularly relevant when it comes to getting and keeping a job. It is astounding to think that as recently as





The Children's Epilepsy Surgery Service (CESS) increased the number of children accessing surgery by 61% between 2012 and 2015



25 years ago, a person could be openly discriminated against on the basis of epilepsy – a medical condition – with no legal consequences.

In 1994, Epilepsy Action worked hard to raise the political profile of epilepsy, supporting MP John Battle in setting up the All Party Parliamentary Group on Epilepsy. Epilepsy Action pushed to have epilepsy included within the legal definition of 'disability'. The following year, the new Disability Discrimination Act came to be, which now also covered people with epilepsy. For the first time, it became illegal to discriminate against people with epilepsy.

Even with this in place, we still hear from people who come up against discrimination in their daily lives because of their epilepsy. The work against discrimination is not over, but this milestone in epilepsy history means that people with epilepsy have legal protection in their corner.

## 6. Children's Epilepsy Surgery Service (CESS) (2012)

Epilepsy surgery has long been an option as epilepsy treatment. Historically, it might have been seen by some doctors and patients as a last resort. It's a daunting thought and can feel like quite a drastic step. But over the years, neurosurgery has been advancing in leaps and bounds, with new research and new technology refining its use and boosting its success.

Research has shown that epilepsy surgery in suitable candidates can be successful and result in fewer seizures or seizure freedom in many people. Research also

shows that the earlier epilepsy surgery is considered, the better the outcomes.

With this in mind, Epilepsy Action worked with others to urge the NHS to create the national Children's Epilepsy Surgery Service (CESS), which came to fruition in 2012. Four specialist CESS centres were set up in England that would review children with difficult to control epilepsy. It is estimated that 340 children could benefit from epilepsy surgery each year. The creation of this service increased the number of children accessing brain surgery by 61% by 2015. Nearly two-thirds (58%) went on to be seizure free one year after their surgery. The CESS still continues to offer this life-changing treatment option to children with intractable epilepsy who could benefit.

## 7. Personal Independence Payment (PIP) (2017)

We all know that the experiences we have with epilepsy are incredibly varied. Some of us might be able to get control with epilepsy medicine, while others might be living with exhausting and debilitating seizures or medicine side-effects. But it seems that this knowledge is not as widespread among people without epilepsy.

So, for some of us, government benefits to support us while we seek a better treatment could be the only way we can put food on the table. And the threat of this support being reduced or taken away is incredibly stressful.

In 2017, Epilepsy Action launched a national Personal Independence Payment

(PIP) welfare campaign. The organisation had identified issues with the assessment process for PIP which left people who really needed this help, without it. The assessment failed to take into consideration just how varied the effects of epilepsy could be.

Chris has epilepsy and uncontrolled seizures, which affect his ability to work and his daily life. Chris needs support with everyday activities like cooking and taking a bath, as they could put him at risk if he had a seizure. His husband Sam also changed his work in order to be able to care for Chris. When they took the PIP assessment, they found it quite straightforward, until the decision came in. Sam said: "We were shocked when Chris scored zero on everything. We were quite angry that they had failed to recognise the genuine difficulties that Chris faces."

Chris and Sam had to go through a lengthy appeals process in order to receive the financial support they needed to ensure Chris had the care he needed and they could still put food on the table.

Epilepsy Action campaigned to highlight these problems and, as a result, the assessment process changed. For the first time since 2013, the number of people with epilepsy to be successfully awarded PIP after their initial assessment rose to nearly two-thirds (63.5%) from just over one-third (37%).

After 70 years of hard work and reaching important milestones in improving the lives of people with epilepsy, there is still more to be done. Epilepsy Action hopes that in the coming years, one of the next big issues it will help to tackle is the treatment gap, maximising seizure freedom for all. Currently, only around half (52%) of people in the UK living with epilepsy are seizure free. With the right treatment, this could be as much as two-thirds (70%). In plain terms, that's 108,000 more people living a life free from seizures.

The organisation is intent on continuing to help optimise treatment, educate and raise awareness around epilepsy, aiming always to improve the lives of people living with epilepsy.



# 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 perampanel.



Perampanel (PER) was licensed in the UK as add-on treatment for focal epilepsy in 2012 in anyone over 12 years old. Also, more recently, it was licensed for genetic generalised tonic-clonic seizures without a known cause. It has a unique mechanism of action, working by reducing excitation in the brain. PER breaks down slowly, taking 2-6 days to reduce by half in the blood, so this makes it suitable for once daily dose. Treatment should start with a single dose of 2mg PER at bedtime. This dose can be increased in 2mg steps every 2 weeks, aiming for a maintenance amount of 4-8mg a day depending on whether

seizures are still happening. Some people require and tolerate higher PER doses, up to a recommended maximum of 12mg daily.

As with all epilepsy medicines, the higher the dose the more likely side-effects are to occur. The commonest problems with PER are dizziness, sleepiness, tiredness, irritability, nausea and falls. Weight gain can also be an issue. Behavioural complications, such as anger, hostility and aggression, can present or worsen, particularly at PER doses at or above 8mg a day. Teenagers are particularly susceptible to this type of side-effect. The possibility of emotional problems arising with PER should be discussed with the person with epilepsy and their family when the medicine is first prescribed. It should be discussed again when the dose is increased to 6mg or more daily. These are unusual complications, but they can cause great anxiety within families. PER should not, therefore, be prescribed for people with known anger management issues. Care should also be taken in people with learning disabilities or dementia. Again, a warning should be given about this potential complication

when PER is first prescribed. Sometimes, a lower dose will solve the problem without loss of seizure control, other times, it would have to be stopped.

Other epilepsy medicines, such as carbamazepine, phenytoin and oxcarbazepine, which increase liver function, can cause PER levels in the blood to reduce by as much as half. This often means a higher dose of PER is needed to get the best seizure control. If things are going well and there are no side-effects, 12mg PER daily or more can be tried.

Women taking 12mg or more of PER daily, who also take a birth control pill, should discuss with their doctor taking a higher dose birth control. There is no evidence to suggest PER can cause birth defects in babies, although this information is difficult to verify as this medicine is usually used as an add-on treatment. There are few other interactions with PER.

PER can be a successful treatment for refractory focal seizures in people who tolerate it well.



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 them without discussing it with your GP or specialist. Suddenly stopping your epilepsy medicine could cause you to have more, or more severe, seizures.**

# My journal



val was diagnosed with epilepsy at 71. But her diagnosis didn't shock her as much as it may have, as it was not her first encounter with epilepsy



At the age of 71, in August 2018, I started to have what was first seen to be transient ischaemic attacks (TIAs), also known as mini strokes. I had suffered two of these a few years earlier and the symptoms were very similar.

They started with a weakness and a slight drop in the left side of my face and this weakness then travelled down my left arm and occasionally down my left side and leg. Each time I had one of these, I was instructed to attend the local A&E immediately to be ushered up to the emergency stroke unit.

Over the following three weeks, these events happened quite frequently so I was up and down the hospital, often twice a day, and sometimes I was kept in overnight in the stroke ward. This was not particularly pleasant, although the staff were excellent.

Each time I went in, I had the same tests over and over again – often three times a day. Through all this, I didn't feel too bad. I never lost consciousness and they didn't last very long. The implication was that I could be heading for a major stroke. You

can imagine how worrying this was and when I was at home, I started trying to organise my arrangements, just in case.

Eventually I had an MRI scan and the same afternoon the stroke consultant called to see me on the ward and announced that "it's not strokes – you are having epileptic seizures".

He didn't understand why I then smiled. But, to me, it was such a relief that these events weren't strokes. I felt confident that I could probably cope with epilepsy, the amount of experience I had had over the years. This is because one of my daughters has epilepsy.

## First run in with epilepsy

For many years, epilepsy wasn't a part of my life. I was born in Suffolk in 1947 and grew up in a small seaside village. I had a very happy childhood and spent many wonderful, sunny summers with my many cousins. I went to a local Catholic primary grammar school and then to university where I studied sociology.



Val and Rhian

A year after graduating, I was offered a job as a contract teacher in Sierra Leone. This was an incredible experience and I had amazing adventures working and travelling around West Africa. We had no running water, no electricity and the doctor and dentist were 70 miles away cross country. Transport was very limited and we had no phones or radios. There were no such things as mobile or smart phones or the internet at the time. But luckily, during all this time, I remained fit and well.

It wasn't until some years later that we had our first run in with epilepsy. I had come home from Africa and moved to Wales, where I started working part-time as a social worker, mainly with children and adults with various disabilities (a job I had until the age of 64). I met my husband, David, a local farmer, and we had our two beautiful daughters – Rhian, now 42 and Catrin, now 40.

At the age of 18, Rhian was diagnosed with epilepsy. It took several years to find a balance with her medicines, but she is quite well at the moment. She often goes several years without seizures.

I was able to help her while she was living at home. But I was constantly concerned as the support we needed locally was non-existent and the GPs had very limited experience. Eventually we had to insist that she saw an epilepsy consultant which moved things on a bit. She is now more or less controlled, although she does have occasional breakthrough seizures. She lives independently, works full time and has a very positive attitude to life. Catrin, who lives in Surrey, is also a great supporter of Epilepsy Action and our Aberystwyth group. She raised around £1,000 running the Cardiff half marathon in October 2019.

In 2009, a small group of us got together and set up a new branch of Epilepsy Action in Aberystwyth. We had the help of Ann Sivapatham, local services Wales manager at Epilepsy Action. We wanted to bridge the gap in support and create the network

for people with epilepsy that we never had. We wanted to develop awareness and understanding of epilepsy, offer support to individuals and families, encourage the development of much-needed epilepsy services and maintain fundraising. Over the years, the branch and some of its members have been given volunteer awards from Epilepsy Action, including me and Rhian in 2015.

I was branch secretary, accredited volunteer and a regional coordinator for Epilepsy Action Cymru, learning a great deal and thoroughly enjoying the different experiences. I feel we were a very hardworking and successful branch and we had a very good team! Moving on from our branch efforts, we are now a support group providing regular meetings and sharing our knowledge of epilepsy and its many concerns. We held many popular and successful study and awareness days.

### *Jacksonian seizures*

So, after many years of getting to understand epilepsy in my daughter, my epilepsy diagnosis wasn't perhaps as much of a shock as it would be to others. It appears I have a rare kind of epilepsy, known as Jacksonian seizures. This is a type of focal seizure and it doesn't usually cause a loss of awareness. It can spread to a tonic-clonic seizure in some people, but I haven't personally experienced that. When I finally had my MRI scan, there was some scarring identified in one part of my brain. So far, this has affected my left side only. I get a tingling in the hand, which moves up the arm and I lose grip and strength. Sometimes my face droops on the left side. This makes it look very similar to the mini strokes I had experienced a few years earlier.

After my diagnosis, I returned my driving licence without delay. I knew that, having experienced several seizures over one month, I would not be considered safe to drive. After a short rest, I continued most other activities – but with care.

*"I get a tingling in the hand, which moves up the arm, I lose grip and strength and sometimes my face droops"*

The day after taking my first epilepsy medicine tablet (lamotrigine), the seizures stopped completely. My licence was returned a year or so later. I know this is very fortunate and others might not be as lucky with their medicines. In recent years, slowly but surely, more epilepsy medicines have been developed. They're not always successful, but many people can live safe and happy lives with good control. At the moment, despite a few small side-effects, I'm happy to remain on my medicine. But, ideally, I think we would all prefer more remedies with fewer side-effects. If I start to need increased control of my epilepsy, I would have to contact the epilepsy clinic in Cardiff to arrange expert advice. We have no epilepsy clinics or specialists in our area. The nearest is approximately 70 miles away.

Since my medicine controlled my seizures successfully, I had no further complications with physical and mental activity. I had





*Catrin running the Cardiff half marathon for epilepsy*

retired from work in 2011, but I still needed to travel for various activities. The main difficulty was transport. We live on our farm, in the country, about eight miles from the main town and all health and social centres and conveniences. There were only two buses a week, so I had to rely on my long-suffering husband to be on call when I needed him. I quite enjoyed the bus rides into town, but this wasn't always ideal. Living in a rural area in mid-Wales, this has been an ongoing problem for many years. The transport system is very limited and any long-distance travelling can be very difficult and expensive, especially if you have extra needs and need help to travel.

## Positive and active lives

I was happy to talk about my epilepsy with people. As soon as I was diagnosed, I told my family, colleagues and friends straight away. Most of them knew that my daughter had epilepsy and that I had several years of experience of the condition and how it affects people. I'm aware that's not the case with many people though. Some older people may find it difficult to accept or talk about their epilepsy when first receiving their diagnosis, which is completely understandable.

I do believe that attitudes to epilepsy have changed over the years, though. In our area, in mid-Wales, where our group is and most of our volunteers work, most people seem keen to find out more. Many people had connections with epilepsy, but knew very little about it.

Our epilepsy group's study days and awareness events are very well supported. Our trained volunteers travel around Wales talking to various organisations, such as schools, police and businesses, to increase awareness. I believe that this work has made a significant contribution to the improvements in attitudes and confidence here and similar work is affecting different areas all around the UK.

I have only been diagnosed recently and my difficulties have fortunately been minor. But, in chatting with others, various worries are common – making sure to take medicines regularly, managing safety if you're living alone and going out and about safely.

As well as that, we are living in difficult times, we have many restrictions affecting our daily lives. That can really add to the challenges of epilepsy. I find getting outside a bit and keeping going with hobbies and interests really helpful, where this is possible. I enjoy reading, cycling, walking, gardening, yoga, volunteering with Epilepsy Action Cymru and doing local church projects. Age has limited some of the activities I used to enjoy. We recently retired from farming and from running a small stud of Arab horses which we bred and showed. I also find spending time with my grandchildren very cheering (when we're out of lockdown, of course).

Nowadays, it seems that most people with epilepsy, with proper support and reasonable health otherwise, can live positive and active lives. Some people may have been diagnosed with epilepsy many years ago and, hopefully, have adjusted to life with the diagnosis. Others, like myself, may not have been diagnosed until much later in life – I was 71. This can be a shock after so many years without experiencing seizures. Regardless of age, it's important to look for every treatment avenue open to us and not just put up with treatment that's not right for you.

I would suggest that the more information a newly diagnosed person can acquire, the better. Talk to your GP, your neurologist, your epilepsy specialist and your epilepsy specialist nurses, who are extremely helpful. Epilepsy groups can be a source of support, where people can share and discuss the many concerns they may have. The Epilepsy Action Helpline is easily accessible too, and there is lots of information on their website.



*Val doing yoga with her granddaughter*

## Council of Management 21 July and 4 August

As a result of the coronavirus and COVID-19 pandemic the Council of Management has not been able to meet in person this year. Meetings scheduled for April and May had to be cancelled due to lockdown. However, throughout this time the Council has remained engaged with the activities of the charity and has been able to exercise its governance role remotely.

On 21 July the Council of Management held a business meeting by video conference for the first time.

Normally the trustees' annual report and annual accounts are approved by the Council in April. This year that approval had to be postponed until July in order for the auditors to fully satisfy themselves about the impact of the coronavirus and COVID-19 pandemic on the charity's finances going forward.

The additional tests demanded by the unique circumstances have been passed and this allowed the trustees' annual report and annual accounts for 2019 to be approved by the Council. These reports will now be circulated to the members of the charity and presented at the Annual General Meeting (AGM) on 29 September. They will show that Epilepsy Action enjoyed another very successful year – having contact with more than 2 million people and spending more than 3.7 million pounds to support people with epilepsy.

The Council considered the financial performance of the charity in the first six months of 2020 and looked at future projections of performance until the end of the year. They were pleased to note that despite the inevitable impact of the pandemic on income, especially income from fundraising events,

the finances of the charity remained robust. It was felt that no major adjustments were required at this time to plans for the remainder of the year.

Not more than every other year the Council can recognise an outstanding personal contribution to improving the lives of people with epilepsy by awarding the Association's Lord Hastings Award. This year the Council unanimously decided to make the award to Beth Irwin, an epilepsy specialist nurse with more than 30 years experience working in Northern Ireland.

The Council also made some changes to the membership of its Scientific Awards Panel. This is the group of experts who advise Council on its research grants. Dr Catrin Tudur-Smith and Dr Helen McEwan have stepped down after completing their maximum term. Nigel Bennett has been appointed as a new member.

On 4 August the Council of Management held its second meeting of the year by remote video conference. The agenda was deliberately limited to cover only essential items.

The Council approved a set of guidance points for the formulation of a revenue budget and business plan for 2021. This takes account of the current difficult circumstances and future uncertainty caused by the coronavirus and COVID-19 pandemic. The Council also approved the first ever seven winners of Epilepsy Action's new Helping Hands awards.

The next meeting of the Council is scheduled for 6 October.

### 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 that many of you take comfort from meeting others affected by epilepsy through our branches and coffee and chat groups. As we aren't currently able to offer that support, our virtual groups are a great way of connecting with others.

You can find information on all our support services at: [epilepsy.org.uk/virtualgroups](https://www.epilepsy.org.uk/virtualgroups) You can also get more details by calling us on: **0113 210 8800**.

#### Online resources

Epilepsy Action also has an online space where people can meet others with epilepsy and exchange stories and information about their condition. This is called forum4e and can be found at [forum.epilepsy.org.uk](https://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.



Are you  
suffering  
from  
seizures  
that  
your  
medication  
alone can't  
control?



When medication can't provide the control you deserve, it's time to consider other options. 1 in 3 people with epilepsy have the kind that is resistant to anti-epileptic drugs.<sup>1</sup>

**Take the next step.**

Talk to your Epilepsy Nurse or Neurologist about Drug Resistant Epilepsy (DRE) and VNS Therapy.

Download our DRE Discussion Guide, designed to help you have a conversation about the next steps in your treatment plan.

Visit [www.vnstherapy.co.uk/get-started](http://www.vnstherapy.co.uk/get-started)

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cardiac rhythm increases known as ictal tachycardia. Incidence of adverse events following stimulation (>5%) included dysphonia, convulsion, headache, oropharyngeal pain, depression, dysphagia, dyspnea, dyspnea exertional, stress, and vomiting. Visit [www.vnstherapy.com](http://www.vnstherapy.com) to learn more and view important safety information.

<sup>1</sup> Brodie MJ. *Epilepsia* 2013; 54 (Suppl. S2):5-8.

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