

# Epilepsy Review

Tackling internet trolls who target people with epilepsy online

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How to make sure you get your free flu vaccine this winter

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It feels something of a relief to be able to publish this issue of *Epilepsy Review*. It hardly needs saying that 2020 has been turned upside down by Covid-19. And from us all at the Epilepsy Society, our first thought is that you are all well, safe and coping. Epilepsy does not disappear because there is a new enemy at the door and we are always here to support you.



If, prior to the pandemic, the world was hurtling in a digital direction, the speed of change has been accelerated by the virus. Our lives have been dragged through a portal to be lived largely online with much time spent waiting for the host to let us in.

Zoom, Teams, Facetime, WhatsApp have been lifesavers and thank heavens for technology. But we're only ever as connected as our internet allows and if your internet 'is unstable', then you're on your own.

Which is why it is such a pleasure to bring you *Epilepsy Review*. There's no password (unless of course you're reading our digital version). You won't turn to page 12 and find the magazine suddenly freezes and you can't get any further. You won't find yourselves muted while you read through the content. And the magazine won't crash.

Most importantly, you won't need to subscribe to a particular make of armchair or coffee table in order to access the magazine – you can lie back on the sofa and browse to your heart's content. Old school reality at its best!

There is barely a page in the magazine that doesn't mention the pandemic, I'm afraid, but our lives have been shaped by this invisible enemy and we can't get away from that. There have been some really low points this year, particularly with a sustained and ongoing

attack on people with epilepsy by internet trolls. But I hope you will see how our campaigning work is tackling this and other issues, including the omission of those with epilepsy from the free flu vaccine group.

We have advice from our top neurologist Dr Fergus Rugg-Gunn on how to make the most of your online health appointments. And, to ensure you end the year with laughter, we have a wonderfully uplifting piece from our funny girl, Juliet Stephens who brings a fresh perspective to the pandemic.

I hope you enjoy this issue of *Epilepsy Review* – not just the content but its good, old fashioned tangibility and existence in real time. You can't click 'like' or respond with an appropriate emoji. But you can still share by passing onto friends or family once you have read the magazine.

If 2020 has taught us anything, it is to appreciate what we have. So hold on to your hats and here's hoping that 2021 will be better.

A happy Christmas and a brave New Year to you all.

Nicola Swanborough  
Editor



#### Front cover

Thank you to everyone who shared their photos on social media under the hashtag #DoILookEpileptic. What a stunning front cover they make! And this is Jodie McMaster, the student nurse behind the campaign to raise awareness of epilepsy as an invisible condition (see page 3).

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## CLIMATE CHANGE

# How hot summers are affecting seizures



A survey carried out by the Epilepsy Society has shown that 62 per cent of people with uncontrolled seizures experience an increase in seizure activity during unusually hot weather.

More than 1,000 people took part in our survey, including 969 people whose epilepsy does not respond to current treatments. A total of 598 of this group said that they experienced a change in their seizure activity during very hot weather. This included an increase in frequency, severity or a 'breakthrough' seizure even when they considered their epilepsy to be generally well controlled.

The survey was carried out following the week of 21-27 June 2020, when temperatures soared above 30 degrees Celsius.

Researchers at the charity are keen to understand more about how hot weather affects epilepsy and the impact that climate change might have in the future.

Anecdotal evidence has already suggested an increase in seizure activity for children with Dravet syndrome, a severe childhood epilepsy. Dravet syndrome UK, has shown that the high temperatures of summer 2018 resulted in children with this rare condition experiencing more seizures and greater lethargy.

But the Epilepsy Society's survey is the first time data has shown a link between excessively hot weather and seizures in a large group of people with epilepsy in the UK.

Forty per cent of respondents expressed concern that climate change would affect their epilepsy or the epilepsy of the person they cared for. And 75 per cent said they would like to see more research into the impact of climate change on the condition and how to address it.

Professor Sanjay Sisodiya, Director of Genomics at the charity said the survey highlighted concern among people with epilepsy that unless we take measures now to control global warming, their own health could be adversely affected.

"If the hot summers that we are experiencing now are contributing to worsening control of some people's seizures, then we, as their doctors, need to understand that connection and take appropriate action to reduce risk by helping to tackle climate change or to mitigate its effects," he said.

As we went to press, Professor Sisodiya's international consortium – Epilepsy Climate Change (EpiCC) – was hoping to hold its first virtual Epilepsy Conference, planned before the pandemic, to reduce carbon emissions by eliminating the need to fly.

## BREXIT

# Medicine supply from New Year

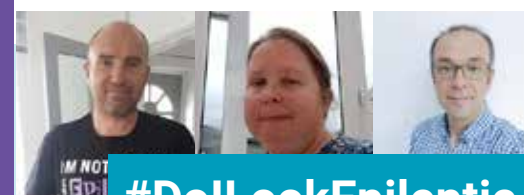
A new relationship between the UK and the European Union comes into effect from 1 January 2021, following the Brexit transition period.

We are meeting regularly with the Transition Team at the Department of Health and Social Care (DHSC) to monitor any potential issues around the medicines supply chain, particularly when the NHS is already under pressure from Covid-19 and winter illnesses such as flu. Contingency plans include:

- Re-routing freight away from short crossings between the UK and EU
- Express freight service for urgent medicines and medical products
- A 'trader readiness' campaign for new custom arrangements
- Medical suppliers ensuring six weeks' buffer stocks in the UK.
- Negotiations are under way to bolster resilience of supply chains
- The DHSC's Medicines Supply Team has well established procedures to deal with actual or potential medicine shortages.

People with epilepsy are encouraged not to try stockpiling medication themselves, but to make sure they get their prescription to their pharmacy in good time, up to seven days before required.

If the pharmacy does not have your drugs in stock, this gives the pharmacist time to order stock or to access it elsewhere.



## #DoILookEpileptic

When student nurse Jodie McMaster created the hashtag #DoILookEpileptic, to highlight epilepsy as an invisible condition, we were inundated with people posting photos of themselves across all our social media platforms. Jodie explains:

"Whenever I met new people, I would always tell them I was epileptic and the first thing they would say was 'you do not look epileptic.' So, I would ask them 'what is an epileptic person meant to look like?' That is why I created the hashtag #DoILookEpileptic to prove epilepsy

does not have a face."

We are thrilled to be able to share just a small number of the hundreds of positive, engaging photos on our front cover. You can see more across our social media channels. Thank you Jodie for this important awareness raising campaign.





# Sodium valproate: the Cumberlege Review

## First Do No Harm

The report of the Independent Medicines and Medical Devices Safety Review



This summer, after a two-year review led by Baroness Cumberlege, the Independent Medicines and Medical Devices Safety Review team published its report into three medical interventions: the epilepsy medication, sodium valproate; the hormone pregnancy test, Primodos; and pelvic mesh implants.

The report, entitled “First Do No Harm”, calls for wide-ranging and radical improvements to the healthcare system, setting out nine recommendations to bring much-



needed help and support to those whose lives have been devastated by these interventions.

This follows a long running campaign over many years, led by women, including those who were prescribed sodium valproate during pregnancy without being told of the risks to their unborn baby. An estimated 20,000 babies in the UK have been affected by the drug, with 40 per cent of those exposed to valproate during pregnancy, being born with a physical or neurodevelopmental disability.

But while the Cumberlege Review was widely welcomed – a milestone that holds the past to account and that could reset the

clock for future generations – the campaign is not done. Epilepsy Society, along with other charities and the women leading the campaign continue to press hard for the recommendations to be implemented.

And the All Party Parliamentary Group on Epilepsy, chaired by Valerie Vaz MP, has written to Health Secretary Matt Hancock, demanding action, with an implementation task force appointed to ensure that the recommendations are enacted.

Baroness Cumberlege has formed a dedicated ‘First Do No Harm’ group with former Health Secretary Jeremy Hunt. But we know we still face an uphill struggle set against the current climate of the coronavirus and Brexit. To date, the only recommendation that has been carried out is the first one, with a full apology from Matt Hancock. But sorry is not enough.

Here you can read Baroness Cumberlege’s recommendations and our Chief Executive Clare Pelham’s response to the review.

**“I have conducted many reviews and enquiries over the years, but I have never encountered anything like this; the intensity of suffering by so many families and the fact that they have endured it for decades. Much of this suffering was entirely avoidable.”**

Baroness Cumberlege



**Clare Pelham, Chief Executive at the Epilepsy Society, writes:**

“I feel unbelievably sad that the Safety Review concludes that we have a healthcare system with a fatal flaw. It does not have patients at its heart. And that is truly shocking.

“There is so much that is excellent and inspiring about the NHS and those who devote their lives to its service. But, over many decades, the leaders of this national institution have allowed a shameful white-coat culture of arrogance that let down not only the patients it was there to care for, but also the healthcare professionals whose lives have been genuinely dedicated to the care of others.

Macpherson said the police were institutionally racist. Cumberlege says that the healthcare system is institutionally elitist. Patient views and experience were quite simply not recognised as valid evidence. And so, the decades went by with more and more women condemned to desperate pain and their babies born with avoidable disabilities because doctors could not or would not listen to them.

“The review pulls no punches in highlighting the widespread inadequacies of a healthcare system that, for example, believed silence was an option when prescribing

valproate to young women with epilepsy. The culture of “doctor knows best” must end now. I support every one of Baroness Cumberlege’s recommendations and I hope that the Government will appoint an implementation task force at speed.

“The appointment of a Patient Safety Commissioner is imperative to listen to patients and enable their voices to influence improvements to patient safety. But the commissioner must be one of us. They must be a patient, like any of us who goes to see their doctor in their hour of need full of trust and confidence and deserves openness and a willingness to learn from mistakes, as well as care and understanding.

“Similarly, radical culture change at the regulatory body for medicines and medical devices, the MHRA must be a priority, with independence at its core. No longer do we want big pharma and medics marking their own homework.

“Through the IMMD Safety Review, Baroness Cumberlege has written a long overdue prescription for change. It will be a bitter pill for many to swallow. Particularly now, when we are so deeply grateful to the amazing staff of the NHS. Things will only get better if the leaders of the healthcare system step down from their pedestal and accept that they have as much to learn from their patients as their patients do from them.

“The campaigns around valproate, hormone pregnancy tests and pelvic mesh implants, have been fought by courageous women, who have been ignored and dismissed in turn. We cannot take away their pain. But we can make sure that it doesn’t happen again. And the only way to do this is to make patients the beating heart of the healthcare system. And the shame of it is that thousands of women and children had to suffer first.”

## The response from the campaigners

“We are delighted with the recommendations from the review. We are pleased to see that it not only took on board our evidence found at National Archives but acknowledged the many heart-breaking stories from families affected by sodium valproate. An apology has been a long time coming. We now look forward to the statement from Government and working with them as recommended by Baroness Cumberlege for prompt action.”

**Emma Murphy and Janet Williams, Fetal Anti-Convulsant Syndrome Association and In-FACT (below)**

“We are very pleased with the patient focused approach and the way the review team have given patients many opportunities to have their voice heard. They have listened to our experiences with compassion and welcomed our suggestions on how to improve Medicine and Devices Regulation.”

**Emma Friedmann, FACSaware Campaign Director**

“The group fully welcomes, acknowledges and agrees with the findings of the Independent Medicine and Medical Devices Review. Now we need action from Government to be speedy so not to deny these families justice any longer.”

**Cat Smith MP, Chair of the All Party Parliamentary Group for Valproate and other AEDs in Pregnancy**



## The recommendations

- That the Government immediately issues a fulsome apology on behalf of the healthcare system to the families affected by Primodos, sodium valproate and pelvic mesh.
- That a Patient Safety Commissioner is appointed. This person would be the patients’ port of call, listener and advocate, who holds the system to account, monitors trends, and demands action.
- Separate schemes should be set up for Hormone Pregnancy Tests, valproate and pelvic mesh to meet the cost of providing additional care and support to those eligible to claim.
- A Redress Agency for those harmed by medicines and medical devices in future should be established.
- The establishment of specialist centres, including one for those affected by medications taken during pregnancy.
- The regulator of medicines and medical devices, the MHRA, needs to put patients at the heart of its activity, and to overhaul adverse event reporting and medical device regulation.
- That a central database should be created by collecting key details including the patient, the implanted device, and the surgeon.
- That the register of the General Medical Council (GMC) should be expanded to include a list of financial and non-pecuniary interests for all doctors, as well as doctors’ clinical interests and specialisms.
- Finally, that the Government immediately sets up a task force to implement the Review’s recommendations.



# Me and my epilepsy Evan Molloy

GB judo fighter Evan Molloy is visually impaired and has epilepsy. In spite of the Covid-19 pandemic crushing his dreams of competing in the Tokyo Paralympic Games this year, the 21-year-old still describes 2020 as 'an amazing year' as he finally got his seizures under control. Evan tells his story.

I had my first seizure when I was four years old and initially it did not affect me that much. But as I reached puberty, the seizures got a lot worse. I had been training in judo at my local village hall since I was 13, but as I started to train and compete at county and then national level, this also affected my seizures. My body was going through a lot of changes. I was fitter and stronger, but everything was hectic in my life.

I was in and out of hospital and was not stable on my medication. Seventy to 80 per cent of my seizures are convulsive and no-one knew where they were coming from or why they were happening. Epilepsy was a suspicion but never a diagnosis. It was very frustrating for my parents who really wanted some answers.

I have always been able to cope with my sight problem. It's all I've ever known since birth so you

just get on with it. I would say it's almost very easy in comparison with epilepsy. Seizures are much tougher. You never know when they are going to happen. I have had a couple when I am on the judo mat and that can affect everyone around you – my dad and coach had to catch me at one point as I fell during a seizure.

In 2017, I moved from my home in Wiltshire to Birmingham to train with the British Judo Centre of Excellence. My epilepsy got worse. I was in a dark place with my seizures. I was really struggling. I was running on empty, 24/7 and surviving with little sleep.

My neurologist in Birmingham sent me for tests at a London hospital where I had a brain scan and underwent videotelemetry for five days. For the first time they were able to confirm that I had epilepsy but they didn't change my medication so it didn't really help.

Then last year I was put in touch with the Epilepsy Society's Chalfont Centre in Buckinghamshire. I was admitted for five days and again went through rounds of tests including more videotelemetry. This time they were able to pinpoint the location in my head where the seizures were coming from and to explain how they were affecting me. The best thing is they were also able to change my medication so that for the first time, I was taking drugs that were right for my type of seizures.

**Now I just want to get to the Paralympics and get on that podium. That is what I am aiming for.**

I also started to realise that to get my seizures under control, I needed to help myself to help my condition. And it involved a lot of changes. As an athlete you push yourself to the limit both physically and mentally. It can be really tough. I needed to follow a good diet to give my body time to sleep well and recover. I needed to take my medication regularly, day and night.

After going to the Chalfont Centre, amazing things started to happen. I had to transition my medication slowly over six months, making sure not to introduce more changes while I was travelling as an athlete. And I made changes to my lifestyle that meant my life started to work for me.

And now, since 13 December 2019, I haven't had a seizure. One hundred per cent, it is such a relief. My mind is at rest. At one time I would not have thought this would be possible. You struggle at the

time and think that there is never going to be an end to this, but there is.

It makes a massive difference, not just for me but also for my family, my team mates, my coach. They don't have to worry about me. My mum, dad and step-mum have all been really supportive, trying to keep me calm and get me to appointments on time. When I was in hospital for videotelemetry, my dad did not leave my side – he really is my hero.

Now I can focus on next year. I am in the Paralympic potential GB Judo set up. In my life I have achieved so many personal goals and broken so many barriers. Now I just want to get to the Paralympics and get on that podium. That is what I'm aiming for in my head. I am lucky that I have found something that I love doing. I have extreme passion and drive for judo. That drive just keeps me ticking.



On course for Tokyo: training and competing with the British Judo Centre of Excellence





# Tackling internet trolls

Since May of this year, Epilepsy Society and many of our supporters have been victims of an attack by internet trolls who send flashing images via Twitter to try to induce seizures in people with epilepsy. **Katie Frank**, Policy and Public Affairs Manager, brings you up to date with our campaign to bring the trolls to justice and make social media safe for everyone.

In May 2020, the charity and its supporters were victims of a co-ordinated attack by internet trolls who bombarded our Twitter account with hundreds of flashing images designed to trigger seizures in people with epilepsy. A police report was filed and Epilepsy Society began working with Twitter, GIPHY, Tenor and TikTok to stop these malicious attacks. One of the victims targeted by the trolls was nine-year-old Zach Eagling who has epilepsy and

cerebral palsy. His mum, Claire Keer, had posted videos of Zach (then aged eight) taking part in our 2.6 fundraising challenge after he was inspired by Sir Captain Tom Moore. Zach has raised over £20,000 for Epilepsy Society. Although thankfully Zach remained unharmed, several of our followers experienced seizures and psychological trauma on account of the tweets. One young man, newly diagnosed with epilepsy, had been

directed to our Twitter account to find information and peer support. Instead, he was hit with flashing images which triggered a tonic clonic seizure, leaving him traumatised and afraid to return to the social media platform. In recent years we have seen a growing number of malicious attacks aimed at people with epilepsy and we have been campaigning to bring those responsible within the jurisdiction of the law. But following the most recent incidents, we accelerated our campaign to tackle the issue, renaming the campaign “Zach’s Law” after schoolboy Zach Eagling. We want to criminalise the abusive online behaviour and hold social media companies to account through tighter regulation of their sites and fines for those who do not safeguard their users. The charity strongly believes that the current law is not fit for dealing with this type of offence and has been campaigning vociferously for the behaviour to be made a specific criminal offence under “Zach’s Law”, and for the

Crown Prosecution Service to instruct how criminals can best be prosecuted. Inspired by the campaign, our supporters wrote to their MPs asking them to back our call for Zach’s Law and tougher regulations. Prime Minister Boris Johnson responded when one of his constituents, Epilepsy Society’s Service Manager, Tracy Cousins, wrote to him. The Prime Minister promised action. He told Tracy: “I recognise your specific concerns about the deliberate targeting of epilepsy sufferers online and would be happy to raise this issue with the Secretary of State for Digital, Culture, Media and Sport as we consider the next stages of the Online Harms Bill.”

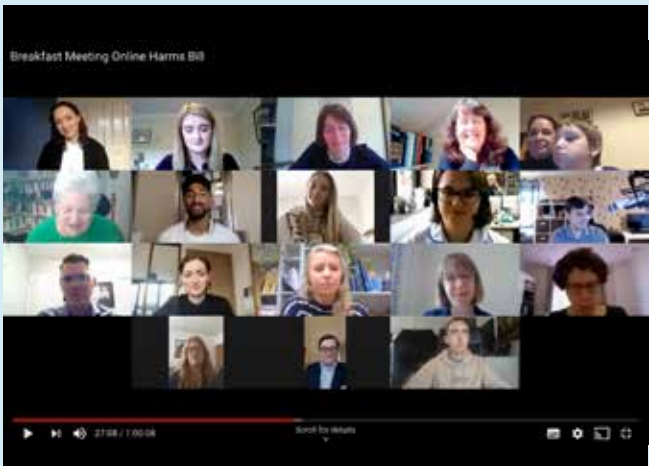
**We want to criminalise the abusive online behaviour**

The Government’s Online Harms Bill is currently being considered by parliament and sets out to make the internet a safe place for all users, while preserving freedom of expression. It puts forward ambitious plans for a new system of accountability with a robust regulatory framework for online safety, overseen by an independent regulator. The Government has engaged the Law Commission to carry out

a second phase of their review into abusive and offensive online communications, and we have been working closely with their team to address online abuse aimed at the epilepsy community. We have been encouraged that the Law Commission has listened to Epilepsy Society’s recommendations and the voices of people with epilepsy and are pushing the Government to review current legislation on assault. The Law Commission’s current proposals include reforms to two acts: The Malicious Communications Act 1988 and the Communications Act 2003. These reforms would criminalise behaviour where a communication is likely to cause harm. Clare Pelham, Chief Executive at the Epilepsy Society, said: “The Law Commission’s proposals will fast forward the English justice system into the 21st century and meet these criminals head on. Social media has developed at a pace that far outstrips the law, providing a safe space for internet trolls to brazenly target disabled people and cause physical harm.” The Commissioner for Criminal Law, Professor Penney Lewis told the Epilepsy Society: “As the internet and social media have become an everyday part of our lives, there has been an increase in abuse targeted at a range of groups including people with epilepsy. “Our proposals aim to tackle this harmful behaviour and we hope to hear from those targeted in this

**The Law Commission’s proposals will fast forward the English justice system into the 21st century and meet these criminals head on.**

way so that we can better protect them from this abuse. We know that someone who sends flashing images to a person with epilepsy, thereby causing a seizure, could potentially be guilty of an offence against the person, for example assault causing actual bodily harm. But there is more we can do.” Sadly, we know that the law can only achieve so much in tackling the type of online abuse we are seeing at the Epilepsy Society. Many of the internet trolls appear to be operating from abroad and there would be considerable challenges in bringing them within UK jurisdiction. That is why it is imperative that the Online Harms Bill ensures robust regulatory frameworks across all social media platforms and poses tough fines for those who fail to comply. Only financially painful penalties will force the social media giants to invest in effective regulations that will safeguard their users. And particularly people with epilepsy. ▶



## Breakfast Meeting

In October, Epilepsy Society hosted an online Breakfast Meeting which gave Commissioner for Criminal Law, Professor Penney Lewis, the Law Commission team, and members of the Department for Digital, Culture, Media and Sport a chance to hear direct from people with epilepsy about their experiences with malicious posts. The meeting was hosted by Dame Cheryl Gillan MP and speakers included Zach Eagling and his mum, Claire Keer; their MP, Tracy Brabin; and Portland Vale football captain Leon Legge. You can watch a recording of the meeting at [Youtube.com/epilepsysociety](https://www.youtube.com/epilepsysociety)



# Working together

**Paige Dawkins**, Social Media Officer at the Epilepsy Society, explains our work with social media companies to make their platforms safer for people with epilepsy

In the last six months, we have been working with social media platforms to help introduce changes to safeguard people with photosensitive epilepsy from online harm.

Twitter has now banned epilepsy-related search terms from its GIF (animated image) search function, meaning that any content tagged with these terms is no longer accessible, including any tagged flashing images.

We have also established a direct line of report with Twitter to allow for faster identification of abusive troll accounts to stop a co-ordinated attack in its tracks. Unfortunately, this is still not enough to stop trolls using 'back-up' accounts to continue their abuse after their original account is banned or suspended. Additionally, certain Twitter account suspensions only last a limited time, after which repeat offenders have continued to disseminate malicious content.

GIPHY, a GIF (animated image) library, has also taken action to reduce the risk for people with photosensitive epilepsy online. GIFs are used on social media platforms including Instagram and Twitter. Many GIFs used in the attacks were in the library, and flashing images also appeared in the results for many epilepsy-related search terms.

A bespoke fast-track reporting line has been created for us to work with GIPHY efficiently to locate malicious or harmful content. GIPHY has deleted GIFs within their library that Epilepsy Society identified are used frequently by the trolls.

GIPHY has also introduced additional moderation practices to reduce the availability of harmful content in the library. The charity's

social media team have raised concerns with the GIF library Tenor about similar issues.

These changes mean that internet trolls may find it more difficult to disseminate harmful content, but it will not stop their access completely. However, these are important steps within a toolkit of measures needed to reduce the online risk to people with epilepsy. They also begin to address the issue of flashing content on social media that is not posted with malicious intent but may still inadvertently trigger a seizure.

The Harding Flash and Pattern Analyser is used by broadcasting companies to detect potentially harmful flashing frequencies and patterns. We believe that similar technology implemented across social media platforms would be an effective long-term solution to keeping people with epilepsy safe. The charity is therefore urging platforms to take appropriate responsibility for the safety of their users and develop this technology as a matter of urgency.

We are pleased to announce that TikTok, a popular video sharing platform, has taken a significant step in safeguarding its users with epilepsy. They are introducing a feature allowing users to filter photosensitive content and remove it from their feed. This gives us hope that other platforms will now feel pressure to do the right thing and follow suit.



## What you can do

You can help to make the internet a safer place by writing to the Law Commission and your MP about your own experiences online and about why you support our campaign to bring in Zach's Law.

Our Zach's Law campaign has gathered pace but it is vital that the momentum does not stop.

You can write to the Law Commission about their proposals at the addresses below. And you can find out more at [epilepsysociety.org.uk/law-commission](https://epilepsysociety.org.uk/law-commission). The deadline for response is 18 December 2020.

- **Email:** [online-comms@lawcommission.gov.uk](mailto:online-comms@lawcommission.gov.uk)
- **Post:** Online Communications Team, Law Commission, 1st Floor, Tower, 52 Queen Anne's Gate, London, SW1H 9AG.
- **Or you can write to your local MP and tell them about our campaign around Zach's Law. You can find a template letter and instructions on finding your MP at [epilepsysociety.org.uk/MP](https://epilepsysociety.org.uk/MP)**



Since the pandemic, most of us are having health appointments via video, telephone or online. **Dr Fergus Rugg-Gunn**, Clinical Lead at the Epilepsy Society, explains how to make the most of your appointment

The Covid-19 pandemic has radically changed the way we live, including the way we access healthcare.

In recent years, telemedicine – health appointments delivered virtually through video conferencing, telephone, email and online – has been trialed and adopted in remote areas of the UK where access to health services has been challenging.

But the pandemic has meant that today all of us are living remotely and accessing health services virtually. Depending on your own GP surgery and neurology services, you may be having

your regular appointments by video, phone or through an online platform. What is standard for most of us, is that for the moment, we are not sitting patiently in waiting rooms until we are called in to see the doctor.

For all of us – doctors, neurologists, epilepsy specialist nurses, those we care for – telemedicine is something we have had to adapt to rapidly. And the technology has presented challenges. But the bottom line is that it allows continued provision of health services while reducing hospital footfall and limiting the spread of coronavirus.

And there are advantages. No long and often costly journeys. No sitting in a crowded waiting room. No frustration when the vending machine isn't working. You can see or talk to your doctor from the comfort of your own home. And you can guarantee that your tea or coffee will be to your liking.

It is likely that telemedicine will be with us long after the pandemic



is brought under control – not for every appointment, but certainly for some. So how do you make the most of your new virtual appointment? We have put together a few tips, over the page, to help ensure that your appointment is as productive as if you were seeing your doctor in their surgery.



## Video conferencing

Your doctor or GP practice will advise and send details of which online platform to use for your appointment. If you are using a health portal, make sure you have all the log-in details and passwords to hand. If you are using a non-health app such as Facetime, What's App or Zoom, make sure you are familiar with the platform. If possible, have a practice with friends and family.

Wherever possible, make sure you have a good internet connection.

Click on the video link five minutes before the time of your appointment and check your camera and audio functions are both working. Use the 'test my equipment' button, if there is one. Check that you are not on mute, so that your doctor will be able to hear you.

Ideally you should have your appointment in a space that offers privacy and which is well lit, so that your doctor can see you easily. Make sure your device is angled so that your whole face

fills the screen. Finding a private space is not always possible, but it is not a good idea to have your appointment while you are in a public space, or in a car.

Try to reduce any background noise, such as television and radio, air conditioning or traffic. You may wish to wear headphones to help you concentrate on what the doctor is saying. (If you can't see or hear the doctor, make sure you say. Make sure the camera/microphone is in the best position for you to see and hear each other.



## Telephone appointment

If you are using a mobile phone, make sure you are in an area with a good connection and that your battery is fully charged.

As described above, try to find a private space in which to talk and reduce any background noise or interference that might compromise your call.

Put your phone – either mobile or land line – on 'speaker' so that you are hands free and, if you wish, can make notes when you are talking to your doctor.

Obviously, your doctor will not be able to see you, so will be dependent on you describing clearly how you are feeling. While

a GP or neurologist may be able to pick up on feelings such as anxiety or depression when you are talking to them face to face, this could be missed in a phone call, so make sure you are direct and honest in saying how you feel.



## Tips across all platforms

An appointment with your neurologist should be 15 minutes in length, but a GP appointment is likely to be less – around 10 minutes. If you feel you need more time, ask your GP surgery whether it is possible to have a double appointment.

Make a list of questions you would like to ask, or points you wish to cover. If you have a lot of issues to discuss, try to prioritise the top ones that will make the greatest difference to your well being.

Have a list of your medications with you or, better still, have your medications to hand. You might also like to refer to your seizure diary. If you have videos of your seizures, discuss with your doctor how best to share these. Videos are an important tool in helping to diagnose epilepsy and different seizure types.

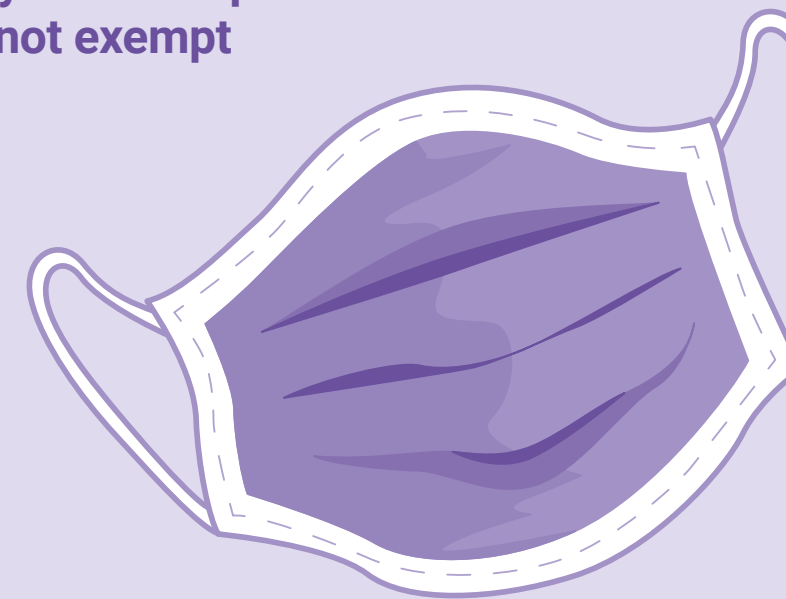
If you would like a family member, friend or carer to join your call, tell your doctor that they are with you and that you have

consented for them to be there. If the person supporting you is not with you, but at a different location, speak to the surgery beforehand to arrange for them to join the call.

Make notes of what your doctor says or ask the person supporting you to make notes. Ask the doctor to clarify anything you are unsure of. A clinical letter summarising the important points of the consultation is typically sent to you and your GP after the appointment.

## Wearing a face mask is mandatory in indoor public spaces. People with epilepsy are not exempt

- If you have ongoing seizures, try not to wear your mask for long periods, but take short breaks in a safe location away from others.
- If wearing a mask will cause you distress, you can carry one of the Government's exemption cards [epilepsysociety.org.uk/exemption-cards](https://epilepsysociety.org.uk/exemption-cards)
- If a person is having a seizure or is in the recovery position, remove their mask, if it is safe to do so and will not put you at risk. This will aid their breathing.
- Always remove a person's mask if they need emergency medication such as buccal midazolam



## Our Helpline Manager, Andrée Mayne, talks about anxiety and why it is ok not to be coping

The challenges posed by the pandemic can cause anxiety, whether we are in lockdown or restrictions have been eased.

Guidance around social distancing is ever changing and often open to interpretation. Many fear going out in case they have a seizure in public and people are worried about the risks in helping them.

And wearing a mask, or not wearing a mask, can cause added anxiety (see above).

The world is a far more uncertain place. Routines that we took for granted have been swept aside by the coronavirus, and a degree of isolation has become an expected part of our lives.

Social interaction has retreated online, and while a life saver in many ways, does not compensate for sitting opposite a friend and enjoying a chat. Even a trip to A&E feels like a risk rather than a remedy.

Anxiety is a natural reaction to the challenges we are facing today, particularly when coupled together with epilepsy. Talking about our worries is key to

dealing with them. Knowing that someone else feels exactly the same way, can help to ease the burden.

Sharing our feelings with friends and families, gives them the opportunity to help and reduce the anxiety. Asking them how they feel, may reveal that their own anxieties – though not epilepsy related – are very similar.

There are many ways to connect with other people. The conversation is always very lively and supportive on our social media platforms: you can find us on Facebook, Twitter and Instagram @EpilepsySociety. Or, to talk to someone who understands, our Helpline is open five days a week for information and emotional support.



**Call 01494 601400 (Mon-Fri 9am-4pm, Wed 9am-7.30pm)**





# Muir's magic

Muir Maxwell has had severe epilepsy since he was a baby and, at 23, is unaware of how his experiences have changed the lives of many children like him. But here his mum, Ann, tells **Nicola Swanborough** how a Trust, inspired by Muir, has funded vital epilepsy services and makes possible some of our groundbreaking genomic research at the Epilepsy Society.

**A**nn Maxwell describes her son, Muir, as the happiest and healthiest she has ever seen him.

"Of course I have had dark moments in the middle of the night, when I lay awake and thought 'oh no, it is months since we have been able to hug him and kiss him and really be with him.'

"But in a strange way, this pandemic has enabled Muir to fly the nest just as his brothers, Connor and Rory (above), have done. He is settled in adult social care and I think, for the first time, he is going to start thinking of that as his home, as opposed to us."

Muir Maxwell is 23 and has Dravet syndrome, a severe form of epilepsy. He had his first seizure at four months old and since then, family life has been a revolving door of ambulances, status epilepticus and the myriad challenges that accompany a life dominated by seizures.

But there is a certain poetry in Muir's new-found independence. Letting go and moving on is very familiar territory this year for Ann and her family. For the last two decades, Muir has been the inspiration and driving force behind the Muir Maxwell Trust (MMT), a charity set up to support the needs

of children and young people with epilepsy and associated disabilities.

MMT has followed the experiences of raising Muir. "Where we found that services were lacking, we fundraised and provided these services and then established a partner fund to ensure that the service continued and was sustainable," says Ann.

But this year, Ann and her husband Jonny (right), decided the time was right to wind the charity up: to step back from what has been their life's work for almost 20 years.

"I would have liked to have been able to fix epilepsy for Muir and others, but I can't. One has to

recognise one's own limitations. But when I look at the projects we have supported, the initiatives we have created and the contribution we have made to the lives of families affected by epilepsy, I think the Trust has a huge and wonderful legacy. It is right to go out on a high.

"We have been able to quietly change lives, and that is all down to Muir. The world would be a different place for so many people without him and when we look at his legacy, we are absolutely bursting with pride."

The impact that Muir and the MMT have had on epilepsy is immeasurable. Their journey began when sleepless nights were a way of life for Ann and Jonny as they were on permanent alert in case Muir had a seizure in his sleep as a small boy. Driven by the need to have peace of mind at night time, they began distributing potentially life-saving epilepsy alarms to thousands of families with similar problems across the UK.

In response to the many needs of Muir who has severe learning challenges including speech and language disabilities, they have gone on to provide a raft of world class, state-of-the-art epilepsy services under the MMT banner. These include an epilepsy centre at Edinburgh University, a wing named after the Trust at the Young Epilepsy Neville Medical Centre, and the UK's first genetic diagnostic service for childhood epilepsy in Glasgow.

**I would have liked to have been able to fix epilepsy for Muir and others, but I can't**

The Trust has supported research at the Epilepsy Society since 2016. And their legacy continues for another year through the pioneering work of their Muir Maxwell Research Fellow, Dr Simona Balestrini, who is investigating the genomics of complex epilepsy and how

treatment can be personalised for the individual.

Dr Balestrini's research includes a suite of innovative techniques such as 3D images which map the face in order to establish whether genetic changes that cause epilepsy also cause subtle changes in facial shape and asymmetry.

She is also using Transcranial Magnetic Stimulation combined with EEG to understand the link between genetic changes and alterations in brain activity, including how a person responds to treatment.

Her ultimate goal would be to see genetic testing established as a regular part of clinical practice in epilepsy, just as MRI, EEG and blood tests are today. The charity already runs monthly genomics clinics and the hope is that this practice will one day be replicated across the UK.

Ann attributes much of Muir's renewed vigour for life to the care he has received at the Epilepsy Society. The Trust played a key part in the arrival of the first NHS approved cannabidiol (CBD) treatment for children with complex epilepsy – Epidyolex. Muir was not involved in the trials, but now, under the supervision of his neurologist at the Epilepsy Society, he is one of 30 patients on a compassionate programme for Epidyolex. And Ann says the changes in him were instantaneous.

"We literally saw the benefits within 24 hours," she says. "It wasn't so much about his seizure control but about his quality of life.



Muir was a young man who was struggling with his epilepsy, having to take time out during the day to sleep because of his seizures. Overnight he transformed into someone who was jumping out of bed at 8am with a really tangible joy and energy for life.

"He has had a rough ride with his seizures and I would not say that the medication is the holy grail. But it has changed him as a young man – it has had a really positive impact on his cognitive abilities and mood.

"He is busy and creative and is always outdoors, jumping in puddles and feeding the animals. He is all smiles, laughter and humour."

Early in Muir's childhood, Ann admits that she would find herself mourning the loss of the child she never had. But not anymore.

"We very much celebrate the young man Muir has grown into and all that he has achieved," she says. "Through all his seizures and his challenges, he has been the inspiration for the Muir Maxwell Trust, and he has changed lives."



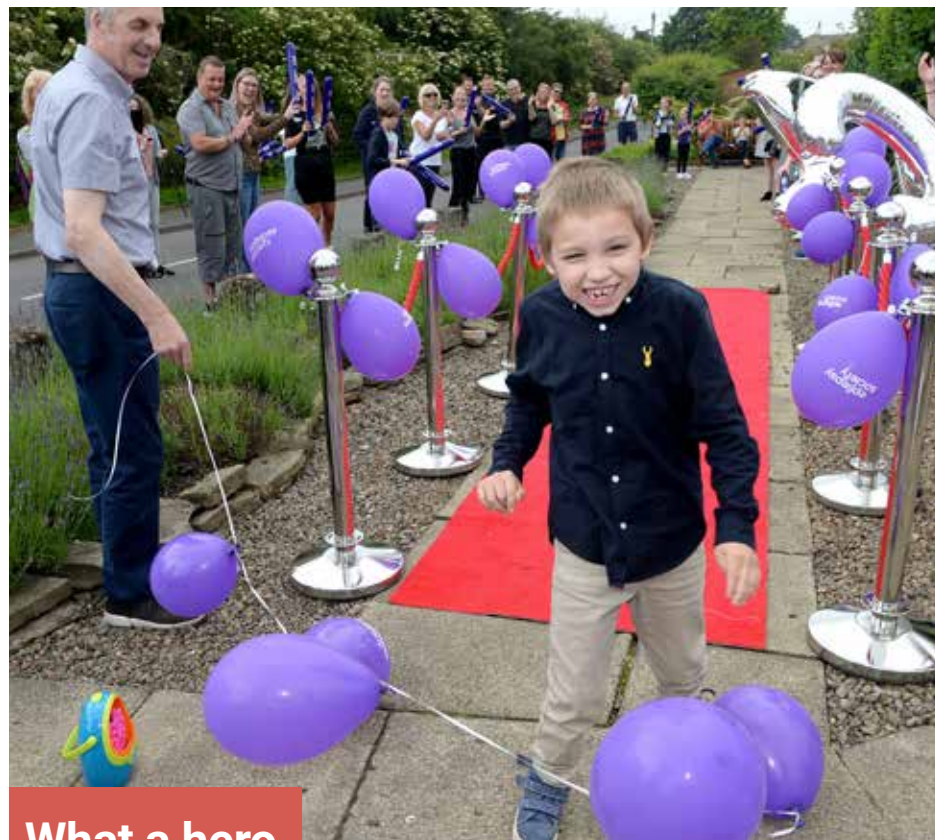
# Thank you for sticking with us

**Gordon Craig**, Epilepsy Society's new Fundraising Director, explains how important our loyal supporters are to us during these difficult times

I was delighted to take up the role of Fundraising Director in April for such a wonderful charity doing so much to help those affected by epilepsy. Obviously times have been tough in the last few months and like many other charities and organisations, our income has been hit hard with a decrease of about 50 per cent in the first months of the pandemic, compared to previous years. That said, there has still been plenty of support and fundraising going on.

Purple Day on 26 March was affected by the Covid-19 crisis, but never-the-less many activities still happened virtually across the country. On the 26 April, the weekend the London Marathon was meant to take place, the 2.6 Challenge was launched in the UK and the nation was tasked with doing anything related to 2.6 or 26.

We raised over £35,000 which included more than £20,000 from young Zach who has epilepsy and cerebral palsy and walked 2.6km in his back yard. Peter Hook (bassist with the hugely successful eighties



**What a hero**

**Zach Eagling who has epilepsy and cerebral palsy took on the enormous challenge of walking 2.6km around his back yard unaided. Inspired by Captain Tom he has now raised over £20,000.**



**In their own time**

**Three tortoises took on the 2.6 metre challenge, racing each other over the finishing line. Spitfire from Epilepsy Research UK came in first at 13.5secs, followed by Fred from Epilepsy Positivity at 1min 15secs, with Tilly from Epilepsy Society bringing up the rear at 2mins 35secs. You can watch the race at [epilepsysociety.org.uk/tortoise](https://epilepsysociety.org.uk/tortoise)**

band Joy Division) organised an online showing of a past gig, celebrating the life of Ian Curtis, the lead singer who had epilepsy and tragically ended his life at a young age.

The concert helped raise awareness of Epilepsy Society to millions of Joy Division fans and raised over £20,000.

**“Purple Day on 26 March was affected by the Covid-19 crisis, but never-the-less many activities still happened virtually across the country.**

At the beginning of the crisis local companies stepped up and supported us with donations of personal protective equipment,

so vital in those early days for our Care Services, and local restaurants supplied the residents with plentiful takeout food at a time when they could not go out. Companies, generous supporters, trusts and foundations have continued to give one-off lump sums at a time when other forms of fundraising were not possible.

We launched an urgent fundraising appeal in September which was delivered to around 7,500 supporters. The appeal featured Jasmine Wright. We have supported Jasmine throughout her epilepsy journey and were delighted to showcase her work as an intensive care nurse helping to care for people with Covid-19. To date I am delighted to say we have raised over £40,000.

We also recently launched a fundraising campaign on Facebook to promote some hard-hitting videos showing how severe epilepsy can be and encouraging people to support ▶

## All about Gordon

### Our new Fundraising Director

Gordon was appointed Fundraising Director of Epilepsy Society in April 2020. He has over 20 years experience of fundraising in the charity sector, most recently in interim Director of Fundraising roles with Prostate Cancer Research Centre, St Clare Hospice and Starlight Children's Foundation.

Previously he was the Director of Fundraising and Marketing at The Royal Star & Garter Homes. He has also worked for Macmillan Cancer Support and WWF-UK. Gordon is a member of the Institute of Fundraising and a Clore Social Fellow.

Gordon has been married for 20 years, has a daughter at University and a son undertaking his GCSE year. He likes to keep fit by running and more recently through Joe Wicks' HIIT Training! He would love to travel more when circumstances allow. In the meantime, he says he is enjoying home-cooked food more than he should.







## Home run

**Louise Berry ran the London Marathon on home territory, supported by friends and family. Well done Louise!**

us. The campaign has been a great success. To date over 3,000 people have got involved and we hope to bring onboard hundreds of new supporters willing to regularly donate by setting up a monthly direct debit.

The Virgin Money London Marathon – The 40th Race – took place on Sunday 4 October and, despite the pouring rain over most of the country, 20 ran their own race and raised over £20,000 for us. The Virgin Money London Marathon will take place in October 2021. We have 45 places and hope to raise at least £65,000.

I want to pay tribute to our fantastic fundraising and marketing team who have worked tirelessly from home during such difficult times. Their dedication and commitment to the cause has been unwavering and through it all the whole team has achieved much,

supported each other and remained positive, upbeat and cheerful in order to raise as much money as possible for the charity we love.

Finally I would like to take this opportunity to thank everyone who supports the Epilepsy Society. Of course everyone is focused on the pandemic, but our work to help those with epilepsy must carry on and we are so grateful to all those who have donated to us during these times.

You, our loyal supporters are more important than ever. Thanks for sticking with us during these tough times and here's to better times in the future and a return to fundraising events where we can all revel in that shared sense of being together and doing something wonderful.

In the meantime all your donations make such a difference and are hugely appreciated.



## Walking tall

**Melica Khansari took on a glamorous but painful challenge, walking 2.6 miles whilst wearing six inch heels. She raised over £1,700.**

**The Virgin Money London Marathon took place on Sunday 4 October... 20 ran their own race and raised over £20,000**



## We did it

**The 2.6 challenge saw 39 people – and animals - from across the UK taking on all sorts of wonderful challenges in support of our work. In total our team, including cats, dogs and tortoises, raised over £35,000.**



## Super Sarah

**Epilepsy Society staff member Sarah Pearson took part in The 40th Race alongside the River Thames and raised £591 whilst beating her PB time as well. Sarah ran 26.2 miles in 3 hours 23 minutes, placing her at 22nd in her age category, 200th woman and 1,745th overall. Amazing.**

**If you would like to donate, you can do so at [epilepsysociety.org.uk/donate](https://epilepsysociety.org.uk/donate) or to discuss any aspect of supporting us call our Donor Care Team on 01494 601 414.**



# Making sure you have the flu vaccine

This year the Government expanded its free flu vaccine programme across the UK. But in spite of our campaigning, it still does not include people with epilepsy. **Nicola Swanborough** looks at the reasons and explains how you can still request a free vaccination


Earlier this year, the Government announced an unprecedented expansion of its free flu vaccination programme across the UK. This would include all those who were on the Covid-19 shielded patient list and members of their household; school year groups up to year 7; people aged over 65; pregnant women; and those with some pre-existing conditions including at-risk under 2s. The programme would also be expanded further to include all those aged 50-64. But it did not include people with epilepsy. This was disappointing news, particularly as it placed the UK behind other countries such as the US, Canada and New Zealand where the benefits of a free flu vaccine are widely recognised for people with epilepsy. Every year people contact us who cannot access a free flu vaccine. Every year we press the UK Government to include people with epilepsy in the list of those who are eligible. Seizures are serious

and can be fatal. A free flu vaccine for people with epilepsy would lower the risk of increased seizures caused by a fever and could mean a reduction in hospital admissions, ultimately saving the Government money. But this year there was an extra urgency. As the country prepared to go into lockdown, the UK Government drew up a list of those who were clinically vulnerable to Covid-19 and at high risk of serious illness. The Department of Health and


Social Care told us that those with epilepsy were not automatically included because they do not meet the criteria to qualify for a free annual flu vaccine. So, we stepped up our campaign to persuade the Government to include people with epilepsy in the free flu vaccine group. We carried out a survey of 680 people who had epilepsy or who cared for someone with the condition. Our survey showed that:

- 70 per cent of people experienced a seizure as a result of a fever


### 680 people replied to our survey looking at the impact of fevers on seizures




**70 per cent of people had experienced a seizure as a result of a fever**



**More than one in five (22 per cent) had paid for a vaccine themselves**



**Almost half (49 per cent) had not been offered a free flu vaccine by their doctor**



**86 per cent would accept a free flu vaccine if it was offered**

- Almost half (49 per cent) had not been offered a free flu vaccine
- More than one in five (22 per cent) had paid for a vaccine themselves
- 86 per cent would accept a free flu vaccine if it was offered.

Medical Director at the Epilepsy Society, Professor Ley Sander (above), was not surprised: “Every day I hear reports in clinic of seizures triggered by high temperatures. For people whose seizures do not respond to current treatments, it is common sense to remove potential triggers where possible.”

In support of our campaign, Dame Cheryl Gillan MP, challenged Health Secretary Matt Hancock in the House of Commons, as to why people with epilepsy were not entitled to a free flu vaccine. She asked him to remedy the situation in order to protect this “valuable cohort of people.”

Mr Hancock told the chamber that the latest information, including the impact of coronavirus on people with epilepsy, would be taken into account in reaching a decision about whether they should qualify for a free flu vaccine.

But when the extended free flu vaccine list was published, those with epilepsy were still omitted. Public Health England’s Immunisation team told us: “In 2011 the Joint Committee on Vaccination and Immunisation (JCVI) considered the inclusion of epilepsy within the clinical risk categories for influenza vaccination and agreed that most

individuals with epilepsy have the disease well controlled and have no co-morbidity (accompanying conditions). Therefore, influenza does not disproportionately impact those with epilepsy compared with the healthy population. Individuals with severe neurological disability are at greater risk from influenza and may also have epilepsy and this group should be offered vaccination according to guidance.”

We believe our survey shows otherwise. When the risk of a seizure increases due to a fever, the risk of physical injury increases along with impact on employment, education and social life.

Our report to the JCVI highlighted that epilepsy is often accompanied by other conditions such as cardiac, gastrointestinal, strokes, dementia and migraine. Additionally, depression, Alzheimer’s disease and migraine are more common in people with epilepsy and are risk factors themselves for developing seizures.

We have since met with Public Health England’s policy team to press further for epilepsy to qualify for a free flu vaccine. They have promised to review the situation with the JCVI and we are currently awaiting their response.

So where does that leave people with epilepsy now? It is important to stress that though epilepsy does not automatically qualify for a flu vaccine, anyone with the condition is still entitled to request a vaccine from their GP.

The NHS has published a list of serious long-term health conditions which qualify for the free flu vaccine. However, it stresses that the list is not definitive and it should always be an issue of clinical judgement.

It states a GP can assess your risk of flu making any serious underlying illness worse, as well as your risk of serious illness from

“Every day I hear reports in clinic of seizures triggered by high temperatures. For people whose seizures do not respond to current treatments, it is common sense to remove potential triggers where possible. This is particularly so in the case of the flu. I always recommend that those in my care have the flu vaccine and I firmly believe that everyone with epilepsy should be entitled to receive it for free.”

**Ley Sander, Medical Director at the Epilepsy Society**


flu. The vaccine should always be offered in such cases, even if you’re not in one of the risk groups. This means that **anyone with epilepsy is entitled to request a free flu vaccine from their GP, even though they are not in the defined risk group.**

Professor Ley Sander is a firm believer in the benefits of the flu vaccine. He said: “I always recommend that those in my care have the flu vaccine and believe everyone with uncontrolled seizures should be entitled to receive it for free, in the interests of their health and safety.”

He has written the following letter which you can download from our website at [epilepsysociety.org.uk/flu-vaccine](https://www.epilepsysociety.org.uk/flu-vaccine) and take to your GP, supporting your request for a free flu vaccine.

### Letter of support from Professor Ley Sander.

(If you are unable to download and print the letter, you can request a printed version by emailing [enquiries@epilepsysociety.org.uk](mailto:enquiries@epilepsysociety.org.uk) or calling 01494 601 300.)



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# Tonic comic

Stand-up comic and all-round funny girl Juliet Stephens has the last laugh when it comes to her epilepsy

Not even Nostradamus saw this coming. Which is ironic given that 2020 vision is said to be so accurate. This has been a strange, scary, year with so many unprecedented features, including unprecedented use of the word 'unprecedented'. Rarely, since the Middle Ages, has the whole world been brought together by a single health event and thankfully there have been some pretty significant medical advancements since the Black Death.

People with epilepsy probably wouldn't have done very well during those superstitious times, so I'm relieved that we are alive now rather than being driven out of the village by an angry mob because someone's cow had died.

I do wonder about our 14th century ancestors – did they try to practise social distancing, how did they find quarantine without the internet, did they also try to master making sourdough bread...? I wonder about the 14th Century SAGE meetings (which would likely have endorsed literal sage as a cure) and a Middle Ages Chris Whitty advising the adolescent Edward III about social health policy. At least toilet roll hadn't been invented so there was no squabbling and hoarding in the aisles at Sainsbury's.

Before March, I thought Zoom was an ice lolly from my childhood, but now we're working and socialising on it and 'Zoom fatigue' is a recognised phenomenon.

Pandemics change things, perhaps they even change us. Who

ever imagined that we would have 'celebrity epidemiologists' or that we would all learn how to pronounce the word 'epidemiologist'.

I had an appointment with my neurologist over Zoom, which was weird, particularly the moment when I thought his screen had frozen but in fact he was just listening intently. Doctors train in developing a really good bedside manner, though traditionally this has always implied the patient's bedside, not the side of the futon in the doctor's spare

**Even senior government advisers don't know their Rs from their elbow**

bedroom. With Zoom you only see the other person's head and shoulders but what might have been under the desk? Pyjamas? Bermuda shorts? Some exotic hosiery?

I don't think any of us has come through this year totally unscathed, either in terms of physical or mental health. It's unnatural for humans to be isolated from each other, and it creates a lot of anxiety about our own health – and of protecting others. I've washed my shopping, but I haven't hugged my Dad.

We have all had to endure a great deal of loss this year and that may be the loss of a loved one, but we have also lost (at least for some periods of time) freedom of movement, of physical contact with

friends, perhaps loss of a job, loss of things we were looking forward to – a birthday, a wedding, an overseas holiday. There's been no Eurovision, no Glastonbury or Edinburgh Festival, no football, no Wimbledon.

And only Six People...unless there are more in your household and unless they go to school, but they must be in their bubbles and if you can work from home you should, though do try to make it into work, and go out to the pubs for half price to help out, but don't stay out past 10pm, especially if you have a phone number that ends in a three, or if you're left handed or have ever been to Alton Towers...

So many rules! All designed to keep the 'R rate' down (another piece of jargon we have picked up this year). It really has been very hard to keep track, so it's understandable that even senior government advisers have been forgiven for not totally knowing their Rs from their elbow.

Perhaps like me you thought that the national lockdown in March would be over by the summer. Pah! How naive we were. It's a Marathon. Actually, it's becoming an Ultra-Marathon. That doesn't mean it'll all be bad. We'll get tired, emotional, and frustrated. We'll also make the odd loaf of banana bread, and watch a classic film to make us laugh.

Ultra Marathon runners take their time, knowing that they are going a long distance, and I think we could do well to learn from them. They are advised to: pace yourself, keep eating, be prepared to spend a lot of time alone, remember that the tough times will pass, and try to enjoy yourself. Wishing you all well in this next stretch.

**Juliet Stephens**  
*Laughing allowed*

## Society matters

### How working together kept residents safe

We have around 100 people living in our care at the Epilepsy Society's Chalfont Centre in Buckinghamshire. All of them have complex epilepsy and associated disabilities. Many of them are in the clinically vulnerable group for Covid-19.

Keeping everyone safe during the pandemic has been a challenge throughout the year and continues to pose ongoing hurdles. But thanks to the incredible dedication of staff, the sacrifice that families and friends have made in not visiting their loved ones unless safe to do so, and the huge support from our local community, we have found ways to cope together.

Very early into the pandemic, our staff recognised that they were possibly the biggest threat to residents, with the fear of bringing the virus into our care homes from outside. Before it became government guidance, we adopted a universal approach of all staff wearing protective personal equipment so as to limit risk.



Masked heroes

We established a system of prompt isolation for any suspected cases of Covid-19, with our Sir William Gowers Centre being repurposed as a safe space for infection control.

And Covid-19 testing was carried out on site and analysed at the Francis Crick Institute. Where we have had isolated cases of Covid-19, we have been able to ensure that the virus has not been transmitted among staff and residents.



Stand and deliver – top takeaways at Epilepsy Society

To say that this has been a Herculean effort would be an understatement. We have increased our team of support workers, with hairdressers, actors, marketing experts and many more retraining to work in care (see Steve Turner's story, opposite).

And we were inundated with help from the local community, including delivery of 300 takeaways for staff and residents from two restaurants in Chalfont St Peter, Chef Zhu and Spice (see above).



Testing times for Matthew Whitson

And a special thanks to Matthew Whitson a physiotherapist from Chalfont St Peter who found himself out of work due to the restrictions of lockdown. Rather than sitting at home, he chose to volunteer at the Epilepsy Society, driving swabs for Covid-19 tests on a weekly basis to London.

Care Services Director at the Epilepsy Society, Jonny Anders-Cannon said: "I have no doubt that Matthew's selfless contribution in driving back and forth to London, often with his wife, helped to preserve life here at the Epilepsy Society."



Steve Turner's story

Find out how Steve Turner swapped marketing for the life of a support worker at [epilepsysociety.org.uk/Steve-Turner](http://epilepsysociety.org.uk/Steve-Turner)

### Grateful families

**Nicola Davies' daughter Emma lives at the Epilepsy Society. There has been limited opportunity for family visits due to restrictions but Nicola found comfort in the kindness and dedication of staff.**

"During lockdown, the staff at Epilepsy Society have been absolute heroes. Not being able

to visit Emma for weeks on end could have been a nightmare. When you have a daughter with severe epilepsy and severe learning difficulties you cannot explain to her that Covid has come and that's why I'm not coming to visit you.

But reassurance came so quickly. I heard about staff teams who were committed, dedicated, selfless and cheerful; who came to work each day despite their own

Covid fears and their own families at home; staff who showed such compassion and understanding when they knew how difficult it was for relatives not to visit.

As relatives we owe them so much gratitude for putting themselves daily at risk whilst looking after our loved ones whilst we could only look helplessly on. They really are simply the best."

**Nicola Davies**





## Helpline

**01494 601 400**

Monday to Friday 9am to 4pm,  
Wednesday 9am to 7.30pm.  
Confidential, national call rate.  
Information and emotional support.

### Epilepsy Society

Chesham Lane  
Chalfont St Peter  
Buckinghamshire  
SL9 0RJ

Enquiries 01494 601 300

Fundraising 01494 601 414

[epilepsysociety.org.uk](http://epilepsysociety.org.uk)



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## Give a little love Leave a lasting legacy

By leaving just 1% of your total worth to Epilepsy Society in your will, you can help fund valuable scientific research to help us treat and beat epilepsy.

To receive your legacy pack call us on 01494 601414 or email [donor.support@epilepsysociety.org.uk](mailto:donor.support@epilepsysociety.org.uk)

To find out more about leaving a lasting legacy visit [epilepsysociety.org.uk/loveliveson](http://epilepsysociety.org.uk/loveliveson)