epilepsy action

epilepsytoday

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Felix's story

Felix's mum Sophie talks about staying connected to her son who died of SUDEP by writing him letters

Also in this issue

- an update on **COVID-19 and epilepsy**
- three people share stories of having their **seizures misunderstood**
- in-depth look at research into **epilepsy medicines in pregnancy**

editor's **letter**

Welcome to the March 2021 issue of *Epilepsy Today*.

We've welcomed in a brand new year, but it feels a bit like groundhog day. We are still in lockdown, still keeping our distance, still aren't able to hug our friends and family and still wondering what's next. But this time, there's a crucial difference – the COVID-19 vaccine. It holds the promise of a better year and an eventual relaxation of the rules currently in place.

The vaccine is important for everyone, but especially those who are at an increased risk of more severe COVID-19 symptoms. A recent study suggests this risk could be slightly higher for people with epilepsy than people without. On page 8, we go into more detail about these findings, and the importance and possible side-effects of the vaccine.

Another piece of recent research has found that more epilepsy medicines than just valproate might cause birth abnormalities in babies if taken during pregnancy. We take a more in-depth look at the findings and share Patricia's story on page 14.

We have a wealth of people sharing their stories in this issue. On page 28, Richard describes his and his wife Sue's experiences being diagnosed with epilepsy in later life, undergoing brain surgery, and living with injuries from ongoing seizures. On page 10, you can read about what Richard, Tayyibah and Amy's seizures have been mistaken for in the past, and why they champion raising more awareness of epilepsy. And you can find the story of our cover star, Felix, on page 20. Sophie describes her son, who loved films, theatre and reading, and how she coped after his death from sudden unexpected death in epilepsy (SUDEP). This is a very difficult topic to think about, but awareness is vital to try to minimise the risks around SUDEP.

Finally, in this issue, we offer up some more recent research. Alice Winsor discusses her research into sleep and epilepsy in children and suggests some ways for a better night's sleep on page 24. Meanwhile, on page 18, you can read about three recent papers on epilepsy service provision, stem cell therapy and a promising seizure prediction study.

This year has started off as challenging as the last, but let's keep our chins up and look forward to an end to this extraordinary pandemic that halted the whole world. We hope you enjoy this issue.

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this **issue...**

Netherlands to honour UK cannabis oil prescriptions

The Netherlands government has confirmed it will continue to supply Bedrocan oil (cannabis-based medicine) for existing UK prescriptions until 1 July 2021, the Department of Health and Social Care (DHSC) has said.

This comes after Brexit took effect on 1 January 2021, and led to prescriptions issued in the UK no longer being honoured and dispensed by EU member states.

This left around 40 children with severe epilepsy, who currently have UK prescriptions for cannabis oil that they source from the Netherlands, in a serious and vulnerable position. A problem with the supply of these medicines would put them at risk of more, more severe or prolonged seizures.

The DHSC added that it will use the time between now and July to come up with a more permanent solution.

Epilepsy Action has written to the Prime Minister to raise concerns around access to cannabis-based medicines. The organisation said that while the actions taken are welcome, they do "not address wider issues around accessing and funding these products on the NHS".

Epilepsy Action is calling on the government to provide financial support for private cannabis oil prescriptions or establish access routes through the NHS.

There is more information at *epilepsy.org.uk/cannabis*

Slightly higher risk of more severe COVID-19 symptoms in people with epilepsy

There is a slightly increased risk of hospital admission and death from COVID-19 in people with epilepsy, according to a new study in the *British Medical Journal* (*BMJ*).

The research, published in October 2020, looked at risk factors for hospital admissions and death from COVID-19 in 6.08 million adults across England. The data were collected between 24 January and 30 April.

Among the risk factors, were conditions for which people are advised to shield, and conditions moderately associated with increased risk of complications from COVID-19, according to current NHS guidance.

The evidence from the research by Clift and colleagues showed a small increase in risk of hospital admissions and deaths resulting from COVID-19 in both men and women with epilepsy. The risk appears to be slightly higher still in men than in women.

As the COVID-19 vaccines have been developed and are beginning to be administered, people with epilepsy aged 16-64 were placed in priority group six out of nine. People 65 years and older will receive the vaccine earlier, based on their age and any other health conditions.

Unpaid carers will also be placed in priority group six for vaccinations.

Among the highest risk factors, according to the *BMJ* study, were conditions like Down's syndrome and sickle cell disease or severe immunodeficiency, as well as treatments like higher grade chemotherapy.

Until now, there was no evidence to suggest people with epilepsy were at an increased risk of more severe symptoms of COVID-19.

A FAIR Health White Paper published in November 2020 looked at risk factors for death from COVID-19 among privately insured patients in the US. The findings of this paper are in line with the *BMJ* study when it comes to epilepsy – it identified a slightly increased risk.

Dr Markus Reuber, professor of Clinical Neurology at the University of Sheffield, said: "Epilepsy emerges as a factor associated with a slightly higher risk of death or of hospital admission due to COVID-19 in this dataset. This does not mean that epilepsy is the cause of this higher risk."

Dr Reuber explained that a diagnosis of epilepsy could be a marker of other features more directly linked to the risk of more severe COVID-19 infection. These could include more contact with professional carers, attendance of educational settings and other conditions linked to or causing the epilepsy.

Dr Reuber also pointed out that further social withdrawal could be harmful for some people with epilepsy, especially in people already facing stigma or social exclusion.

Dr Rhys Thomas, consultant neurologist at the Newcastle upon Tyne Hospitals NHS Foundation Trust, said: "Population data have identified health features that increase the risk for COVID-19 severity. It is unclear how this contributes to an individual's risk. People with an intellectual disability appear to be at a greater risk of COVID19 severity, and to a much lesser extent the same appears to be the case for people with epilepsy."

Dr Thomas concluded that this risk is not high enough to ask people with epilepsy to strictly shield. However, it is enough to show the importance of continuing to wear face masks, keep a distance from others and wash our hands as advised.

The full *BMJ* study is available online at *bit.ly/2Kjn4Lr*

There is more information about epilepsy and COVID-19 on the Epilepsy Action website at *epilepsy.org.uk/COVID*

You can read more on this story on page 8.

SUDEP deaths doubled in pregnant and post-natal women with epilepsy

A "concerning doubling" in maternal deaths due to sudden unexpected death in epilepsy (SUDEP) was seen between 2016-18 compared to 2013-15, a new report has shown.

Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK (MBRRACE-UK) published their report '*Saving Lives, Improving Mothers' Care 2020* in January. Of the 2.2 million women who gave birth over the two years, 547 women died during pregnancy or up to one year afterwards. The report found that generally, pregnancy remains very safe in the UK.

However, it said a "key focus" in this year's report is the fact that the number of women with epilepsy dying during pregnancy or the year after pregnancy from SUDEP had doubled. According to the report, "in many instances, these deaths are linked to inadequate medications management for these women either before or during their pregnancy".

The report stressed that SUDEP needs to be discussed in this group. It found that "most women with epilepsy who had died had clear risk factors for SUDEP, but had not had risk or prevention measures discussed with them".

MBRRACE-UK advises that women have a pre-pregnancy discussion with their epilepsy team well before considering pregnancy, to agree a plan. The report stressed that women shouldn't stop taking their epilepsy medicines when they become pregnant, but should instead discuss them with their epilepsy specialist team. The team can help women make the right choices for them.

The report suggests that women with epilepsy need to be aware of the risks of SUDEP and epilepsy and how they can be reduced. A free app called EpSMon (available at sudep.org/epsmon) can be used to help with this.

MBRRACE-UK is also calling on healthcare professionals to support women with epilepsy with their pregnancies as early as possible. Health professionals should check that conversations have been had about minimising SUDEP risk and about the valproate Pregnancy Prevention Programme, it says. They should use a standardised safety tool, such as the SUDEP and Seizure Safety Checklist (sudep.org/checklist). The report also highlights the importance of joined up working between different specialists in maternity and epilepsy services.

Philip Lee, Chief Executive at Epilepsy Action, said: "It is extremely concerning to hear of the findings of the MBRRACE report, which found that the number of women with epilepsy dying during, or after pregnancy has increased from 13 in 2013-15, to 22 in 2016-18.

"We support the recommendations and urge healthcare professionals to work together to ensure issues are fully discussed and women are appropriately supported. Importantly, women must not stop taking their epilepsy medicines without talking to a healthcare professional first."

The report has also found that outcomes also differ across different areas and ethnicities for women. Those who are from more deprived areas, and those of Asian, Black or Mixed ethnic groups are at a higher risk of dying in pregnancy. Heart disease remains the leading cause of death in pregnancy, followed by blood clots.

The Epilepsy Action website has more information at *epilepsy.org.uk/SUDEP* and *epilepsy.org.uk/pregnancy*

The full report is available at *npeu.ox.ac.uk/mbrrace-uk*

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New TikTok feature to protect people with photosensitive epilepsy

Social media platform TikTok is adding a new feature to protect people with photosensitive epilepsy from landing on content that could trigger a seizure.

The feature will work by bringing up a warning on content that contains flashing images that could trigger a seizure in people with photosensitive epilepsy.

People will have the option to 'skip all' similar content as well, according to TikTok's director of product, trust and safety, Joshua Goodman. He explained the feature was designed after speaking to epilepsy experts about the challenges faced by people with this kind of epilepsy.

The global platform previously included a feature allowing content creators to put a seizure warning on their own content. While useful, this missed the mark in protecting users with photosensitive epilepsy from deliberate attacks.

Earlier this year, TikTok was under pressure to act to protect people with epilepsy again, by removing harmful #seizurechallenge videos.

There is more information on photosensitive epilepsy at *epilepsy.org.uk/photosensitive*

Open letter calls for more access to cannabis medicines

The families of the campaign End Our Pain have written an open letter to the Prime Minister Boris Johnson to ask for his support with cannabis-based medicine prescriptions.

The campaigners, alongside Epilepsy Action, have been calling on the government to deliver on promises made two years ago to increase access to cannabis-based medicines for those who need it.

In November 2018, it became legal for specialists to prescribe cannabis-based medicines to those with "exceptional clinical need". However, since then, only three prescriptions for medicines containing cannabidiol (CBD) and tetrahydrocannabinol (THC) have been made, according to End Our Pain. CBD and THC are both parts of the cannabis plant, but THC is associated with the part of the plant that causes the feeling of a 'high'.

The open letter asks the government to provide financial support or provide alternative access to cannabis-based medicines through the NHS as a matter of urgency.

The organisations are also asking for the government to honour previous commitments to an 'alternative study' into the safety and effectiveness of these medicines. They stress that these trials and studies are needed urgently and should be undertaken as soon as possible.

More epilepsy medicines linked to birth defects if taken during pregnancy

Several epilepsy medicines carry risks when taken in pregnancy, a review published on 7 January by the Medicines and Healthcare products Regulatory Agency (MHRA) has found.

The review, from the Commission on Human Medicines, looked at all the available safety data about 10 of the most commonly prescribed epilepsy medicines. The full review is available at: *bit.ly/3bgdsMp*

The medicine sodium valproate is known to cause an increased risk of birth defects and developmental problems in babies if taken during pregnancy. This prompted the review of the risks for other epilepsy medicines.

The review found that four out of the 10 epilepsy medicines increased the risk of a baby being born with a physical birth abnormality if taken during pregnancy. These were carbamazepine (brand name Tegretol), phenobarbital, phenytoin (brand name Epanutin) and topiramate (brand name Topamax).

Some of the medicines also increased the risk of children having learning or thinking difficulties later in life, or of babies being born smaller than average.

None of these medicines carried as high a risk if taken during pregnancy as sodium valproate, according to the review findings.

Lamotrigine (brand name Lamictal) and levetiracetam (brand name Keppra) were found to be safer in pregnancy.

A further 11 medicines were included in the review, but there was not enough evidence to reach a conclusion about their safety when used during pregnancy. More data are needed on these medicines to be able to comment on their safety during pregnancy.

More information on the medicines involved in the review and effects if taken during pregnancy is available on the Epilepsy Action website at: *epilepsy.org.uk/medicines-pregnancy*

Epilepsy Action stresses that it is important women do not stop or change how they take their epilepsy medicine without speaking to their doctor. Uncontrolled epilepsy can cause harm to both the mother and the unborn baby. The organisation advises anyone worried about their medicines to contact their epilepsy doctor or nurse.

Epilepsy Action is pushing for the swift circulation of these findings to healthcare professionals so they can help patients make informed choices. The organisation warns that mistakes made handling the safety information of sodium valproate must not be repeated.

Epilepsy Action says this information could affect the choices of thousands of women with epilepsy, as well as raise concerns about the effects of these medicines if they've been taken during pregnancy in the past.

Louise Cousins, director of External Affairs at Epilepsy Action, said: "It is imperative that this information is circulated to doctors and nurses widely and quickly. Past mistakes must not be repeated. We know that the consequences of women not knowing information such as this can be devastating. No woman or girl should be taking an anti-epileptic medication without them, or their family, being aware of the risks.

"We know that this new information may cause women with epilepsy and their families to feel worried. We urge anyone with concerns about medication they are taking, or have taken in the past, to speak to their doctor or nurse, or call the Epilepsy Action Helpline on 0808 800 5050."

The organisation has written to Health Secretary Matt Hancock, calling for the reintroduction of pre-conception counselling for all women with epilepsy as an indicator in the Quality and Outcomes Framework (QOF). This will encourage GPs to talk to women about their options and the risks associated with these before becoming pregnant. Epilepsy Action has recently begun a new study with the University of Liverpool to design an ideal pathway for pre-conception counselling.

Epilepsy Action is also pushing for the recommendations of the First Do No Harm report published following the Cumberlege review into three 'public health scandals', to be implemented in full.

There's more on this story on page 14.

Step Together report on services for epilepsy and learning disabilities

New guidance to improve epilepsy treatment for people with learning disabilities was launched in November 2020.

The guidance report, Step Together, reveals that huge variations in levels of care might be failing people with epilepsy and a learning disability.

Four out of every 10 people with epilepsy also have a learning disability and are at a higher risk of premature death than the general population.

The guide describes good quality joined-up services for people with a learning disability and epilepsy. It allows commissioners to assess whether needs are met by the current services. It also offers examples of ways to increase joint working, improve services and reduce the variation of levels of care.

The report was created jointly by a number of organisations. They include Epilepsy Action, the International League Against Epilepsy – British Chapter, the Royal College of Psychiatrists, Research in Developmental Neuropsychiatry and the Epilepsy Specialist Nurses Association UK.

Dr Rohit Shankar, consultant neuropsychiatrist and project lead for Step Together, said the guidance will be useful to care providers and commissioners. He said it will allow them "to recognise what is currently available to people and what could or should be available if their needs are going to be fully and satisfactorily met". He added that the guidance should be used to transform services and be ambitious for good epilepsy management and getting the best possible seizure control for people with epilepsy and a learning disability.

"It is clear more [joint] working between general practice, learning disability mental health services, specialist nursing services, and neurology and epileptology services is needed," Dr Shankar added.

Angie Pullen, director of Epilepsy Services at Epilepsy Action, said: "People with epilepsy and learning disabilities, their carers and families have told us that they need services to work better together. Too often they have difficulty understanding how to access the support they need. People found that no one was listening to their concerns or taking action to put things right. This Step Together guidance adopts the principles of 'Ask Listen Do' which are used by Epilepsy Action and promoted by NHS England. The launch of Step Together marks the start of a journey towards improving the experiences of people with epilepsy and a learning disability and working together for better care and support."

The full report is available at *bit.ly/2MqW8u0*

Remote versus face-to-face seizure clinics

Epilepsy Action and Epilepsy Research UK are jointly funding a new research project comparing remote and face-to-face seizure clinic consultations.

The research, led by Prof Markus Reuber, will aim to help clinicians improve how they communicate in remote clinics and avoid pitfalls in this type of appointment.

The study will look to understand why remote seizure consultations, which have become widespread around the coronavirus pandemic, appear to be generally shorter. It will also shed light on how clinicians can reduce the risk of misunderstandings and how to best involve patients in making decisions about their healthcare when they are not talking face-to-face.

The study will start at the beginning of 2021 and will be carried out by the University of Sheffield in the UK.

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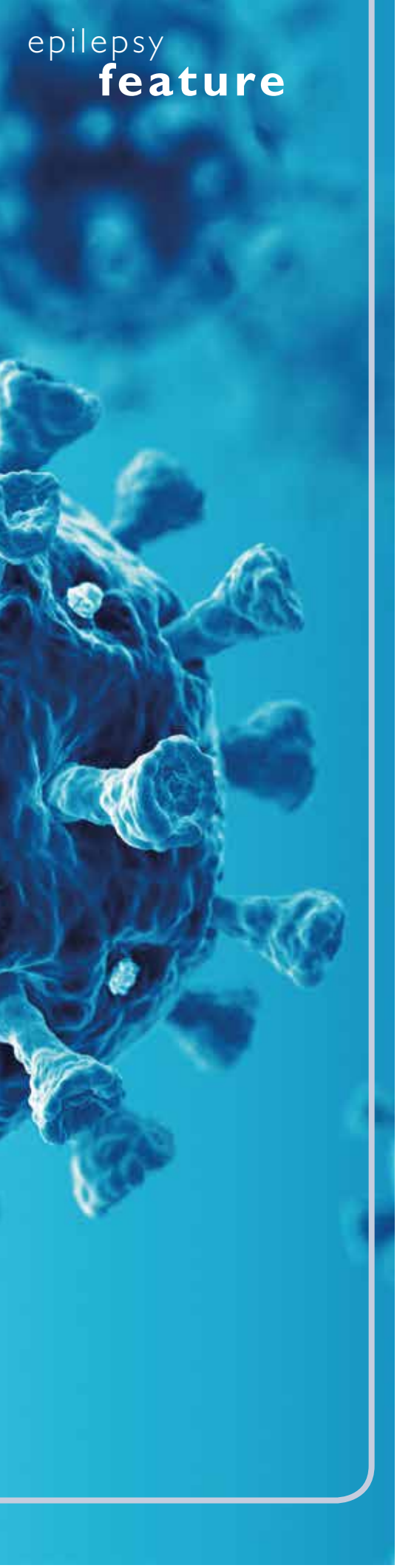
Epilepsy Action deputy chief executive retires

After 19 years of service as the deputy chief executive of Epilepsy Action, Simon Wigglesworth retired at the end of 2020.

Mr Wigglesworth has been instrumental in improving health services for people with epilepsy, including supporting the implementation of The National Institute for Health and Care Excellence (NICE) guidelines. He has also been part of campaigning for wider access to epilepsy surgery for children and raising awareness of the need for pre-conception counselling for women with epilepsy. He was previously a trustee of the Neurological Alliance for six years. He was also a trustee and treasurer of the Joint Epilepsy Council, an umbrella body of epilepsy charities in the UK and Ireland, for eight years.

Philip Lee, chief executive of Epilepsy Action, said: "Simon is leaving us with our heartfelt thanks for everything he has done for the charity and for people with epilepsy. Everyone at Epilepsy Action would like to wish him all the best in whatever adventures he has in front of him. Epilepsy Action has now begun the search for a new deputy chief executive who we hope will come into post early in 2021."



COVID-19 and epilepsy update

A month into our third national lockdown, we take a more in-depth look at some of the recent news around COVID-19, epilepsy and the COVID-19 vaccine

As we welcomed 2021 in, we hoped for a better year than 2020. Four days in, and a new national lockdown was announced to try to control the spread of a new, fast-spreading variant of the infamous coronavirus. Despite a seemingly tougher start than last year, there is a lot to be optimistic about. Last year we saw the development of the fastest vaccine ever created, benefitting from the full attention of the relevant research facilities, and enough funding to get it made. This year, the government plans to roll out the vaccine in order of priority to try to reduce the devastating impact of COVID-19.

This gives a lot of hope for reducing the number of deaths associated with COVID-19, as well as for loosening the restrictions which have been taking their toll on many people's mental health and wellbeing.

However, for people with epilepsy, there are still concerns around COVID-19. In October 2020, a study reported in the *British Medical Journal* (*BMJ*) that people with epilepsy could be at a slightly higher risk of hospital admissions and death than the general population (more on page 4). This was taken on board by the Joint Committee on Vaccination and Immunisation, which advises the UK health departments on vaccine priority. In December, the committee said people with epilepsy should be included in one of the groups who receive the COVID-19 vaccine earlier.

All of this can be understandably quite worrying for people. While the *BMJ* study did show a slight increase in risk of more severe symptoms of COVID-19 in people with epilepsy, epilepsy specialists warn that these findings aren't necessarily the whole story. Prof Markus Reuber, professor of Clinical Neurology at the University of Sheffield explained that the findings don't necessarily mean that epilepsy itself is the cause of this increased risk.

Prof Reuber explained that a diagnosis of epilepsy could be a marker of other features more directly linked to the risk of more severe COVID-19 infection. These could include more contact with professional carers, and other conditions linked to or causing the epilepsy.

Prof Reuber said that the *BMJ* study findings suggest that there could be an increased risk for people with epilepsy, but it does not prove a definite link. He also stressed that there is a harm in further social withdrawal in some people with epilepsy, especially where they are already facing stigma or social exclusion.

Dr Rhys Thomas, consultant neurologist at the Newcastle upon Tyne Hospitals NHS Foundation Trust said it is unclear how the findings of the *BMJ* paper contribute to an individual person's risk. "[The risk identified by the study] is not sufficient to ask people with epilepsy to strictly shield or to identify themselves as highly vulnerable. But it further emphasises the need for all of us to keep up our efforts to wear face masks, keep our distance from others and wash our hands, as advised."

In light of these findings, people with epilepsy have been placed in the sixth out

of nine priority groups for the COVID-19 vaccine. Group six includes people aged 16-64 with underlying health conditions which put them at higher risk (which includes epilepsy). Anyone aged 65 and over will receive the vaccine before this, as older age itself is a risk factor for more severe COVID-19 symptoms. It is important to note that unpaid carers of people who would be at risk if the carer became ill will also be included in priority group six.

The COVID-19 vaccines approved for use in the UK have met the safety standards set by the Medicines and Healthcare products Regulatory Agency (MHRA). Epilepsy Action explains that millions of people have been given a coronavirus vaccine and reports of serious side-effects, such as allergic reactions, have been very rare.

The MHRA has told Epilepsy Action that the risk of a vaccine interacting with any medicines, including ones for epilepsy, is very low. This is because vaccines work in a different way to conventional medicines.

However, some people have shared concerns with Epilepsy Action about fever being a possible side-effect of the vaccine. For some people, fever can be a trigger for their seizures. Dr Rhys Thomas explained that this is a fair concern. He gave as an example the safety data of the BioNTech vaccine, developed by Pfizer. He explained that looking at the side-effects data, after the second dose, around one in three people aged 18-55 had a high temperature. However, he added that the data also showed that where a fever did occur, most people's (93%) temperature didn't rise over 38.4°C, so was unlikely to trigger a seizure.

The Moderna vaccine had a rate of around one in six people aged 18-64 having a fever after the second dose of the vaccine. Of these, only around two in 100 people had a fever of over 39°C. For both this and the BioNTech vaccine the risk of fever was lower in higher age groups.

Another vaccine, AstraZeneca, developed by the University of Oxford, has been approved by the MHRA for administration in the UK. Safety data from this vaccine suggest that fever can affect up to one in 10 people. However, safety data show that after either dose, only around three in 100 people had a temperature that was over 38.4 °C.

People with epilepsy are in priority group six for the COVID-19 vaccine

Dr Thomas also stressed that it's important to remember the risk of a fever and possible resulting seizures is smaller with the vaccine than it is if a person was to get COVID-19. In the event of a fever, the NHS says people can take paracetamol or ibuprofen to help bring the temperature down. Epilepsy Action says that both are safe for most people with epilepsy, but people should check with their pharmacist that they don't interact with their epilepsy medicines.

The government has begun its vaccination programme, with those most vulnerable and most exposed to the virus receiving the first doses. This includes older adult residents of care homes, and their carers, people over the age of 80 and frontline health and social care workers. The government plans to continue to move down the priority groups in the coming months.

It is an understandably concerning time for many people, and for people with epilepsy, there are extra considerations. We have faced a strain on epilepsy services, causing rescheduled appointments and delays in treatments such as brain and VNS surgery. Many of us have tackled social isolation and loneliness resulting from now three national lockdowns and 10 months of restrictions. And now we can add to the list concerns about how COVID-19 may affect us if we were to become ill with it.

But we do have a lot to be hopeful about. Our NHS staff have worked incredibly hard to help bridge the gaps left by COVID-19, with measures such as video clinics in place so people continue to have contact with their health professionals. The vaccine itself is a big beacon of hope that we may soon return to what we used to know as 'normal'. It is also encouraging to know that the potential slight increase in risk of severe symptoms of COVID-19 in people with epilepsy has been taken seriously enough to be placed further up the queue for the vaccine.

If you are worried about the risks around more severe COVID-19 symptoms or a possible fever resulting from the COVID-19 vaccine, it may be helpful to discuss this with your epilepsy doctor, epilepsy specialist nurse or GP. They would be able to advise you on your individual level of risk, taking into account your specific epilepsy and any other medical conditions you may have.

There is more information about epilepsy and COVID-19 on the Epilepsy Action website at: *epilepsy.org.uk/COVID* or you can call the Epilepsy Action Helpline for free on 0808 800 5050.

Mistaking seizures

Richard, Tayyibah and Amy share their experiences of their epilepsy and seizures being mistaken and misunderstood

Epilepsy is often misunderstood. People think it's a mental health condition, or that it's 'just seizures', or – even to this day, albeit rarely – that it's a supernatural possession. The misunderstandings don't end there. Most of us will have likely had our seizures mistaken for something else at one time or another. People might have thought we were drunk, under the influence of drugs, daydreaming or rude, when we've actually been having or recovering from a seizure.

These misunderstandings might seem like harmless mistakes, but they can actually be quite upsetting and isolating for many people. They can have an impact on self-confidence which can then impact a person's social life. They can also cause problems if they are made by authority figures, such as teachers or police officers. The seizures themselves usually render us vulnerable and unable to explain what is happening.

This is a reality for many people with epilepsy. Richard, Tayyibah and Amy share their experiences of having their epilepsy misunderstood and their seizures confused for other behaviours.

Richard

I have had temporal lobe epilepsy since I was born. My mum told me I had my first seizure when I was not even a day old. I have tonic-clonic seizures and focal seizures. I take lamotrigine and oxcarbazepine for my epilepsy and I also have a vagus nerve stimulator (VNS).

When I've had tonic-clonic seizures in the past, people usually recognised these as a seizure or as epilepsy. I had warnings, which I now realise were focal seizures, but they used to last less than a minute or two. In more recent years, I don't always go into a tonic-clonic, so I might just have focal seizures for several minutes. During these seizures, I become unaware, and I instinctively try to move away from people. I've been told I lose my balance, fall over and grab at things to try to stand up again. I can't respond to people at that time, so people often think I'm drunk or that I've taken drugs.

Once I was out with friends and I had a focal seizure. It was getting late in the evening and some police community support officers thought I was drunk even though my friends told them this

wasn't the case. They tried to restrain me during my seizure, and I and one of the officers ended up injured because of this. My friend called an ambulance and when they arrived, the paramedics told the community support officers that they would handle the issue.

Another time, I had a seizure while waiting in A&E at the hospital. Security staff had assumed I had been taking drugs, as I was losing my balance and making strange sounds. I think I must have been trying – and failing – to talk. I was told afterwards that security were trying to make me leave the hospital. My sister intervened and explained what was happening, and a doctor came over and moved me to a secure room. If it had not been for the doctor taking over, I think I would have been physically removed from the hospital. On many occasions the general public confuse my seizures

> **Some police community support officers thought I was drunk**, even though my friends told them this wasn't the case

for other behaviour, but I didn't expect it at the hospital. I made a complaint and was told steps would be taken to educate non-medical staff on medical conditions which could be mistaken for someone who's had drugs or alcohol.

These misunderstandings are an issue for me. I've had bruises and injuries resulting from attempts to physically restrain me. People not knowing about epilepsy has also caused them to call ambulances for me when it's not been needed. One time I had a seizure while waiting for an interview for a benefits assessment. I was taken to hospital in an ambulance and missed the interview, and it was recorded that I didn't attend. My benefits were suspended for a week while we cleared up what had happened.

I would like to see more awareness of epilepsy, and more unusual seizures in particular, in the general public. I'd especially like figures of authority, like police and security staff, who may come into contact with people with epilepsy, to better understand different types of seizures.

Tayyibah

I was diagnosed with epilepsy at 11 years old. I have medicine-resistant epilepsy with no known cause. I have a whole range of focal and generalised seizures – absences, tonic, clonic, tonic-clonic, atonic and myoclonic seizures.

I have focal aware seizures, where I get a rising feeling in my stomach, and stiffness in some parts of my body or tingling in my arms and legs. I also have focal impaired awareness seizures, where I make random body movements like moving my arms uncontrollably, picking at my clothes, rubbing my hands or smacking my lips. My absences can look like I'm daydreaming, but sometimes my arms would jerk slightly as well. My myoclonic seizures are just short twitches or jerks, but these can cluster, so several can occur in a short space of time – often, for me, it's soon after waking up.

My epilepsy seemed mild in childhood, with fewer seizures, but when I started taking medicines, my seizures increased significantly. I also started having heart palpitations and anxiety.

I've tried a number of medicines but they haven't seemed to stop or even reduce my seizures – they seem to make my seizures worse. I've also had huge rashes on my body from medicines. I briefly tried the ketogenic diet, but because I have an eating disorder and anaemia, the treatment had to be stopped immediately. My weight was rapidly dropping and this was increasing my seizures and affecting my heart.

The general public, and more specifically the Asian community, misunderstand my epilepsy on a daily basis. Despite it being the 21st century, I have still had my seizures associated with religion, linked to the devil or believed to be a supernatural curse, rather than being a medical

Tayyibah's absence seizures at school were mistaken for nervousness and a lack of confidence

Amy said people sometimes laugh when she has a seizure or think that she is drunk

condition. Members of my community cut ties with me and treated me like an outcast, and I have faced verbal abuse.

Misunderstandings of my condition have also led to bullying at school by other students and by teachers. My absences were often mistaken for daydreaming or clumsiness. A teacher put me in a lower set despite my promising grades, as he mistook my seizures for being nervous and unconfident in myself and my work. Even once he knew I had epilepsy, he made me stand up in front of the class, which was humiliating. The other children laughed at me and impersonated my seizures, and when I got home I just cried with embarrassment.

Another time, I had a focal aware seizure in front of a bus. It nearly hit me but my sister pulled me back. The bus driver thought I was joking around and deliberately trying to irritate him, so he got out of the bus and started yelling at me and using foul language. This was in the middle of the busy city centre and people were gasping at me and thinking I was playing a sick joke that put people's lives at risk.

All of this caused my mental health to suffer and I developed anorexia, which eventually led me to being admitted to hospital. I was lonely and isolated and I was refusing to accept that my relationship with food had changed. My condition was very severe and had the potential to make my seizures even worse. My family have also struggled to understand the impact my epilepsy has on my mental health. For example, through university, they organised for me to have a chaperone all the time, thinking this would keep me safe. This made it really difficult and uncomfortable to try to make friends. I tried to confide in my sisters, but they just laughed.

My epilepsy has also affected my ability to work. I have successfully impressed employers with my academic ability but failed miserably when employers asked after my health. I have faced numerous rejections from employers and I've also faced obstacles trying to get volunteering work and apprenticeships because of my condition.

I want to see more education for children in schools from an early age about epilepsy. I also want to see more awareness among everyone – people of all ages, cultures, religions and walks of life – about epilepsy and how to help someone having a seizure. I would love to see more motivational talks from famous people with epilepsy and more government funding into the condition.

Amy

I have generalised epilepsy with tonic-clonic and absence seizures. I also have dissociative seizures and occasionally have jerks or tics. My main triggers are loud noises, stress, anxiety or panic attacks, lack of sleep and becoming too hot. Hormone changes and low blood sugar can also affect my seizures.

It took nearly six months to get diagnosed with epilepsy after my first tonic-clonic seizure. For my epilepsy, I take levetiracetam and lamotrigine twice a day.

When I have absence or dissociative seizures, it looks like I'm daydreaming, except that I start to blink a lot and I rock slowly back and forth. But unless you are aware of this, you wouldn't notice. People assume when I'm having an absence or dissociative seizure that I'm not paying attention. This can cause them to become irritated with me as they think I don't care about what they're saying, when, in fact, I can't help not being able to respond.

> I would like to see people who don't have epilepsy be educated on **how to treat someone with epilepsy in general and during seizures**

Occasionally, when I'm having an absence seizure, my face can fall on one side and my eyes can cross. Unfortunately, due to lack of understanding, people either laugh at me or think I'm drunk. When I have a tonic-clonic seizure, people tend to panic

and, unless they are trained in first aid, they tend to do the wrong thing like pin me down.

I often feel like an outsider because the first thing I have to do is tell people I have epilepsy and what to do if I have a seizure. This affects my social life as well, because I don't want to be out in public and be taken to hospital if I have a seizure. Also, in my experience, people assume epilepsy is a mental health condition which can be cured, when in reality it's a neurological condition which needs to be managed.

People misunderstanding my epilepsy has really knocked my confidence and lowered my self-esteem, but when people are ignorant or dismissive about my epilepsy, that hurts the most. One example of this is when I was at work and the health and safety officer, who was aware of my condition and that loud noise is a trigger, did a fire drill. I had a big tonic-clonic seizure as a result and when I came round, in my confusion, I had a panic attack. Once I had recovered somewhat, I went to get checked over by the doctor and I'd sustained a mild concussion and lots of pulled muscles.

I would like to see people who don't have epilepsy be educated on how to treat someone with epilepsy in general and when they have a seizure. It would be good if more people knew to look for medical ID bracelets or information on phones or in wallets in a first aid situation. I feel that epilepsy first aid should be taught in schools, colleges and universities as epilepsy is a common condition and knowing what to do could potentially save lives. Most people only know about tonic-clonic seizures, and there are many different types, so people should be educated on other types of seizures and how to help with these too.

Awareness

Raising awareness about seizures and epilepsy is incredibly important to try to combat many of these misconceptions. It is clear that these mistakes aren't always harmless and can have an impact on a person's daily life, mental health and self-confidence. Educating figures of authority on what is one of the most common neurological conditions seems like an important step to protect and support people with epilepsy.

Epilepsy Action has online materials for schools, workplaces and health and social care workers, and offers epilepsy and first aid training. For more information, visit ***epilepsy.org.uk/training***

Help while you're winning

For just £1 you can win up to £25,000 in cash with the Epilepsy Action weekly lottery!

And if that's not enough, 50p of every £1 played goes to support work to help people living with epilepsy.

The more you play, the more you help – and the more chance you have of a massive cash prize!

So far, Epilepsy Action supporters have won over £18,000 in prizes from the weekly lottery. Proceeds from entries contribute over £11,000 a year to vital services like the Epilepsy Action Helpline, website and support groups.

You can enter the Epilepsy Action weekly lottery for as little as £1 a week. There's a draw every Friday and the big prize every week is a huge £25,000! There are also prizes of £1,000, £25 and free extra entries into future draws.

Join the weekly lottery today at ***epilepsy.org.uk/win*** or by calling Jenny on 0113 210 8822.

Medicines and pregnancy

The risks of taking valproate in pregnancy have been receiving a lot of media attention recently. But a new review has raised concerns that other epilepsy medicines also carry a risk in pregnancy

A review was published on 7 January this year by the Medicines and Healthcare products Regulatory Agency (MHRA) showing epilepsy medicines other than valproate also carry a risk to babies if taken during pregnancy.

Valproate medicines have been the subject of much scrutiny over the last few years because of their effects if taken during pregnancy. In this latest review, they were still found to have the highest risk to unborn babies. Figures suggest it can cause physical birth abnormalities in one in 10 babies and learning or thinking difficulties in up to four in 10 babies born to women taking the medicine during pregnancy. Valproate medicines include sodium valproate and valproic acid. Brand names include Epilim, Depakote, Convulex, Episenta, Epival, Kentlim, Syonell, Orlept and Valpal.

A lack of transparency about these effects for many years created a public health scandal, with an estimated 20,000 children in the UK affected by this medicine.

A two-year review, carried out by Baroness Julia Cumberlege, which was published in 2020, made "wide-ranging and radical" recommendations to improve the healthcare system. The review urged the government to offer support to those affected by sodium valproate and two other medical products included in the review, Primodos and pelvic mesh.

The gravity of the situation was not lost on Baroness Cumberlege, who 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."

As well as urging the government to acknowledge how people have been affected and take action to support them, the review also prompted the MHRA to look into the effects of other epilepsy medicines.

The new review by the MHRA published this year (page 6) highlights that other epilepsy medicines could also increase the risk of babies being born with physical birth abnormalities or learning or thinking difficulties.

The review looked at the available safety data for epilepsy medicines. As well as valproate, four others were found to increase the risk of a baby being born with a physical birth abnormality – carbamazepine (Tegretol), phenobarbital, phenytoin (Epanutin) and topiramate (Topamax).

In the general population, about two or three in 100 babies are born with a physical birth abnormality. In women taking carbamazepine or topiramate,

around four or five babies in 100 are born with a physical birth abnormality. In those taking phenytoin, the risk rises to around six babies in 100, and for those taking phenobarbital, it is six or seven babies in 100. In valproate, the risk is 10 babies in 100 – or more simply, one in 10 – being born with a physical birth abnormality.

Taking phenobarbital or phenytoin during pregnancy was also found to increase the risk of a child having learning or thinking difficulties later in life. The exact risk is not known, but it is thought to be smaller than if taking valproate.

Phenobarbital, topiramate or zonisamide taken during pregnancy also increased the risk of a baby being born smaller than expected compared to the general population, according to the study.

The review found that taking lamotrigine (Lamictal) or levetiracetam (Keppra) during pregnancy was safer than other epilepsy medicines. They did not increase the risk of physical birth abnormalities in babies compared to the general population. There was not enough information to be sure if they carry a risk of learning or thinking difficulties in children, but the limited information did not suggest a risk.

It is important to note that other epilepsy medicines were also included in the review, but there was not enough data on their use in pregnancy to draw a conclusion on their safety. These included gabapentin, pregabalin, zonisamide and clobazam. The report says that some research suggests that taking pregabalin or clobazam during pregnancy may slightly increase the risk of physical birth abnormalities in babies. However, this can't be confirmed or ruled out, as more data are needed to draw a firm conclusion.

Louise Cousins, director of External Affairs at Epilepsy Action, stresses that no woman or girl should be taking an epilepsy medicine without the risks in pregnancy being made clear to her or her family. She warned that women not knowing information like this can be devastating.

Ms Cousins said: "Women with epilepsy often face difficult choices when they consider how to manage their condition through pregnancy. It is essential that they receive pre-conception counselling so they can work with their health professionals to make an informed choice.

"The review was unable to establish the risk in pregnancy of more epilepsy medications than those it was able to reach conclusions about. This is deeply concerning. We are urgently calling for more research looking into the risks of epilepsy medicines in pregnancy, including the risks of taking more than one medication at once – something many people with epilepsy have to do."

It is essential that women with epilepsy receive pre-conception counselling so they can work with their health professionals to make an informed choice

This information can be very alarming, but it is important not to stop taking your epilepsy medicines, unless advised to do so by your doctor. Stopping your medicines can cause an increase in seizures which can be dangerous for you and your unborn baby.

Epilepsy Action is urging anyone worried about their medicines to speak to their epilepsy doctor or epilepsy specialist nurse, or to call the Epilepsy Action Helpline for free on 0808 800 5050.

For anyone taking epilepsy medicine and considering starting a family, medical professionals advise having pre-conception counselling before becoming pregnant. This can provide the best chance of having a healthy pregnancy, provide an opportunity to ask questions and allow for medicine adjustments, if they are needed.

Unfortunately, the medicine review findings also mean that families may have already been affected by taking an epilepsy medicine that carries a risk during pregnancy.

Patricia was diagnosed with juvenile myoclonic epilepsy (JME) when she was around 20 years old. She has been prescribed several epilepsy medicines to help with her seizures.

"The first medicine I was prescribed was Epilim (sodium valproate) and I have remained on it ever since. This was gradually increased over time, until I was on a high dose of 2000mg a day. In addition to Epilim, I have also been prescribed other AEDs including phenytoin, clonazepam and lamotrigine, all of which have been used alongside the same high dose of Epilim."

Patricia has two children – Joseph, who is 20, and Amèlie, who is 11, both of whom have been affected by the epilepsy medicines she took during pregnancy.

Joseph had to go in an incubator when he was born, because of a problem with his windpipe and to keep his temperature steady.

"Over the years, he has been diagnosed with learning difficulties, dyslexia, autism, extreme anxiety and a sleep disorder. His anxiety is so severe, it causes him pain in his chest and stomach, as well as panic attacks. Things out of his routine

Patricia was not warned of the risks of taking her epilepsy medicine during pregnancy


Patricia and Joseph

cause him an immense amount of distress and anxiety. Joseph also has flat feet and shortened Achilles' tendons, for which he needed a lot of treatment when he was younger, including splints, castings and physiotherapy. Despite all of this, he still walks on his toes and can't stand with his feet flat on the floor."

Joseph has also had to have surgery for a hernia and has been diagnosed with a heart murmur. He is sensitive to light, noise and touch, and Patricia worries that his learning difficulties make him very vulnerable.

"He is unable to organise himself and needs a lot of repetitive input and prompting from us in order to get him to complete tasks. He has no real concept of money and is extremely vulnerable with this. He has sadly previously been taken advantage of in this respect."

When Amèlie was born, she needed resuscitation. From a newborn, she didn't respond to her hearing screening tests and was later diagnosed with hearing loss. She had surgery as a two-year-old which improved her hearing a little, but she still has hearing loss and gets regular ear infections. As a baby she also had problems with her eyes and was later diagnosed with juvenile cataracts and astigmatism.

"She had significantly delayed speech and she didn't talk until after she was three years old. Her first language prior to this was sign language. Because of her eye conditions, she now wears glasses and is very sensitive to bright lights. She has processing sensory difficulties, which means she finds the feeling of certain clothing on her skin distressing. She is also sensitive to noise, despite her hearing loss, so she often needs ear defenders. Amèlie was diagnosed with global developmental delay, and like her brother, with anxiety and autism."

Patricia explained that she had shared her concerns about her epilepsy medicines with her specialists all along with both of her pregnancies.

"We had been in contact with so many clinicians during both my pregnancies – neurologists, obstetricians, gynaecologists, epilepsy specialist nurses (ESNs) and midwives. They all knew I was taking various epilepsy medicines and all knew that we were concerned about them. Our concerns were dismissed by many. One ESN told me that I was 'not the first woman with epilepsy to have a baby' and I 'certainly wouldn't be the last'. I felt very belittled by his response and that my questions and concerns were of no importance.

> **I as devastated, particularly as we had not been warned** about any of these epilepsy medicine side-effects

"I first learned about FACS (foetal anti-convulsant syndrome) and FVS (foetal valproate syndrome) in 2016, by which time Joseph was 15."

Patricia discovered these conditions when taking an Epilepsy Action survey aimed at women of childbearing potential. The survey aimed to find out how informed women with epilepsy were about the effects of sodium valproate if taken during pregnancy. The survey was stark and eye-opening for Patricia.

"It was heart-breaking to read each question of the survey, discovering that each and every diagnosis, difficulty and disability that our children have are all attributed to my medicines.

"I was devastated, particularly as we had not been warned about any of this, not when I was first prescribed them nor prior to becoming pregnant. I secretly cried lots about it and could not sleep at night for a very long time. I was feeling guilty for having epilepsy and for taking the medication that I needed, which ultimately harmed our children."

After finding out about this, Patricia continued to raise her concerns at her appointments until a paediatrician finally acknowledged them.

"She told me that she was not aware that I had taken valproate during pregnancy. She said it was 'the last piece of the puzzle' that she had needed to finally understand why Amèlie had so many difficulties. That single appointment was a turning point for us. It was some acknowledgement that my medicine had caused harm to our children. We finally managed to see a specialist in this field and both children were subsequently diagnosed with FVS.

"When Amèlie was born, I remember commenting that she could have been Joseph's twin, they looked so much like each other, they were almost identical. When we attended the diagnostic appointment for FVS, the doctor confirmed that they both have facial features associated with FACS. Other

symptoms of FVS that both my children have is flat feet and hyper-mobile joints."

Around the house, Joseph and Amèlie need a lot of support and visual prompts to remember to do certain things like using the toilet, washing hands or brushing teeth.

"We have quite a structured life and tend to go to the same places that the children are familiar with and are less likely to cause distress, anxiety and meltdowns. We always go as the four of us so that there is one parent with each child.

> I think, moving forward, **awareness is key** and I'm glad this is being address

"Joseph and Amèlie will never lead an independent life. My husband and I are concerned about what will happen to them when we are no longer here to look after them both. Will there be a care package available to them, to support all their needs?

"I'd have liked to have had more children, but I am still taking Epilim now and I'm reluctant to change my medication because it helps to control my seizures. I can't run the risk of having more seizures and losing my driving licence. Driving means that I can work, support my children and take them to their appointments."

The lack of information given to Patricia over the years, even when she expressed concerns, has had a profound effect on her and her children's lives. She has found solace and support from others who have found themselves in a similar position.

"That moment when you realise that all of your children's difficulties are as a result of the medicines that you needed, is a horrid, horrid feeling. I was so upset and outraged at how this could have happened. I felt extremely guilty, but I was incredibly fortunate to have been contacted by Emma Murphy and Janet Williams who set up Independent Fetal Anti Convulsant Trust (In-FACT). I joined their support group on Facebook and was able to gain information and support from other parents who were also in my situation.

"If you are concerned that your child has FACS, I would recommend that you get as much information about this as you can and take it to your doctor or your child's doctor. Explain that you were taking epilepsy medicines in pregnancy and what concerns you have, and ask that you are referred to a genetics specialist who works with FACS. The guilt never goes away, but when you realise how many people are sadly in the same position, it helps to put things in perspective. It helps you realise that it was not your fault.

"Although I don't think we should be in a position where safety reviews have to take place **after** the licensing of medicines, I think moving forward, awareness is key and I am glad that this is being addressed. Reviews like these help to raise awareness and allow women to have conversations with their doctors **before** becoming pregnant. This should be happening on a regular basis, not as a one-off conversation that might not be relevant to that person at that particular time in their life. I really hope that this review means that women can have conversations with their doctors and get all the detail they need to make their choices."

The review has shone a light on some other epilepsy medicines, as well as valproate, which carry a risk if taken during pregnancy, which is an important step forward. It is imperative that this information is spread to healthcare professionals and is clearly communicated to women with epilepsy considering pregnancy.

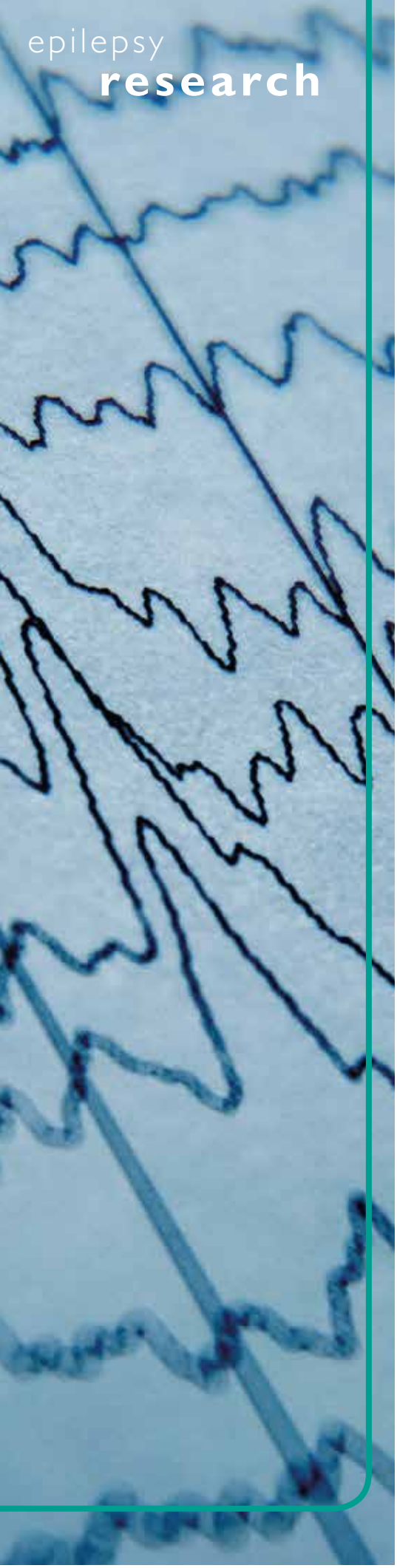
There is more information about epilepsy medicines and risks in pregnancy on the Epilepsy Action website at: ***epilepsy.org.uk/medicines-pregnancy*** or you can call the Epilepsy Action Helpline free on 0808 800 5050. For anyone affected by FACS or FVS, there is more information at: ***facsa.org.uk***

If you have epilepsy and are pregnant, you can join the UK Epilepsy and Pregnancy Register at ***epilepsyandpregnancy.co.uk*** This register was developed to collect more data on having epilepsy and taking epilepsy medicines during pregnancy.

It is important not to stop taking your epilepsy medicines, unless advised to do so by your doctor. If you are worried about your medicines, please speak to your epilepsy specialist.

Amèlie

Patricia's children Joseph and Amèlie have both been affected by foetal valproate syndrome



Research roundup

We look at a few recent research papers showing important and promising findings

For one of the most common neurological conditions, epilepsy is still shrouded in many unanswered questions. Why do some people have epilepsy with no obvious cause? What new ways can we find to treat seizures? How can we predict when a seizure is going to happen? Fortunately, science is always looking for answers. We look at three recent pieces of research offering advice and hope for the future.

Seizure cycles

A new study, published in December 2020 in *The Lancet Neurology*, is shining a new ray of hope for seizure prediction. Dr Timothée Proix and his colleagues said the unpredictability of seizures is one of the biggest burdens on people with epilepsy. They wanted to see if brain activity data from people with epilepsy would show a pattern that would make it possible to predict seizures.

They based their new research on a lot of previous evidence showing that brain activity in people with epilepsy often appears in cycles. These can be over hours – such as the effect of the circadian rhythm – or over days, which the authors call multidien activity.

They wanted to see if brain activity cycles can be used to estimate the likelihood of a seizure happening.

The researchers investigated people aged 18 years old or over with medicine-resistant focal epilepsy from 35 centres across the US between 2004 and 2018. They selected people based on data recorded by a device implanted in their brain.

The device in the people's brains recorded hourly EEG data for over six months. The researchers were interested in the EEG recordings of the brain between seizures. Some of the data were used to train the prediction model, with the rest used to test the predictions success. They were aiming to predict seizures correctly more often than you would predict by chance.

Eighteen people who had seizures only visible on EEG (electrographic seizures) were included in the study. Another 157 people, who had seizures they could report themselves, were also included. The models based on brain activity cycles over a number of days could predict seizures for the next day better than by chance in 15 of the 18 people (83%) with electrographic seizures and 103 of the 157 people (66%) with self-reported seizures. If they were predicting over three days, this dropped to two of the 18 people with electrographic seizures (11%) and 61 of the 157 people with self-reported seizures (39%). A prediction for the next hour, which was only possible in the electrographic seizures group, was successful in all 18 people.

The researchers concluded that using recordings of brain activity cycles between seizures over a number of days, it's possible to forecast seizures days in advance. They added that they hope their study would form a foundation for future trials.

The full research paper is available at: ***bit.ly/2NwqTy7***

Best care for older people with epilepsy

Researchers from King's College London have reviewed a number of recent studies looking at care needs and care provision for older people with epilepsy.

In their review, published in the journal *Seizure*, Gabriella Wojewodka and

colleagues set out to assess care of older people with epilepsy "beyond diagnosis and medical treatment".

The researchers said that there are two age groups in which epilepsy diagnosis is highest – childhood and people over 65. They explained that older people may face more complex needs like other health conditions, needing more medicines for different conditions, frailty and feeling socially isolated.

Their review focused on 33 scientific papers. The papers were grouped into ones dealing with mental health, self-management and health services.

The papers identified that older people with epilepsy can experience anxiety and depression. The findings of the review were that more support should be offered to people to manage their mental health. The papers also identified that older people with epilepsy don't get enough information to help them self-manage their epilepsy. Self-management is linked to better outcomes, but people need more clear information to be confident and effective at self-management. Few older people with epilepsy, included in the studies, had a care plan in place. These could be important to manage epilepsy alongside other conditions and for self-management.

The review considered that older people with epilepsy experienced a lot of stigma and were worried about telling peers about their condition. While research has shown that stigma towards epilepsy is generally low, "people over 65 held more negative stereotypes about epilepsy", the researchers explained. This can lead to social isolation.

The researchers found that older people with epilepsy were referred to neurologists less often than younger people. They said this may be a gap in service provision, which may show a need to better organise care pathways in the health service. However, they suggest that perhaps a health professional with a broader specialism, like a GP or a geriatrician, could be better placed to help people manage their health. These doctors can help to manage all the different conditions a person may have, and may be better placed to manage epilepsy in older people. However, they may need additional training to help better manage epilepsy.

Wojewodka and her colleagues conclude that more research is needed to establish in what ways healthcare professionals can offer effective mental health and self-management support to this group of people.

The full review paper is available at ***bit.ly/3c0YZEB***

Stem cells

A review published in the January issue of the journal *Clinical Neurology and Neurosurgery* has looked at the potential of stem cell therapy in people with medicine-resistant epilepsy.

Assistant professor Hadi Aligholi and colleagues said that in around 30% of people with epilepsy, seizures can't be controlled with epilepsy medicines. As well as being a burden on quality of life, the researchers said uncontrolled seizures can increase the risk of injury and death. This makes discovering new treatments of paramount importance.

Stem cells are cells that can make other cells with specialised functions. Stem cell therapy involves transplanting stem cells into a person to treat a medical condition or disease. The researchers wanted to review available evidence of the effectiveness and safety of stem cell therapy in epilepsy.

Only six related articles could be found for the review. They included 38 adults and 81 children with epilepsy.

The studies showed that around three or four out of 10 people (30-40%) became seizure free after the treatment, and no serious side-effects occurred. The studies showed a general improvement in seizure control and an improvement in brain functions, such as thinking, learning, attention and memory.

However, the researchers explained that the studies were not very high quality, as each study only included a small number of people and they only followed up the people after the treatment for a short amount of time. The studies were also single arm, meaning that they simply gave the treatment to a group of people and compared the effects before and after the treatment. A two-arm study would have a group of people given the treatment and group having a dummy treatment and comparing the outcomes of the two groups.

The review authors conclude that for people who have medicine resistant epilepsy, a 30-40% rate of seizure freedom "would be a significant achievement for stem cell therapy". However, they stress that this level of effectiveness would have to be confirmed by large, well-designed trials for this kind of treatment to be justified in epilepsy.

The full article is available at: ***bit.ly/3oaUhqh***

Older people with epilepsy need more support from healthcare services with self-management and mental health

Letters to Felix

Sophie Pierce shares memories of her son Felix Murdin, who died aged 20 of sudden unexpected death in epilepsy (SUDEP) in 2017. She tells us how she coped by writing him letters, and why she thinks more discussions need to be had around SUDEP

All his life, Felix loved reading and he consumed books avidly. As a family, we used to go for lots of walks by the sea and on the moors near our home in Devon. Whenever we stopped for a swim or a picnic, he would normally get his book out and sit quietly reading. We have so many photos of him doing this!

Felix was just starting to grow in confidence and enjoy life after some difficult teenage years when his epilepsy really plagued him. He had his first seizure when he was 13 years old. It was a sleep seizure, and these continued for the rest of his life. After a while, he started having seizures when he was awake as well. These were tonic-clonic seizures that would go on for a couple of minutes each time. Despite taking epilepsy medicines and trying different types of medicine regimes, his seizures were never fully controlled.

I felt enormous sympathy for Felix because I also have epilepsy myself. I developed epilepsy in my late 20s. I used to have tonic-clonic seizures that affected me in my 30s mostly. I take epilepsy medicine and have been seizure free for about 20 years now.

I felt it was good that I understood what he was going through. I really knew how he felt after having a seizure, having gone through it myself, and I was able to support him. However, I also felt guilt that he had inherited it from me. I inherited it from my grandfather, and we didn't realise he had epilepsy until I had my first seizure. When that happened, my mum looked at my grandfather's death certificate and epilepsy was listed as a secondary cause of death (to heart attack). We asked my grandmother about it, and she said: "Oh yes, he used to fall down". And yet this was never talked about.

For Felix, epilepsy did affect his life quite a lot, as he had seizures quite regularly. He would often have them upon waking, and so would be out of action for that day, feeling exhausted and having a headache and often sore muscles as well. It affected his confidence, although I never once heard him complain.

He loved film and theatre. He was in his first year at the University of Leicester, studying Film and Visual Arts. Towards the end of his life, he felt confident enough to go on stage and act. This was a great achievement for someone having to cope

with the knowledge that he might have a seizure at any time. As well as acting, he had started writing scripts for plays and films.

He was in a production of Shakespeare's Anthony and Cleopatra and was about to appear in the chorus of the musical The Producers. Felix died in March 2017, just before the show opened.

I was the one who discovered he had died. I was travelling up to Leicester to see him in the show. I got to our meeting place but he wasn't there. I went to the university theatre and was told by another student that they hadn't seen him for a couple of days. They'd tried to phone him but without success. I got in touch with his hall of residence who said they'd go and knock on his door and get back to me. I heard nothing, so drove over there. When I arrived, I saw an ambulance outside his building and I felt absolute terror. I rushed over and there was security outside. I wanted to go in but was told I couldn't. Then a paramedic came out and told me what had happened.

It was a horrific situation. First of all, I was taken into the ambulance and given a cup of tea. I had to phone my husband Alex and tell him what had happened. Then I was taken into another room where I had to wait for the police to arrive. This was a sudden death of a young person and so of course they had to be involved, but they ruled out foul play. Fortunately, a dear friend was able to get to Leicester to be with me.

The grief was terrible. I cried in a way I never have before. It was like being assailed by emotion, almost like having a seizure, in a way. I would find myself shaking uncontrollably and gasping and heaving with grief. We took each day at a time. Organising the funeral was helpful, as it gave us a focus. But it was like being thrown into a new world where all our certainties had been abruptly removed. And all the time we just couldn't believe Felix had died. It seemed impossible to comprehend.

Pretty much as soon as Felix died, I started writing him letters. It felt like a natural thing to do. It helped me to write to him every day, to feel I was talking to him, having him by my side as I was going through this terrible loss. I found it helpful to 'talk' to him about my feelings, and to tell him about my love for him. It also helped me to get perspective on what was going on. Somehow, when you write down a thought or feeling, you can step back from it and gain some insight into what you are going through. For me, it became about maintaining my relationship with Felix, even though he is no longer physically with us.

Turning these letters and diaries into a book will, I hope, help other grieving parents. But it's not just grieving parents, but anyone who has experienced grief, which, let's face it, is all of us. The book is not just about grief, but about love, and finding joy even when you are in the depths of despair. I feel that the book will be a permanent memorial to Felix, and something positive to come out of his death.

Support information

SUDEP Action
Supports people bereaved by epilepsy, raises awareness of epilepsy deaths and tackles epilepsy deaths including SUDEP.

support@sudep.org.uk
01235 772852
sudep.org

Child Bereavement UK
Supports families when a baby or child of any age dies, is dying or is facing bereavement.

support@childbereavementuk.org
0800 0288 840
childbereavementuk.org

Cruse Bereavement Care
Offers support, advice and information when someone dies.

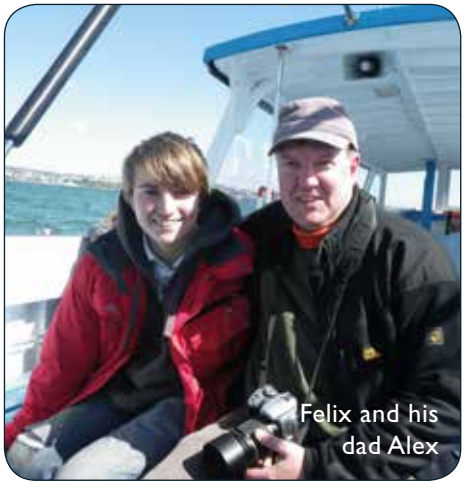
helpline@cruse.org.uk
0808 808 1677
cruse.org.uk

The Epilepsy Related Deaths Register
The Epilepsy Deaths Register provides researchers with anonymised information on epilepsy deaths.

epilepsydeathsregister.org


Sophie with Felix as a child


Felix with his younger brother Lucian


Felix and his dad Alex


The whole family out on a walk


Felix and his family enjoyed walks by the sea

Another important thing we felt we needed to do was to shed more light on SUDEP. After the post-mortem, the cause of death was given as SUDEP – sudden unexpected death in epilepsy.

I had heard of SUDEP before Felix died, because I am the sort of person that always researches a lot around whatever issue is affecting me at the time. I never remotely thought Felix was at risk though. This might be coloured by my own experience as someone who has epilepsy. I have always thought of it as a horrible thing that has to be endured, but I have always felt confident I would wake up afterwards.

I found the charity SUDEP Action online and gave all the details of Felix's death, through them, to the Epilepsy Deaths Register. I think it's vitally important that information is accurately recorded so that hopefully one day we will start to understand why these heart-breaking deaths happen. Then, perhaps, we will find a way of preventing them.

Quite simply, SUDEP is never talked about. At least it wasn't in our experience. I only knew about it because I had read around the subject. None of the doctors or nurses that treated Felix ever told us about it, or about how to minimise the risk.

I think SUDEP and its risks need to be talked about openly. The biggest risk, of course, is having seizures. If you're not having seizures, then you are at less risk of SUDEP. The sad fact is, that even with all the medicines in the world, some people's seizures will not be fully controlled. This was the case with Felix. As a young man who had sleep seizures, Felix was, as we learnt afterwards, in a high-risk group. But perhaps if we had known about this risk, then there might have been something we could have done.

I know it is a difficult subject, but I think people with epilepsy do need to know about the risks, so they can do all they can to stay safe.

You can find out more about Sophie's memoir, The Green Hill: Letters to a Son, at: ***unbound.com/books/thegreenhill/***

SUDEP information

Every year in the UK, around 1,000 people die from causes related to epilepsy. In some of these cases, there is no clear reason why a person has died. This is called sudden unexpected death in epilepsy (SUDEP).

While the cause of SUDEP is not known, evidence shows that it is connected with seizures, particularly tonic-clonic seizures. Researchers are investigating a number of possible causes for SUDEP, including changes in a person's heartrate or breathing that may happen during a seizure.

According to Epilepsy Action, SUDEP is relatively rare, affecting one in 1,000 adults and one in 4,500 children with epilepsy each year. But each person's risk is different depending on what kind of seizures they have and how well they are controlled. Tonic-clonic and sleep seizures can increase the risk of SUDEP, alongside not taking epilepsy medicines as prescribed.

Epilepsy Action suggests some ways to reduce the risk of SUDEP. These include:

- Taking your epilepsy medicines as prescribed by your doctor. If you don't like your medicine or have side-effects, it is advised to speak to your doctor who can make changes to them to try to find a good balance for you
- Finding out what your specialists recommend if you accidentally miss a dose, or have vomiting or diarrhoea after taking it
- Trying to avoid situations that could trigger your seizures. Triggers could include not getting enough sleep, being stressed, missing a dose medicine or drinking alcohol
- Asking to be referred to a specialist for a review of your epilepsy and treatment if your seizures are not controlled

If you have sleep seizures, Epilepsy Action offers suggestions to help reduce the risks of SUDEP. Some evidence suggests that having someone in your bedroom who can help if you have a seizure can reduce SUDEP risk. This could be something to consider for sleeping and living arrangements, if possible.

As well as this, seizure alarms or monitors could be used to alert a carer or family member if a seizure happens in the night. Some reports also suggest sleeping on your back and using a safety pillow may also help. However, researchers say there isn't yet enough evidence to say for sure if these interventions are effective in reducing SUDEP risk.

There is more information on SUDEP and epilepsy deaths on the Epilepsy Action website at: ***epilepsy.org.uk/sudep*** or you can call the Epilepsy Action Helpline for free on: 0808 800 5050

epilepsy action

epilepsy.org.uk/yourchild

Your child and epilepsy

Grow your confidence managing epilepsy in your family

Your child and epilepsy is a new online course for parents and carers of children with epilepsy. It's been developed with parents, epilepsy nurses and psychologists.

This course is a helping hand to support families on their epilepsy journey. It's full of advice and stories from parents. It aims to give parents and carers the confidence, skills and knowledge to support their child to manage their epilepsy.

There are eight parts that cover:

- Understanding epilepsy
- Supporting your child with their epilepsy
- 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

Free course

The course is free and flexible. It can be accessed at any time on a computer, tablet or smartphone with internet access.

Get started at: **epilepsy.org.uk/yourchild**

Get in touch: **learning@epilepsy.org.uk**

Epilepsy Action
Information you can trust

Find out more
epilepsy.org.uk/trust

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Sleep well

Doctoral researcher Alice Winsor discusses the importance of sleep and the complicated relationship between sleep and epilepsy

A lack of sleep can feel like a part and parcel of having a child, especially in the early years. The expected disruption in sleep can sometimes make it difficult to recognise a sleep problem. In a child with epilepsy, sleep issues may also take a back seat to managing their seizures.

But good quality and long enough sleep is vital, especially in those children who also have epilepsy. Alice Winsor, a researcher from The University of Birmingham, explains the complicated relationship between sleep and epilepsy and offers ways to improve sleep habits.

Importance of sleep

Sleep is extremely important for overall physical health and mental wellbeing. It supports processes like learning, attention and memory. Enough good quality sleep is important for growth and development in children. If a child does not get the recommended amount of sleep for their age, this can leave them vulnerable to sleep problems.

Sleep problems are commonly observed in children. They include difficulties falling sleep, night waking or early morning awakening. Some difficulties can have a medical cause. They include sleep disorders such as insomnia (sleeplessness), obstructive sleep apnoea (where breathing stops and starts during sleep) or parasomnias (unusual behaviours during sleep, such as walking or talking).

Sleep and epilepsy

Sleep problems occur even more often in children with epilepsy, and it can have larger consequences in comparison to those without epilepsy. Sleep and epilepsy have a complicated link and both have an effect on each other. On one hand, sleep can impact epilepsy, where not getting enough sleep can make it more likely for a seizure to occur. There are different causes for lack of sleep, such as poor sleep habits or sleep disorders. On the other hand, epilepsy affects sleep, where sleep seizures can disrupt sleep, resulting in brief awakenings.

Interestingly, there is some evidence suggesting that even in epilepsies where seizures occur during the day, sleep can still be disrupted. This implies the epilepsy itself can impact sleep. Epilepsy medicines can also affect sleep, sometimes positively or sometimes negatively depending on the epilepsy medicine itself. Further investigation into managing sleep habits in children can have potential benefits in epilepsy care and management, as well as wider quality of life.

Research

Our team carried out research into sleep and epilepsy which had two main aims. The first was to understand how sleep is affected by epilepsy and how it affects the daytime functioning, behaviour and quality of life in children with epilepsy. The second aim was to understand how brain activity during sleep is associated with seizures. The research was conducted in partnership with Birmingham Children's Hospital and Worcestershire Royal Hospital.

My role was to coordinate recruitment of families and children for the study. This involved meeting families at their video EEG appointment at one of the hospitals taking part. There, I discussed the background of our research and what was involved. Families were given a study pack containing various questionnaires assessing aspects of quality of life. Usual sleep patterns were assessed with the use of an Actiwatch, which detects movement patterns. It was worn for a period of two weeks by the child. This provided us with information on various sleep measures. These were the time it takes the child

to fall asleep, the quality of their sleep, how many times they wake up in a night and the proportion of time they sleep for each night. Parents were required to complete a sleep diary to provide more information on sleep patterns during the weeks. Parents were also given a clinical report with the results from the study to keep. The recruitment for this part of the research has recently ended and is due to be analysed.

Research findings

While some of the research is still ongoing, as another part of our study, our team reviewed previous studies which investigated sleep in children with epilepsy compared to children without. The review included 19 studies, comparing a total of 901 children with epilepsy to 1,470 children without. We found significant differences between children with and without epilepsy across different measures of sleep. These included reduced sleep time, with children with epilepsy sleeping on average 34 minutes less than children without epilepsy. They also spent longer in a lighter sleep and had lower sleep efficiency (the proportion of time spent asleep in relation to the amount of time spent in bed). Finally, we found that children with epilepsy had more frequent and severe sleep difficulties, specifically night waking, unusual sleep behaviours and sleep disordered breathing. These results show that children with epilepsy are particularly vulnerable to sleep difficulties. The results further support the need for screening of sleep difficulties at the diagnosis stage to ensure they are identified early. This may help in seizure control, but also more generally in improving quality of life and mental wellbeing.

Sleep habits

Good sleep habits can help a person have good quality and regular sleep. The need for good sleep habits in children with epilepsy is particularly important for seizure control. They should be the first step in addressing sleep problems. Below is a list of techniques which can help to promote sleep in children:

1. Sleep timing: A sleep routine should start 30 minutes to two hours before bedtime, with fixed night times and awakenings. A sleep routine should consist of activities to help the child relax such as a bath, a story or breathing techniques. Daytime naps which are too frequent or too long, are better to be avoided as they can disrupt the sleep schedule. It's essential to stick to your sleep schedule in order for the child to get used to their routine.
2. Food and drink: Drinks containing caffeine such as fizzy drinks, energy drinks or tea/coffee can stimulate the child, preventing them from falling asleep easily. They should not be consumed in the six hours before bedtime. Timing of dinner should be considered, ensuring that children do not eat their dinner too close to bedtime.
3. The sleep environment: The sleep environment needs to help your child feel settled. This can mean making sure the room is a good temperature and is not too noisy. Within the bedroom, toys which may be tempting for the child to play with should be kept out of sight.
4. Exercise: Many children with epilepsy can exercise safely and should be encouraged to do so. It can help prevent seizures by reducing stress, which can be a trigger for seizures. However, as exercise raises the internal temperature of the body, it can prevent children from feeling drowsy at bedtime. Try and limit energetic activity in the final hours before bedtime and engage them in calming activities instead.
5. Technology: Use of electronic devices such as phones or tablets can hamper sleep. The light emitted from these devices can reduce the release of the natural sleep-promoting hormone, melatonin. It is recommended that these devices are switched off at least an hour before bedtime. If your child requires these devices to help them fall asleep, there are settings on devices which allow you to filter the light or place them into 'night mode'.

The research findings show that poor sleep can negatively affect epilepsy, while uncontrolled seizures can make sleep issues worse. Poor seizure control and poor sleep in a child may seem like an impossible situation. But the good news is that taking steps to improve each problem will likely have a positive effect on the other.

It's important not to overlook sleep issues, especially in children with epilepsy. Speaking to your doctor if you are worried about your child's sleep could help identify and tackle sleep issues, and bring added benefit for their epilepsy.

There is more information on sleep and epilepsy on the Epilepsy Action website at: ***epilepsy.org.uk/sleep***

Alice Winsor is a doctoral researcher from the Centre of Human Brain Health at The University of Birmingham. She is investigating the relationship between sleep and quality of life in children with epilepsy.

A bedtime routine should help your child relax

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 brivaracetam.

Brivaracetam

Brivaracetam (BRV) was licensed in the UK in 2016 as an add-on medicine for focal-onset seizures whether or not they lead on to tonic-clonic seizures. It can be prescribed to adults and children. It is not yet approved for any of the genetic epilepsies, or seizures such as absence or myoclonic seizures, although there is some evidence of benefit. This is not surprising, as brivaracetam has a similar structure to levetiracetam. This means both of these medicines work in a very similar way. For adults, doses of brivaracetam start at 25mg taken in one or two tablets a day. It can then be adjusted depending on side-effects and how well the person responds to it. The usual effective doses range between 25mg and 100mg taken twice a day in adults. In young children (body weight up to 50kg), the doses are lower, starting at 0.5-1.0mg taken in one or two tablets a day. The dose can also be increased in children, depending on how well they respond and whether they have side-effects. The usual effective dose is 1-2mg a kilo taken twice a day. Bigger and older children can follow the schedule for adults.

Professor Martin Brodie

Brivaracetam is generally a well-tolerated medicine in children and adults. The most common side-effects include headache, sleepiness, dizziness, tiredness, feeling sick and vomiting. However, in some people, it can cause irritability, agitation, anxiety, sleeplessness, aggression, depression or even psychosis. Psychosis can include seeing or hearing things that are not there, or believing things that are not true. These can be troublesome problems, which must not be overlooked. There is some evidence that brivaracetam is less likely than levetiracetam to cause side-effects. Switching from levetiracetam to brivaracetam may be possible in a person who becomes seizure free on levetiracetam, but does not tolerate it.

Current experience with brivaracetam suggests that it is an effective, easy-to-use, and usually well-tolerated epilepsy medicine. There is little evidence that it can cause allergic problems, including skin rashes. Its use is currently only as an add-on treatment, so there can be no certainty that it is safe in pregnancy. However, no problems with birth defects in exposed newborn babies have been reported.

Overall, brivaracetam is an add-on treatment effective across a range of common epilepsies in a wide range of doses.

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





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My journal

Richard shares his and his wife Sue's experiences of both living with epilepsy, facing injuries from seizures, and having brain surgery

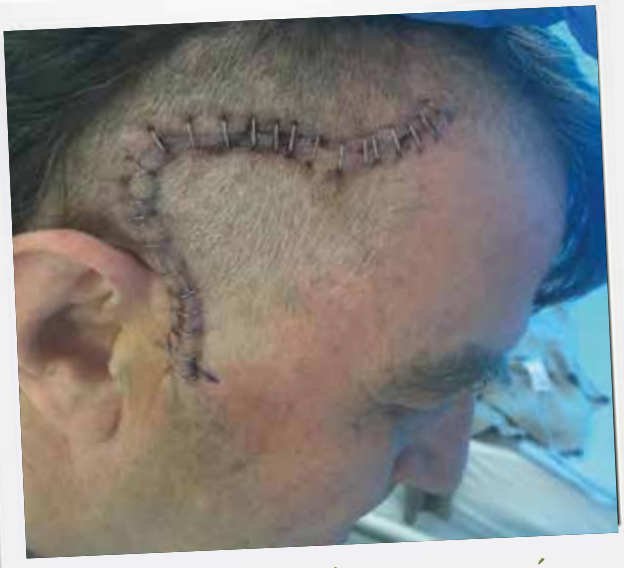
I wanted to share our experiences – a couple of people who have both been diagnosed with epilepsy in later life and who have both had brain surgery.

My wife, Sue, got encephalitis – an inflammation of the brain – in 1991 when she was forty-one. At the lowest point of her illness she was having as many as 40 seizures in a day. She received exemplary care from the neurologists in the Western General Hospital in Edinburgh, some thirty miles from Kirkcaldy where we live. (Although her situation was not improved when a junior doctor accidentally punctured one of her lungs when attempting to inject medicine.) Thankfully, things began to improve, and after five extremely worrying weeks she was allowed home.

We had been warned that one possible consequence of the illness was that she might have short-term memory difficulties. That did not prove to be the case at the time. However, the main problem that quickly became apparent was epilepsy, which has turned out to be medicine-resistant. The seizures are accompanied by many collapses, with resulting physical injuries (and blood-stained carpets). Her injuries have varied from a dislocated shoulder to sprained ankles and wrists, with frequent head injuries and black eyes. In an attempt to establish control over the seizures, she has been prescribed virtually every epilepsy medicine in existence. None of them has brought the seizures fully under control. However, her current combination of carbamazepine (Tegretol), brivaracetam and clobazam have at least reduced the frequency and severity of the tonic-clonic seizures. But clusters of collapses continue to be a problem, which I suspect may be caused by her atonic seizures. On one particularly memorable day, I found her on the floor no less than five times.

For 25 years, I had drawn comfort from the fact that I continued to be in robust health and was therefore able to care for Sue while still working. So, in March 2016, when I was 70, it came as an unwelcome surprise to find myself waking up in a bed in Kirkcaldy's Victoria Hospital. The friendly face of a familiar neurologist was at my side telling me that I had had a series of major seizures. Scans revealed that the cause was a large

Sue's seizures means she often sustains many injuries



Richard had brain surgery in June 2017

right temporal meningioma – a tumour of the membranes that surround the brain. The surgeon in Edinburgh to whom I was referred assured me that he would be able to operate safely, despite my age. But he warned that the longer I postponed an intervention like that, the more risky it would become.

Despite having recently seen a television programme in which brain surgery was described as 'brutal and bloody', I screwed my courage to the sticking place and eventually agreed. I was

"There are occasions when I become very confused and disoriented - on one such occasion, I tried to persuade a clearly puzzled white-van driver that his van was an ambulance"

full of trepidation, but I knew that it would be best to have the meningioma surgically removed (resected). After a while, I received a letter of apology that I should have to wait 14 rather than 12 weeks for the procedure. But so far as I was concerned, they could have kept me waiting even longer.

Surgery was eventually carried out in Edinburgh's Western General in June 2017. The process proved to be much less traumatic than I feared. I was able to make a rapid recovery and return home after only five days. I am currently reviewed on a six-monthly basis by a neuro-oncologist in Edinburgh, with each appointment preceded by an MRI scan. I also have regular appointments with the same neurologist who sees Sue at our local Victoria Hospital in Kirkcaldy. He follows up each appointment with a helpful letter detailing the main points of our discussions.

I still occasionally have episodes when I become very cold, have pins-and-needles down my left arm, with a loss of sensation in my left hand. There have also been occasions when, as part of these episodes, I become very confused and disorientated. On one such occasion, I tried to persuade a clearly puzzled white-van driver that his van was an ambulance. But I am relieved to be able to say that these episodes seem to be being brought under greater control by a gradual change of medication from levetiracetam to lamotrigine.

Our lives became further complicated in June 2017 (not a good month in our calendar). A collapse that had not seemed particularly severe at the time, was found to have resulted in Sue sustaining a fractured skull and a subdural haematoma – a bleeding in the brain. Neurologists thought that the bleeding was likely to stop and be re-absorbed, and initially that appeared to be the case. But, after a further fall, and my observation that Sue was attempting to make coffee by mixing dried onions, cooking oil, milk and hot water in a cafetière, it was clear that all was not well. A further scan revealed that the bleeding was again active and in September 2017 Sue had to have surgery to fix the problem.

The surgery was successful, and Sue was soon home, although we now live with the fear that the bleeding might yet again become active. Unfortunately, and rather disastrously for our daily lives, it quickly became apparent after the surgery that Sue's memory had been severely impacted and that she very easily became confused. Assessment by a neuropsychologist determined that there had been a major loss of cognitive function. She also continues to have regular collapses and severe migraines for which no cause has yet been found, even though she has been monitored by telemetry.

Sue has been adversely affected by her condition more than I have by mine. She has had to abandon her favourite recreation of choral singing after having a seizure and falling off the platform in the middle of a performance. As part of her attempt to live a full life, she decided to take advantage of her teaching qualification by volunteering as a play leader for children awaiting appointments at our local hospital. Perhaps inevitably, she had a seizure on one occasion, and it was made clear to her that her services were no longer considered appropriate. She also finds reading difficult since she is unable to remember what she has already read. One of the greatest restrictions on her life is that it is no longer safe for her to leave home unaccompanied because she would be unable to find her way back. In addition, I am increasingly reluctant to leave her alone at home for longer than is necessary to carry out such activities as short shopping trips.

There is nothing in Sue's appearance that would make anyone aware of her medical problems. Nevertheless, her poor memory can cause problems when, for example, she fails to recognise an old friend. It can also make conversation difficult for her. For my own part, nothing could ever get me used to the fear I feel when she is in another room and I hear her collapse, in case she has sustained another major injury.

Apart from the occasional episode, my own chief problem – more of an irritant really – is that I am not allowed to drive and am unlikely to be able to do so for the foreseeable future. The roads of Scotland are undoubtedly safer without me on them, but it does mean that I am unable to pursue my research interest in medieval architecture to the same extent as I used to.

We have found that cruising is an excellent form of relaxation for us, as well as a way of getting to wonderful places in great comfort (albeit with an excess of high-cholesterol food). It is

Sue's epilepsy caused her to stop her hobby of choral singing

unfortunate that current restrictions mean that it is something we would not consider for the foreseeable future. We do, of course, accept that there are going to be mishaps along the way, and I think I have had to prop Sue up while she has a seizure

"Sue's poor memory can cause problems when, for example, she fails to recognise an old friend. It can also make conversation difficult"

in most of the major cities of Europe, as well as in parts of Egypt and India. The only occasion on which cruising presented a serious problem was when an unsympathetic ship's doctor unsuccessfully attempted to persuade us to leave the ship mid-cruise. She said she could not guarantee Sue's safety after she sustained a nasty head injury as the result of a collapse on a stone floor. That doctor seemed hurt at my lack of gratitude when she said she did not propose to charge us for her services.

Despite all of this, we feel it is important to live our lives as normally as we are able, knowing that help is on hand when needed, at least when we are close to home. We have empathetic and readily accessible support from neurological staff at the Kirkcaldy Victoria Hospital. Beyond this, on the rare occasions I feel it is advisable to call an ambulance, there is invariably a rapid response, and the paramedics are always helpful and friendly. Despite everything we face, I have to say that in general we are able to toddle along happily together, enjoying each other's company.

Richard and Sue enjoy going on cruises

Council of Management 8 December

Note that in between the October and December meetings of Council, there was a special meeting of the Council on 10 November. At that time a revenue budget and business plan for the charity were approved for 2021. At the same time the charity's long term strategic plan was reviewed, revised and extended until the end of 2023.

At a meeting of the Council of Management held by remote video conference on 8 December, the following decisions were made.

- The Council noted the resignation for personal reasons of one of its members, James Sheward, on 27 November and wished him well for the future.
- Council reviewed and renewed the charity's advisory panels covering scientific awards, research, women and health and clinical practice.
- It reviewed, updated and renewed its scheme of delegation. This is the record of how the Council manages its authority.
- It reviewed the charity's corporate risk register and ensured adequate measures are in place to manage those risks.
- It approved a proposal to report on the outcome of Council members' annual personal appraisal as part of their re-election address.
- It reappointed Darren Millar AM and Paula Sheriff as Vice Presidents of the Association when their current term of office expires at the date of the AGM in June 2021.
- It re-appointed Dr Khalid Hamandi and Ian Walker as members of the charity's National Advisory Council for Wales.

- It re-appointed Ena Bingham, David Gilmour, Dr Jim Morrow, Edna O'Neill, Derick Woods and Marion Woods as members of the charity's Northern Ireland National Advisory Council.
- It appointed Maura Mackie, Megan McCarthy and Dr Louise Rusk as new members of the charity's Northern Ireland National Advisory Council.

The next meeting of the Council of Management will be on 13 April 2021.

Epilepsy support for you

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

Join one of our virtual groups

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

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

Online resources

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

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

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Visit www.vnstherapy.com to learn more and view important safety information.

1. Brodie MJ. Epilepsia 2013; 54 (Suppl. S2):5-8.
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