

Building strength

Lauren talks about training to feel in control of her body, being aware during seizures and telling her children about her epilepsy



Also in this issue

- an introduction to upcoming research on **preconception counselling**
 - how you made it another fantastic **Purple Day**
- why three people ran and walked **50 miles in February**

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editor's letter

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

With the weather starting to improve and the rules finally allowing us to see a few friends (and get that long-awaited haircut), many people's spirits are beginning to lift. It's important we all take the next few months at our own pace and adapt to our yet again changing lifestyles. But it is quite eye-opening to see the difference connecting with others can make to our whole outlook. Taking this into consideration, we have a whole host of personal stories from a huge number of fascinating people in this issue. You've seen Lauren, our cover star already. On page 26 you can read about the way training and body building gives her a sense of control over her body, which is something epilepsy had threatened to take away. There, you can also read about Cece, and the way she faces misconceptions about her identity, assumptions about her epilepsy and frustrating memory problems.

Another set of really inspirational stories has come from the '50 miles in February' Facebook challenge, where people pledged to walk or run 50 miles over the month to raise money and awareness of epilepsy. The challenge brought together so many different people with different epilepsy experiences and the group was an inspiration to be a part of. Amy is a nurse, and shares how even though she had seen children have seizures in her line of work, when it was her son Harry, she was in utter panic. Mark describes the nerve-wracking drives to the hospital behind the ambulance after his son Alfie's seizures first started. Claire, who works as a pharmacist, talks about disclosing her epilepsy at a work training evening and feeling like everyone stepped back from her. You can read the full stories on page 18.

On page 16, you can also read how Erin and Luke debated having the COVID-19 vaccine and what convinced them to accept the invitation to have it. This is an individual choice and it's helpful to see how some people made it for their own reasons and managed their individual risks and concerns.

This issue also offers a bit of an 'epilepsy medicines and pregnancy' information bundle. With a lot of recent developments in this area, we have a few news stories about the findings of the newly developed valproate registry and the government's response to recommendations around the valproate scandal. As well as that, Dr Janine Winterbottom and researcher Emily Lloyd talk about the value of preconception counselling and some upcoming research in the area (page 10). There is also a behind the scenes article about the work of the Epilepsy Action campaigns team in helping achieve positive change (page 24).

You can also read about the fantastic efforts for this year's Purple Day (page 14) and the activities for National Epilepsy Week taking place this week, from 24-30 May (page 13). We hope you enjoy this issue!

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Lauren shares what it's like being aware during seizures and Cece tells about facing misunderstandings around her identity and epilepsy



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Epilepsy medicine pregabalin linked to breathing problems

The medicine pregabalin has been associated with some reports of breathing difficulties in people taking it, the Medicines and Healthcare products Regulatory Agency (MHRA) said in February.

A recent European review of the safety data around pregabalin (brand name Lyrica) found that the way pregabalin affects the nervous system could cause breathing difficulties in some people.

In epilepsy, pregabalin is used as an add-on treatment for focal seizures. Some people taking this medicine may need a lower dose to reduce the risk of these side-effects.

The MHRA advises that people should speak to their doctor if they notice

new or increased problems with their breathing. People should also consult a doctor or pharmacist about other medicines they take as well as pregabalin. This is because some medicines taken with pregabalin may increase the risk of breathing problems.

People should avoid drinking alcohol if taking pregabalin, the MHRA has added.

Epilepsy Action says people should not reduce or stop their medicine without speaking to their doctor first. Reducing or stopping epilepsy medicines can cause breakthrough or worsened seizures.

The MHRA has said it will include new warnings about this possible side-effect in



the patient information leaflet for pregabalin.

The MHRA said the review had found a small number of cases worldwide where people experienced breathing difficulties. The majority of cases reported were in older people (over the age of 65).

People may also be more at risk if they have other underlying health problems. These include conditions affecting breathing, the kidneys or the brain.

Pregabalin is also given for pain caused by the nervous system and for anxiety disorder.

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NICE updates guidelines on cannabis-based medicines

The National Institute for Health and Care Excellence (NICE) has made a clarification to guidelines around clinicians prescribing cannabis-based medicines.

The clarification has come after the parents of three-year-old Charlie Hughes, who has severe epilepsy, made a legal challenge over the guidelines. Ali and Matt Hughes said the NICE guidelines were putting doctors off prescribing potentially “lifesaving” cannabis-based medicines.

The challenge was expected to be heard in the high court, but

has been dropped after the clarification made by NICE.

The amended guidance includes a section called ‘Interpretation of the guideline’. This says that at the time the guideline was published, NICE did not believe there was enough evidence to support a “population-wide practice recommendation”.

“The fact that NICE made no such population-wide recommendation should not, however, be interpreted by healthcare professionals as meaning that they are prevented from considering the use of unlicensed cannabis-based

medicinal products where that is clinically appropriate in an individual case,” the update says.

“Patients in this population can be prescribed cannabis-based medicinal products if the healthcare professional considers that that would be appropriate on a balance of benefit and risk, and in consultation with the patient, and their families and carers or guardian.

“There is no recommendation against the use of cannabis-based medicinal products. For more information about why the committee decided not to

recommend against use of these products, see the rationale section of the guideline.”

The use of cannabis-based medicines for severe epilepsies in children was made legal in 2018, but the number of prescriptions made on the NHS has been low. Many families pay thousands of pounds for these medicines privately.

There is more information at [epilepsy.org.uk/cannabis](https://www.epilepsy.org.uk/cannabis)



Improving R20 diagnosis

The charity Ring20 Research and Support UK (Ring20) has partnered up with company Illumina to help improve the diagnosis of ring chromosome 20 syndrome (R20), a rare form of genetic epilepsy.

Illumina is a developer of tools and systems for large-scale genetic analysis. The partnership will aim to raise awareness of whole genome sequencing as a way of diagnosing rare genetic conditions like R20. This technique analyses the whole DNA of an individual, and can help to make more accurate diagnoses, help find more appropriate treatments and support research. The partnership will also undertake a two-phase project. Phase one began in January and aims to allow families affected by R20 to understand the possibilities of whole genome sequencing. The second phase will analyse the genomes of R20 patients to help develop an effective diagnostic test for the future.

Ring20 explained that an accurate diagnosis means better treatment options, more research opportunities and better availability of support groups. The charity said that achieving a diagnosis of R20 can take longer than four years, or leave people undiagnosed or misdiagnosed.

Allison Watson, co-founder of Ring20, said: "If we can unravel the genome of R20 patients, we might discover more about the changes in DNA that haven't yet been detectable and that might just hold some clues to identifying more targeted medical therapies."

For more information, visit epilepsy.org.uk/ring20 and ring20unravel.co.uk

Registry finds women were prescribed valproate while pregnant



Findings from a new registry into valproate and pregnancy show 180 women were prescribed valproate in a month in which they were pregnant, between April 2018 and September 2020.

NHS Digital and the Medicines and Healthcare products Regulatory Agency (MHRA) are developing Medicines in Pregnancy Registries to monitor the use of medicines like valproate in pregnancy.

Valproate is used to treat some types of epilepsy and for some people is a very effective epilepsy medicine. However, it's well known that it could cause birth abnormalities and learning and thinking difficulties in some babies born to women taking it during pregnancy.

The Independent Medicines and Medical Devices Safety (IMMDS) Review carried out on three medical products concluded, among other things, that a registry should be set up to monitor the effects of epilepsy medicines used during pregnancy.

The MHRA has said that valproate should not be

prescribed to "any woman or girl able to have children unless she is supported by a Pregnancy Prevention Programme (PPP)". The Medicines in Pregnancy Registry on valproate is looking to monitor the changing use of valproate in women and the implementation of the PPP.

Despite guidance from the MHRA to avoid prescribing valproate to women or girls being published in 2018, 180 women were subsequently prescribed valproate while they were pregnant. This is out of 462 women or girls who had conceived over the reporting period.

Within the reporting period, 47,532 women and girls were prescribed valproate for one or more months. In September 2020, the majority (89%) prescribed valproate were aged 16-54 years.

However, the findings also showed that there was a general decrease in prescribing of valproate during the reporting period. From the start of the reporting period to the end, there were 5,353 fewer prescriptions for valproate in women and girls.

There were also fewer 'new starters' – women and girls who had not been prescribed valproate in the previous 12 months – in September 2020, compared with September 2019. Also, 238 women and girls had their valproate prescription changed to another treatment before they became pregnant.

Louise Cousins, director of external affairs at Epilepsy Action, said: "This new registry, while very welcome, has highlighted that some women are still being prescribed

valproate while they are pregnant. This is extremely concerning. The evidence that valproate can be harmful to babies if it is taken in pregnancy is well-established and should be well known among the medical community.

"Women with epilepsy face complicated decisions if they become pregnant or wish to start a family. They need access to pre-conception counselling, as well as more support with family planning, so that they are supported and able to make informed decisions about their care."

Recent findings suggest that other epilepsy medicines as well as valproate can cause a risk of birth abnormalities or learning difficulties in babies if taken during pregnancy. Epilepsy Action has been calling for more urgent research into the risks of epilepsy medicines – and taking more than one medicine – in pregnancy. The Department of Health and Social Care has said it will extend the registry to include women prescribed any epilepsy medicines in the next phase of the registry's development.

Valproate medicines include sodium valproate (Epilim, Episenta, Epival, Depakote) and valproic acid (Convulex). You can find more information about valproate and pregnancy on the Epilepsy Action website.

It is important that women do not stop or reduce their epilepsy medicine unless they are advised to do so by their doctor. Stopping or reducing epilepsy medicines could lead to more frequent or more severe seizures. Anyone worried about their epilepsy medicines should speak to their doctor.

APPG meeting raises issues around epilepsy medicines in pregnancy and maternal deaths with MPs



Maternal deaths in epilepsy and the effects of epilepsy medicines when taken during pregnancy were the focus points of the latest All-Party Parliamentary Group (APPG) hosted by Epilepsy Action.

The Zoom meeting, held on Monday 22 March, was chaired by Valerie Vaz MP and Yasmin Qureshi MP.

APPGs are informal cross-party groups representing specific interests in Parliament. They can be an impactful way of raising awareness of important issues among parliamentarians. Together with SUDEP Action, Epilepsy Action is co-secretariat of the APPG on Epilepsy.

Professor Marian Knight presented the findings of the MBRRACE report into maternal deaths during or up to one year after pregnancy. MBRRACE (Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries in UK) published the report 'Saving Lives, Improving Mothers' Care 2020' in January this year. It found that maternal deaths from sudden unexpected death in epilepsy (SUDEP) had doubled between 2013-15 and 2016-18, going from 13 to 22 women.

Very few of the women had documented pre-pregnancy counselling. Epilepsy Action has called for all women with epilepsy to receive pre-

conception counselling and family planning advice so that they can make an informed decision about their medicine.

Professor Knight's presentation was followed by Jane Hanna, CEO at SUDEP Action. Jane Hanna also discussed the MBRRACE report, and concerns that the risk of SUDEP are not properly communicated to women with epilepsy.

Sarah Mee, the senior medical assessor at the Medicines and Healthcare Products Regulatory Agency (MHRA), also delivered a presentation. She shared the work the MHRA is doing to communicate the risks of taking certain epilepsy medicines in pregnancy. This included communicating the findings of the recent CHM review on epilepsy medicines, and work to establish the valproate registry. More on this on page 6.

Following these two presentations, the APPG heard from a number of leading clinicians about

what next steps need to happen to ensure that the issues raised are addressed. This included further research into epilepsy medicines, more epilepsy nurses and more funding for epilepsy services.

There was also a powerful and important story from Joanne Doody about her son Peter who died due to SUDEP at the age of 21.

APPG chair Valerie Vaz has written to the Department of Health and Social Care to outline the key points raised during the meeting. She has asked Health Secretary Matt Hancock to attend a future APPG meeting to address these points.

The event was attended by almost 50 representatives, including patient groups, clinicians, researchers, MPs and Peers.

There is more information on the APPG on Epilepsy at epilepsy.org.uk/lappg

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Cannabis-based medicines linked to early puberty

Medical cannabis may be linked to early puberty, according to a case published in the *British Medical Journal (BMJ) Case Reports*.

Research suggests that cannabis-based medicines may reduce seizures in some children with some more severe forms of epilepsy.

However, cannabis-based medicines may also affect

a trio of glands, called the hypothalamo-pituitary-gonadal (HPG) axis. These are responsible for regulating several body systems. In cases where puberty begins before the age of nine years old, it is thought that the cause is an early activation of the HPG axis.

Previous studies have linked cannabis to higher levels of testosterone, the male hormone responsible for puberty in men.

In the case report, written by Dr Aditya Krishnan and colleagues, a two-year-old boy had shown signs of puberty about a month after being prescribed cannabis oil to treat his severe epilepsy. This had reduced his seizures from 20 a day, to five.

The boy was treated with medicines to reduce the effects of the hormones that were causing the onset of puberty.

The authors highlighted that this was only one case and that no previous cases have been reported. However, they said doctors should be aware of this possible side-effect of the use of cannabis-based medicines.

They added that more research is needed into the effects of cannabis-based medicines on hormones.

DVLA trials new licence renewal process

The Driver and Vehicle Licensing Agency (DVLA) is trialling a new system to make renewing a driving licence quicker for people with epilepsy and multiple sclerosis (MS).

The new process will affect renewal of short period medical review driving licences, which need to be renewed more often due to a medical condition.

Currently, renewing a short period medical review licence involves filling out a questionnaire and the DVLA making medical enquiries to clinicians before issuing the new licence. In the new trial process, if the answers in the questionnaire don't show a cause for concern, the DVLA won't make a medical enquiry. Instead the person renewing their licence will receive a phone call with some additional questions. They will then be asked to confirm that all the information they have supplied is correct, and their licence will be issued.

However, if an answer in the questionnaire is of concern, the usual process will be followed, including a medical enquiry.

Most people can continue driving while their licence is being renewed.

This process does not include reapplying for a licence after it has been surrendered or revoked due to a seizure. When a person meets the DVLA's rules for reapplying for their licence (usually being a year seizure-free), they will have to follow the current process for this.

Government responds to safety review recommendations around valproate



The UK government is planning to appoint a Patient Safety Commissioner to advocate for patients, after recommendations made in last year's safety review into sodium valproate, Primodos and vaginal mesh.

The government is responding to the recommendations made by the Independent Medicines and Medical Devices Safety (IMMDS) review published in July last year. The recommendations were made to improve patient safety, after the review found major failings by the healthcare system over three "public health scandals".

As well as the Patient Safety Commissioner, the government is putting together a Valproate Safety Implementation Group. This will work to reduce the number of women prescribed valproate and support those women for whom valproate is the only option.

This group will include clinical specialists in neurology and mental health, data experts and system leaders. Other aims for the group include raising awareness of the issues around taking valproate during pregnancy, and trying to ensure the Pregnancy Prevention Programme (PPP) is followed.

A Valproate Safety Registry has also been created to monitor the use of valproate, adherence to the PPP and the number of babies born to women taking valproate. A report on the first data collected by the registry on women currently prescribed valproate in England and any exposed pregnancies, has been published. More on this on page 6.

The government is also responding to recommendations to improve data collection on medicines and medical devices. The Medicines and Healthcare products Regulatory Agency (MHRA) has created an Expert Working Group on Optimising Data on Medicines used During Pregnancy to ensure better data collection and analysis.

A Safer Medicines in Pregnancy and Breastfeeding Consortium has also been set up, made up of 16 organisations, including NHS, regulator and charitable organisations. In addition, the government is putting steps in place to create a UK-wide medical device information system to collect data on medical devices.

Health Secretary Matt Hancock has said that research is ongoing into maternity and neonatal services. He added that the National Institute for Health Research (NIHR) welcomes funding applications for research, including into the use of epilepsy medicines in pregnancy.

Recent findings from a safety review by the MHRA suggest that other epilepsy medicines aside from valproate can also carry a risk if taken during pregnancy. Organisations, including Epilepsy Action, have

called for more research in this area.

The Health Secretary said that there are no plans to introduce a PPP for other epilepsy medicines. The government said that "neither the magnitude nor the nature of the risks observed with the reviewed epilepsy medicines are as severe as [those] associated with the use of valproate during pregnancy".

The government is also still considering a number of the recommendations, months after the IMMDS review made them. One is the creation of a scheme to help people harmed by these medical scandals to pay for the extra care and support needed. Another is putting in place specialist centres to provide treatment, care and advice to those affected by medicines taken during pregnancy.

Philip Lee, Epilepsy Action chief executive, said: "We are pleased to see updates about how the government, NHS England and MHRA are working to make everyone aware of the risks of sodium valproate, and other epilepsy medications when they are taken in pregnancy. But more still needs to be done.

"It is vitally important that women do not stop or change their epilepsy medication, even if they are pregnant, without talking to their doctor or nurse. Doing so would put them at risk of harm. If a woman with epilepsy discovers she is pregnant, or is thinking of becoming so, it is important she talks to her health professional as soon as possible."

The government has said it has no plans to act on a few of the recommendations made by the IMMDS review.

Employer toolkit

Supporting employees with epilepsy in the workplace



**Are you getting
the support you
need at work?**

There are a lot of myths about epilepsy in the workplace, which contribute to a low employment rate for people with epilepsy.

That's why we've launched our new Employer toolkit, an online resource to help employers confidently support their employees with epilepsy. With helpful information, videos and printable resources, the toolkit helps employers to:

- Understand that there are many different types of epilepsy and seizures
- Know how to help in the event of a seizure
- Confidently approach the topic of epilepsy with their employee

- Offer any support that might be necessary
- Understand that many people with epilepsy need little to no extra support

**Take a look or tell your
employer about the toolkit:
employers.epilepsy.org.uk**

Get in touch: helpline@epilepsy.org.uk

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Preconception counselling

Dr Janine Winterbottom and researcher Emily Lloyd MSc discuss the importance of preconception counselling and describe a new piece of research they are carrying out

What is preconception counselling?

Preconception counselling is a process of preparing for pregnancy through which physical, mental and emotional health is the best it can be **before** becoming pregnant. Public Health England describes good preconception health as including two main points:

1. Planning pregnancy – Enabling women and their partners to choose if and when to start or grow their families
2. Fit for pregnancy – Recognising that many pre-pregnancy health behaviours and risk factors can be changed

Having frequent opportunities to review plans for pregnancy is vital, as up to half of women report their pregnancy as unplanned. Preconception care starts before trying to become pregnant for the first time and includes the time in between pregnancies. It supports improving maternal health before becoming pregnant, with a view to improve the health and wellbeing of women and their children.

Why is preconception care important for women with epilepsy?

For women with epilepsy, preconception care is vital because epilepsy and epilepsy medicines can increase the risk of problems for the mother and baby. It gives the chance to improve seizure control. Reducing the frequency and severity of seizures before becoming pregnant improves the chance of seizures remaining stable during pregnancy. Where possible, preconception counselling also

aims to achieve seizure freedom in order to reduce the risk of harm to both the mother and baby. Women who have been seizure free for 12 months have the best chances of their seizures remaining controlled in pregnancy.

Tonic-clonic seizures in pregnancy, especially if they are happening during sleep, or are becoming increasingly frequent or prolonged, increase the risk of sudden unexpected death in epilepsy (SUDEP) in pregnancy. This is why a main goal for preconception care is helping women have the best possible seizure control before becoming pregnant.

Preconception care also allows for epilepsy medicines to be reviewed and gives the opportunity to have a conversation about medicine risks. It can help increase awareness of higher risk medicines like sodium valproate (Epilim). Sodium valproate is known to increase the risk of birth abnormalities and developmental problems in babies born to women taking this medicine. Other epilepsy medicines have also recently been found to increase these risks, but not as much as valproate. Epilepsy Action has more information at [epilepsy.org.uk/medicines-pregnancy](https://www.epilepsy.org.uk/medicines-pregnancy)

Having this conversation gives women the opportunity to make informed treatment decisions before pregnancy. A medicine review can look at switching from higher to lower risk epilepsy medicines, or whether it is safe to try to withdraw a woman's epilepsy medicine before becoming pregnant. The aim is to help

women experience pregnancy on the fewest medicines and at the lowest dose possible – but with the greatest possible seizure control.

Preconception care helps to reduce the risks of:

- Worsening seizure control if a woman stops taking her epilepsy medicines for fear of harm to the baby. This can increase the chance of injury or even death due to seizures
- Birth abnormalities in the baby if a woman becomes pregnant before having the opportunity to review and complete any changes to medicines. This includes becoming unexpectedly pregnant while taking valproate

Preconception care offers the chance to avoid some of these risks by providing an individual health assessment and allowing actions to be taken to make health improvements. Improving women's knowledge about their epilepsy and medicines, and improving their general health, can be one of the first steps. Starting vitamins, such as folic acid, before becoming pregnant can also help reduce the risks of some birth abnormalities.

For women with epilepsy, preconception care is vital because epilepsy and epilepsy medicines can increase the risk of problems

Planning for pregnancy

- Arrange a preconception care appointment. It can improve your chances of getting pregnant by helping you and your partner improve your pre-pregnancy health
- Talk to your doctor about your preconception health if you are sexually active. Preconception care should begin at least three months before you get pregnant, but some women need more time to get their bodies ready for pregnancy
- Discuss your partner's health too

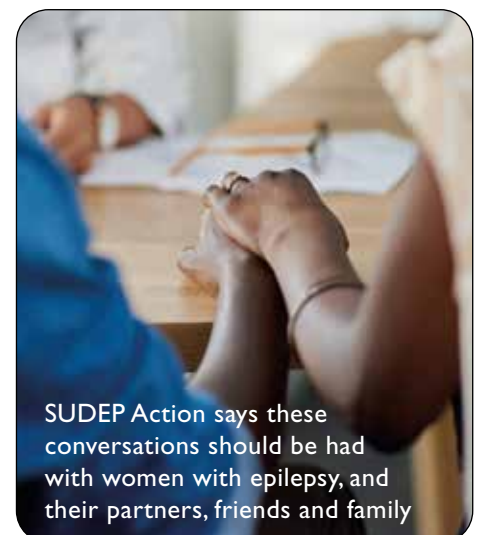
- Get advice about family planning and contraception
- Start folic acid at least three months before trying to get pregnant. Folic acid 5 milligrams daily is recommended for women with epilepsy
- Manage any additional health problems, such as diabetes, asthma, high blood pressure, thyroid disease and depression. It is important to get the best possible control of any long-term condition before pregnancy. This includes discussing with your doctor any medicines you might be taking, and how best to manage these conditions before, during and after pregnancy
- Check immunisations, sexual health checks and smear tests you may need are up to date
- Improve your overall health, such as reaching a healthy weight, making healthy food choices, being physically active, caring for your teeth and gums, reducing stress, quitting smoking, and avoiding alcohol
- Ask your doctor about:
 - Any health problems that run in your or your partner's family
 - Any problems you have had with prior pregnancies, including preterm birth or miscarriage
 - Family concerns that could affect your health, such as domestic violence or lack of support
- Talk to your doctor and epilepsy specialist:
 - if you find yourself unexpectedly pregnant. Continue taking your medicines. Stopping or reducing your medicines without first discussing this with your doctor is very risky and can increase the chances of seizures returning or worsening. This can be the case even when a woman has been seizure-free for many years
 - The main risks for a woman with epilepsy are from seizures worsening and increasing the risk of maternal death. Preconception counselling can help by offering guidance and support for a safe pregnancy for both mother and baby. This involves shared decision-making, and allows women to be made aware of the risks and alternate options to reduce risk
 - Continue to keep yourself safe. For example, don't take risks

- like bathing unsupervised
- Get in touch with your doctor or epilepsy nurse no matter how far along you are in your pregnancy – it's never too late to talk about risks and make informed decisions

Why is research needed on preconception care for women with epilepsy?

There are four important reasons why research is needed on the preconception care currently available for women with epilepsy.

1. Evidence continues to emerge that women with epilepsy don't remember having had a conversation with a healthcare provider about the risks of epilepsy medicines in pregnancy. This includes women who have not been made aware of the risks of taking valproate in pregnancy and women who have not had their annual review. There is also uncertainty around the advice given to women about the risks in pregnancy of the newer epilepsy medicines, for which evidence is limited
2. The organisation SUDEP Action highlights the need to talk about seizure risks in pregnancy with women with epilepsy, as well as their partners, friends and family. Mothers and Babies: Reducing Risks through Audits and Confidential Enquiries across the UK (MBRRACE-UK) published a report in January entitled 'Saving Lives, Improving Mothers' Care 2020. The findings from this highlighted that SUDEP deaths in pregnant



SUDEP Action says these conversations should be had with women with epilepsy, and their partners, friends and family



Preconception counselling helps women make informed choices about their epilepsy medicine

consensus). Within this study, experts of preconception are women with epilepsy (their partner, spouse, family, friends and carers), healthcare practitioners (including GPs, epilepsy nurses and epilepsy specialists) as well as midwives, obstetricians, pharmacists, family planning, voluntary organisations and healthcare commissioners.

The online Delphi survey will involve participants making decisions about what is essential, and ranking statements from least important to most important to refine the content of the preconception care pathway.

You can register your interest by emailing the study team at: preconceptionstudy@thewaltoncentre.nhs.uk

The results of the survey will then be analysed in preparation for the final stage of the study, a consensus meeting. This will involve a smaller group of experts, to discuss and agree on the final content of the care pathway and the outcomes families want. This final stage of this study will involve a representative panel of patients and clinicians, 'key stakeholders', discussing the results of the survey. The results of the final study stage will be to identify the essential support that women need, describe good standards of care, and develop a pathway of stages or steps to support women. The results will help develop a patient-reported outcome, to measure impact of preconception care for women with epilepsy.

For more information or to get involved, please call the research team on 0151 556 3721. You can email the research team at preconceptionstudy@thewaltoncentre.nhs.uk or visit the study website at tinyurl.com/epilepsyconceptionstudy

If you are worried about pregnancy and epilepsy, you can contact the Epilepsy Action Helpline for free on 0800 800 5050 or by emailing helpline@epilepsy.org.uk

Dr Janine Winterbottom – Advanced nurse specialist in epilepsy (Sapphire Nurse), The Walton Centre NHS Foundation Trust Liverpool, principal Investigator.

Emily Lloyd MSc – Co-researcher and person with epilepsy.

or postnatal women had doubled between 2016-18, compared to 2013-15. Maternal deaths in epilepsy remain high when compared to other chronic conditions in pregnancy

3. Availability of preconception care to women with epilepsy is variable across the UK. A mapping exercise of preconception services was carried out in 2020, supported by Epilepsy Action. It found that the majority of respondents had some difficulty in accessing preconception care. Epilepsy Action members continue to say that they don't always know where to go for the help they need when they need it
4. There is a lack of consistent definitions of what support is needed to help women with epilepsy prepare for pregnancy or the best methods of care delivery. For women with epilepsy, the extra challenges and risks they may face are less well known

Preconception counselling research

Dr Janine Winterbottom has been awarded a National Institute for Health Research grant to develop a preconception care pathway for women with epilepsy in the UK. This project is working across the four countries of the UK. Women with epilepsy are invited to take part, along with their partners, families, friends, and professionals involved in providing preconception healthcare to women with epilepsy. This study was developed following a series of engagement events supported by Epilepsy Action members.

The research team based at the University of Liverpool and the Walton Centre NHS Foundation Trust in Liverpool are conducting this study to develop a deeper understanding of what is important for women with epilepsy to achieve from preconception counselling. The team aims to:

- Identify essential support that women need
- Describe good standards of care
- Develop a pathway of stages or steps to support women
- Develop the content of a preconception care outcome measure

The study will be carried out in three stages. Firstly, to gain a deeper understanding of preconception care experience, the researchers will talk to women with epilepsy, and their partners, families, carers and friends in focus group and interviews. The study team is recruiting into this stage, and are keen to hear from people about their experiences. The team is interested to hear about the struggles involved, and when planning pregnancy didn't go to plan, as well as when the plan came together. You can get involved at: tinyurl.com/epilepsyconceptionstudy

In the second stage, the findings from the interviews and focus groups will be combined with a literature review and patient and public consultation to develop the online Delphi survey. Delphi research involves gathering the opinions of experts to form an agreement (also referred to as



Seeing epilepsy

National Epilepsy Week is celebrated from 24-30 May this year and Epilepsy Action is working to make epilepsy seen and better understood by everyone

We often talk about the challenges of invisible conditions such as epilepsy or mental health problems, among many others. Sometimes people don't take these types of conditions seriously, don't appreciate the support that may be required, or downplay our experiences. This can be stressful and debilitating, leaving us misunderstood and without the help we may need. And this is often just because people can't see our condition and struggle to put themselves in our shoes.

Another way that epilepsy has been invisible for many years is on a more public platform. In the past, you may not have seen epilepsy in newspaper headlines, on TV or on government bills. Epilepsy doesn't always get the time and attention it deserves, even though it can affect anyone at any time and can appear seemingly out of the blue. Past misconceptions have made many people feel uncomfortable speaking about their epilepsy, and the condition has tended to be 'out of sight, out of mind' in the public arena.

In recent years, changes in attitudes have helped the condition become more openly discussed and better understood by the public. Organisations like Epilepsy Action have advocated for rights, services and support for people affected by the condition. And many people who have felt supported have built up the confidence to share what their experiences with the condition are like. Each small ripple has built up to big tides of change for people with epilepsy to help the condition become better recognised and understood. But we all know that we have further to go with this.

With National Epilepsy Week upon us, Epilepsy Action is working to get epilepsy and its unique and different challenges noticed by those in government, employers and everyone else in our communities.

Epilepsy Action is looking at life after COVID-19 for people with epilepsy as well as sharing the experiences of people

with epilepsy far and wide. You can contact us to share your story at press@epilepsy.org.uk

The organisation has also produced a new employer toolkit designed to help employers and others in the workplace to better understand epilepsy and support people with the condition. This includes information about epilepsy, safety at work and possible reasonable adjustments an employee with epilepsy may need. With issues around employment and epilepsy always of key importance, this toolkit will be an invaluable resource for employers and employees. You can access this and share it at epilepsy.org.uk/employers

Among the activities taking place this week, people across the country are taking part in a challenge walking 50k for National Epilepsy Week. The pandemic has given many of us a new appreciation for the humble daily walk, and this is one of many different ways people are fundraising and raising awareness of epilepsy. If you'd like to fundraise to help make a difference, you can organise or take part in an event at: epilepsy.org.uk/events

Whatever you are doing to take part, it is important to mark international epilepsy awareness events and raise the profile of this often overlooked but life-changing condition. The more we are able to raise awareness of our experiences, share valuable resources and make people with epilepsy feel supported, the more we can bring epilepsy into view.



Ada

Staying in, purple on!

Despite another pandemic-restricted Purple Day, we saw the purple celebrations continue with verve inside homes, across social media and on our TVs. Here is a catch up of a few activities

For a second lockdown Purple Day, you rallied like the superheroes you are. Despite all the many challenges the last 12 months have presented, the spirit of Purple Day was strong. The purple hair dye was flowing, the purple cakes were baking, and the purple clothes, hats and feather boas were proudly worn.

But more than that, a great many of you shared your epilepsy stories and

experiences with the world. This is a brave and generous act that is the bedrock of changing the tides on misunderstandings about epilepsy and creating greater awareness of the condition. Whether it was people speaking to the media about their experiences, sharing your stories on Facebook with a fundraiser for epilepsy, or just telling a couple of friends about your seizures, it's all a big deal.

More than 400 of you ordered the Epilepsy Action Purple Day packs and held your own fundraising events. Your collective efforts have raised over £13,000 for people with epilepsy!

Clare's daughter Ada, nine, was one of the fundraisers this year, taking part in a sponsored walk for Purple Day. Ada has epilepsy and wanted to raise money and awareness for others with the condition by walking half a marathon (13 miles) in seven days.

Clare said: "Ada walked 13 miles in seven days and raised over £1,600. Her class at

school also supported her on Purple Day, as she has epilepsy herself, so we wanted to raise awareness by wearing purple!"

Epilepsy Action also ran a Purple Day Facebook Challenge – Give It Up in March – encouraging people to give up something over the month to raise money for people with epilepsy. With four thousand people joining the group, it was clear the appetite to support Purple Day is still huge despite the tough year we've all had.

People pledged to give up all kinds of things – from the classics like caffeine, alcohol, snack foods and meat, to the more unusual, like giving up losing your temper or taking on a daily 15,000 step challenge. In a year like we've had, we've come to rely on the home comforts like snack foods and caffeine. It's a time when emotions have been running high too, so our fuses may be shorter than they have been. People took to the challenge to make positive changes in their lives while also helping support a great cause. The challenge is expected to have raised over £40,000 for people with epilepsy – a phenomenal achievement!

One thing I wish people knew

Epilepsy Action also set up a number of TV and radio interviews to raise awareness far and wide about epilepsy. These featured Epilepsy Action spokespeople, people with epilepsy and some famous faces, like comedian Maisie Adam and footballer Jay Bothroyd. Many of these interviews highlighted the findings of two polls that Epilepsy Action carried out to mark Purple Day.

The first poll showed that one in four (23%) people among the general public



believe epilepsy has no impact on a person's life aside from having seizures.

Side-effects of epilepsy medicines, memory problems and impacted mental health are just some of the things that can affect people, the organisation said.

One third of people surveyed said they believe epilepsy does not impact a person's mental health. In addition, two-thirds of people agreed with the suggestion that people "just need to be more positive when living with health conditions".

As well as this, two-thirds of respondents said they would be afraid to even witness someone having a seizure. Epilepsy Action said this exposes a "stark disconnect" in understanding and compassion for people with epilepsy.

These findings are in contrast to a second Epilepsy Action poll, asking people with epilepsy for the one thing they wish people knew about the condition. The results show that nearly half of the respondents prioritised a wider understanding that epilepsy is about more than seizures. One in five people (20%) said their biggest wish was for better awareness that there are many different types of seizures. People also said they wanted more understanding that not all seizures are triggered by flashing lights and that epilepsy is a fluctuating condition.

Louise Cousins, director of external affairs at Epilepsy Action, said: "These new insights are stark but not surprising. The impact of living with epilepsy can take a huge toll on people's lives, their happiness and wellbeing. Everyone's experience of epilepsy is different, but it can't be overcome just by 'being more positive'. This attitude needs to change.

"Lack of knowledge and empathy feeds into fearful, harmful assumptions and people with epilepsy feeling further misunderstood and dismissed. By giving them a voice and encouraging conversations on Purple Day, we can really improve the public's knowledge and compassion and close this gap in understanding."

Purple podcast

The organisation's social media platforms were alive with stories and information

all day, sharing your experiences and flying the flag for people with epilepsy.

One of the things shared was a brand new video from Epilepsy Action explaining epilepsy. For those of us with the condition, it will all be very familiar. But if epilepsy is something we struggle to communicate to those around us, this video is a great place to start. You can find it at epilepsy.org.uk/whatisepilepsy

Two new episodes of epilepsycast, the epilepsy podcast from Epilepsy Action, were also uploaded to mark the day. One told Maisie Adam's story of how she dealt with her epilepsy diagnosis and how she included it into her comedy routine. Maisie was diagnosed with epilepsy when she was 14. She has shared her story for Purple Day. She said: "It's totally normal for people to have those misconceptions about epilepsy, because of the information that's out there at the moment. So much is frustratingly simplified, Hollywood-ified – it's very bite-sized. It's just the understanding that's important and I think that comes from both sides. It's about us being understanding of why people have those misconceptions but just hoping that people don't assume.

"Epilepsy is so different for every single person. Be open to that huge variation."

The other epilepsycast episode featured the experiences of a number of people with epilepsy, who shared the one thing they would like others to understand about epilepsy. It included people like Murray, who explained that he wishes people wouldn't assume someone with epilepsy can't be in a work role with responsibility.

He said: "People with epilepsy aren't stupid because they have the condition. People with epilepsy are found in all walks of life and at all levels in business, government, the arts and professions.

"I've personally had comments in the past from people telling me I shouldn't have been in roles I've held over the years, including managing teams of up to 80 people, just because I have epilepsy.

"If someone ever tells you how you should feel or what you should do with you condition, don't get mad, help them to understand it more."

Charlotte has tonic-clonic, absence and myoclonic seizures. She said: "One of the biggest misconceptions about epilepsy for me is that it doesn't affect your life. I've not had any area of my life not be affected by my epilepsy.

"It's not just 'they fall to the floor and have a tonic-clonic fit', there are knock-on effects. I'm recording this with a very bitten and swollen tongue, having just had [a seizure] yesterday. I can't really eat properly and people don't really think of that stuff. There's so much that's affected by a seizure."

You can find these, and many other episodes at: epilepsy.org.uk/podcast

The positive light of Purple Day was just as bright this year as always, helping make epilepsy better understood, and this is down to you and your support. Thank you.





Erin

Value in the vaccine

Luke and Erin tell Kami Kountcheva what their thoughts and concerns were around having the COVID-19 vaccine, and what reassured and convinced them to get it

The COVID-19 vaccine is one of the best examples of how science and medicine can pull us out of an impossible situation. As we came into March this year, many of us noted that we had made it one year in a pandemic. Much of that year was spent indoors, away from our friends and family and not being able to take part in many of our cherished activities, like going to the cinema or playing sport. And much of that year was also spent not knowing how long we would live like this. As we went from one lockdown to the next, it became clear that staying home was the most effective way to reduce the spread of the virus and reduce the pressure on the NHS. We stopped planning holidays and birthday parties and weddings, because there was no end in sight of the so-called 'new normal'.

When news came of the development of a vaccine, it was the ray of sunshine through the fog that we really needed. The way out of the 'new normal', and a way to protect our most vulnerable and ourselves from the virus.

Many people with epilepsy have welcomed the vaccine. Others are understandably worried about the potential for the vaccine to cause a mild or moderate fever, or whether it may affect the way their medicines work. The Association of British Neurologists (ABN) has said that all COVID-19 vaccines are safe for people with neurological conditions, such as epilepsy. The vaccine is also not expected to interact with epilepsy medicines. It may cause mild side-effects including a fever, but the International League Against Epilepsy (ILAE) suggests taking fever-reducing medicines, such as paracetamol, for 48 hours after the vaccine to reduce

the risk. There is more information at: epilepsy.org.uk/vaccineABN and epilepsy.org.uk/vaccinellAE

For most of us, the vaccine will provide peace of mind and will allow us to eventually be able to get back to some of the people and activities we love. Epilepsy Action took part in a campaign by the Department of Health and Social Care, encouraging people with underlying conditions, like epilepsy, MS and mental illness, to consider accepting the vaccine. Two people with epilepsy share why getting the vaccine is important for them.

'To be able to nip over to somebody's house'

Luke explained that the past year has been challenging on many levels – stress, missing friends and family, missing freedom, work issues and a change in health services, to name a few.

"But even more than this, I've been stressing that I'll catch COVID-19," he said. "If I get an illness like that, it's almost guaranteed that I'd have a seizure. It definitely made sense to me that people with epilepsy were included in priority group six. I know I've certainly had some nasty seizures after getting ill. An illness as potentially nasty as COVID-19 could be very bad for some people with epilepsy."

Luke was diagnosed with temporal lobe epilepsy seven years ago, while he was at university. He has focal and tonic-clonic seizures and has gone into status epilepticus (prolonged seizures) in the past.

"After my first few seizures, I, of course, turned to google. I researched these

episodes I was having, and came to the conclusion they were either panic attacks or seizures. I decided they must have been panic attacks, because seizures seemed very serious. It was only when I had a nasty tonic-clonic seizure on my kitchen floor a year later that I was diagnosed with epilepsy. Take it from me – don't google your symptoms, trust a doctor to look into them for you!"

Epilepsy affected Luke's life in a big way, knocking his confidence, and causing issues with his work. He is undergoing tests to find out if he is suitable for surgery for his epilepsy, which he explains he finds daunting – but worth it. However, the pandemic has put all of this on pause, piling on even more stress for Luke and delaying possible treatment.

"You can probably imagine how keen I was to have my COVID vaccine. And even so, I was worried I'd react to the jab. I went for it in the end, because for me, the benefits of having it done vastly outweigh any negatives. I was also worried it would hurt, but when you have uncontrolled epilepsy, having needles stuck in you becomes par for the course. When it was actually done, it didn't hurt at all – I barely even felt it.

"I did feel rough the day after. I ached and I had a migraine in the morning. Paracetamol helped though. I carried on my work day as normal. I'd say it's worth it if it leads to the pandemic ending!"

Like for many of the rest of us, Luke's first port of call when the pandemic is over would be spending time with family and friends. "I cannot wait to go on holiday. I'm sure I'm far from the only person who needs a break. I'm really looking forward to spending a week in Ireland and seeing my family there. I'm looking forward to seeing my friends too. It's these little things – the freedom to nip over to somebody's house – that I've learned not to take for granted.

"And also, I'm desperate for a haircut!"

'For a tight squeeze from my Nain'

While finding the pandemic to have been a "rollercoaster of uncertainty", like some, Erin started out the first lockdown full of enthusiasm to use the time wisely.

"During the first lockdown, I set my mind to living a healthier lifestyle. I was exercising every day and felt better than ever before. While working from home, I was able to do low-impact exercises during my lunch break and could better regulate my meals. I built up a strong routine and enjoyed quite a few seizure-free months through being less tired and stressed. But when it comes to having epilepsy, the nature of the beast is to interrupt whatever it is that you're doing."

Erin's seizures started as a pre-teen. In her third week of high school, she had a tonic-clonic seizure in class. Doctors presumed the seizures were being triggered by hormonal changes and that she would outgrow them. And they did stop completely in the following years, allowing Erin to learn to drive and go about life as before. However, 2013 brought with it some big changes.

"I was boarding a bus, when I had a breakthrough seizure in the aisle. A formal diagnosis of epilepsy followed a few months later. I'm now 25 and still having tonic-clonic seizures."

For Erin, the sense of independence that came with being able to drive was one of the toughest things to learn to live without. She decided to move away from her rural setting, where transport links were poor, and live in a city environment. This has worked out well for her, and she now has a job she loves and a solid support network.

"My friends and family and I have had some laughs over the random things I come out with post-seizure, while still in various states of disorientation. I feel so incredibly lucky to have that support but it doesn't half hurt to think about the knock-on effect my condition has on others."

During the second lockdown, Erin's seizures started up again out of nowhere. They caused injuries and completely disrupted her newfound routine, which left her feeling lost.

"I've been anxious about catching COVID-19 as well, because I know one of the symptoms is a high temperature. If I caught the virus and developed a fever, there's every chance I could have a seizure

and each one could be detrimental. Everyone has their own opinion when it comes to the restrictions, but for me, there's just no point taking risks."

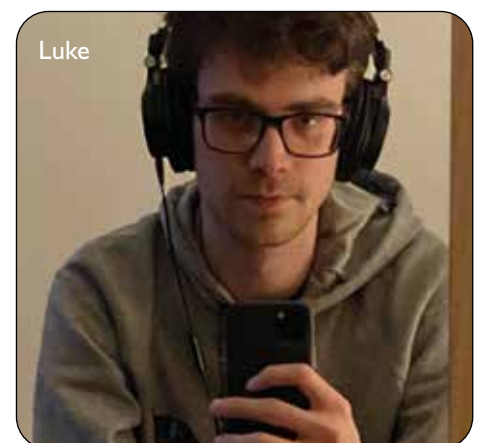
Erin explained that she's very keen to get the vaccine. Her work involves recruiting volunteers to give the vaccines and is glad to see the number of people vaccinated growing.

"I feel that the vaccine is our best chance of regaining some sort of normality. I can definitely understand people's hesitancy around getting the vaccine, but I think we should trust in the science and modern research. There's so much we don't know about epilepsy – and we may never know – so we should take advantage of research results and what is currently known."

Erin explained that her concern about getting the vaccine is the possibility of a fever as a side-effect and the thought of the fact that you can't undo the vaccine. But her research led her to the ILAE and ABN information, which helped to reassure her.

And while there may be many things Erin is looking forward to once restrictions are lifted, there is one thing that is number one on her list. "Getting the vaccine could mean that I'll get to see my Nain. When I'm feeling down, a tight squeeze from her is medicine enough. It could also mean that we'll be able to take my nephew to the beach and my cousin can plan her wedding. I know we're a long way off, but the vaccine is a step forward and offers some hope."

There is more information at epilepsy.org.uk/covid





Amy and Harry

A reason to run

In February, many of you took the Epilepsy Action ‘50 miles in February’ Facebook challenge by the horns, getting outside come rain or shine. Or snow and ice. Three members of the group tell Kami Kountcheva about their motivation to take part

Just before the virus that shall not be named changed the world, I decided I’d try out running. My friends were doing it, my sister was doing it, everywhere I looked strangers and neighbours were doing it. The benefits were obvious – it’s good for fitness, it’s good for mental health, it’s free... But on the other hand, I was also painfully aware that I hadn’t run for longer than 30 seconds since I was a child, so this would be a big challenge.

Nevertheless, I downloaded the NHS app Couch to 5k and started wheezing my way around my neighbourhood streets three times a week. I quickly memorised every tiny section of uphill in my area and my brain became extremely efficient at calculating the best route to avoid them. I completed the programme, and finally started managing to do 5k runs – just, and slowly. But for me it is still an incredibly

big challenge – physically and especially mentally – every time I put my running shoes on, to get to that 5k.

In February, Epilepsy Action held a ‘50 miles in February Challenge’ on Facebook. All kinds of people signed up – people with epilepsy, people with loved ones with epilepsy, younger people, older people, seasoned runners and first-timers. I watched as week-in and week-out people braved the wild weather conditions and made time to go out each week and complete walks and runs that I can only dream of. I was in awe of every person who had the determination, the self-discipline and the generosity to run or walk 50 whole miles in February to raise money and awareness for people with epilepsy. We share the stories of three of the fantastic challenge participants.

Harry

Amy’s son Harry, aged three, is tactile and cheeky. He loves looking at books, playing outside, doing arts and crafts, and dancing.

He has focal epilepsy that sometimes goes into tonic-clonic seizures. His focal seizures mainly affect the left side of his body, making his arm or leg shake uncontrollably, and causing lip smacking and face drooping. He also has absence and tonic-clonic seizures. Amy explained that while his tonic-clonic seizures are short, they tend to cluster, so he needs emergency medicine called buccal midazolam to stop them.

“On the morning of 2 December 2019, I was getting him ready to go to nursery at the hospital site where I work. Suddenly his whole body went stiff and he was shaking. He did this three times, all lasting about a minute. I called Mark, my partner, to come in and hold him and that I thought he was having seizures. He said he thought he was just cold.

“So I got in the car with Harry and Oscar, his twin, to go to nursery. On the way, I looked in the car mirror to see Harry having another episode where he was staring ahead and shaking. I started to cry and felt panicked, but it passed and I kept driving. As soon as I pulled up, I grabbed the boys, ran Oscar into nursery and took Harry straight to A&E.”

The doctors at A&E told Amy that Harry likely has epilepsy. “I already had my suspicions anyway, so as they took a history I confessed that I thought he

had been having absence seizures for a few months. But I had talked myself into believing that it was a behavioural effect and I had not wanted to be branded a paranoid parent by health professionals.

“When he had his EEG, he sat on my lap and I felt him jerking. The technician gave me a look, at which point I knew that he had epilepsy. My eyes filled with tears and I just kissed his head.”

Harry was first prescribed the medicine carbamazepine. But even when he was taking the maximum dose, based on his weight, it wasn't controlling his epilepsy. He was given levetiracetam (Keppra) in addition to his treatment, with the idea to wean him off carbamazepine, but this hasn't happened successfully.

The technician gave me a look, at which point I knew Harry had epilepsy

The medicines have caused some side-effects for Harry as well. “He was drowsy with carbamazepine, which he took twice daily, so his morning dose was split into morning and lunchtime. This has helped with the drowsiness, and now his treatment is more manageable.

“To start with, he would cry and scream before having a seizure. Now we have more warning, as he will tell us that his hand hurts and he has a look of terror in his eyes. He will cling to us until it has passed.”

Harry's epilepsy has greatly affected his speech. Amy said that this, and the side-effects of his medicines making it hard



Harry loves being around other children

for him to concentrate, are some of the biggest challenges Harry has to deal with at the moment.

“Harry loves to be around other children but with his speech delay he can't have conversations with them. But he will play games alongside them and copy their speech. He seems to be a big hit with the girls in nursery and I have heard them say that he is their friend – not Oscar. I wonder if this is because they can mother him?

“He is now in speech therapy and this has helped him so much. He will now speak in four-word sentences but needs time to formulate his speech.

“Before COVID he took swimming lessons, but for safety reasons, one of us was needed in the pool with him. At this stage, that's fine, but as he gets older, I worry that he will see that he is treated differently to his twin brother.

“He also took football lessons and he loved the skills teaching but when it was a match he became overwhelmed by people shouting. So then he would sit on the side and cry while hugging me.”

In September, Harry started attending school nursery, which has been a mixed experience for Harry and his family. Amy

explained: “I tried to prepare them for Harry's epilepsy, but I am unsure that the staff truly understood the impact that epilepsy would have on him.

“The staff have gone above and beyond to accommodate his needs. For example, they trained in giving him his rescue medicine, they give him his daily medicines and they help deliver his speech interventions.

“But initially they were reporting that he was clumsy, had a lack of spatial awareness and that he has severe speech delay. In one instance, a member of staff said that they felt that he had ‘many issues, not just epilepsy’.

“As parents, this made us very upset and concerned. After a meeting with the headteacher and nursery teacher, it turned out that the staff had no training on epilepsy. I sent through links to Epilepsy Action's training materials on his types of epilepsy and the medicine leaflets so that they could learn more about epilepsy. Since then, their understanding of how epilepsy could be making Harry behave in certain ways has improved. The headteacher has said the school is committed to working with Harry and with us as parents to help him reach his full potential.”

Epilepsy is more than just the seizures Harry experiences. It is also the effects on



Amy took part in the 50 miles in February challenge for her son Harry



his life, the side-effects of his medicines, and the effect on his family. As well as his twin, Oscar, Harry has an older brother, Frankie, aged five. Amy said that initially, Frankie was scared to see Harry have seizures. After some simple chats to explain what epilepsy is and what to do if he sees Harry have a seizure, Frankie has really taken his brother's epilepsy in his stride.

“Last summer, during one of our attempts to wean Harry off carbamazepine, Harry was having seizures, and I heard Frankie tell Oscar: ‘This is just a part of Harry. It’s not nice for him and he is scared, so we must look after him as it’s not so scary for us.’ He now also tells us if Harry has had a seizure and he has a name for each one.”

Even at the age of three, Oscar is also a support to Harry when he has a seizure. “Harry and Oscar are non-identical twins, but even so, Oscar seems to know when Harry is about to have a seizure, as he will rub his head,” Amy said.

Amy and her partner Mark have different experiences with epilepsy. As a paediatric nurse, Amy had worked around children with epilepsy before Harry was diagnosed. However, for Mark it was completely new and he didn't know there was more than



one type of seizure. He now recognises many of Harry's seizures and Amy has taught all of Harry's grandparents what his seizures look like. But knowing as much as she does about epilepsy hasn't been that easy for Amy.

“If I'm honest, I have felt more responsible for Harry because of my career and, at times, I've got annoyed that other people don't understand his epilepsy as much as I do.

As a nurse, I had seen many children have seizures,
but when it was Harry, I went into a blind panic

“As a nurse and before that as a care assistant for children with epilepsy and life-limiting conditions, I had seen many children have seizures. I had given rescue medicine, and secured children's airways while they had seizures, and I never once panicked.

“But when it was Harry, I went into a blind panic. One of the first times I snapped my car key in the ignition because all I wanted to do was get him home where I could be close to him. When I gave him his rescue medicine, I was crying and apologising to him. I had



the ambulance service on the phone and I was asking how long they would be as I wanted oxygen on the way. He was breathing but I knew there was a small chance his breathing would stop and I felt like I had no control. I didn't have all the equipment around me that I would have in my work setting.

“I can honestly say that my work background is a mixed blessing. In some ways, it's great because I understand Harry's epilepsy on a good level. In other ways, perhaps I know too much of the bad things with epilepsy, so I am constantly overthinking and worrying.”

Amy had been part of a running group for around a year when Harry was diagnosed. “The day he was diagnosed, I put a status on Facebook saying ‘I want to run, I want to scream, I want to cry...’ The next day was a training session but I didn't sign up because I didn't want to be too far from Harry. The group leader messaged me and said that she would run the session on the road next to mine so that I could run out my frustration and get home quickly if I needed to.

“When I saw the ‘Run 50 miles in February’ group, I immediately signed up. I really enjoyed the Facebook page and feeling the connection with the other members. Some had children with epilepsy, others had epilepsy themselves – it made me feel like I wasn't dealing with epilepsy alone.

“I am going to be running the Brighton marathon for Epilepsy Action in September. I'm not a natural runner but I'll put my all into it. I will do it for all the warriors fighting this invisible condition. They say that a tonic-clonic seizure is equivalent to running a marathon so for all those who endure this daily battle, I can and I will run 26.2 miles.

“For us as a family it’s so important to raise awareness of epilepsy, because many people like Mark are unaware that epilepsy has many forms. People need to be aware of this so that people with focal or absence seizures are recognised as having epilepsy and steps can be taken to keep them safe. As a nurse, I’d had lots of exposure to epilepsy, but I felt overwhelmed, stressed and isolated by Harry’s condition, so I really feel that parents need more support.”

Alfie

Alfie is a very outgoing curly haired 10-year-old, who loves all kinds of sport, especially football and swimming.

Alfie had his first seizure in May 2020 on an evening at his mum Dawn’s house, his dad, Mark, recalls.

“It was around 8pm and he was playing with Lego. It was a terrifying ordeal for his mum and she had to ring an ambulance. She rang me and I flew over as fast as possible, gambling on every amber light. Alfie was taken to the local hospital in Wakefield during the height of the pandemic. All the paramedics had full hazmat suits on – it was like some science experiment had gone wrong. We got to the hospital around 9pm and after blood tests and monitoring we left in the early hours of the morning.

“I’ve had some experience with epilepsy in the past, because my younger sister has seizures, so I was asking a lot of questions. It turned out that I didn’t have to wait too long to see for myself what his seizures were like. Five days later, at around tea time, Alfie had another seizure while at my house, sat with me listening to an audio book – his favourite book about a famous young wizard, points for guessing!



Alfie enjoys football and swimming

“He was slightly responsive, but he forgot who I was and what we were doing and then had a seizure lasting around two minutes. My wife Hannah rang an ambulance again, and I rang his mum, and we made the trip to A&E – his mum in the ambulance with him and me in the car following shortly behind. Luckily, when

Alfie was taken to the local hospital during the height of the pandemic

we got there, the paediatric neurologist was doing the rounds. They said: ‘That’s twice in five days he’s been in – he needs an appointment as soon as possible.’ That made everything else from there get done a lot quicker.”

Alfie was diagnosed with focal epilepsy. “The diagnosis went really well and quickly. Within about four weeks, he had two EEGs – one during the day and one while asleep. We then had a call with a consultant to tell us about his specific epilepsy. We had the support of an epilepsy specialist nurse, we were given rescue medicine and the nurse made a

care plan for school to follow with the best way to support Alfie while in their care. This was the NHS at its very best.”

Alfie will be on medication for the rest of his life. This still needs adjusting now and then to try to get the right balance for him, especially as he is growing daily, Mark explained. His epilepsy mostly affects him when he’s tired or asleep, which makes it very hard for his family to tell when he might have or has had a seizure. Alfie has monitors at his mum’s house and at his dad’s house, so they can listen out for seizures.

“On occasion, he still has absence seizures, but these are rare at the moment, so we just have to take it day by day. We just don’t know what he’s going to be like in the mornings when he wakes up.”

Despite having some experience with epilepsy in the past, managing Alfie’s epilepsy has been different for Mark. He explained that Alfie has got on with things and that, as a family, they have tried to carry on as normal.

“We still play football and try to do other sports, but his mum and I have noticed that he gets tired a lot quicker now than he did before his first seizure. He is also a lot more emotional.



Alfie and Mark



Alfie with his mum Dawn

“I know epilepsy can affect relationships with others, but there is no way that Alfie won’t have friends, epilepsy or no epilepsy. He is very popular at school and with his football team, and loves to be around his peers. School and his friends have been amazing with him and just accepted the situation for what it is. That helped Alfie to just get on with life and when he has a bad day, they support him. It makes me and his mum very happy!”

Alfie’s parents have found that school has been supportive, but it has been a learning curve for all. It was a worry for his teachers at first, with a lot of phone calls to home, but now we are in a routine. The school has now organised a quiet area for Alfie to relax and take some time out. This has helped him immensely, giving him time to recharge and carry on with his day.

Mark said: “It’s taken a long time for Alfie to have one full week at school and not to be leaving before lunchtime. His mum has left her job so she can give Alfie 100% of her time and to be there when needed.

“As a family, we don’t really talk about his seizures but do speak daily about how he is feeling. Alfie has become very aware of his body and how he feels before and after a seizure. He knows when he needs to rest. If he says his legs are tired, that tends to tell us he’s had a bad night.”

Running wasn’t new to Mark, and with his experience with epilepsy, he was keen to take part in the 50 miles in February challenge. “I have all kinds of injuries, so most of the ‘runs’ were actually walks. But I would do another challenge in the future.

“Alfie and his mum have decided to do a cake sale once lockdown is lifted, to raise money for Epilepsy Action. I think that’s

I suspected that I had some type of epilepsy for some time, **but I was scared about the implications**

a fabulous idea. His mum loves to make cakes and people love to eat them! Alfie is such a team player and puts everyone else first, so I think he would make this a massive success!”

Claire

Claire had a déjà vu experience when she was seven years old. Her mum dismissed it as nothing to worry about. But this experience stayed with Claire and she later realised that other people’s

understanding of what déjà vu felt like was different to hers. Claire remembers being told off for daydreaming at school, despite being a conscientious student.

“I also remember I had never slept a night through and could go without sleep for up to two nights. Eventually, I gave up trying to sort it and thought it was just ‘me’.”

Claire was diagnosed with focal epilepsy in February 2017. The déjà vu experiences had become more frequent, lasted longer and now involved a smell and a disassociation (a feeling of being disconnected from yourself or your surroundings).

“I could work through this and continue through it, but I then started getting confused afterwards. I didn’t recognise my husband and I couldn’t work out why the Christmas decorations were up. To be totally truthful, I suspected that I had some type of epilepsy from around 2013, but I was scared about the implications. Strangely, I actually enjoyed the ‘episodes’, which is very hard to explain.”

Claire was diagnosed with focal epilepsy. But the diagnosis process was a problem for Claire. She was referred by her GP urgently, but she had to wait weeks to be seen. The wait was threatening to affect her job as she couldn’t work because of her seizures, which were getting worse.

“I was lucky enough to be able to afford a private consultation instead of having to wait the 18 weeks I was told I would have to otherwise. As soon as my GP received the letter from the consultation, she put me on the medicine and ordered tests for me. She was incredibly compassionate.

“I am on lamotrigine and have been seizure free since starting this treatment.



Claire is a keen runner

Not only that, but my sleep started to get better since I started the treatment too. A year later, I was sleeping through some nights, and now, it's unusual for me to wake up in the night at all."

Even with epilepsy under control, Claire's life has been affected by the condition. She said: "It has knocked my confidence, as my 'brain' was always the best part of me. It was, fast, it had great recall, good problem solving, articulate... To find out something was 'wrong' with it was devastating.

"I am always worrying that I might have a seizure – that never goes away. People don't understand that and think I'm 'cured'.

"My treatment has also caused my blood pressure to increase, and I have to take medicines for this too.

"Not driving for 15 months was awful. I felt so helpless and trapped, my mood plummeted. I didn't realise quite how much it had affected me until I got my licence back. I took three driving lessons once I got my licence back, which was really helpful, although I will never be the relaxed driver I was."

Claire's relationships were also affected, as people around her didn't fully understand the condition. One of these people was her husband, who struggled to cope with the impact epilepsy had on Claire and the family's lifestyle. But today he is a huge support to Claire. "He is so supportive and protective now. He reminds me to take my tablets, and he makes sure he has one in the car and in his wallet at all times."

Claire's epilepsy also took a toll on her job. "We realised that I couldn't continue to work up to 50 hours a week. My work were fab and let me reduce my hours to 30. This has had a major financial impact on us, as I'm the major wage earner. But this has also given me a chance to do the things I hadn't been able to before. I go to birding lessons, I do parkruns, I have become active in the political party I support, and I read and cook more."

Claire works as a pharmacist, and often has contact with people with epilepsy to discuss their medicines. When Claire was diagnosed, she could suddenly see both sides of the coin.

"I had just been diagnosed when I realised there was a training evening for pharmacists about epilepsy. I was chatting to the organiser and she asked if I felt I could say a few words at the beginning. I was happy to do so as these were fellow professionals. But I was horrified when I told them, they all appeared to move back from me.

Not driving for 15 months was awful. I felt so helpless and trapped, my mood plummeted

"As a pharmacist, I do medicine reviews for some patients. People with epilepsy, I had noted, always seemed guarded. Some medicines can be used for pain as well as epilepsy, and people taking it for pain did not like others thinking they had epilepsy. I am very aware of the stigma and always have been.

"Just after being diagnosed and back at work, I did a review with someone on

Epilim (sodium valproate). The gentleman was quite guarded but I explained I had just been diagnosed too and he visibly relaxed and we had a good review. As he was leaving, he told me that you do get your life back.

"I can also now see why people get stressed if they think they can't get their medicine – I am now that person. My epilepsy has also improved my understanding of people coping with chronic conditions and other issues, like depression, that may come with it."

Being no stranger to running, Claire took the opportunity to raise money and awareness for epilepsy with the '50 miles in February' challenge. "I loved it! Except for the weather, it was horrendous. I've never felt so cold before out in weather I would never usually go out in. I found that really hard.

"I had lost my running motivation during the pandemic when parkrun was cancelled, but running with this group of people made me feel part of a club or a family. I felt connected to 'my' people. I hadn't realised how much I missed a running gang."



As a pharmacist, being diagnosed with epilepsy has helped Claire connect with patients



Behind the scenes

Epilepsy Action senior policy and campaigns officer Daniel Jennings gives a glimpse of the recent work going on behind the scenes to improve knowledge, understanding and care around pregnancy and epilepsy medicines

Daniel Jennings is a senior policy and campaigns officer at Epilepsy Action. His role involves bringing important topics in epilepsy in front of MPs and into parliament for discussion, and pushing for improvements. Daniel discusses some of the recent progress made to help enact positive change around risks of epilepsy medicines in pregnancy.

“Sodium valproate is an effective epilepsy medicine and may be the best treatment option for some women with epilepsy. However, there are risks with taking this medicine in pregnancy, as it is linked to physical birth abnormalities and developmental problems in babies. These effects had been known for years, but in many cases had not been discussed with women taking this medicine. An Independent Medicines and Medical Devices Safety review was carried out by Baroness Julia Cumberlege to investigate it in response to pressure from patient campaign groups, charities and others.

“The Cumberlege report, First Do No Harm (epilepsy.org.uk/IMMDSreview),

published in 2020, looked at three health scandals, one of which was around the impact of the use of the epilepsy medicine sodium valproate during pregnancy. It found stark evidence around the knowledge and use of valproate medicines in pregnancy over many years. The review made a number of recommendations to support those affected by the scandals.

“After the Cumberlege review was published, Nadine Dorries, Minister for Mental Health, Suicide Prevention and Patient Safety, made an apology in Parliament to people affected, on behalf of the government.

“In January 2021, the government responded to the recommendations of the Cumberlege review. While they have accepted some recommendations, some have been rejected outright and others remain under consideration (epilepsy.org.uk/reviewresponseGOV).

“In both the written and spoken evidence that Epilepsy Action gave as part of the Cumberlege review, we called for a review

of the use of all epilepsy medicines in pregnancy. We were very pleased to see this carried out by the Commission on Human Medicines (CHM) and the Medicines and Healthcare products Regulatory Agency (MHRA) in January.”

Epilepsy medicines safety data

“The CHM and the MHRA published their review of the available safety data for epilepsy medicines during pregnancy, looking at 10 of the most commonly prescribed epilepsy medicines. It found that four out of the 10 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). Lamotrigine (brand name Lamictal) and levetiracetam (brand name Keppra) were found to be safer in pregnancy than other epilepsy medicines (epilepsy.org.uk/medicines-pregnancy).

“However, the review also found that for a number of medicines there was not enough evidence to reach a conclusion about their safety when used during pregnancy.

“Following the CHM safety review, Epilepsy Action wrote to Matt Hancock, the Secretary of State for Health and Social Care. We raised the need for more research into the use of all epilepsy medicines in pregnancy. We also repeated our call for the recommendations of the Cumberlege review to be implemented in full. In addition, we asked for clarification about how information regarding the four medicines found to increase risk would be communicated to women and girls, as well as clinicians.

“Cat Smith, the MP for Lancaster and Fleetwood, also wrote to the Health Secretary on our behalf, raising these same points. Cat Smith has been a vocal supporter of the valproate campaign, working closely with patient group INFACT, who campaign on behalf of families directly impacted by valproate. Cat is also the chair of the Valproate and Other Anti-Epileptic Drugs in Pregnancy All-Party Parliamentary Group (APPG).”

More research and information

“Nadine Dorries, who has been leading on the government’s response to the Cumberlege review, replied to the points raised. In her reply, the Minister explained that the MHRA is working with the National Institute for Health and Care Excellence (NICE), and other health bodies, to update relevant clinical guidance to reflect the findings of the review. This is intended to help ensure that clinicians are aware of this information and discussing it with patients.

“The Minister acknowledged that gabapentin and pregabalin, two of the medicines identified as having inconclusive evidence about their safety, are the subjects of ongoing studies. However, she did not address the need for research into the other medicines. Instead, the Minister stated that ‘it was considered most appropriate that emerging data from existing data sources, such as the Yellow Card Scheme, and existing pregnancy registries, including the UK Epilepsy and Pregnancy Register, are kept under close review to identify any emerging signals of potential harm.’ This may lead to further information about the safety of these medicines in the future, but would mean waiting for women and families to report that their children had been harmed. Epilepsy Action will continue to push for proactive research into these medicines.

“The Minister also recognised the work that Epilepsy Action has done in this area, saying that ‘Epilepsy Action has been very active in raising awareness with its members of the review and its conclusions’. She also commended the organisation’s ‘continued efforts to help ensure that women with epilepsy of child-bearing age are well informed about the safety of epilepsy medicines in pregnancy.’

“MP Valerie Vaz, who is also chair of the APPG on Epilepsy, tabled a Parliamentary Question about the need for research into the use of epilepsy medicines in pregnancy. The Department of Health and Social Care (DHSC) responded, stating that the National Institute for Health Research (NIHR) welcomes funding applications for research into any aspect of human health, including epilepsy medicine use during pregnancy. This information is needed urgently to ensure that women can make an informed choice about their medication and Epilepsy Action would happily support any funding applications of this nature.”

Epilepsy medicine registry and preconception counselling

“One of the recommendations of the Cumberlege review was the establishment of a ‘registry for all women on anti-epileptic drugs who become pregnant’. Nadine Dorries confirmed that the MHRA and NHS Digital were working to develop a registry to monitor all women prescribed an epilepsy medicine.

“The first findings from the newly developed Valproate Registry were published at the start of the year (epilepsy.org.uk/valproateregistryNHS). This showed that 180 women were prescribed sodium valproate in a month in which they were pregnant, between April 2018 and September 2020. It is extremely concerning that women are still being prescribed sodium valproate while they are pregnant.

“The DHSC has said it will extend the registry to include women prescribed

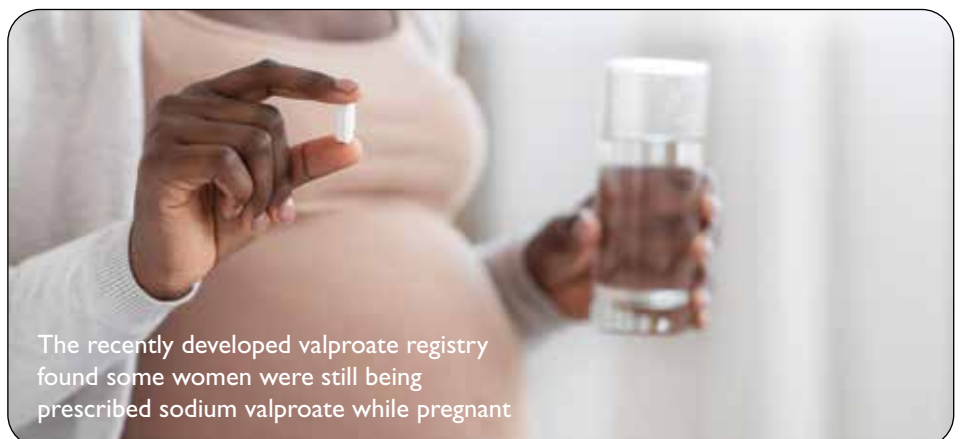
all epilepsy medicines in the next phase of its development, which would fulfil the recommendation of the Cumberlege review. However, they have not provided a timescale for when this will happen.

“Epilepsy Action has also called for all women with epilepsy to receive preconception counselling and family planning advice. This would help ensure that women are provided with the necessary information to make an informed decision about their treatment before they become pregnant, as well as minimise the risks around SUDEP (more on this on pages 7 and 11). We will also keep working with the MHRA, NHS England and others to ensure that healthcare professionals discuss with women the risks of taking sodium valproate and other epilepsy medicines during pregnancy.”

Next steps

“There is still much more work to do on these important issues. Epilepsy Action will continue to work with MPs and other campaigners to ensure that women and girls have all the necessary information to make an informed decision about their medicine. In addition, we will continue to monitor the government’s progress in implementing the recommendations of the Cumberlege review.

“It’s important that women do not stop taking their epilepsy medicines without first discussing it with their doctor. For further information, you can contact the Epilepsy Action Helpline on 0808 800 5050. You can also find more information at epilepsy.org.uk/medicines-pregnancy”

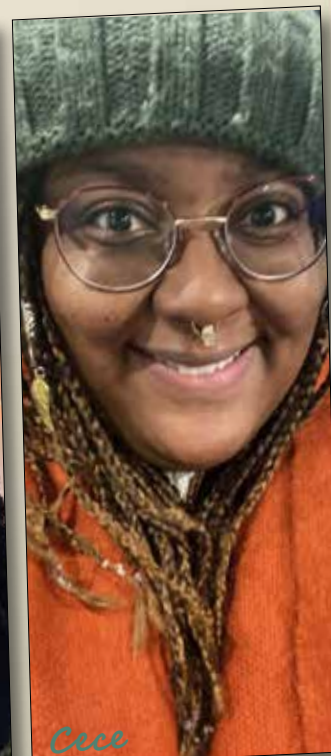


The recently developed valproate registry found some women were still being prescribed sodium valproate while pregnant

My journal



8 March is International Women's Day – a day to celebrate the brilliant women we all have in our lives. We share the stories of two strong and resilient women



Lauren: Your superpower is being yourself

I have tonic-clonic and focal seizures. I predominantly have sleep seizures starting in the left side of the frontal lobe of my brain. When I have a seizure, my head or eyes move to one side and I become unresponsive or have difficulty speaking. Before I go into a tonic-clonic seizure, I usually let out an explosive scream.

My first seizure happened on my 14th birthday. I don't remember much about that night except the blurred image of a torch in my face. My mum has told me what happened though. She said she was going past my room on the way to bed and heard deep, prolonged and laboured breathing. She said when she switched on the light, she saw me staring at the ceiling with empty and unblinking eyes and frothing at the mouth. She called an ambulance but I had fallen back to sleep by the time they got there. The only thing I remember is the torch the paramedic shone in my face. They told my mum

then that it might have been a seizure, but the next day I went to school like nothing had happened – I was just tired and had a headache.

The diagnosis process wasn't easy, because you had to have more than one seizure to be diagnosed with epilepsy. But even when I started having them back-to-back, it still took time. My mum ended up writing to our local MP in Cornwall where we used to live, as nothing was being done. Once we got a response, things started to move much quicker. I've had brain scans, EEGs and video EEGs as well.

One scary thing about my seizures is that I am aware during them. I can hear everything, see everything, yet my body is completely taken over. I see my mum looking away while holding my hand tight. I see my sister in the hallway. I hear my brother talking to me. I sometimes purposely move my head away when a seizure is starting, trying to hide. It's like being completely trapped in my own body just waiting for what feels like forever for the seizure to finally end.



Bodybuilding gives Lauren a sense of control over her body



Lauren's children know about her epilepsy and how to help

I've been on countless medicines, but it seems like my epilepsy will never be under control. The only way it could be controlled is if I were to have brain surgery. When I was 14, I was told I couldn't have the operation for my epilepsy, as my brain wasn't fully developed. More recently, over the last six years, I have been for tests to see if anything has changed. It turns out I can have the operation, but I feel it's just too risky for me. I'm a mother of two now and what may come with the operation – memory loss, loss of control of one side of the body and more – is just something I'm not willing to risk.

Today I'm still scared of having tonic-clonic seizures – I think that's something that will never change

I live with the side-effects of my medicines every day. They have been hard. At first I was extremely tired all the time and felt like I just lost who I was as a person. Now I've been on the same medicine for years, so I know what to expect.

Epilepsy changed my life massively. I missed out on a lot of school as I was in and out of hospital going on and off different medicines. I was bullied when I started going back to school, so I left. I started self-harming and I went on an antidepressant at the age of 14. All I wanted was someone to tell me everything was going to be alright. I felt like the world had turned on me and I was alone. No-one understood what I was going through and I felt alienated, stupid and like a freak.

I went to counselling but I didn't want to talk to strangers. Why would I? I was a teenager that 'knows everything'. How very wrong was I.

I moved up to London with my dad and lost touch with my family. I got a job there and then moved to Brighton for art college.

Today, I'm still scared of having tonic-clonic seizures. I think that's something that will never change. I struggle to get words out or explain things. I slur my words a lot, which doesn't go unnoticed. I have headaches nearly every day, so I make sure to keep myself hydrated. Memory is a massive issue – I forget things very easily and find it hard to concentrate. I even find it hard to read books as I instantly forget the paragraph. I need to write down if I've taken my medicine, as I forget and otherwise I'd end up doubling my doses. Just small daily tasks can sometimes be hard.

I went through domestic violence in my marriage, with a lot of control and manipulation. Once I ended it, I was on my own for three years before I even considered looking for a partner. I wanted to focus on my kids and myself. This gave me strength, even though dealing with epilepsy and having to work while being a single mum was extremely hard.

We all know children aren't ones for being independent when it comes to wanting snacks or help with the toilet. It did become very challenging if I'd have a seizure. Now that they're a little older, they understand. I've taught my eldest to call 999 if my seizures go on too long or if he gets scared. Last week we found ourselves in a little pickle, as I had a focal seizure on the way home picking up the children from school. No-one stops to help, they all just assume you're drunk. Luckily my partner was there and he and the kids held me up as we walked home. I'm very proud of my children.

epilepsy experience

After giving birth to my children and currently going through a divorce, I feel the happiest I've ever been. When my marriage ended and I took some time away, I found myself, who I really am, and I love her.

Now I talk openly about epilepsy as I used to hide it from anyone new that I'd meet. I feel like it's a part of who I am now, but it doesn't define me – never again.

I started weight training to lose my baby weight after my daughter was born and I was hooked. I am now a personal trainer and a bodybuilder, which is definitely an escape. I enjoy helping others and showing them what they are capable of. I've made a career out of what I love.

Bodybuilding is something I will always enjoy. I love how I am in control of my body. Me. Not my epilepsy anymore. I can control my body to grow a certain muscle or to move how I want it. Touching the iron is a powerful feeling. It makes me feel strong inside, battles my depression and keeps me going. I take care to rest if I've had a seizure and I make sure the exercises I do are safe in case of a seizure.

Doing bodybuilding really pushed me out of my comfort zone. I never thought I'd pose on a stage in a bikini, let alone become (bodybuilding association) PCA World Champion. I feel nothing should stop you doing what you want to do, no matter what it is. If you don't like something, change it.

People will always have opinions no matter what you do in life – this is when you keep smiling, keep going and keep being you. Your superpower IS being yourself and no one can do it better. I always get the odd person questioning my life or calling me names. This should make you stronger, as it's them that are behind you, as you are going forward not back.



Lauren's children and her partner Ben

Cece: A secure base to feel safe

I have temporal lobe epilepsy with focal and tonic-clonic seizures. I can't really remember my first focal seizure, I just remember always having them. I think I had my first tonic-clonic seizure when I was 19 or 20, while I was in my second year of university. I'd been really unwell with the flu and had been in bed for a day or two. I felt the aura and then started shaking. Then I remember waking up after what felt like a few minutes. When I tried to explain it to friends, I found it hard to because I just didn't know what happened to me.

The diagnosis was difficult – it took me years to be diagnosed because health professionals didn't recognise that what was happening to me were seizures. It wasn't until I had a tonic-clonic seizure in 2014 and my mum had to call for an ambulance that I was finally diagnosed. I still remember the album I was listening to on my iPod on the day I was waiting to see the consultant – Bombay Bicycle Club's album 'Flaws'. And even now, seven years later, when I listen to that album, I'm still transported back to that seat.

I'm currently prescribed lacosamide and pregabalin. But it's been a hard slog finding the right cocktail of medicines I need. I've been very fortunate because I seem to have found the 'right' combination after only trying for seven years. I know there are many people with epilepsy who spend much longer trying to do this. I've often felt like a guinea pig, it's felt very much like a trial-and-error process. One medicine I tried along the way made me extremely paranoid and made me see things that weren't there.

When I was having seizures, it always felt like my day had been snatched away from me. Before I began my MSc in 2017, I was training to be a teacher and lost my job. That was hard for me. After that, my seizures were out of control and I had to spend a



Training helps Lauren to tackle her depression



Cece deals with memory issues and sets herself reminders

lot of time at home. Thankfully I was able to find something else that I was already really passionate about and now I'm turning that into a career. I'm currently training to be an integrative psychotherapist. The course has been delivered online because of the pandemic, which has been very tough. I started my course just before the first lockdown last year, so have been learning online for a year now. It's very tiring and it's taken me a year to build the confidence to ask for extra breaks and support.

Often, when I tell someone that I have epilepsy, their immediate reaction is to move the furniture out of the way 'just in case'. Or they would switch a programme or film off when there is a warning about flashing lights without even asking me!

Although I haven't been able to see friends, I feel just as close to them as I felt a year ago. Listening to WhatsApp voice notes from friends has become the highlight of my day! I also feel incredibly lucky to be living in lockdown with my fiancée. Now that my seizures are under control, I'm able to exercise again, which I really enjoy.

But as well as controlling my seizures, my medicines have caused a few side-effects. They make it very difficult to wake up in the mornings. I often feel embarrassed when I log into my classroom each week and everyone else has been up since 7am and had

an entire morning of running around (COVID-19 permitting). Meanwhile I've literally just got out of bed and am trying to discreetly finish my breakfast! I often forget what I want to say and I'm also a big music person and it's really sad that I can never remember the lyrics to songs I listen to so regularly. I have to set a lot of reminders for myself, even for little things like 'don't forget to text so and so...' because even with the best of intentions, I know I will forget.

My tonic-clonic seizures usually follow a focal seizure, and usually only happen if something has gone wrong with my medicines, or when my body is extremely stressed. However, often, when I tell someone that I have epilepsy, their immediate reaction is to move the furniture out of the way 'just in case'. Or they would switch a programme or film off when there is a warning about flashing lights without even asking me!

Being a Black, queer woman, I face many racialised adversities. Often people will say racist things unintentionally, but their defensiveness will leave me feeling like the wrongdoer. And then it is forgotten that I have a condition that is triggered by stress. Therefore in these scenarios, I am left to deal with somebody else's fragility as well as my own. It's a massive and very stressful burden to bear.

I have a chosen family. This is a common term used within the queer community where strong relationships are formed with people that replace your birth family. They are a group of people who come into your life, often because of shared experiences. I lost many friends after I was diagnosed with epilepsy, mostly because I couldn't be the party girl I once was and had to start looking after myself. But it was also because people didn't want to look after me. But that's okay! My chosen family are 100% non-judgemental – they provide me with a secure base to feel safe and not like a burden.



Finding the right epilepsy medicine has been challenging

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 lacosamide.

Lacosamide

Lacosamide was licensed in the UK in 2008 as an add-on therapy for focal epilepsy, whether or not the focal seizures go into tonic-clonic seizures. In 2017, it was also licensed for use on its own for this kind of epilepsy. Lacosamide works in a slightly different way to medicines like carbamazepine, lamotrigine and oxcarbazepine, which means it can be used in combination with them. However, all of these medicines can cause similar side-effects, so, if used together, it's important to get the doses of the medicines right to minimise these problems. There



is no evidence from clinical trials to show whether lacosamide is effective for absence or myoclonic seizures. However, some effectiveness has been suggested for young people with these types of seizures.

The recommended starting dose for lacosamide in adults is 50mg taken twice a day. This is usually increased to 100mg twice a day after a few weeks. The maximum recommended dose is 200mg twice a day. However, doses of 300mg twice a day have been used in the original clinical trials and shown to be beneficial, so doctors could prescribe this kind of dose if needed. In children under 17 years old, doses are prescribed based on weight. A doctor could decide to prescribe a similarly increased dose in children, adjusted for their weight.

Lacosamide is generally well tolerated. The most common side-effects of lacosamide are dizziness, headache, blurred vision, nausea and vomiting. Other reported problems include tiredness, tremor and poor coordination. All of these tend to occur when lacosamide is being used in higher doses or when it's combined with other

epilepsy medicines for hard-to-treat epilepsy. There have been occasional reports of irregular heartbeats linked to lacosamide, so high doses should not be prescribed to people with heart rhythm problems. There is no strong evidence linking lacosamide with mental health side-effects, but depression has occasionally been reported. A rash can sometimes develop within a few weeks of starting lacosamide, but this is usually mild and disappears quickly when the medicine is stopped. There is currently not enough information to make any conclusions about whether lacosamide can affect babies exposed to the medicine in the womb.

Lacosamide is an effective, well tolerated medicine for focal seizures, whether or not they spread to tonic-clonic seizures, both in itself and as an add-on to other medicines. Side-effects may appear, especially when used as an add-on, but epilepsy specialists can amend the doses in these cases, to reduce them. There seem to be no other negative interactions with other medicines. Overall, lacosamide is a major addition to the treatment options for focal epilepsy in children and adults.



Professor
Martin
Brodie

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

Council of Management 13 April

At a meeting of the Council of Management held by remote video conference on 13 April 2021, the following decisions were made and actions taken. The Council:

- Noted the resignation for personal reasons of one of its members, Jan Follett, on 17 February and wished her well for the future
- Formally nominated Baroness Ford of Cuninghame for re-election as the Association's President at the 2021 AGM scheduled to be held on 15 June
- Reflecting the wishes of the candidates, decided not to proceed with the reappointments of 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
- Resolved to nominate RSM Audit UK for reappointment as the Association's auditors at the 2021 AGM
- Resolved to close the register of members of the Association for the duration of the Council elections from 16 May to 15 June inclusive
- Approved the Fundraising delivery and monitoring plan 2021
- Approved amendments to the charity's investment procedure as recommended by Council's Finance and Strategic Policy committee to better control the sale of listed investments
- Considered issues around updating the Association's succession plan for the Patron



- Appointed Peter Clough and Rebekah Smith as directors of BEA Trading Ltd., a subsidiary company of British Epilepsy Association
- Appointed Peter Clough as a director of Epilepsy Action Ltd and Epilepsy UK Ltd, both subsidiary companies of British Epilepsy Association
- Approved a plan of recommendations from the Corporate Governance committee to address diversity on the Council of Management
- Approved draft guidelines to support remote attendance by Council members at Council and committee meetings
- Completed a review of the top ten corporate risks the charity is currently managing
- Considered a report on the charity's CRM database project

The next meeting of the Council of Management will be on 11 May 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](https://www.epilepsy.org.uk/virtual-groups) or by calling **0113 210 8800**.

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

Online resources

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

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

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



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

Take the next step.

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

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

vnstherapy.co.uk/DRE-Discussion-Guide.pdf

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INTENDED USE / INDICATIONS:

Epilepsy (Non-US)—The VNS Therapy System is indicated for use as an adjunctive therapy in reducing the frequency of seizures in patients whose epileptic disorder is dominated by partial seizures (with or without secondary generalization) or generalized seizures that are refractory to seizure medications. AspireSR® and SenTiva™ feature an Automatic Stimulation Mode which is intended for patients who experience seizures that are associated with

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

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