

epilepsytoday

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Purple princess

Indiana channels her epilepsy experiences in a whimsical show raising seizure first aid awareness

- Also in this issue
- report looks at health services for **older people with epilepsy**
 - Sue and Pete tell the tales of their complicated **diagnosis journeys**
 - Fran talks public reactions to epilepsy and **loneliness of seizures**

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editor's letter

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

A new report by King's College London has revealed some stark gaps in epilepsy service provision for older people with epilepsy. This group of people may already face extra challenges with their epilepsy, sometimes having a hard time getting a diagnosis in the first place, as well as juggling multiple conditions and numerous daily medicines. The report has highlighted gaps in referring older people to specialist services and inappropriate information provision, among other things. Exposing these gaps is the first step in helping tackle them and you can read more on page 9. If you have a story to share or thoughts on the report, we would love to hear from you – just contact press@epilepsy.org.uk

Speaking of challenges with diagnosis, we have two really interesting stories from people whose diagnosis journeys were not that straightforward. Sue was first diagnosed with a heart condition and had a pacemaker put in to deal with her 'faints'. But when the pacemaker didn't tackle all her 'funny turns', she sought more help and her epilepsy was finally diagnosed. Find out more on page 22. Meanwhile, a lack of EEG evidence meant Pete's seizures were diagnosed as dissociative. But with a gut feeling that there was more going on, and with a very helpful video of one of his seizures taken by his wife, his epilepsy was finally also diagnosed two-and-a-half years later. Read more on page 20.

We also have another set of personal stories, all of which show the way people have chosen turn the difficulties epilepsy has created for them into a positive and defy perceived limits of the condition. On page 14 you can read about how our cover star, Indiana, decided to make a show out of a time when she knew she was about to have a seizure and no one around her knew how to help. She is now committed to raising awareness about seizure first aid among children. Val (page 12) was told she would never work, go swimming or have an independent life when she was diagnosed with epilepsy in 1966. She went on to go travelling, sail on Tall Ships, and have two careers – one as a nurse and one in leisure. On page 26, Fran describes a number of difficult experiences, including having daily seizures and reactions of members of the public. But she channelled everything into writing a book which has recently been published.

Last but not least, we have a report from Dr Hayley Gorton on page 18 on studies she and her team carried out on what they call 'unnatural deaths' and self-harm in epilepsy. While the findings are stark compared to the general population, these are still unusual occurrences. Being armed with this knowledge can help us to take steps to reduce these risks or to reach out for help if it's something we're struggling with.

We hope you enjoy what is left of the summer months and enjoy this issue!

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Fran talks loneliness of seizures, dealing with reactions from the public and where she finds solace

Three in four children who should be considered for epilepsy surgery not referred

Findings from the latest Epilepsy12 report reveal issues among children's epilepsy services in England and Wales with referrals, information provision and school care plans.

The latest Epilepsy12 report from the Royal College of Paediatrics and Child Health (RCPCH) was published in July 2021. Much of it reflects the state of children's epilepsy services during the COVID-19 pandemic as it describes the situation in November 2020.

The report showed that three-quarters (77%) of children who should have been considered for epilepsy surgery had not been referred. Epilepsy surgery in children where a specific part of the brain is affected can cure a child's epilepsy.

The report also found gaps in the safety information given to children and their parents and carers. In one-fifth of care plans, there was no evidence that water safety had been discussed, and a similar proportion showed no evidence of information on general participation and risk

being discussed. Only a third (32%) of children had a school Individual Healthcare Plan.

Less than half (43%) of children and young people with epilepsy, and their families or carers, had received information around Sudden Unexpected Death in Epilepsy (SUDEP) in the first year since diagnosis. There was a significant variation in SUDEP information provided across different regions in England and Wales.

The report also identified issues around timely delivery of care, waiting times for diagnostic tests, like EEGs, and lack of referrals to paediatric neurologists or surgery services. Mental health support services for children with epilepsy were also found to be lacking, with only 15% of Health Boards and Trusts being able to include these within epilepsy clinics.

However, the report also pointed out there was evidence that despite the challenges of the pandemic, there was a good effort to

continue to provide and improve epilepsy services.

Angie Pullen, director of epilepsy services at Epilepsy Action, said: "The pandemic has understandably impacted children's epilepsy services and care for children with epilepsy has undoubtedly been negatively affected. But there have also been missed opportunities to make early epilepsy surgery referrals, along with access to timely diagnostic tests.

"The report also highlights a huge variation in the SUDEP information provided in different regions of the UK. It is unacceptable that where you live could determine the level of potentially life-saving information families receive. It is vital that children and young people, along with their families, are given all the facts about SUDEP so that they can learn the best way to manage risk and live safely."



Mental health and wellbeing should be at the centre of children's epilepsy care, according to Mark Devlin, chief executive of Young Epilepsy. He said: "The findings of this report are of particular concern, as children and young people have had to cope with the impact of the COVID-19 pandemic on their mental wellbeing, whilst still having to come to terms with their diagnosis and the challenges they might face.

"Epilepsy is not a mental health condition, yet children and young people with epilepsy are four times more likely to develop mental health problems than their peers."

The full Epilepsy12 report can be accessed at: epilepsy.org.uk/rcpch-epilepsy12-audit

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New Employer Toolkit launched

A new Employer Toolkit was launched in May by Epilepsy Action to better support people with epilepsy in the workplace. This follows what the charity calls "a dire need for more understanding of the condition" at work.

Only 34% of people with epilepsy of a working age are in employment, according to

figures from the Office of National Statistics. Those who are, earn, on average, 11.8% less than people without epilepsy.

One major barrier for people with epilepsy to get and stay in work is a lack of understanding around the condition, Epilepsy Action said. A 2016 YouGov survey showed that a quarter of respondents (26%) were

concerned about working with someone with epilepsy. Of those, nearly two-thirds (63%) said it was because they didn't know how to help a colleague having a seizure.

The new toolkit is designed to give employers the confidence to help staff with epilepsy. It includes templates to provide support, assess risks and talk

about epilepsy. It also offers descriptions of a range of different seizure types, as well as access to detailed first-aid videos. The toolkit aims to encourage better communication between employees and employers to allow better support and reasonable adjustments to be made. It can be accessed at: employers.epilepsy.org.uk

UK government rejects call for redress scheme for people affected by valproate scandal



The government has rejected the recommendation to set up redress schemes for valproate, Primodos and pelvic mesh, in its full response to the Independent Medicines and Medical Devices Safety (IMMDS) review.

The IMMDS review's report was published in July 2020 and included nine main recommendations for the government to support people affected by these medical products and safeguard the public going forward. The report also included a number of specific recommendations on valproate. The government took six months to set out its initial response to the recommendations and over a year for the full response.

In the latest response, the government rejected the recommendation to set up separate redress schemes for people affected by the three medical products the safety review focussed on. Minister of State for Patient Safety, Suicide Prevention and Mental Health, Nadine Dorries, said: "While the government is sympathetic to the experiences of those patients who gave evidence to

the report, our priority is to improve the future safety of medicines and medical devices."

Daniel Jennings, Epilepsy Action's senior policy and campaigns officer, said this outcome is a devastating blow to families affected by the medical products. "We are hugely frustrated and saddened that the government has rejected the recommendation to set up a redress scheme for the many families who experienced avoidable harm and have additional needs because of valproate. The scheme would have provided much-needed and overdue help with the costs of these additional needs and enabled families to plan for the future."

The government also rejected a part of the recommendation to create specialist centres for people affected by the three products. Specialist centres for people affected by pelvic mesh have been set up, but the government has not agreed to set up any such centres for people affected by medicines used in pregnancy. Ms Dorries said the government didn't believe this was "the most effective way forward". She

said the government would work on improving care for this group within the existing health services.

The latest response mentioned the sodium valproate registry, adding that a second report from it is planned for September 2021. Plans were set out to include the whole of the UK in the registry, as well as other epilepsy medicine in addition to valproate. Ms Dorries also mentioned the letter the NHS sent to women and girls in England who are prescribed sodium valproate. She said the Medicines and Healthcare products Regulatory Agency (MHRA) will work to ensure that pharmacists have to supply sodium valproate in the manufacturer's original packaging, to help make sure the patient information leaflet is always included.

However, the response does not address the report's other valproate specific recommendations, such as establishing a clear process to ensure women are able to get appropriate counselling related to their epilepsy treatment and contraceptive choices.

Mr Jennings said: "Again, the government has not responded to the specific recommendations on valproate in the Cumberlege (IMMDS) review. We wrote to the minister on the anniversary of the Cumberlege review's publication, outlining our concerns about the lack of progress, but are still awaiting a reply."

The outlined concerns include improving access to preconception counselling, identifying, diagnosing and supporting those affected by

valproate exposure, improving the pregnancy prevention programme and better communication from clinicians.

"We will continue to work with MPs and others to ensure that the needs of those families harmed by valproate, and the needs of women and girls taking valproate – now and in the future – are met," he added.

The government's early response accepted a number of the recommendations, including issuing an apology, appointing a patient safety commissioner and the creation of the valproate registry. However, it did not accept a number of recommendations, including creating a redress agency for those harmed by the medical products and the creation of a task force to implement the review recommendations.

Epilepsy Action has previously criticised the government for taking six months to respond to many of the recommendations in the first place, and for a lack of response altogether to some valproate-specific recommendations.

Epilepsy Action advises that women should not stop taking their medicines without speaking to a doctor first. Stopping medicine may result in breakthrough or increased seizures and may be harmful to the woman and any unborn baby. There is more information about sodium valproate on the Epilepsy Action website and people can also contact the Epilepsy Action Helpline.

The full government response is available at: [epilepsy.org.uk/immds-july21](https://www.epilepsy.org.uk/immds-july21)

COVID-19 booster vaccine may be offered from September to most vulnerable



A booster COVID-19 vaccine may be offered from September 2021 to the most vulnerable people in the UK to ensure protection continues over the winter season. This is based on interim advice from the Joint Committee on Vaccination and Immunisation (JCVI).

The JCVI explained that this plan is intended to prolong the protection the initial two vaccine doses provide. The Department of Health and Social Care (DHSC) explained that evidence

shows that two doses of any COVID-19 vaccine provide strong protection from becoming seriously ill from coronavirus for at least six months. However, as with the flu, winter will likely result in a rise in cases and more pressure on the NHS, the DHSC added.

Deputy chief medical officer for England, Prof Jonathan Van-Tam said: "The announcement of interim advice from JCVI is good news. It shows that the vaccine experts are thinking carefully about how best to

use vaccination to protect the most vulnerable and ensure everyone's lives can remain as normal as possible for the autumn and winter."

The interim advice from the JCVI suggests a two-stage booster programme alongside the flu vaccination programme. In the first stage, a third dose COVID-19 booster vaccine would be offered to anyone over the age of 70, those living in care homes for older people and front line health and social care workers. Anyone over the age of 16 whose immune system is suppressed or who is considered clinically extremely vulnerable will also be offered the booster.

In the second stage, adults over the age of 50 and those who are household contacts of a person with a suppressed immune system would be invited for a booster. As well as this, anyone over 16 who

was outlined in one of the government's at-risk groups for the flu or COVID-19 will also be invited. This includes people with epilepsy, who were included in priority group 6 during the rollout of the COVID-19 vaccination programme.

The JCVI's final advice and the ultimate decision on whether this will go ahead is yet to be made, and will be given before September. It will take into account the situation at the time, more data from booster trials and information about the effectiveness of the vaccines on newer variants of the virus.

The DHSC said the latest analysis from Public Health England (PHE) and the University of Cambridge suggests the vaccines so far have prevented an estimated 7.2 million infections and 27,000 deaths in England.

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NHS contacts England women taking sodium valproate

The NHS sent letters with information to 20,000 women and girls aged 12-55 in England who have a prescription of sodium valproate, in June 2021.

The letters contained information about actions to take if women are pregnant, trying for a baby or haven't had a recent medicine review.

Sodium valproate can be used to treat epilepsy and bipolar disorder and may be the most effective medicine for some people. However, it is linked to increased risk of

physical birth abnormalities, autism and developmental problems in babies exposed to it during pregnancy.

The letters from Dr Aidan Fowler, NHS director of patient safety, urged women to continue taking their medicines until they have spoken to their doctor. It encouraged women to continue taking contraceptive measures and ask their GP for a medicine review if they have not had one in the last 12 months. It also advised women to speak to their doctor straight away if they

are pregnant or to seek advice from their doctor before stopping taking contraception if they want to try for a baby.

This letter is part of the NHS' aim to increase patient safety after the findings of the safety review on valproate published in 2020 by Baroness Cumberlege.

Louise Cousins, director of external affairs at Epilepsy Action, said these measures are welcome, although more still needs to be done as there are still women unaware of the risks of valproate. "This NHS

letter, while rather late in the day, should help women taking sodium valproate feel more informed and empowered to prompt conversations with their doctor about their medication.

"Health professionals need to make sure women are fully informed about the risks of sodium valproate before they start taking it. More also needs to be done to identify potential risks of taking other epilepsy medicines in pregnancy. Women should not stop taking their epilepsy medicine before talking to their doctor."

Further recall of neurology patients in NI reveals more cases of misdiagnosis



About one-fifth of patients recalled by the Belfast Trust in Northern Ireland, as part of a second group, have needed a change in diagnosis and treatment, a review published on 20 April has shown.

Around 2,500 patients treated by Dr Michael Watt were recalled in May 2018 after concerns were raised by other doctors about his treatment plans and diagnoses.

A second group of 1,044 people, treated by Dr Watt between 2012 and 2017, was recalled for review in October 2018. This group of patients had either been discharged back into the care of their GPs, or had been discharged and then referred back to neurology services by their GPs. It includes people prescribed epilepsy medicines.

The recall intended to review whether these people had been given a correct diagnosis and whether their treatment and care plans were appropriate. The review found that out of 927 patients, 181

(19.5%) did not have a 'secure diagnosis' and review clinicians were 'uncertain' about the diagnosis of a further 44 people (just under 5%).

While a 'not secure' diagnosis did not automatically mean misdiagnosis, the majority of people in this category received a new diagnosis. Also, for the majority, the original prescribed treatment was not deemed appropriate.

Northern Ireland Health Minister Robin Swann made a statement to the assembly to deliver the findings. He made an apology to the people affected by the situation, adding: "I know that many [people] will have had their confidence in our health service shaken and I remain committed to helping to restore it."

A third group is being reviewed, which includes people treated by Dr Watt between 1996 and 2012 and young stroke patients who had not been reviewed as part of the previous groups.

misdiagnosis does occur, the nature of these misdiagnoses and the ongoing uncertainty for many people is particularly concerning.

"It is right and proper that others who were previously under the care of Dr Watt have now also been recalled. Both recall groups 2 and 3 include people who have been living with an incorrect epilepsy diagnosis for many years. They may have been taking epilepsy medicines that were of no benefit to their health but that could have had potentially damaging side-effects.

"Epilepsy Action Northern Ireland has heard first-hand about the impact of the recall on those affected. It is vital that appropriate support, including mental health support, is made available to those who have been caught up in this process.

"While this is a seemingly isolated case relating to a particular neurologist, it is hard to ignore the context

Carla Smyth, local services Northern Ireland manager at Epilepsy Action, said: "This announcement highlights that three years on from the first patient recall, even more people have been impacted by unsecure diagnoses. While epilepsy is a difficult condition to diagnose and

of overstretched and under pressure epilepsy services in Northern Ireland. It is vital that the various inquiries and reviews associated with the recall are completed as a matter of urgency and that recommendations for improvements are fully implemented and funded.

"Lessons must be learnt, and services must be appropriately supported so that people with suspected and diagnosed neurological conditions receive the care and support they deserve. A situation like this must never happen again."

In the third group under review, people affected have already been contacted. Initial review consultations are being held virtually and clinicians will then decide if a face-to-face appointment is needed. A patient helpline has been set up for those affected, and can be reached at 0800 980 1100.

Mr Swann added that a redress scheme was set up in 2018 to provide compensation to people affected by the "negligent care" of Dr Watt. While its development was paused in 2020 due to the pandemic, work on it is restarting again.

Other reviews will also be carried out on patients of Dr Watt who had died in the 10 years before the recall and more generally on neurology services in Northern Ireland.

For anyone affected by the patient review including those who were previously misdiagnosed with epilepsy, Epilepsy Action Northern Ireland offers a free counselling service – find out more at: epilepsy.org.uk/nireland



Epilepsy care for older people

A new report has looked at issues older people with epilepsy face and the gaps in healthcare services for this group that need addressing

It's a fact widely known in the epilepsy healthcare community that while epilepsy can happen at any age, there are two peaks in diagnosis – one in childhood and one in people aged over 65.

Statistics show that epilepsy affects around one in 100 people, but in people over the age of 65, this number increases to one in 67 people.

Older people with epilepsy tend to face unique challenges with the condition. Older people with epilepsy are often dealing with other health conditions as well as epilepsy, and epilepsy can sometimes develop following a stroke. If people live alone, seizures may not be witnessed and it may be difficult to reach the diagnosis of epilepsy in the first place. Also, in older people, seizures may take different forms than the more widely recognised tonic-clonic seizures, making them harder to spot and diagnose.

As well as these challenges, there is evidence that epilepsy services for older people may be lacking in places and may be leaving people without all the support they need.

Older people were found to feel more fearful of the way people would react to the condition in public, and being rejected by others

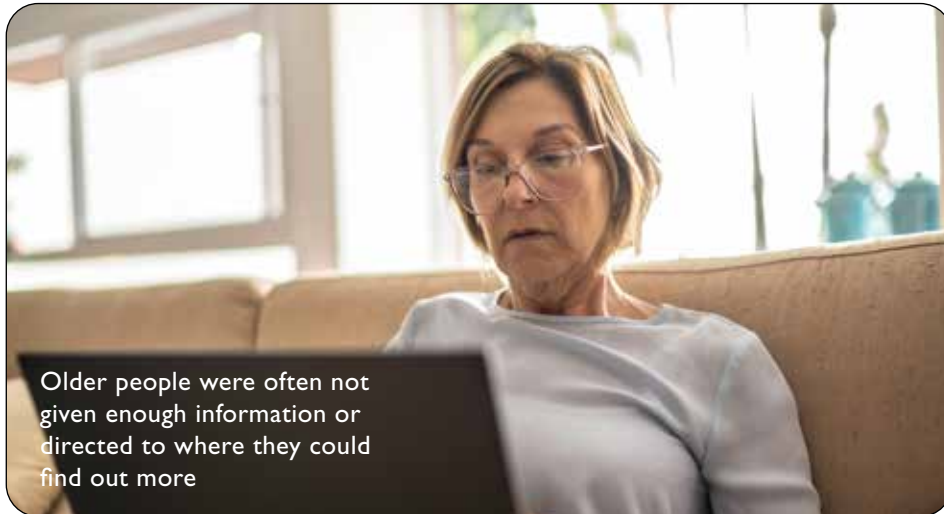
In August 2020, researchers from King's College London published a report summarising the scientific literature on epilepsy and epilepsy services in older age.

The report, entitled 'Older People with Epilepsy: Best Practice and Gaps in Care' was put together by Dr Gabriella Wojewodka, Dr Alison McKinlay and Prof Leone Ridsdale. It looked at different aspects of living with epilepsy in later life and the state of epilepsy services for this group.

Lifestyle and quality of life

One aspect the report looked into was quality of life. The report found that older people with epilepsy were more at risk of experiencing frailty and social isolation. It wasn't clear whether older people diagnosed earlier or later in life had lower quality-of-life scores, as different studies had different outcomes. This shows the shock and disruption a new diagnosis of epilepsy can cause for people, but also the long-lasting effects of the condition.

Older people were found to feel more fearful of the way people would react to the condition in public, and being rejected by others, than younger people. This speaks to the way people with epilepsy were treated in the past, when myths and misconceptions were more prevalent, and the long-lasting effect this can have on many people. In some cases, people may also have their own misconceptions about epilepsy which can make it difficult to accept their diagnosis. One study, which the report looked at, showed that a quarter of older people who were newly diagnosed did not admit to having the condition. Some people also found using epilepsy terms difficult, preferring to go for a term of their own. The report authors said that older people wanted



Older people were often not given enough information or directed to where they could find out more



People worried about epilepsy affecting family roles, like looking after grandchildren

more education about epilepsy for the wider public and better understanding about the condition, particularly around less well-known types of seizures.

Older people who were newly diagnosed were also found to be more worried about falls and bone fractures than people who had had epilepsy for a while, the report said. Memory problems, loss of independence and relying on aids like alarms, pill boxes and calendars were also issues people worried about, all of which can affect a person's quality of life. Older people who had had a stroke and developed epilepsy as a result of that had lower quality-of-life scores, showing the toll both of these conditions can take.

Adding to these effects on quality of life, the report also discovered that older people with epilepsy may be facing more challenges than older people without epilepsy, when it comes to things like memory and problem solving. This could be because of their epilepsy, or because of a combination of

epilepsy and other health conditions. The report also found that people's education experience may have been affected if they were diagnosed earlier in life. In some cases, people can find it difficult to understand or describe epilepsy well enough to others, which can create challenges with things like work and activities.

Treating a person with epilepsy should extend beyond seizure management and include making sure that they can live well with their condition too.

Health and self-management

Anxiety and depression also appear to be a widespread issue for people with epilepsy, with levels being higher than in people without epilepsy. One study found that about three in five adults (60%) with ongoing seizures have been found to experience symptoms of anxiety because of the unpredictable nature of seizures. Another study found that around two in five older people with epilepsy (40%) reported symptoms of depression and low mood, compared to one in five (20%) in older people without epilepsy. The report authors explained that an age-specific risk can't be determined from the studies they looked at. But they argue that it doesn't matter, because the generally increased risk in mental health problems in people with epilepsy means everyone should be screened for these annually and offered appropriate support.

The report also looked at issues with medicines for older people with epilepsy. Often, older people newly diagnosed with epilepsy will be more likely to experience focal seizures, starting in just one part of

the brain. But sometimes a focal seizure can turn into a tonic-clonic, which affects both sides of the brain and involves falling to the floor and convulsing. In many cases, epilepsy can be controlled with epilepsy medicines, but it can be more complex in older people where other conditions – and other medicines – could be at play too. With different medicines, different times of day to take them and possible memory issues linked to epilepsy, it can be hard to stick to the medicine regimen. People may need support with their medicine doses, as well as with medical decision-making and taking down information.

Being more informed and understanding their own condition better feeds directly into how well a person can self-manage their condition. This can be a big part of helping people regain their control, independence and confidence after an epilepsy diagnosis. It is, therefore, important to ensure people receive all the information they need, and ensure they know where to go for more. Many older people in the studies worried about how epilepsy would impact their relationships with friends and family, and roles as care givers. The report explained that there was a sense that older people with epilepsy felt like they didn't have anyone to speak to about their epilepsy and what it's like. Self-management programmes can help people build up confidence about their condition, and work to combat these types of concerns. But none have been developed for this specific age group yet. Existing programmes may need to be adapted to suit the needs of older people with epilepsy more accurately.

Epilepsy services: gaps and opportunities

The report revealed some shortcomings that older people with epilepsy may face within epilepsy services. Based on possible assumptions that some healthcare professionals may make, older people were found to be less often referred to neurology specialists than people in other age groups. The third National Audit of Seizure management in Hospital (NASH3) found that less than a third (30%) of people over 60 seen in emergency departments for seizures had previously had contact with an epilepsy specialist. Only a third (30%) were also reported to have a care plan.

As well as that, only around one in five (22%) were given advice after a first seizure and only a third (34%) were referred to a specialist compared to two-thirds (68%) of younger people with epilepsy. These are quite stark findings and a difference in care like that between different age groups needs attention.

Only a third (34%) of older people presenting with seizures in hospital were referred to a specialist compared to two-thirds (68%) of younger people

Around half of older people with newly diagnosed epilepsy, and most of those who were diagnosed with epilepsy earlier in life, said they had not received enough information despite having seen a neurologist. After a diagnosis, just under half (44%) of people said they had not received written information and one in five (20%) received the hospital's own information. But over two-thirds of people (70%) were not told where to get more information. The report identified that some people had trouble finding further information online, or understanding what they had found. Some people said they were too shy to say that they didn't understand, ask questions or challenge what they were told.

Epilepsy specialist nurses (ESNs) are an important resource for people. They can provide overall care and manage other conditions as well as epilepsy, and they can provide accurate and appropriate information. They can also offer help with care plans and mental health concerns. Having an ESN has shown to reduce the amount of time people spend in hospital for their epilepsy. But at the moment, only around a third (30%) of people with epilepsy aged 65-74 have access to an ESN.

For the 600,000 people with epilepsy in the UK, there are only 958 neurologists –

equivalent to 721 in full-time employment. This shows that there is a problem with capacity. Expanding neurology services alone may not be enough to improve care for older people with epilepsy, so training for GPs and geriatricians (medical specialists dealing with health and care of older people) in epilepsy diagnosis and management may offer another way. More training for healthcare specialists is needed.

Moving forward

The gaps in services were identified as a problem with information provision for older people with epilepsy, care plans and checklists, training for non-specialists and access to specialists.

Information should be provided in writing and healthcare professionals must not assume people will remember the information they were given verbally. Information should be delivered in an appropriate way for the person. This will help people better understand and explain their condition to others and self-manage their treatments and risks. This kind of empowerment can have a big impact on people's quality of life. Epilepsy self-management courses should be developed or adapted to more accurately meet the needs of this group of people.

There need to be clear guidelines to better direct care for older people with epilepsy, especially if they are also being treated for other conditions. GPs and emergency services should be supported with more information about referring older people to neurology services when appropriate. More joined-up working with mental health services is also key to

help support people through problems like depression and anxiety resulting from epilepsy. And, for older people with epilepsy resulting from stroke, post-stroke rehabilitation may be needed to help people recover and live better with these conditions.

Opportunities for GPs and geriatricians to train in epilepsy would help with capacity problems with neurologists and epilepsy specialists. Also, more ESNs in epilepsy teams and in the community would help to make care more consistent and to better support people. More training opportunities for community nurses could also help improve this area. This will help to ensure more people have appropriate care plans in place.

Conclusion

The report has highlighted a number of issues older people with epilepsy could be facing, and the fact that epilepsy services are not always appropriately equipped to support this group. Making changes to improve the care provided to this group is incredibly important, especially considering that this is one of the ages at which epilepsy diagnosis peaks.

You can find more information about epilepsy on the Epilepsy Action website at epilepsy.org.uk and more specifically about epilepsy in later life at epilepsy.org.uk/older-life-epilepsy

If you want to share your own experiences of epilepsy or your thoughts on the report's findings, please contact press@epilepsy.org.uk



Some people needed support with medicines and epilepsy information from loved ones



A flip through the diary

Val shares her seizure diary with a difference – more than seizures, it shows a full life and a defiance to halt her ambitions because of epilepsy or because other people said so

1945

I was born in 20 minutes on the landing of our railway house in Middlesex in 1945. I am number five of six children and we all travelled on trains to many destinations.

At 11 years old, I went to a grammar school 10 miles and four buses away. Nobody we knew had cars so we all cycled. When I was 14, there was a bus strike, so I would cycle to school.

1960

When I was 15 we had a rehearsal, singing The Hallelujah Chorus for a Prize Giving at school. We stood on elevated long steps.

The next thing I remember is that I woke up on the wooden floor, surrounded by nuns, and I thought that I had died and gone to heaven. I'd had a tonic-clonic seizure – my first. My mum was there, having got a lift from someone at work. She was the industrial nurse at Garfield Weston cake and bread factory.

We got a ride home and soon everyone forgot about it.

For four summers after that, while I was still at school, I worked in the cake factory and rolled 1,200 Swiss Rolls an hour, for two shillings and sixpence halfpenny an hour. I also worked on Saturdays at the chemist shop at the top of my road.

I hitch hiked round Europe with two friends from the year above. I love to travel and I hitch hiked 30,000 miles in the 60s. I went around Europe between 1960 and 1963, and around Britain in 1963 and 1964.

1963

In October 63 I started my training as a nurse at Hammersmith Hospital. In our first year, we found a wonderful flat in Barnes and persuaded the Matron to let us move out. On days off, I would go hitch-hiking around Britain and staying in youth hostels.

1966

We had parties, and for my 21st birthday I decided to spend two weeks holiday working in a Jewish care home to earn the money to pay for my party. On my birthday, I had my hair done in a hairdressers near our flat. My flatmates were near there and saw an ambulance on the street outside. They joked that 'it must be for Val'. And it was.

I had had a tonic-clonic seizure and was taken to the West London Hospital on Hammersmith Broadway. When I woke up and came back to reality, I remembered that it was my birthday and I was having a party. I just had to be there. The doctors didn't want to release me until the next day, but I explained it was my party and I'd worked two weeks to pay for it. I told them nurses and doctors would be there, and I promised not to drink, and they let me go. My flatmates came to collect me.

That year, I also went to Canada to see my eldest brother, Mike, in Hamilton, Ontario. Unfortunately, I had another tonic-clonic seizure and was admitted to St Joseph's hospital. I had an EEG and a lumbar puncture and other tests. The story buzzed around the hospital about the sick student nurse and I had many visitors. It was the World Cup

that England went on to win, and they decorated my ward with World Cup decorations. I had cot sides. Mike was very concerned but I asked him not to tell our parents. The doctors prescribed me some medicines and referred me back to my training hospital. There, I was investigated and diagnosed with frontal lobe epilepsy. I was told that I would never work, go swimming or have an independent life. This was unacceptable to me. I am resilient. I'd travelled a lot already as a child and later in life. I was just about to qualify and I did.

I worked in London in the 60s and spent six months at The National Hospital for Nervous Diseases where we employed otherwise 'unemployable' people (in those days) who frequently had tonic-clonic seizures.

I was told that I would never work, go swimming or have an independent life – **this was unacceptable to me**

I sailed on Tall Ships twelve times and was sometimes the ship's nurse. I also went to the Boat Show to be on the stand and enthuse. I am good at enthusiasm but I had a tonic-clonic (previously known as a grand mal) and was taken away in an ambulance again. I returned later in the day.

1971

My daughter Rachel was born. Three years later, I had my second daughter Elizabeth.

1982

I spent 20 years being a nurse and I was on duty in uniform when I had a seizure and status epilepticus. I had a cardiac arrest and was resuscitated. I was about 37 at the time. After the ordeal, I was tired but otherwise okay.

1984

I had a second, exciting career in leisure with the local council. I changed careers

as my husband left and I couldn't do the shift work as a nurse with two children of nine and 12. I did many things and created Going Places, taking people over 50 to wonderful destinations.

One outing, which I accompanied, was to Kent, to a National Trust house. However, I got on the coach at Campus West and by the time we had got to the Forum Theatre in Hatfield, I realised that I was having a vacant day. During these, I can't really put words together. I couldn't connect a sentence, so I mumbled to a customer "somebody look after this bus" and got off, not knowing what to do next.

I had friends working in the Forum but didn't think to ask them to get me home. It was a sunny day and I wandered into the town and saw a bus. I asked the driver in very slow words "Does... that.. bus.. go... to...Welwyn... Garden City?" He realised I wasn't well, so he put me on the bus and drove me to the bus garage, where he picked up his car and took me home.

Another time I cycled to Panshanger Golf Course to be the speaker of the year for The Round Table. I was the chairman's choice because I was unusual and creative and had overcome challenges in my life. But I was having a vacant day, so I cycled straight home.

While I worked there, I took the chairman of our local council, who had epilepsy and didn't drive, to the specialist school for children with learning disabilities at Much Hadham. Many of the children there had epilepsy too. I gave them the money that I raised from running the London Marathon that year. I ran marathons three years in a row and got lost at the Harlow one.

1985

I took my daughters to France with our bikes and tents. On the way back, in the



Val with her daughters and granddaughter

waiting room at the station in Plymouth, I had a tonic-clonic seizure. My young 16-year-old friend, who was with us, had the intelligence to wait until it was over. We then put our bikes on the train to Paddington. We then cycled to Kings Cross and returned home.

This was the last tonic-clonic seizure I had. I still have vacant days but don't lose consciousness.

1987

I've had an exciting year being 42. I did a static line parachute jump to raise funds to build STS Lord Nelson.

2000

I did a tandem glide off a mountain in New Zealand.

2021

I have been very lucky and had many choices and many adventures. I am now 76. I travelled a lot and had two careers and a full working life. I had my two lovely daughters and I got to take them travelling. Rachel lives in Malibu and I helped put together a wonderful creative wedding for her with the help of many friends 24 years ago. My daughter Elizabeth lives five miles away from me. I've been able to do a lot of voluntary work with marginalised people too. I'm fearless and a free spirit and I've spent my life proving that I can do whatever I set my mind to.



Val as a nurse in 1967 aged 22



A fairy tale with a twist

Indiana Collins has faced some scary experiences, knowing she's about to have a seizure and no one around her knowing how to help. So she put her drama skills into action and created, directed and produced a show to help make sure more people know what to do. Indiana tells Kami Kountcheva about it

Kami Kountcheva: Congratulations on the show, *The Purple Princess!* Have you always known you wanted to work in the performing arts?

Indiana Collins: Thank you so much. It means a lot that people enjoy the show but also learn something new. I've always loved reading and watching shows. My

mum was a performer and I used to ask her to sing for me all the time. Growing up in Spain, I was immersed into the world of Flamenco, which I adored.

When I left school, I wasn't sure what I wanted to do. I tried various different jobs and didn't find any enjoyment, but then I started helping out at my aunt's

performing arts school and realised that's where I belong.

When I was 20, I went to drama school to study acting. During my studies, I soon realised my true passion was for directing and producing theatre. I graduated five years ago and I've been lucky to work as a theatre maker ever since.

KK: How did you come up with the story – is it something that happened to you?

IC: Yes it is! I'm the Purple Princess, haha! The concept of the show, some of the lines in the show, the seizures which the princess has and the events that happen are based on my real life. Even the characters are all based on real life people.

I was on a train travelling back from a weekend at my friend's house. I suddenly felt an aura on the train and I quickly asked for help. The train guard didn't know what to do, and neither did the passengers next to me. Some people panicked and even left the carriage. I soon had a seizure and sadly it became a cluster of seizures. Because I didn't receive the help I needed quickly, I ended up being

induced into a coma, because the seizures went on for too long.

I was very shaken after this seizure and from the realisation that people really didn't know how to help me. I spoke to my producer about it and we decided to make an animated story about the event for Purple Day. It got lots of attention and we decided we'd make it into a show to teach people what to do if they witness someone having a seizure.

Two of the actors in the play also have epilepsy, which we felt really added to the authenticity of the script, as they also shared their experiences and their expertise on the matter.

KK: Wow, that sounds scary. How long have you had epilepsy?

IC: I was diagnosed with generalised epilepsy when I was 13, which is when I started having tonic-clonic seizures. But, I believe I had epilepsy long before my diagnosis. Growing up, teachers used to write in reports things like 'Indiana's head is in the clouds', 'Indiana needs to pay more attention', 'Indiana needs things repeating a lot'. I also recall getting very upset as I'd miss deadlines, not turn up to social events and not recall conversations people assured me we'd had. Now we know I have absence seizures as well as tonic-clonic seizures. It makes sense that these absence seizures had started when I was very young.

Most of my tonic-clonic seizures are cluster seizures, so I have multiple seizures consecutively. Currently, my seizures aren't controlled, although they are more controlled than they have been in the past. I'm currently having absence seizures nearly every day and tonic-clonic seizures every six-to-eight weeks. Because my tonic-clonics happen in clusters, eight out of 10 times I need medical help.



KK: How did you find the diagnosis process?

IC: The diagnosis has been complex. I grew up in Spain and when my first tonic-clonic happened at 13 years old, I was prescribed Lamictal (lamotrigine) and diagnosed with epilepsy straight away, as they caught a seizure on an EEG. My neurologist kept increasing my medicine as I kept having more and more seizures. I gained seizure control when I was 17 for nearly two years, but sadly, in the end, the side-effects of Lamictal were too severe for me to handle.

I moved to England when I was 19 to study, where I asked for my medicine to be adjusted. Since then, I've had various neurologists. My seizures are still not under control and the triggers are not fully understood. My medicine is still being adjusted to try and bring my seizures under control and reduce the severity. I'm currently being taken care of by a brilliant team at St Thomas' Hospital in London.

KK: It must be difficult dealing with the effects of uncontrolled cluster seizures – how do they affect you?

IC: Currently, when I have my cluster seizures, I normally end up in hospital and the doctors have to give me diazepam and phenytoin to stop the seizures. Sometimes, I have to be induced into a coma if the seizures don't stop.

Normally I need at least a week off work to recover and sometimes I use aids, such as walking sticks, because the dizziness and pain from all the seizures and medicines makes mobility a real challenge. I'd say, on average, it's around two weeks to physically recover from my cluster seizures. My absence seizures give me bad headaches and often some confusion. However, I can continue my daily life with them.

Since the tonic-clonic seizures started, I live in fear of the next seizure, it feels like I have a stalker on my shoulder and I'm just waiting for them to strike.



KK: Have you found epilepsy has affected aspects of your life?

IC: As well as the seizures, it affected my academic life. I dropped out of school when I was 15 as I couldn't cope with the amount of seizures I was having. I was always trying to catch up with what I'd missed – homework, exams and regular lessons – and it became too much. It also affected my social life and my relationships. School friends were scared to hang out with me. I stopped getting invited to events. Even as an adult I've had friends not want to live with me because of it, or just see my epilepsy as an inconvenience.



Hassan Maarfi is one of the actors in the production

I've been fired from jobs because of having seizures and I've had people just generally not understand my needs and state that they couldn't employ me with uncontrolled epilepsy.

KK: That all sound really difficult. How do you cope?

IC: As I've grown up, although my seizures are still uncontrolled, I've grown to own my epilepsy. It's part of me and it's shaped me into a kind, empathetic and brave young woman who wants to make a difference in the world.

I managed to go to drama school and then got a job as assistant director with the Guildford Shakespeare Company who have been extremely supportive. I also have a loving partner and incredible friends who support me.

I have therapy to help manage my anxiety and depression which is heightened after seizures. I'd like to believe that, although it can feel like my life stops for a while after a seizure, when I do recover, I'm living life to my full potential.

KK: So, can you tell me a bit more about the show?

IC: We have used the concept of a fairy tale world to make the play more child friendly. It meant they were characters they would recognise and it wouldn't be too scary. But it's all based on what has happened to me.

We first see the seizure happen, as it did to me, with people not knowing what to do or doing the wrong thing. All the wrong things that are said, such as 'I thought you only had seizures from flashing lights' or 'you're too young and pretty to be disabled' are all real-life experiences. The things people do wrong in the show are too, such as putting things in my mouth, moving me, throwing water on my face and holding me down.

The fairy godmother then flies in and teaches the audience and the characters what we should have done to help the princess. We then rewind to the moment the princess has a seizure and, through forum theatre, the audience helps the characters deal with the seizure. We created a little ditty 'If you see your friend fall, Calm, Cushion, Call'. And, of course, it all ends happily ever after.

KK: Why did you decide to target the show at school children?

IC: We knew we wanted children as our target audience. Children are like sponges, they learn quick, they care and they have no prejudice. I also feel that the earlier we teach people seizure first aid, the more engrained in them it becomes and the more people with epilepsy can feel safe.

The company is based in Guildford, and we have a relationship with many of the local schools. The production was made possible by generous funding from South Western Railway. Alongside them, we decided we'd tour schools in our local area which are also near to train stations and train lines.



Actors Tom Capper and Isabella Hart both have epilepsy too, and performed the show in schools



Emily Juler is Tom's wife and also has a connection to epilepsy

We hope to tour the show again and go to many more schools in the future.

KK: Had you ever seen anything like it when you were a child?

IC: No and I wish I had. It would have certainly made me feel less like an alien and educated many people around me about how to support me. But also, it would have helped us all realise that not all disabilities are visible and to please be considerate and understanding of others.

KK: What has the reaction been like from the children?

IC: Amazing! It's been so heart-warming to see children chanting the ditty and helping the characters to help the princess. We've had awesome reactions after the show from children telling their parents what to do, explaining it to each other again and practicing the three Cs. We also did a Q&A on epilepsy after the show where we had some great questions, such as 'What does it feel like to have a seizure?' and 'What does your brain do during a seizure?' It was great to see their curiosity for the condition and how they want to help.

Many children said they knew nothing about epilepsy before the show and they now feel fully aware and know how to help.

Teachers and parents have been complimentary. One teacher said: "The children loved watching the show. It was great for them to see something so entertaining and informative at the same time. The vast majority said they had little or no

knowledge of epilepsy and this play helped them understand it more and what they could do to help."

KK: What does it mean to you to be able to raise awareness about epilepsy in schools?

IC: I know how hard epilepsy can be in someone's life and I also know how much of a positive impact having people around you who understand can make.

I believe that the more people who understand epilepsy and other hidden disabilities in general, the safer and kinder place the world will be. I think educating our children is a great way to spread this message and make it 'normal' for people to be different.

But also, on a fast-hitting practical front, people knowing what to do during a seizure can save lives. If we can contribute through theatre to prevent anyone going through what I and many others have done with seizures and a lack of first aid, it'll be a success.

For more information on 'The Purple Princess' and to watch the show online, please visit: guildford-shakespeare-company.co.uk/purple-princess

'The Purple Princess' was made possible with generous funding from South Western Railway.



Indiana dressed as The Purple Princess



The gifts that keep on giving

It's never too early to start planning for the festive season. Picking up a few cards, stocking fillers or gift wrap now will put you in good stead when the holiday rush sets in. If you're on the look out to pick up some Christmas pieces, the Epilepsy Action Christmas collection 2021 has you covered. And, by ordering from the collection, you are also helping to support people with epilepsy. What better gift is there than that?

A small selection of our Christmas range and an order form are enclosed with your issue of *Epilepsy Today*. You can view the full collection or place an order online by visiting: epilepsy.org.uk/christmas2021





Safety matters

Dr Gorton shares some findings from her team's work on 'unnatural deaths' and self-harm in people with epilepsy and shares why understanding these risks is important to keep ourselves safe

Keeping safe and well is a priority for everyone. For people with epilepsy, there's often an added layer of consideration, with increased risks of injuries due to seizures. But there are other factors, such as an increased risk of mental health problems, which can also impact the safety of people with epilepsy. While worrying, knowing about potential harm and risks can help us to reduce them.

Dr Hayley Gorton from the University of Huddersfield and the team, comprising members from the University of Manchester and Swansea University, have been studying risks of self-harm and what they call "unnatural deaths" in people with epilepsy. "When we describe unnatural causes, we mainly mean accidents and suicide," Dr Gorton explains.

Dr Gorton started this work, looking at suicide and self-harm more generally,

when she was completing her PhD. She and the team completed a review, which led them to focus more on epilepsy medicines and then epilepsy more broadly. At this time self-harm and unnatural deaths in epilepsy was becoming a focus for the epilepsy research community too, showing the importance of better understanding this area.

In the team's studies, the risk of deaths by unnatural causes in people with epilepsy was two-to-three times higher compared with people without epilepsy. Dr Gorton explained that some of this had already been found in research. She added some perspective, saying: "That said, it is important to remember that there were over 8,500 deaths in people with epilepsy in our study spanning 1998-2014. Of these, 271 were considered 'unnatural'." The percentage of unnatural deaths was 3%, or three in 100 deaths, meaning most

of the deaths seen over the study period were of natural causes.

When the study team broke down the groups, they found that the risk of poisoning was increased in people with epilepsy. Dr Gorton explained, however, that the studies weren't designed in such a way that would explain why this increase in risk exists. The studies aimed to identify if there was a risk in the first place. Further studies are needed to investigate this further.

Another aspect the team investigated was deaths resulting from alcohol in people with epilepsy. In their study, the researchers found that people with epilepsy were five-times more likely to die because of alcohol-specific causes than people without epilepsy. In people with epilepsy, this was the case in 47 in 15,440 people, which was around 0.3% or three in 1,000 people. This was compared to 0.06% in people without epilepsy, or fewer than 1 in 1,000 people.

She also cautioned that doctors should speak to patients about the role of alcohol in epilepsy and seizures, and make it clear what levels are too high.

The team also looked into self-harm, as well as unnatural causes of death. They found that the risk of self-harm in people with epilepsy was around five times higher than in people without epilepsy in the year after their epilepsy was diagnosed. In subsequent years, the risk fell to around three times more than the general population. In the group with epilepsy, 273 out of 11,690 people self-harmed overall,

which is around 2% or two in 100 people. In the group without epilepsy, this was 0.7% or fewer than one in 100 people.

“We identified self-harm from GP records. It is important to remember that many people might not report self-harm to the doctor or it might not be reported at the time.” This suggests that levels of self-harm may be higher than research suggests, but this may be true regardless of whether someone has epilepsy or not. It highlights the importance for specialists and family and friends to bear this risk in mind and to help support people with epilepsy, especially soon after an epilepsy diagnosis.

While a lot of these studies can't say for sure why there is this higher risk in people with epilepsy compared with people without epilepsy, it's still important to know that there is a risk. Equipped

It is important that people feel able to reach out to someone for help if they are having thoughts of harming themselves

with this knowledge, there are things that we can do to keep ourselves safe and support our loved ones through these kinds of challenges.

Dr Gorton suggests: “People with epilepsy and their loved ones should be aware of these increased risks of suicide, self-harm and accidents.”

People can take steps to help themselves or loved ones to reduce the risk of harm and accidents. Epilepsy does carry some extra risks to the everyday risks everyone takes and manages each day. The unpredictability that seizures often come with means that those of us with epilepsy may need to take extra care around sources of heat or bodies of water. Safety steps could include having someone with you if you're in or near water, getting soft rugs or carpets, hiding away trailing

wires and keeping your bed away from walls or radiators. It can also help to have a medical card or medical ID with you if you go out, which has information about your epilepsy and what to do in case of a seizure. There is more information on safety on the Epilepsy Action website at: epilepsy.org.uk/safety

Dr Gorton continued: “It is important that people feel able to reach out to someone for help if they are having thoughts of harming themselves. Also if epilepsy professionals know about these risks, they can be vigilant. This might help them to ask people the right questions.

“With alcohol, it's also important that people are aware of the increased risk, not just because of the increased risk of death, but also because it can affect seizures themselves. And again, if people are concerned about the amount of alcohol they are drinking, it is important to discuss this with the GP or epilepsy specialist.

“For self-harm, the support that is available for people with epilepsy is essentially the same as that for people without epilepsy. You can talk to your GP or epilepsy specialist and there are some extremely supportive charities. One example is the charity Harmless (harmless.org.uk) and there are many other charities that support mental health and suicide prevention, for example Mind (mind.org.uk) and the Samaritans (samaritans.org).

“We noticed in our study that risk of self-harm among people with epilepsy was slightly increased at times when they were not taking epilepsy medicines, or times of change or addition of medicines. We

think that most of this is a reflection of the fact that at those times, the epilepsy is less well controlled, and not likely to be anything to do with the medicines themselves. It's very important that people don't stop taking their medicines without speaking to their doctor.”

For healthcare professionals, Dr Gorton recommends that the best way to help reduce these risks is to treat people as a whole, rather than just the epilepsy. This includes asking about more than just a person's epilepsy, but also about lifestyle, behaviour and other conditions. They are then able to refer people to other health professionals where needed.

Importantly, if any of these are issues you are struggling with, it's important to know you're not alone and there is help out there.

More support

Epilepsy Action
epilepsy.org.uk
Freephone: 0808 800 5050

Alcohol Change UK
alcoholchange.org.uk
Drinkline: 0300 123 1110

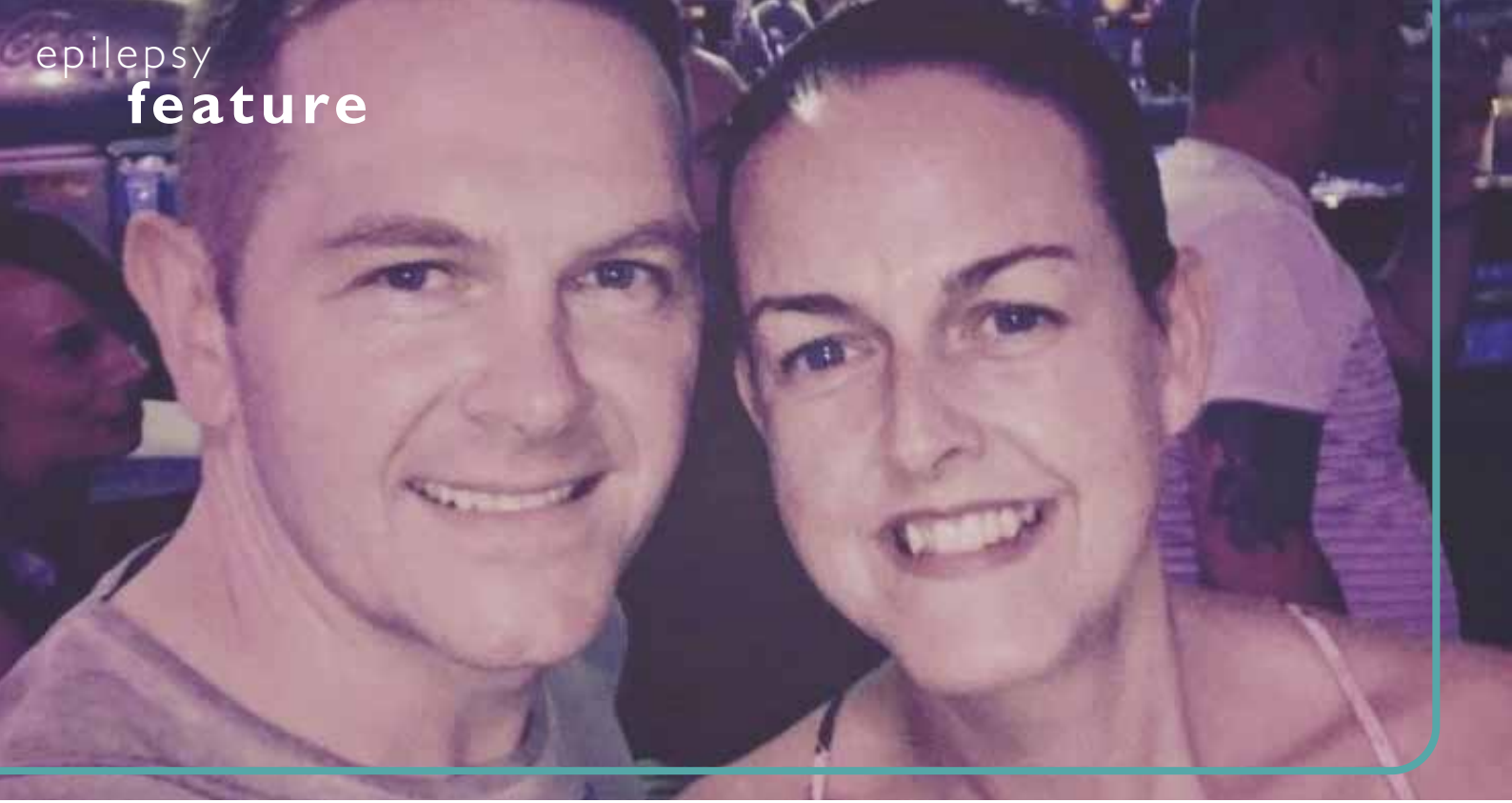
Mind
mind.org.uk
Infoline: 0300 123 3393

Harmless
harmless.org.uk

Samaritans
samaritans.org
Freephone: 116 123



Taking epilepsy medicines as prescribed may help reduce risk of self-harm



The hardware or the software

Peter's diagnosis took two-and-a-half years. He tells *Epilepsy Today* what it was like learning to live with non-epileptic seizures, while also pushing to get his epilepsy diagnosed

My first seizure came completely out of the blue in February 2019. Since then, I've gone on to have over 170 more. Initially, I had two sets of EEG tests – a five-day stay at the Walton Centre with 24-hour monitoring in January 2020 and one at home in the summer of 2020. For the latter, I had the EEG pads put on and I was able to go home. But EEG tests showed no seizure activity linking to epilepsy. I felt numb, to be honest. A letter initially diagnosed dissociative seizures (also known as non-epileptic seizures), with a note to 'keep an open mind'. This was due to me having seizures with auras preceding them, along with several tongue-biting episodes.

I read somewhere a description that said dissociative seizures are a problem with the 'software' and epilepsy is a

problem with the 'hardware' of the brain. I just did not understand at all how suddenly, out of the blue at work or at home, I could have a seizure and it be down to a problem with the 'software'. The first two seizures I ever had involved convulsions and heavy tongue biting. The second one happened at work, and I also had hallucinations and an out-of-body experience.

I did not know what dissociative seizures even were before I was diagnosed with them. I did believe the first diagnosis of dissociative seizures, as the people sat in front of me were the specialists and I was not. And so I tried to get on board with the diagnosis, which was largely made from videos. But I always felt that there were more twists and turns in my journey and that this wasn't the full story.

My superstar wife Jane was able to capture key parts of a seizure in May 2021 on her phone. This, and my own feelings that there was more, spurred me on to be persistent – but always polite – with the doctors at the Walton Centre to go in search of answers. Shortly after my wife recorded my seizure, my doctor saw it and said that I most likely have focal epilepsy. My diagnosis letter now states that I have both focal epilepsy and dissociative seizures. Since this happened, I started taking a different epilepsy medicine along with a higher dose of the medicine I started taking initially, clobazam.

Personally, I've felt like I've been trying to solve a Rubik's Cube for the last two-and-a-half years. Solving one humongous neurological mystery, whilst at the same time being a husband, father and trying to continue with work. I'm a team manager in retail and have been in my current job for 15 years.

The whole period has been scary and frustrating. It's been scary, because of moments like being asked to 'immediately' stop taking lamotrigine because I'd developed a large rash. This medicine, which I started taking in early 2019, had helped me have the longest period of seizure freedom (until recently) of 12-14 weeks. But I had to stop it "cold turkey", as the neurologist's receptionist called it. About a week later, while watching football with my eldest son Joshua (13),

I went from just sitting with him to a tonic-clonic seizure.

It's scary that my son went on to see things I wish he had never had to see. On 31 March, while Jane was out for a short time, my eldest had to hear his dad scream out – I don't remember this at all as it was part of the seizure – and see him have a tonic-clonic seizure. Josh phoned 999 and spoke to the emergency services while looking at me having a seizure!

It's frustrating that perhaps if I'd had more regular reviews, or more appointments, we might have reached the focal epilepsy diagnosis sooner. I might have started carbamazepine sooner (the fourth epilepsy medicine I've tried now) and perhaps both my sons might have been spared seeing their father have any type of seizure.

Waiting for a diagnosis has been torture. But thankfully Jane has been my total rock throughout all of this. She has had to stay calm while seeing me have over a hundred seizures. My two boys Josh and Lewis (8) are also my world. It was easy to go about my life during that time, though, because that was the very thing – my life – that kept me motivated. It gave me an 'I will not be defeated' approach to my seizures. The uncertainty of when the next seizure would occur never overtook the importance of being a father, a husband and a worker in my mind. I've always had the attitude that I could not live my life in a padded room. My family have been an incredible support by bringing fun, laughter and love to my days. I have been with my wife for 21 years and we have been married for 11. My family just being my family was more than enough of a tonic for all the challenges for me.

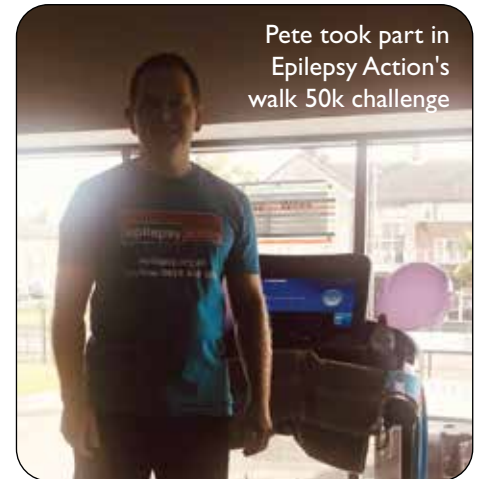
Getting the right diagnosis was a relief and a feeling of a weight being lifted off my shoulders. Since May this year I have been on carbamazepine and a double dose of clobazam. I have had a few seizures since but I have had the longest seizure-free period I've had since my seizures started, which I believe is due to the medicines I have now. Just as important is the fact that since starting the new medicines, the seizures starting

with auras, which I was beginning to have more and more of, have stopped.

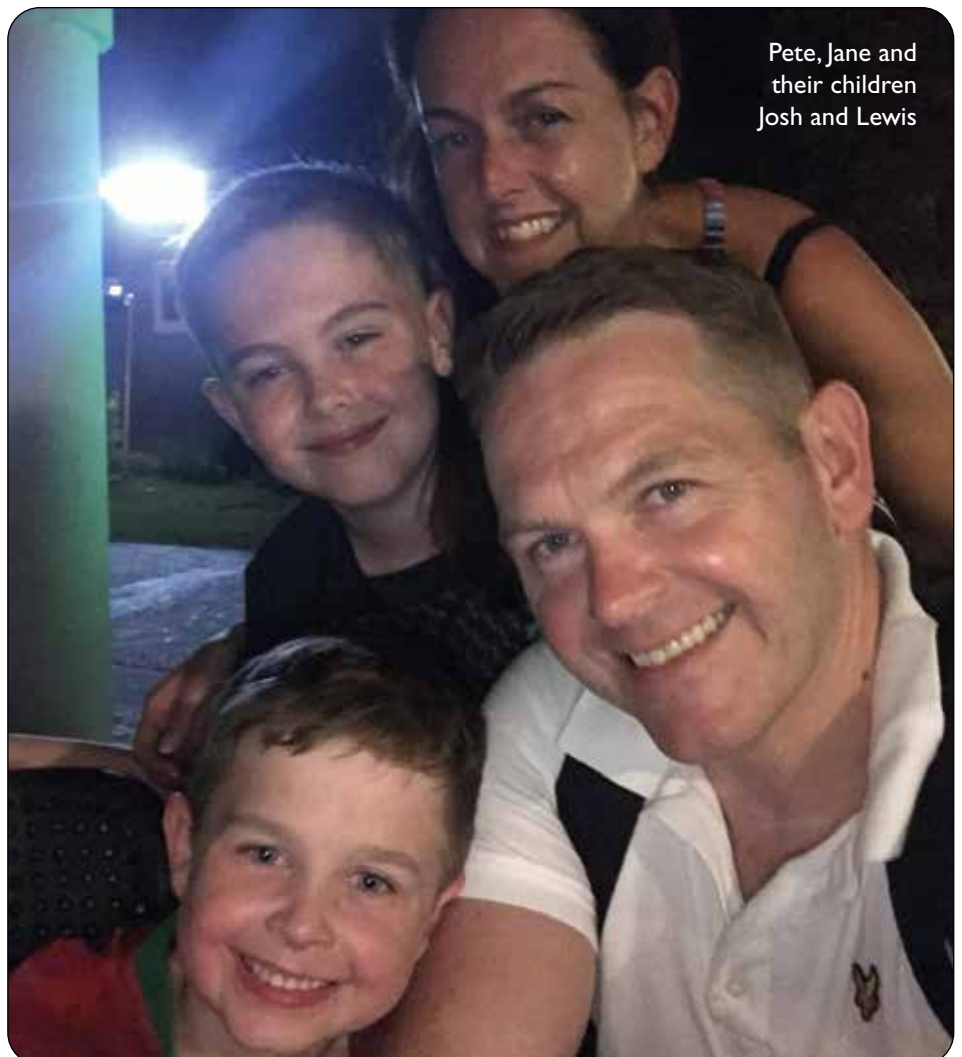
A seizure, no matter what type, impacts the whole family. I think they feel the emotional scars more than me. Honestly, I don't know how people cope with the mental struggles of epilepsy without someone by their side. Charities like Epilepsy Action are so important as they provide a support mechanism to those who need help, especially with coming to terms with diagnosis.

To anyone else having a difficult time with the diagnosis, I would say that clear video evidence of seizures occurring is really important. As difficult as it is for loved ones who see the seizure first hand, try to get the video footage from start to finish. Try to get footage of the whole body, rather than zooming in to convulsions, because you can zoom in

later. Getting the whole body and the face in full view helps, as the smallest things can help to guide diagnosis. To the person experiencing the seizures, hopefully love and loved ones are around you to help. Please stay strong and continue to live your life.



Pete took part in Epilepsy Action's walk 50k challenge



Pete, Jane and their children Josh and Lewis



Your heart or your head?

Sue's journey to getting the correct diagnosis took over two years and several different doctors and hospital departments. She tells *Epilepsy Today* about her extraordinary experiences and why she would like to see more communication between specialties

I'm 59 and I live in Warwickshire. I'm single and I come from a lovely large family with lots of nieces and nephews but no children of my own. I worked as a radiographer for 37 years before I had to take medical retirement. I am a keen road cyclist and like to keep fit and active.

I first became aware of some 'funny turns' in 2017 and started to feel something wasn't quite right. But there was no loss of consciousness at that stage. They were irregular and subtle. They were things like feeling disorientated, forgetfulness, absences, *deja vu*, speech

My GP and I both agreed it was probably going to be a heart issue, not a brain issue. **Little did we realise, it was going to be both**

arrest and feeling vacant. But they started to increase. Secretly I worried I had early dementia as my memory was getting noticeably worse too. I didn't really want to face up to it. However, one day, it happened at work and my colleague (and friend) made me promise to go to my GP. She may well have saved my life.

My GP is great and very proactive. When I initially saw him, he referred me to a cardiologist. We both agreed it was probably going to be a heart issue, not a brain issue. Little did we realise, it was going to be both! Coincidentally, I had a history of a very low heart rate that had been investigated years earlier.

At this stage, I was only getting the 'funny turns' and not actually blacking out. But my GP also ordered a brain scan "just in case" but that didn't show anything untoward.

While I was waiting to see the cardiologist, the turns got much more frequent, and I started to black out. One minute I would be doing something, like working on the computer, and the next thing I knew, I was coming round on the floor. I remember it being really frightening at the time and now I know what was causing it, I should have been positively terrified! As I live alone, it really worried me that I might fall down the stairs or hit my head on something. I couldn't drive, cycle, or go out on my own at all at that point.

We realised then that something more serious was going on. I was fitted with a Reveal device, which can record an ECG, to monitor my heart. Once this was in place, the next time I blacked out, the device showed my heart had stopped for around 20 seconds before

it – thankfully – restarted on its own. The device is really clever, as the hospital could connect to it by Bluetooth through a transmitter I kept at home. Initially, the cardiac technician told me someone would look at the trace from the blackout and get back to me the next day. But, as the trace downloaded on his end, he changed his mind. He told me there and then that an ambulance was on its way and the sirens would be going. I will never forget that conversation!

I was taken into hospital, and I had a pacemaker fitted as an emergency. They didn't want to let me out of their sight now they knew what was happening. The NHS were brilliant.

At this time, my blackouts were diagnosed as sinoatrial arrests, which is when the sinoatrial node of the heart, that normally generates electrical impulses that make the heart beat, stops working. The cardiologist did comment at the time that it was extremely unusual in someone of my age to have this condition.

I had to go for routine check-ups with the cardiology technicians. They could see the pacemaker was switching on when my heart needed it to. But all the other 'funny turns' I was having were still happening and this was really frustrating for me.

We just couldn't get to the bottom of why this was. I was telling them that I was having the episodes, but they didn't correlate with the activity of the pacemaker. I went back to the technicians repeatedly to see if they could find out why.

On one day, the turns were so numerous, I was admitted to hospital. This was at the start of lockdown. Everyone was still thinking it was something to do with my heart, but I was asked several times if anyone in my family had epilepsy, and I said no. And that was that.

During my stay, they altered the settings on the pacemaker. The new settings were awful and they made me very anxious. If my heart rate dropped below 50 beats per minute (bpm), which it frequently did, the pacemaker gave me a burst of beats at 110bpm. This was a horrible feeling as it felt as if I was having a panic attack.

I was discharged and the doctors concluded I had vasovagal syncope, a condition that leads to fainting. I was told I needed to make sure my blood pressure didn't drop too low by keeping extra-hydrated and eating enough salt.

I later had an appointment (over the phone, because of COVID-19) with a local cardiologist and after a further test called a 'tilt table test', he confirmed the diagnosis I was given.

Everything was very stressful and worrying during that time. I just didn't know what to think and couldn't make any plans. The problem was that with what was happening to me, I didn't get any warning beforehand. Little did I know then, this fact was key to my final diagnosis. I had to take early retirement and it seemed my passion for cycling and keeping fit and active was going to be impossible. Although I am normally a very positive person, I admit to feeling very depressed at that point. The future looked bleak, as my life was going to be so restricted.

I rang STARS (Syncope Trust And Reflex anoxic Seizures), an organisation which supports people with the condition. An incredibly helpful and supportive lady there,

Jenni Cozon, went through my symptoms with me. She didn't agree with the diagnosis as my symptoms just didn't match up. I wasn't getting any warning beforehand.

Between us, we decided I needed a second opinion. She suggested a world-renowned cardiologist in London, Dr Boon Lim. He took one look at the results of the tilt table test and told me I had epilepsy, not vasovagal syncope.



Sue had a pacemaker put in to stop her blackouts, but her other funny turns continued



Sue likes to keep active

Sue worried that vasovagal syncope would stop her from her activities, such as cycling



After all the upset and frustration, I could have kissed him! It all finally made sense.

I found out from STARS that vasovagal syncope can be wrongly diagnosed as epilepsy. The irony is that epilepsy can also be wrongly diagnosed as vasovagal syncope. Jenni had picked this up! I now feel like telling people with vasovagal syncope to get checked out in case they have epilepsy.

Dr Boon Lim referred me to a neurologist, who confirmed the diagnosis – temporal lobe epilepsy – and explained to me that some of my seizures had been provoking my heart problems. The electrical activity in the brain during a seizure can change the pulse and this is what was happening to me. My understanding is that it was most likely being caused by an 'ictal systole', which is a rare occurrence in people with temporal lobe epilepsy. The pacemaker was taking care of those seizures where I blacked out and my heart stopped temporarily, but not the smaller focal seizures.

The neurologist also said to me that normally the epilepsy would be diagnosed first and then, when it was apparent it was causing heart issues, they would fit a pacemaker. But my diagnosis had happened the other way around. I was also prescribed Lamictal (lamotrigine).

The epilepsy diagnosis and the whole process really knocked my confidence to start with, and it took some time for me to feel much calmer and at peace

with the diagnosis. I think it was the not knowing what was causing it all. It had taken two-and-a-half years between my GP referring me and getting a final diagnosis. I don't hold any grudges for that whatsoever, as it's rare and my symptoms were very confusing. Everyone I saw was doing the best they possibly could with the knowledge they had. I am also extremely grateful that I had a medical background. This meant that I questioned my treatment and diagnosis all the way through.

The doctor took one look at the results of the tilt table test and told me I had epilepsy, not vasovagal syncope

I had to leave my career of 37 years very abruptly and chose medical retirement as I was not really at an age when retraining in another field was an attractive proposition. That took a lot of getting used to as I imagined I would retire when I chose to, not when I had to!

Also, my pacemaker, which I still need as part of the treatment, is really noticeable, as I have such a small frame. It's the size of a small matchbox and

sticks out at the top of my chest by my shoulder. Some styles of clothing are not suitable now. My bra strap rubs against it and it gets in the way with certain arm movements. I needed to reframe my attitude towards it. I try not to feel embarrassed by it or see it as ugly or a nuisance. Without it, there would be a high chance I wouldn't still be here to tell the tale. So, I now call it my heart angel, as, after all, it did save my life.

I'm still not able to drive until my Lamictal dose is right and my seizures are controlled.

Now I feel incredibly lucky and positive. I think I have got off lightly with my epilepsy now that it has been identified and I'm taking the right medicine. It is very frightening to think that I was at an increased risk of sudden unexpected death in epilepsy (SUDEP) and could have died. I understand that the cause of SUDEP is not always evident, and there may be more than one explanation. But, it is thought that some seizures, which can affect breathing or heartbeat, may be linked. While it is still not fully understood, there are things that can help reduce the risk of SUDEP. It's important to take your medicines exactly as prescribed, avoid any known seizure triggers and ask for a referral to a specialist for a medicine review if your seizures are not controlled.

Now, modern technology means I can pretty much lead a perfectly normal life. I realise I am so much luckier than some other people with epilepsy. It has made me more aware of the condition and the misunderstanding and stigma that can surround it. I am a real advocate for the wonderful work Epilepsy Action does, too.

In my experience, there seems to be a huge gulf between cardiology and neurology that needs to be addressed. If you fall between the two, as I did, it seems that you can easily be misdiagnosed. Who knows where I might be today? Neuro-cardiology as a new specialty? Yes please!

For more information on STARS and vasovagal syncope, visit hearhythmalliance.org/stars/uk

For more information about SUDEP, visit: epilepsy.org.uk/SUDEP

A lucky break

The Epilepsy Action weekly lottery is a great opportunity to support people with epilepsy while also throwing your hat in the ring every week to win £25,000!

The Epilepsy Action weekly lottery is part of Unity, the nation's fundraising lottery scheme. This means that every £1 you play is a chance at winning a great cash prize, but it also helps to support people living with epilepsy.

Playing the lottery is quite a hopeful thing to do. You know that as long as you play there's always hope that it might be you who scoops the big prize. And with the weekly lottery, you also get to bring hope to more people living with epilepsy.

And ultimately, sometimes having hope pays off. Jadene, started playing the lottery a few months ago after receiving some information about it from Epilepsy Action.

"I started playing around April time," Jadene said. "I thought it sounded good

because it still contributes towards supporting epilepsy. Because I set it up so it just comes out of my bank automatically, it's not money I miss, so I thought that's alright, it's a few quid a month and it helps!"

Jadene was recently the lucky winner of the top prize of £25,000. As someone who considers herself "not a lucky person", she was dubious. "I had the call and they said it was Epilepsy Action, and I was told I'd won, so when I came off the call I checked all my emails and my information to make sure it was true. I just didn't believe it!"

As well as other fundraising she has done, this was an easy way for Jadene to support Epilepsy Action. She has a big connection with epilepsy, having two grandparents and an uncle with the condition, and being diagnosed with it herself when she was 11. She is now 31 and has navigated uncontrolled seizures, changes in medicine, having children and losing a friend.

"On Christmas Day 2001, I had a seizure in the car and I spent all day in the car and at the hospital. Then

later on in the New Year, they diagnosed me with epilepsy."

It sounds like a nightmare Christmas, but Jadene is good at finding silver linings. "It was quite nice, strangely, because I had all the attention. I have two other siblings, so it just turned into a day about me, rather than everyone, which is very rare in our family."

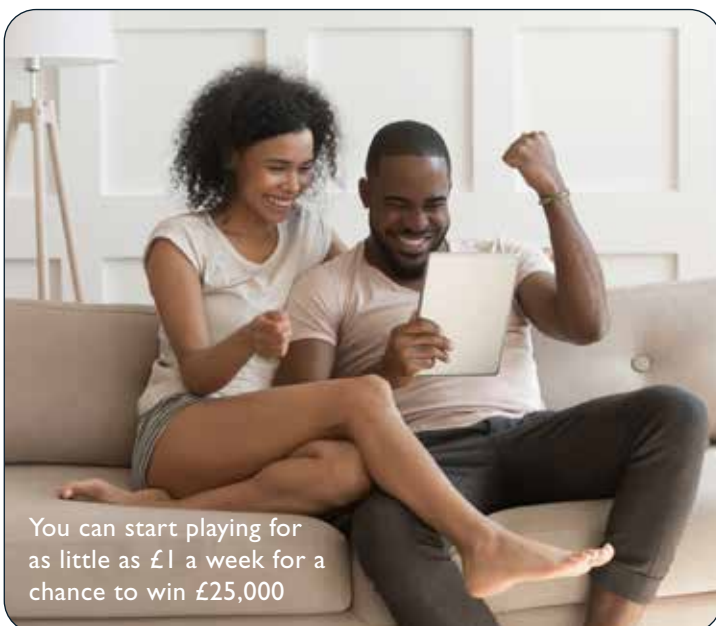
Jadene explained she used to drink heavily from the age of 16 until she was 22. "I would wake up, I'd go to work at the pub, I'd drink at the pub and it was like a vicious cycle. The more I was drinking, the more seizures I was having. Then, when I was 22, my best friend died from a heart attack. He was only 24. He didn't have epilepsy or anything, but this was a wake-up call, because I was having four or five seizures a day.

I started playing around April time – I thought it sounded good because it still contributes towards supporting epilepsy

"So I stopped drinking, my seizures stopped happening so frequently and my doctor changed my medicines from sodium valproate to Keppra (levetiracetam). I then had my two children. My tonic-clonic seizures are controlled but I still get absences. I know when they're happening because it makes my eyes feel heavy. I just try to chill out when that happens."

The winnings will come in very useful for Jadene. "I'll use it to pay all my debts off. It means I'll be able to start afresh with my kids. And after COVID-19, maybe we'll be able to go on holiday. We haven't been on holiday in about four years now."

You can start playing too, for as little as £1 a week. Sign up at epilepsy.org.uk/win and play straight away or call Jenny on 0113 210 8822 for more information.



You can start playing for as little as £1 a week for a chance to win £25,000

My journal



Fran tells Kami Kountcheva about how lonely it can feel to have seizures, dealing with the reactions of the public, and the solace she finds in her family, her gardening and writing



“I remember brushing my teeth, and the next thing I remember was being lifted into an ambulance,” Franziska Thomas said, recalling her first seizure. “My mother looked terrified. I just felt exhausted. I had no idea my life would change from that moment on.”

Fran, 43, lives in London with her husband Tim, 47, and her sons Oskar and Kurt. Fran lives “a stone’s throw away” from where she grew up with her two brothers and two sisters. Her mother is German and her father is Welsh, so she and her siblings had influences from different languages and cultures, and spoke German at home.

Tim is a chief technical officer for a software company and Fran worked as a history and personal social health education (PSHE) teacher. Recently, Fran has changed course, working as an author and fundraising manager for Snowland Journeys, a non-profit organisation supporting children in the Himalayas. As Fran puts it: “I generally spend three days a week writing books and two days writing grant proposals. Bliss!”

But she didn’t always know things would turn out quite so blissful, especially when – exactly three months before her 16th birthday – Fran’s seizures began.

“I was at home for an orthodontist appointment when I had my first seizure. My mother, who used to be a nurse, thought I was having a brain haemorrhage and stuck her thumb in my mouth. Apparently, I almost bit it off.”

Fran didn’t know much about epilepsy before she got her diagnosis. “I was a teenager – I knew a lot about nothing! But actually, my parents had an inkling this might happen. My father was a psychiatrist and noticed what he thought were focal seizures when I was nine years old. I was taken to Great Ormond Street Hospital for an EEG, but nothing was found at that time.

“The diagnosis process for my epilepsy was arduous and time-consuming. I had to have another series of seizures before the diagnosis came. Then, there was the sticking point of where

the epilepsy came from, the left side of the brain or the right. I remember sitting there in the appointments thinking: 'Who cares? Will it change anything?'"

Fran has tonic-clonic and focal seizures. She explains that she also used to have myoclonic seizures, but they seem to have stopped over time. Every three weeks, Fran can have one or two tonic-clonics with her menstrual cycle and in 24 hours she could have up to 25 focal seizures. All of these leave Fran exhausted, especially if they happen at night and affect her sleep.

"I have to take well over 50 tablets a day. I have four epilepsy medicines, split up into four doses to minimise the hand jerking.

"My epilepsy is not controlled by medicines. Two of my epilepsy medicines I've been taking for 20 years, a third I've taken for 10 years and the last one I started 18 months ago. I lost 22kg in the first three months of taking it, so the dose has gone up and down like a yo-yo. Not fun.

"More recently, I woke up to a guy telling a paramedic from the ambulance that I was in my mid-50s. I won't tell you what I said back..."

"For me, it's not so much about controlling my seizures anymore. I think after 20 plus years, that's pretty much impossible for me. I'm not prepared to go through any big medicine changes again, I just want to stay safe and protect my head from hard knocks during tonic-clonic seizures."

One thing a lot of people wish was more widely understood is the fact that epilepsy's effect stretches further than seizures. And for Fran, the side-effects are as much of an issue as the seizures themselves.

"I struggle massively with memory loss, ataxia (which is a group of disorders affecting coordination and balance) and nausea. This leads to stigma from people often thinking you're drunk. I can hear them tutting when my kids are standing next to me. I don't even drink!

"I can't work in a school at the moment, as, since starting the most recent drug 18 months ago, I'd never have the energy. I still feel guilty calling in sick from work, so unless I'm catatonic, I'm there."

It's also not easy on Fran's family, although they have taken it brilliantly. "My kids are incredible. They look after me day in and day out. They get fed up too, of course, but we talk about it and there's always a way through.

"Once, when I'd had a seizure out and about, Oskar chased someone down the street for filming me. He was really

distressed for days. I told him not everyone is good, that's never going to change.

"The main thing to tell them is it's okay if they get fed up with my epilepsy. I get fed up with it, Tim gets fed up with it. It's a human reaction. Tim's amazing at talking to them, too."

Despite the bitter experience Fran and Oskar had, having seizures in public is not always like that. And it's something Fran has found has changed since the pandemic.

"When I've had seizures in public, the reaction is very mixed. Most people are lovely, lots keep wanting to tell me they are a medic – never really understood that one. More recently, I woke up to a guy telling a paramedic from the ambulance that I was in my mid-50s. I won't tell you what I said back..."

"While my seizures didn't really change during the pandemic, what did change was people's reactions to them. In general, I find people are more tolerant and patient than they once were. The realisation that we are all fallible and mortal has changed people's attitude to epilepsy. I think COVID-19 has made people more humane, and, having epilepsy, I feel this more than most."

Fran explained that one of the biggest challenges for her is how lonely and misunderstood it can feel to have the condition.

"The hardest thing can be keeping going when you feel like the world is against you. Everyone knows what it feels like to be dumped, fail an exam, get fired. Going through a cluster of 17 tonic-clonic seizures in two hours and wondering whether you're going to make it to the end of the day is a very lonely experience."



Fran takes four different medicines for her epilepsy

epilepsy experience

So how does she deal with the difficult times? She takes refuge in her family life, her hobbies and her work.

"I like to read, and garden, garden, garden. I try very hard to do things like knit, but I'm useless, Tim has to keep helping me. The whole family has cook-offs. We also have a tendency to do zany things like jumping in the car and driving nine hours to Cornwall for a night, or trekking across the Sahara with a seven- and a nine-year-old. We eat a lot! BBQs, ice cream – you name it! With two growing boys in the house, every minute revolves around the next snack. They also do their cycling and kayaking, but we go walking together. I got my wet suit last week in North Devon, ready to go body boarding in Cornwall this summer.

"My parents and siblings are also an amazing support network. One of my sisters lives five minutes away, my youngest brother lives less than 10 minutes away, my older sister is two miles in the car and my other brother is in LA in the US. My parents live in Suffolk.

"I didn't plan this for my life. You couldn't plan this! My main aim is to tell others: 'If I can do it, so can you. Trust me, I'm nothing special!'"

"I also love and get a lot of respite from writing and watching Miss Marple and Die Hard. Come on, if Bruce Willis can save everyone with no shoes on, who am I to complain?"



Gardening is one of Fran's relaxing pastimes

As well as helping her to relax, Fran's love of writing started from an early age and has spanned to her writing a book about her life called Fits and Starts.

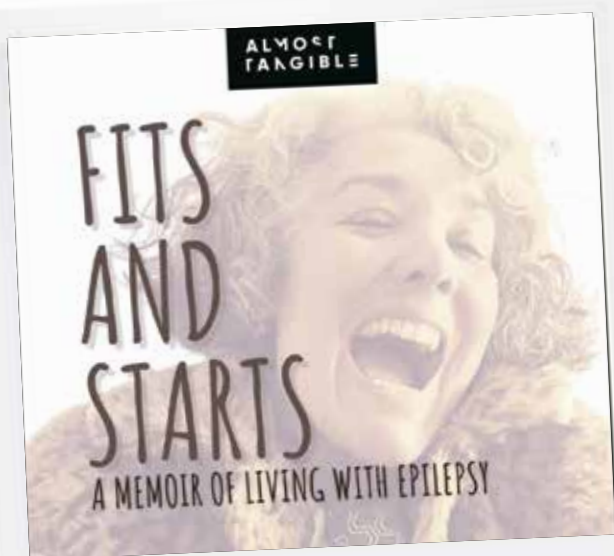
"I didn't know what I wanted to do as a child. The closest I came was wanting to be Mrs Fletcher in 'Murder, She Wrote'. I don't solve real life murders (I'm happy to say!) but my first thriller is going into submission later this year. Any writer will tell you the story just sits and grows until the words eventually spill out like Vesuvius. The trick is having a pen and paper to hand when the ideas come out.

"I decided to write my book about epilepsy because in the months after giving birth to Kurt, I couldn't find anything useful to help me. Everything I read was either too medical or completely superfluous. After three failed attempts to get started, I wrote 5,000 words and just shaped the book from there. Others will be horrified to hear there was no planning involved. Every time I tried to plan, I'd have a massive seizure and forget what I wanted to say, so I gave up on that idea.

"I didn't plan this for my life. You couldn't plan this! My main aim is to tell others: 'If I can do it, so can you. Trust me, I'm nothing special.' Raising awareness through the book and the audiobook is all about helping to get rid of the stigma attached to epilepsy. I want to make the condition less scary to others and let everyone know it's okay to be frustrated at times.

"Epilepsy can be exhausting, but despite this, my best advice to one and all is: don't lose your sense of humour. Laughing will get you through almost anything."

There is more information about Fran and her books and podcast at franziskathomas.com. Her book Fits & Starts is also now available as an audiobook.



Fran wrote a book about her epilepsy experiences

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 phenytoin.

Phenytoin

Phenytoin (PHT) was first used as an epilepsy medicine in the US in 1936. The way it works is similar to a number of other widely used epilepsy medicines, including carbamazepine and lamotrigine. Phenytoin is effective for both focal and generalised tonic-clonic seizures, but can make absences and myoclonic jerks worse. Because it lingers for some time in the bloodstream, doses are usually taken once or sometimes twice daily. Depending on the urgency of the situation, phenytoin can be started typically around 200-300mg once daily or in two divided doses in some adults, and 5-8mg for each kilo daily in



children. If there is no rush, however, the medicine can be introduced more slowly, at, say, 200mg daily. It can then be increased by 50mg amounts at 2-4 weekly intervals until seizure freedom is achieved or the person reaches a point where the side-effects are too much. The way phenytoin is broken down by the liver means that a small increase in a dose can produce a substantial rise in the levels of the medicine in the blood. It can, therefore, be important to monitor the levels in the blood to achieve the best effectiveness. The effective range of phenytoin is 10-20mg a litre. If it's not possible to monitor phenytoin blood levels, starting at a low dose and increasing slowly is advised.

Common side-effects with phenytoin typically happen 8-12 hours after a dose, and include double vision, tiredness, sleepiness, slurred speech and unsteadiness when walking. Unpleasant cosmetic problems, such as swollen gums, coarsening of the features, excess facial hair and severe acne can develop after some years of phenytoin treatment. Other, rarer complications include different types of skin rashes, liver damage and adverse effects in the bone marrow causing problems with the cells in the blood. Phenytoin use has been associated with an increased risk of birth abnormalities in babies exposed to the medicine during pregnancy, compared to the general population.

Another long-term complication associated with taking phenytoin is its potential to speed up the metabolism and lower the blood levels of a number of other medicines broken down by the liver. This includes contraceptives pills, blood thinners, antidepressants, corticosteroids (medicines that reduce inflammation), statins (drugs to lower cholesterol in the blood), immunosuppressants (medicines that stop the body from rejecting a transplanted organ) and anticancer drugs. It also includes, of course, other epilepsy medicines. A range of medicines can, themselves, interfere with phenytoin, increasing its level in the blood which can go to a level that's too high. This possibility should be checked out by the GP or pharmacist when any new medicine is introduced in a person receiving long-term phenytoin treatment. All these potential interactions, together with its many side-effects and the importance of measuring blood levels, means that phenytoin is rarely prescribed nowadays to treat newly diagnosed epilepsy in the UK. However, a number of older people have been taking it long-term and seeing a benefit. The fact that it is globally licensed to be given directly into the blood to treat status epilepticus has undoubtedly contributed to it still being around. It is a cheap and effective medicine, largely used in older people, most of whom have been taking it without problem for many years, usually at a low dose. Phenytoin certainly has withstood the test of time!



Professor
Martin
Brodie

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

Annual General Meeting

29 June 2021 ballot results

1. Summary of Response

	Number	Percentage
Electorate	8,562	100
Valid proxies returned	337	3.94
Invalid proxies returned	9	0.11
Total proxies returned	346	4.04
Members voting at AGM	1	0.01
Total response	347	4.05

3. Confirmation of election of Baroness Ford as President

Votes Yes to confirm	Percentage Yes to confirm	Votes No	Percentage No
325	97.31%	9	2.69%

2. Election of Members of the Council of Management

Candidate	Votes received	Percentage share	Outcome
Richard Chapman	241	11.73	Elected
Jayne Burton	230	11.20	Elected
June Massey	194	9.44	Elected
Sarah Lawson	162	7.89	Elected
Nicholas Hutton	157	7.64	Elected
Avril Coelho	139	6.77	Elected
Joanne Greer	137	6.67	Elected
Tim Melville	136	6.62	Not elected
Rebecca Longley	133	6.48	Not elected
Martin Brennan	121	5.89	Not elected
Gary Thomas	119	5.79	Not elected
Jim Berrington	116	5.65	Not elected
Pamela Threader	93	4.53	Not elected
Ben Sutcliffe	76	3.70	Not elected
Cara Hunter-Rowe	0	0.00	Withdrew

4. Result of resolution 1

Resolution 1	Number for	Percentage for	Number against	Percentage against
Amendment of Articles of Association	313	97.20%	9	2.80%

5. Result of resolution 2

Resolution 2	Number for	Percentage for	Number against	Percentage against
To re-appoint RSM UK Audit LLP as auditors	315	98.13%	6	1.87%

Council of Management 11 May and 13 July

At a meeting of the Council of Management held by remote video conference on 11 May 2021, the following decisions were made and actions taken.

- The Council approved the 2020 year end accounts and trustees' annual report. These will now be presented at

the AGM in June and will be available to members of the Association via the Epilepsy Action website. Printed copies are available on request

- Council confirmed the date of the AGM to be 29 June 2021
- Council approved a resolution to go to the AGM to propose amendments to the Association's Articles of Association. These amendments will allow proxies to be counted as part of the quorum of future AGM's
- Council resolved to close the register of members of the Association for the duration of the Council elections from 26 May to 29 June inclusive
- The Council committee annual reports and terms of reference

were reviewed and updated. All current committees will continue for another 12 months

- It was agreed that the Helping Hands Awards introduced in 2020 would be repeated in 2021 with a maximum of 10 awards
- Membership of the charity's various advisory panels was reviewed and refreshed. There were seven new appointments and three reappointments to the Women's advisory panel. There were six new appointments and twenty four reappointments to the Health and Clinical advisory panel. There were five reappointments to the Research advisory panel

The Council of Management met by remote video conference on 13 July. This was the first meeting of the Council after the Association's Annual General Meeting held on 29 June. Members were delighted to greet three new colleagues who were elected this year – Avril Coelho, Joanne Greer and Nicholas Hutton. Members were also pleased to see the return of Beryl Sharlot to a Council meeting after many months of absence due to poor health.

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

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

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

Council agreed to establish a new Council Working Practices Review Group to ensure that Council is operating as efficiently



as possible. This was charged to report back to Council with any recommendations by May 2022.

Annual reports were received from Council's diversity champion and its champion for research. Jayne Burton was appointed to be Council's diversity champion for the next 12 months. Peter Clough was appointed as Council's champion for research with assistance to be provided by Torie Robinson.

In other business, Council reviewed the charity's financial position and progress being made with this year's business plan. Updated terms of reference for all of the advisory panels were approved. Every quarter the Council looks at the top ten risks on the corporate risk register and selects one for more in depth analysis. On this occasion the new CRM database project was looked at. Members assured themselves that proportionate measures were in place to manage this risk.

The next meeting of the Council is scheduled to be held on 5 October 2021.

Epilepsy support for you

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

Join one of our virtual groups

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

If you previously went to a local support group, they may also be offering a chance to get together online. You can find out if this applies to the group you attended by emailing 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, or ablehere.com for people with disabilities and conditions. Bear in mind that these websites are not part of or run by Epilepsy Action.



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Belgium

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. Not approved in all geographies, consult your labeling. Individual results may vary.