EPILEPSY ACTION

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(Free to Epilepsy Action professional members)

epilepsy professional

Epilepsy in transgender patients
Toward more inclusive and informed care

Nucera | Pasini | Colonna

Missing link in epilepsy care – Michael S Petrides

Beyond seizure counts – Ammar Kheder

Hopes for the future – Kami Kountcheva

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1. Patient's Guide for Epilepsy 2021, LivaNova USA, Inc.
2. Ergene et al, 2000. Epilepsy & Behaviour, 2:284-287. Ryvlin et al, 2014. Epilepsia, 55(6):893-900

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LivaNova Epilepsy

Welcome to the Winter 2025 edition of Epilepsy Professional, an edition that celebrates the 75th anniversary of Epilepsy Action. As always, we have a host of articles to help us as epilepsy professionals to provide better care for our patients.

As Epilepsy Action (formerly The British Epilepsy Association) celebrates and reflects on its 75th year, the editor of Epilepsy Professional, Kami Kountcheva, reflects on the achievements of our organisation and looks forward to the next 75 years, reflecting the hopes of members of the organisation for all people living with epilepsy to have full lives, not limited by their epilepsy.

You need to do MORE for your patients and Dr Ammar Kheder tells us why. Seizure counts and seizure freedom remain important, but binary outcome measures in epilepsy clinics and research ignore other important facets of the patient's experience. The Multidimensional Outcome Reporting in Epilepsy (MORE) framework has been developed as an outcome measure to incorporate not only changes in seizures, but also quality of life and patient experience and is a potential future tool to more holistically monitor outcomes in our patients with epilepsy. Perhaps this could be a new way of measuring outcomes for our patients in busy clinics?
Managing the epilepsy in patients who are also transgender people brings particular challenges. These are summarised by Dr Bruna Nucera Dr Francesco Pasini and Dr Isabella Colonna from Italy. There are particular considerations needed when managing this particularly vulnerable population, including the potential effects of the hormonal treatments used on both their epilepsy and the potentials interactions with anti-seizure medications and vice versa. This is as well as the sensitivities needed to manage the psychosocial nuances of this community.

Last but not least, Michael S. Petrides from the University of Nicosia describes how community pharmacists can play an important role in epilepsy management. Particularly, in helping to distinguish intentional from non-intentional non-adherence to medication and in helping patients to come to strategies to improve adherence and have better control of their epilepsy. A potential further resource for patients, particularly as so many NHS services are struggling to meet the need of our populations in the current difficult financial climate.

I hope you enjoy this edition of Epilepsy Professional.

Seán Slaght
Consultant neurologist
Executive medical adviser
Epilepsy Professional

contents

Epilepsy Action is 75 years old! It's hard to know if that feels like a grain of sand in the hourglass or an entire eternity. Looking back to where it all began, it feels like both at all once...

In September 1950, when the British Epilepsy Association (now known as Epilepsy Action) was first set up, the NHS was only two years old. People with epilepsy were sent to live in communes or asylums. Phenytoin and phenobarbital were the most common treatment choices. Epilepsy Action's role was then – and continues to be now – to improve the lives of people living with epilepsy. And things have advanced hugely since then – in medicine, technology, research and society. But there's always further to go.

Fittingly, this issue's articles really demonstrate a continuing effort towards improving the status quo, embracing holistic care and supporting and understanding each patient as an individual.

On page 10, Dr Michael S Petrides discusses reasons why people may not take their medications as prescribed, and suggests that pharmacists could help bridge that gap. Dr Nucera, Dr Pasini and Dr Colonna share what optimal care might look like for transgender people with epilepsy on page 16 and Dr Kheder shares a new framework for understanding the success of healthcare, which includes seizure frequency, but also gives weight to quality of life and lived experience for people (page 22). And you can read more about our 75th anniversary on page 28.

We hope a look back in time helps you feel proud of how far we've all come, and optimistic about the future, encouraged to bravely push the limits even further.

Kami Kountcheva
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Valproate has "minimal" effect on male fertility, international study says

Sodium valproate has a "minimal" effect on male fertility, according to large-scale, international research by the University of Liverpool and funded by the Epilepsy Research Institute UK, published in Nature Communications.

The Medicines and Healthcare Regulatory Agency (MHRA) last year released a guideline advising men taking sodium valproate and any female partners to use contraception to prevent unplanned pregnancies.

The MHRA warned of a "potential small increased risk" of neurodevelopmental disorders in children born to fathers taking the medication.

Earlier this year, the MHRA confirmed that any new prescriptions of valproate for men under the age of 55 will need to be independently signed off by two specialists. This doesn't affect men currently prescribed valproate or men over the age of 55.

The new research covered 19 countries and more than 200 healthcare organisations. It compared almost 92,000 men with epilepsy or bipolar disorder who had taken sodium valproate with 536,000 men with the same conditions who had not taken the medication.

They found that differences in infertility diagnoses, sperm counts and testicular atrophy (shrinkage of the testicles) were less than 1% between the two groups. Hormone levels in men taking valproate were also found to be within normal ranges.

Dr Gashirai Mbizvo, NIHR academic clinical lecturer and deputy director for Epilepsy Research at the Liverpool Interdisciplinary Neuroscience Centre, who carried out the research, said: "In the largest study of its kind, we found little evidence that valproate impairs male fertility over and above the epilepsy or bipolar disorder themselves or other antiseizure medications – all of which can impair male fertility.

"These results are significant because fear of fertility side effects specifically attributed to valproate can lead men to discontinue the medication, risking uncontrolled seizures, mental health deterioration, hospitalisation, or death in extreme cases.

"It is important to consider the wider picture of what else may be causing infertility. For example, epilepsy, in and of itself, can affect fertility rates, which are two-thirds lower in men with epilepsy than without."

Alison Fuller, director of health improvement and influencing at Epilepsy Action, said: "Many men have expressed their concerns about the impact of sodium valproate on their fertility, and our helpline team receives inquiries relating to this issue.

"We hope that this study provides reassurance for men prescribed this medication, but we know that current MHRA guidance still means that doctors are required to warn patients about the risks of potential infertility.

"This is concerning, as incorrectly telling male patients that they may not be able to have children could prompt them to stop taking their medication, which puts them in danger.

"Epilepsy Action has been consistently raising this issue with the MHRA and asking them to reconsider the published regulations. Given this new study, it is time for them to revisit the evidence and give it consideration."

The researchers advise that more research is now needed to build on this study which looked at diagnoses, hormone levels and semen parameters to establish fertility levels. They said it should focus on whether men taking sodium valproate are successfully able to have children.

The study authors say they hope the evidence will help inform future clinical guidance.

The rules around prescribing sodium valproate in women are already much stricter.

Women under the age of 55 should only be prescribed sodium valproate if two specialists agree that there are no other effective treatments for them. They also must be on the Pregnancy Prevention Programme if they are able to become pregnant.

This is because sodium valproate has been known to increase the risk of birth defects (1 in 10 babies) and developmental disorders (4 in 10 babies) if taken during pregnancy.

There is more information on the risks and rules around sodium valproate in men, women and transgender and nonbinary people on the Epilepsy Action website.

No one should stop taking their medication without speaking to their doctor first, as this could result in more or worse seizures.

"Fit and healthy" footballer died of SUDEP – inquest

An inquest has ruled that 27-year-old footballer Emily Wilcock died of sudden unexpected death in epilepsy (SUDEP) just days after stopping her medication.

Emily, from Radcliffe, died in the bath on 21 August, 2023, but the inquest ruled that there was "no solid evidence of drowning".

The Bury Football Club Greens player was diagnosed with epilepsy in 2016 and was taking what was called a 'minimal dose' of lamotrigine.

She had spoken to her doctor about coming off the medication, as she had been seven years seizure free and she and James wanted to start a family. Her doctor advised that her medication dose was so low that she could just stop taking it, instead of weaning off. She died days after stopping her medication.

According to Dr Nazar Shafar, a consultant neurologist who looked after Emily until 2021, she had been seizure free on a very small dose of lamotrigine. However, her mum Jayne said that Emily still had blackouts and fainting, which Emily's GP had said were fainting and not seizures.

Epilepsy Action NI welcomes Regional Review of neurology services

Epilepsy Action Northern Ireland has welcomed the Regional Review of Neurology Services in Northern Ireland, urging the Department of Health to take urgent action to address the serious challenges facing people with epilepsy.

The review's recommendations will shape neurology services through to 2035, and Epilepsy Action's own evidence has fed into the consultation via the Northern Ireland Neurological Charities Alliance (NINCA).

Following its publication, Epilepsy Action Northern Ireland endorsed NINCA's response and highlighted the need for clear commitments on:

- How new services will be funded and sustainably resourced.
- Timelines for recruiting and training the specialist staff required.
- The development of a detailed and urgently needed epilepsy care pathway.

Epilepsy is the most prevalent neurological condition in Northern Ireland – with the highest prevalence across both the UK and Republic of Ireland – affecting around 22,000 people locally. Yet, people with epilepsy face some of the biggest disparities in specialist nurse provision, with just 14.1 whole-time equivalent Epilepsy Specialist Nurses (ESNs) compared to the 34.2 needed to meet population demand.

Epilepsy Action welcomed several recommendations in the review in particular, including:

- The creation of specialist epilepsy clinics in every Health and Social Care Trust. At present, a postcode lottery means that patients in the Northern Trust area have no access at all to such clinics.
- The trial of patient-initiated follow-ups to give patients more control over their care.
- Investment in neuropsychology services to provide vital mental health support.
- Increased capacity in neuroscience beds.
- Investment in neuropharmacy to address the complexity of epilepsy medicines – including safe prescribing and monitoring of sodium valproate.
- Additional GP training to improve epilepsy management in the community, alongside the funding and support required to make this sustainable.

Carla Smyth, Manager at Epilepsy Action Northern Ireland, said:

"Epilepsy is one of the most common and serious neurological conditions, but people here continue to experience delayed diagnosis, patchy services, and avoidable health risks. The postcode lottery in epilepsy care must end.

"We particularly welcome proposals for specialist epilepsy clinics in each Trust, more epilepsy nurses, better access to mental health and pharmacy expertise, and extra GP training. But these must be matched with clear, funded plans and timelines.

"People with epilepsy need timely access to diagnosis, treatment, emergency medication, and ongoing support – no matter where they live. The Department of Health must now turn these recommendations into urgent action."

MHRA report shows falling sodium valproate prescriptions since April 2018

Prescriptions of sodium valproate in England are continuing to drop since April 2018 in all patients, according to new information from the Medicines and Healthcare products Regulatory Agency (MHRA) published in September.

According to the new report, the overall proportion of women and girls prescribed sodium valproate fell by 56% between January-March 2018 and April-June 2024. New prescriptions in those aged 16-44 years old fell by 77%.

Just under a third (29%) of women and girls in that age group, who were prescribed valproate for epilepsy before May 2018, switched to lamotrigine or levetiracetam without then switching back to valproate.

This fall reflects the changing guidelines from the MHRA since 2018 in the prescription of sodium valproate in women, as it is known to cause risks to unborn babies if taken during pregnancy.

During the same timeframe, the overall proportion of males prescribed sodium valproate fell by 14%. However, new prescriptions in males aged 16-44 fell by 78%, with a lot of this (63% drop in new prescriptions) happening after the introduction of new safety measures in November 2023.

These safety measures advised that men, as well as women, under the age of 55 would need two specialists to independently agree that sodium valproate is the only medication that would work for the person, in order to have it newly prescribed. Women would also need to be part of a pregnancy prevention programme and sign an annual risk assessment form.

Men already taking the medication could continue to take it.

These guidelines followed findings suggesting sodium valproate could affect fertility in men. However, a recent, large, international study has thrown this into question, finding that sodium valproate has a 'minimal' effect on male fertility, and urging for more research on this.

The new report also found that around one in five men (19%) aged 16-44 taking sodium valproate for epilepsy before February 2024 switched to either lamotrigine or levetiracetam without switching back.

Alison Fuller, director of Health Improvement and Influencing at Epilepsy Action, said: "While we welcome this report highlighting the decrease in the number of valproate prescriptions for both men and women, concerns remain about the impact of restricting access to what for many people remains an effective medication.

"We note that the report does not provide information about the outcomes of the men and women who have moved from valproate onto a different medication. It is vitally important that the impact of the withdrawal of valproate is monitored, and that it remains available for those people for who it is the only medication that works to control their seizures.

"People with epilepsy must be at the heart of these decisions, with access to clear information and support. We also urge the MHRA to ensure that monitoring goes beyond prescription rates to include outcomes for patients, so that no one is left without effective treatment."

The MHRA used Clinical Practice Research Datalink (CPRD) to access prescription data and carry out the evaluation. It said this is representative of the UK general population, but other data sources are available for monitoring sodium valproate prescribing too, such as prescribing in pregnancy.

The MHRA will continue to monitor prescriptions, publishing updates every six months.

Trial investigating long-term VNS effectiveness launches

A new project, led by the University of Liverpool will look into the long-term effectiveness of vagus nerve stimulation (VNS)

The seven-year trial, which started in June and will run until May 2032, is called the Vagus Nerve Stimulation for epilepsy in children and adults: Assessment of Longer term clinical and cost Effectiveness in a Randomised controlled Trial (VNS-ALERT).

Led by professor of neurology Tony Marson, the trial will recruit 300 people aged five and above from UK epilepsy surgery centres.

The research will investigate seizure freedom as a marker for VNS success, as well as seizure severity, side effects and death. It will also evaluate the cost effectiveness of VNS and its effect on quality of life.

The research will also include children and adults with intellectual disabilities – a group Prof Marson says is "historically underrepresented in epilepsy research".

The £2.9m project has been funded by the National Institute for Health and Care Research (NIHR) and supported by the Epilepsy Research Institute's Shape Network. The Shape Network ran surveys and workshops to aid the project and influenced the way it will work, allowing all participants to receive a VNS device.

Link between gabapentin and dementia – study

A new study from the journal Regional Anaesthesia & Pain Medicine has revealed a link between the medication gabapentin and the risk of dementia and reduced learning and thinking skills (cognitive decline).

Gabapentin can be prescribed for epilepsy and nerve pain in the UK.

The study investigated the use of gabapentin in 26,416 people with chronic back pain in the US between 2004 and 2024.

The researchers, Nafis Eghrari and colleagues, found that there was a higher rate of dementia in people with six or more prescriptions of gabapentin. This group also had a higher rate of problems with thinking skills (mild cognitive impairment).

In adults aged 18-64, the risk of dementia doubled. The risk also increased with more prescriptions of gabapentin.

The researchers acknowledge that since their study is observational and retrospective, they can't confirm cause and effect and they couldn't account for some variables, like dose or length of use. However, they suggest that doctors should monitor learning and thinking skills in people taking gabapentin.

Clobazam (Frisium) stock

Pharmanovia, the manufacturer of Frisium, has told us that Frisium 10mg is out of stock, with an expected return date of the end of December 2025.

You can find more updates on this medication at: ***epilepsy.org.uk/news/clobazam-frisium-stock***

Accord topiramate stock

Accord has told Epilepsy Action that Accord topiramate 25mg and 50mg are back in stock, after confirming they would be out of stock for at least six months back in March.

Accord's 100mg and 200mg tablets remain long term out of stock, with no current return date.

The information will be updated as we find out more, at: ***epilepsy.org.uk/news/accord-topiramate-stock***

Stock of Accord levetiracetam

Accord has informed Epilepsy Action that there is an expected resupply date for Accord levetiracetam 250mg, 500mg and 750mg tablets of October 2025.

Check ***epilepsy.org.uk/news*** for more updates on medication supplies from Epilepsy Action.

Missing link in epilepsy care

How community pharmacists boost medication adherence and quality of life

Associate Lecturer in the Pharmacy Programme at the University of Nicosia, specialising in Pharmacoepidemiology, Michael S Petrides discusses the crucial role of pharmacists in supporting medication adherence among epilepsy patients, a key factor in improving patient outcomes.

Anti-seizure medicines (ASMs) work only when taken as prescribed. Community pharmacists – highly accessible, trusted and medication-focused health professionals – are uniquely placed to close the 'last-mile' gap in epilepsy management through practical adherence support, counselling and personalised care. New evidence and a recent systematic review highlight what works, where the gaps are, and how teams can integrate pharmacy into routine epilepsy pathways.

Why pharmacists matter now more than ever

Many people with epilepsy can achieve seizure control with the right medicine, dose and support, but adherence is essential. Pharmacists see people more often than most clinicians and can spot early signs of non-adherence, adverse effects, and life-stage changes (pregnancy, job changes, caregiving stress) that drive day-to-day behaviour. As UK practice evolves, pharmacists also help translate safety updates into action – for example, counselling around pregnancy prevention requirements for topiramate and ensuring consistent, documented conversations with women of child-bearing potential.

Pharmacists see people more often than most clinicians and can spot early signs of non-adherence, adverse effects and life-stage changes

What the evidence shows

The big picture: a systematic review

A recent systematic review [Petrides et al, 2025] examined community and outpatient pharmacist-led interventions in epilepsy from 1995 to 2023, identifying only five studies from the US, the Netherlands, and Palestine that met the inclusion criteria:

1. they referred to any epilepsy intervention/service, which involved pharmacists within a community setting or an outpatient clinic
2. they included adult epileptic patients only, and
3. full-text articles were available in English.

Interventions covered medication adherence, quality of life (QoL), and service models integrating pharmacists into epilepsy care.

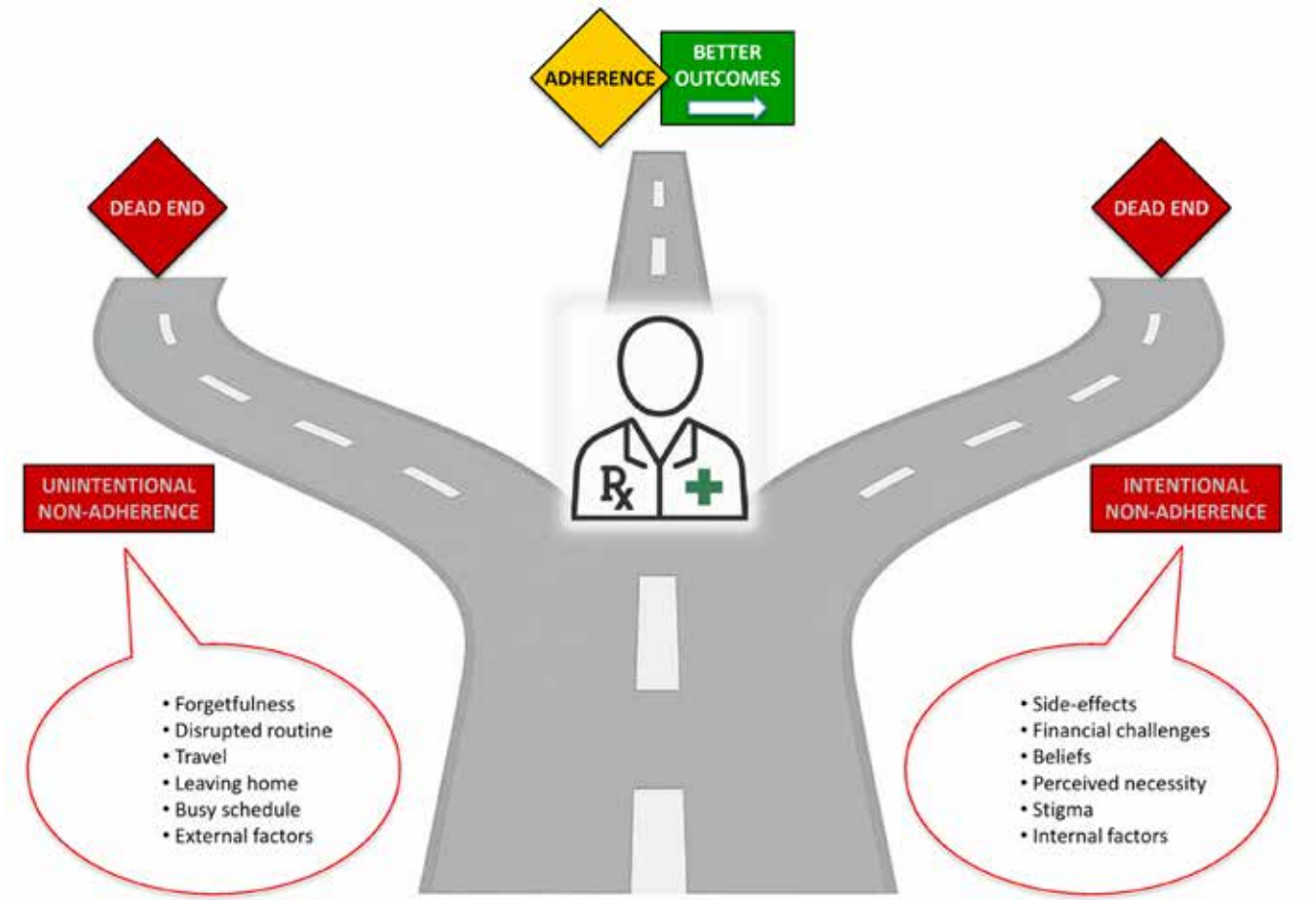


Figure 1. ***Adherence pathways:*** *Intentional and unintentional non-adherence lead to therapeutic dead ends. By identifying barriers, pharmacists can guide patients towards conscious adherence through personalised strategies (e.g. reminders, simplified dosing, pill organisers, education), enabling them to follow prescribed therapy and achieve better outcomes. Copyright 2025 Michael S Petrides.*

The take-home message: pharmacists have the potential to positively influence adherence and QoL, but robust effectiveness and cost-effectiveness data remain limited and uneven, highlighting the need for larger, well-designed trials and service evaluations.

Pharmacist-led intervention

A cross-sectional pilot study in the Republic of Cyprus linked adherence directly with QoL in patients with epilepsy (PWE). High adherence was common. Importantly, "mixed" non-adherence (i.e. both intentional and unintentional) was associated with poorer QoL. Logistic models showed better QoL among those with high/medium adherence. Readiness to change was high as well, suggesting many PWE are primed for behaviour-supporting interventions – an opening tailor-made for pharmacy.

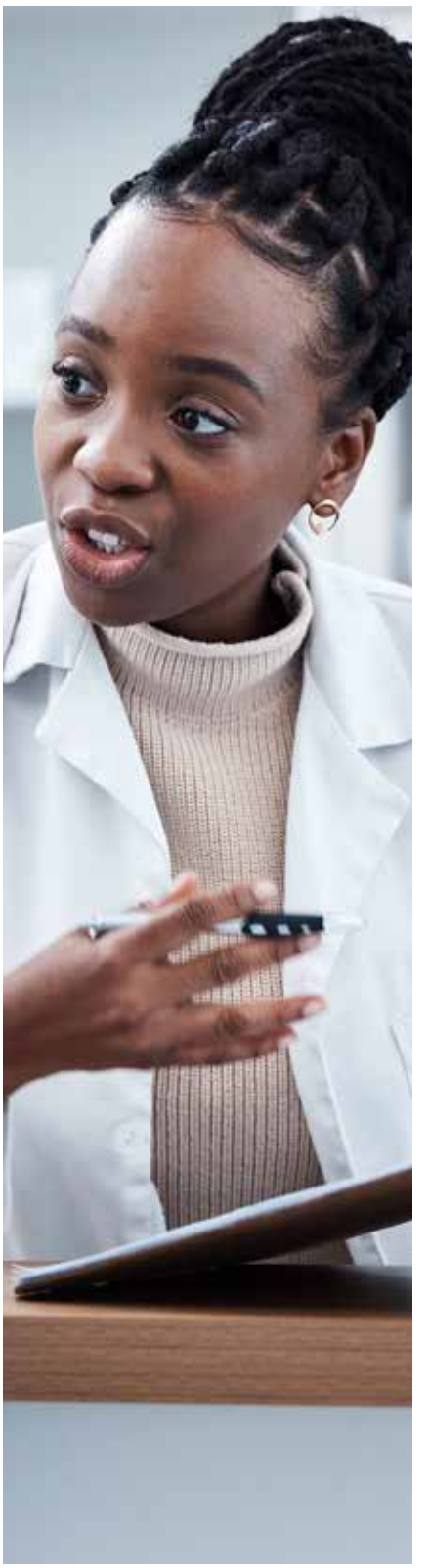
What's the novelty in this context? Beyond single 'adherent/

non-adherent' labels, the study sub-classified non-adherence into intentional (e.g. dose-altering due to side effects, beliefs) and unintentional (e.g. forgetfulness, routine disruption). These are actionable profiles pharmacists can address with distinct counselling strategies, reminders, regimen simplification, and troubleshooting of adverse effects or beliefs.

From evidence to everyday practice: what community pharmacists can do

Pharmacist-led actions for key adherence factors in epilepsy are listed below. Each action is feasible in high street settings and designed to align with neurology care plans.

1. Make adherence visible – and specific
   - Screen briefly, but meaningfully. Use a 1-2 minute, non-judgemental check that distinguishes intentional (e.g. "I cut doses because…") from unintentional (e.g. "I forget on busy mornings") behaviours. Align language with validated adherence assessment questions so patterns are comparable over time. Pharmacists must be trained and have appropriate permission to use any adherence assessment tool accurately and interpret its results.
   - Normalise fluctuation. Explain that routines and symptoms change and that 'mixed' patterns are common; you're there to help stabilise routines and expectations.
2. Turn 'ready to change' into micro-plans
   - Leverage high readiness. Many PWE are motivated if given practical steps – e.g. one cue-based reminder, one simplification, one follow-up. Book a brief adherence review in 2-4 weeks to reinforce momentum.
   - Co-design the next best action. For unintentional lapses, anchor doses to existing habits (e.g. tooth-brushing, breakfast). For intentional lapses, validate concerns and liaise with the prescriber about side effect management or alternative formulations.
3. Optimise the regimen the person actually lives with
   - Routine-proof the plan. Identify shiftwork, travel, caregiving, or sleep-apnoea treatments that disrupt timing. Offer blister packs, calendar packs, or digital prompts; discuss backup strategies for missed doses per Summary of Product Characteristics (SPC)/ prescriber advice.
   - Watch for polytherapy friction. Polytherapy increases cognitive load and adverse-effect risk – two powerful drivers of intentional non-adherence. Raise discrepancies, interactions and intolerances with the prescriber early.
4. Communicate safety clearly, especially in women's health
   - Pregnancy prevention and counselling. Where relevant, cover Pregnancy Prevention Programmes (PPP), risk awareness forms, and safe contraception options for enzyme-inducing ASMs in line with current guidance. Document the conversation and refer promptly for review if pregnancy is planned or suspected; never advise abrupt cessation.
5. Address QoL head-on
   - Connect symptoms to life impact. Use simple questions mapped to the 10-item Quality of Life in Epilepsy Inventory (QOLIE-10) components (i.e. seizure worry, overall QoL, emotional wellbeing, energy, cognition, physical effect, mental



effect, work, driving, social function). People often accept trade-offs they don't realise are modifiable. Track a single composite QoL score over time to show progress. Pharmacists must be trained and have appropriate permission to use any QoL assessment tool accurately and interpret its results.

- Employment and roles. Employment correlated with better QoL in the Cyprus cohort; explore how medicine timing, adverse effects, and seizure worry affect work or caregiving – and feed these insights back to the clinical team.

A practical three-part intervention model for UK community pharmacy

1. **Identify (2–3 minutes at the counter or consultation area)**
   - Brief adherence screen (intentional vs unintentional)
   - Red flags: worsening seizure control, side effects, pregnancy plans, recent hospital/emergency department (ED) visit, regimen changes, topiramate prescribing in women of child-bearing potential without clear PPP documentation.
2. **Intervene (8–12 minutes, same visit)**
   - One tailored adherence tactic (cue-linking, pack type, SMS reminder)
   - One side effect troubleshooting step (timing with food, morning vs evening dosing)
   - One QoL goal (e.g. "less brain fog before work") and how today's plan supports it
3. **Integrate (follow-up + team communication)**
   - Book a check-in in 2-4 weeks; repeat brief screen and QoL prompt
   - Share concise notes with the GP/neurology team: adherence pattern, side effects, requested adjustments (e.g. simplified regimen, alternative ASM).

Importantly, "mixed" non-adherence (i.e. both intentional and unintentional) was associated with poorer quality of life

Metrics that matter (and are realistic in community settings)

- Patient self-reported: change in the adherence score and single-item QoL anchor (0–10) across 4-12 weeks.

Common scenarios and pharmacy responses

- **"I feel drowsy and skip my lunchtime dose at work."** Explore timing changes, food effects, or formulation alternatives;

Quick wins for pharmacists (counter-ready tips)

- Ask a question that captures intentional vs unintentional non-adherence.
- Anchor doses to daily routines (e.g. brushing teeth, meals).
- Offer tailored packs or reminders for shift workers and travellers.
- Counsel proactively about pregnancy prevention and safety updates.
- Track one simple QoL measure (0–10 scale) at each encounter.

align with prescriber. Offer a low-friction reminder that doesn't 'out' the condition at work (e.g. silent phone prompt).

- **"I'm planning a pregnancy."** Provide immediate safety counselling; ensure PPP compliance where relevant (e.g. topiramate), document, and arrange urgent clinical review. Reassure: do not stop ASMs abruptly.
- **"I travel for shiftwork and keep forgetting."** Switch to calendar packs, build cues into shift-start routines, discuss time-zone strategies and what to do if a dose is late. Schedule a follow-up after the first travel week.
- **"My mood is low and I'm thinking what's the point."** Acknowledge impact; screen gently; signpost to epilepsy specialist nurses/GP for mental health support; share concise notes with the team. Tie adherence to tangible QoL goals the person values.

Future directions for the field

The systematic review underscores promise but also fragmentation. Future work should:

1. evaluate multi-component pharmacy services with patient-relevant outcomes and costs,
2. routinely classify non-adherence into intentional vs unintentional to guide tailored support, and
3. embed simple QoL tracking into pharmacy reviews to keep "what matters" central

The Cyprus pilot offers a practical example: brief pharmacist-led assessments, actionable adherence sub-typing (intentional vs unintentional non-adherence types), and QoL linkage – showing that even small, structured touches can align behaviour change with outcomes that matter to people.

Epilepsy medicines and women's health: pharmacist checklist

- Check if the patient is of child-bearing potential.
- Ask about pregnancy plans or contraception.
- Provide counselling on pregnancy prevention programmes (PPP) when indicated.
- Document the discussion and refer to the prescriber if pregnancy is planned or suspected.

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Michael S Petrides also serves as Chief Pharmacy Officer on the Adherence Cartography Advisory Board at Adherence.cc, where he oversees strategic initiatives to improve medication adherence through innovative behavioural stability and fragility mapping – a process that tracks and analyses patient behaviour patterns to support consistent medication use – and to understand and predict where adherence risks are headed, not just detect them.

Further reading

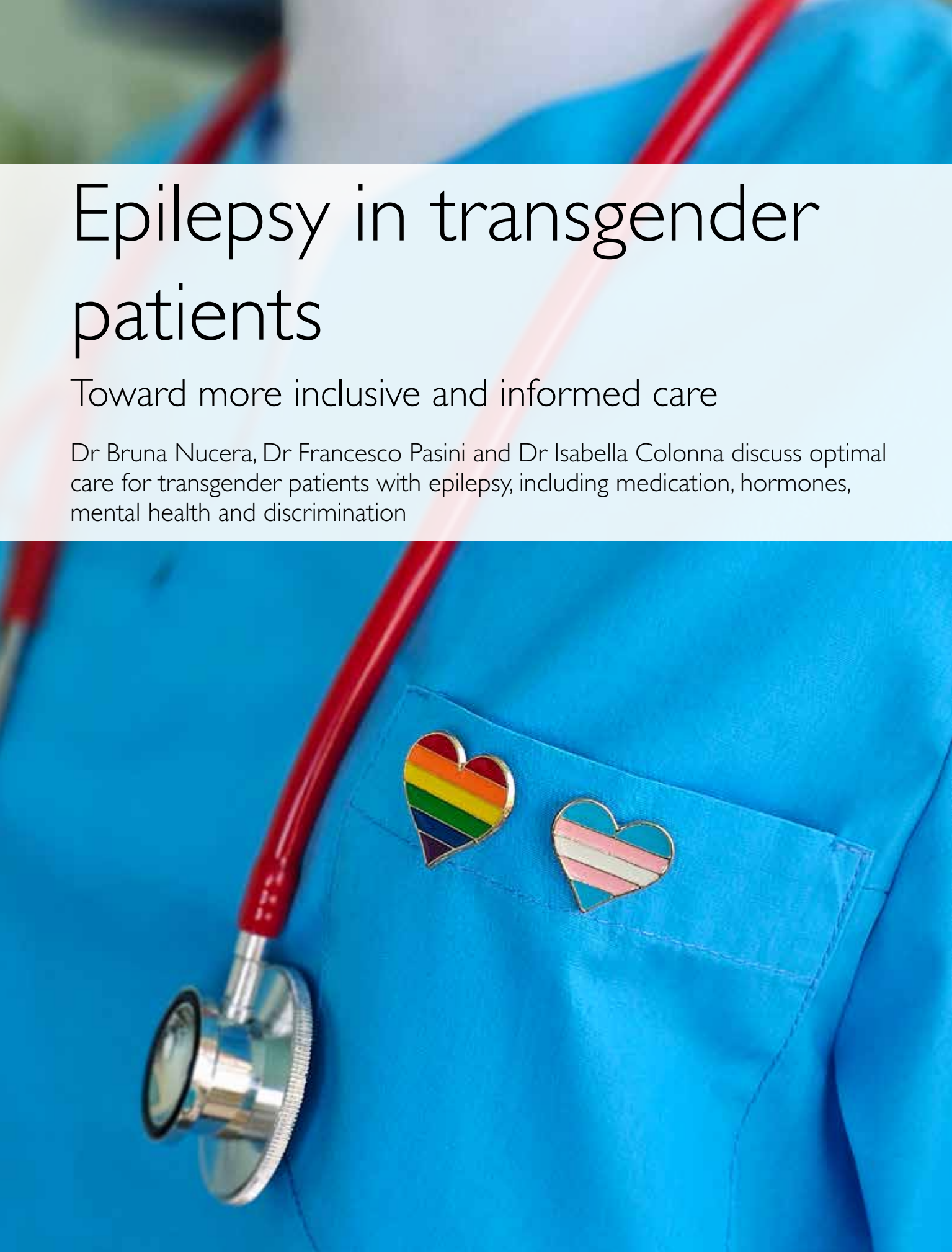
Petrides M, Peletidi A, Nena E, Constantinidis T & Kontogiorgis C (2025) The role of pharmacists in enhancing epilepsy care: a systematic review of community and outpatient interventions. Journal of Pharmaceutical Policy and Practice, 18(1): 2487046.

Petrides M, Peletidi A, Polyzois S, Nena E, Constantinidis T & Kontogiorgis C (2025) Pharmacist-Assessed Medication Adherence and Quality of Life in Patients with Epilepsy. Journal of Pharmaceutical Policy and Practice, 18(1): 2557872.

Epilepsy in transgender patients

Toward more inclusive and informed care

Dr Bruna Nucera, Dr Francesco Pasini and Dr Isabella Colonna discuss optimal care for transgender patients with epilepsy, including medication, hormones, mental health and discrimination



For many years, discussions about epilepsy have often overlooked the unique needs of specific patient populations. However, as our understanding of healthcare expands, it is vital to recognise the diverse experiences within our community. One such group, transgender individuals living with epilepsy, faces significant and often complex challenges that demand careful consideration from both patients and healthcare professionals.

Transgender people are individuals whose internal sense of gender – whether they identify as a man, a woman, both, neither, or something else – differs from the biological sex they were assigned at birth [Winter et al, 2016].

While the global transgender population is estimated to be around 25 million individuals, current estimates suggest that between 150,000 and 450,000 transgender people worldwide may be living with epilepsy [Reisner et al, 2016; Johnson et al, 2017]. Despite this significant number, research specifically focused on this community remains notably scarce [Joseph et al, 2017]. In this sense, transgender individuals living with epilepsy are a unique and vulnerable population who face significant social stigma and numerous challenges in accessing and receiving appropriate healthcare [Winter et al, 2016; Reisner et al, 2016].

One of the most intricate aspects of treating epilepsy in transgender patients relates to the interplay between antiseizure medications and gender-affirming hormone therapy. Many transgender individuals choose to undergo gender-affirming hormone to align their external sex characteristics with their identified gender [Johnson et al, 2017; Waldman et al, 2022]. This typically involves either supplementing oestrogen and blocking androgens (for transfeminine individuals, assigned male at birth, transitioning to female) or administering testosterone (for transmasculine individuals, assigned female at birth, transitioning to male) [Hembree et al, 2009]. The crucial point for epilepsy management is that there are significant bidirectional interactions between gender-affirming hormone and antiseizure medications. While life-affirming for many patients, gender-affirming hormones can introduce pharmacological interactions that could complicate seizure control—and vice versa [Johnson et al, 2017; Waldman et al, 2022].

Transgender individuals living with eplepsy are a unique and vulnerable population who face significant social stigma and numerous challenges in accessing and receiving appropriate healthcare

Many antiseizure medications, especially older ones like carbamazepine or phenytoin, are enzyme-inducing. This means they ramp up the liver's metabolism of other drugs, including hormones [Reimers et al, 2015; Isojarvi et al, 1995]. A transfeminine patient taking oestrogen, for example, may find her hormone levels insufficient if she takes also an enzyme-inducing antiseizure medication [Johnson et al, 2017].

However, some non-enzyme-inducing antiseizure medications can still affect hormone levels. For example, valproate can increase serum androstenedione, which leads to

increased testosterone production [Isojarvi et al, 1995; Waldman et al, 2022]. While this might be a desirable effect for a transmasculine person, it could be undesirable for a transfeminine person [Waldman et al, 2022]. Levetiracetam has also been observed to increase testosterone levels in some individuals [Harden et al, 2010].

This can affect both the clinical goals of gender-affirming hormone therapy and the patient's mental health.

But the reverse is also true: hormones can influence the metabolism of antiseizure medications. Oestrogen has been shown to accelerate the breakdown of lamotrigine, one of the most prescribed antiseizure medications [Reimers et al, 2017; Sabers et al, 2001]. If doses aren't carefully adjusted, this can lead to subtherapeutic drug levels and breakthrough seizures [Reimers et al, 2017; Sabers et al, 2001].

Oestrogen is generally considered to have proconvulsant properties, meaning it can make seizures more likely or more severe [Logothetis et al, 1959; Scharfman & Mac Lusky 2006; Tauboll et al, 2021]. When transfeminine individuals begin oestrogen treatment, there is a possibility of increased seizure activity, potentially requiring medication adjustments [Johnson et al, 2017].

The effect of testosterone and androgens on seizures is more mixed. While some testosterone metabolites have anticonvulsant (seizure-reducing) properties, testosterone is also metabolised to oestradiol, which is proconvulsant [Waldman et al 2022]. However, transmasculine individuals who previously experienced seizures linked to their menstrual cycle (catamenial epilepsy) may see an improvement in seizure control with the cessation of menstruation due to testosterone therapy [Johnson et al, 2017]. Natural progesterone is generally anticonvulsant [Baulieu et al, 2000; Scharfman & Mac Lusky 2006; Tauboll et al, 2021]. However, the synthetic medroxyprogesterone commonly used in gender-affirming hormone therapy may not offer the same protection [Johnson et al, 2017]. Gonadotropin-releasing hormone analogs, used to suppress puberty in adolescents, have also been observed to decrease seizure frequency in women with catamenial epilepsy, possibly by suppressing ovulation [Bauer et al, 1992; Waldman et al, 2022].

It is paramount that healthcare providers, particularly epileptologists, are knowledgeable about the medical regimens used for gender-affirming treatment

These interactions aren't just theoretical—they can have real, sometimes dangerous, consequences if not anticipated and monitored.

Given these complex interactions, it is paramount that healthcare providers, particularly epileptologists, are knowledgeable about the medical regimens used for gender-affirming treatment [Nucera et al, 2025].

Beyond drug interactions and disclosure, epilepsy care in transgender patients extends far beyond just managing medication interactions. This population faces significant comorbidities and social hurdles that greatly impact their overall health and wellbeing [Johnson

et al, 2017]. Mental health conditions, including depression and anxiety, are common in both epilepsy and transgender populations—and even more prevalent when the two intersect [Johnson et al, 2017]. Estimates of depression in transgender persons range from 31% to 64%, significantly higher than in the general population [Reisner et al, 2016]. A national Australian study found that 56% of transgender individuals had been diagnosed with depression (four times higher than the general population), and 38% with anxiety [Winter et al, 2016].

The suicide risk among transgender individuals is deeply concerning. A US survey reported that 41% of transgender respondents had attempted suicide—a number that should galvanise all of us in healthcare [Winter et al, 2016]. Gender-affirming hormone therapy can have a positive effect on mental health, resulting in less depression than in the individuals not receiving it [Witcomb et al, 2018]. Epileptologists must carefully screen and evaluate patients for depression and anxiety [Johnson et al, 2017].

Bone health is another issue that deserves attention. Certain antiseizure medications, like phenytoin and carbamazepine, are known to reduce bone mineral density [Pack et al, 2008]. So can long-term gender-affirming hormone treatment (?), particularly in patients who have undergone gonadectomy (surgical removal of ovaries or testes) without consistent hormonal replacement [Stevenson et al, 2019]. Together, these factors place transgender individuals with epilepsy—particularly transgender women—at increased risk of osteoporosis and fractures [Waldman et al, 2022]. Regular bone density screening and vitamin D supplementation should be part of routine care when indicated [Stevenson et al, 2019; Waldman et al, 2022].

Then there is the issue of HIV risk. The prevalence of HIV is significantly higher in transgender individuals, particularly transgender women (prevalence reported as high as 12–16% overall, and up to 56.3% in African American transgender women) compared to the general population [Poteat et al, 2014; Herbst et al, 2008]. However, data on transgender individuals with both HIV and epilepsy are limited [Waldman et al, 2022]. Importantly, bidirectional interactions between antiretroviral medications and antiseizure medications are common [Volpe et al, 2024]. Antiretroviral therapies can interact with antiseizure medications, leading to reduced effectiveness or toxicity [Birbeck et al, 2012; Siddiqi et al, 2013; Cattaneo et al, 2020]. Navigating these regimens safely requires up-to-date pharmacology knowledge and often consultation with infectious disease specialists. Yet many neurologists receive little or no routine training in managing HIV-positive patients, let alone those who are also undergoing gender-affirming hormone therapy.

Furthermore, any transgender individuals face stigma and discrimination within healthcare settings [Johnson et al, 2017]. Limited data indicates that 70% of transgender individuals in the US have reported discrimination, and a striking 73% hesitate to disclose their identity due to fear of bias [Rosendale et al, 2015]. This fear can lead to significant harm, as patients might not receive the full, appropriate care they need if they do not feel safe to be open about who they are [Johnson et al, 2017]. This can also increase risks for additional health issues [Nucera et al, 2025].

Unfortunately, the healthcare system as a whole, including neurology, has been slow to adequately prepare

for the specific needs of transgender patients. A survey of Italian neurologists, for instance, revealed that while many recognised sexual and gender orientation as key health determinants, only a few neurologists acknowledged the higher prevalence of health issues in sexual and gender minority populations [Nicoletti et al, 2024]. Moreover, a significant number of neurologists still believe the mistaken assumption that equitable, high-quality medicine means treating everyone the same, rather than pursuing personalised care based on each patient's unique characteristics [Nucera et al, 2025]. However, the vast majority of neurologists expressed a need for more comprehensive training and supervision in treating those patients [Nicoletti et al, 2024; Nucera et al, 2025].

Given all these factors, what can clinicians do right now to improve care for transgender patients with epilepsy?
This is the question that came to mind spontaneously and which led to our publication entitled 'Epilepsy Management in Transgender Population: More Research for Better Treatment' in European Journal of Neurology [2025].

The answer we gave ourselves is the following. Managing epilepsy for transgender individuals presents unique, yet often overlooked, challenges related to hormonal interactions, comorbidities, and systemic healthcare biases. It is a

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critical area where more research, awareness, and tailored clinical approaches, including an interdisciplinary and interprofessional network, are desperately needed.

By adopting a patient-centred approach that prioritises acceptance, compassion, respect, and cultural competence, healthcare providers can significantly alleviate suffering and improve health outcomes for transgender patients with epilepsy.

The current knowledge gaps underscore the urgent need for more dedicated research and targeted educational initiatives to ensure equitable and inclusive care for this deserving community.

For healthcare professionals, this means actively seeking education on transgender health, challenging one's own assumptions, and adopting inclusive practices in daily clinical work. Recognising the unique characteristics and risk factors of transgender patients is a crucial step towards personalised care.

By fostering inclusive environments, continuously educating ourselves, and actively supporting dedicated research, we can ensure that the healthcare system truly meet the needs of all its patients [Nucera et al, 2025].

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Beyond seizure counts

How the multidimensional outcome reporting in epilepsy (MORE) framework can redefine success in epilepsy care

Dr Ammar Kheder describes a new framework for establishing success of care, encompassing patients' quality of life and lived experience, as well as striving for seizure freedom.

Why we need to rethink 'success' in epilepsy care

For decades, when clinicians and researchers have spoken about the success of epilepsy treatment – especially after surgery – the conversation has revolved around one central question: Is the patient seizure-free?

That question matters enormously, of course. Seizure freedom can be life-changing. But over time, both research and patient experience have revealed a mismatch between how we measure outcomes and what actually determines a person's quality of life after treatment.

Patients and carers consistently tell us that while reducing seizures is important, so too are independence, memory, mood, the ability to work or study, and even how tolerable the treatment is day to day [Noble and Marson, 2016]. A patient may still have occasional seizures, yet feel dramatically better because they can now drive, go back to work, or live without constant fear. Conversely, a patient who is technically "seizure-free" may still struggle with poor memory, depression, or side effects that keep them from fully engaging in life.

The Multidimensional Outcome Reporting in Epilepsy (MORE) framework was developed to address this gap between used outcome measures and the broader reality of living with epilepsy [Kheder, 2025]. It aims to help clinicians capture a broader picture of treatment impact, not only seizures, but also quality of life and the patient's own lived experience.

The limitations of our current systems

The Engel classification [Engel, 1987] and the International League Against Epilepsy (ILAE) scale [Wieser et al, 2001] remain the standard for outcome reporting after epilepsy surgery. Both focus almost exclusively on seizure frequency. Engel has four categories ranging from seizure-free to no worthwhile improvement. ILAE has six, but with the same emphasis.

This narrow focus presents three major problems:

1. **Binary thinking:** Complete seizure freedom is rated as a success; anything less is often lumped together as a partial or poor result.
2. **Lack of seizure character detail**: These systems do not distinguish between changes in seizure type or severity. A switch from prolonged convulsions to brief focal aware seizures can have a profound effect on a person's safety and independence, but it isn't reflected in the score.
3. **A static snapshot**: Seizure control is measured at one point in time. In reality, epilepsy control can fluctuate, and a single follow-up visit may not reflect the longer-term pattern.

Perhaps the biggest omission is quality of life. Studies have repeatedly shown that cognitive decline, mood disorders, and social barriers can persist even when seizures stop – and that improvements in these areas can matter as much, or more, than seizure counts [Téllez-Zenteno et al, 2007; Langfitt et al, 2007].

The wider impact of epilepsy

Epilepsy is not just about seizures, its effects ripple into almost every aspect of daily life. Any meaningful outcome

framework should reflect that. Five domains are particularly important:

- **Cognitive function** – Memory, attention and language skills can be shaped by both seizures and treatment. Gains here can open doors to education or employment; losses can close them.
- **Psychological well-being** – Depression and anxiety affect up to 60% of people with epilepsy. A therapy that stabilises mood – even without eliminating seizures – can be transformative.
- **Social functioning** – The ability to work, study, travel and sustain relationships or community engagement is a major measure of success.
- **Medication burden** – Many antiseizure medicines cause side effects that limit quality of life. Reducing the number or dose of drugs can be a major gain [Wang et al, 2022].
- **Patient-reported experience** – How the patient feels about the outcome matters: Was the treatment worth it? Would they recommend it to others? Are the side effects tolerable? [Janke et al, 2025].

Introducing the MORE framework

The MORE framework was developed to capture what "success" really means for people living with epilepsy. It balances three equally important perspectives:

1. **Seizure control (40%)** – not just whether seizures stop, but how much they are reduced, how long remission lasts, and whether rescue medication is still needed.
2. **Quality of life (40%)** – changes in cognitive function, mood, daily independence and the burden of ongoing medication.
3. **Patient-reported experience (20%)** – the individual's own view of the treatment, including side effects, social engagement and whether they would choose it again.

Each domain is broken down into practical subdomains that can be scored with a few structured questions during a routine clinic visit. Where possible, these are anchored in validated tools, such as the QOLIE-10-P, to ensure consistency [Patel et al, 2018].

Unlike the Engel or ILAE classifications, MORE is not tied to an all-or-nothing view of seizure freedom. It can recognise meaningful gains even when seizures persist, and it can give weight to harms – such as cognitive decline or disabling side effects – through a built-in negative scoring system.

Why MORE is different

- It gives equal value to independence, mood and cognition alongside seizure control.
- It is applicable across the full spectrum of treatment modalities, from surgery to neuromodulation, medications, or dietary therapies.
- It integrates the patient's own voice into the overall assessment.
- It supports more nuanced decision-making by showing the trade-offs between benefit and burden.
- It allows clinicians to track change over time in the various domains, rather than relying on a single snapshot.

Clinical snapshots – MORE in action

Case 1 – "Exceptional" result after surgery

A woman with right mesial temporal sclerosis underwent temporal lobectomy. She became completely

Table 1.The 11 MORE subdomains

Seizure Control Domain (40%)
1. Seizure frequency reduction – % change compared to baseline. 2. Seizure-free duration – longest seizure-free period post-treatment. 3. Rescue therapy use – change in use of rescue medicines.
Quality of Life Domain (40%)
4. Cognitive function – change in memory, attention, executive skills. 5. Emotional well-being – mood stability, anxiety, depression. 6. Daily functioning – independence in daily activities, work, or study. 7. Medication burden – changes in number/dose of antiseizure medicines.
Patient-Reported Experience Domain (20%)
8. Treatment satisfaction – overall patient satisfaction. 9. Side effect burden – severity and tolerability of adverse effects. 10. Social engagement – participation in work, school, relationships. 11. Would choose therapy again – patient's willingness to repeat the treatment.

seizure-free, regained her driver's licence, reduced medications from four to one, and returned to full-time work. MORE score: 100/100 which reflects not only seizure freedom but major gains in independence and mood.

Case 2 – "Good" result with neuromodulation

A man with bitemporal epilepsy received responsive neurostimulation (RNS). Seizures dropped by 70%, he had no need for rescue medication, and his attention and memory improved. Social participation increased, even though he remained on the same drug regimen. MORE score: 60/100 which acknowledges meaningful life improvements.

Case 3 – "Moderate" result with VNS

A teenager with Lennox-Gastaut syndrome had 80% fewer drop attacks (reducing injury risk) and could attend school regularly, though absence seizures persisted. MORE score: 45/100 which recognises functional and safety gains overlooked by seizure counts alone.

Using MORE in practice

Implementing MORE doesn't require overhauling the workflow in the clinic. Many of the questions it uses are ones we already ask in follow-up: How are you managing daily activities? Any changes in mood or memory? Are you still using rescue medicines? Would you choose this treatment again? Barriers include:

- **Time constraints**: Structured templates in electronic records can help.
- **Resistance to change**: Familiarity with Engel/ILAE is deeply ingrained.
- **Resource differences**: MORE is designed to be modular, so centres can start with the core elements and expand.

Even partial adoption – capturing QoL and patient-reported experience

alongside seizure control – can make a difference in how we understand and communicate outcomes.

Why this matters for the UK context

In the NHS, where treatment access and funding decisions must balance cost with benefit, outcome measures need to reflect what truly improves patients' lives. A framework like MORE can:

- Strengthen the case for therapies (e.g. neuromodulation) that offer significant QoL gains despite modest seizure reduction.
- Provide a standardised language for multi-centre audits and quality improvement.
- Support patient-led decision-making by showing how treatments affect the outcomes they care about.

The road ahead

MORE is not a finished product – it is a starting point for a broader conversation in the epilepsy community about how we define success in epilepsy care. Future work should:

- Validate the scale in multiple centres and patient populations.
- Define minimal clinically important differences for each domain.
- Explore integration with patient-specific goals.

But the principle is clear: if we want to deliver truly patient-centred epilepsy care, we need to measure more than seizures.

Doing MORE for our patients

The Engel and ILAE systems have served the field well, but they no longer reflect the full reality of living with epilepsy in an era of diverse treatment options and patient-centred care. The MORE framework offers a practical, adaptable way to capture the outcomes that matter to patients, their families, and to clinicians making the next treatment decision.

Moving beyond seizure counts is not just a matter of better measurement. It is a matter of better care.

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Research update

Epilepsy Action health improvement coordinator, Krishan Srinivasa, shares updates from Epilepsy Action's research work

Epilepsy Action provides support to researchers working across all areas of epilepsy research, from basic science to translational work. Whether you are developing an idea or conducting a large-scale project, we can help you!

Research partnerships and collaborations

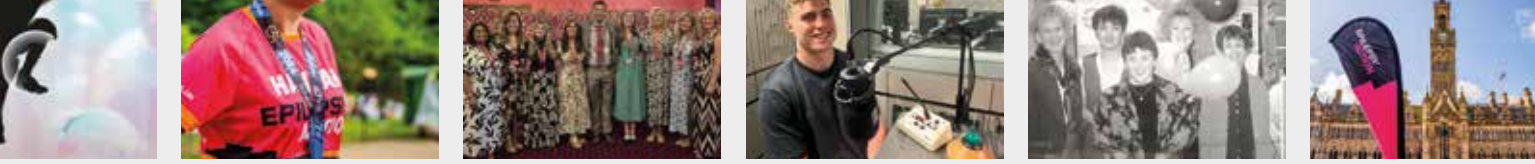
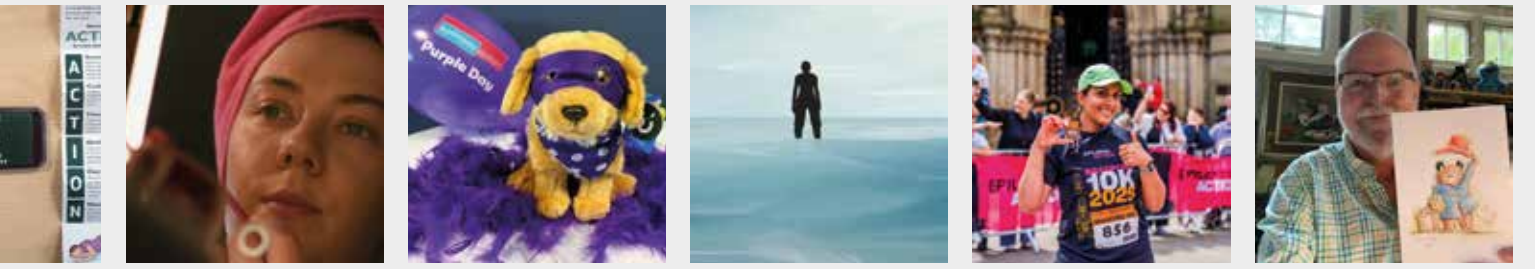
- Research partnerships are collaborative endeavours, where Epilepsy Action work alongside other organisations and individuals to achieve common goals. This can include:
  - Collaborating with academic institutions, NHS bodies, and research organisations.
  - Acting as a research partner or co-applicant on grant-funded studies.
- Our engagement in partnerships can include:
  - Facilitating links between researchers and people affected by epilepsy for co-design or participant recruitment.
  - Providing expert input from members of staff.
  - Taking on a leadership role within the research.
  - Public and Patient Involvement and Engagement (PPIE) activities.
  - Other activities relevant to our expertise.

Public and Patient Involvement and Engagement (PPIE)

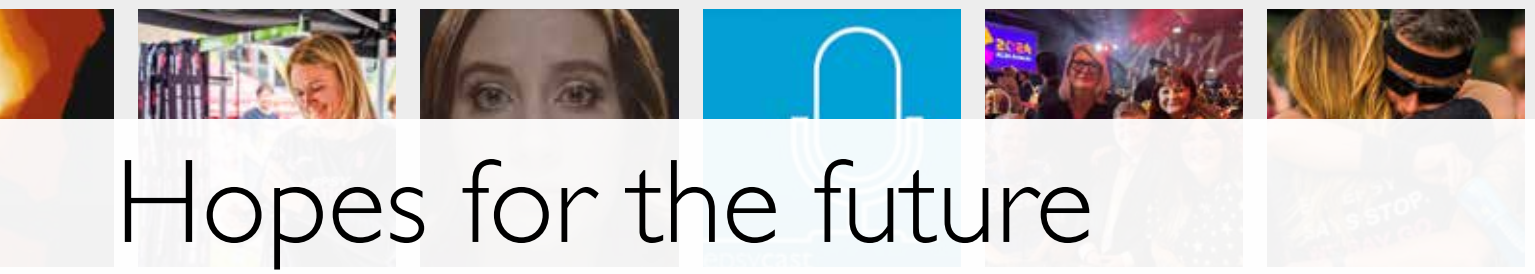
- We can provide PPIE support to research projects as part of a partnership, or as a support organisation within a project.
- There are many ways we can provide PPIE support. These often include:
  - Helping researchers engage people with epilepsy and carers in shaping research priorities, methods, and dissemination.
  - Providing access to our volunteers, panels, and wider community for PPIE activities.
  - Ensuring research is relevant, inclusive, and ethical through lived experience input.
  - Hosting focus groups, surveys, and panels to ensure clinical studies reflect the needs of the wider epilepsy community. For example, for the ongoing Self-Advocacy Project we have set up and conducted focus groups.

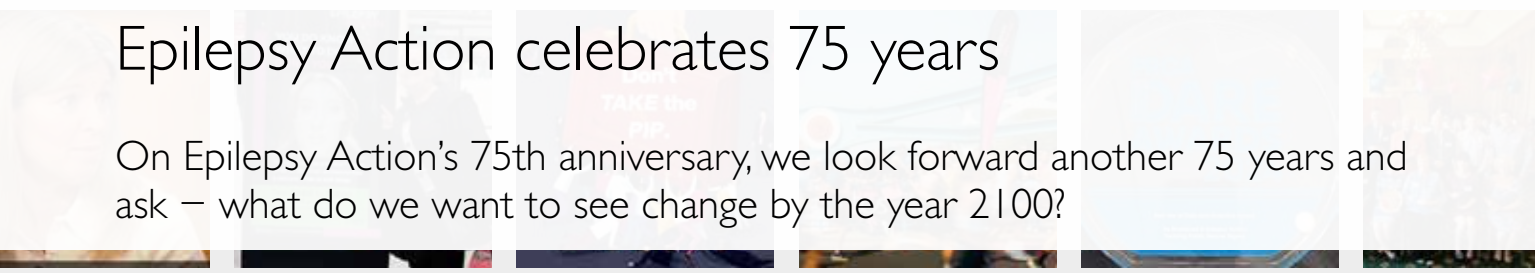
Other Support

- Providing letters of support:
  - We may write letters of support for research projects that we believe are worthwhile and will benefit people affected by epilepsy. These may be shared with Research Ethics Committees, funders, and other relevant organisations.
- Recruiting participants:
  - Advertising research opportunities through our channels (social media, emails, Assemble, etc). For example, for the LEAPEpilepsy Project we shared a recruitment call on our social media, and now they have fully recruited.
  - Assisting with or leading on the design and creation of recruitment materials.
- Patient facing documents:
  - Assisting with, providing feedback on, or leading on the design and creation of patient facing documents.
  - Engaging with volunteers and expert members of staff to provide feedback.
- Dissemination of findings:
  - Sharing research results through our website, social media, and newsletters.
  - Supporting researchers to present findings in accessible formats for people with epilepsy and the public.
  - Advocating for the uptake of evidence-based practice and innovations in care.
  - Providing access to people with lived experience who can assist in disseminating findings and provide a patient voice in the dissemination process.







Hopes for the future

Epilepsy Action celebrates 75 years

On Epilepsy Action's 75th anniversary, we look forward another 75 years and ask – what do we want to see change by the year 2100?

It's quite interesting to think back 75 years. The year 1950. It sounds almost recent in the grand scheme of things, but, actually, life was starkly different. World War II had ended only five years previously. The UK was rebuilding and recovering. In 1950 the NHS – healthcare free at the point of access – was brand new, only two years since its establishment in 1948.

At that time, life with epilepsy was also vastly different. People with epilepsy often were forced to live in communes or asylums. Myths were rife. We were still on the first generation of epilepsy medications, with phenytoin and phenobarbital as some of the most commonly prescribed options. People couldn't have MRI scans for epilepsy.

In the last 75 years, we have come a long way – more so than we might even realise. Communes and asylums are a thing of the past. In that time, we have developed more than 35 new medications for epilepsy. MRIs have become routinely used in epilepsy. Technology has advanced dramatically. Epilepsy surgery has come on leaps and bounds and is safer and more precise than ever before. We can monitor seizures long term. There are now wearable devices that give an accurate picture of seizure activity in a quick download. We can stimulate the vagus nerve to reduce seizures. People with epilepsy and controlled seizures have been allowed to drive. Myths and misconceptions have reduced and steadily, life has improved for people with epilepsy.

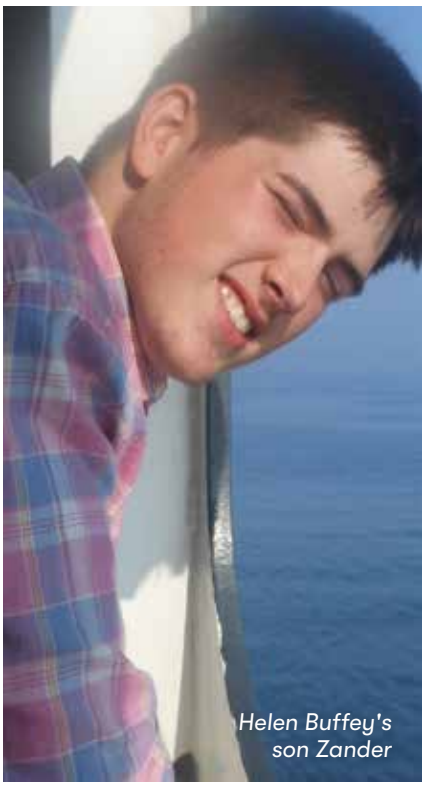
But we still have a long way to go. Even with so many advancements, around a third of people with epilepsy still live with uncontrolled epilepsy. People still face barriers with getting and staying in work and there is still an unacceptable pay gap. It's still a challenge to get essential government support and to feel understood by society.

Another thing happened in 1950. The British Epilepsy Association – now known as Epilepsy Action – was founded on 5 September. Since that time, our organisation has worked tirelessly to support and advocate for people with epilepsy. We've fought to legally and societally end discrimination and for fairer driving rules. We established the Sapphire nurses scheme to help train more epilepsy specialist nurses, we helped to set up the Children's Epilepsy Surgery Service (CESS) and we opened a free national helpline to help inform and support people with epilepsy.

None of this could have been possible without our supporters, members, fundraisers and champions to help direct us, tell important stories and raise vital funds. Together, we've worked hard to influence positive change, help people connect and feel more empowered around their condition, and build understanding and awareness of epilepsy among the general public. Now, with a new strategy of 'creating a world without limits for people with epilepsy' as our North Star, we at Epilepsy Action celebrate 75 years and look forward another 75, to many more advancements and an even brighter future..

A little understanding

To mark the anniversary, we put the question out to you, our community.


Helen Buffey's son Zander


Gus Baker and Ann Jacoby

The responses were heartfelt and humble. It goes to show how little people need – some compassion and understanding – to make their lives overwhelmingly better and easier.

"Not feeling excluded," one person said. "More understanding," said another. "Awareness." "Support."

With the sky as the limit of what people could hope for in the next 75 years, all people seemed to ask for was just to be treated fairly and with empathy. Things that shouldn't be out of reach in this day and age. Employment support and understanding. Help at school. Help with transport. Being made aware of sudden unexpected death in epilepsy (SUDEP). More epilepsy nurses. Better access to services. Better understanding around mental health support. Less discrimination.

A few people also had a simple hope for the not-so-distant future. "A cure, please."

Helen Buffey is a long-time fundraiser for Epilepsy Action in memory of her son, Zander, who died in 2014. Her biggest hope for the next 75 years is very much part of the chorus of the community: "awareness and education from school age onwards, so that as adults and parents, we know what to do".

She explains: "When my son was diagnosed with epilepsy, people shied away from us. He wasn't invited to friends' houses really because the parents were worried 'what happens if…'.

"So, if more people recognised and knew what to do, they (and I) would have been more relaxed and Zander might have had a better childhood.

"As he got older, it was the same really. I was forever worried that if he had a seizure out on his own, people would think he had taken something. A lot of people would walk past and not help.

"Since Alexander died, I have been fundraising to try to help in some way to enable other epilepsy sufferers get some support, both for themselves and for the family, and to hopefully contribute to the ongoing research.

"I'm not sure how things will have changed in the next 25, 50 or 75 years, but we have moved forwards from 75 years ago, so let's pray that we have more control over this horrible condition in the future."

"I'm not sure how things will have changed in the next 25, 50 or 75 years, but we have moved forwards from 75 years ago, so let's pray that we have more control over this horrible condition in the future"

Practical steps forward

Forging partnerships with other organisations and companies has been a key step in expanding our services and extending our reach to even more people.

Angelini Pharma UK-I Ltd supported Epilepsy Action with a grant to expand the helpline service, which now includes more focused information on medication and mental health support. Marking 75 years of Epilepsy Action, Angelini said: "As we celebrate Epilepsy Action's 75th anniversary, we recognise the critical role the organisation plays in driving awareness, support and advocacy for people affected by epilepsy.

"Looking to the future, we hope to see continued investment in

research that deepens our understanding of the underlying mechanisms of epilepsy, enabling earlier diagnosis and more precise, personalised interventions. We envision significant advances in data science, genetics and neurotechnology that could potentially revolutionise how epilepsy is monitored and managed.

"At the same time, we believe that stronger policy frameworks and equitable access to care must remain a priority — ensuring that innovation reaches every individual, regardless of background or geography. As a company committed to improving outcomes for people with epilepsy, we are proud to work alongside Epilepsy Action in pursuit of a future where science, society, and advocacy converge to transform lives."

In 75 years' time, I trust we will live in a world where epilepsy is not only fully understood but entirely preventable

Retired professor of clinical neuropsychology and secretary general of the International Bureau for Epilepsy (IBE) Gus Baker, and retired professor of medical sociology Ann Jacoby shared their hopes for the future: "Here is our wish list:

"1. That significant medical advances will be made for the treatment and management of rare and complex epilepsies.

"2. That the global epilepsy community will work closer to strongly advocate for the needs of people with epilepsy.

"3. That any child or adult with epilepsy will be seen by a multidisciplinary team led by an epileptologist.

"4. That people with epilepsy will no longer be stigmatised and that others will have more benign attitudes and behaviours towards those with the lived condition.

"5. That there would be greater resources and services devoted to the management of epilepsy globally.

"6. That people with epilepsy will be able to live a fulfilled life, with the same opportunities for education, work, and relationships as those without the condition."

ESNs Sarah and Phil Tittensor at Epilepsy Nurses Association (ESNA), also shared their wish-list for the next 75 years. They say they want to see:

"1. Increased numbers of ESNs to improve support for people with epilepsy, their families and carers. This would support services to meet guidelines, which state that everyone with a diagnosis of epilepsy who is still having seizures, should see an ESN every six months and after every A&E attendance for seizures.

"2. More training for healthcare staff and the general public around epilepsy to improve awareness of the condition and how to support people with it.

"3. Better communication between services so support can be co-ordinated.

"4. Increased use of new technologies (such as AI) to support clinical, educational and administrative support for epilepsy services."

Chief executive of Epilepsy Research Institute UK, Rosemarie Pardington, is thinking big and optimistic. She says: "In 75 years' time, I trust we will live in a world where epilepsy is not only fully understood but entirely preventable.

"Due to the increased focus on research in the previous years,


Rosemarie Pardington


Rebekah Smith

advances in neuroscience, genetics and precision medicine will have unlocked the underlying mechanisms of every form of epilepsy, allowing for early detection, prevention and personalised treatments.

"Alongside these long-awaited advances, with enhanced global collaboration and equitable access to care, no individual, regardless of their age, background or geography will live with the uncertainty or stigma that once surrounded the condition. I am optimistic for a future where living seizure-free is the norm, and epilepsy is a challenge of the past, overcome by the relentless united endeavours of clinicians, researchers and scientists world-wide."

Awareness far and wide

Jane Riley, chair of the Board of Trustees at Epilepsy Action, is determined to promote more acceptance and understanding for people with epilepsy. She says progress so far has been tangible, but more is needed – and quickly – for the future. She explains: "We need rapid growth in awareness and support across the UK now more than ever, with our difficult economy and challenging, overwhelmed systems of health and social care.

"We need to educate and inform as widely as we can and be seen and heard in every corner of the country. I feel we need to ensure schools, higher educational institutions and workplaces are all 'epilepsy-friendly' have full understanding of the impact of seizures and the lifestyle considerations that generally need to be made. People with epilepsy, and sometimes their carers and loved ones, can suffer enormously from significant mental health conditions and psychological help needs to be readily available for all, without exception.

"These are just some of my personal thoughts as chair of the Board of Trustees, but also as a mother. We need to continue our journey, deliver our strategy and make the next 75 years a time where people with epilepsy can live their lives without limits."

Baroness Margaret Ford has been Epilepsy Action's Honorary President since 2008, helping to represent the charity in Parliament and with launching campaigns. Thinking of the next 75 years, she is also hoping for more awareness from employers, as well as better care and support. She said: "My hopes would include more specialist clinicians who really understand epilepsy in all its complexity.

I want to see better understanding of the needs of parents with young children with epilepsy. Parents need to know what they can expect for their child and how best to advocate for them

"I also want to see better understanding of the needs of parents with young children with epilepsy. Early education and support for parents and carers is essential in providing children with epilepsy with the best possible start. Parents need to know what they can expect for their child and how best to advocate for them.

"I also want to see better understanding from potential employers. People with epilepsy have

so much to contribute and yet we know that stigma still surrounds the condition – especially when it comes to employers. Having a job is such an important part of wellbeing and contributes so much to healthy self-esteem that we must continue to campaign for better education and understanding from employers."

Our mission is unwavering: to provide ever more personalised, compassionate support to everyone affected by epilepsy, and to empower the healthcare professionals who support them

Meanwhile, consultant neurologist and chief medical adviser of Epilepsy Action's Epilepsy Professional magazine Rhys Thomas says: "For me the epilepsy specialist nurse (ESN) is inarguably the greatest innovation in UK epilepsy care over the last 75 years. More than just clinicians, ESNs are lifelines, providing expertise, advocacy, and a reassuring human connection at the most uncertain moments.

"Their impact is measurable: better seizure control, fewer emergency admissions, improved mental health, and empowered patients who feel seen and heard. ESNs remind us that the most powerful tool we have is expert, compassionate, consistent care.

"In [another] 75 years? No one with epilepsy should feel lost or unsupported."

Fulfilling our purpose

We can – and should – dream big for what the next 75 years hold. Hope for epilepsy to be as well-known and understood as the common cold. Hope for a cure, for prevention. And while we take leaps towards that, you can rest assured that we're not going anywhere.

Epilepsy Action chief executive Rebekah Smith has the final word: "I'm hopeful that the next 75 years will bring much greater strides in overcoming epilepsy than has happened over the last 75 years. As our knowledge of the brain deepens and technology continues to break new ground, I believe we are moving to a future where no one will have to live with epilepsy. Perhaps, in 75 years' time, there will be no need for a charity like Epilepsy Action, because the condition itself will be a thing of the past.

"Until that day comes, our mission is unwavering: to provide ever more personalised, compassionate support to everyone affected by epilepsy, and to empower the healthcare professionals who support them. Equally vital is our commitment to ensuring the world truly understands epilepsy: breaking down misconceptions and building a society that embraces and supports those living with it. This will always be at the very heart of what we do.

"In the nearer future, we need bold leadership from the Government to invest significantly in epilepsy research, so that Epilepsy Action can turn groundbreaking discoveries into tangible quality improvements in care and support.

"If, within the next decade, people with epilepsy can say that the only limits on their lives are the ones they themselves choose, not those imposed by their condition or by society, then we will know we have truly fulfilled our purpose."

Barones Margaret Ford

Jane Riley and her son Matthew

Highlights

Top picks from *Seizure*

Editor of the journal *Seizure*, Professor Markus Reuber highlights his key papers from the latest editions

While epilepsy surgery (especially when it involves complex planning based on multiple brain imaging, neurophysiological and neuropsychological investigations) remains a treatment which can only be offered to a small minority of patients with epilepsy, it is an intervention which is typically used when seizures have proven particularly difficult to treat medically, and it is the only treatment for epilepsy which regularly causes those who have benefited from it to consider themselves cured of their seizure disorder.

Epilepsy surgery may involve the relatively simple identification and removal of epileptogenic lesions such as hippocampal 'scar' tissue (e.g. in those with mesial temporal sclerosis), tumours or areas of focal cortical dysplasia. However, increasingly it has been considered as a treatment option when no lesion has been identified on brain imaging. In such cases, the investigation that is most relevant to answering the question whether epilepsy surgery is feasible or not is the invasive EEG recording of seizures and interictal EEG. The greatest change of this stage of the epilepsy surgery evaluation process over the last 20 years has been the gradual shift from the predominance of subdural strip electrodes (SDE) and grids to stereoelectroencephalography (SEEG).

Over the first few decades of epilepsy surgery (from around 1940) these two strategies developed in parallel. A predominantly North American tradition, inspired by the recording of cortical functions carried out by Penfield and Jaspers, developed into presurgical mapping and monitoring techniques, often involving multiple large grid electrodes which were sometimes combined with a smaller number of depth electrodes. Several generations of epileptologists learned to pursue and develop this strategy at centres such as the Montreal Neurological Institute and the Cleveland Clinic. Simultaneously, a French (and Italian) tradition developed, based on the stereotactic approach to deep brain EEG recordings initiated by Talairach. The more three-dimensional EEG data captured by this recording method led to a greater emphasis on epileptogenic networks [Reif et al, 2016].

A direct comparison of these two approaches is a challenging issue. There are certain clinical scenarios in which one technique has clear advantages over the other. For cases in which either method could be used, it seems that the majority of epileptologists and neurosurgeons have gradually been persuaded that SEEG is superior, although this view has not been supported by high quality evidence, for instance from a randomised controlled trial (RCT). An RCT would be

difficult to undertake because of differences in indications and pathologies and the fact that very few epilepsy surgery teams are experienced in both techniques. Most previously published papers have, therefore, compared the use of both techniques in different centres. The Surgical Therapies Commission of the ILAE published the findings of an international registry study involving 10 different centres and 1,468 patients of whom 988 underwent resection. In this study, propensity matching was used to allow a comparison of patients investigated with the two approaches. The study revealed that a greater proportion of those investigated with SDE underwent epilepsy surgery but the rate of complications was higher in these patients and the rate of those achieving seizure freedom lower [Tisi et al, 2021].

My editor's choice from volume 129 of Seizure, a systematic review and meta-analysis by Fernando Cotrim Gomes et al. adds to our understanding of the risk/benefit ratio of the two approaches for the surgical evaluation of patients with refractory epilepsy [Gomes et al, 2025]. The review, based on a total of 16 studies involving 3,751 patients, analysed outcomes of 1,750 patients who underwent SDE and 2001 investigated with SEEG. Both groups achieved similar rates of seizure freedom at last follow-up (OR 1.05; 95% CI 0.61-1.81). However, fewer complications were observed in the SEEG group (OR 0.50; 95%CI 0.28, 0.91), there were fewer major bleeding events (OR 0.23; 95%CI 0.11, 0.49), post-operative neurological deficits (OR 0.39; 95% CI 0.21, 0.73), and a shorter operative time (MD -76.28 minutes; 95%CI -101.86, -50.70).

This review suggests that SEEG offers advantages over SDE in terms of safety and healthcare utilisation. However, while the findings support the growing adoption of SEEG as a preferred method for epilepsy surgery, the fact that the review also confirmed the finding of the ILAE registry study that resections were carried out less frequently in patients investigated with SEEG than in those explored using SDE provides food for thought: The 40-day odds ratio of a completed resection was only 0.4 in the SDE group (95% CI 0.25; 0.6). This indicates that SEEG is now used in circumstances in which it is much less likely that it will be possible to offer epilepsy surgery. This may well outweigh the health economic benefits of this strategy and raises the possibility that the number of patients experiencing complications of epilepsy surgery evaluation has not declined with the adoption of this method. There is still much learning to be done – not least to ensure that SEEG is performed less often when it cannot be followed by successful surgery.

ASMs and risk of ASD in pregnancy

It has been recognised for a long time that the intrauterine exposure to antiseizure medications (ASMs) is associated with teratogenicity. The link between antiseizure medications and their teratogenic effects was easiest to discover for malformations apparent at birth, such as spina bifida. It has been a much slower process to establish links between ASM use in pregnancy and adverse outcomes in affected offspring when these are not associated with any (definite) visible features at birth and only manifest in later childhood [Meador, 2020]. Even now, there is much more certainty about the links of some drugs (especially valproate) with adverse educational and behavioural outcomes than others (and how to manage when

This review suggests that SEEG offers advantages over SDE in terms of safety

women who benefit from these treatments in terms of seizure control are contemplating pregnancy or find themselves pregnant) [Toledo et al, 2021].

Initial studies combined a broad range of neurodevelopmental outcomes to demonstrate that intrauterine ASM use put children at risk [Adab et al, 2004]. These studies were not of sufficient size to explore links between ASMs and autistic spectrum disorders. Larger studies have since been undertaken [Bjørk et al, 2022], but these still struggle with the fact that the definition and recognition of autistic spectrum disorders has changed substantially over the last few decades, reflected by a dramatic increase in the number of children now receiving this diagnosis [Hirota and King, 2023].

My editor's choice from volume 130 of Seizure, a systematic review and meta-analysis by Amaral de Lara et al., summarises what we know and – equally importantly – what still remains uncertain about links between autism and the intrauterine exposure to antiseizure medications [Amaral de Lara et al, 2025]. It synthesises the findings of 10 cohort and cross-sectional studies describing a total of 54,747 exposed children. The authors conclude that there are clear signals that not only valproate (hazard ratio [HR] 3.4) but also carbamazepine (HR 1.5) and oxcarbazepine (HR 2.3) are associated with an increased risk of children being diagnosed with autism. The association of ASM exposure and autism remained significant when only the subgroup of women with epilepsy was studied who had taken ASMs for the purpose of seizure control. Several questions remain unanswered despite the large patient pool this systematic review draws on: Is there a dose-relationship between intrauterine ASM exposure and the subsequent risk of an autism diagnosis? What are the effects of epilepsy severity? What role do autistic traits play in mothers or fathers?

While these uncertainties must be acknowledged, this systematic review provides information that should be shared with patients considering their epilepsy treatment options in pregnancy. It also highlights the importance of greater awareness of autistic spectrum disorders in children exposed to ASMs in pregnancy and underlines the need for larger prospective studies with follow-up investigations specifically designed to capture neurodevelopmental outcomes.

Further reading

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Why patients refuse new treatments

Having returned after a lovely summer with time at home and away with family and friends, like many of you, I'm sure, it's back to a full schedule. During a gap in my out-patient clinic this morning I read an article, published in Epilepsia, on the reluctance of patients to proceed with epilepsy surgery and its evaluation in Singapore [Tan et al, 2025]. It's something I guess I have encountered here in the UK, but rarely. Reasons stated in this paper included an overestimation of the procedural risks, and, despite the known SUDEP risk in epilepsy surgery cohorts, a general perception in the study population that epileptic seizures were non-disabling.

This caused me to reflect on my experience of why patients say no, initially to epilepsy surgery, but also why they say no to other epilepsy interventions which may have benefit, such as starting new anti-seizure medications (ASMs), enrolling in clinical trials and participating in new methods of delivering clinical care, such as patient initiated follow-up instead of the conventional routine clinic appointment, and use of AI.

I am relatively new to epilepsy surgery evaluation, but, of the patients who have paused on the programme here locally or who have declined, reasons stated often were not around surgical effectiveness or procedural risk, but rather around the financial impact of the evaluation over multiple appointments, inpatient drug withdrawal and the protracted course of the assessment usually being over several years. Contrary to the Singapore experience, of my patients whom I have considered for epilepsy surgery, it is really only the younger, more care-free patients, in my experience, who seem maybe not yet quite in tune with the seriousness of their problem.

In a similar vein, why do patients with refractory drug resistance say no to pharmaceutical trials? Increasingly, the strict inclusion criteria prohibit a patient's inclusion, but, again, I have some patients in whom therapeutic options are limited and yet they say no. Reasons seem to relate to the unknowns of the product, the frequent appointments, seizure diary entries and the financial impact.

Even today in clinic, I had a patient in whom I thought the introduction of a new ASM could have been a game changer, yet she said no, and wanted to remain on her three top-dose ASMs, despite ongoing seizures. Why? I guess maybe she's been here before, cycled through many ASMs with minimal benefit, is tired of learning to tolerate new dose titrations and side-effects or has general anxiety about the unknown of the new ASM. Or maybe its naïve of me to expect a patient who has suffered a life-long condition to change again even if our experience of the new drug is revolutionary. Sometimes patients with epilepsy reach a point of acceptance, thinking that this is their lot in life? I guess this is also true of many aspects of living outside the world of epilepsy.

These are the challenges of the human condition – we like the status quo, we don't want to upset the apple cart, change is always difficult, facing the unknown is not easy. Maybe our job as epilepsy clinicians is to really challenge this, to try to understand why patients say no and present the facts of any proposed epilepsy intervention correctly. As we consider epilepsy, a severe, life-threatening condition, we must be able to communicate risk and benefit effectively, so our patients don't miss out on a drug treatment, groundbreaking research, a clinical trial or a surgical intervention which could improve their quality of life. Let's challenge the status quo of saying no.

Further reading

Tan et al. Why patients say no: Patient barriers to epilepsy surgery among patients with drug resistant epilepsy in Singapore. Epilepsia 2025 Open published online ahead of print. Accessed September 2025.

Dates for the diary

Dates and events may be subject to change – please check on the relevant websites.

2025

22 October
Paediatric Epilepsy Training 1
Online
ilae.org/congresses/paediatric-epilepsy-training-1-22-october-2025

7-9 November
3rd Advanced Course on the Pharmacological Treatment of Drug Resistant Epilepsies
Palma de Mallorca, Spain
2025.drugsresistantepilepsy.com

10-11 November
42nd International Conference on Advances in Psychiatry and Mental Health
Dubai, UAE
neurologyconf.com/psychiatry/

13-14 November
Paediatric Epilepsy Training 2 and 3
Newcastle, UK
ilae.org/congresses/paediatric-epilepsy-training-2-newcastle
ilae.org/congresses/paediatric-epilepsy-training-3-newcastle

3-4 December
Encephalitis 2025
London, UK and Online
encephalitis.info/encephalitis-conference/

2026

19-23 January
15th ILAE School on Pre-Surgical Evaluation for Epilepy and Epilepsy Surgery
Brno, Czech Republic
ta-service.cz/epodes2026/

3-6 May
18th Eilat Conference on New Antiepileptic Drugs and Devices
Madrid, Spain
bit.ly/3Wq6dcc

Next issues:

Dr Chris Serrand

Dr Serrand discusses his team's recent research into mortality in adults and adolescents and the particular risk discovered in young women.

Tom Shillito

Tom Shillito summarise key sessions from the recent ILAE British Branch ASM

If you are interested in submitting a research paper for inclusion in *Epilepsy Professional,* please contact the Editor:

kkountcheva@epilepsy.org.uk

EPILEPSY ACTION

We need more experts to join our forces!

Our health information needs professional feedback to continue to be PIF tick accredited.

If you can lend your professional skills to review information on an occasional basis, send an email to **health@epilepsy.org.uk** with the area you specialise in.

This is a great opportunity for your CPD portfolio as well as making a huge difference to people affected by epilepsy.

Trusted Information Creator

Patient Information Forum