EPILEPSY
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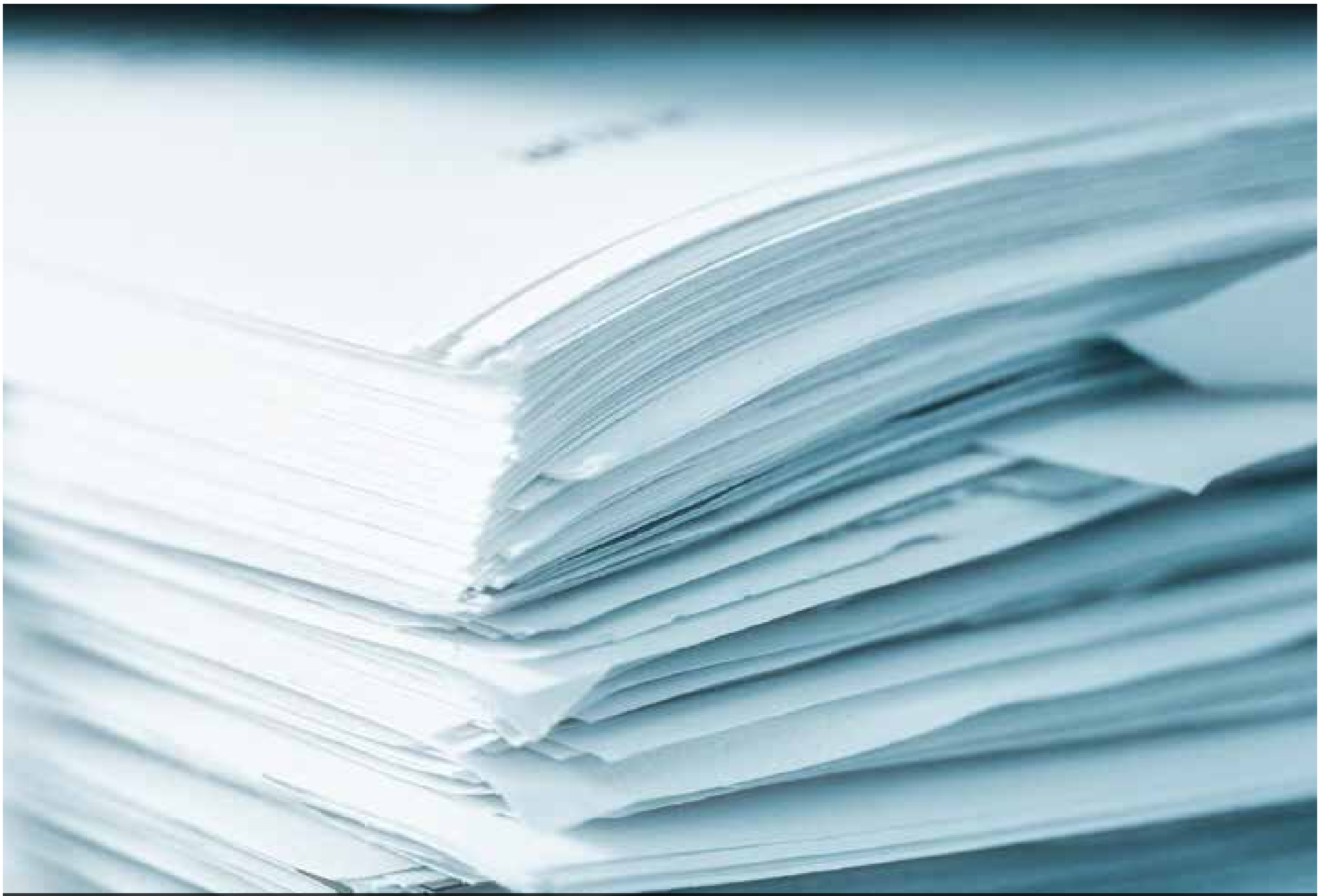
(Free to Epilepsy Action professional members)

epilepsy professional



Seizure classification

A summary of the updates for clinical practice

Sándor Beniczky

Liquid crystal lenses – Ahmed | Ghannam

A place I'm meant to know – Epilepsy Action

Needs-based follow-up – Marte Roa Syvertsen

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1. Elliott, RE., et al., (2011) Epilepsy & Behavior. 20; 478–483.
2. Patient's Guide for Epilepsy 2021, LivaNova USA, Inc.
3. Orosz, I., et al., (2014) Epilepsia 55(10):1576-84.
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5. Spindler, et al., (2019) Seizure, 69:77-79.

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Sometimes the very best advice comes from the Greatest Hits. Mick Jagger once intoned: *"You can't always get what you want"*, adding, *"but if you try sometimes, well, you might find, you get what you need."* It was never clear to me whether he was describing our epilepsy specialist nurse led hotline, or not. So how do you help people get what they need? This is an important patient-centred initiative run by the forward-thinking Marte Syvestren from Drammen, Norway. Why do we see some people at six months? Why do we see some people at a year? The right time to see someone is when they need you.

Reflex seizures continue to amaze. They can have common and less-so-common triggers which can be both internal and external. One of the best understood and most frequently seen is environmental photosensitivity. Zubair Ahmed and Rami Ghannam dissect what can be done with filtering lenses to reduce the chance of patterns and flashes from triggering seizures in photosensitive epilepsy. They describe a new form of liquid crystal lens that can be tuned to specific frequencies. More than a theory, they have a prototype for these lenses now. Manfred Mann, The Weeknd and The Streets have all been *"Blinded by the Lights"*, and of them, Mike Skinner of The Streets may have the greatest needs for these lenses as his epilepsy began at seven years old.

Bowie sung about *"ch-ch-changes"* on a song of that name, but it is the quote: "Change? Change! Aren't things bad enough as they are?" by Lord Salisbury) that comes to mind first when the ILAE revises seizure classification again. But keep up we must, so this report is required reading. We are still dancing on the head of the pin trying to disentangle what is awareness, what is consciousness, what is dyscognitive. All we can agree on is that terms are easier for to explain to the lay-person than a 'complex partial seizure'.

When it comes to communication, if you are 35 or under and the question starts with "How..?" the answer will be found on YouTube. So we need to speak the language of our patients and be where they are finding their epilepsy information. Epilepsy Action's short film 'A Place I'm Meant To Know' speaks to this need. There is an opportunity for someone to be the Tiktok epilepsy influencer (FitTok?) or, better still, using micro-films for education and support. The composer of the music for the featured short film themselves has epilepsy.

Surely that's more than enough for a single edition. On reflection, I'm going to be cautious about unsolicited life advice from the Rolling Stones, but perhaps it is preferable to Stephen Still's motto of "If you can't be with the one you love, love the one you're with" or Frank Zappa's "Watch out where the huskies go, and don't you eat that yellow snow".

Rhys Thomas
Consultant neurologist
Chief medical adviser
Epilepsy Professional

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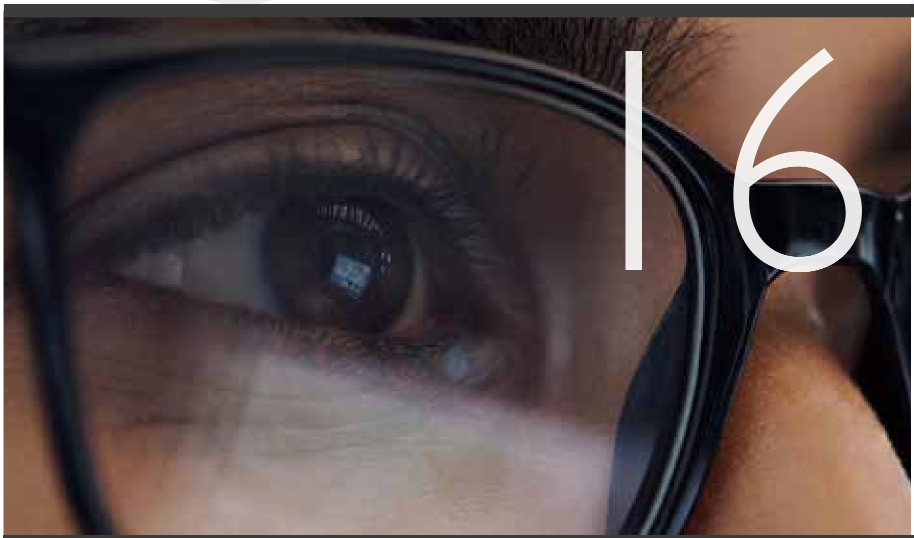

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A patient perspective

Epilepsy Action released a short film earlier this year aiming to help viewers really understand what a seizure might feel like and help build empathy and understanding for people with the condition

It's not always easy to understand someone else's experience. Even when we try really hard, even when we think we get it, even when we understand the mechanics and biology of something, we may still not have the first clue as to the lived experience of it. I learned that acutely when I had my first child. "I hope you're ready for the sleep deprivation, it's a doozy!" they'd tell me. And I'd think, "I did some all-nighters at uni, it wasn't that bad. I've got this." The naivete is almost - *almost* - funny, if it hadn't have been such a rude awakening (pun intended).

By the same token, at Epilepsy Action, we created the short film, A Place I'm Meant To Know, to help people really connect with the lived experience of having a seizure. Real people with epilepsy underpin the descriptions of the seizures and the film's music score. It's a real, relatable glimpse into what patients go through and is important watching to help us connect to and better understand patients. Further on the topic of helping to improve understanding, Prof Sándor Beniczky describes the importance of updating seizure classification as we learn more over time, and outlines the main changes in the latest update (page 10).

Also this issue, Prof Zubair Ahmed and Prof Rami Ghannam discuss developing liquid crytal lenses for photsensitive epilepsy (page 16), and Dr Marte Roa Syvertsen describes Norway's model of needs-based follow-ups for patients with epilepsy (page 26).

We hope you enjoy this issue and that it brings you a little closer to patients and colleagues.

Kami Kountcheva
Editor

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My Neuro Survey reveals financial and mental health struggles in epilepsy

More than four in five people with epilepsy reported mental health challenges as a result of their condition, the latest My Neuro Survey from the Neurological Alliance has revealed.

The patient experience survey, published on 25 June, showed sustained mental health challenges for people with epilepsy, with 84% reporting this in 2025, up slightly from 83% in 2022.

The results also highlighted that people with neurological conditions are not getting the mental health support they need.

Of the respondents, more than two thirds (69%) of people who needed them said they couldn't access neuropsychiatry services. Just under two thirds (62%) said they couldn't access neuropsychology and just under half (48%) said they couldn't access counselling.

Only one in three people with a neurological condition felt that services met their care needs.

The Neurological Alliance, of which Epilepsy Action is a member, advocates for people with neurological conditions to help ensure they have access treatment, care and support.

The My Neuro Survey also revealed that more than a quarter of people with epilepsy report that they can't afford the additional costs of their condition.

The survey results found that 28% of respondents with epilepsy said they couldn't afford the extra costs of their condition. Additionally, 29% said their condition affects their ability to manage financially.

Half of people said they rely on benefits for financial support.

These findings come just days after the government published its welfare bill detailing plans to cut benefits, making Personal Independence Payments (PIP) more difficult to access.

Research from the Office for Budget Responsibility found that about a third of current PIP claimants with epilepsy – nearly 11,000 – stand to lose out.

Epilepsy Action believes the reforms will be "damaging", not least because people often rely on PIP to help them access and stay in work.

Tom Shillito, health improvement and research manager at Epilepsy Action said: "Yet again these figures show that epilepsy remains a hidden condition in one more ways than one, with those affected falling through the cracks and being overlooked.

"We know people with epilepsy face more challenges with their mental health due to many factors, including medication side-effects and the unpredictability of seizures on all areas of their life. Combine this with the fact that people with epilepsy face a significant pay gap and discrimination in the workplace, and we have the perfect storm for a situation that urgently needs fixing.

"The government has spoken a lot recently about how the welfare system needs reforming to address the mental health epidemic in the UK and to get more people back into work. Taking away people's support isn't going to do that – we need a joined-up healthcare system that recognises and supports the needs of people with epilepsy.

"At Epilepsy Action, we want integrated mental health care to be part of every neurology pathway to ensure that people with epilepsy get the care and support that meets their specific needs."

Georgina Carr, CEO of the Neurological Alliance, said people with neurological conditions are being left behind.

She said: "We need urgent action to tackle workforce shortages in neurology and associated specialties, deliver a dedicated implementation plan for neuro services, and ensure no one is turned away from mental health support because of their neurological diagnosis.

"We know what good looks like: joined-up services, empowered professionals, and meaningful partnerships with the voluntary sector. Now is the time to act – and the forthcoming NHS workforce plan and 10-year strategy must deliver for the one in six."

The Neurological Alliance has created an open letter to the Health Secretary Wes Streeting, urging the government to take action in support of the one in six people with a neurological condition. You can sign the open letter it here: *bit.ly/4ngWe4h*

Pioneering treatment trialled for Dravet syndrome

A promising new medication, zorevunersen, is being trialled for Dravet syndrome across the UK and the US. Recent news reports have highlighted the positive effect the trial has had on two children from Sheffield Children's Hospital.

The medication, manufactured by Stoke Therapeutics, is still in its trial stages and is expected to take several years to become more widely available across the UK.

Zorevunersen has completed Phase 1 and 2 trials in the UK and the US for use in Dravet syndrome in children aged between two and 17 years. In the UK study, 19 children took part from Sheffield Children's Hospital, The Royal Hospital for Children, Great Ormond Street Hospital for Children and Evelina Children's Hospital.

The results of this study are expected to be published around the beginning of 2026.

A Phase 3 study is intended to begin in the summer of 2025, looking at how effective, safe and well tolerated the medication is.

This novel medication works by increasing the protein SCN1A. In Dravet syndrome, this protein is impacted by a faulty SCN1A gene.

Two children from Sheffield Children's Hospital, who took part in the trial, have reportedly had 'life-changing' results from the medication.

Freddie and Albie, both seven, have Dravet syndrome and took part in the trial. Freddie started taking the medication in 2021 and went from more than a dozen seizures in the night to one or two brief seizures, lasting only seconds, every three to five days.

Freddie's mum Lauren said the trial has "completely changed" the family's lives and given them a life they didn't think would be possible.

Albie took part in the trial in 2022. His seizures have reduced dramatically as well since starting. His mum Lauren said she feels like she's "won the lottery", and the trial has been "life-changing".

Consultant paediatric neurologist at Sheffield Children's Hospital Dr Archana Desurkar called this "one of the most novel trial in children's epilepsy".

NICE loosens prescription rules on cenobamate for focal epilepsy

Healthcare professionals with expertise in epilepsy can now access and prescribe cenobamate more easily, after an update to the National Institute of Health and Care Excellence (NICE) recommendations.

NICE initially only allowed cenobamate (brand name Ontozry) to be given in tertiary centres providing advanced specialist services.

Epilepsy specialists can now more easily access and prescribe the medication without having to refer to tertiary centres.

NICE said it has changed the recommendations following "concerns raised by the clinical community that restricting starting treatment in a tertiary care setting has resulted in inequitable access to the treatment".

Consultant neurologist Dr Rhys Thomas at the Royal Victoria Infirmary Newcastle, said: "This is undoubtedly a major boost for the many people with epilepsy who, for no fault of their own, happen to have their care coordinated outside of the major University clinics.

"This will break down unnecessary barriers to accessing treatments and reduce the inherent postcode lottery."

Cenobamate is used to treat focal seizures in adults with drug-resistant epilepsy. It is prescribed as an add-on treatment alongside a person's other epilepsy medication, if two or more medications have not been able to control their seizures.

All Wales health boards failing to meet first seizure treatment standards – report

Sioned Williams MS, Becci Smart, Jan Paterson and Daniel Jennings

Every single health board in Wales is failing to meet waiting time guidelines for treatment after a first seizure, a new report by Epilepsy Action Cymru shows.

The guidelines, set by the National Institute for Health and Care Excellence (NICE) say people should have a follow-up within two weeks of having their first seizure. However, according to the Seizing Change report, launched on 17 June at the Senedd, this standard is not being met anywhere in Wales.

Some patients, like those served by the Hywel Dda health board, are waiting up to 36 weeks to be seen – the longest waiting time on record.

The report is calling for urgent change and investment into epilepsy services.

Furthermore, more than two in five people (43%) are not being referred to any kind of specialist treatment after a seizure.

The report also warns that Wales is facing a neurology workforce shortage, with not enough specialists to give patients the care they need, Epilepsy Action Cymru says.

There are only 17 full-time epilepsy specialist nurses (ESNs) in Wales for the 36,000 people living with epilepsy. This equates to more than 2,000 patients per ESN, when epilepsy charities recommend a caseload of around 250-300 patients per ESN.

There are also only 12 specialised neurologists for that population.

Some improvements have been made since 2022, with more staff recruited at the Swansea Bay and Cardiff and Vale health boards.

However, Epilepsy Action Cymru says there is still a pressing need for investment into the workforce and improvement of healthcare pathways for people with seizures and epilepsy.

Janet Paterson, Wales manager at Epilepsy Action, said: "There is still so much to be done to reach the right level of care for people with epilepsy in Wales. We're nowhere near where we need to be.

"Since 2022, when we highlighted the workforce crisis facing NHS neurology services in Wales, we've managed to get the Senedd's attention on the issue, securing a dedicated debate.

"But while some progress has been made and some new staff recruited, it's clear this hasn't been fast enough or at all.

"Too many patients keep telling us they're waiting months for an appointment, or they can't get a hold of a neurologist because they have too many patients.

"And the data speaks. It's practically impossible to serve a population of over 30,000 people with epilepsy with a dozen specialists.

"Not just this, Wales has a higher rate of incidence of epilepsy than the rest of the UK and the epilepsy population is growing, but services continue to be underfunded and, very obviously, not meeting the standards. This needs to change. Now."

Luke Fletcher, Member of the Senedd for South Wales West, sponsored the session at the Senedd to launch the report. He expressed concern over the growing epilepsy population in Wales from 32,000 in 2022, and the lack of specialists, especially in rural areas.

Mr Fletcher MS also spoke to other MSs to highlight the issues facing epilepsy services in their areas and what they can do to address these.

He said: "The Welsh Government cannot continue to drag its feet on this issue. It has had ample warning from clinicians, patients, from charities like Epilepsy Action Cymru and through scrutiny in the Senedd.

"If we are serious about delivering a fair and effective system for epilepsy care in all parts of Wales, we must urgently invest in the neurology workforce, ensure that care pathways between primary and secondary care are fit for purpose, and support health boards to meet the standards patients deserve.

"The time for slow reviews and half-measures has passed. The Welsh Government must accelerate the pace of change – otherwise, it will be knowingly allowing thousands of people with epilepsy to be put at risk."

Heart problems in DRE – study

A new study has found that drug-resistant epilepsy in children and adolescents could increase the risk of heart problems.

Researchers from Thailand investigated change in heart rate variability (HRV) in 54 children and adolescents aged between six and 20 years old.

Of the 54 children, 27 were in the epilepsy group and were diagnosed with drug resistant epilepsy. Within this group, three quarters had been diagnosed with drug resistant epilepsy for more than 10 years. Just under half (44%) had daily seizures, with generalised tonic-clonic seizures being the most common type.

The results of the study found that the children and young people with drug-resistant epilepsy had lower HRV measures.

Lead study author Chinnuwat Sanguansermesri and his colleagues warned that this may make this group more likely to have heart-related health problems. They added that HRV can be used as a biomarker to assess heart health in people with drug-resistant epilepsy.

You can find the full study online at: *bit.ly/4ljil8V*.

Don’t Sub My Drugs leaflet launched

Epilepsy Action has created a new resource, the Don’t Sub My Drugs leaflet, offering information to patients around medication substitutions.

This free resource explains why switching between different versions of anti-seizure medications (ASMs) can be risky and offers support to help patients keep themselves safe.

The leaflet includes:

- Clear information about ASMs and the importance of consistency
- Guidance on how to check if they’ve been given a different version of their medication
- Advice for patients on talking to pharmacists and prescribers
- Steps they can take to get the right version for them

Epilepsy Action is encouraging healthcare professionals to provide the leaflet to their patients with epilepsy and display or keep copies of it in clinics, pharmacies or practices.

Earlier this year, 45 MPs signed a letter calling on Health Secretary Wes Streeting to review the medication supply chain to address the cause of medication shortages.

The letter detailed the risks people with epilepsy have been facing around shortages, including patients having to “go without their medication or switch to inadequate alternatives”.

With this resource, Epilepsy Action wants to help patients feel informed, confident and safe around medication.

You can find out more and download the leaflet at bit.ly/44jxzol.

Climate change neuro effects film

A new film from a team of neurology organisations is calling for urgent action on climate change which is putting our brain health at risk.

FutureNeuro Research Ireland Centre and The Royal College of Surgeons in Ireland (RCSI) in collaboration with the ILAE produced the 16-minute film. It highlights the problems climate change is causing in neurological conditions, including epilepsy, multiple sclerosis and dementia. It discusses emerging research around inreasing temperatires and seizures and brain function, as well as effects of severe weather events. Watch at: *bit.ly/445JjL0*

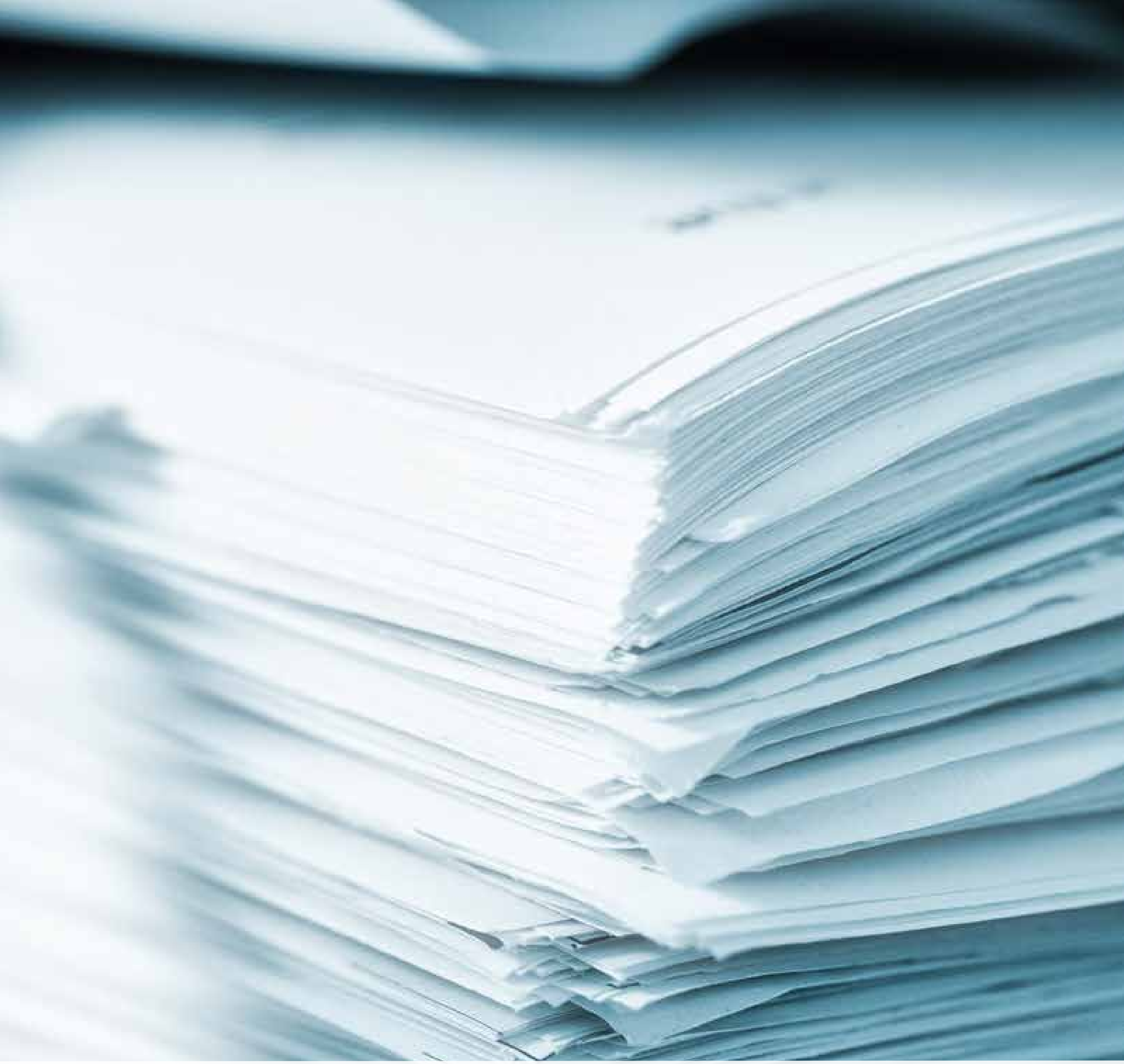
Air pollution ups epilepsy risk

Researchers from Canada have connected air pollution with an increase in the risk of new-onset epilepsy.

In a recent paper in the journal Epilepsia, Tresah Anataya and colleagues estimated the link of long-term exposure to elements of air pollution in Ontario residents and the risk of new-onset epilepsy.

They included 24,761 people who developed epilepsy between 2010-16, and 118, 692 controls.

The researchers found that particulate matter and ozone may be associated with an increased risk of new-onset epilepsy. Anataya said this has the potential to reduce the number of new epilepsy cases.



Seizure classification

A summary of the updates for clinical practice

Prof Sándor Beniczky describes the key updates made to seizure classification for clinicians and discusses the reasons for and importance of the changes.

Sándor Beniczky

Why was an update needed?

The 2017 seizure classification by the International League Against Epilepsy (ILAE) introduced an operational, clinically oriented framework [Fisher et al, 2017]. However, its implementation revealed limitations: ambiguity in some terminology (notably the use of ‘awareness’ instead of ‘consciousness’), challenges in classifying certain seizure types (eg. epileptic spasms), and feedback from clinicians that certain subdivisions lacked clinical utility. Moreover, the need to ensure accurate classification across different languages and levels of care prompted a structured reassessment. In response, the ILAE established a working group to refine the framework based on real-world experience and evidence.

How was the update developed?

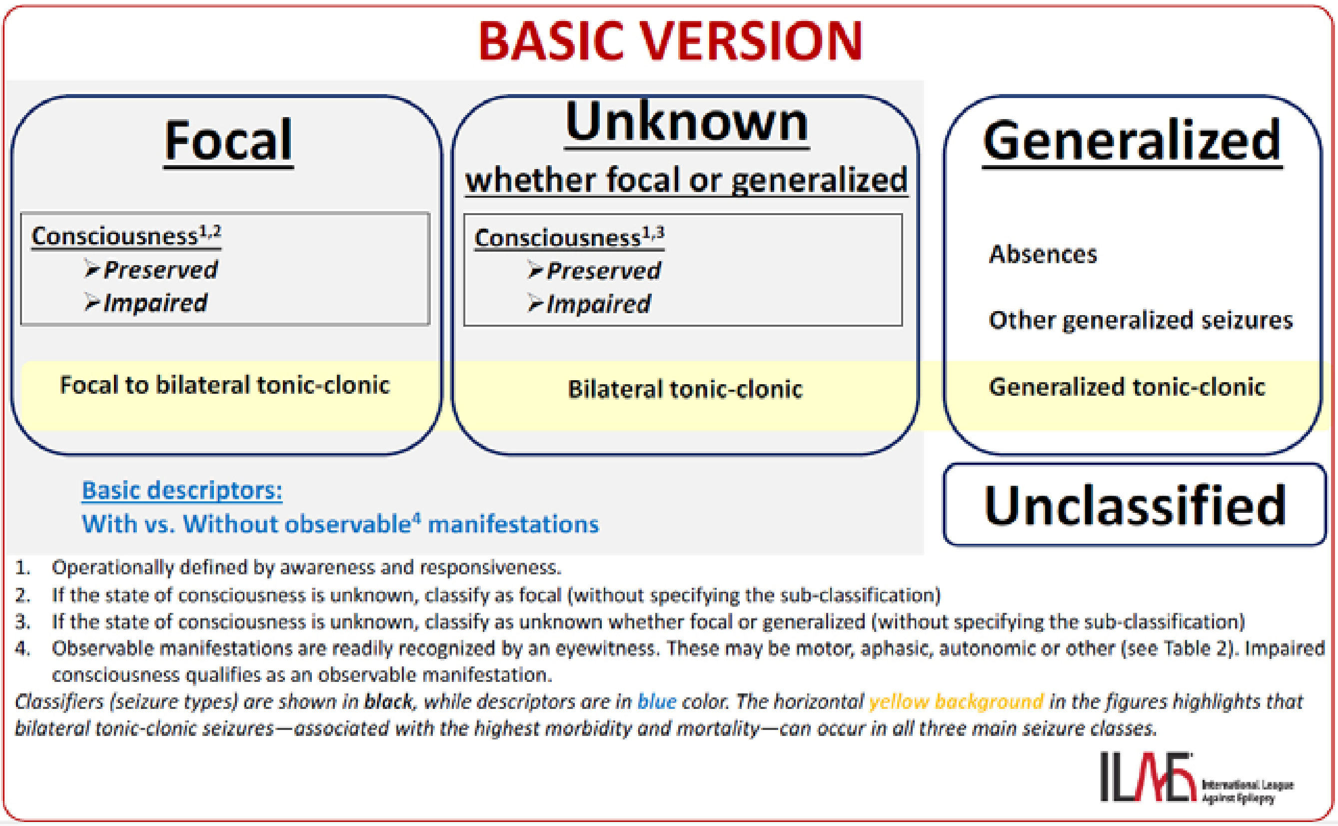
A 37-member working group appointed by the ILAE Executive Committee undertook the revision process, ensuring global and multidisciplinary representation [Beniczky et al, 2025a; Beniczky et al, 2025b]. A systematic literature review, workshops, and a rigorous modified Delphi consensus process (requiring ≥2/3 approval for each proposal) guided decision-making. Public comments were invited and reviewed by a dedicated Revision Taskforce. The process culminated in a classification that retains the 2017 structure while addressing practical shortcomings.

> **The ILAE established a working group to refine the framework based on real-world experience and evidence**

Key changes in the updated classification

1. *Main framework preserved*: Four main seizure classes remain – Focal, Generalised, Unknown whether focal or generalised, and Unclassified.
2. *Consciousness reinstated*: The term ‘consciousness’ replaces ‘awareness’ as a classifier for focal and unknown seizures. It is defined operationally by both responsiveness and recall (awareness).
3. *Observable manifestations*: A new, clinically relevant dichotomy replaces motor/non-motor: seizures are described as either with or without observable manifestations.

Figure 1. A basic overview of the ILAE's new classification [Beniczky et al, 2025a]



BASIC VERSION

Focal

Consciousness[1,2]
- *Preserved*
- *Impaired*

Focal to bilateral tonic-clonic

Unknown
whether focal or generalized

Consciousness[1,3]
- *Preserved*
- *Impaired*

Bilateral tonic-clonic

Generalized

Absences

Other generalized seizures

Generalized tonic-clonic

Unclassified

Basic descriptors:
With vs. Without observable[4] manifestations

1. Operationally defined by awareness and responsiveness.
2. If the state of consciousness is unknown, classify as focal (without specifying the sub-classification)
3. If the state of consciousness is unknown, classify as unknown whether focal or generalized (without specifying the sub-classification)
4. Observable manifestations are readily recognized by an eyewitness. These may be motor, aphasic, autonomic or other (see Table 2). Impaired consciousness qualifies as an observable manifestation.

Classifiers (seizure types) are shown in black, while descriptors are in blue color. The horizontal yellow background in the figures highlights that bilateral tonic-clonic seizures—associated with the highest morbidity and mortality—can occur in all three main seizure classes.

ILAE International League Against Epilepsy

4. *Epileptic negative myoclonus recognised*: Now included as a specific seizure type.
5. *Refinement of generalised seizure types*: Absence seizures are no longer called 'non-motor'; they are now directly classified by subtype (eg. typical, atypical).
6. *Epileptic spasms better integrated*: Recognised both as a generalised seizure type and as a semiological descriptor in focal and unknown seizure classes.

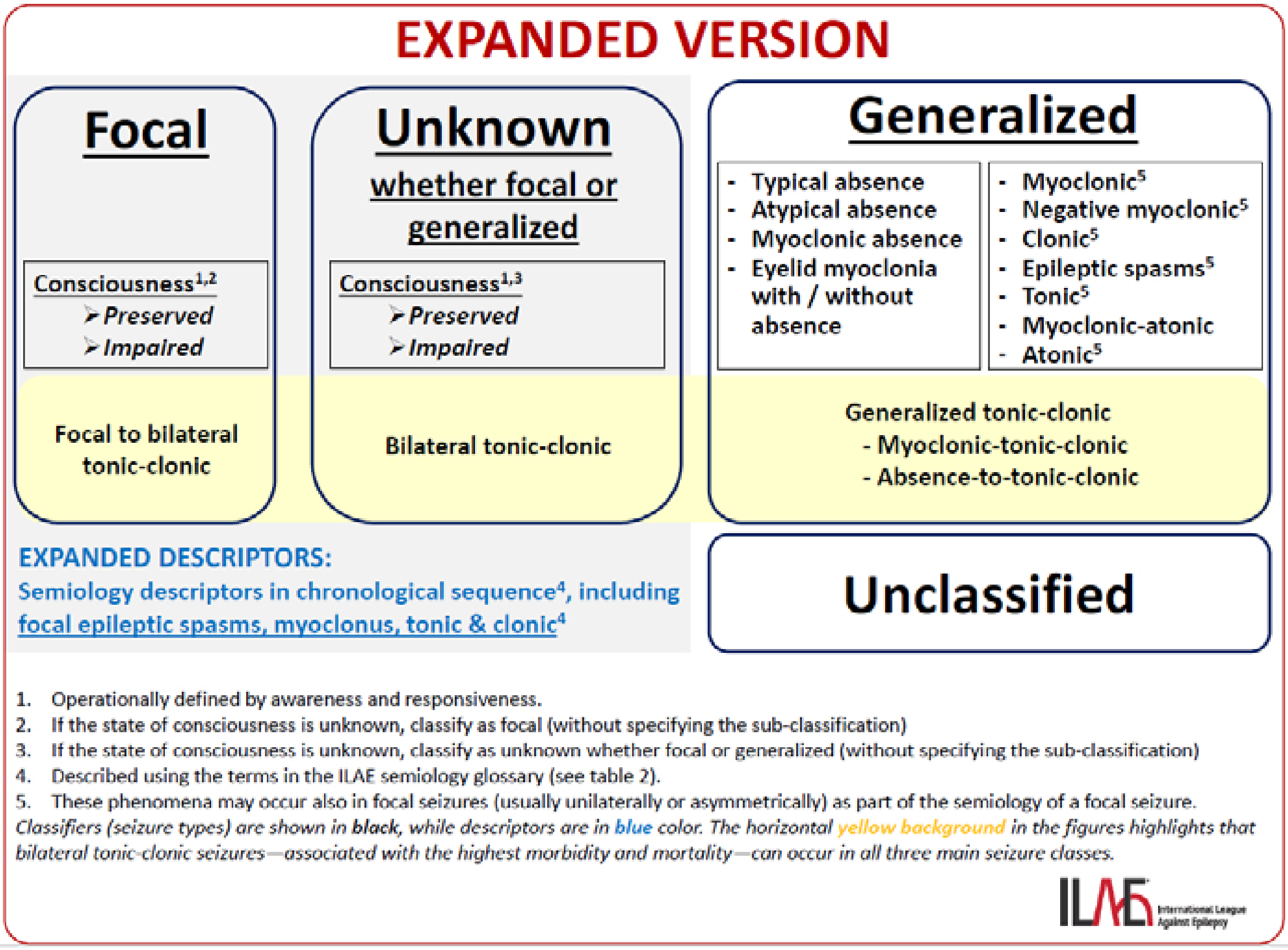
The updated classification: an overview

The classification comprises a basic and an expanded version (see *Figure 1* and 2).

1. Main seizure classes

- Focal seizures: Originating in one hemisphere; consciousness may be preserved or impaired.
- Generalised seizures: Originating in bilateral networks involving both hemispheres; onset may be focal, but with rapid propagation through the bilateral networks; include absences, tonic-clonic seizures, and other generalised seizures.
- Unknown whether focal or generalised: Used when onset is unclear; classified similarly regarding consciousness.
- Unclassified seizures: When

Figure 2. Expanded overview of the ILAE's new classification [Beniczky et al, 2025a]



EXPANDED VERSION

Focal

Consciousness[1,2]
➢ *Preserved*
➢ *Impaired*

Focal to bilateral tonic-clonic

Unknown
whether focal or generalized

Consciousness[1,3]
➢ *Preserved*
➢ *Impaired*

Bilateral tonic-clonic

Generalized

- Typical absence
- Atypical absence
- Myoclonic absence
- Eyelid myoclonia with / without absence

- Myoclonic[5]
- Negative myoclonic[5]
- Clonic[5]
- Epileptic spasms[5]
- Tonic[5]
- Myoclonic-atonic
- Atonic[5]

Generalized tonic-clonic
- Myoclonic-tonic-clonic
- Absence-to-tonic-clonic

Unclassified

EXPANDED DESCRIPTORS:
Semiology descriptors in chronological sequence[4], including focal epileptic spasms, myoclonus, tonic & clonic[4]

1. Operationally defined by awareness and responsiveness.
2. If the state of consciousness is unknown, classify as focal (without specifying the sub-classification)
3. If the state of consciousness is unknown, classify as unknown whether focal or generalized (without specifying the sub-classification)
4. Described using the terms in the ILAE semiology glossary (see table 2).
5. These phenomena may occur also in focal seizures (usually unilaterally or asymmetrically) as part of the semiology of a focal seizure.

Classifiers (seizure types) are shown in black, while descriptors are in blue color. The horizontal yellow background in the figures highlights that bilateral tonic-clonic seizures—associated with the highest morbidity and mortality—can occur in all three main seizure classes.

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there is insufficient information even to place the seizure into a broad category.

2. Consciousness as a Classifier
In focal and unknown seizure classes:

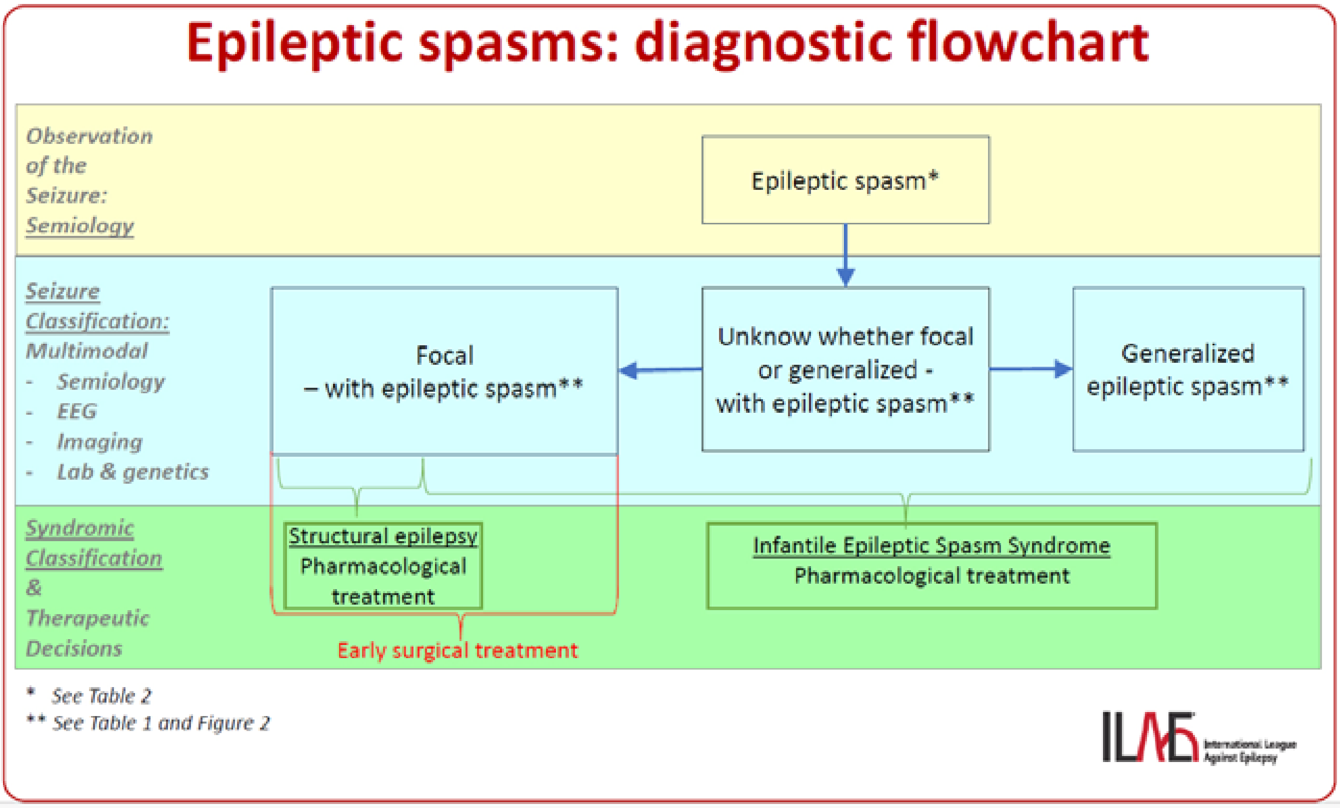
- Preserved consciousness: Both awareness and responsiveness are intact.
- Impaired consciousness: Both awareness (recall) and responsiveness are compromised. If information is available only on one of these, and it is compromised, then consciousness is considered impaired.
- Unknown: If neither can be reliably determined.

Clinical note: Impaired consciousness implies observable manifestations, aiding both diagnosis and safety risk assessments (eg. fitness to drive).

3. Observable Manifestations
Basic descriptors of seizure semiology:

- With observable manifestations:Visible to eyewitnesses (motor, aphasic, autonomic, etc.).

Figure 3. ILAE's diagnostic flowchart for epileptic spasms [Beniczky et al, 2025a]



- **Without observable manifestations**: No outward signs, though the patient may still experience internal symptoms.

Expanded descriptors of seizure semiology:

In advanced settings, seizures are described using semiology features in chronological order of their occurrence during seizure (eg. aura → automatisms → impaired responsiveness). This allows for precise lateralisation and localisation, which is especially useful for presurgical evaluation. (See *Figure* 2 for a visual summary.)

4. Special Consideration: Epileptic Spasms

Epileptic spasms are now better integrated across the classification:

- As a generalised seizure type (in the 'Generalised' class).
- As a descriptor in Focal and Unknown seizure classes (eg. 'focal seizure with epileptic spasm').

Spasms are particularly urgent in infants (eg. in Infantile Epileptic Spasms Syndrome, IESS), where early recognition and treatment significantly affect developmental outcomes. If spasms have focal features (eg. unilateral or asymmetric movements) or structural correlates on imaging, early surgical referral should be considered. A diagnostic flowchart (*Figure* 3) assists with their classification and management.

Case examples from the position paper

Below are selected cases that illustrate application of the new classification:

A 25-year-old woman experiences auditory auras and becomes unresponsive. EEG and clinical data support focal onset with impaired responsiveness and awareness. Classification: Focal impaired consciousness seizure (FIC; 1.2)

A 22-year-old man describes piloerection and flushing with full recall and responsiveness. Classification: Focal preserved consciousness seizure (FPC) with observable manifestations: piloerection and flushing.

A teenager with juvenile myoclonic epilepsy exhibits myoclonic jerks followed by tonic-clonic activity. Classification: Generalised myoclonic-tonic-clonic seizure (GTC; 3.2.1)

A three-month-old infant with clusters of brief flexor spasms, hypsarrhythmia on EEG, and developmental regression. Classification: Generalised epileptic spasm (GES; 3.3.4)

A 14-month-old girl with asymmetric spasms, EEG focus over left parietal region, and cortical dysplasia on MRI. Classification: Focal seizure (F; 1) with epileptic spasms (ie. focal epileptic spasms)

Conclusion

The 2025 seizure classification update refines and simplifies the 2017 framework while enhancing clinical relevance. The use of consciousness as a classifier, focus on observable signs, and clearer integration of epileptic spasms reflect lessons learned from clinical practice. Designed to be flexible, the classification can be applied from community clinics to epilepsy surgery centres. It also promotes international standardisation and patient-friendly communication.

Clinicians are encouraged to familiarise themselves with the basic and expanded versions, use appropriate terminology in documentation, and apply the classification in conjunction with clinical, neurophysiological, and imaging data to optimise care for people with epilepsy.

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Liquid crystal lenses

Filtering out light wavelengths that give rise to seizures in photosensitive epilepsy

Professor Zubair Ahmed and Professor Rami Ghannam describe a new prototype lens that has the potential to filter out 98% of light at wavelengths of 660-720nm that are associated with photosensitive epilepsy.

Ahmed | Ghannam

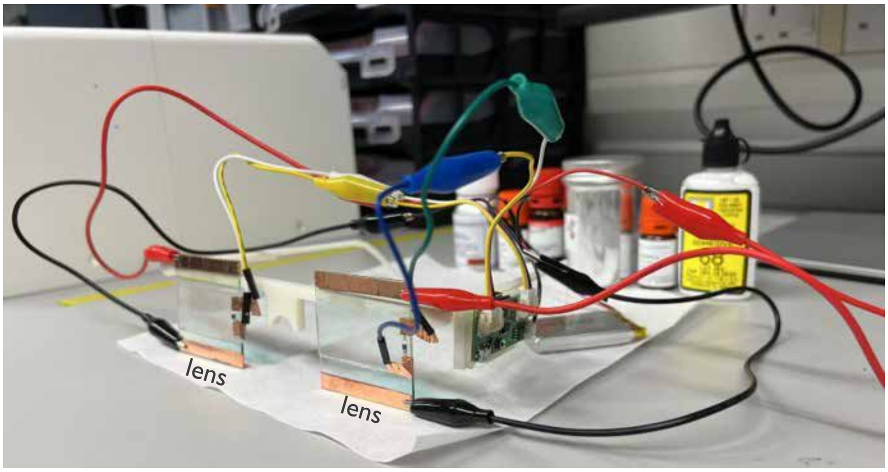
photosensitive epilepsy

It is estimated that up to 5% of people with epilepsy suffer from photosensitive epilepsy. In this, seizures may be triggered in response to flashing lights at certain rates, colour flicker, or by looking at contrasting light and dark patterns. Photosensitive epilepsy is more common in young people and children, who are five times more likely to be diagnosed with this condition than people later in life. This leaves children particularly vulnerable, as they generally tend to spend longer looking at things like computer screens, televisions and cinema screens.

The chance of seizures in people with epilepsy is often higher when they are tired, stressed or excited. In those with photosensitive epilepsy, being close to a TV or cinema screen, for example, such that it takes up their whole visual field might also be triggers. Additionally, looking at light and dark patterns that move quickly or change direction rapidly might cause disorientation or seeing these effects in a dark environment can be triggers. Sometimes people are triggered by looking at sunlight through trees, blinds or its reflection on water. Other things to be wary of are cameras with multiple flashes, strobe lights in nightclubs and even fireworks.

Possible triggers for photosensitive epilepsy include flashing or flickering images or high-contrast dark and light patterns (eg. black and white stripes)

To help reduce the chances of photosensitive epilepsy, people are recommended to use flatscreen TVs and monitors, take regular breaks, sit back from the screen, be in a well-lit room, as well as using special glasses (darkened lenses or polarising sunglasses) that may help to reduce the effect. However, it is important to note that these strategies reduce the



Prototype cholesteric liquid crystal (CLC) lenses with attached electrodes to apply heat to cause changes in the CLC that activate their light filtering properties.

risk but do not prevent seizures. As well as the above recommendations to reduce the risk of seizures in photosensitive epilepsy, current pharmacological treatments include anti-seizure medications (ASMs), such as valproate, topiramate, levetiracetam and lamotrigine. However, their use helps to lower the risk of getting seizures but does not completely prevent them. A combination of both medications and avoiding the triggers of photosensitive epilepsy is the most effective way of reducing seizures.

In terms of technologies that are available for people with photosensitive epilepsy, these include things like wearing dark glasses that reduce brightness by about 80%, but for some, cobalt blue lenses are effective, as they filter out red light. However, previous studies demonstrate that colour-filtered glasses can filter around 50% of red light, which can help to reduce the symptoms of epilepsy [Wilkins et al, 1999], but this still remains inefficient. Conventional glasses also use fixed coloured lenses and therefore pose an inconvenience to patients, especially if they have to wear them in all circumstances. For example, dark or blue lenses should not be used whilst driving at night due to visibility issues, whilst blue lenses make recognising red stop lights more difficult, even during daylight.

We recently reported a new form of liquid crystal (LC) lens that works by filtering out certain wavelengths just by changing the orientation of the LC molecules within them

To address some of the drawbacks of fixed coloured lenses, we recently reported a new form of liquid crystal (LC) lens that works by filtering out certain wavelengths just by changing the orientation of the LC molecules within them [Xia et al, 2024]. This means that the lenses, which are clear

View through a prototype lens before and after activation of 660-720nm light filtering (ie. light associated with photosensitive epilepsy). Note the slight 'blue' tinge once activated.

> **These lenses have the potential to significantly improve the lives of people with photosensitive epilepsy, helping them to lead a more normal daily life**

and normally allow all light to pass through, can be dynamically 'tuned' to selectively reflect certain wavelengths of light from the wearer. In this way, they can protect against light triggering seizures in people with photosensitive epilepsy, while still transmitting most other wavelengths of visible light. Also, the lenses are clear and, without light at wavelengths of 660-720nm, all other light wavelengths can pass through allowing the user to use these glasses at all times, even during the night. These lenses therefore have the potential to significantly improve the lives of people with photosensitive epilepsy, helping them to lead a more normal daily life.

LCs have unique properties and can exist between conventional liquids and those of solid crystals. For example, LCs flow freely like a liquid even though their molecules may be arranged in a common direction like that of a solid. They can change their molecular arrangement in response to temperature or electrical fields and return to their original state once the stimulus has been removed, making them reusable and long-lasting. LCs have been used for many applications including LC displays (LCDs) for television and head-mounted displays (HMDs), beam steering for telecommunications and other tunable optoelectronic devices such as sensors, antennas or reconfigurable lenses.

The lenses we have created work by taking advantage of what are called 'cholesteric liquid crystals (CLCs)'. These are liquid crystals with optical properties that are highly responsive to temperature or electrical fields. For example, at room temperature the

lenses work as normal glasses and the CLCs are arranged in such a way that they allow all light to pass through. However, as the temperature rises to 36.5°C, the CLC molecules rearrange themselves and efficiently block light (660-720nm wavelength) that can cause seizures in photosensitive epilepsy. Therefore, at room temperature, the CLC lens may be regarded as in the 'off' position whilst at 36.5°C the lens may be regarded as 'on', filtering out light at 660-720nm wavelength. Our laboratory tests showed that the CLC lenses were extremely efficient, blocking 98% of light at these wavelengths. These lenses block wavelengths associated with seizures to a significantly greater degree than others currently available, which are reported to reduce light at these wavelengths by around 50%.

Tin oxide coating on the glass allows heat levels to be controlled by direct voltage, generating the small amount of heat required to change the arrangement of the CLCs within the lens to filter out 660-720nm wavelength light. This electronic system was powered by a 3.7-volt lithium battery which is ideal for wearables as it can be built into the arm of say a pair of glasses to power the device. A microcontroller unit was built into the system to monitor the voltage variations and can also communicate with external devices through its built-in Bluetooth capability, allowing users to change the modes of lenses through a smartphone or computer. At the moment, in this prototype version, hot weather with air temperatures around 36°C will activate the light filtering capability. However, the team is currently working on developing lenses that can be used at higher temperatures too.

These lenses are highly 'optically tunable', depending on the composition of the CLC lenses and this means that eyeglasses can be tailored to the individual and used in other applications as well as for photosensitive epilepsy patients. For example, dyslexia is a condition that affects up to 20% of the general population and affects reading, writing and spelling. However, wearing yellow or blue filtered glasses can help dyslexia patients improve reading speeds as it reduces visual stress, a condition that is highly debated in the literature to be linked to dyslexia [Singleton and Trotter, 2005]. In addition, a common problem with digital screens and light-emitting diodes is blue light, and excessive exposure to blue light disrupts the normal circadian rhythm by suppressing melatonin production. Melatonin helps us fall asleep but exposure to digital screens can lead to sleep disturbance which can then impact on our overall wellbeing [Wahl et al, 2019; Tahkamo et al, 2019]. Therefore, these tunable glasses could be used by users of all sorts of digital screens such as mobile phones, tablets and computer screens to not only extend use but also to prevent the effects of blue light on the circadian rhythm. One can imagine that the

One can imagine that the tunable nature of these glasses means that users can integrate these CLC containing lenses into their normal prescription glasses and easily switch between them during the day

tunable nature of these glasses means that users can integrate these CLC containing lenses into their normal prescription glasses and easily switch between them during the day. With the ability to change the properties of the lenses through Bluetooth integration using smartphones and computers, glasses made from these lenses could therefore be transformative to photosensitivity sufferers, allowing them to lead a seemingly more normal daily life.

We are very excited by this discovery of tunable lenses, however, much work remains, including demonstrating the effectiveness of these lenses in clinical trials of patients with photosensitive epilepsy, before these lenses may be available for use by photosensitive epilepsy and other patients

Now that we have developed protype lenses that work efficiently in preventing light of different wavelengths, many challenges remain before these glasses can become a reality for people with photosensitive epilepsy. For example, we need to reduce the heating and cooling time to allow more instantaneous switching between light filtering and non-light filtering states. We believe that as technology improves, we can imagine advanced electrodes with enhanced thermal conductivity that will facilitate these temperature changes such that the CLC lenses will change properties seamlessly between filtering and non-filtering states.

It is important to bear in mind that whilst we have demonstrated laboratory-based efficiency of these highly tunable lenses, much work remains, including clinical trials to demonstrate efficacy of this technology in real world conditions and in photosensitive epilepsy patients. However, we are excited by this advancement and we are now working towards further refinement of the lenses so that our desire to make this available for photosensitive epilepsy patients may soon be realised.

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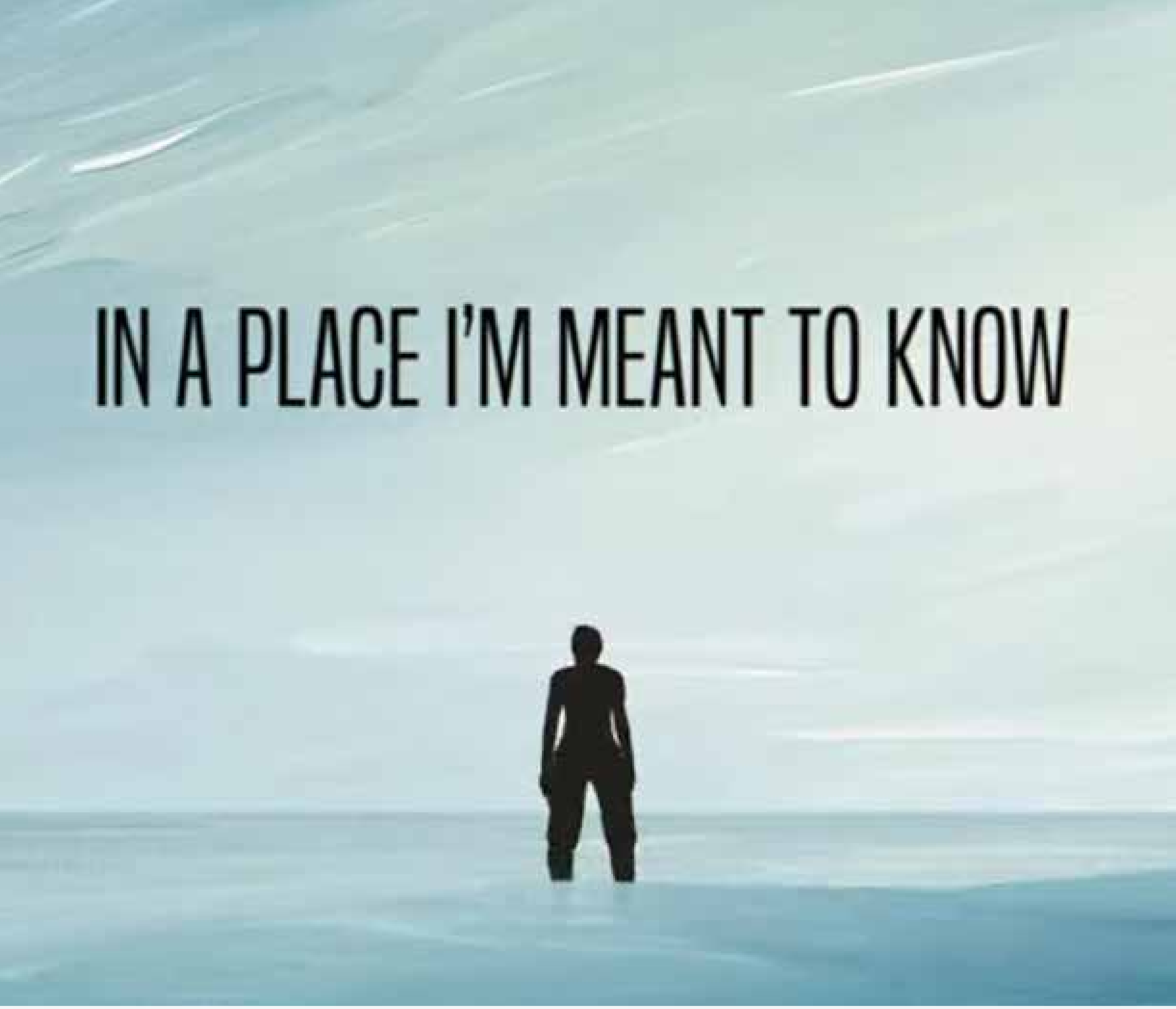


A place I'm meant to know

Epilepsy Action's new short film putting viewers at the centre of the experience of a seizure

Epilepsy Action released a short film earlier this year aiming to help viewers really understand what a seizure might feel like and help build empathy and understanding for people with the condition.

“I’m being pushed underwater. I lose vision – it goes blurry – and I lose my sense of hearing, so all the sounds merge into one as a jumbled noise.

“I’m still conscious, I’m still standing, but I can’t make sense of anything around me.

“From there, it goes into what I call a hallucinogenic nightmare, where I’m seeing things that make me panic and get stressed, so I end up sweating.

“I’m trapped. I’m trapped underwater with no escape.”

This sounds like an awful nightmare, but for Katie, it’s not a dream at all but a reality. Until recently, Katie used to have seizures and each would elicit those feelings for her. They would leave her exhausted and she would need to sleep for hours after coming round from one.

But epilepsy is still misunderstood, still often undermined, and still feared and discriminated against. It’s often invisible in the political sphere, invisible to policymakers, invisible in the media and invisible to the public. And yet, it is one of the most common neurological conditions in the world, with 630,000 people in the UK living with epilepsy.

In a recent survey of nearly 800 people with epilepsy, nearly two thirds (65%) said their condition is still misunderstood by most.

For someone like Fathiya, who is from Somalia, misconceptions can be even more commonplace. She has had epilepsy for 18 years, and says there is still stigma in her community. She says: “After a seizure, I feel like I’ve been thrown under a bus and [been] ran over by it. I feel exhausted, tired, mentally and physically.

“On top of that, I have to deal with the stigma that comes with epilepsy from my community, because they

think I've been possessed by the devil, or that epilepsy is highly contagious."

The survey also revealed that epilepsy affects how people are treated. A third of people said they have been bullied or harassed because of their epilepsy. More than half (57%) of people reported feeling depressed because of their epilepsy, and a third of them even admitted they had thought about taking their own life.

A sinking feeling

This year, Epilepsy Action has released a powerful short film, A Place I'm Meant To Know, which transports the viewer in the centre of a seizure. This emotive and immersive project is aiming to shake up public perception of the condition.

It asks the world to stop and finally see epilepsy for what it truly is, pushing for a change in attitudes towards it.

A Place I'm Meant To Know was created using real life testimonials from people with epilepsy about exactly what it feels like to have a seizure. They shared visceral descriptions of their experiences, including "you feel very far away", "going into a dreamlike state", "a sinking feeling" and "an out-of-sync sensation between the body and the brain".

The film's emotive soundtrack, which won Best Soundtrack at the Phare International Film Festival, was composed by musician and producer Alex Marchisone, who has epilepsy. While his epilepsy is now controlled with medication, he remembers vividly what seizures feel like.

He says: "Seizures have just been horrific for me. Aside from the various physical injuries I suffered (including a broken shoulder and various spinal disc fractures and wedging) it's the sheer number of postictal symptoms that have left a scar. Long periods of ill synaesthesia, impending gloom, strong sensorial confusion."

Alex first got involved with this project after attending an Epilepsy Action Talk and Support group in London and hearing other people's experiences. "I remember I saw some real suffering there, and I thought that, amid the ever-noisy communication-driven and social media world we live in, this wasn't expressed and spoken about.

I'm still conscious, I'm still standing, but I can't make sense of anything around me. From there, it goes into what I call a hallucinogenic nightmare

"I reached out to the wonderful team at Epilepsy Action and after a few talks, we landed on starting this project, which has been nothing short of amazing on both a human and artistic level."

Deeply gloomy 'leftovers'

Starting the project, Alex was keen to translate all aspects of seizures into music in an accurate and honest way. He explains: "I wanted to try and convey just how powerful seizures are, and how much they affect the person experiencing them. The music needed to be powerful, as a seizure is, and convey some of the feelings that hardly can be expressed in words: sensorial confusion, synaesthesia and so on.

"I wanted to do something more unexpected, avoiding some of the composing-for-media cliches. All in all, I wanted the piece to be powerful, and I wanted it to convey some of the hard-to-communicate feelings and some of those deeply gloomy 'leftovers', while retaining an aspect of 'beauty' to the music and a sense of solace for people with epilepsy.

"The music needed to make sense on its own, too, and represent my point of view as a composer and music producer."

Rebekah Smith, chief executive at Epilepsy Action, says 2025 is the year to bring epilepsy out of the shadows. "We are so proud to be launching 'A Place I'm Meant to Know'. We're hoping it will really get people to stop and think about what it feels like to have epilepsy.

"It wants to give a voice to people with epilepsy, helping to visualise and bring to life something they feel but may struggle to put into words for others to understand.

You're looking through a kaleidoscope, where you can see lots of vivid images and patterns. Then you get a similar sensation to when you've fallen in your dream, only that is in almost slow motion

"We often say that epilepsy is the ultimate hidden condition. It very rarely gets mentioned or portrayed in the media, when it does it's too often in a negative way. What's more, many people have no idea about it despite it being so common and we still hear too many discrimination stories, day in and day out.

"We want 2025 to be the year epilepsy finally comes out of the shadows. Before we can change attitudes around epilepsy, we need to make it visible. We wanted to do this in an unexpected way, through music, visuals, and the real stories of people with epilepsy."

Falling in slow motion

Lewis has had tonic-clonic seizures, and wishes people knew more about what it feels like before and after a seizure like that.

He says: "The best way that I can describe a seizure is that you're looking through a kaleidoscope, where you can see lots of vivid images and patterns. Then you get a similar sensation to when you've fallen in your dream, only that is in almost slow motion.

"Having epilepsy takes a big toll on the body, both physically and mentally, particularly when you're coming round from a seizure, because the brain has essentially had to reset itself.

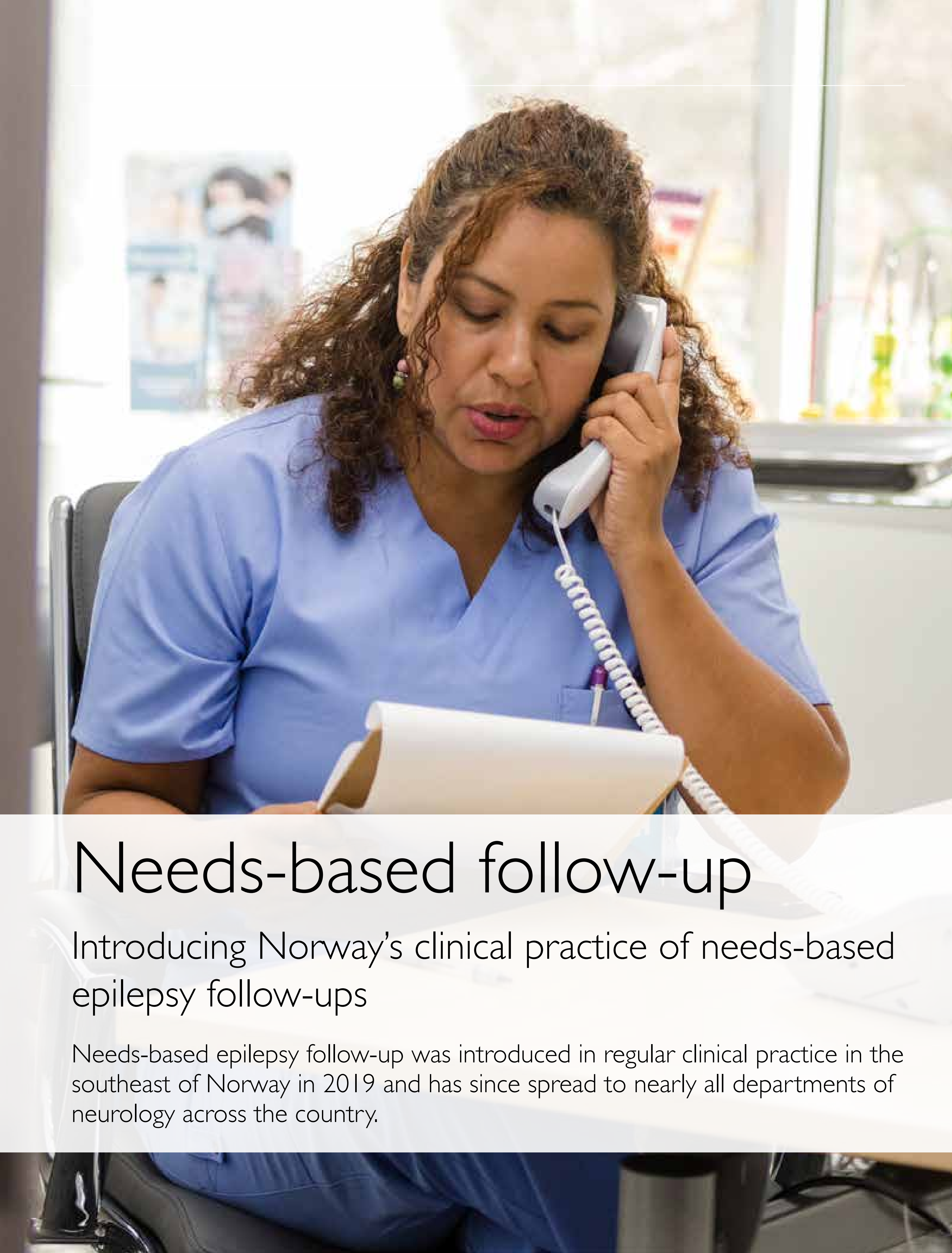
"And this can lead to other challenges. So, for me, after a seizure, I battle with tiredness, grogginess, and even memory challenges on occasion, which can be quite upsetting.

"And people don't really see that either, they only see the physical damage from the seizures, if the individual's cut their tongue or bruised themselves when they've fallen."

Lewis, like many others, wishes that people would take the time to understand more about what having epilepsy is actually like, including the experience of seizures and what it's like to come round from one, rather than believing the misconceptions.

"I feel like people only see the seizures and assume you'll be fine when you come round from that," he says.

"But there's a lot more to it than that."



Needs-based follow-up

Introducing Norway's clinical practice of needs-based epilepsy follow-ups

Needs-based epilepsy follow-up was introduced in regular clinical practice in the southeast of Norway in 2019 and has since spread to nearly all departments of neurology across the country.

Marte Roa Syvertsen

epilepsy follow-ups

Epilepsy is a highly heterogenous condition with a large variation in needs for health care. Psychiatric comorbidities like anxiety and depression are common, and the seizure situation may vary based on the occurrence of stressors like sleep deprivation, intercurrent illness, and psychological stress. Nevertheless, the standard of care in Norway has been calendar-based appointments with the specialist, normally once a year, but sometimes twice a year or every three months if the seizure situation is unstable, or there has been a change of medication. National guidelines state that all patients with epilepsy should have regular specialist follow-up. However, in a regular clinical setting, there are not enough resources to offer all Norwegian patients under treatment for epilepsy a calender-based specialist appointment. Waiting lists are growing, and patients often find it hard to get in touch with their neurologist.

Waiting lists are growing, and patients often find it hard to get in touch with their neurologist

With this as a starting point, and looking to Denmark, where some hospitals had distributed questionnaires for patient reported outcomes in epilepsy for a few years already, the newly founded Norwegian network for evidence-based epilepsy care, EpilepsiNett, designed a new questionnaire – Patient Reported Outcomes in Epilepsy (PRO-EPI). PRO-EPI was tailormade to clarify the individual patient's need for follow-up at the moment, in close collaboration with user panels, EpilepsiNett's multidisciplinary network of epilepsy experts, and the Norwegian Epilepsy Association (Epilepsiforbundet). PRO-EPI was distributed to patients for the first time at Drammen Hospital in Vestre Viken Hospital Trust, in December 2019.

Incoming PRO-EPI responses are handled by epilepsy nurses, who contact the patient by telephone when needed. The epilepsy nurse reports to the responsible neurologist when

Drammen, Norway

needed. If there are issues which cannot be solved by telephone either by the epilepsy nurse or the neurologist, the patient is offered a physical appointment at the outpatient clinic. PRO-EPI is distributed to patients twice yearly, but patients can contact the epilepsy nurse any time in between, by a secure system for written messages.

The Norwegian Forum for epilepsy follow-up with PRO-EPI now consists of 17 hospitals and more than 50 clinicians and epilepsy nurses from all over Norway. PRO-EPI has been revised three times based on feedback from the forum, the latest revision following a workshop with epilepsy nurses at the yearly meeting of the Norwegian chapter of the International League Against Epilepsy (ILAE) in 2024. PRO-EPI 4.0 is available free of charge in Norwegian and English at EpilepsiNett's homepage www.epilepsinett.org.

By delegating conversations and needs-based follow-up to epilepsy nurses, neurologists work more efficiently and can follow a larger number of patients than previously

Experiences with needs-based epilepsy follow-up so far are positive, both from patients, epilepsy nurses, and neurologists. By delegating conversations and needs-based follow-up to epilepsy nurses, neurologists work more efficiently and can follow a larger number of patients than previously. Standardized follow-up questions ensure that all patients are asked the same, irrespective of personal knowledge and/or geography and background. The dynamic messaging system ensures that patients may get in touch with specialist care when needed, and moving from calendar-based to needs-based follow-up ensures that patients are not offered appointments when they are not needed.

Currently, there are two PhD-projects dedicated to the effects of needs-based epilepsy follow-up, one focusing on clinical aspects and patient safety, the other focusing on resources, economical and societal aspects. As a part of patient safety analyses, the clinical PhD project will investigate non-responders and their characteristics. PRO-EPI response rates are high, generally above 80 %, and non-responders get two reminders by sms, and finally a reminding telephone call from the epilepsy nurse. If they still don't return the PRO-EPI questionnaire, they are offered regular calendar-based follow-up instead. As to the responders, the experience from epilepsy nurses and neurologists so far is that the standardised questions of PRO-EPI captures clinically important issues the patients did not always think of mentioning spontaneously, including newly arisen adverse events, planned pregnancies, or nocturnal seizures. The PhD projects are work in progress, and the findings will be published in peer-reviewed scientific journals.

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Highlights

Top picks from *Seizure*

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

Despite the effects of vaccinations, prevention programmes for conditions such as malaria and improved sanitation on the prevalence of febrile illness, febrile seizures are still one of the commonest acute neurological problems in paediatric practice. Although benign in the majority of cases, these seizures, typically first manifesting under the age of six, can indicate more serious neurological pathology or be a harbinger of unprovoked epileptic seizures in later life. This means that they often cause disproportionate concern. As our understanding of febrile seizures has matured over the past three decades, so too has the need for a nuanced, evidence-based approach to their management – one that emphasises appropriate triage, conservative intervention, and robust parental education [Corsello et al, 2024].

Clinically, febrile seizures are classified as either simple or complex. Simple febrile seizures are generalised, last less than 15 minutes, and do not recur within 24 hours. These account for the vast majority of cases and are not associated with long-term neurological sequelae or a significantly increased risk of epilepsy. Conversely, complex febrile seizures – those that are prolonged, focal, or recurrent within 24 hours – warrant closer evaluation and may suggest an underlying neurological predisposition or infection [Steering Committee on Quality Improvement and Management, 2008].

Historically, the pendulum has swung away from an aggressive workup. In the 1990s and early 2000s, it was not uncommon for children presenting with febrile seizures to undergo neuroimaging, lumbar puncture, EEGs, and to receive prophylactic anticonvulsant therapy in the absence of specific additional epilepsy risk factors. However, multiple studies have since demonstrated that these interventions offer little benefit in the absence of red flags such as meningeal signs, focal neurologic findings, or persistent altered consciousness [Berg and Shinnar, 1996; Kimia et al, 2012].

For children presenting with a first simple febrile seizure and no concerning clinical features, routine imaging or lumbar puncture is not indicated

Current best practices emphasise a more judicious, individualised approach. For children presenting with a first simple febrile seizure and no concerning clinical features, routine imaging or lumbar puncture is not indicated. The American Academy of Pediatrics and other guideline bodies recommend supportive care and observation, with acute management reserved for seizures exceeding five minutes, often treated effectively with rectal diazepam or intranasal midazolam [American Academy of Pediatrics, 2011; McIntyre et al, 2005].

My Editor's Choice paper from volume 127 of Seizure supports this approach. Based on South Korean national registry data and an impressively large group of 130,248 patients diagnosed with FS, and median follow-up period of 11.8 years, Eu Gene Park and Il Han Yoo found that only 3,047 patients (2.3%) were subsequently diagnosed with epilepsy. A higher number of FS episodes (2 episodes, odds ratio (OR) 1.61; 3 episodes, OR 2.17; 4 episodes, OR 2.40; 5+ episodes, OR 4.85) and prolonged FS (OR 25.82) were associated with a significantly greater risk of developing epilepsy [Park and Yoo, 2025].

Epilepsy now has the highest age-related incidence in those older than 65, however, we still know astonishingly little about the aetiology, characteristics or optimal treatment of epilepsy in this patient population

While future studies, ideally taking account of a broader range of clinical features, serological or genetic risk factors, are urgently needed to allow a more specific individualised prediction of seizure risk (and potentially intervention before epilepsy develops), this study should provide reassurance to most patients and families who have faced the frightening experience of a febrile seizure.

Late-onset epilepsy – a neglected population

After stroke and dementia, epilepsy is the third most common neurological disorder in people over 65 years. And in view of demographic change, and the fact that stroke and dementia increase the risk of epilepsy themselves, the number of older people who develop epilepsy is bound to rise substantially. Indeed, epilepsy, once most common in children, now has the highest age-related incidence in those older than 65 [Sen et al, 2020]. However, we still know astonishingly little about the aetiology, characteristics or optimal treatment of epilepsy in this patient population.

One important reason why our knowledge of epilepsy in older adults in general or late-onset epilepsy is limited is that this patient group is vastly underrepresented in specialist care settings. There is evidence for this assertion from the UK, a country where all people should have access to free healthcare at the point of need, where national epilepsy guidelines have recommended an initial diagnostic assessment by an epilepsy specialist for over 20 years [NICE, 2004], and where age discrimination is strongly discouraged. In 2010, we examined the records of 846 adults under the current care of our epilepsy service and used data from a previous epidemiological study to estimate the proportion of local patients accessing our service in different age groups. Whereas 43.7% of adults younger than age 20 were using the specialist service, only 2.3% of people with epilepsy who were 85 and older had been referred [Reuber et al, 2010]. When we went on to interview clinicians to find out why older patients were less likely to be referred to specialist services than younger ones, they all explained that their referral practices were the same regardless of patient age. However, they were all able to provide reasons why other clinicians may discriminate on the basis of age, citing reasons such as likely difficulties accessing hospital, patient reluctance to attend clinics, unclear referral pathways, a complex differential diagnosis or gaps in referrer knowledge [Blank et al, 2013]. When we asked older adults with epilepsy themselves, they dispelled most of the clinicians' assumptions [Blank et al, 2013]. They would have been very happy to be seen in a specialist clinic. Older adults often feel invisible. This seems to be doubly true for older patients with epilepsy!

My task of picking a single Editor's Choice article from the current Special Issue of Seizure proved impossible. This whole issue is dedicated to the neglected population of late-onset epilepsy. As I might have chosen every single article from the exciting volume 128 of Seizure, I decided to pick the introductory editorial by Helmstaedter et al. instead [2025]. This editorial provides an overview of the 18 expert reviews covering aetiology, pathogenesis, investigations, epidemiology, mental and physical comorbidities, neuropsychological features, clinical management and outcomes. By summarising what is known these reviews also demonstrate the current limits of our knowledge and represent a call for action.

Paediatricians often remind us that children are not just small adults. This Special Issue of Seizure is a reminder that older adults with epilepsy are not just a little more aged than younger ones, and that we will need to pay more attention to the particular characteristics of late-onset epilepsies if we want to deliver optimal care to patients in the final third of their lifespan.

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Greater triumphs

Imagine you are sitting in your clinic, having just taken a history and examined your first new patient of the day. They have come to see you after their third seizure in as many months, and the history is convincing, both from the patient and their wife, of epilepsy.

You convince yourself from your thorough clinical examination that there is no underlying structural lesion and there is no need for a pneumoencephalogram, but you will ask your assistant to run an electroencephalogram, which you will read at the end of the clinic.

The first question is whether you start them on either phenobarbital or phenytoin. The bigger question is what you tell them and the family; will you need to send them to the local asylum in case their family is not able to manage? As much as you know the asylums and colonies are going out of fashion, you still think they have their place.

Luckily, this is not how any of us working to help our patients manage their epilepsy in 2025 will be thinking. But 75 years ago, this was probably the cutting edge of epilepsy care. Seventy-five years ago, when the British Epilepsy Association (the official name of Epilepsy Action) was set up, people with epilepsy had very limited options.

Since that time, Epilepsy Action has helped to advocate for people with epilepsy and to help us, the epilepsy professionals, to support our patients to live better lives with epilepsy. Epilepsy Action was instrumental in advocating for care of epilepsy to be in the community and not in colonies and asylums. It helped lead to safe and just regulations to enable patients with epilepsy to drive when the risks are low, reduce discrimination by including epilepsy as a disability in the Disability Discrimination Act, and in helping to make it clear that patients with epilepsy need additional support from the government in the form of Personal Independent Payments (although recent changes in policy have made this harder for patients again).

Epilepsy Action has helped to push the knowledge of the epilepsies, and the available treatments, forward by supporting research and helping patients to have access to contribute to research.

Hopefully the next 75 years will lead to even greater triumphs, both in the social understanding and social acceptance of epilepsy. Despite progress, there remains work to be done on this front, but also in the understanding of the pathologies and available treatments. The people with epilepsy and their epilepsy professionals in 75 years' time will hopefully have access to a much better understanding of their conditions and many disease-modifying treatment options.

Dates for the diary

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

2025

5-29 August
XVIII Workshop on Neurobiology of Epilepsy (WONOEP 2025)
Cascais, Portugal
ilae.org/congresses/xviii-workshop-on-neurobiology-of-epilepsy-wonoep-2025

30 August-3 September
36th International Epilepsy Congress
Lisbon, Portugal
bit.ly/3uz1ARq

4-6 September
5th International Congress on Mobile Health and Digital Technology in Epilepsy
Copenhagen, Denmark
na.eventscloud.com/website/74027/home/

9-12 September
19th European Congress for Clinical Neurophysiology
London, UK
eccn2025-london.com

14 September
ILAE British Young Epilepsy Section (YES) Early Career Building Day
Bournemouth, UK
bit.ly/4e6tqax

15-17 September
ILAE British Branch Annual Scientific Conference
Bournemouth, UK
ilaebritishconference.org.uk

2026

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

5-9 September
16th European Epilepsy Congress
Athens, Greece
ilae.org/eec2026

Next issues:

Dr Bruna Nucera

Dr Nucera delves into epilepsy in the transgender population and best practice when it comes to treatment in these patients

Mr Michael Petrides

Mr Petrides describes the role of pharmacists in epilepsy management

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

kkountcheva@epilepsy.org.uk

Epilepsy Professional's advisory panel

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.

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