

# A FAIRER FUTURE FOR EPILEPSY

## WALES MANIFESTO 2026

Our manifesto sets out the **urgent changes** needed to ensure every person living with epilepsy in Wales gets the **care, support, and opportunities they deserve**. Inside, you'll find the five priorities that will help deliver a **fairer future for people with epilepsy** – because **no one's future should be limited due to epilepsy**.

**A CHARITY SUPPORTING**  
**36,000**  
**PEOPLE LIVING**  
**WITH EPILEPSY**  
**IN WALES.**

We work to improve access to care and treatment and to improve outcomes for people with epilepsy. We are the collective voice for the community to ensure they are heard and reflected in service design, national policy, and clinical practice, to achieve a world without limits.

People with epilepsy have told us their **5 PRIORITIES** the **2026 Senedd** needs to address.

These priorities can make a difference to improve the lives of everyone living with epilepsy in Wales to access the care and support they need. But first some more facts that show **why you need to care.**



## DO YOU KNOW THAT:

**1 in 88** people in Wales has epilepsy – higher than in England or Scotland.

In our survey of patients in 2024, only **57%** of patients have been referred to a specialist following first seizure.

All Health Boards in Wales fail to meet the NICE target of a **2-week** referral post-seizure (National Epilepsy Data Dashboard 2025 (NHS)).

Wales has only **14** epilepsy specialist nurses (ESNs) and **11** neurologists serving **36,000** people. Most neurologists do not specialise in epilepsy.

**Over 80%** of people with epilepsy report mental health challenges; 31% have experienced suicidal thoughts.

Poor access, deprivation, and geography are creating avoidable risk and inequality, costing Wales **£100m** per year.

# WE ARE ASKING PARTIES, SENEDD MEMBERS AND CANDIDATES TO PLEDGE TO SUPPORT THESE PRIORITIES IN 2026 SENEDD ELECTIONS.



# THE FIVE PRIORITIES

Our cheat sheet to help you understand the impact you can make to people's lives.

## PRIORITY 1

Ensure there is equitable access to the right care at the right time.



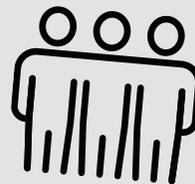
**The Welsh Government must:**

- As a minimum introduce a waiting-time guarantee for epilepsy care aligned to the Programme for Government
- Establish a Neurology Backlog Recovery Fund modelled on the National Neurodivergence Improvement Plan (Feb 2025).

## PRIORITY 2

Invest in a sustainable and equitable workforce to deliver epilepsy care.

**The Welsh Government must:**



- Increase the number of epilepsy specialist nurses (ESNs) to a minimum of 9 per 500,000 people, so everyone has access to an ESN.
- Ensure every Health Board has as a minimum, one consultant neurologist with a specialist interest in epilepsy.
- Implement a Welsh Epilepsy Workforce Plan with
  - a) funded ESN training bursaries, rural retention payments
  - b) a national recruitment drive for consultant neurologists specialising in epilepsy.

## PRIORITY 3

Timely access to mental health and counselling support.

**The Welsh Government must:**



- Ensure all newly diagnosed patients with epilepsy have a mental health screening assessment and are offered access to a counselling service within 6 weeks.
- Invest in third sector organisations such as Epilepsy Action to deliver early mental health interventions for people with epilepsy and support NHS service provision.

## PRIORITY 4

Reducing the impact that epilepsy has on health inequalities and social deprivation.



**The Welsh Government must:**

- Review the provision of services centred around the needs of people with epilepsy within rural and deprived areas, by introducing:
  - Community epilepsy hubs
  - Mobile clinics
  - Nutrition advice
  - Seizure safety training
  - Targeted outreach
  - Mental health support

## PRIORITY 5

Strengthen primary care intervention for people with epilepsy.



**The Welsh Government must:**

- Ensure every GP practice in Wales follows national guidance on epilepsy care and has clear, rapid referral pathways to neurology and specialist support.
- Acknowledge the need for GP training to support ongoing management of patients with epilepsy in primary care, and support the Waiting Well Policy.

# FURTHER INFORMATION

## PRIORITY 1

### INCREASE ACCESS TO THE RIGHT CARE AT THE RIGHT TIME (PRIMARY AND SPECIALIST CARE).

#### Why this matters:

Non-compliance with national guidance.

1. Recent data identifies that only 57% of patients are referred to a specialist service following first seizure
2. All health boards in Wales are failing to meet the NICE target of seeing patients within two weeks of a first seizure. All health boards record their activity in the national data base.
3. Delays in diagnosis lead to avoidable hospital admissions and £100 million in avoidable costs each year.



Reading about advanced epilepsy treatments elsewhere frustrated me because they felt out of reach in parts of Wales.

## PRIORITY 2

### BUILD A SUSTAINABLE AND EQUITABLE EPILEPSY WORKFORCE.

#### Why this matters:

1. There are 14 ESNs (mix of full and part-time) in post to cover the population of 36,000 people with epilepsy in Wales. That is less than 2 per 500,000 - not in line with national recommendations.
2. Large areas of Wales have no epilepsy specialist support available. Powys Teaching Health Board has no neurology service for a population of 133,000 people.
3. Patients feel “lost in the system” especially in rural and areas of deprivation. Many patients must travel for hours to access the care they need.



The advice sometimes ignored the reality of epilepsy care in Wales, like the lack of specialised epilepsy nurses in smaller hospitals.



There are always months between appointments, which makes it difficult to treat on a consistent basis, despite regular A&E visits.



The neurologist is not a specialist in epilepsy and the nurse are difficult to get hold of because they have too many patients each.

## PRIORITY 3

### TIMELY ACCESS TO MENTAL HEALTH AND COUNSELLING SUPPORT.

#### Why this matters:

1. 64% of people reported in 2024 that they waited up to six months for mental health support. Existing NHS pathways do not offer counselling support at a time of crisis.
2. Over 80% of people with epilepsy report mental health issues with 31% report suicidal thoughts.
3. Adoption of counselling support provided by Epilepsy Action has demonstrated significant positive outcomes with 100% of users recommending it. Our Counselling Service has also just been awarded Silver in the Best Mental Health Support Service in Wales.



The challenges I face in living life with epilepsy are as emotional as they are physical, and I cannot stress enough how vital providing extra support to help people with epilepsy in Wales live safer, freer lives would be.

## PRIORITY 4

### REDUCING THE IMPACT THAT EPILEPSY HAS ON HEALTH INEQUALITIES AND SOCIAL DEPRIVATION.

#### Why this matters:

1. The most deprived areas are served by Aneurin Bevan, Swansea Bay, Cardiff and Vale, Hywell Dda and Cwm Taf UHBs. This accounts for approximately 57.5% of the population of Wales.
2. People with epilepsy in rural areas such as the Valleys, Pembrokeshire and Powys, have little to no access to epilepsy services.
3. People with epilepsy consistently report that they cannot get to their appointments, due to the lack of public transport and financial issues. These missed appointments lead to worse outcomes and health risks.



There wasn't much discussion about managing epilepsy when Welsh ambulance wait times can be so long in rural areas.



I must travel to Glangwili (from Pembrokeshire) early in the morning for an appointment that is too short and infrequent.

## PRIORITY 5

### STRENGTHEN PRIMARY CARE INTERVENTION FOR PEOPLE WITH EPILEPSY.

#### Why this matters:

1. 43% of people were not referred to a specialist service following a seizure, despite national guidance.
2. GPs often lack access to consistent guidance or training on epilepsy, leading to misdiagnosis, delays, or inappropriate management.
3. Patients report difficulty getting appointments, being seen by clinicians with epilepsy expertise, and feeling unsupported between neurology reviews, which is a patient safety issue and increases demand on secondary care.



A lot of advice came from people in urban areas of England, which didn't always apply to rural Wales, where getting to a neurologist can mean hours of travel.

# PLEDGE FOR **SENEDD** MEMBERS

Ahead of the 2026 Senedd elections, we are asking all Members to pledge to commit to:

- Champion epilepsy services during the next Senedd.**
- Support our manifesto priorities through Senedd questions, briefings, and debates.**
- Meeting with people affected by epilepsy in their constituencies to understand their lived experience.**



**PLEASE HELP US BUILD A WORLD  
WITHOUT LIMITS FOR THE 36,000  
LIVING WITH EPILEPSY IN WALES.**