EPILEPSY ACTION
Cymru

04/07/2025

Thank you for the opportunity to provide an update to the Petitions Committee on the progress – and ongoing challenges – related to health services for people with epilepsy in Wales.

Since our original petition was submitted, Epilepsy Action has continued to work with people affected by epilepsy across Wales, as well as with clinicians and policymakers, to push for system-wide improvements in care. In May 2025, we published a new evidence-based report, Seizing Change*: A Review of Epilepsy Services in Wales (2025)*, which presents a stark picture of continuing gaps, despite the welcome attention the issue has received in the Senedd.

Key findings from the 2025 review:

- **Prevalence is increasing**, with an estimated **36,000 people** now living with epilepsy in Wales – a higher rate than in England or Scotland.
- **NICE guidelines are routinely missed**: only **57%** of patients are referred to a specialist clinic after a first seizure, and **all Health Boards** fail to meet the two-week target.
- There is a **severe workforce shortage**: Wales has just **14 Epilepsy Specialist Nurses (ESNs)** (some part-time) and **12.5 neurologists** to support tens of thousands of patients. Some Health Boards, such as Powys, have no dedicated Neurology services at all.
- **Mental health needs are not being met**: over **80% of people** report that epilepsy has negatively affected their mental health, with **31%** experiencing suicidal thoughts. Yet two-thirds wait **up to six months** for help.
- **Inequality is entrenched**: people in rural or deprived areas face serious barriers to care, including poor transport, missed appointments, long waits, and lower-quality support.

What patients told us:

People described trying to access epilepsy care in Wales as like “navigating a maze.” They spoke of:

- **Long travel times** to reach neurologists – often only available in urban centres;
- **Months between appointments** even for those with frequent seizures;
- **Poor communication and follow-up** between primary care and specialists;

- And a sense that epilepsy is “ignored” in the system compared to other long-term conditions.

Positive steps

We welcome the recent Senedd debate on epilepsy services, the support of Members such as Luke Fletcher MS, and the recognition that these issues deserve urgent attention. We are also proud of our pilot **epilepsy counselling service**, funded through the National Lottery, which has supported over 100 people with specialist mental health input and received 100% positive feedback.

What still needs to happen

Despite these developments, we remain deeply concerned about the pace of change. We are calling on the Welsh Government to:

1. Introduce a **waiting-time guarantee** for epilepsy referrals and treatment;
2. Fund a **national epilepsy workforce plan**, including ESNs and specialist neurologists;
3. Expand access to **third-sector mental health support**;
4. Tackle **epilepsy inequalities** in rural and low-income communities;
5. Strengthen **primary care pathways** and referral guidance.

These measures are not only urgent, but cost-effective. Delayed care currently results in avoidable A&E attendances, missed employment, and poorer outcomes – costing Wales an estimated **£100 million per year**.

We hope Members will consider these findings carefully and recommend stronger action from the Welsh Government. We would welcome the opportunity to present the report to the Committee in more detail if useful.

Thank you once again for your continued support for people with epilepsy in Wales.