

SEIZING CHANGE

A REVIEW OF EPILEPSY
SERVICES IN WALES



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INTRODUCTION

In 2022, we published a powerful report exposing the critical gaps in epilepsy services across Wales, with a spotlight on the severe shortage of specialist healthcare professionals. Shared with every health board, the report was subsequently picked up by Member of the Senedd (MS) Luke Fletcher who raised the issue directly in the Senedd. In turn, the Cabinet Secretary for Health and Social Care was pressed to respond, providing much-needed clarity and accountability on the provision of epilepsy care.

This momentum grew stronger in 2023, when Luke Fletcher MS successfully secured a dedicated Senedd debate on epilepsy services – a major milestone in our advocacy efforts. During the debate, seven additional MS's joined the call for change, highlighting the urgent need for better care, stronger services, and serious investment in the specialist workforce that people with epilepsy deserve.

This report summarises the findings from the 2025 review.



SO WHERE ARE WE IN 2025?



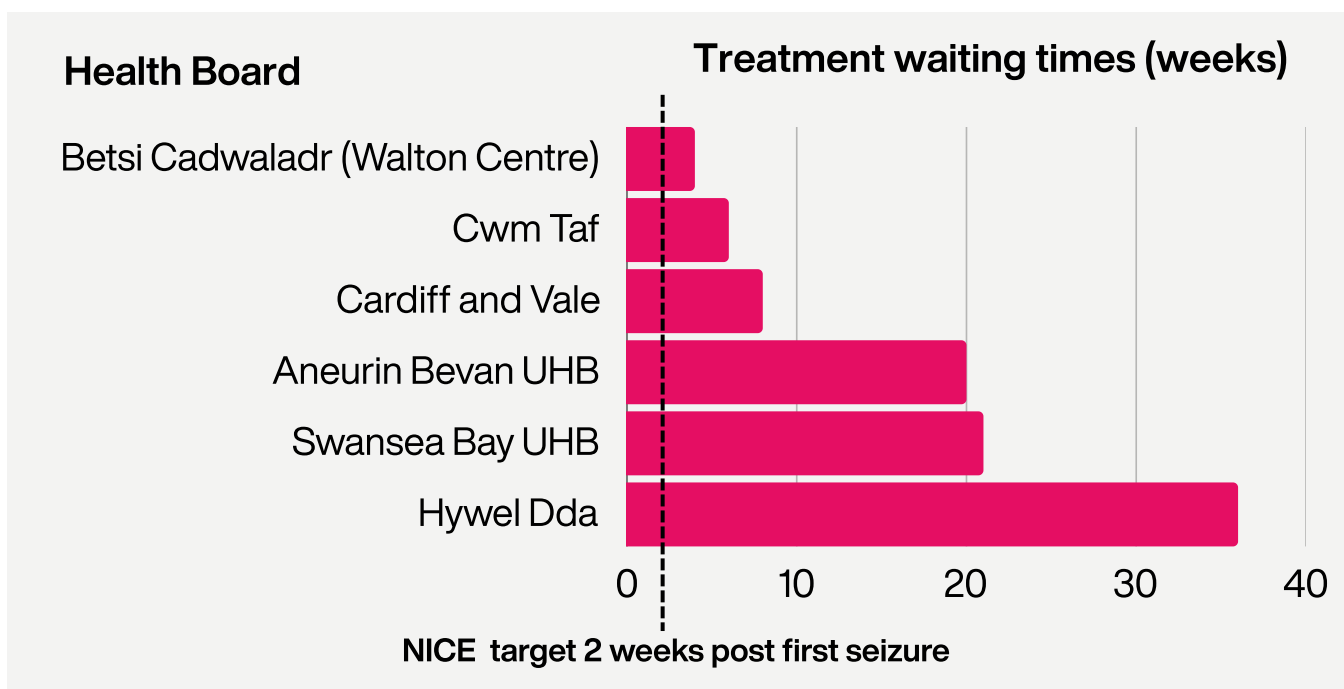
**1 IN EVERY 88 PEOPLE IN
WALES HAS EPILEPSY**

That is a total of 36,000 patients, an increase on 2022 (32,000). This is a higher prevalence than England or Scotland.

- 20% of people with epilepsy will be taken to an emergency department
- 50% will require hospital admission
- 43% of patients are not referred to any kind of specialist service following a seizure

The economic burden caused by disruption to people's lives, poor scheduled and unscheduled care, time off work, inability to get an appointment costs £100 million per year in Wales. NHS Wales targets treatment within 26 weeks, but reports indicate that many patients are waiting far longer.

All Welsh Health Boards miss NICE targets of seeing patients within two weeks of a first seizure.



WHAT ARE PATIENTS TELLING US?

We asked people with epilepsy in Wales to share their experiences of accessing health and social care services. They highlighted challenges similar to trying to navigate a maze: difficulties with transportation in rural areas, long waits that feel like endless queues, and a shortage of staff, like a team too small to manage the growing crowd.

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.

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

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

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



WHAT'S YOUR EXPERIENCE OF ATTENDING EPILEPSY CLINICS AT YOUR LOCAL HEALTH BOARD?

None are in Pembrokeshire. I must travel to Glangwili early in the morning for an appointment that is too short and infrequent.

DO YOU HAVE EXPERIENCE OF WAITING A LONG TIME TO ACCESS SERVICES?

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

DO YOU FEEL THERE ARE ENOUGH STAFF TO SUPPORT YOU WITH YOUR CONDITION IN YOUR AREA?

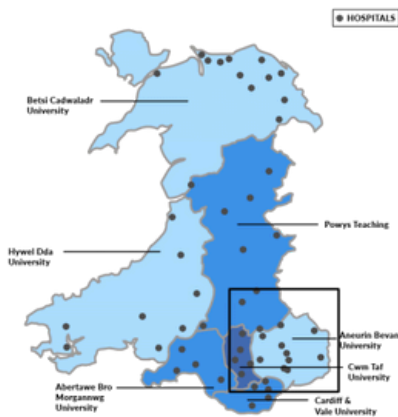
The neurologist is not a specialist in epilepsy and the nurse are difficult to get hold of because they have too many patients each

WORKFORCE CRISIS IN WALES CONTINUES

There is an extreme shortage of neurologists, especially those with a specialist knowledge in epilepsy, and epilepsy specialist nurses (ESNs) in Wales.

There are only 14 ESNs (three are part time) and 11 neurologists serving a population of 35,953 people. Some of the neurologists do not even specialise in epilepsy.

Aneurin Bevan UHB



- Ysbyty Ystrad Fawr (YTF)
- Ysbyty Aneurin Bevan (YAB)
- Ysbyty'r Tri Chwm (YTC)
- Nevil Hall Hospital
- County Hospital
- St Cadoc's Hospital
- St Woolos Hospital
- Royal Gwent Hospital
- Chepstow Community Hospital
- Monmouth Hospital (Monnow Vale)

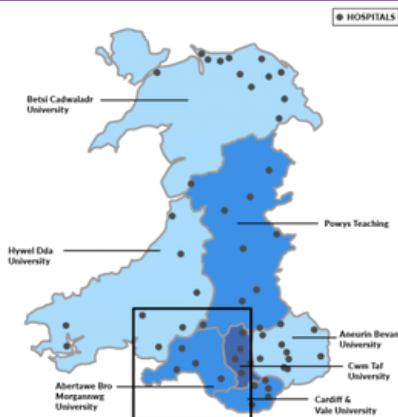
Number of people with epilepsy 6,200

Number of ESNs
2022 4
2025 4

Number of neurologists 2

Total number ESNs required 2025 2

Swansea Bay University Health Board



- Morriston Hospital
- Singleton Hospital
- Neath Port Talbot General Hospital
- Princess of Wales Hospital

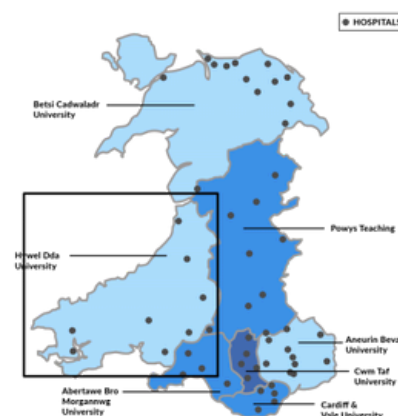
Number of people with epilepsy 5000 adults

Number of ESNs
2022 4
2025 2.5

Number of neurologists 3

Total number ESNs required 2025 11

Hywel Dda UHB



- Bronglais General Hospital
- Tregaron Community Hospital
- Llandovery Hospital
- Amman Valley Hospital
- Prince Philip Hospital
- Glangwili General Hospital
- Withybush General Hospital
- South Pembrokeshire Hospital

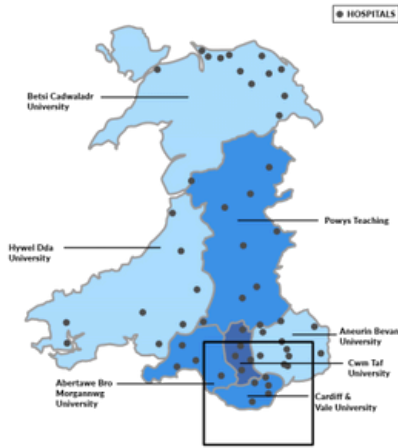
Number of people with epilepsy approximately 3,856 adults

Number of ESNs
2022 3
2025 2

Number of neurologists 0

Total number ESNs required 2025 8

Cardiff and Vale UHB



- Barry Community Hospital
- Rockwood Hospital
- University Hospital of Wales (UHW)
- St David's Hospital
- University Hospital Llandough

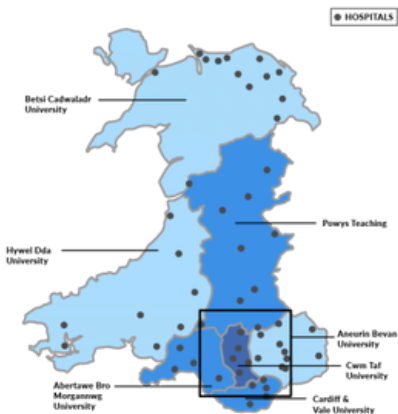
Number of people with epilepsy 5000 adults

Number of ESNs
2022 4
2025 5

Number of neurologists 3

Total number ESNs required 2025 9

Cwm Taf UHB



- Royal Glamorgan Hospital
- Pontypridd Cottage Hospital
- Ysbyty Cwm Rhondda
- Ysbyty Cwm Cynon
- Prince Charles Hospital

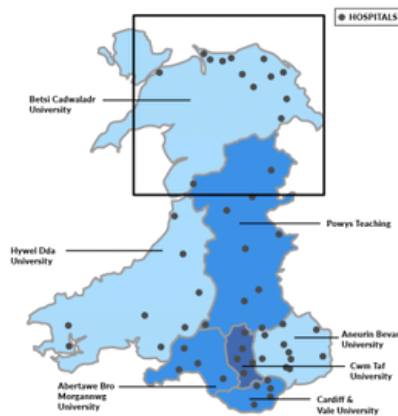
Number of people with epilepsy 4,500

Number of ESNs
2022 2 Pediatricians
0 Adult service
2025 1 Pediatricians
0 Adult service

Number of neurologists

Total number ESNs required 2025 5

Betsi Cadwaladr UHB North Wales



- Ysbyty Gwynedd
- Llandudno General Hospital
- Colwyn Bay Hospital
- Abergel Hospital
- Glan Clwyd Hospital
- Denbigh Community Hospital
- Ruthin Community Hospital
- Holywell Community Hospital
- Mold Community Hospital
- Deeside Community Hospital
- Wrexham Maelor Hospital
- Chirk Community Hospital

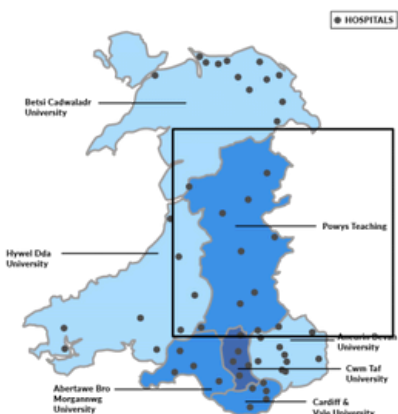
Number of people with epilepsy approximately 5,020 adults with epilepsy

Number of ESNs
2022 5
2025 5

Number of neurologists 4

Total number ESNs required 2025 9

Powys THB



- Ystradgynlais Community Hospital
- Brecon War Memorial Hospital
- Bronllys Hospital
- Llandrindod Wells Hospital
- Llanidloes War Memorial Hospital
- Machynlleth Community Hospital
- Welshpool Hospital (the Victoria Memorial)
- Newtown Hospital
- Knighton Hospital

Number of people with epilepsy provides services to a total population of 133,000 (no available information about epilepsy population)

Number of ESNs
2022 No dedicated neurology service
2025 No dedicated neurology service

Number of neurologists 0

Total number ESNs required 2025 2

WHAT IS THE DATA TELLING US?

Since the 2022 report, we have gathered and reviewed new data from various sources, including Epilepsy Action's national surveys and Welsh Government statistics against health inequalities, mental health, and healthcare delivery.

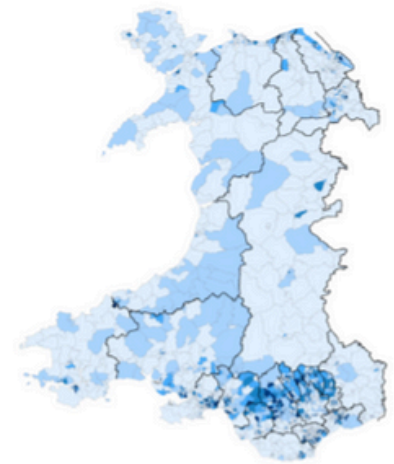
RISK TO PATIENTS

Impact of Health Inequalities associated with Epilepsy

1. Living Conditions and Financial

Difficulties: A significant number of patients with epilepsy reside in socially deprived areas, often facing financial difficulties. These challenges contribute to poor attendance at scheduled hospital appointments, leading to delayed treatment reviews and reduced access to necessary support.

Overall



2. Consequences of Poor Attendance:

The inability to attend medical appointments on time can result in a lack of timely treatment adjustments and continuous care, potentially exacerbating the condition and increasing the risk of complications.

By Lower Super Output Areas



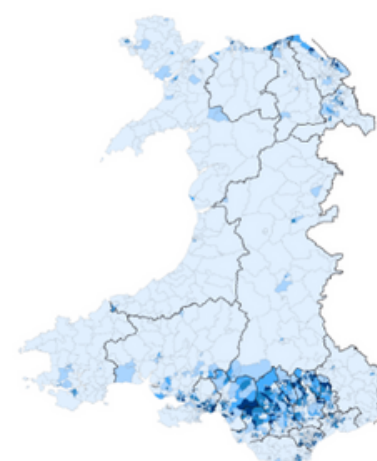
3. **Low Income and Nutrition:** Low income in these populations often results in poor nutrition, which can directly and indirectly impact health. In the context of epilepsy, inadequate diets may worsen symptoms, hinder effective management, and contribute to other health complications. Addressing nutritional challenges is vital to improving outcomes and ensuring comprehensive care for individuals with epilepsy.
4. **Geographical Impact on Services:** 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 people with Wales.

Implications for Healthcare

- **Targeted Interventions:** Addressing the healthcare needs of socially deprived populations with epilepsy requires targeted interventions that consider both the social determinants of health and the medical aspects of epilepsy care.
- **Nutritional Support:** Incorporating nutritional guidance and support into epilepsy care plans, especially for those in deprived areas, could potentially improve outcomes by addressing one of the underlying contributors to poor epilepsy management.
- **Accessibility:** Improving accessibility to healthcare services, including flexible appointment scheduling and community-based support, could help reduce the barriers faced by these patients.

Health



By Lower Super Output Areas

Most deprived	Rank
	1 to 191
	192 to 382
	383 to 573
	574 to 955
	956 to 1909
Least deprived	

MENTAL HEALTH AND EPILEPSY


People with epilepsy are significantly more likely to experience mental health challenges, with rates of depression and anxiety higher than in the general population.

To better understand the impact of epilepsy on mental health, Epilepsy Action conducted a national survey between January and February 2024, which included responses from Wales.


A total of 1,646 individuals participated in the survey. Over 80% of respondents reported that their mental health had been affected by their epilepsy.



1646
responses



85%
reported anxiety and
70% experienced
depression



69%
said epilepsy limited
their independence



50%
reported feeling
lonely or isolated



64%
waited up to six
months for support



31.1%
reported having
suicidal thoughts



SPECIALIST COUNSELLING SERVICES

100%

of Epilepsy Action counselling service users rated this service as excellent.

100%

said that they had started making changes in their lives

100%

would recommend this service to others

In response to long NHS waiting times for mental health support and the heightened psychological impact of epilepsy, Epilepsy Action secured National Lottery funding to establish a dedicated counselling service in Wales.

The service offers timely access to specialist, tailored support for people affected by epilepsy. It ensures early intervention, reduces reliance on overstretched statutory mental health services, and has evaluated well in meeting the needs of service users.



TIME TO ACT

This report shines a spotlight on the ongoing challenges in the delivery of epilepsy care in Wales. To build on this momentum and drive lasting change, we are setting out the following key recommendations:

1 Meeting National Guidelines

That all patients presenting with a suspected first seizure are seen in a specialised clinic within two weeks. Only 57% of patients currently are.

2 Workforce

Increase Epilepsy Specialist Nurses (ESNs) to meet NICE standards (9 per 500,000 people).

Increase neurologist numbers to at least the UK average of 2 per 100,000, with ambition towards international best practice (4 per 100,000).

3 Primary Care

Have in place:

a) clear referral pathways between primary care and neurology in partnership with NHS leaders and health boards.

b) national GP guidance and education on epilepsy management, referral criteria, and routine care.

430%

OF PATIENTS AREN'T GETTING
REFERRED TO ANY KIND OF
SPECIALIST SERVICE
FOLLOWING A SEIZURE

4 Data Collection

Review epilepsy data collection to include quality indicators, outcomes, and demographic factors such as deprivation.

That the data is available across service providers and relevant third sector organisations.

5 Mental Health

Invest in specialist counselling services for people with epilepsy, including those provided by Epilepsy Action. Expand access to neuropsychology and neuropsychiatry services.

6 Social Deprivation

Deliver targeted interventions in deprived areas to improve healthcare access, tackle social determinants of health, and provide nutritional support.



