

# Improve health service for people with epilepsy living in Wales

Y Pwyllgor Deisebau | Mawrth 2021  
Petitions Committee | March 2021

Reference: SR221851-2

Petition Number: P-06-1240

Petition Title: Improve health services for people with epilepsy living in Wales.

**Text of petition:** We are concerned that the current services for people with epilepsy living in Wales are not providing people with the help and support they need. Epilepsy Action recommends a caseload of no more than 250 people per Epilepsy Specialist Nurse (ESN), in order to minimise the effects of their condition and provide the best possible care. Currently no area in Wales is meeting this recommendation. There is a lack of ESNs and waiting times to see neurologists are over 12 months in many areas.



# 1. Background

Almost **1 in 100 people** in the UK have epilepsy. In Wales, **approximately 32,000 people** have epilepsy.

Epilepsy is a **neurological condition** that affects the brain and causes seizures or unusual sensations and behaviours. Epilepsy can start at any age and there are many different types. Some children will outgrow the condition as they age. But for many people epilepsy is a life-long condition. Further details are available on [the Epilepsy Action Cymru website](#).

Treatment can control epileptic episodes. Epilepsy medicines can't cure epilepsy but Anti-Epileptic Drugs (AEDs) **can help to stop or reduce the number of seizures**. Other types of treatment include brain surgery, or a special diet (the ketogenic diet) can sometimes be used for children.

**Epilepsy Specialist Nurses (ESNs)** play a significant role in the care of people with neurological disorders such as epilepsy.

The previous Welsh Government published a [Neurological Conditions Delivery Plan](#) in 2017. A Neurological Conditions Implementation Group was set up to oversee the delivery plan and to support Health Boards and partners to deliver their local plans.

The Neurological Conditions Implementation Group, which covers conditions including multiple sclerosis, motor neurone disease, epilepsy, Parkinson's disease, muscular dystrophy and Acquired Brain Injury sits within the **NHS Wales Health Collaborative** (a national organisation working on behalf of the health bodies that make up NHS Wales).

The Welsh Government hasn't updated the Neurological Conditions Delivery Plan. Instead, [the Welsh Government's National Clinical Framework \(NCF\)](#) published in March 2021, describes how clinical services (such as neurological conditions) will be supported by a range of **quality statements** that set out high-level policy intentions and describe the standards and outcomes expected of clinical services. A quality statement on neurological conditions hasn't yet been published.

## 2. Welsh Government action

In her response to the Chair of the Petitions Committee, the Minister for Health and Social Services, Eluned Morgan MS says the Welsh Government is “continuing to work with the **Neurological Conditions Implementation Group (NCIG)** to improve services for all those with neurological conditions across Wales, including epilepsy”. The Minister sets out a number of priorities the NCIG is currently working on including:

- Developing a **data dashboard for epilepsy**; to support business cases for developing services and support for people with epilepsy going forward.
- Developing a **quality statement for neurological conditions**; setting out expectations of how people with neurological conditions can be better supported.
- **Liaising with the UK Department of Health and Social Care**; to ensure the UK Government’s strategy on neurological conditions takes into account that health services are devolved in Wales.

The Minister makes clear that **Health Boards and Trusts remain responsible for planning and delivering services** for those with neurological conditions including epilepsy.

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