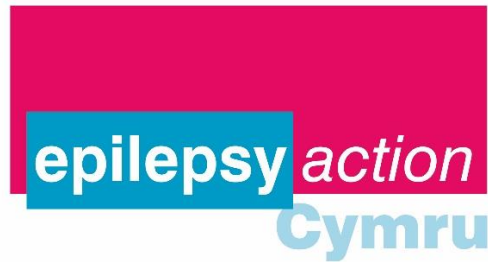


P-06-1240 Improve health services for people with epilepsy living in Wales –  
Correspondence from the Petitioner to the Committee, 18 February 2022



The response from Eluned Morgan, Minister for Health and Social Services, does not adequately address the concerns raised by the petition, or indeed wider concerns about the lack of epilepsy services across Wales and the urgent need to ensure that each Health board and trust has a properly funded, staffed and resourced epilepsy service.

While we welcome information around the work of the Neurological Conditions Implementation Group (NCIG) and the National Clinical Framework, neither of these represent the real and immediate need for improvements to epilepsy services in Wales, where many people are currently facing waits of 12 months or more to see a neurologist.

As highlighted by the petition, a cost-effective and quick way to address the issues around epilepsy services in Wales is to significantly improve the number of ESNs.

Epilepsy is a complex, long-term condition and because of this at least 60% of people with epilepsy will require ongoing access to an ESN. The NICE guidelines recommend that all patients with epilepsy have access to an ESN. The role of the ESN involves managing and adjusting medication, education of people with epilepsy, promoting self-management, education of carers and family, interception of emergency admissions and urgent clinic appointments through telephone calls. One study has shown that the appointment of a new ESN reduced A&E attendances for people with epilepsy by 50%.

Around 52% of those with the condition will go on to become seizure free with currently available treatments – but this number could be higher with better care and treatment. Those whose seizures cannot be controlled with existing treatments continue to face additional risks due to their epilepsy. Each year epilepsy is linked to over 100,000 unplanned hospital admissions and 1000 early deaths in the UK. As many as 40% of these deaths could be prevented.

The Minister's reply makes no reference to any government plans to address the lack of ESNs, or to reduce the caseload of current ESNs. NICE guidelines state that all patients with epilepsy should have access to an epilepsy specialist nurse. We have listed the number of adult and paediatric epilepsy specialist nurses in each Health Board below:

- Aneurin Bevan University Health Board – 1 full time and 2 part time adult ESNs (however, one of the part time nurses is leaving soon), 4 part time paediatric ESNs
- Betsi Cadwaladr University Health Board – 1 adult ESN and 3 paediatric ESNs

- Cardiff & Vale University Health Board – 3 WTE adult ESNs and 1 WTE paediatric ESN
- Cwm Taf Morgannwg University Health Board – 0 adult ESNs, 2 paediatric ESNs
- Hywel Dda University Health Board – 1 full time and 1 part time adult ESNs, 1 paediatric ESN
- Powys Teaching Health Board – 0 ESNs
- Swansea Bay University Health Board – 2 adult ESNs and 2 paediatric ESNs

The petition also highlighted that Epilepsy Action recommends a caseload of no more than 250 people per Epilepsy Specialist Nurse (ESN), to minimise the effects of their condition and provide the best possible care. In addition, Welsh government's own Steers report in 2008 recommended a ratio of 300:1 and recommendations from the Royal College of Physicians and the Association of British Neurologists suggested a minimum of 9 ENS per 500,000 population, a ratio of 550:1. Based on the ESN figures above, and the number of people in Wales who have epilepsy, the current caseload in Wales is 2195 patients per adult ESN. It is therefore clear that the target caseload is not being met. Implementing the Steers report recommendations would mean that Wales should have **70** ENS and urgent action is needed to address this service gap.

[The ESPENTE report](#) shows the long-term savings through having an adequate number of ESNs, in addition to saving physician's time. For example, the report highlighted the role of two specialist epilepsy nurses at University Hospital Cardiff, where patients suspected of having an epileptic seizure are seen by one of two specialist epilepsy nurses within 4 hours of arriving at the accident and emergency department. Patients received a review before being referred to an enhanced first seizure clinic. It is a system that has already saved £45,000 in its first year. A US-based study undertook a cost effectiveness analysis of a shared assessment clinic with a physician working alongside a nurse specialist. The evaluation found that physician time was reduced by 66% and the cost of a clinic visit was reduced by 39% by using the expert nurses.

One [study](#) showed that 70% of patients with epilepsy attending clinics run by ESNs had previously unidentified problems successfully resolved by the nurse including misdiagnosis, overmedication and lack of awareness of drug adverse effects.

The epilepsy health professionals that we have spoken to are all open to recruiting nurses with generic skills and upskilling them to specialist nurse level and beyond, where those with particular skill set are not yet available. They are keen for this to happen sooner rather than later. We recognise that the final report of the Review of

Neurology Services is yet to be published with workforce included in its remit, but we feel that urgent action is needed to improve the care of people with epilepsy and reduce pressures on both the specialist epilepsy workforce and neurology waiting lists.

This [study](#) highlights the valuable role that an Open Access Model run by ESNs can play in optimising the care of people with epilepsy – “These interventions by the ESN prevented 268 clinic appointments over 3 months. At a cost of £130 per clinic appointment, this extrapolates to a potential saving of £34,840 in three months, or £139,360 annually.”

In addition to concerns around a lack of ESNs across Wales, there are further concerns about the need for more consultant neurologists in addition to increased funding for services across all health boards in the country. While addressing these issues remains important, it will take longer to do, and so increasing the number of ESNs across all health boards in Wales would be a way to start addressing these issues in the short-medium term.

Kind regards

A handwritten signature in blue ink that reads "J. Paterson". The signature is written in a cursive style with a large initial 'J'.

Jan Paterson  
Wales Manager for Epilepsy Action Cymru