

Northern Ireland – Epilepsy briefing

In Northern Ireland approximately **20,000 people have epilepsy**. Epilepsy can affect anyone at any age and from any walk of life. 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.

Epilepsy Action Northern Ireland:

- Raises awareness and increases understanding of epilepsy
- Lobbies and campaigns for a better future for people with epilepsy
- Supports people through our network of volunteers, branches and groups
- Organises information events for both people living with epilepsy and health professionals
- Provides counselling to adults with epilepsy, carers and parents of people with epilepsy

Ahead of the elections in May, we are highlighting the main issues affecting people with epilepsy in Northern Ireland and asking that you commit to addressing these issues.

Healthcare

Epilepsy services in Northern Ireland are experiencing a severe lack of resources and funding, which is having a serious impact on the level of healthcare people with epilepsy are receiving.

Northern Ireland currently has the **longest waiting times for services** in the UK. We have heard from people in Northern Ireland who have been told they have to wait years to see a neurologist, including people newly diagnosed or waiting a diagnosis of epilepsy. NICE Guidelines recommend that people with a suspected diagnosis of epilepsy be seen by a neurologist within two weeks, but the current waiting times are far from meeting these standards and clearly unacceptable.



Epilepsy services in Northern Ireland are experiencing a severe lack of neurologists and particularly epilepsy specialist nurses (ESNs).

At present there are:

- Two full time ESNs (based at the Royal) covering the adult epilepsy population in the Belfast Trust, Northern Trust and South Eastern Trust. The epilepsy specialist nurse team in Belfast also provides the only epilepsy specialist midwifery services in Northern Ireland and they also oversee the UK epilepsy and pregnancy register.
- One full time (Altnagelvin) and one part time (Omagh) ESN covering the adult population in the Western Trust
- A new team of five ESNs covering both the adult and learning disability epilepsy population in the Southern Trust (St Luke's).

It is recommended that there a caseload of no more than [250 people per ESN](#) in order to minimise the effects of the condition and provide the best possible care and, as you can see, we are a long way off that number.

[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 cost effectiveness analysis of a shared assessment clinic with a physician working alongside a nurse specialist 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.

Increasing the number of ESNs would be a cost effective way of making immediate improvements to epilepsy services in Northern Ireland.





To improve outcomes for people with epilepsy we are asking you to commit to supporting the following measures:

- Urgent action from the government and the Department of Health on addressing the length of waiting lists
- Increase in staffing and resourcing of epilepsy services – particularly epilepsy specialist nurses and neurologists – and encouraging best practices to better utilise existing resources – such as Open Access systems
- Call on Stormont to introduce the 3 year budget
- Proper support and funding for the Review of Neurology Services
- Ensure people with epilepsy have access to mental health services

Welfare

Too many people with epilepsy are not getting the help and support they need through PIP. The current PIP assessment process is not working for people with epilepsy.

The process does not properly assess the impact epilepsy has on an individual's daily life. The assessment is not able to capture and reflect the nature of epilepsy. Too many people with epilepsy are not successful in their initial assessment for PIP and are forced to go through the **lengthy and stressful appeals system** to get the support they should be entitled to.

In order to ensure people with epilepsy get the support they need through PIP Epilepsy Action is calling on the government to make changes to the current process:

- People with epilepsy should be assessed by someone who has a proven understanding of the condition.
- The PIP form is too complicated to fill in. The form should be simplified and additional support to complete them should be provided to those most in need.
- Allow people the choice of whether their assessment takes place face-to-face, or by telephone or video.
- Improve feedback from successful appeals to assessment providers, to ensure that the correct decision is made at initial assessment and people are not forced to go through mandatory reconsideration and appeals.
- End of the use of informal observations as part of the assessment process

Employment

People with epilepsy have one of the lowest rates of employment among disabled people. **Just over a third (34%)** of people with epilepsy are in employment.

Northern Ireland had the **lowest employment rate for disabled people - 37.8%**. The **disability employment gap for NI in 2020 was 42.2%**, compared to 27.9% for the whole of the UK. Since 2014, the disability employment gap has consistently been higher in Northern Ireland than the rest of the UK.

Research by the Trade Union Congress (TUC) has also highlighted that **people with epilepsy**

in work are paid on average 11.8% less than non-disabled workers. This means that not only are people with epilepsy less likely to have a paid job, but when they do, they earn less than their non-disabled peers.

Epilepsy Action is therefore calling for the Government to:

- Introduce mandatory disability employment and pay gap reporting for employers – including reporting on the employment gap for specific impairment groups
- Introduce measures to support the job retention of people with disabilities, as staying in work can be as important as finding employment
- Provide more focused employment support for people with hidden and fluctuating conditions and better support for people with epilepsy from Disability Employment Advisers - including ensuring that job coaches with training and understanding of epilepsy, and the employment barriers they face, are available to people with the condition
- Introduce requirements to report the experiences of disabled people who work at the company and those who have unsuccessfully applied for a role
- Consider organisations' employment practices regarding disability equality when making funding and procurement decisions
- Extend the full range of statutory employment rights to all workers, regardless of employment status or type of contract



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