

Epilepsy Action

# MANIFESTO 2024



**HEALTH AND  
SOCIAL CARE**



**JUSTICE**



**WORK AND  
BENEFITS**

There are **630,000** people living with epilepsy in the UK.  
**This is what they want from the next government.**



## HEALTH AND SOCIAL CARE

Epilepsy to be prioritised within health and social care and the shortage of specialist nurses and neurologists to be addressed.

**Our country has one of the worst ratios of neurologists to patients. Only Ireland and Uzbekistan have worse ratios amongst high-income countries.**

p3-7



## JUSTICE

Justice for the most vulnerable people with epilepsy.

**The prevalence of epilepsy among prisoners is more than twice that of the general population and in the last 18 years, 19 people with epilepsy died in UK prisons.**

p8-13



## WORK AND BENEFITS

Empower people to access work and benefits so that people with epilepsy are able to live independently.

**Only 42% of people with epilepsy are in work. And of those who do work, 60% face discrimination.**

p14-18



# HEALTH AND SOCIAL CARE

## The problem:

Epilepsy services remain underfunded, understaffed and under resourced.

- There are 1.1 full-time-equivalent neurologists per 100,000 people in England. Both France and Germany have one consultant for 25,000 people or fewer.
- NICE recommends that for a population of 500,000, nine Epilepsy Specialist Nurses (ESNs) should be available. Epilepsy Action's research shows there are about 230 ESNs in England, equating to two ESNs for 500,000 people.

## The change we need:

- Urgent investment in epilepsy and wider neurology services to reduce waiting times in line with NICE guidance.
- Recruit and develop a sustainable workforce. We need enough neurologists and ESNs to provide sustainable epilepsy services. To match France we need 1,156 new roles by 2030.





# HEALTH AND SOCIAL CARE

## **The problem:**

People with epilepsy struggle to access timely healthcare and treatment. They do not have a strong voice in the neurological community.

## **The change we need:**

Alongside the Neurological Alliance, we are calling for a national Neuro Taskforce. This will strengthen the voice of people with epilepsy. We want the Department of Health and Social Care to endorse the Neuro Taskforce.





# HEALTH AND SOCIAL CARE

## **The problem:**

Living with epilepsy has a psychological impact on an individual's mental health. According to a 2024 report from Epilepsy Action:

- 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

*While Epilepsy Action supports the NHS by providing an effective counselling service in Northern Ireland and Wales, there is no equivalent in England.*

## **The change we need:**

- Integrated Care Boards and Integrated Care Systems must ensure mental health safety is a requirement when planning services, care and treatment.
- Mental health assessments and referrals to be regular and appropriate.





# HEALTH AND SOCIAL CARE

2024

2025

2026

2027

2028

2029

2030

2031

2032



**By 2026 we need:**

A Neuro Taskforce to prioritise epilepsy in health and social care.



**By 2030 we need:**

An increase in the number of epilepsy specialist nurses and neurologists.



# HEALTH AND SOCIAL CARE

## VICKY

*I had my first two seizures in December 2022. I ended up being referred to the neurology services at two different hospitals.*

*I started telephoning both hospitals at the start of the following year, to find out where I was on the waiting list and who could offer me the earliest appointment. I recall being told my appointment would take place towards the end of the year due to severe backlogs.*

*I was scared to go out of the house in case I had another seizure and I started to suffer with severe anxiety. My partner mentioned trying to fund neurology care privately, as there was no way of telling how long it would be before I got an appointment with the NHS, let alone a diagnosis, and we were both extremely concerned. I didn't want to go down the private route because of the cost, but to us, there was no other option.*

*I want the new government to improve waiting times and support the NHS as a key priority.*





# JUSTICE

## **The problem:**

An estimated 20,000 children have been harmed by sodium valproate, some of whom require 24-hour care. Both the Cumberlege Report (2021) and the Hughes Report (2024) recommend a redress scheme to provide financial help to affected families. Despite this, no significant progress has been made.

## **The change we need:**

Implementation of the sodium valproate compensation scheme.







# JUSTICE

## **The problem:**

In the last 18 years, at least 19 people with epilepsy have died in prison. There have been at least six deaths in police custody in the same period.

The root cause is a lack of awareness and inappropriate management. This is more than one death per year. Every death is one too many.

## **The change we need:**

We are supporting INQUEST's No More Deaths campaign, calling for a National Oversight Mechanism: an independent public body that collates, analyses and follows-up on recommendations arising from inquests, inquiries, official reviews and investigations into state-related deaths. We need the government to support and implement this campaign.

**NO MORE  
DEATHS**





# JUSTICE

## **The problem:**

The prevalence of epilepsy among prisoners is more than twice that of the general population. Police and prison staff lack awareness, which puts people with epilepsy at risk.

## **The change we need:**

Epilepsy awareness and first aid training to be part of mandatory training for police officers and prison staff.





# JUSTICE

## **The problem:**

Many police forces do not include a recognised risk factor for epilepsy in their missing persons policies, despite the increased risks.

## **The change we need:**

Police force missing persons policies to recognise the increased risks of having epilepsy.





# JUSTICE

2024

2025

2026

2027

2028

2029

2030

2031

2032



**By 2026 we need:**

A sodium valproate compensation scheme.



**By 2030 we need:**

No more epilepsy deaths in prisons.



# JUSTICE

## PRISONS

*We want the next government to protect prisoners with epilepsy, who are too often forgotten about.*

*Epilepsy Action is aware of two recent deaths of prisoners with epilepsy, linked to concerning failures within the system.*

*In one instance we are aware of, a prisoner had been prescribed and administered medication, but 40 days' worth, unused, was found in their cell after their death. The prisoner had no care plan and no seizure diary. If the communication between prisoner, medical professionals and prison staff had been better, this prisoner might not have died.*

*We are also aware of a prisoner with epilepsy who took his life in prison after his mental health deteriorated. At his inquest, the coroner raised concerns about the lack of processes in place to ensure prisoners took their medication as prescribed.*

*We know that prisoners feel anxious when collecting medication and avoid it for fear of safety in the prison environment. We also know that communication between medical professionals and prison staff is often lacking. What we don't know is how many more vulnerable prisoners with epilepsy will die before the government acts.*





# WORK AND BENEFITS

## **The problem:**

People with epilepsy are less likely to have a paid job, and when they do, they earn less. Only 42% of people with epilepsy are in work – one of the lowest rates of employment among disabled people. People with epilepsy in work are paid 12% less than non-disabled peers. They also face discrimination in the workplace. The latest survey by Epilepsy Action (2023) showed:

- 60% faced discrimination at work
- 42% of employers would avoid hiring someone with epilepsy to save their company potential challenges
- 40% said their employer refused to provide reasonable adjustments
- 36% have heard derogatory comments about their epilepsy from a colleague, manager or employer
- 33% have been bullied because of their condition
- 28% have been in disciplinarys for having seizures.





# WORK AND BENEFITS

## The change we need:

- Mandatory disability employment and pay-gap reporting.
- Jobcentre Plus Disability Employment Advisers to use available, skilled job coaches to support people with hidden and fluctuating conditions.
- To ensure the Equality Act (and Disability Discrimination Act 1995 in Northern Ireland) is fit for purpose.
- A minimum fine for any employer discriminating against disabled employees. This should be a percentage of the employer's annual turnover. The government should ensure the proceeds of these fines are given to the victims of discrimination.





# WORK AND BENEFITS

## **The problem:**

Many people with epilepsy are unable to drive because the DVLA and DVA (Driver and Vehicle Agency) require people to be seizure free for 12 months. This means they rely on public transport. Over the past two years, cuts to bus and train services have left people with epilepsy isolated.

Many places do not acknowledge the use of a disabled bus pass before 9.30am. This means travel to work is compromised.

## **The change we need:**

A disabled bus pass should be available at all times of the day, across the UK.







# WORK AND BENEFITS

## **The problem:**

People with epilepsy, like many others with a disability, already face higher daily costs because of their condition – but many are not being granted Personal Independence Payment (PIP). The process of applying for PIP is repeatedly failing people with epilepsy as the criteria overlooks critical challenges people with the condition face, such as the side effects of epilepsy medications or the injuries that can be incurred as a result of seizures.

Being refused daily living allowance means claimants cannot access further benefits, such as the enhanced disability premium, council tax relief and housing benefit deductions. At a time when people with epilepsy are already feeling the weight of increased financial pressure, PIP assessments need to take into account the intricacies of individual conditions to be fit for purpose.

## **The change we need:**

The PIP assessment system must take into account the needs of a fluctuating condition and the higher costs of living with a disability.





# WORK AND BENEFITS

2024

2025

2026

2027

2028

2029

2030

2031

2032



**By 2026 we need:**

Mandatory disability employment and pay-gap reporting.



**By 2030 we need:**

The employment rate for people with epilepsy to increase to more than 60%.



# WORK AND BENEFITS

## HEATHER

“ I think what unifies a lot of people with epilepsy in the workplace is the employer’s fear around the condition. I have been told after a period of sick leave that they “didn’t think this was the career for me”. I have had performance reviews that highlight issues to do with my reliability, and specifically say my “reliability improves when health improves.

At the stage I had my first convulsive seizure in the office, I had been with the business for 18 months, and the first aiders had not been told that I had epilepsy and had not been trained on what to do.

I want the new government to focus on training. Epilepsy has one of the highest unemployment rates of any disability. The idea that we cannot work or cannot be kept safe while we work is ludicrous. ”





## By 2026 we need:

- A Neuro Taskforce to prioritise epilepsy in health and social care.
- A sodium valproate compensation scheme.
- Mandatory disability employment and pay-gap reporting.

## By 2030 we need:

- An increase in the number of epilepsy specialist nurses and neurologists.
- No more epilepsy deaths in prisons.
- The employment rate for people with epilepsy to increase to more than 60%.

# WE NEED YOU

Epilepsy Action is calling on the next government to take the needs of people with epilepsy into account. We will be sending this manifesto to all political parties ahead of the general election.

We need epilepsy to be on the political agenda. You can help us do that!

**SEND**

to your local  
candidates

**SHARE**

our manifesto  
on social media

visit: [epilepsy.org.uk/manifesto](https://epilepsy.org.uk/manifesto)