Response to the Regional Review of Neurology Service Final Report

niNCA
Neurological Charities Alliance

July 2025

Summary

Since the Regional Review of Neurology Services was commissioned by the Department of Health in 2018, neurology services have continued to decline. People with long-term neurological conditions feel abandoned and let down by a fragmented system that fails to meet their needs.

The evidence we have gathered should sound the alarm with the Health Minister and his review team, as it demonstrates the high levels of need across neurology services and highlights the critical importance of adequate funding to deliver for patients.

Patients and carers need clear, consistent, and compassionate care pathways to feel supported and understood. Standardised pathways must be introduced urgently, alongside better communication and improved access to specialists, to ensure people receive the care they need when they need it. These changes will empower individuals, improve outcomes, and enhance quality of life for those living with neurological conditions.

Through a series of focus groups and an online survey, we have listened to the voices of 270 local people to understand their lived experience within the current system, and the impact this has upon those people who live with a long-term neurological condition. Throughout this process we have also listened carefully to what people need from healthcare professionals and services to ensure our consultation response is reflective of the neurological community across Northern Ireland.

Our findings paint a picture of a broken system that is harmful to staff and patients. The consequences are far-reaching and cast a shadow across a dedicated and committed workforce.

Now is the time to act and transform neurological services across Northern Ireland. Patients and the workforce can’t wait any longer.

Recommendations

Priority Recommendations

- A funded delivery plan to support the implementation of recommendations made by the Neurology Review Team.
- Urgent implementation of condition specific pathways that should be achieved within the first 6 months of the review implementation.

Additional Recommendations for the Department of Health

- Provide GPs with the necessary resources, funding, and training to meet the demands of managing neurological conditions effectively, as outlined in the review.
- Reduce reliance on private treatments and diagnosis by reducing wait times and regional disparities.
- Recognise the role of Geriatricians and the crossover of care needs with neurological services to ensure a streamlined service.
- Provide targeted education and training programmes to improve the understanding, diagnosis, and management of neurological conditions for Non Specialist Healthcare Professionals.
- Invest in integrated, evidence-based services for FND.
- Improve communication and ensure better collaboration between GPs, specialists, and secondary care providers to ensure coordinated, patient centred care for individuals with neurological conditions.
- Develop and fund comprehensive palliative care services tailored to the specific needs of people living with neurological conditions, ensuring dignity and quality of life.
- Design and deliver social care packages that meet the complex and specialist needs of individuals with neurological conditions, ensuring appropriate support is available.
- Expand nursing and care home provision to include holistic, condition-specific support for patients with neurological conditions.

- Improve Access to Respite Services for Carers. Increase the availability of respite services for carers and establish a clear, streamlined referral process to support those caring for individuals with neurological conditions.
- Provide sustainable and long-term funding for charities to ensure they can continue delivering vital support services, addressing the needs of the neurological community and bridging gaps in care.
- Ensure adequate staffing and resources are in place to enable consistent and timely review appointments, ensuring patients receive ongoing care and support.
- Prioritise medication management and access to Neuropharmacists so those living with neurological conditions can achieve better symptom control, reduced side effects, and an improved quality of life.
- Ensure that all patients prescribed time-critical medications receive their medication on time every time while admitted to hospital.

Northern Ireland Neurological Charities Alliance (niNCA)

niNCA is a membership organisation that provides a voice for people living with a neurological condition in Northern Ireland. We are the leading coalition of organisations who support people living with neurological conditions. We are made up of 20 organisations who work together to ensure that every person affected by a neurological condition can access the right treatment, care and support at the right time.

niNCA aims to increase awareness of the needs and issues faced by those living with a neurological condition amongst the public and elected representatives. Through our work we influence and support local health service design, commissioning and delivery. While lobbying to ensure people with neurological conditions have access to accurate and timely diagnosis and appropriate multidisciplinary treatment, care and support.

We thank the Department of Health for the recognition given to the work of niNCA in terms of co-production to date to support, shape and influence the review to try to ensure that it is reflective of the lived experience of the neurological community in Northern Ireland.

Living With a Neurological Condition

There are currently more than 40,000 people living in Northern Ireland with a long-term neurological condition. As of September 2023 19,536 people were waiting on a first time neurology appointment[1]. According to the Department of Health's own figures, more than 11,000 people are overdue review appointments.

Behind these numbers are individuals with families, jobs, hobbies and responsibilities. For too many, their quality of life is being swept away as they sit on a waiting list unable to access adequate and timely care, treatment and support services. They deserve better.

---

[1] https://datavis.nisra.gov.uk/health/ni-outpatient-waiting-times-sep-23.html Last full set of data before Encompass.

Understanding the experiences of people living with a neurological condition is vital to ensure the system meets their needs. This is important to identify gaps in our system but the voice of people with lived experience needs to go beyond that.

Living with a long-term neurological condition brings a complex range of challenges that impact the lives of patients and those who care for them. The Regional Review of Neurology Services must do more than address the obvious gaps but take a holistic approach to ensure quality of life improves for the more than 40,000 people relying on the system.

Background and Context of the Review

The Review of Neurology Services, launched in 2018, followed the largest patient recall in NHS history. Nearly 5,500 people were found to be eligible for recall and over 4,000 neurology patients were reviewed. That such a large-scale recall was required reflects deep-rooted issues caused by years of underinvestment and low prioritisation of neurology services.

Almost one in five patients were later told their original diagnosis was 'insecure', showing a major breakdown in the delivery of safe, reliable care. Whilst the subsequent Independent Inquiry confirmed widespread problems in systems and governance, it also drew attention to Dr Watt's unmanageable and unsupervised workload—made worse by long-term staff shortages, unfilled posts, and a lack of peer support.

The recall had a major impact on public confidence in neurology services, and the feedback we received during our consultation suggests that this damage has not yet been repaired. Many patients who were re-diagnosed with Functional Neurological Disorder (FND) say they felt they 'fell out of the system' and have received little or no follow-up care since.

The effects of long-term underinvestment in neurology have been both clinical and reputational. Rebuilding public trust and delivering safe, high-quality care within Neurology Services should be a priority for the Department of Health.

Priorities for Change Based on Lived Experience

Our evidence is clear. Neurology services must be transformed from the point of access through to treatment and ongoing support services. The people we spoke to know exactly what needs to change and appreciated the opportunity to be heard.

Who We Engaged With

In total, we engaged with 270 members of the neurological community in Northern Ireland. 30 people attended our in person consultation events, 17 online, and 223 completed our online survey.

Sharing lived experience across a range of neurological conditions with many living with multiple diagnoses, including:

- Acquired Brain Injury
- Alzheimer's
- Brain tumour
- Cerebral Palsy
- Dementia
- Dystonia
- Epilepsy
- FND
- Hydrocephalus
- kIF5A phenotype
- ME
- Migraine
- MND
- Multiple Sclerosis
- Parkinson's
- Post hepatic neurologia
- Sensory Guillain Barre
- Stroke
- Syringomyelia Arnold Chiari

Evidence from Online Survey

Our qualitative evidence points to a community of people living with a range of long-term neurological conditions who describe feeling abandoned, isolated, hopeless, depressed and anxious, with many feeling they have nowhere to turn.

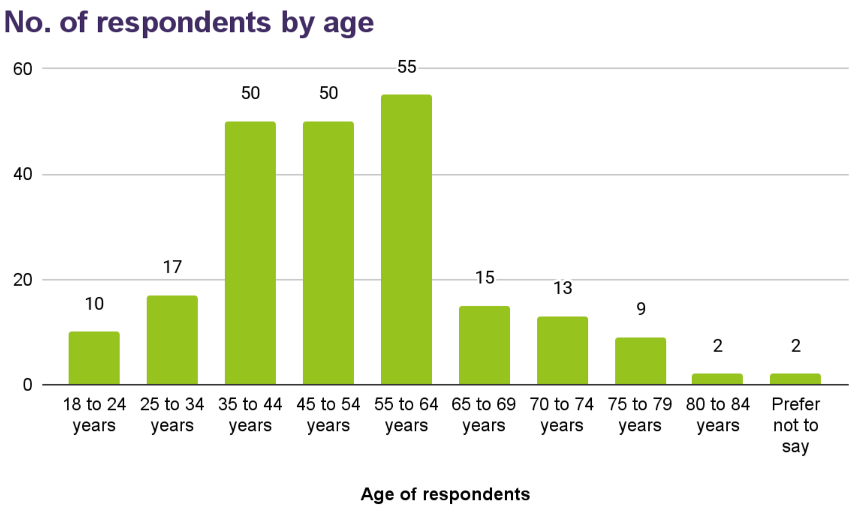
For most, their diagnosis upended their lives, impacting their day-to-day experiences. This includes their independence, how they interact with family, and how they access work and civic life. Expectations of the health and care they should receive is overall very low as their expectations are based on lived experience of the poor care currently available to them.

For the majority, their clinical pathways are unknown therefore the expectation of what ‘good care’ looks like is also unknown. Too many have sought private healthcare and are paying a heavy price with savings drained, and yet they remain unsupported by NHS neurology services. Review appointments are scarce and access to support services often remains a ‘nice to have’ if personal finances allow or an emergency hospital visit forces the need.

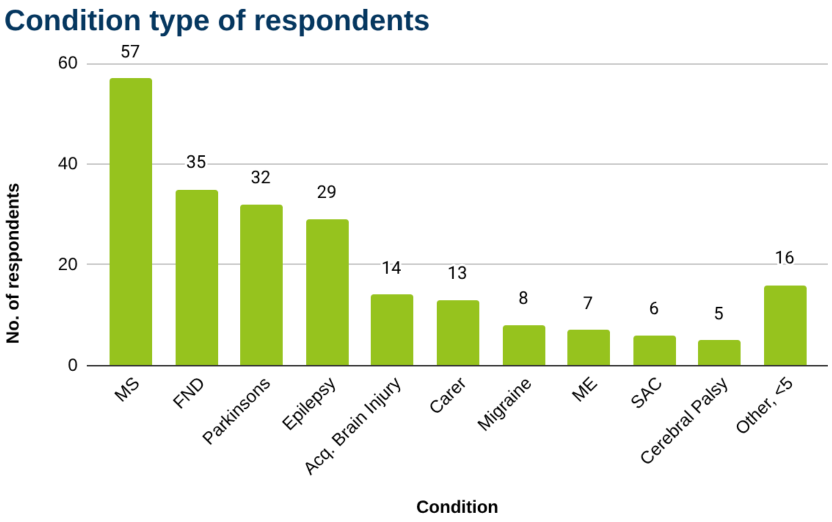
For most, their physical health has deteriorated while they wait for care, but the toll goes beyond the physical and almost all participants told us their mental health has been negatively impacted. There were multiple accounts of suicide attempts as desperation escalated. Many explained how they continue on for loved ones, but for too many a sense of hopelessness was clear.

Overview of Respondents

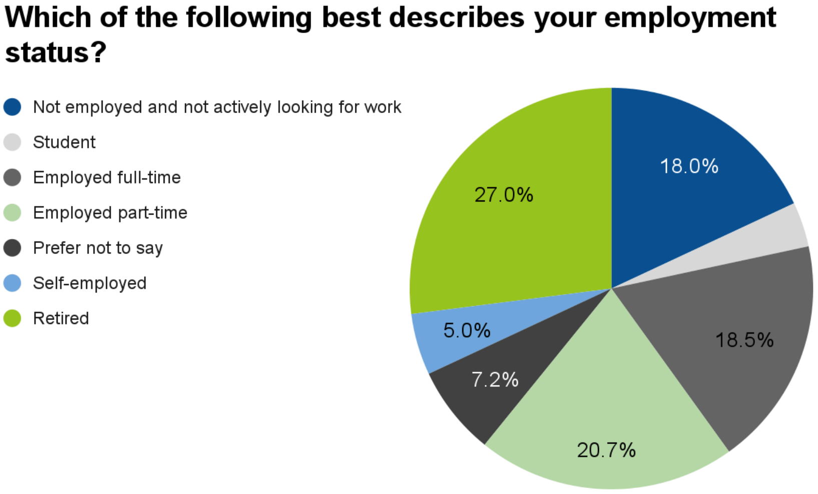
We opened our online survey on 20 May and closed it on 8 July. Over the seven week period we had 223 responses from those living with a neurological condition and carers. Experience was shared across a wide age range from 18-84 years old, however 70% of respondents were aged between 35 and 64 years old. 76% of respondents were female and 23% male with one respondent selecting non binary and two preferring not to answer.



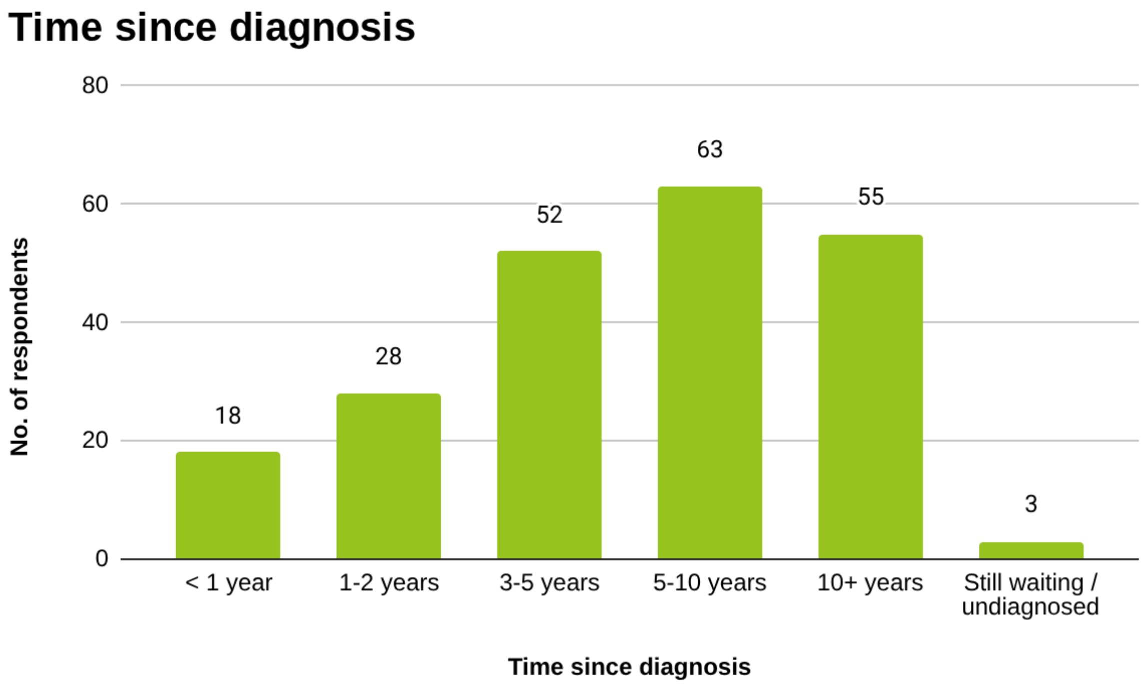
Some respondents live with multiple conditions with the graph highlighting most common, others included Dystonia, Dementia, Gillian-Barre Syndrome, Peripheral Neuropathy, and Stroke.



Respondents were mixed in terms of employment status.



The length of time that respondents had been living with their condition varied widely, with 18 individuals being newly diagnosed and 55 living with their condition for over 10 years. This diversity of perspectives enriched the data, providing a comprehensive understanding of the challenges faced at different stages of living with a neurological condition.



1. **How long did it take you to get a diagnosis?**
    - Almost 1 in 5 (18%) waited one-two years before they were diagnosed
    - Almost 1 in 10 (9%) waited two-three years
    - 1 in 10 (10%) waited seven- twelve months
    - 1 in 4 (25%) waited one-six months
    - Over 1 in 10 (14%) waited under a month
2. **Did you receive your diagnosis privately?**
    - Almost 3 in 10 (29%) received a private diagnosis

3. **When asked to rate on a scale of 1 to 5 on average, how much your neurological condition impacts your ability to carry out day to day tasks.**
    - Almost all participants (90%) gave a three or above rating

4. **How easy have you found it to access support for your neurological condition in the last 12 months?**
    - Over half (57%) said it was difficult to access support in the last 12 months
    - 1 in 4 (26%) said it was easy to access support in the last 12 months

5. **Have you experienced delays in accessing neurology services?**
    - Almost 8 in 10 (76%) told us they have experienced delays
    - 1 in 10 (12%) said they hadn't
    - 1 in 10 (13%) weren't sure if they had

6. **Do you feel that delays in your care have negatively impacted your physical health?**
    - Over 7 in 10 (74%) felt that their physical health has been impacted by delays

7. **Do you feel that delays in your care have negatively impacted your mental health?**
    - Over three quarters (77%) felt that delays have had a negative impact on their mental health
    - 1 in 10 (11%) didn't know
    - 1 in 10 (10%) didn't think it had

8. When you were diagnosed, how clear were the next steps in your treatment or care plan?

- Almost half (48%) said they were unclear about the next steps following diagnosis
- Almost 4 in 10 (39%) were clear about the next steps

9. Following diagnosis did you feel supported by the healthcare system?

- Half of participants (50%) felt unsupported
- 3 in 10 (32%) felt supported

10. Following diagnosis were you signposted to a charitable organisation for ongoing support?

- 6 in 10 (60%) said they were not
- 36% said they were

11. Do you have a designated point of contact to support you with your neurological condition?

- 4 in 10 (42%) said yes
- 4 in 10 (42%) said no
- Almost 1 in 5 (17%) weren't sure

12. How easy do you find it to access your designated point of contact?

(Those people who said they had a designated point of contact 42%)

- 4 in 10 (42%) said it was easy to access their designated point of contact
- Almost 3 in 10 (27%) said it was difficult or very difficult

13. **How worried are you about the current neurological services available to you?**

    - The majority (80%) of participants are worried

14. **Do you access support from a local charity for your neurological condition?**

    - Over half (52%) of participants don't access charity support
    - Over 4 in 10 (44%) participants said they do access charity support

15. **What type of support do you access?**

Support Accessed from a local charity	
Local groups and branch activities	50%
Help and advice about living with a neurological condition	48%
Peer support services	43%
Social cafes	29%
Mental health support such as counselling	27%
Family / carers support	25%
Physical activity sessions i.e. dance, table tennis, swimming	20%
Healthcare such as physiotherapy	17%
Help and advice about financial support	13%

16. **What do you consider the biggest challenge facing neurology services in Northern Ireland?**

17. **If you could change one thing about neurology services in Northern Ireland, what would it be**

My Neuro Survey Data

In addition to the evidence we gathered during the consultation period, the Northern Ireland specific data set from the 2024-25 My Neuro Survey supports our findings.

- **Over half (55%)** did not know who to contact if they need support for their condition between appointments
- **Over half (54%)** said they do not have a consistent healthcare professional to avoid having to explain their condition repeatedly to different people
- **6 in 10 (60%)** said they are unable to get follow-up appointments easily and when they need them
- **Less than a quarter (22%)** felt supported by the health system
- **Less than half** (48%) agreed that medical information is explained clearly
- **Less than 1 in 4 (35%)** agreed they had enough time at appointments
- **1 in 3 (30%)** don't feel involved in decisions about their treatment, care, and support plan
- **Almost 1 in 3 (28%)** don't understand their condition(s) and treatment options available to them
- **Almost 1 in 4 (37%)** have had at least one emergency hospital visit due to their neurological condition
- **6 in 10 (61%)** have had at least one planned hospital visit due to their neurological condition
- **Less than 1 in 10 (9%)** said that they feel confident and capable in their day-to-day life
- **Almost all (88%)** struggle to complete daily tasks
- **Almost 8 in 10 (79%)** said that their condition has a high (52%) or medium (27%) impact on their daily life

- **Over 8 in 10 (84%)** said living with a long-term neurological condition affects their work
- **Over 6 in 10 (65%)** revealed that they are not coping well with their condition
- **Almost half (48%)** cannot afford the additional costs associated with their condition
- **Almost 1 in 3 (28%)** said they have been discriminated at work because of their condition
- **Over half (51%)** said they have stopped working because of their condition
- **Over 4 in 10 (43%)** said that they don't have someone to talk to about mental health[2].

---

[2] Figures obtained from My Neuro Survey 2024-2025, Northern Ireland data set only – available on request.

Q. In the last 12 months, have you used any of the following services for your neurological condition(s)		
Care planning		
Access and it met needs	Access and it did not meet needs	Have not been able to access it
21%	14%	58%
Neurologist		
Access and it met needs	Access and it did not meet needs	Have not been able to access it
38%	23%	34%
Continence support		
Access and it met needs	Access and it did not meet needs	Have not been able to access it
35%	8%	44%
Counselling		
Access and it met needs	Access and it did not meet needs	Have not been able to access it
25%	16%	50%
Pain services		
Access and it met needs	Access and it did not meet needs	Have not been able to access it
11%	21%	64%
Physiotherapy		
Access and it met needs	Access and it did not meet needs	Have not been able to access it
36%	31%	31%
Scans (MRI, CT)		
Access and it met needs	Access and it did not meet needs	Have not been able to access it
58%	14%	25%
GP		
Access and it met needs	Access and it did not meet needs	Have not been able to access it
41%	40%	14%
Inpatient neuro rehabilitation		
Access and it met needs	Access and it did not meet needs	Have not been able to access it
7%	2%	82%
Neuropsychiatry		
Access and it met needs	Access and it did not meet needs	Have not been able to access it

12%	3%	80%
Neuropsychology		
Access and it met needs	Access and it did not meet needs	Have not been able to access it
12%	11%	71%
Neurosurgery		
Access and it met needs	Access and it did not meet needs	Have not been able to access it
32%	18%	39%
Occupational therapy		
Access and it met needs	Access and it did not meet needs	Have not been able to access it
43%	20%	33%
Outpatient neurorehabilitation		
Access and it met needs	Access and it did not meet needs	Have not been able to access it
19%	7%	69%
Specialist nurse		
Access and it met needs	Access and it did not meet needs	Have not been able to access it
39%	8%	50%
Respiratory services		
Access and it met needs	Access and it did not meet needs	Have not been able to access it
37%	9%	49%
Palliative care		
Access and it met needs	Access and it did not meet needs	Have not been able to access it
30%	0%	20%
Speech and language therapy		
Access and it met needs	Access and it did not meet needs	Have not been able to access it
35%	12%	48%
Respite care		
Access and it met needs	Access and it did not meet needs	Have not been able to access it
14%	10%	62%

[3]

---

[3] Ibid

1. Access to Neurological Services

Neurological care in Northern Ireland must urgently improve to meet the needs of people living with neurological conditions. Long waiting times, staff shortages, and inconsistent care are leaving patients and carers struggling physically, emotionally, and financially. People deserve timely, coordinated, and equitable care that supports their well-being and helps them live fuller lives.

Without immediate action, individuals and families will continue to feel abandoned and overwhelmed by a system that should be there to support them. Change is needed now to ensure everyone receives the care and support they deserve.

First Time Appointment

The last full set of available NISRA data for Northern Ireland as of 2023[4] highlights the severe challenges facing neurology services. The median wait for a first-time neurology appointment was an alarming 71.1 weeks, with at least 1 in 20 patients waiting over five years (260.9 week). In comparison, Scotland's[5] median wait was 17.8 weeks (with the longest being 98.7 weeks), England's[6] median wait was 14.7 weeks (with the longest at 45.2 weeks), and in the Republic of Ireland[7] 75% of patients were seen within 52 weeks.

Across Northern Ireland, there are disparities between Trust areas[8], with patients in the Belfast and South Eastern Trusts waiting a median of 64.6 weeks compared to 107 weeks in the Northern Trust. The phased introduction of Encompass in the short term has made it harder to track data, but what is available shows a fragmented and inconsistent service across NI, leading to a postcode lottery for care.

---

[4] https://datavis.nisra.gov.uk/health/ni-outpatient-waiting-times-sep-23.html

[5] https://www.nhstaysidecdn.scot.nhs.uk/NHSTaysideWeb/idcplg?IdcService=GET_SECURE_FILE&dDocName=PROD_375165&Rendition=web&RevisionSelectionMethod=LatestReleased&noSaveAs=1

[6] https://waitinglist.health.lcp.com/data-and-method

[7] https://www2.hse.ie/services/activity-performance-data/waiting-for-care/waiting-lists/outpatient-waiting-times/

[8] https://datavis.nisra.gov.uk/health/ni-outpatient-waiting-times-dec-24.html

Reflected in our survey responses:

- Almost 1 in 10 (9%) waited two-three years for a diagnosis
- Almost 6 in 10 (57%) people told us it has been difficult to access support for their neurological condition in the past 12 months.
- 14% of people said they have been unable to access support in the past 12 months
- 75% of people completing our online survey have experienced delays in accessing neurology services.

"I moved house and was hit by the postcode lottery. I had a GP who understood about Parkinson's, moved house and had no one."

These stats demonstrate the dire situation faced by Neurological services.

Healthcare System

Workforce shortages, insufficient funding, and poor communication between healthcare professionals is exacerbating delays and reducing quality of care. Long waiting times for diagnosis, reviews, and treatment are common, with appointments often cancelled without timely rescheduling.

- Over half (57%) of respondents found it difficult or very difficult to access support for their neurological condition in the last 12 months.

Patients feel unsupported and have to fight for their care, often relying on charities for guidance and emotional support.

"Passed around the neurology department, frustrating as over 4 years, saw 3 different neurologists but had to start at the beginning every time about my health – why are my notes not transferable ?"

"Postcode lottery on what support you get. Waiting lists for the same consultant number of weeks in one trust and 5 years in another-when you get specialist support in the right place it is amazing!"

"Both my neuro nurses and Doctor are all off on long term sick and no specialist nurses available to discuss concerns or issues. "

Private Treatment

Long waiting lists for neurology services and significant postcode disparities are forcing people to seek private care, which is often unaffordable and unsustainable.

- 29% of survey respondents received their diagnosis privately.

This has a compounded impact, as even though they have received a diagnosis, they cannot access NHS services or support for that diagnosis and have to remain on the NHS waiting list.

"I had no choice but to go private to see a neurologist."

"I cannot access the Parkinson's nurse as I was not diagnosed by an NHS neurologist….this has been very distressing and after 4 urgent referrals and on a Northern trusts NHS neurologist I am told that it will be October/November 2027 before I'll be seen….it's a disgrace, question is…what assistance can I get [in the] meantime!!!!."

Review Appointments

Limited access to nurse specialists and neurologists is leaving patients without regular reviews or proper medication management. The community shared that waiting times between appointments had grown significantly, leaving them with unmanaged side effects or ineffective treatments. In some cases, patients wait years for follow-up appointments creating a situation where they are unable to plan for the future.

- 6 in 10 (60%) survey respondents said they are unable to get follow-up appointments easily and when they need them

"Its atrocious – seen a neurologist twice in 6 years."

"As my seizures are under control, I feel that I am forgotten about."

"Normally my consultant would see me every 6mths approx but I've not been seen now for almost a year! Appointments are slowing down big time!."

GP and Specialist Knowledge

GPs provide crucial support to those living with neurological conditions. They are the gateway to specialist support and are the first point of contact. However, the community acknowledged that they are becoming increasingly hard to access, and feel that they often lack training, knowledge and understanding of neurological conditions leading to dismissive attitudes, mismanagement, and sadly at times delays in care.

"I can never get through to my GP in the morning and when I do all the appointments are gone. They don't do routine appointments either so I feel awful ringing for an 'emergency' appointment when I sometimes can wait, I just need to talk to someone about an issue that's been getting worse over time."

"GP hard to access and unsupportive with neuro conditions often use an excuse not to treat."

With 318 GP practices in Northern Ireland caring for 2,041,000 registered patients, the pressure on the system is already immense. Alarmingly, 98 practices have sought help from the Improvement and Crisis Response Team, highlighting the widespread strain. Between 2022 and 2023, 13 practices handed back their contracts, unable to sustain operations. By the end of 2023, 39 practices were assessed to be at risk of closure[9].

It is essential that the review recognises the additional pressure the recommendations will put on GPs who are already in crisis and under extreme pressure struggling to meet the growing demands of patients while dealing with resource and staffing challenges.

Geriatricians

In many cases, Geriatricians support older people living with neurological conditions, particularly those with more than one core morbidity. Their role in interacting with neurological services and the crossover of care needs to be recognised, ensuring a streamlined service.

---

[9] https://www.niassembly.gov.uk/globalassets/committee-blocks/pac/2022-2027/access-to-gp-in-ni/ni-audit-office-report---access-to-general-practice-in-northern-ireland.pdf

Specialist Nurses and Multidisciplinary Teams

Specialist nurses are highly valued but in short supply, with some covering thousands of patients. Patients support the need for multidisciplinary teams, including physiotherapists, psychologists, and pharmacists, to provide holistic care.

"You have to phone, leave a message and you are never sure when you'll get a call back though when you do the specialist nurses are very good."

"It is impossible to speak to an M.S. nurse. You get a message saying that all the operators are busy, speaking to others."

Currently, there are major challenges in accessing therapies such as physiotherapy, Speech and Language Therapy, and Occupational Therapy, with long referral waits. These services are crucial to keep people living well with their condition and can reduce the workload of consultants and specialist nurses.

Multi-Disciplinary Teams (MDTs) are key to transforming healthcare and reducing pressure on GP services. However the roll out has been slow across Northern Ireland. By March 2023 MDTs were introduced in 7 of Northern Ireland's 17 GP Federation areas, but only the Down area had fully implemented them[10]. Progress across other areas remains partial and inconsistent, highlighting the need for faster and more equitable implementation.

A major issue that impacted on current service delivery is staff absence. Raised by several respondents throughout the survey and focus groups, it was noted that staff absences due to long-term sickness, especially among MS, Epilepsy and Parkinson's nurses, have severely impacted service availability and continuity of care.

"There is absolutely no service within the SE trust the nurses are off sick, as is our consultant."

---

[10] https://www.niassembly.gov.uk/globalassets/committee-blocks/pac/2022-2027/access-to-gp-in-ni/ni-audit-office-report---access-to-general-practice-in-northern-ireland.pdf

This demonstrates clearly that the system is stretched so thinly that routine issues such as sickness or bereavement can bring the system to a standstill.

Time Critical Medication

Many patients with neurological conditions, such as Parkinson's, epilepsy, and diabetes, depend on time critical medications that must be administered at specific times to prevent severe symptoms and complications.

However, during hospital stays, these patients often miss vital doses due to a lack of knowledge and understanding among staff on general medical wards and limited access to Neurology specialists. Even minor delays or early administration of these medications can result in reduced efficacy, adverse effects, or worsening of the patient's condition. Addressing this issue requires improved staff training, flexible medication administration schedules, and better access to specialist input to ensure the safe and timely delivery of these essential treatments.

Physical Accessibility Barriers to Services

To improve healthcare utilisation for those living with neurological conditions who have mobility challenges , we need better access to services through improved scheduling, accessible equipment, and inclusive facility design. Flexible appointment options, transportation support, and staff trained to understand mobility needs can help reduce delays and make care more accessible. Facilities by default should have wheelchair-accessible entrances, restrooms, and equipment, along with clear signage and enough space to move around comfortably.

Underserved Communities

It is essential that ongoing service development acknowledges and explicitly identifies vulnerable, isolated, or underserved groups with neurological conditions, such as rural patients, ethnic minorities, and non-verbal individuals. These groups often face unique barriers, including limited access to specialists, cultural or language challenges which can lead to delays in diagnosis and treatment. Recognising these challenges is key to promoting equitable care and improving health outcomes for all.

Impact of Lack of Access

Patients expressed frustration, anger, and depression due to a lack of support, delays, and being dismissed by medical professionals.

“Delays impact physically, mentally, emotionally - impacting all aspects of a person’s life.”

The lengthy delays for access to services are compounding the symptoms experienced by those living with neurological conditions and actually making them sicker.

- Nearly three quarters (74%) of survey respondents felt that delays impacted their physical health.

Patients state these delays lead to the worsening of symptoms and a deterioration of physical health, ultimately resulting in reduced quality of life.

“Not having the right support and medication has made my condition chronic [migraine]. I haven't had a pain-free day for years, always in pain.”

Respondents also reported impacts to their mental health:

- Over three quarters (77%) of survey respondents felt that the delays had negatively impacted their mental health.
- Over 4 in 10 (43%) said that they don’t have someone to talk to about mental health.

These issues lead to increased anxiety, stress, depression, and feelings of hopelessness.

“It causes extreme stress and anxiety.”

Several individuals felt abandoned or neglected by healthcare services, struggling to access appointments, proper medication, or supportive therapies like physiotherapy. This creates feelings of loneliness with some patients experiencing severe mental health crises, and others reporting they have contemplated or attempted to take their own life.

“Have attempted suicide twice.”

“From going from someone who could do everything to a person that struggles to open a packet of crisps at times it has made my mental health pretty bad at times, I had 2 suicide attempts 2 yrs ago.”

“Mental health affected me, made me ill…. I had a heart attack after my husband passed from all the stress.”

The financial strain of living with a long term condition, especially one that is unmanaged due to lack of access, is significant. Many people have had to resort to paying for private care and treatments at their own expense.

“Financial worries, life’s savings gone – as unable to work due to being primary carer, so from two incomes to none.”

The neurological community also faces a loss of income due to their conditions impacting their ability to work, having to significantly reduce their hours and often no longer sustaining a job.

- Over half (51%) of online survey respondents have stopped working because of their condition

“Unable to hold down a job, have a routine and a ‘normal life’.

“My MS would be considered mild, but it still affects me especially with fatigue…no-one understands.. as I appear fine there is no help, I get no benefits etc but have had to reduce work hours to help manage the condition.. I would like to drop hours more as my job is very stressful and I can feel it affecting MS symptoms… but like I say I look fine, I can walk, run so get no help.”

Having timely intervention and the right support is life changing.

“Following the right intervention and treatment plan [I] can now live again, socialise, work and engage. Whereas being unmanaged meant that I couldn't live, having to manage and try to predict symptoms.”

Functional Neurological Disorder (FND)

During our engagement, it became clear that many people living with a diagnosis of Functional Neurological Disorder (FND) are particularly underserved and feel deeply let down by the healthcare system.

The majority reported receiving little to no support or follow-up care and felt that their condition is poorly understood across services. Many described experiences where their symptoms were dismissed as purely psychological, or worse, not believed at all—leading to further distress and, in some cases, a serious decline in their mental health.

"I've gave up asking for help as there's no point... I'm really no further on and feel like no one's interested, even though my life's been destroyed and I do struggle to stay here at times"

A clear and urgent message from those with FND was the need for a properly resourced and coordinated care pathway. While the investment into Neuropsychology proposed by the Review was welcomed—particularly in addressing long waiting times and regional inequalities—people strongly advocated for a fully multidisciplinary approach. This would include access to physiotherapy, speech and language therapy, pain management, and community-based rehabilitation.

Consultation feedback also highlighted an urgent need for greater awareness and education about FND across the health system, particularly in primary and urgent care. It is estimated that up to 4% of Emergency Department admissions involve people with FND (a figure likely to be conservative due to inconsistent coding). Many of these attendances could be avoided with earlier, more appropriate care.

There is a clear opportunity to reduce pressure on acute services, improve patient outcomes, and rebuild trust by investing in integrated, evidence-based services for FND.

Findings linked to the review:

- Creation of person centred services ensuring individuals with neurological conditions and their care partners are at the centre of their care.
- A designated point of contact for all patients with a long-term or complex neurological condition.
- Increase neurology workforce to reduce waiting times to access specialist support.
- Condition specific pathways are needed to ensure timely, consistent, and person-centered care across all Trust areas.

- Reduction of regional disparities through the establishment of General Neurology Clinics in each Trust for equitable access, alongside Regional Specialist Clinics.
- Local Neurology teams established in each Trust to focus on rehabilitation and symptom management.

Missing from the review

- Provide GPs with the necessary resources, funding, and training to meet the demands of managing neurological conditions effectively, as outlined in the review.
- Prioritise medication management and access to Neuropharmacists so those living with neurological conditions can achieve better symptom control, reduced side effects, and an improved quality of life.
- Reduce reliance on private treatments and diagnosis by reducing wait times and regional disparities.
- Recognise the role of Geriatricians and the crossover of care needs with neurological services to ensure a streamlined service.
- Provide targeted education and training programs to improve the understanding, diagnosis, and management of neurological conditions for Non Specialist Healthcare Professionals.
- Invest in integrated, evidence-based services for FND.
- Ensure that all patients prescribed time-critical medications receive their medication on time every time while admitted to hospital.

2. Condition Specific Patient Pathways

Essential Role of Care Pathways

Care pathways enhance clinical outcomes, reduce costs, and improve patient satisfaction by standardising care based on evidence-based best practices. They strengthen communication between healthcare professionals and with patients, ensuring better information sharing and coordination. Particularly beneficial for patients who move through different parts of the health and social care system, care pathways improve the quality of care, streamline resource use, and boost overall health system efficiency[11][12][13].

Current Experience

The absence of clear and consistent care pathways leaves patients and carers feeling unsupported and overwhelmed. The urgent introduction of standardised pathways, better communication, and increased specialist access, are needed to improve outcomes and quality of life.

- Almost half (48%) of survey respondents shared that they did not have a clear or structured care pathway
- Almost 1 in 3 (28%) don't understand their condition(s) and treatment options available to them.

The neurological community did not have an understanding of what they could expect in their care journey. This has resulted in feelings of confusion, anger, frustration, and uncertainty about next steps. Half of our online survey respondents felt unsupported and disconnected by the healthcare system and reported being left to advocate for themselves in a fragmented system. Living with a long term neurological condition is hard enough, but on top of that they are fighting for basic access to care and support to keep them living well.

---

[11] http://www.cpa.org.uk/information/reviews/CPA-Rapid-Review-Effectiveness-of-care-pathways.pdf

[12] https://www.economicsbydesign.com/health-system/integrated-care/the-value-of-care-pathways-explained/

[13] https://bmjopen.bmj.com/content/bmjopen/8/7/e020411.full.pdf

"Long waiting for appointment, still waiting on onward referral, no pathway given, no treatment given, neurologist refused to refer me for neuropsychologist as he said the waiting time is 6 years and most people get well after reading a website."

Inconsistent and Unequal Care

Access to services varies widely by Trust, creating not only a postcode lottery of access to care but also an inconsistency in the care and support provided. Severe shortages of specialist nurses, Neurologists and AHPs hinder timely care, medication reviews, and ongoing support. Rural communities face additional challenges due to poor transport links and lack of local services.

Members of the neurology community need to be able to see the right person at the right time. This isn't always a Neurology consultant. By building an expansive multidisciplinary team we can reduce the burden on neurologists, especially if this can be done in local areas.

Information Gaps

Patients receive little to no information at diagnosis, leaving them uncertain about their condition, available support, or treatment options.

- Over half (55%) did not know who to contact when they need support for their condition between appointments.

The voluntary and community sector plays a crucial role in supporting people with neurological conditions, helping them live well and manage the challenges they face. Over 4 in 10 (44%) survey respondents said they sought help from a local charity providing a wide range of services, including mental health support such as counselling, healthcare services like physiotherapy, and practical advice on living with a neurological condition.

Many also accessed advice on financial support and benefits, as well as peer support services that connect individuals with others who share similar experiences. Local groups and branch activities, along with physical activity sessions such as dance, table tennis, and swimming, help promote physical and emotional well-being. Social cafés create informal spaces for building connections, while family and carer support services provide essential resources for loved ones and caregivers.

By offering these services the voluntary and community sector fills a critical gap in formal healthcare systems helping people to live well with their condition, and providing a sense of empowerment, belonging, and improved quality of life for individuals and their families.

However, the vital role of the voluntary and community sector is often overlooked, with its services frequently being the first to face cuts in efforts to 'save money.' To ensure sustainability and continuity of support, the sector's contributions must be fully recognised, valued, and appropriately resourced to meet the needs of those living with neurological conditions.

End-of-life and Palliative Care

End-of-life and palliative care are incredibly important for people living with long-term neurological conditions who have a wide range of physical, emotional, and psychological challenges that require specialised care. However current services are practically non-existent.

The neurological community needs to be supported in a way that understands their condition and prioritises comfort, dignity, and quality of life throughout the course of the illness, including during the final stages.

Recognition of Carers

Carers play a crucial role in supporting people with neurological conditions, providing physical, emotional, and practical support every day. However their own needs go unrecognised and unsupported, and often this has a significant impact on their own mental and physical health.

Carers NI State of Care survey 2024 found that. *"There are 220,000 unpaid carers in NI, nearly 60% of whom are women. NI has the highest proportion of unpaid carers anywhere in the UK and the highest proportion of people providing the most intense level of care ie 50+ hours. Each year, unpaid* *carers in NI save the public purse £5.8 billion in care costs, yet carers receive pennies per hour despite providing round-the-clock care."*

Carers shared their experience of having to continually *"fight"* and navigate the system on behalf of the person they care for and describe it as "*exhausting."* They also struggle to get the help they need, including financial support as well as practical support.

The adult social care system is reliant upon the unpaid care delivered by family members, however carers are overworked and unsupported in this role. Care packages and support for those living with complex neurological conditions is very hard, often impossible to find. There is very little access to respite for carers, particularly those supporting someone with complex neurological needs. This lack of respite can make an already challenging role even harder, and it can also impact the care their loved ones receive.

Findings linked to the review:

- Urgent implementation of condition specific pathways. This is a top priority and needs to be achieved within the **first 6 months of the review. It cannot wait.**
- Increase neurology workforce including increasing the number of specialist nurses, neurologists and AHPs to ensure timely care.
- Creation of person centred services ensuring individuals with neurological conditions and their care partners are at the centre of their care.
- A designated point of contact for all patients with a long-term or complex neurological condition.
- Effective partnership working between Trusts and the community and voluntary sector must be specifically addressed in service planning.

Missing from the review

- Improve communication and ensure better collaboration between GPs, specialists, and secondary care providers to ensure coordinated, patient-centred care for individuals with neurological conditions.

- Provide targeted education and training programs to improve the understanding, diagnosis, and management of neurological conditions for Non Specialist Healthcare Professionals.
- Develop and fund comprehensive palliative care services tailored to the specific needs of people living with neurological conditions, ensuring dignity and quality of life.
- Design and deliver social care packages that meet the complex and specialist needs of individuals with neurological conditions, ensuring appropriate support is available.
- Expand nursing and care home provision to include holistic, condition-specific support for patients with neurological conditions.
- Improve access to Respite Services for Carers. Increase the availability of respite services for carers and establish a clear, streamlined referral process to support those caring for individuals with neurological conditions.
- Provide sustainable and long-term funding for charities to ensure they can continue delivering vital support services, addressing the needs of the neurological community and bridging gaps in care.

3. Priorities for change

Our evidence is clear. Neurology services must be transformed from the point of access through to treatment and ongoing support services. The people we spoke to know exactly what needs to change and appreciated the opportunity to be heard.

Access to Care

Having access to neurology services is a top priority for the people we spoke to. It was widely understood that preventative care offers the best outcome for patients.

Delays in accessing neurology care are having a significant impact across the neurological community. This means having timely access to specialist healthcare to prevent further and unnecessary deterioration. It means speaking to a specialist who understands their condition and can ensure they receive the best care possible. A large part of this is having access to review appointments to monitor medication and progression and refer to support services if required. Our evidence indicates for most people this care is simply not available.

- Almost 6 in 10 (57%) told us it has been difficult to access support for their neurological condition in the past 12 months
- Over 1 in 10 (14%) said they have been unable to access support in the past 12 months
- Three quarters (75%) of people completing our online survey have experienced delays in accessing neurology services
- Almost three quarters (73%) believe that delays in their care have negatively impacted their physical health.
- Three quarters (75%) felt that delays in their care have negatively impacted their mental health.

"It has been 2 to 3 years since I have had my medication reviewed."

"I have not had a face-to-face appointment in about 6 years, my last telephone check-up appointment about 3 years ago."

"I have not seen a neurologist in 2.5 years for [an] annual review. I cannot remember the last time I saw or heard from an MS nurse, and it took well

over a year to see a physiotherapist. Whilst this was useful, I was given 6 sessions and left with more unresolved issues than I started."

Condition Specific Pathways and Designated Point of Contact

There was a clear call from all participants that they wanted to know what care they should be receiving and have one point of contact to help them when they needed support.

Neurological conditions are complex and for many people unpredictable. Symptoms can fluctuate and change, requiring varying levels of support throughout a patient's lifetime. This can be difficult for patients, and the people who care for them, leading to increased health anxiety and untreated symptoms. The evidence we gathered points to a lack of coordinated care that leaves patients feeling abandoned.

'What one thing would you change?'

"Someone who I can contact for help and reassurance that is empathetic. When my symptoms are severe or I have a new one, a professional that can tell me yes this is normal with this condition, and you're going to be ok or someone to tell me no, this is a cause for concern and I will help point you in the direction you need for help."

During our focus groups people described the stress of trying to access care during relapses or the onset of new symptoms. This is echoed in recent evidence collected from the 2024-25 My Neuro Survey[14]:

- Over half (55%) of people from Northern Ireland did not know who to contact if they need support for their condition between appointments
- Over half (54%) said they do not have a consistent healthcare professional to avoid having to explain their condition repeatedly to different people
- 6 in 10 (60%) said they are unable to get follow-up appointments easily and when they need them.

While our online survey reinforced the situation further:

---

[14] Figures obtained from My Neuro Survey 2024-2025, Northern Ireland data set only - available on request.

- Almost half (48%) told us that after diagnosis they were unclear about the next steps in their treatment or care plan.
- Half (50%) said following diagnosis they felt unsupported by the healthcare system.
- 6 in 10 (58%) didn't have or were unsure of a designated point of contact to support them with their condition.
- 1 in 4 (27%) of those with a designated point of contact (43%) found it difficult to access that person/service.

Improved Training

A top priority for everyone involved in our research was adequate training across all practitioners, starting with GPs and emergency departments as they were seen as the gateway to all care needs, and a significant barrier to accessing care.

We heard time and time again from patients about a lack of understanding from healthcare professionals about their condition, and the impact this has upon accessing adequate care. Most people we spoke to felt frustrated and had low expectations around the care they should be receiving due to the lack of knowledge about their condition.

Awareness raising for less well-known conditions such as FND was considered critical to improving health outcomes as many living with these conditions report being dismissed and belittled by healthcare professionals.

"There is no care plan with the NHS and the condition is not widely well understood so accessing appropriate and useful care is entirely down to the patient. Neurophysio helped to a point but the 2nd time was unhelpful and distressing because my physical symptoms were not being taken seriously. After that I didn't know what to try and doctors don't know how to help."

Training on neurological conditions but also the importance of person-centred care is essential to improving the system and should be a priority going forward.

It was clear from the people we spoke to that self-advocacy is necessary to receiving care; however, there were numerous accounts of healthcare professionals repudiating patient concerns and requests for help and support.

"The thing that made the experience the most difficult was Drs not listening to me and trying to write me off. If I didn't have the strength to fight for myself I would have left hospital and suffered at home. The whole experience has been very traumatic and I believe that it added to the stress and made the symptoms much worse at the beginning."

Access to Support Services

Most people understood the importance of using support services as a preventative approach and considered access to support services as a priority going forward.

People living with a long-term neurological condition deserve to live well and this means having ongoing access to essential support services. The people we spoke to expressed their frustration that access to services such as neuro physiotherapy, mental health support or occupational therapy was very difficult, limited and often only accessed after a negative health episode.

"I'm left untreated with life changing symptoms while on a waiting list, no diagnosis means no treatment. The only thing that keeps me alive is the love for my children. Otherwise, I'd end this suffering and pain every day. It's inhumane."

Increased Support From Charities

Sustainable funding for charities to continue to deliver support and meet demand was considered a priority for many.

Our research reveals a significant reliance upon charitable support. Many people spoke about the importance of the services and advice they receive from condition specific charities. They also recognised the need for these services to be adequately funded as waiting lists for support like counselling, physiotherapy and wellbeing activities continue to grow. There was clear agreement that charities are filling the gaps left by the health service. As demand for charity support continues to grow, the gap closing is becoming less apparent and charity waiting lists are being introduced.

Despite this reliance upon charitable support, our online survey revealed that although over 4 in 10 (44%) said they access support from a local charity for their condition, following diagnosis 6 in 10 (60%) people were not signposted to a charity for ongoing support.

Findings linked to the review:

- Increase neurology workforce including increasing the number of specialist nurses, neurologists and AHPs to ensure timely care.
- Creation of person-centred services ensuring individuals with neurological conditions and their care partners are at the centre of their care.
- A designated point of contact for all patients with a long-term or complex neurological condition.
- Urgent implementation of condition specific pathways.
- Effective partnership working between Trusts and the community and voluntary sector must be specifically addressed in service planning.

Missing from the review

- Ensure adequate staffing and resources are in place to enable consistent and timely **review appointments,** ensuring patients receive ongoing care and support.
- Provide sustainable and long-term funding for charities to ensure they can continue delivering vital support services, addressing the needs of the neurological community and bridging gaps in care.
- Provide targeted education and training programs to improve the understanding, diagnosis, and management of neurological conditions for Non Specialist Healthcare Professionals.
- Prioritise medication management and access to Neuropharmacists so those living with neurological conditions can achieve better symptom control, reduced side effects, and an improved quality of life.

4. Consequences of Not Delivering Change

All the evidence we have gathered should sound an alarm for the Health Minister and the neurology review team. Patients living in Northern Ireland with long-term neurological conditions are experiencing poor care and this must change. Long delays in diagnosis followed by inadequate ongoing treatment and care are harmful to both patients and the hard-working and dedicated neurology workforce.

"I DO NOT WANT TO LIVE LIKE THIS. Mostly because there's no help and I feel abandoned by everyone except my wife."

Inaction will have catastrophic consequences for patients, carers, families, and the healthcare system. Without adequate funding and an implementation plan, the system will continue to crumble, leaving people isolated, unsupported, and facing worsening health outcomes. Immediate investment and systemic changes are essential to ensure equitable, effective, and compassionate care for all.

Cost To The Workforce

Although everyone we spoke to shared frustrations in trying to access the care they need, there was resounding agreement regarding the heavy workload of healthcare workers and a growing concern for their welfare amid a crumbling system. Many people spoke of their reluctance to seek help unless they really needed it as they witnessed first hand the strain placed on healthcare staff. Long-term workforce shortages and growing waiting lists will continue to be detrimental to the neurology workforce.

The Department of Health needs to invest in training places across all aspects of neurology services to ensure the workforce is sustainable. A failure to do so will result in further decline with patients bearing the brunt.

"A bare minimum of staff (NHS) available and overworked. Inpatient/acute care couldn't have been better however the aftercare has at best been minimum. The tiny number of staff are trying their best, but I felt totally abandoned, isolated and very frightened trying to navigate everything alone."

"The staff are overwhelmed at the volume of need within the department and this shows as they can on occasions not retain all the information for the patient."

Cost To Patients

As patients wait longer and longer to access care, treatment, and support services their physical and mental health will continue to decline. This comes at a great personal loss to individuals and the people who care for them as their quality of life deteriorates over time. The 2024-25 My Neuro Survey found alarming results on the cost to patients:

- Less than 1 in 10 (9%) said that they feel confident and capable in their day-to-day life
- Almost 8 in 10 (79%) said that their condition has a high (52%) or medium (27%) impact on their daily life
- Over 8 in 10 (84%) said living with a long-term neurological condition affects their work
- Over 6 in 10 (65%) revealed that they are not coping well with their condition
- Almost half (48%) cannot afford the additional costs associated with their condition
- Almost 1 in 3 (28%) said they have been discriminated at work because of their condition
- Over half (51%) said they have stopped working because of their condition.[15]

"Delays in my care and indeed diagnosis have had a huge impact on my health. My employers did not support me with adaptations in the workplace as advised by occupational health, I was subjected to manipulative and bullying and harassment, and I was forced to resign for the sake of protecting my mental health. All of these factors coupled with a failing to address my physical health needs led to worsening symptoms, reduced mobility, increased difficulties with activities of daily living, no relief from pain and discomfort. Disgraceful."

Cost To The Economy

Investing in health spending makes fiscal sense. A report from the NHS Federation reveals that for every £1 invested in health, the RoI to the economy is £4. Spend £1 in primary and community care and the RoI to the economy rises to a staggering £14 while £1 spent on acute care yields

---

[15] Figures obtained from My Neuro Survey 2024-2025, Northern Ireland data set only – available on request.

an £11 return[16]. Failing to invest will have the reverse effect and is played out in poorer health outcomes, late and missed diagnosis, lost productivity, higher unemployment and ultimately an increased cost to the health service and wider public services.

"I can't work and that was one of my greatest joys, I love my work and my colleagues, but the fatigue and mobility issues have extremely limited what I am able to do. I wonder if I [will] get the opportunity to work again. I feel extremely low and although trying to keep myself motivated the sedentary lifestyle has caused wait gain and added pain. I am trying to keep moving but the fatigue is overwhelming."

When it comes to neurology services, one of the most under-resourced specialisms in Northern Ireland, the situation is bleak with more people experiencing often preventable declining health. The estimated cost to the economy is huge, sitting at 4.3% of the UK's GDP, or £96 billion annually, according to a study carried out in 2024. The same study estimated that with timely intervention and access to care the cost could be reduced by one third[17].

Summary

The evidence gathered from over 270 individuals with lived experience of neurological conditions in Northern Ireland paints a stark picture of a broken system in crisis. Long delays in diagnosis, inadequate follow-up care, and a lack of access to specialists are leaving patients abandoned, with negative mental health impacts and physical deterioration due to delays. Workforce shortages, fragmented care pathways, and reliance on private treatment are compounding the challenges, while carers are left unsupported and overwhelmed. Without urgent investment and prioritisation, the system will continue to fail, leading to worsening health outcomes, increased strain on families, and higher long-term costs to the economy. Fully funding and transforming neurology services is essential to provide equitable, timely, and compassionate care, rebuild public trust, and improve quality of life for over 40,000 people living with neurological conditions in Northern Ireland.

---

[16] https://www.nhsconfed.org/publications/creating-better-health-value-economic-impact-care-setting

[17] https://impact.economist.com/health/value-action-mitigating-impact-neurological-disorders-united-kingdom

Contact

niNCA would welcome the opportunity to discuss our response. Please email: info@ninca.org.uk