Thriving not surviving: A right to neurorehabilitation

A UK-wide consensus statement

For people living with progressive neurological conditions

March 2026

Contents

Supported by

acpin
Connecting knowledge and practice

ATAXIA

Endorsed by
Chartered Society of Physiotherapy

Huntington's Disease Association

MND Association

MS Society

MS Trust

Multiple System Atrophy Trust

MUSCULAR DYSTROPHY UK
OUR MUSCLES MATTER

niNCA
Neurological Charities Alliance

THE NEUROLOGICAL ALLIANCE

neurological alliance of scotland

Parkinson's UK
For every Parkinson's journey

Parkinson's UK
Northern Ireland

RCOT
Royal College of Occupational Therapists

RCSLT

British Society of Physical & Rehabilitation Medicine

the british psychological society

CYNGHRAIR NIWROLEGOL CYMRU
WALES NEUROLOGICAL ALLIANCE

Executive summary

‘The fact that I’m still going basically is due to the services I’ve had… I’ve been lucky not all my friends have. Everyone deserves to get the support they need when they need it, to live a good life, whatever that means to them.’
Person with MS

At least 1 in 6 people in the UK are impacted by a neurological condition. These conditions are the global leading cause of disability.[1] These complex conditions affect every aspect of daily life, from physical function and mobility to mental wellbeing and independence. Neurorehabilitation is essential for helping people maintain function, adapt to change, and preserve quality of life — for example, supporting someone to manage fatigue, improve mobility, regain communication skills, or remain in employment and independent living. It also equips people with self-management strategies to maintain function between episodes of active support.

Neurorehabilitation encompasses services from intensive hospital-based specialist units to teams working in the community. For people with progressive neurological conditions, specialist community neurorehabilitation teams are essential but severely under-resourced. These multidisciplinary teams — physiotherapists, occupational therapists, dieticians, speech and language therapists, neuropsychologists, support workers, rehabilitation medicine physicians, and specialist nurses — deliver care in the community where people need it most.

Neurorehabilitation pathways also include voluntary and community sector services that offer peer support, counselling, and targeted activities, as well as accessible leisure services.

These community-based resources form an essential part of comprehensive neurorehabilitation care. Evidence demonstrates that community-based activities and peer support contribute to secondary prevention, with research showing these interventions can help slow disease progression for some people with neurological conditions.[2]

Specialist nurses, including MS nurses and Parkinson's nurses, play a particularly vital role within these teams. They often act as a consistent point of contact for people with progressive conditions, coordinating care across services, supporting symptom management between episodes of supervised rehabilitation, and helping people navigate complex health and social care systems.

This consensus statement focuses specifically on progressive neurological conditions. It examines the unmet need, sets out ten principles for transforming care, and calls on policymakers to take urgent action.

Nearly 330,000 people in the UK have multiple sclerosis (MS), Parkinson's, motor neurone disease (MND), and Huntington's disease.[3]

These are life-long conditions which can be hard to predict, with symptoms that fluctuate and change over time, requiring episodic support throughout.

Yet the system fails people with progressive conditions.

The My Neuro Survey 2024/2025, based on responses from over 10,000 people with neurological conditions, reveals that only one in three report their healthcare needs are being met. Almost 7 in 10 who needed neuropsychiatry couldn't access it, and over 6 in 10 couldn't access neuropsychology. More than half who needed pain services or outpatient neurorehabilitation were unable to get them.[4]

Meanwhile, waiting lists for community neurorehabilitation in England have grown by 52% since November 2022, with some people waiting over a year just for initial assessment by which time their condition deteriorates and opportunities for early intervention are lost.[5]

The wider impact of this inefficient, reactive care is both profound and measurable. The economic cost of just ten neurological conditions exceeded £96 billion in 2019, which was more than 4.3% of GDP, and is likely to have increased significantly since.[6]

Research demonstrates that £30 billion of this burden could be prevented if everyone who would benefit from evidence-based interventions such as rehabilitation and coordinated care had access to them.[7]

In 2023–24, one in seven people with MS had at least one unplanned hospital admission. Many of these could have been prevented if the person had been able to access timely community support.[8] Similarly, emergency hospital admissions for people with Parkinson's cost £325 million 2024/2025 a 24% increase on 2021/2022.[9] The human cost is immeasurable: careers ended prematurely, independence lost unnecessarily, mental health declining without adequate psychological support.

This consensus statement sets out ten principles endorsed by the UK's leading neurological charities.

Ten principles for change

1. **The right to neurorehabilitation**
   Everyone living with a progressive neurological condition has the right to timely, high-quality, patient-centred neurorehabilitation, regardless of postcode, ability to pay, or specific diagnosis. Access to neurorehabilitation should be needs-led, and should not be refused based on a person's condition.
2. **Care closer to home**
   Neurorehabilitation should be delivered as close to home as possible, embedded within community and neighbourhood health services where appropriate.
3. **Mental health and cognition as core components**
   Depression, anxiety, cognitive changes, and emotional distress must be addressed as part of routine care, not treated as optional or secondary. Mental health services shouldn't exclude people on the basis of a neurological diagnosis. Access should be determined by mental health need and the likelihood of benefit, not by diagnostic labels. It's crucial that people who experience cognitive difficulties can access appropriate neuropsychological expertise to support them to live well.
4. **Workforce investment and capacity**
   Governments and commissioners must invest in training and expanding the rehabilitation workforce to meet population need.
5. **Standards, pathways, and quality**
   Evidence-based standards such as NICE guidance and The General Standards for Neurological Support must be consistently implemented across all areas.
6. **Supporting economic participation and independence**
   Neurorehabilitation should support people to remain in or return to work, education, and community life where desired.
7. **National neurology plans and data transparency**
   Each UK nation must publish comprehensive neurology plans with measurable targets and annual public reporting.
8. **People with lived experience at the heart of service design**
   Services must be designed with, not just for, people living with neurological conditions.
9. **The right to a named care coordinator**
   Everyone should have a named professional, acting as a single point of contact responsible for coordinating their care.
10. **From pathways to practice: Monitoring and accountability**
    Health systems must routinely measure delivery against national guidance and take corrective action where care falls short.

People with progressive neurological conditions deserve the chance to thrive, not merely survive.

The challenge: Living with unmet need

Progressive neurological conditions: A long-term challenge

'Anything I'm offered I'll try it. I've had physio, orthotics, I use the neurotherapy centre, I've done Tai chi, I go to the gym.' Person with MS

Progressive neurological conditions are characterised by their long-term nature and the way symptoms fluctuate and change over time. Unlike a stroke or acquired brain injury where there is typically an initial acute phase followed by a recovery trajectory, progressive conditions require a different model of care. One that provides episodic access to rehabilitation throughout a person's journey, responding to relapses, adjustments in symptoms, and evolving needs. For example, someone may need little intensive support for 6 weeks, then rapid access again when symptoms change.

The journey with these conditions varies considerably between individuals and between different conditions. Some people may experience relatively stable periods punctuated by relapses or sudden changes; others face gradual progression. What unites these conditions is the need for ongoing, flexible support that can adapt as circumstances change, not a single course of time-limited rehabilitation.

Yet the current system is structured around acute, time-limited interventions rather than the episodic, long-term model that progressive conditions require. People need rapid access when symptoms worsen, the flexibility to return when needs change, and support that adapts as the condition evolves. Too often, they encounter rigid pathways, lengthy waits, and services that discharge them just when ongoing support becomes most critical.

Reframing rehabilitation: Beyond recovery

There is a widespread perception that rehabilitation is only for those who have become acutely unwell, and that its purpose is to help people 'recover' or 'improve.' In progressive neurological conditions, rehabilitation serves different but equally vital purposes.

NICE guidance, endorsed by England, Wales and Northern Ireland emphasises that rehabilitation for people with MS should focus on 'maximising their level of functional activities (that is, minimising disability and dependence) and helping them maintain social roles.'[10] This represents a fundamental shift from recovery-focused to maintenance-focused care.

Research advocates for early rehabilitation in MS as a preventative approach, arguing that it should ‘commence early and be consistently available throughout the entire disease course’ to build cognitive and physical reserves before significant decline occurs.[11] This prevention model of ‘reserve and brain maintenance’ proposes that building capacity early may help preserve function and defer the onset of permanent impairments.[12]

However, services are typically structured around reactive symptom management rather than proactive prevention, with rehabilitation often only accessible once significant functional problems have developed.[13] Shifting these perceptions and service models is essential to enabling people to maintain independence and quality of life throughout the disease journey.

Unmet need: The reality from patients

‘My Neuro Survey 2024/25’ exposes the extent of unmet need.[14]

1,140 people with MS across the UK who responded said in the in the last 12 months:

- **Mental health support is often absent:** 25% lived with a mental health condition, yet 41% described having no one to talk to.
- **62% of adults with MS were failed by counselling services:** 50% couldn’t access support at all, and 12% of those who could were dissatisfied with the service they received.
- **Neuropsychology failed to reach people:** 59% sought neuropsychology; 51% couldn’t access it, and 22% of those who did said it didn’t meet their needs.
- **Mobility needs went unmet:** 94% experienced mobility issues, yet among those who tried physiotherapy, 43% were unable to access it or left dissatisfied.
- **Work and study were heavily affected:** 76% said MS impacted their ability to work or study.

Rehabilitation is as essential to good health as medicines and surgery. Yet access to support and evidence-based therapies proven to maintain function, prevent deterioration, and preserve independence remains a postcode lottery. The gap between what people need and what they can access represents lives diminished by preventable decline.

Community health services, which should form the foundation of care delivered close to home, are under severe strain. Nuffield Trust analysis shows that waiting lists for adult community services in England have increased by 23% since October 2022, reaching almost 1.2 million people. In neuro rehabilitation this increase is 52%. Some face waits of over a year for assessment during which symptoms become entrenched, function declines, and opportunities for early intervention are lost. The system lacks the flexibility to see people quickly when their condition changes, instead operating on rigid appointment schedules that don’t accommodate the fluctuating nature of progressive neurological conditions.

The postcode lottery

Geographic inequality compounds these challenges. Two people with the same condition can face vastly different outcomes depending on where they live. One may access timely rehabilitation that maintains independence; another may wait months or be unable to access services at all. While the NHS England adult neurology service specification defines the requirements for specialist neurology care, community neurorehabilitation sits outside its scope and is commissioned separately.

In 2025 we issued Freedom of Information requests to all ICBs, which revealed huge variations in how local health systems provide service care pathways. Some ICBs have strong neurology leads and leaders with clear pathways and networks, while some seem to lack awareness of their own services and have no community rehabilitation teams.

People affected by progressive neurological conditions have told us about the reality of this variation: no standard referral pathways at diagnosis; waiting times of 12 to 14 months in some areas; reported workforce shortages, even where services are commissioned; and transport barriers that exclude those unable to travel.

This variation is reinforced by geography, with specialist workforce and service capacity concentrated around urban neuroscience and teaching hospital centres, leaving rural and more remote areas disproportionately affected by workforce shortages, delayed access, and fragmented neuro-rehabilitation pathways.

'You always have to wait when you're referred to… There's always a wait… probably about 6 months 8 months maybe.' Person with MS

'I was diagnosed and I went to see a neurologist… and I had no referrals, so I was told to take vitamin D and to go away. So that was it.' Person with MS

'After 50 years of seeing a consultant annually it's been decided I no longer qualify for ongoing monitoring. There are very limited, occupational therapy, physio and orthotics support at the… it's very basic… One visit off you go.'
Person with MS

'It can be difficult to refer people as there is such variable access to neuro rehab across the region. Services often have completely different referral forms which change and make it difficult to keep track of. We know that are often long waiting lists and by the time patients have told us what they need we know that we will have missed our golden window.

I often see in the notes, "patient is a hoist transfer" when a sensible goal might focus on their baseline, the upper limb function and how independent they can be. One of the parts of being an MS nurse is that point of advocacy and bringing to the fore the need for individualised care plans that truly reflect optimising for that person.'
MS Specialist nurse

Financial barriers compound geographic inequality. When NHS services are unavailable or have unacceptable waiting times, those with financial means turn to private physiotherapy, psychology, or speech and language or occupational therapy, while others go without.

‘I see so many people struggling to pay for physiotherapy fees in… but there is nowhere else to go for that level of support. Physiotherapy works wonders but at £100 an hour, anything long-term is beyond most people needs.’ Person with MS

Charities and the third sector also increasingly step in to fill gaps in NHS provision.

‘We are a charity and completely rely on fundraising and donations… with no government funding… Our local specialist nurses and practitioners often refer people to us as generally NHS Services are at capacity or the waiting list is very long.’

‘Due to demand we too have to operate a waiting list where many face several months.’ Lead physio, Neuro Therapy centre

‘I know people who travel in 1 hour to go the neuro therapy centre.’ Person with MS

Third sector organisations provide invaluable specialist support and fill critical gaps with dedication and expertise. Many people rely on these services and value them highly. However, excellence in charitable provision cannot substitute for comprehensive, equitably commissioned NHS services, nor should people have to depend on the postcode lottery of voluntary sector provision to access essential rehabilitation.

Geographic inequality isn’t just about fairness — it drives unnecessary costs and poorer outcomes across the system.

Workforce crisis

Rehabilitation services in England are already facing a workforce crisis. In 2025, 78% of occupational therapists reported their teams were too small to meet demand, and 55% said insufficient staffing directly affected their ability to deliver care.[15] Nearly half of the Chartered Society of Physiotherapy (CSP) workforce representatives now report recruitment freezes or delays in filling vacancies, and one in ten CSP members report their organisation has completely frozen recruitment of all clinical staff.

This is happening while two in three NHS physiotherapists say they do not have enough staff to do their jobs properly, and at a time when demand for physiotherapy has never been greater.[16]

The workforce number of rehabilitation physicians in the UK is ten times less than the average numbers in other European countries.[17] RCSLT data published in 2025, shows that 6 in 10 respondents (61%) said their job often or always involved unrealistic time pressures. It also showed that workforce shortages remain a significant challenge with not enough practitioners available to meet demand and reduce waiting lists.[18] Given that neurorehabilitation requires additional specialist skills within these same professions, workforce shortages are likely to be even more acute in neuro-rehabilitation services.

'They have no neuro physio post; no neuro OT posts. There were two and sometimes three neuro occupational therapists in that service. They don't even have a post now. Are we back in the 70s and 80s?' Person with MS and former neuro occupational therapist

The economic case for change

The £96 billion burden

The wider impact of inefficient, reactive care is both profound and measurable. The economic cost of just ten neurological conditions exceeded £96 billion in 2019, representing more than 4.3% of GDP. The cost today is likely to be significantly higher.[19] This encompasses direct healthcare costs, social care expenditure, and the substantial indirect burden of lost productivity, reduced employment, and diminished earning capacity. Approximately half of this burden is indirect: people unable to work, carers reducing their hours, and lifetimes of potential lost.

Research by Economist Impact demonstrates that implementing evidence-based interventions including accessible neurorehabilitation and coordinated care pathways could reduce this burden by approximately £30 billion annually.[20] The interventions exist, the evidence is robust, and the potential savings are substantial. What is required is sustained investment and equitable commissioning.

Preventable hospital admissions

When people can't access the community support, they need, preventable health issues can escalate into emergency hospital admissions. Hospital Episode Statistics data for people with multiple sclerosis in England show that in 2023–24, almost one in eight (11.9%) unplanned admissions were due to pneumonia and pneumonitis.[21] These admissions cost £20.4 million and accounted for over 45,000 bed days. Aspiration pneumonia and pneumonitis often reflect problems such as swallowing impairment and reduced airway protection, which timely speech and language therapy within community neuro-rehabilitation can help mitigate.

Workforce shortages, long waits and variation in service access increase the risk of such potentially avoidable hospital stays, placing additional strain on individuals, carers and the health service.

Why neurorehabilitation matters

What neurorehabilitation offers

'I have physio as and when, so I'll go to physio for about six weeks then I'll have however long off and then when I need something else, I'll be going back to it. My neuro rehab team is community based. I have seen the occupational therapist for fatigue management course, speech therapy. They have a very good neuro rehab service.'
Person with MS

Neurorehabilitation should be a coordinated and multidisciplinary approach, encompassing physiotherapy, occupational therapy, speech and language therapy, neuropsychology, rehabilitation medicine physician and mental health support. Crucially, for progressive neurological conditions, rehabilitation is not a one-off intervention. People need rapid access when their condition changes, episodic support throughout their journey as needs evolve, and the flexibility to return when symptoms fluctuate.

Access to professionals with specialist neurological knowledge is critical. Generalist therapy services, while valuable, cannot provide the condition-specific expertise needed to manage the complex, fluctuating symptoms of progressive neurological conditions.

'There is a big difference between those who are able to give neuro rehab compared to just normal physio. For my time at university in London, the physio was just ineffective because my condition was progressive. They would give me exercises that were general for people doing physio but nothing specific. When I came back to Leeds and managed to get into neuro rehab, it was too little too late. Things had continued to progress.'
Person with MS

For conditions like motor neurone disease and Huntington's disease, there is often a misconception that rehabilitation has limited value or should only be offered late in the disease course. This view is outdated and harmful. Early and ongoing access to specialist rehabilitation helps people adapt to changes, maintain function for longer, manage symptoms, and preserve quality of life throughout their journey.

Rehabilitation is not about cure or recovery it is about living as well as possible with a progressive condition. It is not only vital for the person with the condition but also for unpaid carers, who benefit from training, guidance, and structured support that can prevent burnout and improve quality of life for the whole household.

The evidence base is robust. Studies demonstrate a benefit to cost ratio of 16:1 for inpatient rehabilitation, with lifetime cost savings of up to £1.1 million per person when delivered early.[22] These savings arise from reduced long-term care needs, fewer hospital admissions, and enhanced capacity for independence. Yet current service models, which are often time-limited and discharge focused, don't accommodate the reality of progressive conditions.

The Chartered Society of Physiotherapy's Return on Investment study, using Treasury approved methods, demonstrates that physiotherapy returns £4 for every £1 invested when health and wider economic benefits are combined, delivering £145 million in annual net savings to the NHS and £1.88 billion in total benefits to the UK.[23]

In the community, the scale of need and the potential return on investment remain poorly understood. As the British Society of Physical and Rehabilitation Medicine (BSPRM) highlights:

> **'The community is a comparative data desert, and the NHS currently collects no systematic information on the number of patients needing specialist rehabilitation and the capacity to provide for them.'**[24]

This lack of data makes it difficult to plan services adequately, commission appropriately, or demonstrate the true scale of unmet need.

Effective neurorehabilitation requires rapid initial assessment and the ability to return for support when needed. Current structures make both difficult to achieve, leaving people to deteriorate while waiting for appointments or discharged just when ongoing support becomes critical.

Mental health: An urgent priority

Mental health conditions in progressive neurological disease are often not separate comorbidities — they can be direct neurological consequences of the condition itself. Depression, anxiety, psychosis, and cognitive changes can arise from the same brain changes that cause physical symptoms. Understandably, people can also experience poor mental health related to the challenges associated with living with a neurological condition. This can include reduced mobility, having to give up work, and fear of the future.

This is why mental health support must be delivered as an integral part of neurorehabilitation, by professionals who understand the relationship between neurological conditions and mental health. If a person requires more extensive mental health support, then their neurorehabilitation service would be able to educate mental health services about neurological conditions, helping them provide high-quality and joined-up care.

Mental health is central to quality of life for people with progressive neurological conditions, yet it remains underprovided and poorly integrated. Depression rates are 5 to 7 times higher in people with MS (25.3%) than the general population (3.8%).[25] Across progressive conditions, access to mental health support falls far short of need, with many services reporting that fewer than 25% of patients requiring psychological or psychiatric care are able to receive it.[25] In motor neurone disease, 44% of people experience anxiety and 30% experience depression.[26] Most strikingly, people diagnosed with MND face a six-fold increased risk of suicide compared to the general population. For people affected by Huntington's disease, these gaps are particularly stark. A survey found that almost one third of patients were denied access to local mental health services, while suicide rates are four to six times higher than in the general population.[27]

One family member described the impact:

'We battled for 7 years to get my husband the help he needed but were constantly told he had capacity... He was eventually sectioned after endless meetings... Finally, he is in a specialist neurological unit after years of distress to him and his family.'

Nearly half (46%) of Huntington's disease services report difficulty accessing healthcare professionals with specialist expertise locally, highlighting systemic workforce and commissioning barriers. Similar access challenges are reported across other neurological conditions.[28]

The consequences of unmet mental health need are evident across settings. In Parkinson's, a study of 50 hospitalised patients found that mental health issues accounted for 95.8% of 1,084 hospital bed days, with psychosis associated with the longest admissions and delayed discharge.[29] Evidence from Huntington's disease services shows a recurring pattern in which people are denied mental health care until they reach crisis point, by which time symptoms are more severe, treatment is slower, and hospital stays are substantially prolonged.

People with Huntington's disease who are denied access to mental health services often can access it when in crisis. At this point, the Huntington's disease has declined further the neuropsychiatric symptoms take longer to treat, meaning people often stay in hospital for 6 to 9 months.[30]

Mental health need is consistently identified as a top care priority by people living with progressive neurological conditions and their families. A 2023 study of 153 people affected by Huntington's disease found mental health support to be the most frequently cited unmet need for both individuals and caregivers.[31]

Improved access to community mental health support would reduce crisis admissions, shorten hospital stays, prevent avoidable deterioration requiring long-term inpatient care, and improve outcomes for individuals and families. Mental health must be embedded as a core component of neurorehabilitation.

Services should measure psychological wellbeing alongside physical function, with neuropsychology and mental health therapies funded in line with clinical need and supported by clear, integrated care pathways between neurology and mental health services. Addressing mental health is critical, as poor psychological wellbeing can prevent people from fully engaging with neurorehabilitation, whereas timely mental health support can enhance participation and improve overall rehabilitation outcomes.[32]

Care closer to home

Neurological rehabilitation should be delivered in communities, close to where people live, as part of multi-disciplinary neighbourhood health services. This model prevents hospital admissions, reduces the need for institutional care, and enables people to maintain social connections and, where appropriate, employment. It aligns with the NHS 10 Year Plan's in England commitment to 'effective rehabilitation in the community'as standard care.[33]

However, current provision falls significantly short. Many areas have limited or no community neurorehabilitation services. Where services exist, they are often time-limited and unsuitable for people who need episodic access throughout their journey. Reported workforce shortages of 40 to 50% in some areas mean that even commissioned services can't be delivered.

Realising the vision of care closer to home requires investment in community teams, flexible models that accommodate fluctuating needs, and rapid access when symptoms change.

The challenges outlined in this report (unmet need, geographic inequality, workforce shortages, and preventable harm) demand urgent, coordinated action. The evidence is clear, the economic case is compelling, and the human cost of inaction is unacceptable.

The following principles, set out the transformation required to ensure people with progressive neurological conditions can thrive, not merely survive.

Principles for action

The principles below are grounded in evidence and people's experiences. We, the undersigned neurological charities, call for transformation in how progressive neurological conditions are supported in the UK. We endorse the following principles:

1. The right to neurorehabilitation

Everyone living with a progressive neurological condition has the right to timely, high-quality neurorehabilitation, regardless of postcode or ability to pay. Unwarranted geographic variation in access to essential services must be eliminated.

Action required
Commissioners must ensure equitable access to multidisciplinary neurorehabilitation within every Integrated Care Board, Health Board, and Health and Social Care Trust. This must include transparent waiting-time standards, clear referral pathways from diagnosis, and rapid reassessment whenever needs change.

2. Care closer to home

Neurorehabilitation should be delivered as close to home as possible where appropriate — embedded within community and neighbourhood health services.

This includes enabling community activities, wellbeing services, talking therapies, and accessible leisure services. In England, neighbourhood health hubs should prioritise neurological conditions alongside other long-term conditions, providing support and secondary prevention.

Action required
Across all UK nations, commitments to community-based rehabilitation must be supported by dedicated funding, workforce expansion, and measurable targets for reducing preventable admissions. Services must be flexible, responsive to fluctuating needs, and designed to provide ongoing support rather than time-limited episodes of care.

3. Mental health and cognition as core components of rehabilitation

Mental health is not optional or secondary. Depression, anxiety, cognitive changes, and emotional distress are integral features of progressive neurological conditions and must be addressed as part of routine care.

It's crucial that people who experience cognitive difficulties can access appropriate neuropsychological expertise to support and maintain daily functioning, including employment type activity.

Action required

Neuropsychology and mental health therapies must be funded in line with clinical need. Routine cognitive assessment and review must be embedded alongside mental health screening as standard practice, recognising cognitive change as a core feature of progressive neurological conditions. Integrated pathways between neurology, neuropsychology, and mental health services must be established. No one should be excluded from mental health services on the basis of a neurological diagnosis.

4. Workforce investment and capacity

Severe workforce shortages mean that many commissioned services cannot be delivered. Without sufficient staff, waiting times grow, continuity of care is lost, and outcomes worsen.

Action required

Governments and commissioners must invest in training and expanding the workforce across professions including physiotherapy, occupational therapy, speech and language therapy, rehabilitation medicine and neuropsychology. Workforce planning must be based on current and projected population need rather than historical provision, with strong retention strategies including competitive pay, career progression, and specialist training.

5. Standards, pathways, and quality

Evidence-based standards such as the NICE guideline on rehabilitation for chronic neurological disorders (NG252) and Optimal Clinical Pathways define what good neurological care looks like. These standards must be consistently implemented, not selectively applied.

Action required

Every Integrated Care Board, Health Board and equivalent must ensure services align with national guidance, including rehabilitation assessments at diagnosis, regular reviews, rapid access when needs change, and effective multidisciplinary team working. Clear benchmarks must guide commissioning, quality assurance, and service evaluation.

6. Supporting economic participation and independence

Where desired, neurorehabilitation should support people to remain in or return to work, education, and community life. This is about enabling choice, independence, and participation — not mandating employment.

Action required
Vocational rehabilitation must be embedded within neurological care pathways, with clear referral routes and collaboration between health services, employers, and wider support systems.

7. National neurology plans, population need, and data transparency

Without clear national neurology plans, local systems lack direction and accountability. Understanding population need and measuring impact are essential for driving meaningful improvement.

Action required
Each UK nation must publish and maintain a comprehensive neurology plan with measurable targets for workforce, capacity, access, and outcomes.

In England, this should include a Modern Service Framework for neurological conditions.

In Wales, the Welsh Government to support the on-going work of NHS Performance and Improvement and implement a consistent neurological rehabilitation pathway across Wales.

In Northern Ireland, the Department of Health must commit full funding to implement all recommendations of the Regional Review of Neurology Services, ensuring neurorehabilitation is properly resourced as part of wider neurology investment.

In Scotland this should be incorporated into the Scottish Government’s strategic approach to Long Term Conditions

Any plans must be informed by published population-level needs assessments. Annual public reporting must include waiting times, workforce levels, service availability, patient-reported outcomes and experience measures, and standardised outcome measures, with accountability for failure to meet agreed standards.

8. People with lived experience at the centre of service design

Neurorehabilitation services must be designed with, not just for, people living with neurological conditions. 'Nothing about us without us' must be a core principle of commissioning and delivery.

Action required

Every Integrated Care Board, Health Board, and equivalent must meaningfully involve people with neurological conditions and their unpaid carers in service planning, commissioning, transformation and evaluation. People with lived experience must be involved in defining outcomes and judging whether service changes have made a meaningful difference. Providers should be required to demonstrate genuine co-production in service specifications and reviews.

9. The right to a named care coordinator

Everyone with a progressive neurological condition should have a named professional, acting as a single point of contact responsible for coordinating their care. This ensures continuity, reduces duplication, and helps people navigate complex systems as needs evolve.

Action required

Commissioners must ensure every person is allocated a named care coordinator, embedded within local pathways and clearly communicated to the individual and their family. This is a core standard of care, not an optional enhancement.

10. From pathways to practice: Monitoring and accountability

Published pathways and guidance only improve lives when they are properly implemented, resourced, and monitored.

Action required

Each Integrated Care Board, Health Board and equivalent should appoint a designated neurorehabilitation lead responsible for ensuring these systems are applied and clinical pathways remain effective.

Health systems must routinely measure delivery against NICE guidance (England and Wales), Optimal Clinical Pathways, and local neurorehabilitation standards. Claims of improvement must be supported by evidence of impact on patient outcomes, not solely process measures such as referral times. Transparent reporting and service evaluation must be published annually by Integrated Care Boards, Health Boards, and Health and Social Care Trusts, with corrective action plans where care falls short.

A call to action

We, the undersigned charities representing people with progressive neurological conditions, commit to fighting for these changes. We will work with commissioners and policymakers to drive implementation. We will amplify the voices of those who cannot access care.

People with progressive neurological conditions deserve the chance to thrive, not merely survive.

Endorsed by

ACPIN
Ataxia UK
Chartered Society of Physiotherapy
Huntington’s Disease Association
MND Association
MS Society
MS Trust
Multiple System Atrophy Trust
Muscular Dystrophy UK
Neurological Alliance
Neurological Alliance of Scotland
Northern Ireland Neurological Charities Alliance
Parkinson’s Northern Ireland
Parkinson’s UK
Royal College of Occupational Therapists
Royal College of Speech and Language Therapists
The British Psychological Society,
  Division of Neuropsychology
The British Society of Physical &
  Rehabilitation Medicine
Wales Neurological Alliance

Thank you to all contributors with particular thanks to the MS Society Rehabilitation Steering group, the MS Society Experts by Experience group, Huntington’s Disease Association, MND Association, MS Trust, and Parkinson’s UK.

References

1 Global, regional, and national burden of disorders affecting the nervous system, 1990–2021: a systematic analysis for the Global Burden of Disease Study. 2021. Lancet. GBD 2021 Nervous System Disorders Collaborators Accessed 25/2/2026: https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(24)00038-3/fulltext

2 Christenson, Franzen, Hvid, Dalagas. Exercise as medicine in Parkinson's disease. Journal of Neurology, Neurosurgery and Psychiatry. 2023. Access. Exercise as medicine in Parkinson's disease | Journal of Neurology, Neurosurgery & Psychiatry. Access 25/2/2026: https://pubmed.ncbi.nlm.nih.gov/38418216/

3 Taken from current published figure for each neurological condition adults and children — MS (152,000) Parkinson's figures (166,000), Huntington's (7,000–10,000), MND (5,000) (7,956)

4 Neurological Alliance. My Neuro Survey. 2024–2025. Research Findings Report https://www.neural.org.uk/wp-content/uploads/2025/06/My-Neuro-Landscape-Report-150625.pdf

5 Nuffield. How will waiting times in community health services affect the shift towards neighbourhood health? Nuffield Trust (2025) https://www.nuffieldtrust.org.uk/resource/how-will-waiting-times-in-community-health-services-affect-the-shift-towards-neighbourhood-health

6 Economist Impact. The Value of Action: Mitigating the Impact of Neurological Disorders in the United Kingdom. 2024. Accessed 25/2/26: https://impact.economist.com/health/value-action-mitigating-impact-neurological-disorders-united-kingdom

7 Economist Impact. The Value of Action

8 MS Society. A Different Path: Rethinking MS Hospital Care. Analysis of hospital admission data for people with MS in England, 2023-24. 2025. Accessed 25/2/2026 https://www.mssociety.org.uk/about-us/how-we-work/our-evidence/different-path-rethinking-ms-hospital-care

9 Public Health England Neurology Dashboard. Hospital Episode Statistics data 2024/2025 Excellence Network data dashboards | Parkinson's UK Accessed 25/2/2025 https://www.parkinsons.org.uk/professionals/resources/excellence-network-data-dashboards

10 NICE. Multiple sclerosis in adults: management. NICE guideline [NG220]. June 2022. Accessed 25/2/2025 https://www.nice.org.uk/guidance/ng220

11 Aarts J, de Groot V. To halt disease progression rehabilitation in MS should start early: Yes. Mult Scler. 2024:30(10):1249-125. Accessed 25/2/2026: https://pubmed.ncbi.nlm.nih.gov/39548692/

12 Brandstadter R, Katz Sand I, Sumowski JF. Beyond rehabilitation: A prevention model of reserve and brain maintenance in multiple sclerosis. Mult Scler. 2019;25(10):1372-1378. Accessed 25/2/2026: https://pubmed.ncbi.nlm.nih.gov/31469354/

13 Ennals T, Fong Yan A, Hawkins R, Jones K, Playford ED, das Nair R. Implementing vocational rehabilitation for people with multiple sclerosis in the UK National Health Service: a mixed-methods feasibility study. Disabil Rehabil. 2024. doi:10.1080/09638288.2024.241703 Accessed 25/2/2026 https://pmc.ncbi.nlm.nih.gov/articles/PMC11856266/

14 MS Specific data shared by Neurological Alliance. My Neuro Survey 2024. Key findings. Accessed 25/2/2026 https://www.neural.org.uk/wp-content/uploads/2025/06/My-Neuro-Landscape-Report-150625.pdf

15 RCOT. Workforce Study 2023 Workforce survey report 2023 The Royal College of Occupational Therapists. Accessed 25/2/2026 Workforce survey report 2023 | The Royal College of Occupational Therapists

16 CSP. CSP Takes Action CSP takes action to address graduate recruitment concerns | The Chartered Society of Physiotherapy Accessed 25/2/2026 Graduate recruitment: stop the freezes | The Chartered Society of Physiotherapy

17 Sivan, M. et al. (2022) A proposal for expansion of the medical specialty of rehabilitation medicine. Rehabilitation Process and Outcome. https://pubmed.ncbi.nlm.nih.gov/36419648/

18 Royal College of Speech and Language Therapists (RCSLT) (2024) Retention and waiting times. Available at: https://www.rcslt.org/speech-and-language-therapy/workforce/retention-and-waiting-times/ Accessed: 11 March 2026

19 Economist Impact. The Value of Action

20 Economist Impact. The Value of Action

21 MS Society. A Different Path: Rethinking MS Hospital Care.

22 NICE. Stroke Rehabilitation for Adults. 2025 Return on investment for physiotherapy in the UK | The Chartered Society of Physiotherapy Accessed 25/2/2026: https://www.csp.org.uk/publications/return-investment-physiotherapy-uk

23 The Chartered Society of Physiotherapy. Return on Investment for Physiotherapy in the UK (2025). Accessed 25/2/2026: Chartered Society of Physiotherapy. Published 21 November 2025. Accessed 25/2/2026: https://www.csp.org.uk/publications/return-investment-physiotherapy-uk

24 Chartered Society of Physiotherapists. British Rehabilitation Standards Community Rehab 2021. Accessed 25/2/2026: https://www.csp.org.uk/professional-clinical/improvement-innovation/community-rehabilitation/key-rehab

25 Huntington Disease Association. Huntington Disease. Unseen and Unheard. The Need to Improve Mental Health with people with Huntington's disease. 2024 Unseen and Unheard. Accessed 25/2/2026: https://www.hda.org.uk/get-involved/campaiging/what-we-are-campaigning-for/mental-health/

26 MND Association. Position Paper Access to Talking Therapises. November 2023

27 Huntington Disease. Unseen and Unheard

28 Huntington Disease. Unseen and Unheard

29 Foley JA, Willis C. Prevalence and impact of mental health issues in Parkinson's disease unplanned hospital admissions. Parkinsonism & Related Disorders, vol. 115, Oct 2023. Accessed 25/2/2026: https://www.researchgate.net/publication/373197059_Prevalence_and_impact_of_mental_health_issues_in_Parkinson's_disease_unplanned_hospital_admissions

30 Huntington Disease, Unseen and Unheard

31 Huntington Disease, Unseen and Unheard

32 Bucma, Sladajevic. Impact of Anxious and/or Depressive Reactive State on the Effectiveness of Rehabilitation of Patients with Multiple Sclerosis. Medicica. 2024. Accessed 25/2/2026: ORCID

33 DHSC 10 Year Health Plan. July 2025 Accessed 25/2/2026: https://www.gov.uk/government/publications/10-year-health-plan-for-england-fit-for-the-future