# What we think about NHS Continuing Healthcare

**POSITION STATEMENT.** LAST UPDATED: *June 2025*

## Key messages

People with motor neurone disease (MND) often face delays, denials, and appeals when applying for NHS Continuing Healthcare (CHC). Many are left without essential care, forcing them and their families to navigate a broken system, bear significant financial burdens, or go without the specialist support they urgently require.

The NHS CHC system is complex, ambiguous, and inconsistently applied, making it difficult for people living with MND to secure the funding they need for their care. While a National Framework exists, there is a lack of accountability in ensuring its standards are implemented and is therefore applied differently across regions. The eligibility criteria for NHS CHC are open to interpretation, leading to a postcode lottery and high rejection rates. Those who receive CHC funding often rely on CHC-funded carers to manage their complex needs, yet these carers are frequently denied access to hospital settings, putting individuals at risk of inappropriate or unsafe care.

The CHC assessment process must be made clearer, fairer, and more consistent. This should include refining the criteria of what constitutes a 'primary health need' and increasing transparency to prevent regional disparities and unnecessary appeals. There must be multi-disciplinary assessment teams involving those with specialist MND knowledge involved in the patient's care, in line with the National Framework. Investment in the social care workforce is needed to guarantee sufficiently skilled care agencies and the workers necessary to undertake specialist CHC support for those with MND. Finally, CHC-funded carers must be permitted to continue providing essential support in acute hospital setting to ensure the safety and wellbeing of people with MND.

## Background

NHS CHC is a package of care arranged and fully funded by the NHS that some people are entitled to as a result of disability, accident, or illness. CHC is available to adults in England who are proven to have a 'primary health need', meaning their care requirements are primarily delivered by healthcare, as opposed to social or personal care. The principle of CHC is that the care required for those with a 'primary health need' is above what can be provided by local authorities and therefore the NHS has a duty to deliver it.

Eligibility requirements are evaluated via a two-step process: an initial standard 'Checklist' followed by a full assessment conducted by a multidisciplinary team (MDT), which consists of at least two health and care professionals with relevant expertise. This assessment uses a 'Decision Support Tool' (DST) to examine 12 domains of care, including breathing, cognition, mobility, and continence, assessing the nature, complexity, severity, and unpredictability of a person's needs. Based on this, the MDT makes a recommendation to the local Integrated Care Board (ICB), which determines eligibility and releases funding for CHC care packages. The Standard Pathway allows up to 42 days from the initial checklist request to the final decision. For those nearing the end of life with a rapidly deteriorating condition, a Fast Track Pathway is available. In this case, an appropriate clinician can bypass the checklist and DST so that care can be in place within 48 hours.

Many people with MND live with highly complex health needs in the community, necessitating sufficient and effective care packages. Due to these complex needs, many people with MND should meet the criteria for CHC funding. Yet many do not, leaving them with unmet health needs and increased financial strain.

## The challenge

There are many challenges that exist with NHS CHC. Many individuals with MND and their families are unaware that funding exists, leading to a lack of applications and missed opportunities for fully funded care. For those who are aware, the system is opaque and highly complex, lacking clear points of contact within ICBs, resulting in ambiguity around how the assessment and appeals process work, resulting in high variability in quality and access across regions. There is confusion among both patients and healthcare professionals around how to navigate NHS CHC. As ICBs are responsible for funding decisions, there exists significant regional variation and a post-code lottery of access to CHC with eligibility rates between 7% and 43% across regions. While there is a National Framework to adhere to, it is often applied inconsistently depending on geographic location.

### Assessments and appeals

People with MND frequently struggle to navigate the CHC assessment process due to its complexity, misinformation, and the lack of specialist knowledge among assessors regarding neurodegenerative conditions. Previous research by The Nuffield Trust indicated a lack of awareness around CHC and challenges such as delays and insufficient understanding of specific conditions, noting that "CHC is a complex and often daunting process for individuals and their families". Suboptimal assessments are commonly reported, with assessors failing to adhere to National Framework guidelines. One of the most concerning practices is the use of single-person assessments, rather than the required MDT approach involving NHS and local authority representatives, those with specialist knowledge of the patient’s condition and involvement in the patient’s care. Also worrying is that many people are inaccurately ‘marked down’ in assessments, underestimating the impact of their condition on daily life. These issues are especially concerning to people with MND, an often rapidly progressing terminal condition, where many will significantly deteriorate or die before getting the care they need. Given these potential consequences, there needs to be an enforceable national standard for how long CHC applications and appeals can take, with specific time limits and a duty to publish regular data on adherence to these standards. Oversight of these standards would ensure that any delays are identified and addressed so that no one with MND is left waiting in crisis.

The CHC eligibility criteria hinges on the concept of a “primary health need,” yet this term lacks a clear definition and does not appear in any primary legislation. Therefore, application of the criteria is open to individual interpretation. The DST assesses 12 care domains, but its use varies significantly across ICBs, leading to inconsistent determinations of eligibility. NHS England data shows that over the past seven years, the number of DSTs completed has fallen by 14%, suggesting that fewer people are even reaching the stage of full assessment. There is a systemic inequity in the assessment processes whereby individuals with the same level of need often receive different outcomes based on regional interpretations of CHC guidelines. A report by the House of Commons Library states that "services provided by the NHS are free at the point of use whereas those arranged by local authority social services in England are means-tested," therefore those who are deemed ineligible for CHC can face significant financial implications.

It is generally acknowledged that a lack of capital funding for CHC impacts assessments whereby people are not meeting the eligibility thresholds despite clear and significant health and care needs. The increase in those applying for CHC is made up almost entirely of Fast Track applications, which have increased by 23%. Meanwhile those applying for the Standard Pathway are less likely to be successful, with eligibility rates dropping from 31% in 2017 to 19% in 2024/25, indicating that those applying via the Standard Pathway are being deferred in favour of Fast Track applications.

A significant proportion of individuals with MND who are initially denied CHC funding must engage in lengthy and stressful appeals processes. One in six appeals following local resolution result in a decision being overturned, and this rises to 70-75% with representation from Beacon – a dedicated CHC advocacy service. There are also significant regional disparities – for instance, a 7.3% eligibility rate in Gloucestershire compared to 42.5% in Leicester, Leicestershire, and Rutland between January and March 2024. It is also concerning that those following an appeals process are now less likely to be successful, with eligibility approvals from appeals dropping from 20% in 2017 to 15% in 2025. The entire appeals process is complex, time-consuming and opaque, adding further unneeded distress to individuals and their families. Given the rapid progression of MND, these issues often mean that by the time funding is granted, if at all, individuals' care needs have significantly escalated.

To ensure people with MND receive the care they are entitled to, ICBs need to ensure greater adherence to the National Framework, guaranteeing proper assessments for CHC applicants. This should include implementing training and education programmes for assessors to enhance their understanding of complex neurodegenerative conditions like MND. The National Framework emphasises that assessments should be carried out by an MDT comprising professionals from both health and social care backgrounds, and those involved in the patient's care. ICBs should enforce this MDT approach to prevent single-person assessments that may not give a comprehensive assessment. Ongoing monitoring is also important to ensure that the DST is consistently applied across all regions to mitigate disparities in eligibility determinations. Once these measures are in place, ICBs should then establish a consistent and transparent appeals process with regular audits to uphold the integrity of CHC assessments.

## Workforce issues and care package quality

Even when CHC funding is approved, the care packages commissioned often fail to meet individual health needs, particularly for people with MND who have complex care requirements. Many recipients receive insufficient hours of care or inappropriate support that does not align with the severity of their condition. Approved CHC packages are frequently left unfulfilled, with contracts handed back due to a lack of available and appropriately trained care providers. CHC packages are delivered by the same social care providers and workfroce commissioned by local authorities, so when that workforce is under pressure, CHC delivery suffers. The social care sector is experiencing a workforce crisis driven by high vacancy rates, low pay and career progression, and rising demand. Skills for Care estimated that 8.3% of social care posts were vacant in 2023/24, while the population continues to age and requests for social care support rise year on year. The ADASS Spring Survey found care market sustainability to be a major concern, with 66% of Directors reporting that providers in their area had closed, r. This results in gaps in care provision and places additional strain on families and unpaid carers. With eight in ten local councils set to overspend their budget, and 95% relying on one-off funding sources to cover this overspending, the current model is not fit to deliver on future demand. The sustainability of care markets in each local authority needs to be made a priority so councils can source the right care providers for the right care packages.

There need to be efforts to make social care a desirable career path to ensure there is a workforce to manage increasingly complex CHC packages. It is a positive step forward that the Labour government have agreed to continue the development of the Care Workforce Pathway, the first national career framework for adult social care, and introduce the Fair Pay Agreement which “will set fair pay, terms and conditions, along with training standards” to the adult social care sector. There are also early proposals to create a National Care Service, which aims to provide community-based, person-centred social care to those who need it. This, in principle, could bring about greater coherence and the much-needed change to address these issues. However current plans are vague and fall short of the transformational change required. Despite these promises, there are disparities in pay across regions, planned funding for training and development has been reduced by £115m for 2024/25, and the second round of the adult social work apprenticeship fund has been scrapped, which would have enabled councils to recruit around 130 social work apprentices in 2024/25. Additionally, the government’s decision to increase employer National Insurance from 13.8% to 15%, which according to the Nuffield Trust will cost England’s 18,000 independent adult social care providers £940m in 2025-26, sealing the fate of many care providers across the nation. Any plans to develop the social care workforce should focus on recruitment and retention to guarantee sufficiently skilled care agencies and the workers necessary to undertake specialist CHC support for those with MND, and national policy should reflect this

## CHC carers in acute settings

CHC-funded carers can play an integral role in ensuring the safety and wellbeing of people living with MND. These carers provide essential support, including assistance with communication devices, repositioning, non-invasive ventilation (NIV), and other aspects of care that require specialist knowledge of MND. However, despite their critical role, CHC carers are often denied access to acute hospital settings. This exclusion is often due to some ICBs considering the provision of care by CHC staff in hospitals as ‘double funding’. This assumption fails to recognise the distinction between clinical and CHC care. It also fails to take into account the risk of acute hospital staff not having specialist MND knowledge and thus being unaware of the person with MND’s unique and complex care needs and not having the capacity to meet non-acute needs. The hospital staff may also be unfamiliar with the correct use of vital assistive equipment, or the positioning requirements and support needed during movements of the person with MND.

The absence of a familiar carer can have serious consequences and can put people with MND at increased risk of harm. Hospital staff may struggle to communicate effectively with them, leading to distress, frustration, and inappropriate care decisions, possibly leading to unnecessary deterioration, complications and delayed discharge. This in turn places additional strain on already stretched NHS staff, who may not have the capacity or expertise to manage the complexities of MND care. ICBs must recognise that CHC-funded carers are not an unnecessary duplication of resources but an essential part of ensuring safe and effective care for people with MND, regardless of the setting. Preventing these carers from providing support in acute settings undermines the purpose of CHC funding, which is to provide comprehensive, person-centred care that meets the needs of those with a primary health need.

## What changes do we want to see?

**From Government**

- Government should commit to social care funding that is sufficient, sustainable, and well planned to ensure all people can access the support they need. This should ensure there is sufficient capital funding for local authorities to administer the true number of eligible CHC applicants.

**From ICBs:**

- ICBs need to ensure greater adherence to the National Framework, guaranteeing proper assessments for CHC applicants through auditing, national guidance and targets, national training, sharing best practice and clear points of contact.
- ICBs need to ensure they have a sustainable local care market, guaranteeing sufficiently skilled care agencies and workers necessary to undertake complex care packages for MND.
- ICBs must ensure that CHC-funded carers are permitted to provide essential support in acute hospital settings, recognising their role in delivering specialist care that cannot be replaced by hospital staff.

## What MND Association is doing

- Producing CHC information and resources to support people living with and affected by MND including: CHC animation; CHC webpage; information leaflets; online peer support group; podcast; and a webinar and professionals' leaflet.
- Influencing the system as part of the CHC Alliance Group who regularly engage with CHC teams across NHS England and Department for Health and Social Care.
- Reviewing national guidance to improve the delivery of CHC, including DHSC's *Previously Unassessed Periods of Care* guidance.
- Highlighting the poor delivery of CHC and its impact on people with MND, such as through the *NHS 10-Year Plan.*
- Working closely with Beacon CHC to signpost our community to additional resources and advocacy services where needed.

## References

1. Beacon. *NHS Continuing Healthcare (CHC) support*. Available at: https://beaconchc.co.uk/.
2. Beacon. *Guide to Continuing Healthcare Assessments.* Available at: Guide to Continuing Healthcare Assessments - Beacon
3. NHS England. *NHS Continuing Healthcare and NHS-funded Nursing Care*. Available at: https://www.england.nhs.uk/healthcare/.
4. Department of Health and Social Care. (2018). *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care*. Available at:
5. https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care.

Prepared by MND Association's Policy Team. For more information, contact **Kielan Arblaster, Policy Manager at kielan.arblaster@mndassociation.org**

6. Nuffield Trust. (2022). *Falling Through the Gaps: A Closer Look at NHS Continuing Healthcare*. Available at: https://www.nuffieldtrust.org.uk/resource/falling-through-the-gaps-a-closer-look-at-nhs-continuing-healthcare.
7. House of Commons Library. (2020). *NHS Continuing Healthcare in England*. Available at: https://commonslibrary.parliament.uk/nhs-continuing-healthcare-in-england/.
8. NHS England. (2024). *NHS Continuing Healthcare: Statistical Work Areas*. Available at: https://www.england.nhs.uk/statistics/statistical-work-areas/nhs-chc-fnc/.
9. ADASS (2024). *ADASS Spring Survey 2024*. Available at: https://www.adass.org.uk/wp-content/uploads/2024/07/ADASS-Spring-Survey-2024-FINAL-1.pdf
10. NHS England. (2025). *NHS Continuing Healthcare: Statistical Work Areas*. Available at: https://www.england.nhs.uk/statistics/statistical-work-areas/nhs-chc-fnc/
11. House of Commons Library. (2024). *Social care workforce in England: Recruitment and retention*. Available at: https://commonslibrary.parliament.uk/research-briefings/cbp-9615/#:~:text=Rising%20demand%3A%20demand%20for%20social,more%20experienced%20staff%20has%20narrowed.
12. UK Parliament. (2024). *Written Question 14656 – Social Services: Labour Turnover and Recruitment.* Available at: https://questions-statements.parliament.uk/written-questions/detail/2024-11-18/14656/.
13. Skills for Care. (2024). *Changes to funding for learning and development for adult social care*. Available at: https://www.skillsforcare.org.uk/Funding/Workforce-Development-Fund/Changes-to-funding-for-learning-and-development-for-adult-social-care.aspx
14. Department of Health and Social Care (DHSC), 2023. *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care: July 2022 (Revised, Corrected July 2023).* London: Department of Health and Social Care. Available at: https://assets.publishing.service.gov.uk/media/64b0f7cdc033c100108062f9/National-Framework-for-NHS-Continuing-Healthcare-and-NHS-funded-Nursing-Care_July-2022-revised_corrected-July-2023.pdf
15. Age UK, 2021. *Continuing to Care: NHS Continuing Healthcare Report.* London: Age UK. Available at: https://www.ageuk.org.uk/siteassets/documents/reports-and-publications/consultation-responses-and-submissions/health--wellbeing/continuing-to-care---nhs-continuing-healthcare-report.pdf
16. The King's Fund, 2024. *Key facts and figures about adult social care.* Available at: https://www.kingsfund.org.uk/insight-and-analysis/data-and-charts/key-facts-figures-adult-social-care
17. Nuffield Trust (2024) *Social care providers at risk of collapse as analysis reveals cost to sector of employer National Insurance hike*. Available at: https://www.nuffieldtrust.org.uk/news-item/social-care-providers-at-risk-of-collapse-as-analysis-reveals-cost-to-sector-of-employer-national-insurance-hike
18. Labour Party (2019) *Towards the National Care Service*. London: Labour Party. Available at: https://labour.org.uk/wp-content/uploads/2019/09/12703_19-Towards-the-National-Care-Service.pdf

Prepared by MND Association’s Policy Team. For more information, contact **Kielan Arblaster, Policy Manager at kielan.arblaster@mndassociation.org**