Policy Briefing
June 2026

Carers' experiences of NHS Continuing Healthcare briefing

Background

- This is a briefing on carers' experiences of using NHS Continuing Healthcare in England and recommendations for improvement.
- The data within this briefing is derived from our annual State of Caring survey, which was run from 16 June until 10 August 2025, specifically focusing on the question relating to carers' experiences of using NHS Continuing Healthcare.
- We received 10,539 responses in total to the survey, 5,999 of which were from respondents in England. The data included here is based on the 4,778 responses from respondents in England who answered the question.
- This briefing provides key statistics, a summary of the key findings by emerging themes, as well as experiences from carers who were interviewed on this topic.

Key findings

1. There is a lack of awareness of NHS Continuing Healthcare (CHC) amongst unpaid carers as well as health professionals. Carers are not being told about NHS CHC by healthcare staff for the person they care for and even being advised that it is for end-of-life care only or being encouraged not to apply at all.

2. Recent trends have shown the number of people who are being found eligible for standard NHS CHC is falling. 24% fewer people were assessed for standard CHC in quarter 4 of 2023/24 when compared to quarter 2 of 2017/18.[1] A recent Kings Fund review has highlighted a continued fall in CHC eligibility.[2] Carers report that it is becoming increasingly difficult for those they care for to meet the eligibility criteria, despite having complex needs.

3. There is a wide variation between eligibility for NHS CHC across England and inconsistent application of the National Framework and eligibility criteria, leading to a postcode lottery for carers and the person they care for.

4. Carers are experiencing significant delays waiting for an eligibility decision for the people they care for and find it difficult navigating what they deem to be a complex assessment process for CHC. This process and frequent reassessments places a significant administrative burden on unpaid carers.

5. Even when the people they care for are found eligible for NHS CHC, carers report experiencing a lack of empathy from healthcare professionals who have not had relevant training. Carers are living with a constant fear of having NHS CHC being

[1] Hutchings R, Davies M and Curry N (2024) *"Falling through the gaps? A closer look at NHS Continuing Healthcare", Nuffield Trust explainer*
[2] The King's Fund (2026) *'No Man's Land': the experience of patients at the interface of health and social care*

taken away during reviews or due to lack of local funding, despite having no changes in the needs of the person they care for.

Summary

What is NHS Continuing Healthcare (CHC)?

- NHS Continuing Healthcare (CHC) is a fully funded care package arranged and paid for by the NHS for adults who are aged 18 and over and are found to have a 'primary health need, which has arisen from a disability, accident or illness.'[3]
- A 'primary health need', means the person's care needs are predominantly health-related (physical and/or mental), rather than social care related, which is outlined by the CHC National Framework.[4]
- NHS CHC is free at the point of delivery, unlike social care arranged by local authorities, which is means-tested and may require individuals to contribute based on savings and income.[5]
- Once eligibility for CHC has been awarded, the NHS will have responsibility for all of that person's health and related social care needs, including residential accommodation, if needed.[6]
- CHC can be provided anywhere outside hospital that meets assessed needs, however it is usually in a person's own home or residential environment, such as a care home.[7]
- The Integrated Care Board (ICB) is responsible for the provision of NHS Continuing Healthcare.
- Sometimes, however, an ICB may decide that someone is not eligible for NHS CHC, but the person's needs are also beyond the duty of the local authority or the local authority cannot meet the person's assessed needs on their own. This means the ICB will be required to pay for some of their care and a joint package of health and social care will be agreed between the Local Authority and ICB.[8]

How eligibility for CHC is determined

- Eligibility for NHS CHC is dependent on the level and type of someone's day to day health needs, rather than a particular diagnosis or reasons behind needing care.[9] If these needs exceed the limits of the local authority's duty to provide care, eligibility is granted.[10]

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[3] Department of Health and Social Care (2022) *Public information leaflet: NHS continuing healthcare and NHS-funded nursing care*
[4] Department of Health and Social Care (2022) *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care*
[5] Department of Health and Social Care (2022) Public information leaflet: NHS continuing healthcare and NHS-funded nursing care
[6] Department of Health and Social Care (2022) *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care*
[7] Age UK (2025) *Factsheet 20 NHS Continuing Healthcare and NHS-funded nursing care*
[8] Ibid.
[9] Department of Health and Social Care (2022) *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care*
[10] Age UK (2025) *Factsheet 20 NHS Continuing Healthcare and NHS-funded nursing care*

- The process of granting eligibility involves one of two different pathways. Either the Standard Pathway or the Fast Track Pathway is used, the latter of which is designed for those who have a rapidly deteriorating condition that may be entering a terminal phase and nearing the end of life.[11]
- The Standard Pathway involves an initial 'Checklist' screening to see if a full assessment is needed. If someone meets the requirements of the checklist, they are then referred for a full assessment by a Multidisciplinary Team (MDT). The team comprises of at least two health and care professionals, as required by the National Framework.[12]
- The MDT team will use a 'Decision Support Tool' (DST) to assess someone's needs relating to twelve different areas, such as breathing, cognition, mobility and continence. Needs in these areas will be assessed by their nature, complexity, severity and unpredictability and the level of care required to manage them.[13]
- From the time of a checklist being requested, to a decision being made, the Standard Pathway allows for a 42 day wait time. For those who are rapidly deteriorating and may be entering a terminal phase, however, the Fast Track pathway bypasses the checklist and DST stages, speeding up the process and allowing individuals to access care usually within 48 hours of a decision being made.[14]
- If someone is successful in their assessment for NHS CHC, a review of their needs should take place three months later, and, following this, at least once a year.[15] The National Framework outlines the purpose of these reviews as establishing that care packages are still adequately meeting people's needs and expects that in most cases, there should be no need for a reassessment of eligibility.[16]
- The process for those under 18 is called Children and Young People's Continuing Care and is similar to the process for adults. A child is considered eligible when they are assessed as having complex health needs that can't be met by local or specialist health services on their own.[17]
- If someone is unsuccessful in their assessment, they are entitled to appeal the decision to their ICB. The initial appeal should go through a standard local resolution procedure, followed by an Independent Review if a negative decision is reached. If unsuccessful again, one can complain through the Parliamentary and Health Service Ombudsman.[18]
- The CHC National Framework outlines the principles which should be followed during these processes, including a person-centred approach, involving both the patient and their representative.[19] The framework explains that staff should tell patients if they are eligible for NHS CHC and their care should be arranged to

[11] Age UK (2024) *Continuing to care? Older people let down by NHS Continuing Healthcare*
[12] Ibid.
[13] Ibid.
[14] Ibid.
[15] Ibid.
[16] Department of Health and Social Care (2022) *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care*
[17] Contact (2025) *How Continuing Care for Children fails those with the most complex health needs (England)*
[18] Age UK (2024) *Continuing to care? Older people let down by NHS Continuing Healthcare*
[19] Ibid.

ensure that the patient and their representative, such as their carer, understand the process and can participate in an informed manner.[20]

- Despite this, our evidence shows that many carers have negative experiences of navigating the NHS CHC application process, when processes have not followed such guidance.

Eligibility for NHS CHC is falling

- Nuffield Trust research shows that the number of people assessed as eligible for CHC has fallen in recent years. Their data shows that '24% fewer people were assessed for standard CHC in quarter 4 of 2023/24 when compared to quarter 2 of 2017/18, while there was an 18% increase in the number of people assessed for fast-track.'[21] This raises questions as to whether patients and their unpaid carers are only getting access to the support they need when nearing the end of life.
- Age UK data has uncovered a similar pattern, finding that 'since 2017/18, the gap between Standard and Fast Track referrals for NHS Continuing Healthcare has almost tripled to 11,000 cases. In Quarter 1 2017/18, the difference between Standard and Fast Track referrals was approximately 3,500 cases in favour of Fast Track. By Quarter 1 2024/25 this had increased to around 11,000 cases.'[22]
- Research from Just Group retirement specialist has found 75% of over 45s have never heard of NHS CHC, describing it as the NHS' 'best kept secret,'[23] which our findings support. One of the most common qualitative themes was carers who were completely unaware of the existence of NHS CHC.
- Healthwatch Lambeth has called for greater public awareness raising to help people access information on the application process, which could help to reduce the pressure on unpaid carers.[24]
- Age UK has found that the number of new recipients receiving Standard NHS Continuing Healthcare has declined by almost half since 2017/18, from 4,628 in Quarter 1 2017/18 to 2,651 in Quarter 1 2024/25.[25]
- Contributing factors include changes to the National Framework which suggested it was no longer appropriate for staff to assess for CHC while patients were in an acute hospital. This was derived from the 'Discharge to Assess' process, which suggests you would have a clearer view of someone's needs when they were back home. However, this meant there may have been less incentive for staff to undertake assessments to free up hospital beds. [26]
- A review of the National Framework or CHC could help to create guidance that better reflects the experiences of patients and their unpaid carers.

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[20] Department of Health and Social Care (2022) *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care*

[21] Hutchings R, Davies M and Curry N (2024) *"Falling through the gaps? A closer look at NHS Continuing Healthcare", Nuffield Trust explainer*

[22] Age UK (2024) Continuing to care? Older people let down by NHS Continuing Healthcare

[23] Just Group (2021) NHS Continuing Healthcare remains 'best kept secret' in care financing, Just Group research reveals

[24] Healthwatch Lambeth (2023) *Continuing Healthcare Service user and carer experiences of applying for NHS Continuing Healthcare funding*

[25] Age UK (2024) Continuing to care? Older people let down by NHS Continuing Healthcare

[26] Age UK (2024) *Continuing to care? Older people let down by NHS Continuing Healthcare*

- The Nuffield Trust also found that 'the proportion of people who have undergone assessment and are then found eligible for standard CHC (the 'assessment conversion rate') has dropped from 27% to 21% since mid-2017.' Carers UK analysis of State of Caring 2025 survey data supports this, as qualitative data indicates many unpaid carers felt it very difficult for the person they care for to be assessed as eligible, despite having very complex needs.
- The checklist threshold is set deliberately low to ensure anyone who needs an assessment has the opportunity.[27] However, this can lead to false hope for many patients and their carers, as eligibility levels are falling. The NHS Confederation has recommended that DHSC reviews the checklist to be closer to the CHC eligibility criteria, to help avoid this.[28]
- Carers of children who need Children and Young People's Continuing Care are facing similar problems. In 2023-4, half (53%) of the children and young people referred for continuing care assessment were denied support.[29]

Eligibility for NHS CHC is a postcode lottery

- The Nuffield Trust also found that eligibility for NHS CHC varies dramatically depending on the region. For example, 'in the year to March 2024, total eligibility (standard and fast-track) ranged from 36.9 per 50,000 population in Cornwall and the Isles of Scilly ICB to 301.03 per 50,000 in Lincolnshire ICB.'[30]
- This is also reflected by the freedom of information request by Winston Solicitors to NHS England, showing a disparity of £203.4 million of expenditure on standard CHC, between ICB's with the lowest and highest expenditure.[31]
- This variability also exists even within ICB regions. Between 1 January 2024 and 31 March 2024, just 7.3% of people who were assessed for standard CHC were found eligible in Gloucestershire ICB, whereas 42.5% were eligible in Leicester, Leicestershire and Rutland ICB.[32] This may unfairly impact unpaid carers as their ability to receive support and reduce pressure on their caring responsibilities, is subject to a postcode lottery.
- Data from Age UK supports this, finding that 'across ICB's, there was a 3.5 fold difference in the number of people receiving NHS Continuing Healthcare in 2024. Across Sub-ICB's, the percentage of NHS Continuing Healthcare assessments that result in eligibility range from 5% to 58.3%.[33]
- The Nuffield Trust highlights how this variation in eligibility suggests there are inconsistencies in how the National Framework is interpreted and implemented across regions.[34]

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[27] Age UK (2025) *NHS Continuing Healthcare and NHS-funded nursing care factsheet*
[28] NHS Confederation (2022) *NHS Continuing Healthcare: delivering excellence*
[29] Contact (2025) *How Continuing Care for Children fails those with the most complex health needs (England)*
[30] Hutchings R, Davies M and Curry N (2024) *"Falling through the gaps? A closer look at NHS Continuing Healthcare", Nuffield Trust explainer*
[31] The Carer (2025) *NHS CHC Postcode Lottery Leaves Patients at Risk, New Data Shows*
[32] Hutchings R, Davies M and Curry N (2024) *"Falling through the gaps? A closer look at NHS Continuing Healthcare", Nuffield Trust explainer*
[33] Age UK (2024) *Continuing to care? Older people let down by NHS Continuing Healthcare*
[34] Ibid.

- The Parliamentary and Health Service Ombudsman has raised the need for regular training for assessors to ensure best practice in the framework is always followed.[35] The government should follow in the footsteps of the Welsh government and commit to a review of CHC policy.[36]

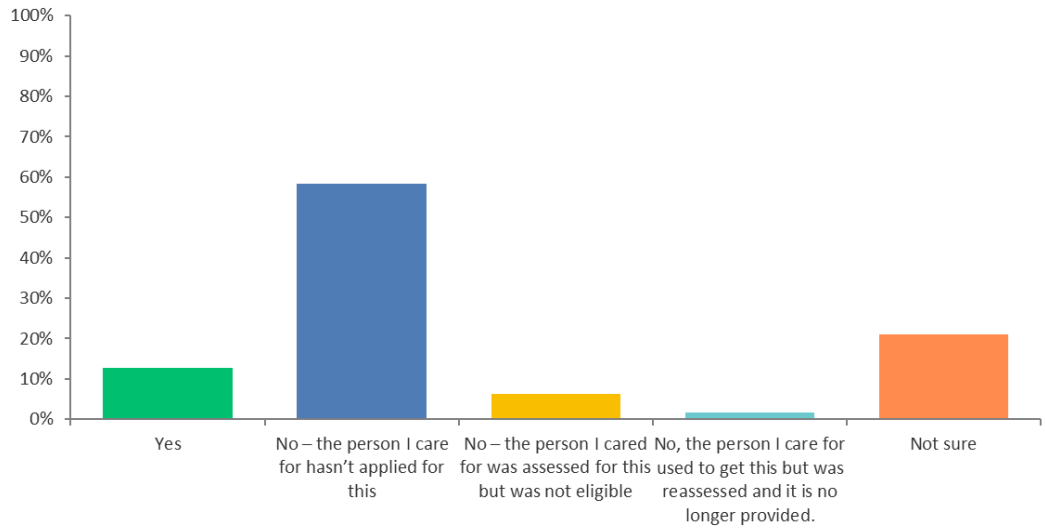
Delays for NHS CHC decisions are common

- Another key issue patients and unpaid carers are facing is delays to receiving their eligibility decision.[37] Despite the National Framework stating that the overall assessment process should take no longer than 28 days from when the ICB receives a positive checklist[38], Nuffield Trust data shows this is often not the case. They found that 'as of 31 March 2024, 1,730 referrals were incomplete and had been delayed by more than 28 days. This included 612 people who had been delayed by an additional two weeks, and 40 who had been delayed by over 26 weeks.'[39]
- Our State of Caring 2025 qualitative data reinforces this, with delays during and after the assessment process being a key issue for those who responded to the survey.

The impact of NHS CHC failures on unpaid carers - key findings from our State of Caring 2025 survey

Key findings are based on the following question, answered by 4,778 respondents in England, in our 2025 State of Caring survey:

Does the person you care for receive NHS Continuing Healthcare?



[35] Parliamentary and Health Service Ombudsman (2020) *Continuing Healthcare: Getting it right first time*
[36] Hutchings R, Davies M and Curry N (2024) *"Falling through the gaps? A closer look at NHS Continuing Healthcare", Nuffield Trust explainer*
[37] Ibid.
[38] Department of Health and Social Care (2022) *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care*
[39] Hutchings R, Davies M and Curry N (2024) *"Falling through the gaps? A closer look at NHS Continuing Healthcare", Nuffield Trust explainer*

- **58%** of respondents said the person they care for hasn't applied for NHS Continuing Healthcare.
- **21%** of respondents said they were not sure if the person they care for receives NHS Continuing Healthcare.
- **13%** of respondents said the person they care for receives NHS Continuing Healthcare.
- **6%** of respondents said the person they care for was assessed for NHS Continuing Healthcare but was not eligible.
- **2%** of respondents said the person they care for used to get NHS Continuing Healthcare but was reassessed and it is no longer provided.

Qualitative analysis of key themes derived from comments from respondents:

A prevalent theme was that respondents found it incredibly difficult to meet the eligibility criteria set out by CHC, despite the person they cared for having complex needs.

- *"My Mother received continuing health care after a hospice assessment but when she was reassessed in the care home by an NHS nurse she was refused, despite losing 20 kilos, being almost blind and unable to do anything for herself, she couldn't even sit in a chair without slumping and had dementia (unspecified as she was not capable of doing any of the tests) she died two weeks later."*
- *"Been assessed for this more than once due to complexity of care my daughter now needs but still turned down. 30 hospital admissions in 4 years!"*
- *"In 2022, I applied for NHS Continuing Healthcare for my mother (now deceased). She had been moved to a nursing home because the care home could no longer meet her needs. She was in very late stages of Alzheimer's disease - completely bedridden and immobile, with double incontinence and unable to communicate in any meaningful way. CHC was declined and, with an appeal, again declined. Though it was agreed she had severe cognitive impairment, the fact that she couldn't communicate meant it was impossible to prove any levels of stress or discomfort or anxiety - though she had clearly experienced those when she had been able to speak."*

One of the most common themes from our survey includes carers being completely unaware of the existence of Continuing Healthcare. This is despite National Framework Guidance recommending ICB's have processes in place to identify individuals for whom it is appropriate to be screened for CHC.

- *"Years ago [my] husband was discharged from [his] consultant and told there was nothing else they could do for his primary progressive MS. We were told to just see a [GP] to adjust medication as and when. No one discussed with him or me about any support for us. He used to have physiotherapy before Covid happened. Then that stopped. [Nobody] checks in with us and we never see an MS nurse. It's like we are a lost cause. I have never felt so alone and scared of what is to come in all my life."*

- *"Never heard of it. Do not know who to go to. Far too many potential support structures require me - [the] main carer - to do the research, apply etc. I am already exhausted from actual caring and trying to survive on a daily basis to have extra tasks to deal with."*

For those who were eligible for CHC, some respondents experienced having their funding removed with no notice. Others are living with a constant fear of having funding taken away during reassessments. Regular re-assessments also present a significant administrative burden to unpaid carers, who are often leading on providing evidence for re-assessments and obtaining documentation.

- *"Even though my son's condition is lifelong he still has to be re-assessed for continuing health care funding which can be distressing."*
- *""With [my] other parent the CHC review every 12 months and they'd always try to take it away. It took me days to prepare the family statement if needs and care home records were appalling. CHC assessor won't believe anything that's not written down and carers don't have time to document everything."*
- *"I believe this [NHS CHC] was stopped incorrectly after taking over a decade to put in place this led to catastrophic results."*

Often respondents were told they would not meet the criteria before they had even tried applying for CHC. This advice came from the very health professionals, such as GPs or social workers, who should be actively encouraging people to apply.

- *"Nobody in the NHS has even mentioned this. I work within the NHS (admin role) and nobody in my Trust seems to even know this exists! [The] person I care for asked about help getting a wheelchair or rollator and was told they don't qualify as they can move about inside the house."*
- *"I was told it was difficult and they probably wouldn't accept mum. But everything that keeps her in bed is health related and she is EOL."*
- *"I talked to the GP about this for dad but was advised it probably wasn't likely. I haven't pursued it for mum. The message always is it isn't worth bothering."*
- *"The social worker has said my dad will not qualify for this so will not apply!"*
- *"I have been told we wouldn't qualify so haven't bothered with [the] lengthy application."*
- *"Just was told by [a] social worker that it is only for people in care homes."*
- *"I've been told repeatedly I won't get any help and Dad won't qualify and the checklist hasn't even been done as both NHS and Social care said the other agency is responsible for doing this. So it seems impossible to access!"*

Respondents believed CHC to be mostly designed for those who are reaching the end of life. People were either told this inaccurate information by health professionals or learned this through experience.

- *"[It] felt like [it was] only available to end of life people. Mum is bedbound and doubly incontinent, has dementia and can't move without [paid] carers but apparently isn't eligible."*

- *"There is no point applying - everyone knows it's only for those whose needs are nursing level home care."*
- *"The criteria is far too complex you practically have to die within a few days to get it."*
- *"I am told this [is] rarely available unless [the] patient is expected to die within 12 months."*
- *"It is ironic that if a person is well cared for, or their health problems are being managed with medication, they score lower, so then fall out of the eligibility criteria for continuing care!"*
- *"This was only granted after my spouse received a Stage 4 cancer diagnosis."*
- *"We have just started the process for one parent. I tried to initiate this myself with the help of the GP and Social Prescriber, but they both refused saying it was for end-of-life care only."*

There seems to be variability in the granting of funding based on different conditions, with carers feeling like CHC favours certain conditions over others, despite the National Framework explicitly specifying that eligibility should not be based on this factor.

- *"Had to apply twice and then appeal before getting it awarded. Not a system designed for conditions such as Huntington's Disease."*
- *"We were told by Adult Social Services to not bother as my sister wouldn't get it as she "only" has Cerebral Palsy."*
- *"A proper assessment wasn't done I was just told they wouldn't qualify - one parent has late-stage Vascular Dementia, one has Progressive Supranuclear Palsy."*
- *"I don't understand why dad was eligible with lung fibrosis and heart failure, but mam isn't with bronchiectasis, cancer, arthritis, osteoporosis and polycythaemia."*
- *"Everything is very bias[ed] towards physical conditions."*

Carers also raised issues with inconsistencies within the CHC assessment process, mirroring research around inconsistent application of the checklist and National Framework. Carers found the opinions of different health professionals differed greatly.

- *"We had this for my mother. It was generous and good. There seems to be some inconsistency as others with more health issues were refused even at the point when palliative care should have been provided. It worries me that there are huge [inconsistencies]."*
- *"I could write a book on this point. I applied for continuing healthcare funding for my husband in January/February this year and he passed the first checklist assessment. The full meeting was held in March and lasted 5.5 hours. I prepped for the meeting for a week. I had the evidence ready. After about 3.5 hours the NHS assessor said that my husband had passed the threshold and she agreed he would get NHS funding. As I also care for a disabled son, I left the meeting at this stage. The next day the assessor changed her mind and said she had been too hasty. She instructed me to withdraw the application as otherwise it would be rejected. At this stage I did*

not have the emotional energy to do more so felt I had no choice but to accept her direction. I was utterly exhausted in every way. My husband died 9 days later."

- *"I don't understand that despite the DST deciding one thing, a manager later decided he did not qualify for further funding. A few months later he qualified for CHC. Nothing material had changed. Seems like a lottery and managed on someone's whim despite it supposedly all being governed correctly. Frustrating, waste of time which was incredibly stressful for all involved with review meetings cancelled at v short notice."*
- *"1st assessment thought dad should get continuing care. The follow up assessment decided he didn't. To my mind he is the worst a person can be. Doubly incontinent. Can no longer walk. Can't feed himself properly. Doesn't understand what's going on around him. Often terrified when having to be cleaned up. Often lashing out and fighting. It is so sad. And someone who has never met him made a decision that he isn't ill enough!!!"*
- *"Inconsistency in case managers dealing with case. Always having to repeat information to a different person which is not easy to do."*

Many respondents reported finding the process of applying for and navigating CHC difficult and complex, receiving little support, as well as experiencing significant delays. Carers often experienced waits of weeks or even months, far exceeding the timelines specified in the National Framework.

- *"The process of applying for Continuing healthcare was very complicated and very little advice is available. It took me months of preparation for evidence gathering and the outcome very much depended on the assessor and not the criteria based evidence."*
- *"We do not have a named CHC manager so we speak to whoever answers the phone. This means you can't build up a relationship with anyone. The person you speak to doesn't know the person you care for. There is no continuity."*
- *"Where to start! It has been a nightmare. The first assessment was lost (still no answers as to how, GDPR etc). Second assessment completed nine months after my initial request, took three months to provide [a] decision which was to refuse CHC. I have appealed and have the meeting later this month!"*
- *"The assessment is very difficult, we received no support with it apart from a quick meeting with an OT from social services. The assessment was done via video call, my mum had no idea what was going on and kept falling asleep. I was very unprepared. Any questions I had were disregarded by the nurse assessor and my mums needs were deemed predictable therefore not high enough needs. Since that assessment my mum had 3 more hospital stays and no one suggested the assessment again despite her needs clearly being advanced. The system is set up to deny you the support."*
- *"Still waiting on outcome from 12 month assessment from January 2025."*
- *"We have been waiting four months so far for the assessment."*
- *"We are still waiting on a response some 6 months after the appeal and have had to get advice from a solicitor. All very stressful."*

- *"Applied in January but still asking for more evidence."* (Survey undertaken in July/August).

Many respondents also highlighted the impact the stressful, time-consuming nature of the process has had on their wellbeing. A system which should be helping reduce pressure on unpaid carers appears to be having the opposite effect.

- *"This process itself is too stressful. We have to deal with too many things at the same time, in addition to all the intrusions, team meetings, paperwork. Even if we decide to put us through all these, there's no guarantee that we would get the care and even if we do, it will be short lived. We'll have to start all over again. This affects our physical and mental wellbeing."*
- *"I understand that we can apply but have been warned it is not readily affordable. The form my daughter downloaded from [the] NHS is far too long, lengthy, complex and takes so much more time I haven't got."*
- *"Very difficult to get and I can't emotionally cope with yet more forms and battles."*
- *"Assessment meeting convinced we would win, that was overturned by the committee making the decision on grounds of not enough evidence, as happened again at appeal. We then gave up, humiliated and demoralised."*

Another key theme raised by carers was a lack of empathy among staff who were involved in NHS Continuing Healthcare. Staff were often described as inexperienced and had not listened to carers' perspectives.

- *"There is very little support, they operate in a business-like manner, they are not in communication with me and are slow to respond to my queries. They offer no social support [and] absolutely do not recognise the value of carers. They do not connect with social services and any council run organisations. [They] cannot comprehend any care situation that isn't overseen by social workers. Therefore, it is an isolating and frustrating place to be!"*
- *"[The] process is opaque and arbitrary. Every annual assessment is a battle. Nurse assessors do not listen and have their own agenda. They ignore parental views, and those of teaching / therapy staff who know my child well. You'd think they were paying for the care out of their own pocket. It is an extraordinarily adversarial process."*
- *"Continuing health care keep saying they need to speak with her (consent) which I agree with, but questions aren't tailored for her understanding levels. For example, discussion was had about referring her to mental health services for counselling, but I highlighted that a counsellor needed awareness of people with LD [learning disabilities] and a generic referral wasn't appropriate. Basic stuff that a consultant should have known. This adds to carer stress as you have to 'educate' professionals who should already have this awareness."*
- *"The NHS CHC is the most horrendous and traumatic process. Social workers are not knowledgeable enough to support the client."*

While few and far between, comments from those who specified having a positive experience with NHS CHC described it as a lifeline, raising further concern for carers who are left to struggle without it, due to inconsistencies in the assessment process. One carer said that her friend was only 65 years old and gave her the choice of living in the community, which is where she really wanted to be. Another carer described it as:

- *"[CHC] has been a life changer."*

Carers' experiences of CHC

Dorothy, cared for her husband, Melvin

Background:

Dorothy cared for her husband, Melvin, for 17 years until he died in June 2025. Melvin had ataxia, a degenerative neurological condition which affected his movement, communication, and ability to do daily tasks. About seven years ago, Dorothy gave up her career as an occupational therapist, running her own business, to care for Melvin full-time. He could no longer be left alone safely, was experiencing frequent falls, and increasingly relied on Dorothy's help to move around. "He needed my care," she says, "that was it. I just couldn't leave him alone and I thought I have to do this."

Dorothy's experience with NHS Continuing Healthcare:

Melvin was referred to St Peter's Hospice, despite not being a terminal patient at the time. The hospice could not provide any support but did help Dorothy with an NHS Continuing Healthcare (CHC) funding application, which was incredibly complex and took a long time. They were eventually granted funding, in the form of 3 weekly visits to Melvin which provided Dorothy with respite care, allowing her to do household and admin tasks.

Dorothy and Melvin continued to receive this support until the COVID-19 pandemic. Due to Melvin's condition, they had to shield and care support was paused as care workers could not guarantee they had been vaccinated or were infection free. Once they had both been vaccinated, Dorothy wanted to reinstate the care they have previously received. Dorothy was told that Melvin's needs had increased beyond the point that care workers could offer support. Because of this, Dorothy received no respite or care support for 5 years.

Throughout this period, Melvin was frequently hospitalised. On one occasion the multi-disciplinary team (MDT) decided that it was safer for Melvin to return home, but this decision only came following up to three weeks of disagreement among professionals. Dorothy said it felt as if "they were fighting over him." During this time, Melvin contracted infections in hospital and Dorothy asked for him to be sent home. Melvin was discharged with a five-week package of care, but after that, Dorothy was left with full responsibility for his 24/7 care. She said following this hospitalisation "he'd already lost a lot of conditioning." Dorothy said that on multiple occasions decisions were

made around discharge that were not appropriate for Melvin; on one occasion, Melvin had an unfit discharge and was re-admitted to hospital within 24 hours.

Even when Dorothy did have financial support, she found accessing appropriate care difficult. “When I had CHC funding, I still couldn’t find a care agency to meet his needs. About 15 months ago, when he was in hospital, he had CHC funding – but they removed it and told me to go through social services. I said that he would get worse, he had a degenerative condition, and it would only get worse”.

When Melvin was readmitted to hospital earlier this year, Dorothy faced a panel of five professional teams: Occupational Therapy, physio, CHC, social services and medical consultants. Dorothy says, “they said now that he’s on End-of-Life care, you can have your NHS funded care back again. I asked what End of Life care was, what does that mean? Do we get the care that we haven’t had in years?”

At this point, Dorothy and Melvin were granted 12 weeks of NHS-funded care. However, once again, no care agency had the capacity to meet Melvin’s needs. A care agency conducted a three-hour assessment with Melvin, but following this Dorothy was informed that due to a shortage of care workers, the agency would not be able to provide any support.

When the 12-week funding period ended, Dorothy was told that they had reached the limit of the care provision. Dorothy said, “but I didn’t actually get any care”, but was told that her 12 weeks had come to an end. Shortly after this, Melvin was readmitted to hospital as an emergency. Dorothy was able to ensure that he came home, and Melvin died at home in June 2025.

Geoff, cares for his wife, Jean

Background:

Geoff cares for his wife Jean who was diagnosed with relapsing and remitting Multiple Sclerosis (MS) in 1997, for which there is no cure. It took her a long time to be diagnosed, and she had to live with the symptoms while waiting for a diagnosis. Unfortunately, her condition worsened rapidly, and she is now quadriplegic and uses a wheelchair.

Geoff’s experience with NHS Continuing Healthcare:

Jean’s care package was initially funded via the Independent Living Fund and direct payments from St Helens council, which allowed Geoff to stay in work in his role as headmaster of a primary school. However, when Geoff retired, they lost the funding.

Luckily, Geoff was a councillor on St Helen’s Metropolitan Borough Council at the time and was informed about NHS CHC. They had a successful assessment for Jean. Geoff acknowledges that his knowledge helped him, where others may have missed out had they not known about it.

Geoff and Jean received funding for around 98 hours per week, spending some of this on a number of personal assistants (PAs), with one becoming their main source of support. They employed the PAs themselves, acting as a small business. They also received support alongside this from a commissioned service.

Geoff and Jean have received this CHC funding consistently for around 20 years and Geoff has described it as a '*lifesaver*.' *'I would put my hand up and say, yeah, it's a great system. I felt very, very fortunate and very lucky that the assessments had been, you know, say 98 hours. It's never changed. I've never asked for more because it was sufficient. It has allowed us, which I guess is what's all about, to carry on with a normal life*.'

It has enabled Geoff to fulfil his passions, explaining: *'I'm a governor of a couple of schools, and I'm also chair of the Board of Education for Liverpool Diocese. And I also am an independent visitor for the custody suites here in Merseyside.'*

However, recently Geoff's experience with NHS CHC has taken a sharp turn for the worse, which he describes as the polar opposite of how his experience has been over the past 20 years. This began when Jean's main personal assistant went on an extended period of sick leave. Geoff had to contact CHC who provided a temporary alternative from a care agency.

Following this, Geoff started to receive texts and emails from the direct payments section of St.Helen's Borough Council (St Helen's Council administers the financial aspects of NHS CHC) asking to provide proof of details such as pay slips, tax returns and bank statements, which he had never had to provide before. He explained: '*Obviously, the bank statements were to prove that, you know, the money's gone to somebody's account. They were quite aggressive, actually. It was quite upsetting*.'

A nurse assessor who Geoff had known for years and done assessments for Jean before, also paid them a visit during this time, asking questions about their situation and suggesting that they would be better served via a nurse led care company. Jean and Geoff agreed and they changed their care company. Soon after, Jean's personal budget payments suddenly completely stopped. While Geoff had expected that the 24 hours a week from the care worker who had gone on sick leave might be removed, he was shocked to see all of their money had disappeared and reached out to NHS CHC.

Geoff was told an audit was being done, so assessors came over once again. Geoff and Jean were shocked to learn during this visit that the previous visit had actually been a reassessment which they had not been informed about. Jean's hours of support had been cut by two thirds from ninety-eight to thirty-two hours, without their knowledge.

Geoff explains, *'I'm shocked that this has happened, particularly with somebody we've known for a very long time. I think it's disingenuous to reduce it by so much without saying anything. We never got an e-mail or a letter to say you've had an assessment and we feel the hours should be changed. There was absolutely nothing. No communication whatsoever.'* He describes feeling *'a false sense of security, really, because I thought we were just having a chat, and it turns out we're actually having*

an assessment.' Geoff believes the reason behind this could be due to saving on costs.

Geoff has challenged the decision, as Jean's needs have actually worsened in recent years and she needs significant support. Despite receiving a letter from NHS CHC saying they would send more detail, accepting that Geoff and Jean didn't know it was an assessment and that NHS CHC would organise another assessment and send an agenda across, Geoff has heard nothing now for months. The full payment has however, now been reinstated into the account, without any explanation, leaving Geoff unsure as to whether this might happen again.

Geoff and Jean were also contacted by NHS CHC, saying that due to the reduction in hours Geoff and Jean had been overpaid and so they owe £21,000. Geoff simply cannot pay this as he has already spent the money on paid care workers, as nobody had communicated this to him.

Geoff describes the situation as *'horrifying'* and he has been left, along with his family, facing a huge amount of worry and *'sleepless nights.*' Geoff describes how he has had to try and shield Jean from this worry, *'I only told Jean when the two ladies from the CHC were coming because I knew they'd talk about it and I knew I would talk about it.*'

Geoff's story shows that when NHS CHC is properly promoted and accurately reflects carers' needs, the results can transform people's lives, improve well-being and allow them to contribute fully to their communities. However, when it is solely treated as a cost-cutting exercise, the impact on carers' wellbeing can be profound, leading to poorer health for both the carer and the person they care for, which could in the long term increase the likelihood of hospital stays, defeating the original purpose of NHS CHC.

Tim, cared for his mother

Background:

Tim cared for his mother, who had dementia as well as serious physical health conditions. He started caring in 2012, then from 2017 he provided 24/7 live-in care until his mother passed away in 2020. Tim is also a volunteer for Carers UK, a member of his local authority Carer Partnership Board and an Expert by Experience for his local mental health trust.

Tim's experience with NHS Continuing Healthcare:

Tim applied for NHS Continuing Healthcare (CHC) for his mother, as he thought she was clearly eligible for this based on her condition and level of need. However, following an assessment, they were told she was not eligible. Tim said that her failed assessment and the challenges he has faced in trying to appeal it, has been "*the single biggest and most distressing issue I faced as a carer".*

Tim had several concerns about the assessment. Although ICB statutory regulations and the CHC Framework state that the assessment must be done by a multidisciplinary team, the assessment for his mother was carried out by two nurses specialising in mental health, when the assessor should have been from a different health profession. In addition, the Decision Support Tool (DST) had been signed by another ICB nurse assessor who was not present at the assessment, bypassing the other speciality nurse who did, which is not permitted under the framework. Tim also noticed that the DST made clinical comments based on an alleged GP report about his mother, but when Tim spoke to the GP practice they had no record of being asked to provide this. Tim then realised that the report did not in fact exist nor had his mother's health records been requested from the GP or other services.

When Tim raised concerns about these issues, he felt that the ICB were unhelpful and evasive. For several years he continued to challenge the ICB, and eventually the ICB and the local authority admitted to failures in compliance with the rules and the CHC National Framework. Tim had to seek help from the Information Commissioner to access documents from the GP and ICB, and both were ultimately infringed for GDPR failures. This included shredding all the information Tim had provided them during the assessment. Tim said the "*litany of failings, non-compliance, misrepresentation and misinformation that have been exposed is truly staggering*".

Tim's local MP recently helped him raise his concerns about his mother's case with the Minister for Care, but Tim was unhappy with the response he received. One of his key concerns is that NHS England is not holding ICBs to account for CHC assessments and appeals. He feels that carers "*bear the brunt"* of dealing with "*the financial and emotional impact of failed assessments not least through losing the funded respite that it should have afforded them."* He also considers the system to be *"corrupt"* because the process for appealing failed assessments is so long and complex that the person has often died before things are resolved. This was his own experience as by the time the ICB upheld his complaint, and posthumously overturned the original, incorrect ineligible decision, his mother had long since passed away.

Tim recently worked with his local carers' support service to co-produce a leaflet on NHS Continuing Healthcare and is keen to support other carers with this. He feels that the current system is so complex that carers do not always understand what they might be entitled to. He is also concerned that CHC assessments come at "*a time when the assessor and their carer are in crisis and that with little knowledge of the process are unable to spot or challenge things being done non-compliantly.*

Anonymous carer for her husband and son:

"I was successful in getting CHC for my husband - to contribute to his nursing home costs, there were no problems and I expected the same for my son. He had spent three months in hospital, very ill and was unable to go back to his own home and supported living. He was assessed and the money was agreed. He moved out of hospital joint funded by the LA and CHC money and moved to a specialist rehab unit.

But after a few months the CHC money abruptly stopped. The ICB holding the money (agreed using the national criteria) said it had no longer got the money. ICBs have been complaining about insufficient levels of funding for agreed commitments and I think we were unlucky. The money ran out before time.

There are agreed procedures for challenging problems with [C]HC payments but we decided that time and cost (of legal representation[)] plus a depleted [C]HC budget were against us and we had to accept the situation. In any event there was a waiting list for the rehab unit and they could not wait. The LA could not cover the cost (about £9,500 a month) without co-payment and I could[n't] muster the absent £4,500 a month.

I feel very frustrated because the rehab unit was a health facility; neither the LA nor myself should have been asked to pay for a time-limited specialist treatment facility. My son had to move to a nursing home; his health and care needs were too complex to move into ordinary residential care or back home. I think it was unfair, short-term thinking and the net result is someone with complex health and care needs which could have been lessened if the proper treatment had been available. Like many other families we are particularly angry that the outcomes of a very thorough assessment and rehab plan could be summarily cancelled without warning and without any proper replacement planning."

Recommendations

Department for Health and Social Care should:

- Establish new duties for ICBs through legislation to identify unpaid carers, provide information and advice and improve their health and wellbeing.
- Work with the NHS to run an awareness raising campaign on NHC CHC among the public and healthcare professionals.
- Ensure mandatory training for health and social care staff who may be in a position to advise and support carers on the CHC application process.
- Modify the National Framework guidance to ensure greater weight is given to evidence provided by unpaid carers in assessments and re-assessments.
- Seek to reduce number of re-assessments in order to minimise the administrative toll on unpaid carers.
- Monitor and act on evidence where there is variability in outcomes of assessments, ensuring that assessments are conducted consistently in line with the requirements of the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care.
- Improve consistency of CHC assessment processes by sharing good practice, learning, and improved training for assessors, including information on the role of unpaid carers.

ICBs should:

- Refer carers for a carer's assessment if required.

- Ensure that the care commissioned for eligible individuals takes account of the role of unpaid carers and their need for breaks.
- Establish clear and transparent processes and policies for how care is commissioned for people eligible for CHC, ensuring that funding is not cut suddenly for those who are eligible.

Sources of advice for carers

If you would like to access more information or advice, the following resources may be useful:

- Carers UK – NHS Continuing Healthcare guidance
- Age UK – NHS Continuing Healthcare guidance
- Carers UK – Helpline and support services

About Carers UK:

Carers UK is a charity set up to help the millions of people who care for family or friends. We are a membership organisation of carers, run by carers, for carers. We provide information and advice about caring alongside practical and emotional support for carers. We also campaign to make life better for carers and work to influence policy makers, employers, and service providers, to help them improve carers' lives.

Contact us:

For further information, please contact:

- Tamara Sandoul, Head of Policy and Public Affairs: tamara.sandoul@carersuk.org
- Josie Chadband, Policy and Public Affairs Officer: josie.chadband@carersuk.org