

‘This is tip of the iceberg – full

FAMILIES across Britain are facing potentially catastrophic care costs after being wrongly denied NHS funding which is supposed to support people with major, long-term health-care needs, according to a Yorkshire lawyer.

James Urquhart-Burton, Continuing Healthcare expert at Leeds-based Winston Solicitors told *The Yorkshire Post* that flaws in the application of the NHS's Continuing Healthcare (CHC) scheme are forcing relatives of people with chronic health conditions to face a traumatic process, at a time when declining eligibility figures have not been fully explained.

CHC is NHS-funded care for adults whose needs are primarily health-related. If found eligible, the NHS funds all assessed care costs, Mr Urquhart-Burton said. If not, individuals may face substantial means-tested social care charges, which means it is one of the most ‘consequential decisions’ in health and social care.

However, Mr Urquhart-Burton said that eligibility rates are falling at a time when completing referrals have increased and reviews by Integrated Care Boards (ICBs) – the organisations responsible for managing the local NHS budget – and their external providers sometimes hastily result in previously awarded funding being withdrawn.

At the end of December 2024, the total number of people deemed eligible for CHC funding – for both standard and fast-track CHC – was 52,008, falling 9.1 per cent from 57,216 at the end of June 2017, according to a Nuffield Trust report.

In December 2024, the report said that the number of people assessed as eligible ranged from 20 to 95 per 50,000 adults between ICBs – an almost fivefold difference.

Eligibility for standard CHC has fallen, with less than a fifth (18.6 per cent) of assessed individuals found eligible in October-December 2024, compared with just under a third (31.2 per cent) in April-June 2017.

Mr Urquhart-Burton said the need for CHC comes at the worst of times for any family, but the process they face to receive the monies thousands of them are legally entitled to is gruelling.

He added: “It can be lengthy, complex and at times inconsistent. We regularly encounter cases where decisions are later overturned on appeal, or where retrospective reviews identify individuals who should have been assessed for CHC during their lifetime. That inevitably raises questions about whether the process always identifies eligible individuals when it should.”

He said issues surrounding the provision of CHC are very well and recently documented. The topic was debated in Parliament in March, while a Nuffield Trust report in September 2025 ‘grimly dubbed it an all or nothing scheme but despite this, still nothing has been done to fix it’.

The Nuffield Trust report called for “urgent action” to improve consistency and fairness in how CHC operates, adding: “There are concerns that financial pressures are playing a key role in the operation of CHC, with all parts of the system facing significant pressure to keep costs down.”

The Trust, Age UK and the National Audit Office have also highlighted “persistent concerns” about a lack of public awareness, complex assessments and the financial and emotional stress on families linked with the process of applying for CHC.

Mr Urquhart-Burton, who has specialised in Continuing Healthcare claims for 15-years, reports that in recent years, there have been growing numbers coming to him to appeal rejected claims or fight for retrospective monies following a loved one's death. Much of that work arises from serious concerns that the guidance is being applied correctly, or that an assessment was never even carried out when it should have been, he said.

“The NHS is meant to provide healthcare for all, but when it comes to CHC, we’re finding vital care funding refused or withdrawn in circumstances where the decision does not appear to be properly supported by the clinical evidence,” said Mr Urquhart-Burton. “We’ve also witnessed an increasing number of decisions being made that do not clearly align with the National Framework for CHC.”

He said: “People who come to us for advice have realised that CHC is incredibly difficult to access. Your loved one may have



SPECIAL REPORT BY GREG WRIGHT

Carers of vulnerable people across Britain are facing a “catastrophic personal cost” due to flaws in a system which is supposed to act as a lifeline for people with complex, severe and often life-limiting conditions, MPs and lawyers have warned.

very complex needs but still faces a battle to receive CHC support.

“If you’ve got a parent who needs to be assessed, you really need to educate yourself about how this process works. We regularly advise families who have been told their loved one is not eligible for CHC, only for questions to arise later about whether the assessment was conducted properly and in accordance with the National Framework.”

Since 2007 we’ve had a National Framework for assessing CHC eligibility – most recently updated in 2022 – but evidently, the criteria aren’t being applied consistently across England, he said.

“This is likely to be – at least in part – a training and consistency issue among NHS staff. For instance, as an advocate, I will attend CHC assessments around the country. One day I might be representing a client in Surrey, and another day in West Yorkshire. My personal experience is that there remain significant variations in how the criteria are applied across England and between individual assessors.

“ICBs will not all have the same budget or the same population size in their area. The criteria requires assessors to look at the na-



CONSEQUENTIAL DECISIONS: Above, James Urquhart-Burton, continuing healthcare expert at Leeds-based Winston Solicitors, based in Leeds.

ture, intensity, complexity and unpredictability of an individual's needs before exercising professional judgement on eligibility; which inevitably creates scope for variation. “The number of referrals into the system has increased, which could be due to greater awareness from families and professionals, as well as an ageing population. However, that increase has not been matched by a corresponding increase in the number of people being found eligible for CHC, and that’s where the concern lies.”

“At the moment, our experience on the ground is that people in West Yorkshire are not being assessed as promptly as they should, and case decisions are slow to arrive. But, as a lawyer working around the country, I see similar systemic issues everywhere.

“The CHC assessment should be multi-disciplinary, and the professionals who make the eligibility recommendation should be individuals who have personal knowledge of the patient's needs, where possible. “We’re increasingly seeing ICBs refuse to allow knowledgeable professionals to take part in making the recommendation, and multi-disciplinary teams making clear recommendations to the ICB, only for individual ‘verifiers’ to reject those recommendations, and substitute their own decision on eligibility.”

The decision families ultimately receive is increasingly no longer truly multi-disciplinary in nature, but instead a decision made by an individual decision-maker. Families are having to deal not only with a catastrophic health event and profound deterioration of the health of a close family member, compounded by the worry of cost and how the care will be paid for.”

“In the worst cases, the personal consequences is that people live out the remainder of their time in a care home, leading to significant family wealth consumed by care fees.

“A bad decision can ruin a family emotionally and financially. There is no sugar coating that. Whilst I would never advocate for a ‘tick box’ approach to assessing an individual's needs, the eligibility criteria must be simplified.”

“People are calling for a complete overhaul of the system. At the very least, the criteria should be clear and consistently applied for everybody, and there should be collaboration between the NHS and key stakeholders, to develop a national standard for principles of assessment and training assessors so there isn’t this regional variation.”

Mr Urquhart-Burton said recent examples have included a case where the initial screening assessment showed the patient required a full eligibility assessment for CHC, but the assessor incorrectly interpreted the report they had produced.

As a result, a full assessment wasn’t carried out and the incorrect report was then relied upon as the benchmark for subsequent annual reviews. The patient died without ever receiving a proper assessment, he said.

He also cited a case where an Integrated Care Board accepted that a patient had been wrongly denied NHS Continuing Healthcare funding for part of the time she was receiving care, but refused funding for an earlier period despite evidence that the patient's needs remained complex.

“It has taken three months for a reimbursement offer to be received from an ICB and the family are expected to appeal the decision relating to the earlier period.”

“This is just the tip of the iceberg – the full extent of which is scandalous; especially when looked at in the context of an ageing population that will undoubtedly lead to the numbers qualifying for CHC growing significantly over the next 20-30 years.”

Responding to the concerns raised by Mr Urquhart-Burton, a Department of Health and Social Care spokesperson said:

“No family should face distress or financial hardship because they cannot access the care their loved one is entitled to.

“Local Integrated Care Boards are responsible for decisions about providing funding for NHS Continuing Healthcare.”

Any measures to manage cost pressures should not impact someone's eligibility to access NHS Continuing Healthcare.

“NHS England provides detailed assurance and oversight of Integrated Care Boards, including comparing NHS Continuing Healthcare eligibility and referral rates, as well as investigating outliers for drivers of unwarranted variation.”

Call for ‘a transparent, consistent and fair’ CHC system

MP’S PLEA

A Yorkshire MP is calling on the Government to deliver a “transparent, consistent and fair” NHS Continuing Healthcare system to ensure vulnerable people don’t face anxiety and delays.

Iqbal Mohamed, inset, the independent MP for Dewsbury and Batley, said that no family should have to battle bureaucracy for care that should be funded by the state. “When NHS Continuing Healthcare support is suddenly questioned or withdrawn, it creates enormous stress and uncertainty for people who are often at their most vulnerable,” he said.

“Time and again, we hear of people who have gone through assessments, had their care needs confirmed, and then suddenly find themselves facing uncertainty because of a new review or administrative process.

“The Government must deliver a system that is transparent, consistent and fair, with strong safeguards to ensure families are properly heard and that care remains

in place unless there is clear evidence that someone's needs have changed. Families deserve certainty, not constant anxiety about whether essential support will disappear.”

In March, the House of Commons was told by Ayoub Khan, the independent MP for Birmingham Perry Barr, that CHC was created to protect those with the most severe and complex needs, “but today it often does the opposite: it confuses, delays and denies”.

“CHC is a lifeline for people with the most complex, severe and often life-limiting conditions, making it all the more crippling when funding is stripped at short notice without a clear reason, and yet there is a body of evidence, which is growing year on year, to suggest that the system is unfair, inconsistent and often inaccessible to those who need it most.”

Mr Khan told MPs: “Investigations have also revealed private companies are being contracted to review CHC eligibility and, in

some cases, to reduce care packages, raising serious ethical concerns about profit being tied to cuts in vital care provision. A system where decisions are not always driven by clinical need but by cost containment will inevitably fail to protect and care for some of our most vulnerable individuals.

“Since 2017, despite an ageing population and increasing complexity of need, the number of people eligible for CHC has fallen by more than 9%. Over the same period, the proportion of people found eligible after a full assessment has dropped dramatically, from around 31% to just 18.6%. That means that more people are being assessed, but fewer are receiving support.

“For families, that often means a gruelling process, characterised by a mire of lengthy assessments, appeals, delays and uncertainty, at the most difficult time of their lives. Confusion, exhaustion and distress are mainstays of that process. Even for those

who are fortunate enough to be granted CHC funding, it can be withdrawn upon review, leaving families in a state of permanent anxiety that they could be plunged back into crisis at any moment.”

Responding to Mr Khan, Stephen Kinnock, the Minister for Care, told the Commons that NHS continuing healthcare provides critical support to some individuals with the highest needs, offering a fully funded package of health and social care.

“This supports our 10-year health plan ambition by helping individuals to live more independently outside hospital and to care closer to home and to loved ones. The last Labour Government introduced NHS continuing healthcare, which, despite the challenges set out today, is supporting thousands of people across the country with their care needs. We also set out our statutory guidance, the first national framework to ensure a consistent approach.”

In the year ending March 2025, over 164,000 people across England were found to be eligible for NHS continuing healthcare—an increase from the 160,000 eligible

individuals in 2017. Every one of those individuals should receive an appropriate package of care that meets their assessed health and care needs. Our statutory guidance is designed to support integrated care boards to provide the most appropriate care for every eligible individual.”

“I want all individuals who are eligible for NHS continuing healthcare to receive support in a timely manner, and I want the assessment process to be as smooth, clear and transparent as possible.”

“We were told in no uncertain terms that we only had a matter weeks to find a care home for her.” That would’ve been hard at the best of times, but this was during the lockdown, so we had to do the whole thing

extent of which is scandalous’

‘Battle with a system that feels like it’s making things harder’

CASE STUDY 1

KAREN Hargrave's husband James was a civil servant who had been living a healthy, active life until the pandemic struck in 2020. Today, he cannot hold Karen's hand or engage in conversation. James contracted Covid for a second time in 2022, when he was in his mid-30s, which later developed into long Covid.

Ms Hargrave recalled: “As part of that he developed very severe ME, a condition that is often not well understood. He has extremely limited energy: tasks like swallowing or moving slightly in bed can involve too much energy for him to manage.

“He deteriorated very quickly and one year later, he was totally bed-bound. He was unable to speak or chew, and he had difficulty swallowing. He was on a liquid diet and needed full time care.

“I’ve been going through a long process to ensure that people live out the remainder of their time in a care home, leading to significant family wealth consumed by care fees.

“We owned a flat but we couldn’t live in it because it wasn’t accessible for James, so this was treated as an asset and meant James didn’t meet the financial criteria for social care funding. We came across CHC support which seemed to be exactly what we needed.

“We had a full assessment in April 2025 and it’s been a nightmare since then. The assessment concluded that James was eligible for CHC. It was carried out by a nurse and a social worker who was already familiar with our case.

“However, the process at the local Integrated Care Board (Surrey Heartlands) resulted in him not receiving the funding despite the assessment finding him eligible. That blew my mind.

“I was astounded. The board has now also rejected our appeal. We’ve never really been told what was wrong with the conclusion of the initial assessment. I think another layer of difficulty for us is that James suffers from ME which isn’t well understood by the NHS: there can be some quite dismissive attitudes.

“One of the biggest challenges was financial; we sold our flat to help cover care costs



STRUGGLE: Karen Hargrave with her husband James Herring, who was totally bed-bound after a year of his illness.

cial; we sold our flat to help cover care costs and we’re now in a position where the local authority has stepped in a year after the assessment.

“In the last month we have received a care package from the local authority (Surrey County Council) to help meet James’s needs.

“We just want someone to explain to us what was wrong with the initial assessment. I’m now a full time carer to my husband at the age of 36 and dealing with the

fact that, because of his debilitating symptoms, he is too sick for me to hold his hand, give him a hug or have a conversation with him. I can’t lead a normal life with my husband. There’s a grief that comes with watching him suffer every single day.

Ms Hargrave added: “The last few years have been a nightmare, and on top of that, you’re having to fight this battle with a system that feels like it’s actively making things harder.”

A spokesperson for NHS Surrey and Sussex Integrated Care Board said: “We are very sorry that Karen and James found their NHS Continuing Healthcare process confusing.

“NHS Continuing Healthcare assessments follow a nationally prescribed process to determine whether an individual has a primary health need and is therefore eligible for NHS-funded Continuing Healthcare.

“We understand that James has a range

of needs but following completion of the full assessment process in this case, it was determined that James did not meet the national eligibility criteria for NHS Continuing Healthcare because they were not assessed as having a primary health need.

In some cases, an initial position may be shared with a family, however this would always be subject to review once all relevant information has been gathered and a multidisciplinary assessment takes place.

In James’s case, his assessment identified that his needs were more appropriately met through social care support, and we understand that the local council is providing a package of care to meet his needs.

“We understand that decisions about ongoing care and support can be difficult for individuals and their families.

“We are committed to ensuring that assessments are carried out fairly, consistently and in line with the national NHS Continuing Healthcare Framework.”

‘Care home fees should be capped to ensure fairness’

CASE STUDY 2

PATRICIA Devitt, a retired self-employed hairdresser, was diagnosed with dementia in 2014 and was looked after at home by husband, Joe until he was diagnosed with the same degenerative disease in 2018.

In October 2020, and the middle of Covid her son, Mark and his two brothers took the tough decision to move both parents into care as they could no longer look after them.

Sadly, Joe died on New Year’s Eve in December 2020 after contracting COVID and developing a blood clot. Patricia died in November 2024 having spent well over half the money she and her husband of 62 years had accumulated and saved throughout a lifetime.

Patricia was given an initial screening assessment for CHC funding, known as the Checklist, which showed she required a full, multi-disciplinary assessment of eligibility, but this was incorrectly interpreted and was marked as failed, according to her family. The family said Patricia never received the full eligibility assessment she was entitled to, and subsequent “light touch” reviews did not pick up on substantial deterioration in her needs as time went on.

Mark Devitt, who is a client of the Leeds-based law firm Winstons, is an advocate for people taking into account the potential for illness and care costs when planning for their retirement and that everyone is “properly educated” as to the different kinds of funding available.

Mark Devitt, who lives in Hornchurch, east London, said: “During Covid, it was difficult to get independent advice. I didn’t really know what my options were, so I followed the advice of the professionals



‘UNFAIR SYSTEM’: Mark Devitt, a client of the Leeds-based law firm Winstons, with parents Patricia and Joe, who have both been diagnosed with dementia.

involved and signed the house over to help pay for my mum and dad’s care.

“My dad didn’t live for too long after he went into care, but Mum stayed there for four years. It cost around £60,000 a year to pay for Mum’s care. We’ve now found out that the assessment they use, which involves a point scale, should have pro-

vided a point scale, should have provided that she’d lived in for well over 25-years while the country was in lockdown. Lots of things were thrown away that in normal times and without the pressure of time and mounting care bills we would’ve shared and treasured.”

“Had a CHC Funding assessment been done at that point – and we now believe Mum was eligible for full funding then – it wouldn’t just have saved all that additional heartache, it would have meant we wouldn’t have had to sell the house at that stage.”

“We eventually took legal advice – speaking to James Urquhart-Burton for the first time on the advice of one of his colleagues – and this led to the NHS accepting that

we should have received CHC funding for the final year of her life. However, we continue to believe she should have been found eligible much earlier and are preparing an appeal in relation to years that still aren’t covered by this retrospective funding award.”

The woman continued: “Throughout everything, we’ve been left on our own, having to find out everything for ourselves. It really is incredibly frustrating and feels very disrespectful to my mum and everything she worked towards in her life.”

“The appeal feels the most important thing for all the family right now. Not financially, but because it doesn’t feel like Mum can be properly at rest until the NHS provides what they should have.”

Care boards ‘working hard’ to streamline processes

RESPONSE

INTEGRATED care boards are “working hard” to streamline administrative processes and ease the burden on vulnerable people can access the care they need sooner, MPs have been told.

During a debate in Parliament in March, the then Minister of State at the Department of Health and Social Care, Stephen Kinnock, said the Government was committed to reducing the running costs of integrated care boards and to redirecting the funding to frontline services.

The Labour government’s 10-year health plan sets out that integrated care boards must focus on their role as strategic commissioners, ensuring the best possible value in securing local services that improve population health and reduce inequalities, Mr Kinnock said.

“However, NHS England has been clear that, although transformation is required, it must be carried out with clear safeguards in place to protect frontline responsibilities. Legal duties in relation to NHS continuing healthcare must continue to be met. This means that running-cost reductions should aim to make administrative and corporate functions more efficient. They are not there to change funding for direct care or statutory services.”

In response to questions from MPs: Mr Kinnock acknowledged that integrated care boards have worked intensively to strengthen their plans for 2025-26, focusing on areas where efficiencies and savings can be made.

“I thank NHS England for working with integrated care boards to monitor spend against the limits of what the local authority is working closely with NHS England on how responsibilities will be delivered from April 2027 onwards, when—subject to the will of Parliament—NHS England will be abolished. Until those changes are made, the Department and NHS England will continue to carry out their statutory functions. In the interim, teams are increasingly working together closely under an integrated joint decision-making process on NHS continuing healthcare.”

Mr Kinnock said that addressing some of the issues MPs have raised about NHS continuing healthcare would require wider reform of the social care system, adding: “That is why Baroness Casey is chairing an independent commission into adult social care.”

He added: “Baroness Casey rightly raised challenges with NHS continuing healthcare. We are carefully considering her reflections. I acknowledge existing tensions between integrated care boards and local authorities regarding NHS continuing healthcare eligibility decisions. Those decisions hinge on whether the support required by an individual is above the line of what the local authority can provide. Integrated care boards must consult with the relevant local authority before making any decision about an individual’s eligibility for NHS continuing healthcare, putting individuals at the heart of the decision-making process.”

Mr Kinnock acknowledged that, in practice, it was not always straightforward to determine clearly who is responsible for meeting an individual’s needs. “So we are working with NHS England to better join up support between the NHS and local authorities, exploring areas where good joint working is helping to improve outcomes for people accessing NHS continuing healthcare.”

“Through the development of our neighbourhood health services, local authorities and integrated care boards are encouraged to consider how services can be reconfigured to focus more on prevention and early intervention, embedding new ways of working to set the direction of travel for future years.”

Mr Kinnock said there was a robust dispute resolution process in place for when a full assessment for NHS continuing healthcare has been undertaken and the person or people concerned disagree with the outcome.

He added: “First, an individual or their representative can ask for a local review from the relevant integrated care board. All integrated care boards should have developed a local resolution process that is fair, transparent and includes timescales. Where it has not been possible to resolve the matter, individuals can then apply to NHS England for an independent review panel to review the decision. Finally, if the original decision is upheld and there is still a challenge, the individual can make a complaint to the Parliamentary and Health Service Ombudsman.”

“The threshold for initial referral by GPs, social workers and others is deliberately low, so more than anyone who may be eligible is fully assessed. For that reason, many individuals will not go on to receive NHS continuing healthcare. However, an assessment is also a gateway to other forms of NHS-funded support.”