December 2024

Continuing to care?

Older people let down by NHS Continuing Healthcare

Contents

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Executive summary

This report sets out some of the key numbers relating to NHS Continuing Healthcare in England and the stories and experiences of older people and their families attempting to access it.

For those that are eligible, NHS Continuing Healthcare (CHC) provides fully funded social care, integrated with wider health care support. To be eligible, you must be assessed as having a 'primary health need' that requires a package of care, either delivered in your own home or in a care home (or any suitable setting, including a hospice). Unlike the normal routes to access social care, an individual is not means tested and is not expected to make a contribution to the costs of this care.

There are two ways to access CHC – the Standard Pathway, requiring a team of professionals to carry out the assessment and can take many weeks to arrange; and the Fast Track pathway which can be triggered by a single professional and must be in place very quickly. The latter is intended for people who have a rapidly deteriorating condition and are typically at the end of life.

The overall number of recipients of CHC has increased over recent years. However, the increase is made up entirely by new Fast Track recipients with the number of people on the Standard pathway declining by 20% since 2017/18 (approximately 12,000 cases). The number of new referrals to the Standard pathway has only declined by 6%.

There is significant variation between different parts of the country. Comparing the NHS bodies responsible for CHC – Integrated Care Boards or ICBs – the number of recipients varies by from 86 per 50,000 population up to 300. The proportion of assessments that result in eligibility varies from 5% to 58.3% depending on where you live.

The pattern of Fast Track accounting for all the growth in the number of CHC recipients continues and may be accelerating. The data, and accounts of older people that feature in this report, suggest that CHC as a long-term intervention to support people with complex needs to live well is becoming less available. There is also evidence that suggests that those that do receive Fast Track CHC are increasingly losing eligibility at review.

NHS Continuing Healthcare sits amongst the wider challenge of a social care system that is not able to meet the demand of people with care and support needs. It also reveals a wide postcode lottery that impacts the care available to people with similar needs and their personal liability for costs associated with their care.

1: What is NHS Continuing Healthcare?

Throughout our lives, we all rely on the NHS to help us stay well. For many, our interaction with the NHS will be sporadic, coming down with a minor illness or needing care after an injury or accident. For others, it can be a lifelong relationship due to one or many long-term conditions or disability or following a life-changing injury or trauma.

For some in this position, they might also need additional support for activities of daily living, ie those everyday essential tasks such as washing, dressing or preparing food, which they are not able to do entirely themselves. This can include having to move to a residential care or nursing home. This can be arranged yourself or by family or is organised and/or provided by your local authority, or council, based on an assessment of your needs and is usually called social care.

We are all familiar with the fact that the care delivered by the NHS is free at the point of delivery and funded through general taxation, whether that care is happening in your home or a hospital, or anywhere else. However, any care that is delivered as social care is means tested, which means that if you have income, assets, or wealth above a certain threshold, you are expected to pay for the total costs of that care, while those below that threshold will contribute some of the costs.

This could include the cost of carers coming to your house to help you with daily tasks or it could be the fees to pay for a care or nursing home. For some of us, these fees will run into the hundreds of thousands of pounds in our lifetime.

Decisions over which institution is responsible for your care – the NHS (free at the point of delivery) or the local authority (means tested) – have long been heavily contested. A number of challenges in the 1990s, including a significant Court of Appeal judgement in 1999 [1], established the principle that where someone's primary need was a health need, the responsibility is with the NHS. In practice, this means that for those people, their social care support will be funded in full by the NHS. This is what is known as NHS Continuing Healthcare (CHC).

NHS Continuing Healthcare means a package of ongoing care that is arranged and funded solely by the National Health Service (NHS) where the individual has been assessed and found to have a 'primary health need' as set out in the National Framework. Such care is provided to an individual aged 18 or over, to meet health and associated social care needs that have arisen as a result of disability, accident or illness.

National Framework for NHS Continuing Healthcare and NHS funded Nursing Care, 2022

Who is eligible?

The National Audit Office, in its investigation of CHC in 2018, described three scenarios where CHC was typically awarded. These are included below as a very broad overview of the circumstances under which CHC comes into play:

Scenario	Example	Time period
1. People near the end of the lives	Advanced cancer or heart disease, or older person with frailty with a rapidly deteriorating condition and may be entering a terminal phase of their life.	Typically weeks and months.
2. Frail elderly people with complex physical or psychological needs	An older person with frailty with a number of conditions, such as dementia, Alzheimer's or Parkinson's disease.	Relatively short periods up to several years.
3. People, aged 18 and over, with long-term healthcare needs	Someone who had an accident that has left them with long-term healthcare needs, such as a spinal injury. It may also include people with long-term conditions such as multiple sclerosis.	Often many years, potentially moving in and out of eligibility depending on need[2].

Typically, if a health professional or team believes someone needs CHC for their ongoing care, they request or undertake an initial standard '**Checklist**'. If that person meets the criteria set out on the Checklist, or if they have been referred directly, they then have a full assessment by a Multidisciplinary Team (MDT), a group of health and care professionals (at least two as set out in the National Framework) with a range of relevant skills and knowledge of the person being assessed.

This assessment, using what is called a 'Decision Support Tool' (DST), looks across 12 'domains' of care, such as needs relating to breathing, cognition, mobility and continence (see **Appendix** for full list).

The MDT will assess the nature, complexity, severity and unpredictability of these domains in order to get an accurate picture of the person's needs and what is required to meet those needs. If it is determined that these needs cross the required threshold for complexity etc, that person is eligible for CHC and the responsible NHS body, the Integrated Care Board (ICB)[3], releases funding for their package of care[4].

This is the Standard pathway. There is also what is called the Fast Track Pathway. This is typically used for people near the end of life where they have a rapidly deteriorating condition, and therefore require care to be set up very quickly. The Standard pathway allows up to 42 days to elapse from the request for a Checklist to decision to award CHC. The Fast Track Tool is used by an 'appropriate clinician', bypassing the Checklist and DST but using the same principles, and care should be in place within 48 hours of a decision.

(For a more detailed description of CHC and these assessments, you can see **Age UK's factsheet**.)

An individual has a primary health need if, having taken account of all their needs (following completion of the Decision Support Tool), it can be said that the main aspects or majority part of the care they require is focused on addressing and/or preventing health needs. Having a primary health need is not about the reason why an individual requires care or support, nor is it based on their diagnosis; it is about the level and type of their overall actual day-to-day care needs taken in their totality.

National Framework for NHS Continuing Healthcare and NHS funded Nursing Care, 2022

What happens next?

Once the team of health and care professionals has determined someone is eligible for CHC, the Integrated Care Board must ensure that the services and support required for that person are planned and made available to them.

This may include a room in a nursing or care home or carers and nursing support in their own home. The person also has a right to request a personal health budget (PHB)[5] for their CHC. This allows someone to hold either a notional or cash budget (direct payment) to organise their own care in a way that works for them.

For some people who are not eligible, they may be considered separately for NHS-Funded Nursing Care. If eligible, this provides a fixed-price payment that goes towards the nursing element of someone's care in a nursing home, contributing to the fees payable to that setting. For more information, see **Age UK's factsheet**.

After an eligibility decision has been made, it is expected that a review of that person's needs will take place after three months and then at least every 12 months (or at any point at which there has been a change in someone's care needs). The National Framework for CHC is explicit that these reviews are primarily there to ensure the care package remains appropriate for that person's needs. For the majority of cases, there should be no need to reassess for eligibility.

For people who are deemed to be not eligible for CHC, they have the option to appeal this decision to the ICB (or in some cases others can appeal on their behalf). The first step is to go through a standard local resolution procedure to determine if a negative decision should be overturned. If the person is not satisfied by this outcome, they can then apply for an Independent Review, for which NHS England may convene a panel of experts to examine the decision (determined by an initial desktop review). If the person is still not happy with this outcome, they can lodge a complaint with the Parliamentary and Health Service Ombudsman (PHSO), who can decide if procedures were properly followed (but ultimately has no powers to award CHC).

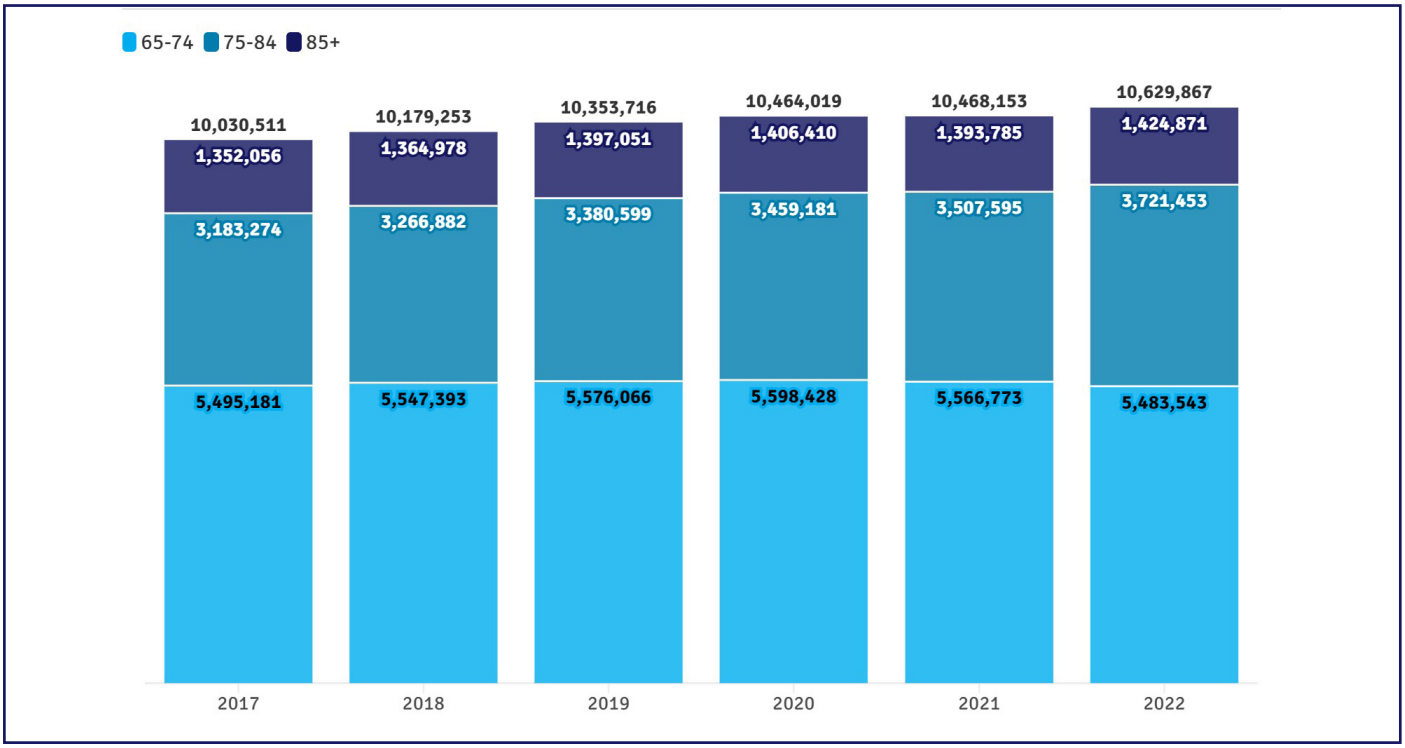
2: NHS Continuing Healthcare in numbers

Before examining the published data on NHS Continuing Healthcare (CHC), there are other population and patient statistics that provide important context. CHC figures provided below are all ages, however the majority of those eligible are older people, and likely to include large concentrations in the oldest old (85+). The figures featured in this report cover 2017-2024, the furthest back the current dataset goes. In just the period between 2017 and 2022, the population in England age 65+ has grown by 6% (599,356) and those over 85 by 5.4% (72,815). The vast majority of this growth has been in the 75-84 age group.

Figure 1:

Since 2017, there has been a 6% growth in people 65+ and a 5.4% growth for those 85+ in England

Population estimates for people aged 65+, 2017-2022, England.



Source: Age UK (2024): Analysis using ONS (2024). Estimates of the population for the UK, England, Wales, Scotland and Northern Ireland.

40% of people over 65 and 57% of people over 80 live with a limiting long-term condition[6], and the numbers living with such conditions is growing[7]. We already know that the numbers of people getting long-term social care support from their local authority is not keeping pace with the growth of the older population and is in fact going in reverse[8]. Before the pandemic, approximately 5,000 people were delayed in hospital on a typical day when otherwise fit for discharge (either waiting for other NHS or social care services)[9]. In 2024, that number is around 12,000[10].

People eligible for NHS Continuing Care

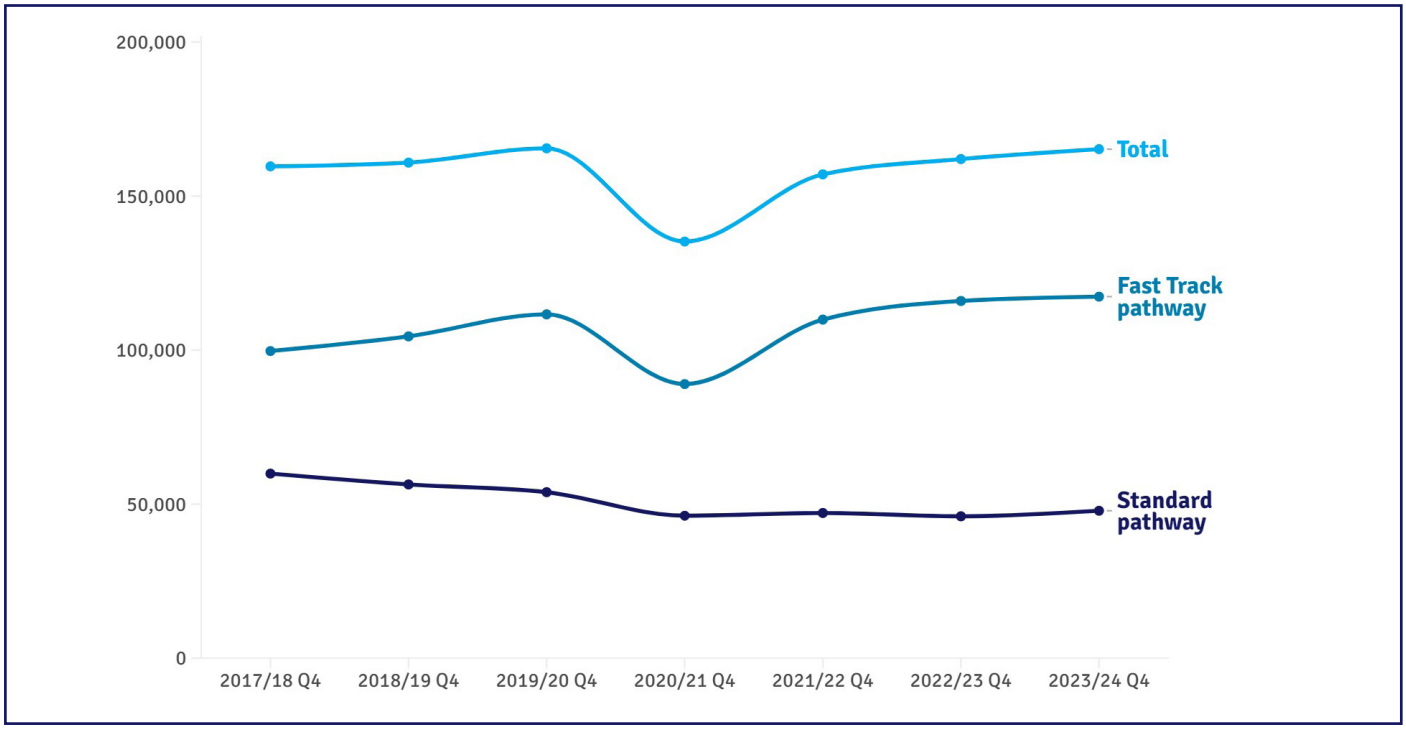
In a typical year, there will be around 160,000 cases* eligible for CHC. The majority of these will be Fast Track recipients – they are typically for much shorter periods of care and is much quicker to access, so cumulatively, more people will pass through that pathway. However, at any one time, around 50,000 people will be receiving CHC funding, of which around 65% will be on the Standard pathway.

The total number has been stable since 2017/18, with the exception of a steep drop in 2020/21 at the beginning of the COVID pandemic. However, the numbers receiving CHC on the Standard pathway have declined by 20% in that period, or approximately 12,000 cases. This is a pattern the NAO had already observed in their 2018 report[11].

Figure 2:

People recieving NHS Continuing Heathcare on the standard pathway has declined by approximately 12,000 cases since 2017/18

Total in receipt of NHS Continuing Healthcare via Standard and Fast Track pathway, year to date, 2017/18 to 2023/24, England.



Source: Age UK (2024): Analysis using NHS England Statistics (2024) Continuing Healthcare and NHS - funded Nursing Care.

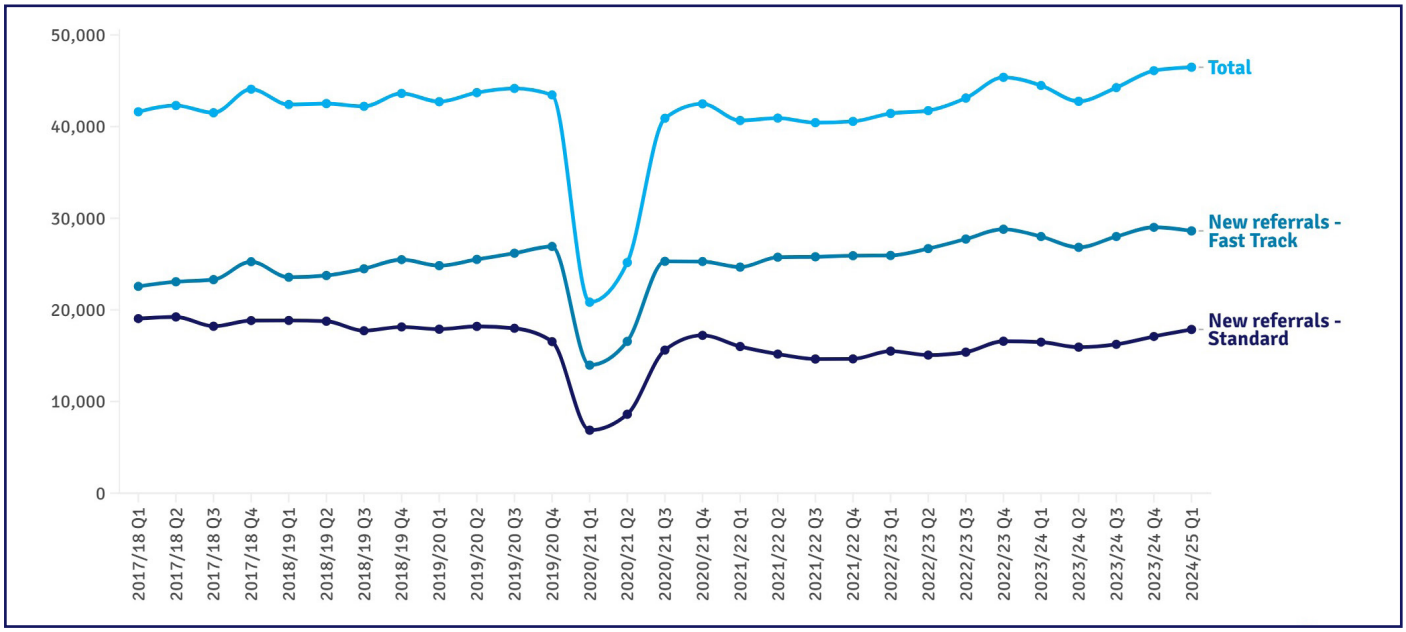
There has also been a decrease in the number of referrals to the Standard pathway, but at a much lower rate – 6% between Quarter 1 2017/18 and Quarter 1 2024/25. However, there is also a growing gap between new Standard and Fast Track referrals as seen in **Figure 3**. In Quarter 1 2017/18, the difference 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.

* "Cases" refers to the cumulative total of all people eligible for CHC during that year. For those on Fast Track the vast majority will be new cases that year. For those on Standard, it will be a mixture of people that are newly eligible and those that have been receiving it on an ongoing basis, in some cases over multiple years.

Figure 3:

Since 2017/18, the gap between Standard and Fast Track referrals for NHS Continuing Healthcare has almost tripled to 11,000 cases

Number of new referrals recieved for NHS Continuing Healthcare, 2017/2018 to 2024/25 Q1, England.



Source: Age UK (2024): Analysis using NHS England Statistics (2024) Continuing Healthcare and NHS - funded Nursing Care.

There are two underlying factors that could have influenced this pattern. One is a change to the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care in 2018. The Framework was modified to state that it was no longer appropriate to assess for CHC while someone was in an acute hospital[12]. This was based on the approach, known as 'Discharge to Assess', that you would have a clearer idea of someone's longer-term needs when they were back home or in their normal place of residence, following a period of recovery.

In practice, previously people could be delayed in hospital waiting for a Standard CHC assessment, incentivising the clinical team to undertake it. After the change, they could just be discharged. At home, their condition may stabilise and the need for CHC might reduce and therefore a prospective assessment may find they are not eligible. It could also be the case that at home, without the incentive of clearing a hospital bed, the assessment does not ultimately take place.

The second factor were changes during the COVID-19 pandemic. In the general push to discharge people as quickly as possible from hospital to clear beds for incoming COVID-19 patients, a period of fully-funded social care through what was called the discharge support fund was put in place. This formally ended in March 2022, though many areas have continued to provide post-discharge support of this nature. What this meant was that there was another option available to the health and care teams to have some level of social care made available to people leaving hospital, alongside other health care and rehabilitation services.

The combined effect of these changes is that 26% of Decision Support Tool assessments on the Standard pathway took place in acute hospitals in 2017/18 (12,962), reducing to virtually 0% in 2023/24 (135).

Variation

Another defining feature of the data is variation. A person's chance of receiving CHC can often rely on awareness – whether you know to request it; the willingness of health and care staff to refer or acknowledge you might have eligible needs; and then the quality of the assessment.

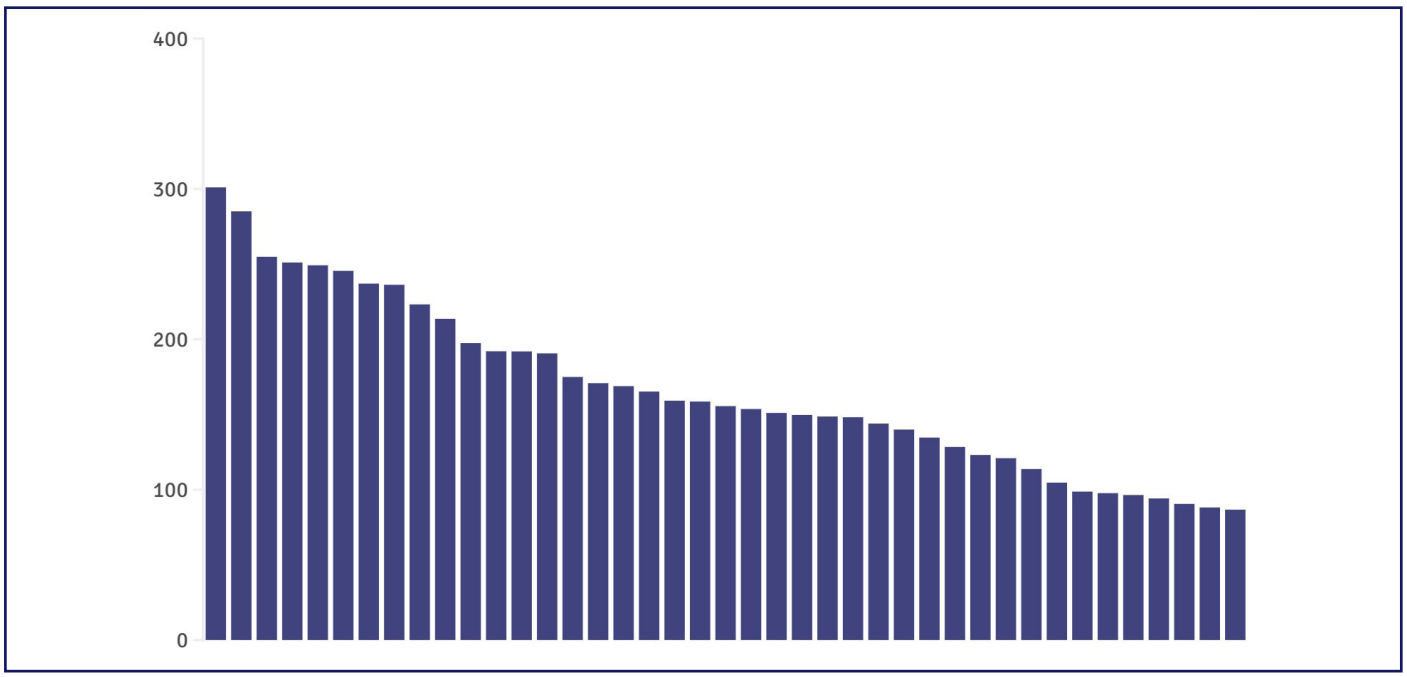
After the assessment, the ICB makes the final decision of eligibility, based on the recommendations of the health and care team that carried it out. The National Framework is explicit that only in exceptional circumstances should their recommendation not be followed and that the "final eligibility decision should be independent of budgetary constraints, and finance officers should not be part of a decision-making process". However, ICBs, and their predecessor organisations, have been under pressure to make efficiency savings in CHC for at least the last 7 years. [13]

Comparing different ICB areas, and removing one outlier, the number of people receiving CHC in one year, per 50,000 population, ranged from 86 people up to 301, a 3.5 fold difference. **Figure 4** shows the number of CHC recipients per capita in 2023/24, with each column representing a different ICB.

Figure 4:

Across ICB's, there is a 3.5 fold difference in the number of people receiving NHS Continuing Healthcare in one year

The number of NHS Continuing Healthcare recipients per 50,000 population, by ICB, 2023/24 Q4, England.



Source: Age UK (2024): Analysis using NHS England Statistics (2024) Continuing Healthcare and NHS - funded Nursing Care. ● Each column represents a different NHS ICB. An outlier has been removed.

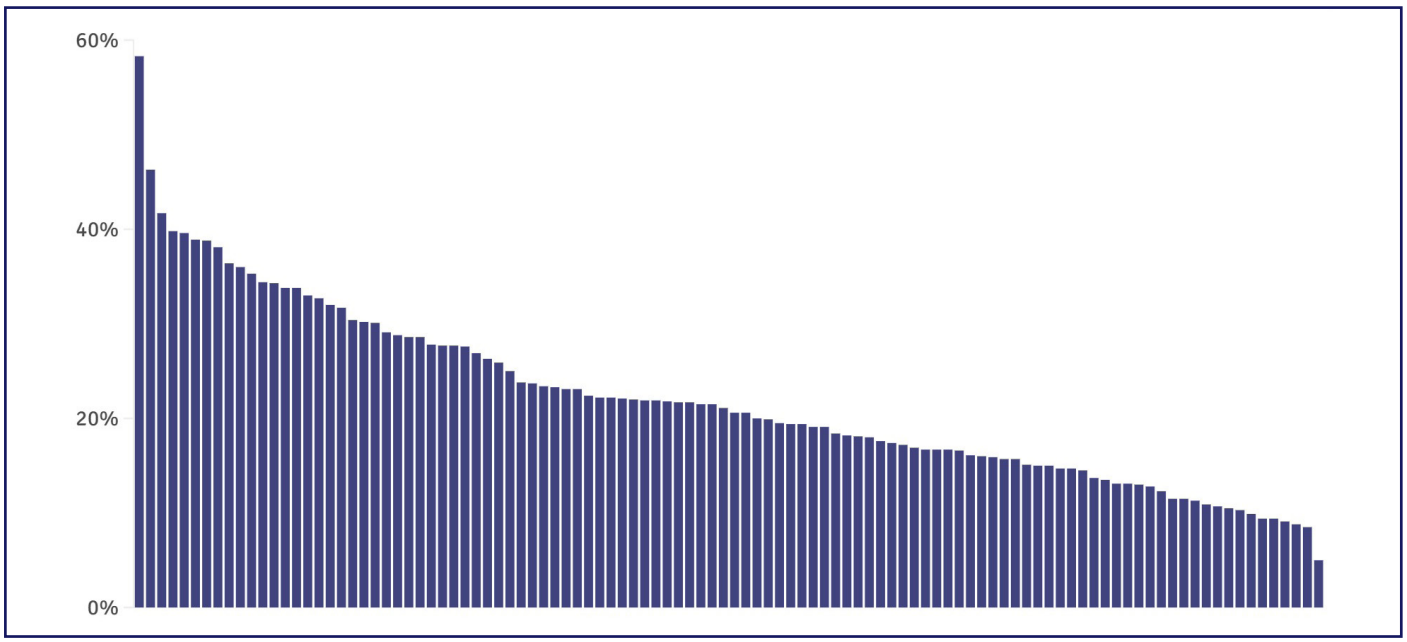
Some of this variation may be accounted for by demographic differences, particularly with regards to deprivation (though the National Audit Office have previously concluded that this is not a sufficient explanation). [14] However, this may be less of a factor for the conversion rate of local areas, ie the percentage of CHC assessments that are converted into eligible decisions.

We can explore this data within smaller local units, what are called Sub-ICBs. These represent the final geographical footprints of clinical commissioning groups (CCGs) before they were combined to form ICBs. Even greater variation is evident at this level with at one end, 58.3% of all assessments deemed eligible, while at the bottom end, just 5% were. In fact, in Q4 2023/24, the two extremes were in the same ICB. Even if you exclude the top and bottom five areas, there is a 4-fold difference in conversion rate depending on where you live.

Figure 5:

Across Sub-ICB's, the percentage of NHS Continuing Healthcare assessments that result in eligibility range from 5% to 58.3%

The percentage of NHS Continuing Healthcare assessments that are converted into eligible decisions, by sub-ICB, 2024/25 Q1, England.



Source: Age UK (2024): Analysis using NHS England Statistics (2024) Continuing Healthcare and NHS - funded Nursing Care. ● Each column represents a different NHS sub- ICB.

What are these graphs telling us? They suggest that accessing CHC has become more difficult unless someone is near the end of life. For Standard CHC across every measure published by NHS England, numbers being referred, assessed, or awarded are going down. In contrast, Fast Track equivalents have all increased.

Furthermore, the variation between local areas, an issue that has been explicitly identified since at least the 1990s, continues. This is despite the fact the National Framework was published in 2007 to help address this very problem. These are only the very topline issues.

In the next section of the report, we will look at what impact this has had on older people and their families.

3: What is the impact on older people and their families?

The challenges we described above are not new ones and have been described in a number of reports over the years. Notably, the Parliamentary Public Accounts Committee concluded in 2018 that patients:

"are not receiving the care that they are entitled to because they are not made aware of the funding available, or because the system is too difficult for them to navigate." [15]

The National Audit Office said, the same year that:

"there may be differences in the way [clinical commissioning groups] and local authorities are interpreting the national framework to assess whether people are eligible for CHC due to the complexity of this framework"[16]

They further explained that the variation they noted could not be fully explained by demographic differences. There is a great deal to indicate that things have got worse since these reports were published, despite their extensive recommendations.

Age UK conducts an annual survey of older people and their carers to ask questions about their health and wellbeing and to invite comments about their experiences of the NHS [17]. In the latest survey, we asked specifically about their experience of NHS Continuing Healthcare (CHC) and a selection of their responses feature in this section. We have also used some experiences that came through our national Advice Line.

These are organised along a set of key themes covering different points on the journey of seeking CHC.

Getting an assessment and getting turned down

The first hurdle to getting CHC is knowing that it exists at all. Some older people may not ever be made aware that they could be eligible and some families only discover CHC after someone has died. People currently receiving care can simply not know it's there. As one person told us:

"GP didn't know about CHC and when we researched it and contacted him to complete the form he told us to Google the form and complete it. Eventually he realised he had to complete so he completed the form in early Jan but didn't fast track. A [charity] cancer care nurse visited my mother and managed to fast track it as my mother was so ill and clearly reaching end of life."

Finding out via a charity is not unusual:

"Once in the CHC fast track system [the care] happened but getting to that point was another huge battle. I only found out about the CHC during a conversation with a charity."

"The only help and support received during my mother and father's journeys have been via charities. The NHS don't seem to know what's available within their own set up."

Once people have been made aware of CHC and have been assessed, many are deemed as not eligible, despite having often complex needs. There can be a lack of information about the process and no clarity on what was needed to qualify in the first place. A report by Healthwatch Lambeth described how **"some people recalled being told the application may or may not be successful, but little else"** [18].

For some people, this can make the final weeks and months of a loved one's life incredibly difficult:

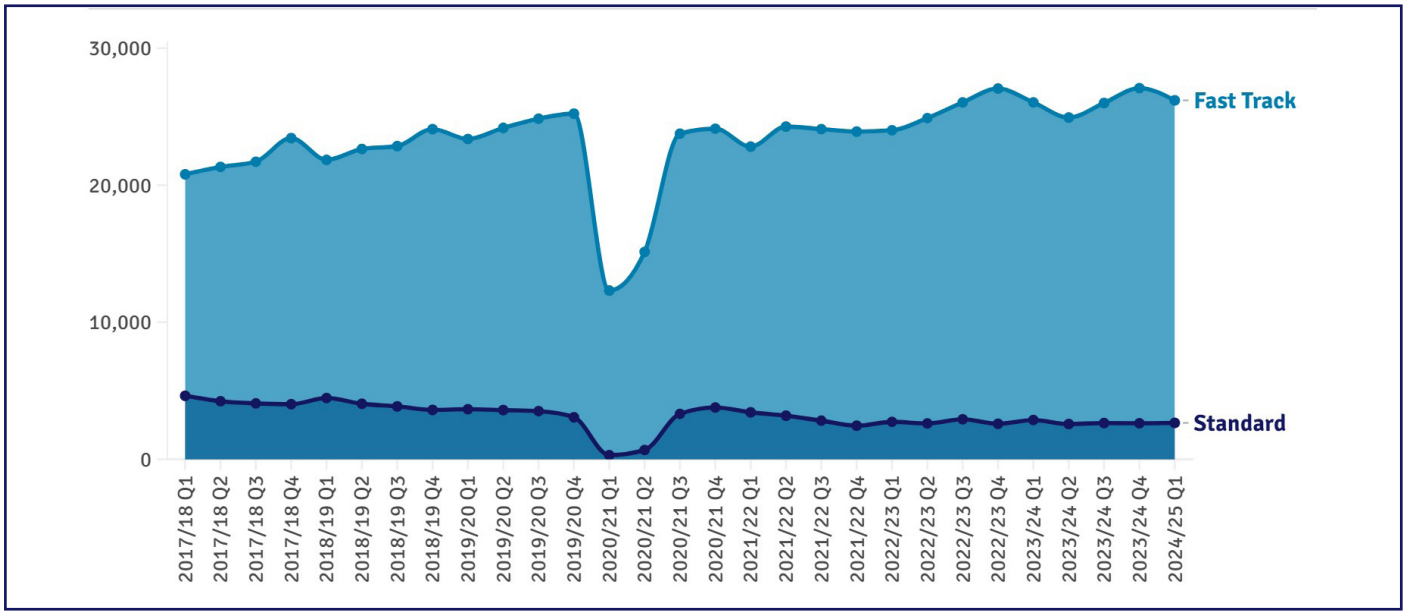
"When she died, she had five health conditions that could have been helped with surgery if she had not been so frail but none of these qualified her for help. It seems very unfair that she had to die with so little help."

There has been a decline in Standard CHC recipients over the years and huge disparities between local areas in the conversion rate, ie the proportion of successful applications following an assessment (see **Figure 5**). Nationally there is an overall decline in the numbers of people newly assessed as eligible on the Standard pathway, from 4,628 in Quarter 1 2017/18 to 2,651 in Quarter 1 2024/25. This is a **decline** of almost half (43%). In contrast, over that same period, the number for Fast Track has **increased** by almost a third (30%).

Figure 6:

The number of new recipients of Standard NHS Continuing Healthcare has declined by almost half since 2017/18

Number of people newly assessed as eligible for NHS Continuing Healthcare, 2017/18 Q1 - 2023/24 Q1 England.



Source: Age UK (2024): Analysis using NHS England Statistics (2024) Continuing Healthcare and NHS - funded Nursing Care.

Some people can be assessed for CHC, but find they are repeatedly turned down, despite high level care needs linked to their health condition/s. People can be told that their **"needs have to be clearer"** or that they are **"not reaching their rehabilitation potential"** before making a determination for CHC. This means the healthcare team believes there is still scope for improvement in their health, despite in some cases people having care needs that have run over many years.

"Several reviews for CHC during her eight-year stay in a nursing home, during the last five of which she needed continuous and ALL personal care. She fulfilled all published criteria for CHC but was always denied it - no reason given officially but told because budget insufficient and others worse. This whole aspect was time-consuming and a total farce. Dad was also three years in the home with progressive dementia to his death in 2017: between them, they spent over £300,000 (savings, pension income and sale of residence) on their care."

These frustrations are not uncommon. Families that have contacted the Age UK Advice Line describe very complex needs linked to one or many healthcare conditions, yet do not meet the criteria. The outcome can put incredible pressure on carers.

"Last assessment was January. CHC was declined.

"Bear in mind my father is doubly incontinent and non-verbal, the assessor's parting words to me were, 'I'm sorry you will have to continue to pay for your father but you'll be pleased to know he's not that bad'.

"I'll never forget that parting shot to my dying day.

1. **Dad has little money left after nearly 6 years in care at £48,000 year, the money is his and providing his care is good that is no issue to me.**
2. **The assessor had clearly no experience with a family member with Alzheimer's or she would know the utter heartbreak that causes. Dad and I have lived this together for seven years now. The daily pain and frustration does not lessen. The assessor was clueless in her conclusion."**

Another family told us:

"Failed on the Decision Support Tool. The bar for CHC funding is too high. Carers have repeatedly failed to manage my dad's constipation and skin care/pressure area care adequately. I have to step in to do that. If carers can't manage a need then it must be a healthcare need. But then we all know this."

These frustrations can come from a lack of clarity or misconceptions around the criteria for CHC. As complex as some needs are, they will not in themselves automatically qualify someone for CHC. However, given the large variation across the country, it may be the case that similar needs may qualify in one place but not another.

The process is the punishment

By its nature, CHC comes at a time when people and their families are highly vulnerable and dealing with complex health and care issues. Going through the process of requesting and being assessed for CHC is itself complex and for even those that are successful, it can be punishing. The National Framework outlines the values and principles that should underpin CHC decision-making:

> There are many elements to a person-centred approach, including:
>
> 1. ensuring that the individual and/or their representative is fully and directly involved in the assessment process;
> 2. taking full account of the individual's own views and wishes, ensuring that their perspective is incorporated in the assessment process;
> 3. addressing communication and language needs;
> 4. obtaining consent to any physical intervention/examination as part of the assessment process (where the individual has capacity to give this);
> 5. obtaining consent to the sharing of personal data with third parties (e.g. family, friends, advocates, and/or other representatives) (where the individual has capacity to give this);
> 6. dealing openly with issues of risk; and
> 7. keeping the individual (and/or their representative) fully informed.
>
> National Framework for NHS Continuing Healthcare and NHS funded Nursing Care, 2022

Furthermore, it states clearly that **"a positive experience of the assessment process is crucial"**. Older people and families paint a very different picture:

"Appalling and too gruelling and stacked against them to go into in detail. Feels like an utterly rigged system. The final decision was made by four people, only one of whom had met my family member for about an hour. The reasons given were spurious. We have given up, beaten."

Many people feel that they are not at the centre of the decision-making process, again as prescribed by the National Framework. As one family member explained to us:

"It was the attitude of the 'Assessors', who treated us with no respect at all and made us feel as though we were asking for something we didn't deserve for her. They had obviously been instructed to refuse cases wherever possible. It left us feeling devastated and very upset."

Many are left with the impression not that it is a fair assessment of needs, combined with a plan to meet those needs, but in fact a battle with a tightly controlled budget.

"I felt stressed and uninformed about my possible choices, as I was trying get funding for my 90-year-old mum who had Alzheimer's and several other serious health problems and I felt that I was being pressured into accepting that she wasn't eligible for CHC so that I would have to sort care out myself. I finally managed to get fully-funded nursing care allowance for her, but only after dogged persistence. I felt both my mum and I were being treated purely as another number in the system, to be got rid of as soon as possible. I was warned that it was almost impossible to get full CHC funding."

An experience echoed by another family:

"Having my mother assessed for CHC was initially and continues to be difficult, time-consuming and to be honest belittling. They forget to include me in meetings, don't send me letters re outcomes of reviews. It is the only part of the NHS I consider to be unfit for purpose. This view is not based on the decision but on the process."

The outcome for people who are not eligible is typically to enter the social care system. However, as described in our annual State of Health and Care report, the numbers of people receiving long-term care from their local authority has been declining in recent years[19]. At the same time, more than one in four (28%) people who had asked for a social care assessment had been waiting six months or more to get one[20]. Older people and their families are frequently left with nowhere to turn.

Too little too late

For some people, CHC can come too late to make a real difference to their care. It could be that the application is finally resolved weeks or even days before their death but in some cases, families only discover their loved one may have been eligible months or years after they have died.

With an often long and convoluted eligibility process, this family's experience was repeated in many of the comments we received in our survey:

"I also had a similar battle for my mother who had dementia [and was] in a care home; made several appeals; won my case eventually and she got a refund of her care home fees, but died within two weeks of receiving it! This process takes a great deal of perseverance and an ability to challenge in a knowledgeable way - very time consuming and tiring. I did both of these in my 60s and 70s!"

For this family, the months that passed from the initial request suggests that when they finally got a response, they were near end of life and put on to Fast Track:

"I have Power of Attorney for my sister who is terminally ill and in a nursing home. I've just been through the decision meeting process. Chair of meeting changed at last minute, Social Worker failed to turn up! Individuals with no one to support them have no chance as nobody tells you anything, you have to find everything out for yourself. I spent months swatting for the meeting and it turned out my sister should have been on Fast Track pathway anyway!"

The National Framework expects the assessment and decision to happen within 28 days of a positive Checklist. Yet for those that do not pass the Checklist and/or are not referred for an assessment, despite their family asking for one, there is no deadline for a response.

"My father was [assessed for CHC], but I had to push for the assessment for over a year, then when it was done I never got the results and he died before anything could be put in place. He had 'end of life care' but there were big holes in the system in my opinion. He should have had better/more support (not means tested) towards the end. We were self-funded all the way and I did 80% of the caring duties. (Unpaid - I was not eligible for carers allowance.)"

Families do not have a choice but to make their own arrangements for a loved one's care. In these cases, it can feel like a lottery whether or not the CHC will arrive, making those final weeks and months more distressing than they need to be.

"CHC struggled to find provider. We made our own arrangement with the provider we were paying privately, in the hope that CHC funding would be approved, which it was, two days before he died."

There is a mechanism for claiming retrospectively for CHC, known as 'previously unassessed periods of care' (PUPoC) [21]. This can often be used by people whose loved one has since died. In these cases, people can be reimbursed of the money they have spent on, for example, care home fees [22]. In this family's case, this approach was preferable given their worry about the impact of applying when their mother was alive.

"We put in a retrospective claim for Mum to have received CHC, after her death. I was too scared to put in the claim while she was alive as I thought it would affect her healthcare. The claim was successful. My father, at 101, was on a list waiting for assessment of CHC when he died. He was clearly eligible, but it was clearly going to be a struggle to get a successful outcome for CHC. Too many hurdles are put in the way for people."

This will typically be an even longer process than applying for it in the first place.

"My husband did not receive CHC when discharged from hospital into a care home even though he was bedridden due to cancer. The appeal eventually went to the [Trust] and I received the money back. It took over two years."

Review

After the decision has been taken that a person is eligible for CHC, they should be reviewed within three months and, subsequently, on at least an annual basis. The National Framework says:

> **These reviews should primarily focus on whether the care plan or arrangements remain appropriate to meet the individual's needs. It is expected that in the majority of cases there will be no need to reassess for eligibility.**
>
> National Framework for NHS Continuing Healthcare and NHS funded Nursing Care, 2022

In contrast, many feel that eligibility is central to this review process.

"She received Fast Track funding for full-time live-in care when she was discharged from the Hospice after two weeks of pain management in May 2022. The funding was reviewed and completely withdrawn in October 2022. They acknowledged that she needed full-time care but said she'd have to pay for it herself until she ran out of money."

The impact of this can be devastating for people. Because the level of care needed has often not changed, the high costs of delivering that care falls straight back onto the person and their family.

“The person received CHC following hospital admission and then discharge to end of life hospital ward. When they did not pass away after the two week criteria they were fast tracked for CHC. After being in receipt of CHC and transferred to a care home they were re-assessed. At the [Decision Support Tool] it was decided the person did not warrant CHC although they were still presenting much the same. They remain in bed 24/7, they cannot move or reposition, they are unable to carry out any bodily functions and they are deemed end of life. Now, though, they have to pay to be in the home, dying as I write this. The fees will mean their home has to be sold to pay for the care, at 96 years old already, trying to organise a sale of the home will not be without difficulty.”

(It can be the case that someone loses eligibility following a period of Fast Track funding even with identical needs where, for example, they are reassessed using the criteria of the Standard pathway instead (with Decision Support Tool etc).

In some cases, the funding is removed after many years of supporting someone. In such a scenario, it can be unclear in what ways a person has fewer needs given they are living with progressive health conditions.

“Had someone in Nursing Home who finally got CHC after years of pushing from me. Five years later, decision overturned. He had not improved. Was older. Frailer. Had beginnings of dementia. Had had four strokes. Heart attack. Diabetic. Hundreds of chest and urine infections. Appealed and appealed but he died before final appeal decided.”

Even if a person’s condition has stabilised, it may be contingent on the care being delivered by CHC. ‘Unpredictability’ is one criteria in the Decision Support Tool, but reviews are supposed to take account of the stabilising effect of a CHC package, what is known as the well managed needs principle, and the risk that removing it will compromise their improvement.

Removing CHC can also impact the level of care someone is receiving.

“The person has been assessed as end-of-life patient. They did not die within the timescale set out by the hospital and were moved to a care home enhanced bed facility. When they outlived this they were assessed as CHC criteria. Now, they have been assessed again and the funding removed. The care being given by this same establishment is not the same, now the enhanced nurses are not involved, the patient is having their choices taken away and the staff are not bringing the foods and fluids that the person is requesting. The person is fast becoming sleepy, tired and very tearful and sad. The hallucinations are worse and they are frightened.”

For other families, the fear of the review process can take its toll on its own.

“Mum has CHC but it’s reviewed every year. She is getting worse not better but the threat of it being withdrawn is all too real. It creates a human cost for the families of the person in care as they experience their own struggles with health due to the pressures of the system. My own mental health has been affected at a time when my focus should be on spending quality time with my Mum and supporting her, not worrying about myself and coping with the fight for funding every 6/12 months. It’s a progressive disease (Alzheimer’s) but feels like you have to prove how ill someone is despite a diagnosis.”

It is important to note that eligibility is not based on a diagnosis or particular presentation, but on care needs. A deteriorating condition can also mean decreasing needs, for example when someone becomes less mobile over time. However, these examples illustrate that the ultimate impact on people and their families is not being sufficiently considered by the process.

Outliving eligibility

Many of the issues identified in these testimonials have been around CHC for a number of years. However, more recently, we have found that many more people appear to be losing Fast Track eligibility at review. As a reminder, Fast Track decisions are taken when someone's condition is rapidly deteriorating, and the person may be entering a terminal phase. Virtually all Fast Track assessments are approved. The overall increase in eligibility decisions for CHC over recent years has been entirely because of the increase in Fast Track decisions as shown in **Figure 2**, with Standard awards declining.

"Well, it took three goes before we were given it. I think the third time it was mainly because everybody was expecting for my husband not to live much longer, so he got it under emergency funding."

However, when at review, often at three months, they are still alive, the CHC funding appears to be taken away, despite for many people there being no material change to their needs.

"Disaster. Arrogance. Excuses. When my husband was desperately unwell and I, with paid carers, was looking after him at home, I went through all the procedures of CHC to no avail. Only when the hospital he was admitted to cast him aside to die did they fund a nursing home for three months, then cancelled - as he was still alive! He died eight months later, after paying huge fees."

A call to the Age UK Advice Line told a similar story (summarised by the adviser):

"[Caller's mother, 90s], living independently until last March. Had a stroke, left her paralysed and not been home since. Went to nursing home following discharge. Put on end-of-life care – hospice – stabilised. Fast track [CHC funding granted] – reviewed in October [no longer eligible]. Turned [Mother] down because doesn't have a primary health care need. [Mother] is still paralysed, can't get out of bed, sleeping a lot."

And again from another caller. Both are representative of a number of calls in recent months through the Age UK Advice Line (again, summarised by the adviser):

"Caller ringing about mother in law who is in a care home at end of life stage. She had previously received NHS CHC funding but this was stopped in November last year. They appealed but lost the appeal. Mother in law is now [local authority] funded, but caller wanting to understand why the CHC funding was stopped when mother in law's condition has not changed."

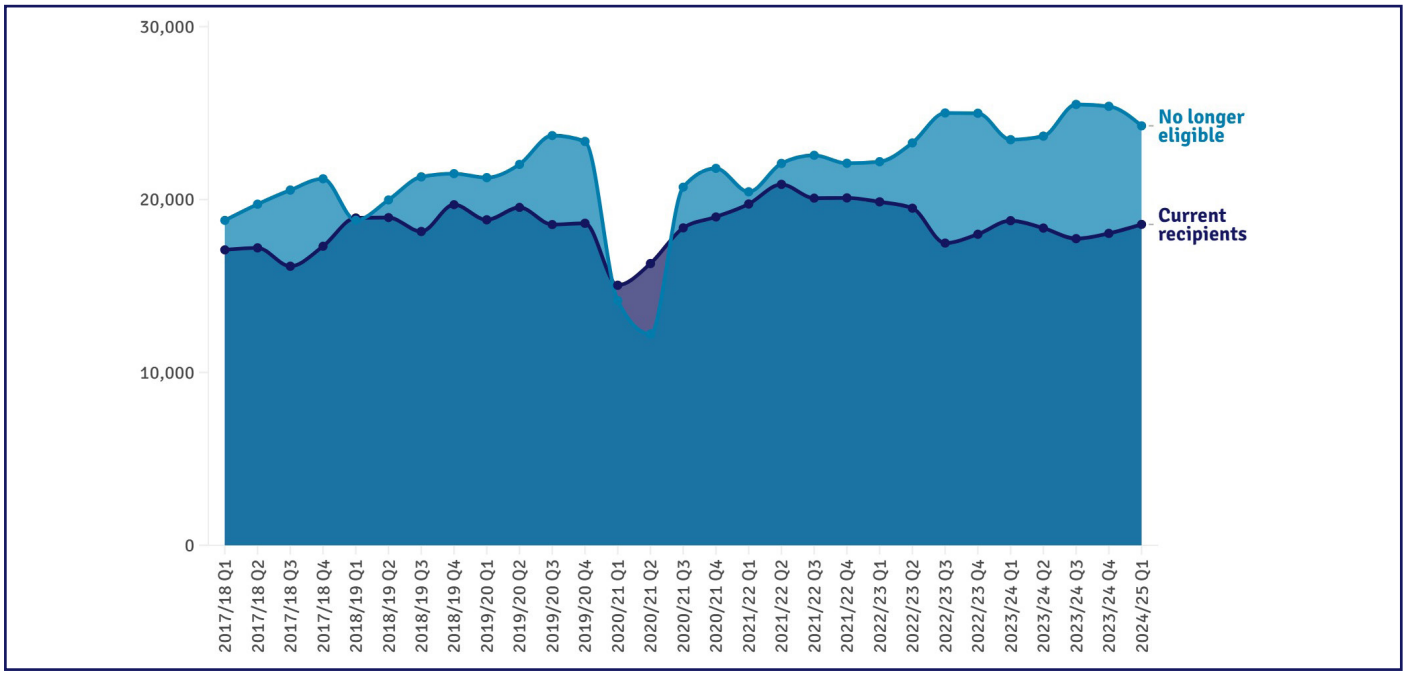
Again, in line with the National Framework, these may be legitimate decisions, but the impact on people and their families is no less devastating. They can feel left to fend for themselves in the extremely challenged social care sector.

However, data on CHC appears to reflect a proportionate increase in those losing eligibility following a Fast Track decision. **Figure 7** depicts the number of people no longer eligible for Fast Track CHC and those currently in receipt of it, per quarter. With a few exceptions (in the main those caused by the pandemic) the 'no longer eligible' figure is always higher. However, the difference has grown substantially in recent years.

Figure 7:

The number of people losing eligibility for Fast Track NHS Continuing Healthcare is rising faster than the number of current recipients.

The number of Fast Track NHS Continuing Healthcare recipients and those no longer eligible, 2017/18 Q1 to 2024/25, Q1 England.



Source: Age UK (2024): Analysis using: NHS England Statistics (2024). Continuing Healthcare and NHS - funded Nursing Care.

Whereas the number in receipt at any one time has broadly stayed the same since 2017/18 (an increase of 8.6%), the number no longer eligible has grown by 29%. Between Q1 2021/22 and Q1 2024/25 alone, this number has grown by 19%.

It could be that in general people are not surviving as long under Fast Track compared to previous years. However, it could also be explained by it becoming more likely that people are losing their Fast Track on review.

People who have contacted us speak of their fear of it being withdrawn.

"My mother was refused CHC at least twice, until she needed end of life care when it was granted, but she has not yet died, living on for several months, so this may possibly be withdrawn on review, although she clearly fills the criteria. In my experience CHC assessment outcomes are completely dependent on funding, or lack of, to be precise."

End of life care has always been one important component of CHC funding. However, given the increases in the number of Fast Track recipients and the decline in Standard awards, it appears that palliative care need is an even more dominant factor in accessing CHC. Even when people are awarded Fast Track CHC, rather than it supporting them through to a dignified death, they are losing it at review despite no material change to their needs.

It is likely that people that may once have received Standard CHC are now having to wait until they are 'rapidly deteriorating' before receiving it as Fast Track. There may even be a misconception amongst professionals that CHC is only applicable to people at the end of life.

4: What is the story here?

NHS Continuing Health Care (CHC) can be a lifeline for people. At a moment of highest need, often towards the end of life, it can provide the care and support someone needs to sustain their health and wellbeing. For many, it can take a huge amount of pressure off friends and family, themselves having to compromise their own health and wellbeing to support a loved one.

However, getting CHC has long been one of the most pernicious postcode lotteries. Having to find out about it in the first place, successfully go through a checklist, then an assessment, and too often an appeal is a heavy burden to place on anyone. And these are all hurdles that individually can trip them up let alone having to do each one in turn.

This is all too evident in the huge variation between areas in **Figure 5**. For those that bypass some of these stages through the Fast Track process, they can hit another set of challenges when they're reviewed, risking losing their care when their needs haven't changed.

Sitting under these challenges is the tension of the NHS > social care divide. That CHC needs to exist in the first place is because the NHS has responsibility for meeting continuing health care needs when there exists sufficient complexity, intensity, need for clinical supervision etc.

Ever since the NHS was founded, the bodies responsible for social care have held that supporting people in these circumstances is beyond what they can be reasonably expected to deliver, most recently formally set out in the Care Act 2014.

In one world, this could be a simple administrative distinction that for the individual has no bearing on the availability and quality of their care. However, in the real world, this butts up against one service that is free at the point of delivery and another that is means tested. An NHS that has an overall annual budget of £155 billion and a social care system that is chronically under-funded.

Even the NHS with that larger budget sees CHC as a significant cost. The last time it was estimated, NHS England projected CHC spend to hit £5.1 billion a year by 2020/21, prompting them to encourage local NHS bodies to reduce spending by £855 million by that time. The decline in Standard CHC eligibility since 2017/18 suggests that they may have had some success in that regard.

Sitting at the sharp end of these issues are older and disabled people and their families. It is their stories that have featured in this report. It is a system that does not provide clarity or security for people at their most vulnerable and that turns life-changing decisions about their care to something akin to a lottery.

In one scenario, you live somewhere with lower pressure on their budgets and access to a proactive and multi-professional team to carry out your assessment, and the result is fully-funded health and social care through CHC. In another scenario, you have identical needs, you live somewhere with a team struggling to manage CHC, perhaps with too few staff, are given a cursory assessment, sometimes by a single professional, and now you fall back into the crumbling social care system and risk paying hundreds and thousands of pounds for your care.

So what about social care?

It may be reasonable to ask at this point, would we need CHC if there was a functioning social care system? Certainly, organisations like the King's Fund have previously proposed funding free social care for everyone with 'substantial' and 'critical' needs using money allocated to CHC [23]. It is true that the very stark divide between CHC and social care would be smaller were social care functioning even in a way that meets the standards set by the Care Act 2014.

However, it is likely that there will always be a need for CHC. With people living with complex needs, who in previous decades may have stayed for long periods in hospital because of the need for constant clinical supervision, there is no doubt that responsibility for their care sits with the health service. Now, the NHS aims to minimise the time people spend in hospital and to support people to live well, or have a dignified death, at home.

There is an ideal world where social care is sufficiently funded, supported and fully integrated with the NHS that would see CHC becoming a quirk of the past. However, we're a very long way from achieving that and in the meantime, older people and their families deserve a much better experience of CHC.

Glossary

NHS Continuing Healthcare (CHC)

"NHS Continuing Healthcare (CHC) means a package of ongoing care that is arranged and funded solely by the National Health Service (NHS) where the individual has been assessed and found to have a 'primary health need' as set out in this National Framework. Such care is provided to an individual aged 18 or over, to meet health and associated social care needs that have arisen as a result of disability, accident or illness" [24].

NHS Funded Nursing Care

"NHS-funded Nursing Care is the funding provided by the NHS to care homes with nursing to support the provision of nursing care by a registered nurse".

Checklist

"The Checklist is the NHS Continuing Healthcare screening tool which can be used in a variety of settings to help practitioners identify individuals who may need a full assessment of eligibility for NHS Continuing Healthcare".

Decision Support Tool (DST)

"Once an individual has been referred for a full assessment of eligibility for NHS Continuing Healthcare (following use of the Checklist or, if a Checklist is not used in an individual case, following direct referral for full consideration), then, a multidisciplinary team must assess whether the individual has a primary health need using the Decision Support Tool.

"The DST is designed to ensure that the full range of factors that have a bearing on an individual's eligibility are taken into account in reaching the decision, irrespective of client group or diagnosis. The tool provides practitioners with a method of bringing together and recording the various needs in 12 'care domains', or generic areas of need. Each domain is broken down into a number of levels."

See **Appendix** for the 12 Care Domains.

Fast Track Pathway Tool

"The intention of the Fast Track Pathway is that it should identify individuals who need to access NHS Continuing Healthcare quickly, with minimum delay, and with no requirement to complete a Decision Support Tool (DST). Therefore, the completed Fast Track Pathway Tool, with clear reasons why the individual fulfils the criteria and which clearly evidences that an individual has a rapidly deteriorating condition and the condition may be entering terminal phase, is in itself sufficient to establish eligibility".

Integrated Care System (ICS)

Formally established in July 2022, an ICS is a partnership of local bodies responsible for the planning and joining up of health and social care. They include NHS organisations, local authorities (councils) and can include other organisations such as local voluntary and community sector services. There are 42 ICs across England and their average size of population covered is 1.5 million.

Integrated Care Board (ICB)

An ICB is the body within each ICS responsible for the planning and delivery of local health services, managing the overall NHS budget for their area. This includes responsibility for NHS Continuing Healthcare, for which they will have a team that oversees the local budget and that makes the decision on eligibility based on advice from healthcare professionals.

NHS Continuing Healthcare Reviews

"Where an individual has been found eligible for NHS Continuing Healthcare, a review should be undertaken within three months of the eligibility decision being made. After this, further reviews should be undertaken on at least an annual basis, although some individuals will require more frequent review in line with clinical judgement and changing needs".

Previously unassessed periods of care (PUPoC) guidance

This guidance deals with previously unassessed periods of care. These refer to a specific request to consider eligibility for a past period of care where there is evidence that the individual should have been considered for NHS CHC eligibility, but was not considered at the time, and the individual has funded that care either in full or in part.

Appendix

Domains of care used in the Decisions Support Tool

1. Breathing
2. Nutrition
3. Continence
4. Skin Integrity
5. Mobility
6. Communication
7. Psychological and Emotional needs
8. Cognition
9. Behaviour
10. Drug therapies and medication
11. Altered states of consciousness
12. Other significant care needs

These domains are assessed against the following characteristics:

Nature: This describes the particular characteristics of an individual's needs (which can include physical, mental health or psychological needs) and the type of those needs. This also describes the overall effect of those needs on the individual, including the type ('quality') of interventions required to manage them.

Intensity: This relates both to the extent ('quantity') and severity ('degree') of the needs and to the support required to meet them, including the need for sustained/ongoing care ('continuity').

Complexity: This is concerned with how the needs present and interact to increase the skill required to monitor the symptoms, treat the condition(s) and/ or manage the care. This may arise with a single condition, or it could include the presence of multiple conditions or the interaction between two or more conditions. It may also include situations where an individual's response to their own condition has an impact on their overall needs, such as where a physical health need results in the individual developing a mental health need.

Unpredictability: This describes the degree to which needs fluctuate and thereby create challenges in managing them. It also relates to the level of risk to the person's health if adequate and timely care is not provided. An individual with an unpredictable healthcare need is likely to have either a fluctuating, unstable or rapidly deteriorating condition.

National Framework for NHS Continuing Healthcare and NHS funded Nursing Care, 2022

References

1. The Coughlan judgement, see annex B of the National Framework for NHS Continuing Healthcare and NHS funded Nursing Care, 2022.
2. National Audit Office (2018), Investigation into NHS continuing healthcare funding.
3. An Integrated Care Board (ICB) is the local body with statutory responsibility for planning and organising NHS services in their area, including CHC, as part of an Integrated Care System (ICS). There are 42 ICS's across England.
4. This is a simplification. In practice, one domain rated as priority or two of severe would indicate a clear recommendation. Beyond this, the guidance states that one severe with needs across a number of other domains or a number of domains with high or moderate needs may indicate a primary health need. There is no clear threshold as they need to take into account how those needs interact with one another.
5. You can see more information on Personal Health Budgets in the Age UK factsheet available **here**.
6. NHS Digital (2023). Health Survey for England: Adults' health: General health, acute sickness and longstanding conditions.
7. Watt, T., Raymond, A., Rachet-Jacquet. L., Head. A., Kypridemos. C., Kelly, E. and Charlesworth, A. (2023). Health in 2040: projected patterns of illness in England. The Health Foundation.
8. Age UK (2024), State of Health and Care of Older People in England.
9. NHS England (2020), **Delayed Transfers of Care Data 2019-20**.
10. NHS England (2024), **Discharge delays (Acute)**.
11. National Audit Office (2018), Investigation into NHS continuing healthcare funding.
12. The 2012 framework did discourage this practice, but did not explicitly forbid it.
13. See for example **here**.
14. National Audit Office (2018), Investigation into NHS continuing healthcare funding.
15. Public Accounts Committee (2018), NHS continuing healthcare funding: Report.
16. National Audit Office (2018), Investigation into NHS continuing healthcare funding.
17. The content of this report comes from the survey which took place in the Autumn of 2023, during which we received 17,000 responses to the overall survey.
18. Healthwatch Lambeth (2023), **Continuing Healthcare: Service user and carer experiences of applying for NHS Continuing Healthcare funding.**
19. Age UK (2024), State of the Health and Care of Older People in England.
20. Older people are often waiting far too long for the social care they need avaliable **here**.
21. This only applies to periods of care after April 2012.
22. They should be restored to the financial state they would have been in had the eligibility decision been made at the appropriate time, including interest.
23. King's Fund (2014), Commission on the Future of Health and Social Care in England.
24. All definitions in quotation marks come from the National Framework for NHS Continuing Healthcare and NHS funded Nursing Care, 2022.

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