



DementiaUK

Helping families face dementia

Guiding the way: a better continuing healthcare system for dementia



Guiding the way: a better continuing healthcare system for dementia

Executive summary	3
Background to our report	6
About us	8
Our research: overview and methods	9
Findings	10
Case study: Rachael’s story	18
Recommendations	20
Next steps	26
Thanks and acknowledgements	28



Executive summary

NHS continuing healthcare (CHC) provides a lifeline for many people with long-term and complex health needs and their families, by offering NHS funding to pay for care on a needs basis.

However, for too long, the system of applying and assessing eligibility for CHC has been flawed, as demonstrated by reports from organisations including the Parliamentary and Health Service Ombudsman (PHSO) and The CHC Alliance. This situation leads to many families affected by dementia struggling to navigate the system – if they are aware of CHC as an option at all – as well as frustration and disappointment over decisions made which do not appear to reflect the true nature of their loved ones' health challenges. A rejected CHC application also means that families miss out on funding that would have paid for their loved one's care. This may mean they find themselves facing increased caring responsibilities; they may also have to fund the person's care themselves, putting a strain on their finances.

In this report, we outline the key challenges faced by families affected by dementia within CHC, many of which seem to have persisted despite numerous calls for change in recent years. Our report is based on qualitative research undertaken with family carers and our dementia specialist Admiral Nurses, who work directly to support families affected by dementia. Our research focuses on the system in England, though there are comparable but different schemes within Scotland, Wales and Northern Ireland.



People affected by dementia and their families often face significant obstacles applying for CHC in England. These include:

- assessors ignoring or misunderstanding the variable impact dementia may have on individuals and their families
- a lack of support within the process
- a confrontational, rather than supportive, process

Fundamentally, we are concerned that many people with dementia who may be eligible for CHC are not receiving it. This may be due to a lack of knowledge about CHC among professionals, meaning that families are unaware of the option, or due to significant flaws in how the system works for people affected by dementia. Equally, even for those who are deemed eligible, the system appears to present a stressful and thankless process to some applicants.

While we have highlighted these challenges, we are also focused on offering workable solutions to improve the experience of families affected by dementia in the CHC process. We are committed to working with partners in health – locally, regionally and nationally.

We are grateful that CHC and the support it can provide to patients and their families exists. But this system needs to work for everyone.



As part of our report, we lay out a set of recommendations for improving CHC for people with dementia and their families, and commit to working with partners to:



1. Raise awareness of the CHC funding option among families and professionals



2. Improve quality and consistency of the system

We break our second recommendation down into three components:

- improve the process
- improve understanding of dementia among CHC assessors
- improve understanding of the CHC process among health and social care professionals



3. Offer support for families throughout the process

With the release of this report, we are launching our **Guiding the way campaign** to champion these necessary changes. Working with our supporters, Admiral Nurses and partners, we will be engaging with local CHC leads, NHS England, the Department for Health and Social Care in England and other stakeholders to make our recommendations a reality.

In addition, we are launching a range of new information resources to support families around CHC, available from dementiauk.org/continuing-healthcare. Our Admiral Nurses will also provide ongoing support to families around the CHC process, both locally and via our Helpline and Closer to Home clinics.

CHC funding is not available, nor appropriate, for everyone affected by a long-term, complex health condition, including some people living with dementia. But the system needs to be fit for purpose so that people who may be eligible can be supported every step of the way to apply, with healthcare professionals and assessors who truly understand the impact dementia can have.

We ask our colleagues within national and local CHC delivery to work with us, so that CHC can work for everyone.

Background to our report

Continuing healthcare (CHC) funding is provided by the NHS in England to some people with long-term and complex healthcare needs to pay for care. Comparable schemes exist in Wales and Northern Ireland, with a separate system in Scotland for care delivered in hospital rather than care packages delivered in people's homes or a care home. This report and our research focus on the system in England.

A person's eligibility for CHC funding will depend on the specifics of their primary healthcare needs. Applications are made via 'standard' or 'fast-track' processes, with the latter used when a person's condition is rapidly deteriorating and they are likely approaching the end of life.

Dementia is a progressive, long-term condition which often presents complex challenges. As a result, some people with dementia may be eligible for CHC funding. The process of applying can be lengthy. As outlined by [NHS.uk](#):

To be eligible for NHS continuing healthcare, you must be assessed by a team of healthcare professionals (a multidisciplinary team). The team will look at all your care needs and relate them to:

- what help you need
- how complex your needs are
- how intense your needs can be
- how unpredictable they are, including any risks to your health if the right care is not provided at the right time¹

Significant issues have been highlighted recently around the process and delivery of CHC by expert voices such as the Parliamentary and Health Service Ombudsman² and the Continuing Healthcare Alliance.³ These reports have highlighted failings in assessments, long waiting times for applicants, and some people being forced to fund care on top of funding provided by CHC.

¹ NHS website (2021) NHS Continuing Healthcare page, available at [nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/nhs-continuing-healthcare/](https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/nhs-continuing-healthcare/), accessed on 5th October 2021

² Parliamentary and Health Service Ombudsman (2020) Continuing Healthcare: Getting it right first time, available at [ombudsman.org.uk/publications/continuing-healthcare-getting-it-right-first-time](https://www.ombudsman.org.uk/publications/continuing-healthcare-getting-it-right-first-time), accessed on 5th October 2021

³ Parkinson's UK in association with the Continuing Healthcare Alliance (2016) Continuing to care? Is NHS continuing healthcare supporting the people who need it in England?, available at [parkinsons.org.uk/get-involved/continuing-healthcare-alliance?gclid=CjwKCAjwtfqKBhBoEiwAZuesiO54Aq7GuNfsYCj1z9PtXiP8i4Cr4srg6s4o8zqkQ1eWgeYI4eEXRoCPIMQAvD_BwE&gclid=aw.ds](https://www.parkinsons.org.uk/get-involved/continuing-healthcare-alliance?gclid=CjwKCAjwtfqKBhBoEiwAZuesiO54Aq7GuNfsYCj1z9PtXiP8i4Cr4srg6s4o8zqkQ1eWgeYI4eEXRoCPIMQAvD_BwE&gclid=aw.ds), accessed on 5th October 2021

Recommendations from these reports included better support for people going through the CHC process, ensuring packages of care are truly based on need rather than financial considerations, and improving skills for practitioners. Despite some progress, the Covid-19 pandemic among other factors has contributed to ongoing challenges in many people's access to, or wait for, CHC funding.

There is also a stark difference between the approval of CHC funding between fast-track and standard applications. Over the last five years there have been:

374,754

CHC assessments completed under the fast-track system (ie for people who are likely approaching the end of life and whose condition is rapidly deteriorating)

228,928

CHC assessments completed under the standard system⁴

However, 99.93% of fast track assessments were approved over this time period (only 275 were rejected), whereas only 25.42% of standard assessments were approved.

While it could be expected that assessments of people who are approaching the end of their life may be more likely to be approved, this means that three out of every four standard assessments failed. Even if all those decisions were justified (and the relatively high success rate of appeal from 17-25% over recent years would suggest many are not)⁵, the fact that the majority of funding assessments fail illustrates a system which is – at the very least – causing many families and professionals unnecessary work and increased stress. Literally hundreds of thousands of people with a variety of different health needs have been rejected for this funding, with all the emotional and financial impact that may entail for the applicants themselves and their families.

At Dementia UK, via our local Admiral Nurses' work, we hear regularly of specific challenges facing families affected by dementia in accessing CHC. We also receive hundreds of calls a year to our Admiral Nurse Dementia Helpline from family members about accessing CHC, and the topic is raised in many other calls relating to the care a family member receives.

As a result, we have undertaken research (detailed below) to identify the common challenges faced and the changes that could be made to improve the support families should receive.

⁴ NHS England (2021) CHC and FNC – National Time Series Q1 2017-18 to Q1 2021-22, available at england.nhs.uk/statistics/statistical-work-areas/nhs-chc-fnc/, accessed on 13th October 2021. See Tab 1.2 in Quarter for numbers of assessments quoted. Period covered is from the first quarter of 2017-18 to the first quarter of 2021-22

⁵ See Tab 1.2 in Quarter in reference above

About us

We are Dementia UK – the specialist dementia nurse charity.

Dementia is a huge and growing health crisis. Almost all of us will know someone with dementia – whether it’s a family member or a friend.

There is no cure for dementia. But there is care. And care can change lives.

That’s why Dementia UK is here. Our nurses, called Admiral Nurses, who we continually support and develop, provide life-changing care for families affected by all forms of dementia – including Alzheimer’s disease.

For families affected by dementia, they can be a lifeline.



Our research: overview and methods

In June and July 2021, Dementia UK carried out qualitative research into experiences of families and Admiral Nurses relating to CHC funding in England. This involved:



nine interviews with family carers (one interview included two people, from Dementia UK's Lived Experience Advisory Panel (LEAP), so a total of 10 interviewees.) These families had a variety of caring situations, and between them, had experiences of both successful or unsuccessful CHC decisions.



three focus groups for Admiral Nurses. Each focus group was made up of four to eight Admiral Nurses with varied experiences of CHC, working in a variety of settings (community, care home, acute) in different geographical locations.

These interviews and focus groups were based on a semi-structured interview schedule prepared by Dementia UK's Insights and Evaluations Team, highlighting specific areas of interest to cover, but allowing for participants to raise issues or topics important to their experience. Copies of our discussion schedules are available on request.

Findings

Based on our research, we have detailed the key findings relating to families' and Admiral Nurses' experiences of CHC.



Family carer interviews

Broadly, the experiences shared by family carers in their interviews can be summarised into three topic areas related to the CHC process: access, support, and necessary improvements.

(a) Access to the CHC process

The family carers interviewed explained how they had become aware of CHC funding. The varied experiences they described included:

- CHC was suggested or brought up by professionals involved in the care of the person with dementia (five interviewees)
- Family carers already knew of CHC because of their own professional experience (three interviewees; one interviewee had to be prompted by a nurse at the time, as they thought CHC could not be awarded unless the person was on oxygen support)
- Family carers found out about CHC by chance/from a charity's website (two interviewees)

One interviewee said they had received incorrect information from other professionals; specifically, they had been told that the person with dementia did not qualify for CHC because they did not have cancer.

“ No professional member told us about CHC. It was the dementia specialist team [at Dementia UK] who told us about CHC. When we found out, we thought it was [untrue] because surely someone would have told us about it?”
(Family carer)

(b) Support during the CHC process

Experiences of the process differed between family carers, with the majority reporting significant challenges:

- For two out of the 10 interviewees, professionals led on the application process. However, for one of those two interviewees, the process became stressful later on with re-assessments
- Two other interviewees **had good experiences where there was a professional who coordinated the whole process**, took an interest in the family and was knowledgeable about CHC

“The nursing home he was at was very, very good. The main matron there said straightaway as soon as my dad was admitted they would take us through the process and that my father definitely was eligible due to his incontinence, he has meds and he needs nursing care... He’d really struggled in residential... The main matron pretty much coordinated the whole process for us and it was very smooth. It was a real relief.” (Family carer)

- The other six interviewees reported **very difficult and distressing journeys through the CHC process**, with no support other than from family members or friends, with multiple challenges experienced. These included:
 - assessors who did not understand dementia
 - assessments lost
 - delays
 - information not passed on, generating further delays
 - unnecessary repeated assessments
 - perceived unjust temporary withdrawal of funding
 - unqualified staff providing evidence
 - decisions made without proper assessments of the person with dementia
 - conflicting advice given by different professionals
 - feeling not heard/not believed as family members
 - general hostile/uncaring tone in the official communications

“I didn’t have help and I didn’t know about YOD [young onset dementia] when [my daughter] was diagnosed in London. When they discharged her back to Coventry, we were told there weren’t many nursing homes that can cope and we were given limited resources to turn to... If I could turn the clock back, I would like to be able to see somebody who knew exactly what our options were in regards to funding going forward and how do you access that person. Why didn’t the hospital point us in the direction of that person?” (Family carer)

- Five of the interviewees mentioned having an Admiral Nurse on board during this process – the level of support varied, but included sharing information and acting as an advocate

(c) Improvements necessary to CHC process

The family carers interviewed suggested a range of necessary improvements to the CHC process. In no particular order, the following were the most commonly cited:

- **better professional expertise in the CHC process**, as well as knowledge about dementia and other related conditions for the assessment and decision-making stages. It was seen as important that professionals have (or have access to) specialist knowledge. This would be both clinical (to appropriately articulate the needs of the person) and process-related (to understand the CHC framework and what's needed.) This would include taking a holistic approach to the person's needs
- **high quality support and advocacy for the family**, including coordinated care both during the preparation stage and the assessment meetings. This would help family carers articulate the needs of the person with dementia and their circumstances in a way that would be understood by the assessors

“That's what they need, they need their hand holding through the process because when you're dealing with it... you can't think and if somebody says no they are not eligible, then nine times out of 10 they [the family] are going to say oh well OK... they haven't got the energy.” (Family carer)

- **continuity of professionals throughout the process**, including a named person taking a lead on the process. This would also help to ensure the same information is shared by professionals, and keep families in the loop

“The meetings are a great idea but they need to be supported by the right people or it doesn't work. At the very first point people need to be aware that it is a long and difficult process and you will need support, and here is the support. You know, somebody that could talk you through it, like Dementia UK [Admiral Nurses].” (Family carer)

- **clarity about the process**, so that this is explained to people affected by dementia and their families clearly at the outset and throughout, with relevant information available to families. This would include letting families know about the option of CHC; explaining the process, what family carers need to do, and how to respond to questions; and guidance or support with filling out the forms (which represents a skill in itself)

“You can't do it on your own with the system as it is. It just needs to be more open and honest, the whole process. You've got to get a team together that will be honest and say what people need and what their limitations are.” (Family carer)

While not in the 'top' improvements cited, interviewees also suggested shorter timescales for the process would be welcome.



Admiral Nurses' focus groups

Feedback from the Admiral Nurses' focus groups could also be divided into a short set of topic areas, namely: assessment of people affected by dementia; the impact of Covid-19; and specific challenges faced by families. Improvements needed were also covered as a topic area but we will discuss these in our Recommendations section.

(a) Assessment of people affected by dementia

Overall, CHC was reported as being a frustrating, often inconsistent process, due to the factors below.

- There is **wide variation in the assessment process**. There is a National Framework but little consistency in how families are assessed for CHC. There are:
 - **geographical disparities:** Admiral Nurses reported that Social Services are involved in some areas while completely absent in others. Equally, there are dedicated CHC teams in some localities, but a lack of a dedicated CHC lead for the process in others
 - **service disparities:** how a CHC process is undertaken appears to differ between health and care settings. For example, in acute settings, the Admiral Nurses interviewed said that the process was more likely to be fast-tracked, which is logical given the likely condition of patients within an acute service. However, it was also reported that sometimes CHC assessments are not initiated in hospital because a person's needs are not stable, and because it is perceived that delays in the CHC process could 'block beds'
 - **timing disparities:** while some applicants have more time, requests for evidence are often made with very little notice (eg two days.) Nurses who raised this point said that this is insufficient time to gather evidence or bring together expertise

“ Families don't understand what they even need to do to trigger that process and who do they need to go to. It is a National Framework but a different process across the country.” (Admiral Nurse)

- There is a **lack of understanding about dementia within the CHC system**. Interviews highlighted several contributing factors:
 - **a lack of emphasis on/scope for dementia in the Decision Support Tool (DST.)** The DST has been produced by the Department of Health and Social Care to help a Multidisciplinary Team make recommendations on CHC funding applications⁶. However, many of the Admiral Nurses interviewed felt

⁶ Department of Health and Social Care (December 2018) NHS continuing healthcare Decision Support Tool, available at gov.uk/government/publications/nhs-continuing-healthcare-decision-support-tool, accessed on 8th October 2021

Findings

the DST fails to take account of the condition's complexities, fluctuations and variable presentation. The tool, or at least its application, appears more suited to physical, rather than mental health conditions. For example, if the needs of a person with dementia are currently well managed, they may be 'downgraded' in the CHC scoring system, despite the objective reality of their high needs. Likewise, given that a person's dementia symptoms may vary from time to time, if the 72-hour assessment period coincides with a better-than-average 'presentation' of their condition, this may also lead to downgrading, and potential rejection of the CHC claim

- **a lack of understanding from some assessors about dementia.** Physical health challenges appear to be better understood by assessors than cognitive, mental health or behavioural issues. It was reported that this often results in applications for people with dementia being rejected or sent back with requests for more information. It was also raised that some assessors have been cautioned not to 'double-count' needs that might be due to cognitive impairment. However, this can miss ways in which dementia can affect other health challenges (eg incontinence), and means that people with dementia may fail to have the whole spectrum of their needs reflected in their final assessment 'score'

“Dementia is not well covered in the DST... The nature of its intensity, complexity, unpredictability [means] this is quite open for individual interpretation... Dementia is complex and I do not think, particularly where dementia is of concern, that it is in anyway whatsoever a fair tool to be used.” (Admiral Nurse)

“A need doesn't go away just because it's a met need, it still remains a need. It's just that people are doing their job [caring for the person with dementia] really well.” (Admiral Nurse)

There were a number of examples given by the interviewed Admiral Nurses where misconceptions have played a role, with submissions rejected because:

- the person “cannot be depressed” if they have dementia
- the “care home can deal with it”

“With cancer, you've got a projection of what might happen and how quickly the person might deteriorate... What the CHC doesn't take into consideration is that people with dementia can be up and down, where they might have frequent delirium, or people with Lewy body that might have very good days and very bad days. Also, how they decline might vary because some people have a gradual decline and for some people it can be very rapid.” (Admiral Nurse)

- The experiences of the nurses were also of the **CHC system being 'confrontational'** with the implied expectation from the assessors or system that applicants are lying or exaggerating

“ I just find it now a very confrontational exercise and the relatives or care home staff I think are penalised for not being able to record what the CHC needs... so managed needs by skilled staff and very careful assessment of the patient will not score whereas in fact they might be highly labour-intensive and highly skilled staff managing that need. I've seen people that have been rated for lack of evidence and some CHC assessors saying 'well, that's not an issue because we haven't got the evidence', and I think families aren't given that awareness or that need in order to prepare themselves.” (Admiral Nurse)

In fact, many family carers will 'play down need' as they either do not recognise or have not been fully briefed on the complexities of the need or what evidence is required.

“ Carers underestimate their roles because they do it for their husband or wife or child, so they underestimate... As a professional you have to prep them on certain words to say and tell them to talk about their worst days because they undersell themselves because they don't recognise themselves as carers.” (Admiral Nurse)

As a result, some of the Admiral Nurses interviewed said this system has the effect of **discriminating against family carers** who may not have the expertise or time (due to their caring responsibilities) to complete application forms. Families will typically lack daily clinical notes or observations, plus the one-to-one interventions and support they deliver are not weighted the same as interventions from paid carers. An observation shared in one of the focus groups was that a person in a care home with an identical presentation of dementia has more chance of being awarded CHC than a similar person being cared for in their family home.

This was demonstrated by one Admiral Nurse's discussion of a common scenario:

“ A person in his 60s, with a rare dementia, lives with his wife who provides all the care. He had a CHC assessment but how do you look at the fact that his wife lives with and sleeps in the bed next to him, so every time he moves she knows that and she supports him with his toileting needs and [she's aware that] when she is preparing a meal he tries to grab and eat anything including raw chicken?

How do you put that across to a CHC assessor when in a care home he wouldn't have access to the kitchen, and if he was in a care home he probably would have been awarded CHC because the interventions that would have been required to manage his needs throughout the 24-hour period would have been that much greater than him living at home with his wife, who has the ability... to understand what he needs.

It's one-to-one care isn't it? How do you look at that and say that isn't a high level of healthcare?” (Admiral Nurse)

In the experience of the Admiral Nurses interviewed, **the majority of applications are refused**. Indeed, some of the Admiral Nurses gave some examples where even though the CHC assessor had believed that the person was eligible, the request was still turned down by the panel. In addition, we heard some applications had been refused or delayed even for care in the last 12 weeks of life, which should be free.

(b) Impact of Covid-19 on the assessment process

The Admiral Nurses interviewed reported variable experiences across the English regions covered. For example, a nurse working in the West Midlands found that their local DST meetings were easier and quicker to convene.

However, among others, key issues highlighted with the online process included:

- assessors not being able to capture all relevant evidence without a face-to-face assessment of the person with dementia
- lack of family input in decisions, including not being informed about meetings

At the time of the focus groups (June–July 2021), there was estimated to be a backlog of 3,015 assessments⁷, plus outstanding reassessments, meaning many families are having a long wait for any results. This will lead to increased financial pressures and hardship for families while they wait for a decision on funding. That said, this backlog has seen improvement from an estimated high of 25,000 assessments in August 2020⁸.

(c) Challenges faced by families

A key concern reported by Admiral Nurses is **a lack of awareness about CHC or its specifics** among families. For instance:

- CHC may not even be mentioned to families by professionals, who themselves may not be aware of the funding stream

“It is so complicated that even people that work in healthcare don’t always understand it, so for relatives you’ve got all of that emotion involved as well and they might have their own financial pressures or they might be worried about having to sell their house... If it could be made more streamlined and easy for people to understand I think it would be so much better.” (Admiral Nurse)

⁷ NHS England (2021) CHC and FHC Statistical Release Q1 2021–22, available at [england.nhs.uk/statistics/wp-content/uploads/sites/2/2021/08/CHC-and-FHC-Statistical-Release-Q1-2021-22_3vYUR2.pdf](https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2021/08/CHC-and-FHC-Statistical-Release-Q1-2021-22_3vYUR2.pdf), accessed 16th September 2021

⁸ Community Care (25th August 2020) Continuing healthcare assessments resume following Covid suspension with backlog of 25,000 to clear, available at [communitycare.co.uk/2020/08/25/continuing-healthcare-assessments-resume-following-covid-suspension-backlog-25000-clear](https://www.communitycare.co.uk/2020/08/25/continuing-healthcare-assessments-resume-following-covid-suspension-backlog-25000-clear), accessed on 16th September 2021

Findings

- Families are often not informed about certain CHC funding conditions, such as:
 - the prohibition of private top-up (ie self-funding a shortfall in CHC funding)
 - CHC only funding healthcare needs that are beyond the social care needs. So while someone may present with a host of needs, if they do not pass the threshold of what social care should support, they cannot be awarded CHC funding. This distinction is not made clear to all families
 - some decisions around care may also be taken away from the family if funding is awarded, eg if home care costs outweigh the cost of a care home then it may be that the person will be told to go to a care home irrespective of their wishes or those of their families

In addition, it was reported that **professionals do not always keep families in the loop during the CHC process**. Families are often not informed about meetings, which leads to a lack of family input in decisions, or awareness of decisions that have been made.

These factors can lead to a heavy emotional toll on already stressed family members.

“ This woman has gone into care and her daughter is paying £6,000 a month for the care home. I did say it would be worth looking into CHC funding but the daughter said she has looked into the Framework and paperwork and said that she won’t even go there. She doesn’t have the emotional strength to sit through it. That is how despondent people can be.” (Admiral Nurse)

Because of these factors and the complexity of the system, families then often look for advice from multiple sources to understand how they could be ‘seen’ in a system perceived as unfair. It was reported that some families hire private brokers who promise to achieve the funding, which have led to mixed experiences – some positive, some negative.



Common themes

As shown above, a number of common themes emerged from both the family carer interviews and Admiral Nurse focus groups. These included:

- lack of awareness or expertise about the CHC process among some health and social care professionals
- families not being made aware of the CHC process by health and social care professionals
- poor and inconsistent processes
- lack of awareness or understanding of the needs of people with dementia among CHC assessors
- poor or inconsistent support for families, with inadequate information or guidance provided at each stage of the process

Case study

Rachael moved back home to Hull during the pandemic to help her parents care for her grandfather, who has Parkinson's dementia, and grandmother, who has Alzheimer's disease. Both of her grandparents still live at home. Rachael and her parents visit at least once a day, and domiciliary services visit four times a day.



Above: “Grandma and Grandad on their wedding day”

“I couldn't get my point across”

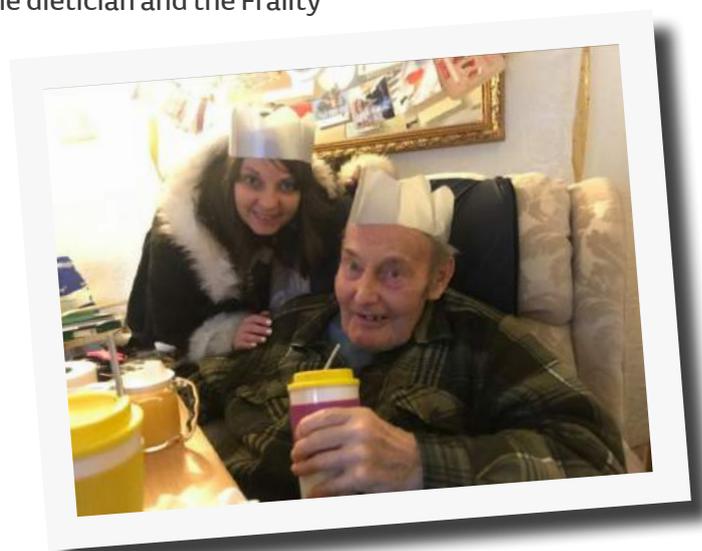
I thought applying for CHC for Grandad would be clear-cut because he has so many health needs that have taken over his life – including a painful degenerative spinal condition, mobility problems and falls, problems with eating and drinking, hallucinations, and depression.

We started the application back in October 2019 and the Decision Support Tool (DST) meeting was eventually held in April 2021. There was no one in charge so the initial Checklist had to be repeated three times as it was either lost or kept on hold for so long that it expired. I kept chasing but nobody would ring me back.

A good number of professionals offered to write statements, including the Parkinson's nurse, the Speech and Language Team, the dietician and the Frailty Support Team. However, none of these professionals were present at the DST meeting. It was just me, our new Social Worker who had little knowledge of CHC, and the CHC assessor. There was no clinician present, which meant that there was no one to make the case for my grandad's needs.

I have a health and care background and even I found the system hard. You just question yourself. I couldn't get my point across and was asked to be quiet and let the professionals talk.

Below: “Me and Grandad last Christmas”



“There was no knowledge, no support”

We've had such a hard time trying to explain Parkinson's dementia to healthcare professionals: there's just no knowledge, no support. Grandad was repeatedly marked down because the District Nurses and other professionals did not understand his form of dementia. I think a lot of healthcare professionals think dementia is just Alzheimer's, and if it's a different type of dementia, then they just don't get it.

We had healthcare professionals tell us that Grandad had full capacity because they didn't understand that although his short-term memory is quite good, his reasoning is really bad. He has paranoid delusions where he strongly believes things like healthcare professionals conspiring against him – all sorts of things that mean he can't make a rational decision about care.



Above: “Grandma and Grandad 10 years ago on their 50th wedding anniversary”

“Families caring for a loved one need support”

Families need to talk about what happens on the person's worst day. I think families often feel really embarrassed or discouraged about this and whether it will be perceived as them not providing the right level of care.

Families need to have an advocate who understands dementia and how the CHC process works, who can share information and help families to articulate their case. Although our Social Worker was great, she'd never done a DST before and she didn't understand what she was supposed to be arguing. I don't think a lot of health and care professionals know enough about CHC and don't have enough support either. That's why families caring for a loved one with dementia need support from an advocate who has a specialist understanding of the needs of the person and an understanding of the DST process.

“It's two years since we applied”

Our CHC application was declined because they said Grandad didn't have a primary health need. I felt that the application didn't allow me to properly articulate how his condition affected all domains, which I feel led to them not realising the complexity of the care need.

We have now finally been given an appeal date. I'm not quite sure how to sum up how I feel about the whole process. I have felt anger, embarrassment, just pure frustration and exhaustion. It has been a battle that I don't feel I am anywhere near the end of. I'm a carer for two vulnerable people who I know I have very little time left with, and I'm wasting it arguing with people who are supposed to be helping us.

Recommendations

All interviewees were asked what changes to the CHC process they would recommend to make it work better for people with dementia, their families and professionals involved. We collated their views and have created a set of key recommendations for CHC improvements.



1. Raise awareness of the CHC funding option among families and professionals



2. Improve quality and consistency of the system



3. Offer support for families throughout the process



Recommendation 1

Raise awareness of the CHC funding option among families and professionals

A first step to improving support available would be to raise awareness that CHC may be an appropriate option for many people with dementia. However, as detailed above, CHC is not well known or understood by families, or indeed many professionals. Raising awareness among these groups would require greater promotion of CHC, the options it offers and the process by Clinical Commissioning Groups (CCGs) and other relevant organisations.

To aid this process, Dementia UK has produced specific [CHC information for families](#) following our research. Our Admiral Nurses can also provide advice and support to families on a local level, and nurses on our Admiral Nurse Dementia Helpline and in our Closer to Home clinics can talk through the key processes.



Recommendation 2

Improve quality and consistency of the system

It is clear that there remain significant issues with how the CHC process is experienced by families and delivered by practitioners. This recommendation can be broken down into three categories:

(a) Improve the process

Key changes should include:

- ensuring staff and/or family carers have sufficient time to gather evidence. This could be aided by sharing a ‘pre-assessment pack’ two weeks in advance, to help prepare them for submission. We would be happy to collaborate with local providers to produce this resource. We would also urge that this is reflected in the National Framework for NHS continuing healthcare and NHS-funded nursing care⁹, which sets out the principles governing this process
- ensuring that a specialist in dementia is present on the panel and in attendance throughout the application process

 There should be a requirement for there to be someone in attendance who actually has an in-depth knowledge of dementia to support people... Nothing should go ahead without them.” (Admiral Nurse)

⁹ Department of Health and Social Care (October 2018) National Framework for NHS continuing healthcare and NHS-funded nursing care, available at [gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care](https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care), accessed on 8th October 2021. The most relevant section for these additions/amendments would likely be p31, points 94-99.

As above, this provision should be added to the National Framework¹⁰. In addition, in staff training, it would be vital to emphasise CHC point 126 of the National Framework:

“It is important that those contributing to this process have the relevant skills and knowledge. It is best practice that where the individual concerned has, for example, a learning disability, or a brain injury, someone with specialist knowledge of this client group is involved in the assessment process.”

- improving the DST to better reflect needs relating to dementia, and their impact on families and carers. It may be useful to consider:
 - adjusting the DST into a flowchart model (‘If this is happening, then...’) to enable reflection on the complexities of various conditions
 - allowing for family carers’ experience and expertise
 - ensuring that the impact of caring is considered when reaching a decision

Fundamentally, some of the challenges with CHC are inherent in a system which separates funding between health and social care. However, merging the health and social care systems is outside the intended scope of this report. There are also significant changes proposed to the health system in England via the Health and Social Care Bill 2021¹¹, including the replacement of CCGs (which have responsibility for CHC assessments) with Integrated Care Systems. At present, it is unclear how CHC responsibilities would function within Integrated Care Systems, but we are engaging with relevant stakeholders to plan for this transition.

(b) Improve understanding of dementia among CHC assessors, including appreciation of the needs of people with dementia among CHC assessors

It would be necessary to support/train assessors to:

- focus on need, rather than diagnosis¹², given the varied way dementia symptoms will present and the fluctuating nature of the condition. Dementia will vary between different people, and between different types of dementia diagnosis, including rarer dementias. For instance, Alzheimer's disease in a 90-year-old and in a 30-year-old will likely present very differently. CHC assessments may often be weighted towards physical illness or need. By the time a younger person with dementia is eligible for assessment under CHC, they may still be physically strong or active but have significant needs in relation to cognition or behaviour risk, which can

¹⁰ See above. The most relevant section for these additions/amendments would likely be The Multidisciplinary Team section, p38, points 119-123

¹¹ Houses of Parliament (2021) Health and Social Care Bill 2021, available at bills.parliament.uk/bills/3022, accessed on 8th October 2021

¹² This is in line with p21 of the CHC National Framework: see gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care, accessed on 8th October 2021

be more difficult to demonstrate using the current system. Currently, the criteria in the DST do not use language that would pull out symptoms or difficulties that a younger person with dementia is experiencing, or the risk they may pose to themselves or others

- understand that any reviews for dementia should purely be about checking whether more support is needed, rather than reassessing eligibility – at this point, there is no prospect of the healthcare needs of a person with dementia improving long-term¹³
- understand and recognise the presence of co-morbidity in dementia
- be aware of, and adhere to guidance around, dementia and the Decision Support Tool (DST)
- understand dementia as a progressive, disabling condition
- recognise the sensitivity of some topics discussed at the assessment meeting, such as sexualised behaviours, in front of a person's spouse/parent
- recognise that carers may underplay their role or the severity of the needs of the person with dementia, in order to 'not make a fuss'

It would be important to ensure this culture change is applied to those on the assessment panel, as well as the assessors.

This recommendation echoes the 'Getting it right first time' report from the Parliamentary and Health Service Ombudsman (PHSO.) The report's 'Recommendation 1: supporting the skills and experience of NHS CHC practitioners locally' called on CCGs to ensure that assessors and other practitioners are 'appropriately skilled and experienced'¹⁴.

(c) Improve understanding of the CHC process among health and social care professionals

Among other areas of awareness-raising and training required, it would be vital for professionals who support and help with applications to understand:

- the process of fast-tracking for people at end of life, including relevant wording to use in submissions (eg 'rapidly deteriorating' as the key sentence to be used in one specific CCG), as well as awareness of how the end of life process in dementia may progress. This process can be slow and gradual. It is not always possible to always tell when a person is entering or in an 'active dying stage' (as opposed to a clearer, more predictable dying trajectory in cancer, for example)

¹³ This is in line with p3 of the CHC National Framework: see [gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care](https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care), accessed on 8th October 2021

¹⁴ Parliamentary and Health Service Ombudsman (2020) Continuing Healthcare: Getting it right first time, p8, available at [ombudsman.org.uk/publications/continuing-healthcare-getting-it-right-first-time](https://www.ombudsman.org.uk/publications/continuing-healthcare-getting-it-right-first-time), accessed on 14th September 2021

- the need for a transparent, easily understood CHC pathway
- that dementia specialists such as Admiral Nurses should be actively involved in the assessment
- the need to collaborate with other professionals and family members involved in the care of the person with dementia

This could be achieved through the development and delivery of training or relevant materials. Given the challenges facing the health and social care workforces, we recognise that staff time and capacity are at a premium, so it would be important to consider the best means of improving awareness and skills for different staff groups.



Recommendation 3: Offer support for families throughout the process

From our research, it is clear that many families require better support through the CHC process. We are not the first to highlight this point; offering support for families throughout the process was also recommended by the PHSO's 'Getting it right first time' report, with their 'Recommendation 4: supporting people and providers through the NHS CHC process'¹⁵.

Making this recommendation a reality would require specialist support and/or relevant, high quality information and guidance actively provided to families at each stage of this process. There would need to be a consistent named health or care professional available throughout to support, or accurately signpost to support for, the application, decision-making and so on.

Information for families about CHC would ideally be available through different means, eg online training and leaflets, as well as access to an expert who could give the right information at the right time. This material could be added to, or referenced by, the National Framework¹⁶. We propose this information should include:

- an overall pack for carers explaining the process and everyone's roles in an easy-to-understand format. The other resources below could potentially form part of this pack, or be separate to it
- example forms
- glossary of terms

¹⁵ Parliamentary and Health Service Ombudsman (2020) Continuing healthcare: getting it right first time, p8, available at ombudsman.org.uk/publications/continuing-healthcare-getting-it-right-first-time, accessed on 14th September 2021

¹⁶ Department of Health and Social Care (October 2018) National Framework for NHS continuing healthcare and NHS-funded nursing care, available at gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care, accessed on 8th October 2021. The most relevant section for these additions/amendments would likely be PQ 12 What information needs to be given to the individual when completing a Checklist? p109, points 12.1-12.2

- a flowchart to help families better understand the evidence that is required, eg ‘Is this happening? Y/N – collect this evidence’ etc. This might include explanations on how to present the case (eg the need to think of the person’s needs on the worst day) so they know what questions to ask, what language to use, and not to downplay their role or the severity of the need
- clarification of legal rights (examples made of legal cases brought forward in the past)

For our part, we have produced an information video about the CHC process broken down into chapters, alongside a leaflet covering much of this material. Our Admiral Nurse Dementia Helpline, Closer to Home clinics and our local Admiral Nurse services can also provide information and signposting to families considering or currently going through the CHC process.

Embedding these recommendations would not only help address CHC disparity for family carers highlighted by our interviewees, but also help improve professional competence in the system. This would also likely benefit people affected by conditions other than dementia.



Next steps

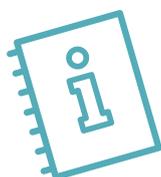


Our campaign

We are committed to making our recommendations a reality and improving the CHC process and experience for all families affected by dementia who may be eligible for this funding. We are focusing on the system in England initially, but subject to capacity, we will expand our work to address similar issues in the comparable systems within Wales, Northern Ireland and Scotland.

With the release of this report, we are launching our new campaign – Guiding the way – to improve the CHC process for families affected by dementia. Working with our supporters, Admiral Nurses and partners, we will be engaging with local CHC leads, NHS England, the Department for Health and Social Care in England and other stakeholders to make our recommendations a reality.

More information on our Guiding the way campaign can be found at dementiauk.org/guiding-the-way



Our information resources

Alongside this report, we are launching the following information resources to support families around CHC:

- [CHC advice video](#)
- [CHC leaflet](#)

The resources provide advice on what CHC is, eligibility and how to apply for it.



Support from our Admiral Nurses

Our Admiral Nurses may provide a range of support to families around CHC, mainly/largely by offering an overview and some advocacy, support and signposting, rather than becoming the primary source of information. This might include:

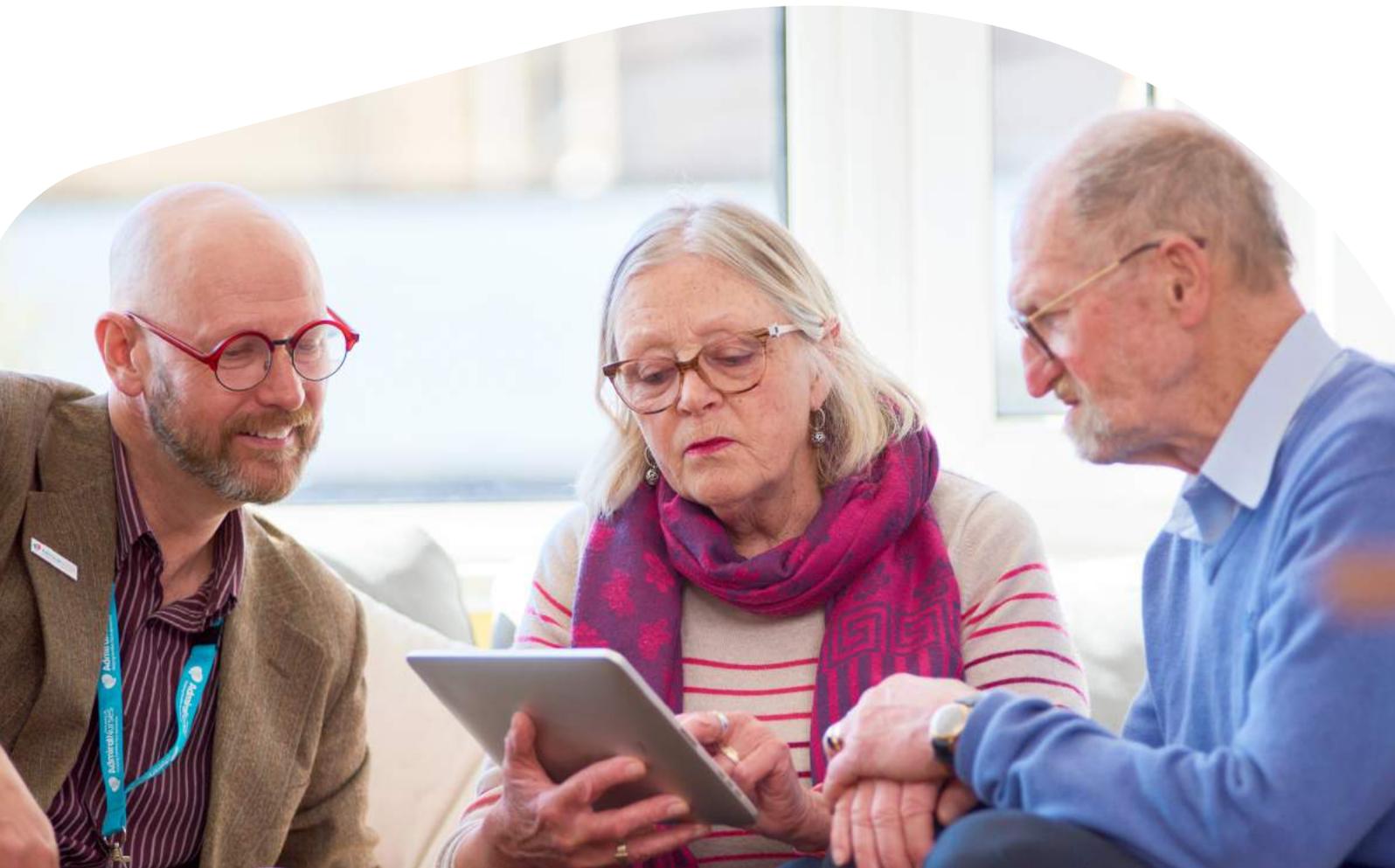
- supporting family carers to make sense of CHC so they know what questions to ask, what language to use, not to downplay their role or the severity of the need, etc
- encouraging family carers to write diaries to support the application, which would help provide continuous written evidence of need. This may be particularly important for younger people with dementia, as their overall needs are perceived to be even less understood by assessors

- depending on the circumstances and environment, an Admiral Nurse may be able to attend the assessment with the family carer as an advocate. To be clear, neither Admiral Nurses, nor family members, nor assessors are able to attend the panels

Admiral Nurses work in a variety of settings, including primary care, acute care, care homes and hospices, and geographical locations, and therefore their involvement in the CHC process may vary. They may work with the family as an advocate or as an active part of the CHC assessment process.

Dementia UK will also support Admiral Nurses to continually develop their knowledge and understanding of CHC so they can better support families, including helping to share knowledge among other healthcare professionals.

Dementia UK can also offer information via our current (and future) CHC-specific resources and advice to family carers directly through the Admiral Nurse Dementia Helpline on **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December, or by email at helpline@dementiauk.org or by booking a Closer to Home clinic appointment with an Admiral Nurse by visiting dementiauk.org/closer-to-home



Thanks and acknowledgements

“I did this interview in memory of Dad and for other families that still continue to go through this, and I hope that our experience, however bad and hard it was, helps make things better for the future.” (Family carer)

This research would not have been possible without the contribution made by the families affected by dementia and Admiral Nurses who participated in our interviews and focus groups. Thank you so much for your support and for sharing your time, experiences and insights.





If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

**Call 0800 888 6678 or email helpline@dementiauk.org
Open Monday-Friday, 9am-9pm
Saturday and Sunday, 9am-5pm**



dementiauk.org • info@dementiauk.org

Dementia UK, 7th Floor, One Aldgate, London EC3N 1RE
Dementia UK is a registered charity in England and Wales (1039404) and Scotland (SC047429.)