

# NHS Continuing Healthcare Guide for Dementia Carers

Coproduced by Birmingham City Council  
Dementia Citizen 'CHC working group'



## What is continuing healthcare?

Continuing Healthcare (CHC) is a package of care fully funded by the NHS for adults (18+) who have significant, ongoing health needs. To qualify, a person must be assessed as having a “primary health need,” meaning their main care requirements are health related rather than social care.

## Why do dementia carers often struggle with CHC process?

The CHC assessment process can be very challenging for families affected by dementia.

- Dementia symptoms vary and may present as health needs but be the responsibility of social care.
- Families are often under pressure, making it difficult to gather evidence and advocate strongly during assessments.
- Families are unaware of CHC or are unsure about the process; often feeling overwhelmed by all the information.

This booklet gives **general information only** and aims to help families affected by dementia understand what CHC is, how the process works and the key facts they need to know.

## How is eligibility decided?

- CHC is awarded based on the person’s **primary health needs**, not their diagnosis.
- NHS Integrated Care Boards are the final decision-makers, working with Adult Social Care where appropriate.
- CHC is not lifelong, funding is reviewed regularly, initially at 3 months, then annually thereafter. As individuals needs change over time, so may their eligibility. If there are significant changes then an eligibility review decision may be scheduled with Adult Social Care.
- Only a small number of people are found eligible. Around 20% of all applications were approved (January to March 2024).

## The CHC process

1. **Initial Checklist** – a trained professional completes a screening tool to see if a full assessment is needed. If the checklist is positive you progress to full assessment.
2. **Full Assessment** – a multi-disciplinary team (MDT) uses the “Decision Support Tool” (DST) to assess over 12 Care Domains (see Table 1) and 4 key characteristics (see Table 2). Complexity and Unpredictability are then used to identify whether a primary health need is present.

Table 1: 12 Care domains	
1.	<b>Breathing</b>
2.	<b>Nutrition – food and drink</b>
3.	<b>Continence</b>
4.	<b>Skin and tissue viability</b>
5.	<b>Mobility</b>
6.	<b>Communication</b>
7.	<b>Psychological &amp; emotional needs</b>
8.	<b>Cognition</b>
9.	<b>Behaviour</b>
10.	<b>Medication/drug/therapies</b>
11.	<b>Altered state of consciousness</b>
12.	<b>Other significant care needs</b>

3. **Final Decision** – The MDT recommendation goes to the ‘NHS Integrated Care Board’ (ICB) who make the final decision.

If the person with dementia is rapidly deteriorating or nearing end of life, there’s a fast-track pathway.

## Checklist scoring

The scores show the **level of need** in each domain: A (High) B (Moderate) and C (Low) need.

To move to a full assessment, the Checklist must show:

- 2 or more domains scored as A
- 5 or more domains scored as B
- or 1 domain scored A and 4 domains scored as B.

Table 2: 4 Key characteristics defined	
<b>Nature</b>	The type of needs such as physical, mental, psychological and their effect on daily life.
<b>Intensity</b>	The quantity, severity and continuity of needs.
<b>Complexity</b>	The skill needed to deal with one or more needs or several needs, and how they connect or affect each other.
<b>Unpredictability</b>	How much the needs vary and thereby create challenges in managing them.

The Checklist threshold is set **low** so people who might need CHC can get a full assessment. For information please click onto the **Checklist guidance**.

## Full assessment

The MDT looks at all the evidence, uses the DST to score the 12 Care Domains, and then considers how the needs fit together across the four key characteristics (shown in Table 2). The scoring in the DST is in more detailed, where an individual may score an A in the checklist, in the DST this may represent a moderate weighting.

The assessment process is complicated, and domain level scores alone do not determine eligibility. For more information please click onto **DST guidance**.

### An example of the level of need in the 'Nutrition' domain:

Level of need	Description
Low	<ul style="list-style-type: none"><li>• Need supervision, prompting with meals, or may need feeding and/or a special diet. <b>Or</b></li><li>• Able to take food and drink by mouth but requires additional /supplementary feeding.</li></ul>
Moderate	<ul style="list-style-type: none"><li>• Needs feeding to ensure enough intake and meals take <b>30+ minutes</b>. <b>Or</b></li><li>• Can't eat or drink by mouth, but all nutritional requirements are being fully maintained by artificial means (e.g., stable PEG).</li></ul>
High	<ul style="list-style-type: none"><li>• Problem swallowing requires skilled support to ensure adequate nutrition/hydration and minimize the risk of choking and clearing the airway, <b>Or</b></li><li>• Subcutaneous fluids that are managed by self or trained carers, <b>Or</b></li><li>• Nutritional status is <b>"at risk"</b> due to significant unintended weight loss, <b>Or</b></li><li>• Significant weight change from an eating disorder, <b>Or</b></li><li>• Problems relating to a feeding device that require skilled assessment and review.</li></ul>
Severe	<ul style="list-style-type: none"><li>• Cannot take any food/drink by mouth and needs artificial feeding that requires <b>24 hour professional monitoring</b> (e.g., IV fluids, TPN), <b>Or</b></li><li>• Cannot take food/drink by mouth and artificial feeding is <b>not appropriate or possible</b>.</li></ul>

**Source:** National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care - July 2022 (Revised) - corrected May 2023.

The **final decision** depends on the overall picture. This includes how the different needs link together and how they affect the person's safety, health, and daily life.

## Possible outcomes

The MDT will make one of **3 recommendations**:

- 1. Eligible for CHC.**
- 2. Eligible for NHS Funded Nursing Care.** This applies only if the person is in, or planning to move into, a nursing home.
- 3. Not Eligible for CHC.**
  - You can appeal or reapply if the persons' needs change.
  - If someone is found not eligible for CHC then sometimes Social Care and the ICB will hold a joint funding meeting to consider health contributions towards some of their care.

## Practical tips to help you prepare for the MDT meeting

- Understand the process – Beacon CHC offers free 90 minutes advice (see further support section).
- Keep daily notes on behaviour, risks, sleep, eating, mobility, confusion, and supervision. Highlight safety risks, unpredictability, and the level of supervision and support or type of care required. Bring written notes, you won't remember everything under stress.
- Ask health professionals to provide written reports that support the evidence (see useful evidence section).
- Attend all assessments; clearly explain the impact dementia has on their daily living. Describe the worst days, not just the average days. Describe what the risks would be if the person's current support was removed.

- Focus on **needs**, not diagnosis, when describing challenges.
- Ensure someone who knows the person well attends the meeting and can describe their day to day needs accurately. You can bring someone to support you too, such as a dementia adviser.
- Be aware not everyone in the room will know the person.** The MDT usually includes professionals who have never met the individual. Your input becomes even more important in helping them understand the full picture.
- The CHC process is complex, and some people choose to use private advocacy or consultancy services. Be cautious – while initial advice may be free, full advocacy support can cost anywhere from £3,000 to £4,000 or more.

## Useful evidence to support 'health needs'

- Health Needs Assessments
- Occupational Therapy assessment
- Speech and Language Therapy assessments
- Care Act 2014 Needs Assessment
- Physiotherapy reports
- Behaviour logs
- Care plans
- Incident reports
- GP letters, detailed 24/48-hour care diaries
- Specialist nurse reports
- Risk assessments
- and carer/family views.

## Carers told us

*"If I'd understood the 'level of need' this process looks for, I would have realized that what feels like a high need to me isn't always viewed that way. No one should have to go through a process that feels so upsetting it leaves them in tears."*

*"If this information had been available when I had to go through this process with my dad, it would have been much easier to understand the process and decisions made."*

*"A friend explained the CHC process to me after he had been through it with his father. Knowing what to expect, the various meetings and timescales made the whole thing much easier to deal with for me and my family."*

## Further support

1. **Beacon CHC** Free information and advice service.
2. **NHS Continuing Healthcare** Social care and support guide.
3. **Public Information Leaflet** NHS continuing healthcare and NHS-funded nursing care.
4. **Forwards Carers** For general, non-specialist CHC support is available to carers. We are Forward Carers and we care for carers across the country.
5. **Living Well** Wellbeing support for family? Free Mental Health Service for Birmingham & Solihull.

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