



DementiaUK

Helping families face dementia

Guiding the way:
a better continuing
healthcare system
for dementia

Executive summary



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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.



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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.



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

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