Beth Britton highlights the growing challenge of funding dementia care and speaks to Dementia UK for advice on NHS Continuing Healthcare funding

Who cannot fail to be shocked by the figures Alzheimer's Society have shared this Dementia Action Week showing the staggering cost of dementia care for UK families?

Amongst the headlines from the research for the Alzheimer's Society - that saw records analysed of 26,000 people dating back seven years - is that dementia costs £42 billion per year in the UK, and that figure is set to rise to £90 billion by 2040. The majority (63%) of this cost is being shouldered by people living with dementia and their families. As dementia progresses, total costs increase from £29,000 per year to £81,000.

How families are being impacted by the costs of dementia care

Paul Kemp (57), from Kent, whose wife, Sandy (55), lives with early-onset dementia, told the Alzheimer's Society:

"I've had to give up work to become a full-time carer for Sandy and my mother, and sell personal items to pay for care and buy essentials. I feel that no-one in government understands the financial pressures carers face, especially when trying to claim for benefits is like screaming into the wind – no one's listening."

Funding dementia care

When you need professional dementia care, either to fully support a person living with dementia or to provide supplementary care alongside a family carer, this is means tested. Care Choices have an excellent guide that looks at care funding which details the threshold for local authority support and what happens to people who have assets above the threshold and are therefore deemed 'self funders'.

However, another option known as NHS Continuing Healthcare (CHC) is something that should also be considered. CHC is a means of fully funding dementia care through the NHS for a person who is considered to have a 'primary health need'. This is different from the majority of people's needs which are classed as 'social care needs' and are therefore met through adult social care services (via your local authority).

To obtain CHC, a person needs to go through an assessment process, which has proven to be complex and extremely difficult for many people living with dementia and their families. This often results in individuals and families missing out on this funding, leaving many people in a desperate situation.

Dementia UK's 'Fix the Funding' campaign to urge the government to review CHC

In 2023, Dementia UK recognised the immense struggles many families were facing when trying to access CHC funding and launched their 'Fix the Funding' campaign to urge the government to review the CHC process which Dementia UK have described as 'flawed' and 'not recognising the unique and challenging needs' of people with dementia. They recently took their campaign to parliament to raise its profile and call for urgent action.

I spoke to Paul Edwards, Chief Nursing Officer at Dementia UK, to find out more:

"*NHS continuing healthcare can be a lifeline for many families living with dementia. However, the system is causing huge distress for families. Our 'Fix the funding' campaign calls on the government to urgently review how continuing healthcare is awarded to ensure a fairer and more consistent process recognises the long-term complex health needs faced by people living with dementia.*"

Advice if you are considering, or currently involved, in the CHC assessment process

I asked Paul what he would advise families who are looking to begin a CHC funding application or who are currently involved in the CHC system. Paul said:

"When applying for CHC funding, there are a number of steps you can take to ensure you are well prepared. These include:

- *Consider using an advocate who has specialist knowledge of dementia and CHC applications.*
- *Contact the coordinating assessor to confirm when the assessment is happening and what they require from you. If possible, it's best to attend in person.*
- *Tell the assessor which professionals are involved in the person's care so they can be consulted.*
- *Familiarise yourself with the DST forms and think of specific examples of the person's needs in each area. You can download these forms from the website of the local NHS body responsible for CHC funding.*
- *Gather as much evidence as possible about the person's needs – you could keep notes or even record short video clips of them. Ask family, friends and others involved in the person's care for their views too.*
- *Focus on describing the person's needs on a bad day – not a good or average day, or the day of the assessment.*
- *Be specific and give examples of changed behaviour.*
- *Ask for clarification if there is anything you don't understand.*

- *If something occurs to you after the assessment which you think you should have mentioned, follow up with the coordinating assessor."*

Dementia UK have more tips and guidance for navigating the CHC application and assessment process here.

If you have been impacted by the cost of dementia care, or struggled with the CHC process, you may wish to join Dementia UK's Fix the Funding campaign.

Further resources

- Alzheimer's Society – What is NHS Continuing Healthcare?
- Alzheimer's Society – Tips on preparing your case for NHS Continuing Healthcare
- Care to be Different – Free Guides
- Care to be Different – My dad has dementia so will he automatically qualify for CHC funding?
- Compass - Continuing Healthcare and Dementia

About Care Choices

Care Choices is a leading publisher of social care information in the UK. Via their free printed regional care directories and their website, they provide information and advice for care seekers in their time of need. www.carechoices.co.uk

About Beth Britton

Award-winning Content Creator; Author of D4Dementia; Consultant; Campaigner & Speaker; Trainer & Mentor. Specialist in Ageing, Health & Social Care.

Beth is a former carer to her father who had vascular dementia for 19 years. She is an expert content creator who won 'Best Independent Voice on Older People's Issues' and is the author of D4Dementia, one of the foremost dementia blogs in the world.

Beth's campaigning, including being a speaker and media spokesperson, centres around improving dementia care and support, the challenges in social care and issues facing family carers.