

People with dementia

Record numbers of people are being diagnosed with dementia in England.

[NHS England figures show](#) that in July 2024, nearly half a million people in England (490,163) had a diagnosis.

We want our regulatory work to influence and drive improvement in the provision of services, models of care and the quality of health and care services for people living with dementia.

To achieve this, we will be developing a cross-sector dementia strategy shaped by the central question, 'How can CQC use its role to improve the experience of using health and social care services for people living with dementia and their carers?'

The first phase of our project has involved speaking with a range of stakeholders, including people with lived experience of dementia and their carers.

Alongside analysis of the significant information and data we collect through our regulatory work, these discussions have directed our work and illustrated some of the challenges faced by people with dementia and their families and carers in navigating primary, secondary and social care, as well as what good care looks like.

Summary findings from our first phase of analysis

From our analysis of NHS Urgent and emergency care and Adult inpatient surveys, we found some key issues:

- hospital staff do not always understand the specific needs of people living with dementia, which can have an impact on the quality of their care and treatment, as well as their experience of care
- the busy hospital environment can be distressing for people with dementia, especially if they are waiting a long time to be treated
- family members and other unpaid carers play an essential role in supporting people with dementia to access services and to receive appropriate care and treatment, but their own needs often appear neglected, or they feel poorly communicated with
- it is especially important that care is joined up and discharge is safe when caring for people with dementia
- positive experiences can help to highlight what is important to people with dementia and their carers.

These findings are illustrated through the mixed experiences of some respondents to our NHS Adult inpatient survey:

“The people treating him didn't know how to communicate and shouted at him about causing distress. I intervened on several occasions. We were left for long periods of time with no explanations.”

“Mum was moved ward and became very disorientated. She was very confused and frightened. She volunteered to be moved but don't think her dementia was taken into account.”

“I was unable to leave her, even for the toilet, due to her wandering and ripping out her cannula. I didn't eat or drink anything for over 26 hours as I had to remain by her side. I had a stool (no proper chair) to prop on all night while she slept and was freezing cold.”

“He was also given his medication to take back to the care home. He has dementia and is not capable of knowing that he had the medication. This was particularly dangerous as he could have taken the tablets without knowing what he was doing.”

“[Person's name] was taken into a small back ward to be assessed and treated. Wow, well done everyone involved and thank you NHS for working hard to improve your services even when under such pressure. It made my time less stressful.”

Through our Give feedback on care service, we found similar themes about adult social care services and dementia care:

- the levels of staff, their ability and behaviours did not always meet the additional and complex needs of people living with dementia, especially when their condition deteriorates
- stimulation, interaction with others and familiarity with surroundings are important components of good dementia care, but these were sometimes lacking in people's care
- examples of high-quality, compassionate care for people living with dementia helped to highlight what good care can look like.

People described the impact of these experiences:

“Clients do not have regular hygiene needs met. My father sleeps in his clothes and the family do all of his basic needs. Staff have a poor understanding of dementia and how to meet needs.”

“Dad was left to his own devices in his room alone. No interaction. The staff either sat in the TV room on their phones, or in the dining room out of the way. In 2 and a half months I never saw any classes or therapy to help residents.”

“In hospital, Mother was under 24-hour observation, but with very little human interaction witnessed from the staff. Last week I visited Mother in the home and she was sitting fully dressed in the lounge quietly singing Christmas carols while one of the carers was giving her a head massage – who wouldn't thrive in an environment such as this?”

Adult social care providers used the provider information return to tell us about some of the challenges they were facing in supporting people with dementia, including:

- access to external services, such as GPs, mental health services and dental care, with assessments generally subject to long delays
- the recruitment and retention of staff with the appropriate skills and experience to provide consistent care for people living with dementia
- more people being admitted with a higher level of care need, or a more advanced stage of dementia.

Despite these challenges, care providers told us about the approaches they were taking to improve people's experiences, such as:

- adapting living environments to be more 'dementia friendly', therefore supporting people to lead more independent lives, improve accessibility, and reduce the risk of falls
- supporting people to eat and drink, as people living with dementia lose their appetite, and may have difficulty swallowing
- using a variety of inclusion approaches that cater specifically for the care of people living with dementia, including dementia-friendly activities, accessible communication and equipment
- acknowledging the combined impact of dementia and protected equality characteristics, such as disability, ethnicity and LGBT+ – although this was an area of limited awareness where we plan to do more work.

Acknowledging the combined impact of dementia and protected equality characteristics

A man kept leaving his care home. It became apparent that he was going outside to urinate. There were issues around him using the toilet and he was getting very distressed. Through [guided] life story work, the staff were able to see that this man believed that he was in 1940s/50s rural Punjab, where you went into the fields to go to the toilet. So, there was a conversation within the care home about how the staff could create a safe space for him, rather than making him use a toilet or stopping him from getting fresh air.

(Example from [commissioned research by RSM UK Consulting LLP.](#))

Sue was diagnosed with Alzheimer's Disease and moved to a residential care home. At the home, Sue started to refer to herself as Cliff. Sue would increasingly become distressed at her appearance and physicality. The care home managers had no contact with Sue's family or awareness of her medical history, so they were unaware she was a trans woman.

A worker at the care home asked a local charity for advice on how to remain sensitive to Sue's gender identity. A partnership was set up to support Sue's needs, which included care home staff, the GP service and local voluntary organisations. Awareness training on trans identities was also organised for care home staff.

As Sue's dementia progressed, staff were able to offer her appropriate support, knowing that their approach was tailored to her needs.

(Example from [National Care Forum, Dementia care and LGBT communities: A good practice paper](#))

We plan to share our findings in more detail in 2025, as part of a strategy over several years that aims to improve the outcomes for people with dementia and their families and carers.