

Study finds people with dementia and caregivers face stigma, barriers to care

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A study led by King's College London has found that people with dementia and their caregivers are frequently met with misunderstanding and social stigma by local community health care services, which is

creating a barrier for timely and adequate access to the support they need.

Researchers from the Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation at King's College London conducted a series of interviews with people with dementia and current and bereaved caregivers from across the UK. The paper, "[Exploring access to community care](#) and [emergency department](#) use among people with dementia: A qualitative interview study with people with dementia, and current and bereaved caregivers," is published in the *International Journal of Geriatric Psychiatry*.

A participant with dementia said, "I won't say it's insulting, but it is not given the seriousness that I think that the disease should have. It's only when you're the older gentleman or older lady walking down the middle of the road in your pajamas not knowing where you're living that 'argh, argh bless, poor thing, they don't know they have Alzheimer's," or 'they don't know they have some sort of dementia.'"

A bereaved caregiver said, "Mum had a right for her voice to be heard and it wasn't and she was ignored, totally. And my concerns on exactly the same issue were dismissed. Yeah. I mean, very nicely, they weren't rude when they said, but from their point of view, they had no choice."

Researchers found there is a clash between the changing needs of individuals affected by dementia and a health and social care system that does not respond to dementia as a life-limiting condition, with three themes emerging from the study:

- Once diagnosed, people with dementia and their families had little guidance when accessing care services, and often had to push to have their needs met, while those with greater resources

were better able to gain support than others.

- Many people with dementia and caregivers found that dementia was not taken seriously and not seen as a life-limiting condition, due to [social stigma](#) that focuses on the neuropsychiatric symptoms of dementia.
- Emergency department visits were seen as a last resort, as these environments were often confusing and anxiety-inducing for patients waiting for treatment. However, due to [poor access](#) to clinical expertise in the community, the emergency department frequently became the path of least resistance to accessing care.

Professor Katherine Sleeman, Laing Galazka Chair in Palliative Care at the Cicely Saunders Institute in King's Faculty of Nursing, Midwifery & Palliative Care, added, "Like any life-limiting condition, dementia is worthy of dedicated care. Yet the quality of end-of-life care available and accessible to people with dementia varies across regions, ethnicities and levels of deprivation. As the leading cause of death in the UK today, we must ensure efforts focus on better supporting the near-million people living with dementia and the 700,000 family members caring for them."

Previous research has shown that more than 75% of people with dementia had at least one unplanned hospital admission after their diagnosis, and that eight out of ten patients diagnosed with [dementia](#) had at least one hospital visit in the last year of their lives, with a quarter of all attendances in the last year of life happening in the final month before death.

More information: Lesley E. Williamson et al, Exploring access to community care and emergency department use among people with dementia: A qualitative interview study with people with dementia, and

current and bereaved caregivers, *International Journal of Geriatric Psychiatry* (2023). [DOI: 10.1002/gps.5966](https://doi.org/10.1002/gps.5966)

Provided by King's College London

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