

# Research highlights need for better support for thousands of informal dementia carers

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Directly involving the thousands of family members and friends who serve as 'informal carers' for people with dementia in the evaluation of patients' symptoms and behaviour could offer improved insights for healthcare professionals and help alleviate feelings of stress, guilt and isolation felt by many who fulfil these duties, a new study has found.

The findings highlight a need for more structured educational programmes covering broader knowledge around the disease for informal carers, who often have no formal training or support networks to depend on. Information on disease progression, guidelines on dealing with challenging behaviours and financial and legal advice could better prepare carers about what to expect. It is hoped that the findings from researchers from the University of Lincoln, UK, will lead to national improvements in [dementia](#) care with a goal to create a better educational package for carers.

The research, conducted by an inter-disciplinary team of experts, collated insights from carers and [health care](#) professionals and identified key themes which capture the main challenges faced by carers, as well as the type of support they want from [health care services](#).

Dementia - which includes conditions such as Alzheimer's - is a progressive [degenerative neurological disease](#) with no known cure. Currently, there are approximately 800,000 UK dementia patients, cared for by around 670,000 'informal caregivers'. It is estimated that by 2050 there will be more than 100 million people suffering from the disease

world-wide.

Previous research found that informal caregivers of people with dementia often display increased levels of depression and stress as well as poor self-rated [health](#). Research also identified increased feelings of entrapment and guilt leading to further depression and a lack of self-belief in the quality of the care that they can offer.

New findings show that existing health and social care services are often fragmented which can make communication between [healthcare professionals](#) and care providers difficult. Healthcare professionals also stated that while they have a theoretical knowledge of the disease, they felt they often lack knowledge of how it is to live with dementia which can make it difficult to know how best to support caregivers.

Despina Laparidou, a researcher in the University of Lincoln's School of Health and Social Care who led the study, said: "The care being given by informal carers frequently goes beyond simply caring for a patient's health and becomes a crisis management role which can exacerbate feelings of stress and burden."

Professor Niroshan Siriwardena, Professor of Primary & Pre-Hospital Health Care at the University of Lincoln, said: "Our study has recognised a need for better information and education not only for carers but for healthcare professionals to create a better and more empathetic understanding of the physical and behavioural deterioration of the disease as well as surrounding issues like financial pressures and modifying the home environment to compensate for patients' every day difficulties."

Professor Terence Karran, a co-author on the study based in Lincoln's School of Education, added: "Our research has also shown that caregivers have an important role to play in the monitoring of patient

behaviour and behavioural triggers. It was felt that keeping a daily diary of symptoms and behaviour could help to empower caregivers as well as improving communications with healthcare professionals."

**More information:** Despina Laparidou et al, Caregivers' interactions with health care services – Mediator of stress or added strain? Experiences and perceptions of informal caregivers of people with dementia – A qualitative study, *Dementia* (2018). [DOI: 10.1177/1471301217751226](https://doi.org/10.1177/1471301217751226)

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