

'Rare positive result' in trial of new support intervention for people with dementia and their family caregivers

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Research led by Claudia Cooper, Professor of Psychological Medicine at Queen Mary University of London, shows that a new therapy, NIDUS-

Family, helps people with dementia and their family caregivers attain their personal goals.

The NIDUS-family package of care and support focuses on practical changes people can make, with sessions designed around the specific priorities of the person with [dementia](#). It can be delivered to the person with dementia and family caregiver together, or the family caregiver alone, by phone, video call or in person.

In the NIDUS-family trial involving 302 pairs of [family caregivers](#) and people with dementia published in *The Lancet Healthy Longevity*, participants were supported to set their own goals. These might be enabling the person with dementia to carry out more activities, experience better mood, sleep, appetite, relationships or social engagement, or to improve caregiver support and well-being.

Those receiving the new support package met with a therapist six to eight times in six months, then received two to four further support phone calls over the next six months. The support provided was tailored to the goals they set.

The trial results show that family caregivers and the people they supported with dementia who received the NIDUS-family intervention were significantly more likely to achieve the goals they set than those who received their usual care over a year. This was true whether the intervention was delivered by video call, phone or in person.

The intervention was delivered by non-clinical facilitators, who were provided with supervision and training. Only 9.3% of intervention arm versus 13.3% of control arm had moved to a care home or had died after one year. The researchers will be following up trial participants for a further year to see whether the new support helps people with dementia stay in their own homes longer.

The [new therapy](#) has the potential to be rolled out to support consistent, evidence-based personalized dementia care across the NHS. The findings coincide with a call from the All-Party Parliamentary Group (APPG) inquiry on dementia for a leveling-up of diagnosis rates and the care people receive after a diagnosis, recommending that high-quality post-diagnostic support services for dementia must be available more equitably across England.

Alzheimer's Society Associate Director of Research and Innovation, Dr. Richard Oakley, said, "Currently 900,000 people live with dementia in the UK and for many personalized post-diagnostic support is often lacking, leaving them feeling isolated and vulnerable. [...]NIDUS-Family has shown it can help people living with dementia achieve their goals aimed at living independently for longer. It is the first post-diagnostic support program which can be delivered remotely and without clinical training, acting as a lifeline to thousands of caregivers across the UK.

"We're delighted that the researchers have secured further funding to take these findings to the next level and make the program more inclusive and accessible. This will help to deliver the universal care and support people living with dementia desperately need."

Lead author Professor Claudia Cooper said, "Because NIDUS-family can be delivered by people without [clinical training](#), it has the potential to enable many more people to access good quality post-diagnostic support. NIDUS-Family is the first readily scalable intervention for people with dementia that is proven to improve attainment on personalized goals, and can be remotely delivered, and it should be implemented in health and care services."

A family caregiver who took part in NIDUS described how it helped the family: "There was lots of little things that we would never have thought about but I think the main thing was the understanding of how my mum's

mood affected her and how she was and her behavior. So for us to get to the bottom of that and understand that a bit more, we could deal with the whole situation in a different way."

Around 885,000 people in the United Kingdom have dementia. Although national guidelines recommend that everyone with dementia receives personalized, post-diagnostic support, few do. Nearly two-thirds (61%) of those aged over 65 with dementia in the UK live in their own homes, rather than in care homes. However, unmet needs, poor self-care, home safety risks and burden reported by family caregivers are common reasons necessitating a move to a care home.

The Wolfson Institute of Population Health has a large and growing portfolio of dementia research. It hosts one of two NIHR Policy Research Units for Dementia and Neurodegenerative disease.

More information: A new psychosocial goal-setting and manualised support intervention for Independence in Dementia (NIDUS-Family) versus goal-setting and routine care: a single-masked, phase 3, superiority Randomised Controlled Trial., *The Lancet Healthy Longevity* (2024). [DOI: 10.1016/S2666-7568\(23\)00262-3](https://doi.org/10.1016/S2666-7568(23)00262-3)

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