

Research highlights what helps people live well with dementia

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New research has identified the factors that enable people with dementia and their carers to live as well as possible.



Led by the University of Exeter, the research seeks to inform <u>support</u> <u>services</u> and guide policy on where resources should be spent to support the 50 million people worldwide that have been diagnosed with a dementia to optimise their ability to "live well".

Now, a large-scale study has produced two new papers published in *Alzheimer Disease & Associated Disorders*. A wide range of factors were found to play a role in living well. The team found that psychological aspects, such as optimism, self-esteem and whether they encountered loneliness and depression was closely linked to the ability to optimise quality of life and wellbeing in both people with dementia and carers. Experience in other areas of life influences psychological well-being and perceptions of living well. Physical health and fitness was important for both groups. For both carers and people with dementia social activity and interaction also ranked highly.

For people with dementia, their social situation and their ability to manage everyday life were important factors.

Carers rated their caregiving experience, and whether they felt trapped or isolated, as a key indicator in whether they could live well.

The research was conducted in the Improving the experience of Dementia and Enhancing Active Life (IDEAL) cohort. Funded by the National Institute for Health Research and the Economic and Social Research Council. The study comprised 1,547 people diagnosed with mild to moderate dementia and 1283 carers. Both groups of participants provided ratings of their quality of life, satisfaction with life and wellbeing, in relation to dementia and to overall health.

The research team combined the findings into one overall "living well" score for people with dementia, and one for carers.



Lead author Professor Linda Clare, of the University of Exeter, who also leads the IDEAL study, said: "It's so important to find ways for the 50 million people worldwide who have dementia to live as well as possible. Our research sheds new light on what factors play a key role in maximising factors such as wellbeing and quality of life. This must now translate into better ways to support people with dementia."

Co author Dr. Anthony Martyr, of the University of Exeter, said: "Our research gives more specific guidance on where we should focus efforts to help people live as well as possible with dementia. For example, looking at how we can help people with dementia to avoid depression or stay physically and socially active. For carers it could involve strengthening community ties and building strong networks. We now need to develop and research programmes to establish what really works in these areas."

Dr. James Pickett, Head of Research at Alzheimer's Society, said: "People with dementia have the right to live well—however without clear definition it can be hard to determine what 'living well' really means. After looking at several factors, the IDEAL programme has found that psychological health has the biggest impact on people affected by dementia living well. Too many people face dementia alone without adequate support, and interventions that improve self-esteem, challenge negative perceptions towards ageing and reduce depression or loneliness could all help improve the psychological health of people affected. Research will beat dementia and while we strive to find a cure, we also need to improve life for the 850,000 people with dementia in the UK today. Alzheimer's Society is proud to be supporting this study and looking further into these interventions—as well funding over £12m of other research to improve dementia care."

The careers paper is entitled 'A Comprehensive Model of Factors Associated With Capability to "Live Well" for Family Caregivers of



People Living With Mild-to-Moderate Dementia'.

Provided by University of Exeter

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