

Changes in awareness of condition in people with mild-to-moderate dementia: longitudinal findings from the IDEAL cohort

Do people with dementia notice more difficulties over time?

People who have dementia generally have some day-to-day difficulties. Some people notice their difficulties more than others. We wanted to see whether noticing or being aware of these difficulties changes over time.

We used information from the IDEAL programme for 917 people diagnosed with dementia. Using a checklist, we asked whether they had noticed any problems in different areas. This included difficulties in remembering, thinking, making decisions and managing everyday tasks.

At the beginning of the study, most people said yes, they had noticed some problems from the checklist. But 83 people said no, they had not noticed any of the problems.

We followed up these 83 people. Although some dropped out, some stayed in the study for another two years. They answered the checklist questions again at one year and two years later. By then, most people said they had noticed some difficulties. Only five people continued to say they hadn't noticed any of the problems on the checklist.

We looked to see if these five people were different from the rest in other ways. It was hard to find reasons to explain the difference. These five people may have had more medical problems as well as dementia. The other problems might have troubled them more than the dementia symptoms.

The people who said they noticed difficulties were encountering more problems with remembering, thinking and managing everyday tasks by the end of the study. This may have made them more aware of their difficulties.

We were interested to see that over time more people said they noticed dementia-related difficulties. Researchers and medical staff often assume that people with dementia become less aware as time passes. However, in the early stages of dementia, it may take a while for people to fully understand and accept the changes in their lives.



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There are likely to be different personal reasons for this. It is important to recognize that people may need different types of support as they become more aware of difficulties with dementia.

This is a summary of a [research article](#) which appeared in the **International Journal of Geriatric Psychiatry** in March 2022.