Trajectories of cognitive and perceived functional decline in people with dementia. Findings from the IDEAL programme

What changes do people with dementia notice in their ability to do everyday tasks over time?
Do carers notice the same changes?

Dementia makes it harder for people to remember. Dementia also makes it harder for people to do everyday tasks like shopping, cleaning, and dressing.

We asked 1537 people with dementia to tell us how well they could do these kinds of tasks. We also asked them to do a memory test. We asked 1266 family carers to rate how well they thought the person with dementia was able to do these everyday tasks. We collected this same information three times over two years.

We found that people with the most memory problems said that they had the most problems with everyday tasks. Family carers also said this.

As time went on, we found that memory problems grew. We also found that problems with everyday tasks increased.

Ratings from people with dementia suggest that problems in everyday tasks increased as memory problems increased. On the other hand, ratings from family carers suggest that problems in everyday tasks increased much more than problems with memory.

This tells us that people with dementia have a good idea of the problems they experience with everyday tasks. They were good at recognising that changes in their ability to do these tasks was linked to how their memory changes.

This also tells us that family carers think problems with everyday tasks increase more quickly than problems with memory. This might be because other things, like stress for example, affect how carers rate ability in everyday tasks.

It is important to listen to the opinions of both the person with dementia and the carer. People with dementia can tell health and social care professionals how things are going to get the right support. Carers who identify a lot of difficulties could be offered further support to help them cope.
This is a summary of a research article which was published in the Alzheimer's & Dementia journal in September 2023.