Does awareness of condition help people with mild-to-moderate dementia to live well? Findings from the IDEAL programme

Some people who have dementia are more aware of their diagnosis and the difficulties of having dementia than others. We wanted to see whether being more aware of dementia was helpful in being able to ‘live well’. By living well we mean how people rate their quality of life, well-being and satisfaction with life.

We used information from the IDEAL programme to look at answers from 917 people with dementia. We looked at how they saw their condition and what they said of their diagnosis. Most people had some awareness of their condition. Just over 10% of these were very aware about their diagnosis. But nearly 1 in 10 showed little awareness of their condition. These people did not appear to recognize any difficulties.

We compared people’s awareness about dementia with their mood and living well scores. People with less awareness of their difficulties had better mood. They reported better quality of life, well-being and satisfaction with life. They were more likely to be over 80 years old and from poorer areas of Britain. The people who were most aware of their diagnosis had lower scores on living well. This group reported more depressed mood. They tended to be under 80 years old.

We also looked at answers from 755 carers. We asked the carers how stressed they felt. Carers of people with high awareness and the carers of people with low awareness had similar levels of stress. Awareness did not make any difference to how stressed the carers felt.

The results highlight a challenge for health-care workers such as GPs and memory nurses. How should they offer information and support about dementia to people who have little awareness of their condition? Will talking about dementia and giving a diagnosis make people feel worse about their situation? For people who are aware of their diagnosis, how can we support them to live well through change? We need to consider each person’s level of awareness when talking about dementia and supporting people. This could help us meet people where they are and provide more personalized care.

This is a summary of a research article which appeared in the BMC Geriatrics journal in September 2021.