

How do people living with dementia in the IDEAL cohort make sense of the condition?

People living with a long-term illness find their own ways of making sense of the condition. These common sense ways of understanding the illness are called 'illness representations'. The type of 'illness representation' people develop can affect how they feel about their situation and how they cope with it. An 'illness representation' can be helpful or unhelpful.

This way of thinking about living with an illness could help us understand how to support people living with dementia.

We decided to explore how people living with dementia make sense of the condition. We wanted to find out what types of 'dementia representations' they develop. We also wanted to know whether people with certain types of 'dementia representations' have better well-being than people with other types.

There are lots of things that could influence the type of 'dementia representation' a person develops. These include what the person is told about the condition, the specific symptoms the person has, and whether the person feels stigmatised. The way in which people in wider society view and talk about dementia could be important too.

In an earlier study we talked to 64 people living with dementia about how they made sense of the condition. We developed a questionnaire based on what they told us.

In this study, we asked 1,109 people living with mild-to-moderate dementia in the IDEAL cohort to complete the questionnaire and tell us about their experiences. We found there were 5 groups with different 'dementia representations':

People who saw their difficulties as a disease and called it by a medical name, such as Alzheimer's or dementia (13%).

People who saw their difficulties as a disease but did not use a medical name for it (45%).

People who thought of their difficulties as part of normal ageing (11%).

People who were unsure how to make sense of their difficulties (24%).

People who thought they did not have any difficulties (7%).

Most people had a 'dementia representation' that was quite different to the

way a medical doctor would understand the condition.

People who saw their difficulties as a disease and used a medical name for it tended to be younger and to do better on tests of memory and thinking ability than people in the other groups.

People who saw their difficulties as part of ageing, were unsure, or thought they did not have any difficulties scored higher for well-being, quality of life and satisfaction with life. They tended to have more positive attitudes to getting older. They were less likely to have low mood or depression.

This raises some important questions. For example, what kind of 'dementia representation' is most helpful? Can some types of 'dementia representation' be harmful? And what can enable people to develop a helpful 'dementia representation'?

It also gives some useful pointers for better ways of supporting people with dementia. If we know about a person's 'dementia representation', we can offer information and support in a way that is more personally relevant. This could help to improve the quality of care and support.

This is a summary of a [research article](#) which appeared in the **Psychology & Aging** journal in December 2021.