**Lay summary: Carers’ beliefs about dementia**

When people develop dementia it is often family members or friends (here referred to as ‘carers’) who first notice changes in the person. Carers will develop their own beliefs about what the condition is, what causes it, what will happen over time, and what can be done about it. In this study we wanted to explore how carers understand the changes in the person with dementia.

For this study we used information collected from the IDEAL study. The IDEAL study follows a group of people with dementia and their carers over time, looking at what helps people to ‘live well’ with dementia. We used the information provided by 1264 carers who had taken part in the IDEAL study.

Carers completed questionnaires on well-being, satisfaction with life, and care-related stress. They also completed questions on:

* What they called the person’s condition
* Whether they knew the diagnosis
* What they thought caused the person’s condition
* Whether they thought there was anything the person could do to control the effects of the condition
* How they thought the condition would progress over time

We found that just under half of carers used a diagnostic term to refer to the person’s condition, e.g. dementia or Alzheimer’s. Others used descriptive terms, e.g. memory loss. Most carers were aware of the person’s diagnosis. Most carers felt that the person’s condition was due to ‘changes in the brain’ or ‘illness disease’. Half the carers thought there was something that the person could do to control the effects of the condition. Most carers felt the person’s condition would get worse over time.

We looked at how carers’ beliefs related to their well-being, satisfaction with life and care-related stress. Carers who used a descriptive term to refer to the person’s condition, thought the cause was due to ageing or didn’t know the cause, or believed that the condition would ‘stay the same’ had higher well-being, satisfaction with life, and lower care-related stress. Those who thought there was little the person could do to control the effects of the condition had lower well-being, satisfaction with life, and higher care-related stress.

The findings show that it is important for healthcare professionals to ask carers about their understanding of the condition. This would help healthcare professionals to tailor how they talk to carers about the condition and to offer effective support.