

## Longitudinal predictors of informant-rated involvement of people with dementia in everyday decision-making

## Do people with dementia get to make decisions about their daily life?

We all make many decisions every day. We decide what to eat, what to wear, where to go and how to spend our time. These decisions are based on our personal preferences.

We work with people with mild-to-moderate dementia who live at home. Often they want to make their own decisions. Sometimes, other people may make decisions for them. We wanted to find out which decisions people with dementia make and how these change over time.

We asked family members who support people living with dementia about decision-making. We call these family members 'carers'. We asked them the same questions again one year and two years later to see what changed over time.

Carers told us about the kinds of decisions people with dementia make, and the kinds of decisions that they make for the person with dementia. Carers also told us:

- how much help they give the person with dementia
- how stressed they feel
- how well they get along with the person with dementia.

People with dementia told us how well they get along with their carer.

Carers told us that people with dementia make lots of everyday decisions. People with dementia are very involved in some decisions like when to get up and what to eat. They are less involved in other decisions like where to go and when to visit friends.

Our results showed certain patterns:

- Women with dementia are more involved in making everyday decisions than men with dementia
- Carers who are husbands and wives of people with dementia make more decisions for them than carers who are daughters, sons or other relatives
- Carers make more decisions as the person's dementia progresses
- Carers who do not get along well with the person with dementia make more decisions





• Carers who are more stressed make more decisions for people with dementia.

Overall, carers are doing well at involving people with dementia in decisions. Some carers may need support to be able to keep the person involved in making decisions. Carers who feel stressed or feel they do not get along with the person with dementia may need more general support.

This is a summary of a <u>research article</u> which appeared in the **Journal of Applied Gerontology** in October 2022.

