

'Living well' trajectories among family caregivers of people with mild-tomoderate dementia in the IDEAL cohort

Are carers of people with dementia 'living well' over time, and if not, why not?

Family members provide most of the care and support for people living with mild-to-moderate dementia. They are often called 'carers'. Supporting a family member with dementia has many positive aspects, but it can also be very demanding. Some carers find it easier than others to cope with this.

It is important for people with dementia to be able to 'live well' with the condition. It is just as important that carers are able to 'live well' too. 'Living well' means experiencing a sense of well-being, feeling satisfied with life, and having a good quality of life.

We wanted to find out whether carers feel they are 'living well' and whether this changes over time. If it changes, we wanted to know why.

Carers of people with dementia in the IDEAL study told us about their experiences of 'living well'. We asked them when they joined the study and again one year and two years later.

The average scores for all the carers changed very little over time. Average scores can hide differences between individuals. Some people did change their ratings, so we looked to see whether we could find any patterns in these changes.

We found that carers fell into three groups. Two-thirds of the carers started off with higher scores for 'living well' that got only slightly worse over time. A quarter of the carers started off with lower scores that stayed low over time. A smaller group, about seven in every hundred, started off with higher scores that got worse over time. This seemed to be because the person with dementia developed more difficulties and needed more support.

All carers may need support to 'live well'. Carers need extra support if they are not 'living well' or if they become less able to 'live well' over time.

This is a summary of a <u>research article</u> which appeared in **The Journals of Gerontology: Series B** in July 2022.

