Does quality of life change over time for people living with mild-to-moderate dementia?

We wanted to find out whether people with mild-to-moderate dementia change how they view their quality of life as time goes on. If so, we wanted to know why.

Over 1500 people living with dementia rated their quality of life when they joined the IDEAL study. They rated it again one year and two years later. We used statistical models to find out whether the ratings changed over time. The ratings stayed the same for the group as a whole.

The average scores stayed the same, but some people did change their ratings. We looked to see whether we could find any patterns in these changes.

We found that people fell into four groups. Each group had a different pattern.

Two groups started off with higher quality of life ratings. The biggest group, three-quarters of all the participants, had ratings that stayed the same. A smaller group, about one in twelve, felt that their quality of life declined over time. They were more likely to feel lonely or depressed, and to struggle with everyday activities.

Two groups started off with lower quality of life ratings. The larger group, which included one in eight participants, faced challenges such as social isolation and ill-health as well as loneliness and depression. Their ratings stayed low over time. A smaller group, just one out of every 25 participants, felt their quality of life improved over time; they started off with lower scores on tests of memory and thinking ability.

Understanding these patterns can help with personal care planning.

We can help people maintain a good quality of life by supporting their psychological well-being and ability to manage everyday activities. For those who start off with low quality of life ratings, we also need to tackle social isolation and poor physical health.

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