Impact of COVID-19 on carers of people with dementia in the community: Findings from the IDEAL cohort

What has the COVID-19 pandemic been like for carers?

Carers are family members, friends, or other supporters who provide help and support to people with dementia. The COVID-19 pandemic has been a difficult time for carers. They may have had to provide more care to the person with dementia. They may have found it difficult to access services. We wanted to better understand the experiences of carers during the pandemic.

For this study we collected information from carers taking part in the IDEAL study. The IDEAL study follows a group of people with dementia and their carers over time. The study looks at what helps people to ‘live well’ with dementia. We collected information from 242 carers between 21st September 2020 and 30th April 2021. We compared this information with information we had already collected before the pandemic.

We found that just under half of carers felt the pandemic had affected their healthcare needs for the worse. They talked about cancelled or postponed healthcare appointments. Some carers struggled to get face-to-face appointments. Most carers talked about how they coped well during the pandemic. Compared with the situation before the pandemic, we found that some things were better:

- Carers had more contact with relatives.
- Carers were more likely to identify someone to help them with caring.
- Carers felt more optimistic.

Carers found some things more difficult:

- Carers felt more lonely.
- Carers felt less satisfied with their lives.
- Carers felt more trapped by their caring role.

Overall, the carers in this study seemed to be coping well. These findings may just reflect how they have currently adapted to the situation. In the longer-term they may find it more difficult to cope. Carers need support to maintain their well-being and reduce feelings of loneliness. Services need to
consider how to improve access to health care. This includes resuming face-to-face appointments.

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