

Effects of social restrictions on people with dementia and carers during the pre-vaccine phase of the COVID-19 pandemic: experiences of IDEAL cohort participants

How did the pandemic affect people with dementia and carers?

We knew COVID-19 rules caused problems for some people with dementia early in the pandemic. We wanted to find out how people with dementia and carers were coping just before vaccinations became available. We wanted to know if the news of the vaccines had helped.

We spoke with 11 people with dementia and 12 carers. They were already taking part in the IDEAL study. We asked about their feelings and views during November and December 2020.

People with dementia were worried that their dementia symptoms had got worse. Some worried their symptoms had made it more difficult to meet people. They tried to stay positive by keeping their minds active. It was also important to stay in touch with friends and family. The news of the vaccines did not change things for them.

Carers also worried about the changes in the person with dementia. People with dementia needed more care. Some carers thought this could affect their relationship.

Both people with dementia and carers felt let down and forgotten. Without outside help, many did what they thought was useful.

People with dementia and carers liked it when they were contacted from charities or groups they knew. They liked face-to-face medical appointments more than video or phone. This was because they felt they could explain their issues more easily. They also wanted ideas how to stay busy and help to return to social activities.

This study shows the importance of social contact. People with dementia and carers need to feel cared for and part of society. Services and groups should try to remain in contact with people during future pandemics. This may help to reduce feelings of neglect. More choice for face-to-face appointments would allow people with dementia to get the right treatment.

This is a summary of a [research article](#) published in the **Health and Social Care in the Community** journal in June 2022.