

Living with dementia under COVID-19 restrictions: coping and support needs among people with dementia and carers from the IDEAL cohort

How did the COVID-19 rules affect people with dementia and carers?

The lockdown rules at the start of the pandemic were very strict. People were not able to see each other. Face-to-face meetings stopped and groups were closed. We wanted to find out what difference this made to the lives of people affected by dementia.

We spoke at length to 11 people with dementia and 11 carers during the first lockdown in early 2020. All of these people were already part of the IDEAL research programme. They were all living at home.

We found that some people with dementia thought they were doing reasonably well, but others struggled to cope. Some felt their usual activities had got harder. Many people found it difficult to keep track of the official information. Confusion about COVID-19 rules meant people were frightened about leaving the house.

For carers, keeping their loved one safe was stressful. Some were worried that the person with dementia was more at risk of getting the virus, because keeping to the distancing and hygiene rules was hard. The lack of organised activities for people with dementia meant that carers had less time to themselves. Some felt they did not know where to go for information about managing their own health during lockdown or keeping the person with dementia well.

Feeling safe when going outside was important to many people. Keeping in touch helped people feel less alone. Some people received calls from dementia groups to check how they were and found this comforting.

During the pandemic, the type of support people needed was not available. People with dementia and carers managed as best as they could, but some struggled. We need to find those who are struggling most and find out what they need. We can then try to give them help that fits their personal situation.



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