

Navigating the coronavirus pandemic two years on: Experiences of people with dementia from the British IDEAL cohort

How have people with dementia coped with the COVID-19 restrictions over time?

Early in the pandemic, people with dementia faced unique challenges. The COVID-19 rules stopped people doing their usual activities. These activities normally gave people with dementia a sense of purpose and helped them to live independently. Having less contact with people caused problems with getting the right health support, worsened mood, and made people worried about their dementia getting worse.

We wanted to know if the problems people experienced early in the pandemic would be the same two years later. We wanted to know how people with dementia were coping. The new rules allowed everyone to go out more. However, many services had not returned to normal. There was a new wave of infections from the 'Omicron' variant.

We re-interviewed nine people we had spoken to earlier in the pandemic. We wanted to understand what life was like for them and how they were doing at this point.

Five people had young-onset dementia and were aged between 51 and 68 years old. The other four people living with dementia were aged between 71 and 89. There were similar numbers of people living alone and living with a spouse or partner.

We found three common themes across the interviews:

1. Navigating a changing world
2. A downward spiral
3. Access to support

The first theme was 'navigating a changing world'. People were not comfortable with mixing because they felt unsafe. However, people also wanted to live fuller lives again. They did this by 'navigating' the situation and still taking precautions like wearing masks or restricting face-to-face contact.

A second theme was 'a downward spiral'. In earlier interviews, people had concerns about their dementia getting worse. Now, people noticed changes in their skills, and were less confident. Although this made it more difficult to do

some things, people did what they could to practise their skills.

The third theme was about 'access to support'. Some people felt they could get the support they needed and others did not. Being in contact with family or friends, or having good neighbours, made things easier.

Many health and social services remained closed or were only available online. Some people struggled to get appointments. Although some had received medical help by phone or by using the internet, not everyone found this useful.

People with dementia continued to struggle even after social restrictions had eased. It is important to understand who may be in most need of help. Support groups and health services need to be available in ways that allow more people to access them.

This is a summary of a [research article](#), which was published in the **Dementia** journal in February 2023.