

Living with dementia during the COVID-19 pandemic: insights into identity from the IDEAL cohort

What was the COVID-19 pandemic like for people living with dementia?

We wanted to talk to people later into the pandemic (January-May 2021) after the vaccinations had started. We interviewed seven people living with mild-to-moderate dementia to ask about their experiences. Everyone we talked to was living in their own home. Three people lived on their own. Most people were living in England and one person was living in Wales.

Most people said they had accepted the restrictions like 'stay at home'. They had just 'got on with it'. Anyone who had been 'shielding' because of health problems had found things more difficult. The people we spoke to had also had the vaccine. The vaccine was just seen as something you had to get done.

What people found difficult was worrying if their dementia had got worse. Some people felt they had lost a year of their lives. This also meant that people had lost confidence in going out again. They were now trying to make themselves do more.

People had missed having things to do but had tried to keep a routine. The people we spoke to did things like walking every day or helping others by talking to them online. This had given them a sense of purpose. Not being able to do the things they enjoyed had made people feel differently about themselves. One person who could not volunteer anymore felt she had lost that part of herself. Doing things is important for our sense of who we are.

There were also a few people we spoke to who had young onset dementia. They very much missed their dementia support groups. People with young onset dementia missed having someone to talk to who they felt was like them. Talking to someone who understood what it was like to be younger and have dementia was important. We also noticed that some people were happy for people to know they had dementia. A few spoke up for people with dementia and helped run dementia support groups.

When we were in 'lockdown', people we spoke to also missed their family and friends. A few people had had help with things like food shopping from neighbours and people in their community. Some people had got used to calls

with family and friends on Zoom or Facebook instead. They still missed seeing people in person. They would like to have used things like Zoom to talk to people like their doctor but did not get the choice. Other people felt that no one had checked in on them except for charities like Alzheimer's Society. This meant they had felt forgotten about. They had also wanted to know when things like their dementia groups would be starting again.

A few people suggested they had not had much support after they were diagnosed. Problems with getting support looked like these were from before the pandemic.

Services need to think about how people living with dementia can get more help. This is particularly important as the pandemic has continued, even though services are under pressure. People may need help to get their self-confidence back or support so they do not feel on their own.

This is a summary of a [research article](#) which was published in the journal **Ageing & Society** in January 2023.