



‘Pushing back’: People newly diagnosed with dementia and their experiences of the Covid-19 pandemic restrictions in England

Why did we carry out the research?

There was a feeling that people with dementia would face a lot of challenges during the pandemic and that this would badly affect their well-being and life quality.

How did we carry out the research?

We spoke at length with 21 people who had been diagnosed with dementia during the previous year and who were participating in our DETERMIND and DETERMIND-C19 studies.

What did we find out?

Some people with dementia certainly did face difficulties when trying to live well with dementia during the pandemic. People spoke of losing some of the social contacts they had previously enjoyed as part of their daily routines and this sometimes left them feeling lonely. They also found it difficult to access some services during this period, either because they had closed or because they used dementia-unfriendly practices. This was particularly the case with health and social care services that decided to carry out many appointments over the telephone or online, which our participants found difficult to use.

BUT it was definitely not all doom and gloom! Some participants took the opportunity to develop new skills and hobbies such as carrying out home improvements or learning how to use online communication platforms so they could speak with their family and friends. Others took on advocacy roles to challenge dementia-unfriendly practices and provide support and solidarity to other people living with dementia. People also changed some of their daily routines to ensure they could still get out and about into their local neighborhoods but at times when it might be less busy such as early morning. This provided them a great form of exercise and a way to clear their heads without the risk of bumping into lots of people and so increasing their chances of catching COVID-19.

What are we going to do with these findings?

Our findings show us that people with dementia are often very adaptable and capable of doing a lot themselves to keep healthy and well, even during really difficult times such as the pandemic. However, it is important that we use these findings to encourage family, friends and dementia support services to think about ways they can support people with dementia to do this. This might include helping them to undertake new activities and learn new skills or providing a friendly ear with regular ‘check-in calls’ to see how they are coping.

Where can I read more about this work?

Our research is freely available for anyone to read at the International Journal of Geriatric Psychiatry. You can find the paper at the following link:

<https://onlinelibrary.wiley.com/doi/full/10.1002/gps.5803>