

# Lockdown and dementia: For some, COVID-19 has created an isolated, confusing but calmer world

26 January 2021, by Catherine Talbot



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The approximately [850,000](#) people living with dementia in the UK have been badly affected by COVID-19. Many live in care homes, which have arguably been hit hardest by the pandemic, experiencing a [heavy death toll](#) during the first wave.

The pandemic has also caused significant global disruption, affecting people's daily lives, mental health and wellbeing. The estimated [two-thirds](#) of people with dementia who live in the community may be particularly vulnerable to the effects of this disruption, and face distinct challenges when transitioning out of [lockdown](#).

I have [conducted research](#) with Professor [Pam Briggs](#) at Northumbria University to examine how COVID-19 has impacted these individuals. We interviewed people with early- to middle-stage dementia about their experiences of the pandemic, conducting these between June and July 2020, as lockdown restrictions first started to ease in the UK. Here's what we discovered.

## Lockdown's negative effects

People with dementia felt their symptoms deteriorate during lockdown, reporting changes in speech, memory, concentration and balance. This mirrors the findings of [a survey](#) conducted by the Alzheimer's Society of people with dementia and their carers, in which 82% of people reported an increase in symptoms among people with dementia.

The people we interviewed attributed these changes to a lack of cognitive stimulation and loss of routine. They were no longer able to take part in activities they found stimulating or meaningful, such as tending to allotments, attending [support groups](#) or walking groups. Instead, they were limited to more mundane tasks, which appeared to negatively affect their dementia and self-worth.

People with dementia also had limited access to their usual support networks, including friends, family and others with dementia. Consequently, participants reported feeling lonely or socially isolated, and some experienced symptoms of depression.

We found that these factors then impacted participants' confidence to participate in a post-lockdown society. For example, one person said: "Getting my confidence back is going to be a challenge. I've been put in a situation where I'm isolated and don't really have anything to do with anybody else for the last few months. So I think actually getting back to normality seems as big of a step as going into lockdown."

In a [2010 study](#), researchers found that familiarity with the outdoors was key for enabling people with dementia to spend time outside. Yet for people with dementia, the outside world has become increasingly unfamiliar. They may find different shop layouts disorientating, signs and floor

markings confusing, and people in masks unsettling or difficult to understand. felt there was a lack of support when exiting the first lockdown.

The people we interviewed expressed concerns about their ability to follow safety procedures and were often worried about how others would react if they did something wrong. One person said: "People aren't considering the problems that people with dementia might have remembering the rules. I think that's stopping a lot of people going out; it's certainly stopping me."

### **But it wasn't all bad**

We found there were also unexpected, positive consequences of lockdown for some people with dementia. They reported feeling safe and secure in their "lockdown bubble", which provided a break from the loudness and busyness of everyday life.

Others said lockdown provided them with a safe space to learn new skills or return to past hobbies such as crafting, gardening or photography. Lockdown provided opportunities for achievement for some people, where they did not fear failure. One person said: "I haven't had to go out of my way. I haven't had to stress about things. I haven't had to fail, which has been a massive part of my life the last few years."

Clearly, we must work towards creating a more inclusive society, in which people with dementia feel empowered to pursue achievement and engage in activities they find meaningful.

Our research showed there was a tension between the outside world being a source of anxiety and the home environment being a safe space for people with dementia. This tension caused some people to feel anxious and reluctant to venture into the outside world post lockdown.

### **Exiting lockdown this time**

It is essential that people with dementia are supported by carers, services, organizations, the government and wider society when transitioning out of lockdown. Unfortunately, we found that people with dementia felt "forgotten" and "abandoned" by society during the pandemic and

At a personal level, it is important to remember that people with dementia may face difficulties remembering the rules—they may not be able to wear a mask or understand why they need to wear one. In somewhere like a supermarket, they may find it difficult to follow signage. Remember to treat these people with patience, kindness and compassion.

At a wider level, it is vital that [dementia-friendly practices](#) adopted by many stores before the pandemic—such as clear signage, slow shopping lanes and staff who are visible and trained to support customers with dementia—are not abandoned. Guidance should be communicated clearly, concisely and in a variety of accessible formats. Importantly, people with dementia should be consulted to develop responses that promote their wellbeing and social inclusion.

The Alzheimer's Society [has advice](#) for supporting a person with dementia at home during the pandemic.

If you need dementia support and advice, you can speak to the [Alzheimer's Society](#) on its Dementia Connect support line—0333 150 3456.

The Alzheimer's Society also offers [online support](#).

If you are a carer for a person with [dementia](#), [Carers UK](#) offers help and advice.

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