

## **‘Caring beyond capacity’ during the coronavirus pandemic: resilience and family carers of people with dementia from the IDEAL cohort**

### What was it like for family carers of people with dementia one year into the COVID-19 pandemic?

We interviewed seven family carers of people with dementia in 2021. We were interested in their experiences one year into the COVID-19 pandemic and after the vaccine had been introduced. We were also interested in thinking about how resilient they were, and why. All but one person was caring for a spouse or partner. One person was a daughter caring for her mother. Everyone we spoke to was living with the family member they cared for. Our youngest family carer was 53, and our oldest was 89.

People told us what it was like caring for their family member during a later stage of the pandemic. They said that they still had to protect the person they cared for by avoiding the risk of COVID-19. Some were taking “small steps” in going out again. Earlier in the pandemic, one person had stopped paid carers coming in, saying: “we didn’t want [COVID-19] brought into the house for us”. Some people felt that their family member had declined. This was because they had not been able to go out. People wanted to care for their loved ones, but caring for a family member with dementia could be quite an intense role. One person said: “I live at a high level of adrenalin much of the time”. People also had little or no time to pursue their own interests. Two people found it difficult to combine caring with full-time work. Because of social restrictions, people were also caring in isolation. Family members could not offer support in person.

Not everyone we spoke to said they felt stressed, but some people said they felt ‘burned out’ and abandoned. They had been caring beyond their capacity. People said no one had been ‘checking in’ on them except for charity volunteers telephoning them. Later in the pandemic, some people said there were fewer of these phone calls. Also, groups like dementia cafés had not restarted yet. Day care and respite care were also still absent or limited. One person spoke about needing to access respite care but felt guilty about this: “...if I could, I would spare [my partner] the kind of abandonment. But on the other hand, I ... I would not trust myself to be ... to keep going forever”. Another person was told he would need to wait for six months to get a health and social care assessment for his wife. People also said that lack of support from health and social care was nothing new, but the pandemic seemed to have made this worse. Even before the pandemic, people said that their

family members had not had much follow up after their dementia diagnosis. Mostly families seem to have been managing on their own.

Family carers want to care for their loved ones with dementia but this can be difficult. Their experiences during the pandemic have further exposed why appropriate service support is so important. Without it, family members are caring on their own and may 'burn out'. Some researchers think we should try to make family carers better able to withstand this kind of stress. We argue that trying to make individual carers more mentally resilient is insufficient on its own. To support family carers of people with dementia, there needs to be sustained support from services after diagnosis and improved access to appropriate health and social care. Family carers' own needs, separate from their caring role, also need to be considered.

This is a summary of a [research article](#), which was published in the **International Journal of Care and Caring** in May 2023.