

Five ways to support people with dementia and carers in COVID-19 lockdown

27 April 2020



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New guidance has been developed as part of a major project to support people with dementia and family carers who are facing isolation and reduced services as a result of COVID-19.

A new leaflet features five simple tips, developed using the latest robust research and with the input of people affected by dementia. The leaflet is part-funded by the National Institute for Health Research (NIHR), in a project led by the University of Exeter and the NIHR Older People and Frailty Policy Research Unit, with partners including Alzheimer's Society, Manchester University, Bradford University, Brunel University London and the NIHR Applied Research Collaboration South-West Peninsula (PenARC).

The leaflet is the first output of an ongoing project to support people living with dementia and their carers through the COVID-19 global health emergency. The project recognises that people with dementia are particularly vulnerable to the psychological and social impacts of isolation and lockdown. The project takes into account the concerns expressed by people with dementia

through partner networks such as Alzheimer's Society, [Innovations in Dementia](#) and the [DEEP network](#). They are describing concerns about maintaining supplies of food and medications, anxiety about what would happen if they were admitted to hospital, lack of confidence, feelings of loss and grief, increases in symptoms like agitation, and a more rapid decline in cognitive and functional ability.

For carers, lockdown means they are more captive in their role and lack respite opportunities. Many carers are finding it difficult to explain the current restrictions and enable the person with dementia to remain safe, and are deeply worried about the safety and well-being of their relatives.

Professor Linda Clare, of the University of Exeter Medical School, who led the project, said: "While not currently classed as "vulnerable" on health grounds, people with dementia and their [family carers](#) are disproportionately affected by social distancing, isolation and lockdown. Our research tells us that many people living with dementia and carers felt isolated and lonely before COVID-19, and now these feelings will be amplified. They can feel overwhelmed by the volume of generic advice and guidance available, and may be unsure how to select information that is relevant to them and their families and what information to trust. This project aims to provide robust information, developed with the crucial input of people affected by dementia, to offer support through this crisis."

The leaflet, available online here www.idealproject.org.uk/COVID/ gives practical and self-help tips, as well as signposting sources of support, on five key points:

- Staying safe and well
- Staying connected
- Keeping a sense of purpose
- Staying active
- Staying positive

The advice builds on University of Exeter-led research from the IDEAL programme which seeks to understand, and find ways to improve, the experience of living with dementia. The study recruited 1,547 people diagnosed with mild to moderate dementia and 1283 carers and is following as many as possible over six years. The study recently reported on the extent of loneliness of carers of people with dementia living in the community in a pre-COVID-19 era, highlighting social isolation as one of the key factors that led to feelings of loneliness. Telephone interviews will be conducted with people with dementia and carers participating in the IDEAL programme as part of the current project, to gather information about their experiences and concerns and ensure that the renewed guidance remains relevant. The new guidance also incorporates findings from the NIHR-funded [GREAT trial](#), which focuses on practical ways of enabling people with dementia to manage daily life and stay as independent as possible.

Keith Oliver, Alzheimer's Society Ambassador, who is living with dementia, said: "It has been a very challenging time for us and it has really shocked me. More than half of my care plan is around doing activities like being an ambassador. All that support that I used to get from these things has just dried up. I thought being at home was going to take me back to when I was first diagnosed."

Professor Martin Rossor, National Director for Dementia Research at the NIHR, said: "It is vital to ensure that people with dementia and their carers feel supported during this uncertain time. Research funded and overseen by the NIHR is providing some of the quality evidence that supports resources like these."

Fiona Carragher, Chief Policy and Research Officer at Alzheimer's Society said: "It's great to see the publication of this practical guidance for people with dementia led by the Exeter team that also leads one of Alzheimer's Society's Centre of Excellence in care research. From all the calls we receive to our Dementia Connect support line, we know loneliness is a real issue for people affected by dementia, and strict lockdown measures due to the [coronavirus](#) pandemic have exacerbated this by shutting people with dementia and their carers

away from loved ones and other forms of support. We're expanding our services in response to this need, and this new guidance will form part of our support to ensure people affected by dementia don't feel forgotten and alone."

The guidance is available online here www.idealproject.org.uk/COVID/ and is being distributed online through a network of organisations who support people affected by [dementia](#). It will form part of Alzheimer's Society's support package via helplines and frontline staff.

Provided by University of Exeter

APA citation: Five ways to support people with dementia and carers in COVID-19 lockdown (2020, April 27) retrieved 5 June 2022 from <https://medicalxpress.com/news/2020-04-ways-people-dementia-carers-covid-.html>

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