

# Rare Dementia Support

Advice Community Learning

## Living with dementia and COVID-19: an emergency kit

### Contents:

- Introduction Page 1
- Advice and support Page 2
- At-home activities Page 5
- Carers: Looking after yourselves Page 7

## Introduction

**The following information from Professor Alistair Burns explains how people with dementia and other forms of cognitive impairment may be vulnerable to COVID-19, the respiratory illness caused by the new coronavirus. This includes how associated factors such as age, previous medical conditions and dementia-related behaviours may affect risk for COVID-19.**

There are an estimated 850,000 people with dementia in England, the majority of whom are over 65 and have underlying health conditions. This makes them particularly vulnerable to develop severe symptoms and complications. They are supported by a similar number of carers, most of whom are older people themselves. A quarter of people in acute hospitals and three quarters of residents of care homes have dementia.

Most likely, dementia does not increase the risk of getting COVID-19, just like dementia does not increase the risk of flu. However, dementia-related behaviours, increased age and common health conditions that often accompany dementia may increase risk.

For example, people with Alzheimer's disease and other dementias may forget to wash their hands or take other recommended precautions to prevent illness. In addition, diseases like COVID-19 and the flu may worsen cognitive impairment due to dementia.

People with dementia are much more prone to develop delirium (a confusional state) if they develop an infection. It is important that healthcare staff are aware if a person has dementia so they are alerted to this increased risk. Other considerations for those caring for people with dementia and healthcare staff:

- Going into hospital is frightening enough and particularly so for someone with dementia - staff involved in screening and treatment should be aware if a person has dementia and be prepared to take extra time while assessing and treating them. Avoiding unnecessary hospital admissions is important.
- Some people with dementia may have difficulty understanding complex instructions about self-isolation or handwashing - keeping information accessible and repeatable is key.
- People with dementia may lack awareness of, and be less able to report, symptoms because of communication difficulties. People should be alert to the presence of non-verbal signs as well as symptoms of the virus.
- People with dementia may have swallowing difficulties, putting them at increased risk of developing chest infections and dehydration. A swallowing assessment may be helpful.

*From Prof. Alistair Burns*

**We have compiled a list of helpful advice and resources to help you manage at this difficult time. This includes dementia-specific support, legal and financial guidance, at-home activities and advice for carers.**

## Advice and support

### NHS and Government advice

[NHS Coronavirus \(COVID-19\) advice page](#)

[Government Coronavirus \(COVID-19\) advice page](#)

[Government Coronavirus \(COVID-19\) advice for home care provision](#)



### Home care advice

[Home Instead Coronavirus \(COVID-19\) advice](#)

[SweetTree Coronavirus \(COVID-19\) update](#)

[Bluebird Care Coronavirus \(COVID-19\) advice](#)



### Care home advice

[Barchester Coronavirus \(COVID-19\) update](#)

### Easy read resources

There are some very good resources for people with communication difficulties, to help understand staying safe:

[Information about Coronavirus \(COVID-19\)](#)

[Advice for self-isolating](#)

### Dementia-specific information

[Dementia UK Coronavirus \(COVID-19\) advice](#)

[Dementia UK Coronavirus \(COVID-19\) questions and answers](#)

[Alzheimer's Society Coronavirus \(COVID-19\) advice](#)

## Living with dementia and COVID-19: an emergency kit

### **Dementia-specific support**

Volunteer community groups, with appropriate expertise, could be positively encouraged to provide support for carers and people with dementia, particularly those living alone. There will be an additional burden on carers, many of whom are in high risk group themselves and may become ill and unable to care. If services can help plan so that friends, relatives and volunteers can maintain daily phone or other contact with each other, this should reduce the need for emergency calls on the NHS and social care.

Many community groups are helping with shopping deliveries and NHS Volunteers delivering prescriptions. This includes:

- [Age UK's practical ways to help older people](#)
- [COVID-19 mutual aid groups](#)
- [ACORN community support](#)
- [Alzheimer's Society's Dementia Connect service](#)
- [Age UK's staying safe at home guide](#)

People with dementia in their own homes may already feel isolated. If they need to further self-isolate, additional assistance and support may be needed to help lessen the practical and emotional impact of separation. It is important to put care plans in place to do this, including updated Lasting Power of Attorney (LPA) documentation and advance directives.

### **Legal and financial advice**

[Advicenow's Coronavirus \(COVID-19\) advice](#)

[Universal Credit Coronavirus \(COVID-19\) information](#)



### **Communication advice**

If relatives and friends are not allowed to see a person in a care home, this could have a detrimental effect on residents with dementia. The use of technology may help improve communication between families, both at home and in care homes.

This can be done by phone, post, text message, email or using online apps. Apps and social media platforms that allow the person to use video calling such as Skype, WhatsApp and Zoom might be worth a try. Seeing someone's face as well as hearing their voice can help feel more closeness. This could be arranged at a regular time of day to connect, to help give the person structure and to have something to look forward to. Everyone is different, so people should use whichever method is most comfortable for them and the person they care for.

### **Behaviour advice**

The risk of exposure to COVID-19 may be increased by the behavioural symptoms associated with behavioural variant frontotemporal dementia (bvFTD), which typically include a lack of self-awareness as well as a lack of awareness of others and their needs. People with bvFTD may have a reduced insight into the need for social distancing precautions at this time. Understanding the information about COVID-19 may be additionally difficult for people. Their ability to express their understanding or feelings will also be impacted. When people feel confused, challenged, apprehensive or frustrated, their behaviour often reflects this in ways that are irrational and unprecedented. People with a rare dementia are no exception.

It might be helpful to limit exposure to endless 'news' programmes which present the facts from a range of viewpoints. Instead, tune in to just one comprehensive and well sourced daily update. Selecting alternative channels to watch, watching films, reading books or listening to music may be helpful in reducing anxiety. When talking about the news, it might be helpful to break the news items down into manageable chunks, which you can repeat as necessary.

It is extremely important to keep some structure and routine in the day. This includes having the one walk in the fresh air if possible and ensuring there are home-based activities planned.

Melatonin dysregulation, and consequent sleep disruption, is an issue that can arise from not being exposed to enough sunshine. This boosts the likelihood of an increase in delusions and challenging behaviours in people with dementia. This risk can be reduced by ensuring people spend as much time as possible in outdoor space such as gardens, home terraces and balconies.

Behavioural changes, delusions and confusion can also arise from a disruption in routines. This is particularly true for people who find staying active and being outside therapeutic. It will be helpful for people to start preparing a contingency plan, with scheduled routines and a heads up to friends and family to be ready in case extra support is needed.

## At-home activities

There are a huge variety of resources available, some of which are highlighted in the article below:

[Coronavirus \(COVID-19\) and self-isolation useful resources](#)

### Outdoor activities

Gardening

Nature walks around the garden

Listening to Audio Books outside

Yoga/Tai Chi

#### Workouts (can be done inside or outside)

- [PE with Joe Wicks](#)
- [20-minute exercise workout for beginners and seniors](#)
- [Seated chair exercises](#)
- [British Heart Foundation - Strength and flexibility exercises](#)

#### Games

- Giant Connect 4
- Giant Jenga
- Boules
- Ball games

### Indoor activities

Puzzles, games, quizzes

Arts and crafts

Online activities:

- [AcTo Dementia accessible apps](#)
- [My House of Memories app](#)
- [UCL's Dementia and the Arts online educational course](#)

Make a favourite music playlist using one of the below:

- [Playlist for Life](#)
- [BBC Music Memories](#)

Or join [The Sofa Singers](#)



Living with dementia and COVID-19:  
an emergency kit

**Online Virtual Tours**



- [A list of Museum Exhibits, Symphonies, and Operas you can enjoy from home](#)
- [12 World-class museums you can visit online](#)
- [The Louvre online tours](#)
- [The Cliffs of Moher virtual tour](#)
- [Uffizi Gallery virtual tour](#)
- [Google's Arts and Culture collections](#)
- [Madrid's Caixa Forum virtual tour](#)
- [National Gallery virtual tour](#)

## Carers: Looking after yourselves

Any period of isolation brings with it a unique set of challenges. Embracing isolation amid the current fears and uncertainties caused by COVID-19 inevitably adds to those challenges.

Being a carer often means people will already experience anxiety, and the current situation may well bring additional anxieties and concerns. People are likely to be feeling additional levels of stress at this time. This can manifest itself in different ways. For example, people may have a constant feeling of raised stress levels, or they may be more prone to high level reactions - going very quickly from 1 to 100 in terms of stress and fear. People may also find themselves responding, reacting and behaving in ways that are out of character. It is important to remember that this is normal and you are not alone!

Some strategies which may help carers:

- Try to find moments in the day where you can safeguard yourself. Even a couple of minutes to yourself is worth taking.
- Speak out or write down your stresses, fears or anxieties. This can help minimise the control they have over you.
- Take control over the things you CAN do. For example, time in the garden, cooking a meal, baking a cake, listening to an audio book or a favourite radio programme.
- Practice some simple breathing exercises. There are many variations on these, but at their simplest: Breathing in for a count of 4, holding for count of 3, then breathing out for a count of 4 (as far as is comfortable for you). This can help you to slow down, focus and gain perspective.
- Be 'mindful'. Even in these days of limited access to resources, we can make a conscious effort to maximise the experiences available to us. Take a moment to really feel the sense of the water on our body when we shower, or the feel of the softness of the soap suds when we wash up, the smell of the washing as we hang it out, the textures of the ingredients we are preparing, the taste of the food we are eating.
- When fearful of the worst, take a moment to actually consider what the worst thing that can happen might be, and also what the best thing that happen might be. Try to position yourself and your thinking in a manageable place somewhere between the 2 extremes.
- When it feels as if everything is getting too much, try a simple distraction strategy. For example: Look around you and identify 5 things you can see, 4 things you can touch, 3 things you can hear, 2 things you can smell and 1 thing you can taste. For the minute or so that it takes you to work through this exercise, you are thinking of nothing else, allowing your mind to re-focus and move you into a different place.
- Use your hands. It can be very therapeutic to garden (even a window box if you have no outside space), bake, knit, sew, colour or do a jigsaw. Using your hands and focusing on the task really helps to divert your thoughts.



## Living with dementia and COVID-19: an emergency kit

- Sleep is key. Try and keep a good sleep routine and keep the bedroom just for sleeping if possible. Shut off screens at least an hour before bedtime and have a warm drink or bath to aid restful sleep. If you are restless and waking during the night, don't toss and turn but get up and leave the bedroom and make yourself a drink, perhaps read a book or listen to some quiet music.
- Remember YOU ARE IN CONTROL OF YOUR THOUGHTS. Don't allow them to bully you!

**You are doing an amazing job!**



As always, please do not hesitate to get in touch with us if you would like to check in, have specific questions, or would like to share any tips and suggestions you have for managing at this difficult time,

### **The RDS Direct Support Team**

Rare Dementia Support runs specialist support group services for individuals living with, or affected by, a rare dementia diagnosis. Our vision is for all individuals with or at risk of one of these forms of dementia to have access to information, support and contact with others affected by similar conditions. Rare Dementia Support is a fund held by The National Brain Appeal (registered charity number: 290173).

**DISCLAIMER:** Please note that you assume full responsibility and risk in the use of information contained on our website, in our newsletters, at support group meetings and in subsequent correspondence. Our support group based correspondence is generic in nature and we are limited in our ability to offer specific advice via this means. We aim to ensure that all information is as accurate as possible but we accept no responsibility for any errors, omissions or inaccuracies, or for any adverse consequences of any kind arising from the use of support group based content. Please see the clinician responsible for your care, a social services representative, or your GP if you have specific needs which require attention. Any medical decisions should be taken in discussion with an appropriate health care.