

Providing person-centred support at home for people living with dementia during the COVID-19 crisis

This information sheet has been developed by the Association for Dementia Studies at the University of Worcester (www.worc.ac.uk/dementia) to help those who support family members or friends living with dementia at home during this difficult time. It is best practice at the time of writing and is general advice only. The latest national sector guidance should be followed.

Any change to normal routine can be stressful for a person living with dementia and those supporting them at the best of times; even more so during this crisis. This guidance aims to help you reduce this stress and be person-centred during this challenging time. Every person is different and so the way they are experiencing this crisis and the help they need will also be different. When caring for someone else it can be easy to forget to look after yourself but doing what you can to help yourself relax and find enjoyment is also very important.

It is important to remember throughout that the Mental Capacity Act gives us guidance on how to support a person living with dementia, particularly when they may lack the capacity to make an informed decision about how to live day-to-day during this crisis. People have the right to have good decisions made on their behalf: decisions that aim to achieve their best interests in the least restrictive way possible. This will mean **balancing the need for social distancing, isolation and infection control with any negative impact or distress those measures may cause to the person**. Whilst social distancing/infection control are in a person's interests, there are different ways to achieve these and you should aim for the one that physically restricts the person the least and emotionally supports their well-being the most. This is a careful, individual and changeable judgement call.

Strategies to help the person understand the COVID-19 situation

It can be easy to assume that a person cannot understand what is happening, but people often take-in more than we think. Finding a few simple ways to explain the current situation can be very helpful. Having a 'ready to go' answer can be particularly useful if someone asks repeated questions; it will mean you can help them whilst not becoming too stressed yourself.

- Use a simple written explanation of the situation. You could read it with the person sometimes and at other times leave it with the person to read themselves. Even if someone does not read much anymore, having something physical to hold that explains things can be very reassuring.
- Display a simple poster in key places for the person (e.g. the front door or near the kitchen sink).



- Decide on a simple verbal explanation for the situation that you (and others) can use consistently with the person (e.g. *“there is a very nasty bug around at the moment and so we have been told to stay inside to keep everyone safe”*). Repetition of an explanation may help some people to remember after a while. It also means that you’ve got something to say ready, even when you’re feeling anxious or overwhelmed yourself.
- Remember that some of the things associated with the pandemic (people wearing PPE, ‘death-tolls’ on daily news etc.) can be very frightening and so reassurance will need to be given even after you’ve have become used to the situation.

Useful links and resources

- An easy-read guide to social distancing: [Easy Read - 'Keeping away from other people'](#)
- Dementia: The Montessori Way provides a [simple COVID-19 poster and booklet](#)

Strategies to help keep the person occupied during this time

The key to encouraging a person to stay in a particular place is to make that space interesting. A lot of distress and seeking-out behaviour stems from boredom, so combatting that is particularly important at the moment. Finding ways to keep a person occupied or settled, even if only for five minutes, also helps to give you a little bit of space for yourself as well.



- Maintain as much of the same routine at home as you can and support the person to do the same familiar, daily activities as possible. If there is a regular activity that cannot happen (such as a trip to visit friends) try to replace it with something similar (e.g. a regular ‘zoom’ call to someone, or a walk around the garden).
- Create a daily plan based on the person’s favourite music, TV and hobbies. This should focus on providing engaging activity *throughout* the day be pitched to the abilities of the individuals (e.g. folding laundry, sorting items in a rummage box, tidying a drawer, looking at photos, painting a picture, reading or watching a specific DVD). On that plan, mark the times when the person may need less support from you and identify something you would like to do in that ‘slot’ (this could be as simple as sitting in the kitchen and looking at the garden for a few minutes – but it helps to know when those times are coming up).
- If you are needing a bit of space, set the person up with an activity (e.g. painting a picture) and get them started, before you step away. Some people living with dementia can find initiating things very difficult but can carry on much more easily.
- Whilst routine is important, don’t be afraid to try something new. There are lots of activities being done online (singing, exercise etc.) and now they’re more accessible than ever. Many people have found them an enjoyable addition to their routine.
- If they can, try to help the individual stay active. You can access exercise videos that are being posted online. This could be a part of the new daily routine.

- Ask family or friends to help you with your daily plan. Can anyone arrange to telephone or chat online for half an hour each day? Could someone send regular postcards and handwritten letters? This could give you a little bit of time to yourself or help maintain connections with the world outside your home.
- You could contact a local primary school to see if some of the children there would like to write letters that can be sent to the person living with dementia.
- Music is known to be very powerful for people living with dementia. Unless it distresses the person or conflicts with an alternative activity, ensure the person has music playing that they enjoy. Pay special attention to music that comforts and relaxes the person.

Useful links and resources

- The [National Activity Providers Association](#) has made their resources free
- COVID 'mutual support' groups are community-run groups of people who are willing to offer support to others during this time. You can find your local groups [here](#).
- [Playlists for Life](#) is a great website for music in dementia, including some covid-19 resources
- [Active Minds](#) sell activity kits for people of all abilities and designed with infection control in mind
- A guide to: [online resources for activities for older people](#)
- Many exercise classes have moved online, such as this 'dementia friendly' [seated exercise class](#) or these ones from [Leominster Meeting Centre](#) Facebook page and on [You Tube](#)

Using the home environment to encourage distancing or isolation

The physical environment is a useful tool for helping to orient an individual and encouraging or discouraging certain activity. However, it is very important to make sure that measures aren't overly-restrictive as this can cause greater frustration and activity from the person, increasing risk.

- Make sure the person can see out of the window and that the view is not obstructed by large items on windowsills or TV screens.
- Maximise connection to nature/the outside by making sure curtains are not blocking natural light. You could make a simple [birdfeeder](#) for them to watch.
- Make sure the person can see their favourite items from where they spend most of their time. This is particularly important if the person is unsteady on their feet or not able to move around safely on their own.
- Consider using assistive technology to help with safety at this time (e.g. door alarm).



Strategies to meet people's need for human contact

It is very important to remember that contact with others is a basic human need and so people living with dementia will naturally seek it out. Social isolation may be in a person's best interests right now, but that means we need to try and meet the need for human contact in other ways. The better you achieve this, the less likely the person is to try and seek out that contact or show their frustration through their behaviour. Keith Oliver, a well-known speaker who lives with dementia himself has encouraged people to think in terms of **physical** distancing rather than 'social distancing', because social contact is so important for people's well-being.



- Try to facilitate safe time outside of the house several times a day, especially if this is part of the person's usual routine. This could be a walk in the garden or around the block looking at and talking about nature. Physical exercise will help relax a person and improve sleep.
- Facilitate regular contact with families and friends via writing letters, telephone and online calls.
- Reach out to neighbours or local volunteer groups (lots of groups have sprung up during the crisis). You could ask for letters, friendly waves when passing or a chat over the garden fence.
- Consider facilitating participation in online groups such as singing for the brain, seated exercise etc. Even if you've never done these things before, remember that lots of other people will be trying these things out for the first time as well, it's not just you!
- If the person receives it well, a soft toy can help to provide physical comfort.
- Consider using technology to help connect with others. Platforms such as [ZOOM](#) and [WhatsApp](#) can facilitate this and can be downloaded on iPads, smartphones or computers. You can be creative with this: are there young children in the family or neighbourhood who need to practice their reading or school work? Could they record a video diary, read a story book or play an instrument onto an audio or video? The use of technology can also be used to facilitate carer support.

Useful links and resources

- Several dementia-friendly singing groups have been made available online:
 - [Blue Skies Singing Group Online Session 1](#)
 - [Singing for the Brain - session 2](#)
 - [Singing for the brain session - Spring](#)
 - [Singing for the Brain - session 3](#)

Strategies to encourage a person to follow infection control measures

- Always explain what is happening and why each time you interact with the person.
- Have simple, clear notes or posters in the kitchen and bathroom explaining why it's important to wash your hands more regularly.
- Do the activity alongside the person (e.g. wash your hands as well). Copying an action can be easier for some people than following verbal instructions.
- Singing and listening to music whilst trying to carry out a task can help to make difficult tasks more relaxing for the person and you. Use music, singing and general chat to make sure these interactions are enjoyable. This is more important than ever during this time.



Looking after yourself during this time

It is normal to be feeling emotional, anxious, lonely and/or down during this time. Being responsible for another person can add stress to an already difficult time. Looking after yourself is essential, as it helps the person you're supporting as well as you.

- Reach out for help from family, friends, neighbours. It can be really hard to ask, but it is something many people are doing right now. Remember that for many people, the chance to help someone else is a very positive thing and helps them to cope with this situation as well.
- Check out your local carers' groups, community groups (e.g. churches, community centres) and see if any online events have been arranged or whether any support is being offered.
- Talk to your local council or GP surgery who may know about support arrangements in the local area for people who need to stay isolated or are unable to get out to supermarkets etc.
- Identify at least three small things that you can do everyday to care for yourself. This could include listening to your favourite song, connecting with a friend, or eating a bar of chocolate. Having the intention to 'self-care' (even if its only something small) can help you to remember that you and your needs are important as well as the person you support.



Useful links and resources

- The [Alzheimer's Society](#) can provide telephone and online support and also signposts to lots of useful resources
- The Samaritans provide some simple [guidance](#) about looking after yourself, including mindfulness exercises
- [Dementia Carers Count](#) and [Carers UK](#) also have a helpful websites and advice lines.
- [Headspace](#) provides information on mindfulness, and is offering free support during the COVID-19 pandemic

Remember: These are tough times, but they will end. Why not keep a list of all the things you would like to do when social distancing is no longer required?