

Providing person-centred community support 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 community groups and their staff and volunteers provide support to people living with dementia and their family members during this difficult time. It is best practice at the time of writing and general advice only, the latest national sector guidance should be followed.

Any change to normal routine can be very stressful for a person living with dementia at the best of times; even more so during this crisis. Family members and informal carers are also likely to be under a lot of stress in the current situation. This guidance aims to help you reduce this stress and provide person-centred support during this challenging time. You may find yourself in a position where you are being asked for advice from carers, as well as trying to provide support directly to the person living with dementia as an extension of the face-to-face support you would normally be offering. It is therefore important to think not just about your support but also ideas and advice that you can pass on to carers. Every person is different and so the way they experience this crisis and the help they need will also be different. It is also a difficult time for support workers, so this guidance should reassure you that you're providing good support, even though circumstances are very unusual and demanding.

It is important to remember throughout that the Mental Capacity Act still applies to the way we work with people living with dementia. When someone lacks the capacity to make an informed decision about how to live day-to-day during this crisis, they 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 could mean supporting family carers and informal carers to **balance the need for social distancing, isolation and infection control with any negative impact or distress those measures may cause a person** who cannot understand the current situation. Whilst social distancing/infection control are in people's best interests, there are different ways to achieve these and you should encourage ones that physically restrict the person the least and emotionally support their well-being the most.

Strategies to help a person with dementia understand the COVID-19 situation

When supporting a person living with dementia it can be easy to assume that they cannot understand what is happening, but people often take in more than we think. Helping a family member or carer to find a few simple ways to explain the current situation can be very useful. However, if the person living with dementia appears to be distressed by any of these, do not pursue them.



- Whenever possible try to ensure the same staff member or volunteer acts as the main point of contact. This will help provide reassurance and familiarity in an uncertain time.
- Provide a simple written explanation of the situation. It could be sent to a carer to read with the person, or sent directly to the person if they live alone. It could also be read during a support session or socially distanced visit with the person, and then left for them to read again later in their own time.
- Suggest displaying a simple poster around the home in key places for the person (e.g. front door, or above the kitchen/bathroom sink).
- Recommend using a simple explanation for the situation that can be consistently used by everyone (e.g. *“there is a very nasty bug around at the moment and so we have to stay inside to keep ourselves safe”*). This will help some people to remember and also ensure that other people’s worries are not inadvertently passed onto the individual.

Useful links and resources to direct people to

- 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 ensure that people’s homes are well-equipped during isolation

It can be useful to encourage people to ensure that their home is well-equipped during the isolation period, especially as there may be a significant reduction in familiar visitors and outside support. Any items brought in from outside the home will need to be quarantined/disinfected prior to being used, so forward planning is important.



- Suggest having significant items easily accessible in the person’s home. These might include photographs, diary, important objects, handbag etc.
- Consider whether using technology could help with safety at this time (e.g. fall alarms, door sensors etc.).
- Encourage carers to ask other family members/significant people to write a letter, record a film or audio message reassuring the individual that they are safe, that family/friends are in touch, and that there are special rules everyone has to follow at the moment. This can be used regularly with the person.
- Suggest making sure that the items such as TV, radio, CD player and/or digital music player are working.

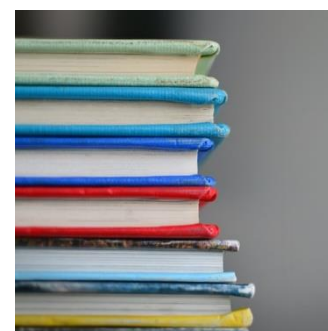
- If the person does not have a family member or carer, you may be able to have some of these discussions directly with the individual. In these cases, knowing more information about the person can be helpful.

Useful links and resources

- The ["this is me" document](#) is a simple way to gather information to get to know the person if you don't know them well

Strategies for staying occupied at home during isolation

The key to encouraging a person living with dementia to stay at home is to make that space interesting and reassuring. A lot of distress and seeking-out behaviour stems from boredom. Encouraging occupation should therefore also help family members/carers in their caring role, as well as being enjoyable for them.



- It can be useful to maintain as much of the same routine as possible for the person living with dementia. For example, building a schedule around regular TV or radio programmes shows can help carers to maintain a sense of normalcy. Providing your organisation's support in a regular, consistent manner, for example an online activity session at the same time each week, can help with this sense of routine.
- Music is known to be very powerful for people living with dementia. Unless it distresses the person or conflicts with an alternative activity, encourage carers to play music that they both enjoy. You could recommend paying special attention to music that comforts and relaxes the person.
- Consider using simulated presence: If a person lives alone, could you get an audio or film recording from a significant person that reassures the individual that they are safe, and that family and friends have not forgotten them? Carers could get creative with this: maybe a young family member who needs to practice their reading could be filmed telling a story and shared with the person?
- Encourage carers to try to help the individual stay physically active where possible. You could suggest accessing exercise videos that are being posted online, or depending on your support service you could create and share your own exercise videos. This could be a part of the new daily routine.

Useful links and resources to direct people to

- The [National Activity Providers Association](#) has made their resources free including this [Guide to activities during social distancing](#)
- [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](#)
- Resources used by Meeting Centres during this period have been brought together on the [Meeting Centres blog](#)

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. Carers are also likely to be missing contact with other family members and friends. 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. 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. Community groups have a key role to play in this area as they bring people together and provide social contact with people outside of individual households.



- Encourage carers 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 as simple as sitting in the garden for lunch or a trip down the street looking at neighbour's gardens. Physical exercise will help relax a person and improve sleep.
- During 'virtual' sessions or contacts you have with people, talk about familiar things rather than focussing on the current situation. Remember that some of the things associated with the pandemic (people wearing PPE, 'death tolls' on daily news etc.) can be very frightening, so reassurance will need to be given to both carers and people living with dementia even after people have become used to the situation.
- Encourage carers and individuals to have regular contact with families and friends via writing letters, telephone and online calls. These people may need reminding that their contact is really helpful at this time. Many people living with dementia have managed to learn how to engage online and meet with other people using platforms such as Zoom and WhatsApp during the crisis and have found it very helpful.
- Think about whether there are any weekly newsletters you can send out with activities in such as bird bingo, sunflower seed competition, word searches or poems. Many community organisations have created online and postal resources during this time, so see what other groups have done and use it as inspiration for your own group.

- Suggest participation in other online groups such as singing for the brain, seated exercise etc. there are some links below and you'll be able to find others. Remember, you don't have to do it all yourself, so don't reinvent the wheel if there's already something useful out there!

Useful links and resources to direct people to

- Several dementia singing groups have been made available online:
 - [Blue Skies Singing Group](#) with [lyric sheets](#)
 - [Sing 4 Health and Happiness](#) – Singing for the Brain sessions

Strategies to encourage a person to follow additional infection control measures

Carers may find it difficult to get people to understand the need for some infection control measures. The following may be useful tips and advice to pass on to them to help in this situation if they are struggling.

- Suggest that carers have simple, clear notes/posters in the kitchen and bathroom explaining why it's important to wash your hands more regularly.
- Encourage carers to do the activity alongside the person (e.g. wash their hands as well). Copying an action can be easier to follow than verbal instructions.
- Suggest using music, singing and general chat to make sure these interactions are enjoyable. This is more important than ever during this time.
- If a person likes to be busy, carers could provide them with anti-bacterial wipes and encourage them to clean (e.g. kitchen surfaces). This may be particularly useful for people who need to be very active to help ease frustration.



Important points for your community group to consider

- Think about different ways in which you could provide support. This could include virtual online sessions using Zoom (or similar), telephone calls, socially distant visits, WhatsApp groups, one-to-one sessions via WhatsApp and FaceTime, emailing or posting newsletters and activity books, writing letters, getting school children to draw pictures. Get creative, and don't be afraid to try things out. If they don't work, don't worry, try something else. People have individual preferences, so it may take a bit of trial and error to work out what suits different people in different situations.
- If you are running virtual sessions, think about what might work well in an online group situation. Too much discussion could become confusing if people talk over each other, and it may be more difficult to follow conversations if you cannot see a person clearly. Smaller groups may work better for some activities. Also try to have elements for both the carers and people living with dementia; make it inclusive. You may want to consider having separate sessions for

carers if you can see that there is a need for this; in some online sessions you can have breakout groups where carers could go for a chat while an activity session is delivered for the people living with dementia.

- You may want to consider activities that can be done by people at home between sessions to encourage occupation, interaction and engagement. This could be doing some like baking, drawing a picture, finding an object in the garden etc. Photos of these can then be shared during the next session to promote discussion and potentially make people more likely to join in with a session.
- Work out what time and duration works best for people, including yourself. Shorter sessions may be better in terms of maintaining concentration. Evenings may work better for carer sessions, but don't feel that you have to provide support outside of normal working hours.
- Encourage everyone to look after themselves. This doesn't just mean carers and people living with dementia but yourself and your staff/volunteers too. It is normal to be feeling emotional, anxious, lonely and/or down during this time. Having the intention to 'self-care' (even if it's only something small) can help you to remember that you and your needs are important as well as those of the people you support.
- While you want to support everyone, it's important to recognise that there is a limit to what you are physically and mentally able to provide. You don't have to do it all. Find out what other services are available in your area and make sure people have contact details for these. Now more than ever it's about working together and supporting each other, rather than feeling that services are competing against each other.

Useful links and resources

- The [Alzheimer's Society](#) can provide telephone and online support and also signposts to lots of useful resources
- Tips and advice on running online support sessions are available from both the [Meeting Centre blog](#) and the [Association for Dementia Studies blog](#).
- 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

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