

A CARER'S GUIDE TO COPING DURING THE CORONAVIRUS

This is a challenging time for us all. As a carer, you may be worried about your own health, as well as the person you are caring for. You might feel anxious, overwhelmed, upset or stressed at times. These are understandable emotions in the pandemic we are experiencing.

Many of the suggestions in this document are taken from the following sources:

- ✚ The Northern Health and Social Care Trust's guide to supporting people with dementia during Covid-19 (Duffy and Richardson, 2020). This can be downloaded here: <http://www.northerntrust.hscni.net/services/dementia-services/clear/>
- ✚ Dementia UK: <https://www.dementiauk.org/get-support/coronavirus-covid-19/questions-and-answers/>

Share your ideas and feedback!

We plan to keep updating this document and we'd love to include your ideas too! If you have feedback or suggestions, please let us know:

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Some general guidance

- ✚ **Routine** is very important; having a structure to the day will help both you and the person you are caring for feel more in control and stay occupied.
- ✚ **Memory aids** might be useful for the person with dementia at this time. These could be visual or digital reminders, for example guidelines for handwashing.
- ✚ **Ask for help if you need it.** Haringey Connected Communities can help with essentials (020 8489 4431), or try asking trustworthy neighbours or friends.
- ✚ **Stay active** to support mental and physical wellbeing for yourself and the person you care for. This could be through activity in the garden or sitting exercises.
- ✚ **Look after yourself too!** Caring for somebody can be tough. Try to be kind to yourself and do something that you enjoy each day, if only for a short while.

Important factors to consider

For people with dementia, this is likely to be a very confusing time where they are experiencing changes in their usual routine and activities. They may be feeling bored or anxious. They may also find it harder to express themselves and what they need, which could result in feelings of frustration.

This could lead to behaviour that is interpreted as verbally or physically aggressive. It may be useful to look for any patterns of when this behaviour happens more often and considering some of the factors below:

1. Physical Health

Our physical health can really impact on how we feel and result in changes to our behaviour. When caring for someone with dementia, it is important to consider how their physical health impacts their mood and behaviour. Ask yourself questions such as: Are they in pain? Do they have a medical problem? Do their glasses or hearing aids need updating? Are they thirsty, hungry, cold or hot? If you are concerned about a possible change in health, for example, a new infection, please do seek help or advice by telephoning your GP or NHS 111.

2. Communication

Dementia may make verbal communication more difficult. It can be hard for the person to understand words and sentences, or they may struggle to find the words to express themselves. However, people with dementia can also be very sensitive to changes in atmosphere or feelings. They may pick up on changes in how you are feeling, or changes in their routine, and in turn become more anxious or show other behavioural responses.

If you are feeling tense, try to notice how your relative is responding and consider how you might 'reset the balance' with some calming or distracting activity. What can you do to give the person reassuring signals that things are ok? Try to avoid arguments and negatives. For example use positive instructions like "shall we go here?" instead of "don't go there".

3. Supporting meaningful occupation

Activity can help to structure the day and give purpose. Creating a predictable routine each day can also help create a stronger sense of safety. It can sometimes be difficult to judge the right level of stimulation for somebody with dementia. Too much can be overwhelming, but not enough means they may be bored and restless – and this may lead them to look for their own stimulation in ways that are not helpful to those around them.

If routines have changed because of the Coronavirus, your family member may be feeling lost and confused, and missing things they used to enjoy. Try to create a new routine that can help give them a sense of purpose or distract them from worrying about what is missing in their lives at the moment. This could include 'jobs' which make them feel useful, entertainment or familiar areas of interest or hobbies.

4. Walking (or 'wandering')

When someone is walking, they are usually trying to go somewhere or do something. If the person with dementia wants to walk, is there a safe space in the home, garden or local area where they can walk comfortably, in line with social distancing guidelines? (Currently keeping at least 2 metres away from others – please follow the latest government advice).

Although it can be inconvenient for other family members if someone is pacing around the home, if the person with dementia is happy doing this, can you find a way to accommodate them? If it is causing problems, or if the person is trying to walk in the wrong places, can you re-direct them into another kind of activity?

See if you can find out if they have an idea in their minds about someone or somewhere they want to get to and, if so, try to find another way to help them with this. For example, if they want to visit a particular friend, could you help them call or write to that person instead? If they think they need to get to work, can you ask them to help with something around the house?

5. Sleep problems

Dementia can have a big impact on sleep patterns. Sleep hygiene can really help, for example: reducing daytime naps, avoiding caffeine in the evening, checking the temperature in someone's bedroom and ensuring the person is comfortable. If the person cannot sleep or experiences nightmares, it may be worth helping them to leave their bedroom for a short while before returning to bed.

The disruption to routines associated with the Coronavirus may also impact sleep. If the person has less activity or stimulation during the day, they may be less tired in the evening. Napping more during the day can also confuse their night-time routine. If you want them to sleep at the same time that you do, then keeping them active and involved when you are awake may help.

Try as well to make day and night clearly different in terms of activities, lighting levels and all the cues in the environment about what time of day it is (eg whether curtains are open or closed). As evening draws in, try to see what helps to create a soothing calming atmosphere for the person with dementia, for example reduce noise and stimulation.

6. Anxiety and frustration

Everyone is likely to be feeling strong emotions at the moment. Anxiety and frustration are common. Anxiety is related to worries about safety and security, while frustration often comes about when things are not turning out the way you want or need them too.

It can be hard to tell these feelings apart, especially when someone has dementia. These feelings can show themselves as restlessness or awkwardness. For example, someone with dementia who is feeling anxious may show this by asking more questions, or trying to get to somewhere or someone that makes them feel safe (this can include people who are no longer in their lives but are still present in their memories). They may also feel that they don't have much control over things, which might lead to them becoming angry or refusing to do the things you ask of them.

Some of these responses can be very frustrating for others, but letting this frustration show will likely make the person with dementia more anxious, and thus increase the problem. Try to keep in mind what the person you are caring for might be feeling (this might not be obvious) and adapt your response accordingly. This could simply be a case of acknowledging how they feel. Try naming the feelings, for example "I can see you are worried about this".

If your own feelings are getting strong too, try to step away into your own space for a moment (either physically or in your mind) to collect yourself and address your own needs.

Some frequently asked questions

How do I explain the situation to a person with dementia?

- ✚ Use simple and short sentences that you can repeat regularly, rather than trying to explain things in detail.
- ✚ You could tell them that there is a flu outbreak and people are being advised to stay home. Having this message written on notes throughout the house may help, particularly on the front door, at eye level.
- ✚ If the person with dementia insists on leaving the house, assess the level of distress this would cause if you were to try and persuade them otherwise. Sometimes it is better to go for a short walk, following social distancing advice, and then go home for a cup of tea and a biscuit once they are ready.

The person I am supporting does not want to wash their hands. What do I do?

- ✚ Try putting signs by the sinks saying there is a virus (or flu) outbreak and reminding them to wash their hands.
- ✚ Tell them that the doctor has said they need to do this to stay healthy.
- ✚ You could ask them to help you set a good example about hand hygiene for others in the house, e.g. if you have children living with you.
- ✚ Try making it a pleasurable activity, eg: use their favourite soap; massage their hands with hand cream after; or sing a song together while you wash your hands (to encourage them to do this for the required length of time).

The person I am supporting keeps asking for a family member or significant other who they are not able to see. What do I say and do?

- ✚ Ask them if they are missing that person. Tell them when the person last visited and explain where they are now.
- ✚ Spend time reading letters and cards, listening to voice messages or watching video messages if family and friends have sent these.
- ✚ Look at photographs of family and friends and engage in conversation about them. Help the person to focus on happy memories and good times.
- ✚ If appropriate, explain that family/friends cannot visit (and you cannot visit them) because of the COVID19.

The person I am supporting wants to leave home. What do I do?

- ✚ Find out where the person wants to go.
- ✚ Acknowledge how they might be feeling and try to address their concern, for example, "You're worried about the children, shall we call them and see how they are? (Or: "We spoke to them recently and they are doing well...")

- ✚ As you walk with them, ask them to help you to do something – purposeful activity will reduce the person’s need to leave.
- ✚ Trying looking together at photographs of the person or place they want to visit.
- ✚ If the person is asking to go to work, tell them that they do not have to go to work today but you need them to help you with a job around the home.

The person I am supporting is living in a care home. How can I support them?

- ✚ Arrange frequent phone calls. Explain the situation using simple and short sentences that can be repeated on a frequent basis. For example, there is a virus going around and for the safety of people in the home, people cannot visit at the moment.
- ✚ Post letters or cards to the person and ask staff to read them out.
- ✚ Use video technology such as Facetime. Check with the home what they use.
- ✚ If they like flowers, you could send a small bouquet and ask the care teams to help the person arrange them as an activity
- ✚ Send photographs with notes explaining who the people in the image are. The staff at the care home can then start conversations with the person about the photos
- ✚ Try doing activities over the phone, such as quizzes or word games.