

Supporting Carers and Care Staff to Understand and Respond to Changes in Behaviour in People with Dementia During the COVID-19 Pandemic



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We hope you enjoy this booklet which is designed to provide information to help support people with dementia during the COVID-19 pandemic.

Please talk through the suggestions with all family, carers and care staff who are involved in providing support.

We hope this booklet will help during this very challenging time and reduce stress and distress for both the person with dementia and those who love and care for them.

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Context

Government restrictions have been implemented to protect public health during the COVID-19 pandemic. Many care homes are closed to visitors and people living at home are advised to stay at home.

This document has been created to help carers and care staff to understand potential changes in the behaviour of people with dementia and offer suggestions on appropriate supports.

Carers and care staff

Carers and care staff will be worried about their own health, their family and those that they love and care for. They are likely to experience a range of emotions, for example feeling anxious, overwhelmed, upset or stressed. They may be worried that they have COVID-19, that they will pass it on to those they care for, or that they will become infected if the person they are caring for becomes infected. These fears are normal and understandable because this pandemic is not like anything we have experienced before.

If colleagues become unwell this can increase anxiety and a sense of vulnerability. There may also be staff shortages which impacts on workload and stress.

Talk to trusted friends and colleagues about how you are feeling. They are likely to be feeling the same.

Develop a routine with as much structure as possible to help you to feel a sense of control at a time where things may feel out of control.

Take breaks from caring and practice self-care by taking some time to do things that you enjoy.

People with dementia

There will be a significant change in routine for people living with dementia. People they love are no longer able to visit and they may not have access to the activities that they enjoy which provide meaningful occupation.

It is likely that there will be changes to staff who offer support if care staff who normally offer support become unwell or have less time to spend with the person if there are staff shortages.

This may result in fewer interactions for people with dementia. As a result, they could become bored and also anxious. They may not understand the need for physical distance, why changes in routine are happening or why the care staff that they have become familiar with are no longer there or less available.

The person with dementia will also pick up on the emotions of their carers. The anxiety that carers and care staff experience will also be experienced by the person with dementia.

When we are worried our natural tendency is to be with the people we love and feel safe with to seek comfort and support. This support may be less available during this time of restricted visiting. The emotional reaction to the changes and lack of understanding may result in behaviours which carers can find difficult to understand.

Isolation for people with dementia

There is a significant challenge for people with dementia who need to be isolated from others because they have COVID-19 or because others are infected. This affects both the person and also those who care for them and offer support.

The person may not understand that they need to stay in their room. They may be confused and also lonely. Purposeful, meaningful activity will reduce the distress and reduce their need to leave their room for company or occupation.

Meaningful Occupation

Care staff are extremely busy and there is the risk that increased pressure and workload means that activities are reduced. Maintaining occupation and social connection is even more important during this time of increased stress for everyone. This does not mean that busy carers and care staff need to do more, but they may need to do things differently.

When we become bored we look for something to do. The same is true for a person with dementia. The challenge is the person with dementia may be unable to tell us what they want or need. If they are stopped by a carer when trying to find something to do, it could lead to behaviour that is interpreted as verbal or physical aggression.

Impact of Personal Protective Equipment

During the COVID-19 pandemic staff may need to wear protective equipment or masks. This could be frightening for the person with dementia. This also means that they may no longer recognise the carers or care staff that they are familiar with, who are offering support.

It may be helpful to laminate your name and a picture of your role attached to your clothing or on a string around your neck. This could be cleaned frequently.

If you are wearing a mask, the person will not be able to see you smiling and may find it more difficult to pick up on body language. Laminate a smiley face and attach this to your clothing or carry it with you. This may help the person to feel safer.

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Physical Health

Changes in physical health contribute to changes in behaviour and emotional wellbeing. The following should be considered but this is not an exhaustive list.

- Is the person in pain?
- Do they have an infection?
- Are they experiencing a delirium?
- Are they dehydrated?
- Are they constipated, incontinent or need to use the toilet?
- Do they wear glasses and hearing aid, are these up to date and working?
- Does their medication need to be reviewed?
- Do they have any long term health conditions which need to be reviewed?
- Are they hungry, thirsty, or too cold or hot?

Understanding behaviour and offering support

All behaviour is a form of communication and is often driven by need. The challenge is that the person with dementia cannot always tell us what they need.

The following sections include examples of behaviours that the person may engage in and, at times, carers and care staff may not know how to respond.

In addition to using the suggestions on how to respond to the behaviour, it may also be helpful to look for patterns. Are there particular times in the day when the person engages in a specific behaviour?

Use CLEAR Dementia Care © (Duffy, 2016, 2019) Behaviour Record Charts to identify patterns in behaviour. If you know when a particular behaviour is likely to happen you can put strategies in place to support the person and meet their needs at these times.

Communication

When talking about COVID-19 with residents, use communication cards to help you (see <http://www.aphasiafriendly.co/covid-19-accessible-information.html>)

The person with dementia is likely to mirror your mood and behaviour. Fear can be contagious. Try to remain calm, smile and remain positive when talking or offering support. Even if you are wearing a mask, the person can see the smile in your eyes.

- Every time you meet the person, say hello, tell them your name and what your role is. “Hello SadieIt’s ClareI’m the nurse”
- Show them your name, picture of your role and the smiley face if you have these.
- If the person wears a hearing aid or glasses make sure they are wearing them to help with communication.
- Use short, simple sentences.
- Give the person time to process what you have said and respond.
- Listen to what they are saying.
- Give positive instructions ‘Shall we go here?’ instead of ‘Don’t go there’.
- Their reasoning may be affected by dementia. Arguing, disagreeing or correcting may lead to frustration.

Supporting Meaningful Occupation

How we spend our day affects how we feel and how we behave.

Activity gives our day structure, occupies us and gives purpose and meaning to life.

- Continue to offer a predictable routine each day with a variety of activity to help provide a sense of safety and security.
- Write the daily plan on a white board that is in view. Tick off each activity when it has finished.
- Follow guidelines on hand washing and ensure activity items are thoroughly cleaned before and after use.
- Support the person to stay connected with family and friends as much as possible using Phone, WhatsApp call, video, audio note, Skype and Zoom apps.
- Ask the family to send letters, card, photographs, voice and video messages and support the person to access these at regular intervals.

In a care home, it may be helpful to offer more group activities. Maintaining guidelines for physical distance, if a group of residents are in the lounge engaged in an activity, this may free up time for the remaining staff to complete personal care tasks with other residents. If the residents are engaged they are less likely to seek staff.

Focus more on doing the activity rather than the end result. Support residents to watch if they don't want to take part. Below are examples of activities but this is not an exhaustive list:

- Most people enjoy singing and this has a positive impact on mood.
- Offer each resident a balloon to play with.
- Play skittles or bowls with a plastic ball, cleaned with disinfectant wipes between each person.
- Choose some objects and pictures or photographs of famous people and engage in reminiscence.

- Recite proverbs and poems from childhood for reminiscence. Use a white board to help people remember the proverb or poem.
- Play music and ask residents to “name that song”.
- Play a game of colour bingo.
- Paint, colour, draw or make cards.
- Set up a gardening station at a table.
- Offer some activities that do not require active participation, such as listening to music or watching TV, a short audio book.
- Stream concerts from YouTube.

Examples of other activities can be found at:

<http://napa-activities.co.uk/membership/free-resources#things>

<https://musicmemories.bbcrewind.co.uk>

<https://www.rcot.co.uk/about-occupational-therapy/living-well-care-homes-2019>

<https://remarc.bbcrewind.co.uk>

For people who are in self isolation, living at home or when individual activity is being supported in addition to the activities above:

- Check in with the person frequently to see how they are and engage in brief conversation.
- The person may need help to start an activity.
- Try a range of activities to see what they enjoy doing.
- Try to create a rummage box.
- Offer colouring or puzzles on paper or on a tablet or computer.
- Involve the person in tidying, cleaning or sorting cupboards in their room where possible.
- Offer photographs, pictures, books and magazines.
- Support the person to go outside for a walk if possible.

There are different views on the use of dolls and children’s toys. If used in the right way, a doll or a soft toy can meet the needs for comfort and attachment and give the

person the opportunity to nurture and protect. This may be of particular benefit when the opportunity for engagement with family and friends is not possible.

A doll or soft toy can also provide the opportunity to increase communication between the person and their carers.

Asking to go home

The person may not recognise the people or things around them as familiar. They may be confused and anxious about where they are.

Home is not just a building. It's a feeling of safety and security, and the people and memories associated with the building.

When someone asks to go home they are looking for the feelings of comfort, safety and security that home brings. If family and other familiar people are not visiting or there are changes in staff, the person may experience this even more.

Support:

- Telling the person that they are at home may add to their confusion and distress.
- Ask if they are missing their son/daughter/husband/wife/significant other.
- Engage them in conversation about that person.
- Support them to look at photographs if available. This may help the person to experience familiarity, connection and feel safe and secure.
- If possible, ensure there are personal objects and photographs in their room.

Attempting to leave home

The person may not recognise where they are and want to go home. They may believe they have somewhere important to be, for example going to work or collecting children from school.

They may miss and worry about family members or significant others, especially as they have not been able to visit.

If they are prevented from leaving, they will worry about what will happen and their level of distress will escalate.

Support:

- Asking the person to come and sit down or telling them they cannot leave is unlikely to help.
- Find out where the person wants to go.
- Acknowledge how they might be feeling, for example, “You’re worried about your childrenLet’s see if we can find out where they are”
- As you walk with them, ask them to help you to do something.
- Purposeful activity will reduce the person’s need to leave.
- If the person is asking about their children or family they may be missing them. Support them to look at photographs of family if available.
- 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.

Asking for family members or significant others

A person with dementia may have a poor concept of time and feel like they haven't seen family members for a long time. This will be even more difficult during a time when family cannot visit. Where possible, maintain contact by phone, or video calls.

When they ask about someone it means they are thinking about that person and may be missing them.

Sometimes residents ask for dead family members and it can be difficult to know what to say. They may not remember that they have died, even if they attended the funeral.

Support:

- Ask if they are missing that person.
- Tell them when the person last visited. Explain where the person is now, for example, home or at work.
- Spend time reading the 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 because of the COVID-19. Use communication cards from <http://www.aphasiafriendly.co/covid-19-accessible-information.html> to help.
- If the person is occupied with activity they are less likely to become distressed.
- When a person asks about a dead relative, do not give them inconsistent messages. Remind them that the person has died. Tell them you understand it is a sad time and you know they are missing the person.
- If telling the truth causes significant ongoing distress, do not continue to remind them that the person has died.

Personal care

Because of their dementia, the person may not be aware that they need support with personal care and they may be confused and frightened about what is happening.

They may not know who you are or why you are in their personal space. They may be less likely to recognise you if you are wearing a mask. Strangers do not normally come into our bedroom and remove our clothing.

The person may feel embarrassed, cold or in pain.

They may behave in a way to defend themselves from what they perceive as an assault or to stop you from moving them and causing pain. This may be perceived as aggression.

Support:

- Say hello and tell the person who you are. Give them time to process what you have said and respond.
- If being supported by multiple carers, only one person should talk at a time.
- Hold out your hand and say “Shall I help you to get out of bed?” or “Shall I help you to get dressed?”
- Provide visual cues about what is happening. For example, show them the towel and face cloth.
- Support with upper body washing/dressing before moving onto the lower half.
- Encourage the person to be as independent as possible, for example, give them the cloth to wash their face and support them to choose an outfit.
- Slow the pace. If the person declines, give them time.
- Engage in conversation using short sentences to help them to feel safe.
- Keep the person covered as much as possible to keep them warm, protect their dignity and reduce potential embarrassment and distress.

Walking

When a person walks (sometimes referred to as wandering or pacing) they are either going somewhere, looking for someone, wanting to do something or simply want to get some exercise.

If a person sits in the same location for a period of time with no activity to engage them, they are likely to become bored, get up, walk and seek something to do. This will be more likely if the person has to stay in their room because of the need to self-isolate.

Support:

- When you see someone walking, ask them if there is something they need. If they cannot use language, pictures may help.
- Try activities that may be related to previous jobs, roles, routines and things they enjoyed doing.
- Be aware of the person's ability to attend and engage with the activity. They may need help to get started and the activity will need to be changed at times to reduce boredom.
- If possible go for a walk with them.

Sleep problems

Dementia can cause disruption of the sleep wake cycle. The person may fall asleep easily during the day but find it difficult to get to sleep at night. They may waken during the night or find it difficult to get back to sleep.

The person may get up in the night believing it is day time. They may dress for work, not remembering that they no longer work.

They may experience vivid dreams, nightmares or hallucinations, particularly in Lewy body dementia. Delirium, physical health problems and pain may also contribute.

Support:

- Assess for physical health changes which may be disrupting sleep.
- Orientate the person to the time throughout the day.
- Reduce daytime naps and avoid caffeine in the evening.
- Ensure there is good light during the day and it is sufficiently dark at night.
- Ensure the person's bedroom is not too cold or not too hot.
- Ensure their bed is suitable and they have comfortable night wear.
- If there is a risk of falls it may be appropriate to use a device to alert that the person is up.
- If the person experiences vivid dreams, nightmares or hallucinations at night, listen to them and provide reassurance.
- It can sometimes help to support the person out of their room for a short time before supporting back to bed.

Anxiety

Anxiety is an understandable response to the daily stress and distress the person experiences as they try to make sense of the world around them and meet their needs. Their anxiety may escalate during the COVID-19 pandemic as the person knows that something is wrong and is missing their usual routine and visitors.

Anxiety can make someone feel upset, irritable, cause difficulty concentrating and sleeping, cause them to sweat, feel dizzy and experience heart palpitations or panic attacks.

The person may seek frequent reassurance from carers, other residents or care staff.

Support:

- Telling someone not to worry or calm down usually doesn't help.
- Support the person to a quieter area if they are distressed.
- Talk to the person and ask them what is upsetting them. Acknowledge how they feel, for example "It sounds like you are feeling worried."
- A person with dementia may mirror and reflect your mood and behaviour. If you appear anxious, this may cause the person to feel even more anxious.
- Be patient with the person. A warm, positive and friendly approach will help.

References

Duffy, F. (2016). Look at all of me: A CLEAR model for dementia care, *The Journal of Dementia Care*, Vol. 24, No. 3, pages 27-30.

Duffy, F. (2019). *CLEAR Dementia Care © : A Model to Assess and Address Unmet Need*. Jessica Kinglsey Publishers.