

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



Dr Frances Duffy
Consultant Clinical Psychologist
&
Jill Richardson
Associate Psychologist

April 2020

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.

The original ‘Supporting Carers and Care Staff to Understand and Respond to Changes in Behaviour in People with Dementia During the COVID-19 Pandemic’ was developed by Dr Frances Duffy, Consultant Clinical Psychologist and Jill Richardson, Associate Psychologist, Psychology Of Older People Service, Northern Health and Social Care Trust (NHSCT). A special thanks to everyone who participated, including the NHSCT Dementia Home Support Team.

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The most recent version of the document is available at:

<http://www.northerntrust.hscni.net/CLEAR>

For further information, please contact:

**CLEAR.DementiaCare@northerntrust.hscni.net /
enquiries@innovations.hscni.net**

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.



Appendix 1

Understanding Changes in Behaviour in People with Dementia during the COVID-19 pandemic Posters

Dr Frances Duffy
Consultant Clinical Psychologist
&
Jill Richardson
Associate Psychologist

April 2020

We hope you enjoy these posters which are designed to provide information to help support people with dementia during the COVID-19 pandemic.

You may find it helpful to print and laminate these posters and place them in locations where all care staff, carers and families can see them.

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

The original 'Understanding Changes in Behaviour in People with Dementia during the COVID-19 pandemic' was developed by Dr Frances Duffy, Consultant Clinical Psychologist and Jill Richardson, Associate Psychologist, Psychology Of Older People Service, Northern Health and Social Care Trust (NHSCT). A special thanks to everyone who participated, including the NHSCT Dementia Home Support Team.

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Changes in physical health contribute to changes in behaviour and emotional wellbeing.

- Is the person in pain?



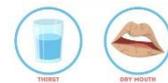
- Do they have an infection?



- Are they experiencing a delirium?



- Are they dehydrated?



- Are they constipated, incontinent or need to use the toilet?



- Do they wear glasses and/or hearing aid(s), are these up to date and working?



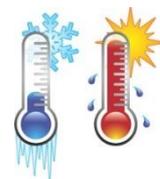
- Does their medication need to be reviewed?



- Do any long term health conditions need to be reviewed?



- Are they hungry, thirsty, or too cold or hot?



A person with dementia is likely to mirror your mood and behaviour.

Fear can be contagious.

Try to remain calm and smile 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 a laminated card with your name, photograph or the picture of your role and a 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.
- 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.



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

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.



- Offer a predictable routine each day with a variety of activity to help provide a sense of safety and security.
- The person may need help to start an activity.
- Try a range of activities to see what they enjoy doing.
- Focus more on doing the activity rather than the end result.
- Check in with the person frequently to see how they are and engage in brief conversation.
- Support the person to stay connected with family and friends as much as possible using Phone, WhatsApp, video, audio note, Skype and Zoom apps.

Examples of activity: music and singing, audio books, TV, gardening, colouring, painting, making cards, playing with balloons, cards or puzzles, rummage boxes, walking outside, reminiscence using photographs, pictures, books, magazines, skittles or bowls, bingo, reciting poems and proverbs, household tasks such as tidying, cleaning, sorting. The use of dolls and soft toys, if used in the right way, can meet the needs for comfort and attachment.



Anxiety is an understandable response to the daily stress and distress a person with dementia may experience 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 they are missing their usual routine and visitors.

Anxiety can make someone feel upset, irritable, cause difficulty concentrating and sleeping. It can also 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, a warm, positive and friendly approach will help.

A person with dementia will miss family and friends who cannot visit during the COVID-19 pandemic. 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.

Support:

- Ask if they are missing that person.
- Explain where the person is now, for example, home or at work.
- Spend time reading letters, 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>
- If the person is occupied with activity they are less likely to become distressed



A person with dementia 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.



A person with dementia 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 children.....Let’s see if we can find out where they are”
- Gradually change the topic and ask them to help you to do something.
- Purposeful activity will reduce the person’s need to leave.
- 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.

A person with dementia may call or shout out because they:

- Are in pain.
- Need something and have difficulty communicating what this is.
- Feel worried or frightened, lonely or isolated.
- Are bored and have nothing to occupy them.
- Are responding to a hallucination.

The person will continue to call out unless we respond to their distress and support them to meet their needs.

During COVID-19 people they may feel even more lonely or isolated, worried or frightened, and they may have less to occupy them due to a change in usual routine and activity.



Support:

- Telling the person to stop calling out is likely to increase distress.
- Find out what the person needs - are they hungry, thirsty, in pain, too hot/cold.
- If they are feeling frightened, upset or lonely, spend time listening to them and engaging in conversation to help them feel valued and cared for.
- Check in with the person at regular intervals. Let them know you are there.
- Offer a consistent routine with opportunity for activity.
- Where possible, support them to engage with others socially. Use phone and apps such as WhatsApp and Zoom to communicate with family and friends.

A delusion is when a person believes that something is true when it is not true. For example, they may falsely believe that someone is trying to poison them, imprison them or steal from them, or that their partner is having an affair.



Support:

- It is usually not helpful to try to convince the person that what they believe is untrue. What the person is experiencing is real to them.
- Ensure the person is wearing their hearing aid(s) or glasses.
- Check for sounds that might be misinterpreted, such as noise from a television or an air conditioner. Look for lighting that casts shadows, reflections or distortions on the surfaces of floors, walls and furniture. Turn on lights to reduce shadows. Cover mirrors with a cloth or remove them if the person thinks that he or she is looking at a stranger.
- Offer reassurance that you are there and they are safe.
- Stay calm and listen to what they are saying.
- Support them to a quiet area as loud environments may increase distress.
- It may help to go for a walk or move to another room.
- Engage the person in conversation or an activity to distract from the delusion.

Sometimes a person with dementia will seek close proximity to carers. They may call after or follow the carer around or become upset when the carer leaves the room, even if it is only for a few minutes.

At times of loss, danger or stress, our need for safety and security is even greater. Being close to another person can help us to feel safe. This may be particularly evident during COVID-19.



Support:

- Help the person to feel safe by maintaining a familiar environment with familiar people and objects as much as possible.
- Listen to what the person is saying.
- Are they thirsty, hungry, need to use the toilet, are they in pain or discomfort?
- When you leave the room, tell them where you are going and when you will be back, for example, "I'm going to the kitchen.....I will be back in 15 minutes."
- Support the person to engage in activity, look at photographs, watch TV or listen to music while you are away.
- Check in with them at regular intervals to ask if they are ok.

If you are feeling stress as a carer consider:

- Are you getting any breaks from caring or do you need further support?
- Helplines and online support forums can help.
- Speak to family and friends via phone or video.

Hallucinations are when the person experiences something that is not there.

- Visual hallucinations are seeing things that are not there. For example, the person may see people or animals.
- Auditory hallucinations are hearing sounds that are not real, such as a knocking sound or footsteps.
- Olfactory (“tasting”) or tactile (“feeling”) hallucinations are less common but can sometimes occur.



The person may experience a range of emotions such as fear, irritation, amusement or bewilderment. The person may respond to hallucinations, by talking or pointing and this can cause distress for carers.

Support:

- It is usually not helpful to try to convince them that what they are experiencing is not real.
- It is important to rule out a delirium with a sudden onset of hallucinations.
- If distressed, support the person to a quiet area. Stay calm and listen to what they are saying. Offer reassurance that you are there and that they are safe.
- It may help to go for a walk, move to another room, or engage the person in conversation or activity to distract from the hallucination.
- It may take time for the person’s distress to reduce.
- If you are concerned about the hallucinations seek medical advice.

Inappropriate Urination

A person with dementia may sometimes urinate in places other than the toilet or bathroom. This can feel embarrassing and frustrating for both the person and their carers.



Because of the person's dementia they may be:

- disorientated or unable to remember where the toilet is
- have difficulty getting to the toilet in time
- misidentify a cupboard for the bathroom
- be unable to ask for help with the toilet
- be embarrassed about having to ask for help
- be experiencing incontinence



Support:

- Do not draw attention to their incontinence.
- Signs that the person may need to use the toilet include:
 - Getting up from their seat, leaving the room or walking the corridor.
 - Entering other people's rooms or bathrooms.
 - Fidgeting with their clothing, waistband, belt or removing their clothing.
- Use pictures and word signs on the toilet doors.
- 20-30 minutes after meals or fluids, approach the person and say 'Shall I walk with you to the toilet?'
- If you are concerned about urinary incontinence or other physical health problem, contact the person's medical practitioner or continence service.



Sometimes a person with dementia may go into other people's personal space, take or rearrange their belongings. Sometimes they may try to care for others, for example trying to feed them or give them a drink.

This can cause distress for other people if they do not want the person to be in their space, take their things or touch them. If the person is asked to stop or others refuse their help, the person may become confused and upset.

The person is most likely trying to help or looking for something to do.

Support:

- Thank the person for their help and gently direct them to another activity.
- Their life story may help to identify activities they enjoy to help them feel useful and valued, for example, jobs around the home.
- A consistent routine with a range of activities is important.
- 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.



Life changing events can trigger low mood and depression. COVID-19, the associated changes in visitors, routine and activity, and the feelings this can bring, may mean people with dementia are at increased risk of developing low mood or depression.

Some common symptoms of depression include:

- Loss of interest in previously enjoyed activities or hobbies.
- Lack of energy.
- Problems sleeping.
- Reduced appetite and weight loss.
- Changes in behaviour include wanting to be alone, restlessness, irritability, aggression, tearfulness and refusing support.



Support:

- Support the person to eat a healthy diet.
- Offer a consistent, predictable daily routine with meaningful activities including exercise.
- Spend time with them at intervals throughout the day.
- Support the person to tell you how they feel, if they can and want to.
- Focus on what they can do rather than what they cannot do.



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 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.

Support:

- Say hello and tell the person who you are. Give them time to process what you have said and respond.
- 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.
- 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.



For a person with dementia, the world can be a confusing and frightening place. With loss of independence, if the person is unable to communicate their needs, or if their needs are not met in a timely manner, this can cause further frustration.



They may be frightened and think someone has come into their personal space with the intention of hurting them or stealing from them.

They may also be in pain.

If the person feels threatened they may attempt to defend themselves.

This may cause them to hit out, kick, grab or hurt others physically.

Support:

- Offer support in a way that helps the person to understand what is happening.
- Respond in a calm and patient manner. This can be difficult if you feel the person is being aggressive but this may help to stop their frustration from escalating.
- Your body language, facial expression and tone of voice can help to reduce the emotion.
- If the person can understand, ask them what has upset them and try to support with what they need.
- Supporting the person to move to a different environment can help.
- When the person is feeling calmer, offer an activity, a walk or a cup of tea.



The person may not remember that they have specific health conditions so may not understand why they need to take medication. At times a person may refuse medication but, when it is offered a short time later they take it.



We all have different ways we like to take medication and it isn't always a pleasant experience.

Support:

- Find out how the person likes to receive their medication e.g. in their hand, in a medicine pot, on a spoon or with a specific drink.
- Encourage them to be as independent as possible taking the medication.
- Talk to the person for a few minutes before offering medication.
- Explain what each medication is for, for example, 'This tablet will help the pain in your legs'.
- Be patient and give them time.
- Think about when medication is offered. Sometimes it is unhelpful to provide medication when someone is eating, getting dressed or doing another task where they are already occupied.
- If they continue to refuse medication it is important to seek medical advice.

The person may not be able to tell others they don't like the food or that it is too hot or cold.



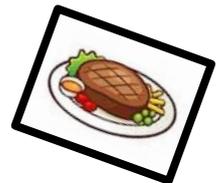
If the person doesn't recognise where they live, or if they now eat with other people whom they don't know, this may cause anxiety or distress and they may not want to eat. If the environment is loud or busy this may also cause distress at meal times.

Support:

- Their life story will help to know their food preferences.
- Food and fluid intake charts can help to identify times they are more likely to eat and what food and drinks they prefer.
- Offer a choice (2 options), for example, "Would you like a sandwich or soup?".

Pictures may help.

- Try to encourage the person to be as independent as possible.
- Give them time, say less and smile more.
- If the person is distressed, spend a few minutes talking with them and providing reassurance.
- If the person refuses, come back a while later and offer again.
- Provide smaller meals and snacks more frequently.
- Use coloured plates and bowls.
- Liaise with the person's GP, dietician and speech and language services as appropriate.



Repetitive questions and stories

When we talk to someone it is usually because we want to engage in social interaction.

When we ask a question it is usually to find out something we need to know or sometimes we just want to start a conversation.



When the person can't remember what happened recently or what is going to happen next, they may feel worried. For example: "Am I going to miss an appointment?" During COVID-19 they may ask more questions about where their family is or what is happening.

Because of their dementia the person will not remember that they have told the story or asked the question before, often multiple times.

Support:

- Telling the person that they have already asked the question or told the story is unlikely to help and may lead to an argument or cause distress.
- Listen to what the person is saying and answer in a consistent way.
- If they repeat the story, gently move the conversation to a different topic.
- If the person can read, write information about appointments or answers to common questions on a white board that they can easily see.
- Engage the person in an activity to take their mind off the story or question.
- A structured, predictable routine can help.

Sexually disinhibited behaviour

Many people with dementia continue to have sexual needs.

For some people, if they have a sexual thought, because of their dementia, they may be unable to control the urge to act upon the thought. The person might also:



- misidentify others as their husband/wife/partner
- misinterpret the actions of others, for example, support with personal care as a sexual advance
- be trying to get dressed and come out of their room in a state of undress.



Support:

- Check if the person is too hot, is in pain, has an infection or other physical illness which may be making them uncomfortable.
- Review medications for any side effects.
- If the person is in a state of undress, maintain their dignity.
- Refer to the person by their name and avoid using terms of affection like “pet”
- If the person is touching inappropriately or making sexualised comments, calmly tell them that you do not like that, do not become angry.
- If a person has something in their hands they may be less likely to touch.
- Change the conversation to a different topic or engage them in activity.
- Show a photo of their partner or family and engage them in conversation.
- Support the person to engage in social activities and build relationships with others to reduce loneliness and meet the need for social interaction.

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.



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.



Because of their dementia, the person may not be aware that they need a bowel movement. If they have experienced faecal incontinence or had an accident, they may be embarrassed and attempt to clean up. When doing this they touch and smear their faeces because of difficulties with coordination.



Faecal smearing may happen because the environment is understimulating and the faeces are something to touch or feel for sensory input.

The person may misidentify their faeces as a piece of food or other object. If they have reduced taste or smell sensations they may not realise what it is.

Support:

- Review the person's physical health.
- It is understandable to feel upset, shocked or embarrassed but patience and understanding is important. If the person becomes aware that you are distressed, this may cause them more embarrassment and distress.
- If the person wears continence pads, ensure these are changed regularly.
- Check that the person is not too warm or experiencing discomfort or itching.
- Making the room more stimulating can help – using light and light projectors, use diffusers and other pleasant smells, play music or other sounds, using sensory items e.g. fidget blankets.



A person with dementia may not always have control over their emotions or what they say or do. If they are doing something and are told 'no, you can't do that', they don't understand that they have done anything wrong and are likely to be confused. They may shout because they don't understand why you are interfering in their business.



A person may be cross if they are experiencing pain, if they are frustrated about their difficulties, or if they are experiencing anxiety or low mood. It is difficult not to take this personally but it is important to remember that it is unlikely that the person is deliberately trying to upset others.

Support:

- Rule out pain or physical illness.
- Talk to the person to try to establish what they need and why they are upset.
- Remain calm and do not raise your voice.
- Use short phrases, say less and listen more when the person is upset.
- A positive facial expression and soft tone of voice can help.
- If you cannot find out what they need, offer them an activity, for example, to go for a walk or a cup of tea.
- Give the person space to calm down.
- Avoid using negative language or phrases such as 'No, you can't do that', 'That's bad/wrong' or 'Get out of there'

When a person walks 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:

- Offer a structured routine with a variety of activity.
- 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.
- 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.

