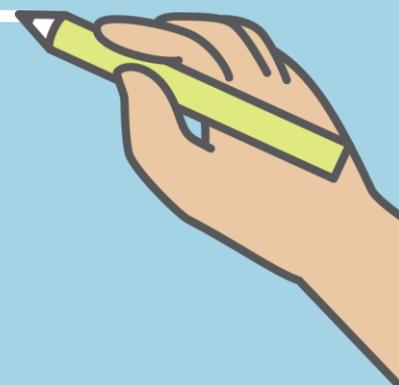


DEMENTIA UNITED COLLATED RESOURCES FOR CARE HOME STAFF

In relation to dementia and COVID-19
Last modified 16 April 2020

NOTE: THIS IS A WORKING DOCUMENT AND WILL BE UPDATED ON THE DU
WEBSITE: [HTTPS://DEMENTIA-UNITED.ORG.UK/](https://dementia-united.org.uk/)



INTRODUCTION

Dementia United have collated some of the resources, in to one place in order to enable care home staff to have access to any good practice and guidance, without having to work through the vast amount of information coming in. We recognise that we are in challenging times for care homes and this impacts on care home residents who are living with dementia, family members and staff. Today, around 70% of people living in care homes have dementia, a prevalence which has risen from 56% in 2002.¹

It is a Greater Manchester (GM) working document. Dementia United have collated resources that have been circulated in the last few weeks, either produced since the COVID-19 pandemic or that we found and considered would be applicable in the current challenging times. It is not intended as a definitive resource, as evidence keeps changing and guidance is emerging. Dementia United plan to make amendments for GM Care Homes as needed with further updated documents.

1. Restrictions to family members in visiting

We recognise that care homes have had to restrict family members from visiting and this could be increasing the distress for residents as well as resulting in increased anxiety for family members.

Suggestions in relation to restrictions to family visiting (Dementia UK 2020)

- Speak to family proactively about ways they can keep in touch. Find out which is the best way for them. Including video calling, telephoning and email.
- Arrange a time in advance that is suitable.
- Even if the person does not appear to understand verbal communication, hearing a familiar voice from a family member could still be beneficial
- Plan ahead with the family members in case there is a need when the person becomes distressed to speak to family i.e. during the night. Is this okay? Which family member and document this.
- Ask families to be creating and sending in a life story book, click the link [Life Story Book](#) for more details or ask them to complete a This is me – double click the link.



ThisIsMe_v2.pdf

- This is so that you have personal information about the resident in terms of background, interests, hobbies, music they like etc. This will also enable families to feel they are contributing to their loved one's care. This information would also be of value if their loved one has to go into hospital.

- Ask families if they would welcome sending in cards, photos, personal items that they are happy to send in or drop off, if they can
- Support residents to write to family members, sitting with them and help them to write – can these be sent by email rather than post? Keep in touch with families, let them know what you are doing to work through the difficulties you may be having and ask for any suggestions. If there are circumstances where a family need to visit, then a risk assessment would need to be completed for the family attending and explain this to the family in advance. Some families are keeping in contact through conversations through windows and patio doors. There has been government guidance provided for adult social care in relation to family visiting at the end of someone’s life.
- If there are circumstances where a family need to visit, then a risk assessment would need to be completed for the family attending and explain this to the family in advance. Some families are keeping in contact through conversations through windows and patio doors. There has been government guidance provided for adult social care in relation to family visiting at the end of someone’s life.⁷

If family members are expressing concerns about managing being apart from their family members, due to the restricted visiting, they may welcome being directed to accessing support themselves. Here are some helplines and support groups:

- [Silverline](#) Aimed at people over 55. Their helpline is open 24 hours a day, every day of the year. Telephone: **0800 4 70 80 90**
- [Age UK](#) Information and advice. Their helpline is open 8am-7pm, every day of the year. Telephone: **0800 678 1602**
- Further information is available too, via the Mental Health website link [here](#).

If carers have any concerns about caring for someone with dementia the below support may be helpful:

- [Dementia UK](#)
 - Speak with a Specialist Admiral Nurse. Their helpline is open seven days a week, 9am-9pm Monday to Friday, and 9am-5pm on weekends. Telephone **0800 888 6678** or email helpline@dementiauk.org
 - Click on the [Dementia UK link](#) as this provides families with guidance about keeping in touch during COVID-19
- [Alzheimer’s Society](#)
 - [Dementia Connect](#) is a support line where trained advisors can provide advice and guidance. Telephone: **0333 150 3456**
 - [Dementia Talking Point](#) is an online community where people affected by dementia can receive valuable support from people in similar situations.
- The [Relatives & Residents Association](#) is for family members who have relatives in 24 hours care. They are open Monday-Friday 09:30am-1.00pm. Telephone **020 7359 8136**
- [Together in dementia everyday](#) have a private Facebook group. It is a safe place for you to chat with other carers. You can join the group [here](#).

2. Impact of staff wearing Personal Protective Equipment (PPE)

During the COVID-19 pandemic, the staff team 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 care staff that they are familiar with, who are offering support.

Suggestions for managing staff wearing PPE

- 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.²

3. Impact of changes in the staff team

It is likely that staff may become unwell or having to self-isolate at home, if a family member becomes unwell with a suspicion of COVID-19 symptoms. It will also be challenging for health and social care teams in the community who work to support the care homes, as there will be different staff coming from these teams, or they may be working virtually with care homes.

This may result in fewer interactions for people with dementia. As a result, they could become bored and 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 staff can find difficult to understand.²

Looking after your staff team

- It is important that the staff team feel supported. Greater Manchester Health and Social Care Partnership are directing people to freely accessible resources to help with mental health and wellbeing during COVID-19. They can be found [here](#).
- [Shout crisis service](#) has already launched a text messaging support service. Social care staff can send a message with 'FRONTLINE' to 85258 to start a conversation. This service is free on all major mobile networks and is a place to go for support if you are struggling to cope and you need help.
- It is important for staff to reflect and learn from each other. This could help people to feel more able to do their job, learn from each other, share experiences and feeling. 10 minutes at the end of the shift may work well. Think about what worked well, what didn't, what would you do differently next time; in relation to responding to residents who are presenting with behaviour that challenges us.

4. Person centred approaches to managing increased anxiety and distress in residents

We have already mentioned that residents may be experiencing increased anxiety and distress given the changes in the staff team, and lack of contact with family. Care home staff may well be experiencing an increase in some residents presenting with behaviour that challenges them. We need to support staff to use effective strategies to reduce the risk of escalation in behaviour that challenges, when staff intervene.

What is the cause of the behaviour that challenges?

We start with looking for clues as to why the resident is presenting with anxiety, distress or behaviour that challenges.

Delirium

If a person living with dementia has a physical health problem (including COVID-19) they are at a high risk of having a delirium, causing an increase in confusion, reduced attention and other symptoms. The British Geriatric Society have put together [guidance](#) around COVID-19 and delirium and our colleagues in Yorkshire and Humber have produced a useful [bulletin](#). However, we still need to put into place individualised non-drug interventions to minimise the risks as well.³

Assessment for other factors

There may well be other reasons for the increased anxiety and distress. The presence of behaviour that challenges staff is the resident communicating and it is our job to try and find out what they are communicating.

Assess for all factors that cause behaviour that challenges us. This could include a need for **love, attachment, comfort, identity, occupation and inclusion.**



Image taken from Greater Manchester Mental Health NHSFT Guidance on Challenging Behaviour

Example – a resident walking with purpose

- **Attachment** - Is the person missing someone and/or something and trying to find them? Or are they lost?
- **Comfort** - Are they seeking the toilet or something to eat and drink? Do they want to exercise? Perhaps they enjoyed walking in the past and this brings back positive memories and helps to reduce anxiety. They could be walking to relieve pain maybe as a result of an infection or perhaps they are having difficulties using the bathroom (constipation or incontinence).
- **Identity** – Is the resident looking for items that contribute to their identity e.g. the clothes they like to wear, music they like to listen to, a way to wear their hair how they like. Were they previously a dog walker so walking is something that feels a part of their identity?
- **Occupation** – Did their occupation used to be quite active? Has something in their daily routine changed that used to occupy them with meaningful things so they are now bored and are walking to keep occupied?
- **Inclusion** - The person might feel lonely and want company.
- **Love** – Can range from loving a person, an activity, a favourite food, to loving their religion and feeling self-love. Are they seeking any of these by walking?

Some additional questions that might be useful when assessing needs and desire to walk

- Have they always been a person who walks a lot or is this something new?
- What do they do when they walk – do they gather things, rub surfaces, move furniture, push trolleys or go into other's rooms?
- Are they usually safe walking or is there a falls risk?
- What sort of things (or time of day) are they more likely to sit down for?³

Under normal circumstances, we would not attempt to intervene with ‘walking with purpose’ unless: there is a risk to the person’s food/water intake; it is causing extreme tiredness; risk of falls; or distress to the person or others.

However, if the person has a suspected or confirmed case of COVID-19, the care home may receive clear medical guidance to isolate the resident to their bedroom.⁴

Follow [Dementia UK](#) for more information on how to understand changes in behaviour of those living with dementia. The Social Care Institute for Excellence also has [good advice](#).

What possible solutions are there to meet the needs of people who display challenging behaviour?

- When you are considering how to meet these needs of an individual, speak with family members and use information you may have in a [This is Me](#)



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- Or information from a life story book – click on this link [Life Story Book](#). Knowing the resident will help you understand their behaviour.
- Make a note of the times of day a particular behaviour occurs and check if there are any patterns that may help you to plan.
- Make a note of what has helped and what has not.
- This will help you to come up with a person-centred plan for each resident.

Activities

The following activities could be meeting someone’s need for **love, attachment, comfort, identity, occupation** and **inclusion**.

- **Physical exercise** Try walking with the person, encouraging them to use an area that can be walked in e.g. creating separate isolation areas with access to the outdoors. Walking alongside at a slower pace may mean the person slows down in step with you. Try dancing and swaying by putting music on and joining in. Seated exercise could be useful or throwing a bean bag or soft ball. This [leaflet](#) is designed for older adults to help them keep moving whilst isolating.
- **Doll or pet therapy** – These can help with people who are reassurance seekers and can ease anxiety. They will not work for all residents. Please refer to the Dementia UK [Guide on using dolls in dementia care](#)

- **Twiddle muffs** are designed to provide a stimulation activity for people living with dementia if family are able to knit these. Click [Here](#) for a knitting pattern.
- **Rummage bag** Ask family members to provide a bag or box and add in personal items. Family can provide items that can be washed or wiped clean – however this bag or box is unique to that person.
- **Occupation** Ask the family what the resident's occupation was. Is there a repetitive task they could do to mimic their old occupation e.g. ordering of papers, folding etc. Try and incorporate whatever you can, even with reduced staff time. For example, offer pens and paper, encourage and assist to tidy own drawers and wardrobes. It is not about the output, more on the engaging the person in an activity that keeps them occupied and engaged.
- **Magazines or papers** Again ask families to help with this. Images in the magazines could be used to distract and engage in conversation.
- **Music or a favourite TV show/film** These can be used as distraction, for pleasure, to bring back memories and enable attachment. Below are some good music resources:
 - Dementia UK click on this [Guide on Music Therapy](#)
 - Dementia radio www.mdf.co.uk
 - Radio reminiscence <https://radioreminisce.com/>
- **Play list for life** <https://www.playlistforlife.org.uk/>
- **Virtual activities**
 - **Liverpool Museum** – click on [My house of memories app](#)
There is a short animation explaining how to use the app and then how to view the objects in the museum. It enables you to develop a person-centred memory tree with objects from the museum. Along with the picture of the object, there is information about it, as well as music and discussion points.
 - **National theatre** live releases a new play every Thursday at 7pm on [You Tube](#). It's then available for the rest of the week to access for free.
- **Aromatherapy** may address a need for relaxation and reduced stress. Dementia UK have produced a [useful guide](#) to aromatherapy.

Below are activity summaries:

- This [link](#) takes you to a great resource and video about inspiring care home residents to be creative as well as links to physical exercise resources.
- This is a [link](#) to the Alzheimer's Society resource on different activities for people living with dementia during COVID-19

General calming techniques

Refer to Dementia UK [document](#) about calming techniques when coping with distress for a person with dementia and for yourself.

- Communicate in short 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.
- Sit and hold their hand, if they will accept this.
- Use distraction
 - Change the scenery – try going into a different space
 - Offer a drink
 - Offer a snack
 - If sundowning ([changes in behaviour at dusk](#)) is evident, turn the lights down to ease the transition into night-time and close the curtains
 - Utilise one of the above activities

If the person cannot be encouraged to remain in their room and there is a need to try and keep them away from other residents as they have symptoms of COVID-19

- Close other's bedroom doors, unless this poses a risk, as they are less likely to open a closed door.
- Can a portion of the unit be given over to them, so they have the space to move around?
- If you are trying to get the person to stop doing something (i.e. walking), you may have to walk with them and match their speed, then gradually change the rhythm or pattern rather than opposing them.³

5. Legal and ethical issues

Planning for the difficult decisions that may need to be made in relation to COVID-19 pandemic.

- There will be decisions in relation to an individual’s wellbeing and overall public good, within the care home. It may help to use principles from [ethical frameworks](#) in considering these decisions.
- It is important to ensure that in such crisis situations, individual needs and preferences are not automatically considered secondary to collective or community needs.
- However, public health approaches clearly involve a degree of restriction of ordinary freedom in the context of social distancing. This may need to be enforced, especially for individuals in our care who are vulnerable – this will require careful consideration in each instance. Please refer to the Royal College of Psychiatrists COVID-19 [ethical consideration](#).

The Mental Capacity Act (MCA)

The Mental Capacity Act (MCA) applies, when an individual is assessed as lacking the mental capacity to make a specific decision. With regards to COVID-19, this could include decisions relating to their care e.g. the resident does not understand the need to use oxygen therapy to help their breathing. If the resident is assessed as not having the mental capacity to make the decision, then the MCA requires staff to consider making a best interests decision. Check if the resident has a Health and Welfare Lasting Power of Attorney or Court Appointed Deputy as they will be the decision maker. Speak to family to involve them in all best interest decisions. The government guidance, on the 9th April 2020, indicates that the principles and safeguards of the MCA remain. The guidance recognises that some of the new arrangements needed to support someone to self-isolate for example, may be more restrictive than usual during the COVID-19 pandemic. The guidance stresses that each decision, using the MCA needs to be made in relation to that individual.

It will not be possible to hold a face to face best interests meeting, however it may still be possible to consult family using conference calling or virtual meetings via Skype or Zoom, or over the telephone. Family might be able to help you make a compromise that respects everyone’s safety and wishes. The government has provided guidance in relation to the Mental Capacity Act, as of 9th April 2020 “ in many cases, it will be sufficient to make a best interests decision in order to provide the necessary care and treatment and put in place the necessary arrangements, for a person who lacks the relevant mental capacity”.



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The MCA cannot be used for the protection of others e.g. if the decision relates to the resident's understanding of the need to remain quarantined for the protection of others; Public Health Law (such as the Coronavirus Regulations 2020) would apply and you can record in the patient's clinical records that the patient's liberty is restricted for the wider public interest.⁵ For each resident, the staff will need to balance clinical need (both mental and physical), patient safety and risk.⁶

6. Other resources

- British Geriatric Society [COVID-19 End of life care and dementia](#)
- British Geriatric Society [COVID-19 End of life care in older people](#)
- British Geriatric Society [COVID-19 Dementia and Cognitive Impairment](#)

7. References

1. [NHS England 2020 - The framework for Enhanced Health in Care Homes.](#)
2. [Dr Frances Duffy \(Consultant Clinical Psychologist\) and Jill Richardson \(Associate Psychologist\). Northern Health and Social Care trust March 2020. Supporting Carers and Care Staff to Understand and Respond to Changes in Behaviour in People with Dementia During the COVID-19 Pandemic](#)
3. Thwaites and Marshall 2020



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4. British Geriatric Society [Managing the COVID-19 pandemic in care homes](#)
5. National Association of Psychiatric Intensive Care and low secure Units (NAPICU) March 2020 - managing acute disturbance in the context of COVID-19
6. [NHS England and NHS Improvement - Managing capacity and demand within inpatient and community mental health, learning disabilities and autism services for all ages. Version 1. March 2020.](#)
7. [Department of Health and Social Care. COVID-19: Our Action Plan for Adult Social Care released 15.04.2020](#)



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