

COVID 19 – Advice note for Care Providers supporting people experiencing dementia (Suffolk County Council 07/05/2020)

This advice note has been produced in response to concerns raised by the care sector as to the best way to support people living with dementia during the Coronavirus pandemic.

People living with dementia often thrive in environments that are familiar to them. The Coronavirus pandemic is bound to cause disruptions to the things that they find familiar, be that contact with familiar people, places or routines.

This advice note is an overview of key guidance from various local and national sources, all of which are referenced and included throughout this document for further reading and information.

People who walk with purpose

- Think about the “need” that the person has for wanting to walk, what is it they do when they walk and does it happen at a certain time of the day– it is likely due to one of the following reasons:
 - Exercise – they may have been a life-long active person.
 - Occupation – are they fulfilling a previous work or home-life role?
 - Seeking – are they looking for a particular person or place or seeking reassurance, company, food?
 - Pain – we know some people who have back or joint pain are more likely to walk excessively.
- Think about what else maybe able to fulfil that “need” – for example if they are someone who used to have a hobby like gardening, can the garden be bought inside instead?
- A list of suggested online resources is available at Health Innovation
<https://healthinnovationnetwork.com/healthy-ageing/maintaining-activities-for-older-adults-during-covid19/>

Susannah Thwaites (Occupational Therapist) and Dr Joanna Marshall (Clinical Psychologist)
Supporting people living with dementia who ‘walk with purpose’ during the COVID-19 pandemic
available at <https://www.eastsussex.gov.uk/socialcare/providers/covid-19-asc/>

<https://arc-w.nihr.ac.uk/Wordpress/wp-content/uploads/2020/04/Dementia-and-walking-COVID-review.pdf>

Guidance on exercising: [https://www.healthysuffolk.org.uk/uploads/2020-04-28 Permitted Exercise Guidance during COVID \(Public facing\) .pdf](https://www.healthysuffolk.org.uk/uploads/2020-04-28%20Permitted%20Exercise%20Guidance%20during%20COVID%20(Public%20facing).pdf)

Social distancing/isolation

Please refer to the Suffolk County Council document “MCA, social distancing and isolation”
<https://suffolksp.org.uk/assets/Social-distancing-and-self-isolation-for-people-who-may-lack-capacity.pdf>

This document explains that during this time if someone lacks capacity to understand the Public Health guidance regarding social distancing and isolation then decisions will need to be made in their best interest. An individualised approach needs to be taken for each person and this must adhere to the least restrictive principles.

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For people with dementia who walk with purpose this may be more challenging, and each of these best interests' decisions should involve all relevant people in the person's life. If the decision is complex and there is difficulty in balancing the need to prevent infection spreading vs. the person's physical and/or psychological well-being this should be discussed with the DoLS Team via

DOLSteam@suffolk.gov.uk

Consider ways to lessen potential distress to people; is it viable to allow people to walk around a unit if others are ok to have their doors closed for short periods of time, does time need to be factored in to spend some 1:1 time with them when they are more likely to show distress, can visual barriers such as bunting be used across doorways to discourage people from leaving their rooms? For those living within Extra Care schemes, where they have their own front door, consideration needs to be given as to whether an application to the Court of Protection for authorisation of restrictions that amount to a Deprivation of Liberty (to ensure someone is social distancing or isolating as necessary) is required.

Socialisation and Loneliness

Lack of contact with family and familiar people coupled with loneliness and boredom will undoubtedly increase stress for some people living with dementia. Care providers are working hard to reduce the impact of people being separated from their loved ones and usual activities. Dementia UK has the following suggestions:

- Arrange frequent phone calls. Explain the situation using simple and short sentences that can be repeated on a frequent basis, for example, that there is a virus going around and for the safety of people in the home, people cannot visit, temporarily
- Asking relatives and friends to post letters to the person and asking staff to read them out
- Using technology to keep the person in contact with loved ones. Many homes use Facetime or similar platforms to communicate; so, check with loved ones what they use. Remember that you may need to help some people to use the technology to stay in touch
- If the person likes flowers, ask relatives if they could send a small bouquet and help the person arrange them as an activity
- Ask family and friends to send photographs with notes on (listing the people in the photo) so the person and you know who they are. You can then start conversations with the person about the photos

For activities again use the link above from the Health Innovation site and also ideas from Alzheimer Society: <https://www.alzheimers.org.uk/get-support/coronavirus-activity-ideas-people-living-dementia#content-start>

- Remember to use the VERA framework when supporting someone to help to reduce distress:

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VERA Framework



- **Validation** – accept person's reality
- **Emotion** – acknowledge emotion
- **Reassurance** – you are here to help
- **Activity** – meaningful distraction

Blackhall A., Hawkes D., Hingley D. & Wood S. (2011) VERA framework: communicating with people who have dementia. *Nursing Standard* **26** (10), 35-39.

VERA framework Caring for People with Dementia
<https://www.youtube.com/watch?v=craoo582xm0>



Other important considerations:

- People with dementia are much more prone to develop delirium (a confusional state) if they develop an infection – being aware that a person may have dementia will alert staff to this increased risk. Equally a sharp deterioration in a person's cognitive ability may be due to the onset of Delirium rather than as a result of Dementia. In such instance it is important that the cause of the delirium is identified and addressed
- Going into hospital is frightening enough and particularly so for someone with dementia – staff involved in screening and treatment should be aware if a person has dementia and be prepared to take extra time while assessing and treating them. Avoiding unnecessary hospital admissions is important
- Some people with dementia may have difficulty understanding complex instructions about self-isolation or handwashing – keeping information accessible and repeatable is key
- People with dementia may lack awareness of and be less able to report symptoms because of communication difficulties – people should be alert to the presence of signs as well as symptoms of the virus (“look beyond words”)
- People with dementia may have swallowing difficulties which could put them at increased risk of developing chest infections and dehydration – a swallowing assessment may be helpful

Taken from: <https://www.bgs.org.uk/resources/covid-19-dementia-and-cognitive-impairment>

In addition to the DoLS Team, support can be provided from the **Dementia Intensive Support Team (DIST)** on 01473 891733 or 07852 769172. These numbers are staffed between 9am and 5pm each day. An answerphone is available outside of these hours. Also, Social Work Services via Customer First on 0800 800 4005 and local community health care teams.

Support for people living in their own homes including Extra Care Housing is also available from Dementia Together: <http://www.dementia-together.com/home/about>

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General Resources & References

Tips for housing providers supporting people with dementia

<https://www.housinglin.org.uk/Topics/type/Coronavirus-COVID-19-Tips-for-the-housing-sector-on-supporting-someone-affected-by-dementia/>

Guidance on managing the pandemic in care homes

<https://www.bgs.org.uk/sites/default/files/content/attachment/2020-04-14/BGS%20Managing%20the%20COVID-19%20pandemic%20in%20care%20homes%20V2.pdf>

Alzheimer's society resources

<https://www.alzheimers.org.uk/get-support/coronavirus-covid-19>

Guides from Alzheimer's Disease International

<https://www.alz.co.uk/news/adi-offers-advice-and-support-during-covid-19>

<https://www.alz.org/professionals/professional-providers/coronavirus-covid-19-tips-for-dementia-caregivers>

Are you caring for a person with dementia?

Practice these tips during COVID-19



 Try to 	 Avoid
<ul style="list-style-type: none">✓ Keep in regular contact with loved ones via phone or video calls✓ Place reminders around the house to wash hands✓ Exercise regularly, but listen to your body - don't overdo it✓ Try keeping to a daily routine✓ Limit watching or reading the news to once or twice a day	<ul style="list-style-type: none">✗ Scare tactics to keep people washing hands or practicing physical distancing✗ Unnecessary news or media noise✗ Unscheduled napping or prolonged sleeping which may cause sleep issues✗ Getting upset if the person is confused or upset by the situation