

**How to support people with dementia living in care, who ‘walk with purpose’ (during the COVID-19 pandemic)**

The COVID-19 pandemic raises particular challenges for care home residents, their families and staff that look after them. Recent guidance from the British Geriatrics Society states:

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| * *“Once care home staff have a suspected case they should isolate that resident to their room and commence use of the personal protective equipment (PPE)”* |
| * *“This will pose particular challenges for residents who ‘walk with purpose’ (often called ‘wandering’) as a consequence of cognitive impairment but require isolation”* |
| * *“Community mental health and dementia teams should be prepared to prioritise support to care homes who need to isolate a resident ‘walking with purpose’”* |
| * *“An antecedent, behaviours, consequences approach should be used to understand the behaviour and try to modify it where possible”* |
| * *“Physical restraint should not be used”* |

There are normally many positive aspects to people living with dementia ‘walking with purpose’ (e.g. exercise, stress reduction), so it is often appropriate to provide safe walking areas, rather than deny people the opportunity to engage in this behaviour (James, 2011). Under normal circumstances, we would not attempt to treat /intervene with ‘walking with purpose’ unless: there is a risk to the person’s nutritional intake; it is causing extreme fatigue; 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 (Gordon et al., 2020).

We know that most behaviours that challenge happen around interactions with carers when they are trying to get people to do what they do not want to do, either to stop some problematic behaviour (e.g. stop going into someone else’s room) or to start a behaviour aimed at enhancing a person’s wellbeing (e.g. start taking medication or start getting washed/dressed) (Stop Start Scenarios). If care home staff are instructed to isolate a resident and stop them ‘walking with purpose’, this intervention itself may trigger an escalation in behaviours that challenge (e.g. physical/verbal aggression).

There are many common biopsychosocial causes of walking with purpose (James, 2011). Understanding the reason or **need** that the ‘walking with purpose’ is meeting / trying to meet for the person will help us to decide what interventions might be appropriate to try to meet this need.

To help understand why the person living with dementia ‘walks with purpose’, you may find it helpful to answer the following questions:

* **Prior to COVID-19 what was their level of activity?** Have they always been a person who walks a lot or is this something new? Did they enjoy a daily walk outside or any form or exercise? Perhaps they walked for a newspaper or walked the dog each day?
* **Do they ‘walk with purpose’ because they have ‘time shifted’ and believe they are elsewhere**? They may believe they are at work or in their childhood home. If so what did they do for a job, what were their hobbies and their daily routine?
* **What do they do when they ‘walk with purpose’**? – Do they gather things, rub surfaces, move furniture, push/pull items or go into different rooms? Do they say anything when doing this? Are they seeking out a particular person, place, company, food or reassurance?
* Are they usually safe ‘walking with purpose’ or **is there a falls risk?**
* **Is there a time of day when they are more likely to need to be active and ‘walk with purpose’?** Is the time of day significant to them? For example, is it the time they used to go to/return from work, is it the time they would do a specific chore, e.g. walk the dog or collect the children?
* **What sort of things (or time of day) are they more likely to sit down for?**
* **‘PINCHME’** (PAIN, INFECTION, CONSTIPATION, HYDRATION, MEDICATION, ENVIRONMENT)
  + Could the person be in pain or discomfort? What is their current pain relief? Are they compliant with this? We know some people who have back or joint pain are more likely to walk excessively.
  + Could the person have a water or chest infection?
  + Could the person be constipated?
  + Could the person be dehydrated?
  + Could the person have missed/taken too much medication?
  + Could the person be responding to anything new/different in the home environment? What has changed around the home?

We may not be able to eliminate the risk or stop the person ‘walking with purpose’ completely, but every effort needs to be made to meet the person’s needs in other ways while they are isolated, minimising the risk.

**Primary preventative strategies**

(Things we do to improve the person’s quality of life and reduce the likelihood of Behaviour that Challenges)

Interventionsneed to be chosen according to what we think the unmet need may be. The following is not an exhaustive list, but ideas could be:

**Exercise seekers:**

* Playing ‘football’ with a large exercise ball up and down the corridor, when others are not around, or in their room if it is large enough.
* Dancing to lively music that they like.
* More use of garden areas if on the ground floor. Allow them time in the garden when others are not using it and encourage them to be active e.g. carrying a watering or sweeping.

**Being busy seekers:**

* Can they have an individualised rummage box in their room that has objects that are more easily sanitised?
* Encourage them to sort their drawers and wardrobe, even if this means messing things up first so that they need to sort, fold and put the things away.

**Reassurance / company seekers:**

* The BGS guidance recommends that care homes should take advantage of videoconferencing software on smartphones, tablets and portable computers as much as possible to maintain human contact for residents (Gordon et al., 2020).
* Consider Simulated Presence Therapy (SPT) if the sight or sound, on audio or video, of a loved one may provide comfort and reassurance. Having a video/audio recording may enable care home staff to play this repeatedly if videoconferencing contact is forgotten by residents with dementia.
* If the person is calm and does not walk if they have another person with them this may build a case for a period of one to one staff support.

**Environmental adaptation:**

* Try to make the person’s room as recognisable as their space and homely as possible. Family cannot come in to visit but may be willing to drop off some extra items to help with this. If the room is not enriched, they will seek elsewhere.
* Do they have access to individualised music (such as Playlist for Life)?
* Do they have access to a TV and programmes on that do not need too much understanding of language? Be careful of having the news on or programmes with distressing content that they may interpret as real.
* Do they have access to a DVD player and DVDs of familiar and favourite films, sports they like?

**Secondary (reactive) strategies**

(Things to do when we notice a behaviour occurring or getting worse (i.e. if a resident tries to leave their room)

* People are most likely to ‘walk with purpose’ when they have moderate/severe dementia. At this cognitive level, the person will have little understanding of what is said to them and is unlikely to be aware of, or retain information about “coronavirus” or “COVID-19”. They are unlikely to benefit from verbal explanations about the risks to themselves or others of leaving their room.
* A simple explanation such as “There is a nasty flu”, “We need to stay in our rooms” may be helpful. Please refer to the document*: ‘How to talk to someone living with dementia about COVID-19’* for further guidance.

If the person cannot be encouraged to remain in their room:

* 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 (Snow, 2012).
* Avoid telling a person to stop doing something, instead greet them with a smile and a wave, say their name and ask the person for help with something. Ensure the task/activity is meaningful to them and their interests.

**If you are struggling to care for a resident who ‘walks with purpose’ and the person has a suspected/confirmed diagnosis of COVID-19, please contact your local Community Mental Health Team or Care Home Liaison team who may be able to support you by developing a personalised Behaviour Support Plan for the person.**

**References**

* Gordon, A., Burns, E., Astle, A., Barker, R., Kalsi, T., Williams, C., and Clegg, A. (2020). *Managing the COVID-19 pandemic in care homes. GOOD PRACTICE GUIDE.* www.bgs.org.uk/COVID-19.
* James, I.A. (2011). *Understanding Behaviour in Dementia that Challenges: A Guide to Assessment and Treatment.* Jessica Kingsley Publishers.
* Snow, T. (2012). *Dementia Caregiver Guide; Teepa Snow’s Positive Approach techniques for caregiving, Alzheimer’s and other forms of dementia.* Cedar Retirement Community.