Supporting people living with dementia who 'walk with purpose' during the COVID-19 pandemic

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The COVID-19 pandemic raises particular challenges for care home residents, their families and the staff that look after them. Recent guidance from the British Geriatrics Society (BGS; Gordon et al., 2020) states:

➢ *"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 person's wellbeing (e.g. start taking medication or start getting washed/dressed) (Stop Start Scenarios; James and Hope, 2013). 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). We need to support mental health staff to assess the needs that may be driving the 'walking with purpose' behaviour and to develop individualised Behaviour Support Plans to attempt to meet these needs in other ways while they are isolated, minimising the risk of residents walking out of their bedrooms. We need to support care home staff to use effective communication strategies to reduce the risk of escalation in behaviour that challenges when staff intervene (James, Marshall and Thwaites, 2017). 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 minimise this risk. If a person living with dementia has or is suspected of having COVID-19, they are a high risk of having a delirium, which could contribute to their presentation and 'behaviour'; however we still need to support the care home to implement individualised non-pharmacological interventions to minimise the risks.

Use the Behaviours that Challenge Clinical Link Pathway (CLiP)

- As part of the **Assessment:**
- Gather information about the person (personal history document)
    - What did they do for a job, what were their hobbies, routines?
- Ask questions to establish their level of dementia
    - Communication skills, GEM level, visual field
- Prior to developing symptoms of COVID-19 what was their level of activity? 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?
- Is there a time of day when they are more likely to need to be active and walking?
- What sort of things (or time of day) are they more likely to sit down for?
- PINCHME – Could the person be in pain or discomfort and what is their current pain relief regime, compliance etc.?

Develop an individualised **Behaviour Support Plan:**

- There are many common biopsychosocial causes of walking with purpose (see Table 2.5 in James, 2011).
- What is **the need** that the 'walking with purpose' is meeting / trying to meet for the person?
- 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.

Primary preventative strategies - (Things we do to improve the person's quality of life and reduce the likelihood of Behaviour that Challenges)

- **Interventions** need to be chosen according to what we think the unmet need may be. The following is not exhaustive list but ideas could be:

Exercise seekers:

- Playing 'football' with 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 – carrying a heavy watering can, sweeping etc.

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 (Amber or Ruby on GEMS). At this cognitive level, the person will have little understanding of what is said to them, so are unlikely to benefit from verbal explanations about the risks to themselves or others of leaving their room.

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).

References

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