

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

* There are normally many positive aspects to people living with dementia ‘walking with purpose’ (also known as ‘wandering’), for example it is a form of exercise and stress reduction.
* Therefore, rather than seeking to deny people living with dementia the opportunity to engage in this behaviour, it is often more appropriate to support them to safely ‘walk with purpose’; whether that be at home, in the community, in hospital, or in a care home.
* Generally speaking - under normal circumstances - clinicians and care staff would not attempt to treat/intervene with ‘walking with purpose’. Treatment/intervention would only be considered if there is a risk to a person’s nutritional intake, it is causing extreme fatigue, there is a risk of falls, and/or it is causing distress to the person or others.
* The current Government guidance around social-distancing and self-isolation (due to the COVID-19 pandemic) means that we are all being encouraged to “stay at home” for the foreseeable future. For someone living with dementia - who has a cognitive impairment - the Government’s advice is likely to be difficult to comprehend, retain and adhere to, with the restrictions particularly problematic for those who ‘walk with purpose’.
* We know that most ‘behaviours that challenge’ (also known as ‘challenging behaviours’) happen around interactions with carers. This often happens when carers are trying to get someone to do what they do not want to do, either to stop some problematic behaviour (e.g. stop someone going outside of the house) 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; James and Hope, 2013).
* If a person living with dementia is forced to self-isolate at home (due to the COVID-19 pandemic), which in-turn limits their freedom to ‘walk with purpose’, this may result in an escalation in ‘behaviours that challenge’ (e.g. physical/verbal aggression towards yourself as their carer).
* In such a situation, whilst you may not be able to eliminate the risk or stop the person ‘walking with purpose’ completely, every effort should be made to minimise this risk.
* This can be achieved by trying to meet the need(s) of the person living with dementia, and through the use of effective communication strategies.

**QUESTION 1 - What ‘need’ is the ‘walking with purpose’ meeting/trying to meet?**

* There are many common biological, psychological and social causes of ‘walking with purpose’. Thus it is important to ask this question.
* In seeking to understand why the person living with dementia for whom you care ‘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?
    - 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 house?

………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………….

**QUESTION 2 - What can you do to improve the person living with dementia’s quality of life, and reduce the likelihood of their behaviour – including ‘walking with purpose’ - becoming challenging?**

* 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:
  + For **‘exercise seekers’:**
    - Playing ‘football’ with a large exercise ball in the living room, when others are not around.
    - Dancing to lively music that they like.
    - More use of garden/outdoor space (so long as social distancing is maintained). Allow them time in the garden and encourage them to be active – carrying a heavy watering can, sweeping etc.
  + For **‘being busy seekers’**:
    - Do they have a personal ‘rummage box’? This should be accessible and contain lots of activities to keep them busy and items/objects to fiddle with/fix.
    - Encourage them to ‘sort’ any drawers and wardrobe, even if this means messing things up first so that they need to sort, fold and put the things away.
  + For **‘reassurance/company seekers’**:
    - Take advantage of videoconferencing software on smartphones, tablets and portable computers as much as possible to maintain human contact with friends and extended family.
    - Consider ‘Simulated Presence Therapy’ (SPT) if the sight or sound of a loved one may provide comfort and reassurance. Having a video/audio recording may enable you to play this repeatedly if videoconferencing contact is forgotten by the person living with dementia.
    - Please refer to the document: *‘How to maintain wellbeing and/or reduce acute distress in people living with dementia during the COVID-19 pandemic’* for further information/advice.
  + **Environmental adaptation:**
    - Bring the outside inside – do you have any plants that can be tended to inside the house?
    - Do they have access to individualised music (such as Playlist for Life or through Spotify/YouTube)?
    - Do they have access to a TV and programmes, ideally ones that do not need too much understanding of language? NOTE - 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?
    - Please refer to the document: *‘How to maintain wellbeing and/or reduce acute distress in people living with dementia during the COVID-19 pandemic’* for more ‘virtual environment’ activities.

**QUESTION 3 – What to do when you notice a behaviour occurring or getting worse (i.e. if the person living with dementia is ‘walking with purpose’ and attempting to leave the house)?**

* People are most likely to ‘walk with purpose’ when they are living with moderate/severe dementia.
* At this cognitive level, the person living with dementia 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 the property/not adhering to social-distancing/social-isolation guidance. 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 the property:
  + Ensure the front entrance/ gate is appropriately secured at all times. Consider having ‘door sensors’ installed if this is a common occurrence.
  + If the person living with dementia chooses to open the door and steps outside, bring to their attention the fact that the “road is quiet”/”everyone else is indoors”/”everyone else is at home” “because of the virus”.
  + Redirect them to a room inside the house by asking them to support you with a specific task or activity (“I need you to xxxx”, “please will you xxxx”, “you said you would do xxxx for me”). Ensure the task/activity is meaningful to them/their interests.
  + If they are adamant about going outside the house, redirect them to the garden/outdoor space. If you are able to divert and distract them, support them to engage in a meaningful activity, e.g. sweeping the leaves, watering the plants, washing the windows, planting seeds, tidying the shed (all with supervision).
  + If the person with dementia is adamant about walking, support and guide them to walk to a secluded outdoor space where social distancing can be adhered to at all times. Support the person living with dementia to walk a circular route, which ends back at home. Again, bring to their attention the fact that the “road is quiet”/“everyone else is indoors”/“everyone else is at home”.
  + NOTE - We know that, if you are trying to get the person to stop doing something (i.e. walking away from home), you may have to walk with them and match their speed, then gradually change the rhythm or pattern rather than opposing them (Snow, 2012).