Supporting people with Dementia who Walk with Purpose: Infection control guidance for care homes in Hull.

The Covid-19 pandemic has created many new challenges for people who live in care homes and for staff. This guide builds on lessons learned throughout the pandemic for care homes supporting people with dementia who "walk with purpose" and:

- Have, or are suspected to have, Covid-19 or another communicable disease such as seasonal flu or norovirus
    - Public Health guidance is to isolate these individuals

Why do people walk with purpose?

When a person with dementia walks (sometimes referred to as wandering or pacing) it is usually because they are going somewhere, looking for someone, wanting to do something or wanting to get some exercise – they are trying to meet a need.

If a person sits in the same location for a long time with no activity to engage them, they are likely to become bored, get up, walk and seek something to do. This will be more likely if the person has to stay in their room because of the need to self-isolate with a communicable disease.

Walking with purpose can be positive for people living with dementia. Normally, we would not attempt to limit this activity unless there are risk factors such as the person's nutritional intake; causing extreme fatigue; risk of falls; or distress to the person or others.

Trying to make a person 'stay put' can itself trigger further distress. This may lead to a change in the person's behaviours as they are unlikely to understand why they cannot leave their room. The need that walking usually fulfils will go unmet. So, it is important to try to understand what is going on for the person, and achieve cooperation.

Getting further advice and support:

Hull City Council Adult Social Care Response Team – asccovid19@hullcc.gov.uk

GP Practice – contact the resident's GP practice, especially if there have been changes to the person's usual mood and behaviour. These could be related to the onset of pain, discomfort, or an acute delirium (see below).

Frailty Team – Specialist frailty team is available if further advice is needed on medical management of the infectious disease, delirium or dementia. The team are available on 01482 450078

Hull City Council Deprivation of Liberty Safeguards – dols@hullcc.gov.uk – please let the DoLS team know if your setting is currently experiencing a communicable disease outbreak.

"Think Delirium"

Delirium may be caused by Covid-19 or other infection, or by other problems such as pain or constipation. It can case rapid onset of distress and changes in behaviour, including agitation and restlessness (hyperactive delirium), or drowsiness and inactivity (hypoactive delirium). When a person with dementia has an acute delirium, it might appear as if the dementia is "getting worse".

Hypoactive delirium has been reported as a possible early sign of Covid-19 infection, for people living with dementia and frailty.

Please seek urgent medical advice for any concerns regarding delirium.

<u>Steps to follow – managing “walking with purpose”</u>

Always think about the need that the person is trying to meet by walking. What do you know about the person and their life history? What can family and friends tell you?

The following areas are ideas of how to support the person. Even though these ideas may be familiar to you, they are included as a prompt to revisit things which might not have felt relevant to the person previously. Not every idea will be suitable for every person and so a blanket approach is not advised.

Step 1: Strategies to support the person to stay in their room:

- For people who are seeking physical activity/exercise:
  - Playing ball games with a balloon, beach ball or soft ball in their room
    - For infection control purposes, please ensure that the soft balls are wipeable ones, not foam or grooved or material.
  - Dancing – familiar music that the person likes might be the most settling; though it’s worth trying different music, at a pace which suits the person’s agility
- For people who like to be busy and are seeking occupation:
  - Can they have an individualised rummage box in their room that has objects that are easily sanitised?
  - Encourage them to do some cleaning or sort their drawers/wardrobe, even if this means messing things up first so that they need to sort, fold and put the things away
  - Try activities that may be related to previous jobs, roles, routines and things they enjoyed doing, for example planting seed trays for someone who enjoyed gardening
- For people who are seeking reassurance or company:
  - Use phone or video calls to maintain contact with family and friends, including other residents within the care setting
  - Consider audio or video recordings from loved ones – repeated playing might be a comfort for some people 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
- General considerations:
  - Try to make the person’s room as personal and homely as possible. Family may be willing to drop off some extra items to help with this. If the room does not create a feeling of “belonging” the person will look elsewhere to find this.
  - Does the person have access to a TV and help to choose and watch the programmes that interest them? Be careful of having the news on or other potentially distressing content.
  - Is there anything irritating the person that they’re trying to get away from? Is there noise outside or from adjoining rooms? Has a television or radio been left on too long, or switched to a channel that doesn’t reflect personal tastes?
  - Does the person have access to a DVD player and DVDs of familiar and favourite films or sports they like?
  - Could the person be in pain? Does their pain relief need reviewing?

Step 2: Strategies to minimise risk if the person does not remain in their room

- Playing ball games up and down the corridor, when others are not around
- Use of garden areas. Allow the person time in the garden when others are not using it and encourage them to be active – e.g. carrying a watering can, sweeping up.

- Close other bedroom doors (unless this poses a risk) as generally people are less likely to open a closed door.
- Hand hygiene – this could be made into a therapeutic ‘hand massage’
- Resident wearing PPE – a few may be able to tolerate this
- Can a portion of the unit be given over to the person, all or some of the time, so they have the space to move around? Public Health guidance also suggests that residents with confirmed Covid-19 could be ‘cohorted’ together
- 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.
- Can a member of staff follow the resident around and conduct enhanced cleaning of any touch points and re-direct the resident away from contact with others?

Please be aware that any of these activities will require infection control measures after e.g. wiping surfaces that the person has touched.

Step 3: Exceptional considerations

- Many people with dementia will feel upset, confused and even abandoned by the loss of visits and outings. This can be the case even when a person has forgotten names and exactly how they know their family members and friends. The impact as the weeks and months pass, will be profound. The advice below covers ways of maintaining contact without physical visiting; offering empathic support; and exceptional situations when visiting could be considered.
- UKHSA does allow for visits from “next of kin in exceptional situations…”. When lack of contact is causing severe distress and that in turn causes other risks, consideration should be given to this option.
  - Visiting to prevent distress is acknowledged as an exceptional circumstance in NHS guidance on hospital visiting
- If a person needs to be isolated but cannot be supported to stay in their room then a higher level of observation/company/guiding away from other residents may be required. There are arrangements in place for social workers to consider this e.g. in advance of a hospital discharge and for care homes teams to initiate additional staffing to support management of distress. It is important to be clear about how enhanced staff support would work in practice to reduce risk.

Step 4: Considering restrictions on liberty

Good person-centred care practice will resolve most situations, and is the best way to achieve sustained cooperation. This good practice approach must continue after any restrictions on liberty have been put in place. Solutions to achieve cooperation can be found over time, even if urgent steps to protect health are required in the meantime. Arrangements must always be kept under review to minimise individual distress and restrictions.

This section of the document looks at what to do when it seems impossible to reconcile the two aims of: individual liberty – the freedom to walk around as we please; and health protection – for the person walking around, and/or other people living or staying in the same place.

Any decisions on restrictions on liberty must be made in partnership with others:

- Deprivation of Liberty Safeguards
  - Can provide advice on any matter relating to deprivation of liberty safeguards, including how the DoLs authorisation process works, and how a person’s rights will be protected
- Safeguarding referral
  - A referral should be made via Hull City Council’s contact centre if:

    - If a person's behaviour risks causing harm to others; or
    - If a restriction is imposed to protect others; the referral will provide a check/balance/review on the proportionality of the steps taken
- Involve family or advocacy services
    - Family members, friends and paid advocates provide a 'voice' for the person who lacks capacity or needs support to advocate for themselves

Mental Capacity Act and Deprivation of Liberty Safeguards:

The care and treatment of people who may lack the relevant mental capacity must be guided by the principles of the Mental Capacity Act 2005 (MCA) and may in some cases include the safeguards provided by the Deprivation of Liberty Safeguards (DoLS).

Where decisions may need to be made in relation to Covid-19 care or treatment, for someone who may lack the relevant mental capacity, practitioners should follow their usual processes including the best interest decision making process.

Any completed DoLS forms must be sent to: Dols@hullcc.gov.uk

NB: DoLS only applies to care homes and hospitals (including hospices). In other settings, such as supported living, restrictions on liberty related to mental capacity need authorisation from the Court of Protection. This is obtained by making an application to the Court.

Always keep any restriction on individual liberty under review, and always use the least restrictive options consistent with managing risk. Actions must always be proportionate, whether under Mental Capacity Act or Public Health Powers.

NB: The Liberty Protection Safeguards (LPS) will replace the Deprivation of Liberty Safeguards (DoLS).