

Supporting People with Dementia who Walk with Purpose during the COVID-19 Pandemic: Guidance for Care Homes in Leeds

Introduction

The COVID-19 pandemic is presenting many new challenges for people who live in care homes and for staff. This guide is for care homes supporting people with dementia who “walk with purpose” and:

- have, or are suspected to have, COVID-19.
 - Public Health guidance is to isolate people, providing care in a single room.
- do not have symptoms of COVID-19.
 - isolation in one room is not required, but ‘social distancing’ rules still apply.
 - People who are ‘extremely clinically vulnerable’ and shielding

Much of the advice will be helpful for other health and care settings.

This document covers:

- Ideas to achieve co-operation with isolation and social distancing.
- Who to contact; help is available from NHS services and Leeds City Council.

The aim is to keep everyone else in the care home safe and minimise the spread of infection.

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.

Walking with purpose can be positive for people living with dementia. Normally, we would not attempt to limit it 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 behaviour 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 co-operation.

Person-centred care – asking “why ?”

There are many common reasons why people with dementia walk. Examples include:

- Exercise – they may have been a life-long active person.
- Occupation – are they fulfilling a previous work or home-life role, or simply looking for something to do because they are bored?
- Seeking – are they looking for a particular person or place or seeking reassurance, company, hungry/thirsty? Are they missing family visits - has ‘seeking behaviour’ increased as a result ?
- Pain – we know some people who have back or joint pain or who are constipated are more likely to walk or be agitated

Getting help:

"All care providers can and should look to their local authority and local health services for support".

Department of Health and Social Care – *COVID-19: Our Action Plan for Adult Social Care*

There are ideas below ("steps to follow") that you might wish to try first, or you might wish to seek help straight away, especially if a situation is urgent. We do want to hear from you. Please contact:

- **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).
- **NHS specialist Care Homes Service:** The local specialist mental health service for care homes is provided, for most of Leeds, by Leeds and York NHS Partnerships Foundation Trust (LYPFT).
 - 8am - 8.30pm Monday to Friday and 8am - 6pm Saturdays, Sundays and Bank Holidays.
 - Referral via LYPFT Single Point of Access: 0300 300 1485
echteam.lypft@nhs.net
tel: 0113 855 8774
 - *NB. Some care homes and GP practices link with neighbouring specialist NHS Trusts, eg. TEWV, SWYFT. Please use local referral arrangements. They all have care homes liaison services; the level of service / operating hours may differ.*
- **Care Quality Team - Leeds City Council.** This team works with care homes to improve the quality of care. During this time it is extending its offer to work with providers and NHS colleagues to develop bespoke solutions for individuals. The team includes experienced former care home managers with specialist dementia training. It is not a clinical team.
 - Monday-Thursday 8am-4pm; Friday 8am - 3.30pm.
 - carequality@leeds.gov.uk
Jenny Minton 0771 210 2464
Susan Meehan-Stanier 0789 127 9941

'Think Delirium'

Delirium may be caused by COVID-19, or other infection, or by other problems such as pain or constipation. It can cause 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.

Steps to follow - managing 'walking with purpose'

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 are ideas of how to support the person. Even though these ideas may be familiar to you, they are included here 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.

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.
 - 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 more 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.
 - 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 – eg. 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.

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.
- Public Health England guidance 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). This article by a care provider considers this difficult issue and some practical steps:
<https://johnscampaign.org.uk/#/post/how-to-manage-a-care-home-visit-for-those-in-exceptional-need>
- 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 eg. in advance of a hospital discharge, and for LYPFT care homes team 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 co-operation. This good practice approach must continue after any restrictions on liberty have been put in place. Solutions to achieve co-operation 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.

Help and advice

Make these important decisions in partnership with others. Bring your expertise as a care provider together with the knowledge and expertise of others, to make the best possible decisions. None of us have faced situations like this before. If you have to make a difficult decision urgently, do your best, and seek advice and share responsibility as soon as possible.

➤ DoLS Helpline

The usual arrangements apply for forwarding requests under Deprivation of Liberty Safeguards, to: ASC.DoLS.Referrals@leeds.gov.uk

The DoLS helpline 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.

tel: 0113 535 0004 - Monday to Friday, 10 am-12pm / 1pm-3:30pm

➤ Public Health England – Health Protection Team (HPT)

- HPTs are essential contacts for managing outbreaks of Covid-19. Contact details have been provided to all care homes. Public Health Officers are empowered to impose proportionate requirements (including screening and isolation), on a person suspected or confirmed to be infected with COVID-19.
- In the first instance, explore the use of the Mental Capacity Act as far as possible. Public Health powers only apply when isolation or other restrictions on liberty are purely to prevent harm to others or the maintenance of public health.

➤ Safeguarding referral: A referral should be made via Leeds 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.
- Advonet in Leeds provides independent advocacy for people who don't have family or friends to support them, or when there is conflicting opinion, or other reason to involve paid advocacy services. Tel: 0113 244 0606

<https://advonet.org.uk/how-we-can-help-you/make-a-referral/>

Mental Capacity Act and Deprivation of Liberty Safeguards – forms & COVID-19 policy:

- Specific guidance has been issued for the COVID-19 pandemic covering the Mental Capacity Act, and Deprivation of Liberty Safeguards (DoLS).
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/878910/Emergency_MCA_DoLS_Guidance_COVID19.pdf
 - This guidance describes circumstances when existing DoLS arrangements are sufficient, and when new DoLS arrangements are required.
- As usual, completed DoLS forms must be sent to: ASC.DoLS.Referrals@leeds.gov.uk
 - ‘Form 1b’ has been produced alongside the Covid-19 guidance, to grant urgent authorisation. The maximum period allowed is 7 days, and a further 7 days can be requested:
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/878930/Annex_B_DoLS_urgent_authorisation_form_Covid19.docx
 - ‘Form 1’ remains in place for both standard and urgent arrangements. The full set of DoLS forms can be found here:
www.adass.org.uk/mental-health-drugs-and-alcohol/public-content/new-dols-forms
- 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.

THANK YOU for reading this guide. It is important to:

- meet people’s needs with person-centred care
- respect individual liberty alongside protecting health
- seek help when dealing with difficult situations
- be open and honest about actions taken
- share our learning and keep in touch

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Crooks, S., Conway, G., Wilkie, L., Walsh, A, & Rickardsson, N. (2020). *Walking with purpose and COVID-19*. Edinburgh Behaviour Support Service, NHS Lothian.

Thwaites, S. & Marshall, J. (2020). *Supporting people living with dementia who ‘walk with purpose’ during the COVID-19 pandemic*. Care Home Liaison Mental Health Services for Older People, Consett, County Durham.

Duffy, F. & Richardson, J. (2020). *Supporting Carers and Care Staff to Understand and Respond to Changes in Behaviour in People with Dementia During the COVID-19 Pandemic*. Antrim: Northern Health & Social Care Trust.



If you have any comments or questions about this guidance, please contact:

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