Patients living with dementia who 'walk with purpose or intent' in the COVID 19 crisis

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Research Question

How to manage care home residents with dementia who 'walk with purpose or intent' such that infection prevention measures are not breached during an epidemic such as COVID 19.

Verdict

The British Geriatric Society (BGS) gives clear guidance during the COVID 19 crisis on the approach of care home staff for residents with dementia who 'walk with purpose or intent'. This guidance focuses on isolation of suspected cases and behavioural approach to ameliorating potential unsafe activities of residents. Further guidance by Twaites & Marshall and by the British Psychological Society's Faculty of the Psychology of Older People (FPOP) describes in more detail primary preventative and secondary reactive behavioural approaches that can be used to care for residents during the COVID 19 outbreak. These documents have been developed using expert opinion and experience supported by a broad perspective of the evidence in this field and are consistent with the person-centred approach to dementia care.

What does the evidence say?

This evidence summary comprises evidence from four high quality systematic reviews of non-pharmacological interventions for people with dementia who 'walk with purpose or intent' [Hermans 2007] [Price 2000] [Robinson 2006] [Robinson 2007] and two guidance documents [BGS 2020][[Thwaites & Marshall 2020] on managing people with dementia who 'walk with purpose or intent' and the more general guidance from FPOP around supporting people with dementia in care homes during the COVID 19 outbreak.

Main findings

- Overall, the systematic review evidence concludes there is insufficient evidence both in volume and quality to come to any conclusions on non-pharmacological interventions for people with dementia who 'walk with purpose and intent.' The exception is Robinson 2007 systematic review that states **'there was some weak evidence for exercise'** for ameliorating this behaviour. This research is not specifically for infection control.

- The national guidance from the British Geriatric society (BGS) recommends
  a) Community mental health and dementia teams should be prepared to prioritise support to care homes who need to isolate a resident 'walking with purpose'.
  b) Once care home staff have a suspected case, they should isolate that resident to their room and use personal protective equipment.
  c) An antecedent, behaviours, consequences approach should be used to understand the behaviour of the person with dementia and try to modify it where possible.
  d) Physical restraint should not be used.

- The local guidance [Thwaites & Marshall 2020] based on the BGS national guidance also outlines assessment, primary prevention and secondary reactive intervention guidance for care home staff to aid with the approach advised in c) above in their care of people with dementia to assist in ameliorating 'walking with purpose and intent' which could lead to COVID 19 infection risk.

- The national guidance from the British Psychological Society's Faculty of the Psychology of Older People (FPOP) provides general guidance about helping people living with a dementia to understand remember and follow covid-19 related advice. This includes specific advice minimising distress that may result when the unmet needs that underpin behaviour (including walking with purpose) is interrupted.

Strength of the evidence

The systematic reviews are conducted to a high standard but report that the included studies of interventions are limited in number and in quality. Two of the included systematic reviews are Cochrane reviews and have no meaningful results or conclusions as they sought RCT evidence [Hermans 2007] [Price 2000]. The remaining two reviews are two versions of the same review with the 2007 version being an updated version of a 2016 HTA report; this team also highlights the overall lack of evidence and the lack of quality of included studies. [Robinson 2006][Robinson 2007]

It is not possible to meaningfully conduct quality appraisal of the national and local guidance submitted by the local health practitioners but the former are produced by the British Geriatric Society and the British Psychological Society and the latter by experienced practitioners; all are informed by the broader research picture and with clinical expertise and opinion. They are also consistent with best practice recommendations that non-pharmacological interventions should be tried in the first instance, and that interventions should fit within a person-centred framework in which behaviour is assessed in order to generate an individual response that meets the person's underlying needs (e.g. Brechin et al, 2017; Jackman and Beattie, 2015; James and Jackman, 2017).

Summary of searches

Two types of evidence have been used for this rapid review: a formal search of the Medline database via Ovid to identify relevant systematic reviews of interventions for people with dementia who 'walk with purpose or intent' and a compilation of clinical guidance send via email from local Bristol clinical practitioners working in the field [DC, JM].

The Medline search identified 19 citations of which only four were directly related to 'walking with purpose or intent' behaviour in people with dementia. The Cochrane reviews were also identified in the initial searches of the COVID resources detailed below. A further three systematic reviews of the original 19 were related to the research question but did not help to answer it. [de Oliveira 2015] [Olley R 2018] [Padilla R 2011] The search of the WHO database also found a further related systematic review, but it did not have any evidence regarding 'walking with purpose or intent' behaviour. [Huang 2020]

Local health practitioners sent in two guidance documents which are cited in the text and table, but these practitioners also sent related information/guidance to the topic area which aided the write up. e.g.
www.alzheimers.org.uk/sites/default/files/2018-09/Positive%20language%20guide_0.pdf
www.alzheimers.org.uk/sites/default/files/pdf/factsheet_walking_about.pdf

Date question received: 20.04.20
Date searches conducted:20.04.20
Date answer completed:21.04.20

References

Used as evidence

Guidance

British Geriatrics Society (BGS). COVID-19: Managing the COVID-19 pandemic in care homes for older people. GOOD PRACTICE GUIDE.
(https://www.bgs.org.uk/resources/covid-19-managing-the-covid-19-pandemic-in-care-homes).

British Psychological Society: Faculty of the Psychology of Older people, supporting older people and people living with dementia during self-isolation.
https://www.bps.org.uk/sites/www.bps.org.uk/files/Member%20Networks/Faculties/Older%20People/Supporting%20older%20people%20and%20people%20living%20with%20dementia%20during%20self-isolation.pdf

Thwaites S, Marshall J. Supporting people living with dementia who 'walk with purpose' during the COVID-19 pandemic. 2020 Personal communication

Systematic reviews

Hermans DG; Htay UH; McShane R. Non-pharmacological interventions for wandering of people with dementia in the domestic setting. Cochrane Database of Systematic Reviews. CD005994, **2007** Jan 24.

Price JD; Hermans DG; Grimley Evans J. Subjective barriers to prevent wandering of cognitively impaired people. Cochrane Database of Systematic Reviews. (4) CD001932, **2000**.

Robinson L; Hutchings D; Corner L; Beyer F; Dickinson H; Vanoli A; Finch T; Hughes J; Ballard C; May C; Bond J. A systematic literature review of the effectiveness of non-pharmacological interventions to prevent wandering in dementia and evaluation of the ethical implications and acceptability of their use. Health Technology Assessment (Winchester, England). 10(26): iii, ix-108, **2006** Aug.

Robinson L; Hutchings D; Dickinson HO; Corner L; Beyer F; Finch T; Hughes J; Vanoli A; Ballard C; Bond J. Effectiveness and acceptability of non-pharmacological interventions to reduce wandering in dementia: a systematic review. International Journal of Geriatric Psychiatry. 22(1):9-22, **2007** Jan.

Additional literature

Brechin, D., Codner, J., James, I. A., & Murphy, G. (2017). *Alternatives to antipsychotic medication: psychological approaches in managing psychological and behavioural distress in people with dementia*. The British Psychological Society: Leicester, https://www.bps.org.uk/news-and-policy/alternatives-antipsychotic-medication-psychological-approaches-managing

de Oliveira AM; Radanovic M; de Mello PC; Buchain PC; Vizzotto AD; Celestino DL; Stella F; Piersol CV; Forlenza OV. Nonpharmacological Interventions to Reduce Behavioral and Psychological Symptoms of Dementia: A Systematic Review. BioMed Research International. 2015:218980, 2015.

Huang H-T *et al.,* How to prevent outbreak of a hospital-affiliated dementia day-care facility in the pandemic COVID-19 infection in Taiwan, Journal of Microbiology, Immunology and Infection, https://doi.org/10.1016/j.jmii.**2020.**04.007-

Jackman, L., & Beatty, A. (2015). Using the Newcastle Model to understand people whose behaviour challenges in dementia care. *Nursing older people*, *27*(2).

James, I. A., & Jackman, L. (2017). *Understanding behaviour in dementia that challenges: a guide to assessment and treatment*. Jessica Kingsley Publishers: London.

Olley R; Morales A. Systematic review of evidence underpinning non-pharmacological therapies in dementia. Australian Health Review. 42(4):361-369, 2018 Aug.

Padilla R. Effectiveness of environment-based interventions for people with Alzheimer's disease and related dementias. American Journal of Occupational Therapy. 65(5):514-22, 2011 Sep-Oct.

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Systematic Reviews: four systematic reviews focusing on non-pharmacological intervention for people with dementia and who 'walk with purpose or intent'

Author (year)	Search Date	Inclusion criteria	Number of included studies	Summary of results	Risk of bias
1& 2 Robinson 2006/2007 Robinson 2007 is an update of the 2006 HTA report by the same authors so only these results reported)	Inception of data bases until 31st October 2015	**Types of studies:** i) Effectiveness: randomised and non-randomised controlled trials, controlled before-and- after studies, cohort and case-control studies. ii) Cost effectiveness: studies costing the intervention strategies or wandering behaviour and full economic evaluations assessing the intervention strategies. iii) Acceptability: surveys of opinion, qualitative studies and discussion papers. **Participants**: people with dementia (diagnostic criteria DSM IV or ICD 10) and acquired cognitive impairment in any setting. **Interventions:** physical barriers; restraints; electronic tagging/tracking devices; behavioural interventions; carer interventions; exercise, music therapy, homeopathy; sensory therapies eg aromatherapy, multi-sensory environment, and environmental designs. **Outcome measures**: *Primary:* any measure of wandering behaviour. *Secondary:* accidents; deaths; withdrawal from treatment (as an indicator of tolerability); satisfaction with intervention; quality of life of person with dementia and informal carer(s);	Eleven studies, including eight randomised controlled trials, of a variety of interventions: Multisensory environment (n=3) Therapeutic touch (n=1) Music therapy (n=1) Special acre unit (n=2) Aromatherapy (n=2) Individual behaviour management (n=1)	**Authors summary** '(i) *Clinical effectiveness* There was no robust evidence to recommend any intervention, **although there was some weak evidence for exercise**. No relevant studies to determine cost effectiveness met the inclusion criteria. (ii) *Acceptability/ethical issues.* None of the acceptability papers reported directly the views of people with dementia. **Exercise and music therapy were the most acceptable interventions** and raised no ethical concerns. **Tracking and tagging devices were acceptable to carers but generated considerable ethical debate. Physical restraints were considered unacceptable**.' **Authors conclusions**	Low overall as determined by the four domains of ROBIS

Author (year)	Search Date	Inclusion criteria	Number of included studies	Summary of results	Risk of bias
		anxiety/distress of person with dementia and informal carer(s); costs of care; use of health and social services and costs of intervention and its implementation. There was no language restriction. Foreign language texts were translated by relevant experts.			
3) Price 2010 (update from 2000 – no changes)	Inception of database until 9 March 2009	Randomized controlled trials (RCTs) and controlled trials provide the highest quality evidence, but interrupted time series are also considered as they may contribute useful information. **Participants** are people with dementia or cognitive impairment who wander, of any age, and in any care environment - hospital, other institution, or their own home. **Interventions** comprise exit modifications that aim to function as subjective barriers to prevent the wandering of cognitively impaired people. Locks, physical restraints, electronic tagging and other types of barrier are not included. **Outcomes:** All outcomes that are meaningful to people making decisions about the care of wanderers are recorded.	No RCTs or controlled trials were found. The other experimental studies that we identified were unsatisfactory. Most were vulnerable to bias, particularly performance bias; most did not classify patients according to type or severity of dementia; in all studies, outcomes were measured only in terms of wandering	**Authors conclusion** 'There is no evidence that subjective barriers prevent wandering by cognitively impaired people.'	Low overall as determined by the four domains of ROBIS

Author (year)	Search Date	Inclusion criteria	Number of included studies	Summary of results	Risk of bias
			frequency rather than more broadly in terms of quality of life, resource use, anxiety and distress; no studies included patients with delirium; no studies were based in patients' homes.		
4) Hermans 2007	From inception of database to 11 May 2006	Randomised clinical trials with no control or usual/standard care Participants: people with dementia in the domestic setting who wander. Interventions: no-pharmaceutical interventions Outcomes: all relevant outcomes	No suitable trials of non-pharmacological interventions for the prevention and management of wandering in the domestic setting were found. As no randomised controlled trials were found, no results can be reported.	**Authors conclusion** **'**There is an urgent need for randomised controlled trials of non-pharmacological interventions for wandering in the domestic setting.'	Low overall as determined by the four domains of ROBIS

Primary studies: - guidance documents

Author (year)	Description/Aim	Key recommendations
British Geriatrics Society 30 March 2020	**COVID-19: Managing the COVID-19 pandemic in care homes for older people. GOOD PRACTICE GUIDE.** The COVID-19 pandemic raises challenges for care home residents, their families and the staff that look after them. This guidance has been developed to help care home staff and NHS staff who work with them to support residents through the pandemic.(https://www.bgs.org.uk/resources/covid-19-managing-the-covid-19-pandemic-in-care-homes).	BGS produce 15 broad guidance points but the most relevant points on people with dementia who 'walk with purpose or intent' are as follows 1. Care homes should have in place standard operating procedures for individual residents with suspected and confirmed COVID-19 infection, including appropriate infection control precautions to protect staff and residents. 2. Care homes should have standard operating procedures for isolating residents who 'walk with purpose' (often referred to as 'wandering') as a consequence of cognitive impairment. Behavioural interventions may be employed but physical restraint should not be used. 3. Care homes should consider whether it is feasible to manage residents entirely within their rooms during the COVID pandemic. This will have implications for safe staffing, which should be considered before adopting such a policy. In addition, this guidance says: Community mental health and dementia teams should be prepared to prioritise support to care homes who need to isolate a resident 'walking with purpose'

Author (year)	Description/Aim	Key recommendations
James, Marshall and Thwaites (personal communication)	**Supporting people living with dementia who 'walk with purpose' during the COVID-19 pandemic** Susannah Thwaites (Occupational Therapist) and Dr Joanna Marshall (Clinical Psychologist) Guidance based on BGS 2020 guidance cited above plus James, I.A. (2011). *Understanding Behaviour in Dementia that Challenges: A Guide to Assessment and Treatment.* Jessica Kingsley Publishers. James, I.A., and Hope, A. (2013). 'Relevance of emotions and beliefs in the treatment of behaviours that challenge in dementia patients'. *Future Medicine, 3,* 6, 575-588. James, I.A., Marshall, J. and Thwaites, S. (2017). Improving communication skills in dementia care: utilising the BPS's stepped-care model for treatment of behaviour that challenges. *FPOP Bulletin*, 137, 36-41. Snow, T. (2012). *Dementia Caregiver Guide; Teepa Snow's Positive Approach techniques for caregiving, Alzheimer's and other forms of dementia.* Cedar Retirement Community.	Additional guidance to BGS cited above: (not all infection-control relevant) **Use the Behaviours that Challenge Clinical Link Pathway (CLiP)** 1) **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.? 2) **Develop an individualised Behaviour Support Plan:** • There are many common biopsychosocial causes of walking with purpose (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.

Author (year)	Description/Aim	Key recommendations
		• Occupation – are they fulfilling a previous work or home-life role? • Seeking – are they looking for a 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. 3) **Primary preventative strategies** • **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:**

Author (year)	Description/Aim	Key recommendations
		• 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?

Author (year)	Description/Aim	Key recommendations
		4) **Secondary (reactive) strategies** - 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).
British Psychological Society (Faculty of the Psychology of Older People), 8th April, 2020	*Supporting older people and people living with dementia during self-isolation* This guidance adapts established psychological principles and practice to identify how practitioners and carers can help people with memory problems and living with a dementia to understand, remember and follow advice about adapting to Covid-19?	Provides general person-centred guidance about responding to distress: • Use posters and reminders in the house. Pictures and words are best. Put them on the doors, next to the sink and in places that are regularly passed. Point out the poster and make a clear statement 'We need to wash our hands'.

Author (year)	Description/Aim	Key recommendations
		• Keep communication as clear as possible and try to focus on what you need to do rather than why you must do it • Tell the person with dementia that this is advice from a person they trust – maybe the GP, their children, the government so they understand this isn't your choice. • Link washing hands with a song, music or story. Pay close attention to details such as how the water feels, the smell of the soap and memories linked to times when you wash hands • (work, school, hospitals). • People with dementia, at all stages of difficulty, will pick up on anxiety and panic. Try to stay calm, matter of fact and upbeat • Prioritise getting on well if you can, behaviours are easier to change if you keep the mood light and encourage functional behaviour • If the person living with dementia becomes suspicious about the advice and the isolation, then reassure them that they are safe and keep in mind a list of activities, songs, conversations and interests that you can use quickly to maintain their wellbeing • Those with dementia can easily develop a delirium. Pay close attention to changes in levels of confusion or unusual behaviour. Seek medical advice if you think they are showing symptoms – NHS 111 or phone the GP/CPN • Use the Herbert Protocol with your local police force. This lets them know all about the person living with dementia and allows for quick

Author (year)	Description/Aim	Key recommendations
		action if they go missing. Find more information by calling your local Police station or calling Age UK.

Search details

Initial project screen:

Source	Link	Relevant Evidence Identified
CEBM, University of Oxford	https://www.cebm.net/covid-19/	No relevant literature found
Evidence aid	https://www.evidenceaid.org/coronavirus-resources/	No relevant literature found
Cochrane Methodology Review Group	Infection control and prevention: https://www.cochranelibrary.com/collections/doi/SC000040/full Evidence relative to critical care: https://www.cochranelibrary.com/collections/doi/SC000039/full	Two Cochrane reviews: Hermans D, Htay UH, Cooley SJ. -Non-pharmacological interventions for wandering of people with dementia in the domestic setting. Cochrane Database of Systematic Reviews 2007, Issue 1. Art. No.: CD005994. DOI: 10.1002/14651858.CD005994.pub2. Price JD, Hermans D, Grimley Evans J. Subjective barriers to prevent wandering of cognitively impaired people. Cochrane Database of Systematic Reviews 2001, Issue 1. Art. No.: CD001932. DOI: 10.1002/14651858.CD001932.
Department of Health and Social Care Reviews Facility	http://eppi.ioe.ac.uk/COVID19_MAP/covid_map_v3.html	No relevant literature found
UCSF COVID19 papers	https://ucsf.app.box.com/s/2laxq0v00zg2ope9jppsqtnv1mtxd52z	No relevant literature found
PHE Knowledge and Library Services	https://phelibrary.koha-ptfs.co.uk/coronavirusinformation/	No relevant literature found
WHO Global Research COVID19 database	https://www.who.int/emergencies/diseases/novel-coronavirus-2019/global-research-on-novel-coronavirus-2019-ncov	Huang H-T et al., How to prevent outbreak of a hospital-affiliated dementia day-care facility in the pandemic COVID-19 infection in Taiwan, Journal of Microbiology, Immunology and Infection, https://doi.org/10.1016/j.jmii.2020.04.00

		7- no evidence on 'walking with purpose or intent ' behaviour
CDC COVID19 guidance	https://www.cdc.gov/coronavirus/2019-ncov/hcp/index.html	No relevant literature found

Search for SRs and Primary studies

Source	Search strategy	Number of Hits	Relevant evidence identified
KSR Evidence	Not searched		
Medline	Database: Ovid MEDLINE(R) <1946 to present> Search Strategy: --- 1 Dementia/ or Frontotemporal Dementia/ or Dementia, Vascular/ (56711) 2 wander*.mp. (4855) 3 1 and 2 (329) 4 "Systematic Review"/ (125808) 5 3 and 4 (19) **********	19	**7 systematic reviews of which:** **4** systematic reviews focus specifically on non-pharmacological interventions for walking with purpose or intent by people with dementia. (wandering) Price 2000, Robinson 2006, Robinson 2007, Hermans 2007. Plus found but not used in this report. **3** systematic reviews focus specifically on non-pharmacological interventions for people with dementia looking at broader outcomes e.g. agitation, wellbeing as well as Padilla 2011, Piersol 2015, Olley 2018
Rayyan "COVID-19 Open Research Dataset"	Not searched		