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Understanding and supporting safe walking with purpose among people living with dementia in Extra Care, Retirement and Domestic Housing

Abstract

Purpose

The purpose this paper is to explore walking with purpose in extra care, retirement and domestic housing settings in order to better understand and support people living with dementia in these settings, develop recommendations and inform practice.

Design/methodology/approach

A mixed-methods study was employed: scoping literature review; online survey of extra care and retirement housing managers in the UK; case studies involving interviews with staff and family carers (n=14) of ten individuals who engaged in walking with purpose in the different housing settings.

Findings

Although residents who walk with purpose constituted a minority (0-2 residents), managing walking with purpose can be challenging and time consuming. Distraction or redirection was the most common response. Other strategies included identifying the resident's motivations and accommodating their wishes or walking with them. Culture of care, staff training and dementia friendly design are key to effective support for safe walking with purpose.

Responses to walking with purpose in the domestic housing settings raised serious deprivation of liberty issues.

Research limitations

The study had a number of limitations. The completed survey questionnaires represent a self-selected sample of extra care and retirement housing settings and responses are based on the perceptions of the staff members completing the survey. There were a relatively small number of case study sites (3 extra care and 3 retirement housing) and it was not possible to interview family members for all of the residents who walked with purpose.

Originality/Value

This study provides unique data on walking with purpose in extra care and retirement housing setting in the UK.

Introduction

There is no standard definition of walking with purpose and no clear consensus about what exactly is being described. Many different terms occur in the literature, particularly 'wandering' but also 'walking', 'walking about', 'walkabout', 'roaming', 'ambulation', 'exit seeking' and 'elopement'. A review by Cipriani *et al.* (2014) found multiple definitions in the literature, including 'aimless movement without a discernible purpose'; 'locomotion with no discernible, rational purpose'; and 'difficult aimless behaviour'. The review suggested that on average one in five people with dementia 'wander', with reported rates varying from 17.4% to 63% among people living in the community.

It is apparent that 'wandering' suggests aimlessness, whereas in fact there is often a purpose or aim behind this activity in the context where the term is used (Alzheimer's

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2
3 Society, 2019). In recognition of this, in this paper we use the term 'walking with purpose',
4 which includes 'wandering' as a normal and valuable human activity in its own right.
5

6 Extra care housing (ECH) and retirement housing (RH) are widely viewed as an alternative
7 to care homes that can provide greater opportunities for maximising independence while
8 providing flexible, personalised care and support services (Evans, 2014). In most ECH
9 schemes, care is available at any time, whereas RH schemes (including sheltered housing)
10 have a manager who can arrange any services that residents need. While the Alzheimer's
11 Society (Thraves, 2016) estimated that 70% of care home residents in the UK are living with
12 dementia, comprehensive prevalence data across all providers of ECH and RH is lacking.
13

14 Responding to walking with purpose in such independent living settings can be a challenge
15 and there is some concern about whether these facilities provide a suitable environment and
16 service to residents living with dementia (Twyford, 2016).
17
18
19

20 **Impacts**

21 There is a paucity of research on the impacts of walking with purpose. A study of missing-
22 person records over a four-year period in one UK policing region (Bantry White and
23 Montgomery, 2014) found that, although the frequency of getting lost is low for people with
24 dementia (0.5% of the regional dementia population), for a small minority there are
25 considerable risks with five percent of the 281 occurrences of getting lost resulting in
26 significant harm, including two deaths. A recent study found negative impacts on the
27 physical and mental health of family carers (sleep disturbance and mental fatigue) due to the
28 'risky wandering behaviours' of eloping (walking away from a safe residence) and getting lost
29 (Peng *et al.*, 2018).
30
31
32

33 **Perceptions**

34 When people living with dementia walk with purpose it is commonly seen as a 'problem', as
35 reflected in the terminology used, with many negative outcomes including distress for people
36 with dementia and their caregivers and admission to residential care (Cipriani *et al.*, 2014). It
37 is often classed with 'behaviours that challenge' or 'difficult situations' and has been
38 associated with a range of other behaviours including depression, delusions, hallucinations,
39 sleep disorder and, most often, agitated behaviour (Cipriani *et al.*, 2014). A range of medical
40 responses are adopted, including the use of medication to reduce walking as a manifestation
41 of agitation.
42
43
44

45 To many authors the clinical, pathological and problem-based approach misses the point. As
46 Dewing (2006) acknowledged, actual problems related to 'wandering' are unusual, but a risk-
47 averse attitude towards older people in general and people with dementia in particular
48 among health and social care organisations can lead to exaggerated perceptions of the risks
49 on the part of carers, both professional and unpaid. Dewing suggested that while 'wandering'
50 may be problematic for some people with dementia, more often it is the caregivers'
51 responses that cause problems. While this is undoubtedly true, it is also important to
52 recognise that for some people with dementia walking with purpose can require specific
53 support and responses in order to ensure appropriate safeguarding.
54
55

56 Dewing (2006) and Graham (2017) proposed that 'wandering' is actually a fundamental
57 human activity, often a pleasurable one, that we all engage in at some point in our lives. To
58 that extent, Dewing (2006) suggested that we need to change the values and beliefs of
59 practitioners, carers and society rather than call it something else. Similarly, Graham (2017)
60

1
2
3 proposed viewing 'wandering' as intention to be alive and to grow, rather than the product of
4 disease and deterioration.

5 6 **Responses**

7 A range of responses can be adopted to the perceived risks, harm and benefits associated
8 with walking with purpose. For example, a more restrictive approach might include locking
9 doors and using medication to sedate a person, while less restrictive approaches could
10 involve setting up safe walking routes, meaningful activities, social engagement or using
11 redirection or distraction (Dewing, 2011). Robust research on the effectiveness of different
12 interventions is lacking (Neubauer *et al.*, 2018).

15 Dewing (2005) recommended a screening process to identify people who need specific
16 support with walking with purpose and consideration of underlying factors such as continuing
17 a habit or interest, relieving boredom or pain, lack of physical activity, responding to
18 anxiety/stress and confusion about the time. Graham (2017) states that approaches to
19 managing walking with purpose must take into account the "deep personal and social
20 meaning" (p. 745) and support residents' freedom of movement.

23 While many providers of ECH and RH have policies for addressing the perceived risks, most
24 do not have guidance that supports safe walking with purpose without deprivation of liberty.
25 Cultures of care would appear to be key (Dewing, 2006; Graham, 2017).

28 Much of the literature concerns use and acceptance of technology to help manage walking
29 with purpose (e.g. Mulvenna *et al.*, 2017). Such technologies can alert carers when
30 someone has left their bed, chair or room, and track the person's location. A recent review of
31 the literature identified 83 devices, of which only 19 had been clinically tested (Neubauer *et al.*, 2018). Potential benefits included reductions in risk and caregiver burden.

34 The physical environment plays an important role in supporting wayfinding and orientation
35 for people living with dementia and numerous design guidelines exist (e.g. Davis and
36 Weisbeck, 2016; Marquardt, 2011). Various design features can support safer walking with
37 purpose, including safe indoor and outdoor walking routes with places to rest, interesting
38 visual features and activities, and strategies for encouraging residents to use specific areas
39 and facilities (e.g. Algase *et al.*, 2010; Benbow, 2017).

42 A recent study by Neubauer and Liu (2020a) involving thirty eight phone interviews with
43 various stakeholders across Canada found that a wide range of high- and low-tech solutions
44 were used or suggested for supporting safe walking with purpose. Success of a particular
45 approach was seen as dependent on factors such as risk, culture, geography and stigma,
46 suggesting that a unique combination of approaches is required for each individual. The
47 authors developed and validated a conceptual model and guidelines (in three versions: care
48 homes, community and people living with dementia) to assist in appropriate identification of
49 strategies, dependent on level of risk of getting lost, to manage walking with purpose
50 (Neubauer and Liu, 2020b)

54 **Extra care and retirement housing settings**

55 The few studies that examined walking with purpose in long-term care settings focussed on
56 approaches to managing the walking, while the perceptions, risks, impacts, challenges and
57 successes are largely unknown. The most recent literature focuses on the effectiveness of
58 particular interventions in reducing agitation and walking with purpose (e.g. Ray and
59 Mittelman, 2017 – music therapy; Traynor, Veerhuis, Johnson, Hazelton and Gopalan, 2018
60

1
2
3 – structured physical activity programme) and wayfinding difficulties for people living with
4 dementia (e.g. Caspi, 2014; Mazzei *et al.*, 2014; O'Malley *et al.*, 2017).
5

6 There is little research into care staff perceptions of walking with purpose. Yayama *et al.*
7 (2013) found that nurses' subjective assessments of walking with purpose were in
8 agreement with objective measures, based on videotaping and direct observation, during the
9 day shift (but not at night). Koder *et al.* (2014) found that shouting, restlessness and walking
10 with purpose were the most common and distressing symptoms of dementia for nursing
11 home staff. MacAndrew *et al.* (2017) found that family and staff carers' perceptions of
12 'wandering related boundary transgression' (into out-of-bounds or potentially hazardous
13 areas) varied from having little or no impact when unwitnessed by others to being a troubling
14 behaviour, needing more effective management and potentially hazardous for the individual
15 or their co-residents when witnessed by others.
16
17
18

19 **Aims, design and methods**

20 The principle aim of the study reported in this paper was to explore walking with purpose
21 among people living with dementia in ECH and RH settings, along with the perceptions and
22 responses of staff and family carers, in order to inform practice.
23

24 Specifically, the study objectives were to explore:

- 25 • Existing evidence relating to walking with purpose among people living with
26 dementia.
- 27 • The prevalence, awareness, perceptions, understanding, responses, policies,
28 procedures and support with respect to walking with purpose in ECH and RH
29 settings.
- 30 • In more depth, the causes, implications, impact and outcomes of walking with
31 purpose for the lives of individual residents living with dementia in Housing 21 ECH
32 and RH schemes.
33

34
35
36 Walking with purpose in domestic housing (also known as mainstream and general needs
37 housing) was also examined for comparison.
38
39

40 The mixed-methods study comprised three stages. A scoping literature review drew together
41 published and grey literature on walking with purpose among people living with dementia in
42 long-term accommodation and care settings and domestic housing.
43

44 An online survey, created using Survey Monkey, for managers of ECH and RH schemes in
45 the UK gathered data on the prevalence, awareness, perceptions, understanding,
46 responses, policies and procedures with respect to walking with purpose.
47

48 Case studies explored in greater depth issues relating to walking with purpose in ECH and
49 RH schemes owned by the housing provider Housing 21. **In this qualitative stage of the
50 study a thematic approach was taken.** Structured interviews with managers or staff members
51 with experience of responding to walking with purpose focused on specific residents with
52 dementia who engaged in this behaviour. Potential interviewees, identified by the scheme
53 managers, were given information sheets explaining the study and what the interviews would
54 involve. Family members of these residents were also invited to be interviewed. Interviews
55 with informal/family carers of people with dementia living in domestic housing who attended
56 a Housing 21 day care centre, identified by the centre manager, were included to get a
57 broader picture of the challenges and how these affect general needs housing. Prior to
58
59
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1
2
3 interview, participants gave informed written consent to take part in the study and for their
4 research data to be used in publications or reports. All person identifiable information was
5 fully anonymised. **The study was approved by the relevant University Ethics Committee.**

6 **Data analysis**

7
8 Survey responses were analysed within Survey Monkey and using Microsoft Excel for
9 descriptive and comparative statistics. Qualitative free-text responses were manually
10 analysed to identify common themes.
11
12

13 **A thematic approach was used in the analysis of the qualitative interview data.** The interview
14 transcriptions were analysed for thematic content to identify overarching themes using
15 specialist software (NVivo 11). The transcriptions were also used to construct a vignette of
16 each case study individual who walked with purpose.
17

18 **Results**

19 **Survey of extra care and retirement housing schemes**

20 Initial questions about the scheme were completed by 148 respondents; of these, 106 (72%)
21 worked in a RH scheme and 42 (28%) in ECH. The general questions about walking with
22 purpose had 103 respondents, while 50 answered the specific questions about residents
23 who currently engaged in walking with purpose.
24

25
26 The prevalence of people living with diagnosed dementia in RH schemes (5% of the total
27 number of residents) was lower than in ECH (14%). However, the proportion of people with
28 suspected but undiagnosed dementia was similar (5%). The majority of schemes (92%) had
29 up to two residents who engage in walking with purpose. This constituted, on average, 22%
30 of all the residents living with diagnosed or suspected dementia for both types of schemes.
31
32

33 **Key survey findings**

34 Key survey findings are given in Table I, below.
35
36

37 *[Table I here]*
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39
40

41 **Challenges and successes**

42 Although residents who walk with purpose constituted a small portion of the total number of
43 residents, around half of respondents considered managing walking with purpose to be a
44 challenge and the majority rated staff as only moderately successful in addressing walking
45 with purpose. Managing walking with purpose was more of an issue in ECH than in RH in
46 terms of staff time. Challenges related to ensuring individuals' safety, especially when they
47 leave the scheme, scheme design and stigma and misunderstanding around dementia. The
48 main factor contributing to a scheme's effectiveness was staff awareness and knowledge,
49 followed by scheme location.
50
51

52 Examples of successful responses to walking with purpose included:
53

- 54 • improving staff understanding so that they can better support residents;
- 55 • raising dementia awareness among other residents and families;
- 56 • use of technology;
- 57 • improving activities provided;
- 58 • providing a secure environment;
- 59
- 60

- greater understanding in the local community.

Policies, procedures and guidelines

Survey findings suggested that not all schemes are set up to consider people living with dementia who walk with purpose. This omission was more evident for RH than ECH (Table 1). Few respondents were aware of organisational policies, procedures or guidelines for supporting safe walking with purpose (18.5%).

Responses

The most common and effective responses to walking with purpose were to understand why the resident is walking, distract or redirect them and walk with them. Respondents highlighted the fact that the most effective approach depends on the individual, so it is important to get to know the person. The majority felt that walking with purpose did not create problems relating to human rights or deprivation of liberty.

Environmental design and assistive devices

Many schemes had multiple design features to support safe walking with purpose. ECH had a wider range than RH, although the most common features were similar in both: places to sit and rest along indoor routes (54% of respondents), clearly labelled doors (52%), and safe indoor routes for walking (50%). However, around half of the respondents wanted design changes in order to better support safe walking with purpose. The most commonly used design feature to deter residents with dementia from entering a particular area or leaving the building was black mats in front of exit doors (four ECH schemes and five RH schemes). Other features, used by three or less of the respondents, included stop or U-turn signs, rope barriers, mirrors in front of doors, concealed door knobs and concealed/masked doors.

Just over half of the respondents used assistive technology devices to support safe walking with purpose. The most common devices used were CCTV and door alarms on individual apartment doors. ECH schemes used more and a wider range of devices than RH schemes. Additional responses suggested that the low use of these devices may be due to lack of demand, lack of awareness and high costs.

Improvements

Respondents' suggested changes to how their scheme supports walking with purpose included better understanding of walking with purpose, more training and awareness for staff and residents, appropriate environmental design and greater funding for assistive technology.

Case studies

Fourteen case study interviews were conducted, focussing on specific individuals living with dementia who engaged in walking with purpose: five living in three different Housing 21 ECH settings (five interviews with managers and one with a family member); three people living in three different Housing 21 RH settings (three interviews with managers, two with family members); and two people living in mainstream housing (two interviews with family carers).

The case studies enabled a clearer understanding of why residents living with dementia in ECH and RH engage in walking with purpose, the impacts on a scheme and the responses adopted by scheme managers and staff to manage these impacts and address the risks created for the residents.

Policies, procedures and guidelines

1
2
3 None of the three ECH case study schemes had policies, procedures or guidelines for
4 supporting safe walking with purpose. One of the RH schemes had such policies and
5 procedures, one did not and at the third the manager did not know.
6

7 *Causes and risks of walking with purpose*

8 The vignettes showed that walking with purpose had a unique cause or motivation for each
9 individual. It could relate to personal life history, e.g. re-enacting their usual afternoon routine
10 or the job they used to do, or be due to internal triggers, e.g. boredom, feeling upset or
11 anxious, loneliness, need to go to the toilet or hunger. Depending on an individual's
12 situation, different risks were faced, including level of mobility and where and for how long
13 they walked. Risks identified included: tripping/falling; becoming lost; health impacts
14 (dehydration, hypothermia); negative interactions with other people (e.g. theft).
15

16
17 "Her biggest risk really is getting lost isn't it, and she has a fall." (Retirement scheme
18 manager)

19 "Dehydration is a main factor, it concerns me quite a lot, yes." (Retirement scheme
20 manager)
21
22
23
24
25

26 *The impact of mobility*

27 The more mobile the resident, the greater the challenges, work and stress for staff due to the
28 resident exiting the scheme. However, those with poor mobility, even if they stayed within
29 the scheme, were at greater risk of falls and resulting injuries.
30

31 "Just falling, basically. I mean, she fell into that glass lamp and cut her head." (Son)
32

33 *Responses*

34 Various responses to walking with purpose were reported, although the preferred method in
35 both ECH and RH was distraction/redirection. However, in such independent living settings,
36 this approach was not effective if the resident was determined to leave. Understanding a
37 resident's life story and their reasons for walking with purpose were recommended for more
38 effective distraction or redirection. Even scheme managers who tried to accommodate a
39 resident's walking with purpose by enabling them to do so as safely as possible, would often
40 try distraction or redirection first.
41
42

43 "We distract her with... She loves the royal family so if we've got books upstairs with
44 the royal family we just show her pictures of that or show her, her photos and get her
45 talk about her photos ... when she was younger and her children when they were
46 babies. There're so many different things we can distract her with." (ECH scheme
47 manager)
48
49
50

51 In both of the mainstream housing case studies, included for comparison purposes, the
52 person with dementia was only able to leave the house if accompanied by their carer.
53

54 "The front door's locked and we're in the house. Now I know he's safe in the house,
55 he can't get out." (Son)
56

57 *Impacts on management and staff*

58 While the case study schemes had very few residents who engaged in walking with purpose,
59 they could occupy a disproportionate amount of time and effort and cause stress for
60 management and staff. Residents living with dementia who regularly left, or tried to leave,

1
2
3 the scheme created time pressures and stress. Residents who became agitated, distressed
4 or aggressive towards staff when trying to leave were a particular source of stress for staff. If
5 a resident left, a person that managers feel responsible for was out of their sight and they
6 could not ensure their safety. If a resident was then away from the scheme for several hours,
7 managers become especially anxious and finding the resident to bring them back to the
8 scheme was very time consuming.

9
10
11 “I used to go around her routes. I’d spot her with her bus pass, she’d wave to me and
12 get on the bus. She got to know my car and it was falling apart for me, you just don’t
13 know what to do for the best.” (ECH scheme manager)

14
15 Addressing walking with purpose that takes place only within a scheme could also be time
16 consuming, if the resident was doing so regularly, and stressful if that resident is likely to fall.

17
18 “Just the worry of her falling, we want to keep her safe obviously” (ECH scheme
19 manager)

20 21 *Other residents*

22 In schemes with good dementia awareness, other residents played a part in ensuring safe
23 walking with purpose by watching the individual, alerting staff, distracting/redirectiong the
24 individual and even returning them to their apartment.

25
26
27 “They’ll keep an eye on her, they’ll let us know if she seems a bit unsettled.” (ECH
28 scheme manager)

29 30 *Environmental design*

31 The design of the scheme was a major factor in enabling residents to find their own way
32 back to their flat and ensuring safety.

33
34 “It’s okay to walk round the garden but they can go beyond the cars and then they’re
35 in the street. She went through the garden then up into the car park then out onto the
36 road.” (ECH scheme manager)

37
38
39 One of the case study ECH schemes and two of the RH schemes used black doormats in
40 front of exit doors.

41 42 **Discussion and conclusions**

43 The study reported in this paper provides unique data on the prevalence of walking with
44 purpose in ECH and RH schemes in the UK. In terms of impacts in these settings, the
45 literature review found little evidence, particularly with respect to staff. This paper shows
46 that, although residents who walk with purpose constitute a minority of people living in RH
47 and ECH schemes (0-2 residents), managing walking with purpose can be a challenge for
48 management and staff and occupy a disproportionate amount of their time. While the survey
49 showed that managing walking with purpose was only a moderate or slight contributor to
50 staff stress, the case studies found that addressing this behaviour can impact negatively on
51 managers in terms of time, effort and emotional wellbeing.

52
53
54
55 While much of the literature focused on technological solutions and design of the physical
56 environment, our study uncovered the approaches adopted by managers and care staff in
57 response to walking with purpose. Distraction or redirection was the most common strategy,
58 and usually the first response tried in order to dissuade the resident from leaving the
59 scheme. Other strategies included identifying the resident’s motivations and accommodating

1
2
3 their wishes, or accompanying them when they leave the scheme. The literature review
4 found that the care culture is key to successful support of walking with purpose (Dewing,
5 2006; Graham, 2017). The preference for dissuading residents living with dementia from
6 leaving the scheme could be indicative of a risk-averse care culture that perceives walking
7 with purpose as a problem. This is not consistent with the ethos of ECH and RH living, which
8 purport to encourage independence and choice. However, it is also a reflection of the
9 pressures under which staff operate.

10
11 Staff training in understanding and addressing walking with purpose appears to be key to
12 effective support for safe walking with purpose. The survey findings suggested that many
13 scheme, particularly RH, are not set up to consider or cater for people living with dementia
14 who walk with purpose, staff are not equipped to effectively support them and it is not
15 embedded into the care culture.

16
17 The literature review found that design of the physical environment plays an important role in
18 supporting the wayfinding abilities of people living with dementia and supporting safer
19 walking with purpose. In the reported study, design that better supports safe walking with
20 purpose was widely called for. Use of deterrents to entering or exiting, such as black
21 doormats and mirrors, raises serious ethical issues. These methods exploit the visual-spatial
22 distortions people with dementia can experience (Dewing, 2011). Black doormats can be
23 perceived as a hole and mirrors can cause confusion and distress (Montague, 2018).

24
25 Clearly, more needs to be done to ensure dementia-friendly design of the physical
26 environment that is supportive of safe walking with purpose.

27
28 Many assistive technology devices are available to support safer walking with purpose,
29 although most have not been rigorously tested. Our findings suggest that the low use of such
30 technology may be due to lack of awareness and high costs.

31
32 The response to walking with purpose in the two domestic housing settings in the case
33 studies, while clearly due to concerns about safety and security, raises serious deprivation of
34 liberty issues.

35
36 This study had some limitations. The survey respondents represent a self-selected sample
37 of ECH and RH settings. It may therefore be the case that the people who completed the
38 survey are those doing more work around, or have more concerns about, walking with
39 purpose. Furthermore, the responses are based on the perceptions of the staff members
40 completing the survey. There were a relatively small number of case study sites (n=8, 3
41 ECH, 3 RH and 2 domestic housing) and a relatively small number individuals who engaged
42 in walking with purpose (n=10; 5 living in ECH, 3 in RH and 2 in domestic housing).

43
44 Furthermore, it was not possible to interview family members for all individuals who walked
45 with purpose, due to unwillingness to participate or lack of contact with the individual
46 concerned.

51 52 ***Implications for practice***

53 Based on the study results and advice given by interviewees, the following
54 recommendations for supporting walking with purpose in ECH and RH can be made:

55 56 *Understanding the individual*

57
58 **Services and support need to be personalised and person-centred to ensure that the specific
59 needs and preferences of the individual are met and continuous assessment is key to
60 supporting walking with purpose in any setting. To determine how best to support an**

1
2
3 individual's walking with purpose, it is crucial to get to know them and their reasons and
4 motivations for walking.
5

6
7 It is crucial to ensure that the family accept the situation and understand why the resident's
8 need to walk with purpose should be accommodated. It therefore helps to develop and
9 maintain good communication with the resident's family carers.
10

11 *Care culture, management and staff*

12 In terms of the culture of care, a positive approach to risk-taking is necessary to promote
13 walking with purpose and training for management and staff in understanding and supporting
14 walking with purpose is key. A local support network of ECH/RH scheme managers enables
15 managers to share experiences, ideas and advice.
16

17 *Policies and Procedures*

18 Policies and procedures should include processes to support safe walking with purpose such
19 as carrying out risk assessments for walking with purpose for residents living with dementia
20 and allocating more care time to managing residents who walk with purpose. Schemes
21 should inform the correct agencies (e.g. LA adult services and the Police) when a vulnerable
22 person has left the scheme. It helps to develop and maintain good communication and
23 relations with other stakeholders e.g. the GP, the mental health team, Local Authority.
24
25

26
27 Use of the Herbert Protocol can make finding a vulnerable person easier and quicker should
28 they go missing. The Herbert protocol is a national initiative coordinated by UK Police Forces
29 (Agespace, 2020). Carers provide useful information relating to a vulnerable person such as
30 medication required, carer's contact details, a photograph, places they previously lived and
31 other places of interest or significance (places they are likely to go). Having a local network
32 of 'eyes' supports safer walking with purpose outside the scheme and can make
33 management of residents who have a tendency to leave much easier. Thus, it is important to
34 foster connections and good relationships with the local community and businesses – ensure
35 that they are aware of those residents who, having left the scheme, are at risk of getting lost
36 and not being able to find their own way back. Should a resident who walks with purpose
37 spend more than an agreed length of time away from the scheme, such measures will
38 reduce amount of time, effort and stress for management and staff.
39

40 *Other Residents*

41 Other residents can play an important role in keeping an eye on residents who engage in
42 walking with purpose. This can be facilitated by ensuring that other residents have an
43 awareness and understanding of dementia and walking with purpose. If understanding is
44 lacking, dementia awareness sessions are recommended to reduce stigma and
45 misunderstanding.
46

47 *Environmental design and assistive devices*

48 More needs to be done to ensure dementia friendly design of the physical environment so
49 that it is supportive of safe walking with purpose in ECH and, in particular, RH. Design
50 recommendations that emerged from this study include: gardens and outdoor spaces must
51 be secure and enclosed; provide safe indoor and outdoor walking routes with frequent
52 places to rest and interesting things to see and do along the way; design features to assist
53 with wayfinding (e.g. colourful, familiar or personally meaningful visual cues positioned at
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1
2
3 **key decision points and outside residents' rooms**); consider use of assistive devices such as
4 contact ID wristbands, door sensors, GPS trackers and alarm mats.
5
6

7 ***Turning research into practice***

8 In response to the study reported here Housing 21 has made a number of changes to its
9 services both in ECH and RH. **Housing 21 recognises that additional resources will be
10 needed to put in place the recommendations of this research. However, the organisation is
11 fully committed to supporting people living with dementia and is willing to absorb additional
12 cost to support this. In addressing the risk adverse response, it is highly probable that staff
13 will require more time to support residents who walk with purpose which again is
14 acknowledged and supported.**
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16

17 To encourage understanding and empathy for residents who are living with dementia,
18 Housing 21 has a target to make 10,000 residents Dementia Friends by 2022, and a figure
19 of over 4,500 has already been achieved. **Dementia Friends is an Alzheimer's Society
20 initiative in England that aims to give people a better understanding of dementia. To become
21 a Dementia Friend a person needs to attend a free dementia awareness session delivered
22 by a Dementia Champion (a volunteer who has attended a training course), which have
23 been rolled out across England.** Housing 21 has a number of Dementia Champions who are
24 encouraged to deliver Dementia Friends sessions to the local community. This will be further
25 encouraged with the view to supporting the development and maintenance of Dementia
26 Friendly Communities.
27
28

29 Within ECH, all residents have a support plan that includes personal information that aids
30 staff if a resident does walk with purpose. Additional resources are planned for RH, including
31 the Alzheimer's Society 'This is me' leaflet and the Herbert protocol. The leaflet will be used
32 to facilitate a conversation with the resident when moving into the scheme or when dementia
33 is diagnosed / suspected. The importance of maintaining these documents and knowing the
34 person will be emphasised throughout ECH and RH.
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38 A protocol will be developed that guides staff on how to support people living with dementia,
39 including guidance on how to be less risk adverse and addressing the issue of walking with
40 purpose being seen as a problem. It will also contain strategies on how to work effectively
41 with the resident and their family.
42

43 In terms of design and wayfinding, when RH courts are refurbished each floor has a different
44 colour scheme and distinguishing features are placed at wayfinding locations, such as
45 outside a lift. Good dementia design is integrated into all new ECH schemes. A design audit
46 has also been developed that allows Court Managers to assess how dementia-friendly their
47 court is and make changes where necessary.
48
49

50 Housing 21 has launched Dementia Advocates – staff members who receive a higher level
51 of training and information about dementia and support other staff through signposting and
52 awareness raising. They also feed into and critique the training that is developed.
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54

55 A pilot scheme is underway looking at technologies available to support people living with
56 dementia. The most appropriate technology will be trialled to enable Housing 21 to signpost
57 residents and their families to technology that could support them. **The organisation is
58 currently looking at the roll out of Wi-Fi into their schemes, which will facilitate greater use of
59 assistive technology. It is probable that Housing 21 will signpost families towards that**
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3 technology which is over and above the Disabled Facilities Grant.

4
5 All of the above will help to further embed the dementia-friendly ethos of Housing 21.

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Finding	% respondents	% extra care respondents	% retirement housing respondents
A tendency to engage in walking with purpose was taken into consideration for new residents.	42	65	31
Carry out a risk assessment for walking with purpose for people living with dementia.	35	63	23
Staff had not received any training on understanding and addressing walking with purpose	58%	56%	59%
Scheme has policies, procedures or guidelines for supporting safe, risk free walking with purpose	18	16%	20%
Consider walking with purpose a challenge	49	46	51
Walking with purpose creates problems relating to human rights or deprivation of liberty	12	17	7