

# HDRC report

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## **All those who wander are not lost<sup>1</sup>**

### Walking with purpose in Extra Care, Retirement and Domestic Housing

April 2019

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<sup>1</sup> Tolkien, J. R. R. (1954). The Lord of the Rings.

## **Acknowledgements**

We would like to thank all the family carers, staff and managers at the case study sites who took part in the interviews for giving up their time and sharing their views and experiences. We would also like to thank the managers at the case study sites for helping to identify family participants and, for the case study site visits, providing a suitable room for conducting the interviews.

We are also grateful to Vanessa Pritchard-Wilkes (Head of Strategic Engagement, Housing 21) for identifying case study sites from the Housing 21 retirement housing and extra care housing schemes and facilitating contact with the managers at these schemes.

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# Executive summary

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This mixed methods study explored walking with purpose in extra care, retirement and domestic housing settings, along with the perceptions and responses of staff and family carers, in order to better understand and support residents living with dementia in such settings and to develop good practice guidelines.

Increasing numbers of people with dementia are supported in specialist housing. Extra care housing is now widely viewed as an alternative form of accommodation to care or nursing homes that can provide opportunities for maximising independence while providing flexible, personalised care and support services. However, there has been much debate on whether these facilities provide a suitable environment and service to residents who have dementia, particularly in terms of supporting behaviours such as walking with purpose.

When people living with dementia have a need to walk it is often seen as a 'problem'. The terminology that is widely used reflects this viewpoint, particularly when it is described as 'wandering' or a 'behavioural problem'. However, there is no clear consensus about what exactly is being described. While 'wandering' has become a label with negative overtones in the context of dementia care, it is considered by some researchers as in fact an activity, and often a pleasurable one, that all of us engage in at some point in our lives. It is also apparent that 'wandering' suggests aimlessness, whereas in fact there is often a purpose or aim behind this activity. In recognition of this, in this proposal we have adopted the term 'walking with purpose' while also acknowledging that this includes 'wandering' as a normal and valuable human activity in its own right.

Very little is known about the prevalence of walking with purpose among people living with dementia or its many forms, contributory factors, outcomes or how best to support and safeguard individuals who engage in this behaviour. Extra care and retirement housing providers, such as Housing 21, face particular challenges in understanding and responding to residents living with dementia who engage in walking with purpose. It is hoped that the findings of this study will help such housing providers to better understand and support residents living with dementia who engage in walking with purpose in their housing schemes. In recognition of the fact that approximately 75% of people living with dementia do so in the community, and for comparison purposes, walking with purpose in domestic housing (also known as general needs and mainstream housing) settings was also examined. The goal is for this research to be useful for the wider housing sector, not just specialist housing providers like Housing 21. Limiting the research to specialist housing will limit the applicability and usefulness of it to the housing sector. It is unlikely that any general

needs housing providers or indeed private sector landlords will do this research, so this is an opportunity to understand the walking with purpose issue across the sector as a whole.

## **Study aims, design and methods**

The principle aim of this study was to explore and understand walking with purpose among people living with dementia in extra care, retirement and domestic housing settings, along with the perceptions and responses of staff and family carers, in order to develop good practice guidelines.

Specifically the study objectives were to explore:

- Existing evidence relating to walking with purpose among people living with dementia
- The prevalence, awareness, perceptions, understanding, responses, policies and procedures, support and outcomes with respect to walking with purpose in extra care and retirement housing settings.
- The impact, challenges, responses and outcomes in relation to walking with purpose among people living with dementia in domestic (mainstream) housing.
- In more depth the causes, implications, impact and outcomes of walking with purpose for the lives of individual residents living with dementia in Housing 21 extra care and retirement housing schemes.

The pilot study, comprised 3 stages:

### **Stage 1 – Literature review**

A scoping literature review that drew together the published and grey literature on walking with purpose among people living with dementia, specifically in long-term accommodation and care settings but also in mainstream housing.

### **Stage 2 – Online surveys**

Two online surveys with different target recipients: an organisation level survey (distributed to housing providers) and scheme level survey (cascaded to individual extra care and retirement housing schemes). The organisation level survey gathered data on prevalence, policies, procedures, provisions and challenges with respect to walking with purpose in the extra care and retirement housing settings belonging to housing providers in the UK. The scheme level survey gathered data on the prevalence, awareness, perceptions, understanding, responses, policies and procedures, support and outcomes with respect to walking with purpose in extra care and retirement housing settings in the UK.

### **Stage 3 – Case studies**

In-depth exploration of the issues relating to walking with purpose in at Housing 21 extra care schemes and retirement housing schemes via interviews with key staff and family members at the case study sites. The interviews focused on specific residents living with dementia who engaged in walking with purpose in order to produce a vignette/mini case study of each resident.

Interviews were also conducted with the informal/family carers of people living with dementia in mainstream housing in order to get a broader picture of the challenges and how this affects general needs housing.

## **Key findings**

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

Due to a low response rate, the findings of the organisation level survey were inconclusive and have not been included in this report. The scheme level survey initially had 148 respondents (71 Housing 21 respondents) who completed the questions about the scheme, the number of respondents then dropped to 93-103 (49 Housing 21) who completed the questions specifically about walking with purpose. Later on, only respondents who currently had residents who engage in walking with purpose were required to continue the questionnaire, so the number of respondents dropped further to 50 (28 Housing 21).

Across all the survey extra care schemes, residents living with a diagnosis of dementia constitute 14% of the total number of residents (also 14% for Housing 21 schemes only) with a further 5% living with suspected but undiagnosed/undeclared dementia (7% for Housing 21 schemes). These prevalence figures correspond well with the prevalence data from individual housing providers belonging to the HDRC. As would be expected, the prevalence of people living with diagnosed dementia in the survey retirement housing schemes was lower (5% across all respondents and 6% across Housing 21 respondents), however the proportion of people with suspected dementia was similar to that for extra care housing (5% across all respondents and also Housing 21 respondents).

The vast majority of all survey schemes have up to two residents who engage in walking with purpose. This constituted, on average 22% (24% for Housing 21) of all the residents living with diagnosed or suspected dementia for both types of schemes. The proportion of residents living with diagnosed or suspected dementia that walked with purpose in retirement housing was higher than in extra care housing.

Although residents who walk with purpose constitute a small portion of the total number of residents, around half of all the respondents and Housing 21 respondents

considered managing walking with purpose to be a challenge. Furthermore, majority of both extra care and retirement house respondents rated staff as only moderately successful in addressing walking with purpose. The severity of the challenge of managing walking with purpose was more variable for extra care than for retirement housing and could be of high severity in some extra care housing schemes; very high severity for some Housing 21 extra care schemes. Challenges described related to ensuring the resident's safety, especially when they leave and are away from the scheme, the scheme design and the stigma and misunderstanding around dementia. The severity of the challenge for extra care housing is reflected in the findings that the majority of extra care respondents felt that their scheme was moderately effective in supporting safe walking with purpose; responses for retirement housing respondents were evenly spread over very effective to slightly effective. This also applied to Housing 21 responses only. Staff awareness and knowledge was given by the majority of respondents as the main factor contributing to how effective a scheme was, followed by location of the scheme (these two factors were considered equal contributors to effectiveness by the majority of Housing 21 respondents).

Managing walking with purpose was also more of an issue in extra care housing than in retirement housing in terms of staff time, with this difference being even more evident for Housing 21 schemes. However, managing walking with purpose was considered to be only a moderate or slight contributor to staff stress for all respondents. Successes experienced in relation to walking with purpose at the survey schemes were connected with: improving staff understanding so that they can better support residents; raising awareness of dementia amongst other residents; use of technology; improving activities provided; working with families to improve their awareness and find solutions; greater understanding in wider community, e.g. local shopkeepers, and providing a secure environment.

Survey findings relating to potential new residents, risk assessments, policies and procedures suggested that not all extra care and retirement housing schemes are set up to consider or cater for people living with dementia who walk with purpose moving into the scheme and this omission is more evident in retirement housing than extra care housing. Very few of the schemes in the survey had policies, procedures or guidelines for supporting safe walking with purpose. More schemes may have had such policies or procedures because 40% of the respondents did not know whether they did, however, the fact that they did not know points to inadequate communication at the organisational level.

The most common and effective methods used to address walking with purpose were to try to understand why the resident is walking, distract or redirect the resident and walk with the resident. Respondents highlighted the fact that the most

effective technique depends on the individual resident, so it is important to get to know the person.

The majority of all respondents felt that walking with purpose did not create problems relating to human rights or deprivation of liberty, however a substantial proportion of respondents did not know. Deprivation of liberty was considered to be more of an issue for extra care housing respondents than for retirement housing respondents.

Although many respondents indicated that multiple design features were used at their schemes to support safe walking with purpose, especially extra care housing schemes, around half of the respondents wanted design changes in order to better support safe walking with purpose. Clearly, more needs to be done to make extra care and retirement housing schemes fully supportive of safe walking with purpose.

Just under half of the survey respondents used none of the examples of assistive technology devices to support safe walking with purpose in the survey and, for the rest, by far the most common devices used were CCTV and door alarms on individual apartment doors. Extra care schemes used more and a wider range of assistive technology than retirement housing schemes. The additional survey responses suggested that the low use of these devices may be due to lack of demand, lack of awareness and high costs.

Almost half of the respondents made suggestions about what they would like to change about the way their scheme supports residents who engage in walking with purpose. Suggestions were related to better understanding of walking with purpose, training and awareness for staff and residents, environmental design and greater funding for assistive technology.

### **Case studies**

A total of 14 case study interviews were conducted that focussed on:

- five people who engage in walking with purpose in Housing 21 extra care settings (five interviews with managers and one interview with a family member)
- three people who engage in walking with purpose in Housing 21 retirement housing (three interviews with managers, two with family members)
- two people living with dementia who walk with purpose in mainstream housing (two interviews with family carers)
- issues relating to walking with purpose at a dementia specialist day care centre (interview with a day care centre manager)

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

Each person's walking with purpose story was unique, with each of the people studied having different, personal motivations and reasons for walking. They also faced different risks depending on their personality, mobility, where and for how long they walked and their ability to get back to their chair/apartment/the scheme. Consequently, various responses to the walking with purpose were seen, although the preferred method of addressing walking with purpose appeared to be distraction/redirection. Understanding a resident's life story and their reasons for walking with purpose were recommended to assist with distraction or redirection. Even those scheme managers who tried to accommodate a resident's walking with purpose, enabling them to do so as safely as possible, would still try distraction or redirection first.

As with the schemes in the survey, the case study schemes had very few residents living with dementia who engaged in walking with purpose. The three case study retirement housing schemes currently had only one, one and two residents who walked with purpose and the three extra care housing schemes had one, two and seven. However, even if there is only one resident who walks with purpose, depending on the frequency and nature of walking with purpose, managing it can take up a disproportionate amount of time and effort for management and members of staff and can cause them stress. The case studies enabled an understanding of why this is the case. Residents who regularly leave or try to leave the scheme are particularly time consuming and stressful for management and staff. On the one hand, addressing the walking with purpose at the point when the resident is trying to leave the scheme using distraction or redirection can take time and be stressful if the resident is determined to leave and becomes agitated or distressed or even angry or aggressive towards staff. On the other hand, allowing the resident to leave the scheme means stress and anxiety for managers because a person that they feel responsible for is out of their sight and they cannot ensure their safety. If a resident is then away from the scheme for a few hours or more, managers become especially fretful and finding the resident to bring them back to the scheme is very time consuming. It is easy to see why managers and staff may prefer to address a resident leaving the scheme by trying to dissuade them from doing so. The managers of both the extra care and retirement housing case study schemes felt a great sense of responsibility and duty towards their residents and when their ability to ensure a resident's safety is taken away, this is a great source of stress and anxiety. Addressing walking with purpose that takes place only within a scheme can also be

time consuming if the resident is doing so regularly and can be a source of stress if that resident has a tendency to fall.

In schemes with good dementia awareness among residents, other residents play a part in ensuring safe walking with purpose for those who engage by keeping an eye on them.

For case study residents who walked with purpose within the scheme and were unable to find their own way back to their flat the design of the scheme was felt to be a major factor. Physical design of the environment that supports safer wayfinding for people living with dementia is important for supporting walking with purpose within a scheme.

Just as the purpose, reasons, risks and responses varied in the case studies, so did the outcomes for the residents who engaged in walking with purpose. Only one resident had to be moved out of the scheme, largely due to the impact that her walking with purpose had on people other than herself and the scheme staff. Other residents who regularly walked with purpose were at risk of being moved to accommodation that provides a greater level of care largely due to the risk their walking with purpose was perceived to create. Two of the case study residents who regularly walked with purpose died a few weeks after the interview, while a further two became more settled at the scheme and no longer engaged in walking with purpose. For others, having additional support to that provided by the scheme, either from family or private carers enabled them to remain living at the scheme. Keeping the resident occupied with activities and accompanied walking or outings was key to managing their walking with purpose and preventing it from being a challenge for the scheme. The benefits of occupation and activities to a person who engages in walking with purpose can be seen from the experiences of the manager and staff at the dementia specialist day care centre.

As can be seen from the case study vignettes, none of the three extra care schemes had policies, procedures or guidelines for supporting safe walking with purpose. The retirement housing schemes were mixed; one had such policies and procedures, one did not and at the third the manager did not know.

In terms of managing walking with purpose for people living with dementia in mainstream housing, the fact that, the people of interest in the case studies were kept locked indoors and could only leave the house if accompanied by their carer, with one being medicated to help them sleep at night, raises serious deprivation of liberty issues.

## Overall discussion and conclusions

The survey and case studies showed that, although residents who walk with purpose constitute a minority of people living in retirement and extra care housing schemes, managing walking with purpose can be a challenge for management and staff and can occupy a disproportionate amount of their time. The survey showed that the severity of this challenge and the impact on staff time was felt to be greater for extra care housing than for retirement housing. Similarly, the effectiveness of attempt to support walking with purpose was more varied for extra care than for retirement housing. However, the case studies found that, depending on the frequency and nature of walking with purpose, addressing this behaviour can be impact negatively on both retirement and extra care housing managers in terms of time, effort and emotional wellbeing.

While all the survey respondents felt that managing walking with purpose was only a moderate or slight contributor to staff stress, the managers interviewed in the case studies told a different story with many becoming stressed and anxious, particularly when residents leave or try to leave the scheme. While ensuring residents' safety when they leave the scheme was mentioned as a specific challenge by the survey participants, being able to explore the negative impact on managers in more depth in the interviews enabled a clearer understanding of why it has such an impact. The managers of both the extra care and retirement housing case study schemes felt a great sense of responsibility and duty towards their residents. When a resident living with dementia leaves the scheme they are no longer able to ensure that resident's safety, which is a great source of stress and anxiety. The case studies also revealed that addressing walking with purpose that takes place only within a scheme can also be time consuming if the resident is doing so regularly and can be a source of stress if that resident has a tendency to fall.

The preferred method of addressing walking with purpose in the case studies was distraction or redirection. Getting to know the resident by understanding their life story, likes and dislikes and their reasons for walking with purpose were recommended to assist with distraction or redirection. Other strategies adopted were to talk to the resident to try to explore their motivations, try to accommodate their wishes and accompany the resident on a walk outside. Similarly, in the survey, understanding why the resident is walking, distraction or redirection and walking with the resident were the most common and effective methods used to address walking with purpose. Getting to know the resident was also recommended by the survey respondents in order to discover and provide the most effective response to an individual's walking with purpose. Even those case study scheme managers who were willing to accommodate a resident's walking with purpose, and enable them to do so as safely as possible, would firstly try distraction or redirection. The case

studies enabled a greater understanding of why managers prefer to dissuade a resident living with dementia from leaving the scheme – once they have left the scheme this causes stress and anxiety for the managers and, if procedures such as the Herbert protocol are not in place, finding the resident and bringing them back can involve a lot of stress, time and effort for management and/or staff. However, using distraction/redirection could be viewed as staff trying to prevent a resident from leaving the scheme and indicative of a risk averse care culture that perceives walking with purpose as a problem. This is not consistent with the ethos of extra care and retirement housing living, which purport to encourage independence and choice.

Staff training in understanding and addressing walking with purpose appears to be key to effectiveness in supporting safe walking with purpose. Both the survey respondents and the managers interviewed in the case studies mentioned greater staff training in how to support people whom walk with purpose as a desired change. This is unsurprising, bearing in mind more than half of the extra care and retirement housing survey respondents stated that staff at their schemes had not received any training on understanding and addressing walking with purpose.

In addition to a lack of staff training at more than half the schemes surveyed, findings indicated that not all extra care and retirement housing schemes are set up to consider or cater for people living with dementia who walk with purpose. This omission is more evident in retirement housing than extra care housing. A large proportion of respondents were also unaware of whether their scheme had any policies, procedures or guidelines for supporting safe walking with purpose, which could mean that they did not have any or that they did but this had not been communicated to them by the organisation. A lack of such policies or procedures was also evident at the case study schemes.

The design of the physical environment plays an important role in supporting the wayfinding abilities of people living with dementia and there are numerous design features available to specialist accommodation settings to support safer walking with purpose. Examples include safe indoor and outdoor walking routes, with places to rest and interesting things to see and do along the way, and methods of deterring residents living with dementia from going into some areas and encouraging them into others. In both the survey and the case studies various design features were used by the schemes, with extra care housing schemes more likely to have a greater variety of features than retirement housing schemes. Design that better supports safe walking with purpose was a desired change mentioned by both survey respondents and case study managers, although with the case studies this was more of an issue for retirement housing schemes. One notable finding from the survey is that four of the extra care housing schemes (one Housing 21 scheme) and five of the

retirement housing schemes (four Housing 21 schemes) used black mats in front of exit doors. One of the case study extra care housing schemes and two of the retirement housing schemes also used these. Black mats are perceived as a hole in the floor by some people living with dementia and therefore deters them from leaving the building. This approach or course raises serious ethical issues. Use of deterrents to exiting such as black mats and the fact that design that better supports safe walking with purpose was a desired change for scheme managers mean that more needs to be done to ensure dementia friendly design of the physical environment that is supportive of safe walking with purpose in extra care housing and, in particular, retirement housing.

There are now many assistive technology devices available to ensure safer walking with purpose. Among other things, assistive technology can enable carers to know when a person who walks with purpose has left their room, bed or chair, track their location both within and outside the scheme, and help find the person should they become lost. The survey responses and case studies suggested that little use of such technology may be due to lack of awareness and high costs.

## **Recommendations**

### **The resident who engages in walking with purpose**

- Get to know the resident, find out their motivations and reasons for walking and try to accommodate their wishes. Understand the resident's life story and their likes and dislikes by talking to them and their relatives – this will help determine what will work to effectively support their walking with purpose. Through understanding, it is possible to address walking with purpose.
- Have patience, listen to the person and respect their wishes.
- Services should be personalised and person-centred, not just blanket services for all residents, to ensure that the specific needs of the individual are met.
- Have continuous assessment in place for the resident. This already happens in extra care housing but also needs to take place in retirement housing.

### **Care culture, management and staff**

- Train management and staff in understanding and addressing walking with purpose and the importance of understanding the particular resident's background and needs.

- Educate the staff to understand that it is worth the risk to let a person live as they want to. Discourage a risk averse attitude and encourage positive risk taking approaches.
- Ensure that all staff and residents are aware that if someone wants to walk out of the building they should not be prevented from doing so, rather enable them to do so in a safe manner e.g. ensure they are in appropriate clothes and shoes and watch them.
- Foster connections and good relationships with the local community and businesses. Ensure that they are aware of those residents who, having left the scheme, are at risk of getting lost and not being able to find their own way back. Having a local network of 'eyes' supports safer walking with purpose outside the scheme and can make management of residents who have a tendency to leave much easier.
- A local support network of Extra care housing/Retirement housing scheme managers enables managers to share experiences, ideas and advice.
- Carry out risk assessments for residents who walk with purpose.
- Allocate more care time to manage residents who walk with purpose.
- Inform the correct agencies (e.g. LA adult services and the Police) when a vulnerable person has left the extra care scheme.
- Use the Herbert protocol for residents who are at risk of leaving/getting lost outside the scheme.

### **Other Residents**

- Ensure other residents have an awareness and understanding of dementia and walking with purpose to reduce stigma and misunderstanding. Other residents also play a role in keeping an eye on residents who engage in walking with purpose. If understanding is lacking, dementia awareness sessions are recommended.

### **Family and other stakeholders**

- Develop and maintain good communication with the resident's family carers.
- It is crucial to ensure that the family understand and accept the situation with respect to their partner's/parent's dementia and their walking with purpose. It is also important for the family to understand why the resident's need to walk with purpose should be accommodated.

- Develop and maintain good communication and a good relationship with other stakeholders e.g. the GP, the mental health team, Local Authority. Be honest and open with everyone you need to work with.

### **Design and assistive technology**

- More needs to be done to ensure dementia friendly design of the physical environment that is supportive of safe walking with purpose in extra care and, in particular, retirement housing. The design of the physical environment plays an important role in supporting the wayfinding abilities of people living with dementia and design recommendations and guidelines are available (e.g. Davis, 2016). Example design recommendations that emerged from this study include:
  - Gardens and outdoor spaces must be secure and enclosed.
  - Provide safe indoor and outdoor walking routes with frequent places to rest and interesting things to see and do along the way.
  - Design features to assist with wayfinding.
- Consider use of assistive technology devices such as contact ID wrist bands, door sensors, speaking door sensors, GPS trackers and alarm mats.

# Introduction

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## Walking with purpose terminology

Many different terms are used in the literature to refer to the behaviour of walking with purpose including: wandering; walking; walking about; wander-walking; roaming; ambulation; movement; getting lost events; aberrant motor behaviour; exit seeking; elopement (walking away from a safe residence) and unescorted exiting.

The terminology used reflects the common view that walking with purpose is a problem, particularly when it is classed in the literature with other ‘challenging behaviours’, ‘behaviours that challenge’, ‘behaviours that concern’, behavioural disturbances’, ‘behavioural symptoms’, ‘disturbed/disturbing behaviours’, ‘distressed behaviours’, ‘aberrant motor behaviours’ or ‘difficult situations’.

However, there is no clear consensus about what exactly is being described and a standard definition is lacking. A review by Cipriani et al. published in 2014 recognised that ‘wandering’ is used as a broad term encompassing a wide set of behaviours but most researchers and health-care providers agree that wandering refers to seemingly aimless or disoriented ambulation, often with observable patterns such as lapping, pacing, or random ambulation. Among the many various definitions of ‘wandering’ there appear to be only two common features: an individual moving through space and being cognitively impaired. Cipriani et al. (2014) also listed multiple definitions that have been used in the literature, including ‘aimless movement without a discernible purpose’; ‘locomotion with no discernible, rational purpose’; and ‘the most difficult aimless behaviour to manage in demented patients’. While ‘wandering’ has become a label with negative overtones in the context of dementia care, it is now considered by some researchers and health professionals as an activity, and often a pleasurable one, that all of us engage in at some point in our lives. It is also 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 Society, 2019). In recognition of this, in this proposal we have adopted the term ‘walking with purpose’ while also acknowledging that this includes less purposeful ‘wandering’ as a normal and valuable human activity in its own right.

## Prevalence of walking with purpose

Very little is known about the prevalence of walking with purpose among people living with dementia or its many forms, contributory factors, outcomes or how best to support and safeguard individuals who engage in this behaviour. A review by Cipriani et al. (2014) suggested that on average one in five people with dementia ‘wander’, with reported rates varying, for example from 17.4% to 63% among people

living in the community and 50% among ‘people with severe dementia’ (Cipriani et al., 2014). It can take place both indoors and outdoors, and in care settings it can exhibit as persistent attempts to leave a confined area. There is some evidence to suggest that it is more common among those living with Alzheimer’s Disease than other dementias, among those with more severe dementia and among males.

## **Perception of walking with purpose**

When people living with dementia have a need to walk it is often seen as a ‘problem’. The terminology that is widely used reflects this viewpoint, particularly when it is described using terms such as ‘wandering’ or a ‘behavioural problem’. In addition, the term ‘wandering’ is often associated with agitated behaviour (Cipriani et al., 2014). Dewing (2006) and, more recently, Graham (2017) recognised the negative perception of ‘wandering’ in the context of dementia care. Both authors proposed an alternative viewpoint that it is in fact a fundamental human activity, and often a pleasurable one, that everyone engages in at some point in their lives. To that extent, Dewing (2006) suggested that we need to change the values and beliefs of practitioners, carers and society rather than call it something else. However, it is also apparent that ‘wandering’ suggests aimlessness, whereas in fact there is often a purpose or aim behind this activity (Alzheimer’s Society, 2019). Graham (2017) also proposed “depathologizing” ‘wandering’ and seeing it not as a product of disease and deterioration but rather as intention to be alive and to grow. Graham also notes that the shift towards person-centred dementia care has been accompanied by the adoption of the term “people who like to walk” rather than “wanderer”.

However it is described, many negative outcomes have been widely attributed to walking with purpose, such as distress for people with dementia and their caregivers and admission to residential care. It has also been associated with a range of other behaviours including depression, delusions, hallucinations, and sleep disorder (Cipriani et al., 2014). A range of medical responses has been adopted, including the use of medication to reduce walking as a manifestation of agitation.

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

## Responses to walking with purpose

A range of responses can be adopted in addressing the potential risks and harm associated with walking with purpose. For example, a more restrictive approach might include locking doors and using medication to sedate a person, while a less restrictive approach could be based on introducing activities that involve interaction and setting up a safe, circular route within a building and gardens.

Dewing (2005) recommended the use of a screening process so that people who need specific support with 'wandering' can be identified. This forms part of a more person-centred approach to walking with purpose that can also consider underlying factors such as continuing a habit or interest, relieving boredom or pain, lack of physical activity, responding to anxiety/stress, feeling lost (especially in a new environment), memory loss, and confusion about the time. In addressing such challenges, it is important to give due consideration to human rights issues including independence, safety, dignity and liberty.

While many organisations have policies for addressing the risks that are believed to be associated with 'wandering', most do not have guidance that support safe 'wandering' as a recognised part of the care needs of people with dementia. Cultures of care would appear to be key (Dewing, 2006; Graham, 2017). This subject also raises ethical challenges, including the possibility that preventing residents from walking freely might be a deprivation of liberty. Graham (2017) states that approaches to managing walking with purpose must take into account the "deep personal and social meaning" of walking with purpose and find ways to support resident's freedom of movement.

As can be seen in Table 2 below, a large portion of the literature found in the review concerns use of technology to manage the walking with purpose. There are now many assistive technology devices available to help manage walking with purpose and improve the safety and independence of those that do so. A scoping review of the literature on such devices found 83 devices described, ranging from alarm devices to mobile locator devices, only 19 of which had been clinically tested (Neubauer et al, 2018). Such devices alert carers when a person who walks with purpose has left their room, bed or chair, and enable them to track the person's location and find them should they become lost. The benefits of using such technologies included reductions in risk and caregiver burden and, bearing this in mind, the reviewers felt that such devices should be more affordable (Neubauer et al, 2018). The reviewers also highlighted the need to address the ethical issues of using such technologies.

## Impacts of walking with purpose

The impacts of walking with purpose on the people living with dementia who engage and their family carers is seriously under researched. Only one study was found on the impacts of walking with purpose on the person living with dementia who engages and this concerned the impact of ‘aberrant motor behaviour’ on weight changes in older adults living with Alzheimer’s Disease (Secher et al, 2013). Only one study was found on the impacts on family carers, which examined the effect of ‘risky wandering behaviours’ on family carers’ physical and mental health (Peng et al, 2018). There is more literature on the impact of being a family carer of a person living with dementia. No literature was found on the impacts of walking what purpose on staff or other residents in accommodation and care settings.

## Walking with purpose in extra care and retirement housing settings

Extra care and retirement housing providers face particular challenges in understanding and responding to residents living with dementia who engage in walking with purpose.

In extra care housing schemes and other forms of housing with care residents live independently, in a self-contained unit with its own front door, within a community that provides flexible, personalised care and support services, where a care team is onsite and care (planned and emergency) is available 24/7. Retirement housing schemes (also known as sheltered housing) have independent, self-contained homes with their own front doors, designed for older people, and there is usually a manager on-site or nearby who manages the scheme and helps arrange any services residents need.

Increasing numbers of people with dementia are supported in long-term care settings and extra care housing is now widely viewed as an alternative to care homes that can provide greater opportunities for maximising independence (Evans, 2009). While an estimated 70% of care home residents are living with dementia (Alzheimer Society, 2016), the prevalence of dementia among extra care housing residents is less clear, largely because comprehensive prevalence data across all housing providers has never been gathered. Data collected in 2017-18 by three housing providers belonging to the Housing and Dementia Research Consortium (HDRC) in the UK (MHA, Housing & Care 21 and the Extra Care Charitable Trust) found that 14-17% of extra care housing residents are living with dementia and 7-8% have suspected but undiagnosed/undeclared dementia (source: HDRC).

There is very little in the literature that examines walking with purpose in accommodation and care settings (see Table 2, below) and it is primarily concerned with managing the walking. The most recent literature is mainly concerned with the effectiveness of particular interventions on reducing agitation and walking with

purpose (e.g. Traynor et al, 2018 – structured physical activity programme; Ray et al, 2017 – music therapy) and wayfinding difficulties for people living with dementia in such settings (e.g. Caspi, 2014; Mazzei et al, 2014; O'Malley et al, 2017). No literature was found on the impacts of walking what purpose on staff or other residents in accommodation and care settings.

On addition to Dewing (2006) and Graham (2017) three other papers were found on the perceptions of care staff of residents who engage in walking with purpose. One investigated the most common and distressing behavioural and psychological symptoms of dementia for staff in nursing homes and found that shouting, wandering and restlessness had the highest incidence, frequency and difficulty ratings (Koder et al, 2014).

## **The Herbert Protocol**

The Herbert Protocol is a national initiative coordinated by Police Forces that involves carers compiling useful information that could be used in the event of a vulnerable person going missing. This would include information such as medication required, carer's contact details, places they previously lived and other places of interest or significance (places they are likely to go), a photograph, etc. In the event of the vulnerable person going missing, having this information already compiled can make finding the person easier and reduce the time taken to do so.

## **Aims and objectives**

The principle aim of this study was to explore and understand walking with purpose among people living with dementia in extra care, retirement and domestic housing settings, along with the perceptions and responses of staff and family carers, in order to develop good practice guidelines.

Specifically the study objectives were to explore:

- Existing evidence relating to walking with purpose among people living with dementia (via a literature review)
- The prevalence, awareness, perceptions, understanding, responses, policies and procedures, support and outcomes with respect to walking with purpose in extra care and retirement housing settings (via an online survey).
- The impact, challenges, responses and outcomes in relation to walking with purpose among people living with dementia in domestic (mainstream) housing (via telephone interviews)
- In more depth the causes, implications, impact and outcomes of walking with purpose for the lives of individual residents living with dementia in Housing 21 extra care and retirement housing schemes (via interviews with staff and family members at case study sites)

# Study design and methods

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The study comprised 3 stages:

1. Literature review
2. Two online surveys (at organisation and scheme level).
3. Case studies in extra care housing, retirement housing and mainstream housing settings.

## Stage 1: literature review

### Scope and aims of the literature review

The literature review was an essential part of the walking with purpose study as it informed the subsequent stages and fed into the development of the online survey, telephone interviews and case study interviews.

The literature review took a scoping approach to draw together the published and grey literature on walking with purpose among people living with dementia, specifically in long-term accommodation and care settings but also in mainstream/domestic housing.

The aims of the literature review were to explore:

- The evidence on walking with purpose among people living with dementia.
- The terminology surrounding walking with purpose and its categorisation as a behaviour.
- How walking with purpose is perceived by other people, carers of people living with dementia (both informal and formal) and housing providers.
- The impacts of walking with purpose for people living with dementia, their carers (both informal and formal) and housing providers.
- How walking with purpose is addressed in accommodation and care settings and domestic housing and related deprivation of liberty issues.

### Guiding research question for the review

What is currently known about walking with purpose in extra care, retirement housing and domestic housing settings in terms of perceptions, assessment, risk, impacts, addressing the issue and associated deprivation of liberty concerns?

### Method

Relevant literature was identified by electronic and manual searching, including bibliographies and reference lists of included papers and the identification of, and contact with, research centres, individual experts and practitioners in the field. The electronic databases and search terms used are shown in Table 1. Conference

papers, websites and news articles were also important sources of information as were communications with HDRC members and project advisory group members.

*Table 1: Literature review search strategy*

An electronic search of:	University of Worcester library services, Academic Search Complete, Scopus, ASSIA, British Nursing Index, CINAHL complete, Cochrane Library, DARE, Embase, Ingenta, JRF, The King's Fund, MEDLINE, Proquest central, PsycINFO, PubMed, Proquest, Social Care Online (SCIE), NICE evidence, Web of Science, ScienceDirect, Google Scholar, Mendeley Suggest.
An electronic and hand search of:	Grey literature including that held by Third Sector, Shed Organisations and research centres. Key sources included: HousingLIN, Innovations in Dementia, SCIE and The Kings Fund. Key journals included: Psychogeriatrics; International Psychogeriatrics; Home Healthcare Nurse; Nursing and Residential Care; Journal of Gerontological Nursing; Journal of Housing for the Elderly; Dementia; Housing, Care and Support; The journal of nutrition, health & aging; Social Science and Medicine; Quality in Ageing and Older Adults; Applied Psychology: Health and Well-Being; Ageing & Society; Age and Ageing; Health and Social Care in the Community; Journal of Ageing Studies; Gerontology; Gerontologist; Health and Place.
<b>Search Terms: <i>The following terms and all their variations were incorporated into the search strategy</i></b>	
Dementia	Alzheimer's; dementia
Walking with purpose	Walking with purpose; wandering; walking; exit seeking/exit-seeking; elopement
Risk and safeguarding	Risk, risk assessment, safeguarding
Impact	Impact, challenge/challenging
Health and wellbeing	Health; well being/well-being/wellbeing; quality of life; impact
Housing	Extra care; housing with care; assisted living; supported housing; sheltered housing; retirement housing; residential care; care homes; domestic housing; mainstream housing; general needs housing
Responses	Technique, approach, intervention, response, addressing, coping, tackling.
Design	Environment, design, assistive technology, wayfinding, orientation.
Assistive technology	GPS, tracking
Deprivation of liberty	Deprivation of Liberty, liberty, human rights.
<b>Inclusion criteria</b>	

Publications	Articles, books, book chapters and reports, websites, newspaper reports written in the English language over a ten-year period from 2008 to date relating to walking with purpose among people living with dementia.
Studies	Will be included if they describe walking with purpose among people living with dementia.
Study participants	Data will be included from older people where this clearly includes people living with dementia.
Outcomes	Included studies should consider any measure of the impact of walking with purpose, or how an intervention impacts on people living with dementia, their carers or staff.
Study designs	No study design will be excluded.
<b>Exclusion criteria</b>	
Studies	Studies not designed to include people with dementia; Publications not written in the English language.

A log was kept of the databases and websites searched, key words used and results of the searches. Titles and abstracts of publications to be considered for retrieval were downloaded into reference management software (Mendeley) and sorted into the categories (folders in Mendeley) shown in Table 2:

The titles and abstracts of identified publications were reviewed and the inclusion and exclusion criteria (See Table 1) applied to judge relevance to the study. The full texts of studies that appeared to meet the criteria were obtained and stored within the Mendeley category folders, and the criteria reapplied to exclude any irrelevant or duplicate articles from the final review. The number of documents (journal articles, books, book chapters, academic reports, theses, websites, presentations, newspaper reports, government white papers, reports and reviews) totalled 141 and the number within each category are given in Table 2 (note some documents sit in more than one category).

*Table 2: Literature categories and number of documents*

<b>Category</b>	<b>Number of publications</b>
Terminology/definition	5
Assessing/understanding	34
Models	3
Relation to other behaviours	2
Reasons/triggers	12
Assessing risk	4
Risks	15
Perceptions	
• People living with dementia	2
• Family carers	4
• Staff	5

Impacts	
• People living with dementia	1
• Carers	1
• Specialist housing – staff	0
• Specialist housing – other residents	0
Case studies	6
Location/environment	9
Responses/addressing/managing	
• Mainstream housing	8
• Specialist housing	20
• Design	11
• Assistive technology	27
DOL/ethical issues	5
Specialist housing	14
<b>Total:</b>	<b>188</b>

As can be seen in Table 2, much of the literature relates to assessing and understanding walking with purpose and responses to/managing walking with purpose, particularly through the use of assistive technology. There is a paucity of literature on the perceptions, impacts and ethical issues around walking with purpose, some of which is explored in the Introduction above, and also on how this behaviour may relate to other behaviours seen in people living with dementia.

The full literature review is available as a separate stand-alone document.

## **Stage 2: Survey of housing providers and schemes in the UK**

Two online surveys with different target recipients were developed: an organisation level survey (for completion by head office managers) and a scheme level survey (for completion by the managers of extra care housing and retirement housing schemes). The key inclusion criteria for survey recipients at the scheme level was that the scheme includes people with dementia at point of entry and has people with diagnosed dementia currently living there.

Together, the two surveys were designed to gather information on:

- Prevalence
- Screening processes for new residents
- Policies, procedures or guidance to support safe walking
- Policies for addressing risk
- Staff perceptions, awareness and understanding of walking with purpose
- Staff training specifically on dealing with walking with purpose
- Contributory factors
- Negative and positive outcomes
- Barriers and enablers

- Issues of design (building and outside space) and scheme location that make it easier or more difficult to deal with walking with purpose
- Responses to walking with purpose, if any and the results of these
- Support and safeguarding measures used and the results of these
- Any technology used and the results
- Deprivation of Liberty issues
- Challenges and successes

Links to the surveys were distributed by email via the HDRC network of housing providers and commissioners (around 25 members) and members of the Housing and Learning Improvement Network (Housing LIN). Instructions were given to forward the organisation level survey link to appropriate managerial staff at the housing organisation and to cascade the scheme level survey link to the managers of extra care and retirement housing schemes.

### **Response rates**

As the invitation to complete the online survey was disseminated with the intention of it being cascaded to other members, networks and housing providers then on to the accommodation and care settings themselves, it is not known how many people were actually invited to complete the survey. There was a total of 12 respondents for the organisation level survey with only 10 going on to complete the walking with purpose related questions, although 30 people accessed it. It is uncertain why 18 people did not go on to answer any questions; possibly, it was because they did not feel the questions were relevant to them or their organisation or that they did not have the necessary knowledge to answer. Due to this low response rate, the findings of the organisation level survey were inconclusive and have not been included in this report.

For the scheme level survey, 148 respondents completed the questions about the scheme but this dropped to 93-103 going on to complete the walking with purpose specific questions. The number of respondents completing the walking with purpose section of the scheme level survey further dropped to 50 or less for later questions. Thus, although a good sample size started the survey and most of the questions were compulsory, it appears that many people left the survey part way through for unknown reasons. Nevertheless, the scheme level survey responses enable us to gain an understanding of what is currently going on in terms of walking with purpose in extra care and retirement housing settings. The scheme level survey questionnaire can be found in Appendix A.

### **Stage 2 data analysis**

Survey responses were analysed within Survey Monkey and using Microsoft Excel for descriptive and comparative statistics to allow profiling of walking with purpose in

extra care and retirement housing settings. Additionally, the qualitative free-text responses were manually analysed to identify common themes and add to the richness of the findings.

### **Potential limitations**

It should be noted that the 148 completed scheme level questionnaires represent a self-selected sample of housing providers and extra care/retirement housing schemes. It may therefore be the case that the people who completed the survey are those doing more work around addressing walking with purpose. While this in itself is not an issue, it may mean that the views of those from housing providers and schemes that do not address walking with purpose or have struggled to manage walking with purpose are under-represented. This should be kept in mind when considering the findings.

It should also be appreciated that the survey responses are based on the perceptions of the individual staff members completing the survey.

## **Stage 3: Case studies – people living with dementia in extra care and retirement housing settings**

This final stage of the pilot study involved an in-depth exploration of the issues relating to walking with purpose at 6 Housing 21 case study sites: 3 extra care housing schemes and 3 retirement housing schemes.

For each case study site interviews were conducted with key staff and family members, focusing on specific residents living with dementia who engage in walking with purpose in order to produce a vignette/mini case study of each resident. The interviews took place either by phone or at the scheme where a suitable quiet room was provided for the interviewer and participant to sit in. For some of the case studies a follow-up phone call to the manager was made 10 weeks later.

The interviews were designed to gather information on:

- The resident's life story and how this may relate to their walking with purpose;
- Staff and family perceptions of walking with purpose and the resident's reasons for engaging in this behaviour;
- The implications, impacts and outcomes (both positive and negative) of walking with purpose for the resident's life in the extra care scheme;
- The implications, impacts and outcomes of the resident's' walking with purpose for the staff and family members;
- The individual factors that enable or hinder walking with purpose (e.g. mobility, fear of falls, ability to communicate) for this resident;
- The contextual factors that facilitate or hinder walking with purpose for the individual (e.g. policy, design of scheme, location of scheme, size of scheme, age of scheme);

- How the staff respond to and support the resident's walking with purpose;
- Challenges, enablers and successes in relation to the resident's walking with purpose.

Each case study interviewee scheme manager was asked to complete the survey questionnaire, whether or not someone at their scheme had already completed one as part of the survey, so that the researcher could refer to their questionnaire responses during the interview. The interview guides are given in Appendix B.

### **Case study sites**

Potential case study sites (extra care and retirement housing) were selected by the Housing 21 members of the study advisory group. These schemes were known to have at least one resident who engaged in walking with purpose and managers who were willing to take part in such a study. The managers of the schemes were contacted by the researcher, as described in 'Participants and recruitment' below. Of the six extra care schemes and five retirement, housing schemes proposed for participation, the managers of three extra care schemes and three retirement housing schemes responded and took part in the study. The final six case study schemes represented a good range of difficulties experienced (e.g. prevalence, supporting walking with purpose, risk, safeguarding, deprivation of liberty issues). Information on the participating case study sites is given in Table 3.

A Housing 21 day care centre (for up to 20 people living with dementia per day) attached to a residential care home was also included in the study. This centre was attended by the two people living with dementia in mainstream/domestic housing who were included in this study (see below). In addition, the manager of the day care centre was interviewed to understand any issues relating to managing walking with purpose in such a setting.

Table 3: Case study sites

Site Code	Size (no. apartments)	Total capacity/Current number of residents	No. residents with diagnosed dementia	No. residents with suspected dementia	No. of residents who walk with purpose	Model of dementia care (extra care only)	Location and building characteristics
<b>Extra care housing</b>							
EC1	32	64/33	18	0	1	Integrated	East England Suburban Fully purpose built
EC2	38	39	4	7	7	Integrated	Southeast England Suburban Fully purpose built
EC3	40	60/38	11	0	2	Integrated	Northwest England Suburban Fully purpose built
<b>Retirement housing</b>							
RH1	37	42	3	2	1	-	East Midlands Rural Fully remodelled from 5 existing blocks of flats built in 1976.
RH2	29	35	5	-	1	-	Southwest England Rural Fully remodelled from 5 existing blocks of flats built in the 1970's.
RH3	38	44	3	1	2	-	Yorkshire and the Humber Suburban Fully remodelled from a single block built in 1972 and originally owned by the Royal British Legion.

## **Participants and recruitment**

Potential participants (family carers of residents living with dementia who engage in walking with purpose and appropriate managers/staff) at the case study sites were identified by the scheme managers. The lead researcher liaised closely with the managers to assist them in making recruitment decisions and ensure that ethical principles were adhered to in the process. Each scheme manager at the potential case study sites received an information sheet informing them about the HDRC, the study, the purpose of the interviews and the process for recruiting appropriate interview participants (see Appendix C). The manager also received the participant information sheets for the family carers and the staff (See Appendices D and E) to give to potential participants to help them to decide whether they would like to take part. The managers were made aware that a quiet space was required in which to carry out interviews that took place at the case study site.

Participant inclusion criteria for the staff:

- manager or member of staff who is directly involved with residents living with dementia;
- has experience of responding to walking with purpose;
- willing to take part in an interview either by phone or at the scheme.

Participant inclusion criteria for family members (extra care/retirement housing):

- has a relative living with a diagnosis of dementia at the scheme who engages in walking with purpose;
- could be living in their own home or at the scheme with their relative;
- willing to take part in an interview either by phone or at the scheme.

## **Stage 3: Case studies – people living with dementia in mainstream housing**

Interviews were conducted with two informal/family carers of people living with dementia in mainstream/domestic housing in order to get a broader picture of the challenges associated with managing walking with purpose and how this affects people who live in general needs housing. The interviews took place at the Housing 21 dementia specialist day care centre attended by the people living with dementia in a suitable quiet room.

The interviews explored the following general topic areas:

- The life story of the person living with dementia and how this may relate to their walking with purpose;
- The perceived possible reasons for walking with purpose;
- How the family carer responds to walking with purpose;

- Managing risk;
- Support and safeguarding measures used and the results of these;
- Any technology used and the outcomes;
- The implications, impacts and outcomes (both positive and negative) of walking with purpose for the resident's life;
- The implications, impacts and outcomes (both positive and negative) of walking with purpose for the family carer;
- Challenges, enablers and successes experienced by the family carer;
- The individual factors that enable or hinder walking with purpose (e.g. mobility, fear of falls, ability to communicate);
- The contextual factors that facilitate or hinder walking with purpose (e.g. design of the home, location of the home).

### **Participants and recruitment**

For the people living with dementia in mainstream/domestic housing, the two interview participants were family carers of people living with dementia who attended a Housing 21 dementia specialist day care centre a few days a week. They were recruited to the study with the help of the day care centre manager. The manager was also interviewed to understand any issues that are encountered in relation to walking with purpose in a day care setting and to compare with the extra care and retirement housing settings.

Participant inclusion criteria for family carers (mainstream/domestic housing):

- Current or recent family carer for a person living with a diagnosis of dementia;
- the person they care for currently engages, or recently engaged, in walking with purpose;
- lives/lived with the person they care for in their own home, that is mainstream/domestic housing (not independent living in sheltered, retired or extra care accommodation);
- Willing to participate in an interview either by phone or at the day care centre.

### **Stage 3 data analysis**

The information gathered from the Stage 3 interviews, focusing on specific people living with dementia that engaged in walking with purpose, was used to construct a vignette/mini case study of each resident. These mini case studies aimed to provide us with a deeper understanding of the triggers, implications, impacts and outcomes of walking with purpose for the lives of the individual residents concerned. The qualitative data from Stage 3 interviews were also analysed for thematic content to identify the overarching themes with the aid of specialist software (NVivo 11). Analysis adopted a grounded theory approach (Glaser & Strauss, 1967) which

enables the development of theory from the research data and is particularly appropriate to address under-researched areas such as the topic of this study.

## **Research ethics and governance**

This study was approved by a Research Ethics Committee at the University of Worcester.

In keeping with established practice and in accordance with the Data Protection Act 1998, all data were stored on password protected servers (ESRC, 2010). The project was subject to established research governance monitoring processes at the University of Worcester and the methodology followed the principles set out in the University of Worcester Ethics Policy.

# Stage 2 results: scheme level survey

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## Respondents

The scheme level survey initially had 148 respondents who completed the questions about their scheme, e.g. type of scheme, location, number of apartments, model of dementia care and number of staff, residents and residents living with dementia. The number of respondents then dropped to 93-103 who completed the questions specifically about walking with purpose. The reasons for this are unknown but may have been due to respondents lacking time, feeling it was irrelevant to them or not having the required information. Later on, after the questions on policies, procedures and guidelines, the number of respondents dropped further to 50 or less for most of the remaining questions. This second drop in number of respondents was because respondents were asked if they currently considered walking with purpose to be a challenge for their scheme and those that responded 'no – we do not currently have residents who engage in walking with purpose' were directed to the end of the survey, skipping the remaining questions.

126 respondents provided a name for their organisation (optional): 71 people worked for Housing 21; 28 people worked for Hanover/Hanover Housing Association; 18 people worked for Guinness Care/The Guinness Partnership; 5 people worked for MHA; 2 people worked for West Kent Housing Association; 1 person worked for Belong; 1 person worked for Connect Housing.

Of the 71 respondents who worked for Housing 21, 50 completed the questions about walking with purpose and further dropped to 28.

## Schemes and residents

Of the 148 people who responded, 106 (72%) worked in a retirement housing scheme while 42 (28%) worked in an extra care housing scheme. For the 71 Housing 21 respondents, 50 respondents (70%) worked in a retirement housing scheme while 21 (30%) worked in an extra care housing scheme.

### Model of dementia care

For the extra care schemes, 38 of the respondents (90%) said that people living with dementia are integrated throughout the scheme, one said that the scheme has a separate floor or wing for residents living with dementia and three were dementia specialist/dedicated schemes.

For Housing 21, of the 21 respondents working in an extra care scheme 19 responded, with 18 saying that in their scheme people living with dementia are

integrated throughout and one scheme was dementia specialist. There were no schemes using the separated model.

## Part of the country

148 respondents provided information about the location of their scheme.

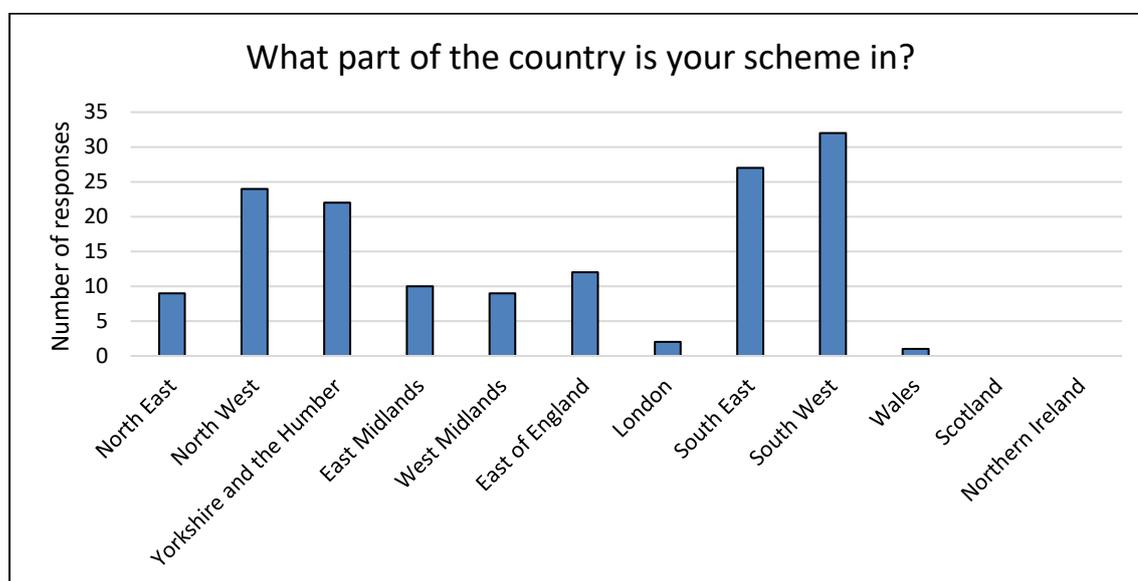


Figure 1: Scheme location

The majority of respondents were in the south east, south west and north wests of England and Yorkshire and the Humber. There were no respondents in Scotland or Northern Ireland. For Housing 21 the majority of respondents were in the south east, south west and north west of England.

## Area

Similar proportions of respondents worked in schemes in urban (40%) or suburban (36%) areas, with less working in rural areas (24%).

The figures for Housing 21 schemes were 33% Urban, 41% suburban and 27% rural.

## Type of building

The majority of respondents (81%) reported that their scheme was fully purpose built. 12% were partly purpose built and partly remodelled and 7% were fully remodelled from an existing building. The split was similar for both extra care housing and retirement housing.

For Housing 21 schemes, 76% of respondents reported that their scheme was fully purpose built with 14% partly purpose built and partly remodelled and 10% fully remodelled. Although the majority of both retirement and extra care housing schemes were fully purpose built, the second most common type of building for retirement housing was fully remodelled from an existing building, whereas for extra

care housing it was partly purpose built and partly remodelled (see the bar chart below).

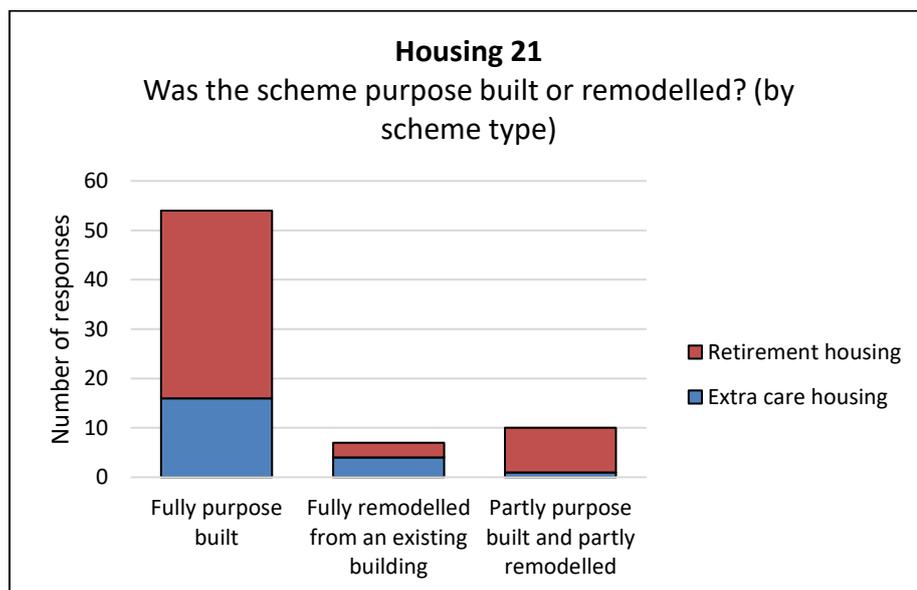


Figure 2: Type of building

### Number of apartments

Of the 148 respondents, the majority (57%) reported that their scheme has between 21 and 40 apartments. The maximum number of apartments was 176. 64% of retirement housing schemes had 21-40 apartments, compared to 41% of extra care housing schemes.

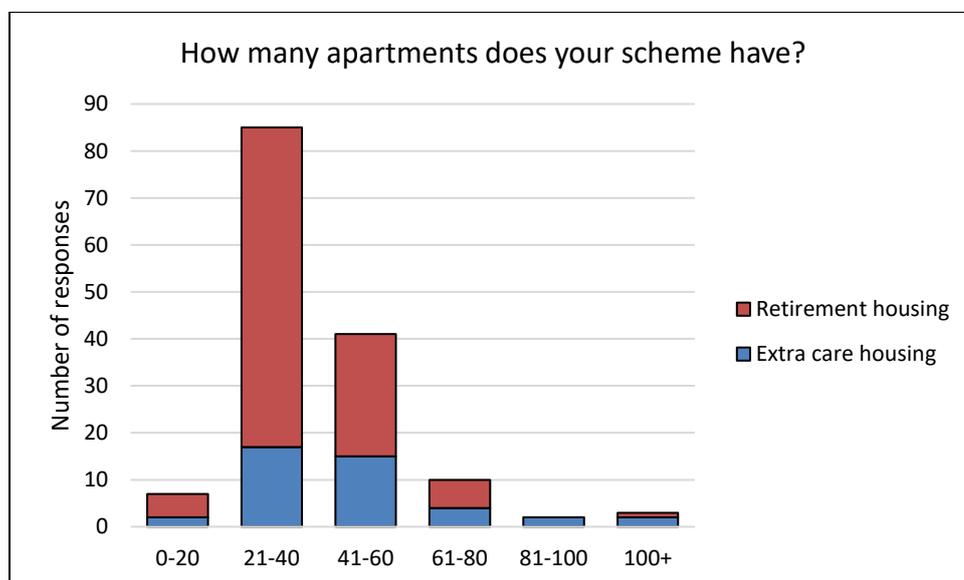


Figure 3: Number of apartments

For Housing 21 respondents, the majority (61%) reported that their scheme has between 21 and 40 apartments. The maximum number of apartments was 176. 64% of retirement housing schemes had 21-40 apartments, compared to 52% of extra care housing schemes.

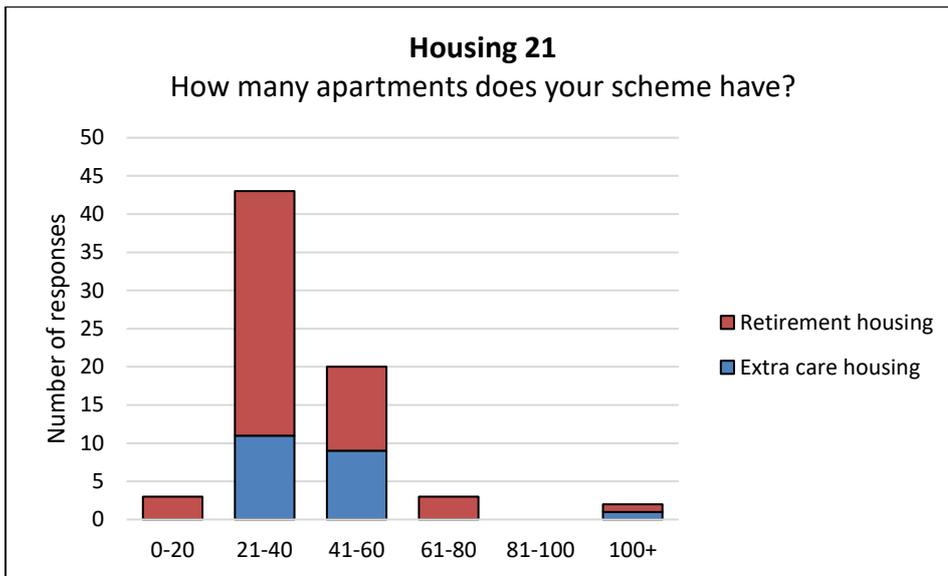


Figure 4: Number of apartments – Housing21 schemes only

### Number of care staff

Of the 148 respondents, 123 provided information about the number of care staff. 71 (58%) said that there were no care staff in the scheme, although one person did clarify that there were ‘several private ones’. The maximum number reported was 130 for an extra care scheme. One respondent said that the number of care staff depended on ‘shifts and numbers of residents’. Retirement housing schemes have fewer staff than extra care schemes, with 97% of retirement housing schemes having up to 5 care staff compared to 29% for extra care schemes.

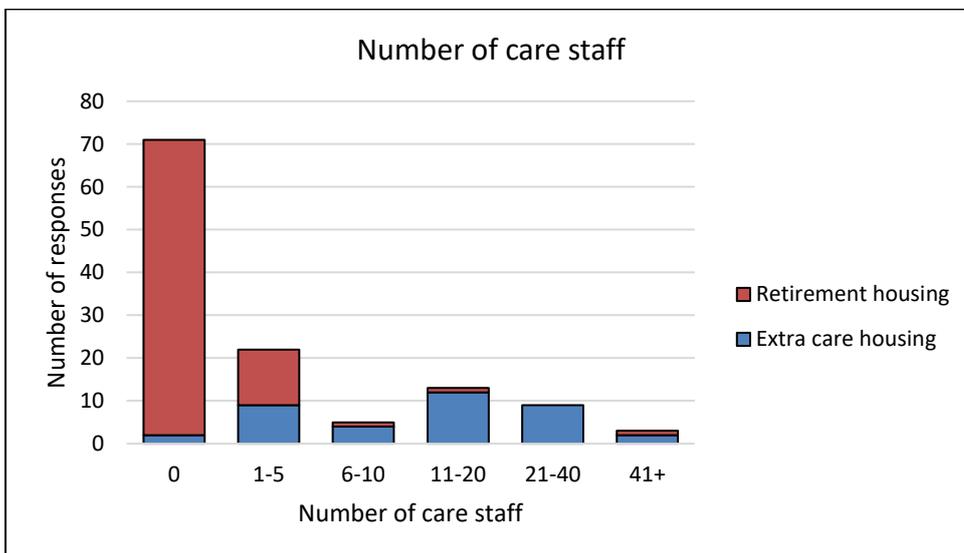


Figure 5: Number of care staff

65% of Housing 21 respondents said that there were no care staff in the scheme, all of which were retirement housing schemes, although one person did clarify that there were ‘several private ones’. Retirement housing schemes have fewer staff than

extra care schemes, with no retirement housing schemes having more than 5 care staff.

### Total number of residents

Most respondents said that their scheme could have up to 50 residents. This was also the case for Housing 21 respondents. The maximum reported was 191 (a Housing 21 extra care housing scheme).

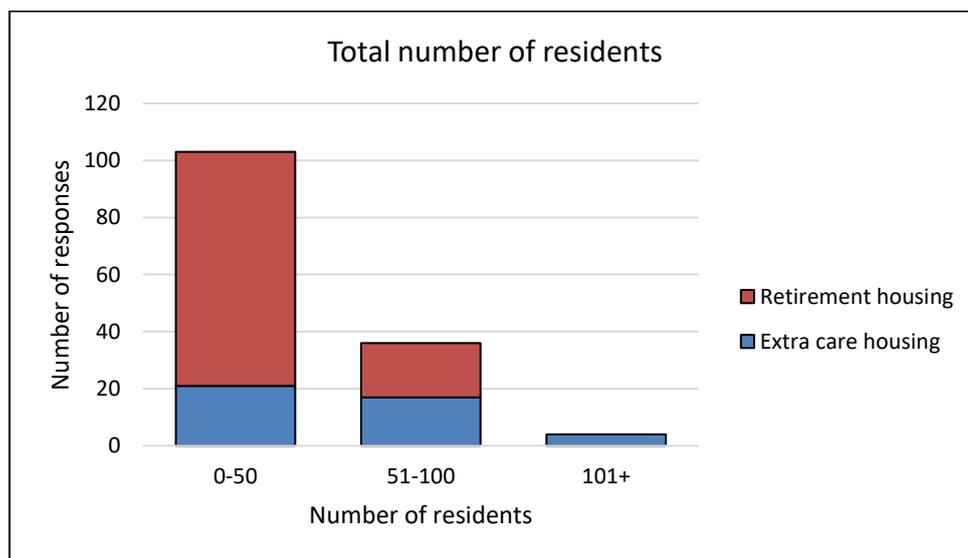


Figure 6: Total capacity of the scheme

81% of retirement housing schemes had a maximum of 50 residents compared to 50% of extra care housing schemes.

For Housing 21 schemes, 79% of retirement housing schemes had up to 50 residents compared to 62% of extra care housing schemes.

### Number of residents with a dementia diagnosis

Most schemes had up to 10 residents with a diagnosis of dementia. This was also the case for Housing 21 schemes.

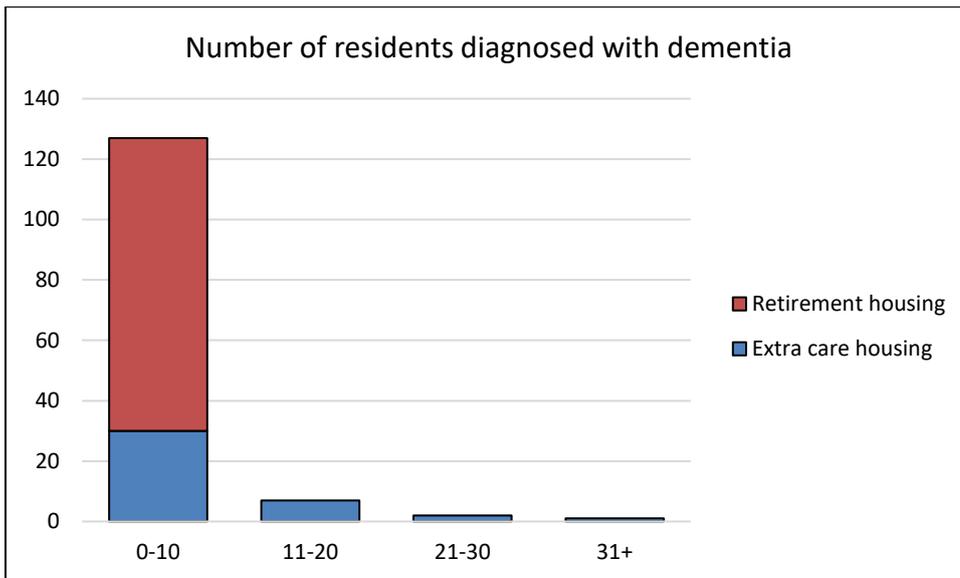


Figure 7: Number of residents diagnosed with dementia

### Number of residents with undiagnosed/undeclared but suspected dementia

Most schemes had up to 10 residents who are suspected to have dementia but have not been diagnosed. Again, this was also true for Housing 21 schemes.

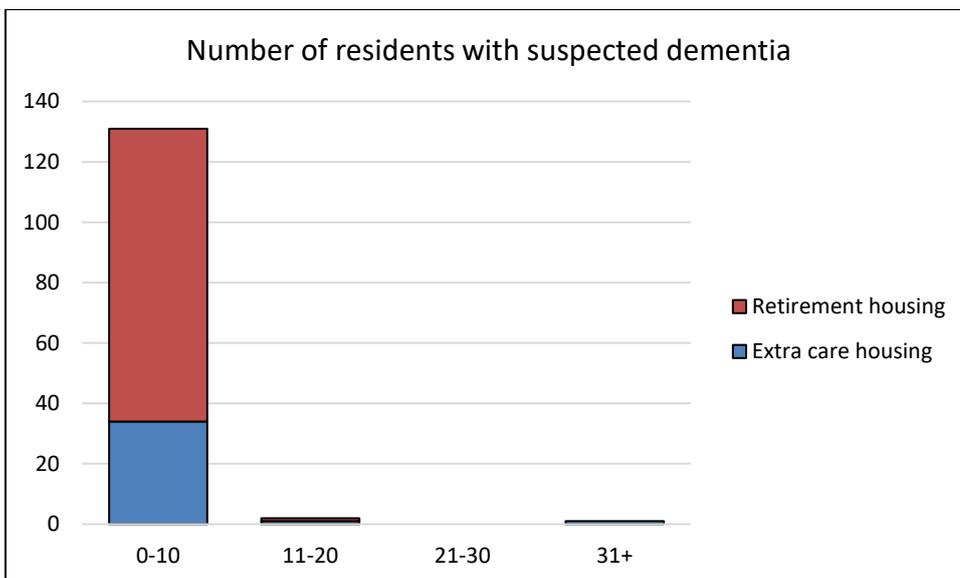


Figure 8: Number of residents with suspected dementia

## Summary of residents

It should be noted that some respondents gave estimates of the numbers of residents, so the following may not be entirely accurate.

Table 4: Summary of residents in all schemes

All respondents	Extra care housing			Retirement housing		
	Total across all respondents (as % of all residents)	Range	Average	Total across all respondents (as % of all residents)	Range	Average
All residents	2362	8-191	56.24	4247	2-89	42.05
Residents with dementia	335 (14.2%)	1-33	8.38	206 (4.9%)	0-9	2.12
Residents with suspected dementia	126 (5.3%)	0-34	3.5	209 (4.9%)	0-12	2.13

Table 5: Summary of residents in Housing 21 schemes

Housing 21 respondents	Extra care housing			Retirement housing		
	Total across all Housing 21 respondents (as % of all residents)	Range	Average	Total across all housing 21 respondents (as % of all residents)	Range	Average
All residents	1111	24-191	52.9	2024	16-85	43.1
Residents with dementia	155 (14.0%)	1-30	7.8	111 (5.5%)	0-9	2.3
Residents with suspected dementia	81 (7.3%)	0-34	4.5	95 (4.7%)	0-12	2.0

## Walking with purpose

### Number of residents who walk with purpose

Of the 98 people who responded to this question, 38 (39%) said no residents with dementia currently engaged in walking with purpose. This represents 45% of the retirement housing responses and 26% of the extra care responses.

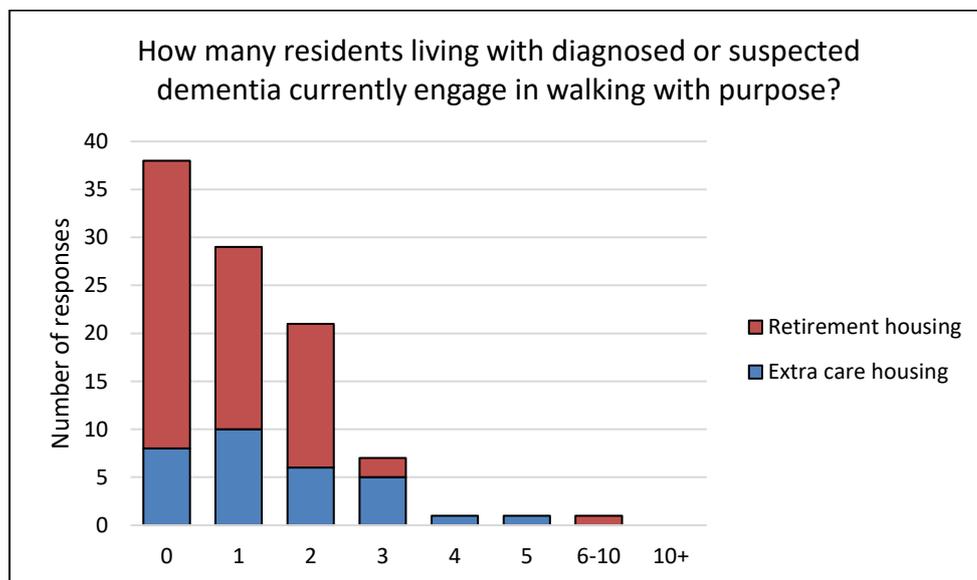


Figure 9: Number of residents who currently walk with purpose – all schemes

Of the 49 Housing 21 respondents to this question, 47 (96%) said that up to 2 residents with dementia currently engaged in walking with purpose.

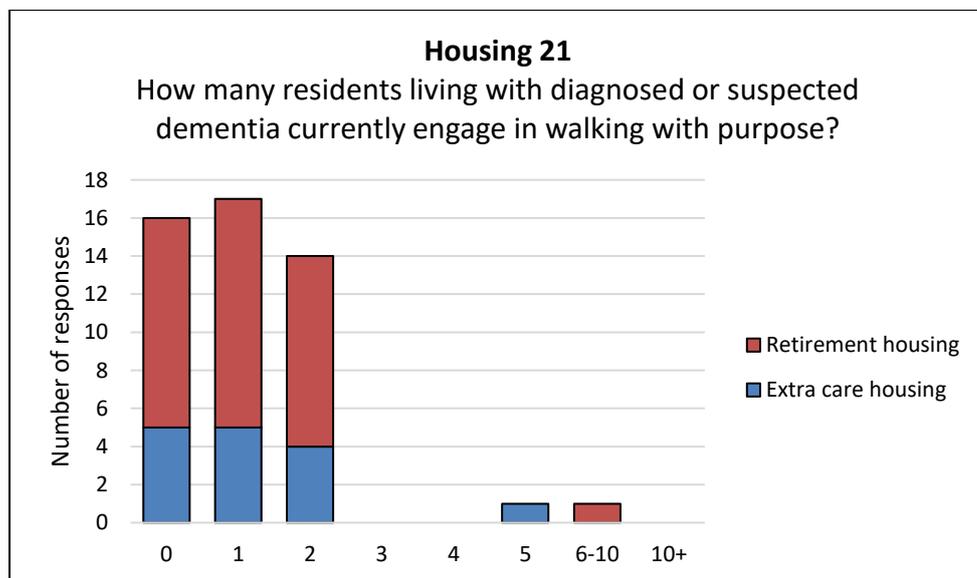


Figure 10: Number of residents who walk with purpose – Housing 21 schemes only

Where respondents provided sufficient information, it was possible to see that, on average, those engaging in walking with purpose currently represent 22% (24% for Housing 21) of all the residents living with diagnosed or suspected dementia. In extra

care housing this was 15% and 25% in retirement housing (11% for Housing 21 extra care housing schemes and 30% for Housing 21 retirement housing schemes).

### **Challenges encountered**

93 respondents indicated a variety of challenges that they have encountered in relation to walking with purpose among residents living with dementia. These included:

- Ensuring resident safety, especially when they leave and are away from the scheme
  - Particularly in relation to the risk of falling
  - Getting lost
  - Leaving the scheme without staff/family knowing
  - Getting into cars with strangers/going into other people's houses or apartments
  - Inappropriate (or no) clothing
  - Inability to describe to others where they are trying to go/get back to
- The stigma and misunderstanding around dementia
  - Other residents finding it 'weird' or seeing walking as 'nuisance behaviour'
  - Getting family to accept it
- The scheme design
  - Size
  - Stairs
  - Wayfinding not ideally marked
  - Openness of the complex
  - Ease of access to outside
- No real issues

These issues also applied to Housing 21 schemes.

### **Successes**

100 respondents also described a variety of successes that they have experienced in relation to walking with purpose among residents living with dementia. These included:

- Improving staff understanding so that they can better support residents who engage in walking with purpose
  - Walking with residents and spending time with them

- Distraction techniques
- Building walks/outings into care plans
- Raising awareness of dementia amongst other residents
  - Encourage them to support/engage with residents with dementia
- Using door sensors/alarms and other types of technology
- Improving activities provided
  - Walking group
  - Memory group
- Working with families
  - Working with families to find solutions
  - Improving awareness with family
- Greater understanding in wider community, e.g. local shopkeepers
- Providing a secure environment

These successes also applied to Housing 21 schemes only.

### **New residents**

Of the 103 respondents, 43 (42%) stated that a tendency to engage in walking with purpose was taken into consideration for new residents. For the 50 Housing 21 respondents, 24 (48%) felt that a tendency to engage in walking with purpose was taken into consideration for new residents.

There was a difference between scheme types, with extra care schemes appearing to be more likely to take into consideration a person's tendency to walk with purpose (65% compared to 31% for retirement housing schemes). This also applied to Housing 21 respondents only (almost 70% for extra care schemes compared to almost 40% for retirement housing schemes).

### **Risk assessments**

Of the 103 respondents, nearly half said that their scheme did not carry out a risk assessment for walking with purpose for people living with dementia. This also applied to the 50 Housing 21 respondents.

There was also a difference between scheme types in terms of whether risk assessments are carried out, with extra care schemes appearing to be more likely to do them (62% compared to 22% for retirement housing). This also applied to Housing 21 respondents (75% for extra care schemes compared to 26% for retirement housing schemes).

## **Staff training**

Of the 103 respondents, 58.3% said that staff had not received any training on understanding and addressing walking with purpose. The responses were very similar for both extra care housing and retirement housing.

For 50 Housing 21 respondents, 50% said that staff had not received any training on understanding and addressing walking with purpose. There was no real difference between the two types of scheme.

## **Policies, procedures and guidelines**

Of the 103 respondents, only 19 (18.5%) said that their scheme has policies, procedures or guidelines for supporting safe walking with purpose. However, the high proportion of 'Don't know' responses (43%) means that more schemes may actually have relevant policies.

Of the 50 Housing 21 respondents, only 10 (20%) said that their scheme has policies, procedures or guidelines for supporting safe walking with purpose. However, this means that just over half of the respondents who did have such policies or procedures worked for Housing 21.

When asked about other policies or procedures they would like to introduce to better support safe walking with purpose at their scheme, several suggestions were made including:

- Staffing levels – and Social Care building this into their budgets for care
- Risk assessments to work alongside support plans
- Simple instruction booklet for staff and other tenants
- Risk assessments at sign up for new residents
- Clarity of the responsibility of the scheme manager
- Better engagement from Adult Services
- A list of professionals to contact for advice, especially around equipment

The first three on this list were suggestions from Housing 21 respondents.

While some respondents felt that any further advice or information would be good, others felt that because everyone is different/has different needs, guidance on supporting safe walking with purpose might not cover everyone.

## Types of policies

55 respondents commented on the policies/procedures that their schemes have (see the bar chart below), although nearly half of them (42%) were unsure of what was in place. The most common procedure was to use the resident's history or life story to understand what is triggering the walking and create an individual plan to deal with the behaviour (42%).

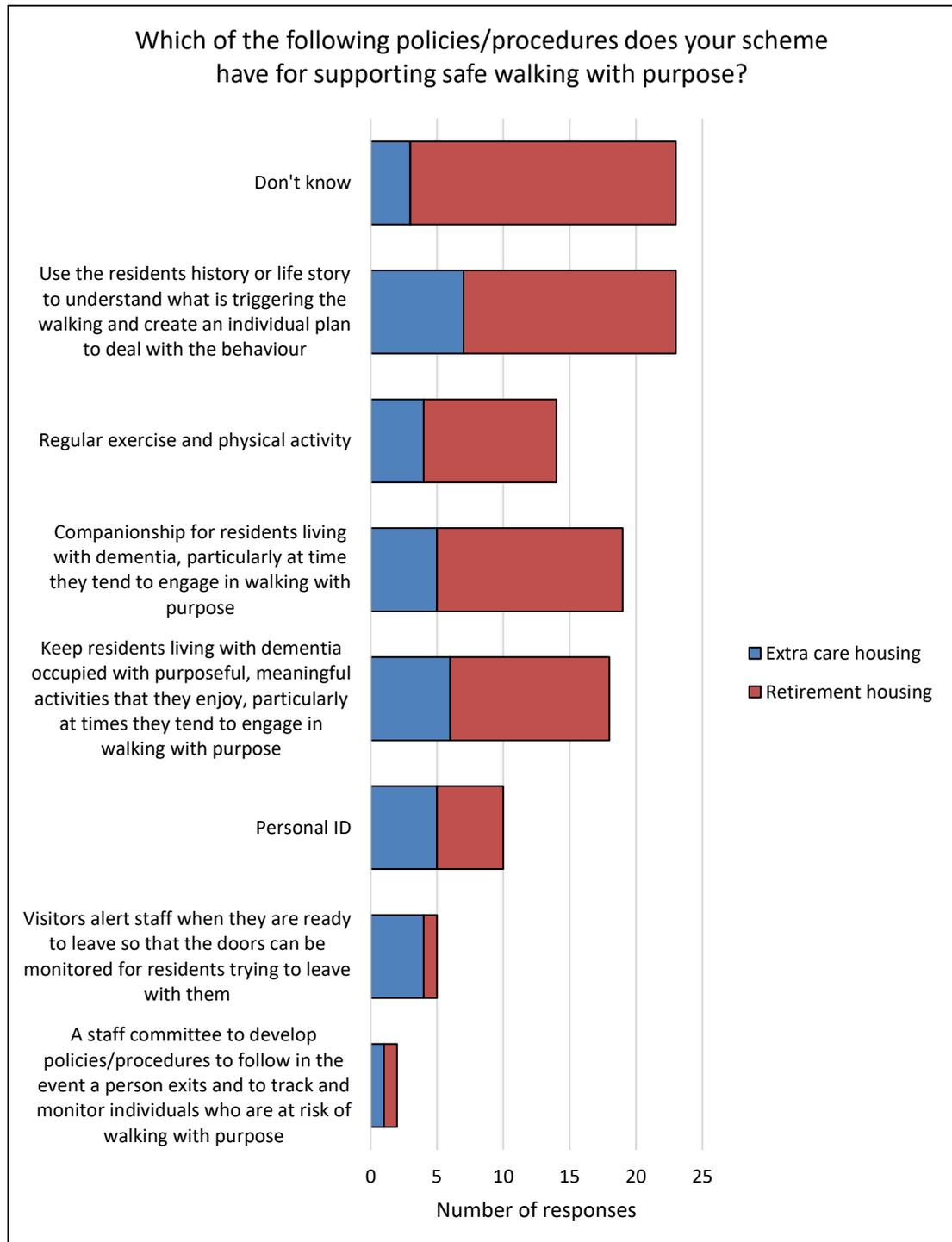


Figure 11: Policies/procedures for supporting safe walking with purpose – all schemes

Only 23 Housing 21 respondents commented on the policies/procedures that their schemes have (see the bar chart below), with 9 of them (39%) being unsure of what was in place. As for all respondents, the most common procedure was to use the resident's history or life story to understand what is triggering the walking and create an individual plan to deal with the behaviour.

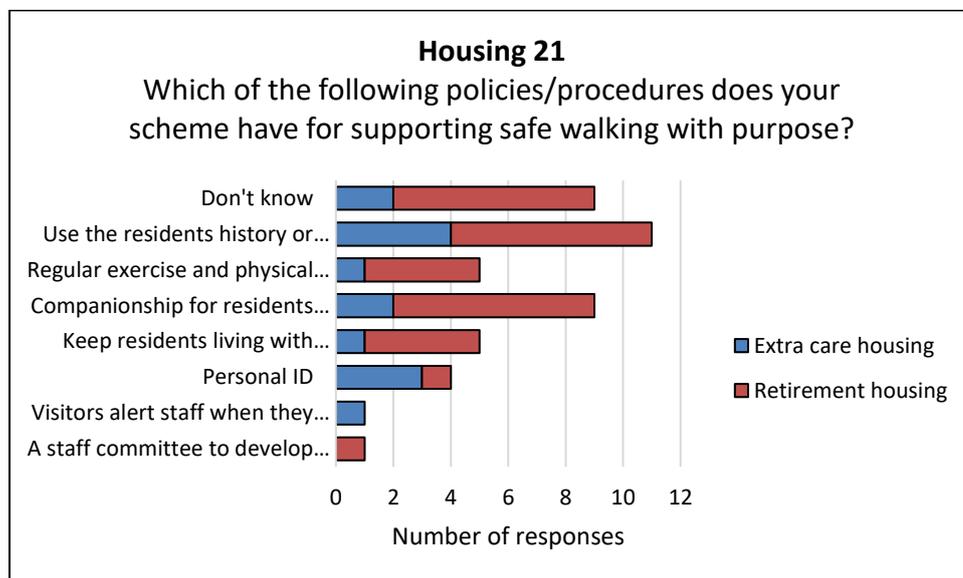


Figure 12: Polices/procedures for supporting safe walking with purpose – Housing 21 scheme only

### Success of policies/procedures/guidelines

Of the 55 respondents who commented on their policies, only 29% felt that they had been successful in supporting safe walking with purpose and 60% didn't know whether or not they had been successful.

Comments included:

- Not being able to prevent residents from leaving schemes, especially where independent living is promoted
- Extending the length of time residents can remain at a scheme
- Being more about personal experience and trial and error than about policies and procedures
- Not knowing much about the policies (but being prompted to do so by completing the survey)

For the 23 Housing 21 respondents, 44% felt they had been successful in supporting safe walking with purpose and 39% didn't know.

### Perspectives on walking with purpose

While 32% of 94 respondents considered walking with purpose to be a challenge for their scheme, a similar proportion (35%) did not currently have residents who

engage in walking with purpose. Effectively, this means that of the respondents who have residents engaging in walking with purpose, 49% consider it a challenge.

For the 44 Housing 21 respondents, 41% felt that it was a challenge and 23% did not currently have residents who engage in walking with purpose. Effectively, this means that of the respondents who have residents engaging in walking with purpose, 53% consider it a challenge.

There was a slight different between type of scheme. Overall, a smaller proportion of respondents felt it was a challenge in retirement housing schemes (30%) compared to extra care schemes (37%). However, if we only consider the respondents who actually had residents engaging with walking with purpose this is reversed with a larger proportion considering it challenge in retirement housing (51%) compared to extra care (46%).

For Housing 21 respondents, a larger proportion felt it was a challenge in retirement housing schemes (45% or 54% of those who actually had residents who walk with purpose) compared to extra care housing schemes (33% or 50% of those with residents who walk with purpose)

### Severity of the challenge

Although aimed at the 30 people who said walking with purpose was a challenge for their scheme, 49 respondents answered the follow on question about the severity of the challenge. Most respondents rated the challenge as ‘low’ to ‘moderate’.

There was a difference between type of scheme, with retirement housing respondents likely to rate the challenge towards the less severe end of the scale while the extra care responses were spread more evenly across the whole scale.

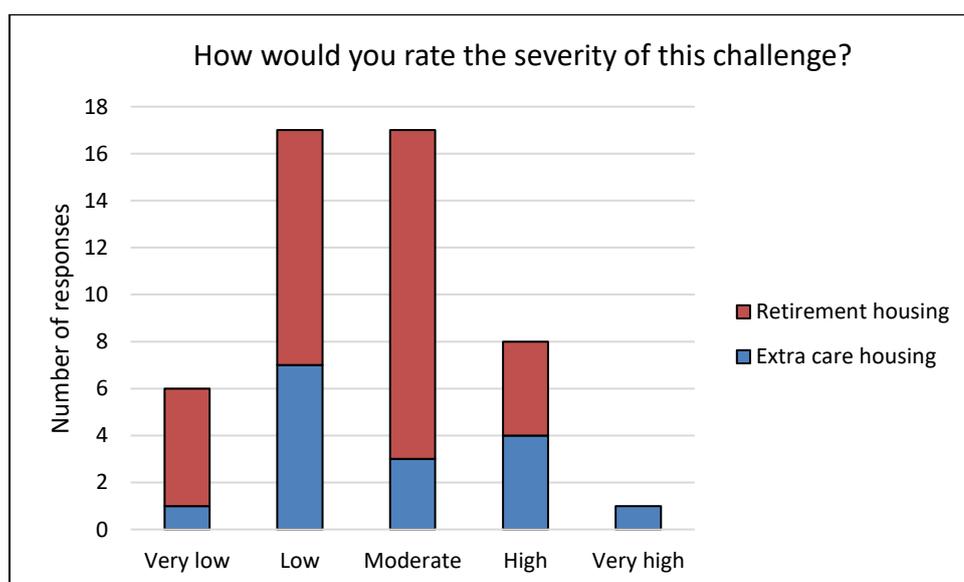


Figure 13: Severity of the challenge – all schemes

For Housing 21 respondents, of the 18 who considered walking with purpose to be a challenge, most rated the challenge as ‘moderate’ and, once again, retirement housing respondents tended to rate the challenge towards the less severe end of the scale while the extra care responses were spread more evenly across the whole scale.

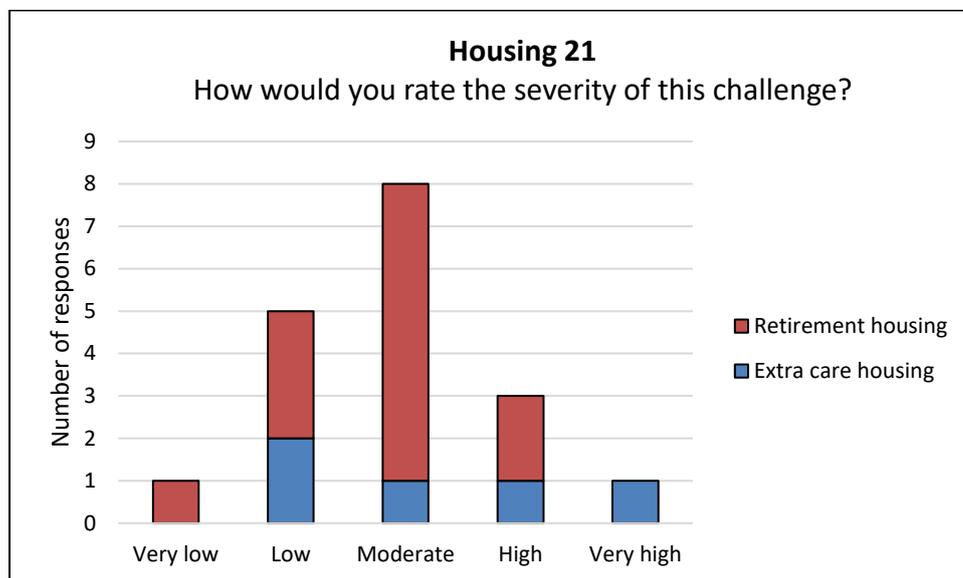


Figure 14: Severity of the challenge – Housing 21 scheme only

### Effectiveness of support from scheme

Of the 50 responses to this question, the majority (48%) felt that their scheme was ‘moderately effective’ in supporting safe walking with purpose. For the 28 Housing 21 respondents, the majority (36%) felt that their scheme was ‘very effective’ in supporting safe walking with purpose.

The retirement housing responses were evenly grouped around the middle of the scale, while the extra care responses were mainly ‘moderate’ but did cover the whole scale. This also applied to Housing 21 responses only.



Figure 15: Effectiveness in supporting safe walking with purpose

The majority (62%) felt that staff awareness and knowledge was the main factor contributing to the effectiveness or lack of effectiveness, followed by location of the scheme (52%).

The pattern of responses was very similar when considering only Housing 21 respondents, with staff awareness and knowledge and location of the scheme being considered equal contributors to effectiveness by the majority of Housing 21 respondents (57% for both).

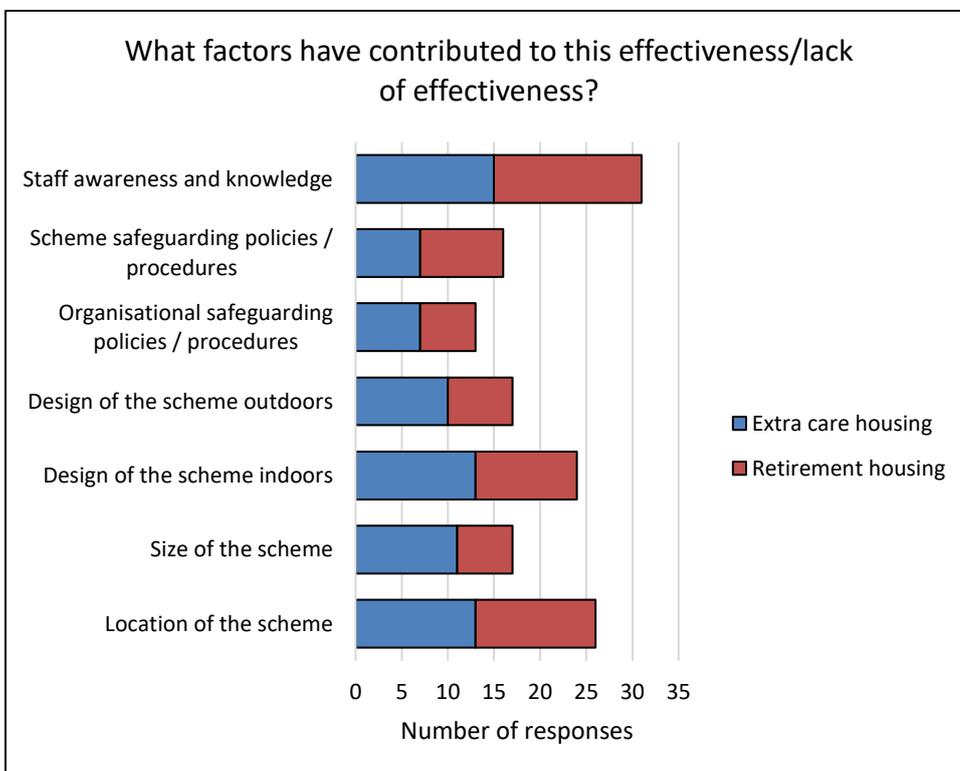


Figure 16: Factors contributing to effectiveness/lack of effectiveness

'Other' comments included:

- Support from local authority
- Support from tenants
- Support from family
- Monitoring outside of normal office hours is a challenge
- Too few staff with too many responsibilities/roles
- Support during the day as carer only works at night
- Poor signposting/wayfinding
- Scheme being independent living, not care

The first 5 in the list applied to Housing 21 respondents.

### **Staff success**

The majority of the respondents (58% of all respondents and 57% of Housing 21 respondents) felt that staff were 'moderately successful' in addressing walking with purpose. This applied to both retirement housing and extra care housing respondents.

### **Methods used by staff to address walking with purpose**

Respondents indicated that staff tend to try more than one method. The most common was trying to understand why the resident is walking (82% of all respondents and 86% of Housing 21 respondents), followed by distracting or redirecting the resident (68% of all respondents and 75% of Housing 21 respondents) and walk with the resident (64% of all respondents and 71% of Housing 21 respondents). Only a few extra care housing respondents stated that staff would take residents to a quiet room to calm them down and no respondents gave residents medication to calm them down. 'Other' information included examples of distraction techniques, checking that residents have their keys, reminding a resident to take their walker/mobility aid with them, finding residents a job they can do to help, and engaging residents in conversation and having a cup of tea together.

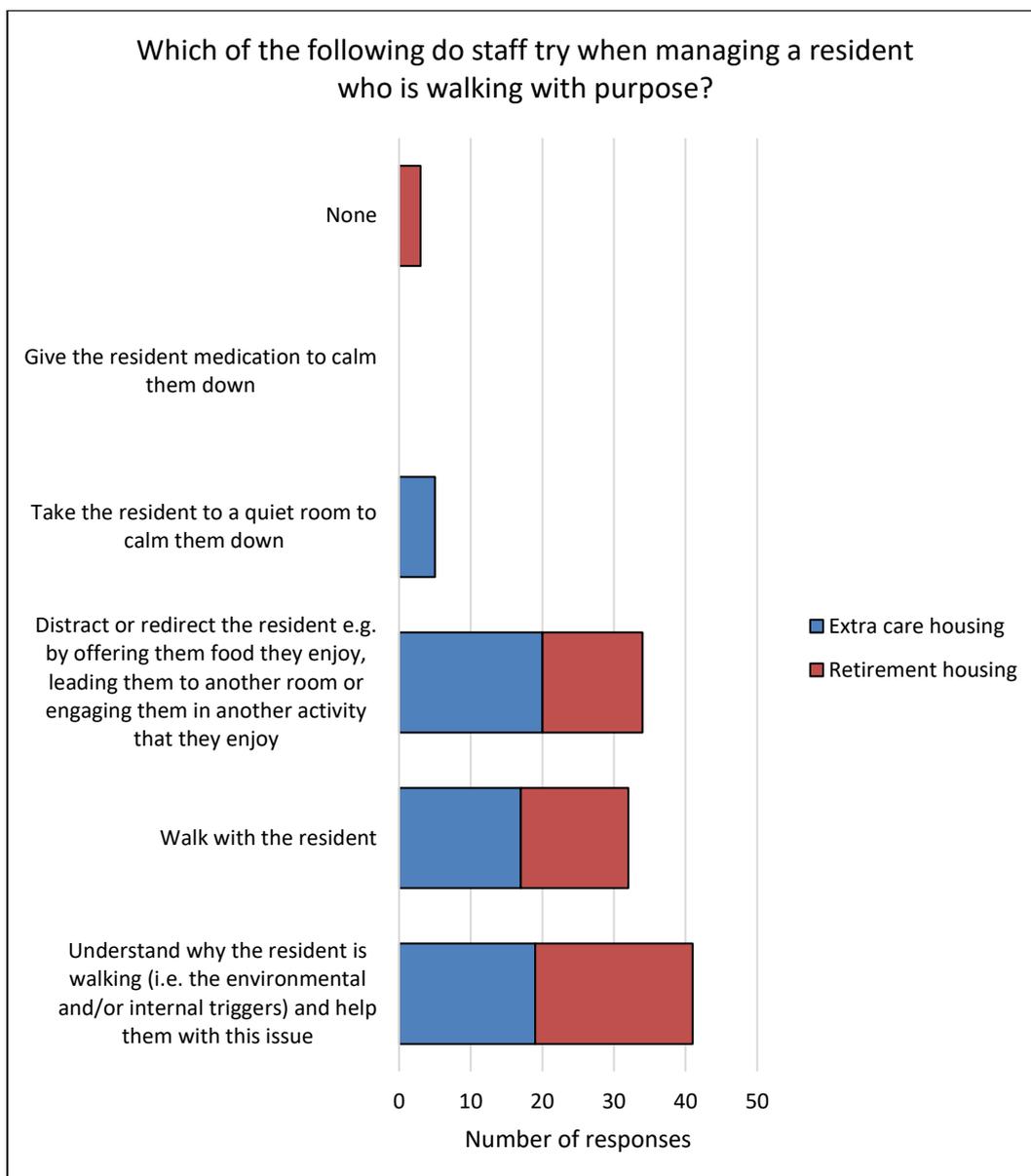


Figure 17: Methods used to address walking with purpose

### Effective methods

Distraction, walking with the resident and talking to the resident to find out what they want were the considered the most effective methods by the majority of respondents. Other comments indicated that different methods work for different people, 'so getting to know your tenant is key to success'.

### Staff time

60% of respondents (64% of Housing 21 respondents) felt that managing walking with purpose does not take up a disproportionate amount of staff time.

Managing walking with purpose was more of an issue in terms of staff time in extra care housing than in retirement housing (35% compared to 22%). This difference between types of housing was more evident for Housing 21 schemes, with 45% of

extra care housing respondents feeling that managing walking with purpose takes up a disproportionate amount of time compare to 21% of retirement housing respondents.

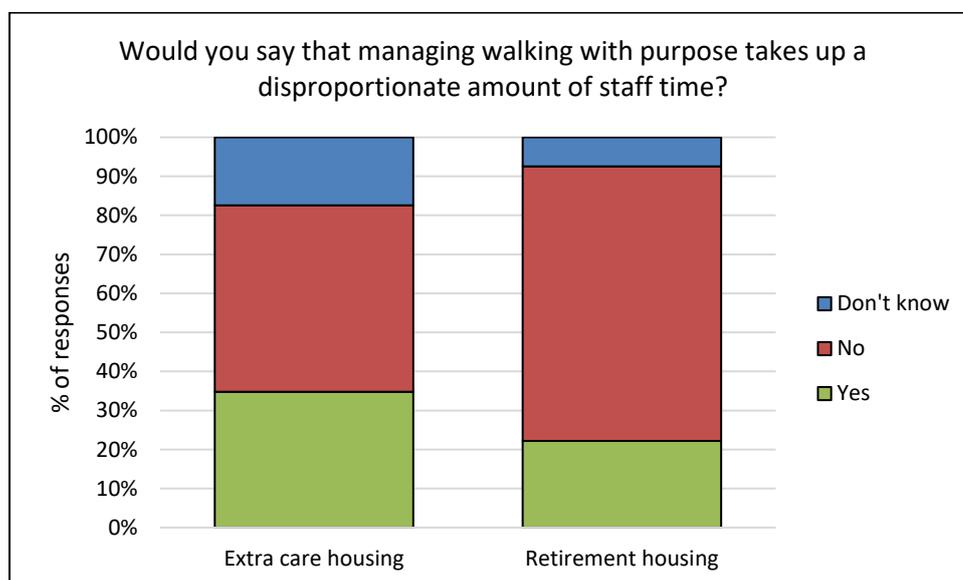


Figure 18: Managing walking with purpose and staff time

### Staff stress

In terms of how much walking with purpose contributes to staff stress the most comment response was 'slightly' (36% of all respondents, 46% of Housing 21 respondents) followed by 'moderately' (30% of all respondents, 29% of Housing 21 respondents). The proportion of 'slightly' and 'moderate' responses were equal for extra care housing but there was a greater number of 'slightly' responses for retirement housing (for all respondents and Housing 21 respondents).

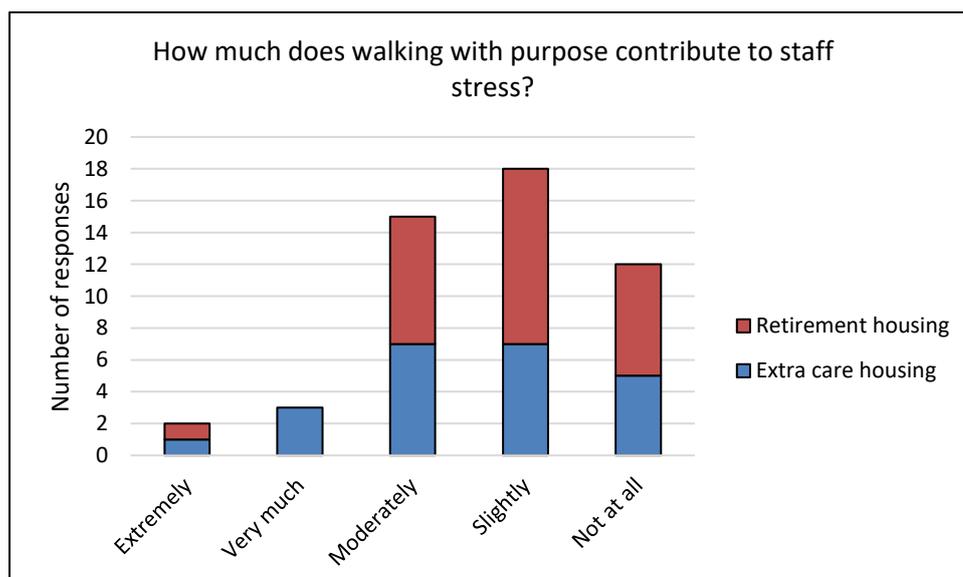


Figure 19: Walking with purpose and staff stress

## Deprivation of liberty

Of the 50 responses, only 6 (12%) felt that walking with purpose creates problems relating to human rights or deprivation of liberty, 64% felt that it did not and 24% did not know. Of the 28 Housing 21 respondents only 2 (7%) felt it created such problems, 61% felt that it did not and 32% did not know.

Comments included:

- Not currently, but the situation could change
- Feel that distraction or trying to encourage someone to stop walking can be seen as depriving the resident of their right to walk
- Can affect other residents as carer may have to interrupt their time with one resident to respond to an alarm indicating that someone else is going for a walk
- Residents cannot go out of the grounds without staff letting them out, but if someone becomes really distressed a staff member or relative will take them out
- Residents are strongly advised not to go out as the scheme is on a very busy main road. *“They often feel they are being forced to stay in even though there isn’t a lock on the door.”*

Deprivation of liberty was considered to be more of an issue for extra care housing respondents than for retirement housing respondents.

## Scheme design features

The 50 respondents to this question indicated that many schemes had multiple design features to support safe walking with purpose. The most common were places to sit and rest along indoor routes (27 or 54%), clearly labelled important doors (26 or 52%), and safe indoor places and routes for walking (25 or 50%). Some of the features are used to deter people living with dementia from entering a particular area or leaving through exit doors, such as stop or U-turn signs, rope barriers, mirrors in front of doors, black mats in front of exit doors, concealed door knobs and concealed/masked doors.

Extra care housing appears to have a wider range of design features than retirement housing, which were more likely to have ‘none’, although the most common features were similar in both types of scheme. Extra care housing made more use of the deterrents to leaving mentioned above, of which retirement housing schemes used only stop or U-turn signs and black mats in front of exit doors. Black mats are perceived as a hole in the floor by some people living with dementia and therefore deters them from leaving the building.

Other comments indicated that as some schemes are not dementia specific/not designed for dementia, they do not have such features.

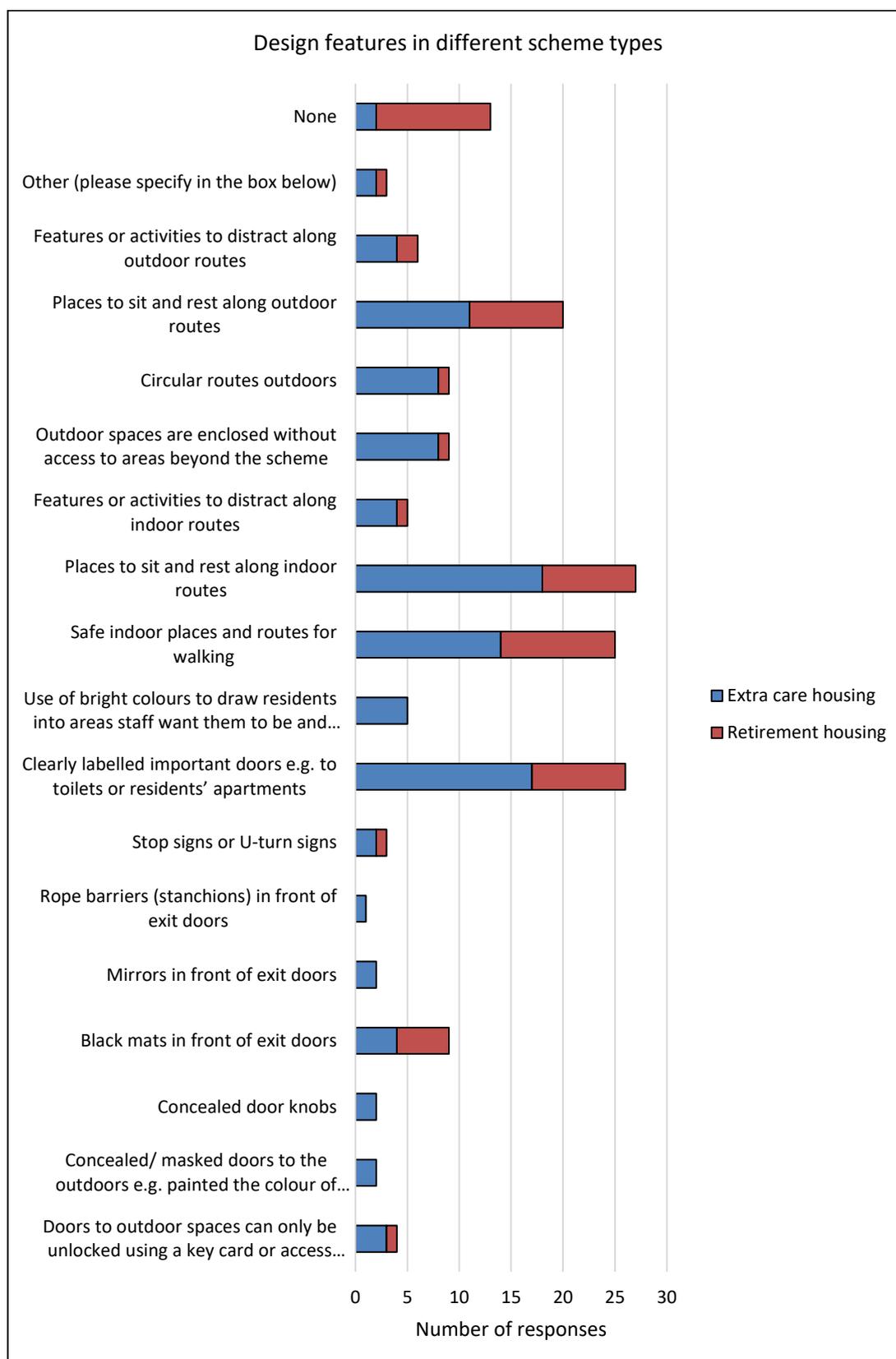


Figure 20: Design features used in schemes to support safer walking with purpose – all schemes

The 28 Housing 21 respondents also specified multiple design features, the most common being clearly labelled important doors (46%), places to sit and rest along indoor routes (43%), and safe indoor places and routes for walking (43%). None of the schemes had rope barriers in front of exit doors, concealed door knobs or concealed/masked doors to the outdoors. Both types of Housing 21 schemes had a range of design features, although retirement housing schemes were more likely to have 'none'.

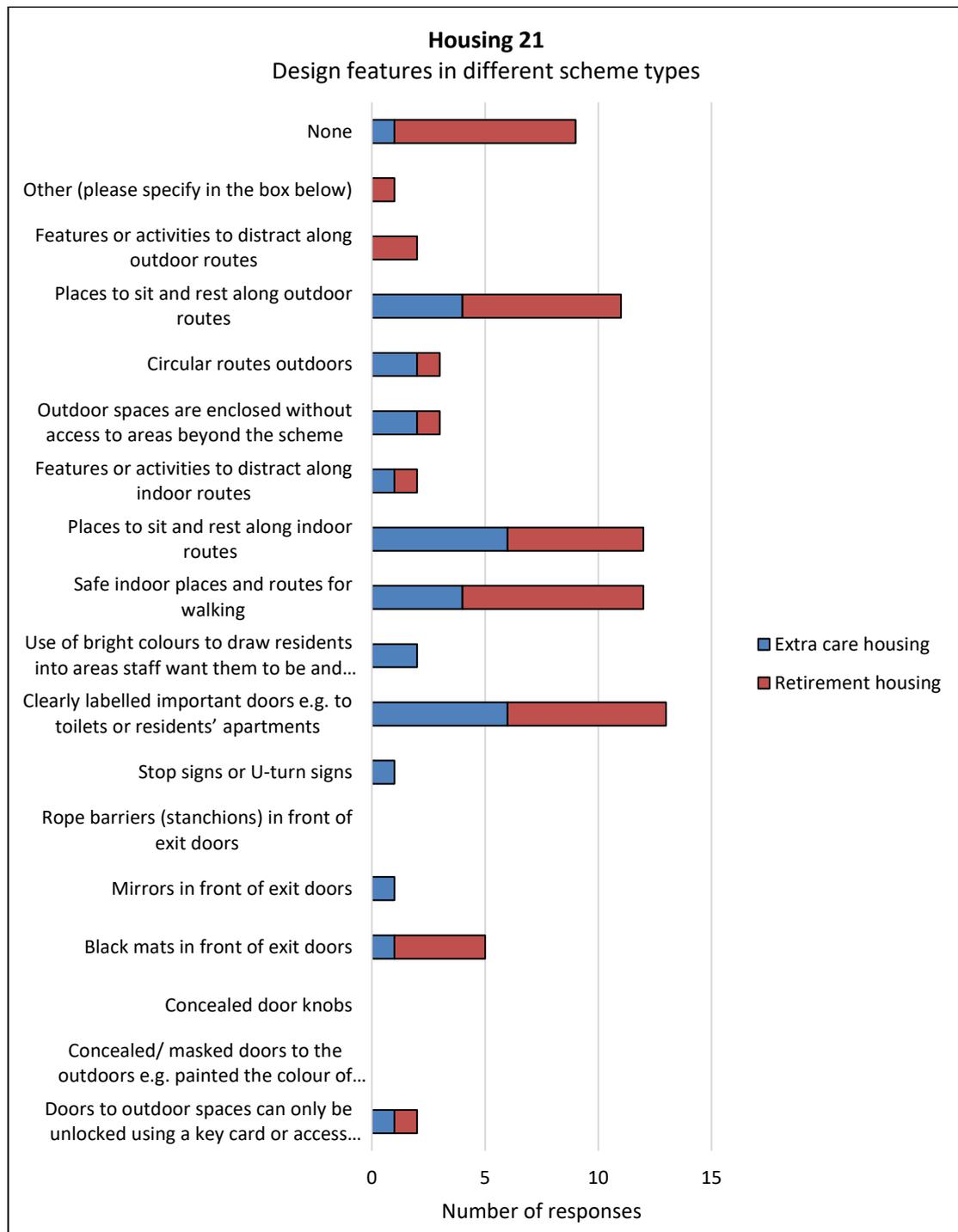


Figure 21: Design features used in schemes to support safer walking with purpose – Housing 21 schemes only

## Design changes

32 respondents described changes they would like to make to the design of their scheme to better support safe walking with purpose. These included:

- Entrances and exits
  - Main exit to be fob release not button release
  - Make building more secure
  - Difficult as community hub so doors are open to the public until 4pm
  - More ramps and removal of steps
- Corridors
  - Wider corridors
  - Covered radiators in corridors
  - More recognisable flat doors and toilet doors
- Communal areas
  - Colour-coded levels/floors
  - Improved art work/wall displays
  - More seating areas
  - Better signage
- Outdoor space
  - Make garden more secure
  - Make floor more even in external areas
  - More seating areas
  - More interesting garden (different smells, textures, flower beds, seating etc.)

## Assistive technology

Of the 50 respondents, 21 (42%) said that their scheme used none of the examples given in the survey of assistive technology to support safe walking with purpose. Of the 28 Housing 21 respondents, 16 (57%) said that their scheme used none of the examples of assistive technology. The most commonly used device was CCTV (40% of all respondents and 44% of Housing 21 respondents) followed by apartment door alarms (30% of all respondents and 25% of Housing 21 respondents). It was indicated that many devices would be available if needed, but there was no current demand from residents.

Other assistive technology devices that respondents would like included (for all respondents and Housing 21 respondents):

- Visual interface in flat to make it easier to speak to residents without having to physically go to a flat
- Sensor mats to alert staff to night time walking

There was also a feeling that people did not necessarily know what was available, and more information was required.

Extra care housing schemes were more likely to use assistive technology, and also a wider range of items, than retirement housing schemes.

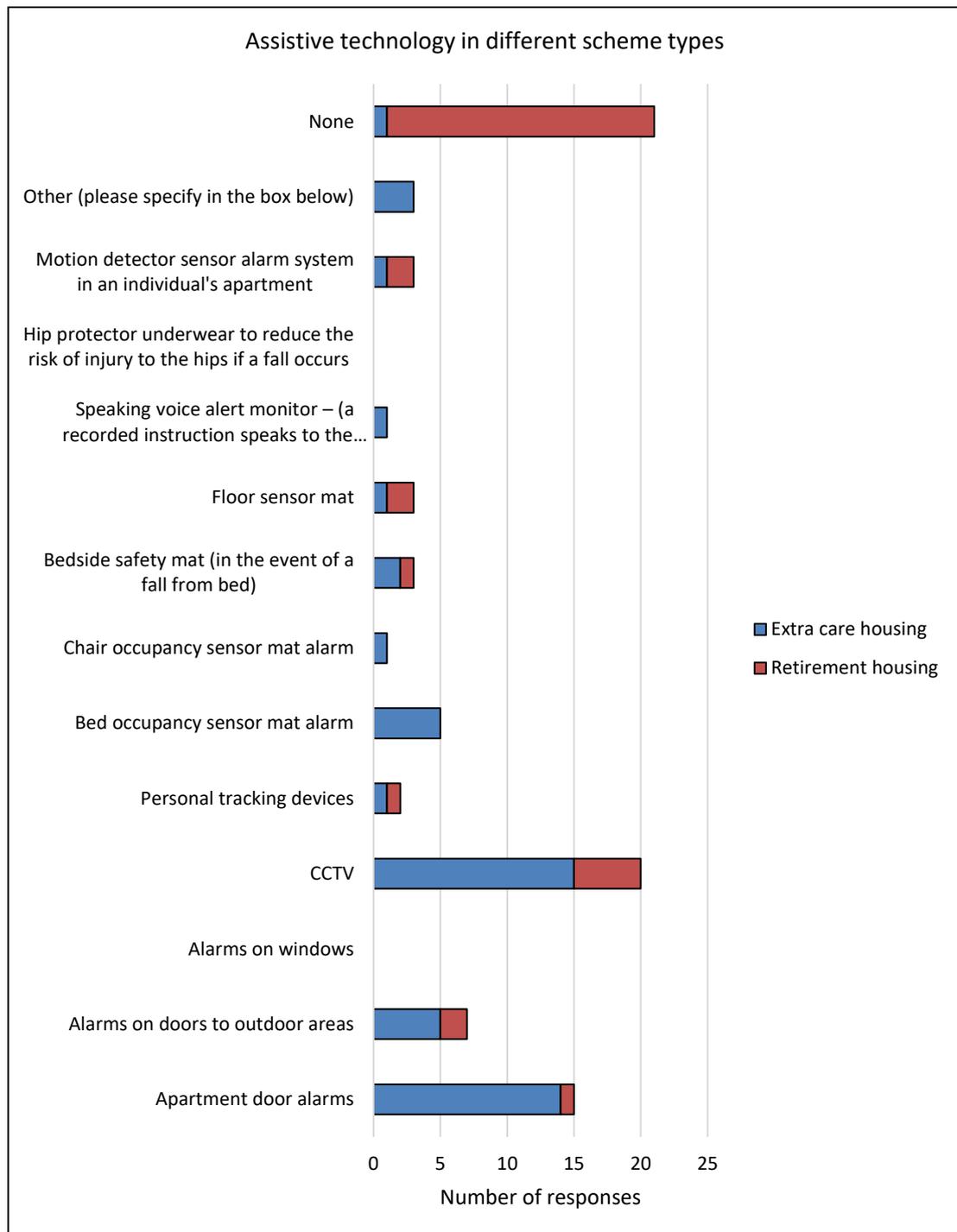


Figure 22: Use of assistive technology – all schemes

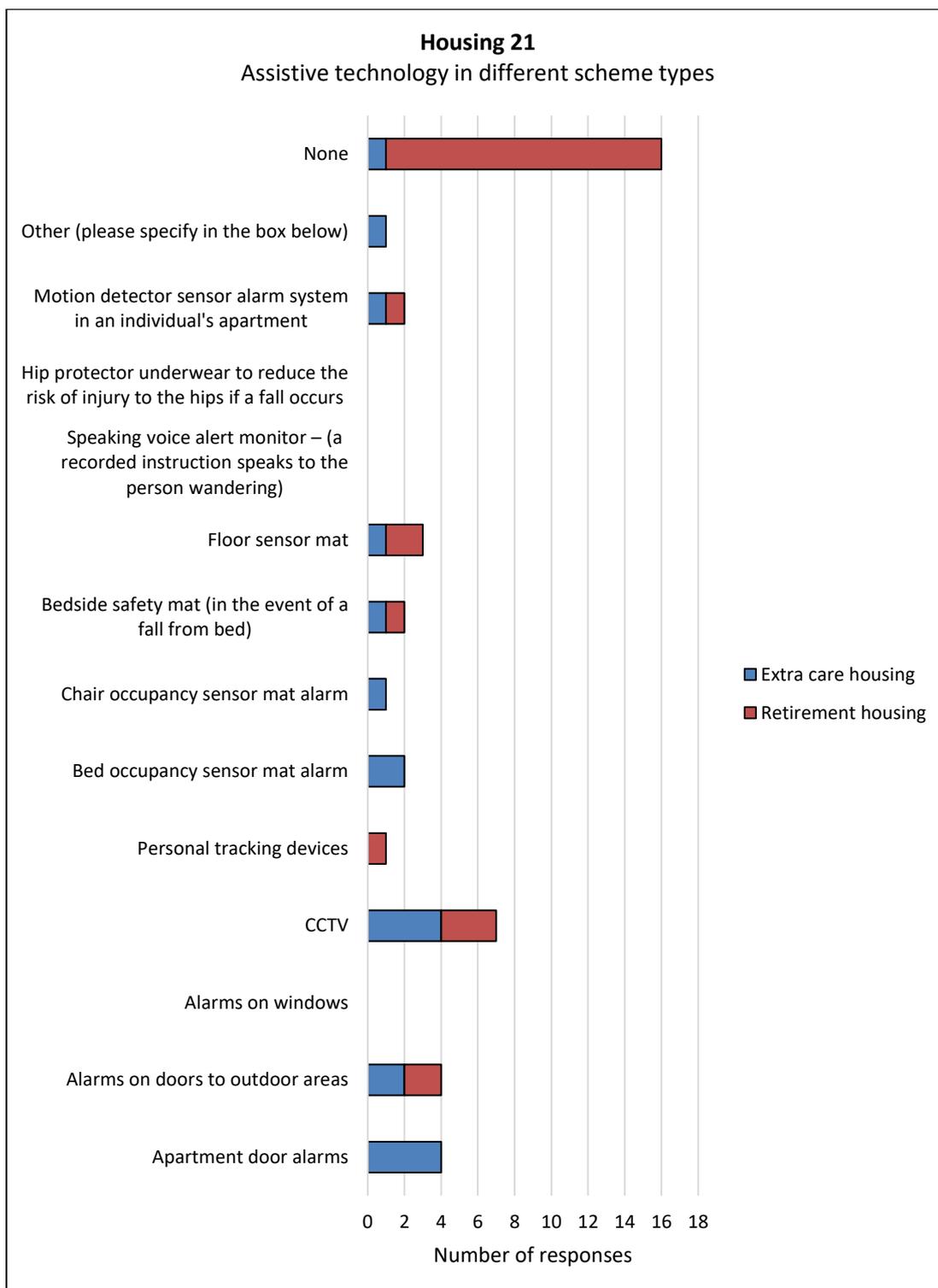


Figure 22: Use of assistive technology – Housing 21 schemes

### Changes to scheme

21 respondents made suggestions about what they would like to change about the way their scheme supports residents who engage in walking with purpose. These included:

- Awareness and understanding

- A realisation that retirement living has many people with dementia
- Better understanding of staff support needs
- Training and awareness
  - For staff
  - For residents
- Environmental design
  - Better signage and lighting
  - Safer outdoor areas
  - Flats more recognisable
  - Indoor design
  - Outdoor design
- Improved funding
  - Enable easier access to assistive technology

## Survey summary and discussion

Across all the extra care schemes that took part in the survey, residents living with a diagnosis of dementia constitute 14% of the total number of residents (also 14% for Housing 21 schemes only) with a further 5% living with suspected but undiagnosed/undeclared dementia (7% for Housing 21 schemes). These figures correspond well with the prevalence data from individual housing providers belonging to the HDRC (see Introduction). As would be expected, the prevalence of people living with diagnosed dementia in the survey retirement housing schemes was lower (5% across all respondents and 6% across Housing 21 respondents). However the proportion of people with suspected dementia was similar to that for extra care housing (5% across all respondents and also Housing 21 respondents).

A large majority of all survey schemes have up to two residents who engage in walking with purpose. This constituted, on average 22% (24% for Housing 21) of all the residents living with diagnosed or suspected dementia for both types of schemes. The proportion of residents living with diagnosed or suspected dementia that walked with purpose in retirement housing was higher than in extra care housing.

Although residents who walk with purpose constitute a small portion of the total number of residents (see survey), around half of all the respondents and Housing 21 respondents considered managing walking with purpose to be a challenge. Furthermore, a majority of both extra care and retirement house respondents rated staff as only moderately successful in addressing walking with purpose. The majority of retirement housing respondents rated the challenge as low to moderate whereas

the extra care scheme respondents ratings were more evenly spread between low to high (low to very high for Housing 21 respondents). It appears that the severity of the challenge of managing walking with purpose is more variable for extra care than for retirement housing and can be of high severity in some extra care housing schemes; very high severity for some Housing 21 extra care schemes. Challenges described related to ensuring the resident's safety, especially when they leave and are away from the scheme, the scheme design and the stigma and misunderstanding around dementia. The severity of the challenge for extra care housing is reflected in the findings that the majority of extra care respondents felt that their scheme was moderately effective in supporting safe walking with purpose; responses for retirement housing respondents were evenly spread over very effective to slightly effective. This also applied to Housing 21 only responses. Staff awareness and knowledge was given by the majority of respondents as the main factor contributing to how effective a scheme was, followed by location of the scheme (these two factors were considered equal contributors to effectiveness by the majority of Housing 21 respondents).

Managing walking with purpose was also more of an issue in extra care housing than in retirement housing in terms of staff time, with this difference being even more evident for Housing 21 schemes. However, managing walking with purpose was considered to be only a moderate or slight contributor to staff stress for all respondents. Successes experienced in relation to walking with purpose at the survey schemes were connected with: improving staff understanding so that they can better support residents; raising awareness of dementia amongst other residents; use of technology; improving activities provided; working with families to improve their awareness and find solutions; greater understanding in wider community, e.g. local shopkeepers, and providing a secure environment.

A tendency to walk with purpose was not taken into account for potential new residents at more than half the schemes in the survey, although extra care housing schemes were more likely to do so than retirement housing schemes. In addition, nearly half the schemes did not carry out a risk assessment for walking with purpose for people living with dementia, although, once again, this was more likely at extra care housing schemes than retirement housing schemes. Furthermore, at more than half of the schemes staff had not received any training on understanding and addressing walking with purpose – this applied to both extra care and retirement housing. The findings for Housing 21 schemes only were very similar in relation to these aspects. It appears that not all extra care and retirement housing schemes are set up to consider or cater for people living with dementia who walk with purpose moving into the scheme and this omission is more evident in retirement housing than extra care housing. This conclusion is further supported by the finding that very few of the schemes in the survey had policies, procedures or guidelines for

supporting safe walking with purpose. More schemes may have had such policies or procedures because 40% of the respondents said that they did not know. However, the fact that they did not know points to inadequate communication at the organisational level.

The most common and effective methods used to address walking with purpose were to try to understand why the resident is walking, distract or redirect the resident and walk with the resident. Respondents highlighted the fact that the most effective technique depends on the individual resident, so it is important to get to know the person.

The majority of all respondents felt that walking with purpose did not create problems relating to human rights or deprivation of liberty, however a substantial proportion of respondents did not know. Deprivation of liberty was considered to be more of an issue for extra care housing respondents than for retirement housing respondents.

While respondents indicated that multiple design features were used at their schemes to support safe walking with purpose, extra care housing had a wider range of design features than retirement housing, which were more likely to have 'none'. More than half of the respondents went on to describe scheme design changes that they would like in order to better support safe walking with purpose. Clearly, more needs to be done to make extra care and retirement housing schemes fully supportive of safe walking with purpose.

Just under half of the survey respondents used none of the examples of assistive technology devices to support safe walking with purpose in the survey and, for the rest, by far the most common devices used were CCTV and door alarms on individual apartment doors. Extra care schemes used more and a wider range of assistive technology than retirement housing schemes. The additional survey responses suggested that the low of use of these devices may be due to lack of demand, lack of awareness and high costs.

Almost half of the respondents made suggestions about what they would like to change about the way their scheme supports residents who engage in walking with purpose. Suggestions were related to better understanding of walking with purpose, training and awareness for staff and residents, environmental design and greater funding for assistive technology.

# Stage 3 results: case studies of people living with dementia who walk with purpose

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A total of 14 case study interviews were conducted that focussed on:

- five people who engage in walking with purpose in Housing 21 extra care schemes (five interviews with managers and one interview with a family member)
- three people who engage in walking with purpose in Housing 21 retirement housing schemes (three interviews with 'Court Managers', two with family members)
- two people living with dementia who walk with purpose in mainstream housing (two interviews with family carers)
- issues relating to walking with purpose at a dementia specialist day care centre (interview with a day care centre manager)

Summary information on the interviews at the different case study sites is given in Table 5. The people of interest (people living with dementia who engage in walking with purpose) have been given pseudonyms. The case study reports (Appendix F) give more detailed information about the case study sites, the people who were the focus of the interviews (people living with dementia who engage in walking with purpose) and their walking with purpose. These reports describe: the person's life history; the scheme that they live in; the nature of their walking with purpose (how long it has been taking place, how often it occurs, when it occurs and the time spent, where it takes place and how the person gets back to the scheme or their apartment); the risks to the person of interest; how the management and staff respond to and manage the walking with purpose; safeguarding and reducing the risks; impact on the resident; impact on the management and staff; impact on other residents; challenges; successes; desired changes; suitability of the accommodation for the person of interest and future plans; advice on addressing walking with purpose. For three of the residents, a 10 week follow-up phone call was made to the manager who took part in the interview for an update on the outcomes of particular responses to the walking with purpose that were about to take place at the time of the interview.

Table 5: Case study interviews

	Scheme	Person of interest	Interviewees
Extra care housing	EC1	Sheila	Housing and Care Manager
	EC2	Pat	Assistant Care Manager and son
		Liz	Assistant Care Manager
EC3	Vera	Housing and Care Manager	
	Anne	Housing and Care Manager	
Retirement housing	RH1	Jean	Court Manager and daughter
	RH2	Brenda	Court Manager and husband
	RH3	Len	Court Manager

In the sections below, the case study reports on the individuals of interest have been condensed into vignettes of the people living with dementia and their walking with purpose.

## Key findings and overarching themes

### Purpose/reasons/triggers

- All the case study residents' walking had an identifiable purpose e.g. to find carers, visit friends, do chores, seek company, have a change of scene, go home, collect children from school.
- The context for the case study residents' walking with purpose was varied and unique. Some were related to personal life history e.g. their usual afternoon routine, the job they used to do or how they used to live. Other reasons were internal triggers such as boredom, feeling upset or anxious, loneliness, the need to go to the toilet, hunger.

## Risks

Risks that were mentioned in relation to the case study residents when they engaged in walking with purpose included:

- Falling and resulting injuries

“She could have a fall, she could be picked up by the paramedics, put in her chair, explained that you’ll be in hospital if that happens again, and ten minutes later she’s up again.” (Extra care scheme manager)

“If she falls obviously she’s going to hurt herself. I mean, you say take the frame, take the frame, you know. Like I say we’re just waiting for an accident to happen.” (Son)

“I think the biggest risk to her would be to fall over and hurt herself.” (Retirement scheme manager)

“He has fallen, he fell earlier on in the year, about February/March, and he cut all his face.” (Retirement scheme manager)

- Becoming lost, having left the scheme, and staying away from the scheme for long periods of time

“When she's gone for long periods of time, it does cause anxiety. And that's purely for how vulnerable she is in the centre of [town] or if she was to go into the countryside, because it would be like finding a needle in a haystack.” (Retirement scheme manager)

“Her biggest risk really is getting lost isn't it, and she has a fall or something like that. But I think the biggest risk really would be if she got disorientated, which is highly likely, and she did start panicking.” (Retirement scheme manager)

“I just had visions, there’s a bus stop right outside, I thought, if he gets on that bus, I don’t know where he will end up.” (Retirement scheme manager)

- Health (e.g. dehydration, hypothermia)

“The most recent was last month when it was over 30 degrees, and they hadn't had any fluids for the whole nine hours.” (Retirement scheme manager)

“When somebody is dehydrated with Pick's disease, or any form of dementia, it's really quite significant and serious, because not everybody fully understands the impact it can have.” (Retirement scheme manager)

“She’s quite good at eating, but my mum’s a tea-aholic, so she won’t really drink enough water ... there’s risk of dehydration.” (Daughter)

“Hyperthermia, it worries me.” (Retirement scheme manager)

“Dehydration is a main factor, it concerns me quite a lot, yes.” (Retirement scheme manager)

“She was just going too long, too long, come back cold. She hadn’t had a drink for hours and then little things where she would never, ever, ever...so, like, she always used to wear little petticoats and slips, like, she’d come back and her slip was hanging down, she was tired, cold, hadn’t ate, freezing, come back soaked once, soaking wet in the rain.” (Extra care scheme manager)

- Risk from others (e.g. stolen purse)

“She'd go off with a bundle of cash. I'd be worried sick because she used to draw out £500.” (Extra care scheme manager)

“It's more her vulnerability around those who are substance users in [town] which is of concern. (Retirement scheme manager)

“She doesn't always understand that not everybody's got a good intention when they need help. So she'll generally go up to people thinking that they need help, and unfortunately that has resulted in her purse being stolen.” (Retirement scheme manager)

“She’s vulnerable to being robbed. She’s not a violent person. She can get on with everyone. But the problem is because she can get on with everyone she doesn’t see the danger in anyone. She’s very kind natured. If she saw a homeless person she wouldn't hesitate to go and get them a drink or something.” (Daughter)

- For the people living with dementia in mainstream housing the main risks when at home were leaving the house and becoming lost, tripping over or bumping into things in the house, walking into rooms where they are hazards e.g. the kitchen or cleaning cupboard.

“We have had incidences where he’s gone from the carpet to the cushion flooring, that he’s tripped up because he’s got his hands in his pockets; where I took him down to the hospital.” (Family carer)

“He’d open the door; sometimes he’d go; this is when we first moved and we were decorating, my dad was in the flat, he’d go off and have a walk up the street”. (Family carer)

“Turned the cooker on and blew the flame out, the ignition flame. And I’d gone around the shops, come back, and the whole house was just... And he was sat there smoking a fag.” (Family carer)

“He shuffles now, he won’t lift his feet. I feel he is [at risk of falling], yeah, especially going down the steps to the...you know, if we’re going to get in the car, we have to go down these three steps. I’ve had handrails fitted; and I’ll say to him, hold onto the rail ... and he’s not holding the rail, he’s moved into the middle of the step. Because he doesn’t lift his feet, that’s the thing, so he’s tipping his feet as he’s going up and down stairs.” (Family carer)

“If he was sort of going somewhere or getting out, I thought if he’s gone, I can’t chase him.” (Family carer)

- Tripping was the main risk at the dementia specialist day care centre.

“There’s identified hazards because there’s so many service users that come to the day centre, they will bring handbags, they will bring Zimmer frames; because they’ve got dementia they don’t always think about hazards, so they tend to put their handbags down on the floor. So when that person is walking around we have to consider those potential trip hazards.” (Day care centre manager)

## **Mobility**

- The more mobile the resident is, the greater the challenges, amount of work and stress for staff in terms of preventing them leaving the scheme. The managers were aware of this as demonstrated by the interview quotes below. One extra care manager even stated that if the resident had fallen and reduced her mobility she may have been able to remain at the scheme rather than moving into a nursing home due to the challenges created by her walking with purpose.

“I don’t even like to say it, but if Anne had fallen and lost a bit of mobility, she would have probably stayed here.” (Extra care scheme manager)

“That would have been nice for her to stay with us, but she was too fit.” (Extra care scheme manager)

“I have spoken about that with family, of getting a GPS device purely for the wide area she can cover, because she's very quick on her feet”  
(Retirement housing manager)

- However, those with poor mobility, even if they only walk with purpose within the scheme, were perceived to be at greater risk of falls and resulting injuries.

“Well falling. Just falling basically. I mean she fell into that glass lamp and cut her head.” (Son)

- Several of the interviewees stated that pendant alarms were not used because the people of interest either forgot to press them or constantly pressed them.

### **Other residents**

- In some schemes, other residents play an important part in keeping an eye on those who walk with purpose. They will alert staff, distract/redirect the person and even returning them to their apartment. An awareness and understanding of dementia and walking with purpose among residents is key.

“He does get on really well with this lady on his corridor ... She's really good, and she knows how to deal with it, and she took him back to his flat.” (Retirement scheme manager)

“I mean, if this lady is out, or I'm not here, if we're all in bed there's going to be nobody to stop him.” (Retirement scheme manager)

“People will keep an eye out on her. One of the residents has started helping her in the garden, so she has something else to do.” (Retirement scheme manager)

“...they'll push their pendant alarms to alert us or... they'll always come and let us know.” (Extra care scheme manager)

“They'll keep an eye on her, they'll let us know if she seems a bit unsettled.” (Extra care scheme manager)

“And the other residents usually go upstairs for their tea about four o'clock so that's why nobody had spotted her [leaving] at this time.” (Extra care scheme manager)

“Because the other residents know her so well as well. I told you she loves her ice cream and she knows how to go down to the restaurant and quite often you'll see her sat there with a bowl of ice cream which they've given

her because they know that, that's what she loves. (Extra care scheme manager)

### **Impact on management and staff**

The impact of a resident's walking with purpose on management and staff at an extra care or retirement housing scheme depended on the frequency and nature of walking with purpose and the circumstances of the individual resident, e.g. the resident's level of mobility and tendency to fall, whether the resident could be easily distracted or redirected, whether the walking with purpose took place only within the scheme and its grounds or involved the resident attempting to leave/leaving the scheme and how determined the resident was to leave. However, the following general observations can be made:

- Although residents who walk with purpose constitute a small portion of the total number of residents (see survey), managing walking with purpose can take up a disproportionate amount of time and effort for management and members of staff and can cause them stress. This is especially the case with those residents who regularly leave or try to leave the scheme.

"It's trying, it's hard, because, I mean, last week was absolutely horrendous with this gentleman who we're talking about." (Retirement scheme manager)

"I'll be honest, the first year was horrendous, absolutely horrendous. Because I was out of my mind. Because she'd get up, the sun was out and the wanderlust was back." (Extra care scheme manager)

"It was awful, because she's got nobody else, you feel...I don't know, I was really sick, I really was, I never slept." (Extra care scheme manager)

"I can't guarantee that I would be able to persuade her to stay in." (Extra care scheme manager)

"So I used to go around her routes and I'd spot her with her bus pass and wave to me, got on the bus and I was, like, oh, she's on the bus. So she got to know my car and it was falling apart for me, you just don't know what to do for the best." (Extra care scheme manager)

- Addressing walking with purpose that takes place only within a scheme can also be time consuming if the resident is perceived as doing so excessively and can be a source of stress for management and staff if that resident has a tendency to fall.

“It’s trying, it’s hard, because, I mean, last week was absolutely horrendous with this gentleman who we’re talking about.” (Retirement scheme manager)

“Just the worry of her falling, we want to keep her safe obviously, and we want to keep her here as well, we don’t want her to have to go off to a care home. And that’s the family’s wishes as well.” (Extra care scheme manager)

- Residents who are determined to leave the scheme can become distressed and aggressive if staff try to distract or redirect them from leaving, which seemed to be the preferred method of addressing walking with purpose. For reasons explored below, staff preferred the resident to remain inside the scheme; however, if a resident was clearly distressed or angry by staff intervening in this way, the staff would let that person leave.

“I’ve found, if you’re too, like, straight and say, no, you’re not off, because you don’t do that, then they tend to get really, really agitated, and you’re fighting a losing battle.” (Retirement scheme manager)

“I felt like she was becoming, like, recognising me as this person who wouldn’t let her do what she wanted to do.” (Extra care scheme manager)

“We’d speak to her, say, you know, try and take her back, you know, do stuff that we always use, you know, with the open questions? But she became aggressive, she was starting to become aggressive, you know.” (Extra care scheme manager)

“But no, it’s always distraction with her. If something doesn’t work, you’ll know. You’ll know straight away because she’s not going to listen to you anyway. And then obviously our troubles start then.” (Extra care scheme manager)

“The only time I’d say staff have difficulty is when she is going to leave. She walks so quick and she’s on a mission, she’s going to leave. She stands at the top of the stairs and you’re like oh. Quick.” (Extra care scheme manager)

“...there was no way, you could see in her face, you know. Never stopped her going.” (Extra care scheme manager)

“... it became, oh okay, I’ll go back for 10 minutes, but as soon as they’ve gone, I’m away again. So, yeah, we let her go.” (Extra care scheme manager)

- When a resident has left the scheme and is then out of sight, the manager can no longer ensure their safety and this is a source of great stress for scheme managers.

“Once she's left the vicinity of the court, it really is quite difficult.”  
(Retirement scheme manager)

“The affect for me was the worry, again, the worry of being gone too long.” (Extra care scheme manager)

“... they said to me, can you say to us between the hours of two and four, you can guarantee her safety. And I can't.” (Extra care scheme manager)

“When she's gone for long periods of time, it does cause anxiety. And that's purely for how vulnerable she is in the centre of [town] or if she was to go into the countryside, because it would be like finding a needle in a haystack.” (Retirement scheme manager)

- It can be uncomfortable for managers and police to collect someone who has left the scheme in order to bring them back, particularly if they don't want to return.

“So it was becoming a bit unattainable for me and the police agreed, they were saying, well, we can only do so much and it's not nice for us to be stopping our police car, getting her out, putting her in, it didn't feel right and I understand that.” (Extra care scheme manager)

- Extra care housing managers do not want the resident to move out of the scheme and will do their best to enable them to stay, even if it involves extra time and effort on their part. There is a sense of responsibility and duty. There is also a fear of letting the resident down and the feeling of having failed if a resident moves out.

“We want to keep her here as well, we don't want her to have to go off to a care home.” (Extra care scheme manager)

“You know, she's mine, I don't want her to go to a nursing home, like, you feel like you've let her down, you know, but at the end of the day, you can only do so much.” (Extra care scheme manager)

- Retirement scheme managers also have a sense of obligation to the residents. In one case, the manager was more worried than the family carer about the resident when she left the scheme and in another case the manager would go out to search for a missing resident even out of working hours.

“I think [manager] worries more than I do, because I know my mum very well. We’re very close. And I know how far her dementia has got, so I know her capabilities. Whereas I think [manager] thinks she’s a lot further on.”  
(Daughter)

“On two occasions [manager]’s got the police involved when it’s not really been necessary to get them involved.” (Daughter)

“That’s in my own time, I work eight until four, so it’s delving into my time.” (Retirement scheme manager)

“I have to leave my family to go and get him.” (Retirement scheme manager)

- Walking with purpose was a relatively minor issue at the day care centre staff because clients were kept occupied with activities throughout the day.

“We find with the day centre, I find it’s so much easier for us, because the staff are there to use techniques to get people occupied.” (Day care centre manager)

### **Impact on family**

Family involvement in the care of scheme residents of interest in this study varied considerably, from occasional visits to living with the resident in a retirement housing flat (Bill who cares for his wife, Brenda) or staying with the resident in their extra care housing scheme (David who stays with his mother, Pat, in her flat during the day). Consequently, the impact of the walking with purpose on the lives of family members varied and was greatest for those who were more involved in the care of the resident. This is reflected in the case study reports on the individuals of interest (Appendix ??), some of which have no section on impact on family, while others have sections of varying length.

- For four of the five extra care scheme residents there was little family involvement beyond weekend visits. For one of these residents (Liz), the children had arranged for private carers to visit during weekdays, keep Liz busy, and take her out for walks. Thus, Liz’s walking with purpose had little impact on her children. For the remaining extra care scheme resident (Pat) the son effectively lived with his mother at the scheme during the daytime (he worked at night), so that she could remain living at the scheme and avoid transfer to a care home. Although Pat only walked with purpose inside the scheme, her poor balance and mobility, tendency to forget her walking frame and high likelihood of falling and being injured were sources of great concern and stress for her son who could not watch Pat all the time (because he worked at night, he needed to sleep in the spare bed in her flat during the

daytime). He found managing his mother's walking with purpose exhausting and worried that her increasing walking with purpose and frequency of falls would result in serious injury, such as a broken hip, or the need to move her to a care home.

"You get angry as you have to keep saying sit down, sit down, sit down, sit down and like I say it goes in one ear and out the other." (Son)

"I could've had months off work with stress, but I said to my boss I'd rather come into work. It just gets you mind off it." (Son)

"It is really annoying because you can't follow her around all the time. Well you just can't." (Son)

"It's a nightmare. It wears you out sometimes." (Son)

- At one of the retirement housing schemes there was no family involvement in the resident's care. At another retirement housing scheme (the only case study scheme to use the Herbert protocol), the manager and daughter had very different perceptions of the risk to the resident (Jean) from her daily excursions into the town. The scheme manager becomes very anxious when Jean is away for a long time due to worrying about how vulnerable Jean is in the town, possible dehydration or that she may be lost in the countryside. The manager is conscious that, when Jean leaves the scheme, it is not possible to manage the risks to her safety. However, the daughter felt that the retirement scheme manager worries too much and alerts her too soon and the police unnecessarily. The daughter stated that she always knows where her mother will be when she is contacted by the scheme manager to report that her mother is 'missing'.

"When she's gone for long periods of time, it does cause anxiety. And that's purely for how vulnerable she is in the centre of [name of town] or if she was to go into the countryside, because it would be like finding a needle in a haystack." (Retirement scheme manager)

"Once she's left the vicinity of the court, it really is quite difficult." (Retirement scheme manager)

"We've generally had the police to bring her back." (Retirement scheme manager)

"I think [manager] thinks she just wanders, when really she knows exactly where she's going, and she always manages to make her way home. But on two occasions [manager]'s got the police involved when it's not really been necessary to get them involved." (Daughter)

“I know that she can find her own way back.” (Daughter)

“When I was with the police officer I said to him I know exactly where my mum will be now.” (Daughter)

“I did put a complaint in about [manager] because we didn’t see eye to eye at the beginning. I felt like she was always targeting my mum and trying to prove that she wasn’t of sound mind, when I know my mum very well.” (Daughter)

- At the third retirement housing scheme the resident of interest, Brenda, lived with her husband, Bill, who acted as her carer. Bill did his best to keep an eye on Brenda to ensure that she does not leave the scheme, however, Brenda had left the scheme grounds a few times. Although Bill felt that he was successful, in managing his wife’s walking with purpose, the manager stated that he was finding it hard to cope and was “worried that he will have to put her in a home”.

“Brenda has her ambitions of what she wants to do and I try to manage them.” (Bill)

“She knows I’m watching her, watch her 24/7.” (Bill)

“So I think definitely [husband] finds it difficult and I think he's worried that she's going to have to...they're going to have to make the decision to put her in a home.” (Retirement scheme manager)

- As would be expected, caring for a person living with dementia in mainstream housing who engages in walking with purpose had a significant negative impact on the health, wellbeing and quality of life of the carers in this study, not only due to the walking with purpose but also other aspects of caring. John, who lived with and cared for his father, Ted, suffered from exhaustion due to lack of sleep and was greatly annoyed with his father because he believed that Ted walked around the house at night checking to door handles to wind him up deliberately. Two years ago, John developed a drinking problem, which he attributed “solely” to the stress caused by caring for his father, and was hospitalised due to a haemorrhage.

“It can be very trying; especially with the lack of sleep sometimes, when it’s constant.” (Family carer)

“It’s constantly checking the door handles; and he does it really slowly; and it’s annoying, you know, when you’ve got that creak.” (Family carer)

“And it’s almost deliberate, it’s not a swipe of the door, it’s a very slow, determined movement ...so it makes a noise.” (Family carer)

“Sometimes he’ll get up two or three times after, and laugh in your face. You know, it can be very trying at times.” (Family carer)

“I had an incident two years ago where the stress and everything got to me, I was drinking heavily. I’d sought help for it, at the doctor’s; doctor says, you’ve got to help yourself before we can help you. And then a couple of weeks later I had an incident where I’d haemorrhaged.” (Family carer)

- Carol, who lived with and cared for her husband, Bob, in mainstream housing used to worry about not knowing where Bob was when he went out of the house and, due to her poor mobility, not being able to go out and find him if he got lost. However, she no longer worried because she had started locking the external doors when they were in the house. She also used to be exhausted due to lack of sleep because Bob walked with purpose at night. This became less of a problem once he had medication to calm him down and help him sleep better although Carol was still exhausted due to caring for Bob in general and the fact that he follows her around all day and cannot go into a room by himself.

“Well, it’s just the worrying not knowing where he was, if he was sort of going somewhere or getting out, I thought if he’s gone, I can’t chase him.” (Family carer)

“I’d never find him, I just wouldn’t know where to look for him. So, this is why I’ve locked the doors. My daughter told me, she says, Mum, keep the doors locked.”

“I’m absolutely shattered by the time it’s time for bed.” (Family carer)

- Both carers living in mainstream housing experienced aggression from the person they cared for.

“His latest trick is when you’re holding him, so you’re holding him from behind, he’ll try and run you into, you know, the door frame.” (Family carer)

“He’s started getting more aggressive to me, nobody else. I’m scared, because he pushes me, you see, and I’m frightened I’ll fall over and damage something.” (Family carer)

## Responses/managing the walking with purpose

Staff responded to the case study residents' walking with purpose in extra care housing and retirement housing schemes in various ways:

- Distraction/redirection

"If you said to her, do you want to come and have a cup of tea and a chat, she'd be quite happy with that and she would go for a cup of tea and a chat." (Retirement scheme manager)

"Like, Friday, for instance, he was on about he was off to the bank in town, and I said, look at it out there, and you're not going to the bank today because it's shutting soon, anyway, and look at the weather." (Retirement scheme manager)

"We try and make her a cup of coffee, sit her down and put her favourite programmes on the telly." (Extra care scheme manager)

"You could always coax her with an ice cream. So, if she's wandering about or trying to get into somebody's flat give her an ice cream and she'll be fine, and she'll go back into her flat and you won't hear anything else." (Extra care scheme manager)

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

"And you try and persuade against the idea, about the weather, and try and talk about things in the past, do you remember that time you got a taxi." (Extra care scheme manager)

"So yeah, mainly distraction, yeah. Try and talk about the past and... She loves Christmas, she loves this time of the year because she loves Christmas. She knows that she's got a couple of events to go on, a coach trip to the panto. She loves music, loves it." (Extra care manager)

"She loves dogs. So if one of the tenants' families has brought a dog in, we'll take her to see the dog." (Extra care scheme manager)

- Distraction / redirection was the preferred approach for most staff, but it didn't always work:

"But no, it's always distraction with her. If something doesn't work, you'll know. You'll know straight away because she's not going to listen to you

anyway. And then obviously our troubles start then.” (Extra care scheme manager)

- Talk to the resident to try to find out what they want and try to accommodate their wishes.

“They talk to her, try and find out what it is that she wants to do. And then try and accommodate what she wants. Most times, she says she wants to go back to her flat.” (Extra care scheme manager)

- Walk with the resident outside to ensure their safety.

“And sometimes we try and get her to come for a walk in the garden. So they’re taking a full walk round the garden.” (Extra Care Scheme Manager)

“Sometimes if I need to go to the shops across the... there’s a petrol garage. If somebody’s ran out of something I’ll just say, Liz, would you like to come, and she’ll love to come and walk.” (Extra care scheme manager)

- Allow the resident to walk by themselves within scheme and keep an eye on them.

“I mean I’d let her go for a walk. If she wanted to go down the corridor I’d let her go because it’s exercise. That’s the way I see it. As long as she’s got her frame she’s pretty safe.” (Son)

“What he’s told me, she’s allowed to walk away for a bit, but he just makes sure she’s alright and then he catches up with her and brings her back.” (Retirement scheme manager)

“I let her have a little walk and then I looked for her out the window and then I went and got her.” (Husband)

- Allowing the resident to leave the scheme and putting procedures in place to minimise the risk.

“Let her go, but obviously the mental health team knew... and the local police, like I told you, they were brilliant the local police.” (Extra care scheme manager)

“If she’d gone too long sometimes I’d think, oh, I’ll just go and take a quick spin in my car so that...just see if I can see her” (Extra care scheme manager)

“We had made links with the local authority to log when she’d gone, with Alert we got in touch with hotels in Blackpool. They knew her. We made

contact with all the hotels in Blackpool just to tell them that they may get a visitor and it will be Vera, they all knew her. We made links with the police out in Blackpool and [local] police. They were really good too. Just to put all those things in place, because we couldn't stop her going.” (Extra care scheme manager)

- When a resident regularly leaves the scheme, it is important for the manager to have a good relationship and good communication with local police and staff at the places the person is likely to go. The Herbert protocol is especially useful in these cases (only used by one retirement scheme in this study).

“Or she was going down onto the docks where she had lots of homeless friends ... we made some contacts, in the early days I had to, with security guards and people around big buildings where she'd hang around. I made some contacts with people there.” (Extra care scheme manager)

“We've got the Herbert Protocol in place as well, which we've updated since the last episode of walking.” (Retirement scheme manager)

“The police know her very well, they know what she looks like.  
(Retirement scheme manager)

“It's more so we didn't have to keep giving them pictures every time”  
[Herbert Protocol] (Daughter)

“So we have had to do quite a lot of work around, you know, how long we say is too long before we need to call the police for support to find her, for the Herbert Protocol. We've put four hours. And also, to check that she's not in the church or certain charity shops, or sat on the bench near Primark, which are her prime spots to go to.” (Retirement scheme manager)

“They [the 'prime spots'] have family contact details just in case.”  
(Retirement scheme manager)

- Moving to a care home

“If it's managed or manageable, I mean, I always fight to keep people on my court. Over the years, I've actually, for their safety, had to have a few...I mean, over the last two years I think I've had four where I've had to get onto social services and just say, look, the time now has come where they need more care.” (Retirement scheme manager)

“We lost her in the end because we couldn't take the fixation of the family home away and people who are living in it now were scared.” (Extra care scheme manager)

- Contact ID wristband (one retirement scheme resident)
- Assistive technology used: door sensors, speaking door sensor, GPS tracker, alarm mat
- The three case study extra care housing schemes had various design features to support safe walking with purpose, including:
  - black mats in front of exit doors;
  - safe indoor places and routes for walking;
  - features or activities to distract along indoor routes;
  - outdoor spaces enclosed;
  - places to sit and rest along indoor and outdoor routes;
  - clearly labelled important doors e.g. to toilets or residents' apartments;
  - use of bright colours to draw residents into area staff want them to be and pale colours in other areas.
- The three case study retirement housing schemes were all remodelled from existing blocks of flat originally built in the 1970's so had few design features to support safe walking with purpose. Features indicated in the survey questionnaire were: black mats in front of exit doors (2 schemes); places to sit a rest along indoor routes (1 scheme); places to sit and rest along outdoor routes (1 scheme).

In mainstream housing, the two family carer interviewees managed the walking with purpose in the following ways:

- Keep external doors locked to stop the person with dementia from going out and becoming lost.

“The front door's locked and we're in the house.” (Son)

“Now I know he's safe in the house, he can't get out.” (Son)

“Just leave him to it. I've got the doors locked. Just know where he is.”  
(Wife)

“I keep all the doors locked now so he can't get out.” (Wife)

“The front door and the back door are locked; that's the only two doors he can go out of. And I take the keys out, and I put them somewhere, I know where they are.” (Wife)

“I’d never find him, I just wouldn’t know where to look for him. So, this is why I’ve locked the doors. My daughter told me, she says, Mum, keep the doors locked.” (Wife)

- Lock internal doors to prevent access to rooms that might present a risk e.g. cleaning cupboard, kitchen)

“Lock all the interior doors, like there, the cupboard for the cleaning, because there’s obviously chemicals and what have you.” (Son)

“Lock the doors, and the interior doors that you don’t want them... you know, so it restricts their movement within a safe environment. So the kitchen isn’t a safe environment, you’ve got the kettle in there, the washing machine, you’ve got crockery, knives and et cetera; obviously the cooker.” (Son)

- Never let the person go out alone

“Wherever we go I’m with him, I don’t let him go very far; if we go shopping in the supermarket, I let him push the trolley for me so I know that he can’t ... he does tend to wander off with trolley...” (Wife)

- Medicate at night to ensure a good night’s sleep – one carer did this, the other did not and, consequently, suffered from lack of sleep and exhaustion due to being disturbed by his father walking with purpose at night.

“Locked him in and given him a tablet for a night.” (Wife)

“If he hasn’t had a good day we’ll be up at 12 o’clock, we’ll be up at three o’clock, or two o’clock, and then again at four o’clock; and it can be like that.” (Son)

- Move any tripping hazards and furniture that they may bump into out of the way so that they have a clear path when walking with purpose within the house.

“He’s got a clear run from his bedroom to the toilet; and same with the front rooms, the settees are all back to the wall, so he’s got a clear space to walk round.” (Family carer)

At the dementia specialist day care centre, the preference was to enable clients to walk with purpose, accompanied by a member of staff.

- Indoors, where there could be tripping hazards, the staff would walk with the person to ensure their safety.

“So when that person is walking around we have to consider those potential trip hazards; so generally a staff member will walk with them.”  
(Day care centre manager)

- Staff will also go outside with a client if they wish to go for a walk in the garden; if staff are not available to do so, they will distract or redirect the client with an activity or, based on their life history, find something they will be interested in.

“As long as you can distract them or get them involved with something, or an activity.” (Day care centre manager)

“We generally ask the families to complete quite a comprehensive life journal, so we really get to know that individual and that background; so we might know what jobs they’ve done, what their interests are, who the people are that are important to them. So if somebody is restless or looking for something, we can sit down and we can actually connect to something that’s important to them.” (Day care centre manager)

The individual vignettes provide a better understanding of the responses, which varied depending on the nature of walking with purpose and the reasons or triggers for each individual (see below).

## Challenges

The main challenges for the managers in addressing walking with purpose at their schemes were:

- Finding and keeping safe residents who leave the scheme and go missing, especially if they are very mobile or use public transport.
- Addressing the stigma and lack of understanding associated with walking with purpose; educating other residents, visitors and families to understand that walking with a purpose is not 'trying to escape' and can be sensitively accommodated.
- Some assistive technology doesn't work for residents living with dementia who walk with purpose e.g. pendant alarms are not used when the wearer falls, sensor mats at exit doors that alert staff to someone leaving can be stepped over.

At the dementia specialist day care centre walking with purpose was less of an issue but if a client did wish to go for a walk the main challenge was having enough staff to commit to walking with the person.

## **Desired changes**

Changes desired by the scheme managers to support safe walking with purpose included:

- A more dementia friendly scheme, especially for those schemes remodelled from existing blocks of flats.
- More secure garden so that residents cannot walk out onto the road.
- Training for staff on how to better support walking with purpose. (EC)
- More time allocated to the care of residents who walk with purpose. (EC)
- Policy detailing a set procedure to risk assess and manage walking with purpose.
- Herbert protocol as part of the care/support plan for residents who are at risk of leaving/getting lost outside the scheme.
- Even when a scheme is classed as independent living, the support plan needs to be more in depth than merely family contact details e.g. contain the resident's life story. (RH)

## **Successes**

The main successes in addressing walking with purpose for the scheme managers were:

- Staff: reducing stigma around walking with purpose and improving their understanding and knowledge.
- Other residents: improved awareness and understanding (dementia friends sessions).
- Family: acceptance and understanding.
- Assistive technology: GPS keyrings.
- Successfully managing a resident's walking with purpose, e.g. by getting to know what works best for distracting/redirecting them.
- Working together with the family, police, social services and community mental health team to put contingencies in place and create a Herbert Protocol.

## **Advice**

At the end of each interview, the scheme managers were asked if there was any advice that they would give to other extra care housing/retirement scheme managers on addressing in walking with purpose at their scheme. The advice given has been incorporated into the recommendations, below.

## **Vignettes of people living with dementia who engage in walking with purpose**

The case study reports on five people living with dementia in Housing 21 extra care housing schemes and three people living in Housing 21 retirement housing schemes who engaged in walking with purpose (in Appendix ??) were condensed into the vignettes presented below. The two vignettes for the people living with dementia with their family carers in mainstream housing are also provided for purposes of comparison.

## Extra care housing

Sheila, 64

Alzheimer's disease  
(diagnosed 7 years ago)

### Characteristics:

- Divorced and has one son.
- Used to work as a carer.
- Was very social, liked going out clubbing.
- Dog lover and Michael Bolton fan.
- No comorbidities and good mobility.
- The only resident who walks with purpose.
- Lives on the ground floor.

### Housing:

- Suburban location in the east of England.
- Fully purpose built single block of 32 flats.
- Two floors with four wings and a central communal area
- Integrated model scheme.
- Total capacity 64 residents; currently 33 residents.
- 18 residents with a diagnosis of dementia and none with suspected dementia.
- Manager feels that it is not dementia friendly.
- Design features to support safe walking with purpose: black mats in front of exit doors; safe indoor places and routes for walking; outdoor spaces enclosed; places to sit and rest along indoor and outdoor routes.
- No policies, procedures or guidelines for supporting safe walking with purpose.

### Staff:

- 18 care staff on-site.
- No training on understanding and addressing walking with purpose.

## Walking with purpose

**How long?** Started walking with purpose "in the last couple of weeks".

**How often?** "Not excessive" – every day, at least twice a day, but the frequency is increasing.

**When/time spent?** First thing in the morning, for about half an hour, then 5-8.30pm in the evening.

**Where?** Within the scheme (inside and outside). Tries to enter other residents' flats. Never leaves the scheme grounds.

**How does she get back?** If Sheila wants to go back to her flat, a member of staff takes her.

### Purpose/Reasons

#### Seeking company and reassurance/reduce loneliness and anxiety.

- Sheila is constantly looking for her staff carers. When she finds them and they ask her what she wants, she apologises and says she doesn't know or wants to go back to her flat.
- The manager does not know the reasons for Sheila's walking with purpose.
- Staff can get her settled in her flat for a short time but she will soon be out again, seeking a carer.
- When they take her back, she wants them to stay with her, even at night.  
*"Most times, she says she wants to go back to her flat. But she wants the carer to stay with her ...and that's one of the things that the carers are finding difficult."* (Scheme manager)

### Risks

- The manager feels that there are no risks for Sheila when she walks with purpose.
- She has good mobility and balance so there is currently a low risk of falling.
- When the doors to flats are closed, most of them are locked so there is a low risk of her getting into other residents' flats.

### Impacts

#### Resident

- Starting to walk with purpose coincides with a change in mood, especially in the evenings when she is particularly down, anxious and confused.

#### Staff

- The recent change in Sheila's mood has had a negative impact on the staff who have found it difficult to accept the sudden change.
- The manager is frustrated by the fact that she has not been able to find out the reason for Sheila's walking with purpose and, therefore, has not been able to accommodate her needs.
- The staff feel restricted by the fact that their care time is structured. They are unable to stay with Sheila when she asks them to but do not want to leave her in an anxious and confused state, which they find stressful.

#### Other residents

- The other residents are also concerned about the recent sudden change in Sheila.

Responses/managing	What makes the walking with purpose safe/safeguarding/reducing the risks	Outcomes (10 week follow up)
<ul style="list-style-type: none"> <li>The scheme manager is dissatisfied that they have not been able to understand Sheila's reason(s) for walking and therefore have not been able to help her with this, which appears to be the managers preferred method of addressing walking with purpose. <i>"We've yet to find why and how we're going to help that." (Extra care scheme manager)</i></li> <li>When the staff take Sheila back to her flat they try to distract and calm her by getting her a drink and finding one of her favourite programmes on the TV or putting some Michael Bolton music on. However, she will only stay in her room for a short time before she leaves to find her carers again. <i>"She'll settle for about half an hour. And then she'll be back up and out and doing exactly the same again." (Extra care scheme manager)</i></li> <li>The staff also address Sheila's walking with purpose by talking her for a walk around the garden, visiting the chickens and, if any visitors have brought a dog in, take her to see the dog because she likes dogs.</li> <li>The manager has requested a review of Sheila's needs in the hope that she will be allocated more care time.</li> <li><i>"We have obviously requested a review of her needs and stuff like that." (Extra care scheme manager)</i></li> </ul>	<ul style="list-style-type: none"> <li>Currently, Sheila's walking with purpose is safe because she has good mobility and balance and stays within the scheme and its grounds.</li> <li>The garden is large, enclosed, safe and secure and has walking routes with places to rest, although the manager would like to add things that attract people's attention visually. There are also walking routes indoors with places to rest. There are black mats in front of exit doors to deter people living with dementia from going out. <i>"We've got really nice grounds, which are quite large. So if we can encourage...if they want to go outside, we can encourage them to go outside and they can walk in the garden in a safe and secure environment. Quite nice. And within the building, it's...although it's quite a straight run, go upstairs, downstairs and round when they take walks." (Extra care scheme manager)</i></li> </ul>	<ul style="list-style-type: none"> <li>Sheila's dementia progressed considerably since the interview and she has become increasingly anxious.</li> <li>The staff still do not know the reasons for her walking with purpose.</li> <li>Sheila began to follow the carers excessively (known as trailing) – the manager stated that she "clung to the staff". Even if she was in her room spending time with another resident she would leave her room to find a member of staff.</li> <li>Being with a member of staff used to decrease her anxiety, however, recently, being with a carer did not seem to have any effect on her anxiety. If there was a carer with her in her flat, she would leave her flat to find another carer.</li> <li>An extra two hours has been allocated to spend time with Sheila but the manager thinks her anxiety is so high what is really needed is anti-anxiety medication, however she states that when she asks the GP to prescribe this "the GP just says it is the dementia".</li> <li>At 10 weeks post interview, staff are suddenly finding it easier to manage Sheila's walking with purpose because she has become good friends with a male resident and if she is with him she will stay where she is and not try to seek a member of staff.</li> </ul>

## Extra care housing

Pat, 84 | Dementia (diagnosed 2 years ago)

### Characteristics:

- Widow with two sons.
- Parkinson's disease (diagnosed 7 years ago).
- One son has been her carer for seven years.
- Worked in a hotel from age 15, first child at age 19.
- Used to enjoy dancing, watching TV and listening to the radio.
- Frail, poor mobility and walking posture. Frequent falls. Uses a walking frame.
- Lived at scheme for three years. Her son stays with her during the daytime.
- Lives on third floor of scheme in a two bedroomed flat.
- One of seven residents who walks with purpose.

### Housing:

- Suburban location in the southeast of England.
- Fully purpose built block of four floors and 38 flats.
- Integrated model scheme.
- Total capacity 76 residents; currently 39 residents.
- Four residents with a diagnosis of dementia, seven with suspected but undiagnosed/undeclared dementia.
- Designed to be dementia friendly and has numerous design features to support safe walking with purpose.
- No policies, procedures or guidelines for supporting safe walking with purpose.

### Staff:

- Ten members of staff; no training on understanding and addressing walking with purpose.

## Walking with purpose

**How long?** Started walking with purpose nine months ago.

**How often/time spent?** "Excessive" – every day, many times a day, frequency is increasing.

**When/Time spent walking with purpose?** Throughout the day and night.

**Where?** Inside the scheme. Gets lost in the scheme.

**How does she get back?** Pat's son or a member of staff take her back to her flat or her chair in the lounge, otherwise she would be able to find her own way back.

Purpose/ Reasons	Risks	Impacts
<p><b>Doing chores that she used to do/"pottering".</b></p> <ul style="list-style-type: none"> <li>• Her walking has a clear purpose – her son and the staff understand that she is trying to do the things that she used to be able to do such as wash up, put the laundry away, tidy up, feed the cat, catch a bus to go shopping.</li> </ul> <p><i>"There's always something she wants to do, which obviously she used to do, but she can't do it now." (Son)</i></p>	<ul style="list-style-type: none"> <li>• High risk of falling and resulting injuries due to:                             <ul style="list-style-type: none"> <li>- Poor mobility</li> <li>- Despite many injuries and hospital visits, has no fear of falling</li> <li>- Forgets to use walking frame and grab rails</li> <li>- Doesn't use pendant alarm when falls.</li> </ul> </li> </ul>	<p><b>Resident</b></p> <ul style="list-style-type: none"> <li>• Frequent falls, Injuries and hospital visits</li> </ul>
		<p><b>Family</b></p> <ul style="list-style-type: none"> <li>• Pat's son works on a night shift. He stays at the scheme, caring for Pat, during the day. He sleeps for a few hours during the day, in his bedroom in Pat's flat. This is when Pat walks around the flat or leaves the flat, without her walking frame. <i>"...you can't be there all the time" (Son)</i></li> <li>• He worries about her falling and being injured. He is expecting her to have a serious fall and break a hip, in which case he is fearful that she will not survive an operation.</li> <li>• He feels stressed by her constant walking with purpose and the fact that he cannot keep an eye on her all the time.</li> <li>• Managing his mother's walking with purpose is exhausting. <i>"It's a nightmare. It wears you out sometimes." (Son)</i></li> <li>• He feels he needs to be with Pat in the day otherwise she will be moved into a care home, which he doesn't want.</li> <li>• He has been considering giving up his job and living at the scheme with his mother so that she can remain there.</li> </ul>
		<p><b>Staff</b></p> <ul style="list-style-type: none"> <li>• The staff worry about Pat falling. They want to keep her safe. They want her to stay at the scheme until end of life.</li> </ul>
		<p><b>Other residents</b></p>

- The other residents look out for Pat and alert staff if she starts walking when her son is not present.

Pat, 84

Responses/managing	What makes the walking with purpose safe/safeguarding/reducing the risks	Outcomes
<ul style="list-style-type: none"> <li>• Distraction, the technique favoured by the staff, does not work with Pat. For example, putting the TV on for her to watch only works for a few minutes, then she will be out of her chair and walking again. Instead, the staff walk with Pat to ensure she is safe.</li> <li>• Pat has been given a walking frame to make her walking with purpose safer and reduce the likelihood of falling. Her son and the scheme manager both believe that her walking would be much safer if she remember to use the frame.</li> <li>• The manager has tried tying colourful ribbon on Pat's walking frame to make it more visible to her when she wants to walk out of the flat. However, this has been unsuccessful in increasing her use of the frame. <i>"I've tried...the other day I tied ribbons onto her frame so that that was like a focus for her, but still the frame was still sat there when I went back. And I think that's the main thing that makes her walking unsafe."</i> (Extra care scheme manager)</li> <li>• If Pat wants to walk out of the flat, her son makes sure she takes her walker and he lets her walk for a short distance down the corridor, then he brings her back to the flat. Pat is unable to find her own way back to her room. <i>"I mean I'd let her go for a walk. If she wanted to go down the corridor I'd let her go because it's exercise. As long as she's got her frame she's pretty safe."</i> (Son)</li> <li>• Pat's son uses a wheelchair to take Pat downstairs or out of the scheme.</li> <li>• Recently obtaining a hospital bed for Pat has stopped her getting out of bed, walking and falling during the night. <i>"No, she can't get out of bed, she's just got a new bed, it's a hospital bed and it can be raised slightly and she can't get out of it..."</i> (Extra care scheme manager)</li> <li>• A sensor mat is going to be obtained for Pat (to be placed by her bed at night and in front of her chair during the day) to alert staff when she has got out of her bed or up from her chair.</li> </ul>	<ul style="list-style-type: none"> <li>• The fact that Pat's son stays with her in the scheme during the daytime greatly reduces the risks. She has got the walking frame which makes her walking safer, but only if someone reminds her to use it. However, Pat's son cannot watch her all the time, he needs to have a sleep during the day. <i>"I'm here most of the time. I watch her."</i> (Son)</li> <li>• Pat has never walked out of the scheme building so she only gets lost inside the scheme where she can be easily found by staff or other residents, who will alert the staff. There is CCTV throughout the inside of the building and in the outside areas.</li> <li>• During the night, when Pat's son is not at the scheme, the night staff regularly check that Pat is in bed. <i>"We have somebody checking on her every hour during the night to make sure that she is in the bed; I don't think she can get out and I don't think she'll try."</i> (Manager)</li> </ul>	<ul style="list-style-type: none"> <li>• At the time of the interview, Pat was still walking with purpose around the scheme without a frame when her son was sleeping.</li> <li>• She was frequently falling, often in her own flat, and getting injured (she had been to hospital 17 times that year)</li> <li>• On the day of the interview, Pat had several bandages and dressings and her face was bruised.</li> <li>• Pat's son felt that, with his presence, the scheme is a suitable place for Pat to live.</li> <li>• The scheme manager was advising Pat's son against giving up his job to live with his mother at the scheme.</li> </ul>

<ul style="list-style-type: none"> <li>The care staff requested, and have been given, extra time from the local council to care for Pat (to ensure that she is safe and to escort her back to her flat or chair).</li> <li>Staff do hourly checks along the corridors for any residents walking with purpose.</li> </ul>	<ul style="list-style-type: none"> <li>Pat no longer walks or falls at night since getting a hospital bed.</li> </ul>	<p><b>Follow up (10 weeks)</b></p> <ul style="list-style-type: none"> <li>Pat died a few days after the interviews took place.</li> </ul>
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Extra care housing		Walking with purpose		
Liz, 85	Alzheimer's disease (diagnosed before moving into scheme)	<p><b>How long?</b> Started walking with purpose about four years ago (the reason she moved into the scheme.)</p> <p><b>How often?</b> "Not excessive" – once or twice every fortnight.</p> <p><b>Where?</b> Usually within the scheme (inside and outside). On one occasion, she left the scheme and its grounds via the garden and car park to the rear (the garden is not enclosed)</p> <p><b>How does she get back?</b> Within the scheme, Liz can find her way back to her flat by herself. On the occasion that she left the scheme, a member of staff happened to drive past and phoned the manager.</p>		
<p><b>Characteristics:</b></p> <ul style="list-style-type: none"> <li>Widow with two daughters and one son. One daughter visits every Saturday and takes Liz out for the day.</li> <li>A private carer visits every evening on weekdays, cooking dinner for Liz and taking her out for a walk around the local area for around 1 hour. Another visits every Monday and Tuesday afternoon, cooks her lunch and stays for 2-3 hours, keeping Liz busy with activities.</li> <li>Worked as a domestic science teacher.</li> <li>Used to do yoga classes and kickboxing.</li> <li>She loves ice cream, the Royal family and talking about her children when they were young.</li> <li>No comorbidities.</li> <li>Very good mobility, walks fast and steadily.</li> <li>Lived at scheme for three years and eight months.</li> <li>Lives on second floor of scheme.</li> <li>One of seven residents who walks with purpose.</li> </ul> <p><b>Housing:</b></p> <ul style="list-style-type: none"> <li>Suburban location in the southeast of England.</li> <li>Fully purpose built single block of 4 floors and 38 flats.</li> <li>Integrated model scheme.</li> <li>Total capacity is 76 residents; currently 39 residents.</li> <li>Four residents with a diagnosis of dementia, seven with suspected but undiagnosed/undeclared dementia.</li> <li>Designed to be dementia friendly and has numerous design features to support safe walking with purpose.</li> </ul>		Purpose/Reasons	Risks	Impacts
		<p><b>Triggered by agitation.</b></p> <p><b>Possibly looking for parents</b></p> <ul style="list-style-type: none"> <li>Walks with purpose when agitated.</li> <li>Becomes agitated when there is a change to her usual routine.</li> <li>The staff have been unable to identify a reason for her walking around the scheme.</li> <li>The occasion that she left the scheme, her private carer did not come and Liz went on her usual walk by herself. She stopped a passer-by to ask for help, saying that she was trying to get to Newcastle to see her parents.</li> <li>The scheme manager is not sure whether Liz would have been able to find her</li> </ul>	<ul style="list-style-type: none"> <li>Risk to her safety if she leaves the scheme due to busy road.</li> </ul>	<p><b>Resident</b></p> <ul style="list-style-type: none"> <li>Liz has not left the scheme since the single incident, nor will she now go out into the garden unaccompanied, even if the back doors are open. The scheme manager believes this is because she "got a scare" from her experience.</li> </ul>
				<p><b>Staff</b></p> <ul style="list-style-type: none"> <li>Usually, when Liz walks with purpose inside the scheme, this doesn't create a challenge for the staff. They know the best ways to distract or redirect Liz and this method of addressing walking with purpose is currently working well. The scheme manager believes that the staff are currently extremely successful in addressing Liz's walking with purpose.</li> <li>When Liz left the scheme by herself the staff were very worried when they couldn't find her within the scheme. The manager considers this occasion to be the greatest walking with purpose related challenge and the worst walking with purpose incident that they have had with a current resident.</li> <li>The staff were worried for a while that Liz would leave the scheme again, but, thus far, she has not.</li> </ul>
				<p><b>Other residents</b></p>

<ul style="list-style-type: none"> <li>No policies, procedures or guidelines for supporting safe walking with purpose.</li> </ul> <p><i>Staff:</i></p> <ul style="list-style-type: none"> <li>Ten members of staff; no training on understanding and addressing walking with purpose.</li> </ul>	<p>own way back had she not been found.</p>		<ul style="list-style-type: none"> <li>The other residents know Liz well and keep an eye on her, alerting the staff if she seems “unsettled” or is walking with purpose. They also know how to distract her with the offer of ice cream.</li> </ul>
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Liz, 85

Responses/managing	What makes the walking with purpose safe/safeguarding/reducing the risks	Outcomes
<ul style="list-style-type: none"> <li>The staff have got to know Liz and know what works to distract/redirect her when she is walking with purpose. Distraction is the scheme’s preferred method of addressing walking with purpose. In addition, knowing the resident’s life story and what they like is useful for understanding what will work to distract them. For example, they know that she like ice cream and can always be distracted/redirected with the offer of ice cream. She also likes the royal family and the staff will distract her from her walking and calm her when she is agitated by showing her a book on the royal family. Photographs from her past also work to calm her by triggering reminiscence.</li> </ul> <p><i>“You could always coax her with an ice cream. So, if she’s wandering about or trying to get into somebody’s flat give her an ice cream and she’ll be fine, and she’ll go back into her flat and you won’t hear anything else.” (Extra care scheme manager)</i></p> <p><i>“We distract her with... She loves the royal family so if we’ve got books upstairs with the royal family we just show her pictures of that or show her, her photos and get her talk about her photos ... when she was younger and her children when they were babies. There’re so many different things we can distract her with.” (Extra care scheme manager)</i></p> <p><i>“It’s getting to know the person. I think you need to get to know the person and then find what they like, you know, just finding the right techniques for individuals because everybody’s different” (Extra care scheme manager)</i></p> <ul style="list-style-type: none"> <li>For a few weeks following the incident when Liz left the scheme the staff were extra vigilant with her.</li> <li>Liz’s private carer had been instructed to ring Liz’s daughter if she is not going to be able to visit that day or if she will be late. The daughter then rings the scheme to let them know.</li> </ul>	<ul style="list-style-type: none"> <li>Liz has good mobility and balance so she is not at risk of falling.</li> <li>Liz usually walks around the building and has not been outside the scheme since that time she left on her own. <ul style="list-style-type: none"> <li><i>“I don’t think she even goes out in the garden on her own.” (Extra care scheme manager)</i></li> </ul> </li> <li>Although Liz has been the only resident thus far to leave the scheme via the garden at the rear, and she has done this only once, she has shown that it is possible for residents to walk out of the scheme that way and onto a busy road. Thus, the scheme manager would like the garden to be enclosed and secure. <ul style="list-style-type: none"> <li><i>“If the garden was enclosed the incident wouldn’t have happened, but like I say it hasn’t happened since ... I can’t say in the future with the other people because it’s</i></li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>The scheme manager believes that the extra care scheme is a suitable place for Liz (whose dementia is “severe”) to live but acknowledges that this may only be the case because Liz has a lot of extra support in place.</li> </ul>

<p>However, on the occasion that Liz left the scheme the daughter did not ring. The carer has now been instructed to ring the scheme as well as Liz's daughter. If the carer is not able to come or is going to be late, the staff at the scheme will now keep a close eye on Liz.</p> <ul style="list-style-type: none"> <li>• The staff will sometimes take Liz for a walk outside.</li> <li>• The staff do hourly checks along the corridors for any residents who are walking with purpose.</li> </ul>	<p><i>not ideal." (Extra care scheme manager)</i></p>	
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<b>Extra care housing</b>	<b>Walking with purpose</b>
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<b>Vera, 72</b>	Vascular dementia (diagnosed 15 months ago)	
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- Characteristics:**
- No family in UK. Had a brother who lived in Australia who is now deceased and whose money she inherited.
  - Little is known about Vera's past except that, as a child, she lived in foster care and, as an adult, she was homeless.
  - Also diagnosed with paranoia and displays obsessive-compulsive behaviour.
  - Very independent, determined and strong willed.
  - Found it hard to settle at the extra care scheme.
  - Enjoys music, singing and dancing.
  - Always very well presented and dressed.
  - Good mobility, walks fast and steadily.
  - Has lived at the scheme for six years.
  - Lives on the ground floor.
  - One of two residents who walks with purpose.
- Housing:**
- Suburban location in the northwest of England.

**How long?** Since she moved into the scheme.  
**How often?** Visits Blackpool once a month, more frequently in the summer, is away for 2-4 days.  
**When/Time spent?** Leaves the scheme when the weather is nice. Goes to Blackpool during the summer and at Christmas time.  
**Where?** Into the city, down to the pier head or docks and for trips to Blackpool. She goes to Blackpool by train and stays in a hotel there for a few days. She is known to the rail transport police.  
**How does she get back?** Vera finds her own way back to the scheme, except one Christmas when she left the Bristol hotel, did not return to the scheme and was missing for two weeks. She was found and brought back by the police. The manager considers this the scheme's worst incidence of walking with purpose.

<b>Purpose/Reasons</b>	<b>Risks</b>
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**Visiting friends from her homeless days/"Wanderlust"**

- Vera has a "wanderlust" (manager) stemming from being homeless and also a desire to see friends from those days.
- The manager doesn't know why Vera travels to Blackpool but speculated that she may have friends there from when she was homeless.

Risk from other people, especially as she carries £500 in cash.

<b>Impacts</b>	
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<b>Resident</b>
Vera becomes angry if staff try distract her or redirect her when she wants to leave the scheme.
<b>Staff</b>

<ul style="list-style-type: none"> <li>• Fully purpose built single block with two floors and 40 flats.</li> <li>• Integrated model scheme.</li> <li>• Total capacity 60 residents; currently 38 residents.</li> <li>• 11 residents with a diagnosis of dementia, none with suspected but undiagnosed/undeclared dementia.</li> <li>• Designed to be dementia friendly. Design features to support safe walking with purpose: clearly labelled important doors; places to sit and rest along indoor and outdoor routes.</li> <li>• There are two retirement housing blocks on the same site and the three blocks form one large community.</li> <li>• No policies, procedures or guidelines for supporting safe walking with purpose.</li> </ul> <p><b>Staff:</b></p> <ul style="list-style-type: none"> <li>• 32 care staff plus some office staff. Received training on understanding and addressing walking with purpose.</li> </ul>	<ul style="list-style-type: none"> <li>• When Vera decides she is going to leave the scheme, she cannot be stopped.</li> <li>• The manager worries when Vera 'is out of sight' about what she is doing and what could happen to her.</li> <li>• The manager considers Vera's walking with purpose to be a challenge. Because Vera leaves when the weather is nice, a sunny morning makes the manager dread what was going to happen.</li> <li>• When Vera was missing for two weeks, the manager was very worried for her safety, found it very stressful and began to doubt her decision to manage Vera's walking with purpose by letting her leave the scheme.</li> <li>• The manager considers her greatest challenge in managing walking with purpose to be other residents' lack of understanding. The residents of the nearby retirement housing blocks are particularly prone to complain about extra care residents walking into their buildings (see below)</li> </ul> <p><b>Other residents</b></p> <ul style="list-style-type: none"> <li>• The other residents are inquisitive about Vera's whereabouts and questioning of the scheme manager's management of her walking with purpose. The manager has to handle the questions sensitively.</li> </ul>
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## Vera, 72

Responses/managing	What makes the walking with purpose safe/Safeguarding/reducing the risks	Outcomes
<ul style="list-style-type: none"> <li>• The manager soon discovered that if she tried to stop Vera from leaving the scheme to go to Blackpool or the docks, this would make Vera even more determined to leave. Thus, the staff had to let her leave.</li> <li>• Realising that she could not stop Vera from leaving the scheme, the manager set about making the trip to Blackpool as safe as possible by putting various procedures in place.</li> </ul>	<ul style="list-style-type: none"> <li>• The manager made links with the local authority, the local police and police in Blackpool and the hotels in Blackpool. <i>"We had made links with the local authority to log when she'd gone, with Alert we got in touch with hotels in Blackpool. They knew her. We made contact with all the hotels in Blackpool just to tell them that they may get a visitor and it will be Vera, they all knew her. We made links with the police out in Blackpool and [local] police. They were really good too. Just to put all those things in place, because we couldn't stop her going."</i> (Extra care scheme manager)</li> <li>• The manager spoke to Vera about her trips and gained her trust so that Vera would tell the staff when and where she was going. The manager would then book the train for her and let the hotel know she was coming. <i>"We built trust up with her in the end where she used to let us book her train for her, let the hotel know she was coming."</i> (Extra care scheme manager)</li> <li>• The scheme manager arranged for the hotel staff to phone her to let her know when Vera had arrived and when she left. In fact, eventually Vera would ask the hotel staff to ring the scheme because she knew the scheme manager would worry.</li> </ul>	<ul style="list-style-type: none"> <li>• When Vera was missing for two weeks the scheme manager was very worried for her safety. The manager found it very stressful and began to doubt that she had taken the correct actions in allowing Vera to leave the scheme to go on her trips to Blackpool. In fact she began to doubt her decision to accept Vera into the scheme and felt that perhaps extra care living was not suitable for Vera.</li> <li>• However, Vera has recently settled at the scheme and is no longer leaving the scheme.</li> <li>• Vera now considers the scheme to be her home, appears to be happy and</li> </ul>

	<p><i>"I mean it became that good that she'd give them my phone number, the work phone number, for staff to ring to tell me." (Extra care scheme manager)</i></p> <ul style="list-style-type: none"> <li>The scheme manager would also phone Careline (a 24-7 contact centre run by the local council for all social care enquiries and referrals, which can be called to report a child or adult at risk) and the Police when Vera left the scheme to inform them that a vulnerable adult has just left the scheme and gone to Blackpool and that she could not be stopped because the scheme is extra care housing.</li> <li>The scheme manager also built up contacts at the places Vera would go when she visited the docks. <p><i>"We made some contacts, in the early days I had to, with security guards and people around big buildings where she'd hang around. I made some contacts with people there." (Extra care scheme manager)</i></p> </li> <li>When Vera went missing for two weeks after a stay at the hotel in Blackpool, the scheme manager informed the local and Blackpool police. <p><i>"So [local] Police are great, so are Blackpool Police and they put onto Facebook, and the usual Twitter and all the rest of it." (Extra care scheme manager)</i></p> </li> </ul>	<p>settled there, walks only within the scheme and meets and chats with June (her imaginary friend) in the scheme's communal areas.</p> <ul style="list-style-type: none"> <li>The manager now believes that extra care housing is suitable for Vera. <p><i>"But for me it just makes me feel better that she's gone through the whole process and has actually nested and stayed with us." (Extra care scheme manager)</i></p> </li> <li>The manager considers Vera to be the scheme's greatest success in terms of managing walking with purpose.</li> </ul>
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Extra care housing		Walking with purpose	
Anne, 85	Alzheimer's disease (diagnosed 8 years ago)	<p><b>How long?</b> Uncertain. Was walking with purpose when she moved into the scheme.</p> <p><b>How often?</b> Excessive. Every weekday following the same routine.</p> <p><b>When?</b> At 2pm Anne would leave the scheme. Anne would never walk with purpose at night.</p> <p><b>Time spent walking with purpose?</b> When Anne first moved into the scheme she would be away from the scheme for around one and a half hours but over time the duration of her absence grew longer until it was around four hours.</p> <p><b>Where?</b> To the family home, then the nearby school that her children used to attend and then back to the scheme.</p> <p><b>How does she get back?</b> Anne usually returned to the scheme by herself at around 4pm. If out later, which increasingly became the case, the manager would drive along Anne's usual route to find her and bring her back. If the family currently living in Anne's old home called the police, the police would bring Anne back to the scheme.</p>	
<p><b>Characteristics:</b></p> <ul style="list-style-type: none"> <li>Widow with two sons and one daughter.</li> <li>Was a primary school teacher.</li> <li>Came to live in the scheme after the death of her husband who was her primary carer.</li> <li>No comorbidities and very mobile.</li> <li><b>Past resident.</b> Lived at the scheme for about four years. Now lives in a nursing home.</li> <li>Lived on the ground floor of scheme</li> </ul> <p><b>Housing:</b></p> <ul style="list-style-type: none"> <li>Suburban location. Northwest of England</li> <li>Fully purpose built single block with 2 floors and 40 flats.</li> <li>Integrated model scheme.</li> </ul>		Purpose/Reasons	Risks
		<p><b>Collect children from school/go home /carry out her old weekday afternoon routine.</b></p> <ul style="list-style-type: none"> <li>After visiting her old house and then the school, she would return to her flat at the scheme at around 4pm to make cucumber sandwiches and tea for her husband.</li> <li>Later on she became more "fixated" on her old family home and would be outside the front of the house at the same time every weekday.</li> <li>She would stand outside the house for a long time, staring up at a bedroom window. This upset, frightened and stressed the family currently living there.</li> </ul>	<p>Health risks of spending up to 4 hours outside, in the dark during winter. On several occasions, she was found cold, wet, dishevelled, thirsty, hungry and exhausted.</p>

<ul style="list-style-type: none"> <li>Total capacity 60 residents; currently 38 residents</li> <li>11 residents with a diagnosis of dementia, none with suspected dementia.</li> <li>Designed to be dementia friendly. Design features to support safe walking with purpose: clearly labelled important doors; places to sit and rest along indoor and outdoor routes.</li> <li>Forms a community together with two retirement housing blocks on the same site.</li> <li>No policies, procedures or guidelines for supporting safe walking with purpose</li> </ul> <p><b>Staff:</b></p> <ul style="list-style-type: none"> <li>32 care staff plus some office staff. Have received training on understanding and addressing walking with purpose</li> </ul>	Impacts		
	Resident		
	<ul style="list-style-type: none"> <li>Anne would become visibly distressed if the staff tried to distract or redirect her away from her purpose of leaving to collect her children from school, as would any mother who was being delayed in collecting her children from school.</li> <li>Anne became increasingly wary, distrustful and aggressive towards the scheme staff. Her walking with purpose changed into “trying to escape”.</li> </ul>		
	Staff		
<ul style="list-style-type: none"> <li>When Anne spent increasingly longer away from the scheme, the manager began to worry about her and her health.</li> <li>After a few hours the manager went out and drove along Anne’s route to look for her and persuade her to return.</li> <li>Consequently, managing Anne’s walking with purpose began to take up a disproportionate amount of her time.</li> <li>Dealing with Anne’s walking with purpose was a challenge for the staff. Trying to distract her from leaving didn’t work.</li> <li>Over time, the manager began to dread the afternoon ahead whenever she saw that Anne was preparing to leave.</li> <li>It also distressed the manager that Anne was becoming increasingly wary and distrustful of her and her staff.</li> <li>The manager was also stressed from having to deal with the complaints from the family now living in Anne’s old house.</li> </ul>			
		Family members	
		<ul style="list-style-type: none"> <li>Anne’s walking with purpose, “escaping” and “loitering” outside her old family home was causing her children stress.</li> </ul>	

## Anne, 85

Responses/managing	What makes the walking with purpose safe/safeguarding/reducing the risks	Outcomes
<ul style="list-style-type: none"> <li>When Anne would leave the scheme the staff would ask her where she was going and try to distract her from her purpose. However, this method of managing walking with purpose would never work with Anne, rather it would make her become visibly distressed. Thus, the staff had to let Anne exit the scheme. <i>“...there was no way, you could see in her face, you know.”</i> <i>“Never stopped her going.” (Extra care scheme manager)</i></li> <li>If Anne was away from the scheme for a long time, the manager would get in her car and drive along the routes that she knew Anne took and look for her.</li> </ul>	<ul style="list-style-type: none"> <li>Anne’s balance and mobility was good and she was not at risk of falling.</li> <li>The manager did not worry about Anne’s safety when she left the scheme in terms of other people because she did not have the appearance of a “vulnerable old lady”. <i>“She was, smart, intelligent, well groomed. She looked amazing, amazing for her age, you’d probably say 65, you know, blonde, lipstick, the lot,</i></li> </ul>	<ul style="list-style-type: none"> <li>Anne was moved to a nursing home two years ago due to the issues caused by her walking with purpose. Anne has a Deprivation of Liberty Order at the nursing home.</li> <li>The manager did not want Anne to move out of the scheme. She felt somewhat ashamed and that she had let Anne down, but also knew that it was not fair on her to keep her there. She felt that she had lost</li> </ul>

<ul style="list-style-type: none"> <li>The manager called a meeting at the scheme with the family currently living in Anne’s old family home and Anne’s children so that everyone would understand the situation.</li> <li>There was a Multidisciplinary team meeting to discuss Anne’s walking with purpose and possibly moving her out of the scheme. There were a number of reasons for this: <ul style="list-style-type: none"> <li>the manager couldn’t guarantee her safety while she was away, but she couldn’t stop her leaving;</li> <li>frightening the family currently living in her old family home;</li> <li>becoming increasingly wary, distrustful and aggressive towards the staff;</li> <li>the discomfort that the police and manager felt when they picked her up;</li> <li>the manager’s time away from the scheme to look for Anne;</li> <li>her walking with purpose changed into trying to escape;</li> <li>her excellent mobility.</li> </ul> <p><i>“I don’t even like to say it, but if Anne had fallen and lost a bit of mobility, she would have probably stayed here.” (Extra care scheme manager)</i></p> </li> </ul>	<p><i>immaculate”. (Extra care scheme manager)</i></p> <ul style="list-style-type: none"> <li>There was a sensor on the front door of Anne’s flat to alert staff.</li> <li>When Anne was away from the scheme for a few hours the scheme manager would drive around Anne’s known routes looking for her and bring her back.</li> </ul>	<p>and Anne had beat her. It was a very difficult decision for the manager to make.</p> <p><i>“She’s mine, I don’t want her to go to a nursing home, like, you feel like you’ve let her down, you know, but at the end of the day, you can only do so much.”</i></p> <p><i>“She’s ours and she’s been a success and then it all starts to get ... she, sort of, beat me, you know, she beat me ...”</i></p> <p><i>“The day she went was awful, because it was one of those emergency meetings that you’re there for hours and hours and making a decision and no one gets the one that gets moved on, you know, it’s horrible that, isn’t it?”</i></p>
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Retirement housing		Walking with purpose	
Jean, 72	Pick’s disease (diagnosed 3.5 years ago)	<p><b>How long?</b> Jean engaged in walking with purpose before moving into retirement housing.</p> <p><b>How often/time spent?</b> She goes out daily for up to 2 hours. Around twice a month she will go out for several hours.</p> <p><b>When?</b> Any time of day.      <b>Where?</b> Short walks in the local area. Into town by bus. Frequently visits charity shops.</p> <p><b>How gets back?</b> When out for up to 2 hours she usually returns by herself. According to the scheme manager states that Jean has never found her own way back when she is out for a long time (over 4 hours), then she is brought back by the police or her daughter. Conversely, Jean’s daughter believes her mother always knows where she is going and can make her own way home.</p>	
<p><b>Characteristics:</b></p> <ul style="list-style-type: none"> <li>Divorced and has five daughters, one of which is responsible for her care.</li> <li>Divorced a long time ago. Violent husband.</li> <li>The daughter works two days a week and on the days she is not working, she visits Jean.</li> <li>Jean worked in factories and as a cleaner.</li> <li>Enjoys knitting and long walks.</li> <li>She likes to go into town to visit the charity shops and have a cup of tea.</li> <li>Also has poor hearing.</li> <li>Very mobile. Can walk long distances.</li> </ul>		Purpose/Reasons	Risks
		<p><b>Seek company/change of scene/alleviate loneliness and boredom</b></p> <ul style="list-style-type: none"> <li>The scheme manager and Jean’s daughter agree that she walks to alleviate boredom, reduce loneliness, for a change of scene and because she prefers to be outdoors.</li> </ul>	<ul style="list-style-type: none"> <li>Dehydration when out for long periods.</li> <li>The worst incident, according to the scheme manager, was in August when Jean had been lost for around 9 hours at night and the police and drones were searching for her.</li> <li>Due to a very trusting and helpful nature Jean can approach people who appear to need help, including drug users. This once resulted in her having her purse stolen. She has also recently started smoking cannabis.</li> </ul>

<ul style="list-style-type: none"> <li>Has lived at the scheme for 1 year 2 months. Previously lived with daughter for 10 years.</li> <li>Lives on the ground floor of scheme.</li> <li>The only resident who walks with purpose.</li> </ul> <p><b>Housing:</b></p> <ul style="list-style-type: none"> <li>Rural location in the East Midlands and has a limited bus service into town.</li> <li>Remodelled from existing blocks of flats built in 1976</li> <li>37 flats in four blocks with communal entrances.</li> <li>42 residents currently.</li> <li>Three with a dementia diagnosis and two with suspected dementia.</li> <li>No policies, procedures or guidelines for supporting safe walking with purpose</li> </ul> <p><i>Staff:</i></p> <ul style="list-style-type: none"> <li>Court manager and cleaner. Manager has received training on understanding and addressing walking with purpose.</li> </ul>	Impacts	
	Resident	
	<ul style="list-style-type: none"> <li>A long duration away from the scheme without eating and drinking can have an adverse effect on Jean's health.</li> </ul>	
	Staff	
	<ul style="list-style-type: none"> <li>The manager becomes very anxious when Jean is away for a long time. She worries about how vulnerable and unsafe Jean is in the town or that she may be lost in the countryside where it would be hard to find her. Also, when Jean leaves the scheme, it is not possible for the manager to manage the risks to her safety.</li> <li>The manager is worried about people taking advantage of Jean.</li> <li>Assessing Jean's risks and devising ways to address her walking with purpose takes up a significant amount of time.</li> </ul>	
Family members		
<ul style="list-style-type: none"> <li>Contrary to the manager's attitude and approach to Jean's walking with purpose, her daughter sometimes gets anxious but states that she knows her mother and her capabilities well, and knows she will always return by herself.</li> <li>She feels that the scheme manager worries too much and alerts her and the police unnecessarily too soon. When the manager contacts her because Jean is 'missing', she states that she always knows where her mother will be.</li> <li>Jean's daughter initially found it very difficult to cope with her mother's increased tendency to walk with purpose. It came at an already difficult time for her and she is the only daughter involved in her mother's care.</li> </ul>		
Other residents		
<ul style="list-style-type: none"> <li>There was some prejudice towards Jean due to her dementia.</li> </ul>		

Jean, 72

Responses/managing	What makes the walking with purpose safe/safeguarding/reducing the risks	Outcomes
<p><b>Retirement scheme manager</b></p> <ul style="list-style-type: none"> <li>The manager has got together an MDT (Multi Disciplinary Team) – she is working in partnership with social services, mental health/NHS Continuing Care, the police and the family – to put appropriate procedures in place (Herbert Protocol) to reduce the risk and support safer walking with purpose e.g. identify her 'prime spots' and set a time limit (4 hours) before the daughter and police are alerted.</li> </ul>	<ul style="list-style-type: none"> <li>The Retirement scheme manager has put appropriate procedures in place, to ensure that Jean can be found if she is away from the scheme for more than 4 hours.</li> <li>The Herbert Protocol is regularly updated.</li> <li>The prime spots where Jean is likely to be (e.g. Charity shops) have her daughter's contact details.</li> <li>Jean is well known to the local police.</li> </ul>	<ul style="list-style-type: none"> <li>Now that her daughter regularly drives Jean into town, she only walks to local places, which has reduced the risks to her safety and health. <i>"Because I get her out enough now – I take her to lots of different places – she's got that variety now"</i></li> </ul>

<p><i>“We have said four hours, and definitely if she isn't back by sort of three in the afternoon, when it starts to get darker and colder, they're the cut-off points.”(Retirement scheme manager)</i></p> <ul style="list-style-type: none"> <li>• Walking with Jean to “get a stand-alone risk assessment done”.</li> <li>• Distracting/redirecting Jean when she sees her leaving by inviting her for a cup of tea and a chat.</li> <li>• Asking Jean what she has got planned for the day (this helps with finding her later if she has gone missing).</li> <li>• Taking Jean to a quiet room to calm down.</li> <li>• Advising Jean not to purchase little bags from people she meets in the town.</li> <li>• Meeting with Jean and her daughter to devise and plan different activities that may interest Jean and keep her occupied.</li> <li>• Working towards making the scheme more dementia friendly.</li> <li>• Holding Dementia Friends sessions</li> </ul> <p><b>Daughter</b></p> <ul style="list-style-type: none"> <li>• Limits the money in Jean’s purse to £20 and removed her cash card.</li> <li>• Having now learnt to drive, she drives Jean into town.</li> <li>• On the days she is working she has arranged for a carer to visit Jean and she also makes sure she phones her mother for a chat during the day (she bought Jean a mobile phone)</li> <li>• Got her mother a guinea pig to help tackle her loneliness, which Jean is very fond of.</li> </ul>	<ul style="list-style-type: none"> <li>• The Retirement scheme manager maintains good communication with all stakeholders.</li> <li>• Understanding Jean’s life story and why she might be walking with purpose.</li> <li>• The daughter feels that she has now got a better routine in place for her mother now (taking her mother out in the car, carers visiting and phoning her mother on the days she is at work ) <i>“We’ve just got a better routine with everything now.” (Daughter)</i></li> <li>• Her daughter is starting to plan for a move to extra care housing for when Jean’s needs increase</li> <li>• The manager has spoken to Jean, her daughter and social services about getting a GPS to better support safe walking with purpose for Jean and to enable her to continue to live independently for as long as possible. Although this will incur some expense for the daughter, she is considering or the future, for “peace of mind” and making things easier to find her mother should she go missing.</li> </ul>	<p><i>where she doesn’t need to go off on her own.” (Daughter)</i></p> <ul style="list-style-type: none"> <li>• Jean tends to forget to take her mobile phone with her when she leaves the scheme. Managing her walking with purpose would be much easier if she did take it. <i>“She doesn't always remember to take it. So if that was in her handbag all the time, it would make things easier, so at least family or myself could get hold of her.” (Scheme manager)</i></li> <li>• Dementia Friends sessions for residents has reduced the prejudice towards Jean.</li> <li>• Both the scheme manager and Jean’s daughter feel that the retirement scheme is currently a suitable place for Jean to live due to the better routine (daughter) and having the correct support plan in place (manager).</li> </ul>
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<b>Retirement housing</b>		<b>Walking with purpose</b>	
<b>Brenda, 83</b>	Alzheimer’s disease and vascular dementia (diagnosed 3 years ago)	<p><b>How long?</b> Since moving into the retirement housing scheme.</p> <p><b>How often/time spent?</b> Once a week for a short duration.</p> <p><b>Where?</b> Brenda usually goes for short walks within the grounds of the retirement scheme while her husband keeps an eye on her. The manager stated that Brenda has walked out of the scheme.</p> <p><b>How gets back?</b> She has never found her own way back to her flat. Her husband usually brings her back, otherwise other residents or people living in the neighbouring estate bring her back.</p>	
<p><b>Characteristics:</b></p> <ul style="list-style-type: none"> <li>• Lives with her husband and carer, Bill (age 89).</li> </ul>		<b>Purpose/Reasons</b>	<b>Risks</b>

<ul style="list-style-type: none"> <li>• They have two sons that live in the U.S. and a daughter that lives nearby.</li> <li>• Had several different jobs over her working life, until she was age 70, including assistant pharmacist, doctor's secretary, sheltered housing scheme warden and working in retail.</li> <li>• Enjoys music and going to the theatre and knows the words to all the musicals.</li> <li>• Brenda and Bill go out at least once a day in the car (Bill drives) to have a coffee or go to the beach and get involved in the activities at the scheme.</li> <li>• She has had a stroke. She is mobile without a walking aid but her walking is slow.</li> <li>• They have lived at the scheme for four months.</li> <li>• They live on the first floor.</li> <li>• She is the only resident who walks with purpose.</li> </ul>	<p><b>Looking for her parents? To calm down when upset or agitated.</b></p> <ul style="list-style-type: none"> <li>• The Retirement scheme manager states that Brenda is looking for her parents. However, Bill states that while Brenda misses her mother and father and recently started mentioning them, he doesn't believe she goes out looking for them.</li> <li>• Bill believes the main reason for Brenda's walking with purpose is to calm down because she only walks with purpose when she gets upset or agitated due to wanting to go home (their home before moving into specialist housing), dissatisfaction with their flat or him upsetting her by saying the wrong things.</li> <li>• Brenda's husband and GP believe that her walking with purpose and confusion was triggered by recent events. They went to the U.S. to visit their sons and, on returning to the UK, found that their daughter had moved them into the retirement scheme. They had one week at the scheme then had a holiday in Switzerland (a gift from their son).</li> </ul> <p><i>"The doctor quite rightly said, on reflection, it was all too much for Brenda" (Bill)</i></p>	<ul style="list-style-type: none"> <li>• Bill believes Brenda's walking with purpose is "perfectly safe" because he is always there to keep an eye on her and the scheme is safe.</li> <li>• Conversely, the manager is more concerned about Brenda's safety and that she may get lost because Bill is not always aware that Brenda has left the flat.</li> <li>• The manager is also concerned that, at some point in the future, Brenda may have a fall.</li> </ul>
<b>Impacts</b>		
<b>Staff</b>		
<ul style="list-style-type: none"> <li>• With Bill caring for Brenda's her walking with purpose has little impact on the retirement scheme manager.</li> </ul>		
<b>Family members</b>		
<ul style="list-style-type: none"> <li>• Bill clearly cares about his wife and does his best to keep an eye on her and to keep her occupied.</li> <li>• However, the manager states that Bill finds it hard to cope and "is worried that he will have to put her in a home". The manager is a Dementia Champion and has given Bill some advice.</li> </ul>		
<b>Other residents</b>		
<p>The other residents are concerned about Brenda and play a part in keeping an eye on her.</p>		

<b>Brenda, 83</b>		
<b>Responses/managing</b>	<b>What makes the walking with purpose safe/safeguarding/reducing the risks</b>	<b>Outcomes</b>

<p><b>Retirement scheme manager</b></p> <ul style="list-style-type: none"> <li>Because Brenda lives with her husband, who is her carer, the scheme manager has had little to do with addressing Brenda's walking with purpose. <ul style="list-style-type: none"> <li><i>"I haven't seen her doing it, do you know what I mean. So, I think it's something going forward, if it gets worse, then obviously I will get involved with her husband and her daughter, and we would probably sort some of plan out what we could to help. But at the moment, it's not really affecting me at all."</i> (Retirement scheme manager)</li> </ul> </li> <li>The Retirement scheme manager is planning to increase the dementia awareness of the other residents by getting them to attend Dementia Friends sessions.</li> <li>There is no Herbert protocol in place (the manager had not heard of it).</li> </ul> <p><b>Family members</b></p> <ul style="list-style-type: none"> <li>Bill allows Brenda to go out for a walk in the scheme gardens for a while to calm down, then he brings her back into the flat. <ul style="list-style-type: none"> <li><i>"I let her have a little walk and then I looked for her out the window and then I went and got her."</i> (Bill)</li> </ul> </li> <li>Brenda's children have got her a bracelet with her name, address and contact details on, in case she does go walking beyond the scheme and gets lost.</li> <li>Their daughter has spoken to the other residents and people living in the neighbourhood to explain about Brenda's dementia, that Bill lets her go for a walk in the scheme gardens and that she may wander out of the scheme and get lost. She asked them to keep an eye out for Brenda. The scheme manager was unable to do this because she would be revealing confidential information about Brenda.</li> </ul>	<ul style="list-style-type: none"> <li>Bill and Brenda "do everything together" and keep busy by going out at least once a day and getting involved in the activities at the scheme. <ul style="list-style-type: none"> <li><i>"You know, we've been out more times to the seaside than I think we've been out in our life."</i> (Bill)</li> </ul> </li> <li>There are places to sit a rest along outdoor routes.</li> <li>Bill keeps an eye on Brenda, as do the other residents.</li> <li>Brenda is known to people living in the neighbouring housing estate who will bring her back or alert the scheme. <ul style="list-style-type: none"> <li><i>"It's always been successful getting her back because even the people that live opposite in a different estate, they have alerted people here or brought her back as well."</i> (Retirement scheme manager)</li> </ul> </li> <li>Brenda walks slowly, so cannot go far in a short space of time.</li> <li>Brenda is currently not a risk of falling.</li> <li>The use of a contact ID wrist band, although the Retirement scheme manager is not certain people would know to look for the band.</li> <li>The Retirement scheme manager stated that there are black mats at the entrance to each block of flats, but acknowledged that this could work both ways: deterring people living with dementia from getting out but also preventing them from getting in. <ul style="list-style-type: none"> <li><i>"On every entrance to every block, we've got a big, black mat. So it could work both ways. It could work a way where the person doesn't want to go out because they think it's a black hole or water or something. But also, it could work the other way, couldn't it, do you know what I mean. So we do have that, which I'm not sure is so good."</i> (Retirement scheme manager)</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Managing Brenda's walking with purpose may be a challenge for Bill when she is at her most confused and agitated. He states, however, that she is now calming down about where they live and the walking with purpose has become less of a problem.</li> <li>The manager states that they have always been successful in bringing Brenda back when she walks with purpose. Either Bill, one of the other residents or, if she ventures further, people from the neighbouring estate, bring her back.</li> <li>The manager feels that the scheme is currently a suitable place for Brenda to live because she has Bill to care for her. If Brenda was living on her own it would be a different matter and the scheme would not be a safe place for her to live because she could walk out and get lost. <ul style="list-style-type: none"> <li><i>"If it was just the wife on her own, it would be a different story I think, and then we would be looking to get extra help in for her, or even looking at where she lives."</i> (Retirement scheme manager)</li> </ul> </li> </ul>
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Retirement housing		Walking with purpose
Len, 89	Vascular dementia (diagnosed 2 months ago)	How long? One week ago, when he returned from hospital (admitted for breathlessness and dehydration).

### Characteristics:

- Widower with two sons (one estranged and the other visits every Saturday) and a daughter (lives in Australia, phones every Saturday).
- Len had his own business as an electrician.
- The scheme manager describes him as a loner but he joins in scheme meals and events.
- About six months ago his health, personal care and mood (angry) started to deteriorate.
- Has good mobility but has fallen once.
- A carer visits him every morning to carry out personal care and give him breakfast
- Lived at scheme for 6 years, on the ground floor.
- One of two residents who walk with purpose.

### Housing:

- Suburban location in Yorkshire and the Humber.
- Fully remodelled from existing block of flats built in 1972 and owned by the British Royal Legion.
- 38 flats in a single block with two floors.
- Manager feels that it is not dementia friendly. Design features that support safe walking with purpose: places to sit and rest along indoor routes.
- Total capacity 47 residents; currently 44 residents
- Three with a dementia diagnosis and one with suspected dementia.
- The manager states the scheme has policies for supporting safe walking with purpose.

### Staff:

- Court manager. No training on understanding and addressing walking with purpose.

**How often/time spent?** “Excessive”. He leaves or tries to leave the scheme nearly every day. He also visits the Retirement scheme manager’s office many times a day and sometimes sits outside the office for long periods.

**When?** Mainly afternoon and evening.

**Where?** Mainly visits the manager’s office. On the two occasions, thus far, that Len has managed to leave the scheme, he the manager found him in the local take away and post office.

**How gets back?** The scheme manager or another resident who lives on the same corridor as Len usually intercept him and take him back to his flat before he leaves the scheme.

### Purpose/Reasons

**Seeking company/change of scene/wants food/alleviate boredom and loneliness/life history.**

- He is often trying to go home, to another city in that region, where he lived as a child until he was 11 (he doesn’t believe that the scheme is where he lives).
- Work related: on one occasion that he went missing, in the early morning, the scheme manager found him in the local post office looking for the staff canteen because, having been working on the night shift, he was hungry.
- Looking for, or going to meet, deceased family members (mother, brother, wife).
- Len visits the manager’s office to alleviate boredom, for a change of scene and the company of others. Also often asking for food, even though he may have just eaten.

### Risks

- Getting lost if he leaves the scheme.
- Dehydration or hypothermia if he gets lost.
- Falling.

### Impacts

#### Resident

When Len left the scheme one night, he was clearly upset and exhausted on his return.

#### Staff

- The scheme manager finds it hard to manage Len’s behaviour and his walking with purpose is a source of concern and stress (particularly because it is unpredictable) which takes up an excessive amount of her time.
- The manager fears that Len may get on a bus (there is a bus stop right in front of the scheme) and become lost.
- The manager worries about Len’s health and wellbeing, should he leave the scheme and become lost.
- The manager feels that, when Len leaves the scheme, the onus is on her to bring him back. The occasions that he has left the scheme so far have been when the manager is not at work and is at home (located within the scheme) with her family. So, going out to search for Len and bring him back has taken place during her free time.
- Support from other Retirement scheme managers in the area helps her to cope.

#### Other residents

His neighbours worry about his walking with purpose. One of his neighbours plays a large part in ensuring he doesn’t leave the scheme.

Len, 89

Responses/managing	What makes the walking with purpose safe/safeguarding/reducing the risks	Outcomes
<ul style="list-style-type: none"> <li>• Len has a carer who visits him for one hour every morning, provided by social services. However, the manager feels that this is insufficient and has asked for this care to be increased.</li> <li>• If the Retirement scheme manager sees Len trying to leave the scheme she will talk to him to find out why and where he is going and then try to dissuade him from doing so. She has found, from past experience, that being firm with people living with dementia who are walking with purpose can make them become agitated. <i>“I’ve found, if you’re too, like, straight and say, no, you’re not off, because you don’t do that, then they tend to get really, really agitated, and you’re fighting a losing battle.”</i> <i>(Retirement scheme manager)</i></li> <li>• The Retirement scheme manager keeps a record of Len’s walking and ensures that his son, GP and the social services are made aware.</li> <li>• In the past, with other residents that walked with purpose, the manager as made a request, to the mental health team, for one of these to be fitted to Len’s flat door so that it will speak to him when he opens his flat door to go out.</li> <li>• The manager feels that it is time for Len to move out of the retirement housing scheme and into accommodation that provides a greater level of care. She has arranged for an assessment by the mental health team.</li> </ul>	<ul style="list-style-type: none"> <li>• A resident living on the same corridor as Len will check on him if she hears him leaving his flat and will take him back if he is confused and disorientated. <i>“If she hears him she will take him back.” (Retirement scheme manager)</i></li> <li>• The gardens at the back of the scheme are enclosed and secure.</li> <li>• The manager’s home is located so that she can hear Len shuffling past on his way out. However, this serendipitous safeguarding only works if it is quiet and the manager is in her home and awake. <i>“It was 10 o’clock at night, it was dark. I mean, the only reason I heard him was, because he doesn’t walk properly now he shuffles, and I could hear his slippers shuffling outside.” (Retirement scheme manager)</i></li> </ul>	<ul style="list-style-type: none"> <li>• The manager feels that she has been moderately successful in managing Len’s walking with purpose. She acknowledges that, on the two occasions he left the scheme, the fact that she found him was just lucky. It was also fortunate that on the other occasions he was trying to leave the scheme, another resident prevented him from doing so.</li> </ul> <p><b>Follow up (10 weeks)</b></p> <ul style="list-style-type: none"> <li>• 1 week after the interview the retirement scheme manager had started the procedure to move Len to a nursing home. However, he died of pneumonia soon after.</li> </ul>

## Case study summary and discussion

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

The great variation in the case study vignettes shows that each person's walking with purpose story is unique, with each of the people studied having different, personal motivations and reasons for walking. They also faced different risks depending on their personality, mobility, where and for how long they walked and their ability to get back to their chair/apartment/the scheme. Consequently, various responses to the walking with purpose were seen, although the preferred method of addressing walking with purpose appeared to be distraction/redirection. Understanding a resident's life story and their reasons for walking with purpose were recommended to assist with distraction or redirection. Even those scheme managers who tried to accommodate a resident's walking with purpose, enabling them to do so as safely as possible, would still try distraction or redirection first.

As with the schemes in the survey, the case study schemes reported few residents living with dementia who engaged in walking with purpose. The three case study retirement housing schemes had a total of four (1 + 1 + 2) residents who walked with purpose and the three extra care housing schemes had ten (1 + 2 + 7). However, even if there is only one resident who walks with purpose, depending on the frequency and nature of walking with purpose, managing it can take up a disproportionate amount of time and effort for management and members of staff as well as causing them worry and stress. The case studies enabled an understanding of why this is the case. Residents who regularly leave or try to leave the scheme can be time consuming and stressful for management and staff. On the one hand, addressing the walking with purpose at the point when the resident is trying to leave the scheme using distraction or redirection can take time and be stressful if the resident is determined to leave and becomes agitated or distressed or even angry or aggressive towards staff. On the other hand, allowing the resident to leave the scheme means stress and anxiety for managers because a person that they feel responsible for is out of their sight and they cannot ensure their safety. If a resident is then away from the scheme for a few hours or more, managers become fretful and finding the resident to bring them back to the scheme is very time consuming. It is easy to see why managers and staff may prefer dissuade the resident from leaving the scheme. The managers of both the extra care and retirement housing case study schemes felt a great sense of responsibility and duty towards their residents and when their ability to ensure a resident's safety is taken away, this is a great source of stress and anxiety.

Addressing walking with purpose that takes place only within a scheme can also be time consuming if the resident is doing so regularly and can be a source of stress if that resident has a tendency to fall.

In schemes with good dementia awareness among residents, other residents play a part in ensuring safe walking with purpose for those who engage by keeping an eye on them.

Four of the case study residents (at two of the extra care and two of the retirement housing schemes) who walked with purpose within the scheme were unable to find their own way back to their flat. The managers of the two retirement schemes felt that their scheme was not designed to be dementia friendly. The manager of one of the extra care scheme felt that it was not designed to be dementia friendly and the other commented on the challenges of poor signage and non-intuitive floor numbering. Design that supports wayfinding for people living with dementia is important for supporting safe walking with purpose within a scheme.

Just as the purpose, reasons, risks and responses varied in the case studies, so did the outcomes for the residents who engaged in walking with purpose. Only one resident had to be moved out of the scheme (Anne, who moved from extra care housing to a nursing home) and this was largely due to the impact that her walking with purpose had on people other than herself and the scheme staff (the people who were now living in her old family home). Other residents who regularly walked with purpose were at risk of being moved to accommodation that provides a greater level of care. This was largely due to the risk their walking with purpose was perceived to create, e.g. repeated injury due to falling, becoming lost or being away from the scheme for long period of time. Two of the case study residents who regularly walked with purpose died a few weeks after the interview (Pat and Len), while a further two became more settled at the scheme and no longer engaged in walking with purpose (Sheila and Vera). For others, having additional support to that provided by the scheme, either from family or private carers (Liz, Jean, Brenda) enabled them to remain living at the scheme. Keeping the resident occupied with activities and accompanied walking or outings was key to managing their walking with purpose and preventing it from being a challenge for the scheme. The benefits of occupation and activities to a person who engages in walking with purpose can be seen from the experiences of the manager and staff at the dementia specialist day care centre.

As can be seen from the case study vignettes, none of the three extra care schemes had policies, procedures or guidelines for supporting safe walking with purpose. The retirement housing schemes were mixed; one had such policies and procedures, one did not and at the third the manager did not know.

In terms of managing walking with purpose for people living with dementia in mainstream housing, the fact that, the people of interest in the case studies were kept locked indoors and could only leave the house if accompanied by their carer, with one being medicated to help them sleep at night, raises serious deprivation of liberty issues.

# Overall discussion, conclusions and recommendations

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The survey and case studies showed that, although residents who walk with purpose constitute a minority of people living in retirement and extra care housing schemes, managing walking with purpose can be a challenge for management and staff and can occupy a disproportionate amount of their time. The survey showed that the severity of this challenge and the impact on staff time was felt to be greater for extra care housing than for retirement housing. Similarly, the effectiveness of attempt to support walking with purpose was more varied for extra care than for retirement housing. However, the case studies found that, depending on the frequency and nature of walking with purpose, addressing this behaviour can be impact negatively on both retirement and extra care housing managers in terms of time, effort and emotional wellbeing.

While all the survey respondents felt that managing walking with purpose was only a moderate or slight contributor to staff stress, the managers interviewed in the case studies told a different story with many becoming stressed and anxious, particularly when residents leave or try to leave the scheme. While ensuring residents' safety when they leave the scheme was mentioned as a specific challenge by the survey participants, being able to explore the negative impact on managers in more depth in the interviews enabled a clearer understanding of why it has such an impact. The managers of both the extra care and retirement housing case study schemes felt a great sense of responsibility and duty towards their residents. When a resident living with dementia leaves the scheme they are no longer able to ensure that resident's safety, which is a great source of stress and anxiety. The case studies also revealed that addressing walking with purpose that takes place only within a scheme can also be time consuming if the resident is doing so regularly and can be a source of stress if that resident has a tendency to fall.

The preferred method of addressing walking with purpose in the case studies was distraction or redirection. Getting to know the resident by understanding their life story, likes and dislikes and their reasons for walking with purpose were recommended to assist with distraction or redirection. Other strategies adopted were to talk to the resident to try to explore their motivations, try to accommodate their wishes and accompany the resident on a walk outside. Similarly, in the survey, understanding why the resident is walking, distraction or redirection and walking with the resident were the most common and effective methods used to address walking with purpose. Getting to know the resident was also recommended by the survey respondents in order to discover and provide the most effective response to

an individual's walking with purpose. Even those case study scheme managers who were willing to accommodate a resident's walking with purpose, and enable them to do so as safely as possible, would firstly try distraction or redirection. The case studies enabled a greater understanding of why managers prefer to dissuade a resident living with dementia from leaving the scheme – once they have left the scheme this causes stress and anxiety for the managers and, if procedures such as the Herbert protocol are not in place, finding the resident and bringing them back can involve a lot of stress, time and effort for management and/or staff. However, using distraction/redirection could be viewed as staff trying to prevent a resident from leaving the scheme and indicative of a risk averse care culture that perceives walking with purpose as a problem. This is not consistent with the ethos of extra care and retirement housing living, which purport to encourage independence and choice.

Staff training in understanding and addressing walking with purpose appears to be key to effectiveness in supporting safe walking with purpose. Both the survey respondents and the managers interviewed in the case studies mentioned greater staff training in how to support people whom walk with purpose as a desired change. This is unsurprising, bearing in mind more than half of the extra care and retirement housing survey respondents stated that staff at their schemes had not received any training on understanding and addressing walking with purpose.

In addition to a lack of staff training at more than half the schemes surveyed, findings indicated that not all extra care and retirement housing schemes are set up to consider or cater for people living with dementia who walk with purpose. This omission is more evident in retirement housing than extra care housing. A large proportion of respondents were also unaware of whether their scheme had any policies, procedures or guidelines for supporting safe walking with purpose, which could mean that they did not have any or that they did but this had not been communicated to them by the organisation. A lack of such policies or procedures was also evident at the case study schemes.

The design of the physical environment plays an important role in supporting the wayfinding abilities of people living with dementia (e.g. Marquardt, 2011) and there are numerous design features available to specialist accommodation settings to support safer walking with purpose. Examples include safe indoor and outdoor walking routes, with places to rest and interesting things to see and do along the way, and methods of deterring residents living with dementia from going into some areas and encouraging them into others. Various design features were used by the schemes that participated in the survey, with extra care housing schemes more likely to have a greater variety of features than retirement housing schemes. In the case studies the three extra care housing schemes were fully purpose built and had more

design features to support safe walking with purpose than the three retirement housing schemes, which were remodelled from existing blocks of flats built in the 1970's. Design that better supports safe walking with purpose was a desired change mentioned by both survey respondents and case study managers, although with the case studies this was more of an issue for retirement housing schemes. One notable finding from the survey is that four of the extra care housing schemes (one Housing 21 scheme) and five of the retirement housing schemes (four Housing 21 schemes) used black mats in front of exit doors. One of the case study extra care housing schemes and two of the retirement housing schemes also used these. Black mats are perceived as a hole in the floor by some people living with dementia and therefore deters them from leaving the building. This approach or course raises serious ethical issues. Use of deterrents to exiting such as black mats and the fact that design that better supports safe walking with purpose was a desired change for scheme managers mean that more needs to be done to ensure dementia friendly design of the physical environment that is supportive of safe walking with purpose in extra care housing , in particular, retirement housing. Design recommendations and guidelines are available (e.g. Davis, 2016; Montague, 2018).

There are now many assistive technology devices available to ensure safer walking with purpose. Among other things, assistive technology can enable carers to know when a person who walks with purpose has left their room, bed or chair, track their location both within and outside the scheme, and help find the person should they become lost. The survey responses and case studies suggested that little use of such technology may be due to lack of awareness and high costs.

## Recommendations

### **The resident who engages in walking with purpose**

- Get to know the resident, find out their motivations and reasons for walking and try to accommodate their wishes. Understand the resident's life story and their likes and dislikes by talking to them and their relatives – this will help determine what will work to effectively support their walking with purpose. Through understanding, it is possible to address walking with purpose.

“I think the biggest thing is finding out what it is that they're walking for, what they're wanting to do. So it is finding out what it is that they need to do and finding a way to accommodate that.” (Extra care scheme manager)

“To get to really know the resident, get to know the family and talk.” (Extra care scheme manager)

“Have those discussions about somebody's life history, try and see if there is an actual purpose, if you can link anything up.” (Retirement scheme manager)

“The more you know your service users, the better you can personalise everything.” (Retirement scheme manager)

“Definitely got to be person-centred and the person has to take the lead, whether it's from their life story or from current situations, because unless you know the person, you can't put services in place to meet those needs.” (Retirement scheme manager)

- Have patience, listen to the person and respect their wishes.
- Services should be personalised and person-centred, not just blanket services for all residents, to ensure that the specific needs of the individual are met.

“They need to understand from the person's point of view how it needs to be personalised them and not just blanket services.” (Retirement scheme manager)

- Have continuous assessment in place for the resident. This already happens in extra care housing but also needs to take place in retirement housing.

“I just wish that more people used the narrative theory more, to be honest, when they're doing their social work assessments. You know, it's such a pinnacle point of the assessment and it helps then when they move into extra care or supported housing for that continuous assessment to keep taking place, working together.” (Retirement scheme manager)

### **Care culture, management and staff**

- Train management and staff in understanding and addressing walking with purpose and the importance of understanding the particular resident's background and needs.

“Get advice, training for staff. Staff need to be patient, to be honest, have a good knowledge on her background and a bit of history. I do think it's about staff training.” (Extra care scheme manager)

- Educate the staff to understand that it is worth the risk to let a person live as they want to. Discourage a risk averse attitude and encourage positive risk taking approaches.

“And your staff knowing that sometimes the risk...where's the risk for Vera? I don't know. She deserves some sort of choice, doesn't she, where to go. You can't stop her.” (Extra care scheme manager)

- Ensure that all staff and residents are aware that if someone wants to walk out of the building they should not be prevented from doing so, rather enable them to do so in a safe manner e.g. ensure they are in appropriate clothes and shoes and watch them.

“I always tell staff...well everybody really, that if somebody is wanting to walk out of this building, it's always...you know, never say, no they can't. Allow them to do that in a safe manner, whether that's to make sure that they've got, you know, sensible clothing on and shoes and stuff like that and then watching them...because quite often what they'll do is once they walk outside, they then think, oh I want to go back now. And they walk...nine times out of ten walk back in to the building or want to come back.” (Extra care scheme manager)

- Foster connections and good relationships with the local community and businesses. Ensure that they are aware of those residents who, having left the scheme, are at risk of getting lost and not being able to find their own way back. Having a local network of 'eyes' supports safer walking with purpose outside the scheme and can make management of residents who have a tendency to leave much easier.
- A local support network of extra care/retirement housing scheme managers enables managers to share experiences, ideas and advice.
- Carry out risk assessments for residents who walk with purpose.
- Allocate more care time to manage residents who walk with purpose.
- Inform the correct agencies (e.g. LA adult services and the Police) when a vulnerable person has left the extra care scheme.
- Use the Herbert protocol for residents who are at risk of leaving/getting lost outside the scheme.

“Making sure that, you know, if there are any points of interest, that they're all recorded and they need to have a Herbert Protocol in place.” (Retirement scheme manager)

### **Other Residents**

- Ensure that all residents have an awareness and understanding of dementia and walking with purpose to reduce stigma and misunderstanding. Other

residents can play an important role in keeping an eye on residents who engage in walking with purpose, so if awareness and understanding is lacking, dementia awareness sessions are recommended.

### **Family and other stakeholders**

- Develop and maintain good communication with the resident's family carers.

“And speak to family. Those open channels of communication are so vital.”  
(Retirement scheme manager)

- It is crucial to ensure that the family understand and accept the situation with respect to their partner's/parent's dementia and their walking with purpose. It is also important for the family to understand why the resident's need to walk with purpose should be accommodated.

“Get the family to actually understand what's going on and to accept, that is your winner.” (Retirement scheme manager)

- Develop and maintain good communication and a good relationship with other stakeholders e.g. the GP, the mental health team, Local Authority. Be honest and open with everyone you need to work with.

“Well I'd definitely make sure that they're being honest and open and transparent with every single person that you're going to work with. Which is usually the local authority, psychiatric normally.” (Extra care scheme manager)

### **Design and assistive technology**

- More needs to be done to ensure dementia friendly design of the physical environment that is supportive of safe walking with purpose in extra care and, in particular, retirement housing. The design of the physical environment plays an important role in supporting the wayfinding abilities of people living with dementia and design recommendations and guidelines are available (e.g. Davis, 2016). Example design recommendations that emerged from this study include:

- Gardens and outdoor spaces must be secure and enclosed.
- Provide safe indoor and outdoor walking routes with frequent places to rest and interesting things to see and do along the way.
- Design features to assist with wayfinding.

- Consider use of assistive technology devices such as contact ID wrist bands, door sensors, speaking door sensors, GPS trackers and alarm mats.

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