

**Title: The Impact of the Physical Home Environment for Family
Carers of People with Dementia: A Qualitative Study**

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Abstract

Background: Most people with dementia are cared for by their families at home.

This study investigated family carers' identification of barriers and facilitators when caring for a person with dementia at home.

Design and methods: Thirteen co-resident family carers were engaged in semi-structured in-depth walking interviews. Interviews were recorded, transcribed and analysed using thematic analysis.

Results: Home environments can pose a number of challenges and opportunities. Aspects of the architectural and interior environment (e.g. size, condition, layout and accessibility, familiarity) are perceived as important (Theme 1) as well as a plethora of environmental strategies that encourage independence and comfort at home (Theme 2). Carers' scepticism, timing, costs, property characteristics and mistrust of services are some barriers to implementing environmental strategies (Theme 3).

Conclusions: Carers often improvise solutions through trial and error. Environmental strategies can create an enabling and comfortable home environment.

Introduction

The prevalence of dementia is increasing and the numbers of informal carers is expected to rise (WHO, 2012). People with dementia are likely to experience difficulties when interacting with their social and physical environment as dementia progresses, making them sensitive to both over- or under-stimulation (Garcia, Kartolo, & Méthot-Curtis, 2012). Given this dementia epidemic, evidence-based interventions and cost-effective approaches are needed to support these vulnerable people and their family carers, as a matter of public health priority (Gitlin, Marx, Stanley, & Hodgson, 2015; WHO, 2012). Because the care of a person with dementia is typically more demanding and complex, family carers are more likely to provide intensive management in contrast to other carers (Torti, Gwyther, Reed, Friedman, & Schulman, 2004; Zarit, Gaugler, & Jarrott, 1999). On the other hand, carers who live with a person with dementia are especially likely to experience more depression and anxiety (Torti et al., 2004).

Non-pharmacological approaches, especially environmental interventions that create a safe, enabling, and predictable home environment, are considered key to improving the lived experiences of people with dementia and their carers (Garcia et al., 2012; Sadowsky & Galvin, 2012; Soilemezi, Drahota, Crossland, & Stores, 2017; WHO, 2012). Carers develop a range of useful individualised strategies to manipulate the environment, from micro-improvisations, such as removing visual or auditory stimuli and de-cluttering their home, to major changes, such as changing the use of rooms (Wherton & Monk, 2008; Wisniewski et al., 2003).

The person-environment fit model (the ecological theory of ageing) is the dominant framework in research on human behaviour and environmental aspects and the most frequently used model in environmental gerontology research (Kahana, Lovegreen, Kahana, & Kahana, 2003; Lawton, 1990, 1997). This model argues that adaptation is needed to

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2
3 balance the demands of the external environment (“environmental press”) and the
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5 individual’s internal capabilities (“competence”). According to this model, environmental
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7 stressors, such as noise or limitations in physical space, can cause adverse outcomes to both
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9 the person with dementia and carers (Sadowsky & Galvin, 2012; van Hoof & Kort, 2009). In
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11 contrast, an optimal environmental setting could minimise maladaptive behaviours, namely
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13 wandering, agitation, and restlessness (Corcoran & Gitlin, 1991).
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16 Adequate environmental elements and strategies can not only provide comfort,
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18 functional support, social stimulation, and independence for people with dementia, but also
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20 support family carers to deal with the changing needs of their relatives (Brawley, 2001;
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22 Calkins & Namazi, 1991; Corcoran & Gitlin, 1991; Day, Carreon, & Stump, 2000; Gitlin,
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24 Liebman, & Winter, 2003). Increased functionality has been associated with aspects of the
25
26 indoor environment, for example familiarity (Wherton & Monk, 2008), layout of lived space
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28 (Marquardt, Johnston, Black, Morrison, Rosenblatt, Lykentsos, et al., 2011a; Olsen,
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30 Hutchings, & Ehrenkrantz, 1999), lighting (Habell, 2010; Torrington & Tregenza, 2007),
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32 thermal and acoustical environment (van Hoof, Kort, Hensen, Duijnste, & Rutten, 2010;
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34 Wong, Skitmore, Buys, & Wang, 2014), and use of environmental cues (Garcia et al., 2012).
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36 Such compensatory strategies can be cost-effective, especially in reducing costs for informal
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38 care-giving as well as improving the sense of competence for carers (Graff et al., 2006,
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40 2008). Nevertheless, some people may decide to relocate when their home is regarded as
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42 inappropriate or not meeting their current or future needs (Golant, 2015; Kaplan, Andersen,
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44 Lehning, & Perry, 2015; Perry, Andersen, & Kaplan, 2014).
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49 When proposing dementia-friendly design and home interventions, one needs to
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51 address many elements. Firstly, both the needs of the person with dementia and the carer,
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53 because they are not always identical (Gitlin et al., 2013). Additionally, given their memory
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55 difficulties, people with dementia are likely to depend more on perceptual cues, mainly
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Sample

A mix of purposive and convenience sampling was used, followed by snowballing and word-of-mouth referrals. Recruitment was carried out indirectly, using community gatekeepers who distributed study leaflets in local community groups, with an emphasis upon diversity, such as accommodation type, gender, age, and years of caring. The recruitment lasted approximately six months (January – June 2013). The sample was limited to Portsmouth (UK) and surrounding areas.

Carers of people with dementia ($N=13$) were recruited, including two pilot interviews. All participants were interviewed once with no follow-up meeting. From all the potential participants who contacted the researcher, one was not interviewed due to physical illness. Current family carers, co-habiting with a person with dementia at the time of the study, with mental capacity to consent, were considered eligible. All interviews were digitally recorded and later transcribed verbatim; they lasted between 39 and 79 minutes (average 60 minutes).

Procedure

The Science Faculty Ethics Committee (University of Portsmouth) and Portsmouth City Council reviewed this study. A mutually suitable day and time was arranged to visit carers in their own homes. A few days before the interview, participants received a provisional interview schedule, which was advised by a support group leader, to minimise carers' anxiety and encourage reflexivity. Participants provided informed consent and were allocated a participant number. A shopping voucher worth £10 was given to each participant at the end of the interview as a 'thank you' and an acknowledgement of their time.

During the first part of the interview, carers were asked some demographic questions and then about their views on the impact of their home environment. In the second part, carers were interviewed while walking around their home. There was no predetermined route;

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3 the carers themselves were asked to lead the home tour. All rooms used by the carer were
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5 observed. Photographs, direct observations, and house plans were taken (with permission) to
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7 support the data analysis and contextualise carers' verbalisations of their lived experience.
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10 The walking interviewing is an established method in geographical and urban
11
12 planning research, but is a relatively new approach in dementia studies. In comparison with
13
14 the standard sedentary interviews, they have the advantage of encouraging participants to
15
16 connect with their surrounding environment and thus eliciting rich and environmentally
17
18 sensitive data (Carpiano, 2009; Evans & Jones, 2011). By directly observing the participants
19
20 in their natural setting, walking interviews allow for closer examination of environmental
21
22 practices and interactions (Carpiano, 2009).
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27 **Interview schedule**

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29 The aims of the present study and the development of the interview questions were
30
31 structured by the ecological theory of ageing, previous research publications and systematic
32
33 reviews. Examples of the questions used are: 'Thinking about this room and your every day
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35 tasks, how easy or difficult is it to care for your relative in here?', "What task / behaviour /
36
37 equipment do you find particularly troublesome or useful in here and why?'. When barriers
38
39 or challenges were mentioned by the carers, they were asked to think of suggestions for
40
41 improvement. Elements of the environment (e.g. photographs, furnishing) and daily caring
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43 activities (e.g. toileting) were used as prompts, when appropriate, to understand how carers
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45 conceptualised their environment and tasks.
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52 **Analytic approach**

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54 Following the approach by Braun & Clarke (2006), thematic analysis was carried out
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56 in six phases. The first author (DS), a registered PhD student at the time of the study with
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3 previous experience interviewing participants and supporting people with dementia, designed
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5 the study and conducted the data collection and analysis. Firstly, all the transcribed
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7 interviews and the researcher's notes were read repeatedly by the first author (DS) to allow
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9 familiarisation with data and initial ideas. Visual material (photographs, house drawings) and
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11 the researcher's journal were also used to assist with familiarisation of data. This was
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13 followed by line-by-line coding of all transcripts and notes. These initial descriptive codes
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15 were intended to capture the relevant data; the codes could be a couple of words, sentences or
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17 a whole paragraph. The next step was to identify similar codes and cluster them together to
18
19 create initial themes. In order to ensure that these initial themes 'worked' independently and
20
21 together, the initial codes and transcripts were checked to ensure the themes represented the
22
23 relevant data and the entire dataset. Then every theme and subtheme was named and defined.
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25 Once the analysis was complete, the first author (DS) met with the research team to discuss
26
27 the coding and validate the final themes. Once the findings were written, all authors agreed
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29 on the final refinement and selection of participants' quotations. An audit trail of all
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31 analytical stages was saved in QSR International's NVivo 10 Software. Although the analysis
32
33 was data driven, previous research was used as a guidance to categorise the findings
34
35 according to architectural and design principles (van Hoof & Kort, 2009) and home
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37 modifications (Messecar, Archbold, Stewart, & Kirschling, 2002; Pynoos, Steinman, Do
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39 Nguyen, & Bressette, 2012). The second author (PK) prepared the floor plans and spatial
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41 analysis.
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51 Results

52 Participants

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54 All participants were family carers (12 spouses, 1 adult child), of British ethnicity,
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56 White, and lived in a variety of properties, with an average residency time of 18 years (range
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3 <1 to 45 years). Participants had provided care for their relative for an average of 3.5 years,
4 ranging from 1 to 6 years. They lived in their own homes that varied in type, layout and size,
5 ranging from 1 to 6 years. They lived in their own homes that varied in type, layout and size,
6 ranging from a one-bedroom apartment to four-bedroom house (Table 1).
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10 11 12 **Findings**

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14 Three main themes, each with subthemes (Table 2), were identified: (1) important
15 environmental aspects, (2) adapting and improvising, and (3) barriers to implementing
16 environmental strategies.
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23 **1. Important environmental aspects.** This theme explores the importance of the
24 home as a setting of care provision and focuses on home features, in terms of both
25 architectural and interior design. All the participants in this study reported that their home
26 environment presented some barriers to a lesser or significant degree and they had employed
27 minor or major adaptations, mostly to compensate for the physical weaknesses rather than
28 cognitive deficits of their relative. Carers lived in a variety of accommodations, which
29 affected how they reported dealing with individual challenges in promoting safety and well-
30 being at home. In summary, carers reported certain elements that were regarded as very
31 important for either promoting or hindering dementia care: (1) architectural elements
32 regarding the scale of the building, such as size, layout and access, natural light and views,
33 physical condition, and (2) interior design elements regarding the scale of the room, such as
34 decoration and furnishing, brightness and colour, materials and finishes, and the internal
35 sensory (acoustic- thermal- olfactory) environment.
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52 **1.1 Architectural elements.** The majority of carers believed that dwelling size adds to
53 safety. A large property was considered helpful as it can offer choices and space to
54 accommodate equipment, modifications (or even conversions), and implement various
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3 environmental strategies. Ten carers agreed that having more space makes life easier,
4 functional and practical, and enables safe care delivery and accessibility. Lack of enough
5 space meant less room for storage, equipment and appliances and possibility for converting
6 rooms. Lack of space was the reason that two carers decided to move with their relative to a
7 more spacious property. One carer, who moved to a four-bedroom property explained:
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16 We've got more space [here] to move around, as we need more gadgets to help
17 her, and there is more room... but there [the old flat] wasn't much room; I
18 couldn't get the wheelchair around. In the flat we couldn't have room to have
19 the hoist (CA02).
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28 Nine carers reported that a spacious property provided extra rooms, for example a separate
29 bedroom for the carer (or other family members or paid carers) to sleep, space for ideally a
30 second bathroom and availability for, as two of the participants put it, 'escape spaces'. The
31 latter was thought as paramount to enable them to comfort themselves, relax and restore their
32 identity.
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41 It's good that there are rooms to go to, where we don't have to be together; if
42 we were stuck together in a little flat, I think I'd go mental [laughs]... the
43 small room I've turned into my office, which is one of my escape rooms
44 [laughs]... if I was stuck together in a small room, I don't know... I couldn't
45 just sit there (CA05).
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3 On the other hand, the two carers who had moved to a smaller property (one-bedroom
4 apartments) regarded it as more handy and manageable, felt they were more in control, and
5 that it required less attention and housework.
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11 It's a help to me because it's small, and convenient... most of my time, really,
12 is taken up looking after my husband, giving him lots of tablets, and preparing
13 the meals. It's enough to do without having a big house to look after (CA01).
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21 The layout and accessibility of the house were perceived as important in terms of safety and
22 comfort. One-level accommodation, open living space, big windows, flooring and proximity
23 of rooms were mentioned as helpful home elements. Four carers who lived on one level, with
24 no stairs to tackle, explained that it was beneficial and less stressful in terms of accessibility,
25 "I ain't gotta go up and down stairs. Everything's on this level and I know my wife's in a
26 matter of three rooms" (CA08; Figure 1). Eight carers who lived in houses considered the
27 stairs to be a risk for falls, incontinence accidents, and a reason for constant vigilance. Two
28 carers considered the presence of stairs as a reason for future relocation to a property that will
29 not need further modifications.
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43 I feel now that the house is not fit for what we need... They [stairs] are very
44 steep and they do worry me... I can never get out; I worry about him falling...
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47 I just feel that with no steps and everything, that it would make it, in a way I
48 suppose, it might be easier for me because I won't have to be following him
49 everywhere (CA07; Figure 2a,b).
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3 In contrast, one carer living in a three-storey house, actually perceived stairs as a positive
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5 element for two reasons:
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10 Because it's such a long way to go, he wouldn't, I hope he wouldn't, go down
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12 three flights of stairs, and wander off because it's such a long way... in a way
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14 it's positive, because that's the only exercise my husband gets, is going up and
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16 down the stairs (CA10).
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21 Another important aspect of the layout was open-plan living space. Eight carers
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23 thought it was easier and more practical to supervise their relatives as an open-plan layout
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25 offers visual and acoustic access, "it's got a flowing to it and you are not diving off to
26
27 different places. And there is no hiding places if you know what I mean... being aware what
28
29 is going on" (CA11). One carer altered the design to allow for direct observation by knocking
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31 down the wall between the kitchen and living room. However, four carers favoured closed
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33 rooms, especially the kitchen, where they often did not allow the person with dementia to
34
35 enter. In general, participants considered a helpful layout to have a toilet on each level, an
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37 outside space and easy access for wheelchair users: "probably thinking about it, we've had
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39 less accidents since that [toilet]'s been there [downstairs] because it's not so far to go"
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42 (CA05).
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45 Ten carers reported that the location and proximity of the rooms was also important.
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47 Ideally they would like an en-suite or the bedroom next to the bathroom, "he's going to the
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49 toilet 3-4 times in the night, so to have the bathroom right next to him is beneficial" (CA10).
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51 For those carers who sleep in separate bedrooms, the carers' bedroom would need to be next
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53 to the main bedroom for closer supervision and next to the stairs to alert them in the night.
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3 My wife always uses the stair lift... it's right next to the bedroom I go to sleep
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5 in and I hear it and it wakes me up. So it's a lot better; in the other place I could
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7 be in one room and she could be going up the stairs or coming down, I couldn't
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9 hear because it was too far away (CA12).
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14 Another aspect of the architectural design was the presence of large windows to allow
15
16 people to look out and bring more natural light in. A home with large windows was
17
18 perceived as providing sensory enrichment and pleasing views to the outside world for
19
20 the person with dementia, as well as comfort and escape for the carer, "even if it's
21
22 raining or snowing, anything, I don't mind. I can see out and I'm not sort of enclosed
23
24 too much" (CA12).
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27 The condition of the property was regarded as problematic by two carers when it was
28
29 old and requiring a lot of work and facilitative when there was no need for any improvements
30
31 or alterations.
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36 We've always had old houses and they're not so easy to heat and obviously not
37
38 so easy to keep, keep clean and tidy because they're older... this is the first
39
40 time we've had a, a newer house and it is much easier (CA13).
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45 **1.2 Interior design aspects.** Maintaining familiarity in the domestic environment
46
47 (decoration and furnishing), maintaining environmental order and avoiding unnecessary
48
49 changes and re-arrangements were considered crucial in promoting the relative's well being
50
51 and minimising confusion. Even for those carers who moved to a new home, maintaining
52
53 familiarity was perceived as important to make the transition more smoothly.
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3 I've put everything in the same place as it was in the flat... I've put things in
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5 the same cupboards and in the same areas so that if he, you know, like with
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7 making a cup of tea or coffee which he can still do, um where the cups are and
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9 where the coffee is and where the tea is and everything, where the, where the
10
11 spoons are etc (CA13).
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16 Ten carers considered brightness, in addition to the previously mentioned natural lighting
17
18 from windows, important for (literally) lightening their mood: "Lots of light makes me feel
19
20 better" (CA05). The same was reported by five carers about the use of colour as important to
21
22 improve the home aesthetics and subsequently improve the carers' mood: "First colour I've
23
24 introduced is to my bedroom... I think I'm trying to lighten my life a bit... this is the first time
25
26 I've actually added colour" (CA06).
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29
30 Carers also commented on qualities of their flooring and three favoured carpets as
31
32 they were perceived to add comfort and warmth. Six carers, however, favoured the hard type
33
34 of flooring, such as tiles, lino or wooden floor, as they perceived them as more practical and
35
36 easier to clean, "sometimes there is an accident... it's a lot handier when you can wipe a
37
38 floor" (CA04). One carer explained that in anticipation of regular stains, she kept the old
39
40 carpet in the bedroom, "if something happens and you spill something, it doesn't matter, it's
41
42 not a new carpet" (CA02). However, one carer removed the existing lino floor because her
43
44 mother thought it was cold: "She wouldn't go in on the floor because it was white and she
45
46 thought it as marble and cold" (CA02).
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50 Five carers also explained that they were concerned about the thermal comfort
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52 and worried whether the temperature was appropriate and comfortable for their
53
54 relative, and in some cases the heating was kept constantly on. Unpleasant smells from
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3 incontinence, were also identified as problematic for two carers. Good ventilation and
4
5 fresh air were important but sometimes not possible or practical.
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7 The domestic acoustic environment was another important element. For 11
8
9 carers creating a peaceful environment was important to ensure they can relax and get
10
11 enough sleep.
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16 Where we were before... it was always a very noisy environment. Here it's
17
18 very quiet... I'm getting more sleep and I'm more relaxed so it has helped me a
19
20 great deal, which then helps with the caring of course (CA13).
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25 Nine carers also mentioned that listening to music, having the radio or music on was helpful
26
27 for company and as a way to improve their mood, "I do like the music, I can't bear it so
28
29 silent... I always, always have my music on" (CA04).
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34 **2. Adapting and improvising.** This theme explores the environmental strategies that
35
36 carers used to compensate for difficulties, make daily life more practical, help them feel in
37
38 control and give them some 'peace of mind'. Overall, changing the environment was seen as
39
40 a helpful strategy to optimise safety, comfort, and independence while protecting their dignity
41
42 and boosting the confidence of the person with dementia. For the carers this in turn meant
43
44 less time spent in supervising and better outcomes (e.g. less burden, more sleep). The
45
46 bathroom was considered the most problematic room, and all the carers had made
47
48 modifications, such as raised toilet, walk-in wet room, shower seat, door reversal, bath lift,
49
50 grab rails (Figures 3-5). Other types of modifications were implemented in areas of high-risk
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52 concern such as the stairs (e.g. banister, stair lift; Figures 6 & 7) and, in a few cases, the
53
54 kitchen. The bedroom and living room (and/or conservatory if available) were considered the
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1
2 most preferable rooms in the house. Carers installed adaptations and equipment in nearly all
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4 rooms, except in just one case the living room. Notably, all carers adapted their home space,
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6 objects and their behaviours proactively or reactively, following either the advice of
7
8 professionals or by improvising their own solutions.
9
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11 12 13 14 ***2.1 Additive and transformative strategies: carers added novel solutions within their***

15
16 ***environment.*** Carers used a number of technologies and equipment to make life more safe
17
18 and practical, by bridging the gap between functional status and environmental demands.
19
20 These included: everyday technologies, assistive devices, and equipment. Everyday
21
22 technologies refer to appliances and gadgets that are commonly used without addressing any
23
24 care need (e.g. tv, kitchen appliances,); assistive devices compensate for mainly cognitive
25
26 deficiencies and support care need (e.g. sensors, alarms; Figure 8), and equipment to mainly
27
28 address physical/mobility difficulties and can be affixed (grab rails, stair lift) or non-affixed
29
30 items (hoists or chair/bed raisers). Overall, carers reported finding everyday technologies
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32 very helpful; some wished they had more appliances, specifically a dishwasher and a tumble
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34 dryer: “We’re lucky we’ve got washing machines [laughs]... I think the modern things that
35
36 we’ve got now is helpful” (CA04). Seven of the carers used computers and laptops to access
37
38 online services (e.g. shopping, banking), for entertainment and communication with family
39
40 and outside world. As a result of spending long hours indoors, seven carers reported spending
41
42 a lot of time watching television. To compensate for their own visual deterioration, carers
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44 added new lighting, “I’ve had it [a floor lamp] a year or so, but it’s invaluable to me”
45
46 (CA06), or simply adjusting the existing lighting, for example leaving the light on in the
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48 corridor or in the bedroom: “I have a little lamp plugged in... It’s on all the night and she can
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50 see what she wants to do” (CA11). Two carers controlled the temperature by added more
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52 radiators in their relative’s bedroom.
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3 Although it is generally suggested by the health providers and the existing literature to
4 keep the person with dementia in a familiar environment, two carers added new objects and
5 used the unfamiliarity of these objects as a strategy to add safety and prevent the person with
6 dementia from getting harmed: “She doesn’t know how to work the new cooker so she can’t
7 light it, so she can’t injure herself that way” (CA12).
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12 In addition, five carers reported using assistive devices, such as baby monitors,
13 sensors (chair, motion) and alarms (telecare, door alarm). Even those carers, who did not use
14 some of these, were aware of the possibility that they might need some in the future,
15 depending on the development of the illness. Gadgets were perceived as necessary to
16 increase the carers’ independence, offer some reassurance and “peace of mind” (CA03). One
17 participant used baby monitors:
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29 I have the monitors on the bedside cabinet so I can hear her immediately and I
30 can reach through here in seconds...I can actually be anywhere in the house,
31 and that’s the biggest improvement (CA02).
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38 Although assistive devices were used by carers, the equipment (e.g. bed guard, commode,
39 hospital bed, raised toilet seat, stair gates, ramp, stair lift, shower seat, handrails) was put in
40 place for the relatives’ safety and independence. In seven cases, carers reported that they
41 were making use of the equipment as well, for example, using the stair lift to get the laundry
42 and shopping upstairs, “it saves me struggling” (CA13). All the carers recommended the use
43 of equipment as a means to increased quality of life for both the carer and the person with
44 dementia.
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3 Very helpful; I just wouldn't be able to cope. Because I'd be forever sort of
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5 glued to my wife, all the time... it gives her more independence... which I
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7 think makes, helps her dignity as well... I used to have to just follow her up...
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9 it was more sort of a confidence booster for the wife than it was anything else.
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11 But the stair lift is ideal because... it gives her more independence (CA12).
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16 Providing visual cues (Figure 9) and use of colour was another supplementary strategy and
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18 reminder to assist the person with dementia with initiation or completion of a task. It included
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20 leaving notes, using calendars, leaving the door ajar, putting up labels and messages on
21
22 boards, "if he couldn't find me, he could go to the board and see what was happening that
23
24 today" (CA05).
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27 One carer used colour to highlight objects, to attract the attention of the person
28
29 with dementia and assist with personal care.
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34 Sometimes he'd go to the toilet and I didn't realise he wasn't always going into
35
36 the toilet... they said that if you put a dye down the toilet, that guides them to
37
38 the colour... that helps them to concentrate more (CA04).
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43 Carers also commented on the importance of personal items and photographs as
44
45 a strategy to enrich the environment and support familiarity. This was especially
46
47 important for those couples who had moved to new residences and wanted to
48
49 personalise the new home. Family objects and pictures were considered important for
50
51 the person with dementia to provide sensory enrichment and reminisce, but also for the
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53 carers, "makes me feel like I'm still part of a family even if I don't see them very
54
55 much" (CA05).
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3 Five carers used blocking and locking (doors, cupboards, and cabinets) as a
4 strategy to control behaviours, access to rooms or objects. In order to control access to
5 areas or objects, four carers added new locks on doors and cupboards. One carer solved
6 the unpleasant smells in her internal environment by ensuring that doors are closed,
7 “sometimes it doesn’t smell very nice and it would permeate right through so I had a,
8 a
9 spring put on there so it would close the door” (CA13).
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16 Although professionals recommended some of these strategies, some of the carers had
17 themselves improvised these in response to an unanticipated crises, for example a temporary
18 deterioration due to an infection: “He was sort of banging around on the walls; and I had to
19 block the stairs off at night, I had to put something across so that he couldn’t get downstairs”
20 (CA03).
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27 Carers also rearranged their space and objects ranging from a smaller scale to
28 transforming a whole room in trying to monitor and prevent confusion and risks. Examples of
29 smaller rearrangements done by seven of the carers and were: covering mirrors to prevent
30 confusing the person with dementia (Figure 10), shortening cords, repositioning the bed,
31 reversing doors and relocating hazardous items to top shelves: “I’ve reversed a couple of
32 doors, because the downstairs toilet door used to open inwards, whereas if you collapsed
33 behind there, we’d never get the door open” (CA12).
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43 The most common room transformation was the installation of a walk-in shower with
44 nonslip flooring, which was done in five of the properties; even four carers that had not
45 installed one, considered it safer than the bath, useful for future deterioration and handy for
46 other family members (e.g. grandchildren): “The shower’s made an awful lot easier... that’s
47 more practical... it’s brilliant... you got the whole length of it, so it’s a lot safer. He’s not
48 gonna fall so much” (CA03).
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2.2 Subtractive strategies: the removal of elements. Nine carers considered de-cluttering and simplifying the environment to be helpful in making their house more practical and safe. Potential fall hazards were rugs, slippers, walkers with brakes, and small pieces of furniture, which carers had to remove in order to prevent any accidents and to ensure a clear and safe walkway for the person with dementia. Apart from removing or hiding hazardous items, two carers also hid objects to add more comfort: “I have to hide the commodes because it's not very nice when people come in” (CA10).

Removing physical barriers was considered as a strategy to add more safety around the house, meaning that sometimes carers had to balance or compromise between safety, privacy or comfort in their own home: “I was very close to taking the bathroom door off, cause she fell inside with the door shut and the compromise was... if I take the door off, I lose privacy as well” (CA02).

2.3 Behavioural and structuring strategies: manipulating behaviour, existing elements or objects. Maintaining a structured routine and familiarity was considered an effective strategy to a predictable and simplified way of life and care. Two carers, who had professional assistance, made sure that the paid carers were familiar with the caring routine too, “you’ve got to have a routine... So the girls [the paid carers] know the routine” (CA06).

Organising and simplifying was also used by carers to prepare or re-arrange the space for a task for convenience and reduction of time and demand, “I prepare his room for him: pull back the bed, put his pyjamas where he can see them, put the toothpaste on his brush” (CA06). Some carers rearranged cupboards, cabinets and drawers; some carers invented their own organising systems: “I’ve sort of laid all his clothes out in certain places and make sure they’re always in those places so that he knows where they are ... all to hand so it makes life a lot easier, yeah” (CA13).

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3 Additionally, some carers controlled the internal (thermal, olfactory and
4 acoustic) environment at home by pulling the curtains to stop the draft, keeping the
5 heating constantly on, and creating a positive acoustic environment by minimising
6 internal or external noise: “I wouldn’t have the radio in this room... I might have a
7 little bit of music but I wouldn’t have a radio up” (CA02).
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16 **3. Barriers to implementing environmental strategies.** This theme represents the
17 five main factors identified by the carers as preventing them from adapting their domestic
18 setting and it involves characteristics of the carer, the involvement of professional
19 practitioners, property characteristics, available funding and timing.
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25 ***3.1 Carers’ scepticism over the use and importance of environmental strategies.***
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27 Scepticism was the main reason carers did not implement environmental solutions. Four
28 carers claimed that the environment had no influence on the behaviour of their relative, and
29 did not consider it worth exploring further: “It’s his health; the flat doesn’t make it worse...
30 There is no problem in the environment” (CA01). Six carers expressed some scepticism about
31 the usefulness of the equipment and assistive technologies. Four carers believed that their
32 relative would not be able to operate any new device or use any environmental strategy due to
33 functional deterioration, “I don’t think it would make any difference if it [the cabinet] was
34 labelled” (CA13). Another carer thought that using many adaptations and devices would
35 make the environment more complicated for the person with dementia, “I have thought about
36 having a stair lift but that could be dangerous with him cause he wouldn’t know how to work
37 it” (CA10). Two carers had to return the equipment because they thought it was unsafe for
38 their relative, and other carers identified such devices as symbols of disability and
39 abnormality: “I try and keep it very basic and very normal, very normal for her. I think that is
40 essential, I don’t want her to feel she is an invalid” (CA11).
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3 **3.2 Reluctance in involving professionals’.** Ten carers expressed reservations about
4 the involvement of health and social care professionals, believing that they will not offer
5 adequate support, “I don’t think the social worker has any idea about modifications, she’s
6 only a young girl” (CA01) or there will be a long wait, “it would take so long to come out to
7 assess you” (CA03). Three carers were reluctant or did not even think about involving
8 professionals, and implemented modifications themselves through trial and error.
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16 **3.3 Property spatial characteristics.** Carers thought that there were two limitations
17 within their home environment preventing them from implementing environmental strategies:
18 home ownership and size. In the first case, two carers perceived that rental accommodation to
19 be a restriction criterion: “This isn’t our flat, so... I would have it different all together... I
20 don’t want to spend money on somebody else’s property... I may not be here much longer”
21 (CA01). In the second case, for four carers a small space meant that they had no room for
22 adaptations: “Things I would like [to change] but there, but I can’t do it because there’s no
23 room so” (CA03).
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34 **3.4 Financial reasons.** Another barrier was the financial costs involved in
35 implementing adaptations. This was mentioned both by one carer who owned their property
36 and those two who did not: “After he had had a fall I did think that maybe I ought to think
37 about it [nonslip flooring], but knowing how expensive it is, I haven’t done anything at the
38 moment” (CA13).
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45 **3.5 Timing.** The last limitation was the timing of adaptations in relation to the
46 progress of the dementia. Three carers thought that changes and equipment is best introduced
47 early on to prevent further confusion. In two cases, the person with dementia did not
48 recognise devices as familiar items: “They’ve kindly supplied a commode but he won’t use
49 it... because I’ve introduced it too late in the illness” (CA10). On the other hand, three carers
50 thought that adaptations and devices are needed in a later stage. “We don’t feel that we need
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3 them [alarms]... If she deteriorates, then we will come to that decision, if she deteriorates
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5 more but, at the moment, [we are] quite happy with what we got” (CA08).
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8 The participants varied in their responses and the barriers they identified. Only one
9
10 participant identified one of the above-mentioned barriers, six mentioned a couple of them,
11
12 five mentioned three, and one carer mentioned four of them. Reluctance in involving the
13
14 professionals was identified by ten carers, followed by the timing, scepticism over the
15
16 importance of the environment, the property’s spatial characteristics and lastly the financial
17
18 restrictions.
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20 21 22 23 24 25 26 **Discussion**

27
28 This study gathered empirical evidence on all aspects of the home environment and
29
30 utilised indoor walking interviews with family carers of people with dementia. In line with
31
32 previous research, our findings indicate that the size, condition, layout and accessibility of the
33
34 property are important for the carers, (Bentley et al., 1985; de la Cuesta & Sandelowski,
35
36 2005; Lach & Chang, 2007; Olsen et al., 1999). However, the present study also shows that
37
38 the carers identified the proximity of rooms as another important factor for accessibility and
39
40 observation to facilitate navigation and manage care.
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44 Regarding the architectural elements, we found that the size of the property is crucial
45
46 for providing space for equipment, appliances, and ‘escape’ space(s) for the carers. Although,
47
48 for the majority of the carers, bigger properties were regarded as more suitable, two of the
49
50 carers had moved to one-bedroom apartments because they were more handy and
51
52 manageable. However, this can only be achievable in practice for caring relatives, who still
53
54 share the same bedroom. Previous research indicated that space for ‘escape’ and privacy are
55
56 preferable in living well with dementia (Gitlin, 2007; Soilemezi, Drahota, Crossland, &
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3 Stores, 2017; van Hoof & Kort, 2009; Van Steenwinkel, Van Audenhove, & Heylighen,
4
5 2017).

6
7 In general, an open layout allowing visual and acoustic connectivity, appeared to be
8
9 preferable, although some participants disagreed. Previous research also offers mixed
10
11 evidence about an open layout (Marquardt, Johnston, Black, Morrison, Rosenblatt,
12
13 Lykentsos, et al., 2011a; Olsen et al., 1999; van Hoof & Kort, 2009). The presence of stairs
14
15 was considered a reason for relocation for two carers, while a stair-free home was considered
16
17 a facilitator by all but one of the carers, which echoes previous studies (Bigonnesse,
18
19 Beaulieu, & Garon, 2014; Gill, Williams, Robison, & Tinietti, 1999; Marquardt, Johnston,
20
21 Black, Morrison, Rosenblatt, Lykentsos, et al., 2011b; Safran-Norton, 2010). Access to areas,
22
23 for example a toilet in each level, was perceived as very helpful to minimise night wandering
24
25 (and thus reduce risk of falls and incontinence accidents). Previous research has also
26
27 indicated that windows and adequate lighting are important for people with dementia to
28
29 enhance safety and wellbeing (Torrington & Tregenza, 2007; Wong et al., 2014), to provide
30
31 time and season orientation (van Hoof & Kort, 2009) and contributing to the feeling of them
32
33 less isolated or trapped (De Witt, Ploeg, & Black, 2009; Gibson, Chalfont, Clarke,
34
35 Torrington, & Sixsmith, 2007), but our findings highlighted the presence of big windows,
36
37 pleasing views and brightness as important aspects also for carers. This of course depends on
38
39 the surroundings outside, which in densely populated areas, may be problematic due to noise
40
41 and the feeling of exposure.
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47 The location and proximity of the rooms was another significant finding of this study.
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49 Figures 11 & 12 represent the adjacencies of two of the dwellings (floor plans 1 & 2 showed
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51 in Figures 1 & 2) that despite their possible disadvantages include a lot of positive elements.
52
53 The first figure represents a two-level house and the second a single-level apartment, showing
54
55 the issues raised by the interviewees. While architects and designers do not have control over
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3 the size of the dwelling or environment, they have the tools to define the immediate
4
5 environment. As shown in Figure 12, although there are most of the desired adjacencies
6
7 (toilets on both levels, visual connections in the main room, ability to control the stair, a
8
9 garden for views and escape), the space sets a series of obstacles (i.e. small changes of levels
10
11 that may cause accidents), small windows limit the natural light in the living spaces, elements
12
13 that designers could have avoided. On the other hand, Figure 11 presents a more easily
14
15 controlled space, where even with the lack of visual connections, things can be resolved
16
17 through the use of technologies.
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21 Regarding the interior home environment, familiarity was found to be important for
22
23 family carers to reduce their relatives' confusion and hence their caring demands.
24
25 Conversely, unfamiliarity can be a useful strategy for carers when they need to prevent risks,
26
27 for example installing a new oven that is unfamiliar so that the person with dementia is less
28
29 likely to operate it. As a part of maintaining familiarity, carers reported placing photographs,
30
31 favourite furniture and personal objects around their home as a strategy against social
32
33 isolation and a means to provide comfort, a sense of continuity and connectedness with their
34
35 families. This strategy is also reported in previous research (de la Cuesta & Sandelowski,
36
37 2005; Sixsmith et al., 2014; Swenson, 2010). Finally, our study confirms previous research
38
39 indicating the importance of regulating thermal comfort inside home (van Hoof et al., 2010).
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42
43 Carers adapted their home in a range of ways, from simply installing locks on
44
45 cupboards to installing a walk-in shower, and using a number of equipment and devices. The
46
47 majority of these changes were used to compensate for physical rather than cognitive
48
49 difficulties. Although equipment was perceived as beneficial (even used by some of the
50
51 carers), our findings showed a mixed reaction to assistive devices, with five carers reporting
52
53 that they were essential in promoting safety, independence and a sense of control while six
54
55 carers were more sceptical about their use and need. Arguably, the assistive devices may
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2
3 allow for time to be spent in personalised activities.
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5 Organising, simplifying and re-arranging as well as establishing routines were widely
6
7 used as strategies for reducing confusion and demand. In addition, a number of other
8
9 strategies were reported as helpful, such as simple adjustments, visual strategies (such as
10
11 written information and colour cues), hiding, disguising or removing items, controlling,
12
13 which is also documented in previous studies with dementia carers (de la Cuesta &
14
15 Sandelowski, 2005; Donovan & Corcoran, 2010; Redfern, Norman, Briggs, & Askham,
16
17 2002). Reduction of noise was essential to support their relative, consistent with previous
18
19 research that suggests that “noise is for people with dementia what stairs are to people in
20
21 wheelchairs” (Judd, Marshall, & Phippen, 1998; p.17). As expected, the carers utilised
22
23 strategies based on sensory cues as memory prompts. Interestingly, only one carer reported
24
25 colour as a useful strategy for highlighting objects, although previous research has suggested
26
27 that the use of contrasting colour can be useful in dementia care (Mace & Rabins, 2011).
28
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32 The present study identified various reasons why carers did not implement
33
34 environmental solutions: mainly carers’ perceptions and expectations around the usability and
35
36 need, mistrust in the support of professionals, timing, costs and property’s characteristics.
37
38 Routines and habits are difficult to change in older age (Dahlin-Ivanoff et al., 2007) and this
39
40 may explain why some carers did not wish to try new adaptations. Another explanation could
41
42 be that carers lacked information about the progress and symptoms of the illness, or lacked
43
44 understanding of the potential impact of the environment on mood and behaviour and hence
45
46 miss out a lot of available environmental solutions. Not realising the possible importance of
47
48 the environment appears a major barrier to implementing potential solutions.
49
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51 The cost of adaptations was identified as another barrier (see also Boger et al., 2013;
52
53 Hawkins & Stewart, 2002; Kinney, Kart, Murdoch, & Ziemba, 2003; Lach & Chang, 2007;
54
55 Marquardt, Johnston, Black, Morrison, Rosenblatt, Lyketsos, et al., 2011b; Pierce et al.,
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3 2015; Tanner et al., 2008). This is an important finding considering that dementia carers
4
5 report higher levels of financial difficulties than other types of carers (Ory, Yee, Tennstedt, &
6
7 Schulz, 2000) and so more state support and services should be in place for them.
8

9
10 Another barrier to making home adaptations was due to property characteristics:
11
12 space and ownership. Home ownership is considered important as it allows one to exert
13
14 control over the immediate home environment and change, adapt or personalise it (Bentley et
15
16 al., 1985; Dupuis & Thorns, 1998). It has also been associated with healthy ageing and
17
18 independence, but also as influencing one's identity and belonging (Després & Lord, 2005;
19
20 Després, 1991; Saunders, 1989; Shaw, 2004; Sixsmith et al., 2014; Swenson, 2010).
21
22 Arguably, if a home environment is flexible and easily manipulated to accommodate for
23
24 changing needs, ownership may no longer be a barrier.
25
26

27
28 Whether or not a property was rented or owned not only affected the amount of
29
30 money spent on it, but also the perceived responsibility for making the necessary
31
32 improvements or modifications. There is a crucial link here to the modernist concept of "the
33
34 adaptable house," with moving walls and open plans, such as Rietveld's 1924 Schroeder
35
36 house (Kolarevic, 2015), Archigram's 1967 Control and Choice project (Saddler, 2005) with
37
38 the plug-in elements for customisation or more recently the Doug Jackson's DRAPE project
39
40 (Jackson, 2009). Such houses adapt easily, without ownership being an issue anymore.
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45 **Limitations**

46
47 This is a cross-sectional study and the data were derived from the perspectives of
48
49 thirteen carers, all White, conveniently selected and heterogeneous in personal and housing
50
51 conditions. All participants had already been involved with local services and had
52
53 implemented minor or major adaptations. Therefore they were used to dealing with daily
54
55 environmental challenges and accepting them. In some cases, adaptations were in place due
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3 to physical difficulties, before the relative was diagnosed with dementia. It is also possible
4
5 that carers stopped using some of the reported strategies or introduced new ones. Thus, it is
6
7 unlikely that strategies are applicable to all carers or to all stages and forms of dementia.
8
9 Also, carers' perceptions of the researcher as an 'expert' may have influenced the level of
10
11 disclosed information to 'impress' or satisfy the researcher.
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19 **Implications for practitioners**

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21 The issues addressed in this paper are relevant to practitioners in the construction industry
22
23 (architects, interior designers and future housing developers) as well as health and social care
24
25 professionals. In building sustainable housing, one ought to take into consideration the type
26
27 and progression of illness, the environment and the inhabitants. Different types of dementia
28
29 affect different capacities (memory, attention, speech, vision, mobility) and different carers
30
31 face different challenges and circumstances. Housing developers need to understand the
32
33 dynamic relationship between people and their homes and the need to live in flexible living
34
35 spaces to accommodate changes over their lifetime with minimal possible cost, modifications
36
37 and stress (Hawkins & Stewart, 2002; Pierce et al., 2015). They have the great challenge to
38
39 marry together several aspects that are perceived as important for older population (including
40
41 carers of people with dementia), such as adequate size (with at least two bedrooms and spaces
42
43 for escape), costs and location.
44
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47
48 Architects need to carefully consider issues around the accessibility to important areas
49
50 (e.g. bedroom, toilet, outside space), layout (preferably stair-free, toilet on each level),
51
52 proximity (adjacency) of rooms (bathroom with the main bedroom, main bedroom with the
53
54 second bedroom), as well as natural light. It is also important to understand the unique
55
56 personal meanings and experiences of living and caring at home (Aminzadeh, Dalziel,
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3 Molnar, & Garcia, 2010; Soilemezi, Drahota, Crossland, & Stores, 2017) and build in spaces
4
5 for escape. It is advisable to focus on a more proactive approach and design houses
6
7 anticipating how things may change (e.g. children leaving home and ageing). It has also been
8
9 suggested to incorporate permanent safety elements into the interior design of homes, so the
10
11 next generation of people affected by dementia so that these will already be available to them,
12
13 such as reversible doors or safety ovens (Nygård, 2009), as standard and familiar domestic
14
15 elements. While the debate over closed versus open layout is ongoing, visual connectivity
16
17 can be achieved even with the presence of physical barriers, for example with internal
18
19 openings, windows, etc. In multi-level properties, the design of stairs is crucial for enabling
20
21 safety and comfort. The presence of steep stairs was a reason for relocation and this is
22
23 perhaps something that needs to be challenged and addressed by re-examining standards and
24
25 current policies for domestic spaces – as staircases are a problem for both the person with
26
27 dementia and the also ageing carer. In addition, there is also the choice of materials and
28
29 details (e.g. smooth matt skirting, windows that can open inside) that can support the cleaning
30
31 and maintaining of the property for ageing (and often exhausted) carers.
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37 We found that carers often invent solutions and learn new skills without professional
38
39 guidance or support. Perhaps the need for improvisations may indicate that current services
40
41 do not meet carers' needs, because of the inflexibility of those services, bureaucracy, long
42
43 waiting lists, busy workloads and lack of a follow-up evaluation. It could also be that carers
44
45 are unaware of the available services, or even have negative perceptions about them. The
46
47 carers in this study also believed that timing was important: too late and the adaptations may
48
49 be ineffective, whereas too early and they might get rejected by the person with dementia. At
50
51 the same time, health and social care professionals need to consider that often carers do not
52
53 ask for support and practical suggestions in time. As a result, carers may invite professional
54
55 help too late, only when they are too exhausted or an accident or crisis has occurred (Egset &
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3 Myklebust, 2011; Lach & Chang, 2007). Professionals therefore need to reach out to the
4
5 carers and offer continuous needs assessment and support.
6

7
8 Modifications need to be in place as soon as a need arises to be effective (Nijhof, van
9
10 Gemert-Pijnen, Burns, & Seydel, 2013; Nygård, 2009; Petersson, Kottorp, Bergstrom, &
11
12 Lilja, 2009; Pynoos & Ohta, 1991). Insufficient formal support can impact on the quality of
13
14 caring and contribute to the decision to relocate the person to a more supportive setting (e.g.
15
16 an easily accessible property, a warden controlled flat).
17

18
19 In addition, educating the carers in the role of the environment and available
20
21 adaptations is required. Carers may not understand fully the impact of their environment and
22
23 in some cases underreport environmental problems to services. This can be either because
24
25 carers valued their home so highly and/or they might under-estimate some aspects due to
26
27 ‘over-familiarization’ (Oswald & Wahl, 2004), or lack information on the importance of the
28
29 environment and/or available solutions. Carers might attribute any difficulties to themselves
30
31 or their relative’s condition and not necessarily to the home environment. Including family
32
33 carers in the design and management of interventions is important as they have an influential
34
35 role in the compliance to interventions and are a valuable source to identify even the subtle
36
37 changes in their relative’s function levels. Therefore, negotiated joint decisions and
38
39 continuous assessment are needed to ensure the proposed solutions address everyone’s needs
40
41 and cause the least disruptions and restrictions.
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47 **Future research**

48
49 As studies in private homes are very limited, more qualitative studies are needed to
50
51 elicit the experiences and preferences of people with dementia and their carers at managing
52
53 dementia at home (Carmody, Traynor, & Marchetti, 2014; Prince, Prina, & Guerchet, 2013).
54
55 Studies should utilise heterogeneous and cross-cultural samples in a longitudinal design to
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1
2
3 capture possible changes over time and bring more insight to the importance of home and
4
5 environmental interventions for dementia care. In addition, examining all the residents' needs
6
7 could bring more light on whether there are competing meanings and experiences from the
8
9 perspectives of the person with dementia and the carer, in order to reinforce the meaning of
10
11 and interactions with the home for the dyad. More research on home environments is
12
13 essential to better understand which environmental features and strategies are effective and
14
15 perceived as helpful to different forms of dementia carers and at what stage, for example
16
17 open plan versus closed rooms layout or flexible space arrangements. Eight carers in this
18
19 study clearly indicated that an open-plan layout was helpful, whereas only four favoured the
20
21 option of closed off areas. The research into home environments has the potential to close the
22
23 gap between theory-research-application and could contribute to clinical applications and
24
25 inform future housing design (Gitlin, 2003). Naturalistic data collection methods, such as
26
27 walking interviews and home observations, allow the researcher to be exposed to the reality
28
29 of the participants and add validity to the findings. Interviewing people around their homes
30
31 helps recall specific issues and facilitates a more detailed account of experiences and
32
33 concerns (Wherton & Monk, 2008).
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45 **Conclusion**

46
47 This study explored the experiences and views of co-resident family carers of people
48
49 with dementia regarding the role of their home environment. The findings illuminated a
50
51 number of important architectural and design aspects, such as size, layout and condition of
52
53 the property, familiarity, brightness, flooring, and the acoustic, olfactory and thermal
54
55 environment. Family carers implemented a wide range of strategies to tackle daily safety
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3 challenges, and promote autonomy and comfort at home. Often carers adapted their home
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5 through trial and error, without expert advice. Barriers to implementing adaptations
6
7 concerned the carers' scepticism over the use and need of such interventions, mistrust
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9 towards practitioners, financial difficulties, timing and spatial restrictions. In addressing
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11 dementia care, there is no universal solution to satisfy carers' needs. Environmental
12
13 manipulation is not a panacea but is a simple and often inexpensive approach that can offer
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15 the opportunity to a person with dementia and carers to live in a safe and comfortable
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17 environment.
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Table 1. Carers' characteristics (N=13)

Characteristic	N
Sex	
Male	4
Female	9
Age	
50-59	1
60-69	8
70-79	3
80-89	1
Years of caring	
0-5	10
6- 10	3
Type of property	
Flats	3
(1-bed*: 2)	
(2-bed:1)	
Houses	8
(2-bed: 1)	
(3-bed: 5)	
(4-bed: 2)	
Maisonettes (3-bed)	2
Duration of residence	
0 -10	6
11-20	2
21-30	1
31 +	4

*In the UK, the number of bedrooms is commonly used to refer to the size property

Table 2. Main Themes And Subthemes

Main Themes	Subthemes
1. Important environmental aspects	1.1 Architectural elements 1.2 Interior design aspects
2. Adapting and improvising	2.1 Additive and supplementing strategies 2.2 Transformative strategies 2.3 Subtractive and simplifying strategies 2.4 Behavioural and structuring strategies
3. Barriers to implementing environmental strategies	3.1 Carer's scepticism 3.2 Professionals' involvement 3.3 Property characteristics 3.4 Financial reasons 3.5 Timing

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Figure 3: Grab rails installed in shower Photograph 4. Shower seat



Figure 6. Banister installed along the stairs

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Figure 8. Baby monitor in the living room to alert carer



Figure 5. Walk-in shower in the place of a bath

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Figure 7. Stair lift

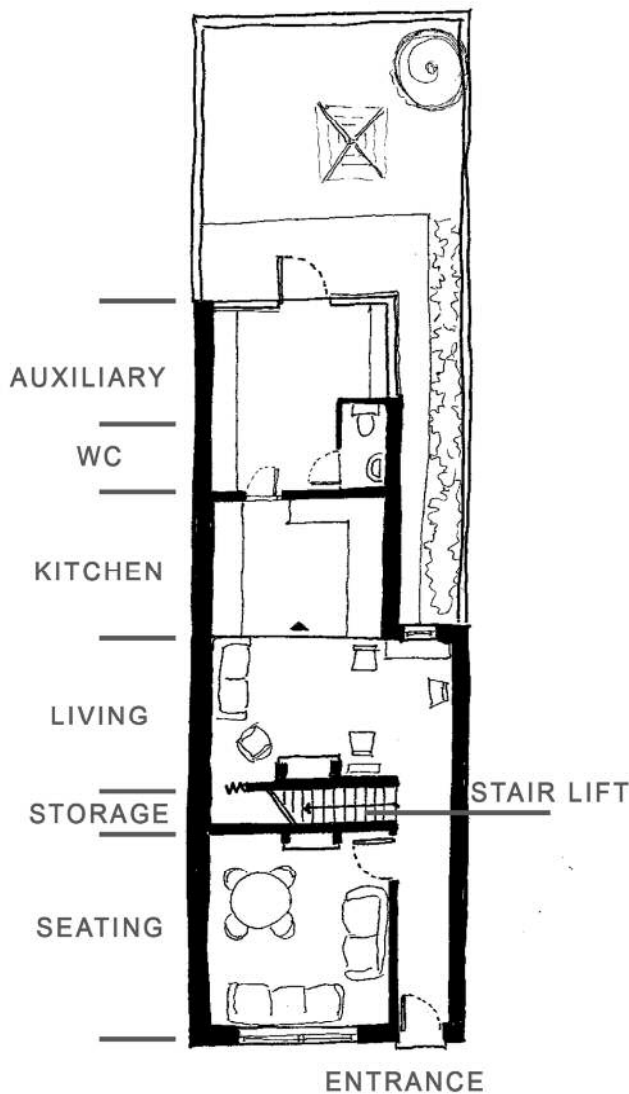


Figure 9. Providing visual cues



Figure 10. Covering the majority of the mirror as an environmental strategy

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126x214mm (300 x 300 DPI)

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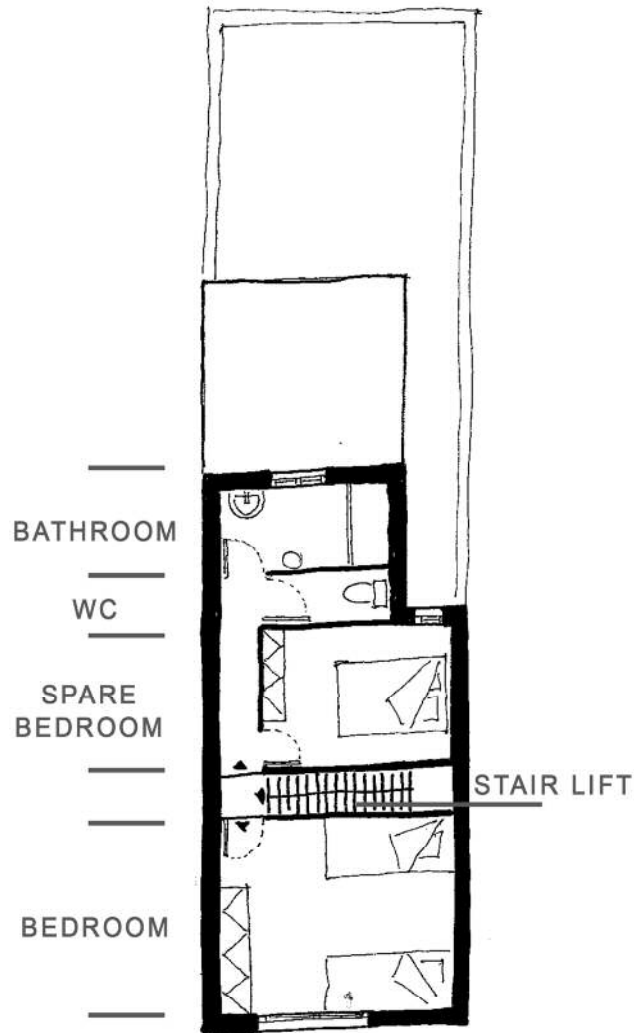
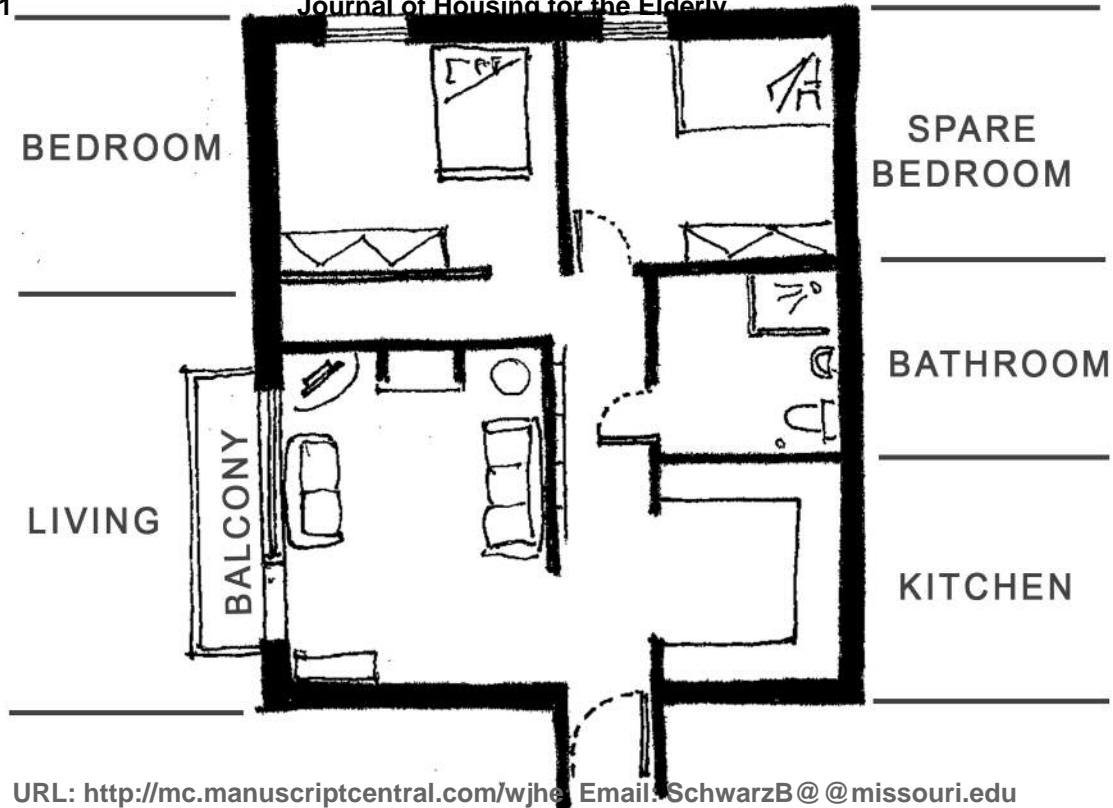


Figure 2a,b. Floor plan of a two-storey house (CA07)

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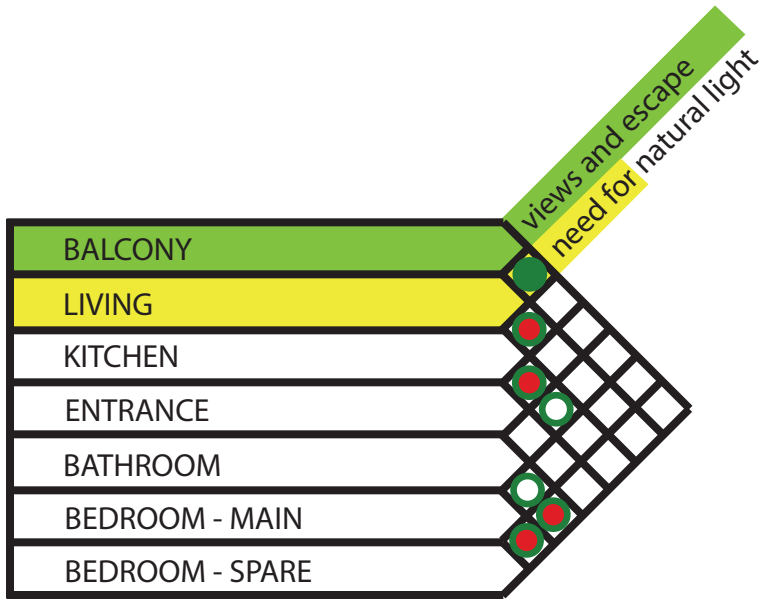
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ENTRANCE

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- Direct - No Visual Connection
- Proximity
- Direct - Visual Connection - Obstacle
- Proximity - Obstacle
- Direct - No Visual Connection - Obstacle - Audio connection

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