Housing and Dementia Research Consortium Summary Report

Exploring the views of people living with dementia in housing with care settings and their carers.

Oct 2016

Authors
Dr Julie Barrett
Teresa Atkinson
Dr Simon Evans
Acknowledgements

The HDRC steering group and ADS would like to thank all the residents and their carers who took part in the focus groups and the staff who took part in the interviews for giving up their time and sharing their views and experiences. We would also like to thank the care managers at the housing with care schemes that took part in the study (Housing & Care 21, MHA, Belong and the ExtraCare Charitable Trust) for identifying participants and providing a suitable room for conducting focus groups and interviews.

We are also grateful to the Institute of Health and Society, University of Worcester and the Alzheimer’s Society for providing funding towards the costs of this research.

Address for correspondence

Association for Dementia Studies (ADS)
University of Worcester
Henwick Grove
Worcester
WR2 6AJ

Tel: +44 (0) 1905 542531
Email: j.barrett@worc.ac.uk
Table of Contents

Background .................................................................................................................................................. 5

Introduction .................................................................................................................................................. 5

Dementia in the context of housing with care ............................................................................................. 5

Themes explored in this study .................................................................................................................... 7

Housing and Dementia Research Consortium (HDRC) research priorities .............................................. 13

Seeking the views of people living with dementia and their carers ......................................................... 15

Aim of the study ......................................................................................................................................... 15

Method ...................................................................................................................................................... 15

Focus groups with people living with dementia and their family carers .................................................. 15

Participants and recruitment ......................................................................................................................... 16

Interviews with staff .................................................................................................................................... 17

Analysis ..................................................................................................................................................... 17

Results ..................................................................................................................................................... 18

Main themes from the focus groups with residents living with dementia and their family carers .......... 18

What they like about where they live .......................................................................................................... Error! Bookmark not defined.

What they dislike about where they live ...................................................................................................... Error! Bookmark not defined.

What they would like to change .................................................................................................................... 19

Main themes from the staff interviews ....................................................................................................... 20

Achievements and successes ......................................................................................................................... 20

Challenges .................................................................................................................................................. 21

Suggested improvements ............................................................................................................................... 21

Additional emerging themes ....................................................................................................................... 22

Models of housing with care for people living with dementia .................................................................... 22

Dementia friendly design ............................................................................................................................... 23

Interacting with the local community ......................................................................................................... 24

Green Dementia Care ................................................................................................................................... 24

Assistive Technology (AT) .......................................................................................................................... 25

Staff skills and expertise ............................................................................................................................... 25

Activities and opportunities to socialise ........................................................................................................ 26

© Association for Dementia Studies 2016
Background

The research presented in this report explored the views of residents with dementia, family carers and staff from housing with care settings. Although the research participants came from a relatively small number of schemes, the results confirm many of the findings from several previous studies that included people with and without dementia. This suggests that the conclusions can be considered in relation to the provision of dementia-friendly environments across a range of housing settings.

Introduction

Dementia in the context of housing with care

With an ageing population and increasing numbers of people with mild cognitive impairment and dementia, demand for care in settings other than the person’s own home is certain to increase (Macdonald and Cooper, 2007). There is growing recognition of the need for housing that suits older people, including those living with dementia, and supports them to continue living in the community for as long as possible. Two settings of this sort that have become increasingly popular in recent years are extra care housing schemes and retirement villages, which are often known collectively as ‘housing with care’. Key features of this broad model are that each resident has their own front door and the full legal rights associated with being a tenant or home owner, along with access to 24-hour on-site care that can be delivered flexibly according to a person’s changing needs (Riseborough et al, 2015). Models of housing with care are built upon principles and values such as maximizing independence; community integration; promoting dignity and privacy; and the exercise of choice and autonomy within a rights based environment.

In recent years there has been considerable expansion in the development of housing with care – with an estimated 60,022 properties in England in 2015 (EAC, 2015) – which is often considered as an alternative to residential care homes (ILC-UK, 2011). A growing body of research evidence has demonstrated the potential of housing with care to promote quality of life and wellbeing for older people (Atkinson et al 2014). Residents value a range of aspects of this later life setting, including independence, privacy, security and the availability of flexible care packages (Baumker et al, 2012). While some housing with care settings specialise in providing care for particular groups with specific needs, such as those with dementia, the majority of such housing schemes and villages aim to support a diverse population by providing personalised support as and when needed. However, despite a common aspiration to provide a ‘home for life’, housing with care often struggles to support residents with dementia and the reality is that many move to residential care when they experience significant problems (Brooker et al, 2009).
The only UK longitudinal study looking at how people with dementia fared in housing with care over a three-year period showed that residents with dementia and their relatives were very positive about housing with care as an experience (Vallelly et al, 2006). However, over half were admitted to other care settings during the first two years. Reasons for moving included ‘challenging’ behaviour, conflicts with staff and other residents and increased distress. People with dementia and other mental health issues living in housing with care are also at risk of social exclusion (Brooker et al, 2009; Callaghan et al., 2009; Evans and Vallelly, 2007).

Estimates of the prevalence of dementia among housing with care residents vary considerably and studies show considerable variation among schemes. In a study of the mental health needs of 268 residents in ten extra care housing schemes of varying size belonging to a single housing provider (Brooker et al, 2009), the percentage of residents assessed as having dementia ranged from five to 47 percent (5-9% for large village schemes and 23-47% for medium and small sized schemes). The study also showed that rates of formal diagnosis are lower than those assessed as having dementia and staff tend to underestimate the number of residents with suspected dementia. Another study of the characteristics of residents in 19 extra care housing schemes (Darton et al, 2012) found that the proportion of residents with cognitive impairment ranged from 24 to 61 percent.

The Housing and Dementia Research Consortium (HDRC) estimated that there are 20% of residents living with dementia in housing with care properties among its steering group member housing providers (Barrett, 2012). The Alzheimer’s Society’s Dementia UK Update report 2014 reported total overall dementia prevalence of 8.1% for those aged 60 years and over among residents of extra care housing, based on the estimates of 13 experts (Prince et al, 2014). Certainly, more comprehensive research on the prevalence of dementia in housing with care populations is required.

With substantial numbers of people with dementia already living in housing with care, housing providers are increasingly called upon to address their needs when planning new services and reconfiguring what exists already to produce safe, accessible housing that people living with dementia want, with an active living environment that meets their social and psychological, as well as their physical needs (Bevan and Croucher, 2011; HCA, 2009; NHF, 2011). There are a variety of models and approaches to the provision of care for people living with dementia in housing with care, but there is a little evidence as to what provisions are in place and ‘what works’ best (Twyford, 2016).

The HDRC carried out a study (Barrett, 2012) in which interviews were conducted with senior care staff at six integrated model housing with care schemes, where people with dementia live in flats alongside all other residents, and one specialist scheme that catered only for people with dementia. The study found little dedicated provision for people with dementia in the integrated schemes, with the exception of one scheme that incorporated specialist person-centred provision for people with dementia – the Enriched Opportunities Programme (EOP). In contrast, the dementia specialist scheme showed well-tailored provision for people with various types and severity of the condition. Differences in provisions were highlighted as was
the need for more comprehensive information on how housing with care is meeting the needs of people with dementia. Although the findings could not be considered representative of housing with care provision across England, the report generated much interest in the sector and was used to raise the profile of housing in drawing up the Prime Minister’s “Challenge on Dementia” action plan (Department of Health, 2012).

One study has shown that the implementation of an intensive person-centred approach to supporting people at risk of exclusion in housing with care settings can have a substantial impact on their quality of life while at the same time reducing the level of moves to care homes and hospital admissions (Brooker et al., 2009, 2011). The “Enriched Opportunities Programme” (EOP) adopts a whole scheme approach including a specialist staff role (“EOP Locksmith”) in each scheme, training of the whole staff team in person-centred dementia care, liaison with the local health and social care and voluntary sector in supporting people living with dementia and other long-term conditions, and facilitation of meaningful activity and occupation. The programme enables people with dementia and other significant mental health issues to remain active and engaged, aiming to reduce the disabling effects of their condition. Through a randomised controlled trial across 10 housing with care schemes Brooker and colleagues demonstrated that the EOP had a positive impact on the quality of life of people with dementia in well-staffed schemes with respect to several measures including reduced depression, fewer moves into a care home, spending less time in hospital as an in-patient, increased contact with community health professionals, higher rates of mental health diagnosis; reduced decline in cognitive function and residents rating their quality of life more positively. The EOP has been fully and successfully implemented across the whole of the single provider’s schemes and remains active seven years after its inception. The intervention and its benefits within this single housing with care provider are well documented but its transferability across other housing providers and other models of dementia care found among housing with care settings is unknown.

Themes explored in this study

Models of housing with care for people living with dementia

Very little is known about the advantages and disadvantages of different models of housing with care (integrated, separated, specialist and hybrid models such as continuing care which offer both independent living and residential care) in terms of outcomes for people living with dementia and their families. It has been shown that significantly implementing the EOP in the integrated model of housing with care can significantly enhance the quality of life of residents with dementia, as demonstrated by the cluster RCT study across 10 ExtraCare Charitable Trust schemes. This approach has now been implemented in all ECCT schemes. Looking specifically at schemes that adopted the separated model (residents living with dementia are clustered together within a separate self-contained area of the scheme e.g. a wing or floor), Housing&Care21 assessed the value of their four “dementia wing” schemes in 2014.
(Housing & Care21, unpublished research presented at the HDRC membership event, June 2015). Recommendations included: move away from dementia wings and promoting integrated schemes; review whether dementia wings are depriving people of liberty; treat each person individually; apartments should be age and dementia friendly; review all schemes to assess dementia friendliness; if dementia wings are used, they should be different enough to warrant their existence; consider having a communal part of the building. However, no comparison was made with the provider’s more numerous integrated schemes.

In June 2015, the HDRC ran a membership workshop for members to share their learning and experience of different models of dementia care. The main output was a list of advantages and disadvantages of different models in order to begin to build an evidence base for larger scale research (Barrett, 2015).

**Dementia-friendly design**

In recent years some housing providers have started to focus on dementia-friendly design, based on principles developed by architects, academics and others. The University of Stirling Dementia Services Development Centre has produced a number of guidelines relating to designing housing to assist people living with dementia (e.g. Dementia Services Development Centre, 2013). The King’s Fund have produced tools for assessing the dementia friendliness of hospitals, care homes, primary care premises and specialist housing (Waller et al., 2016). The tools, which help create supportive design for people living with dementia, were developed as part of the Enhancing the Healing Environment programme and were informed by existing guidelines, research evidence, best practice and a survey of those who have used the tool in practice.

**Interaction with the wider community**

Research addressing issues of loneliness and social isolation among people living with dementia has focused largely on those living in their own homes (Miranda-Castillo et al., 2010; Nikmat et al., 2015). However, successful integration with the local community for people living with dementia in housing with care settings offers an opportunity to improve their quality of life and wellbeing and to foster the generation of dementia-friendly local communities. The Government and Alzheimer’s Society highlight the importance of developing dementia-friendly communities that increase understanding of what is needed to erode stigma and promote the social inclusion of those people living with dementia (DoH, 2012; Alzheimer’s Society, 2013, 2014). This includes addressing these issues through the provision of specialist housing for those living with dementia who are no longer able to remain in the family home (HM Government, 2010; HM Government, 2011, DCLG, 2012). Yet housing with care has been criticised for segregating and isolating residents, fostering ageism within the local community and not fully supporting residents’ independence (Petersen and Warburton, 2012; Croucher et
Residents are at risk of social isolation if housing with care setting does not provide a supportive environment through its design and location and through the provision of activities, services and facilities (Yang and Stark, 2010; Evans et al., 2016). Older people with dementia living in housing with care can find themselves cut-off from the local community and activities that they may previously have enjoyed, resulting in feelings of exclusion and loss that can impact on their quality of life and wellbeing (Croucher et al., 2006; Callaghan et al., 2009).

The ‘community hub’ approach to housing with care makes scheme-based facilities, events and activities accessible to people living and working in the neighbourhood. This can include cafés, restaurants, hairdressers, shops, dementia awareness sessions, arts and craft activities and, fitness and exercise classes. Research into the impact of ‘community hubs’ on the quality of life of residents living with dementia in housing with care settings is limited, although social interaction has been found to be of benefit to people living with dementia (Dutton, 2009). Examining the impact of participation in community and social activities on the social wellbeing and quality of life of residents living in housing with care settings, (Callaghan et al., 2009) suggested that location, and providing a much needed service, such as a shop or café, may be key factors in facilitating participation and combating social isolation.

The potential of housing with care schemes to act as a community hub was also explored as part of the Adult Social Services Environments and Settings (ASSET) research project which examined models for commissioning adult social care in housing with care settings in England (Evans et al., in press). The findings showed that many schemes have a restaurant or café, communal lounge, garden, hairdresser, activity room and laundrette, while many also have a library, gym, computer access and a shop. Many of these facilities were open to the local outside community, reflecting a more integrated approach to community health and adult social care, by sharing access to primary health care and social services between people living in the scheme and those living nearby. Potential benefits of this approach identified in the study include the integration of older people’s housing with the wider community, reduced isolation of scheme residents and increased cost effectiveness of local services through economies of scale and by maximising preventative approaches to health and wellbeing. The study also identified a range of factors that support the successful implementation of a community hub, including a location within or close to a residential area, the provision of on-site facilities that are suited to public access and making community engagement a key part of someone’s role.

Interaction with the local community also involves residents accessing local amenities and activities, which is supported by evidence to suggest that this can make life more interesting, stimulating, exiting and engaging for housing with care residents (Evans and Vallelly, 2007). Research has also shown that people living with dementia still continue to enjoy going out
regularly if the neighbourhood provides a safe, supportive, dementia-friendly environment (Duggan et al., 2008; Mitchell and Burton, 2006).

**Green Dementia Care**

The term “Green Care” refers to a range of health-promoting interventions encompassing living organisms (plants and animals) and natural elements (e.g. the weather). Green care links traditional health care to gardening (horticultural therapy), agriculture (green care farming), animals (animal assisted interventions) and exercising in the natural environment (green exercise) (De Bruin et al., 2012). Many people in care settings have limited opportunities to connect with the natural environment (Clarke et al., 2013), often due to organisational concerns about safety and security. There is growing interest in the physical, mental, social and spiritual impacts of green care for people with dementia (e.g. Gilliard and Marshall, 2012) and some evidence suggesting that engagement with the outdoors and nature is important for people living with dementia and can be of benefit to their health and wellbeing (Clarke et al., 2013; Natural England, 2016). While this evidence base is growing, it remains limited and fragmented and is often anecdotal or based on individual case studies, particularly with reference to green dementia care in extra care housing and residential care settings.

**Assistive Technology (AT)**

There is now a wealth of technological solutions available that aim to support, manage and improve the lives of people affected by dementia, though ethical issues can arise (Foresight, 2016). The fast pace of technology development and the rapidly changing nature of service provision means that any evidence relating to AT in dementia quickly becomes out of date. Online resources such as AT Dementia (www.atdementia.org.uk) exist to inform people and health and social care service about AT that can help people with dementia live more independently. The Alzheimer’s Society also produce a factsheet that is regularly updated.

A scoping review of assistive technology products and services currently available to people living with dementia in the UK (Gibson et al., 2016) highlighted 171 products or product types and 331 services. The review found that assistive technology provision is dominated by ‘telecare’ provided by local authorities, with services being subject to major variations in pricing and information provision. Awareness of the wider range of products beyond telecare for people living with dementia was poor even among health practitioners and social care providers. The researchers concluded that greater attention should be paid to information provision about assistive technology services across an increasingly mixed economy of dementia care providers, including primary care, local authorities, private companies and local/national assistive technology resources and the role of resources such as AT dementia should be expanded.
As a result of the Prime Minister’s Dementia Challenge and Dementia Friendly Communities campaign, Alzheimer’s Society set up a task and finish group on dementia friendly technology in October 2013. The group produced a Dementia Friendly Technology Charter (Alzheimer’s Society, 2015) which explains how technology services can support people living with dementia, and their family and friends, and provides information and advice on identifying the technology solution that may benefit a person living with dementia. The charter aims to tackle the problem of lack of public awareness relating to technology that can support people with dementia to live well. People with dementia and their carers do not know what to ask for or what is available to them, especially if they are paying for the technology themselves. The charter also aims to assist professionals working in dementia, allowing them to better inform people with dementia and their carers of products that may assist their care or enhance their lives (Alzheimer’s Society 2015).

Staff skills
The National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE) published a joint Clinical Guideline on supporting people with dementia in 2006. One of the key recommendations was that all staff working with older people should receive training in dementia care. The NICE Dementia Quality Standard “Quality Statement 1: Appropriately Trained Staff” covers care provided by health and social care staff in direct contact with people with dementia in hospital, community, home-based, group care, residential or specialist care settings. The standard states that “People with dementia receive care from staff appropriately trained in dementia care” and for service providers, this means: “ensure that all health and social care workers are appropriately trained in dementia care according to their roles and responsibilities” (NICE, 2010)

People with dementia and their carers need to be supported and cared for by a trained workforce, with the right knowledge, skills and understanding of dementia to offer the best quality care and support. The National Dementia Strategy (NDS) “Living Well with Dementia” (Department of Health, 2009) highlighted the importance of an informed and effective workforce for people with dementia in care homes. According to the NDS, a lack of understanding of dementia in the workforce can lead to care practices that have a negative impact on the person with dementia and their carers. The strategy also notes that care homes which provide excellent care for people living with dementia tend to pay close attention to leadership and staff management, staff training and development, and person-centred care planning. The need for improved training is a priority that runs across all the themes in the NDS.

A study by CSCI (2008) of care homes showed that the quality of staff communication with people with dementia had a major impact on their quality of life. However, evidence from the Alzheimer’s Society Home from Home report (2007) suggested that the typical care home
resident spends just two minutes interacting with staff or other residents over a six-hour period (excluding time spent on care tasks).

The Home from Home report (2007) stated that, while some of the personal skills required for good dementia care cannot be taught, good induction and ongoing training are needed to develop a good staff team and have important benefits for both staff and residents. The report found that many family carers felt the care home staff’s knowledge of dementia care needed much improvement and suggested that dementia care training can reduce staff turnover and increase job satisfaction. 91% of care home staff said they would like to further their skills in dementia care, with a preference for one-day courses (Alzheimer’s Society, 2007). Thus, providing adequate training and support is likely to improve staff morale and ease recruitment and retention problems in dementia care. According to the Alzheimer’s Society (2007) the top challenges to providing good dementia care from a care home manager’s point of view are developing a staff team with the right attributes and skills and keeping them motivated.

As part of the implementation of the National Dementia Strategy the Department of Health commissioned a guide to training the social care and health workforce: “Common Core Principles for Supporting People with Dementia” (Skills for Care & Skills for Health, 2011). The 8 common core principles are:

1. Know the early signs of dementia.
2. Early diagnosis of dementia helps people receive information, support and treatment at the earliest possible stage.
3. Communicate sensitively to support meaningful interaction.
4. Promote independence and encourage activity.
5. Recognise the signs of distress resulting from confusion and respond by diffusing a person’s anxiety and supporting their understanding of the events they experience.
6. Family members and other carers are valued, respected and supported just like those they care for and are helped to gain access to dementia care advice.
7. Managers need to take responsibility to ensure members of their team are trained and well supported to meet the needs of people with dementia.
8. Work as part of a multi-agency team to support the person with dementia.

The guide describes the common core principles in more detail together with the indicative behaviours that the workforce should demonstrate to show that the principles have been embedded in the way they respond to the person with dementia.

Housing with care is populated by a disparate workforce comprising a combination of housing professionals, social care staff, housing-related support staff and a range of ancillary staff, configured in a variety of ways. All housing with care staff have an important role to play in supporting people with dementia, and the community within which they live (Garwood, 2014).
The HDRC case study report on provision for people with dementia in housing with care schemes (Barrett, 2012) found a large variation in the degree of training for the 6 integrated model schemes examined, ranging from none to 5-day university run courses. At the specialist case study scheme the management and staff had an NVQ in dementia care.

Different levels of training in understanding dementia are available from numerous organisations and staff members will require different levels of knowledge and skills depending on their role. The Alzheimer’s Society leads short sessions of awareness-raising under the Dementia Friends programme. Taking part in Dementia Friends’ session would be a good start but is essentially voluntary. Residents would also benefit from such sessions. Housing providers can adopt a number of approaches to skilling their workforce, for example, on-line courses, local sessions, a range of dementia-specific trainers, many of whom have experience of the housing sector and University courses offering a variety of training options ranging from basic dementia awareness sessions to in-depth topic specific day courses.

Housing and Dementia Research Consortium (HDRC) research priorities

The Housing and Dementia Research Consortium (HDRC), hosted by the Association for Dementia Studies (ADS) at the University of Worcester (ADS), is a membership group of around 90 organisations and individuals, half of which are housing and care providers and commissioners, the rest being academics, architects, advisors, researchers, policy makers and third sector organisations. Members are committed to research and knowledge exchange focusing on ‘what works’ in order to build a stronger evidence base to support the way services and buildings are designed for people with dementia and to directly influence policy and practice in relation to housing and care services for people with dementia.

The HDRC is uniquely placed to understand the housing related priorities of people living with dementia and their carers. In 2014 the HDRC ran a membership workshop (Barrett, 2014) and, in 2015, consulted with people living with dementia their family carers and staff from different housing with care settings (the findings of which are presented in this report) in order to set the research priorities and provide an evidence base to guide the HDRC’s work. The resulting priority research themes were as follows:
1. Advantages and disadvantages of different models of Housing with Care schemes for people living with dementia.

2. The effect of building and environment on outcomes for people living with dementia.  
   2a Impact of interaction with the outside community.  
   2b Green Dementia Care.

3. Suitability of Housing with Care as compared to other forms of housing for people living with dementia and home-for-life issues.

4. Use of assistive technology.

5. The effect of personal budgets.

6. Cost effectiveness of Housing with Care for people living with dementia compared to other living situations.

7. Effective understanding of and communication with people at all stages of dementia.

8. Views of people with dementia living in different accommodation and care settings.


10. Easing the transition from home into housing and care settings and settling in.

The first two research themes were considered by the workshop attendees to be the first and second most important research themes, the remaining themes are in no particular order. The workshop attendees felt that priorities 7 and 8 need to underpin all of the other research themes. Seeking the views of people with dementia using appropriate methods of communication must be incorporated into every research project that the HDRC is involved in (Barrett, 2014).
Seeking the views of people living with dementia and their carers

In 2015, the HDRC undertook a consultation in different housing with care settings, in order to ensure that the HDRC’s research activities target not only the research priorities of its membership but also the concerns and needs of people living with dementia and their family and professional carers.

Aim of the study
The aim of the study was to understand the views, concerns, experiences and needs of people living with dementia, family carers and staff across a range of housing with care settings and models including extra care housing, retirement villages and continuing care.

Method

Focus groups with people living with dementia and their family carers
Six focus groups were conducted with people living with dementia in five different housing with care settings, all of which were drawn from the HDRC membership. The settings were as follows: a continuing care village; extra care housing schemes with different models of dementia care (integrated, separated and specialist) and a retirement village. Details of the five case study sites are given in Table 1, below.
### Table 1: Research sites

<table>
<thead>
<tr>
<th>No. of residents / flats</th>
<th>No. of residents with dementia</th>
<th>Type of housing</th>
<th>Scheme Model</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 54 independent living apartments; 67 residential care beds.</td>
<td>48</td>
<td>Continuing care village: extra care housing scheme and residential care homes with nursing in the same building.</td>
<td>Integrated extra care housing; specialist residential care.</td>
<td>Urban</td>
</tr>
<tr>
<td>2 20 1 and 2 bed flats</td>
<td>N/A</td>
<td>Extra care housing scheme in the same building as another extra care scheme for people with physical disabilities. Day care centre for people with dementia attached.</td>
<td>Dementia Specialist</td>
<td>Suburban</td>
</tr>
<tr>
<td>3 300 1 and 2 bed apartments</td>
<td>21</td>
<td>Retirement village (independent living).</td>
<td>Integrated</td>
<td>Suburban</td>
</tr>
<tr>
<td>4 93 1 and 2 bed flats</td>
<td>N/A</td>
<td>Extra care scheme.</td>
<td>Separated</td>
<td>Suburban</td>
</tr>
<tr>
<td>5 51 1 and 2 bed apartments</td>
<td>N/A</td>
<td>Extra care, sheltered housing and day care centre.</td>
<td>Integrated</td>
<td>Urban</td>
</tr>
</tbody>
</table>

The focus groups began with a general discussion exploring the service users’ views, perceptions, preferences, experiences, needs and concerns relating to their accommodation, care and support in the form of simple “what do you like / dislike” questions. If there was time, the participants’ views of the priority research themes set by the professional members of the HDRC were sought (excluding those priorities that were funding and cost related). The focus groups lasted no longer than one hour.

**Participants and recruitment**

The focus group participants were people living with dementia who had the capacity to understand the purpose of the research and to give consent to participate. For ease of facilitation with participants from this cohort, the focus groups were small, with a maximum of 4 people living with dementia and their family carers if desired. A total of 18 people with dementia and 7 family carers took part.
Participants were identified by the scheme care managers, guided by a letter requesting their cooperation and giving details of the research. Information sheets were provided for the recruits and consent to participate and be audio recorded was obtained prior to the focus group discussion. Ethical approval for the study was obtained from an ethics committee at the University of Worcester.

**Interviews with staff**
At each case study site, the researchers also conducted interviews, lasting no longer than 30 minutes, with two of the care staff in order to understand their views, preferences and requirements in terms of accommodation and support for people living with dementia. A total of 10 staff were interviewed.

**Analysis**
The audio recordings from the focus groups and interviews were transcribed. A thematic analysis of the transcripts was then conducted, aided by the use of affinity diagrams to reveal common themes and differences between housing types / models of housing.
Results

Main themes from the focus groups with residents living with dementia and their family carers

What they like about where they live

The participants’ positive comments about their accommodation related to:

- Feeling safe and secure.
- Having their own apartment containing their own belongings.
- Levels of cleanliness and quality of the food.
- Reduced stress and increased freedom (carers).
- The sense of community and “family” feel.
- The feeling of freedom and autonomy.
- Ample opportunity to socialise, meet other people and take part in the activities and outings offered – but, in some sites, with the desire for some changes (see ‘What they would like to change’, below).

These experiences applied to most of the participants with the exception of those living with dementia in the dementia specialist extra care housing scheme (see below).

What they dislike about where they live

The participants living with dementia in the dementia specialist extra care housing scheme had different experiences and opinions of their accommodation to those reported above. They did not feel as safe because they felt that anyone could “wander in” and also felt insecure when alone in their own apartments. (This scheme shares a building with another scheme predominantly for people with physical disabilities. Residents can move freely between the schemes and have shared dining facilities. In addition, the attached day care centre for people with dementia can be used by scheme residents and the local community). Participants living with dementia in this scheme also raised the following issues:

- Lack of privacy.
- Feeling very isolated, stating that they did not see anyone or their neighbours.
• Not enough activities and opportunities to get out and about.
• The design of the building e.g. having to walk up and down long corridors and use the stairs to get to the dining room, inadequate lighting (“everywhere is dark”).

The participants living with dementia in the separated model extra care housing scheme and their carers felt that residents with dementia were resented and stigmatised by other residents who were not living with dementia, and this angered them. They were not sure how this issue could be tackled and felt that dementia awareness sessions would not be attended.

“In here there's very much a stigma as regards dementia, and a lot of the people that live in here do not think that people with dementia should be here. In fact, one lady said to me, 'People with dementia should be locked away in a place of their own,' and she lives here.” (carer)

“They say that they were conned into coming to the building, that they didn’t realise there were dementia people here.” (carer)

Conversely, the residents in the integrated housing with care settings did not experience such resentment or stigmatisation from other residents.

**What they would like to change**
The changes suggested by participants included:
• More information on dementia and what to expect (carers)
• More activities within the scheme.
• More outings and day trips.
• Activities that are appropriate and specifically organised for people living with dementia.
• Consistent care staff.
• Staff that are identifiable from their uniform (in a scheme where staff did not wear a uniform).

Many of the focus group participants felt it was important for residents with dementia and their family to have a “voice” and wanted the opportunity to express their opinions and to be heard.

“Probably group set-ups with people coming in and bothering to care about asking and telling people what they need to know, or even a group for dementia patients to attend.” (carer)
The residents in the dementia specialist extra care housing scheme wanted:

- More independence but at the same time having staff respond appropriately to their needs.
- More privacy in their own apartments, but also less isolation and more opportunities to mix with other people.
- To maintain contact with their family and friends that they had before moving into the scheme.
- More meaningful activities for people living with dementia that promote social interaction both within and beyond the scheme, and more opportunities to get out and about.
- More information about activities and events.
- A better designed building.
- More support with using assistive technology devices.

Main themes from the staff interviews

Achievements and successes
Staff from the integrated and separated model housing with care settings felt that they helped residents with dementia to live as independently as possible and to maintain their independence for longer than they otherwise would have.

“It helps these people to maintain their independence, you know? They're able to have their choices, make decisions with support if needed.”

Staff from the continuing care village felt that it provided continuity of care and staff and a home for life, starting with support at home, progressing to ‘Experience Days’ (Day Care) at the village, the possibility of a respite stay, then moving into an independent living apartment and finally, if a higher level of care becomes necessary, residential care in the “Households”. They were also proud of the fact that the village was design to be dementia inclusive and felt that the village being open to the local community was beneficial to the residents living with dementia, as was the fact that residents are encouraged to go out into the local community.

Other positive aspects mentioned by individual staff were: lack of resentment and stigmatisation from other residents (in one case in agreement with the focus group participants, in the other case conflicting with their feelings); making the care homes
more homely to foster a sense of family (continuing care village; the achievements of the ‘locksmith’ (a staff member with specific person centred dementia care training in the retirement village); providing different activities for residents and helping people to adjust to moving in (integrated extra care housing scheme).

**Challenges**

Several of the housing with care staff interviewed found it challenging to support some of the activities of residents with dementia, in particular the tendency to walk about and go into other residents’ rooms or leave the scheme and become lost (housing with care provides independent living, so residents are free to come and go as they please).

“... one of the main challenges that we experience is shouting, and aggressive behaviour.”

“Sometimes they can get ... I won’t say aggressive, but they can get a bit angry because they’re confused because they don’t what’s going on, they don’t know where they are, some people.”

Another challenge identified by housing with care staff was understanding people with dementia: how to interpret how they are feeling or what they are trying to tell us from their behaviour and also how to communicate with them.

“You don’t know what they’re thinking. They might be really worrying inside, and that’s why they’re continuously asking. You never know.”

“... if you tell them the truth about their parents or their husband, they’re going to grieve each time they ask that question. If you lie to them it’s not really fair, and sometimes diverting them away from it doesn’t always work.”

Other challenges mentioned by individual staff were: independent living residents not wanting to mix with care home residents in the continuing care scheme; too many roles for staff – more staff are needed; how to value the person the resident has become (with dementia), as well as the person they were before their dementia.

**Suggested improvements**

Many of the staff interviewed wanted more in-depth training to better support, care for, understand and communicate with people living with dementia, in order to support a good quality of life and help them maintain their independence.

Many of the staff wanted to understand better how to make the transition from home into a supported living setting easier for people living with dementia, how best to help
them maintain their independence while effectively supporting their needs and helping them to settle in.

“... it’s that little bit that’s still in them, not wanting to give up their independence.”

Other staff suggestions included:

- Activities that are most beneficial for people living with dementia.
- How to support family carers, peculiarly with regard to end of life issues.
- The extent to which people living with dementia in care settings take on a caring role, i.e. looking out for each other.
- The issue of tenancy agreements and capacity to sign.

Additional emerging themes

Models of housing with care for people living with dementia

Focus group participants felt that the integrated model of housing was preferable in terms of meeting lots of different people and reducing resentment and stigmatisation of people with dementia. This was a view held by all the housing with care participants, regardless of the model of dementia care they were currently living in. Some participants did, however, acknowledge that different models may be suitable for different people and accepted that it is not always possible to move into the scheme you prefer; you have to go to the one that has places available at the time.

“They need to mix, communicate, like if you’ve seen a face, a new face every day ...” (carer)

“Giving people choices as to where they live often isn’t the case, because there aren’t enough places. So that when you need a place, you, more often than not, don’t get a choice.” (carer)

Focus group participants from the continuing care village felt that it worked well in terms of facilitating and easing the transition from independent living to care home living as people’s care needs increase. They said that the move into the care home was easier than it would otherwise be because the residents already know the scheme layout and are familiar with the staff.

In contrast, staff views depended on the model of the setting they worked in. Those who worked in the integrated schemes felt that an integrated model was best for both
those with and without dementia because it did not isolate those with dementia or create a ‘them and us’ society and fostered dementia awareness. Those who worked in the dementia specialist scheme felt that this was the best model due to having specialist staff, preventing people with dementia being stigmatised and enabling them to remain at the scheme for longer. Staff from the separated scheme felt that it was better for residents for dementia to live in a separate wing if they have a tendency to walk about.

**Dementia friendly design**

Several of the participants with dementia had experienced problems with orientation and navigation, particularly when they first moved into a scheme or village. They had developed their own strategies or methods for remembering which apartment was theirs such as writing their floor and room number on their hand or on their apartment door key, or hanging personal items on their apartment door so that they could identify it. If they got lost they would ask a member of staff to help them.

“I can get lost!” *(person with dementia)*

“I’ve got my own system here, just writing on my hand.” *(person with dementia)*

“I’ve got things hanging on my door so I know ...” *(person with dementia)*

Participants living with dementia in the retirement village found it large with confusing floor and room numbers and they stated that visitors often got lost. One person with dementia stated that, rather than trying to navigate the internal corridors, he would go out through an exit near his flat, walk around the outside of the village and go back inside through the main entrance to access the communal facilities. It was suggested that it would help visitors, new residents and people with dementia if the floor and room numbers were logical and there was a well-designed map displayed just inside the main entrance and on a leaflet that people could carry round with them.

Most of the staff interviewees felt that the design of the building was important for those residents living with dementia. One member of staff from the retirement village was concerned that a dementia friendly design would make the building appear too institutionalised and wanted subtle design features that would benefit older people in general.

“The design within the whole setting? Yeah, it’s really important, yeah.”

“People have trouble distinguishing between the flooring. Sometimes the door colours as well, because they’ll go ‘oh, they’re all the same doors’.”

“They do need to look at how they design buildings, and make them much lighter. And corridors as well. And have enough room to wander as well, I think, with people with
"dementia, the number of wanderers that there are. So you need space to walk. And little seating areas even, you know, if you’re walking down a corridor, to have nice little nooks to sit in."

Interacting with the local community
It can be seen from the earlier sections that opportunities to socialise with both other residents and people from the outside local community were important to the participants living with dementia. Several stated that they enjoyed meeting different people and were extremely enthusiastic about day trips or outings that they had been on, talking at length about these experiences that had clearly provided happy memories for them. In some cases, they wanted more opportunities to get out and about and mix with people from beyond the scheme. Participants from the continuing care village also felt it was important to be able to interact with children, which they had experienced through activities that bring groups of local children into the scheme.

“I’d love to go out and meet people.” (person with dementia)

“More outings. More day trips, I should say.” (person with dementia)

Unlike the participants living with dementia in the integrated and separated housing with care settings, some participants living in the dementia specialist scheme felt that they did not have enough freedom and autonomy to go out and about when they wanted to.

“I’d love to go out and meet people.” (person with dementia)

Some staff felt that having people from the wider community use facilities in the scheme would foster dementia awareness within the local community.

“People from outside are more afraid of what they don’t know. If they did know, if they came in here, yes.”

Green Dementia Care
Participants living with dementia and their carers emphasised the benefits of engaging with the natural environment, although not all of them felt they had the opportunity to do so.

“It’s like a lifesaver some days ... where we’re living here you’ve got the woods all the way around you and it’s just a good enough walk ... and that is beautiful, so the situation of these places does help.” (person with dementia)
“What I miss is the woods, because my garden went into the woods and I miss my garden and I miss all that.” (person with dementia)

Staff also felt that interaction with the natural environment was beneficial to the wellbeing of residents living with dementia.

“A lot of these elderly people, they were doing gardening in their heyday and they were planting and they were walking in nature and everything, so when we have this here happening for them, it’s like bringing them back then … and they absolutely love it.”

**Assistive Technology (AT)**

Some of the participants living with dementia were provided with appropriate AT from Occupational Therapists. Others had developed their own solutions for day to day challenges such as way finding and remembering things, e.g. writing lists every day, keeping the room key on a lanyard around their neck, writing their floor and room number on their hand. Family carers had also provided devices such as: a whiteboard with written reminders; a device that detects a person preparing to go out of their front door and speaks pre-recorded messages such as “don’t forget your keys”.

“Put a little list on the door. I’m always writing things down.”

“I’ve got one of those boxes by the door that reminds me, you know, voice prompt, you know, to pick my keys up and, you know, don’t forget this, don’t forget that.”

However, most of the carers were unaware of the technology that is available and were surprised to hear about such devices.

Some of the people living with dementia wanted more support with using AT devices and others wanted reassurance in terms of safety

Some of the staff expressed concern about use of devices that may be considered to constitute a restriction to people’s liberty.

**Staff skills and expertise**

Participants living in the dementia specialist extra care housing scheme felt that care staff needed more training into how best to support people with dementia, including how to respond to residents’ needs while, at the same time, enabling residents to continue to do things for themselves.

“They could come and tell you as much information as they could give us before they showed anybody in or before they brought anybody in.” (person with dementia)
Participants living in the integrated model retirement village and the separated model extra care housing scheme wanted the staff to have a better understanding of the needs of people living with dementia in order to support them, communicate with them and care for them more appropriately and effectively.

“Dementia people ... what they don’t realise is, they can do a lot more than what they think. They just assume they can’t do this, that and the other, instead of finding out what they can and can’t do. They’re very ignorant.” (carer)

“I think a lot of what we do need we don’t get ... but what we get is not necessarily what we need, do you understand what I mean?” (person with dementia)

The views of the staff interviewees concurred with those of the housing with care residents in that they wanted more in-depth training in order to better support and care for people living with dementia to ensure a good quality of life and help them maintain their independence. Staff from the separated model scheme particularly wanted to know how to communicate with people with dementia. This is consistent with the views expressed by the focus group participants at this scheme concerning staff skills in terms of caring and communicating.

Unsurprisingly, staff who had attended in-depth courses on specific dementia care topics felt better equipped to understand and support people living with dementia.

“... a little more in-depth, because with dementia especially, you don’t know what to say to them, and sometimes what to do.”

“... there's more we need to know, too. You learn every day with dementia, you know? Every day.”

“... she was really a challenge, you know, because she would just keep saying, 'Help me, help me, help me,' and you couldn’t understand, but I understood after I went to training on pain and dementia, you see? She couldn’t explain in words.”

Activities and opportunities to socialise

This theme was not specifically explored in the study, however, as highlighted previously, activities and opportunities to socialise with both other residents and people from the wider community was important to the participants living with dementia. Activities that involved going out of the home or scheme were clearly very enjoyable and provided them with salient, positive memories. Some participants wanted provision of more activities within the scheme and more outings and day trips, as well as more activities that were tailored for people living with dementia.
“We’ve got a lot of activities now. You know, we do exercises, and I like it.” (person with dementia)

“I haven’t had a lot of choice, you know … we’ve space for football and stuff at the right time of year …” (person with dementia)

“There’s nothing just for dementia patients. Let’s hope there may be something in the future.” (person with dementia)

Some staff also spoke about the importance and benefit of experiencing activities outside the scheme for residents living with dementia.

“When we took her to the theatre a couple of months ago she absolutely loved it. She would not stop talking about it for a week, you know, so you see the benefit of it for them going out. They still feel connected to the outside world, if we take them out from time to time, which we do.”

Conclusions

The focus groups were successful in capturing the views, experiences, concerns and needs of the people living with dementia in the case study schemes and, where present, their carers.

People living with dementia in housing with care settings and their family carers participating in this study preferred the integrated model because they felt that it facilitates social interaction and reduces resentment and stigmatisation. The participants living in the extra care housing scheme that had a separate wing for people with dementia experienced social isolation, a lack of privacy, and limited opportunities to take part in meaningful activities within and beyond the scheme.

Orientation and wayfinding within housing with care buildings can be challenging for people living with dementia, particularly when they first move in. This can be a particular problem for those living in larger schemes due to the size of buildings and complicated floor and apartment numbering systems. It is therefore important to use evidence-based assessment tools and recommendations for dementia friendly design. These can be applied to new builds and retrofitting.

While friendships with other residents are valuable for people living with dementia in housing with care settings, it is also important to facilitate opportunities for interaction with the wider community. While it is acknowledged that there can be safety concerns and staffing issues, the
findings of this study suggest that the experience is of benefit to the wellbeing of residents living with dementia.

The participants in this study recognised the benefits of interaction with the natural environment for health and wellbeing. This supports with previous evidence, but there is a clear need for large scale research to better understand the impact of interaction with the natural environment on people living with dementia in care settings, particularly in terms of the mental, physical and spiritual health and wellbeing benefits.

Some of the participants living with dementia were resourceful and inventive in coming up with their own solutions to remembering things and wayfinding. However, there is a need to increase awareness of options for using assistive technology through better delivery of information and advice.

Taking part in activities, and the social interaction that it often provides, was important to participants living with dementia and, in several cases, they wanted more opportunities to do so. Some of the housing with care schemes in the study were good examples of how to offer activities that are valued and enjoyed by residents with dementia and their family carers.

It is clear from the experiences of many staff and residents that more in-depth training on dementia care would equip staff with the knowledge, skills and understanding necessary to appropriately and effectively support, care for and communicate with residents living with dementia. Several residents and their family carers felt that their needs were not understood, particularly in terms of supporting independence. Specific challenges identified included helping people with dementia to make the transition from their own homes into a housing with care setting understanding the needs of and communicating effectively with people living with dementia.
References


Dementia Service Development Centre, 2013. *Improving the Design of Housing to Assist People with Dementia*. DSDC, University of Stirling.


Elderly Accommodation Council (EAC) *Statistics on all Housing for Older People in England* (March 2015). Available at: http://www.housingcare.org/eac-services.aspx


© Association for Dementia Studies 2016


Gilliard, J and Marshall, J. Transforming the Quality of Life for People with Dementia through Contact with the Natural World. Fresh Air on My Face. London: Jessica Kingsley Publishers.


National Housing Federation, 2011. Breaking the mould: re-visioning older people’s housing. NHF.


Housing&Care21, unpublished research presented at the HDRC membership event, June 2015


Twyford, K. 2016. *Individuals with dementia living in extra care housing: an initial exploration of the practicalities and possibilities*. Housing LIN

